

Nothing Is Impossible

Adventures in cerebral palsy

By Neil McLeod



the spastic centre



www.thespasticcentre.com.au



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From an unpublished manuscript, 1986
Our gratitude to Jan Bradbury for her work in the preparation of this book.

Cover photograph: Image from early brochure of The Spastic Centre

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Foreword

This is the story of two unique people, Audrie and Neil McLeod, who struggled against the prevailing beliefs of a particular time in Australian history to find causes and solutions for cerebral palsy. It documents the growth of an organisation that would provide the template for so many families also facing the issues resulting from the disabilities of their children. It shows what can happen when the community understands and responds to a call for justice for some of its most vulnerable members.

The Spastic Centre of New South Wales could never have come into existence without the collective power of parents who challenged the status quo which treated them as victims and who were determined that the needs of their child would not be dismissed nor neglected. It is also an Australian expression of the story of mateship, of a 'fair go', of people supporting and nurturing each other, of community development, of conflict, turbulence and change.

This is the story of my family – particularly my sister, Jennifer, who started my parents on their life pathways.

Robin Way

2006



Acknowledgement

The first version of this book was published by the Simul Press in Japan in 1994 as a consequence of the deep and enduring ties formed between The Spastic Centre of NSW and the McLeod Society of Japan, in particular the late Mr Takeo Noda, Dr Takahashi, and Professor Ohtsuka. We are indebted to Professors Toshihisa Nagasaka and Hideo Suzuki, their families and Mrs Rie Amijima for their assistance in ensuring that this work is available to a wider audience.



A Message from the Board of The Spastic Centre of New South Wales

It is said that the most just, noble and honourable visions are often unattainable because of the littleness of those who strive to achieve them. Even emperors and kings cannot do it alone. But it is with shared purpose, common spirit, collaborative doing and the power of collective thinking that such visions have been realised. And so it is with The Spastic Centre of New South Wales.

Neil McLeod's personal account of the growth of a remarkable organisation not only traces an important and salient history but as well, instructs those of us today to continue going forward, challenging the new horizons' boundless goals. It was my privilege to hear Neil McLeod speak of the most critical ingredient in all human endeavour – the giving of something of ourselves.

That giving, begun by Neil McLeod and his wife Audrie on behalf of Australia's children and adults with cerebral palsy and their families was, and remains, the precious gift of opportunity.

The Spastic Centre is proud to publish Neil McLeod's valuable work, 'Nothing is Impossible'.

Marelle Thornton AM

President

PLEASE NOTE:

The language used in this book is a reflection of the era in which it was written, i.e. the period between 1945 and 1986.

To preserve the provenance of this rich history, the manuscript has been reproduced with minimal editing.

Dedication

This Presentation was made to

The Board of Directors, The Spastic Centre of New South Wales

on behalf of all the antecedent members of the Board who, over the years,
supported us loyally in pursuit of our objectives ~ to raise the level of our cerebral palsied children
as far as possible in education ~ medicine ~ engineering ~ social awareness.

To mark the occasion of my retirement
from The Spastic Centre of New South Wales after forty-two years of service and
my 77th birthday on the eighth day of July, 1986.

Neil McLeod



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Preface

In 1970, the Committee of International Geographical Year launched a transcontinental survey of Antarctica. It involved a coast to coast journey of over four thousand kilometres of relatively unexplored country. Two teams were involved and they battled their way through high winds and temperatures ranging to seventy degrees minus. The actual journey took them four months, but preparations involved two years and millions of dollars.

The men in the field were beset with unimaginable difficulties – snow bridges which collapsed over unplumbed crevasses involving the constant threat of loss of life, to say nothing of the physical risks inherent in a journey through the trackless wastes, when blizzards and whiteouts meant instant obliteration, in the primordial environment of Antarctica. Who are the men responsible for such a project? Are they scientific workers interested in measurement, or explorers filling in a forgotten corner of the world's environment? Or is it perhaps, a lifestyle or sport like mountaineering which depends on checking the forces against you in climate, physical and psychological endurance, where the hazards you encounter are matched against the courage and determination which you can muster? We can but wonder!

This book describes a journey of a different kind. It is a journey that started in the mid-thirties, and the end is not yet in sight. But it serves as an enduring model for the hazardous journey we have described above. The people who accompanied me on this expedition had to put up with hardships that were far worse, because they persisted throughout the whole of their lifetime. They had no scientific knowledge to point the way. Their mountain peaks were not named, there was no map. Instead of snow-filled icy crevasses they had to contend with neurophysiological barriers of an entirely different sort, but just as difficult to surmount.

For those who made this journey I commend this book. The rare courage, the determination of them all, guided us through the forty years of strife-torn wandering.

I dedicate this book with admiration, to the children of The Spastic Centre of New South Wales and the adults of Centre Industries.

This is their life's journey.

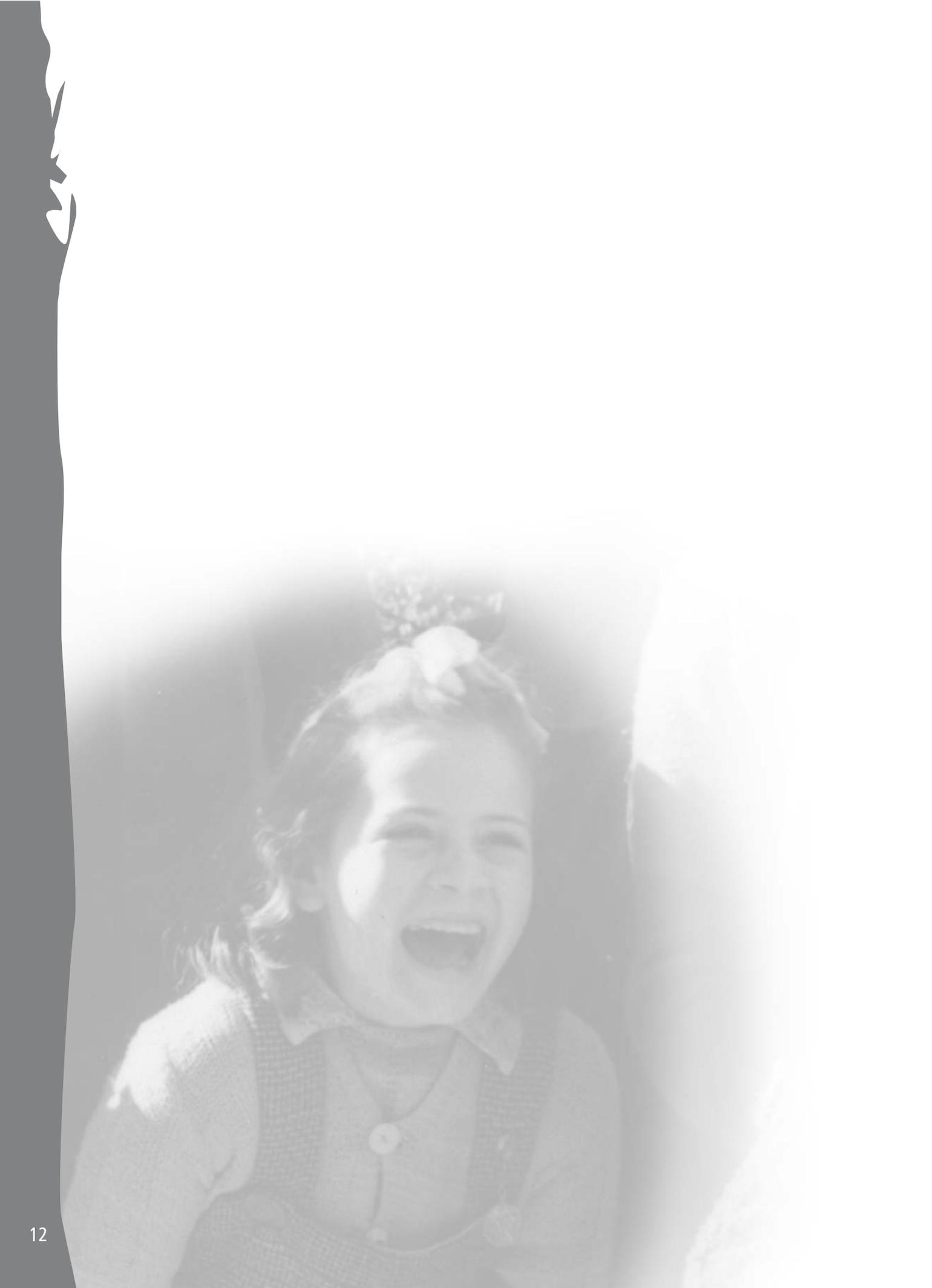
Part One

The Problem

Life is no brief candle to me, it is a splendid torch which I hold for the moment, and I want to make it burn brightly as possible before handing it on to future generations.

G.B.S.

The purpose of this book is to show that the Cerebral Palsied child can be educated. That the Cerebral Palsied adult is capable of more constructive production far beyond the present levels demanded of him.



In the Beginning 1938

Jennifer, my daughter, was born on the ninth of August 1938, in Perth, West Australia, and as is common with any first child, we fussed about her. We, her parents, were very young, very inexperienced and very much in love, and the world was ours alone. We were just climbing out of the Great Economic Depression and we had little money, but my job prospects were good. When the storm clouds gathered with the birth of Jennifer Gay, we did not know for some months what they portended. We did not know from that day onwards, for the next forty years, our lives would violently change their direction.

Apart from feeding difficulties, Jennifer's head was still floppy at the age of six months, but her attending doctor did not seem concerned. My wife Audrie, with a mother's primeval instinct, was alerted, but she suppressed her feelings, thinking that as a first mother she had no knowledge of the behaviour of babies and their ways, and was prepared to accept the advice of the nurses of the Mothercraft Clinic. For my part, I was enthralled with the unexpected delights of fatherhood, and followed each stage of Jennifer's development with loving wonder.

We had difficulty in explaining her condition to our relatives and friends, and the doctors I referred to were no help at all. It was wartime; our local doctor was called up for military service and he sailed for the Middle East without keeping a final appointment. We wrote to him and after some months he wrote back, apologising for the delay and explaining in lay terms the medical history of Jenny, but giving us hope that Jennifer would grow out of her condition.

At eleven months Jenny was examined by a specialist pediatrician who had not seen her before, and for the first time we heard the words 'spastic paralysis'. This was a shock to us. To a lay person the word 'paralysed' had a special connotation. Jennifer was alert and intelligent, but it was true that her head bobbed around like a newborn baby's. However, it was apparent that she had a terrific sense of humour, and the winsome twinkle in her eyes indicated to me, that in her case, the mental process was not affected.

We asked the doctor for his prognosis and he said that Jennifer would never get beyond the kindergarten stage of education, and that the onset of muscular spasms would mean a succession of orthopaedic corrective operations, and she would die before the age of twelve. He said, "Put her in a home and forget her".

I could not accept that conclusion because her spastic paralysis was not evident at that time. The muscles were normal in movement, and there was nothing to explain the word paralysis of the doctor's designation. Diphtheria and whooping cough were raging at the time, and I asked him to give her the necessary preventive injections. His reply was a startling, "Why?"

Looking at the story in retrospect, my wife and I would be the most unlikely couple to have graced the pages of this record. We had nothing but love to offer Jennifer and that, with Robin, who arrived three years later, welded a tight bond surrounding our family. I must also confess that I had a brand of Scottish stubbornness that I put into good use in the years ahead and, also, we were in the right place at the right time.

Robin, our second daughter, was happily normal and did much to hold our young family together and prevent an undue weight being thrown on Jennifer's condition. In the years that followed, her bright laughter and her impish sense of humour, which she hid behind a saint-like air of innocence, did much to restore our balance. She accepted Jenny's physical condition as normal and had no compunction in pulling her out of the stroller onto the floor when she wanted a playmate in her games.

As the doctors could not help us, I turned to books for an answer. I inveigled my way into the 'restricted' section of the Perth Public Library. The restriction, I found out, was to protect the lay public from drawings and photographs which might be used improperly by them.

There I found a monograph published in 1861 by W. J. Little. A prolonged search then disclosed a reference attributed to Sigmund Freud in 1892, but apart from these I could not find any textbook reference that could fully explain Jenny's physical condition.

There were references to pneumonia of the newborn, jaundice, brain injured children, chorea, hydrocephalus, birth trauma and the like. It was not until nearly sixty years later, that an authoritative publication dealing with cerebral palsy was written. I gained the impression that the condition received little attention from the medical profession, because it was assumed that the facial mask of the spastics implied gross mental deficiency.

At that time there was a low expectation of life. The abnormal muscle tone, typical of the condition, inhibited physical mobility. Because most of them were unable to walk, they were bedridden and easily succumbed to respiratory complaints. But all of the references I could find related to retarded mentality, and Jenny's condition was in the control of muscles and not in intelligence. Therefore, I made a vow that I would read everything that could conceivably have a bearing on spastic paralysis, or as it later became known, cerebral palsy, but the vow was a hollow one because of the paucity of medical literature for a generation ahead.

In the meantime, I smuggled out of the library and devoured two books on neurology that gave me the first glimmer of a logical order of inductive reasoning. They were 'A Journey Around Your Skull' and 'Brain and Mind, and they introduced me to a working model of the brain and the nervous system, which I could for the first time relate to Jennifer's injury. I must confess that the hours spent on the sunny sill of the library window restricted the time spent on the sales and installation of accounting machines for my employer, but I always made my sales target.

My reading, though necessarily superficial, was pertinent, for later on in our story of the CP child we needed to know and explain the Rh syndrome and a relationship between stillborn babies and cerebral palsy, which was not then medically apparent.

I visited the Lady Gowrie Kindergarten Centre which the Federal Government had built. I found that they were catering for normal children, not handicapped, but I was entranced with the community of staff and parents, and captivated by children singing, playing, boisterous, riotous, but so constructive. The layout of the building and the use of light and colour revealed the enormous amount of thought which had been given to the project. Each room had a dark observation gallery for staff and parents so that the children would not be disturbed in their work. I was to return to the image of that Centre again and again in later years.

We were faced with a consuming desire to know why. Jennifer was a healthy, not a sickly baby. It was true that she could not hold her head erect or walk unassisted, but she was a beautifully formed child, bright and happy and seemingly perceptive. She could not speak, but she had devised a sign language which she used: 'NO' was a wrinkled nose; 'YES' was an eye blink and she used imperative gestures to make known her needs.

We took her to a masseur (in later years known as a physiotherapist), but without success. Therefore, I started home exercises, walking around Smith's Lake, which was about one and half miles in circumference, when the weather was fine, with Jenny's hands clasped in mine and walking her in the space between my legs. We progressed about fifty metres and then I carried her for the equivalent distance. Her legs were scissored towards each other, so I would lift her up by the arms until they were straightened. She enjoyed this and so did I.

On this route we passed beside a white stork which served as a garden ornament, so we made up stories about this bird that could not walk like Jenny could, so the fairies gave him wings to fly. From this we passed among other birds such as magpies, pigeons, ducks in the swamp and willy wagtails, all of which, with the fairies' help, could fly.

From fairy stories we progressed to nursery rhymes. I framed twenty illustrated nursery rhymes around Jenny's room and we played a game in which we made mistakes in a rhyme. Jenny could not speak in those days, but she stopped me short and would not go on until the right rhyme was produced ('Jack be nimble, Jack be 'slow').

We had a lot of fun in those days. Jenny's head was still floppy, but with her head on my shoulder she fitted snugly into the crook of my right elbow, and I could carry her for hours without getting tired. So we went to the parks adjacent to our home as often as I could, and filled in with bus and ferry trips. We went to the Zoo often, until the lioness pack fixed an unwinking stare at Jenny in my arms. There was only a four metre high linked wire fence between us, and I beat a hasty retreat. Not so with



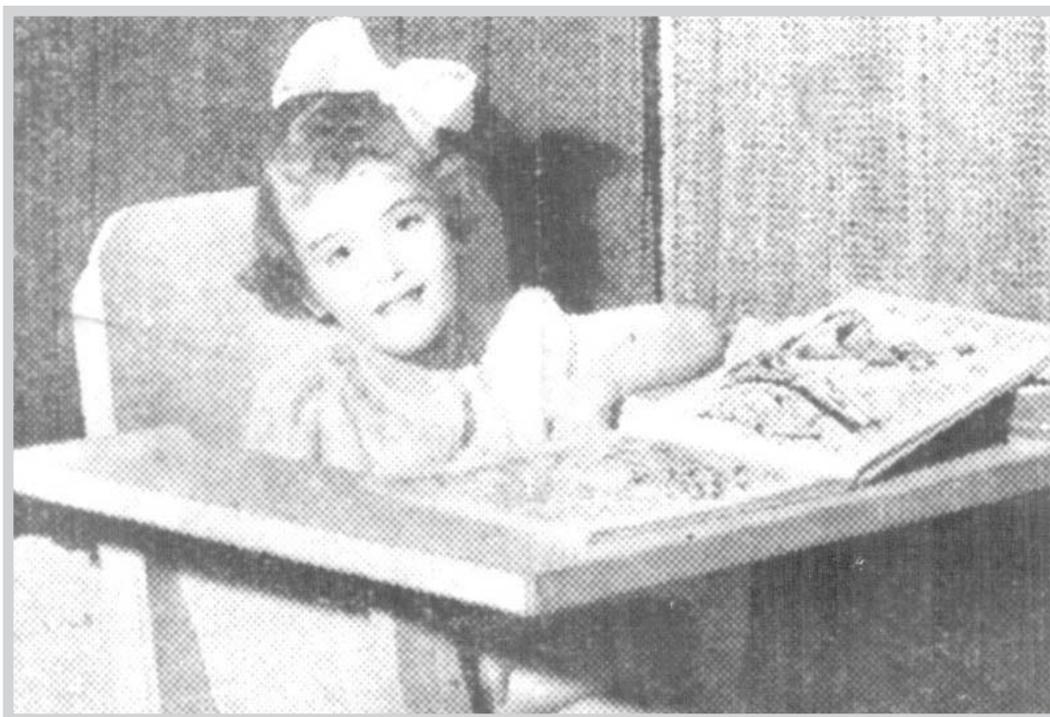
Early Days

'Teddy' orang-utan, who welcomed us with a special clap of his hands for her.

I bought a plump black hen for a Christmas dinner, and in the meantime it adopted the windowsill as an early morning perch, much to Jenny's delight. It became a member of the fast growing menagerie, along with a white rabbit and a green bullfrog.

We did not have much money in those days, so Audrie made all of Jenny's frocks and spent untold hours painstakingly smocking the designs. Jenny was fortunately very pretty and Audrie made the most of her with wide bows of ribbon for her hair and made certain that her clothes were freshly pressed.

We never, in all of those years, heard of another baby with the same condition as Jenny, although in the country towns I grew up in and the suburban streets of Perth they were there – with the blinds pulled down and the doors closed against the neighbours' stares.



Jennifer McLeod

At that time 'Life' magazine had published some photographs of spastic children at a school in Long Island, U.S.A., and after following up that lead I received a copy of a book entitled 'Born That Way', which later became a worldwide bestseller among cerebral palsied people. The theme of the book is that the majority of cerebral palsied are bright and that muscle function can be controlled by programs of muscle re-education and conscious relaxation. The heavily handicapped spastic has, despite his grotesque appearance, made his mark throughout recorded history; their numbers include a Roman Emperor and an English king.

The author, Dr Earl R. Carlson, a young American athetoid, managed, with the assistance of friends, to enter the University of Minneapolis, receiving both a B.A. and M.Sc., and finally obtained his M.D. at Yale in 1931. He established and directed the Department of Rehabilitation of Motor Disabled in New York Neurological Institute from 1932 to 1938. In 1938, he was Director of the School of Corrective Motor Education in Long Island.

The Second World War had come on us quite suddenly with Mr Chamberlain's broadcast at 11.00 a.m. Greenwich time on 3 September 1939, but in Australia it was evening. The broadcast was immediately followed by the Australian Prime Minister, the Honourable R. J. Menzies, who said, "Great Britain has declared war with Germany, and that means that we also are at war". We had followed Hitler's political progress for a number of years, but we could not understand the fact that he really wanted war. My reaction to the news was that millions of people now living will be dead before it is over.

Then followed the 'phoney war', when all the combatants got ready for the battles to come in the following year. I continued in my job until, in 1941, Japan had entered the war. All the news of the war was increasingly bad, and I could not see anything to

stop an onrushing tide of the Japanese army, short of total occupation of the west coast of Australia. I was due to be called up for military service and I decided that my wife and daughters would be safer in a country town rather than taking their chances, with no protection, in the metropolitan area of Perth.

We secured a house in the township of Katanning, a wheat and wood farming area. I settled my family, then returned for my call-up. Unfortunately I was ruled physically 'permanently unfit' with duodenum trouble. The examining doctor said, in explaining his ruling, "The army would kill you or cure you, and wouldn't have time to do either." I had one brother in the Army and the other in the Air Force, whilst Audrie had three brothers in the Middle East or in Malaya.

I obtained leave from my employer 'for the duration', and accepted an executive position in a munitions plant in Kalgoorlie, making ammunition for the Bofors gun.

I was on the train in a twelve-hour journey to Kalgoorlie to take up my new appointment when it happened. It was early in the evening and the train had stopped at a wayside station, when I became aware of a buzz of voices mingling along the train and spreading onto the pavement below. My fellow passengers were disturbed and one of them went along the train. He came back after some minutes, wiping his forehead, and said "The Japs have sunk the 'Repulse' and the 'Prince of Wales' battleships." We were completely stunned. For the first time, war had come down to Australia; Perth on the west coast is closer to Singapore than it is to Sydney.

My thoughts went back to a friend of my sister's, who had spent his leave in Perth just a few weeks earlier, and was responsible for the two thousand Chinese and Malay labourers building Kota Bharu airfield, trying to get it finished before the Japanese took it from us.

The fall of Singapore and the Dutch East Indies followed, and Western Australia found itself suddenly in the front line. The bombing of the fifty refugee flying boats at the northern port of Broome disclosed how weak militarily the West Australian coast was, and how unprepared we were for a war on our doorstep.

Wartime in Australia was marked by the shortage of young men. Two divisions were in the Middle East countries and one was in Malaya. The militia regiments under canvas in camps were weekend soldiers lacking arms, equipment and training. They were deridingly known as 'Chockos', but that was before the New Guinea campaign, when they held the track through the Owen Stanley Range against the might of the Japanese army. There was a severe shortage of consumer goods; meat, clothing and petrol were rationed, chocolates and confectionery were unobtainable. Cigarettes could be obtained under the counter by established customers. Beer was obtainable from the hotel bar provided that you were holding an empty glass or were known to the barmaid; spirits were simply unobtainable. Petrol was restricted to official usage, and most cars and trucks operated on a 'gas producer' obtained from burning charcoal in a portable furnace, or a town-gas bag fitted to the top of the vehicle.

I am a cost accountant by profession, and most of my working life was devoted to the installation of bookkeeping machines and, later, computers for an American manufacturer. The impact of the war meant that secondary industry boomed. Before that time, machine tools were manufactured overseas; now we had to make them ourselves. The Department of Supply, guided by its Board of Area Management, awarded defence contracts. Every small engineering establishment throughout the country that had a lathe and a milling machine was working on components. The larger plants worked ten hour shifts, seven days a week, and there were few complaints. The Army, Navy and Air Force had first pick of manpower, and then the Government allocated labour to essential industry; unskilled labour was directed to the Allied Works Council for aerodrome and road construction.

The war made its presence felt in the accountancy world. Leaders of the profession, like Mr A. A. Fitzgerald set the standard of cost efficiency control high, to protect the Government defence contracts. Their influence continued after the war, when the cost accountant took his rightful place near the head of the management group.

When the Americans arrived with their submarines, ships and aviation, to be followed by the U.S. Army in Guadalcanal, they were treated by civilians as saviours and were regaled quite joyously in their homes. They responded readily with Camel cigarettes, Scotch and nylon stockings. When our own soldiers returned after two or three years away in the Middle East there was, understandably, friction, but that was smoothed over in the New Guinea campaign when they were fighting together.

I had a friend, an air trainee pilot based in Geraldton, who used to stay with us in Perth during his leave. He was reconciled to his fate because he was rostered on a daily sea reconnaissance, on a sole Fairey battle plane. When saying goodbye on each leave, we really did not expect to see him again. He said, "A rooster today and a feather duster tomorrow." A few weeks later he announced that he had 'pre-embarkation leave' and wanted to be married before taking off for Britain. His fiancée was in an Adelaide office of my firm. There was a three-hour delay in trunk line telephones between Perth and Adelaide, and at the end of that time he had to get back to the airstation. So I arranged to take the telephone call for him. I proposed to the unseen girl on his behalf and was immediately accepted. I must have done a good job because their marriage has stood the test of time – now forty years later.

Kalgoorlie was a township of 20,000 population; an island in the desert, depending upon water piped 580 kilometres from the coast, and the centre of the gold mining industry. The local population had assumed that Kalgoorlie would be a bombing target because of their gold production, and consequently every street had a very active air-raid warden. A gleam of light under a blackout curtain called for a strong lecture.

The town was dominated by the man-made tabletopped hills of sand tailings, which represented seventy years production of the gold mines. The gold had been leached out into huge open-topped tanks containing a slurry of cyanide and water; the residue was pumped onto these sand dumps.

My wife, used to her city life, could not easily accomplish the transition to a world which was dominated by flies, the pan system of sewage disposal, and by the red, red dust. The buildings and even the telephone poles were impregnated with layer upon layer of fine red dust, just as if it had been painted there. It entered the house and the wallpaper was covered with rivulets of dust. When it rained, as it sometimes did, the dust settled into a slippery clay mud.

The trams were in service, although the manpower shortage had limited them to one man per tram. It took a bit of getting used to when the driver put his tram into low gear, donned his collector's bag, and issued his tickets from inside the cabin with the tram in motion. Pedestrians and motor cars beware!

Kalgoorlie was a thirsty town. Hannan Street boasted a total of thirty-two hotels, and I was present when one thousand American naval ratings hit the town for an hour's leg-stretch after spending four days crossing the desert by train. The military police, armed with long truncheons, formed a line to keep the ratings back to the railway station, and the ratings were formed about ten deep in a wavering line to oppose them. It was boiling hot, about 45° degrees Celsius, and in the six hotels facing the road glistened the beer glasses which were lined up on the counters. A flying wedge of ratings carried the line forward, but was driven back. Another and another tried, always with the same result. The line held firm until the train whistle sounded, which meant another night spent on the steaming hot train. Had the ratings broken through they would not have been seen for a month; they were completely parboiled.

Kalgoorlie had a rainfall of ten centimetres per year, but in the winter of 1941 it was deluged with storms and flooding. Fremantle was a base for the American Navy at that time, and a yellow air raid signal was mistakenly relayed to the Kalgoorlie air raid precautions, with the result that all the school children were marched out through the rain into their open slit trenches filled with water up to their chins, and kept there until the all-clear signal was given. My wife could not understand this. She said that the authorities were frightened that a Japanese sub-submarine would travel up the water pipeline!

Six months after Japan's entry, the Army decided to rail a battalion of tanks overland from the eastern states to Perth. The transfer entailed a change in gauge of the railway lines at Kalgoorlie, between the Trans-Australian line owned by the Commonwealth and the West Australian State Railways. This meant changing the tanks and spares from one flat rail car to another. Each rail car was put on a weighbridge at the Commonwealth end of their line and duly weighed again at the State end on their separate weighbridge. Each tank of course, was uniform in weight, but the bureaucratic regulations must be served, even in wartime. I wonder if the same process was followed with the triple break of gauge between the Victorian Railways and the South Australian Railways.

My organisation, the Kalgoorlie Foundry, had developed an electric battery operated motor scooter which the Manager of the electrical department used between the head office and his own department. I expressed some interest in the machine and he invited me to try it. It was driven by an on/off switch, without gears, clutch or brakes, so I predictably started at zero mph, which was ten mph by the time I crashed into the wall of the building. I was not hurt, although my dignity was dented.

That experience started me off in my quest for mobility for Jennifer, now aged three years. We began with a pedal-operated child's kiddy car. Jenny could not use the pedals, so they were discarded and we covered the floor with troughs for her feet, leaving a covered space at the centre for the transmission. We then rewound an old Delco generator as a motor to give an estimated speed of one mile per hour, with chain drive to one fixed wheel at the rear; the other wheel was loose on the shaft to act as a differential. It was operated in Jenny's right hand by a forward or reverse lever outside the car's body, in the same manner as an old fashioned automobile, and a 15 cm steering wheel completed the picture.

Because Jenny could not hold her head erect we had to build the car seat up at the back, to the level of her shoulders, and brought the arms up to the level of her elbows. The electric motor and a 12V battery fitted snugly under the original bonnet. She drove it around outside in the garden for two years. She could park it on any indicated position, and used to delight in running into unwary people's legs. When we moved to Sydney there was no flat ground, and inside The Centre was too badly congested. We parked it under the stairs for a period of months, and when I came to look for it I found it had, meanly, been stolen. I only hope that some child got the same joy out of it as its first owner did.

I think that episode was important as an early pointer to what could be achieved with so little physical assistance. For Jenny it represented her first conquest. There were many more to come.

In 1943 I was called to the newly formed W.O.I. (War Organisation of Industry) by Mr L. A. Brumby, a former West Australian whom I knew, and accepted the appointment as Liaison Officer in the Prices Control Department of the W.O.I. in Sydney. So I left my family in Perth and embarked on a rail trip to Sydney to find a house and get myself settled in my new job. My wife joined me some weeks later, after a nightmare trip of four days across the continent with Jenny and my younger daughter Robin, who was eighteen months old. Despite the wartime shortage of housing, with the assistance of my cousin I secured a furnished flat at the seaside suburb of Bondi. Some months later we moved to a house in Gladesville, an outer suburb. Rentals were strictly controlled, but that provided a bonus for the landlords, who asked cash for 'key money' – fifty pounds (\$100) in our case. We established ourselves with our furniture, Jenny's high chair and her 'motor car'.

I was interviewed by the Director of W.O.I., Mr W. H. Ifould. I could not take my eyes off a varnished wooden plaque containing the instruction 'Do Not Mention CHAOS and DESPERATION'. Wartime regulations were coming through all Departments almost hourly, and I wondered what the use of the two words signified. The newspapers were making sport of the use of pink icing on Christmas cakes, and the Director of Clothing Rationing limiting women's corsets to a required number of inches between two reference points. So I did not seek any clarification at that interview. However, at a later stage my curiosity got the better of me and Mr Ifould explained that he was responsible for labour manpower cuts affecting all industries.

His method was to say to each industry leader at an interview, "I know nothing about your trade. I was previously Director of the State Library. So if you are wise you will co-operate with me in finding a solution to the cut in your manpower, because if you do not I will do the job for you, and then God help you!" The spokesman for each trade association had become so dependent on the use of CHAOS and DESPERATION that he became lost in finding an adequate substitute when facing the 'Do Not Mention . . .' instruction.

Some months later, I was in Canberra on departmental business and was introduced to Dr F.W. Clements, an interesting man who was the Director of the Institute of Anatomy. He was the originator of the Lady Gowrie Kindergarten Centres which he set up for an entirely different purpose. He needed access to an organised body of pre-school children in all States at all levels of nutrition, in order to obtain statistics on the changing trend of childhood health over the period of the war years. The Lady Gowrie Centres were his source in the data gathering process.

Dr Clements was aware of the need to repay the children and parents who had participated in the survey. He did this by setting up something of real value in the education of the pre-school child, and the Gowrie Kindergarten Centres, established in each capital city and funded by the Commonwealth Government, were the genesis of the pre-school areas of education for many years.

Dr Clements gave me his time and encouragement, and from that contact we were able to get in touch with Kindergarten Unions in Sydney. They were interested in Jenny's problem, but were not equipped to offer any assistance.

Jennifer was interested in the radio for the music, and to our surprise she located the Australian Broadcasting Commission Kindergarten of the Air session; she was completely entranced with the young actors and with Miss Ruth Fenner, the programme's presenter. Jenny demanded that her mother should make dough for the next day's session, because for the young child plasticine was too hard to model.

We telephoned Miss Fenner to express our appreciation. She was immediately interested, and visited Jennifer together with a photographer, which resulted in the production of a full-page illustrated article in the A.B.C. Radio Weekly. It showed Jenny's response to the programme despite the impaired use of her hands. Jenny was able to follow the programme from her high chair and was able to participate in everything.

Here was the breakthrough!

This publicity put us in touch with the Crippled Children's Society; their physiotherapist suggested that an orthopaedic surgeon was doing marvellous things with a plaster treatment for spastics, but this would mean several months in hospital. We were clutching at straws, so we followed her advice. This was unfortunate for Jenny, who had to adapt herself from a loving over-protective family life to a hospital ward where she was just filling a bed for an endless, long, six months. From that experience she emerged mentally scarred, but also matured beyond her years. And her physical condition was disappointingly unchanged.

Publication of Miss Fenner's article brought us into contact with twenty to thirty other parents of spastics ranging in age from six to twenty-five, none of whom had seen another parent of a spastic child. They all had similar stories to tell; they had gone from doctor to doctor, from hospital to hospital, always to be told, "There is no place where you can send your children for the type of

**RADIO AIDS
SICK CHILD**

FIVE-YEAR-OLD Jennifer McLeod (right), who has suffered since birth from spastic paralysis. She is shown here with her mother, and sister, Robin, aged two. Jennifer's interest in the A.B.C.'s Kindergarten of the Air sessions is remarkably aiding her recovery.

Kindergarten Of Air Helps Cure Girl Cripple

The Australian Broadcasting Commission's Kindergarten of the Air is helping to cure a crippled girl.

The child, Jennifer McLeod, 5, of Western Crescent, Gladesville, suffers from spastic paralysis.

treatment that they obviously need". One of them had travelled to Townsville, a journey by train of 2437 kilometres, with her sixteen-year-old child to see if Sister Kenny could do anything. Sister Kenny was in the midst of a medical controversy over her treatment for polio victims, and she could not offer the mother any assistance for spastics. Parents of two spastics sought treatment in a sporting gymnasium, and non-medical 'quacks' were waiting for them all, complete with fake X-ray photographs. In desperation, some parents had even consulted clairvoyants.

Every new hope was explored, only to end in disillusionment. Babies grew into children and saw their brothers and sisters go off to school, but there was no school for spastic children, because no school would take a child whose fingers could not hold a pencil, who could not sit unsupported, whose speech was indistinct or who could not walk. There was a crippled children's school attached to the Royal Alexandra Hospital, but that in no way met our needs for specialised education for CP children. Heartache and despair drove the parents; drove them to try everything – anything – to get help for their children, and finally to organise a treatment centre themselves.

Jenny's trauma in hospital had a positive side. This was the time when we were exploring every avenue of assistance in the CP world. We were in the process of remodeling our thinking around what we needed for our projected school and medical unit. We were engaged in finding out the things that were demonstrably wrong with the existing system, and the things that we should avoid at all costs. We had settled upon a number of principles. The first of these was that CP children were normal children, suffering from an incidental handicap. They were not sick children. They were not 'crippled children' in the same sense as children affected in the polio epidemic were crippled. But we were dealing with a medical problem in a social application. We conceived our work as being able to marry education with orthopaedics in a non-hospital and non-school atmosphere, and to have the parents fully informed of the basis of their child's treatment. We decided that all treatment should be free and that the parents should work their passage, on a compulsory 'voluntary' work basis. If they did not have enough money to pay for proper treatment, they did have hands, and would work them to the bone in building the facilities and equipment needed, and raising the funds required. If they carried out this part of their job, they would be entitled to look to the Government and the community for support.

I produced a radio play which never went to air, but which outlined the direction of my thinking at that time. The play opened in an imaginary tour of the future, set in a combined hospital and school for spastic children outside the city. There were no beds in the hospital – all therapy was controlled by a doctor in the normal classrooms. In the schoolrooms, the spastic pupils were operating electric typewriters, and magnetic steel boards replaced paper and pencil. There were movie machines for geography lessons. Arithmetic was handled by a giant abacus. Children's wheelchairs were available, and lightweight aluminium crutches and sticks were used. Coloured ground glass screens were used instead of blackboards, music formed an essential part of training, and a mini zoo was established in a playground.

In my association with W.O.I. I had met Mr Arthur Sullivan. He was a hearty, well dressed textile merchant in York Street. Over the war years he had held an import merchant licence for Indian cotton piece goods, but there was no sale for these until Japan entered the war.

Then cotton goods were severely rationed and he could sell his import quota many times over. The Prices Control Department objected to his making an excessive profit from the licence and instituted an enquiry.

Arthur was a Regency buck, born out of his time. He would have done well in 1845 as a merchant promoter of international trade. He was a noted singer with a magnificent voice, and in the years following the war he had arranged for one of his two sons to embark on a professional singing career and to study with a maestro at La Scala, Milan. He would have loved the opportunity in his youth, but fortune made him a reluctant merchant.

I was associated with him over a series of weeks, and in order to distract him from the current Departmental enquiry, I started to talk of my daughter Jennifer and the hopes I had of obtaining a school and medical treatment centre with other parents after the war. To my surprise Arthur Sullivan gave me \$20 as the first donation to The Spastic Centre, as it later became known.

Then he dropped the bombshell! "I have a house at Newport, a farm at Crookwell, and a house that I am now living in at Mosman. If you would like to take half the house at Mosman you can establish your school; you can have it rent free. I will store the surplus furniture in the other half of the house." I let him talk, but I did not think that it would come to anything. People do not make such a grandiose decision on the spur of the moment, but we had not reckoned with Arthur Sullivan. He was insistent on arranging an inspection. That night we parked Robin with a neighbour in Gladesville and went to call on Mr Sullivan at Queen Street, Mosman. Sydney was 'browned out', but the lights were on in the extensive grounds in the house. As you can imagine, we approached the front door with some diffidence.

Someone was playing an organ at full pelt. We were ushered in, to find Arthur Sullivan his wife and his mother. We were uncomfortable. We wondered how his wife and mother would view the idea of giving up their home to complete strangers. So we were very careful and waited for Arthur to give us a lead. We admired his Georgian china, the grand piano and the golden harp that Mrs Sullivan senior played. Arthur conducted us around the grounds, where a stream meandered through the gardens spanned by two Japanese bridges. There were tree ferns and a wealth of other trees, each garlanded with antelope ferns and orchids. We admired them all.

Then over supper Arthur said to me, "What do you think? Do you think it will do for your school?" I looked at Audrie and Audrie looked at me, and I mumbled something. Then Arthur turned to his wife and said, 'What do you think of it, Billie?' And she said, "Well, Arthur, you haven't told me anything about it at all!"

That gave me the opportunity to produce my envelope of photographs of spastic children, and to say what we hoped to do with a school and medical treatment centre for them. We had hoped to do that before the war ended, using the mothers of our children on a rostered basis.

We were late home, travelling by bus, ferry and tram out to Gladesville, but we were both in rose-coloured clouds all the way.

With the surprise loan of Mr Sullivan's house, all of our dreams came true. All we then had to do, in time of war, was to find the medical and teaching staff, the transport system, the furniture and equipment, and the money to get the organisation underway. Then we had to set up the administration of the Parents Group. And all that had to be done quickly if we were to get the children to the proposed school in January 1945.

The Sullivans took a week to arrange their furniture and then we had an empty half-house. We planned to house our family and to operate The Centre in all the space available. Two large rooms were taken for schoolrooms and the therapists did their treatment in the bedrooms. The bathroom became our surgery for the administration of anaesthetic for dental operations and the large balcony became a relaxation room with twelve cots donated by the Children's Hospital. Jenny was still in hospital at the time we moved in.

We got in touch with Mr Heffron, the Education Minister, who promised that a schoolteacher would be made available. The Education Department allocated Miss MacDonald, who was on sick leave following an operation. We were indeed fortunate in the choice, because Miss MacDonald advanced the cause of education of cerebral palsied children over the next twenty years.

In the meantime we had found a temporary teacher to hold the fort until Miss MacDonald appeared, and a friend suggested that Dr Claudia Burton-Bradley might be interested in becoming our first Medical Director. She was, but not until June 1945. Miss C. Gibson accepted the position of physiotherapist and occupational therapist in charge. The president of the Crippled Children's Society, Kenneth Coles (afterwards Sir Kenneth) agreed to sponsor The Spastic Parents Group, which was the forerunner of The Spastic Centre, for \$3000. Whilst we were grateful for their generosity, we wanted to be free to take advantage of Mr Arthur Sullivan's offer of his premises, and to build The Spastic Centre just as far as we could take it, and just as soon as we could afford it.

I still had to earn my living as a Commonwealth public servant, so my wife took over as Honorary Superintendent, a post she maintained on an unpaid basis for nearly forty years, whilst I became Chairman of the Board and Honorary Treasurer. The Board was comprised of parents only, who left the administration of The Centre to my wife and myself. We had a President to act as 'front man' on social occasions, to leave me free for other more vital matters. In addition, I had two offices in the city as required by my responsibility to W.O.I.

We had set the administrative pattern quite deliberately, so that the parents would always be in control of treatment and education, under the guidance of the Board of Directors. The Medical Director would professionally be in control of the medical unit, and the schools would necessarily be under the control of the Department of Education, with a Principal who was expected to liaise with the Medical Director and the Honorary Superintendent. Because we had no facilities for CP in Australia we did not have anybody in authority to withhold any action which we needed, and the State and Federal Governments and their Health Departments were not interested.

My wife and I were primarily responsible for raising money by personal appeal; that meant that we controlled, under the Board of Directors, where the money would be spent. Even in the early years we avoided the cachet of having a prominent person in political, social or business fields appearing on our letterheads. That is not to say that we did not use their facilities for fundraising in appeal committees, but we directed where the money would be spent.

When the Spastic Centre first opened its doors in Queen Street, Mosman on 30th January 1945 little was known professionally about cerebral palsied children. On the first day, when fifteen children attended The Centre, the collective capital of the parents who began the venture was \$58.

By the end of the first year, forty children were attending and it was not long before other parents of spastic children learned of The Centre and made urgent requests for help.

A businessman is trained to look at his business problems in a different fashion. We, on the other hand were solely interested in treatment of our CP children, present and future. To do that required a change of thinking. The Centre is a non-profit company registered as a charitable organisation. The Board of Directors which governs it is comprised of parents of spastic children, and receives no remuneration for its services. The Centre pays no commissions on money-raising activities. The needs of the children are the only consideration, and every cent is channelled towards their care and welfare.

We arranged to incorporate The Spastic Centre under the Companies Act, as a non-profit company limited by guarantee, with membership restricted to parents attending The Spastic Centre and with myself and my wife as Life Members of the Board of Directors. In 1945, we appointed Professor H. Tasman Lovell, Professor of Psychology at the University of Sydney, as head of a Technical Advisory Board. That Board was comprised of people interested in the project, but was not an advisory board in the true sense and it never operated as one.

I produced a large 50 x 40 cm book entitled 'Here is a Plan for Cerebral Palsied Children', with photographs which explained what the children were capable of doing and what their futures might be without hope of assistance from the present hospitals, schools and other facilities. The illustrated pages were headlined as follows:

'In the whole of Australia, there is not one hospital or school providing proper physical and academic training for the cerebral palsied.

Tight muscles and growing bones inevitably lead to deformities unless preventive measures are taken. These are entirely absent. The cerebral palsied cannot benefit from normal schools and even hospital schools do not meet their needs.

There may well be 1000 educable spastic children in Sydney alone. We are in touch with 150 metropolitan children, all of whom are entitled to their chance. Spastic children are not only the most numerous among our physically disabled children, but they are utterly neglected. If you are unfortunate to have a child who is blind, he is taught to see – with his fingertips. If he is deaf, special schools teach him lip reading, so that he learns to hear with his eyes. If his muscles are slack and wasted as a result of infantile paralysis, special hospital facilities will do much to modify his handicap, and special education is available to him in hospital schools. But if he is a spastic, then he is indeed 'damned'. In Australia there are 5000 children who are unnecessarily facing a life of hardship and difficulty which is beyond the comprehension of the ordinary man or woman. Beside each of these children is an Australian mother whose lot, through no fault of her own, may be even worse than that of her child. In the whole of Australia, there is not one single school, hospital or home which provides the special treatment that is absolutely essential for the reclamation of the spastic child. We are satisfied that under a proper scheme of education, fully fifty per cent of educable cerebral palsied children can be expected to become self-supporting, twenty-five per cent partly self-supporting, and few of the remainder will be unable to at least feed, dress and otherwise care for themselves.

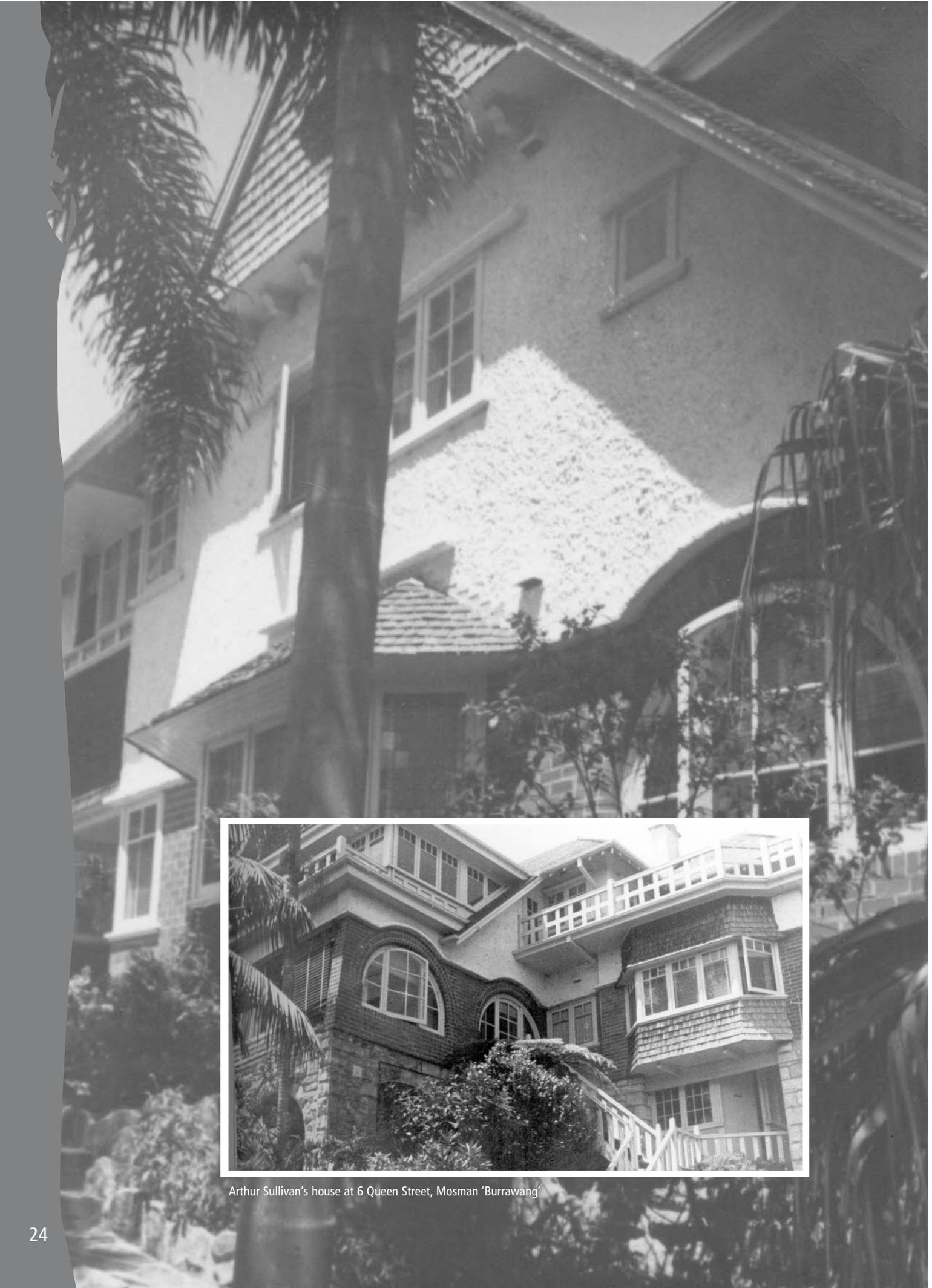
There is no possible cure for the original damage, but with therapy the child can go a long way towards effecting his own improvement.

Domestic troubles loom large enough in any family, but they are intensified by the continuous strain of a spastic child.

Retardation is easily mistaken for low intelligence, and this is one reason why cerebral palsied children are often neglected. One, Dr Earl R. Carlson, could not dress himself at the age of eighteen years, but he succeeded in putting himself through College, and today is a practising specialist in cerebral palsy at the Neurological Institute in New York City. But his physical appearance still remains that of a cerebral palsied person.

Surely it is a medical mystery that concerns the doctors only? The answer is "No". The spastic is only ten per cent a medical problem.

Surely this is a matter for the Government? We not only have to first prove our case, but having proved it, we must fight for something to be done . . . in a world unfortunately, where so much is waiting to be done.'



Arthur Sullivan's house at 6 Queen Street, Mosman 'Burrawang'

I was a comparative stranger in Sydney's business world and we had no contacts or friends in Sydney. I have often been asked how we raised the money from a standing start, without assistance from the Government, a private endowment, or publicity in the press. I think the answer to that question was contained in the photographic evidence in the 'Here is a Plan' book. Photographs of a young child appeal to all the community and the businessman had no difficulty in equating his own child or grandchild among those spastic children depicted. The three examples following will give you some idea of its use:

The first \$200 sponsor we obtained was from the General Manager of Robert Reid Company, a softgoods merchant. I secured an appointment with the help of his personal secretary, with whom I had left the book. He called me later, arranging an appointment at which time he gave me his cheque, with the good wishes of the Softgoods Association.

Following a tip that Mr I. Horwitz was a generous man, I made an appointment to see him, accompanied by my wife. He was curious to know why we had selected him for the proposal and my wife countered that by saying that Mr Horwitz had the reputation of being interested in new progress in the community and that was why we were there. He was an interesting man, and we spent an hour in agreeable conversation with him and we left with \$100 to add to the subscription list.

I had received an invitation to address a lunch hour of the Young Men's Hebrew Association. I did it with mixed feelings, because this was the first time that I had given a speech to such a large audience. I suppose that I was over-sensitive about the doctors who may have been in the audience, but they did not challenge anything I said, and afterwards one of them congratulated me and pressed \$10 into my hand, to go with the \$150 that had been collected and given to me for The Spastic Centre.

Incidentally, while waiting for the lift with a group, I explained that my father had come from Sydney originally but he had died in Perth when I was only three years old, and my mother had died shortly afterwards, so we lost touch with my father's relatives in Sydney. As the lift door opened I heard somebody say, 'It would not happen to Jewish families, would it?' That interested me at that time, because I had assumed it was normal for me not to be interested in my father's forebears. As a result of that new thought, I uncovered an unexpected grandfather and stacks of cousins, uncles and aunts.

When we married, my wife was working in a solicitor's office. Ours was a generation which demanded that a wife should stay home after marriage and a husband should not expect her to work - he should earn enough to support both of them, otherwise he should not marry. The Spastic Centre upset both concepts.

Audrie, in her role as Honorary Superintendent had an infinite compassion for the mothers of her cerebral palsied children and their fathers too. She talked to them at length, always aiming to do something practical. The mothers trusted her. They were inclined to close up in their conversations with the doctors and therapists, but with 'Mrs Mac' they were talking to another mother of a spastic child. The question uppermost in the parents' minds was always: Who will care for my child when I am dead or can no longer cope, and what about the needs of other members of the family, including the father?

The Education Department provided kindergarten furniture and supplies to the limited value of \$150.

The National Emergency Services on air raid precautions loaned us two old but roomy twenty-year-old motor cars - a Packard and a Buick, for a budding transport system.

It was impossible for the parents living in all of the different suburbs to get to Mosman by public transport, so we were forced to provide door to door motor transport. We had arranged a roster system with voluntary drivers. The wartime petrol was severely rationed, but we were able to obtain a minimum allocation monthly. We soon found, that with few exceptions, voluntary drivers could not be depended on to man a fixed roster. That was all right for a start, but paid drivers and parents took over from them after the first few months.

The children travel with a number of their mothers, themselves no less an important part of the scheme. They are rostered to provide two days' work per week and do all of the domestic work at The Centre, including the preparation of the children's hot midday meal, which like treatment and training, is provided free. Some of them are rostered on duties associated with the care of the children at The Centre; they feed the children and toilet them. They provide drinks to the children who need them, and act as aides in the schoolrooms and therapy rooms. They wash walls, scrub the floors, and do the many other things that would cost hundreds of dollars if paid workers were employed. All professional and technical staff are full-time paid employees.

There was a single garage on the street frontage in Queen Street, so most of the motor cars were repaired and serviced on the footpath. Complaints were few because it initially was a quiet street and the neighbours were curious but well meaning.

First intake of children



Mrs Corner, a mother and driver assist a child, Annette Bugden.



Mrs West and the mothers' roster.

During this period my wife and I had interminable discussions on every aspect of a school and medical treatment unit, and this came together with a report to the Committee dated 15 September 1945, which contains a blueprint of our policies:

It is felt that our present efforts must be concentrated on evolving a common policy which will provide: A sufficiently large single group of children under intensive treatment to provide adequate cross section of cases – we propose one hundred children; facilities for training of staff on a specialised basis in such a manner that there is a common approach to the problem without losing the value of individual techniques.

If the work is properly carried out as a piece of experimental research it should be possible to provide within a few years many of the answers which are now beyond us. We propose to build a temporary annexe on the Mosman property which will provide another 971m² of floor space. This will provide adequately for the group of one hundred children. At the end of three years this project will have served its purpose and the permanent buildings may then be erected, in light of experience gained, on the present site or on a better site elsewhere.

We feel responsible for ensuring that within a reasonable time, say three years, every cerebral palsied child is given a sufficient period of scientifically controlled intensive training from babyhood onwards.

Elimination of 'spastic' diagnosis – There is a need for the elimination of the term 'spastic paralysis' in general medical diagnosis of these children. Only the cerebral palsied are admitted to The Centre. It does not, however, seem practicable to eliminate the word 'spastic' for popular use.

Early contact needed – early contact is needed, say at twelve months, to provide for the mental hygiene of parents, early commencement of muscle training, continuous orthopaedic supervision and early intervention if required.

Special facilities needed – These children are not "crippled children" in the sense that they have only locomotive defectiveness and they should not be mixed in training groups with "crippled children" unless, or until, they can compete successfully. Ninety per cent of cerebral palsied children have motor defects other than that of locomotion. In many cases their locomotive handicaps may be the least of their physical handicaps. Therefore, they need teachers with specialised training, different techniques of teaching, different, more specialised equipment and more intensive initial training. Later they may graduate to ordinary crippled children's schools and later still to normal schools, but they do need specialised, rather than mixed, schools to start their work.

Mothers too need urgent help – The restoration of the mother as a social being is quite as important as the reclamation of the child. There is a need for talking it out with other mothers, a need to share in the work done for the child even if the share is only nominal, a need for time away from the constant nervous strain of the child's presence. The mother's work at The Centre is now reduced to two days weekly, the child attending five days.

Breaking of child's dependence – The breaking of the child's dependence upon the mother is a prerequisite to effective physical and academic training. This cannot be done with the mother in sight during the day.

Freeing of child from mother's emotions – The release of the child from the mother's emotional dependence is quite as important but no less difficult.

Assessment of child's ability to benefit – At present it is not possible to assess the cerebral palsied child's capacity to benefit from training by any other method than trial. Standard intelligence tests are not valid for cerebral palsied children.

Group work desirable – Definite benefits are obtained from group activities. The socialisation of the child is the first big step in his education.

Teachers and technicians must work as a single team – There must be complete co-operation between all members of the various departments – both inter- and intra-departmental - to ensure the smooth carrying out of the day's programme and the gaining of the fullest understanding of all the 'problems' of each individual child.

Faulty breathing frequent – Faulty breathing habits are apparent in most cases and treatment requires months of closely supervised individual and, later, group work.

Supervised relaxation periods essential – Rest and relaxation periods of at least sixty minutes daily are necessary and are improved by the provision of suitable music.

Full time speech therapist required – Intensive speech therapy is needed for more than 85 per cent of the children. A full time speech therapist who can work as one of the team of technicians is as essential to adequate training as is a full time schoolteacher or physiotherapist.

Home treatment ineffective – Supplementary home treatment by parents is ineffective except for such things as night splints and specific “do’s” and “don’ts” of the therapists on specific points.

Nursery school teachers can work with “tinies” – Trained pre-school teachers can be expected to do effective work in obtaining the co-operation of the “tinies” from twenty-four months onwards.

Incidence of convulsions not severe – The incidence of convulsions is not severe for the whole group and does not tend to increase under pressure of intensive physical and mental stimulation.

Motor transport not uneconomic – Daily motor transport is not necessarily something to be avoided on the score of cost, or on other grounds. By concentration of facilities the cost of transport may be minimised; the stimulation of street travelling is an excellent schoolroom adjunct and no undue fatigue is apparent despite trips of up to an hour in duration.

Spastics have normal child’s needs also – It is vital that the child should be treated as a normal child with an incidental handicap and not as a “handicapped child” with emphasis on his abnormality.

Residential set-ups may be less effective – There is no evidence that there is any advantage in a residential set-up which removes the child from home life and contact with his family, except in those cases where domestic conditions equal those which would justify moving a normal child from the home environment.’

(A surprising number of these points are as valid, forty years later).

Following an increase in numbers of CP children and their mothers, we desperately needed an increase in our fleet. The Packard with its roomy interior was a sheet anchor. It once carried nineteen passengers, achieved by careful stacking. On one occasion a mother, Mrs. Corner, was driving the Packard with her one-year-old son, David, in her lap and the front and back seats filled with spastics. She was stopped by a policeman in the city square. “Don’t you know, madam, that you should not drive this car with a baby in your lap?” “Oh I am sorry”, she replied, “Reg take David”, and passed the baby across to Reg who was in the back seat, his athetoid arms waving like windmills, as he struggled with the baby on the floor of the car. “Carry on driver” said the policeman, now bereft of his authority.

We could not afford the money, but our whole operation could well founder on our inability to get children to Mosman for schooling and medical treatment. We bought a secondhand 1928 model Erskine, a light four cylinder passenger tourer. Then the proprietor of Scanlon Sweets came to our rescue. He had two Chevrolet panel vans, laid up on blocks during the war, and it could be twelve months before the restrictions of labour permitted their use. In the meantime we were welcome to use them for a year. We were exceedingly grateful to him, and we kept them for two years.

Later, in 1947, my wife was looking longingly at a carpark comprising a thousand surplus army vehicles. They were surrounded by barbed wire and were patrolled by uniformed mounted Lighthorsemen. But needs must when the devil drives, and the Department of Supply issued us with an order to view the Chevrolet ambulances. My wife, who was quite beautiful, had a way with her and, despite a chilly reception at the gate, it was not very long before the custodians were vying with each other to make certain that the two selected ambulances were not only the best in the line but were complete in every particular; or, I must say, that they were ‘over’ complete in every particular.

We paid a magnificent \$406 for the two ambulances to the Department of Supply, and were in business again. Now that we knew how the system worked, it was not long before we added another two army ambulances to our growing fleet.

My wife’s relationship with the Medical Director and the therapists was always good, and she was able to convey the parents’ fears without in any way interfering with the medical treatment. Her guideline is as it always has been – that the needs of the individual cerebral palsied child determine the case, but always felt that she was inexperienced in the control of her expanding staff, and the male drivers in particular. She felt her way slowly, but she had the chance to show her mettle very soon. One day the drivers drove the children into The Centre and then announced that they were on strike for higher wages and would not drive the buses home unless the claim was settled that day. Audrie called the eleven drivers into her office and summarily dismissed them all. She arranged a roster of parents to drive the buses until we employed a new group of drivers. She explained that she

was not taking that action on the drivers' wages claim but, by leaving the children stranded without means of transport, the drivers had betrayed their trust.

In addition, Audrie had to run a household and care for our two young children. She was saddled with the expanding transport system because, with the peak traffic, it was necessary for her to plot the transport runs herself and not to leave that to the initiative of the individual drivers. That meant she had to personally drive over the routes with a stopwatch, looking for short cuts and traffic bottlenecks, and was responsible for the drivers' times of arrival at The Centre, because a late bus would inevitably mean that some children would miss a therapy session. Our children had grown from 71 in 1946 to 110 by 1950, and we could not have handled such an intake without efficiency in timing. She was the Chief Executive of the Board of The Spastic Centre. She had to keep in daily touch with the Medical Director and the School Principal, interview the parents of incoming children and listen with her remaining ear to complaints from the participating parents. For good measure, she had to act as fund raiser for donations and, above all, she had to see that each spastic child received his or her due in medical attention, in education, and in the home environment. In other words, she always was and still is the conscience of The Spastic Centre.

I as a senior public servant had my employment to consider, and had to find the time needed to plan and finance the building projects, obtain supplies of building material and the use of building equipment, personally supervise the weekend voluntary labour as needed and, later, design and obtain the material for the splint project. We both therefore had to fit two days' work into one, and weekends did not exist – and we enjoyed it all.

I must here pay tribute to an American inventor, Alexander Graham Bell, and his instrument; we could not have done it without the unrestricted use of his telephone.

From our opening day in 1945 we were inundated with requests from desperate parents seeking help for their children, and at The Spastic Centre we had planned that it should be at the maximum possible level. To do that we had to put our work on the highest technical level, so that we could learn the quickest and most effective way to give every child every chance. This was indeed a big programme when one considers that we started with a capital of only \$58, no Federal or State Government funding, and no private endowment.

The Board Members were elected from all the parents, and they all necessarily had children attending The Centre. It demonstrates the unanimity of parents having the responsibility of Board Members, making decisions concerning their own child, and transferring this concern to other children of The Centre. Our Board Meetings were always exciting and not always fruitful. One of our members, in our first year, wanted to freeze the children's admissions at the then level of forty-five; another wanted to establish reserves 'for a rainy day'. Yet another member was a solicitor, and you can imagine the horror on his face when I announced that we were planning to build a major building on another man's land, and to order an X-ray unit before we had the money to pay for it, because we had been informed that Bett Rowe's hip joints, and those of other children, were slowly dislocating.

A normal business Balance Sheet did not apply to us. What we listed as assets, like buildings and equipment, were really liabilities because they generated expenditure for staff and supplies in each year they existed. They looked good as a total of the assets side of the Balance Sheet, but they were only accounting figures without any real meaning. While our children needed them they had no value, unless we were forced to close down. In that event, we would have no interest in what happened to them. A businessman looking at our financial statement would apply his cost/benefit relationship, but that had no meaning for us. What is the benefit in teaching a child to walk, or what is the capital value for an individual's speech, or communication by other means? What is the value in cold dollars of a mother's peace of mind about her child, if she has to have a serious operation? Dollars are important. They enable us to do things. But we are dealing with vital and more emotional considerations than money.

The following are extracts from the Report to the First Annual Meeting of the Spastic Parents Group (later incorporated as The Spastic Centre), held in March 1946:

'At our Inaugural Meeting last year, all we had was the use of half of an empty house, without chairs or furniture. We had no money, but were able to collect \$58 at that meeting with a promise of \$200 from the Wholesale Softgoods Association. The Department of Education agreed to provide the services of two teachers and we had engaged an occupational therapist. Up to that time we had not been able to secure the services of any other technical staff. The transport situation looked hopeless, but after a short while the Mosman National Emergency Service provided on loan, a 1927 Packard and a 1926 Buick. On 29 January 1945 we started bringing an average of fifteen children daily, for the first month.

Our teachers and technical staff had no specialised knowledge of the best methods of dealing with the tremendous teaching problem offered by pupils with the multiple handicaps of the spastic, and the first six

months was spent in experimental organisation.

The schooling system started to straighten out after Miss Naomi MacDonald came in April, and then we were fortunate in obtaining the services of Miss Chloe Gibson, whose work in establishing the physiotherapy department offered our first real success. Her fine intellect, insight and great capacity for work and organisation have been of tremendous assistance to the Medical Director and to the children of The Centre.

In June, Dr Claudia Burton-Bradley accepted appointment as Medical Director in charge of all treatment and training and primarily responsible for the future research programme. Miss Eleanor Wray, the only speech therapist in Australia, promised to give us half a day's therapy per week until a new student took over.

The position is that we are operating a team of expensive and highly qualified technical staff. This cannot be continued indefinitely in these premises. The lack of space makes it impossible to provide the facilities necessary for the work.

The Relaxation Group is one of the basic factors of the treatment groups. Here again there is not enough space. One child's restlessness can spoil the whole of the day's work of the existing Rest Group. It is most essential that we should have more space.

It is no use providing certain sections of treatment without following through with all relevant treatments for the individual case.

We have to provide children with effective and intensive treatment in The Spastic Centre. We have to organise research work in such a manner that eventually we will know the answers to questions which at the present time cannot be answered by any medical authority in Australia or overseas. There is no adequate treatment centre in Australia. A certain amount has been done in America, but with a somewhat different slant from our work. Even in the U.S.A. there is not one clinic that treats as many children daily as we do, or carries such a staff. In one of the largest treatment clinics in the U.S.A. charges are eighty pounds monthly per child, approximately \$A2000 per annum.

I would like to mention, in reviewing the work of the Committee, some of the general policy rules which have been adopted during the year. These are points that have arisen from general discussion:

- That the Centre is organised on the principle of the effort of a group of parents, with such outside help as they can obtain, on behalf of their children as a whole.
- That the needs of the group determine the facilities which can be provided to the individual.
- That there can be no principle of preferential treatment other than the need of the child.
- Mothers are expected to attend to provide their fair share of the work of The Centre, and parents generally are expected to contribute in the way in which they can best help.
- That children who in the opinion of the technicians are not benefiting over an extended period be retired for a period, and then given further courses if, in their opinion the child will progress.
- That the needs of the mother be considered in conjunction with those of the child.
- That The Centre generally endeavours to provide all the help possible to spastics in the country and in other States.
- That these principles be regarded as indications of present general policy only and are to be interpreted in their wider sense.
- That the maintenance of the vital policy of free treatment for the children depends upon the co-operation and work of the fathers no less than the mothers. Fathers' attendance at weekend and Wednesday night working bees is to be compulsory as is mothers' work at The Centre for two days each week, unless a substitute is provided.

The only way we can get anywhere is to provide a concentration of children and trained staff in one place. We cannot maintain a small group of twenty children and work comfortably in our present home.

We must expand immediately to provide sufficient facilities for occupational therapists, physiotherapists, speech therapists, orthopaedic work and special schooling. If for lack of facilities we were to lose Dr Burton-Bradley, Miss Gibson or Miss MacDonald, this Centre would close down. As far as public support is concerned, there is nothing that succeeds like success. In the whole of the year 1945 we anticipated we might spend \$4000. Actually, we spent \$14,000, and raised \$18,000. We have to increase this figure to \$28,000 next year. All administrative and office work was done in an honorary capacity.

We have done a good job in 1945. Let us all do a better one in 1946 and we will be well on the way to building a future, not so much for our children who are now attending The Centre, as for the thousands all over Australia who will benefit from our experience and research.

Thank you for your courage and for your splendid co-operation.'



Mrs Duckett and Mrs Potts bringing in the washing.



Clarice Bugden putting on an act watched by Mrs Elderfield, Mrs Duckett and Mrs Simmons.

Reg Duckett

Reg Duckett, now aged forty years, was one of the foundation CP at twelve years of age. In his own inimitable style, Reg has condensed his life story into the following:

'Looking back over the past forty years one gets the feeling of being part of a great moment in history. Man has ventured beyond this planet towards the unknown blackness of the heavens, yet his greatest agreement has been won in the smallest regions of this mother earth. From the eyes of a "smart-nosed" kid to a somewhat battered middle aged man, I witnessed a great many events and schemes take place. In a strange way I have been in a box seat to watch these events taking place.

For the first thirty years I had a pretty good guide in a lovable larrikin by the name of Alf – my Dad. Never the one to mince words, he would tell me to go to hell every day of our lives, or call me a "commo so-and-so" whenever I spoke of new ideas and happenings. We were more like brothers than father and son.

One day we met this chap with great ideas about building a centre for helping and educating cerebral palsied children. Dad was captured the first time he met this long, skinny chap, for although I was twelve years of age I was almost as helpless as a baby of one year. Mum and Dad had to carry out all my bodily functions, including wiping my bum, as Mum loves to remind me today, when I get smart with her.

At the age of twelve a kid does not realise how great a burden he is on his parents, especially when the kid is loved as I was. Always a bad drinker, Mum and Dad had to pour fluid into me from a small Coke bottle – the only way I could stop my thirst. That was only one problem. It has been only in the last ten years that I have been able to give myself a drink by means of a special mug.

To get back to this chap, who from now on I will call "Mac" (sure he won't mind) – he had big dreams for all sufferers of CP including his daughter, who he loves more than anything in the world, after forty years he still does. Mac was possessed by his dreams – talked for hours while Dad and I listened. Yes, I listened to every word that day, because firstly from that day I realised that I was totally different from other people. Not special, not inferior, but different.

A twelve year old kid should be able to read and write; I could not, and that has been the whole crux of my life ever since that day – to learn and understand everything dealing with the planet and the beings who live on it. But where to go to learn? No school would have me – public or private. Mac said he thought he could get the loan of a house in Mosman from a businessman; I never did hear the full story of how Mac got that house, but by God he did!

At the beginning of 1945 Mac and his wife founded what was later to become "The Spastic Centre of New South Wales". With about eighteen other parents, including my Mum and Dad, they begged, borrowed, or (with Dad) stole chairs, tables, china, cutlery and every other thing needed to start a small school for CP. Only one thing was missing – a teacher – but Mac soon got one from the Education Department, by talking their heads off for a week non-stop.

While all this was going on Dad decided he would have a go at teaching me himself, by getting books and pamphlets from the Education Department. Cheeky bloke that he was, he just walked in and asked for these papers, and was turned down flatly unless he brought the boy in for an I.Q. test.

So before I knew what was happening I found myself with Dad in a cramped office facing a somewhat large woman who, without much ado, held up four fat fingers in front of my face. How many, I was asked, then shown a number of black and white pictures, and asked what was in them. Dad and I waited while notes were made. Without expression the woman told Dad that I could never be educated. Test over! Dad and I were both extremely upset, for as Dad said, the whole thing was a bloody farce. Undaunted, Dad went back the next day to the Education Department and told them what he really thought of them and, strangely enough, he got what he wanted.

So I started my education by sitting beside Dad while he drove a truck around the city. Rough as this may seem,

it gave me a beginning of learning which stood me in good stead when the Centre at Mosman opened. Unfortunately the teacher Mac got was in her sixties and found the task of teaching a group of twenty CP of various levels of ages and handicaps far too much to cope with, and retired after about a month. Fortunately for myself personally she was replaced by a lady who had the greatest bearing on my life, both as a teacher and a friend – Miss MacDonald, later Mrs. Kerr. From 1945 till 1957 she taught me and others like me everything she knew and more. She only failed in one thing, and that was to get me to spell, trying everything from spelling the words slowly over and over, to threatening me with a school ruler. Apart from this bad form, I managed to get fairly good marks, especially after the introduction of the electric typewriter in 1947. From that time on this machine has been my source of communication with my fellow man. These days I even earn part of my living from it. By combining it with an electronic calculator I am able to compile a monthly and yearly cost report for the management of Centre Industries. Centre Industries is operated by The Spastic Centre of N.S.W. for industrial and office training of adult CP.

From one man's dreams a whole string of Centres of care and shelter has arisen from bare ground. Well done Mac; and Dad (at rest).'

Reg's father, Alf Duckett, was the mainstay of the voluntary weekend workers on various building projects because of his gregarious nature; he was on first name basis with every volunteer, and he knew what trade they worked in, where they lived, and what kind of beer they drank. He was indispensable.



Reg Duckett

Christopher Nixon

'Now thirty-eight years old, I was born in 1946.' Christopher Nixon said, 'Perhaps the most important and definitely singular things provided me were treatment for my disability and education for my mind. How well I recall the plasters, which I considered diabolical as a child though I now think differently, the pelvic control braces I wore day in and day out for so many years, and the patience of both physios and occupational therapists, plus teachers during my childhood and adolescence.

I shudder to think that, without The Spastic Centre, the odds are great that I would not be using this typewriter now, possibly never learned to read or write to any great degree, and certainly would have no interest at all in mathematics.

These debts I owe are quite clear in my mind. At The Spastic Centre I learned, and gained confidence in myself. I do most sincerely maintain the view that, because a spastic person has more opportunity, if he or she wishes, to observe the complexities of society, it compares to looking through an imaginary microscope at people more fortunate than yourself, and mostly watching them worry themselves sick over problems such as marriage, finance and a home, which you would gladly trade with them for your own problems, such as getting from point A to point B – lack of independence, and the like.

Again, through C.I., I developed the confidence to write and have faith in my writings. I learned to converse with able-bodied children and adults, and I understood that spasticity held no real stigma which somehow might prevent me from living life to the fullest extent possible.

Conversely, it became clear as I reached adulthood – as for everyone in the world – my CP would impose its limits on me harshly. I should never be able to hold my own child, or even hug my own wife in my arms. Harsh limits, indeed, but those which CP of my disability must face.

Today, I have my books, record library and writing to keep me busy. I have many friends – though one can never have enough of them – who understand me and are apparently not concerned with my constant involuntary arm waving or spasms.

Not only do I consider myself very fortunate, but also humbly grateful to the good offices of The Spastic Centre of New South Wales for much of that which I have obtained.'



Christopher Nixon

Childhood

Is Something Precious 1948

It is a hard never-ending fight – which no cerebral palsied child can ever evade. The struggle is entirely personal – no other person can share it – doctors, teachers, therapists and parents can encourage and direct the child. They can arm and equip him for the struggle – but he must still fight out the lonely battle on a ground that is beyond their reach. Whether the terrain favours him or not depends entirely upon the equipment and organisation with which we have endowed him.

In 1947, we produced an illustrated colour brochure outlining our policy; forty years later I would have difficulty in faulting it:

'Contact with childhood gives us all an opportunity of renewing ourselves, or slipping off for the moment our mundane cares and worries and enjoying its clean simplicity. Children should be happy – they are not born to tragedy – there is time enough for that in later years. But what of children like ours who, through no fault of their own, are denied their birthright – bound from the very day they are born; are they to be left in their dungeon of frustration and despair because it costs a high ransom to strike off their bonds? Or are they too, to be released to enjoy the sunshine and the happy shouting of the playground?

It can be done – it is being done here at The Centre every day, but it has a price – a price which is largely paid by the child in long years of unremitting training, treatment and of schooling under conditions which might at first seem impossible. You and I must contribute the price – we must see that the tools are available for their work, and that means – money!

These children have had damage too, or failure of, development of those parts of the brain which direct and control voluntary movement and posture. Anything which causes damage to these areas can produce the condition. Sometimes cerebral palsy is associated with hearing, vision, speech or mental defect.

Damage usually occurs in relation to birth. Most frequently, it is the first child of a family. First births are usually the most difficult. A long labour, a tired mother, a difficult delivery may cause cerebral haemorrhage and thus brain damage. A badly shocked baby does not breathe well and so does not take in an adequate amount of oxygen. This lack of oxygen may itself cause damage to brain cells.

Extreme prematurity is a frequent cause. The very premature baby is susceptible to spontaneous small haemorrhage into the brain tissue and so brain damage. A too quick or precipitate birth may bring about a tearing of the membranes which cover the brain and cause bleeding into the brain tissue.

Recently it has been shown that cerebral damage can occur in association with heavy jaundice of the newborn, due to the Rh

factor and parental incompatibility. Sometimes the condition is acquired after birth through accident or disease such as encephalitis or meningitis, perhaps following measles.

Education and treatment are absolutely essential. Even though they must forego their rightful heritage of carefree childhood, for a spartan training that is beyond the conception of a normal happy child, they are entitled to training and education – they must be given that chance!

The work accomplished by the children in the schoolroom is the final test of the value of our intensive medical and physical treatment and training. It is of little use improving the function of a twisted wrist, if the hand is not then taught to write. It is of little value teaching a child to walk if he is denied an education that will give his walking a purpose. We are very satisfied with the school standard attained by our children in spite of their handicaps.

Reg is using the electric typewriter - he could not read or turn his pages three years ago. Betty, despite her lack of effective speech and difficult hand control, has learned to read and use an adding machine. Despite her poor speech and hand function, June wrote the play for this year's school concert, and has had several of her stories used by radio stations.

These children are clearly on their way – the way is long, hard and exacting, but we are erecting some signposts where we can, and ask that you, too, stand by to give them some aid over the steeper parts of their climb. They can make the grade – they must not be denied the chance. They're worth it.

These eight infant class children are widely different; they have different handicaps, different teaching problems, different potentialities. Their physical handicaps vary from Kerry, who is still unable to walk but whose speech is good, to Stafford, with athetoid movements which are involuntary and sometimes only partially controlled, who works so well and whose speech is so affected to be almost absent.

But they all share one very, very important characteristic – they will face up to any task allotted to them with an intensity of purpose which disregards bodily discomfort and a succession of continual failures until they finally master it.

Can you imagine just what this work means to the individual small personalities whose handicaps have cut them off from so much, often from normal life experiences such as simple learning? Can you imagine Stafford, minus speech, learning his letter by nodding 'yes' or 'no' to his teacher as she places the matching cards in front of him? The time-consuming repetition until he progresses to words, then the slow building of an unspoken vocabulary, the misspelt words on the blackboard, and the flash that illuminates his whole face when the pointer moves over the correct answer? Then for the teacher, equally with Stafford, the quiet bubbling pride in watching him ultimately read from a book.

All of these children have similar stories. Julie is as proud as a peacock of a blue bruise and lump on her forehead, because yesterday, for the first time, she walked three unsupported steps. She fell, but to her the bruise is an accolade.

Beverley last week walked alone for the first time in her life, on rough skis made by her father. She was not satisfied with a three or four yard essay, but insisted on teetering and wavering the whole length of the hall, and then repeating it for good measure without falling once. She has hardly stopped walking since. Her hands are not yet sufficiently improved to hold a pencil, so Beverley is busily spelling out the answers to the blackboard exercises by arranging her letter blocks, but she is expected to start writing very soon now.

Kerry is the popular girl of the class. She can walk and talk, and mothers the others with a comical seriousness. She is writing what Julie dictates, because she must have somebody to turn her pages and write down her answers.

Jennifer, who is still unable to hold her head erect, uses a ballpoint pen because she must support herself by her hands, and a pencil point would break.

Graham started walking the same week as Beverley. This is not a sudden achievement, but is the culmination of more than three years of intensive training, associated with the stimulus of the recent visit of Dr Carlson, which immediately inspired many of our older children to increased effort and confidence.

If, with our unimpaired bodies, you and I could attack the problems of our relatively uncomplicated lives with the fixity of purpose and concentration of these children, who knows to what heights of endeavor we might not aspire?

We are proud of our Nursery children. Whenever our parents or staff members permit themselves the luxury of a fit of the blues, there is a certain cure ready at hand in ten minutes observation of this interesting little group. Completely unselfconscious, reliant and brimful of vigour, they are a sheer delight to watch. Their activities are based upon free play and group activities, controlled in accordance with the individual child's muscle training programme, and their progress is faster and more certain than any other age group. It has been found possible to obtain effective co-operation, even from some babies as young as ten months, and this augurs well for the future preventive work which should be done for every such child.

There is Tim, who has his centres of balance and position impaired. For three years, from the age of sixteen months, Tim has been taught never to relax his attention from what he is doing. Should his attention stray he folds up, and must then hoist himself laboriously to his feet again. The time between falls is gradually being extended, and some day soon he will go through the day without a fall. There is absolute certainty in his future ability to win out in the way in which he accepts the fall and immediately gets to his feet again. He has never stayed down. It would be so easy for him to just give up, but he has never stayed down yet and he never will.

That is why we can never slacken off in our self-imposed task of doing what needs to be done for these babies. With early training they will release themselves from the tyranny of crutches and invalid chairs – without training many are inevitably doomed – we can never give up while they are still prepared to fight on.

To walk – two poignant words that carry such a wealth of magical meaning to a child who cannot move from his chair. If you have spent a few weeks in a hospital bed you will remember the frustration of waiting for a nurse to enter your room. Do you remember the eagerness with which you looked forward to being able to take yourself to the bathroom, or the daydreams in which you tasted the future bliss of just being able to walk unhampered in the sunshine down to the corner of the street? It is heartbreaking to watch the effort some of these boys and girls have to put into the simplest movement – but the underlying sadness of the children's personal tragedies assumes a different quality for those in close touch with their work because of the constant drama of achievement presented. For months, sometimes years, a child will appear to make little physical progress, and then suddenly he commences a spurt. Every success then spurs him on to greater effort, and often a surprising gain is made before he again settles down to a steadier pace.

You can readily imagine the pride and radiance shining from the face of an eight-year-old who, for the first time in his life, stands alone, wobbling against a wall pad or tensely swaying on walking skis. In learning to walk, aids of many different kinds are used. Dawn uses the skis to obtain stability – for her it is a hard uphill climb, but her eyes are on the difficult peaks she must still surmount before she, too, can join the joyous laughter of the children at play. These are the occasions that make a song in our hearts and all the effort worthwhile.

The cerebral palsied, despite the severity of their physical handicaps, must be treated as normal children first and foremost. Their handicaps are incidental only to their needs as a normal child and do not take precedence over them. Only too often treatment facilities are focused entirely upon the alleviation of the child's disability and his needs as a normal child are completely overlooked.

It is little use curing a crippled leg if the process involves crippling the child's mind by denying it the opportunity of developing along normal lines. Education is necessary for all, but it is of absolute importance to the cerebral palsied, whose limbs will always be affected to some extent and who must, therefore, discipline himself by physical and mental training in such a way that he is able to compensate for, and rise above, his deficiencies if he is to successfully adjust himself to normal society. There must be no sentimental half measures involved. A handicapped child can seek and obtain all the emotional sympathy and help that he requires. As an adult he must, in social and economic competition, match up to normal people, irrespective of his disability. He is entitled to assume that his handicap will not be held against him, but he is not entitled to demand that the world gives him special consideration because of it.

The provision of proper plasters, braces and splints, immediately they are needed, is essential to prevent or control deformity otherwise inevitable. We believe that these orthopaedic aids are every child's right.

Can you imagine the eagerness with which the children await their school bus, their distress if it is late, and the speculation if it is diverted for a new passenger? They are not ambulances for sick children, but school buses for healthy but heavily handicapped children. To some the bus represents release from the monotony of a chair in a living room; to all, an interesting, exciting, new world of constructive work and play. New sums today, speech therapy tomorrow, companionship always. Travelling with their schoolmates and achieving for the first time in their lives, a special friend with whom to exchange confidences and special secrets. It is all thrilling, and very, very necessary.

You have seen our Spastic Centre buses, crowded with children in your suburb. In centres as far apart as Hornsby and Hurstville, Mona Vale and Maroubra, Revesby or Parramatta. Every week they travel a distance equivalent to a trip across Australia to Perth and back again. Purchased in poor condition from army disposals as ambulances, they were rebuilt as buses, with special seats to support the more helpless children. Every morning they pick up nearly one hundred children at their homes and return them in the late afternoon. They are our lifeline, without which we cannot function. Our children cannot use public transport and a residential treatment centre is not practicable.

It is not desirable that The Centre should be converted into a residential treatment unit, as this would reduce the numbers of our children to one-quarter, without in any way increasing the efficiency or reducing the costs of the schooling and medical treatment provided. The spastic child, equally with the non-handicapped child, needs the essential stability of a family home, brothers and sisters, relations and friends. We are, however, becoming increasingly disturbed by the plight of the many cerebral palsied country children who are unable to obtain training in any existing hospital or home, and of the difficulties of similar city children during periods when their parents are unable to properly care for them, owing to sickness or other domestic emergency. Think of the tragedy of seeing child after child, capable of benefiting from urgently needed treatment, which cannot be provided because their homes are in the country.

Despite the smallness of our organisation and our lack of funds, buildings and equipment for the purpose, we feel compelled to immediately organise facilities for the residential care of these children on a hostel basis. For the present, the children will be transported daily to The Centre for schooling and treatment. Later, it may be found advisable to add class and medical treatment rooms to the hostel.

All services provided for the children will continue to be free of charge, but parents will be expected to share their portion of the work and expense involved upon a co-operative self-help basis. A small permanent staff will be engaged, but the bulk of the work will be done voluntarily by mothers, their friends and by voluntary helpers.

Here is the simple story of a group of children in search of happiness

The development of the scheme is completely dependent upon securing suitable premises, but it is planned to provide for ten urgent cases immediately and to increase the number to fifty children within two years. As most of the children will be drawn from country districts, it is confidently expected that country people, generally, will assume financial responsibility – it will be money well spent.

This is not a survey of the rapid growth of a new charitable institution, born out of the heartache and bitter impatience of parents unable to obtain treatment for their children. It does not tell of struggles against financial failure and official indifference, or of the difficulties in wartime and afterwards of finding premises, obtaining a well-qualified staff, organising a transport fleet, erecting and equipping a building in the midst of a severe housing shortage, and getting a large group of people of all classes, types and creeds to work efficiently together towards a common end. Such a story might be told, but interesting as it may be, it has no place in these pages, because the real story of The Spastic Centre is the story of its children

Here is the simple story of a group of children in search of happiness. A group of quite ordinary boys and girls, fat babies, little pre-schoolers, school children and adolescents – trapped, through no fault of their own or their parents, on a treadmill of physical disabilities, on which they must remain until the day they die.

On and on they must go, the severity of their handicap determining the effort demanded of them as, lurching and stumbling, they relentlessly drive their stiff muscles, trying to keep pace with the normal world about them. If they falter or fall they are carried remorselessly backwards, and if not aided to their feet in time they are inevitably doomed to the debris of the scrap heap.

Some children fight back hard and learn to match their qualities of courage and determination against the calls made upon them. By utter concentration over long years of training, they learn to minimise the disabilities with which they were brought into the world. Others, whose disabilities are less, or who work harder to overcome them, free themselves from the treadmill altogether, and join their normal contemporaries in competitive society.

Part Two

The Hypothesis

The Spastic Centre was started on a Dream: the dream of every parent of a cerebral palsied child; the dream of a normal future for their child and, more importantly, who will look after my child when I die? In the absence of Government funding, our parents and their friends built their own Medical Treatment Units, school, Splint Workshop, garage, and Residential Hostels, relying on voluntary weekend labour and donated materials. Because our children were unable to use public transport, we needed to develop a Transport System, using minibuses.

In our schools, ineducable children found the joy of learning in a normal classroom. They needed specialised medical help and a way was found where medical treatment and therapy were integrated into the normal schoolroom.

When our adults needed work training, we later turned to the engineering profession to provide a normal working environment.

Normalcy is the keyword for cerebral palsied everywhere, in living, in education, in medicine and in engineering.



Facilities At Mosman

The war was over and people took up the threads of their lives again with a sense of deep satisfaction, rather than rejoicing. There were families mourning the loss of a father or a brother or relatives overseas. The returned soldier was unsettled by his civilian prospects and did not want to go back, necessarily, to his pre-war vocation. Goods were in short supply, but we had become used to that over the long years that the war had lasted. In 1949 on my tour of the United States, I was struck by the wealth of goods displayed in the windows of the department stores. In Australia, Labor was in power in the Commonwealth and State Governments. There was a feeling of change in the air.

By the late nineteen forties The Spastic Centre was firmly established. We knew in what direction our targets for education and medical therapy lay. Then it was only a question of advancing our technical skills to ensure empirical success. We had penetrated the consciousness of our community with the story of our cerebral palsied children, and that provided the empathy and, of course, the funds that followed.

When we engaged our weekend volunteer building programmes in Mosman from 1946 to 1954, and Allambie from 1954 to 1961, we tapped into a new section of our community. We have estimated that ten thousand man-days were provided in voluntary weekend labour during those years. I think that the secret of our success is probably the deep-rooted Australian love for a 'battler' who stands up on his feet and fights for what he wants, and of that small group of parents who, in the face of official apathy, were determined to do something for their cerebral palsied children.

The Federal Commissioner of Taxation advised that gifts to The Spastic Centre would be allowable deductions, and we had our first donations to the organisation. The parents at our opening meeting had collected \$58, and Pizzey Pty Limited had the honour of donating the second \$20 to The Spastic Centre – the first \$20 was, of course, from my friend Arthur Sullivan. The Softgoods Association donated the first \$200, and I have already mentioned that the New South Wales Crippled Children's Society gave us a splendid gift of \$3000 over two years.

We had set our fund raising target at one hundred amounts of \$200 from sponsors and we achieved this at the end of 1947. The conditions for admission to The Centre for free treatment included an undertaking for compulsory work and money-raising activities. At an Annual Meeting of parents, some of the members present said that, situated as they were with a cerebral palsied child, they would not have any hope of participating in fund-raising efforts. My wife rebuffed them with her reply. "The way to get a million dollars is just five cents at a time. You and your friends can afford more than that." Incidentally, it took nine long years to collect the first million.

We had no money, but they could work with their hands, and work they did. As the cerebral palsied children absorb a large part of the family income, we had earlier decided that all treatment, transport, and orthopaedic appliances should be free, and the parents could depend upon their own hands to provide the facilities needed for this treatment and education of the children. We embarked on this policy because we were interested in the progress of the child itself and did not want the treatment discontinued

because of the family's inability to pay, and we needed to be sure that the splints and braces would be applied on the doctor's prescription as early as possible and not when the parents could afford to pay. In the same manner, we intervened in paying for the child's surgical operations, when obviously the parents could not.

As I was dependent on my public servant's salary for my living, my wife took over the running of The Centre as Honorary Superintendent. As one magazine article saw, she ran herself into and through a nervous breakdown without realising it, until afterwards. Small and slight, she wears size twelve clothes, has big blue eyes, a straight nose, curly brown hair and a wide smile that puts crinkles in her cheeks. Her charm of manner has won many a friend for The Centre, and as a public speaker she has swayed many men in an audience to tears. With a subject such as she has to talk about, there is good reason for this display of emotion, for no one without a heart of stone can be unmoved by the brave and earnest little folk who are fighting their way toward normality, and Audrie McLeod has no heart of stone.

As Honorary Superintendent, my wife administered The Centre on a day to day basis, including the transport division which was soon growing rapidly. We appointed a Transport Officer fairly soon. Most of the initial funds were raised by my wife and myself through personal interviews, but as it increased in volume, we were looking forward to a full-time staff person. The charity appeals were traditionally headed by an Appeals Officer, but I wanted something better, so I coined the term 'Public Relations' to describe the office. It must have been a good choice of words, because it has been adopted widely in the business community since that time.

I did the accounts in my spare time; in the mid-fifties we acquired an accountant. Up to that time, we had raised the amount of money collected from \$16,000 in 1945 to \$260,000 in 1952, and our children had increased from 35 to 130 in the same period, with 681 out-patient children in 1952.

In 1945, we started with the description of the medical condition of 'spastic paralysis', so we incorporated that description into the name of The Spastic Centre. In those days, we were faced with the problem of first explaining the children's condition and why we needed money for them. Depending on the force of our arguments and explanations, the cash flow expanded. In America, Dr Phelps had criticised the use of 'spastic paralysis', saying it was not scientifically based and treatment depended upon a reclassification; he promoted the change to 'cerebral palsy'. We agreed with him, but we had six years of public recognition of the name 'The Spastic Centre' and the goodwill surrounding it, so we had no option but to retain the title, but we retained Dr Phelps's 'cerebral palsy' in all our technical writings.

When Dr Carlson had found that CP patients needed to have a rest prior to treatment, we set up a rest group and the children had an hour's relaxation before treatment. That was based on Jacobsen's relaxation textbook, but I do think it applied specifically to cerebral palsy. With the increase in numbers of children over the second year, we could not fit the rest group in the available space, despite the fact that six months after commencing The Centre we had taken over the whole of the house, having prevailed upon Mr Sullivan to move his stored furniture.

So in 1946 we embarked on an ambitious building programme. We had no Government funding for this programme, so we decided to do the job ourselves. We had no money to procure the land, so we had a discussion with Arthur Sullivan, who, agreed to a temporary building on his vacant allotments adjacent to No. 6 Queen Street. Wartime controls still prevailed for building materials, and we were unable to get a permit. The Mosman Municipal Council did not agree to our use of the land for a temporary building, especially since we did not own the land. We had the idea of erecting a military Quonset hut, but building regulations made it necessary to alter the plan to a permanent brick structure.

Mr Sullivan was fascinated by the children's progress in the past year at our school and medical unit, and did not demur at the prospect of our building a permanent structure on land that he owned. I was interested in getting space for our children at any cost, and said we would talk about legal problems later on.

I must here pay a well deserved tribute to Mr Arthur Sullivan, because without his help The Spastic Centre would not have come into existence in its present form. He gave us the precious element of time – time to get the school under way – to organise a transport system – to recruit the medical staff – and most important of all, to organise the parents and their friends for voluntary work. We needed money, but the only way to get it was to show that cerebral palsied children did progress in training – educationally and medically.

All the reports from the government and medical authorities decried as a chimera the use of public funds for the training of the cerebral palsied. We did not have anything to lose, and if we succeeded in our undertaking, we needed more facilities, costing more and still more money, over the years to come.

Arthur Sullivan gave us the required time, but he gave our children much more. He gave them the chance of a lifetime and for the thousands more to be born in the future, some hope for a better and more satisfying lifestyle. I think that he enjoyed our



Brian Comer wielding a blackberry slasher.



Speech therapist with Bruce Comer and Reg Duckett



Fathers, working bee. Neil McLeod, Sid Jones and Tom Giles

continued success. It made him right, in his initial assessment of our story; it gave him his due as the sole patron of the successful Spastic Centre. The fact that our children were improving tremendously under treatment gave him justified pleasure. So we embarked on our ambitious building programme, not knowing from where the finance would come.

We could not afford a building contractor in the usual way, so I had no option but to take the responsibility of the job in the spare time that my position in W.O.I. allowed, and in the evenings and at weekends. I had no building expertise – I am an accountant by profession, but there was nobody else to do the job. So an appeal was made for voluntary weekend labour and donations of building materials and equipment. With my wife and my friend Robert Pollock, the Honourary architect, we drew up the plans and specification of what we wanted the building to contain. Mr Pollock did not know then the building was to be done with weekend voluntary labour, and with mainly untrained staff. That was for the future.

Mr Pollock described how he came to be concerned with The Spastic Centre. He said, "I was walking along Pitt Street minding my own business one day, and I met a friend who was accompanied by Neil McLeod. I should have walked on, but I was not quick enough. So before I knew what had happened, he had enlisted me, without payment, to supervise a new building for a school and medical unit, on land he did not own, and at a cost he could not finance, and staffed by people who did not know what they needed."

Mr Pollock introduced us to Mr Marsden, who was a foreman carpenter, and he agreed to act as a building foreman under my general direction. Among his staff was an apprentice carpenter, Les Smith, who after thirty-five years is still working at The Spastic Centre as a building and maintenance foreman.

Mr Pollock's father was now dead, but he was an architect of the old school, who made the rounds of his buildings dressed in black coat, grey striped trousers and a hat, attended by the foreman who wore hat and coat, even in summer. The workmen did not swear in the presence of Mr Pollock senior, otherwise they would have been instantly dismissed. Needless to say, that was before the advent of the Building Labourers Union. Mr Pollock junior's dress was more informal - he wore a white starched dustcoat on the job and his head was bare, but his father's influence came through when he gave architectural instructions in a clipped, precise, Scots accent, despite the fact that he had been in Australia for forty years. He was my friend and my tutor, on building design and execution.

Wartime conditions still prevailed, with building materials and the buildings themselves controlled by the State Minister for Building Materials. We made an application through the normal channels and after some delay, we were refused permission for the supply of materials. We had talks with the Director of Wartime Building Materials, but the Minister was unapproachable. However, fortune smiled on us because Mr Edward Hallstrom (later Sir Edward), who controlled the Taronga Park Zoo, had received a building permit to enable him to erect buildings for the zoo. Half a mile distant were handicapped children denied a building permit for urgently needed medical treatment and schooling. I simplified that story by saying, quite unfairly, that a permit was available for a monkey house at the zoo, but not for spastic children. That made headlines in the suburban press, and in the meantime our parents campaigned by letter to Mr Hamilton-Knight, the Minister. The Minister finally agreed to see my wife and I, and complained very bitterly about the mounting campaign of letters the parents had written. He said that he was short of staff, and he deplored our attitude, and that he would not be bullied by any such campaign. We denied all knowledge of the campaign, and we left the Minister's office with the promise of a permit.

The following letter was one we sent to all builders' suppliers, dated 12 February 1946:

'You may have heard some reference to the voluntary work of The Spastic Centre in providing free treatment, schooling and motor transport for children suffering from cerebral palsy. Owing to the absence of proper medical treatment facilities in New South Wales, these children have previously been unable to obtain treatment for their physical condition and what is quite as important, they are unable to obtain any schooling.

A normal child who is illiterate has not much chance. But a paralysed child who is also illiterate is indeed damned.

The fathers of our children and their friends have undertaken the big job of erecting a 900 square metre two-storey brick building at Mosman, with weekend voluntary labour. We are getting a sufficient number of workers to ensure the success of the scheme, which is proceeding rapidly.

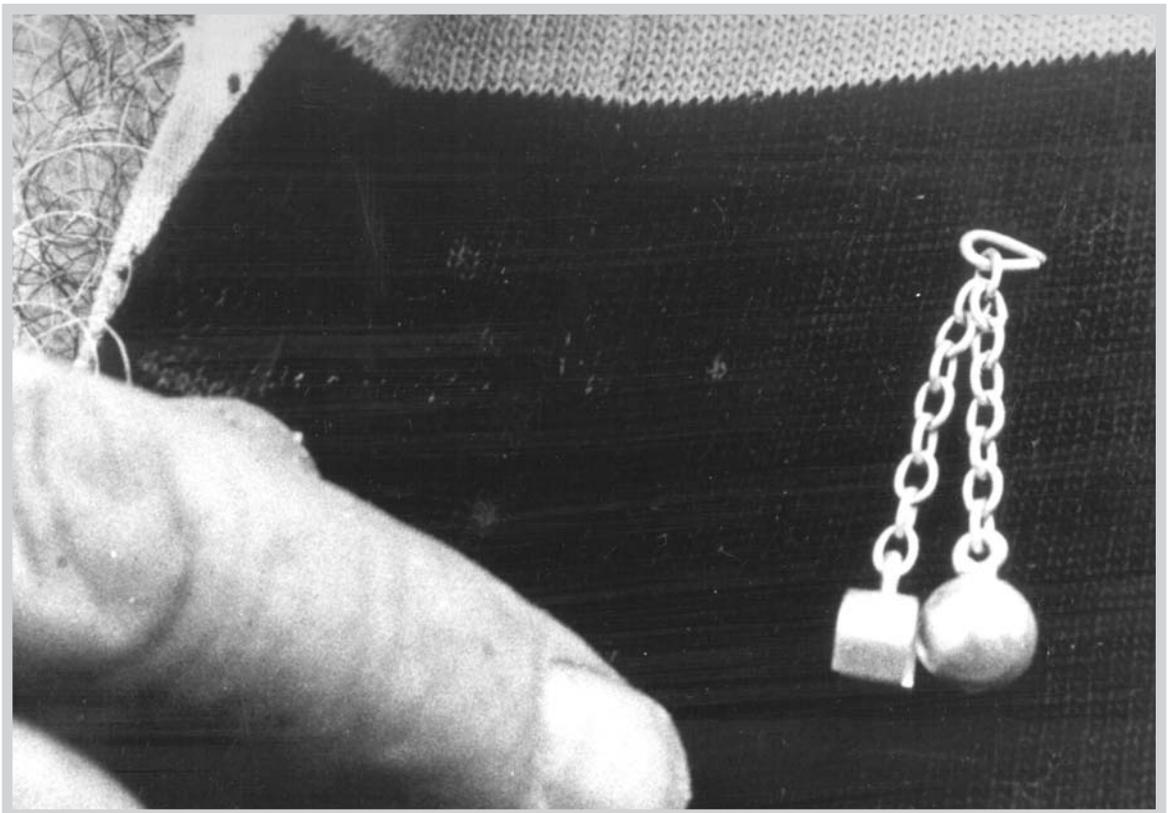
May we suggest that as a donor of building materials or equipment, you may wish to add your name to



The fathers at weekend work on the new medical building watched by Jenny and her friend, Kerry.



The building takes shape.



The ball and chain award for three days consecutive work 'represents the fetters that bind you to a cerebral palsied child for whom you have done something without reward.'

those on the Foundation Stone who are responsible for the gift of this building to the children.

A gift, not of a quantity of wood or of metal or stone, but the priceless gift of walking – of speech – to the many hundreds of these helpless children whose newfound happiness will surely bring you good fortune in the years to come.'

We prepared a listing of all the materials needed for the building, and I canvassed mercilessly by brochure and telephone and by personal calls until I achieved the support of one hundred and twenty-five companies or private persons who undertook their supply.

Materials were all in short supply and delivery was problematical, but once we started the building we did not have any hold-ups. Some of the people did not supply the material themselves, but arranged a substantial discount; others donated money of equivalent value.

We bought the bricks to enable us to obtain immediate deliveries. The timber merchants clubbed together and gave a donation instead of timber. McDonald Wagner donated the engineering specifications for the concrete beams and slabs. Bower & Leard gave us the use of a half-ton concrete mixer which we never returned to them, and Stuart Brothers gave a derrick for the erection of the roof principals. McMahon Brothers provided the use of a motor truck to pick up material through the course of the job. (Mr William McMahon of that Company was afterwards Prime Minister of Australia). We were given the bluemetal, sand, cement, lime, terrazzo, steel rods and RSJs, fibrous plaster, hot water system, glass, lead, baths, sinks, wash basins and wall tiles, not to mention the geraniums for the flower box.

The voluntary labour 'bees' started on 16 December 1945. The workers included the fathers of children attending The Centre and their friends; 'Bumper' Farrell, the captain the Newtown League footballers of the year, and fifteen players, one of whom was Paddy Bugden, a notable 'half' and the father of one of our CP girls. That set the tone for the other football clubs and all sporting bodies, service clubs, the Army, and gangs from the railway workshops, staff of Anthony Horderns, and others. We had established the pattern, and this was to continue in the later buildings. Workers included a Supreme Court Judge and an Army Brigadier, doctors, dentists, Council workers and many who felt impelled to help, on the basis of their good fortune that their child or grandchild was born healthy.

We instituted the miniature silver ball and chain lapel brooch, which was given to every volunteer worker on the third consecutive Sunday. This ball and chain has become a symbol of voluntary work for The Spastic Centre. It symbolises 'the fetters that bind you to a handicapped child, for whom you have done something without reward.'

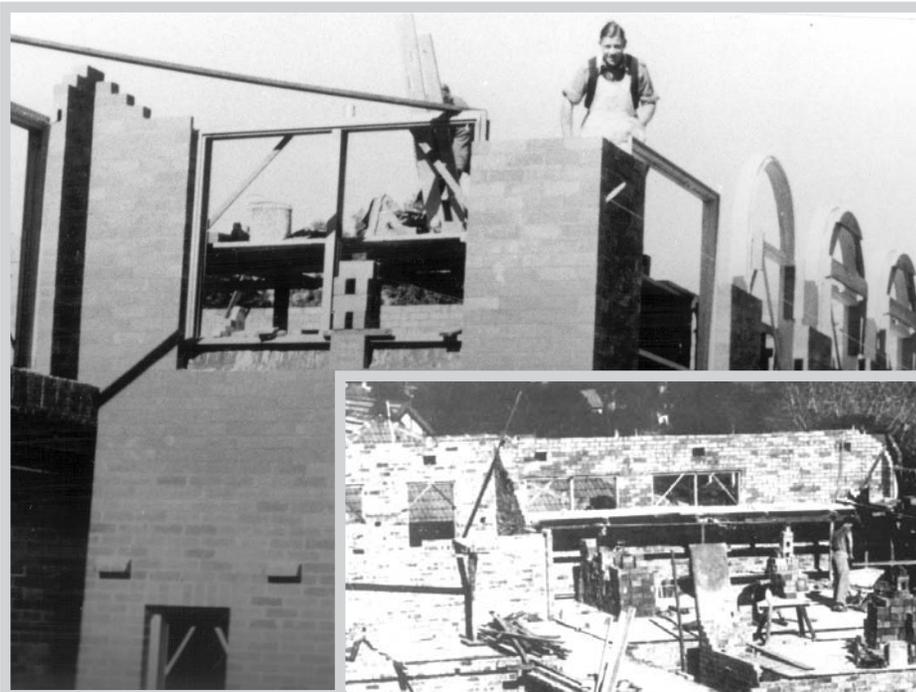
The scheme caught the imagination of the public from the start. Drinkers in hotels stuck coins from their change against the bar varnish, and put money into 'swear boxes' for The Centre. Some hotel managements gave sums outright, others subsidised £ for £ the drinkers' collections. In one hotel a wooden Dutch clog found floating in the harbour was set up as a collection box, was filled and refilled until it produced \$1100 – enough to buy a new bus. There were balls and carnivals, handicraft exhibitions, poster competitions, button days, issues of special stamps.

Gangs of volunteer workers sprang up from everywhere, from surf clubs, social clubs, all manner of organisations, to help with the 'hard yakka'. One group of working men travelled 120 kilometres by bus from Port Kembla on the south coast, after night shift, worked all day at Mosman, then went back again, many of them straight to work. A businessman gave \$2000, the first major individual donation. Another businessman, inspired by a motto on his desk calendar, collected hundreds of pounds for The Centre from his associates and from organisations with which he had contacts. Motorists waved Centre buses to a stop, gave the drivers anything up to \$10 for the organisation. When a party of the children was taken to a sideshow at the Royal Easter Show, the brass-voiced spruiker came running out after them with tears in his eyes, handed the money back and said, 'Here you are, mister, I didn't know'.

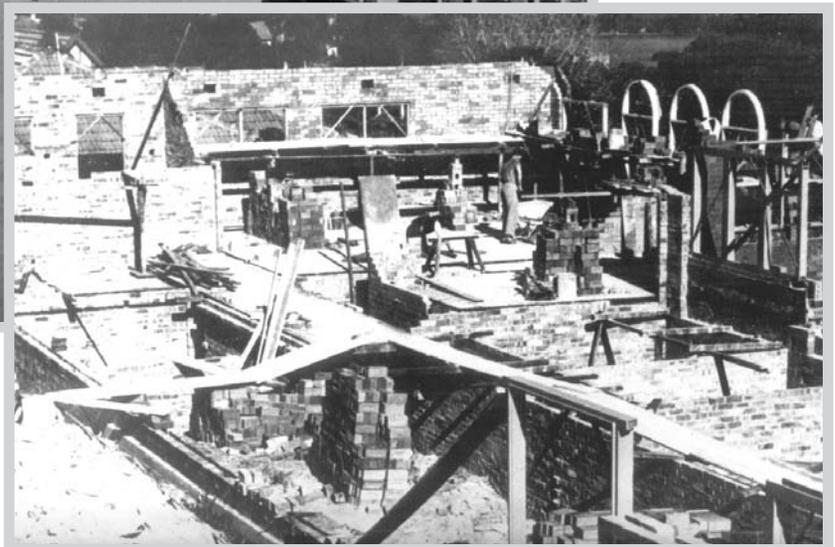
In the year 1946 the fathers' attendance had dropped off, and we were dependent upon them to show the flag among the other volunteer workers whose numbers had increased. My wife had a meeting of mothers who were doing their rostered duty and she explained the difficulty to them. They said, "Leave it to us, Mrs Mac.!" Then they descended upon the site for an hour that afternoon. They wheeled barrowloads of soil, stacked bricks, and prime-coated window frames. I don't know what they told their husbands that night, but we had a full attendance of fathers the next Sunday and that carried through the whole course of the building programme.



Alf Duckett preparing the bed for an R.S.J. Reg Kenny is not lifting the R.S.J. himself, he has ten men out of the picture. Harry Kenny and Reg Duckett watching.



Stan Rust, employed for five days as a brickie, worked as a volunteer on Sundays.



Half way there.

Due to the presence of a sandstone cliff, it was an unpromising site for a building, which was the reason it had not been developed in previous years. We would have to quarry that manually, with rock picks, gads and hammers, and cart it away in wheelbarrows.

To clear the jungle growth of lantana and blackberry from the site, the volunteer labourers, equipped with pick, shovel and wheelbarrow, commenced the heartbreaking job of removing a slice of the hillside rock, forty metres by twenty-five metres, weighing about three and a half thousand tonnes. For inexperienced workers they did a magnificent job, but it took some little time for hands to harden and for sharp experience to teach the importance of avoiding unnecessary risks. It was six months before the site was finally cleared and ready for the foundations.

We had arranged with the Engineer of the local council the loan of a supply of rock picks and long-handled shovels for the weekend, to be returned on Monday. Later, I secured a twenty-page listing of secondhand equipment for building purposes that it was proposed to auction for the Allied Works Council. I put in my bid for \$150 and it was accepted. That gave me a mountain of shovels, rock picks, drills, crowbars, wheelbarrows, leather gloves, bricklayers' trowels, spalling stone and heavy sledge hammers, sheet lead, carpenters' hand tools, an assortment of 300 pounds of nails, paint brushes and finally, a quantity of rope.

As many of my volunteers had spent some time in the Army, they were not above having the hammer that they had been using all day become, 'accidentally', attached to their belt when it was knock-off time. The process in the Army was called 'winning' and it was applauded, when another unit of the Army was involved. But this was not the Army, this was for the spastic children. So I attached a discreet notice, visible when they were going off the job, headed 'PUT IT BACK!' It worked like a charm.

With building materials being in short supply, we were forced to take delivery of these when available, and the restricted site added to our difficulties. So the bricks and timber had to be moved from one stack to another as the job developed.

That was not the way we wanted to organise the project, but time was crucial both for the suppliers and the general public, to maintain the impetus of our volunteer labour gangs. For instance, we received the door and window frames and stored them under tarpaulins on the tennis court, to be used four months later. It was the same with the reinforcing steel for the foundation beams and the concrete floors. It suited the supplier to deliver those for the total order and, as it was donated, we gratefully accepted it and stacked it on the long suffering tennis court.

The foundations of the proposed building were about seven metres above the street level. We could not obtain an access road until we had cleared the sandstone from the site and built a four metre retaining wall lower down the gully. Michael Pate, the actor and producer, will remember that wall because he earned his ball and chain on it. Mr Pate lived in a flat immediately below a four year old spastic boy who was obviously bright although he had little speech.

Michael wondered whether his training in speech development could assist him. He would be pleased to know that the boy, John Morgan, has been working at Centre Industries for the past twenty years and is married with normal twin children, and the sandstone retaining wall is still standing after nearly forty years.

Two sewerage mains crossed the site at right angles to one another, and had to be trenched and laid with concrete before the foundations could commence.

Despite the inexperience of these men and the prevalence of lighthearted horseplay and practical joking, only minor injuries were ever sustained, but there were some narrow escapes. It is humorously claimed by these men that every brick and stone in the building is spattered with their blood and festooned with their blistered skin – and it is almost true.

Having cleared the land, they then had to get to grips with the sandstone. Fortunately, two of the labourers we had engaged had served their apprenticeships with their father, who had been a quarry-master at Frenchs Forest in the old days. By way of introduction, they showed me the correct way to handle the tools, so that the hammer handle would not break, or the gad fly off and break your head (or that of a bystander). They taught me how to recognise the grain of the sandstone so that if you cut along the grain you could, with a minimum of effort, and the use of three or four gads in succession, lift a piece of rock weighing 300 kilograms.

I put that knowledge to good use as we cleared the foundation for the building and then the foundations for the piers, because Mr Pollock insisted that they should be tested up to one metre of solid rock underneath their footings. It was no good saying that near enough was good enough, because he used a scraper gauge and explored the sides of the pier holes for any bands of shale. One of the footings went down a spectacular ten metres because it was broken country, in the gully.

The sandstone was easy to cut when we were working on an existing face of rock, but down a one metre pier hole it was completely different. There we made use of a manual drill, a three metre long bar, rotated by hand, to bore a 25 mm hole into the sandstone base. It took a little while to acquire the skill to rotate the bar and lift it at arm's length vertically, then bite it into a new segment of the hole. You had to keep on doing that each ten seconds of your regulation thirty minute stint when a relief man took over. Due to the proximity of neighbouring houses, we were unable to use explosives.



The sandstone wall leading up to the loading ramp above.



The shoveling gang, Alfie Duckett and Curly Payne on the left.

It is humorously claimed by these men that every brick and stone in the building is spattered with their blood and festooned with their blistered skin and it is almost true.



Fathers preparing the foundations in 1948.

Inspection of the building site by William McKell MLA Premier of New South Wales.



Hydrotherapy Room



Mrs Anis Laubley sculptured this 2m high figure to represent in her mind the spirit of The Spastic Centre.



Mr Robert Pollock A.R.I.B. speaks at the opening of the medical building with the Members of the Board in the background.

In the meantime, the building material had to be manhandled from the street below, by passing it from hand to hand along a human chain. Four hundred tons of bricks were thrown in this manner, first up to the stacks, then up to the bricklayer working on the wall. Many fingernails were lost during this work. Most of the throwers at some time or another had an awkwardly thrown brick bounced off their ribs, stomach or feet. The one hundred and eighty-five tonnes of cement, sand and bluemetal were handled in wheelbarrows on planks in the same manner, with two men pulling as outriders and one pushing. The same chain system was used to move the terracotta tiles to the roof. With this help, the whole of the ten thousand tiles of the main roof were laid in one day.

One of the voluntary roof tilers was a middle-aged paraplegic who had injured himself in a fall from a high roof. He amazed me - he abandoned his wheelchair and clambered up the ladder using his strong arms and ensconced himself on the three-storey roof, supported by the tile battens. He laid more than his stint of tiles throughout the day.

After experimentation, I was able to evolve a system where Fred Marsden took the voluntary building tradesmen and I was responsible for the voluntary labour. This involved a team on the concrete mixers for shovelling the bluemetal, sand and cement into the loader, and a water boy. I operated the concrete mixer myself, because the mix of water was vital to the job and everybody had his own ideas as to what constituted an acceptable mix. Then we had another team manning the wheelbarrows up on the planks and another five to tamp and load the wet concrete into its place on the slab or beams.

On three occasions over the years we exceeded two hundred cubic metres in a single day; in those days we had a team upwards of two hundred volunteers. There was plenty of work for them all: the plumbers gang, the electricians gang, the pipe-welding gang, the brickies gang, the carpenters gang and the labouring gang. The average size of the team was about fifty men during those ten years. We had a separate gang to handle the brickies mortar and to provide them with bricks on the scaffold ahead of their requirement. Another gang handled all the timber, and was ready to hand it up to the carpenters as needed, for the scaffolding and the roof timbers.

It took some time for me to handle the voluntary weekend workers, but fortunately I had six months work on the sandstone in preparation for the building, so when the building started in real earnest, I just grew with the job.

Mr Pollock's practice had diminished during the war and he gave generously of his time. The building specifications were necessarily detailed and they were guarded jealously as an imprimatur of what was possible on 'tradesmen like standards'. If they did not reach that standard, they were simply discarded.

I first had to go through the details of the 'spec' with Mr Pollock or the foreman, Mr Fred Marsden, and arrived at a timetable for the course of the job. Then I had to list all the requirements for material for the building and had to call on each manager of a company in person - tell him what we were doing and then seek his assistance.

Remember, this was wartime and building materials were in short supply, but the number of 'knock backs' were surprisingly limited. Wagner and Priddle, on an honorary basis, had agreed to do the engineering design work for the beams and columns. They were limited on the first building but on the second building, the floors totalled 3,000² metres plus beams and columns. However, they manfully stuck to the task and for good measure designed the column and beams for the Country Children's Hostel. Truly a magnificent contribution!

I took over the responsibility for the blueprints of the construction steelwork of the job which detailed each beam, column and the concrete floors. I became so engrossed in the detailed analysis that I was able to plan Sunday's work ahead of each week without being held up for wiring the particular steelwork required for the next week's concrete pour.

We could not afford an air compressor on this building and bulldozers were things that the Americans used for aerodrome construction, on the movie newsreels. It was all done with rock pick, shovel, wheelbarrow, hammer and manual drill. Similarly, we did not have a reciprocating dumper on the concrete when we were mixing the beams and had to depend on one man dumping the concrete down with a piece of flooring board. This was before the era of ready mix concrete, so the concrete was mixed in a huge concrete mixer which we had borrowed and wore out over the next fifteen years.

Fortunately as it happened, the very first foundation beam that we laid stripped very badly, showing that the concrete had not mixed correctly and had not been dumped down on the steel. It displayed ugly honeycombing on its surface and this weakened the beam considerably. We paid the penalty for this, because Mr Pollock insisted on building an additional column for the displacement of the weakened beam. That entailed a seven metre excavation - about a fortnight's work. So we were very careful after that with the concrete mix and the dumper. We never had another failure with our column and beams over the course of the next ten years. We had learned our lesson well.



The initial medical building. The school was continued in the original building for two years.



A loading ramp at floor height provided a rear entry from the buses. The school is visible in the background.

During the late nineteen forties antibiotics were available to the civilian population, and that quickly controlled the respiratory infection of the lethal high fevers of pneumonia, diphtheria, scarlet fever, whooping cough and many other infections of children. As a result, the life expectancy of the cerebral palsied child was considerably extended. In association with the reduction in these infections, came treatment in our medical unit which made affected children more mobile. It lifted infants into proper postural positions, supported dangling feet with footboards, corrected dislocated hips and prevented over-active muscles and growing bones from distorting joints, thus adding to the possibility of attaining a normal life span.

In our first years, teaching a cerebral palsied child to walk was the primary objective. It took time to realise that the lack of speech was by far the greatest handicap for the cerebral palsied. The ability to speak opened many doors that were permanently closed to the spastic – environmental, developmental and educational.

With our medical unit, no similar building existed in Australia or overseas because treatment of cerebral palsied children was then a comparatively recent development. Its problems differed completely from those of schools or hospitals and were not strictly comparable with those of Crippled Children's or Hospital Schools. They compared more closely with the rehabilitation institutions which were developed after World War Two to rehabilitate military paraplegics and amputees. Our experience over six years was therefore incorporated in the design, by a process of physical trial and error, which could not have been avoided by reference to any medical or other authority at that time.

The first of the new buildings was erected in 1946, comprising a ground floor of approximately nine hundred square metres. This building was planned primarily on the mistaken assumption that each child under treatment would require a period of rest and relaxation purposes each day; as a pre-requisite to physical therapy it was equipped with folding cots for that purpose. That was a mistake because, with the children arriving at 9.00 a.m. and departing at 3.00 p.m., there was not time for schooling and physiotherapy and the doctor's clinic. We had enough trouble in arbitrating Miss MacDonald's claims for more time for school with the Medical Director's therapy programmes. The relaxation periods grew less and less, until we stopped them altogether a year later.

Provision was also made for two isolation rooms to be used as 'crying rooms' by children, whose crying would otherwise disturb the other children resting. However, these rooms were in fact never used for that purpose, because by the time they were completed the children had become contented working groups, to whom new members, including infants, could be introduced without their being unduly distressed. For instance, when the bus called for Chana, the four-year old daughter of an American diplomat, she cried lustily and clung to her mother for the first three days. On the fourth day she was eager and laughing, and did not even say goodbye to her mother. Then it was the mother's turn to weep. She had lost her baby!

The other service rooms included physiotherapy room, occupational therapy room and hydrotherapy room. The latter included a stainless steel heated tank, with a smaller bath for infants, to be used with hot and cold shower heads for muscle stimulation. One of our suppliers, Armco Company, presented an electric hoist as a memorial to their founder. Shortage of trained staff prevented the effective use of the baths, although they provided their value in teaching older children preparatory swimming exercises. The hydrotherapy pool might well have been justified at the time we installed it, but the physical problems involved in shifting from the physiotherapy room to the group rehabilitation tank, of getting the patient in and out, with the therapists in swimming costume, and then drying them off, did not justify the time spent as against the physiotherapist giving her exercises on the treatment table. We pulled the hydrotherapy tank out in later years and now the wheel has turned again. The therapists want to see whether they can now make use of a heated pool.

The sub-basement originally provided for medical office space only, but was invaded to provide plaster and X-ray rooms, speech therapy cubicles and storerooms. This necessitated some stairway traffic and has proved to us that staircases cannot be negotiated with any degree of safety by these children.

This building was a medical unit only and the schoolroom remained up the hill at the original residential building. Due to of the fall in the hillside, the new building was thirteen metres below the schoolrooms. Consequently, the children had to be loaded into a bus from the school and taken around the block to be off-loaded from a ramp at the new medical unit. This was a serious disadvantage in time, but even more serious than this was the fact that it cut communications between the medical staff and the teaching staff. So, it was a temporary solution only.

The children occupied this building twelve months after it was commenced, but it was still not completely equipped.

The success of this building was important for the public goodwill of The Spastic Centre, because it was in tune with the post-war philosophies of free treatment and co-operative self help by the parents. It was a good story and the newspapers and magazines played it up. The voluntary weekend workers were equally important, in that these people were prepared to do something for an

unknown spastic child and despite the restrictions in building materials, we were always able to find somebody anxious to help. The opening ceremony for the new building in April 1947 was officiated by the Premier of New South Wales, Mr William McKell (later Governor General of Australia). We were novices in parliamentary circles at that time and we did not take Mr McKell's speech with the necessary grain of political salt. He had admired our work in erecting the building ourselves and we thought that he would open the door for governmental participation. Forty years later we are still waiting for state government fiscal aid (twenty-eight years for the commonwealth government subsidy).

Following is an extract from an article in 'Woman' magazine in 1945:

'The school for spastics not only brings a touch of heaven to the children, it opens a whole new world to the mothers. From the day her spastic child is born, a mother is completely tied to it. Most social contacts are barred to her because she cannot leave the child for a minute. Friends and neighbours cannot be called upon to mind a spastic child.

In effect, the mother is debarred as completely from social intercourse as is her child. The child makes her nervous and irritable and while she is actually trying to do everything in the world to help it, her nervousness and irritability are transmitted to the child. The unfortunate spastic also affects the mother's relations with her other children and frequently with her husband. There is an alarmingly high percentage of divorce among parents of spastic children.

Some of the mothers are widows. There are several cases of women who lost their husbands in the war and were left with a spastic and other normal children, trying to struggle along on a pension.

Others are in very poor circumstances and all are under a financial strain because maintenance of spastic children is expensive. They must have continuous medical care, need special boots and all kinds of costly equipment.

That is why The Spastic Centre makes no charge. It was realised that even a small fee would prevent some child from obtaining treatment and instruction. So, in addition to their work at The Centre, the mothers work hard trying to raise funds.

A horror seizes the mother of a spastic baby, that she has given birth to an idiot, which makes her cling to him with fierce, possessive love and chains her inescapably to his side. Sometimes mothers become neurotic enough to need help as much as the children do – and many divorces are brought about by bitter quarrels over a helpless, hopeless child.

There is radiance about the mothers who bring their children to the Mosman Clinic and help with the work there – a breathless, inarticulate joy possesses them as they see their children improving daily.

Perhaps I could tell you the story of the two eleven-year old Harrys – comrades in arms in this splendid earth-shaking battle for speech and movement. They are veterans with a strong respect for the fight that each is making. Throughout the year competition between them, in the school and in the therapy room, was dogged and enthusiastic. In a way, both were victorious. The first Harry was best with his school work; the second Harry learned to walk, with irons and crutches, for the first time in his life. His mother, who is Irish and therefore believes in miracles, told me all there was to be told about her Harry.

"My Harry was born a twin" she said, "but the other one was born dead. The doctors don't know how we kept living, Harry and I. From the beginning, it was unfair to him, the way he came into the world, he being with a dead baby in the darkness. He was never given a chance. And he sat at home like a lump of wood year after year, and I took him to doctor after doctor – for nearly six years I took him to the hospital, and they could do nothing. My Harry couldn't go to school. He couldn't go outside the house; if he did he had to be carried every inch of the way. And I'd meet people in trams and trains, strangers sometimes, who'd say to me, 'Why don't you go to that doctor, this doctor' And I'd go to them all, but it was hopeless.

"And then The Centre wrote to me – I didn't have much hope but I thought I'd try it; you try anything when your child is like my Harry was. But, after he'd been at The Centre a while, he started to talk – a word or so here and there. And then my Harry stood up with his crutches – after so long dragging himself around on the floor. When I think that when I brought him here in February I had given up all hope, I want to tell

all the other mothers whose children are like my Harry that there is hope, and there is work being done here that will preserve them from the sorrow and the worry and the bitterness I had.

And there was "my Harry", a chubby, normal little boy, radiant at his first party."

Mrs Anis Laubley, (who was Mr Pollock's sister-in-law and a noted sculptress), designed a mother and child figure to be positioned at the end of the entrance hallway in a specially built apse. The madonna-like figure stood 210 cm tall upon a foundation of black glass and was finished in a light cream colour. In my mind it typified the role of The Spastic Centre.

Unfortunately Dr Burton-Bradley had allocated this space for her medical records and she could not approach the statue with the same enthusiasm, however she eventually forgave me.

In 1947, we were firmly established in our medical treatment unit and it was time for a financial settlement with Arthur Sullivan, and accordingly I wrote to the Delegate of the Treasurer in the following terms:

I hereby certify that these items as included in the purchase price of £6,500 for the 6 Queen Street property owned by Mr A. Sullivan:

1. 'Aeolian Ochestrelle Electric Player organ with automatic blower £500; Venetian Blinds £250; Chandeliers £100; Sundry £175.
Total £1,025.
 2. Additions to the property by the vendors since its purchase in 1941 £885. Licenser Valuer Wilfred Allen No 345 is attached.
(This includes the house and adjoining vacant block situated at 6 Queen Street and Cabban Street Mosman).
-

In those days, Jenny was growing up quickly and she had sprouted from a five year old child to a ten year old Miss. The school was also growing, so much so that it had absorbed all of the space downstairs and we had to build an office for the office staff upstairs and the transport was relocated to the outside balcony.

During the day Jenny wore a collar and heavy aluminium braces, and heavy brown boots. After school they were taken off so she was able to relax on the lounge.



Dr and Mrs Carlson visit he Spastic Centre. Betty Simmons is being examined and her friends look on – Ann Meagher, Noel Giles, Reg Duckett and Harry Kenny.



Reg Duckett operates a Burroughs adding machine with the figures replaced by alphabetical letters. Noel Giles looks on.

In bed at night she wore night boots and they were splinted to stretch the muscles of her feet and that meant, that during the night she had to be turned over.

During the day, Jenny's speech was restricted to a single word amplified by imperative gestures but after sleeping at night, her relaxation was such, that her speech became normal, and we were able to use that time to catch up on her schoolwork and anything else that may have been puzzling her at the time.

One night I awakened to the sound of Jenny's screams. I went in to her bedroom and found her in a complete spasm; and all I could find out from her was that the 'moon is down'. I stayed with her until she calmed down and I told her that she had a nightmare, and then I forgot about it.

It was months later that I was in Jenny's room to turn her over, and the same thing occurred – the 'moon was down' with a vengeance; it was shining like a searchlight from the ground directly into Jenny's window. Momentarily I was shocked, as Jenny had been and the hair on the nape of my neck started to crawl.

The solution was simple – Jenny's window was on the third storey and a neighbouring cottage was lower and it was shadowed beneath a Camphor Laurel tree. The full moon overhead was reflected by the glass of its hopper window, so it gave the effect of being on the ground – where it had no right to be!

In October 1948, we were honoured by the visit of the illustrious Dr Carlson, at which time he said, "I have visited twenty-seven different countries, but never before have I seen anything to equal your Centre. It just showed me what could be done when thought is directed wholeheartedly in any specific effort."

That comment spelled the finish to our plans of four years earlier to take Jenny to America. It was confirmed a year later when I

visited the U.S.A. in connection with the splint project and had long talks with Dr Carlson and his medical confrère. Jenny's treatment would be much better in our own Centre.

In 1948-1949, we used the voluntary labour again to build two additional schoolrooms onto the original house. That did not present any problems and we took advantage of the activity to provide toilets for the children, and in the basement, toilets and washroom for the bus drivers, and extensions to the canteen.

The reason for this extension of the school was that Dr Burton-Bradley and the therapists were finding their way through the conflicting mass of data on the physical and psychological problems of the individual children. In the midst of this the Department of Education with a heavy hand, discharged twelve of our children from the school, on the grounds that they were ineducable. The Education Department was still conducting its school in a building we owned, and they contributed nothing towards transport or even the cleaning of their classrooms, but we swallowed our anger. We decided that these children should not be denied the treatment and schooling on such a short trial and we set up a schoolteacher of our own, not connected with the Department of Education. The activity was known as 'Group Seven' because we did not want to label those children as mentally retarded or ineducable. It did not cross our minds that we were labelling them with the 'Group Seven' label instead.

Investigation of the Group Seven children produced surprising results, which were soon applied to other spastic children. It centred around the children who were described by teachers and therapists as being 'unable to concentrate'. The reason for this was later confirmed by audiometer – these children were all deaf, or hard of hearing in varying degrees. The reason it had not been established before this was that the children had learned to lip read without being taught. When spoken to directly, the child would respond, but when the speaker's face was turned away the child did not. This gave us a new look at the problems of the deaf and the hard of hearing, the associated athetoid movements and the education of the cerebral palsied person. Most of this group proved to be Rh children, confirming Dr Burton-Bradley's analysis.

We had suggested, in view of the work we were doing for spastic children, that the Government of New South Wales, headed by Mr McKell the Premier, should contribute to The Spastic Centre. When Premier McGirr took over, and attended the opening of our newly extended Centre, built with voluntary labour, we renewed our application for some form of financial assistance. He said that we should apply to the Hospitals Commission. Accordingly, in July 1947, we applied to the Hospitals Commission as instructed, for recognition to be made under Schedule Three of the Health Act. The Commission sought refuge in the Minister for Health, Mr Sheehan, who had given instructions that no further applications would be considered under Schedule Three and our application would have to be considered under Schedule Two.

The Hospitals Commission considered our application and stated that registration could be effected upon compliance with the following:

- The abandonment of the present policy of free treatment for children.
- The abandonment of free work contributed by mothers and fathers as their responsibility to The Centre.
- The employment of staff in lieu at Award rates.
- Liquidation of The Spastic Centre and the funding of its assets, membership and management in a new organisation to be formed by donors of ten shillings annually; and (inexplicably)
- The maintenance of The Centre's money raising efforts and activities at its present level.

We made successive applications until September 1949, when Mr Morton again raised the matter in Parliament. Mr McGirr's reply was, 'Mosman Spastic Centre is doing laudable and worthy work, and should not be made a political football. We are anxious to meet the request if The Centre will comply with the law.'

Compliance would have put us and our organisation at the mercy of the Hospitals Commission, without any guarantee of necessary finance. You must remember that the hospitals were not very interested in the plight of the cerebral palsied. The President of the Health Commission admitted to me that we would do better on our own and even the doyen of the medical fraternity in Sydney, expressed the opinion in public that the work of The Spastic Centre was a waste of public funds.

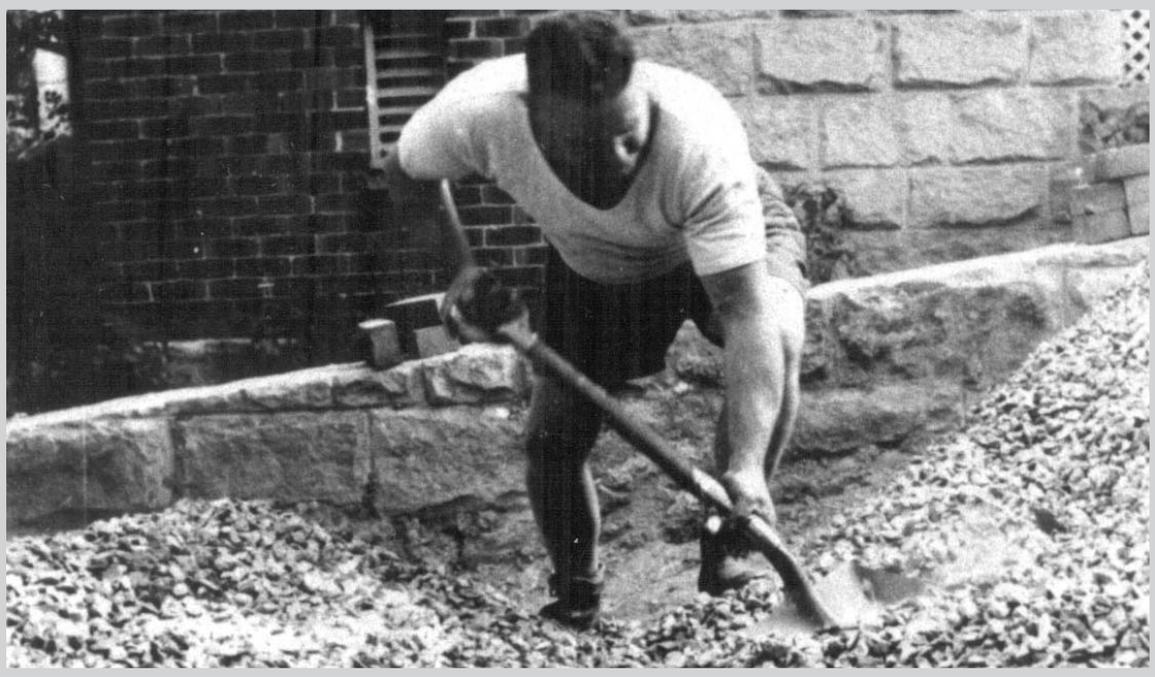
By nagging Premier McGirr unmercifully during the eight years of his office, I believe we made a vital mistake, because we were only a small minority of the community and we 'got his back up'. I think we could have done it differently at the time.

Premier McGirr was followed by Labor Premiers Cahill, Heffron and Renshaw. Then Mr Askin became Premier with the change to a Liberal Country Party coalition government. He was succeeded by Messrs Lewis and Willis and then in 1977 the Labor Government returned to power with Mr Wran as Premier.

the second stage



The start of the second stage of the building designed to bring the school and medical treatment together again. From 1949 to 1952.



Noel Giles, the best shoveller of blue metal on the job



Bernie Stanton shows how



The ubiquitous concrete mixer



Brian Kelly, a gang leader

Had we not antagonised Mr McGirr, but instead persuaded him at all costs to grant us State financial subsidy, it could have been written into the budgets of the Labor ministries which followed, and that would have made it harder for Mr Askin to be the 'odd man out' in subsidising The Spastic Centre. We hopefully live and learn! It is interesting to note that all five of the other states are heavily subsidised by the state government; ours is the only exception.

On the other hand we would have to gauge the effect of the voluntary weekend building labour. Would we have acquired that had we received a full measure of assistance from the state and federal government? I think the government might have put us off with a one or two thousand dollars, whereas the buildings we erected with voluntary labour would have, at the time of the building, cost more than a million dollars. In addition, every hour that a man worked on those buildings made him a friend of The Spastic Centre for all time, and he had the blisters to show for it. And I think that the private and company support would have receded very much with the news of Government support. But it makes me wonder whether we should have gained political support instead of going it alone.

By 1950, our number of daily spastics had grown from 35 to 100, with 200 outpatients, therefore the medical treatment building was obviously too small. I think The Spastic Centre had grown through the goodwill of the public and the medical profession, but unfortunately, every amount of money we received had to be spent on new services and equipment for our growing number of cerebral palsied.

Our honorary architect, Mr Robert Pollock, had supervised the construction of our first building, and was given a free hand in design and colour. Two years later, when the paint was hardly dry on the walls, he was appalled when I wanted to pull off the roof of that building and gut it, to prepare foundations for another new building, four times the size. In spite of this he manfully stuck to the job because, he said, "he was frightened of what I might do if he left me without his supervision"!

It was a tribute to that initial spirit of independence, which permeated the whole structure of our weekend volunteers, that we were able to plan such a large four-storey brick and concrete building to house both our school and medical unit.

We did not suggest that the Education Department should contribute to the building because, had we done so, it might have weakened our policy of having our medical staff and therapists participate in the classrooms with the departmental teachers, in a building which we owned. In that case, it would certainly have made it more difficult to obtain building materials and weekend labour.

We had planned that the projected third storey would be completed up to wall and roof stage but would not be finished inside. This would save the time and money required for a further extension when that became necessary. Unfortunately, by the time the building was finished the third floor was filled with children too.

The foundations of the new building required quarrying at ground floor level and the removal of a mountain of sandstone, three times greater than for the original building from the site alongside that building. So it was back to the early days with rock pick and hammers, only this time, instead of a two metre vertical ledge on which the original building was constructed, it would take it down to ground level for our boundary. This would involve quarrying out a vertical face of about ten metres of sandstone.

One of the problems that unexpectedly came up, was identifying on the site the second of the two sewerage connections that ran through the building. It was marked on the Water Board's plan with a manhole and we later found it. The manhole was two metres below ground level and the reason it had not been found earlier was that a twenty metre camphor laurel tree had grown immediately above it.

Mr Pollock, our honorary architect, had this to say about his work:

'Providing a proper educational environment for cerebral palsied children has become increasingly important in recent years. No longer are they regarded as mentally deficient. Progress in the diagnosis and treatment of the affliction has made it possible for a large percentage to become useful members of society. The career of the cerebral palsied physician, Dr E R Carlson, is a great source of inspiration and hope for the cerebral palsied.'

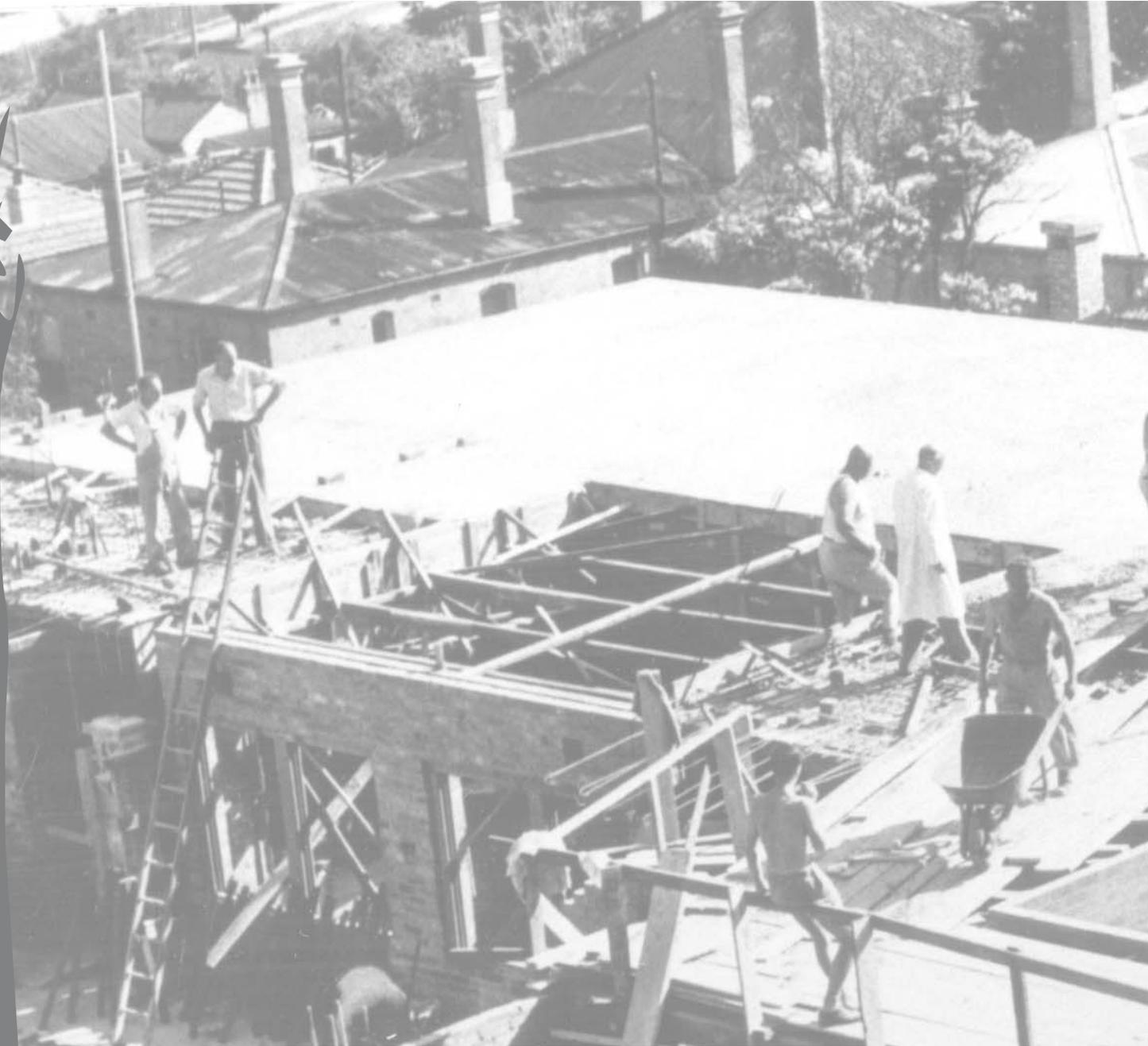
The traditional school is not satisfactory. The particular specialised training that is essential requires a unique physical layout which is a challenge to the architect. By providing the kind of plan, structure, spatial arrangement and facilities that are needed, the architect can supplement the physician, therapist and teacher in helping the cerebral palsied to overcome their handicaps sufficiently to lead satisfying lives.

The architect must familiarise himself with all of the manifestations of cerebral palsy; he must not ignore



Everyone has
a job to do.

Loading the concrete while carpenters are preparing the third floor slab.



Mr Pollock with his white coat superintends the laying of the second slab.

the dangers that confront the palsied from sharp edges, easily overturned furniture, breakable glass, and slippery floors.

We must recognise that many of these children find it difficult to maintain balance. All of these factors must be taken into account in the basic planning of the building.

Wherever training is undertaken, it is essential to create an atmosphere wherein the cerebral palsied child can relax and concentrate on the task at hand. We must plan a building to provide for a wide variety of situations, taking into account the special skills of the children as well as their inadequacies. Some of the children who cannot walk, can drive and ride tricycles.

The school space must provide excellent lighting and acoustic conditions and must be planned to lend every possible protection and encouragement to the educational growth of the palsied child. The building can be of enormous assistance to these children if it is imaginatively planned; the architect should not resort to rigid patterns of space allotments and expect efficient operation. Elasticity should be obtained by recognising the fact that many factors influence spatial arrangements. Such factors include the number and types of the handicapped, the training programme at school and the amount of money available for construction and equipment.

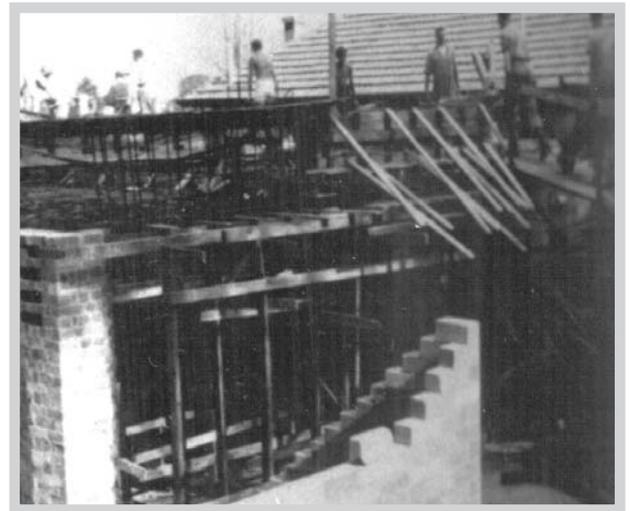
Corridors should be a minimum of 3.3 m in width. This is the required clearance for two children on crutches side-by-side, passing in opposite directions. The corridors must have no obstructions. Doorways used by the children should be four feet wide. Simple, horizontal pipe handrails should be used on all interior doors to assist the children as they move from room to room.

Classrooms should also have multiple handrails and a grab bar at strategic points, since the children are encouraged to walk. To simplify group arrivals in the morning and departures in the afternoon, ample milling area should connect the main entrance with the corridors.

A quiet, restful environment makes it mandatory that ceilings and walls be acoustically treated. The floor surface should be smooth enough to permit easy movement of tables and chairs but, at the same time, it should furnish enough traction to prevent crutches or feet slipping. Floors should be level to prevent accidents to the children as they move about within the school. Perfect floor level is of particular importance to those children who are being taught to walk on 'skis', which are simple flat boards about 60 cm long with pockets for the children's feet and with a pole extending from the front of the 'ski' up to a



Paddy Bugden and his team from the Newtown Leagues Club.



Some idea of the complexity of the job. While the people on the horizon were laying their second slab, the man in the second picture was loading up concrete columns. The tennis court was occupied with prime coating window and door frames. The steel in the foreground was wired into position for the next week's pour.



position where it can be grasped by the hands. Many materials, such as asphalt tile, rubber tile, or dull-waxed hardwood, will meet floor requirements.

All classrooms should have conduits provided for an inter-communication system, radio-phonographs and cinema projection. Plans for wiring should include outlets for microphones which are used at work tables to aid the children with breathing and speaking difficulties. In some instances the affliction is so severe that the throat microphone is an absolute necessity in enabling the child to be heard.

In conclusion, it should be emphasised most strongly that the cerebral palsied children should be given a physical environment which is tailored to their educational needs. The cloth must be cut to the pattern. If the architect succeeds in creating the best possible environment and educational facilities he will have made a major contribution to the work of the teachers, the therapists, and the children themselves who have been struggling along with makeshift facilities for so long.'

We started the planning in 1951, and our objective was to get the three-storey tower building complete, then move our children over to the new building. We then planned to pull the roof off the existing building, double the size of the ground area and take the building up another two storeys.

In planning the new building it was evident that the total space requirement of 3600 square metres could not be laid out on one floor level without placing the rooms at the extremities too far distant for practicable communication. To divert a private roadway through the building and to load the children on/off four flat loading areas in the roadway, use was made of the natural fall of the ground on the hillside which would enable each floor to be on successive ground levels.

The installation of lifts had been considered, but the size of the units required to transport children on crutches, in wheelchairs and being carried by orderlies would have made it a most expensive installation. It would cause a bottleneck which, with the slow moving children, would have made it necessary to provide at least six such lifts – an obvious impossibility. Staircases and ramps are equally dangerous for children – they are impossible for crutch walkers, extremely dangerous for children being carried, and impossible for wheelchair traffic. Mechanical stair hoists and slippery dip types of chutes could be adapted to function efficiently in completely closed corridors which, however, would require too much floor space. The new plans provided staircases for staff communication only. In addition, fire control necessitated entrances at ground floor to provide alternative exits.

The schoolrooms, previously in a separate building from the medical treatment building, were brought together. So that as near as practicable schoolroom, toilet, physiotherapy, occupational therapy, speech and dining room were in the closest proximity and every floor was self-contained, except for specialised services such as X-ray, EEG or plaster work.

Cot rest periods were eliminated for all except babies under three and some athetoids, comprising perhaps 15 per cent of the total number of children. The original cots were replaced by collapsible cots standing on their ends in racks in the schoolrooms; over the years these were discontinued.

The mothers had always had the responsibility of toileting the children. This was intrinsic in the mothers' duties because they learned about children other than their own and from the child's viewpoint the mother approached her job with a tender care. The same principle applied with eating and drinking at lunchtime; here the mothers operated under the supervision of a speech therapist because of the importance attached to speech training.

Separate toilet accommodation for girls and boys had not previously been provided, but as some children were in their late teens this always presented a difficulty. Separate blocks were therefore provided for boys and girls, and the 'Schooler' kindergarten pan provided for pre-school children. In order to give the children more control, all pans were set at varying heights in the terrazzo floor, the lowest at vent height, being 20 cm, and the highest 38 cm. Wash basins were set at staggered heights, with mirrors immediately behind for teeth and face cleaning and hair grooming. Plumbing was standard, with as large a range of standard fittings as possible. A high, control mixing valve controlled the temperature of hot and cold water. A low change table was essential in the girls' toilet, especially for the more helpless adolescents and bars on each side of each pedestal were required to enable helpless children to balance themselves. Sufficient space was necessary to enable an attendant to stand on either side and to the rear to hold the helpless child on the pedestal. The urinal was designed without a step and the floor of the urinal stall was solid and drained into the urinal without obstruction, the corners adjoining the urinal being covered to 10 cm. The crossbar across the face of the urinal was necessary to maintain balance.

The physiotherapy room previously had been arranged on the conventional hospital pattern of cubicles separated by curtains, each containing a physiotherapy plinth. The arrangement of these rooms was changed to a gymnasium type of layout, without the rigidity of the cubicle concept. Fittings included wall and ceiling full-length mirrors, long walking space of more than seven metres with mirrors at each end, and with painted lines on the floor 15 cm apart for training in crutch gait. The plaster room was fitted with a standard stainless steel sink and plaster trap and the floor was terrazzo.

Floor coverings presented one of the most difficult problems associated with such a building. Expense had previously necessitated the use of unpolished scrubbed tallow wood. Our traffic included crutch walkers, children in walking frames equipped with skids, children sliding wooden skis, tricycles and small wheel toys, and wheelchair traffic, and more than 80 per cent of the children were equipped with some sort of metal leg braces. More than half of the children scuffed one or both feet.

The new building forced the abandonment of wooden flooring because its area precluded scrubbing, even with electric machines. Polishing was not permissible, and some cleaning was essential after every meal in each room used for feeding, because all the children were untidy eaters. We experimented with cork carpeting in the physiotherapy rooms, linoleum (lightly polished) in the schoolrooms and asphalt tile (unpolished) elsewhere.

The hallways were all equipped with handrails of three heights and the doors with vertical bars. All door handles and other equipment were placed at standard heights, so that the children became accustomed to normal equipment likely to be met with elsewhere. Thresholds, however, were all placed at floor level, steps eliminated throughout and all staircase heads provided with gates.

Visitors were excluded from treatment rooms, but the continuance of public interest demanded that they should be able to see the children at work. One-way vision windows were therefore set in all hallways to provide a view of work going on in each of the school and treatment rooms.

One large hall was essential to enable all children to be brought together for special events, picture shows, and concerts provided by the children themselves. As few of the actors in this case were capable of walking, they had to perform their parts from their chairs. Long periods of inaction were inevitable in moving one group of children from the stage and arranging the special chairs for the next group. A revolving stage was therefore designed for the assembly room so that this important aspect of the children's year's work could be developed more fully.

The first brick in the new treatment building was laid on 23 January 1952, and, notwithstanding the gigantic problems arising from procurement of material, planning, and general construction, work on the building as envisaged was completed before the end of 1953.

On 23 January 1954, the building was officially opened by His Excellency the Governor, Lieutenant-General Sir John Northcott, K.C.M.G., K.C.V.O., C.B. At a cost of a little more than \$600 per square, the building provided working space of 3600 square metres which permitted us, for the first time, to give daily treatment to a least twice our previous number of children, and an effective out-patients department for the 513 outpatients on our books. New patients averaged three per week. It also gave us space to



The completed building for the school and medical unit combined. We took advantage of the hillside for loading the buses at each level of the four storeys and we had ground floor access to each floor.

bring in more honorary consultants of the medical profession to work in new specialties, such as the hard of hearing, ear nose and throat, and electroencephalograph, and the facilities to do dental operative work.

This new building housed the schoolrooms and medical therapy together in the same classroom. Previously the school was separate from the medical building and consequently there was little communication between the two groups. Now they were together, not only in the classroom, but in the commonroom and this improved the work they were doing for our CP children in every way.

Our Medical Director, Dr C. Burton-Bradley, said during her speech, that never in the history of The Centre had so many children made so much physical progress as rapidly as in the last twelve months. Never had the orthopaedic braces been so effective nor as well made as these had been. The EEG machine, despite its high price, had yielded a wealth of information and the typical spike of epilepsy gave us an opportunity of aborting a seizure before it happened. The EEG positive tracings showed evidence of cortical damage or defect, but were a higher percentage than we originally anticipated. With the knowledge gained from our psychological investigation, we were beginning to attack the specific problems of a number of reading difficulties as they occur in individual children. Dr Burton-Bradley concluded that, for the most part, our outpatients were seeking help at an earlier age.

I well remember the day in 1946 we were planning to start bricklaying on the first job. We had twenty-eight brickies who answered the call and it rained continuously throughout the day. The brickies stayed around for an hour or two and then they gave it away, and we never got that team back again. One indefatigable character rigged up a canopy and laid 500 bricks out of a scheduled target of 20,000. I felt so disappointed. It seemed that the heavens were in league against me and even though I had a picture of the brickie (whose name, appropriately, was Stan Rust) in the newspaper the next day, it did not console me one little bit.

On another day, we had scheduled 200 volunteers for a 100m³ of concrete to pour, and when the first truck containing ten tons of bluemetal arrived on the Friday, the driver had some trouble with his brakes, and dumped the load on the footpath. The rest of the fleet of nine trucks followed his example and dumped their loads on top of his. When I got home that evening, I was staggered by a mountain of bluemetal on the crest of the hill, when it should have been placed by the sand and concrete mixer fifty metres down the hill. I could not hold off the pour and we could not move the heavy concrete mixer up the hill but fortunately I knew a man who had a mini-dozer. He agreed to try it out, but he did not give much hope against the mountain of bluemetal. A full sized bulldozer would not have room to work. Fortunately the mini-dozer did the job in just thirty minutes. Working from the back of the crest of bluemetal, I found to my delight that the bluemetal rolled down the hill to the right alignment. We could not have done that with fifty men shovelling.

The voluntary workers were just ordinary people, with a sprinkling of building tradesmen. They were especially good at labouring jobs, but through ignorance they took tremendous risks, so we instituted a ganger in a red hat; he was responsible for the work of his gang.

One job involved the dismantling of the sheeting on the ceiling underside of a concrete floor. To my horror, I found that they had removed the forest of wooden support poles and left the wooden sheeting still attached to the underside of the concrete, seven metres up. The area of this was ten metres by twenty metres and there were men working below. A single blow from a crowbar could have set the whole mass down among their heads. Fortunately it did not happen before I arrived, yelling my head off. Actually it was my fault – I should not have left them unsupervised for so long.

One of the overriding problems of this building extension was the access roadway through the garden and down the steep hill. The plan was for a 90 cm diameter stormwater pipeline to go underneath the roadway and through the archway of the building. We excavated and then laid each two metre section of pipeline manually, using crowbars and a gang of twelve men. When in position, each junction had to be cemented both inside and outside to make it completely waterproof. The outside was easy, but to my surprise we had difficulty in getting a volunteer to work inside the pipeline. None of the gang I had selected was experienced in this kind of work, but two of them said they would take it in turns. The first of them came out of the pipe and complained of a headache. The second man took over and at the morning tea break, having done only another couple of junctions at the top end, announced that he wanted another job on the surface. I was busy and could not hide my irritation, because I was needed to supervise the laying of the foundation beams, but the pipeline was critical and in the circumstances there was no alternative - I would have to do the job myself.

We had established a modus operandi with an endless rope that carried a bag of mixed cement down to the junction and returned it for refilling when it was empty. Fuming, and armed with a torch, I climbed down the pipe to the lower junction two hundred

metres downhill, and started operations from there. My instructions to the gang were conveyed to a man on the outside through a 5 mm crack that opened to the bright sunlight outside; although I later found that a whisper carried all the way to the top of the hill up the pipeline, which acted as an echoing telephone.

There was an amount of running water in the pipeline that was fed into various networks originating on the hillside two kilometres away. Due to the echoes in the pipeline, that water sounded like a rushing torrent, threatening at any minute to drown me and drive me out into the harbour, two kilometres away in the other direction. A trickle sounded like a passing train. To my surprise I found that the darkness and the echoing water made me sweat, and it was as much as I could do to refrain from the impossibility of scrabbling the crack of sunlight into an opening large enough to get me into the open air. I tried to turn back, but the pipe's diameter of 90 cm, and my long legs and back, prevented this, so I had to reverse on my toes and hands, two hundred metres uphill, with my head down at an angle of 30°. When I approached the daylight at the other end the panic had passed, and I was quite all right again. I said to my gang at the top that I wanted to get another torch and make some adjustments in the rope. I then went down again and without any trouble completed the job in about three hours. I did not confess to my state of panic until the moment of writing this. I was bitterly ashamed of my lack of control.

We had transformed Queen Street, Mosman from a quiet street into a busy thoroughfare with the presence of our morning and afternoon mini-buses and parking facilities for our staff members, to say nothing about the inconvenience of servicing our buses on the footpath. In short, we presented our neighbours and the Municipal Council with a long-standing nuisance and we forced them to put up with it because of our work for spastic children.

Early in 1951 the council suggested that we should erect a temporary transport garage on council property in Rawson Park, about half a kilometre away from Queen Street, and we agreed.

The building was to house a carpenter's shop, the splint shop, and the garage and hoist for the buses. It was a steel frame building of 500 square metres, with corrugated steel roof and sides and a concrete floor. The petrol bowser was installed conveniently inside the garage, with a hoist and compressors. Including the installation of water and electricity, it was built entirely with volunteer weekend labour.

The Spastic Centre buses are specially fitted for the requirements of individual children and could easily be classified as ambulances; The Centre prefers to style them as school buses (and once paid a higher registration) because of the psychological effect on the children. Ambulances would suggest that they were going to hospital, whereas at last they are really going to school, like the normal children around them.

On 20 June 1952, the official opening of The Spastic Centre Splint Shop at Rawson Park, Cross Street, Mosman, was performed by Dr F. W. Clements, Acting Director of the Commonwealth Institute of Child Health. That year we had ten men working in our Splint Shop, when we were dumbfounded by a letter signed by the Chief Property Officer of the Department of the Interior, stating that we had encroached on Army land to the extent of 13³/₄ perches.

In my reply I said, "We feel that the Commonwealth would wish us to place what is otherwise wasteland into effective use, and we therefore request that the Commonwealth permit us to remain in occupancy of the encroached area at the pleasure of the Commonwealth. We are certain that you will agree that the immediate treatment and effective bracing of many hundreds of paralysed children should take precedence over any immediate discussion of property rights of land not needed for use by either the Commonwealth or Mosman Municipal Council. If you agree, may we continue with the erection of the proposed septic tank on the site indicated, at our own risk."

Switching the name of the game to septic tanks was to leave us in command of the department file until it was resurrected twenty years later when we were ready to move out to Centre Industries at Allambie Heights. When that time came, we incorporated the steel frame of the building into the fabric of our new extensions of Centre Industries.

We had confined our efforts to the CPs in New South Wales, and then in helping the other states to get started on an organisational level. As Western Australia was our home state, the success of our school and medical unit did not go unnoticed in other states in Australia. Very soon we were visited by parents from Western Australia, and later my wife paid a visit to Perth and spoke to the parents, telling them what we were doing in Sydney. She stayed there for seven days, and had daily meetings with all the people concerned in setting up a Centre. They were all very interested and one of them was a young officer of the Agricultural Bank who had a spastic son. He took extended leave from his work for twelve months to set up a school and medical treatment unit on the same lines as our Centre, and this was later extended, but he never returned to the Bank. Instead, he

devoted his life's work to The Spastic Welfare Association of Western Australia. My wife reported on her return:

'The establishment of a clinic is urgent and essential. I only saw one child who was splinted or even wore shoes.

The whole situation is tragic for the children and parents, and I cannot overstress the plight of these kiddies compared to our own.'

My wife recommended that Mr J. T. Michell, the Perth Bank Officer, visit Sydney immediately, that we should advertise for a doctor on his behalf, that we should take his son Warwick into our Centre for six months, and we should give training to a suitable teacher. Also, that Dr Burton-Bradley should go to Perth for a short visit to help the doctor when appointed.

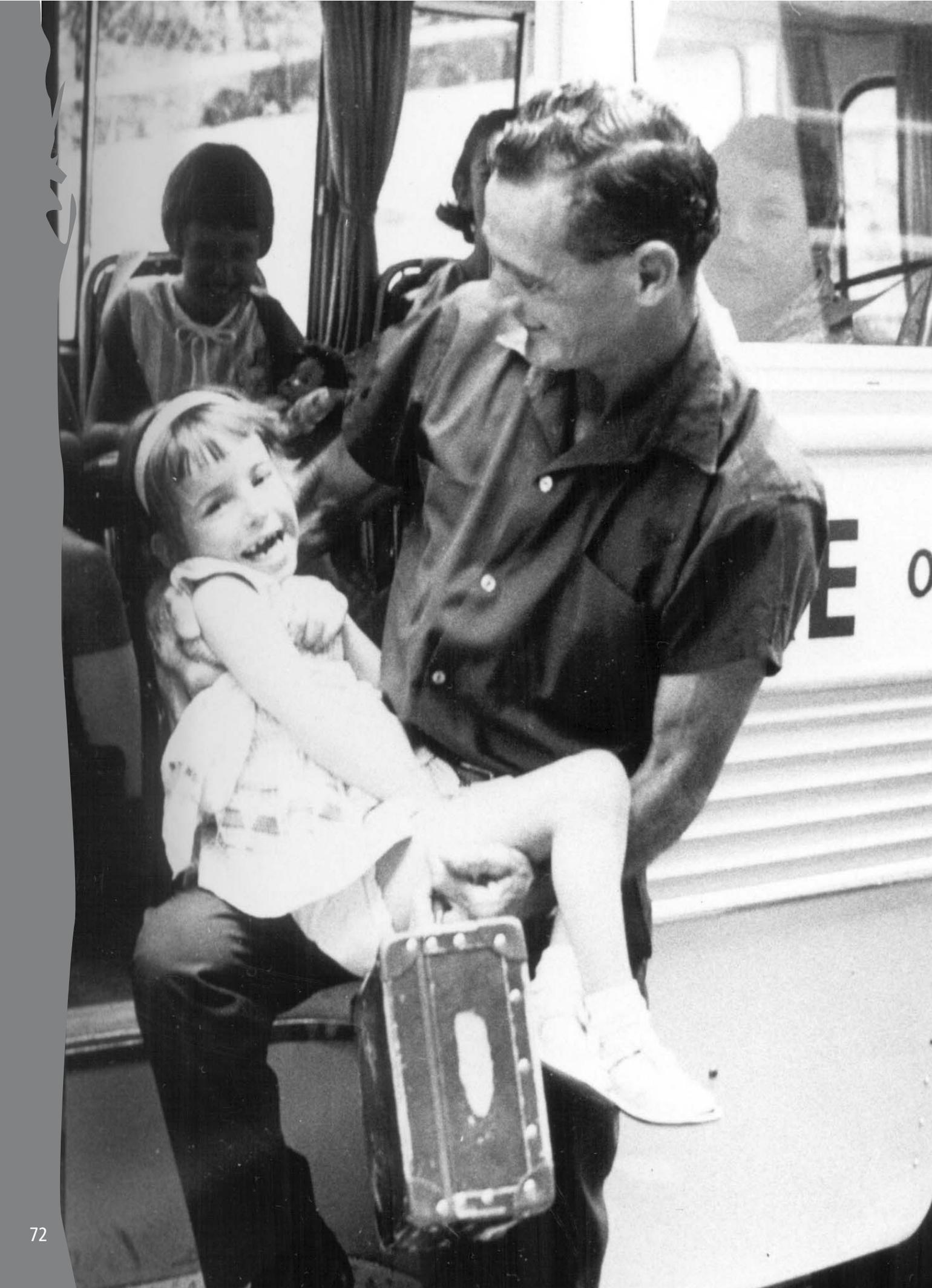
That visit was so successful that the other states followed in quick succession. In Queensland, Dr Harold Crawford, a well-known pediatrician, formed an Appeals Committee to support the Queensland Spastic Welfare League. In Victoria, Mr L. A. Rattray-Wood and his wife, with a spastic child, were the leaders of the Spastic Children's Society in that State. In South Australia, Mr D. L. Brougham formed the South Australian Spastic Paralysis Welfare Association. Mr T. G. D'Alton, a Minister of the state government, took up the challenge in forming the Tasmanian Spastics Association.

It became imperative that we should get together on a national basis to provide an association which we hoped the government authorities in Canberra would listen. In June 1952, we held a meeting in Sydney founding a national society for the welfare of spastics – The Australian Cerebral Palsy Association (ACPA). It did an immense amount of work, with a Medical Educational Symposium at three-yearly intervals. A national body was imperative if we were to make a financial success of the Miss Australia Quest, as we had been invited to do by Mr Bernard Dowd, who was prepared to fund expenses within a reasonable sum. In 1955, Mrs McLeod was named the President of the ACPA and has been connected with the detailed organisation of the Miss Australia Quest in the ensuing thirty years. Later, in 1954, the ACPA had established a national fund raising organisation for the Miss Australia Quest. We succeeded in raising that, from small beginnings into a million dollar project in the 1980s. It was founded on the idealism of 5000 entrants in Australia each year. It is marked by the desire of the young girls to give something worthwhile to our spastic children. With this end in view, they are prepared to give up their social life for a year, and to give their families and friends something worthwhile to do towards the care and education of somebody as heavily handicapped as a CP child. Most girls realise that there is value in what they are doing. If they are lucky enough to get a prize at the end, there are no recriminations from the others. From The Spastic Centre's point of view, it puts us in touch with the community generally, and makes people more aware of the spastic children than they were previously.

My friend Bob Pollock, the architect, had a commission to redesign the building facilities, and he in turn asked me to assist him. Dr Morgan invited me to join his Board of Directors of the Lorna Hodgkinson Sunshine Home for mentally retarded people. A young university graduate recognised the need for a home for the mentally retarded, and for thirty years pledged her own destiny and all her resources and energy to the study of that condition. Before she died in 1954, she appointed Dr Andy Morgan as the trustee of her will. Dr Morgan had the satisfaction of getting the Board together to do something really effective for the seventy handicapped people that Dr Hodgkinson had left in his care. He turned what could only be described as a wasteland into an effective school, a sheltered workshop and a home. Dr Hodgkinson would have been proud to have observed the progress. There I had the gratification of rescuing a fourteen-year-old patient wrongly diagnosed as retarded, when I recognised him to be an intelligent cerebral palsied boy. He is now married and works as a computer operator at Centre Industries.

In 1956, I was engaged in an honorary capacity on a rehabilitation appeal for the Royal Prince Alfred Hospital. I produced a brochure on which the appeal was based, and under the leadership of Sir Herbert Schlink, obtained the premises in which the Rehabilitation Department is still based – in an electrical storage warehouse of the Sydney County Council. The appeal raised \$100,000 for rehabilitation in that hospital.

In the late nineteen forties, we had a voluntary aide to assist the teachers and therapists. She had a son who was mildly mentally handicapped, and she decided that if The Spastic Centre could do so much for its children, why could she not set up an organisation on similar lines for her retarded son. That was the start of The Sunnyfield Association, and other organisations for the mentally retarded soon followed her lead.



Medical

This chapter emphasises, without need for elaboration, our progress in knowledge and application of techniques which had taken place since we opened The Spastic Centre of New South Wales in 1945.

At that time, Dr Earl Carlson of New York made it all possible by saying that it could be done; more significantly, that it was worth doing – that spastics do improve.

Dr Winthrop Morgan Phelps, a Baltimore orthopaedic surgeon, showed how it could be done; by expounding the need for radical surgery during the growth period and heavy bracing. This type of treatment has now changed, but Dr Phelps' enthusiasm was the spur, which in the nineteen forties and early fifties laid the foundations of the orthopaedic treatment which was followed in America, in Europe and in Australia.

In the early nineteen sixties the introduction of the Bobath treatment profoundly affected the basis of physiotherapy. Later, the introduction of early treatment of the infant, in the first few weeks of life, by programmed training of the mother as a significant member of the active therapy team, rounded off this phase of development of modern therapy programmes.

The Spastic Centre regards itself as being responsible for every cerebral palsied child and adult in New South Wales who can be fitted into its programme. As a parents' group it can best discharge its responsibilities to the child by compulsorily involving the parents in the project. No charges are made for treatment and transport but, as a condition of admission, mothers are required to work one day per week performing domestic tasks and fathers one day per month on building maintenance. Parents are required to share in any fundraising functions and their compulsory attendance at The Centre has proved an effective means of developing in them an understanding of both their family's and the child's special problems.

This format, incorporating the parents willy nilly in the child's medical and educational problems, has unsuspected but necessary benefits for the child's future and the parents' peace of mind. Instead of parents being a necessary evil to the child's medical development, the mothers are brought into the picture from the earliest time, so they have a full knowledge of what lies ahead of the child's current treatment. The future is built up slowly from her observation of a peer group of children who can be equated with her own child's progress.

We do not accept the need for any formal group training of parents in those terms. We prefer to have the mother and father in touch with the doctor or the therapist, and the teacher, as needed. This was in 1945, but in 1984 there would not be a children's hospital that did not come around to the same point of view. The mothers learn from one another as they go about their rostered duties; as the fathers do on their building projects. It is good to brag about the progress of your cerebral palsied child, because it diminishes the hurt that you must feel.

We started with thirty-five children in 1945 and had grown to one hundred and ten day children and two hundred outpatients by 1950. We had a staff of five Education Department teachers, eighteen therapists and three splint and leather workers. In addition, we had bought a residential home located at Mosman, for a pilot operation to accommodate twelve country children. This was a forerunner to the Country Children's Hostel at Allambie Heights.

By the term 'cerebral palsy' we mean a child who has had damage to the motor parts of the brain which control movement or balance, either before, during or after birth. Actually the percentage of cerebral palsy sufferers is very small considering the hazards of the birth process and the number of children born. About 75 per cent of the total number are due to injury during the birth process. The use of forceps is often blamed for this, but they frequently prevent such injury and do not cause it. In many cases a haemorrhage occurs on the surface of the brain, and this causes actual damage to the brain.

In other cases, the brain tissue suffers a severe shock due to changes in pressure, or the child is not breathing properly, either because the cord is around the neck, or tiredness after a long labour, or a difficult delivery, or if the mother has had a long anaesthetic, or has been too heavily sedated during labour.

In a certain number of cases the damage occurs before the child is born – the mother may have high blood pressure or kidney trouble, or German measles in the first four months of pregnancy, or perhaps some other severe infection that may cause damage to the developing child. A few cases occur after the birth during the first few weeks of life. The child may get pneumonia, or meningitis, or whooping cough, or may have some operative condition requiring a long anaesthetic, and in all these cases the child's breathing is affected, causing a lack of oxygen to the young brain and a resultant damage.

Originally we were only able to provide Dr Burton-Bradley, our Medical Director, with a salary on a half-time basis, but she worked full-time in any case. After six months we raised the money to afford to pay her at the full-time rate. She served us well during the seventeen years when we were battling for recognition from the medical profession. With no medical precedent to guide her and no guidelines but those that she herself established, Dr Burton-Bradley was faced with setting her medical efficiency and style, to the test of effectiveness.

Most of the children at that time were dosed heavily with phenobarbitone, as much for the mothers as for the children themselves. We soon established that it did not mix with the demands we were making in the schoolroom, and by 1950 it was no longer a problem. The major work that Dr Burton-Bradley handled so successfully in those formative years was in involving herself, her medical specialists, therapists and Education Department teachers in a multi-planning exercise on behalf of the individual CP child. At her weekly clinics, she involved all the people concerned with a child's problem – the teachers, occupational therapist, physiotherapist, speech therapist – without involving those people who were not concerned with the immediate problem.

In 1949, we had installed a Stamford X-ray unit with its own darkroom, because we had a recurrent problem with hip joints slipping out of position. A child's hip joints are formed by weight bearing. In the absence of the weight bearing for a child who is a non-walker, there is a constant danger of the joint slipping out of the upper socket of the pelvic bone, with corresponding shortening of one leg. Its effect is to tilt the pelvic bone to one side, which in turn produces a curvature of the vertebral column, and in order to have shoulders square, a subsidiary movement of the head is necessary to compensate.

For training in walking, we provided a movie camera and a projector for registration of the children's ability in terms of muscular function. Then we were asked to provide an audiometer for the hard of hearing group of our CPs. At that time we attributed the lack of speech in the CP to the parents' failure to teach the child to talk. We needed to break the mother's dependence on the child, as well as the child's dependence on the mother.

We bought an anaesthetic machine because most of our dental work was then carried out under general anaesthetic, and we needed a respiratory machine to remove the dangers of a patient collapsing under too heavy manual sedation.

We were facing a dental problem with our children, whose teeth were atrocious, primarily because local dentists would not take these children into the surgeries, being afraid of jaw spasms breaking their hypodermic needles; and general anaesthetics administered by doctors became major operations. Dr Burton-Bradley used to give her anaesthetics on a makeshift table in the bathroom with a visiting dentist. At one of these sessions a young athetoid boy caused some amusement. He had a fund for equipment needed for his school friends. As he was recovering from the anaesthetic, his speech had improved so much, because of the reduction of his muscle spasm, that he put 'the bite' on the dentist for a contribution to his fund. He went off groggily in the arms of the dentist, waving a pound note in his hands and announcing in wonder, "A quid! A quid!"

For more than thirty years, a panel of honorary dentists and orthodontists, under the leadership of Mr Alan Watson, concerned with the poor dental health of our CP, operated a weekly session at our Mosman Centre. Dental and orthodontic work on spastics is made more difficult by over-active jaw and tongue muscles, but apart from dental caries and the malformation of teeth and gums, it has a serious effect upon the development of speech and on feeding. We remain grateful to this panel for the excellent dental condition of more than six hundred patients. Mr Watson handed over his responsibilities in 1981 – a remarkable effort. During the busy years of his own practice and rostering The Spastic Centre dental group for at least one half-day per week over the thirty-five years, he found time to research and produce two valuable publications on the teeth of the cerebral palsied, which will be referred to in a later chapter.

One of the senior members of a dental supply company, Mr Charles A. Harris, became interested in our problem and arranged to supply a portable dental unit and a secondhand dental chair, and I did the rounds of the dental supply houses, each of whom provided an armful of instruments and dental supplies that equipped the surgery very well indeed.

We ultimately found the means of doing a great deal of the dental work in a chair under local anaesthetic, where previously a general anaesthetic was necessary. For this we thank Dr Watson and his dental panel. We decided to tackle the problem of our out-patients in this manner, but they had grown to a massive three hundred children and we had to provide a complete Dental Unit so that we could make the job as easy as possible for our Honourary dentists. In the seventies we reverted to general anaesthetics for patients with spasms, in the interest of the increased quality of work provided by a stationary dental target.

The physiotherapy room was equipped with standard hospital plinths, which were narrow tables designed to suit the physiotherapist but not the children, whose startle reflexes made them aware of the risk when they spasmed on the high plinths. They were protected by sandbags on their trunks and limbs, but that did not remove the fear of falling through an uncontrolled muscular spasm.

It was another twenty years before we achieved the present system of physiotherapy on mats at floor level, and got rid of the self-induced startle reflex spasm.

Plaster was still a standard method of treatment and in 1949 I brought back from America a Stryker plaster saw which cut through plaster like butter, without abrading the skin at all. Night boots also became a standard technique of treatment in the early nineteen fifties. They were boots with the upper toecap removed, and were fitted with a short splint below the knee, and a heel stop for the ankle joint. They were worn at night, to stretch the soft tissues of the legs, and were supplemented by pelvic band splints in the daytime, with a stand-up table for weight-bearing exercise.

From America I brought back for Miss Grace Ellis (a staff speech therapist), a Chromovox which, in 1949, was a mechanical TV box. It had pictures and designs printed on a four inch paper spool, with red and green lights for 'yes' and 'no', and it was used with an amplifier by hard of hearing students. It worked well until it gave way to the System 80 in 1975, which was much more sophisticated. We also bought her a wire recorder, which pre-dated the tape recorder. Recording was done on a steel wire, and it could be amplified at will. I think our Doctor was more concerned with the big muscles of the limbs in physiotherapy than the small muscles of speech. In her mind, I believe, it was a case of 'first things first' and we did not then appreciate the importance of speech in the vital matters of communication and education.

Most of the outside medical doctors and specialists found it difficult to accept that the medical facilities should be shared with the patients. They assumed that cerebral palsy was an exclusive medical condition. We maintained that it was a social problem in which the parents, therapists, teachers, psychologists, the doctors and surgeons had a major role to play. The medical specialists needed time to establish confidence in Dr Burton-Bradley's ability to manage the individual cases, as did the parents. The poliomyelitis epidemic was still with us and a medical controversy over the results achieved by the Kenny treatment still rankled among the Health Departments and the medical hierarchy. In the meantime, Sister Elizabeth Kenny accepted an invitation to practice in the United States and she left, vowing never to return to Australia. The orthopaedic surgeons were understandably on their guard against a group of parents needlessly intervening between the orthopaedic surgeon and his prospective patient. It was only a question of time and patience, and 'taking care not to put a foot wrong'.

By 1950 Dr Burton-Bradley had established a rapport with her fellow orthopaedic surgeons, some of whom treated spastic muscles as they had been taught to do in polio cases. It took a lot of bad surgery and a lot of tact to establish the difference between the athetoid and the spastic muscles, and what the surgical target was to be. We had fourteen therapists and three aides on her staff – more than the major hospitals – and most of the surgeons were quite happy to pass the responsibility of surgical intervention over to our Medical Director, provided the responsible surgeon conducted the operation himself. At that time we had difficulty with the metal braces and splints which were necessary to complement successful operations and I will refer to this in the following chapter.

At the same time, Dr Burton-Bradley had earned the respect of the attending mothers, although some were still looking for a cure among the non-medical fraternity of 'quacks'. We had some experience of these gentlemen before we got under way and started The Spastic Centre. So we included in the by-laws for admission of the parents and their child to The Spastic Centre, that the treatment would be based on the 'usual professional medical ethics', and the attendance of an unqualified practitioner, entailed removal of the child from The Spastic Centre treatment lists. Most of the parents were looking for a magic cure and the only acceptable answer was to educate them by example, so that they knew what the teachers and therapists were doing for their children. By 1946, most parents had come to realise that their child was receiving by far the best medical care and education at

The Spastic Centre.

Of equal concern was the epilepsy to which our children were subject. At that time, the preferred medical technique involved expressing the air from a sinus of the brain and taking an X-ray of the skull – quite a fearsome procedure for a child. For our new building, we had erected a filtered room for the electroencephalograph (EEG) equipment which we had bought in the United States for the princely sum of \$5000. Thereafter were able to predict the onset of a fit by the typical epileptic ‘spike’ on the tracing paper, thus giving our Medical Director the opportunity to preclude the onset altogether with appropriate medication. It was only the second EEG installation in Sydney, but intuitively we had known that, despite its high cost, we could not do without it.

I should tell you that on testing the machine during assembly, I had the operator do a test run with myself as patient. As the result of a miscalculation, the reading showed a straight line on all the eight channels of the EEG machine. The operator’s diagnosis of the trouble was uncomplimentary, if predictable: ‘There is nothing wrong with the machine, it must be the patient!’

A report by Dr Burton-Bradley stated:

‘We do not know how nerve tissue, of which the brain is made up, functions to produce learning, memory, thought, reasoning and movement, but one thing we do know is that it functions electrically. In 1875, Caton (an English physician) discovered that the brain itself produces electric currents. In 1928, Berger (a German psychiatrist), devised a method to record these electrical rhythms. In 1934, work began in England on making an electronic instrument which was eventually to become known as the electroencephalograph, or EEG. With increased knowledge of electronics, great development has taken place, and today it is usual to make records of the electrical discharges from the brain from eight different areas, simultaneously.

What really is taking place is that the EEG reports the frequencies and amplitudes of the electrical changes in different parts of the brain which are detected by electrodes on the scalp. Their minute currents are amplified and relayed to an oscillograph which activates pens which make the record. The electrical changes which give rise to the alternating currents of variable frequency and amplitude thus recorded arise in the cells of the brain itself.

In the early work, the tracings were all found to be similar and this disappointed the scientists working in this field, for they had hoped to gain information as to thought processes. They then began investigating patients with mental disease and epilepsy. It was in relation to the differences in the tracings from brains of epileptic patients that led to a recognition of the significance of the earlier tracing - that was of the normalcy of these tracings.

Since the beginning of 1954, in the course of investigating our cerebral palsied children and the non-cerebral palsied brain injured children who are sent for investigation, all have had electroencephalographic tracings carried out. Over the years 1954 to 1956, EEG investigations of over 1000 children have been made and of these, 70 per cent have shown abnormal tracings.

Tracings of individual patients may give information as to the probable site of abnormal electrical activity, and the tracing may suggest the medication. Different abnormal wave forms and abnormal wave frequencies are known to be often influenced by drug therapy. Working on the assumption that the nearer normal the tracing can become the better for the child, the drug known to best influence the particular abnormal pattern is now administered. This is usually done whether the child takes epileptic seizures of any kind or not.’

Dr Burton-Bradley concluded:

‘The EEG investigations perhaps, would help a little boy to grow up acceptable to the community and the behaviour of others to be correctly understood.’

Our Medical Director in her first year detected cerebral palsy occurring in births subsequent to the firstborn. The picture as it emerged was a normal birth for the first or second child, then a series of cerebral palsied or stillborn. In one case, the mother had five living CP children, and expressed her intention of risking more, saying, ‘If it is God’s will, I will do so’.

Looking back through her literature, Dr Burton-Bradley wondered whether it had something to do with the then newly discovered Rh blood anomaly. She did blood tests on the mothers and the fathers over the ensuing weeks, and when she added up her score she found a shocking 20 per cent of our children attending The Centre were affected. They all had some auditory handicap ranging from hard of hearing to completely deaf and their hand function was suspect.

We thought that this was a significant finding and suggested that the National Health & Medical Research Council might be interested in sharing the cost of a survey. We made application to the Council in February 1947:

'It is requested that your Council should make a grant of \$700 as a contribution towards the cost of conducting an investigation into the incidence and extent of cerebral damage following upon the clinical condition of Icterus Gravis Neonatorum or Erythroblastosis Foetalis. It is estimated that this investigation will cost this Centre a further \$1400 during the first year and a similar amount spread over the ensuing two years.

This work is urgent and necessary, but this organisation, while recognizing its essentiality, is as yet unable to provide the whole of the funds required without seriously impeding its more urgent therapy commitments.

The work will be closely directed and controlled by our Medical Director who assumes full responsibility for the conduct of the project.

Dr Claudia Burton-Bradley's notes are attached. We estimate at least 20 per cent of our cases display the Rh blood anomaly.'

This application was refused – but it should not have been.

In 1954, after nine years of work on cerebral palsied children, we found that if we could start work on the children before two years of age we could teach most of them to walk, but if left until after six years of age, the advances were only minimal.



Splints and braces. Aluminium Pelvic Control Braces with hip, knee, ankle and foot control manufactured in our own splint shop from 1949 onwards.

Splints/Braces

1949

In March 1949 I proposed the organisation of the Splint Division. Orthopaedic splints in one form or another are required by 80 per cent of our cerebral palsied children. Despite our four years intensive therapy, and following the lessening of radical orthopaedic surgical operations, we needed orthopaedic appliances in order to follow up the surgery and the consequent physiotherapy. The operations implicit in surgery of the lower limbs were dependent in the first place on plasters or metal supports, followed by leg irons which were mild steel, half oval in section, and bent into shape. We needed to have those splints properly fitted on the child before the surgical operation, not a year or two years later when the child would have already grown out of them.

The words 'splint/brace' are used synonymously. 'Splint' is used in England and 'brace' in the U.S.A.

Following the war, people skilled in splint-making were hard to find, so we tried to make do with some part time work from the Technical College students. While this reduced the time of waiting for prescription bracemakers from twelve or even eighteen months, we were only able to give our technical students simple short irons, without ankle joints or foot plates.

Apart from the delay in delivery and the high price that we were paying for unsatisfactory splints, they were atrocious from an engineering standpoint, because they nullified the full effect of the surgery. They were simple calipers, with no effective hip or knee hinges, except those produced by hand-filing for individual cases. Mostly there was no ankle joint at all, which meant that the whole of the foot structure was distorted, with each step taken, against the 'T' leather support. There was no metal sole plates, and this meant a further distortion in the foot, from the coiled spring toe lift, or heel lift. Dr Carlson, who visited us in October 1948, expressed dissatisfaction with the standard of our splinting with good reason.

We needed something better and the only solution was to enter the splint manufacturing field ourselves. We needed to provide for the manufacture of our own splints according to the Medical Director's prescription. If fully skilled splintmakers were unavailable, we would train them ourselves.

I was in touch with two American organisations, which had done a significant amount of research in this area. One was the Mellon Institute of Industrial Research of Pittsburgh, which had set up a Scaife Fellowship for the purpose of making an authoritative survey of present knowledge on the subject of braces. The Pope Foundation of Kanakee was a non-profit organisation and formed for the purpose of providing good cheap braces, by developing and manufacturing prefabricated standardised parts, which were sold commercially to splintmakers in the U.S.A. They were designed for victims of polio, then rampant in the U.S.A. and I had hoped to adapt them for use with our CP children.

We had arranged for the importation of a full range of samples of these parts, together with tools and jigs. The intention was that local manufacturers should be invited to make a quantity of individual parts as a donation to The Spastic Centre, and that production should be on normal production engineering methods.

My Board agreed that I should attend the Second Annual Symposium on Orthopaedic Appliances in September 1949 in the United States, sponsored by The Mellon Institute of Industrial Research. Their press release stated: 'The program will be planned and carried out for the benefit of mankind through the medical profession. Under the guidance of orthopaedists, and with the co-

operation of leading organisations in the field, as well as of manufacturers of orthopaedic appliances, the fellowship will conduct broad scientific investigation and development relating to such appliances. Particular attention will be accorded to problems of mechanical design, improvements in materials of construction and methods of fitting braces and similar orthopaedic devices.'

This symposium was an attempt made to involve three hundred orthopaedic surgeons of the United States and an equal number of their manufacturing bracemakers. It lasted for a week, full time, and it was not until the end of the session that the doctors and bracemakers overcame their antipathy towards one another. The bracemaker suggested that the surgeon scribbled a few lines on an envelope, from which he was expected to know exactly what the brace was meant to accomplish; the surgeon countered this by saying the bracemaker had no idea of human anatomy and less of engineering standards. As a result of the symposium, an American body was set up to provide a register of all members of the newly-formed Orthetists Association and the registration of workshops and labour employed. The registration was to be subject to a four-year apprenticeship, to be in the hands of a central national body of orthetists.

I was an interloper. I was neither a doctor nor a bracemaker, not even a governmental expert. It was true that I bore a letter under a red wax seal with red ribbons from the Prime Minister, the Honourable J. B. Chifley, stating I was a worthy citizen of Australia and seeking my protection. Other than that, the only qualification I had was my complete and utter absorption with the subject of making and fitting braces for the cerebral palsied. I was lonely and nervous of the doctors and the bracemakers, in equal measure to the lecturers. It was my first trip abroad and I wanted to know about everything. I was somewhat surprised that I made friends very easily and at the end of the week I was accepted, in spite of my outlandish Australian speech.

The symposium was held in the Mellon Institute building, which was framed by sixty-four columns of white marble, each twelve metres high, supporting each of the four walls. It was a Grecian design, and more space was needed than was available from the agreed facade, so they excavated another three floors below the ground, lit by a central courtyard for natural light and ventilation. Those three floors housed the laboratories, each of which was equipped with inbuilt services for power, gas, oxygen, acetylene, dionic water, with fume chambers, amongst other facilities.

Starting at 8.00 a.m., with evening sessions included, the week was spent attending multiple lectures from fifty or more staff, and comprised engineering specifications, 'how to do it', metallurgy, anatomy and lectures on every aspect of brace making. They were followed by in-depth discussions with the orthopaedic doctors and practical bracemakers themselves.

I was invited by Dr John Young (the senior of the Orthopaedics Appliances Fellowship) to stay on an extra five days after the conclusion, to review the work of the Fellowship for the two years past. He had worked with spastics and had agreed that much more work needed to be done in the early treatment of the patients, rather than depending on the engineering skill of making braces to correct the damage already done. In the meantime, the braces we made should be as perfect as possible.

Among the many lectures, I have selected three as an outline of the proceedings. The first was by Dr Eugene Murphy, Assistant Director for Research, Prosthetic and Sensory Aids of the Veterans' Administration. Dr Murphy outlined the engineering problems encountered in the production of orthopaedic appliances high loading could be expected.

He covered the general principles of measurement stress and strain loadings, and the characteristics of metal under load, and demonstrated the plastic zone, the modules of elasticity, compression, tension loading, the use of laminates, and shear strength. He said that the loadings in brace joints must be of the clevis or box type. He mentioned that a service brace must stand up to a test of three million cycles with a corresponding load of 150 lbs. Fatigue fractures, or corrosion, always occur at the nicks made by the sharp corners of a vice, or edges not fully rounded

Dr Murphy was a double above-the-knee amputee, and gave an unexpected demonstration when he turned to the blackboard. Making a point, he crashed on his face to the floor. People sprang to his assistance, but by the time they got to him he had climbed, unaided, to his feet and continued his lecture without comment or embarrassment.

I was very interested in a lecture by Dr Phelps, in full cry. He said that he had been working since 1936 on a hit or miss basis on cerebral palsy. In treatment, he said, in reference to surgery, you cannot tell what will happen with transplants, even in normal muscles. He gave examples of athetosis being transferred to normal muscles following transplants, giving approximately the same athetoid movement. Among the many things on which I wanted more information, were the following extracts:

'Braces will not cure any CP, but they are a foremost adjunct of treatment. Gesell's work on the pre-walking child shows definite prerequisites to the use of arms and legs in walking. No bracemaker by the most elaborate apparatus, no surgical operation, no drug medication can cure this condition. In polio muscle transplants, the cortical patterns have been previously learned, as also is the case with amputees.'

Heel cord lengthening by operation is not advisable except in certain adults after the period of growth has finished. If the operation is done at six years, it will require being done at ten years and probably again at thirteen years. Each operation reduces the strength of the muscle and the mechanical advantage is reduced too. This applies only to cerebral palsy, not other conditions. Tests show that a normal man may be able to lift a single heel off the ground under a load of 200 lbs; a spastic man has been tested at 400 lbs, and a six year old child at 150 lbs. Plaster and plastics are obviously useless for the stress involved.

Night splint should consist of a high shoe coming above the ankle so the heel will not slip out. An inside tee strap should be fitted. Elastic or spring joints should not be used to oppose a spastic muscle - it only strengthens the muscle by exercising it continually. There is no difficulty in getting parts that will be comfortable for short leg braces, but extension with the knee straight is not possible unless an allowance of ten degrees is made for comfort. It is best to cut the toes out of a child's night brace and pad the tongue and heels when necessary to fill up the increased space. Rigid brace at knee and plaster wedges will stretch all tissues, but will interfere with circulation in the standing position. In the hip joint torsion of the femur is habit posture defect, caused by sitting/kneeling with lower legs flexed out, and behind at an angle of 45° (tailor fashion).

Correction of the hip position – the same apparent conditions. (1) abductor flaccidity; (2) adductor spasticity; (3) internal rotation corrected by straps; (4) bony reduction of the femur. Too much surgery has been done on the long muscles through ignorance of the causative factor.

With athetosis, like a wrestler, if one set of muscles is pinned, another and another is tried in turn to break out of control. You cannot expect to eliminate the athetoid movement from the body. All you can do is to control it by rigid braces and watch for a favourable or an unfavourable shift of movement. If it is unfavourable, the control must be removed. Under these conditions, surgery is unsuitable as you cannot undo the shift if it is unfavourable. After a year of rigid control, the muscles have learned a pattern that may proceed for half an hour if the brace is removed. In two years, the time may be extended to three hours. After three or four years, you may have a relatively normal gait taught by the brace. For that reason, skis and similar shuffle movements do not help. The motion taught must be a functional one.

Supportive braces used in polio are not needed for cerebral palsy. The hip stop must be set beyond 180°, otherwise the forward leg cannot reach the ground with the trunk upright.

Tests of pelvic control braces are best done with the braces off. They are only considered satisfactory if they will stand erect with the hips locked. Do not spread the pelvic band if it is made too small, or boots will not stay still on the ground if the pelvic band is rotated 90°. Similarly, test the knee 90° arc to see that the caliper ends remain same distance apart. Check thigh length of the brace by sitting with legs over the edge of the table, not flat on the table, because this pushes the pelvic band forward. Gluteal pad below the pelvic band is used to straighten up the child who walks with the knees slightly flexed, and with buttocks stuck out behind. Note the angle of the sole of the boot, it is not level with the ground with the braces off, because the pull of the adductors alters the vertical line of the braces.

To summarise, it is of chief importance that the brace must be stronger than the individual. It must be free running; weight is not of importance, no elastic to be used against spastic muscles. It is inexcusable to use toe springs which are, however, perfectly all right for polio.'

These are notes on a lecture given by the doyen of hand orthopaedic surgeons in America. It interested me because of its adaptation to cerebral palsy patients, from the point of view of hand function at all costs and the unexpected poetry he used to emphasise that point:

'Dr S. Bunnell, Consultant to the Office of the Surgeon General, United States – 'Disabilities of the Hand in Principles of Splinting'.

The hand is the most versatile of all members. On injury it assumes a position of non-function. Keep it in the position of function and keep it moving, otherwise the shortening and thickening of the ligaments prevents function. Then oedema, with its protein deposits, leads to fibrous precipitation of the hand tissue from swelling organisation occurring in the blood vessels. Remember, the position of function with the fingers at their natural degree of flexion and the thumb opposed.

Physiotherapy – be very careful – passive treatment is not much good, the patient must do the work. Forget

bubble baths, occupational therapy is now much better, leading to the first paid piecework and then to the job. Occupational therapy should not be used for diversion or exhibit, it should be by prescription.

Splinting – immobilise; move to the position of function. On infection a plastic operation with nerve and joint repair, form fitting a circular splint full length on three points of pressure – the joint, proximal, distal points of the arc. Splints should be standardised, not too elaborate, light, easy to make, inexpensive, outriggers to slip through sleeves, web belt not leather; put web belt through slots in the metal for easy washing; leather cuffs are most insanitary things.

Holding the hand in a position of function, no tight straps for oedema; dorsiflexion 30°; handpiece curved to the metacarpal arch, rounded at distal crease and for the ball of the thumb crease. Joint should not be put under strain, no banjo splints should ever be used, they are abominations, they ruin the joint, stiffening the fingers, pulling on the tendons, diverges the fingers; the whole hand should not be splinted. Never use a flat splint, that is heresy, it flattens out the metacarpal arch and puts the thumb out at the side.

Splints should be spring or rubber elastic, bringing all parts of the hand to position of function. Hand joints are orthopaedic jewellery and should be treated as precious things. Do not let physiotherapists pumphandle fingers in an effort to stretch the tendons and brutalise stiff joints, traumatising little finger joints with their big arm joints. Instead they must be coaxed little by little, not stretched, over a period of a few weeks while the ligament grows in length.

Rigid splints make rigid hands. Splints to mobilise not immobilise all bones and joints and other elements moving freely and healthily. Psychological splinting for paralysis – fit a spring splint of the same tension as that of the paralysed muscle.'

There was a gala dinner to wind up the meeting, attended by visiting Government representatives and those from the rehabilitation industry and the University of Pittsburgh, so that the number present was close to one thousand people. I was looking forward to the dinner until ten minutes before it started, when I was told that I should sit at the official table and make a ten minute speech of welcome. They explained that they would have trouble if a doctor, or a bracemaker, or a staff member welcomed the gathering. So I was selected, because half of them did not know where Australia was; they said it was somewhere near China.

I stumbled up the steps of the official dais with my Damocles' sword suspended above me, not knowing whether I could make a speech or make an utter fool of myself. The devil looks after his own; I was seated next to Mrs Margaret Pope Hovey, a charming and intelligent lady who at once made me welcome. She had contracted polio in her youth and was in her wheelchair. She was the daughter of Mr William Pope of the Pope Foundation.

I had abandoned the idea that I must get some notes down on paper - time was too short. There was nothing I could do then until the moment arrived, and I stood on my feet with nothing to say. Then quite suddenly I found the words in my mouth. I explained who I was and what I was doing so far from home. Then I said that I was fortunate to be there at all, because before I had left Australia my wife had been pretty cool when I told her about the Symposium, even though I explained how very important it was for the manufacture of braces for the cerebral palsied. She then said, "I know all about the importance of braces and splints, but do you know what a Symposium is?" She continued, "I looked it up in the dictionary; you had better do the same." I did, and read – 'an ancient Grecian after-dinner party with dancing girls and wine.' I then suggested that Mr Weidlein, the Director of the Mellon Institute, had brought me from Australia under very false pretences. That broke the ice, and when the laughter had died away, I made a satisfactory speech.

In addition to my week at the Mellon Institute, I spent time in visiting fifty-nine places in fourteen cities that had cerebral palsied pupils. These visits were referred to in a full report to the Board.

I visited Dr Earl Carlson, Director of the School of Curative Motor Education in East Hampton, Long Island. I was met at the railway station by a young spastic driver, who drove competently, but fast. I was fascinated to observe that he had a severe tonic neck reflex (TNR) and when it became locked out of position he pulled it back into the driving position with a tug on his left ear. I had not thought that he could do that safely.

I met Dr Carlson at lunch and he drove me to the school. I was interested during lunch when he asked for two glasses of sherry, saying, "After two sherris I behave normally, but if I don't have a sherry, people assume that I am drunk."

I met some Australian children at the school, and I met the Principal of the school, another spastic aged about forty-five. He had

had an academic career in his university, but he never qualified. He just switched courses into a new faculty and went on from there, because he felt there was nothing at the end of his academic career. The university authorities finally caught up with him and he was retired. Dr Carlson approached him in his unsuccessful attempts at suicide and gave him the job of School Principal. He had been with the school for ten years at the time of my visit. Sitting in with a group of spastics at a group discussion, I was amazed at the response he got from all the people there. The subjects ranged from geography to mining, and then through the minerals and finally to the manufacture of steel. He did not take the floor himself, he just provoked others and controlled the argument very effectively for a two-hour session. Most of the pupils had a speech defect, but their teacher understood their meaning. When he did not, there was always someone else who would translate for them. As a stranger to them, I understood about a quarter. This was my first lesson on CP communication.

Dr Carlson introduced me to the members of the American Academy for Cerebral Palsy - and it was very interesting talking to doctors who had so much advice to offer. Very little progress was made in the treatment of patients following Dr Little's description of the disease a century before, because of the poor outlook. Although a few physicians began to take an interest in the problem and felt that many of the children could be helped. In 1932, Dr Phelps published the first definitive paper on the subject and proposed that the term 'cerebral palsy' should take the place of 'spastic paralysis'.

In December 1946 in Chicago, following a year of correspondence and discussion (especially among Doctors Carlson, Phelps, Perlstein, Crowthers and Fay) – six remarkable physicians of diverse interests met, in order to form the American Academy for Cerebral Palsy. As members of the newly formed Cerebral Palsy Advisory Committee, they felt the need for an expanded, improved and uniform approach to the treatment of the neuromuscularly handicapped child.

There was an interesting relationship between some of the founders. Dr Crowthers was the senior of the group, and had developed an interest in the therapeutic approach because of his contact with a therapist at Boston Children's Hospital. Dr Phelps, during his Fellowship at Harvard, was influenced by Dr Crowthers, and in turn used this training to help Dr Carlson physically during his medical student days at Yale, and then to encourage him to develop treatment centres for the handicapped. When Dr Phelps moved to Maryland he had considerable contact with Dr Fay in Philadelphia. Dr Deaver was involved initially because of his long interest in children's rehabilitation in New York, and Dr Perlstein had earlier developed a programme in pediatric neurology at Cook County Hospital.

Dr Carlson received the MD degree from Yale in 1931. As a student at Yale, he had a relationship with Dr Phelps. Later Dr Carlson established a Cerebral Palsy Clinic at the Neurological Institute in the Presbyterian Medical Center, in New York. In 1949, he became Director of the Lago del Mare School of Corrective Motor Education in East Hampton, New York and Pampano, Florida. He was President-elect of the American Academy for Cerebral Palsy in 1950. In May 1974, shortly before his death, he was awarded a Certificate of Appreciation by the Academy.

Winthrop M Phelps, MD, the son of an Episcopal priest, was born in 1894 and died in 1971. He served as a Teaching Fellow in Orthopaedics at the Harvard Medical School in 1923, and while there he developed a relationship with Dr Bronson Crowthers. He became Professor of Orthopaedic Surgery at Yale in 1926, and Chairman of Orthopaedics in 1933, which he continued until 1936. Earl Carlson was a student and patient of Dr Phelps, and this contributed to their later relationship in the field of cerebral palsy. At about this time Dr Phelps detected signs of intelligence in a young athetoid woman, tied with rope to a chair in a mental ward. He found on investigation that the restraints originally applied to control her athetoid arm movements had, with staff changes, come to be regarded as a safety measure because she was 'dangerous'. In 1937, he established the Children's Rehabilitation Institute, outside Baltimore, and trained many professionals in the field of cerebral palsy at the Institute. Dr Phelps was the first President of the Academy, serving from 1947 to 1949. He was involved over the years in Academy activities. In addition, he was an accomplished musician, especially as a violinist.

Dr Carlson was primarily interested in neurology and education. Dr Phelps of Baltimore, on the other hand, was more interested in physical measures. He concentrated his efforts on surgery, bracing and plaster. He was a terrific salesman for the rights of the cerebral palsied. I tried to get samples of the Phelps pelvic control brace, from his commercial bracemaker, but I was unsuccessful. He was reluctant to give his designs to a competitive bracemaker, and when I mentioned Australia he was not impressed. All the people I met throughout the United States were very helpful, but this man was an exception. Dr Phelps was much more amenable and I got the designs from him.

Dr Phelps said, "The original failure to observe cerebral palsy as an improvable disease had been largely due to the neglect to differentiate between spastics and other cerebral palsied children, and in technical circles there will be no improvement in conditions until that differentiation is made. In the past, surgery has unfortunately been adapted from polio surgery, such as ankle stabilisation and dislocation of hips. It may be broadly stated in the light of present knowledge that anything that is good for polio is bad for CP, or nearly. For instance, pools are of great value in polio treatment, but no advantage for CP whatsoever,

therapeutically. They may have a psychological value to enable the child to learn to swim, but therapy, no. Of course it must be admitted that the psychological aspect is a good half of the battle, but do not confuse that with treatment'.

In 1949, the shortage of physiotherapists and occupational therapists was restricting further work for CP. Dr Phelps was intent on correcting that failure by opening a \$US10 million school and training centre. He planned to train sixty-eight physiotherapists, one hundred and thirty occupational therapists and thirty-six doctors yearly at Haverstraw, New York.

In 1963, Dr Perlstein was concerned about the Programme of the Institute for the Development of Human Potential, and recommended preparation of a statement. However, the executive committee felt that it could not recommend one treatment over any other. In December 1964, a statement was sent to the membership indicating that there was no evidence that any one approach was superior to another. In March 1968, a statement was issued jointly with eight other organisations criticising the system, emphasising the lack of proof of superiority. Following publication of this, the secretary of the committee which prepared the statement, Roger Freeman, MD, a member of the Academy, was sued by the Institute. The Academy gave some support to Dr Freeman and solicited support from other groups. The court later dismissed the case.

I also visited the Kabat-Kaiser Institute for Neuromuscular Rehabilitation, Washington, which provided outpatients treatment only, no schooling. They handled a large number of adults – multiple sclerosis, old polio, spina bifida and paraplegics, and about fifty cerebral palsied patients of all types. Physiotherapy was concentrated mainly on resistive plinth work with weighted pulleys of all kinds – ships' steering wheels, cranks and bicycles with friction brakes. Painted lines on the floor were for crutch positions. There were sandboxes with iron dumbbells for resistance to finger and wrist movement in the sand, and walking bars and crutch training ladders.

In speech therapy, a great deal of carefully arranged muscle resistive exercise was persisted with for perhaps a year before speech sounds were attempted. The speech therapist used her hands for resistance against the movement required and to check overflow of eyebrows, mouth, jaw or neck, and used a great deal of force in controlling athetoid jaw movements. In breathing control for a 'snorting' athetoid, she shut off breathing for about fifteen seconds and then, with a wide open windpipe, quickly threw her weight on the intercostals and obtained perhaps five good inhalations before interruption occurred. She used tongue depressors and sticks with cotton pads to manipulate the soft palate and larynx, and used a number of tongue instruments to apply resistance to all tongue movements required and to manipulate the muscles on the floor of the mouth, which were so often too tight to allow the tongue to lie properly. Drooling was controlled by activating the saliva glands by finger pressure, and when a good mouth supply was obtained moved the larynx sharply upward with her fingers and commanded the child to swallow, establishing a conditioned reflex.

Similarly, a wooden stylus was used to position the tongue and assist it in some sounds such as 'ng' etc. The work was done on a plinth or chair before a mirror, and was quite strenuous. The therapist was quite rigid in her demands upon her patients, but was able to impose a fairly harsh treatment in such a pleasantly cheerful manner that she obtained full co-operation even from small children and severe athetoids. With the latter she also used a teasing and joking technique to bring on their overflow and teach them to relax and overcome it. You will remember that this was 1949, when little experience had been gained in speech therapy for the CP. The modern speech therapist in the 1980s would perhaps be horrified at the heavy resistance exercises then promoted for tongue control.

Mr William Pope was a manufacturer of nylon stockings, and both during the war and afterwards he made a fortune designing and welding stainless steel forms for the heating of nylon stockings. One of Mr Pope's engineers, Mr Klenzak, had designed a lightweight brace for Mr Pope's daughter, who was Margaret Pope Hovey referred to previously. After some years of research and a series of tests, he provided the design and the materials for the Pope brace. Its oval tubular construction and the ease with which the modular, clevis joints could be fitted on the hip, knee and ankle, gave us the leg and foot control that we needed for our cerebral palsied. Mr Pope established the Pope Foundation, which was to make the Klenzak braces available through brace shops in the United States.

Mr Pope and his General Manager gave me authority to redesign the Klenzak brace under Australian conditions, and provided me with the engineering drawings and the component parts. I made a 16 mm movie version of their production facilities.

In the course of three months, I visited all the treatment centres for cerebral palsied in the United States, and learned a great deal. None of these centres was serving as many children in one unit as we were doing at The Spastic Centre. Consequently, the intensive treatment techniques, which our medical therapy and teaching staff had developed over the four years, compared very favourably with the best rehabilitation units in America. On the other hand, our diagnostic facilities for bracing and our speech

training and psychological work lagged far behind the American trends. The new types of aircraft steel and aluminium orthopaedic braces were developed for the purpose, not of supporting a weakened limb as you might do with polio, but in order to hold a limb in the best position of muscle function whilst a new skill was being learned.

In July 1949, California brought in legislation to provide a \$US500 bonus per annum for every cerebral palsied child brought into a spastics' school. I had visions of getting the same treatment from Mr Heffron, our Minister for Education, but that was a forlorn hope.

At the end of that tour, I paid a duty visit to my employer, the Burrough Corporation in Detroit. This was to be a fleeting visit, but they took advantage of my presence to put me into an instructor school for six weeks, and that was a change of pace. Ray MacDonald was the manager of the export division (afterwards becoming the President of the Corporation), and I prevailed upon him to give me six secondhand electric bookkeeping machines, to be allocated to cerebral palsied schools throughout the United States. These were altered with specially designed letters and syllables to replace the numbers on their keyboards, and they gave the American CP a chance to express themselves, which was denied by the manual typewriter.

I had my first sight of snow in Detroit. I did not wear a hat and my overcoat had been mislaid earlier in my tour. I was too poor to buy goloshes, so I toughed it out. I can still recall the expression on a policeman's face when I approached him on the snow-laden sidewalk, hatless and without an overcoat - what a weirdo!

It was snowing on one occasion when I stumbled into the Museum of Modern Art to get out of the wind, and there I fell instantly in love with a young girl who was born in the fourteenth century. She was grey eyed and two metres in height, and was dressed in a dark green silk brocade gown with spun gold embroidery. Her brown hair was bound in a filigree of a golden diadem. Her painter had used the available light to its fullest extent on her face, with a dark background, and the general effect was vibrant joyous life as it would have been had it been painted yesterday instead of six centuries ago. I visited her as often as I could in my Detroit stay, and I would have smuggled her among my baggage but I did not know how my wife would respond to a fourteenth century member in my family. I never saw her again.

I left in an arctic blizzard, with Ray MacDonald's second best overcoat. I hope he got it back.

When I arrived in San Francisco my baggage, which I had sent on ahead by rail, had not arrived; the plane departed at 10.00 a.m. the next day, and I faced a mountain of Christmas luggage two hundred metres long and piled two metres high. My Christmas presents were all in the luggage and I could not go home without them, so I got permission to ferret among the heap. I had my first success at nine o'clock that night, and I had promised a bottle of Scotch to the luggage hands. At midnight we found the second case. I got up at six the next morning before the luggage staff had arrived, and it looked quite hopeless. I went into the empty freight office to deposit a note and my promised bottle of Scotch to the luggage handlers, and behind the door was my third case. I just made it to the airport bus, which was fortunate, because I was down to my last dollar and could not afford a taxi. I arrived back in Sydney on Christmas Eve 1949, with a twenty-nine hour flight behind me, and with a collection of samples of Pope braces and adjustable tubular aluminium crutches, my precious Christmas presents, including a 'Wettems' doll for Jenny and a child's ambulance kit for Robin.

As an indication of the standards of treatment then obtaining, I list hereunder the recommendations I made to my Board following my visit to America:

'That the Medical Director, Dr Claudia Burton-Bradley, should be invited to undertake training in the United States of America and such training should include: Short course for doctors in cerebral palsy by Dr Meyer Perlstein in Chicago; two weeks at the Mellon Institute Laboratory in orthopaedic appliances; a twelve-week course at the Children's Rehabilitation Institute, Baltimore, under Dr Winthrop Morgan Phelps; and a minimum of two weeks at Dr Carlson's School of Corrective Motor Education.

That improved diagnostic examination facilities should be provided at The Spastic Centre. All children should be processed to ascertain: degree of hearing loss and type of hearing aid to be fitted; sight difficulties and corrective measures; X-ray facilities should be provided by The Spastic Centre to check anomalies; femur rotation, ankle and wrist distortion and chest examination and orthodontic programmes; soft tissue X-ray and physical examination of the speech mechanism of all children under speech therapy to include pharynx, larynx, uvula, hard and soft palate, tongue and teeth; six monthly scoliosis check on all

non-walkers and children placed in long braces.

That The Spastic Centre employ male therapists and teachers.

That the Physiotherapy Department be responsible for schoolroom, bus and home posture of all children.

The Occupational Therapy Department to work in closer liaison with the schoolrooms with the object of merging preschool activities. The OT to be responsible for upper limbs and facial training to specific and immediate target under the Medical Director.

General arts and crafts work to be abandoned except for specified muscular functional objectives, and general child development and stimulation to be transferred to the classroom.

Speech therapy should aim to unload group work by closer liaison with the schoolrooms and therapy department. The speech therapists to use facilities of the schoolrooms and OT Department instead of setting up speech training elsewhere.

That the following changes be made in all physiotherapy bracing: Elimination of toe raising springs by the substitution of loaded ankle joints; elimination of present heel stops and substitution of sole plate stops; provision of heavy athetoid control braces; provision of bilateral pelvic band brace, with lock knee, and lock hips, as routine preliminary to balance and walking training; provision of lead sole ataxic balance shoes (it was thought at that time that lead weight in their shoes may be an advantage for the ataxic cerebral palsied child; however, nothing came of this approach); elimination of caliper ankle joint for all children and the substitution of jointed ankle joints; development of head and back support; elimination of plaster, foot drop night splints, and substitution of single iron night boots; elimination of night time adduction spreaders as uncomfortable and archaic, and substitution of adduction control braces for day work; elimination of plaster hamstring stretching, and substitution of control brace and standing table work daily; provision of working arm splint, adjustable for pronation, elbow extension and wrist dorsiflexion; work on swivel head brace, and continued collar development; work on Bakelite fibreglass plastic spinal braces and chin supports.'

These recommendations made our Medical Director extremely happy and the Board approved them all.

So in 1951, we set about making our own splints. We built a Splint Shop and a Transport Garage on parkland, provided on a temporary basis by the Mosman Council. We set up the machines we needed, drills and capstan lathe, power saw and other items, and engaged a group of fitters and turners, and leather workers with their machines. Apart from the splints, we were inevitably involved in the manufacture of special orthopaedic boots; some of them needed special adaptations and some were rebuilt from the ground up. Bespoke bootmakers were available in Sydney, but that meant a trip to the bootmaker and delays in fitting new boots, and after delivery we needed to dismantle the sole and heel entirely for those people who needed sole plates fitted.

Then we initiated a programme of getting voluntary help from 178 engineering firms, each of whom took the responsibility for one operation, for a batch of component parts. Some of these components were made by the firm using their own labour, and some were made by volunteer labour in their own time, on the weekend, or after hours. In all cases, the Company provided the machines and the material if available. These were assembled in our own Splint Shop from Dr Burton-Bradley's orthopaedic prescription for those children who needed them, without charge, on the understanding that the brace would be returned when no longer needed, so that the joints could be refabricated for another child. We had no compunction in asking people to do this work for our children and we knew that most engineers were sincerely glad to be able to help with this product. I coined a slogan: 'A Helping Hand to a Child Now Avoids a Wheelchair for Life'.

First of all, I talked to the Managing Director of British Tubemakers, who had promised me that they would manufacture the molybdenum steel oval tube required without cost, subject to a six months delivery schedule. It comprised twelve thousand feet of adult molybdenum oval tube and five hundred feet of the lighter oval tube for the pre-school children.

With this measure of the problem solved, I then approached the Australian Forge Company for the forging of the special Vanadium steel, in lots of two thousand for each ankle, knee and hip joint. They had promised that it would not cost us anything if they could fit it into the usual forging contracts.

The Americans were using a special aircraft aluminium, ST24, which could be brought from 5000 lb strength to 80,000 lb strength, by appropriate heat treatment. The ST24 was not available, but a substitute was – ST65 without heat treatment $\frac{1}{4}$ " plate was available from the Australian Aluminium Company.

The fourth significant call was to General Motors at Fishermen's Bend, Melbourne. They had the necessary one thousand ton press for the coining operation of the ankle, knee and hip joints.

Among the companies engaged in the splint making project, Lysaghts Limited provided the roll spring steel for the assembly of ankle stirrups, calf and thigh cuffs, Technico provided three thousand hip lock plungers, and Burns McKay two thousand hip lock levers, and machinery blanks for three thousand, while Anderson Spring Works provided three thousand knee lock springs. AWA provided two thousand plungers, eight thousand nuts and screws and one thousand ferrules, CSR Chemicals provided bandsawing blanks, Armco provided two thousand levers and lever housings, Consolidated Wire two thousand cables, Fletcher Spring provided six thousand ankle springs, G. W. Marner provided two thousand adjusting screws, W. H. Hole provided four thousand spring straps, W. C. Stephens provided one thousand splint knee pads and nuts. These are only representative of the 178 others who shared in the project, over a period of five years from 1949 to 1953. It will give you some idea of the size and complexity of the undertaking.

I think that the following letter would sum up the degree of co-operation everybody in industry exhibited in order to achieve success in this difficult programme:

**GENERAL MOTORS-HOLDEN LIMITED
MELBOURNE
2 September 1949**

Although we will be extremely busy for many months, particularly with Holden production, we are anxious to do what we can for this very worthy cause, therefore I telegraphed you yesterday indicating that we will be pleased to assist you. There will, of course, be no charge for this work.

We will undertake the designing of the coining dies, and the drawings when completed will be sent to you, as it is our understanding that you will have the dies made to our design. It is also our understanding that you will supply us with approximately 8000 forgings which will be coined in our plant at Fishermen's Bend, and when completed despatched to Sydney.

No doubt you will provide us with details as to where the coined forgings are to be sent.

We do require you to supply us, to help us with our design work, with the specification of the material to be used for the forgings. Doubtless you can obtain this information from the people who will be doing the forge work.

You can be assured that every effort will be made to expedite the work that we have undertaken but, on the other hand, we feel sure you will appreciate that there will be occasions on which it will be necessary to give preference to our own production as, naturally, we cannot afford to in any way jeopardise the output of the Holden cars.

I would like to thank you for your telegram which arrived this morning, and I hope that what we plan to do for you will in some small measure assist you in carrying on with the valuable work you are doing.'

And my telegram in reply:

Horn, General Motors, Fishermen's Bend, Melbourne. Thank you for your generous and ready help which now assures the success of our initial splint project. We appreciate your disregard of your own production demands upon the output of these vital presses.

In 1953, we set up a school for six already qualified fitters and turners who we wanted to qualify as splintmakers in our Splint Shop. There was four weeks full time lectures in anatomy and fitting the child to the Pope or Phelps measurement jigs and full scale layouts, a short course in physiotherapy, and 'how to do it' lectures in the aluminium splint and the child's and infant's splint component parts. The course included leather padding and boot repairing. This was followed by eight weeks practical work and then a final examination. Four of those in the original school are still at Centre Industries, and we have the satisfaction of knowing that others who trained with us have set up the splint making facility on a professional basis.

Among the material I brought home from America in 1949, was some plastic for the casting of back splints. This had been developed by the Mellon Institute with the assistance of the Bakelite Corporation. It was simple to use and could be shaped on any position of a body, and would set firm in five minutes. It was fireproof, flexible, and kept its shape, and it could be drilled, filed or sawn. It is now known as 'fibreglass', and is an industry in its own right.

I was fascinated by the new unbreakable glass which was used for airplane windscreens during the war, and I thought this could be the answer for Jenny's head support. Splintmakers made use of celluloid, which was not fireproof and too dangerous for use by children. The windscreens proved too brittle for use, but I.C.I. Company made me a gift of a sample, which was ductile in hot water. I fashioned Jenny's first collar out of this, it was lightweight and sanitary, and she wore it for some years as a chin support, but it did not support her bobbing head. It was replaced with a succession of leather collars for the next twenty years.

I think I should finish off this chapter with a summary which accompanied the splint parts sent for examination to the spastic centres in all Australian States:

We are sending you samples of our aluminium full control brace which is the type best suited to our cerebral palsy training, and which is very similar to the paraplegic type used overseas. The basis of the pelvic control brace is to anchor the splint firmly to the pelvic bone above the trochanter.

We are sending also a steel tubular 'Pope' brace. This is only partly assembled, so as to give you a better idea of its construction. It is better suited for use by polios and similar conditions. The joints of this brace are steel forgings which are very hard wearing and can be reused, if the brace is cannibalised, for use on a second patient. The tubing is a hard chrome molybdenum which cannot be bent while cold. It requires the use of an acetylene torch, and care must be used to see that the tube is not overheated, otherwise all its strength will be lost. The 'Pope' brace is assembled with temporary screws. These, of course, would be discarded and the tube would be silver-soldered, brazed, or welded to the forged joints. We cadmium plate all steel parts to improve appearance and prevent rust. Parts for this brace are available only in this size, and in a smaller infant's size. We contemplate increasing the size for adults if the demand for adult parts justifies the \$10,000 tooling cost for the forgings that would be involved.

The tubular steel brace would require a bridge to offset the hip joint from the pelvic band, except in the case of a child with snake hips. This would be accomplished by building out a welded vee to offset the hip joint by anything from 1 cm to 4 cm.

Most hip joints for normal walking will require a 15 degree stop on posterior extension. This is accomplished on this joint by filing the limit stop on the lower joint.

Grub screws to raise the toe raising springs should be set in gasket cement to prevent them coming undone, after final adjustment is made. These ankle joints may be provided with a posterior stop as required. For cerebral palsied cases, we prefer a solid limit instead of a spring, and substitute a nail in place of the spring to provide a solid forward limit.

A solid foot plate should be provided in all cases to facilitate effective control of the foot. This is fitted under the sole leather and extended forward to the metatarsal heads. The socket may be brazed or welded to the plate. The stirrup construction makes it possible to put the boots on independently of the brace.

The ankle joint as opposed to the caliper type stirrups gives better control of the foot and prevents undue friction from the T-strap, if used.

Aluminium braces are fabricated from 65ST aluminium alloy which has a yield strength of about 65,000 pounds as against the 5000 pounds yield strength of soft aluminium. These parts can be bent cold with proper equipment, but are much easier handled if a flame is used momentarily. Just a little too much heat, however, reduces the yield strength sharply.

The joints on this brace are ball bearing and some care is necessary in driving the taper pins to their final adjustment to avoid stripping the threads in the soft aluminium.

A heavier pelvic band is used in this brace for adduction control.

We can supply all parts in the flat of both types of brace. The aluminium is made in three child's sizes: large, medium, infants.

The steel 'Pope' brace is, however, available in child's size only, but until adult sizes are made, we made-do by using larger section stirrups as sample sent to you. In this case we weld a solid steel section to the ankle joint for greater strength.

We can supply you with all such parts together with aligning and bending jigs to assist in assembly on the basis of cost of manufacture.

The Splint Shop was the real commencement of Centre Industries, but we had to wait another seven years before Centre Industries came to full fruition in 1961.



The Chromovox was a mechanical TV box. It had pictures and designs on a 4 inch paper tape and it was amplified for our 'hard of hearing' people and was equipped with coloured lights for 'yes' or 'no' and in association with the wire recorder it was used for deaf children.



Education 1945

When we started our school and medical treatment unit, we were concerned with cerebral palsied children only. They were the reason for the existence of our parents' organisation, The Spastic Centre.

The job we undertook was so immense that we did not look further than providing medical care and education for our children. To do this, we had to establish a new untried theory: that we could meld into the classrooms our medical assessment and therapy staff, and the teachers of the Department of Education.

This required a new building, money to finance the project, the recruitment of medical and therapy staff, and the establishment of a transport service that could operate daily from every suburb to school and home again.

Most important of all was the role of the parents, leaving to professionals the medical therapy and teaching aspects of education. Mothers - allocated to the toileting and feeding of the children, and kitchen preparation of the midday meal, and the overall cleaning of The Centre. The fathers - to do the new buildings that were required.

The parents' role is to provide the money and the facilities our children need and to participate as effective members of the treatment team.

From our earliest days we assumed that the cerebral palsied child was bright and intelligent and, in spite of their neuromuscular deficits, they would amply repay the cost of education. Now, forty years later, they have abundantly vindicated that assumption.

Ours is a very simple story. We, at The Spastic Centre are like the old woman who lived in the shoe, the only difference is that we know what to do, or rather, what we want to do, but we certainly have too many children! We aim to provide free treatment and training for all cerebral palsied children in New South Wales who need it. We have not the money to build the specialised facilities that are needed, but we have our hands and we have our friends. If we cannot get money from the Government, we must build the schools ourselves.

We had no prospect of Government aid, with the exception of the salaries of the teachers, and a minimum of furniture and school requisites. There were no authorities that we could call on for assistance, and no publications or books were available worldwide, because it was assumed that cerebral palsied children were ineducable.

We had a similar problem in our medical therapy and, there too, much that was known about cerebral palsy was proved to be misleading and inaccurate. The CP who did make good in a normal school system, were shunned by their contemporaries and teachers alike, because of their appearance or 'funny' speech.

I never gave a thought to the possibility of failure. It seemed to me to be very simple – our perceived target was to go ahead as fast as we could irrespective of immediate difficulties and to surmount these as best we could. When we got a setback we disposed ourselves to get around it, in one way or another.

The Spastic Centre's fiscal state was always precarious in the extreme. In the early months my wife, as Honourary Superintendent, used to wait until I got home with my pay from the Public Service Board to raid it for the salaries of her office staff – I got it back, if at all, some days later.

My training as an accountant caused me to worry about spending money without a reserve of assets, and to gamble on getting income from public donations indefinitely. It took me quite a while to realise it was not my problem – it was the community's responsibility. My problem was confined to making the community aware of our children's plight. I could only do that through articles in the news media, and back them up by appealing photographs, with the message that these children were no different from the readers' own. My job was to spend all of the money that we considered necessary for the children's treatment and then to scratch around to get it the best way we could. Reserves were out of the question, when the applications for children seeking admission always exceeded cash donations. Capital expenditure for buildings and plant had to take its place after the children's day to day needs.

After forty years, we are still balanced on a fiscal knife-edge, and it is right that it should be so, because as an organisation we depend on drive, and our determined, courageous children are still the mainspring which prevents us becoming moribund.

In our early days, we did not know for certain that cerebral palsied children were educable. We did not know whether the added pressures of school and treatment would increase their physical problems or whether they could stand up to the pressures of daily transport in our dilapidated fleet of old motor cars. We knew nothing of speech training, less about their neglected dentistry and, apart from our Medical Director, Dr Claudia Burton-Bradley, we had established little confidence in the minds of the medical profession.

In 1945 with the support of the Minister for Education, Mr Heffron, we were fortunate in securing the services of Miss Naomi MacDonald, now Mrs Kerr. She remained our School Principal throughout our formative educational years until 1973. We had been given three old IBM electric typewriters which gave yeoman service for the next twenty years. They were particularly useful for the CP, because the keyboards were electrically operated. The manual operation of the conventional typewriter could not be handled successfully by the spastic child because of insufficient movement of the fingers to tap and release the keys. When the portable electric typewriter became available in 1958, we had had a battery of those typewriters for school use. It followed that the pre-school group learned to type from the keyboard before they were able to form the letters with a pencil.

I think that this was a real advance in pre-school and school education. It emphasised the advantages of our school and medical set-up, where the teachers and the therapists work together in the classrooms. In constant touch with the individual children, the Doctor and the School Principal together set the targets of therapy and for teaching problems. Through the whole of this early period, the Education Department provided staff, but their funds were limited to stationery and some furniture. We provided our school buildings at Mosman, and we provided all the ancillary equipment, including typewriters, until late in the nineteen seventies.

We were fortunate in obtaining, in those early years, the interest and the services of Miss Le Gay Brereton, now an unchallenged authority on the educational development of the cerebral palsied child. She was an educational psychologist, first attached to the Commonwealth Office of Education and later to The Spastic Centre.

She was doing a survey of our spastic children, which we had arranged with the Director of Commonwealth Education, and I had arranged a meeting with her over lunch at the Coq D'or, one of the better restaurants in Sydney. We had an enjoyable lunch, though the service was very slow. We made up for that with the empathy which she exhibited on the problems of education for the CP child. We both had to get back to our respective offices, and at the last moment I discovered that I had left my wallet at home! So Miss Brereton bought our lunch. She joined our staff later, so she evidently forgave me.

I will refer to the work of Miss Brereton in a later chapter. Her publications, 'Cerebral Palsy Basic Abilities: Interaction Games for Severely Handicapped Children Without Speech' and 'Sounds and Symbols' were ample evidence of her breadth of mind and of her technical resources to bring to the aid of CP children.

She retired in 1982, but continued her work in counselling our staff and updating her published books. More than that of anyone else, her work was vital to the future education of the cerebral palsied child.

This report dated 1953 by the Principal of the school, Miss MacDonald, gives some insight into her methods and achievements:

'The school assists the child to grow in intellectual power by understanding and interpreting what is going on around him.

The process of growth is inherent in the child, but it rests with the teacher and the school to provide the condition that will foster his growth.

This aim applies to our school at The Centre just as it does to other schools where the children are physically normal. It is every child's birthright to be given every possible opportunity to develop his mind and body to his full capacity.

In our school, at present, there are almost one hundred children enrolled in classes, in the charge of five Education Department teachers who are fully trained and experienced in handling children who are physically normal. Previous teaching experience is necessary to enable each teacher to have formed a standard of normal progress, and so be able to assess the individual child's progress and achievements here – to make comparisons and contrasts when measuring achievements.

During the past nine years, there have been many children through the schoolrooms. Some of the first enrolments from 1945 are still with us in the senior schoolroom – others have graduated to different schools – while a few, who were very severely handicapped, have retired to their homes. Finally, a small number have gone to work. So that in choosing a curriculum or programme of work, each group with its different possibilities for the future must be considered.

Primarily, we hope to help the child to become socially adjusted – to fit into the environment in which he finds himself. He must also learn the basic skills such as reading, oral and written expression, essential number facts.

At this school, before a pupil is enrolled, an attempt is made to assess his personality, maturity, and academic standard of learning potential. From this assessment, he is placed in a class group where it is hoped he will have the greatest or best opportunity of achieving the maximum development in all directions. The result of this is that in each class you will find overlapping of ages, abilities and standards of work.

Opportunity is given to each child for progress at his own individual rate in reading, number, spelling, particularly as the children get older and are required to attempt more difficult work. To make this possible, each class has intra-class groups, with material and text books supplied for graded standards of work. Among younger children there are more 'whole group' or class lessons given, but with the older groups the emphasis is on individual work in basis subjects and 'whole group' or class lessons for social studies and such subjects as music, art, geography, history, poetry, nature study. Their social studies periods supply the general information and general knowledge lacking through limited experience and limited environment.

Reading is one of the most important subjects taught in the schoolrooms. When a child learns to read and develop an interest in reading, he has opened vast fields of pleasure and information for himself.

Other activities include outings to choral and orchestral concerts, Museum, Art Gallery – inspection of well known buildings such as Cathedrals in the city – a visit to a public school as guests of the Headmaster, staff and pupils – monthly film afternoons at The Centre.

I have found that, as with normal children, once a teacher has established confidence between herself and the group, with a few exceptions, she has few problems of group control. This control is a very hard thing to define, depending mainly on the teacher's own personality, but the authority must be established before she is able to help the children to progress. Good high standards of behaviour are required at all times. No relaxation of manners is allowed because of physical difficulties. Children are encouraged to be independent, but considerate of others in the room and building. On the whole a child in any school likes to be the same as the group in which he finds himself - and on entering a class where there is an established atmosphere of calm and controlled industry, he will quickly fall into line with the others, unless there is some abnormality in behaviour or emotional instability present.

Each teacher establishes her own daily routine to include each day periods of reading, writing, number, music and literature. Other subjects such as geography, history, social studies, are given one or two periods a week. At present, an interesting experiment is being undertaken in the senior class – a discussion afternoon is held each week.

Whenever a child is able to write, whether good or bad writing, he is encouraged to record his own work. If grasp of pen or pencil has not been established, machines such as our Burroughs electric machines with alphabetical letters, electric typewriters, magnetic blocks on steel board, are used to record sums and english work. When a child is unable to use any of this special material, his work is recorded by a helper, teacher, voluntary or pupil from class among older girls or boys.

The Education Department supplies general stock, basic requirements, books, pencils, standard tables and chairs, a limited number of reading books, art material and special kindergarten equipment, but all special machines and equipment are supplied to school by The Spastic Centre organisation. In most cases these special machines are the expensive items needed for the use of the children.

Each classroom has its own library of selected graded books. Interests vary from travel, science, nature knowledge, physiology, to fairy stories and stories from literature and history. All children are encouraged to take books home.

Pupil reporting is another important part of our work, and I cannot stress too much the relation between various departments. I feel that it is important that any one teacher or therapist working with these children should remember that education, whether for the physically normal or physically handicapped child, is the development of the whole child physically, emotionally and socially, and it is necessary for every class teacher to view her children from this point of view.

In conclusion, I would like to say how much my staff and I enjoy our work with the children. There are many compensations to balance the losses in results and achievements.'

It is hard when at the age of three, you cannot walk, your hands do not work well enough to hold a pencil, and you have no speech. How then does your teacher or therapist establish a bridge of communication to get your mind working? A normal active child will have learned to explore its environment and, with endless questions to its mother, will have already learned to make use of language as a working tool of its developing and enquiring mind.

If you are a spastic, you do not learn about things around you by doing, only by looking and listening. You cannot get into the kitchen cupboard to pull out the saucepans for yourself, you cannot even learn the 'must not touch' routine, you just have to sit in one place and 'be good'. So you are dependent upon your teachers and your mother to bring the environment to you and to provide you with all of those experiences that a normal three-year-old obtains for himself – touch and feel, position and manipulate, look, bite and taste, examine and throw away, not as purposeless play, but as basic developmental learning which is a necessary prelude to education.

For the pre-school and school child, there is a normal childhood progression through a specialised school in which classrooms are equipped with specialised aids, and provisions must be made for daily sessions of physiotherapy, occupational therapy and speech therapy. There will be periodic interludes of surgery, and the fitting of braces, and the reduction of muscle spasms by administration of relevant drugs of varying types.

The major difficulty in this phase of development is the intrusion of physical training programmes into classroom time. All therapy procedures necessarily reduce the time available for education, and the work of the classrooms, in turn, is reduced by the reduced speed of communication, in speech, in writing and in hand movement.

Because manual typewriters were not suitable for the finger control of CP children, we tried to find an electric control that would do the work of a typewriter. We found that electric adding machines, converted to alpha letters on the keyboards, gave our CP children the ability to type, taking their time over the setting up of the key and its execution. Many of our children learnt to spell on those machines, before the advent of the portable electric typewriter.

This point brings to mind the experience of Stafford, an eight-year-old boy who had no speech and lacked hand movement. Once, he gave his father to understand that he had a new physiotherapist, but he was unable to give her name. After thirty minutes fruitless search, his father produced the telephone directory and started to go down it page by page, until three hours later he got to 'Miss Manfred'. Acting on that experience, his father taught Stafford the Morse Code – a longitudinal movement of his eyes was a dash, and a vertical movement was a dot. It worked like a charm; a bystander knew they were communicating, but did not know how. Unfortunately Stafford died young. Had he been born in later years, we could have done more for him.

I am inclined to think that though we would have welcomed money from whatever source it originated, we had the best of both worlds in education. We were independent, so if any article or appliance was needed for the schoolroom we went ahead and supplied it from Centre funds. We needed the Department of Education teachers for their professional standing and inspectorial functions, but the school was built by our voluntary labour and invited the teachers to use it. When we wanted to include therapists in the classroom, we did so and there was no Departmental problem.

Had the Department yielded to our pleas and built the school, it would have weakened our position immeasurably. I must say that the School Principal and our Medical Director had no trouble because they, and their respective teachers and therapists, were all working to a common end – the individual progress of the child.

There was another thing that came into the picture – that was the public regard for The Spastic Centre. The fact that we had no difficulty in getting volunteer labour and public donations and the pressure of the spastic buses on the roads in every suburb, meant that in the public eye we were doing things – we were active. If the Government had built the schools, we would have sacrificed our reputation as successful battlers and would have been responsible to bureaucracy for our continued existence.

Dr Elwyn Morey, Department of Psychology, University of Melbourne, Victoria, has said:

'Another point is the problem of communication in the education of cerebral palsied children. I feel strongly that too many of these children have problems in communicating on a reasonable level and this is of prime importance. Like deaf children, they cannot get things over, for they cannot make themselves understood. Their failure to communicate increases their frustration and their stresses. I think that perhaps realistic education, or rather realistic planning, might mean getting into the communication field, right at the word "go"! Then there would be no need to stress communication, communication, and communication. If we cannot teach children to speak intelligibly, then we could give them an alternative system of communication, which might be a mixture of speech and something else.

We could write out a code to give to their mother and their father, and we could tell them that they should spread this code to all their relatives and friends and their neighbours. Then you anticipate some of the problems of the child in communicating and you anticipate and prevent some of the frustration he must feel when he cannot get things over to his playmates. If we did this, then we might quite well in many cases postpone reading and spelling and number and so on until we had at least a good beginning in communication methods.

I feel that for each child there are four things which we need to take into account in Realistic Planning.

Firstly, for every single child, we need a flexible approach. Secondly, in a general way with cerebral palsied children, we must be planning vocationally from the time they are very small. I do not mean we decide this child cannot go to work, or this one can, but we are planning vocationally in a very broad sense and including the child's leisure too. We are planning what he is going to do, what will be his greatest assets in terms of skills. If we cannot find any easily, the task is still for us to find some. We have to exercise our own skill in searching behind the most obvious things to find just what the child can do.

Then a third thing we have to remember for each individual child, is that the most important single element is the conservation of his personality. Personality is far more important, I think, not only with cerebral palsied children, but with normal children as well, than intelligence and academic attainments. We have to realise that we must not give these children too many experiences which might block the satisfaction or the development of a full personality. We have to try to give the child, too, satisfying hobbies for his leisure time. I do agree, that so often parents have been preoccupied with the physical and medical problems of these children, and the areas of their lives like art, literature and music and so on have just accidentally been more or less left out.

The fourth point, and one which is so important, is that cerebral palsied children, particularly as they approach adolescence, and their parents from the time the child is born, do need individual counselling. I include this in Realistic Educational Planning because I think that the cerebral palsied children are perhaps the most in need of psychological support and assistance at all stages. As a child approaches adolescence, he has to face problems such as you and I have never really considered. If he belongs to a group of CP of fairly good intelligence, then these are very real problems for him and all of the other members of the group.'

For far too long, the general attitude of society has been to regard a cerebral palsied person as somebody who is quite different from themselves, apart altogether from the visible disability. The person with athetoid facial grimaces is assumed to have a mental defect, no matter how intelligent he may be. A shambling walk, or a lack of speech, calls for automatic rejection. Based partly on embarrassment, it still contains a measure of primeval prejudice against the unknown.

The solution lies not only in the training of the handicapped themselves, but equally in the education of the community in general. There should be a planned educational programme in primary and secondary school levels, outlining the problems that physically handicapped people have to face. The slogan – 'Your attitude is my handicap' – should not be used in an enlightened community.

The most restrictive handicap suffered by cerebral palsied persons does not lie in the inability to function physically, nor in his appearance. It resides almost wholly in the automatic loss of self-esteem. Their loss is compounded by inability to communicate with people outside the family circle, and sometimes inside that circle.

Normalcy, accepted as a principle, should require that the cerebral palsied child be educated with his peers in normal classes. This ideal situation has not been achieved in Australia or in overseas countries. It predicates educating each cerebral palsied pupil according to his specialised needs and with full knowledge and experience in meeting his needs. It calls for teachers specially trained and for equipment tailored to the special needs of each child.

In making the best of two worlds, we can best serve severely handicapped cerebral palsied children by providing specialised teaching and equipment, and providing a carefully managed transfer of the less handicapped into normal classes as they prove capable of working in the more demanding environment of the classroom. There is danger in making this transfer before the child is ready. It should be recognised that, without careful supervision in the early stages of adjustment, the child may lose in the playground more than it has gained in the more structured environment of the classroom.

'Integration' in the schools is at the moment a fashionable slogan, meaning different things to different people. Used to describe an attainable and desirable objective, it cannot be challenged. Too frequently, it may be used to justify an approach to teaching systems which attempt to isolate the learning problems of the pupil from its physical or neurological problems. Diagnostic labels are often misleading. It is essential that an educational classification leads to an understanding of the hidden strengths and weaknesses of the individual pupil.

In too many cases, the multi-handicapped child gravitates quickly to the back row of the classroom, and his progress slows or ceases. Able bodied children do not thrive in blackboard jungles, but handicapped children do not survive, unless their special learning problems are understood. For the cerebral palsied pupil, an achieved success in a special school is the normal prerequisite to success in a normal class, and in a normal playground too.

Miss Beatrice Le Gay Brereton, Research Psychologist at The Spastic Centre, had this to say:

'This is in the nature of a debate so perhaps one should start by saying whether one is for or against integration. The way I see it, this would be a foolish thing to do – one may be for including handicapped children in normal schools, and against bringing together different sorts of handicapped children under one roof. One may be for integrating children with one type of handicap, but against integrating those with another. One may be in favour of integration at infants school and against it at high school level, and vice versa.

Let me say something about the concept of integration in the sense of placing children in 'normal classes'. This is in itself a doubtful term because in many instances we may be thinking of special classes for slow learning children attached to normal schools.

At worst, the placement of handicapped children in normal schools takes us back to square one. That is where they were before special education started. At best, it should be a highly selective process in which we have to judge very carefully what the child will gain and what he will lose by such a move – rarely is it all gain or all loss.

Socially – will it help him to mix with other children, or will it destroy his faith in himself? Academically – will he be spurred on by competition, or destroyed by the pace of the school machine?

Paramedically – will the need to walk and run improve his walking and running, or will the lack of surveillance bring a recurrence of bad postures and movement patterns?

If I may draw again on my longitudinal study of partially deaf children, the points I should make are these:

Socially – to place a partially deaf child in a normal class will put him in an odds-on situation to be socially unaccepted. The number of children belonging to the most popular third of the class is 7 per cent, and the bottom third 49 per cent. That is, the normal child has one chance in three of being in the upper third, whereas the partially deaf child has less than one chance in ten.

Academically – he is more likely to have unpredictable holes in his information than the corresponding child at a school for the deaf.

Paramedically – he is particularly well placed and he is likely to speak more naturally and understand better.

Turning to cerebral palsied children, a recent publication by Elizabeth Anderson shows that, socially, cerebral palsied children are in very much the same situation as my partially deaf children and that the odds are weighted very heavily against them academically. The possibility of paramedical gains in their case is remote. I know of several who have had to abandon their typewriters, for example, in order to cope after a fashion.

I think we have the task of selecting, out of ten children who might be physically able to get round a normal school, the one or two who will become popular or successful or happier.

Principles of selection should be studied and varied with the sort of handicap and the qualities of the particular child.

There are, of course, other arguments in relation to partial integration – linking cerebral palsied children to normal classes for particular purposes only, or placement in classes attached to normal schools. The point I wish to make is that it is quite wrong to issue a directive such as was done in England stating that: “No handicapped child should be sent to a special school who can be satisfactorily educated in an ordinary school”.

As well as educating these children, it is imperative to minimise the handicap which will, after all, be a feature not just of his time in school, but of his whole life.



'We have no space'



*What a way
to spend a
Sunday!*

Country Children's Hostel

At Allambie 1948-1958

My wife, Audrie, as Honorary Superintendent of The Spastic Centre, was always conscious of the plight of country parents who had a cerebral palsied child. This was exemplified by the plight of one child, sixteen years of age, who started her life in a baby's cane bassinet on wheels, and when she grew out of that the bassinet was extended, until at that time it was one and half metres long. She had had no treatment; her joints had become rigid, and the only movement she could make was with her eyes. They were alight with the brightness of intelligence, and though she could understand everything about her family, she could not communicate anything at all, except by the movement of her eyes.

She was a Gracie Fields fan and had a collection of records which she loved to have played for her. She was desperately loved by her farming family.

We were unable to help her; we did not have the money nor the facilities. Time, and the locusts, had eaten the family's hope, but it should not have been so.

Now after forty years, the haunting image of Pixie comes into my mind when I think of what her life really was and what it should have been.

When The Centre was first started in 1945, there were no proper treatment or schooling facilities for the cerebral palsied throughout the whole of New South Wales, or indeed the whole of Australia. There were no trained staff, no apparatus, no transport and no buildings. In providing these, The Spastic Centre had been forced to first set up the facilities and get the children under treatment, and then work like beavers to pay for it, devoid of Government assistance.

While this policy has meant the building up of a very efficient treatment unit in record time, it has prevented the building up of cash reserves for the future, and rightly so – our job is to get every possible child under effective treatment immediately, to remove the tragedy and the heartache from as many homes as we can.

That is why the essential planning for the new Country Children's Hostel, begun in 1947, took ten years to complete. We had first to complete the medical unit and school at Mosman, and provide for double the number of children seeking admission; and that in itself was an immense undertaking. Then we were free to take our weekend voluntary building teams to Allambie and start on the Country Children's Hostel in earnest. That, we finished in 1957.

For those ten intervening years the families must blame somebody for that dereliction of duty, and the Government must accept the strictures that go with it. A country child has missed his chance of walking; he should have been educated and missed out.



Set on a windy hill with a brave reach of the Pacific Ocean.



Building it the hard way – depending on your own muscle power.

He has missed the bus if his speech or hearing is defective. Childhood is fleeting, but adulthood is a sentence for life. If you have been denied the education and the physical treatment that goes with it, there is not sufficient time to replace those lost years; delays in maturation can seldom be picked up in later years.

All of our services, prior to the opening of the Country Children's Hostel, were confined to metropolitan children who could be reached by our bus transport system, but we were deeply concerned about the rural spastic children. The health services available in the country areas were in the hands of a general practitioner, supported by a local hospital - specialist medical services were only available in the metropolitan area. The larger towns had more medical and nursing facilities, but they were devoid of newly formed therapy services – physio, occupational, speech- and in those days, too, there was no evidence of interest in the cerebral palsied, either in the health services or in the schools. It was imperative that we should extend our services to the cerebral palsied children in the rural districts, and the only way we could do that was to provide diagnostic, residential, educational and medical facilities, long term in the city itself.

Farmers and business people in the rural community could not easily move to the metropolitan area, so it was necessary for the spastic children to leave their homes, relations and friends and come to the city for treatment and education, and the treatment and education may extend throughout their childhood.

You will appreciate how heavy were our hearts when we had to say to a mother of a small child, 'We have no space', and how we were driven to provide that space, despite the fact that we were always heavily in debt. From our opening day, we were inundated with requests from desperate parents seeking help for their children. We could not provide residential care at Mosman, which was built out. The crisis point came when my wife had to say to one country mother that, unless she could find some residential accommodation for her daughter, we could not do anything to help her. The child, Jan, was brightly intelligent, and my wife and Dr Burton-Bradley were agreed that her need for physical treatment and schooling was extremely urgent.

In 1950, two of our voluntary helpers, Mrs Venee Burges and Mrs Florence Deaton, decided to do something about the problem. They enlisted the aid of the Mayor of Manly, Alderman C. R. Scharkie, who approached the Council and the Minister for Lands and, after some delay, we were given title to two hectares of scrubland off Allambie Road, Allambie Heights. In the meantime, Jan's family had moved temporarily to the city.

The land was on a hilltop with a commanding view of the Pacific Ocean; it was scrubby sandstone and clay. It would not have fed a rabbit, but that two hectares of land was the hope of The Spastic Centre's future development. It had not been cleared or fenced; there were no water, sewerage, gas, electricity or telephone services, and the nearest housing development was three kilometres distant.

The Apex Club of Manly cleared the land of scrub and trees, but we could not embark on the building programme; that had to wait until the Mosman building was completed. We had prepared our Country Councils for the raising of funds in thirty-two towns in the country, and during a convention we had arranged to plant a tree in the grounds for every township. On 3 November 1953, a foundation stone was laid by a country athetoid CP from Boggabilla, near the Queensland border. He had prepared a speech for the occasion and had rehearsed it continually, so when it came his turn to speak, his spasm of speech submerged him. He struggled on, sweating, and everyone in the crowd held his breath and struggled with him, until he had finished. Then his relief was so great that his spasm ceased and, laughingly, he then spoke for an extra ten minutes, as an encore. He stole the show!



Planning for next Sunday's working bee.

Only one house was in the immediate vicinity of the site and Allambie Road was not surfaced. A quarry for brick-making shale was immediately behind the proposed building, and the application for relief made to the Mines Department was refused because of the shortage of brick-making facilities in the metropolitan area. When we came to peg out the original building, we found that Wing Three had to be curtailed because it would encroach over the boundary. Finally, after some delays, we arranged with the Mines Department that they issue an alternative lease over a portion of adjoining clay and shale deposits. This enabled the Lands Board to grant an additional lease of thirty metres that was required for our building.

In the meantime, the County of Cumberland Planning Scheme came into existence. That meant a further delay until two Local Government authorities finally agreed to allow restricted building for our hostels on the site, and the Cumberland County Council signified approval for 'Special Purposes Only'.

The problem confronting The Spastic Centre was how to meet the requirements of the Local Government Act, Child Welfare Act, Hospitals Act and the Health Act, and to provide a home for one hundred spastic children, hospital accommodation for twenty-four patients, and accommodation for the trained staff and the country mothers who would be in residence for periods of five weeks each year, looking after the children's welfare.

In 1948, while our residential hostel was in the planning stage, we embarked on a pilot model hostel which we established in Glover Street, Mosman. It was in a small house and took twelve country children. It gave us the opportunity to test the facilities we would need, and the specialised plumbing and equipment needed when we came to the larger Country Children's Hostel. One of the mothers (who was a qualified nurse) was given the role of Matron. She had found it increasingly awkward to provide bathing facilities in an ordinary domestic bathroom, so we set out to build a bathroom addition onto the house. This was built hard up against the boundary, with no windows in the wall adjacent to the boundary; windows were provided in the other three walls. It enabled us to separate the male and female residents for bathing. It was equipped with washbasins and toilets, and four separate stainless steel baths set one metre off the floor, on an island basis, to facilitate assistance from both sides for the heavy patients, together with a drying table. Later this design was incorporated in the Country Children's Hostel at Allambie Heights.

Following investigation by the Metropolitan Water Board, we were advised that it would not be practicable to provide a water service to the residential hostel for ten years, until the Belrose Reservoir was constructed and reticulation laid from it. The Water Board reluctantly accepted an alternative plan whereby the weekend workers had the authority to broach the main supply pipeline that passed half a kilometre below our site. We supplied the reticulation line and a 90,000 litre tank from which a pressure pump would provide a head of water for the requirements of the Hostel. The Warringah Shire Council did not enforce its power over a temporary supply line trench along Allambie Road. That system served us well for twelve years, when the official water was reticulated to us in 1962.

The gas mains and electricity were provided in time for the commencement of the building, and the telephone services were connected shortly afterwards.

In the absence of sewerage, three septic tanks were necessary at three separate locations, with surface drainage areas for each tank. These were a massive four metres long by one and a half metres wide, and were a constant source of trouble because of the clay surface which was impervious to water. This was the case for the next eight years, when we had plans for putting down a deep bore well, five hundred feet below the subsoil. Fortunately, we prevailed upon the Water Board to share the cost of the feeder pipeline for sewerage five kilometres down the valley. This solved our problem and twenty-five years later we are still paying off our share of the cost of \$110,000.

As a sideline to this issue, we had a series of meetings with the Health Department Inspector on the effluent problems, but they ceased for the want of a satisfactory alternative. Going back to the nightsoil, pan system, was inconceivable for our children.

Mr Pollock, who had had ten years experience with The Centre buildings at Mosman, was again our honorary architect. He was a marvellous architect, and he instinctively knew what it was that would appeal to our handicapped children. He said that he had looked at this as a home for children. He produced designs for the accommodation of the country children, with separate facilities for their mothers and for staff.

I think Mr Pollock did not enjoy the supervision of the Mosman building programme, although he realised that our voluntary labour was the only way to get the building erected, and he gave us the full measure of his undoubted architectural abilities. I can still see the expression on his face when he looked around on one crucial 'pour' of concrete, with two hundred volunteers

trampling down his precious steelwork with their big Army boots, behaving like opposing forwards in a League Final football match. He left shortly afterwards, saying that ten minutes was all his sensibilities could stand.

We made it up to him with the Country Children's Hostel. I was by then experienced in handling the volunteers and the building problems, and Mr Pollock's experience with the cerebral palsied was such that he gave us a most imaginative building in its own right, built on a hill overlooking the city and the Pacific Ocean, with its white curvilinear facade complementing the superb hilltop site. It is open to every breeze around the 250° horizon.

The site was capped with seven metres of white pipe clay which was impervious to water, and beyond that was a layer of shale. Fortunately for us, the clay was not suitable for brick or earthenware pipe making, because of the presence of iron mixed with the shale, otherwise we would have had a quarry where the hostel for country children now stands. Owing to the notorious instability of this ground, it was decided to sink piers to rock, in all 137 piers each 75 cm in diameter, the deepest of which was 9 metres, to provide the necessary foundations for the building. Over one kilometre of concrete piers was sunk. Due to the length of the building, which extends 100 metres, all horizontal beams of foundations were laid at ground level, supported by the concrete piers, otherwise the building itself might have broken its back. The curvilinear design of which Mr Pollock was so proud – and it did give the hostel a front façade that is admired even today – led us into constructional difficulties. For instance, the roof tiles were laid on one side of the ridge and needed to be contracted at the ridge pole and expanded against the gutterline. This meant trouble with the tilers, because the reverse had to be the case on the opposite side of the building. Mr Pollock demonstrated that this could be done by allowing a gutter to be placed each eight metres to absorb the difference.

The Hostel was designed for children – a 'home away from home' – where morale is the most important ingredient in medical rehabilitation, where love, warmth and affection are requisites so essential for those away from their families. Our Country Children's Hostel removed, for the first time, the terrible isolation of rural families and their cerebral palsied children.

As children need more in their daily routine than efficient housekeeping and excellent medical and nursing care, mothers of the children work in the unit on a rostered basis of five weeks in the year. Their interest and affection naturally transfers from their own child to all the other children. This assures them all of the hug and comforting kiss that children need when away from home. As well as providing the tender loving care that only a mother can give, this arrangement helps offset the depersonalisation of group residential living, and their presence does much towards contributing to the relaxed home atmosphere. Their attendance, too, trains them in the future needs of their children, helping tremendously in establishing an intelligent awareness of the problems and the aims of prescribed treatment.

It helps the mothers too, whose friendships formed with the other mothers assure them that there will always be a friend on hand to watch over their child when their rostered duty is finished and they return home to the country. Telephone contacts with other mothers and the staff are a necessity for the peace of mind of the country mothers. Some of them are 1000 kilometres distant from their homes.

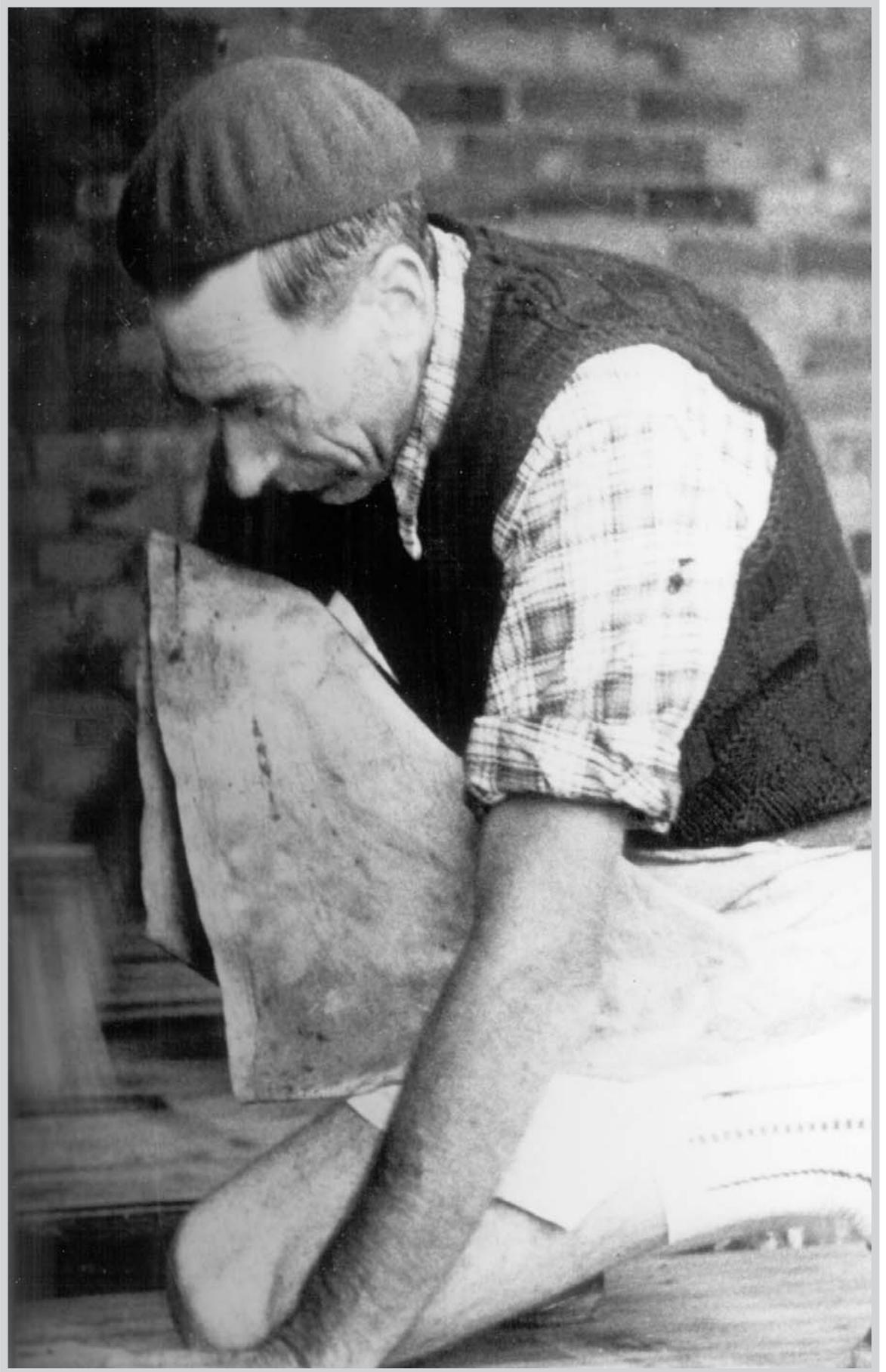
One difficulty is that families grow away from these children, who may return home for holidays and find they are no longer fully a part of an active family. The siblings have their own interests and the cerebral palsied child with a speech defect may find it difficult to share.

The main building, with a frontage of 79 metres to the bend of Allambie Road, contains rooms for play, pre-school, therapy, dining and kitchen and offices. The main corridor off which the wings radiate is 2.8 metres wide to allow for crutch-walking of children and the use of wheelchairs. This section has a northerly aspect so that sunshine is in the public rooms for the major portion of the day. The site was levelled to the main building to allow easy access of the children from the public rooms to the lawns.

In placing the wings, consideration was given to the fact that, by using this type of design, it was possible to get the sun in every room at least once every day, and it also allows the children to be taken by means of roads to any portion of the building in buses, and provides a first class means of escape in case of fire.

The two wings to the north of the building are used for dormitories. The central wing is used for a treatment wing and contains pre-school, kindergarten and therapy rooms. The wing to the south east of the building was designed as a hospital with its own operating theatre, sterilising room, accommodation for nurses and surgeons, kitchens, five single rooms and three wards. It was considered necessary to have a special orthopaedic hospital for cerebral palsied children owing to the lack of facilities and staff in the general hospitals for the handling of these children in post-operative work, when they require special nursing attention.

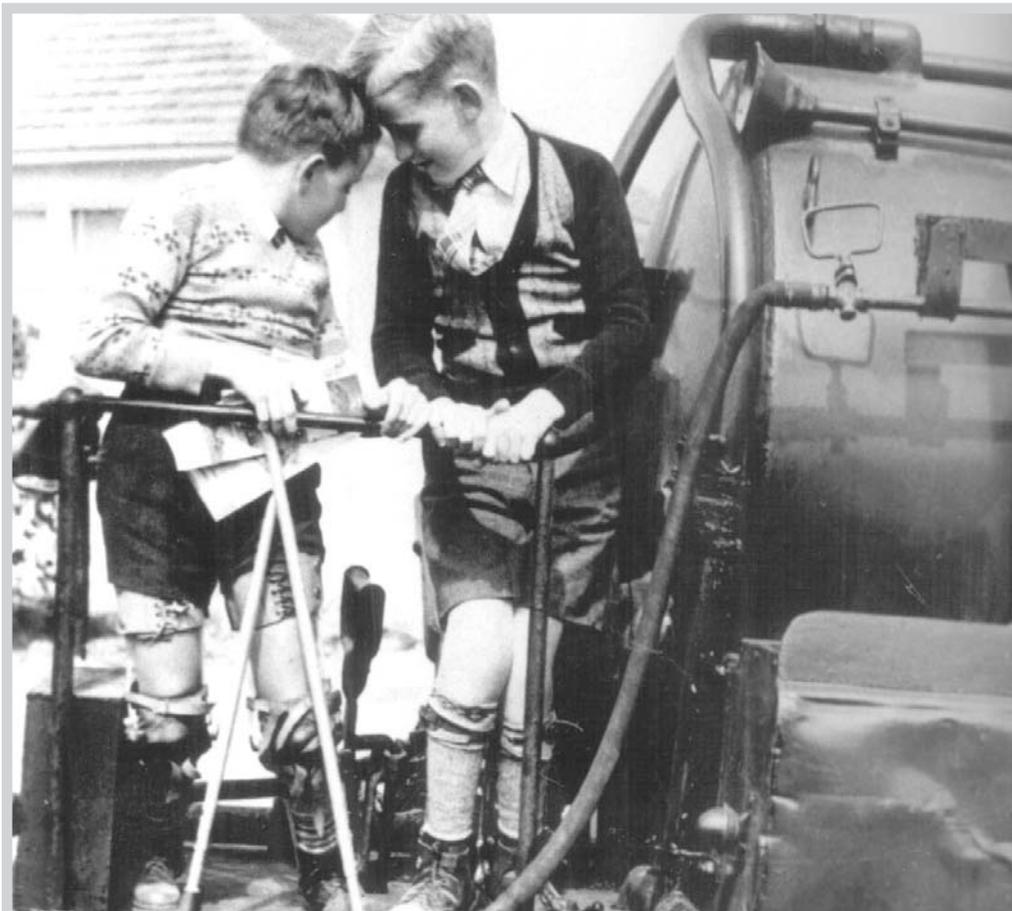
For lack of money, we never got around to setting up our own hospital. Instead, we provided nursing care in our Hostels, and only used the public hospitals for operations and urgent illness. In that way we capitalised on the equipment availability of the hospitals, and provided our own nursing staff to care for the cerebral palsied children in the hospital wards. We took them home



Nailing the floorboards.



H.R.H. Duke of Edinburgh award winners: Cheryl Morgan and Joanne Crumpton



Schoolboys ruin – tar on boots and on wheelchairs – and crutches too: John Anderson and Donald Qusted.

to the Hostel as soon as medically possible. The problems which existed at that time, 1952, still exist thirty years later. The majority of cerebral palsied children could not make their needs known to the nursing staff, because their spasms increased under the stress of the unfamiliar surroundings. In our Hostel the staff understood their nursing needs. That highlights a fact that I shall emphasise again and again – that speech is still the major handicap of the cerebral palsied.

Again, as happened in our previous buildings at Mosman, we finished this building without injury to the voluntary workers, though there were some 'close shaves'. One voluntary worker was a deserter from a Russian ship; he had no English, but he got a job with the foreman assisting the plumber engaged in erecting the roof gutter three storeys up on the western end. His ladder had slipped, resulting in him being suspended by his hands over a partly-secured gutter and shouting directions, and probably swearing in Russian, to the onlookers. It took two or three minutes to erect the ladder again and to rescue him. He loved the Sydney beer and his party trick was biting sixpences in half with his teeth!

On another occasion, one of the building workers was at the bottom of a ten metre shaft that had been filled with rainwater; in the absence of a pump we only had a rope, bucket and windlass. Due to the rain, the slippery sides of the shaft gave way, resulting in the heavy steel windlass whizzing down to the bottom of the hole, but amazingly the man at the bottom saw it coming and flattened himself against the wall. He escaped unhurt, with not even a bruise to show for this experience.

With hindsight, thirty years later, I believe we should have made the bathrooms and the toilets with immediate access to the dormitories, and possibly the dormitories should have been restricted to six or ten beds. The concrete and brick building does not readily allow alterations and extensions to be made, and the cost of these has been exorbitant over the past fifteen years. On the other hand, a more lightly built Hostel, taking advantage of modern building materials, could give us more advantages in correcting design error. Those advantages would have to be equated with the tendency to extend the use of buildings as long as they stand up – in Sydney, temporary hospital wards built in the influenza epidemic in 1919, are still in use.

Completed in 1957, the beautiful Country Children's Hostel, 'McLeod House' at Allambie Heights is a lasting monument to the voluntary labour of skilled and unskilled city men from all walks of life, who over three years erected the building at weekends at a cost of \$387,000, at a fraction of the cost of paid labour, in order that some unknown country child should have the same chance in life as city children.

I must pay tribute to the volunteer workers who laboured so successfully over the years from 1946, until their section of the job came to an end with the building of the Country Children's Hostel and Centre Industries' factory in 1961. During those years, we had teams of two hundred volunteer workers when we had a 'pour' of concrete underway. These pages are a tribute to the kindness and skill of those many hundreds of amateur and professional Sunday builders who wove something of their own generous spirit into the very fabric of these buildings – in order that some unknown cerebral palsied child should 'get a break'.

While the Country Children's Hostel was building, my family was growing up amid all the traumas, excitement and problems of The Spastic Centre. It was all worthwhile, but we had to be available twenty-four hours a day, seven days a week, and the telephone never stopped ringing and you could not ignore it for fear of a transport breakdown or, much less often, an offer of help.

For example: On one Saturday my wife was suffering from a severe migraine headache when the phone rang and the caller said that he wanted to come round and have a discussion with me and my wife. Audrie was barely able to lift her head off the pillow, so in those circumstances I suggested he put the appointment off to the following week. He was evidently miffed, but accepted my apologies. He arrived at the appointed time on the following Saturday, and presented us with a cheque for one thousand pounds. Mr Cliff Miller had raised that amount from his associates at the City Markets. For more than thirty years following, he maintained his identification with fundraising for The Spastic Centre. It taught us a salutary lesson, which we never forgot.

In the ten years that had elapsed since the Centre's foundation, we had established a firm financial and technical basis, and it was time to move out of The Centre and re-establish our own family links. I had a block of land in a suitable position midway between Mosman and Allambie, and there we built our home.

With Mr Pollock's supervision, and drawing upon my expertise as an amateur builder, I put in the foundation beams and engaged a team of bricklayers to build the walls; when this was finished I started single-handed on the roof and floor timbers. I only worked on Saturdays, because on Sundays I was in charge of the volunteers at the Country Children's Hostel – so it was slow work, and one year had gone by since I started on the job.



Esther Woodhart presents a bouquet of flowers to Princess Alexandra.



Princess Alexandra talks to a resident with Mrs McLeod

Nearing the end of the roof section, it was getting late in the day and I had only ten short rafters to nail in a section where the roof valley met a ridge. Unfortunately, I had miscalculated my sawcut and it was short of the length required. I was tired, I forgot my craftsmanship, and I fixed them all a few cm off the square. It did not interfere with the roof structure, and I said to myself it would be hidden by the roof tiles and no one would be any the wiser.

The next Saturday, I was surprised to notice that the rafters had all been replaced – my short sawn ones were neatly piled on the ground. I never found who my good fairy was – but privately I put it down to the spirit of Freddie Marsden, who had been my original foreman/carpenter and who had died shortly after the Mosman school was finished. He was a carpenter and joiner of the old school, and I could just picture him keeping an eye on the progress I was making on my own job, and he would not have liked a botched job, whether it was visible or not.

I laid the roof tiles myself and did all of the floor, architraves, scantlings and inbuilt cupboards, while Audrie put on her oldest hat and creosoted the floor timbers against the ravages of white ants, and painted all the walls and ceilings of the house. She did a good job with her painting, and she would not mind my remarking that she was the only painter in my experience who, when her work was done, washed her face and hair with turpentine!

The building looked superb with its whitewashed walls and the deep green roof tiles, with the eaves finished in a deep coral pink.

We moved in during the Christmas holidays in 1954, with a minimum of furniture because ours had been battered beyond repair after ten years in service at The Centre, but it was all ours. Jenny and Robin had separate rooms. Electricity and water had been connected, but the telephone never rang because the number was not yet published in the phone book, so we had a silent holiday which we enjoyed very much indeed. The temporary building shed stood in our back garden for two years, until we had completed all the things that made the job complete.

On Sunday, 9 February 1958, the Country Children's Hostel was officially opened by the Governor of New South Wales, Lieutenant General E. N. Woodward, C.B., C.B.E., D.S.O. It was raining hard all day and despite the sand that had been strewn on the unfinished lawn, a most attentive audience listened to the speeches under their umbrellas, even though they were in danger of losing their shoes in the gluey, clay bog.



It was built as a place for spastic children, and in its building light and colour riot – and here the cerebral palsied child is King!



The building looked superb with its whitewashed walls and the deep green roof tiles, with the eaves finished in a deep coral pink – or perhaps as a builder I am prejudiced.

In my speech, I said that The Spastic Centre had always operated on the principle that the measure of its services in each case is determined only by the need of the child. That all treatment is provided free of charge, so that it can be applied when it is most likely to be effective rather than when family finances permit – and that if parents cannot pay for their child's treatment they certainly can work for it and work they do, on a very effective voluntary basis, as the building at Mosman and now the Country Children's Hostel demonstrate. I further said, that we have lived from week to week for thirteen years, paying this week's salaries from this week's collections, and admitting more and more children to treatment as the mutilation of the bank overdraft permitted.

Mr Robert Pollock's monument still stands. He gave the cerebral palsied children more than a school and the means of getting medical help; much more than a residential facility for country children. He gave them something uniquely his. He wrote his own epitaph when he said, in relation to the Country Children's Hostel, "This was designed to be a home entirely free from an institutional atmosphere. It was built as a place for spastic children, and in its building light and colour riot – and here the cerebral palsied child is King!"

When we were halfway through the building programme, the telephone rang late one Sunday evening and the caller was an unknown solicitor. He apologised for not speaking to us sooner, but said that he had spent two weeks in bed with chicken pox, which had affected his balance and hearing. He said that one of his clients had died and had left her estate to The Spastic Centre and, while he would be in bed for another week, he thought we were entitled to know. He then said that the amount would be substantial – he could not give us the exact amount, but it would be around the six figure mark, in pounds, not in dollars.

We did not sleep that night and, true to his promise, he met us a week later and told us that we were the proprietors of 'The Seabreeze Hotel' at Tom Ugly's Point, seven kilometres from the city. This timely legacy was from the estate of the late Florence

"This was designed to be a home entirely free from an institutional atmosphere. It was built as a place for spastic children, and in its building light and colour riot and here the cerebral palsied child is King!"

Westbrook, to whose generosity the Hostel stands today, as an enduring memorial.

This generosity, unfortunately, was not matched by the State Treasury who, in spite of our continued protests, grimly extracted \$84,000 probate from our share of the estate, making it impossible for us to complete the hospital wing which, at that time was so necessary for the spastic children.

LETTER FROM AN ENTRANT

(From the Namoi Valley Independent newspaper in 1975)

'My name is Lorna Philpot. I'm from Gunnedah in the Miss Australia Quest. Quite a few people have asked me why I wanted to enter the Miss Australia Quest. I have three main reasons out of many; I want to be able to show Australia that Gunnedah does stand behind the children at The Spastic Centre; Gunnedah has two children in Sydney at the Hostel. By being an entrant in Gunnedah and with their parents taking part in The Spastic Council when they are home, the money I'm able to raise pays for their treatment in Sydney. The third reason is that I knew a small baby who was a spastic child. Her name was Laura-Anne.

About a week after Laura-Anne came home from hospital her mother noticed that her head was going back all the time. She was taken to a doctor who immediately referred her to Allambie Heights, where doctors found that she had no control over her muscle movements. Everything that comes to a baby naturally, Laura-Anne had to be taught. The whole family had to face the fact that their lovely little baby was a spastic child, which meant a lot of sleepless nights and patience, but above all, they had to give Laura-Anne as much love and devotion as they possibly could.

Her mother had to go to Sydney every six weeks to learn new exercises to help Laura-Anne. Laura-Anne's mother would then return home and teach her family how to do the exercises, how to hold the baby, how to play with her, and what to do if she took a fit. For instance, if Laura-Anne held her breath, a small sudden hit on her lips would make her breathe again. As time went by, any little sign of improvement would give her family a little ray of hope – something to hang on to. There were times when all seemed lost, like the time she caught the common cold which developed into pneumonia. She was sent to Allambie Heights and, although it was touch and go for a long while, Laura-Anne's fighting spirit and the skill of the highly specialised doctors pulled her through. On the day she was able to return home she caught the measles, and the long hard struggle began again. It was a hard fight for Laura-Anne, her family and the doctors, but by some miracle, although very thin and weak, Laura-Anne was soon home with her family once more. They had all come through a lot. With the fond devotion of her family Laura-Anne began to put on weight. When she was asleep she looked just like a normal beautiful baby. One night something wonderful happened – she was sitting on her mother's lap and for the first time in Laura-Anne's life she raised her head properly and gave her mother a great big smile. The family was so thrilled; they thought she was getting better. The next morning she was rushed to hospital where later that day this little girl could fight no longer.

Although Laura-Anne's family has the dearest memory of that one very special smile, the world has a memory of a small child who has helped other people to understand about spastic children. There is a film on Laura-Anne called 'A Child is Born', which is still showing all round Australia. I think this film gives courage and strength to the parents of spastic children. It shows how much can be done for these people to realise just what wonderful ideas doctors are putting into practice. I shall always remember my little sister Laura-Anne as a beautiful little girl with an incredible will to go on.'

Note: Miss Lorna Philpot is now Mrs Lorna Bray – she has three beautiful daughters and now lives in Sydney.

Bernard Doran

A four castored walking machine creaked through the Homestead of a sheep station outside Moree. For the ten-year-old boy in the machine, the smoothly paved areas in and around the house represented his world.

Pushing himself to the wide verandah, the boy could look out over the sheepland, see the station hands mustering the sheep into yards. He could see a youngster run across the yard to chase a ball or play with a dog. He could see everyone else ride. He wanted to ride, too.



Bernard Doran laid the foundation stone in November 1953 but we had to wait till we finished the buildings at Mosman before we started on the Country Children's Hostel. It was finished in 1957.

The boy, Bernard Doran, had been born a spastic and had not been able to sit up until he was three years old. He did not walk until he was seven. His grazier father, Walter Doran, poured out money on medical attention for his son but it was the early 1920s and doctors could do little to help spastic victims.

But Walter Doran encouraged the boy to do things for himself and he engaged a private tutor to educate him. He was nearly eleven when the irons were taken off his legs and he walked with great difficulty until he was about fifteen.

The elder Doran gave him a quiet horse and trained it so that Bernard could mount it from the off, or right-hand side. This was the only way he could get into the saddle, because his left leg was not strong enough to take his weight in the swing up.

He improved quickly and gained strength as he cantered about the station, helping with the work, occasionally doing a bit of short droving. One day he had a strong longing to sit, just sit, in the saddle of one of his father's good-looking horses. There was nobody about, so he walked up to the horse, which of course had not been broken to the off-side mounting technique. The only thing to do was to get on the proper side. Doran put his left foot in the stirrup and found he could swing into the saddle. He has always mounted from the left since then.

Bernard Doran now manages his station at Boggabilla, fifteen miles from the Queensland border, single-handed, having taken over from his father, who became ill last year. The rest of the family has scattered. One brother was killed while serving in England with the RAAF during the war.

Developing the Boggabilla property called for plenty of travel, so Bernard Doran taught himself to drive the family car, then graduated to the tractor. Nowadays, with his wife, he thinks nothing of driving twenty miles to Goondiwindi, over the border, to have a game of bowls and do some shopping.

About four years ago he became interested in The Spastic Centre, Mosman. He is now busy raising funds to complete the Centre's new hostel for which he laid the foundation stone.

Ingrid Grigors

With an endearing effort in her second language, unedited, Ingrid Grigors tells us, 'Unfortunately I had brain damage at birth just because the doctor gave my mother a needle to stop labour pains seeing he was too busy to help Mum to bring me into this world. Mum was a trained Sister in her own country which was Latvia; she never ever came across a spastic or any other sort of disabilities.

After I was allowed out of hospital to come home, Mum had to continue feeding me with an eye dropper which took a long time; seeing I couldn't swallow that went on for a while. Then I was fed with a lot of difficulties for about two years. Couldn't sit up without pillows around me seeing my head and my body were like a rag doll. I never started to talk until I was seven years old, still it was limited; used to talk with my face. Before Mum took me to The Spastic Centre outpatients she would take me to different doctors seeking for help but there was no luck.

One day we went shopping at Parramatta; we met a lady who had a son at The Spastic Centre and she told Mum about the place and the small hostel which was in Glover Street. Mum took me to The Centre. Dr Burton-Bradley saw me and told Mum that I was too handicapped to be able to improve and Mum asked her just try and see whether they could help me. Anyway Dr Burton-Bradley agreed to that so The Centre had me for an outpatient with many others.

For three and a half years Mum and I travelled 40km from Windsor to The Centre for my treatments which was physio and speech therapy. I remember this; I used to cry out in my voice box seeing I didn't really understand English and was scared. Mainly I was scared seeing I didn't know what they were doing with me. Mum could translate English into Latvian which I knew, so from then on Mum and Dad used to talk English at home sometimes to get me used to it, which I hated.

In those three and a half years Mum gave me physio at home; I had a standing box and a pair of skis so I could walk around holding Mum's hands. I used to love standing in my standing box because I used to play cars as I was a "tomboy" instead of a girl even though I had dolls to play with. I was very lucky as I had normal little friends of my age who would play with me. They would take me for walks in my stroller around Windsor; one day they took me down to a paddock where they threw dirt at me; I thought it was great seeing I like that sort of thing as I was a tomboy. We did a lot of things together before I was admitted into the hostel at Glover Street.

A year after I was at the hostel Mum started to have my sisters, who are great towards me. Mind you my sisters treated me as a normal eldest sister; we would fight like cats and dogs when I was home for my school holidays. As Judy grew up she would feed, dress and play with me; Judy is seven years younger than me. Sandra is the next one who is eighteen months apart from Judy. At the age of four Sandra would feed me and do little things like Judy. Sandra was more close to me as she would take her time with feeding, bathing, dressing plus doing other things like writing letters to my friends as I spelled the words out on my Communication Board. Sylvia was an unexpected sister but I'm very lucky to have a third sister.

Before I started at Centre Industries in 1968 Mum had me home for three months continuing with my First Year's High School which I never finished at school seeing there was physio, O.T. and speech therapy to attend to. I did my schoolwork by correspondence to try to finish but never did.

When McLeod House was built I lived there until Venee Burges House was built and now I have my own room with the things which I like.

More independent living in Venee Burges House means I can go out on my own to different places; since the Year of the Disabled I have come out of my shell, which is great.

Often I like going out on my own; if I am the only disabled person it makes me happy to think that my disabilities do not stop me like it used to a few years ago.

Last year I joined the Latvian Club which I enjoy, being the only disabled person in the Club.

I love writing letters, listening to the radio and playing cassettes mainly Latvian, German and Italian music and songs. I enjoy listening to "Old Rocks & Rollings", and very light classical music. Somehow, when I cannot concentrate on what I am typing, all I have to do is turn on the radio and I am OK, when I am at home at Venee Burges House.

Often I like going out on my own; if I am the only disabled person it makes me happy to think that my disabilities do not stop me like it used to a few years ago. I know that there are other disabled people who go out like I do but that does not stop me feeling like this.

When I started work in 1968 I stated that I wanted to work as an Instructor. Like all CPs I was put in the Training Unit (we know it today as Special Production Teams). I was there for ten odd years.

All my CP friends went out into the office and on the factory floor and I was still in the T.U. Finally Mr Taylor gave me a job working in the Rehabilitation Section as a typist and still today I am there; my work involved typing up different reports and letters.

About two years ago I asked Jenny McLeod if she needed any help with her Personal Independence which I do with Jenny three afternoons per week. Personal Independence involves teaching CP how to be independent plus take pride in themselves.

Two things which I am aiming for are; a trip to Latvia in the near future, and to improve my speech so people can understand. As I have improved in other ways, I hope I improve in my speech very soon...'

John Harvey

John Harvey tells us, 'I was born with a cerebral haemorrhage in Goulburn in 1949. As the doctors did not expect me to live I was baptised that day at the hospital. As the months went by my parents took me to several specialists to see what could be done for me. My big breakthrough came when I was taken to the Children's Hospital in Sydney where the doctor realised I had cerebral palsy and recommended me to The Spastic Centre.

As there was no accommodation at the hostel I became an outpatient, coming to Sydney every few months. The doctors would advise my parents what exercises to give me. I started walking with my father holding me by two ears! Fortunately these days babies can get expert help at a few months old.

Finally at the age of six they had accommodation at the pilot country children's hostel at Mosman. After eighteen months there we moved to a larger hostel at McLeod House, Allambie Heights.

School life for spastics is not the same as for able bodied children. So much time is spent away from the classroom with speech, occupation and physiotherapy. It was not long before I was walking and using my hands to the best of my ability, but this took treatment and willpower. I reached the stage where I could dress myself completely except for tying my shoelaces. My occupational therapist, realising this, told me one day that she wanted to leave knowing I could be completely independent – she was leaving at Christmastime, which was a few months ahead. This gave me the incentive, and within a few weeks I could do it. I will always be grateful for this unorthodox therapy.

Like most boys and girls we liked playing games and sport. One game I started to play at school was chess. Little did I know then this was going to lead to me playing competitions with a Leagues Club and representing them in many competitions. Recently I played in the inaugural Queensland Disabled Tournament, finishing second. The highlight was having a draw with the Queensland champion.

Like most spastics, my writing is poor, so I learnt to type on a manual typewriter. When I started secondary schoolwork my typing was too slow so I had to use an electric typewriter. This brought problems, as every individual has to work out the best way to manage the keyboard, but once achieved my typing became a lot faster. Schoolwork became important, and I was to achieve the Intermediate Certificate at the age of fourteen.

Tragedy struck the family in my school years when my father was killed in a car accident. After I had obtained my Intermediate Certificate I went home to help my mother in our mixed business. There was not a lot I could do at home. I attended a sub-normal school for a while for something to do, but the different handicaps were too much so after two and half years at home I came back to work at Centre Industries, where I have been working in a clerical job for most of the time.

I am very interested in all sports. Chess is a large part of my leisure time, as well as swimming with volunteer helpers. Also I have had the opportunity to travel with other disabled people abroad.

For a spastic there are many frustrating situations. One of the main frustrations is that disabled people are treated by the majority of the community as "disabled" but not as individuals. Unlike "Mr Average", a disabled person must try not to do anything to give other disabled a bad name.

I have been playing competition chess for a number of years. Occasionally you do play someone who takes one look at you and thinks, "I'll have no trouble with this guy". In a way this doesn't worry me as by the time they realise I am not as bad as they thought it is too late and I end up beating them. In one competition game my opponent threw the pieces down because he obviously didn't like being beaten by a disabled person. In another game my opponent, after a social game said, "Why didn't you tell me you were that good?" I replied that he should play everyone as if they were good. As we are now members of the same club, and roughly the same standard, we have some fantastic battles!

It is very frustrating trying to gain employment outside; although having a clerical job at Centre Industries, I cannot get one with the Public Service. To be a clerk you need your higher school certificate or leaving certificate. I am educationally qualified for a clerical assistant, but because of my athetoid movements that are very unsteady, I should not do things like filing, photocopying. However, tasks which I could do, like financial statements, I cannot do as I am not qualified. This was one of my frustrating times – to know I could do a job well but was not qualified, and the job I could have a go at I was physically unable. It's just like your brain telling your body to do something and your body can't do it and never will.

The one thing I want people to understand is that every disabled person is an individual with likes and dislikes, different talents, and some of the most heavily handicapped have a tremendous sense of humour. For the disabled person, if you have a talent like chess, swimming, painting or anything else, stick with it and make the most of your life.

As treasurer of an outside chess club, I feel as if I have to do a better job than most people, just to prove that a disabled person can do the job. Also, if you have limited speech people tend to only listen to people with good speech even though you might have a far better understanding of the subject.'



Jenny at O.T. work photograph retouching.



Jenny and Narelle Simcoe at the newly finished Country Children's Hostel



Speech Therapist, Miss Grace Ellis with Jenny.

Jenny Takes up the Story

My father and mother decided to come to Sydney from Perth when I was five years old, on the way to America to get treatment for me, but the war prevented this so we settled in Sydney, for which I'm very glad. My parents felt Sydney had more to offer me in possible treatment. My father had come on ahead. It was wartime and my mother travelled alone all the way across Australia with all our belongings, my younger sister who was about eighteen months old on one arm and me on the other arm, clutching my doll 'Sarah' and all her wardrobe. We came by train, and both my sister and I were travel-sick. I remember very vividly when we stopped in the middle of the desert, and aborigines were all round the train and my sister Robin and I were terrified because we'd never ever seen a black person before.

I had a normal little girl's childhood with dolls and fairies and Santa, with the help of my little sister. Then one day my mother put the radio on to 'The Kindergarten of the Air', which was for very young children, and she sent me out of the room for a minute and came back to find me trying to move my limbs in time to the music; that and other things, like every nursery rhyme which I knew off by heart, confirmed her belief that I could learn.

Then we moved to a house in Gladesville which was on a steep hill overlooking the air raid searchlights at night. My father used to take me outside at night to watch the lights. He also fixed up an electric car for me with a battery instead of pedals, with a gear and a steering wheel. At that time I couldn't hold up my head at all. I was floppy and couldn't sit erect, so I used to drive the car with my head down, looking up with my eyes, and I used to take great delight in running into people. I learned to drive it, and could park on the spot. I had a lot of fun out of it, as it enabled me to move freely around the house, for up to this time I had to crawl on my stomach and one leg. Robin regularly got things for me, such as my toys, and she used to pull me out of my chair by my feet if I wanted to crawl. By the time I turned six, my parents were trying to get in touch with other parents with children similar to me.

While they were doing this, I was having the most cruel six months of my life in an orthopaedic hospital, mainly because they didn't know what a spastic child was. The treatment I and others had, was so heartless and difficult that I just could not cope with it. My fear of falling increased because they let me fall over many times, saying I was lazy. I had chicken pox at Christmas time and they burnt all my presents, including Sarah, the day after Christmas, to prevent the infection spreading. My father used to park the car behind the bushes outside the fence, and take me out to wave to Robin who was not allowed into the hospital to see me. While I was still in hospital, a man lent us a big house in Mosman for a school and medical treatment centre. This was the beginning of The Spastic Centre. It started with about forty pounds, approximately thirty children, and a lot of hard work and hope. So one Saturday my father came and dressed me in a pink winter dress and took me out of the hospital, to where Robin was waiting outside the gate, and home at long last. Mother had gone away for the weekend to raise money for The Centre. I can still see Robin dancing up and down on the path.



As I was only six years old, I wasn't aware of the organising of The Centre, only that my parents were so busy, but never too busy to see us. However, this meant that Robin and I had to rely on our own resources more than other children, which in a way was a good thing.

My family had moved into the house in my absence in hospital. Home was a kitchen downstairs, two bedrooms and a lounge room upstairs. Monday came and my father took me down to the school teacher, but I wouldn't let go of him. I was so terrified after my experiences in hospital that it took me quite a long time to get over the fear of other people handling me.

We had two Education Department teachers, one for the older children and one for the infants, in which I was, but I would not let anyone call me an infant. We had one occupational therapist, two physiotherapists and a speech therapist, plus another elderly lady for supervising a rest period after lunch. We all had to lie down and go to sleep for an hour or more, because it was thought that this was beneficial for relaxation. We also had a doctor who was learning and researching. The unpaid mothers did all the housework, cooking for lunch, and did the toileting. We had voluntary drivers in cars who drove the children to and from The Centre. Many of these were parents too.

My mother had a very small office to organise the school and medical unit, transport and to raise money for The Centre. Our day was split up – school either in the morning, with a rest after lunch, or the afternoon, and the other part of the day was split again with physiotherapy, speech, and occupational therapy under the strict supervision of the doctor. This meant that our schooling was slow, especially as some of us couldn't write. So that we had to have either the schoolteacher or the voluntary helpers, or one of the less handicapped ones, do this for us.

This was where I found Julie. She could not write but she could talk, and I couldn't talk but I could write, so we were able to help each other right through school. The short time at school and the spasming of my eyes, which interfered with my reading, slowed down my education, but I wanted to learn, so it didn't matter how I did it!

I used to hate my rest period, but that was the start of my musical interest, because we had records played to us on a gramophone on the old verandah, to make us go to sleep, but I never did. I couldn't see the sense in lying down wasting an hour when there was so much to do. So, many times the elderly lady came over and read softly to me so I wouldn't wake up everyone else, but this soon stopped, and I had to conform.

It was an exciting day when I moved into the older schoolroom. I was nine years old. I had my first desk all to myself. I opened and shut it quite a few times before I could really realise the significance of it. I can remember very vividly that day, because I was so proud of myself, until my teacher gave us multiplication sums on the blackboard, which I couldn't do.

Our bedrooms and lounge room were being used as treatment rooms, and lack of space became a big problem. There were more and more cerebral palsied children who needed treatment and education as parents, and some doctors, heard of The Spastic Centre. This made it necessary to build onto the existing house and grounds. As there was no money, this was done by fathers and voluntary weekend helpers. The Centre was growing as more and more spastics joined us. Our buses were now old Army ambulances with paid drivers. We now had more medical staff, two more teachers, but much more money was needed.

At weekends my father, Robin and I went to the beach a lot, because it was felt that the water might make my movements better and stronger. Robin held my feet and my father my top or my arms, and swung me in the water and I had great fun. One day Robin and my father left me for about a quarter of an hour in a hole in the sand, and some boys came by and threw sand in my eyes and face. My father never left me there again.

I got the blame from my teacher for messing up the schoolrooms on weekends, when it was really Robin, so I used to growl at Robin constantly. We went to the pictures a lot on Saturday afternoons. During weeknights I listened to my radio, mainly for the 'Argonauts', a creative children's programme run by 'Jason' and his 'Argonauts'.

The ages of the children varied a great deal, and we were not in classes of the same age group as in a normal school environment. This did not worry most of us, so long as we were learning and doing real school work.

Owing to my physical handicap, I still could not hold my head up, nor could I sit in an ordinary chair because I

was so floppy, so they made me a plaster front collar and a heavy leather back brace, and sat me in an upright chair fastened at the back, with straps to hold me up. The back brace had straps which did up over my shoulders and made me so sore under the arms as I was so thin. The physios used to rub them with soap and water to help relieve the soreness. As well as all this, I had short calipers. I hated them, but there wasn't much I could do. I think my hand movement was better then than it is today.

In those days physiotherapy was rather different from today. All movement was controlled and every part of your limbs was stretched, and it hurt. Speech therapy was just a bore. However, occupational therapy I liked, because I was making things.

Like most other children I wanted to walk, and the physiotherapist who I had at that time almost had me walking on crutches which we named 'Ginger and Minnie'. She stuck a picture on each crutch. Then, much to my disappointment, she left, and so did my walking.

Physiotherapy was sometimes a very painful effort then, but usually I became very friendly with some of the physios and was able to try a bit harder for some of them. Looking back, I don't think I tried enough in those early days to improve myself. Occupational therapy was making things like baskets, weaving – that sort of thing to exercise your hands.

Speech therapy was still not expressed in a systematic way, and consisted of breathing and making sounds of letters. I must admit that perhaps I didn't try very much, mainly because of lack of improvement. I couldn't see any sense in doing it, although my speech was a word at a time; or some signs made by my face, hands or legs. Like wrinkling my nose when I didn't like something, moving my jaw up and down when hungry, and sticking my tongue out when thirsty, or when I didn't like someone (when they turned their back).

At this stage, I had practically no speech except for a few words which would pop out, however, in the middle of the night I used to wake my father and ask him all sorts of questions, because I was totally relaxed and could speak quite easily. I did this so that I could catch up on the things that puzzled me at school. I did it for ages and ages, until I realised what it was doing to my father, with an hour's conversation at two o'clock in the morning. Yet, during the day I had to use signs, the odd word, and later a communication board. My friend Julie was a very bad athetoid and she couldn't keep her limbs still, but she had good speech and she used to interpret for me, so our friendship grew.

My interest in the Argonauts continued. By writing, drawing and generally communicating, the listeners, from seven to seventeen years old, could become Argonauts too. I was 'Ismeny 3'. It was a programme of participation in which you learnt things. One day when I was only eight years old, the radio people from the Argonauts came especially to see me, which was very exciting. We only had one radio at that time. Robin had her shared time, and I had mine. Actually, the radio taught me a lot of things, and still does.

About a year after I moved into the senior class Julie came up too, and from then on we were constant companions. I had an incurable sense of humour, and Julie made me worse, so I was always getting into trouble with the school teacher, and Julie was to blame. It was said my laugh could be heard right up to Queen Street hill, because I could only laugh on my indrawn breath, and it came out as a funny kind of crow that made everybody else laugh too.

Another big thing happened to me at that time. I went to my first ballet in the Mosman Town Hall with my parents. During the interval my father asked me how I liked it and I said, "He's got no trousers on!" – not having seen a man in tights before. From that night I developed a great love of ballet and it has grown so much that I've always wished I could have been a ballet dancer. The older children went to the Symphony Concerts at the Sydney Town Hall and my teacher, when I asked if I could go when I was eight, said, "When you are nine, Jenny Wren, we'll take you". So I attended these right through school days, and grew to love music more and more.

I was always a child who liked to do things with my hands. In my spare time I made things. I painted and drew, and if I thought I could not do something, I would keep on trying.

I was always anxious to go out and find out for myself what the world was all about. Fortunately, I had parents and a sister who understood this. However, as The Centre grew, my parents had more to do overall to keep it running and to find the money, and so I was fortunate enough to have friends who took me out. One of these



was a voluntary helper who had a mildly retarded boy and two other boys. I went to their home on weekends. They all treated me like a sister and we had much fun together. We went swimming, and the boys would take me in and make me float. Their father every morning put shaving cream all over my face while I was in bed, and I had a hairbrush, and I hit him with it, in fun. The boys did everything for me and made me do things too. They were just like big brothers and always have been since then.

I went and stayed with Julie too. We would commandeer her parents' bed. We would wake up in the middle of the night, talk, giggle and laugh. Her mother used to complain, but we'd still do it. Then Julie came to stay with me; we formed a very firm friendship. Julie used her feet to do practically everything. She could not use her hands at all, and had sticking plaster on her fingers to stop them rubbing together. We had a lot of fun.

Our schooling improved as the years went by. We got hold of three old IBM electric typewriters, which used to 'blow up' regularly, and a few adding machines which were specially made with letters not numbers. These were used as typewriters with rolls of paper instead of the ordinary sheets. We also had magnetic boards with letters on magnetic blocks on them. This made it easier, but having so many children who needed special attention, we had to share these communication boards.

Our teacher was very strict about behaviour, and did not have any favourites at all. I was not the boss's daughter to her, so when she gave us a lecture on anything that we had done, we sat and took it, our faces down low. I was in later life very pleased that she had been so strict, but underneath she was very soft, like the time I had some sweets in my desk and she caught me eating one. She just said, "Don't you think this is not the time to be eating sweets?" From then on I didn't have any more in my desk.

We had occasional Bible reading, and one boy was a complete heathen. David was very handicapped and without any speech. He laughed and giggled and the teacher would put him outside the door. If anyone else giggled at David, they were put out too. When I first knew her she frightened me to death, but much later on I became less scared of her.

We went out a lot from school. To the symphony concerts at the Sydney Town Hall to which all the other schools went, and if any of us made a noise woe betide us the next day. We went to other places like the Art Gallery, the opera, ballet, the Zoo and other very different places. I think that this was her way of widening our horizons. We were of all ages - from nine to sixteen and very handicapped. I cannot think how she managed to cope with all the problems.

The next day, we would either have to write out a description of the outing or make some verbal comments. We were all at different levels, which didn't matter a great deal to me at the time. She knew us all, and she catered for us one by one. She never expected the impossible, but she expected the possible always, so that made us respect her and take what responsibility we could. We had the same subjects as other school pupils – English, maths, history and geography, as well as other things. She gave us the widest education she could, for which I am very grateful and always have been.

The new school and medical treatment building was opened in 1949. Then more children came, and many more outpatients were coming too, so we took on more staff, with better facilities. In 1952, even this building was not enough, so we took off the roof and built on to that again. Because there was not a road from the top school building to the new medical building further down the hill, we had to be transported right round the block in buses. These had Morris motors, and the seats had been specially fitted inside for us. Many times I used to fear falling off the seats because, living at The Centre, the only time I went in the buses was going to and from school, and I hadn't learnt to balance myself.

Things were changing, and ideas were changing. Physiotherapy and posture, particularly. More emphasis was put on stretching muscles, holding them with metal braces, as well as our schooling. Instead of having treatment each day for half a day, we now had a day in the week when we stayed in school all day. This was good, because I got more out of it. Even so, I still needed to rest in the middle of the day after lunch, for an hour on a bed outside the schoolroom.

Julie and another girl needed the rest too, but to rest and relax was harder then because Julie would start me off laughing about something. Our teacher would come out and blow me sky high for making a noise, because there was a lot of work going on in the other schoolrooms around us. So we stuffed handkerchiefs in my mouth to

make less noise, but even so I still got into trouble each day.

There was a panel of dentists who each gave half a day weekly; they still do, which is rather wonderful. Teeth care for us is of the utmost importance, because of their effect on speech, so we had a room set out like any other dental surgery. Each week there was an anaesthetist, and while he was getting ready the dentist did some of the other CP, then they did the other patients together.

My first anaesthetic was given on the dining room table at Bondi when I was six years old, with a terrified anaesthetist, a terrified dentist and a terrified patient! From then on I knew, if I didn't have any breakfast and my parents were making a special fuss about organising other things, I was going to have an anaesthetic. This built up such a fear of the smell of ether that, even now, I cannot control my reaction to the smell. At the slightest whiff of ether I have just got to get away from it. By the time I was fourteen, I decided to try without a general anaesthetic for my teeth. The first time, I met a very nice dentist, calm, cool and collected; I cried a little, but still, that didn't matter. I had my first front teeth filled without the injection, and from then on I never had another anaesthetic for my teeth.

At thirteen, I was growing up and I went into town with my parents to see an orthopaedic surgeon. I was a most modest girl. He wanted me to strip, but I kept on my singlet, and when he had examined me I was dressed out of the room where I waited for my parents to come out. That night I knew something was going on and at first my mother refused to tell me, saying it was all right, don't worry. Anyway, after a lot of pushing I learned that I was going into hospital the next week. After I got over the initial shock, my father explained to me that my left hip had come out of joint, because it had not been required to bear my weight in walking. To get it back the doctor was to 'prick the muscle'. That meant cut, but I didn't know; to loosen my legs so that I could part them. We had an old friend who was a trained sister and who had nursed Robin through rheumatic fever, and it was arranged that she was to look after me.

A few days, later we all went up to the mountains for a bit of a break with friends; Julie and her mother came too. This was to build me up for what I had to go through later. Then I entered a private hospital. I had a big room to myself overlooking the harbour. My mother made sure that I heard her say to Sadie, the sister, 'Jen likes to know things, so will you please tell her whatever you're going to do?' The night before the operation Sadie prepared me, wrapped me in cloths, but she had to use ether for the sterilising. I slept well that night, but was woken by another night-time special sister whom I didn't know. She did the same as Sadie when preparing me and used ether, so I poured some of my precious 'April Violets' perfume onto a hankie and held it to my nose. I never used that perfume again.

About 8.00 a.m., they carried me up the stairs with four nurses each holding one corner of a sheet, to the theatre on the floor above. My parents were there, but they were not allowed to come up. I was laid on the operating table and given pentothal, which was the best part of all.

I didn't know what hit me when I woke up. I was lying on a frame which had rubber padding. It came down from my neck to my feet, but my legs were stretched so wide apart that they weren't part of me. They were bandaged onto the frame, with my feet straight up against a piece of calico attached to the frame, which made me lie straight, but it was so painful. I was in so much pain I didn't know what I was doing. There were no relaxing medications like we have today, so it was positively excruciating. I don't remember much more about the day. I think I was so dopey that I woke and went back to sleep. However, I do remember as I came out of the anaesthetic, there were flowers where I could see them. That night I just screamed and screamed with pain. The special sister I had with me didn't know me very well, and tried to do what she could to ease the pain with an injection of morphine every four hours or so. I remember well that, one time when I was awake, an elderly sister from the hospital came into my room and said to the sister, "Can't you keep her quiet? She's waking up the whole hospital." I remember thinking to myself, if you were here where I am, what would you do?

The next day and night were just as bad, because I just could not stop the spasming at all, with the pull on the muscles of my legs, my feet and back. We tried everything, and Sadie was marvellous – hot water bags, ice, pushing my head right forward with pillows, and just moving me a little bit where she could, but every movement hurt like mad. Then on the third day, the doctor came and moved my legs further apart still, which made it even more traumatic.

By the fifth and sixth day, I was getting used to the position and didn't have quite as much pain, and was settling down when the doctor came again and moved my legs even further apart.

During the week I was in hospital one of the nurses told me that there was a boy in a frame, just like me who had a similar operation, so we sent each other messages via nurses and sisters. I never saw John, but he must have been going through the same thing as I was.

When I was told I was going home in an ambulance, I was quite thrilled at the thought, but I was still spreadeagled onto the frame, and that didn't allow any modesty at all. Sadie wrapped me up tightly in a blanket and then two ambulance men had to carry me on a stretcher, but they had trouble getting me through the doorways without tilting me painfully and I began to wonder if I would fit into the ambulance. When we were nearly home Sadie asked the ambulance men if they would just blow their siren for me at the top of the hill. I got a great kick out of this! When I was being carted upstairs some of the kids from school were lined up all the way to my room. My bedroom was so filled with flowers that there was hardly room for my legs and me. I was still in a lot of pain, and being moved didn't help either, but by the next week it wasn't so bad because my muscles were getting used to the position.

Another problem with all this pain was that I couldn't get any words out at all. Not even yes or no, so I used a wink for yes and either a screwed up nose or head shake for no, with all my other signs. About the end of the second week I was put into a smaller frame which only came up to my hips. My legs were still fighting against the position of being tied so wide apart, and at even the smallest movement I would yell. I wasn't used to sleeping on my back, so my father used to tip me on my front, which gave me some relief. I got a bit more sleep, and he slept in the room with me.

The third and fourth weeks were better, and almost every day Sadie moved me onto the balcony to get some sun, as well as get me out of the room. She read to me, played games with me, or just was there. Julie came up every lunch hour and brightened me up for the day. Everyone was in and out and one day I expressed a wish to my teacher that I would like to go back to school, so they arranged for me to get down the stairs to the schoolroom for a couple of hours a day.

After five weeks or so, I had to be taken off the frame. This meant that for ten minutes a day the physio came to move both my legs. Oh boy, did it hurt! My right leg, once it was undone from the bandage, used to jump up at the knee, and this made me frightened to give it at all. I would scream blue murder at the sight of the physio, but gradually she got me off the frame. I don't know really which was worse, going on the frame or coming off it.

For the next six months any small movement, particularly in my left hip, used to hurt and crack painfully, but at least it helped my hip not to go out as far as other people's did. My right leg still used to jump, so, until I had enough confidence and control over it, we tied it onto the other one for my bath and dressing.

At that time there was a theory that the more braced one was, the more one was in the correct position and the better the treatment. So I wore a full collar to keep my head up, a lighter corset in place of the old leather back splint, and what they called a pelvic control brace. It was a heavy aluminium structure which came around my hips down to my feet, fitting into boots on either side, and because I had been on the frame they put a bar in between my knees to keep them as far apart as ever. The brace was jointed at the hips, knees and ankles so I could move my knees and hips, but this meant a modification of my chair. The chair had a great block of wood in the front of the seat between my knees, to stop me from slipping forward. It was uncomfortable, straight up at the back. However, it didn't give a modest girl a hope of being modest, and I was forever pulling my skirt down in the front. The brace had to be taken off while I had physiotherapy and some of the other girls had to have wardsmen to take their braces off, but I refused.

Physiotherapy was still aimed at straightening one's back, arms and legs, and was most uncomfortable. I became very attached to a physio who looked like my sister Robin, and I found that I did this with some other staff, too. I dreaded new people – mainly, I think, because of my speech difficulty. If I couldn't get out what I wanted to say, I sometimes asked in school if I could write a note, so that I could get my thoughts across, and generally, Mrs Kerr would agree.

One day in school, I was asked to read something from the blackboard, but my eyes would not follow the line from left to right. We didn't know why, or what had caused it, but it did affect the speed of my schooling so

much. Someone had to read everything out to me, and that made it slower. Then we noticed that in very strong light my eyes became stuck to my right side. This was through spasming of the scanning muscles of the eye, and it affected everything I did. The only way I got any relief was to put something over my eyes for a time. This happened at the Town Hall orchestral concerts, because of the bright footlights, so Mrs Kerr would sit behind me and put her hand over my eye, for hours and hours. Sometimes it took time to relax them. The spasming of my eyes meant I couldn't follow a line of print from left to right unless I turned the book sideways. I avoided reading whenever possible; we tried everything to stop that happening, but the eye doctor really didn't understand what the spasming was all about. In fact, several times I felt like hitting him, because he talked to me like a baby. If there was one thing I couldn't stand, and still can't stand, it is being spoken to like a baby or a nong-nong.

I was developing independence, or trying to. As my parents became busier and busier with the development of The Centre, and my father had his own job to do as well, I just had to make my own decisions, although I asked advice when it was something really big. It was hard, but I am glad it happened like that. I was stubborn too, and had a strong mind of my own.

One day when I was about twelve, the midday meal, with pumpkin, was set down in front of me. The schoolrooms were our dining rooms at that time, and an occupational therapist was in charge of feeding. I decided not to eat the pumpkin because I didn't like it at all, so I ate all the other vegetables and left the pumpkin. I sat looking at that pumpkin for an hour and a half, in tears. No matter what the therapist said, or did, I would not eat that pumpkin. So finally they took it away. We had a tuck shop where the voluntary helpers sold sweets and, as I love sweets, I wasn't allowed to buy anything at all that week. After that incident Mrs Kerr came into the room, and I can still hear her saying to me, "That was a silly thing you did." That was all she had to say. The next time I ate a little bit of it, but hated every mouthful.

I was always industrious with my hands, so I used to wake up at 5.00 a.m. and make things – basketry, draw, paint things like coathangers and flowerpots, play with my ten or eleven dolls, have a tea party in bed, or make things for my friends. I found other things to do, and these were done in bed because I was completely relaxed at that time of day. My father would sit me up and then go back to bed for an hour, and then have breakfast, after which either my father or mother would come and give me breakfast in bed, bathe and dress me for school. However, my father was always late, and I would get a glare from Mrs Kerr every morning when I wasn't there at nine o'clock.

As my mother became more and more involved with the administration of The Centre and my father had a position in a big firm in Sydney, we had a series of housekeepers. Most of them were very nice and good to me and Robin, so the first thing I had done for me after school was to have my brace and collar taken off, have a drink, and lie on my lounge. The family dinner hour and after was very precious, because it was one time that we were all together. We had a lot of fun.

The Centre acquired a small house at Cremorne which was used for country children to stay for their treatment and education. We had a Matron who had a spastic son who was a holy terror, to say the least, but his saving grace was that he was intensely musical. Gradually, when our parents had to go out at night, Robin and I would spend part or all of the nights there, until one night when I was about fourteen, I said to my parents that I was not going there in my night clothes any more as I felt I was getting too old. After that, I often stayed there overnight. Sometimes I stayed up with the mothers of the children, playing poker or something else, and occasionally slept on the floor in the hallway, because there were sixteen children there, plus the Matron, in a very small house.

I got very attached to one of the sisters and I felt that she let me down, which hurt a lot at the time, and surprised me too. As I have been hurt by other people over the years, I built up a little wall, without knowing it. When one is handicapped one tends to have a sixth sense about some people. I have had it most of my life, but one has to cope with it the best one can. The sisters were generally happy-go-lucky women. This made it a home atmosphere. I'm very glad that I had those years, because it was getting me ready for life outside my home. It was hard for me to communicate, so I got my father to write out a few hints on the way to dress me, to position me for sleep, and others like my 'yes' sign.

By the time I was fifteen years of age, my right hand started to spasm, and the only way I could get relief was when my father's strong hand held my thumb out and forced my hand to open wide. My spasming had increased to such an extent that I couldn't use my hands for some things, which was very frustrating, because I had been



using them very well for some time. Although the medication helped a lot to relax me, my right hand, which was my best hand, was cramping in the palm. It was so strong that sometimes my father could not force my thumb out to give me some relief. At first I thought that it would pass, but as time went on it got worse, so I had a number of plasters and splints over the years. The plaster seemed to help more than the splints, mainly because the splints used to press painfully on a little bone inside my thumb. This meant I had to change everything over from my right hand to my left hand, to do all kinds of things. I was determined that I would not lose the use of my left hand, so I still did as much as I could with it.

My right hand went its own way, usually in a plaster cast. It was at times embarrassing, for it would swing out and hit people when I didn't want it to. We had a babysitter at one time whom Robin and I didn't like much, but we put up with her. One night as she was rolling me over to go to sleep, my right hand which was in plaster and quite heavy, swung out and cracked her on the lip. Naturally enough, she didn't come back.

During this time, too, I had to have bands put onto my teeth to straighten them, and glasses to help my reading. So it was a standard joke that I was braced from head to toe and only my ears were good.

One day when I was seventeen I had had a plaster off in the morning, and after lunch my hand started to hurt. Mrs Kerr came over to ask if I would like to go down to physiotherapy for some help. I couldn't get 'yes' out, so the automatic wink came. I didn't know she understood my wink, but when I realised that she did, all of a sudden she was not only my teacher but a friend.

I began to realise what a difficult time lay ahead of me, both physically and mentally. I was doing a lot of growing up. Added to my own physical problems, I experienced the same heartaches and the same problems as any able bodied teenage girl. I wanted to do the things I felt they were doing – things like wearing makeup and pretty clothes, going to the pictures, and wanting to go out all the time, but I just had to accept things as they were, which was frustrating and terrible. I went out quite a lot from school, but on other outings like parties I just had to sit, because of my lack of speech, and hope someone would come to talk to me. Consequently, I became a bit shy; however, I fought this and conquered it after many years. My speech was still a barrier in communicating with people. When I couldn't get words out I started to spell them out by pointing to letters on an old typewriter which I used to record my schoolwork. It was very temperamental at times and used to blow up occasionally, but it was a good friend.

In time, instead of the typewriter, I got a card with the letters of the alphabet on it, to communicate with people. We called this a communication card. I found I could make myself understood better with this method, especially in school.

When I wanted to say something, I found if I said it spontaneously the words would come out, more quickly and more clearly, than if I stopped and thought about it. Nobody, including myself, knows why this happened. Unfortunately, my spontaneous speech didn't happen very often. In the end, I just used signs frantically and hoped people would understand me.

We were experimenting with relaxing medications about this time. At that stage, I would do anything to stop my spasms, so I tried some of them and found that they helped me, but only very slightly and slowly. They had to experiment with me. Many times I felt dopey, but it was worth it. I couldn't swallow pills until I learned, much later, to relax my tongue and drink normally. This took years. Also at that time I had throat spasms where I gagged, especially when I was eating. I could not eat ice cream for about eight or nine years, but that, too, I learnt to eat. I always wanted to be a clean eater, but I dribbled. This embarrassed me so much; I wouldn't go to a restaurant for a meal because of the gagging and dribbling. I wore a hankie under my collar, tucked down outside the collar, to make the collar seem less obvious, as I was embarrassed about this also. When I was about nineteen, I started to wear lipstick every day, and gradually I controlled my dribbling. Then I controlled the gagging when I was about twenty years old.

Due to lack of space, even with the big new building, our bedroom and sitting room were being used in the daytime by speech therapy and occupational therapy, or anything else that fitted in. That was the reason for my parents' decision to build our own home. Every weekend for about two and a half years we used to go to the block of land we had chosen in Seaforth. While my parents and Robin cleared it, and built the main shell of the building, I either sat in the car or in my wheelchair feeling so useless. Father built the whole house except for

the plumbing and electricity. Mother did all the bits and pieces, like painting the whole house, inside and out. During this time no one connected with The Centre came and helped, which made me mad because my parents had helped them to build The Centre at Mosman and were still engaged on building the Country Children's Hostel on each Sunday. However, this didn't seem to matter at all to them, and on they went. We moved in on Boxing Day 1954, without the house being finished, so every spare moment my father would do the woodwork as well as other things.

It was quite sad leaving The Centre because my mother insisted on me getting rid of all my dolls. However, I was able to save one. For Robin it was worse, because she had to give away her mother cat who had produced what seemed like one hundred kittens, throughout the five years we had had her.

The first thing we all noticed on entering our new house was the lack of phones, which used to be going day and night at The Centre. There was also so much space. Everything was ours. Robin and I had separate rooms. Mine was eventually pink and mauve. For me, it was an entirely new life. I had bus trips like the other kids to The Centre, picking up people on the way and going home too, instead of just going upstairs. I was pretty tired at first, but I soon got used to it.

My grandparents visited us when our home was being built. My grandpa was a carpenter and joiner in his youth; despite having only one leg, he was helping my father with the handling of the roof timbers, and knocking in nails to the floor. I hadn't seen him since I left Perth, and all I could remember of him was his mop of silvery white hair, and his wartime sign for victory with his two fingers, and he was like that still. My grandma never missed sending Robin and me two dollars for our birthdays.

The night before they left we gave them a party and I was dressed in a very pale pink organza dress, so grandpa sent us six rose bushes for our garden. One of them was a very pale pink, called 'Madame Butterfly', and he said in a letter that that would remind me of him. So I developed an interest and love of roses.

My education was not going well, mainly because of my eye spasms, and I couldn't get things down on paper, only with my electric typewriter which used to break down occasionally, but there was nothing I could do about it, so I just went at my own pace as with everyone else in our group.

We started a senior class Social Club, and this is where I started to learn about people being different from me, because I was the President for a few years. Mrs Kerr guided us without controlling the Club. We had parties, and I tried to get different members to do what I considered the right things: welcoming our guests at the door, taking them inside and handing around food, but I found myself being the only one who would do it. So when the next election came I resigned, but unfortunately when the next party came round everything was just the same. So I decided to try to get back into it and stand for the next election. Again I was back as President. I learnt a lot about organising, planning, and patience from the Club.

Julie was away from school quite a bit for about two years. She had various things wrong with her health, but at that time I did not know how ill she was; she came to school when she was all right, and she would tell me what the handsome doctor did to her. Being a CP or a handicapped person does not mean that one cannot experience the same feelings as any other young girl or boy, or the same frustration, and the same desires. In fact, I think one has more of these.

One morning, when I had just turned nineteen, Mrs Kerr called me into the office and told me there was a new group starting the next year and she asked me if I would like to go there. She asked me to think it over, which I did, and I realised I was not getting as far in my schooling as I would like, so this could be a good move. However, Mrs Kerr told me that Julie was not going to join the group immediately, which was a blow, but I knew she would get there as soon as she could.

I started to cram the schoolwork in as much as I could. I got up to first year English and sixth class maths, and other subjects.

One Monday morning in that November the phone rang at home just as I was waking up. I couldn't hear what was being said, but I sensed that something was wrong. My parents came into the room and told me Julie had passed away – her heart had given out. My world seemed to crumble. I went to school that day, and Julie's lounge was carefully moved out of the schoolroom after we got there. It was a horrible day altogether.

The next few months were awful too, so I was rather pleased to get upstairs into another environment with the



new adult group, although I was quite lost for a long time. I then met my new physio and thought she was quite strange at first. She used to ask me if she was hurting me, which very few physios had asked me before. Anyway, we became friends, and gradually understood each other very well. The adult group, as we were called, comprised nearly all the senior class, with an occupational therapist and an aide. Apart from physiotherapy and speech therapy, we mainly did what we liked, such as writing letters, sewing, reading, carrying on our schoolwork, making baskets, etc. We earned our first small amount of money by doing contract work, although none of us was very keen. Mimi, my physio, spent her lunch hour with me, and through my conversation board talked about anything and everything. Gradually, as we got to know each other, we went out regularly, and this was good for me as it got me out of myself.

We had discussions on ways and means of getting people to come to us. Miss Ellis, our speech therapist, told us "Because you are in a chair and can't go to people, you have to draw them to you by radiating your personality". How right she was! We talked about showing appreciation for things done for us. We all agreed that a smile could say 'thank you' if we couldn't get the words out. This adult group taught us a lot about getting on with other people, and it was good for all of us.

I know other people experience the same feeling, but when you can't talk to people easily, it makes it doubly hard, as they stay away from you. Some people assume that a person who walks unsteadily or sits in a wheelchair is also affected mentally. Others, in speaking to adult spastics, assume a patronising manner and treat them like children. Still others are sorry for us and show it. There are people who can talk easily to us and treat us as they do everyone else. We like to talk to people, even though it takes a long time to get our words out. We realise there are people who are frightened of embarrassing us, and we understand why. We are normal thinking people, inside our handicapped bodies.

We have the same ambitions, the same capacity for being hurt and for being happy and sad, as able bodied people. We just want people to speak to us and treat us like anyone else they meet for the first time. Too much notice should not be taken of our disabilities. If people don't understand what we are saying, we generally have our communication cards within reach. We can use them to spell our words, but it takes time.

I was always a bit shy and frightened of people because of my speech difficulties. Then there was my laugh, which was loud and funny. Instead of breathing out when I laughed, I breathed in. In my early teens, I wouldn't accept the fact that my handicap could prevent me from doing things that other girls did. I didn't want to be different from any other girl. I wanted to go dancing, surfing, ice skating and play tennis. Then quite suddenly when I was seventeen, I started to understand my limitations. I accepted the things I never would be able to do, such as walking.

I began to direct my thoughts and energies toward the things I could do. I accepted the fact that I would never walk, but I still kept on trying. It wasn't easy to face up to these cold hard facts. It took years. Out of all this turmoil sprang a new realisation that there were things with which I could fill my life and compensate for my losses. This gave my life a new meaning. As time went by, my interest in people grew and grew. With my speech difficulty I found it very hard to mix with people, but I wouldn't give up. My one ambition was, and still is, to see the integration and acceptance of spastics into modern society, as people.

My twenty-first birthday party was one of the happiest I had had. I always had a party for my birthdays – always – but this birthday meant far more to me than any other. Friends travelled from all over the State for it. Although I was spasming badly all through the evening, this didn't spoil my enjoyment of it. I had written a speech by myself and Mrs Kerr read it for me. Like other twenty-firsts, there were about eight speeches from various guests. Being twenty-one was so important to me, especially as I could vote, which I had been looking forward to for years. I felt really grown up.

About nine months before, I had talked to Mimi and another therapist about going for a holiday to Melbourne. They were both sworn to secrecy until my twenty-first, but mother, being my mother, guessed something was cooking, and I was rather pleased that she did find out. Boxing Day 1959, I found myself up in the clouds drinking brandy and on my way to Melbourne for a week. This was an experiment to see how I would stand up to travelling as I wanted to go overseas some day. The girls were wonderful companions. Our trip was fun and did me a lot of good because the girls treated me just the same as they treated each other. They expected me to do my share of waiting for them, as much as they waited for me. We all decided where we would go and when.

They teased me about my poor taste in food and wine when we went out to dinner. We were companions the whole time. This helped me to overcome some of my shyness. I found myself saying things like 'thank you' without effort to anyone who helped me.

We spent the first day around the city of Melbourne, and had arranged to have dinner in the dining room of the hotel. It was Saturday night, but fortunately everything was pretty quiet. I felt as though everyone was looking at me, and to make it worse a violinist who was entertaining the guests came over and played mournfully in my ear. I didn't know what to do, so I smiled, which was a mistake, and he went on and on. It was my first experience of this kind of living, so I was a bit overawed at first. I'd not eaten in public for years, because I spilt some food and I felt very shy and embarrassed, but at the end of the week, I felt I could eat anywhere. I had promised myself I would have oysters every night, which I did. We went out every day and night, except one. On the Friday night, Mimi had a telephone call to say her mother had died suddenly, so Mimi went home early on the Saturday and we followed later that day.

When we got home, a miracle happened – my speech was freer and so much more fluent. I was able to talk like mad for some reason. No one knew why – even me. Of course I still needed my conversation board at times, but not all the time. It was like a miracle, and as the years passed it got better and I could more or less hold a conversation with people. I also had a lot more confidence; I don't know if that had something to do with my improved speech.

My father was determined to build a workshop for the new adult group, which included me, and he picked the site down the hill from the Country Children's Hostel. During the next few months there were a lot of rumours going around about what the adult CP would do – salvage, laundry, piecework, process work, making things, typing.

While on business at a large factory, manufacturing relay sets for the Postmaster General's Department, my father noticed the machinery they were using, and he began to think there might be a way of setting it up for us. This business was about to close down, so he persuaded the Board of The Spastic Centre that this sort of machinery could be used by both handicapped and able bodied people, working together.

My father had organised a gang of 300 volunteers to build the workshop and to complete it in one day. It took several weeks to get the materials together, and then he chose one Sunday to erect the building.

I was staying in the Country Children's Hostel, and I tried to put on a demonstration of what the adult group was doing. However, all my special friends didn't show up, and to make it worse not many people came to see our display. By the end of the day, I was feeling a bit jaded. My father came and took me down to the newly finished building about 5.00 p.m. There were a lot of speeches, and then another CP and I were lifted up onto the centre of the floor and my father said to me 'This is the place that you will be working in at Centre Industries'.

This brought tears to my eyes, but I managed to wipe them away. It looked SO BIG – and I was SO SMALL



Neil and Jennifer McLeod

Part Three

The Solution - Children

We started The Spastic Centre in 1945, and Centre Industries in 1961. I feel very humble when I think of the years between; it should not have taken so long. All I can say is that in those years we have established a firm basis for our future work and can use our experience in all areas to plan much more effectively in medicine, education, work training, employment, research and the individual's independent lifestyle.

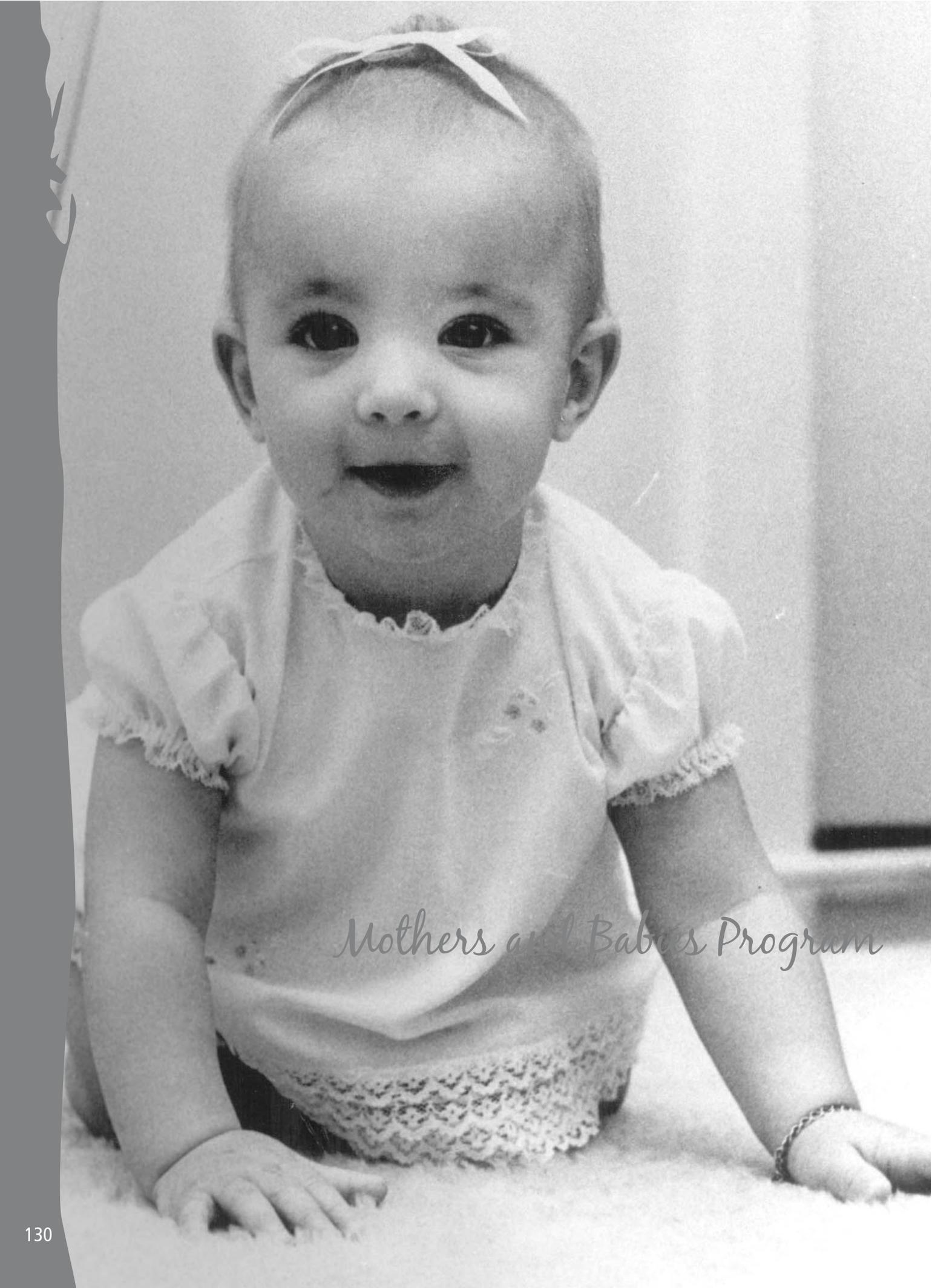
In 1945, we did not know whether the cerebral palsied child was educable; all the professional help we were offered said they were not. The years have proved how wrong they were. Similarly, in Centre Industries we did not know whether adults as heavily handicapped as our cerebral palsied could contribute to their own training from a commercial and manufacturing basis. Now, however, their ability to do so is unquestioned, even for the severely handicapped. The chapters of this book provide us with an invaluable record of the achievements of very many people from our staff and from the people outside our organisation. We are grateful for their participation and for their skilled achievements in our work. On behalf of our children, we offer them all our warmest thanks.

As for the future, we have heights to climb, which will carry our work far beyond existing levels. Starting with the babies, we are looking to increased preventive measures to reduce the total incidence of cerebral palsy, early treatment in the mother and baby programmes to reduce the severity of the action of impaired muscle groups on growing joints, more specialised teaching staff, with equipment designed to enable our children to obtain an education that really does equate with that of a normal child, more sophisticated electronic communication devices, more knowledge of the mechanism of speech, and some means of obtaining effective control of the muscular spasms of the cerebral palsied, apart from drugs, therapy and surgery.

We must keep abreast of the latest techniques of paediatric, orthopaedic and neurological medicine, of educational techniques, and of medical therapy.

Lastly, and perhaps the most important of all, we must obtain full economic and social self-sufficiency for the even more severely physically handicapped, cerebral palsied person.

These are our minimum needs for the future. Who can doubt that it can be achieved?



Mothers and Babies Program

Medical Development

1956

A letter from a mother, 1956:

'When they told me that my precious baby was a spastic, it was if they had turned off the light in my life.

I walked down that long hill from the hospital, unseeing, with my baby in my arms and my heart under my feet. Where could I go but to my darkened home? What could I say to comfort my husband? To whom could I look for help? Where could I go for assistance?

Over the many years my boy has been with The Centre, there have been many problems, trials and tribulations, and always these have been solved with understanding patience, love and compassion. Many of these problems would have been insoluble to me as an individual, and for this reason alone a huge burden has been lifted from our shoulders and has made my son's life more worthwhile and happy than it could possibly have been otherwise.

The Centre's advancement over the years has been nothing short of miraculous. The needs of its children have always been foremost in the minds of the wonderful people who have planned and schemed to make it all possible. Over the years as each scheme for improvement was put forward, many people have said, "It's not possible, you will never get the money, it can't be done."

But it has been done. As I look back and wonder how, I realise this was how it had to be done – there was no other way.'

The Spastic Centre is fortunate in having a group of visiting consultants. They include orthopaedic surgeons, a neurosurgeon, an anaesthetist and a panel of dentists, who are personally involved in our work and who have made their skills available to our children, without restrictions. We could not have provided the standard of medical treatment now attained without their knowledge, their skill and their dedication to their work.

We are grateful too, for the high degree of skill and ready help we are able to command in the many additional fields of medicine in which the multiple disabilities of our children require expert aid. In pediatrics, neurology, radiology, anaesthesia, deafness, we receive unstinted assistance, and in other unexpected areas we can find interested and especially qualified people who readily

align themselves to our aid, such as in the case of evolving new surgical procedures to control drooling, an annoyance to a CP child and his parents, but a major handicap to an adult.

Among these was Dr John Grant, Honorary Neurosurgeon, Royal North Shore Hospital in Sydney, who in 1961 became interested in our children. With the assistance of our Medical Director, Dr Corris Reye, he assumed direction of the neurological medical problems of our children, on an honorary basis, at The Spastic Centre. During that time, many of our children passed through his hands as a neurosurgeon, or as a prized friend for his knowledge of relaxation drugs. He undertook on our behalf a mission to Japan, where he visited Professor Narabayishi of the Department of Pediatrics, University of Tokyo, to report on stereotactic neurosurgery, and a second mission in later years to investigate the results of a cerebellar implant procedure in the United States. He served our children and adults well, over this period of twenty years, and often at the expense of his own busy practice.

For 3½ months we had one of the world's most distinguished orthopaedic surgeons, Dr Carroll M. Silver, M.D visiting us. His visit to Australia (as a Fulbright lecturer) was at the invitation of The Spastic Centre of New South Wales, the orthopaedic surgeons working with The Centre, and the Postgraduate Committee in Medicine of the University of Sydney. Dr Silver was Chief of Orthopaedic Surgery, Miriam Hospital, Providence, Rhode Island, and Consultant Orthopaedic Surgeon, Rhode Island Hospital at Providence.

Dr Silver spent three months in Sydney, and also visited other capital cities in Australia, giving lectures and demonstrations. He visited us briefly in 1967, and impressed our team of orthopaedic surgeons so much with his lectures, supported by slides and movies of operations, that he promised to return the following year. He was operating on CP children at an early age and getting good results. He said that a three - year old child would be considered for surgery if the paediatrician felt that therapy was not preventing deformity, or helping a normal gait pattern to develop. He was an exponent of the need for surgery of the hip joint to be considered, when surgery was contemplated for the knee or ankle.

The figures for surgery tell their own story of the emphasis on Dr Silver's message for early treatment:

Year	Number of Operations
1966	15
1967	31
1968	77 (Dr Silver's visit)
1969	130
1970	89
1971	59

Five years later we had a total of 871 orthopaedic operations on the lower limbs of 520 patients:

On the hips	253
On the knee	143
On the ankle	311
On the foot	67
Total	774

In addition to these figures, we had arm operations:

Upper arm	11
Wrist	59
Hand	27
Total	97

Our team of consultative specialists included: Dr Barry C. Bracken, M.B., B.S. (Sydney), M. Ch.Orth. (Liverpool), F.R.C.S. (Edin.), F.R.A.C.S.; Dr Edward H Bates, M.B.B.S. (Syd.), F.R.C.S. (Eng.), F.R.A.C.S., F.R.F.P.S. (Glasg.); Dr Robert N. Tinning, M.B.B.S. (Syd.), F.R.C.S. (Edin.), F.R.A.C.S.; Dr Bruce D. Shephard, B.D.S. (Syd.), M.A., B.S. (Syd.), F.R.C.S. (Lond.), F.R.C.S. (Edin.), F.R.A.C.S.

Dr Silver insisted that they should do the operations themselves, while he assumed the role of assistant and tutor. They worked hard over very long hours to pick up the backlog of severely deformed cases.

In 1972, he visited Australia again and the team was waiting for him with some interest - in the three years they had established some improvements in Dr Silver's technique and wanted to get his opinion. Dr Silver said that he was only an assistant to the master surgeon, that surgery was a continuing profession, and he would have been disappointed if his Australian colleagues had stood still when facing the individual problems of cerebral palsy. The falling off in the number of cases in 1972 was a direct indication of the success of the early physiotherapy, allied with early intervention of surgery where needed.

EARLY NEURODEVELOPMENTAL THERAPY



PHYSIOTHERAPY SPEECH THER.
OCCUPATIONAL THERAPY

*For Children who have Cerebral Palsy or
Motor Delay with Neurological Signs*

THE SPASTIC CENTRE OF NEW SOUTH WALES

189 Allambie Road, Allambie Heights, Sydney. Telephone (02) 451 9022
A 108 bed nursing home for spastic children and adults.

McLEOD HOUSE: 189 Allambie Road, Allambie Heights. Telephone A.H. (02) 451 6777
Honorary Administrator - Mrs. R.A. Gibbons
Matron - Sister Hamilton
Mothers and Babies Programme - Training and support for country mothers of spastic babies.

Outpatients Department of McLeod House - W.C. Allen Treatment & Training Unit
Aquatic Drive, Allambie Heights.
This unit provides the following facilities -
specialist medical services, physio-occupational-speech therapy, social counselling
and other resources, hydrotherapy pool facilities.

Telephone Medical Officer in Charge - (02) 451 9022 office hours.
Allambie Public School for Spastic Children - in association with the Department of
Education. Aquatic Drive, Allambie Heights.
Telephone Principal - (02) 451 9022 office hours
(02) 452 3168

VENEY BURGESS HOUSE: 189 Allambie Road, Allambie Heights. A.H. (02) 451 9788
A 52 bed nursing home for spastic adults.
Honorary Administrators - Mrs. D. Martin, Mrs. V. Burges
Matron - Sister Eisner

Outpatients Department of Veneey Burgess House, Centre Industries Treatment and
Training Unit. 189 Allambie Road, Allambie Heights.
This unit provides the following facilities -
specialist medical services, physio-occupational-speech therapy, psychological
counselling, hydrotherapy pool facilities and other resources.

Telephone Medical Officer in Charge - (02) 451 5555 office hours.
CENTRE INDUSTRIES: Allambie Road, Allambie Heights. Business hours (02) 451 5555
Provides employment for spastic adults - incorporates training, rehabilitation, and
support facilities for the cerebral palsied.

MOSMAN MEDICAL & EDUCATIONAL CENTRE: 6 Queen Street, Mosman N.S.W.
This unit provides specialist medical services, physio-occupational-speech therapy,
psychological and social counselling and other resources.
Mosman Spastic Centre School - in association with the Department of Education.
Baby Health Centre Support Programme.
Telephone Medical Officer in Charge and School Principal - (02) 969 1666

NEWCASTLE TREATMENT and TRAINING UNIT: Gipps Street, Carrington, Newcastle.
Telephone (049) 61 4426
Provides educational facilities together with specialist medical services, occupational-
physio-speech therapy for spastic children.

ILLAWARRA MEDICAL and TREATMENT CLINIC: 360 Crown Street, Wollongong.
Telephone (042) 28 1113
Provides specialist medical services and therapy for spastic children. At this stage
attendance Mondays and Tuesdays only.

To quote him, Dr Silver said, "While in the States we care very well for the cerebral palsied up to the age of fourteen, after that it is as if a curtain has come down. We just lose track of the boy or girl because we have nothing like your Centre Industries or your Adult Hostel situation in this country".

To this record, we must add our own staff achievements in so many areas of The Spastic Centre operations and, over the years, too many to enumerate individually. Perhaps I could just mention our first Medical Director, Dr Claudia Burton-Bradley. Trained as an orthopaedic surgeon, she was responsible for providing The Spastic Centre with its first medical direction, in the face of severe difficulties, socially, medically and politically. Her achievements over the next seventeen years set the seal of success upon the cerebral palsy movement, in The Spastic Centre generally. Every state in the Commonwealth would be glad to acknowledge her assistance in those vital years.

Dr Burton-Bradley operated successfully from 1945 until she retired in 1962 and Dr Corrie Reye took up her appointment. She was a pediatrician, and it fell to her lot to change the emphasis to the neurodevelopment approach. In her twenty year reign she was responsible for the Mothers and Babies Programme that offered early treatment for cerebral palsied babies as soon after birth as was possible, with treatment for the infant, training and support for the mothers and the fathers, too. She was, additionally, an excellent researcher, with an open mind and unquestioned probity.

To these we must add Miss Beatrice Le Gay Breerton, who spanned the years from 1950 until 1983. She was a research psychologist, and was primarily responsible for saying how the cerebral palsied child should be educated and 'how one of the brave few should attempt this'.

Also Miss Naomi MacDonald, later Mrs Kerr, who was responsible, as the first teacher appointed by the Department of Education, to find out how a cerebral palsied child, with its terrific handicaps, could be melded into a normal curriculum of classroom education. She taught our children to think, but also taught them to see and to feel. Many of her lessons, emotionally and socially, stayed with her pupils throughout their adult years.

Throughout the 1950s, the medical approach was based on orthopaedic surgery and splinting. This gradually changed to the present approach, commencing with the very young infant with the emphasis on the secondary damage to joints, resulting from abnormal muscle tone, and this extended to the Mothers and Babies Programme which we started in 1966, for metropolitan and country babies. It is vital that the treatment of a cerebral palsied baby commence from early infancy, and he be put through a programme of planned development as soon as his condition is diagnosed, which should be within a few weeks of birth.

We, at The Spastic Centre know well the trauma that the young mother and father go through when their baby is diagnosed as cerebral palsied. We know that we cannot mend the hurts to their hearts, instead we can offer the best medical assistance available, the most gentle and skilled physiotherapists, and the companionship of mothers similarly situated. I can still see the mother of a CP baby saying, "That is the first time my baby has been called by her name, most doctors and nurses call her IT!" It is important for the baby to have treatment early, but it is equally important for the whole family to take an interest in the baby's progress. It is also important that the mother maintains social contact among her friends and relations.

A spastic baby left to lie all day on his back will only use the muscles which work freely, while the abnormal tone or tension of the other muscles increases through inactivity. The baby can now be given therapy specifically designed to break the grip of this abnormal muscle tension, and to make the baby experience the natural progression of movements that normal children go through in learning to sit, crawl, stand or walk.

The treatment of cerebral palsy at The Spastic Centre of New South Wales had for many years been along standard orthopaedic lines. Then techniques using a neurodevelopmental approach were introduced, as this form of treatment could be commenced at a very young age and appeared to offer better overall results. The basic principle in this approach is that a framework of automatic postural reactions is necessary for the acquisition of skilled activities, and that the development of these reactions is associated with normal postural tone. These reactions consist of righting equilibrium, adaptive and protective reactions which are acquired in a developmental sequence, some being gradually modified as the child develops. They enable him progressively to turn on his side, roll over to prone, lift his head, get on to hands and knees, sit, and to stand.

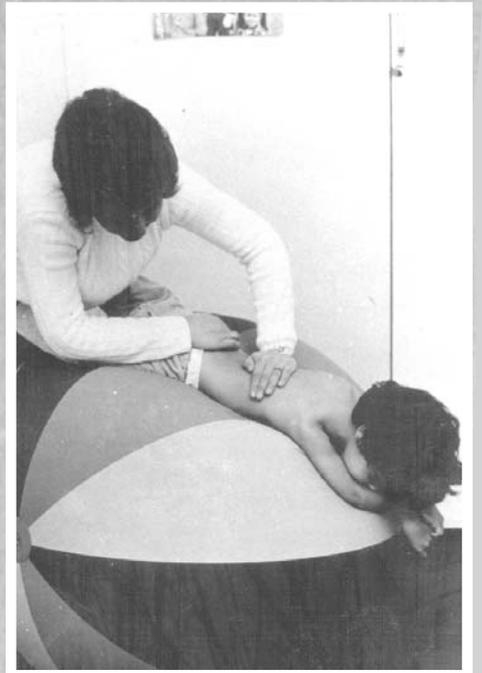
These postural patterns are present in most infants with cerebral palsy, but are generally inhibited by spasticity or abnormal fluctuations of tone. The important fact is that it is possible to reclaim and activate them, especially if the child is treated early enough, preferably under six months, before the abnormal attitudes with associated hypertonus are very obvious. This means that in many cases much of the disorder may be prevented if they are treated in these early ages.

Approximately four hundred children are involved in the state of New South Wales. To avoid the serious consequences of separating the young mother from her child, The Spastic Centre holds clinics at which our doctors, physiotherapy and occupational

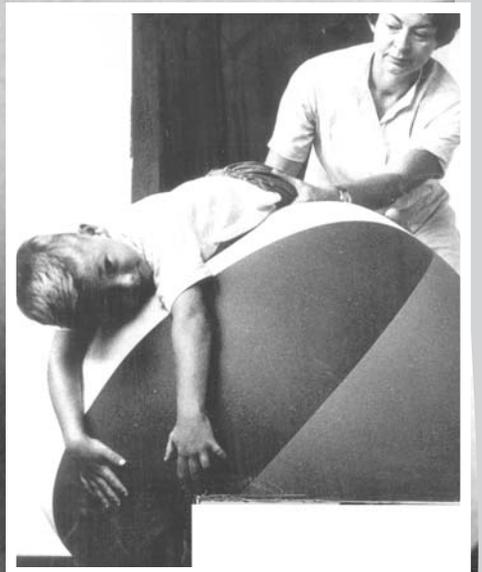
*Physiotherapy
on the Balance Ball*



Speech therapy is responsible for correct feeding



Physiotherapy on the balance ball



therapy are available once per week, at Baby Health Centres in the metropolitan area and at Newcastle and Gosford, or the mother attends once or twice a week for instruction and supervision at one of our two clinics at Mosman or Allambie Heights. The mothers from country areas come into residence with their infants at our Hostel for Country Children. They spend two weeks every eight weeks receiving similar instruction, and as the programme continues the mother is encouraged to report the child's progress. When a child is admitted to school, his programme is worked out according to his needs. All have physiotherapy and occupational therapy. About 65-70 per cent require speech therapy. However, each programme is worked out to allow at least two hours of uninterrupted school work.

There is sufficient evidence that the application of the intensive therapy training regimen, for the very young baby through the mother, substantially reduces the incidence and severity of physical anomalies in the growing child. Overseas authorities agree that a detailed neurological examination of all 'at risk' babies will produce 40-50 per cent confirmation of an original cerebral palsy diagnosis.

This early treatment is designed to take advantage of the young mother's preoccupation with her baby over twenty-four hours daily, to provide the planned environment necessary for the child's neurological development. The therapy sessions, even daily, cannot be sufficient for the baby's continuing progress, and the mother and the father too have someone to refer to at any time.

A report in 1978 by our Medical Director, Dr Corrie Reye, gives some idea of the scale of treatment procedures:

'Over the years, the value of having a large number of cerebral palsied under medical treatment in the one large treatment centre has facilitated the growth of procedures related more to the treatment of the whole person, rather than attempting, by corrective surgery, to improve a single aspect.'

This situation has encouraged the growth of more specialised knowledge of the condition of cerebral palsy, and the development of acceptable surgical procedures for its relief. The major portion of orthopaedic surgery is done on the lower limbs - only a small number of cases will benefit from upper limb surgery. Surgery involving abductor, psoas releases and anterior obturator neurectomy is being done on the greater number of patients, the clearest indication for this being the commencing subluxation of the hip joint. Usually this is in one hip, though bilateral releases are sometimes necessary. Scissoring, lumbar lordosis and scoliosis should be prevented by this procedure. All releases are done through a medial incision in the groin. Abduction plasters are applied and the child goes home from hospital in a week. If of school age, he is brought in daily to school, bus and school seats being adapted to allow for the abduction plasters. At the end of six weeks, the plasters are removed and daily physiotherapy is instituted. As the gradual nudging out of a hip is impossible to pick up clinically, hip X-rays are done every four months.

A commencing 'rocker-bottom' foot is the indication for a tendo achilles lengthening. A subcutaneous tenotomy of medial hamstrings may also be done in these young patients. Older children with tight hamstrings may need open elongation of the tightest of these. Severe valgoid feet in the younger patient may be corrected by a calcaneal wedge osteotomy, with realignment of the heel. Varus deformity may be corrected through a similar incision, to remove a wedge of bone, with insertion of staples. The adolescent patient will need a triple arthrodesis. Operations are done for correction of upper limb deformities, transplant flexor carpi ulnaris into the extensor carpi radialis, or rarely, in the older patient, arthrodesis of the wrist may be indicated.

At this time, normal physiotherapy under the Bobath and other school of training had probably developed to a stage of efficiency which suggests that future development in this area is unlikely to change its pattern.

Drug therapy based on relaxants requires continued increase to be even partially effective, and it is probable that the margin between muscle relaxation and drowsiness does not provide a sufficiently wide activity band. At the present time, little work is being done on the long-term effects of relaxant drugs on cerebral palsy to be certain of the future. On the other hand, you only have to see some of the athetoid patients, racked with muscular spasm so great that any relaxant would be preferable.

In the sixties and seventies, routine testing for the Rh factor in all pregnancies eliminated most of the cerebral palsy births ascribed to this condition. Other control measures have eliminated many of the cases of damage occasioned by too heavy sedation of the mother during childbirth, and by faulty obstetrics which resulted in anoxia. The new threats engendered by such procedures as induced birth and premature labour predict a heavier incidence of brain damage, done to prematurity in the future.

Practically all consultations relevant to the cerebral palsied condition take place with The Centre, in the presence of the Medical Director or one of her assistants. We find this preferable to referring to a busy out-patients

department, as do the consultants. The child is more co-operative in surroundings he is accustomed to, and The Centre's medical staff know the complete background of the child and his family.

The resultant therapy applied to other neurologically damaged infants on the programme is of equal value to both groups in their early childhood development. The programme offers an invaluable screening of the neurologically damaged, estimated to run as high as 50 per 1000 live births, of which 5 per 1000 may be expected to be cerebral palsied.

For validation of the Early Treatment Programme, we need to go no further than the Allambie and Mosman Schools in comparison with a similar group of CP from an earlier generation now at Centre Industries. We do not see the same number of abysmally handicapped in the younger group; they are more mobile, and there does not seem to be the same number with insurmountable speech problems.

More children are currently being moved into schools for able bodied children. The results of their progress in this sphere have yet to be assessed. Careful decisions and placements, hopefully, will enable them to integrate - this has yet to be proved. Some cerebral palsied children will be able to cope in the normal school stream, and some will require placement in special schools and the residential hostels of The Spastic Centre of New South Wales.

Emphasis has recently been placed, by those not closely concerned with the education and treatment of cerebral palsied children, on integration with the normal school population. This would seem impossible for the very handicapped child of good level of intelligence with no speech or with inadequate hand use. With these children, a programme such as Interaction Games will be necessary in the first instance to establish contact with the environment, and communication.

It must be pointed out that the establishment of special annexes within normal schools does not necessarily mean integration. Successful integration requires a happy and successful child. If a child cannot have success physically, he must be successful academically. If level of intelligence or learning problems prevent this, behavioural problems will result. Several children have been admitted to The Spastic Centre of New South Wales on request from the New South Wales Department of Education because of behaviour problems in the normal classroom. Initial placement in a segregated school would have prevented this. Programmes such as 'Basic Abilities' and 'Interaction Games' are given in the therapeutic programme and not in the schoolroom. Though programmes of education within special schools are designated 'Special Education', teachers, except for teachers of the deaf child, receive no special training, and the school curriculum tends to be modelled on normal teaching methods. Special training of these teachers would be an asset.

Typically, CP babies and young children grow up in a world lacking in normal environment stimulus, which robs them of the development that normal children obtain by an exploration of their environment and reaction to the stimuli that this affords.

The visible damage you see in a CP with distorted muscles and facial grimaces during speech is the original damage done prior to birth to the nervous system, which can never be cured. The secondary damage - through the lack of muscular balance - has been allowed to happen, because it is the result of uncontrolled, random, and usually incorrect effort of the CP individual, whose muscular patterns have been set by chance, in his efforts to achieve control.

There are therefore, two phases of control. The first aims at prevention of the condition during pregnancy and the reduction of the emergencies of the birth process. The second aims at reducing the damage done to the individual by amelioration of his physical condition with inhibitory muscle movements, which teach him to control his ineffective and uneconomic patterns of movement, encouraging good and effective patterns which later leads to effective control of his muscles.

The stages of treatment vary as they do for normal children, and for the same reasons. As the maturation of the child's nervous system advances, the programmes which control his internal computer become progressively more complex, and the therapy applied to assist his faulty control changes also.

Bobath states that the motor deficit finds expression in abnormal patterns of movement and posture in association with abnormal tone. The lesion therefore interferes with the normal development of the child. This results in: an insufficiently developed reflex mechanism showing itself in, for example, poor head control, lack of rotation within the body axis, and lack of balance; a retention of early primitive total patterns due to a lack of inhibition of these, for example, moro reflex, crossed extensor kicking, symmetrical and asymmetrical tonic neck

reflexes, grasp reflex, bit reflex, sucking and tongue thrust reflexes; the development of abnormal tone, either hypertonus or hypotonus.

The fundamental basis for a neurodevelopmental approach to treatment is that all skilled movement is built up on a framework of basic postural patterns; that is, righting and equilibrium, propping reactions of the arms and associated postural reactions. These are present in most cases of cerebral palsy, but inhibited by abnormal postural reflex activity. They can be released and activated, especially when treatment commences at an early age. When these are activated, they are established with normal tone.

Therefore, the problem of treatment in cerebral palsy is not one of strengthening and relaxing individual muscles or muscle groups, but one of improving the co-ordination of posture and movement and of obtaining more normal muscle tone. To understand this more specifically, some knowledge of motor learning must be appreciated. The first broad principle in motor learning to be aware of, is that the central nervous system is an organ of integration and that it cannot function without a sensory in-feed. The word 'sensory' is used in the broadest sense. Motor performance is closely associated with perception, which in turn is strongly related to purposeful motor activity. Eccles has said that the human system is the most complex machine existing today and, like the computer, can only produce results from data fed in.

The four major sensory modalities which contribute information for adequate skilled motor planning execution are touch, proprioception, vestibular function and vision. The first three of these come into play for a motor performance on part of the organism concerned. Visual perception is partly dependent upon correlating visual information with that resulting from goal-directed movement. Similarly, goal-directed movement with its associated feedback, is necessary for developing the ability to motor plan, which is necessary for all self-directed motor acts.

In our investigations of 'Basic Abilities' in cerebral palsy, motor planning comes high in the list of difficulties, and we now believe that dressing and undressing and drawing a man, previously attributed to poor "body image" so-called, are due to a difficulty in motor planning.

In the very young, hypertonus is usually not very marked, so that the infant will usually show some primitive and fairly normal movement patterns. In the prone lying, they may still have good reciprocal creeping patterns with abduction of their legs, even if they are unable to lift the head and support themselves on their arms. The existing normal primitive patterns can usually be retained while abnormal reactions and postural tone can be counteracted. Movement can be facilitated following the normal motor development.

Continuing research is necessary in order to increase understanding of the usefulness of all therapeutic programmes.

In 1982 The Spastic Centre was responsible for 165 children at Mosman, 77 in the Allambie School and 20 at Newcastle, apart from those classified as outpatients. The medical staff comprised: 5 Pediatricians, 21 Physiotherapists, 20 Occupational Therapists, 2 Speech Therapists, 3 Social Workers, 3 Psychologists, 1 EEG Recordist, 35 Therapy and teacher aides. Consultants: 4 Orthopaedic Surgeons, 1 Neurosurgeon, 1 Pediatric, 1 Anaesthetic, 1 X-Ray Technician, 17 Dental Panel, 1 Ophthalmic Surgeon.

There were 18 teachers at Mosman, 10 teachers at Allambie, one full-time and one part-time at Newcastle. At Newcastle there was also one physiotherapist and one occupational therapist. Apart from these, there were in Centre Industries, a full-time doctor, two psychologists, six physiotherapists, one occupational therapist, a speech therapist and six splint division workers.

Continuing research is necessary in order to increase understanding of the usefulness of all therapeutic programmes, and to pave the way for the institution of new programmes. Research was commenced in 1962, to identify visuo-motor and visual-perception problems, and this led to the publication of a book entitled 'Cerebral Palsy - Basic Abilities' by B. Le Gay Brereton, C. Reye and J. Sampson, 1966. This was a pre-school training programme suggesting that these defects are developmental rather than 'organic' in origin. This book is to be published in the Japanese text by the 'Kyodo Isho Publisher' in Tokyo. This will be referred to in a later chapter.

A \$10,000 research grant was awarded to Beatrice Le Gay Brereton and Corrie Reye in 1971 by the Commonwealth Department of Science and Education. This was for a study of normal children between the ages of four and five, and its purpose was to determine minimal neurological conditions and to develop tests that could be used to identify learning difficulties, and to allow

a better understanding of normal development at that age. (Paper read at ANZAAS Congress, Perth 1973).

An investigation of cerebral palsied patients exhibiting gastro-intestinal symptoms and anaemia led to the publication of 'Hiatus Hernia and Gastro-oesophageal Reflux in Children and Adolescents with Cerebral Palsy'. This was the first time this had been recognised as a developmental consequence in severe cerebral palsied patients.

Of the many handicaps a cerebral palsied child is subject to, drooling is the most distressing. It interferes with the development of feeding and drinking, and consequently the attainment of unimpaired speech. It disrupts school work - but the greatest effect by far, if it persists into adolescence, is that it makes them social outcasts. People do not like talking face to face with a person whose saliva dribble gives him a perpetual wet chin, and this is exacerbated when the salivary secretions turn rancid, on a bib or towel.

In cerebral palsy, people will make allowances for physical infirmities, and they will make allowances for impaired intelligence, but drooling is a primitive reaction to normalcy that is socially unforgivable.

In 1979, Dr Bruce N. Benjamin, a Sydney ear, nose and throat surgeon, had this to say:

'Attention has been focussed on the surgical management of drooling, particularly in cerebral palsied children and especially in the last five or ten years. We have operated on more than 150 patients in Sydney and had quite a large surgical experience. A lot of this was originally done in Sweden, and I would like to give credit to the surgeons in Sweden who encouraged me in the first place.

It is obvious that the results have been beneficial, because the patients who continue to request operations are referred by the people who are most intimately concerned with the care of the patient. It is estimated that about thirty or forty children are born in Australia each year who have cerebral palsy and will have a continual drooling problem. Persistent uncontrolled drooling of this kind is an embarrassing problem not only to the child but to his parents. It is one of those further handicaps which limits social acceptance. Not only is there drooling, but it may interfere with intelligibility of speech, contribute to halitosis, soil the clothes and even attract insects. Constant attention and cleaning of the face and clothes becomes necessary both at home and at school. Now, why should this occur in some patients and not in others?

The problem is not an overproduction of saliva but rather an inability to handle the normal amount of saliva, so that there is an overflow. Studies in patients afflicted with cerebral palsy and brain damage show, that there is incoordination of the muscles involved in swallowing. Swallowing dysfunction has been shown by studies using cine-radiography and by recordings of pressure within the pharynx and the esophagus. In patients with cerebral palsy, none of the recordings was normal. There were disturbances in the mobility of the pharynx and high tonus during spastic contraction of the muscle, commonly at the junction of the pharynx and esophagus. X-ray investigations showed incoordination of the esophageal and pharyngeal groups of muscles and occasionally there was aspiration of barium into the trachea.

Now, besides this gross incoordination and spasticity, the involuntary swallowing movements of the mouth, tongue and lips were infrequent and the mouth is therefore emptied less often and it can be seen that overflow occurs.

So which patients are suitable for operation? On clinical grounds alone, it is usually possible to assess the patients only roughly into categories - the usual categories of mild, moderate and severe - and at first we went cautiously and only operated on the severe cases, but now operation is offered to almost all but the mildest cases. That is, the patient should have persistent troublesome drooling every day. In general terms, it seems that after operation, seven out of ten of these cases are much improved - either dry or so improved that they are very pleased with it.

The factors to be considered in evaluation for surgery then include: the degree of drooling, the amount of voluntary and involuntary control of the muscles, that is the oral, facial, lip and tongue muscles, the physiotherapy available, and the motivation of the patient and the parents. We do not consider operation before the fifth year of life and some of our patients have been adults up to thirty or forty years of age.

Physiotherapy can be a very useful adjunct to surgery, both pre- and post-operatively, and physiotherapy treatment may improve the results of the various surgical procedures that are available. Drug therapy is not helpful in the long term, unless the dose is such as to cause significant side effects.

Our approach has been to remove one submandibular gland and at the same time, under the same anaesthetic, section the chorda tympany nerve in the middle ear on the other side, thus interrupting the nerve supply to the submandibular and sublingual salivary glands. Sectioning the nerve decreases salivary output, but it is possible that some renewed function occurs later. The combined operations usually take an hour, the patients are usually in hospital about three days, there is relatively little pain or discomfort, and there has been no serious complication. As far as we know, no patient has been worse in any way.

The most disappointing feature about the surgical treatment is the inability to objectively, or scientifically, or statistically assess the drooling before and after the operation and therefore to measure the result with any accuracy. Subjective assessment by teachers, speech therapists, parents and medical attendants have proven variable and quite inconsistent. There have been attempts to measure the salivary flow using radio isotopes, but this also has many drawbacks and experimental errors. Nevertheless, there is general agreement amongst those involved with these unfortunate patients, that most are improved. We are satisfied that operative treatment is worthwhile and we are going to continue until we find something better.'

In 1954, Dr Watson, the originator of our dental panel, produced a paper on the effects of parental Rh incompatibility on deciduous teeth. In 1963, he followed that with a further paper in association with Dr Maurie Massler and Dr Meyer Perlstein of Chicago, entitled 'Ring Tooth Analysis in Cerebral Palsy'. Dr Watson said his thesis was based on the study of the deciduous or first teeth of spastic children over a period of six years. He had found that if the children were suffering from cerebral palsy caused by the Rh blood factor, their teeth displayed certain characteristics. The defect consists of a groove in the enamel which he has named 'Rh-hump'. If the cerebral palsy is caused by anything other than the Rh factor, the children have not got the defect in their teeth. This research was the first breakthrough of The Spastic Centre because, as Dr Watson said, with his customary modesty, "I cannot say I have found out something definite, but I have discovered certain avenues which may lead somewhere".

Dr Watson has also been involved in the work of The Spastic Centre Research Laboratory programme on spastic speech muscles, under Dr Peter Neilson, and has made individual fitted appliances for its use. His untiring energy, skill and forward planning have been vital for the progress of our children. They have more regular teeth than previously and fewer caries. This enhances their appearance, makes their swallowing easier, and is vital to their chewing and speech. He was awarded Honorary Membership of The Spastic Centre of New South Wales in April 1979, and a perusal of the following extracts from his article published in The Australian Dental Journal in October 1979, shows why:

'All CP groups receive dental treatment appropriate to their age, physical and mental capacities. In its original stages, the treatment consisted largely of the placing of many restoration to combat the inroads of dental caries. However, fluoridation of water supplies in Sydney and many country centres has opened up for these patients a new world of preventive dentistry. Not only has the incidence of dental caries been greatly reduced, but a greater awareness has become apparent among the population as a whole.

The provision of electric toothbrushes has been quite a major breakthrough, but for many the brushing of teeth and the chewing of detergent and self-cleansing foods are impossibilities. In spite of this, we find that in 1978 some 70 per cent of the 199 children of school age did not require any treatment at that time. Of the older groups over eighteen years of age, 52 per cent of the 141 adults needed no restorations. The majority of patients in both groups required mainly prophylaxes and general oral hygiene procedures.

This result differs considerably from previous annual reports to the Medical Director of The Spastic Centre following examinations of the children. In these reports up to 1970, it was usual for 70 per cent of those examined to need the filling of active carious lesions, while many required prophylaxis in addition. It was unusual for 30 per cent not to require some form of dental treatment.

It is interesting to note that in the last decade, much more treatment has been carried out under general anaesthetic than in the chair. What does not show, however, is the higher quality of this work. One cannot work to a satisfactory standard on a moving target, which so many spastic patients present. In many cases, it is dangerous for operator and patient, though sometimes the conditions are the same as for normal patients.

Higher quality work has always been sought, which was one of the reasons why, in 1946, the Panel was early in the field of treatment under general anaesthesia.

A total of 5555 units of treatment were provided from the years 1946 to 1978: Patients treated in the dental chair 2567; patients treated under general anaesthetic 808; prophylaxes 319; simple amalgams 4222; complex amalgams 994; synthetics 676; extractions 1100; root canal therapies 186; crowns, inlays, bridges, oral surgery 150.'

Without the work of our Honorary Dental Panel, many of our children would have lost their teeth in early years. As a result, they would have had another insurmountable problem to add to their all over physical disabilities.

These members of the Dental Panel have given up their time over more than thirty-six years, one half-day or more in each week. As professional men, they cannot do honorary work for The Spastic Centre without it affecting their own practices. None of them is a parent, and that makes us more appreciative than ever. In 1978, Mr Watson handed over the reins of Dentist in Charge to Mr J. J. Cooney, who was a serving member of the Panel.

The Spastic Centre is founded upon voluntary work and is in good hands when we are able to call on people of such calibre as the Dental Panel for assistance.

An excerpt from an article published in the Journal of Neurology and Psychiatry, by Dr John Foley of the Cheyne Centre for Spastic Children, London, U.K. says in a review relating to the athetoid syndrome:

'Athetosis is a disorder of movement, not a disease. However, it forms the main feature of a familial syndrome, but its definition is difficult because our concept of the condition has expanded far beyond the terms of the original description...

The layman, untroubled by neurophysiological niceties, sees the problem simply - they can't sit, can't move at will, can't talk, and yet take everything in ...

Athetoids form about a quarter of the cerebral palsied population and, because of their latent abilities, are the cause of the emotive concern for children with brain damage ...

The most remarkable feature of the athetoid syndrome is that, while the voluntary and postural motor systems are completely disorganised, there is preservation of ocular movements, sensation, and often intelligence. Similarly, language is acquired though speech and in over half the cases, is impossible, and facial movements are so distorted that they can only be interpreted by familiars.

There is no other condition in which an intelligent individual may be obliged to spend a lifetime deprived of the ability to communicate or move, or in which there is such a discrepancy between motor intention and accomplishment. There is no other condition in which early prediction of ability is so often belied by ultimate achievement, if modern aids are provided from infancy. Those who are familiar with athetosis are in no doubt that it is imperative that in the early speechless years, non-verbal means of communication must be provided ...

In most cases, a measure of axial stability is ultimately achieved though usually without protective reactions, and these patients live in perpetual peril of an undefended fall. Even the most severe cases seem eventually to be able to manage the control of electronic aids, perhaps because of the relative preservation of ballistic movements. Walking, after a fashion, is sometimes achieved quite late in life if contractures have been prevented, and for this reason physiotherapy should never be neglected in the school years ...

In the accepted sense, there is no treatment. Short of stupefaction, drugs are of little value, and stereotaxic surgery, though pursued with enthusiasm, does not seem beneficial in the long term. Mitigation of the symptom is, however possible, though it demands teamwork. Correct handling and feeding, measures to encourage trunk stability, the careful choice and teaching of codes, and the early provision of non-verbal means of communication add immeasurably to the happiness of the patient and his family. The usual mistake is to underestimate their abilities.

The following are a few simple rules that have been borne in upon the author. An athetoid infant who has had jaundice must be assumed to be deaf until the contrary is proved. If his saccades are normal he should be assumed to be of normal intelligence until, after years of observation, it is proved that he is not. Emotional liability is likely to be due to either postural instability or the lack of a means of communication. Intelligence cannot be assessed in the speechless child until he has been provided with a non-verbal means of communication, and his ultimate physical capability cannot be forecast before he has achieved a reasonable measure of trunk stability.'

In my view, with the athetoids, that says it all.



Sounds and Symbols

Speech

1962

For the cerebral palsied, speech is the heaviest handicap of all they suffer. For many years we had attempted to provide, mechanically, some means of communication, but it was fruitless, until the electronic age set new limits to our technology. Now speech for the CP is technically possible in a number of ways. It only needs the money and time, for its commercial development. What is money? What is the price tag on the gift of speech for a cerebral palsied child?

I was given a sharp lesson on its value when, in 1978, I suffered a stroke which left me speechless for twelve weeks. It was an exercise that I could well have done without, but I discovered what it was like to be personally involved, and the experience, though painful, was well worthwhile. It increased my admiration for the cerebral palsied who have coped with the speech problem, not just for one or two years but the whole of their lives.

The importance of the perceptual motor planning deficit is that all of the work done so far, on the muscles of the cerebral palsied, applies doubly to those of the neuro-transmission problems of the cortex, lead us to believe that the final answer to the riddle of the CP lies directly in those of speech - and the lack of it.

'We now have precise neurological information that allows us to tell people whether they are improving in the right direction and how close to a target they are getting. If on the thirtieth attempt, we can show a person is improving and is a few per cent less disabled, we can reward his achievement with beautiful music, because his achievement is exciting. The achievement is important for that improvement will be the base line we can begin from next session and thus gradually approach the goal of intelligible speech.'

There is little doubt that CP children are particularly prone to variations in ability and that limitations occur frequently, mainly at visuo-motor skills. Although one may argue this is due to brain damage, it might equally be argued that an inadequate or abnormal background of experiences is responsible for this.

It has been obvious that we finish up with a child who is able to adjust much better to a learning task in school than others have formerly. Possibly this is due in part to the fact that tasks in the 'Basic Abilities' programme have been pitched at the learning level of the child, that is, at the point at which correct responses are possible and frequent, but do not always occur.

For the CP child, the ability to walk opens the door, just a crack, to experience the environment. For the child, and increasingly so for the adult, in the absence of effective speech, the door is slammed tightly shut again.

Of all the handicaps the CP is heir to, the most important one is lack of speech. If you can make yourself understood by a stranger, all the other handicaps, important though they may be, can be minimised by some other means - mechanical or electronic. We are now standing on the threshold of synthetic speech and, for the CP, it is truly 'waiting for the sunrise'.

For the CP kindergarten and school child, life is demanding. During this time, intensive therapy must continue and all medical, surgical and paramedical procedures cut heavily into the time available for classroom education. Many CP have difficulties of speech and of hearing as well as visual troubles. Yet, the level of education attained by them offers the only possible hope of escape from the bonds of their physical handicap.

Communication for Non-Vocal Cerebral Palsied Children. Excerpts from a paper delivered to The Spastic Centre by Eugene T. McDonald, Ed. D., Research Professor, Speech Pathology, Pennsylvania State University, 1975:

'I'm going to talk about non-vocal communication for cerebral palsied children. You will notice that I said 'non-vocal' communication rather than 'non-verbal' communication. This is because we use verbal symbols even though expression is achieved through some modality other than speech or vocalisation. Also, I want to stress the word 'communication'. In our early experience with cerebral palsied individuals, speech pathologists spent a great deal of time trying to develop speech even when it should have been obvious that development of speech was no more feasible than the development of walking, or the development of self-feeding.

When we realised that this goal was not always a justifiable objective, speech pathologists began emphasising language training for the young cerebral palsied child. Usually the development of receptive language is emphasised. Language reception is not sufficient for establishing inter-personal relations so I will stress an even broader concept - the development of communication. Our objective should be to help the cerebral palsied child make his feelings, his ideas, his questions "common" with other human beings. If he cannot do this through the usual expressive modality, speech, then we should find some other method which will enable him to be an expresser as well as a receptor of language.

It would be impossible to overemphasise the importance of communication to the cognitive, social and emotional development of the young child. Receptive language is essential, but without the expressive component of communication the child's development will be stunted, hence, we should make early and heroic efforts to find effective ways for the non-oral infant or young child to express himself. We think that it is now possible to identify at an early age, infants who are at risk for failure to develop oral communication skills. For these children there are techniques with which we can intervene early, in order to develop an expressive ability and thus facilitate cognitive, emotional and social development.'

We have in previous pages referred to the work of Miss Beatrice Le Gay Brereton. First, she was involved as a Consultant to the Commonwealth Office of Education. While there she did a series of reports on the educational potentialities of the cerebral palsied child in 1950. The final summary of those reports stated that "the various methods of analysis seems to point to a slightly greater variability in the tests when used with children without cerebral palsy. This is the opposite to what one might expect, and no evidence has been deduced to the effect that specific characteristics of the thought process or in the type of error made by cerebral palsied children result in scores being obtained that vary according to the material of a particular test rather than overall ability of the child".

Miss Brereton was intrigued by her results, and in 1955 she agreed to join The Spastic Centre staff as a Research Officer. As an Educational Psychologist she was responsible for the integration of the teachers from the Education Department with the therapists and medical staff of The Spastic Centre. She worked well with Dr Burton-Bradley, our Medical Director at that time, and then, as the fruit of her capacity, she brought out, with the assistance of Jennifer Sattler and Margaret Ironside, under the direction of Dr Corrie Reye, a book, 'Basic Abilities for Cerebral Palsy', published in 1967. M. L. J. Abercrombie, in the preface to the book, said:

'Current thinking about child development emphasises the overwhelming importance of experience. The concept of the static, innately determined IQ has gone; we now think of a child's level of intelligence as resulting from the complex interaction of the potentialities he had at birth, and all that has happened to him since - what he has smelled, tasted, touched, seen and heard, and all the movements he has made.

So, if a cerebral palsied child is less intelligent than a normal child of the same age, we think this is not only because he was born with a damaged brain, but because his experience has been damaged also. His hearing may be deficient, and he has by no means heard every word that was spoken to him; his eye movements may be erratic so that he has not fixed his attention easily, or for long, on what he has looked at; he may squint. He has been less mobile than a normal child, and such movements as he has been able to make were jerky and ill-controlled. The experience that came to him through movement, both experience of his own

joints and muscles, and experience of the world that exploring it with movement gives, all this has been impoverished.

We recognise for a cerebral palsied child the importance of enriching his experience, of talking and playing with him, even if the signs he gives of responding with understanding are meagre and less rewarding to us than those we expect from a normal child.

A cerebral palsied child's sensory experience is not only impoverished, but it is less ordered. Muscles that are too tense or too slack, so that they do not move the hand or eye skillfully to its target, feed back to the brain a lot of messages it would do better without. The map the child gets of the world, the picture of the relatedness of things in space, must be more chaotic than the one a normal child gets, whose movements are better controlled and more economical. So a cerebral palsied child needs to be helped both to get experience, and to order it, and the sooner it gets help, the better.

It is worth spelling out these basic assumptions as to what the needs of cerebral palsied children are, because rigorous experimental proof that any one form of treatment is more beneficial than another, or than none at all, is not available. The complexities of assessment being what they are, and our techniques so feeble, is it likely to be provided in the near future. Meantime, brain damaged children are growing up.

Faced with these tragic results of some of nature's errors, we must act with informed faith, applying to their treatment carefully assessed general ideas about the way children develop, both normal, and handicapped.'

'The Theory Behind the Treatment' gives us the crux of the Basic Abilities Plan, as follows:

'It is clearly possible to improve perceptual skills in normals. There is a great quantity of evidence about progressive change in acuity, variability and accuracy of perception... It proves beyond a shadow of doubt that the notion of fixed thresholds for a certain set of innate sensory dimensions is over-simplified. Discrimination gets better with practice, both with and without knowledge of results. An example may be taken from the two-point threshold on the skin. The difficulty may well be in maintaining the gains that are made.

The treatment plan has now been in use for a number of years. The children who have received treatment are, on the whole, more ready for formal schooling than they were previously. Their scores on many visuo-motor and perceptual tests compare comparatively frequently with their overall estimates of intellectual ability. The reason for the improvement may be in the actual structuring of the treatment plan, it may lie in the overall effect of individual tuition at an early age, or it may lie in pitching tasks accurately at the appropriate level of difficulty. This is still unknown. The long term effect on intellectual development and on school success is also still unknown.'

Following that publication in 1972, Miss Brereton had published 'Learning Ability and Behaviour of Cerebral Palsy' and I think that the concluding paragraph in the book sums up her whole philosophy when she says:

'In the past we have thought of the cerebral palsied child as a child with a certain level of intelligence and a certain degree of physical handicap. We expected both these features to run a course more or less pre-determined by birth, the factors in the background being certain innate propensities and the presence of pathology of the motor control centre of the brain. Although the information available can be interpreted in this way, it is not conclusive. It is quite possible to consider that inability to learn occurs because the motor handicap distorts visual information or interferes with visuo-motor mechanisms. What might be considered abnormal behaviour, could then be seen as a resultant difficulty in interacting with the environment.'

Then Miss Brereton, with the assistance of Margaret Ironside and under the direction of Dr Corrie Reye, produced 'Interaction Games for the Severely Handicapped Cerebral Palsied Child Without Speech'. I think the introduction to the 'Games' is worth quoting in detail:

'It is usually difficult to establish any form of communication with young severely handicapped cerebral palsied children without speech. These children are often erroneously considered to be grossly mentally retarded. In some, because facial expression is alert and they have a ready smile, teachers and therapists feel intelligence is above this level but are unable to substantiate this. In some, behaviour is predominantly hostile to people outside their family circle, and they may at times have severe screaming tantrums, even at home. Others again are passive and expressionless, perhaps as the result of a withdrawal from situations they are unable to participate in.

The aims, in the past, have been to establish verbal communication in one way or another. First a yes/no response by nodding or smiling is introduced and later, by learning to spell, the use of some form of communication board or typewriter. Pitfalls in relation to the first of these, is that the response is often equivocal - the child both nodding and smiling in one order or the other, to a greater or lesser degree. The basic pitfall in relation to the second, is that little progress can be made until the child has the mental age necessary to learn to read and spell, spelling being considerably more difficult than reading. Many of these children have, in the past, never learnt to read or spell effectively.

The first principle in approaching through Interaction Games, is that the child is in difficulties in relation to the whole situation, not just in relation to the use of words or gestures. Physically, most children would be able to give some indication of a definite choice. One is, however, most unlikely to get a consistent indication of a definite choice. The child does not appear to look carefully and does not show any real interest in the task.

Actual linguistic development is not impeded merely by a lack of ability to articulate. The range of facial expression and gesture is also restricted. For example, facial expression may be used to smile at you, implying a degree of interaction, but the usual range of expressions indicating clear responses such as surprise, or doubt, or displeasure, or anger, are not always present. Similarly, the hands may be used to point but not used communicatively as in requesting something, indicating ownership, establishing contact or indicating direction. These children appear too divorced from their environment to need to communicate with, or about, it.

The second principle of Interaction Games is that the situation that can be made most obviously meaningful, is a non-verbal problem which has to be solved. The successful completion of such a problem can be the basis for communication between the person who sets the task and the person who completes it. Since the inadequate reaction of these children to their environment may result from their inability to participate, the problem set must be simple, so they are successful, and one in which active participation is possible.

The neurological approach to treatment challenges one, not merely to devise ways of bringing these children into effective contact with their environment, but also to start this treatment at the earliest possible age. The first tasks in the programme are, therefore, things that a normal baby can accomplish at nine to twelve months of age.

The successful treatment depends on an effective positioning of the child, so that a gross arm movement is possible, so that the child can get his eye, at least fleetingly, on the task; so his eye can be caught by the eye of the person who sets his task. The introduction of two people into the situation - one identifies herself with the child, facilitates his movements and gauges the child's attention in attempting movement. The other sets the task and acts as a sounding board, to respond to the child's success or failure and the introduction of varied media until one is found that catches the child's interest.

Prior to 1972, the conversation of children without speech depended on their ability to spell. This frequently left them without an effective means of communication until ten years of age or older, by which time the natural flow of language may have been inhibited. Sentences, if they emerged at all, tended to sound as if they were artificially put together. Some children never acquired enough words to be able to express themselves at all adequately.

The overall treatment plan involves a series of strategies. Emphasis is first placed on early interaction with people and objects. Communication is not merely a way of talking, but involves also a desire to make contact with people, dolls, animals or even things. It requires an interest in, and knowledge of, one's environment and of the verbal labels attached to the various items in it. Without the ability to communicate, severely handicapped children may withdraw into themselves, and, as a result, may have little interest in people and large gaps in their information.

Early communication is obtained from birth in the relationship between baby and mother, and it is strengthened by neuro-developmental physiotherapy.

Early expressive development is encouraged throughout the day, through the interpretation of gesture and body language. Frequently this commences with feeding therapy. The mother is shown not only how to feed the child more effectively, but also how to interpret and encourage his responses and indications of needs and gratification. Oral stimulation associated with feeding therapy encourages vocal play, by focusing attention on the mouth. This vocal play amuses the child and increases his interest in talking. The kind of talking at this stage from mother to child would be in simple, short statements about everything

they are doing. This provides information for the child, and the opportunity to respond by looking, reaching out, or showing in some way that he is participating in the communication.

If the opportunity is provided, the child will eventually indicate, in his own way, his choice between playing with a favourite toy or being taken for a walk. This skill can be expanded so that the child can choose what he would like to eat, by selecting one of two or three pictures pasted on the refrigerator door. In this way he learns to associate pictures with chosen items. His tabletop can then be decorated with pictures, drawings or photographs, to provide a wider experience. The pictures used for this decision-making should be of particular objects that really interest him, probably family members, games or toys, television, bath, car and foods.

The number of pictures from which to choose will gradually be built up from two or three as his ability to select and discriminate improves. As his ideas and ability develop, the display is arranged into groups representing areas of interest; for example, a picture of a number of toys, another of his family, and one of several things to eat. It is emphasised that these children need to be encouraged, to a point where they wish to tell about their experiences and delight in having their adventures recounted for them, to other adults or children.

An attempt is made from an early age to bring an interest in other things in the environment into the child's reach. In this, the therapist brings the objects in the programme into visual and hand contact in play by sitting behind the child, supporting him and facilitating his movements. Interest in other people is stimulated from about six months of age. At this stage, a therapist or parent positions the child and helps him to operate. Another therapist sets the child the problem, communicates with the child and watches for facial expression, hand clapping, or other forms of self-expression from him. The therapist, for her part, responds with both words and gestures.

These non-verbal problems include identifying categories into which shapes, colours, objects are sorted. As these games are designed to develop motivation and interaction, the child is never told where to put an item. The therapist just adds items till the child gets the idea. Once the child realises what the game is, the therapist reinforces his decision with verbal patter, such as "that's right, it's a red one and it goes there". More independent experience is developed at the same time by means of electronic toys, page-turners and attention getting devices.

A further step is the development of a reliable yes/no response. Interaction Games can be modified for this purpose. Instead of asking the child to make a choice, the therapist says, "Does this one go here?" or "Is this the one?" This is never as popular with the child as simply choosing, and needs to be approached carefully. In all yes/no training, it is important to use language you know the child understands, and situations to which you know he knows how to respond. As soon as one moves outside this type of question, the child needs to have a way of indicating "I don't know". If he has to resort to using his 'yes' or 'no' response for an answer he doesn't know, it will greatly reduce the strength of his yes/no response. As this response becomes more functional, the child reaches a position to be able to communicate with anyone who is practiced at building up a message by asking questions demanding a yes or no answer.

Thus, as a result of these programmes the child attains an interest in the environment and a desire to communicate, a definite yes/no response, a working level which one might expect of a child aged about 3½ years, the ability to sort into two or three categories, and to recognise that an item may be present which does not belong to either.

The therapist, teacher and the family together, must develop internal unvoiced language, even though the child cannot yet speak intelligibly. Language is a two-way communication, so they will use symbols, which the child can master easily. As they represent a whole category of objects, spelling is not required. Later, the symbols lead on to spelling and a more precise means of communication. When the child is able to spell, he will have an electric typewriter, because he is unable to use a pencil. Should he not be able to operate a keyboard, some other means of operating the typewriter will be found for him. Simple electronic controls, operated by a movement of some other part of his body, such as an intercepting light beam, or operating a special switch, can be fitted.

We, of course, have used symbols over the years, but were not satisfied with the results. The magazine articles on rehabilitation of the cerebral palsied children, particularly in Canada and the United Kingdom, had seemed to proliferate the symbols usage to astronomical heights, aided perhaps by the new minicomputer. It seemed to me that they were in the process of making a new written language like



An electronic pressure switch as an aid in controlling the pointer.



Chinese ideographs, but would still have to come back to basic English, ultimately. That is the reason why 'Sounds and Symbols' was created as a bridge between the symbols and standard English sentence construction.

The rationale of the 'Sounds and Symbols' system is based on a critical examination of a number of alternative means of communication. This indicated that it must have a reasonably extensive vocabulary - it must be easily understood - and it must be easily learnt.

As well as being planned so that it can operate at an early age, it is essential that a method of communication can support a vocabulary of at least twelve hundred words. An understanding of those words is normally attained before a child is 3½ years old. In terms of methods used in the past, this appears a large target, but it is considered an attainable one for many children who would formerly have been able to do so.

Even between intelligent adults, communication based on fluent and accurate words can be quite readily misunderstood. A less precise or makeshift form of communication will be more subject to misunderstanding on the part of the listener. It is essential that the method adopted leads to successful resolution of the problem of what the child has to say, frequently and relatively quickly, or the child will have little incentive to try again.

The clues used must be able to be learnt readily by all the people within the child's environment. In the long term, the child will have to communicate, not just with its mother or its teacher, but with a shifting population who have only a limited opportunity to learn the child's method.

'Sounds and Symbols' uses letters and symbols in a way which an adult can learn to interpret in a matter of minutes. It can be learnt at an earlier age than reading and spelling. It can, however, act as a bridge leading towards increased efficiency in these skills. It should also provide an impetus for increase in the number of words the child understands.

The symbols are diagrammatic drawings, which have a ready acceptance because of their similarity to an object. These are used not for one item only but for a number of items. CP children on the whole, have little difficulty in working with these global concepts.

In making symbols talk, emphasis should be placed on games or situations demanding expression. Which do you choose? Collect a batch of suitable booklets and present the child with an option. Questions involving 'or' are difficult, but if introduced very carefully, should be suitable, as they are normally in the repertoire of 3½ to 4 year olds. Initially, use questions to which we know the answer: How are you today? Who is the biggest person in your house? How did you come to school today?

Remember, although the child uses his array of symbols on his tabletop for everyday communication, varying the media and presentation by taking the child out of his chair in treatment, and working on the floor by dealing cards out, or throwing dice and so on, can make the treatment more fun.

Find pictures that have a lot of things in them, because at this stage one would expect enumeration. Get the child to talk to you about the picture, then take it back to the classroom, in the hope that he will spontaneously tell the teacher about it. Other games and activities to make symbols talk: planning a day at the beach. "What do we take with us?" Adding to or subtracting from a row of pictures or objects and asking the child "What's gone?" or "What's new?" Listing things: "What do we keep in a refrigerator?". The advantage of most of these is that you can anticipate the answer. Remember, it is easier for the child to talk about things he can see in the room.

The child may wish to tell some important or exciting news from home. Spontaneous output may also occur in letters home from children who board away from home. The advantage in this situation is that it is real expression, but the disadvantage is in the difficulty in interpretation. In situations where interpretation is obviously difficult, the child's anxiety or disillusionment can be prevented by the therapist assuming the responsibility for the breakdown in communication. "I'm just not watching very carefully today, am I?" Anything the child says spontaneously must be interpreted, if it is humanly possible to do so.

The "everyday dictionary" attempts to help the child to make a real use of symbols in everyday life. It should travel with him wherever he goes, to help people interpret. It includes not only a selection of frequently used words, but also the words that particular child is known to use.

A simple lecture to parents and another to bus drivers, aides, other teachers and so on can give them both interest and a degree of competence.'

Some years later this study was refined with the publication of "Further Stages of Sounds and Symbols", which stated in its introduction:

'This supplement to 'Sounds and Symbols' describes methods for increasing facility in communications, by using additional symbols and the letters of the alphabet in conjunction with the identification of initial sounds. It also describes development of a 'Larger Dictionary', the facilitation of more complete sentence construction, the development of displays, progress into spelling and the development to date of methods of dealing with children with additional problems.

It is emphasised that the dictionary includes the child's personal words, and words he is particularly prone to use. This means that any talking person who can read can interpret the child's utterance, even utterances that include words that have initially been discovered, with great difficulty, by someone else.

'Sounds and Symbols' has been developed in relation to semantic rather than syntactical principles, for developing verbal expression. The children for whom 'Sounds and Symbols' was primarily designed were children with at least the language comprehension of a 3½ year old. This is in fact listed as a prerequisite for starting. At that level a child can be expected to have a vocabulary of some twelve hundred words, a mean length of utterance of four words, and, although usage is predominantly functional or simple sentences, some conjunctions and many prepositions are already in use. One is not therefore, teaching language concepts or small sentence patterns, for these can be assumed to be present. Rather, one is teaching the child to use language concepts and sentence patterns that he is already familiar with in terms of understanding them when used by others. His difficulty in expressing, assuming he is not also dysphasic, is because it requires more patience, persistence and intellectual capacity to use an alternative means of communication than is needed for ordinary verbal expression. An utterance has to be held in mind longer to be encoded into symbols than to the spoken. Further, the use of symbols and even more so, the use of sounds, requires skills that are later maturing than language skills, even in normal children. The main words are likely to be produced at the expense of sentence structure, because this is the simplest way for the child to deal with a different situation.

A semantic approach implies that normal language patterns emerge, in the long run and predictably, from

a child's early clumsy and ungrammatical attempts to express his interaction with his environment. For example, even if a linguistic form used by a child appears to be a noun, it may be used in practice as a noun, verb or even a sentence, according to the child's connotation of the word at the time.

'Bikky' might imply an object, 'please give to me', or even 'I'm hungry'. The notion of language acquisition, as a process in which language is mapped onto the child's repertoire of basic cognitive concepts, is widely held. If this is true, the child's intent in making an utterance is more significant in facilitating his expression than the apparent grammar used.

Materials in 'Sounds and Symbols' have been designed therefore for teaching strategies based on real situations. These would appear most likely to provide opportunity to increase the child's capacity to use language meaningfully - to gain control over his environment, interact meaningfully with it, and develop satisfying inter-personal relationships. For example, the words selected for inclusion in the 'Everyday Dictionary' include: words that may assist the child to obtain what he wants, words that may imply the development of thoughts leading to utterance, for example, 'on the way to school we saw a fire engine', and words to do with personal relationships.

In treatment sessions, the semantic approach implies that it is important to plan situations in which the child learns through his own interaction. It is the nature of adults to "teach" children to perform tasks, rather than to put the child in a situation in which he has to learn. The latter is however an acceptable, if more difficult teaching strategy. It is particularly effective in relation to teaching language, because language is so much a reflection of the individual's own mind. Attention is drawn to the strategies used in the situational method of teaching English as a foreign language.

It is important to avoid imposing adult forms on a 3½ year old level of utterance. Our object is to elucidate what the child wants to say, whether it is grammatical or not. However, it would be acceptable, as with all children, to say his own sentence back to him conversationally, using the words and constructions we would use ourselves.

Similarly, it is important not to deprive words of their natural flexibility, by extensive use of formal exercises, for example, teaching "on" as a prepositional concept. Even in adult usage the same utterance can convey a different message if said in a different context.

It has always been, and will always be, difficult to classify word units for teaching in terms of function and contextual usage. Certain principles do however emerge. If a child is going to learn to communicate he must have a reason to talk; the rewards must be in terms of obtaining what he wanted, or attention to his information. In any type of structured situation, the significance of its design is its closeness to reality. If, for example, the response "mummy come" is obtained artificially, it should result in the mother coming, and not merely a verbal response "good boy". Real situations for communication probably occur more frequently at home than anywhere else, so that a good relationship with the parent is essential. Other useful areas include lunchtime and arrival and departure; communication demands mutual responsiveness between adult and child. A balance is necessary between the child talking to the adult and the adult talking to the child. Again, it is natural for adults to dominate the situation and difficult for them to restrict their own utterance adequately. The child is likely to obtain most opportunities for expanding his repertoire, not with his peers, who are at the same level as himself, but amongst children talking slightly above his level, or adults monitoring their language at such a level.

Analytical tests are of value in indicating the level to aim at, and in assisting the therapist to monitor her own language at a particular level. A child can often make himself understood if his noun vocabulary, contentive words, content words, concepts, is adequate, even if his syntax is wrong. No degree of accuracy of syntax will help if the content vocabulary is not available.

To encourage interaction, the development of this vocabulary should have priority. If adequate interaction is obtained, it is to be expected that syntax will emerge because the mechanisms that make it develop will start to operate. The capacity to evoke any communication should take precedence, initially over eliciting specific forms of utterances. If shaping is used later in relation to the child's utterances, the topic should be initiated by the child.

Technique of treatment is based at present, mainly on encouraging the child to converse and, when the conversation is completed in itself, going over the sentences used. The whole conversation gradually moves on to a higher plane and new sentence structures have emerged without training.

This does not of course mean that it is not possible to use "Sounds and Symbols" to teach concepts, or to develop formalised utterance, but the materials described in this and other publications are not designed for this purpose.

In summary, the following characteristics of "Sounds and Symbols" are to be noted: The symbols stand for categories of words, not just one word; early concepts are established empirically by sorting exercises; categories cover all the words in the dictionary so that there is the background for a total language; initial consonants are used systematically to establish individual word form; Symbol Word Dictionaries are available; it makes use of residual auditory skills, rather than using an entirely visual basis; it leads into spelling; it involves a minimum of items on the tray, so that quite handicapped children are able to point; unstructured utterances lead directly to formal sentence construction. There is no built-in difficulty developing syntax."

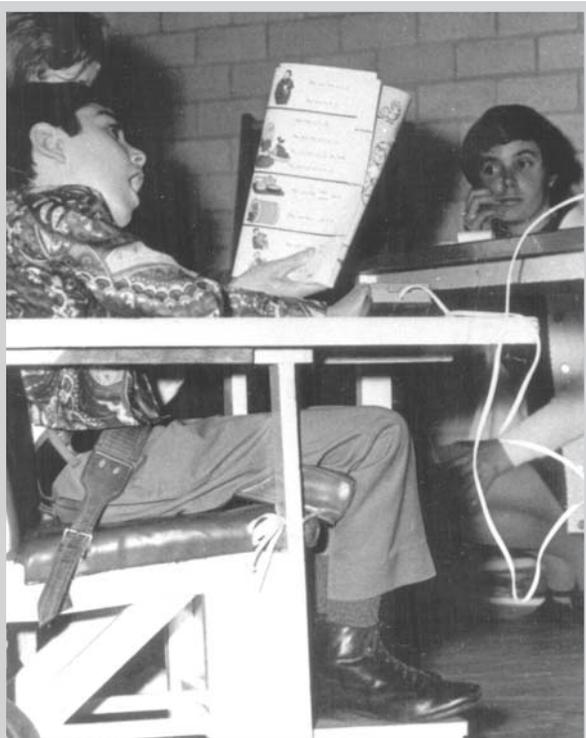
The system is not confined to the English language. It has recently been applied to the Japanese language.

During these impatient years, when developing intelligence out-marches the poor control of the tongue in speech, and of hands and fingers in manipulative skills, the CP child needs access to the world of electronic wizardry, which only now is being harnessed to his educational needs.

Speech technology will have a broad impact on all our daily lives, and small wonder. Synthetic speech, and its sister technology, speech recognition, represent a \$US3 billion market for industry three years from now. The oldest synthetic speech technique is called phoneme coding. Speech sounds or allophones and the rules for stringing those sounds together are stored in computer memory chips. Then, using a microprocessor, the sounds are combined to create speech that is intelligible.

The second approach, called linear predictive coding, involves storing the sounds also in a computer that mimics the process by which sounds are produced, including the motion of the lips, tongue and vocal tract. Finally, what is known as wave-form digitisation. The frequency of pitch and spoken words is broken down into digital pulses, compressed according to a complex mathematical formula and stored in memory for later reconstitution.

For the CP, the intelligibility of the spoken word is all important. The tonal quality, inflection, intonation, can come later. A study has been made on speech defects with athetoid CP translating speech patterns to identify consistent and repetitive errors. They are transcribed into a computer code and, by recognising errors when they subsequently occur, those parts of the original speech are replaced by synthetic speech. So the listener hears the CP speaker's normal voice.



Sounds and symbols associated with an initial letter of a word as a bridge to learning the alphabet.



Education

1972

Let me tell you about one of our small boys, eight years old, who is learning to walk for the first time.

He has been working with his physiotherapist at The Centre every day, since he was four years old. Finally he was up on his crutches and had been walking unsteadily in the physio room for the last two weeks. His mother knew about it because she works voluntarily at The Centre one day a week, but it had been kept a secret from his father.

So one day they smuggled his little aluminium crutches onto the bus as he went home from school. When his father arrived home from work that night, they sent him into the lounge room to wait. Then the boy got onto his crutches and, ever so slowly and with all the pride and joy in the world, he marched up the passage to his father.

Telling us about it afterwards, the mother said that she was so intent on watching every move the boy made that she did not realise for a little while that her husband had disappeared. She found him in the kitchen, with his head down on the table, and he was crying. He said, "It's been so long, and I didn't really believe that it would ever happen".

We see all kinds of tears - bitter scalding tears, and happy joyous tears. They are the stuff that The Spastic Centre is made of - and they are the things that made people come back year after year to work on Sundays, on back-breaking building labour for our schools, because nobody gets anything out of The Spastic Centre - but the children.

Mr John Le Maistre had this to say on modern education in the "Sydney Morning Herald" in April 1983, in words that I would have liked to emulate:

'When everything old is new again ... Some forty years ago, Wendell Johnson, an American authority on speech defects, proposed that the problem of stuttering was very often caused by the actual labelling of the problem itself ...

Irrespective of one's acceptance of Johnson's thoughts regarding the cause of stuttering, his insight into the possible negative consequences of unnecessarily labelling children was most significant.

Subsequent research has demonstrated Johnson's fears to be well founded.

While restraint has been exercised in Australia concerning the adoption of terms with very obvious

connotations, we have accepted other descriptions of learning disorders with enthusiasm. The situation warrants examination.

The labelling syndrome has its foundations in American universities. By the mid-seventies, the quest to label children reached frenzied proportions. The few professionals fearful of the consequences of this trend were lost in an avalanche of literature on the newly found problems of children...

Predictably, an abundance of potential disciples was to be found in Australia. Corridors of schools of education within our tertiary institutions soon echoed to the new jargon.

Supported with some 20,000 books and articles on the subject (a legacy of the labelling movement), the concept of dyslexia, previously a topic of mild academic interest, gained acceptance in all areas of educational enterprise.

The basis of dyslexia is unclear. To some professionals, dyslexia implies a minimal neurological malfunction. Word blindness is often used in support of this viewpoint. Others have attributed the condition to a developmental lag within the child. Sceptics claim dyslexia has no discernable anatomical or biochemical characteristics clinically diagnosable. For the vast majority of children 'suffering' dyslexia, is this diagnosis justified or are we being deceived? Dyslexia places the onus on the child. The child, as a consequence of dyslexia, is failing in school. But could the antithesis hold the truth? Is the school failing the child? Is the school exempting itself from its responsibility by using dyslexia as an excuse for its own inadequacies in the teaching of reading skills?

In the final analysis, only one criterion can be applied in relation to the labelling of children. A label can only be justified if it serves to focus attention upon the special needs of the child leading to appropriate assistance. If this is not the case, there is cause for concern. Putting children with learning difficulties back into the classroom - mainstreaming in the jargon of the educationists - continues to gain momentum. In one sense this is understandable. What responsible person would argue in favour of isolating children with problems from the regular classroom simply because they are different? Why deny these children the opportunity of growing and learning with their more fortunate peers?

In previous years, teachers and parents argued strongly, and most convincingly, for specialised services and programs for children unable to cope within the regular classroom. The psychological consequences of repeated school failure could no longer be ignored. The isolating experience of segregating children became the most often cited criticism. Alternative classes often became child minding centres for under-achievers and behavioural deviates.

The situation is paradoxical. At a time when serious doubt is being expressed regarding the suitability of the regular classroom in meeting the needs of 'normal' children, we are now asked to accept that this environment has improved to the point where it is the preferred setting for teaching children with problems.

Ideally, the assimilation of less fortunate children into the mainstream of schools deserves wholehearted endorsement, but such thinking can only be harmful for all concerned if we blind ourselves to the reality of the situation.

Our philosophy of education reflects the democratic ideal of equal opportunity for all. If translated literally, as has obviously been the case, equal opportunity implies a need to expose children to fundamentally common learning experiences in accordance with chronological age. The thinking is incorrect. It is blatant defiance of fundamentals with respect to child development.

Effective learning is dependent upon a very well established principle. We cannot expect a child to master an advanced skill, irrespective of age, unless the necessary prerequisites for learning that particular skill have been mastered. Children walk before they run.

Diluting the regular school curriculum for children with problems is, in effect, providing a deprived curriculum for deprived children. The practice guarantees failure, for it ignores the vast differences in mental development, and thus needs, within any age group.

While our schools persist in adhering to mainstreaming in its present form, the needs of the vast majority of children with learning problems cannot be met. As was previously the case, these children will flounder with shame and ridicule.

Those who defend mainstreaming will point to the availability of remedial teaching for children who 'fail'. But why make the children fail in the first instance?

The school system demands remediation, not the children.'

Dr Peter Neilson, whose work at The Spastic Centre Research Unit will be referred to in a later chapter, had this to say:

'At about this time (1975), I was most impressed by an insight into the mechanisms of cerebral palsy of Beatrice Le Gay Brereton, who is a psychologist at The Spastic Centre of New South Wales and has spent many years studying motor ability and motor disability in cerebral palsied children. She presented a paper at a conference at The Spastic Centre which I attended where she demonstrated what she considered to be a major problem of cerebral palsy. To quote her: "A cerebral palsied child may appreciate precisely what it is he wants to do, such as draw a triangle; he can understand the task because he can point to triangles when asked, but he is unable to translate this appreciation into appropriate motor commands to achieve the task.'

Miss Brereton also said: 'What do we mean by motor planning? Paramedical definition - with the initial development of the Basic Abilities Treatment Plan, we tried to define six areas of psychological function that showed marked development at four to five years, and that had been considered problem areas in studies of older cerebral palsied children. We did not regard them as inclusive, that is, including all known or useful areas for training, or specific, that is, that there was no overlap or that they had a unitary quality. The reason we tried to define them was in order to pitch training at specific targets, and in this way both improve therapy and quantify results of treatment.

One of those areas we called 'motor planning' or 'planning the movement appropriate to the situation'. We had great difficulty in the early days in describing this in such a way that therapists and visitors knew what we meant. The best way to experience it yourself is to set yourself a novel framework in which a movement has to be planned; you can do this by trying to draw a diamond when you can only see your movement in a mirror. In the book, the actual wording reads as follows: 'A child may be clumsy in avoiding an obstacle such as a chair for more than one reason. It could, for example, happen because his movement is uncoordinated, because his vision is poor, because he doesn't realise where in relation to himself the chair is, or because, although he appreciates the position of the obstacle, he is unable to plan the movement appropriate to the situation. Likewise, his drawing skills may be bad because he does not appreciate shape or distance, or because he is unable to transfer this appreciation into appropriate movement - again the latter being a motor planning problem.

It is to be noted that our definition is not necessarily the same as that of other paramedical writers. We make a sharp distinction between tasks requiring sequential movement, as in drawing, and in tasks requiring the positioning of a single object.

In medical definitions, the ability to learn a skill is a function that would not be expected to be similar to that occurring in the retention of a skill that has been learnt. We would rather speak of a child with a motor planning problem than of a 'dyspraxic child' - the first does not imply any known aetiology, the second may. Within a psychological framework, what we call 'motor planning' would be most likely to be termed visuo-motor skill, and thought to be measured by means of drawing tests. Drawing tests do, however, occur in batteries designed to measure a wide range of features, for example, visual perception, intelligence, motoric efficiency, cognitive style and personality.

To measure visuo-motor skill per se, we would need to control our data statistically at least for age, intelligence and visual and motoric efficiency, and possibly for other variables as well. All we can say is that some children appear to be markedly and specifically handicapped in this way, although they are old enough to perform well, intelligent enough to perform well, and with enough visual and motoric efficiency to do so. It generally occurs in association with some motor handicap, but twice over many years I have observed it in children with virtually no motor handicap at all.

The difference between tasks requiring sequential movement and the placement of single objects, may or may not, occur in children other than cerebral palsied children. As far as cerebral palsied children are concerned, we simply know in practice that we get better and quicker results in relation to pattern copying

by placing individual pegs, pieces, etc. than by drawing continuous lines, in which most of our children are more or less successful plodders. For the clinical psychologist, it is obvious that any drawing test must be evaluated in terms of the precise age and mental age of the subject. Also, we must realise that a drawing test must, since it has so many strong correlations, tap a great deal of cerebral function. This could possibly explain the frequency of occurrence in the very heterogeneously handicapped cerebral palsied group - but again I do not think we know. It is equally arguable that the cerebral palsied child is in difficulties in motor planning per se because of his quite obvious errors in relation to feedback resulting from his erratic movement.

The motoric element, particularly the motoric feedback, is emphasised. Abercrombie has shown in normal children that a line may be drawn, with the hand hidden from view, which emerges as wrongly planned. The child may realise it is wrong and make a spontaneous correction without having seen the actual line drawn.

Why talk about motor planning? I think an understanding of motor planning is a necessary prerequisite to effective treatment and counselling of cerebral palsied children. First, I think it was grossly underestimated in early work. Initially, in the work of Strauss, with his concept of 'the brain injured child', we notice first that the problems of the cerebral palsied, who are basically motor handicapped, and those of the exogenous mental defective or 'brain injured' child who is not markedly motor handicapped, tended to be equated. The cerebral palsied child was labelled as having problems in interpreting visual information and in visual attention. Defects such as these would severely handicap reasoning ability and, if not true, the label could almost be libellous. Reasoning is, I believe, on the whole one of the most effective of most cerebral palsied children's intellectual skills. The Strauss theory dies hard. Even quite recently a child with a pronounced motor planning problem was tested by a school counsellor not working with cerebral palsied children by means of Frostig's Developmental Test of Visual Perception, a test not far removed from the concept of Strauss. He scored poorly on tests described as eye-motor coordination, figure-ground and position in space, and was classified as a child with visual perceptual problems.

Actually, all these sub-tests demanded drawing skill in the response. This boy read well but could not write. His difficulty could have been neatly bypassed by giving him a typewriter, but this was denied him, because his problems were deemed to be essentially visual perceptual in origin.

Later on, there were tendencies to equate the difficulties of cerebral palsied children with those of adults suffering from Gerstmann's syndrome, presupposing defective functioning in the parietal lobes of the cerebrum and resulting in emphasis being placed on concepts such as defective body image. This was considered to be demonstrable in difficulty-in-drawing-a-man tests, or in dressing oneself. Again, up to six years of age, 'drawing a man' has been shown to be prominently a drawing task. Also, the problem in dressing oneself is not in knowing where you are, but where the garment is. Putting it on requires a sequence of vision coordinated movements.

Motor planning appears to us to demand emphasis. It is the feature most prominently amiss in cerebral palsied children. Day to day work on our perceptual training programme has indicated that, as measured by skill in drawing, its incidence is very high, that this is not readily corrected. We have found that, of any ten children attempting our treatment plan, two may be markedly delayed in reaching a four and a half year old level, three more, five in all, markedly delayed in reaching five and a half year old level, and two more, seven in all, in reaching six and a half year old level.

What do we do about it? We work at it with the child in a way that will restore his confidence, not in his motor planning ability, but in himself. We have had children who are so apprehensive about this skill, that they have refused point blank to touch a pencil. It is possible to make them see it as an idiosyncrasy which is not a reflection of their overall ability. We prevent it spreading. Failure tends to encourage failure, and a defect such as this tends to be compounded into a crop of defects over a period of time. It is relatively easy to clear up a number of other defects that tend to be associated with it. We can send to the classroom at five, or mental age five, a child who appreciates the distance, position, and order of objects, and who can set work out in an orderly array on a page, who can analyse details well in pictures, who has no difficulty with figure-ground discrimination or perceptual constancy, and who can match and analyse single shapes effectively. We can generally build up motor planning to a five and half year old level, which implies the ability to draw letter shapes.

Speed of writing is in many cases unlikely ever to approach normal levels, and we encourage the use of a typewriter. How we go about it is described in our training manual. In short, I believe poor motor planning to be a frequently occurring feature in cerebral palsied children, which is significant in relation to school performance and in the general integration of skill and personality. This I emphasise because I think it has been frequently underestimated in the past.'

During the 1960s, at our Mosman School, members increased to 200 and it became apparent that something must be done to ease the situation. We bought a neighbouring residence and that gave us some relief, but I was intent on influencing the Department of Education to provide mobile classrooms on the tennis court of the adjoining property. Unfortunately, the Department's policy was not to build a classroom within five metres of an adjoining boundary, and we had three adjoining boundaries, so that extinguished that building site. We therefore occupied the residence and did the best we could with the available space by using the auditoriums for classrooms, with curtained-off spaces in between classes.

In a previous chapter, I mentioned the long battle of attrition for land usage at Allambie Heights. This involved our State Government and its many departments. The Country Children's Hostel which we had built in 1958, contained barely enough land for the disposal of the drainage problems, and in 1961 Centre Industries demanded room for expansion, and we needed to provide for a school and residential accommodation on our western boundary.

Six years later, our file had grown to enormous proportions, which involved applications in writing and by personal contact with fifty-four separate authorities, each of whom could have provided a negative response to our application. Involved were the Warringah Shire Council, the Manly Municipal Council, the Minister for Local Government, the Minister for Lands and his directors Mr Rowe and Mr Prince, the Minister for Mines Mr Wal Fife, the Chairman of the Land Board, the Chairman of the Cumberland County Council, the State Planning Authority, the Minister for Education Mr E. A. Willis, Mr W. Rose of the Education Department, the Minister for Health, the Secretary of the Metropolitan Water Sewerage and Drainage Board, the local engineer of the Electricity Commission, the engineer in charge of the Mackellar County Council, and last of all Mr G. J. Dusseldorp of Civil & Civic and Lend Lease Companies, who at that time was interested in the public appeals committee of The Spastic Centre.

When we started the campaign, we wanted to ensure that in the future we would have land available for our long-term development. Despite the progress of The Centre based at that time in Mosman, that site was built out, and we could not achieve what we needed to do in the future years without further grants of land at Allambie.

We already had a grant of land on which was the Country Children's Hostel and the first stage of our Centre Industries building. We needed to get our hands on the vacant shale and clay quarry before the developers stole a march on us. This was vital because it provided an internal wheelchair pathway to the projected school, to our Adult Hostels, the Mothers and Babies Unit, and other housing accommodation which we hoped to erect on that land.

Over the years, we made successive applications for Crown land, as the shale mining deposits were exhausted. First of all we concentrated on the disposal trenches for our four septic tanks and later, as Centre Industries expanded over ten years, we needed more room to meet those building extensions. We increased our holding to almost five hectares. Then we had set our hearts on a major development on a ten hectare block adjoining our western boundary.

The Warringah Shire Council wanted to use the quarry as a garbage disposal area, and had already drawn up plans for its subsequent use as playing fields. Finally, when the battle had seemed to be won, I discovered that the Health Department was intent on putting up a hospital for intellectually retarded children, to be moved from another location to this area. We were sympathetic about retarded children. As a matter of fact their parent organisation was built on our success, but we were tied to our location by the Country Children's Hostel and Centre Industries and our school. Other Crown land areas could accommodate plans for a sports area and satisfy the claims of other equally deserving charities who did not have our problem of being tied to one location.

It was recognised that provision of water and sewerage services was a problem, but we operated our Country Children's Hostel for ten years, pumping water through our own pipelines and storage tanks, and had to wait eighteen years before sewerage was connected. This was at a cost to The Spastic Centre of \$110,000 which we are still paying off in 1984.

Mr Dusseldorp finally broke the log jam when he said to the Minister for Lands, "You should really make up your mind about The Spastic Centre's application, and if you have any doubts about its feasibility I will place one of my senior executives at your disposal, to provide you with an unbiased report from which you can make a decision". Mr Dusseldorp gave us Mr Ian Foxall, who investigated all the submissions and then set a timetable by which the Department of Mines would surrender their site in our favour, when the progressive mining operations were nearing completion.

By 1968 the number of claimants seeking their share of this land was multiplying and we had to look forward to the prospect of defeat. I prepared a printed brochure of the claims with the assistance of Mr Dusseldorp's planning experts, on the use which we would make of ten hectares of land immediately to the west of our boundary. For good measure, I added another ten hectares of land below the southern boundary pipeline for projected expansion over the next twenty years.

In my letter to the Minister for Lands, Mr Lewis, I said:

'I am enclosing a copy of a more detailed submission in support of the letters previously forwarded to you requesting a grant of adjoining land at Allambie Heights. We are seriously concerned that the decisions which appear imminent, do not take into full consideration the problems which tie us to this site.

It is not possible for us to move Centre Industries, and it is not possible to operate it successfully without adequate provision for hostels on adjoining land.

We cannot agree that the demands for playing areas justify its retention in competition with people whose whole future is at stake, nor can we agree that the allocation of available areas to the ten claimant charities, however worthy, is justified if it jeopardises our whole future operation.

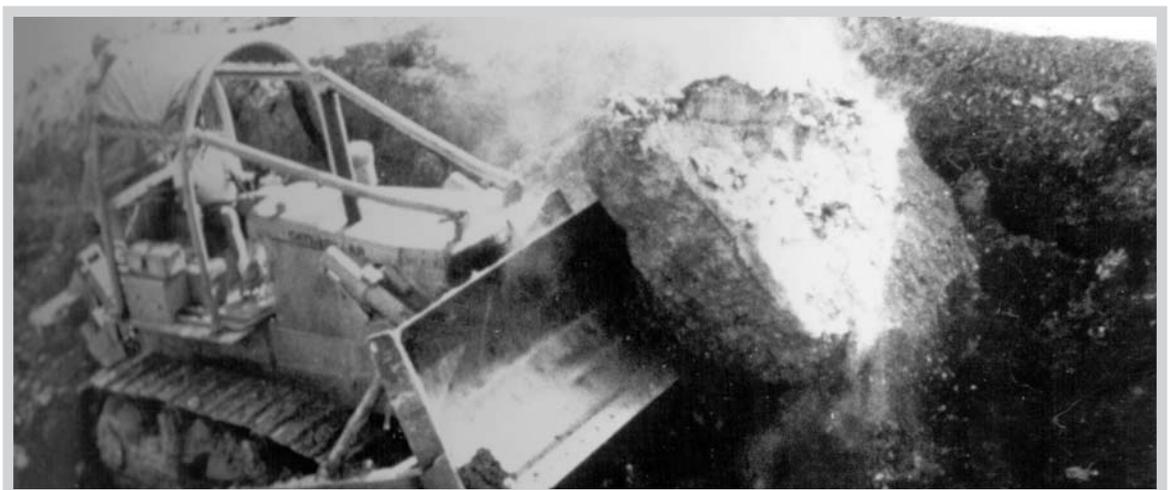
In view of the impact of your decision upon the lives of so many country families, may we request that you make a personal visit to Centre Industries before making your final decision.'



Les Smith (right). A long term employee of The Spastic Centre of N.S.W.



Difficulties of building the Allambie School and Medical Centre on the site of a disused quarry. The foundations needed to be supported on piers on solid rock.



A letter to the Premier, Mr Askin, on similar lines stated:

'The following is a brief summary of the position: Centre Industries has proved to be outstandingly successful in the work training the very heavily handicapped cerebral palsied.

Apart from the large number of country spastics, hostel accommodation is also needed for those spastics residing in the metropolitan area whose parents, with advancing age, allied with physical illness, can no longer care for them because of their increasing weight when bathing and lifting them.

By June 1969, we plan to increase the numbers of heavily handicapped at Centre Industries to 350 people, and to do this require hostel living accommodation on adjacent land.

We cannot move adult workers in wheelchairs by bus, but equipping them with electrically controlled chairs can enable them to travel independently from hostel to work on internal pathways. They could not manage public roadways.

Our application for additional land for the purpose of building hostels has run into serious competition from the local Municipal Councils who want playing areas, from ten other charities whom the Minister for Lands is considering accommodating on the area, and also from the Department of Public Health for space for a retarded children's hospital.

We are tied to the site by our large investment and by the success of our efforts - we cannot operate without the hostels on adjoining land, and our hopes for this are rapidly fading. This leaves the future of The Spastic Centre, and its charges, in serious jeopardy.'

In the meantime, the sports complex which the Warringah Shire Council had planned on this particular site was moved across the valley, to assist us; the Manly-Warringah Parks & Reserves Committee had interests in the memorial reserves but, after hearing our case, supported it. Mr Wal Fife, when Assistant to the Education Minister, and now the Minister of Mining, approved the building of the first school for spastics to be erected by the Department of Education. Booths Industries, which held the lease for clay mining, carefully adjusted their excavations to our needs. We were grateful for all these considerations, and also to Mr Dusseldorp of Civil & Civic, who convinced the Minister of Lands of the total feasibility of our project, and to the Honourable A. H. Jago, Minister for Health, because he over-rode the Government planners who had allocated our land to his Department - in spite of his own needs, Mr Jago unselfishly stepped aside, and relinquished the land in our favour.

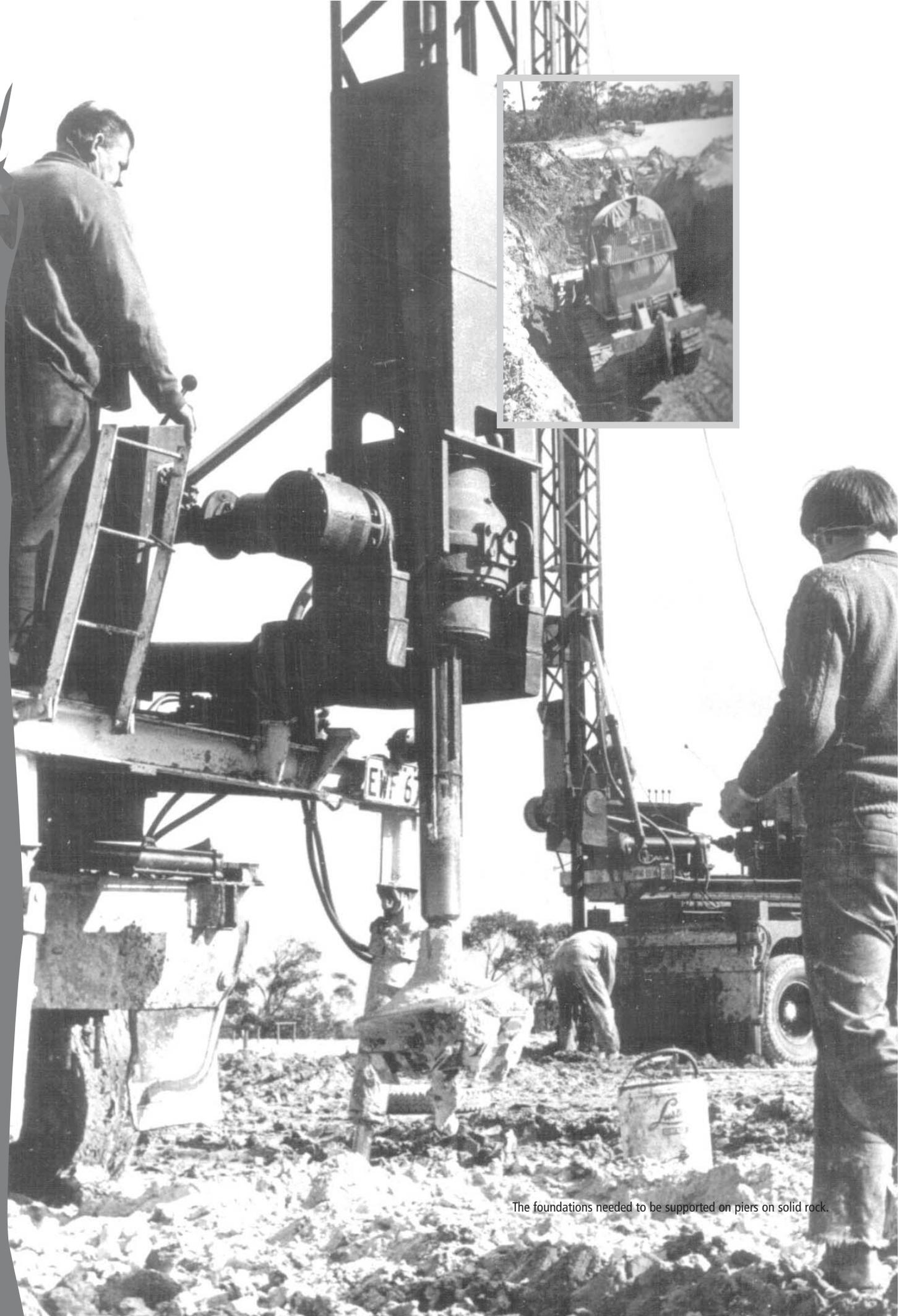
On 2 June 1969, we received a grant of seven hectares of Crown land. Mr Askin advised us as follows:

'As you are aware, there were competing interests for the land in question and unfortunately determination of The Centre's application has taken a little longer than originally expected. However, I understand that you were kept informed on the consideration being given to the matter and that recently you received advice from the Department of Lands concerning the allocation to The Spastic Centre of an area of about seven hectares to the west of your present land.

I was also in touch with my colleague, the Acting Minister for Local Government, regarding the matter. Mr Jago indicated that following consideration of a report by the State Planning Authority, he decided to suspend the provisions of the Warringah Planning Scheme under Section 342Y of the Local Government Act, 1919, in respect of an area of land to the west of The Centre's property at Allambie Heights. He also decided to make an interim development order providing that interim development may be carried out, with the consent of the Warringah Shire Council, for specific purposes. A notice giving effect to the Minister's decision as published in the New South Wales Government Gazette on 9 May 1969 is enclosed for your information.'

It was a closely run victory.

At that time the Government brought in the Handicapped Children's Assistance Scheme, but this did not do anything for us because our school was at Mosman, 9 km away from the hostels and Centre Industries at Allambie. This was an arbitrary decision of the Social Services Department's, and when our school was established at Allambie, one hundred children who were transferred from Mosman became eligible for subsidy whilst their classmates at Mosman continued to be ineligible. My understanding of the regulation was in the meaning of the word 'adjacent'. The ruling was given that 'adjacent' means not over 5 km. Bureaucracy at its worst!



The foundations needed to be supported on piers on solid rock.

Our planning on the school had gone ahead on the assumption that a ten classroom school was needed, with all the facilities and with the addition of a medical treatment service throughout the school. The combined building was done by tenders called by the Public Works Department, acting upon our architect's instructions. Due to the Education Department policy, we had to revoke 1.2 hectares of our hard won victory to the school, but we were more interested in the school itself than in the land rights. The school was built by the Education Department and The Spastic Centre from a budget allocation determined on the usage for a normal school. The Spastic Centre was to be responsible for the inclusion of medical direction and therapy, with the mothers working in the preparation and serving of daily lunches, and toileting.

I was pleased with the Education Department's approval of the Allambie School, so I did not question the Department's policy. Had I done so, I could have pointed out that for thirty years the Department had been occupying a Departmental school for 200 pupils at Mosman, that we had erected the building on land that The Spastic Centre owned, and the Department did not share the costs, or even the cleaning of the classrooms.

The access road was to be used for the school and for future expansion to Benjafield House and similar residential housing.

We had planned this school on the assumption that it was to function with a very close association between medical treatment and education, giving the medical therapy in the appropriate classroom, as was done at Mosman. This meant that we assumed nominally, one-third of the building cost and the Education Department nominally, two-thirds. The location of classrooms remained completely flexible, and the allocation of space was equally flexible. In other words, once the allocation of the building cost was agreed to, the use which we made of the premises in terms of traffic remained flexible according to a compromise between the Medical Director and the School Principal, and was subject to change according to circumstances.

The contract was fully agreed between the Minister for Education and Science and The Centre Board. We assumed two-thirds of the cost of extending the auditorium beyond the area that the Department had specified, because we wanted to use it for The Spastic Centre's business after school hours. The access road was to the Department's cost, because it was ruled necessary for the school, despite the fact that we would want to use it in the future for access to residential accommodation.

The Allambie School, at a cost of \$620,000 (being in fact a medical treatment centre and school) was the start of a much larger and more important venture. This was to include provision for the residential care, treatment and employment of cerebral palsied people of all ages, from babies a few weeks old to adults working at Centre Industries. We planned to service people from the country and those living in the city, young married couples too heavily handicapped to live outside, and babies from our early treatment programme.

The W. C. Allen Treatment Unit, opened by the Hon. A. H. Jago, Minister for Health, and Mr E. A. Willis, M.L.A., Minister for Education, was based upon the model which had proved so successful in the past, because the teaching staff were professionals and education was their business - just as ours was medical therapy and the cerebral palsied children. The design of the building made it easier for the teaching staff to seek the assistance of the therapy staff and vice versa. More and more they operated from the need of the child, rather than two entirely separate fields of endeavour and responsibility.

It is built to accommodate one hundred pre-school and school children in addition to the two hundred who attend the Mosman Centre daily, and Mr Jago stressed the new emphasis on the early treatment of the newborn when he disclosed that forty-two young country infants were already under treatment in the new Centre. The first two to three years of early training of the very young infant, he stated, are probably more productive for improved muscular function than the next twenty to thirty years of the most intensive therapy.

Mrs Neil McLeod, who has worked as Honorary Superintendent since the foundation of The Centre, recalled the 'dream' which she and every other mother has for her child. "This building", she said, "is another dream, but it is only part of the 'big dream' which only now is offering a promise of the future to the newly born baby, the pre-schooler, the schoolchild and the young adult who at Centre Industries is showing that he can compete with the able bodied worker on a basis of equality. But", Mrs McLeod added, "it takes money to turn a dream into reality and ensuring that the dream still exists for spastic babies who will not be born for ten or twenty years."

The Department of Social Services had already supported the hard work that lay behind the dream to the extent of over one million dollars, said Mr F. S. Nixon, Senior Assistant Director of Welfare Services, representing Mr W. C. Wentworth, who was absent from the state. Mr Nixon said that he had watched the progress of Social Welfare from the first five shillings a week payments for child endowment to the present level, and Mr Wentworth's interest and concern for children would find expression in continued and expanding benefits in the future.

Our architects, Mr W. Bell and his son Raymond, did us proud in the design area, and we were assisted by the head of the

Department of Public Works and the Government Architect, who quite rightly insisted upon six or seven alternative plans. From them all, we got a special school with natural sunlight, and ready access to the outdoors from every classroom. Three of the classrooms were wired with under-the-floor loops for the hard of hearing, and special attention was paid to the physiotherapy room for the Mothers and Babies Programme.

We were assisted financially in our part of the building by the generosity of Mr 'Bill' Allen, after whom the W. C. Allen Treatment and Training Centre is named.

The separate heated swimming pool, which we added in 1982 through the Captain Patrick Estate, provides the school and adult cerebral palsied with supervised recreation and therapy.

I look forward to the time when the vocational future of all handicapped CP students does not rest upon a hit or miss decision, to be made only after they have progressed as far as the available educational system has carried them. Education systems should be upgraded in all levels, to enable an informed target to be provided on each individual CP vocational future.

Pre-vocational training should be available at the schools by exposure to the world of work from the age of twelve to fourteen years, preferably by means of regular sessions within the schools. From the ages of fourteen to sixteen years, these sessions should be upgraded by factory and commercial visits and talks by employer groups. This is to be followed by the introduction of individual project studies, designed to make the student familiar with the real world of work, from which he will later make his choice of a career. No attempt should be made to specialise, but this period offers an invaluable opportunity for detailed functional assessments, which will crossmatch residual physical abilities, rather than disabilities, with the minimum standards of various job requirements.

At present the CP workers will enter employment behind their able-bodied competitors in maturation and education. They need all the head start that an earlier degree of specialisation, in pre-vocational assessment, evaluation, and training will give them.



Our projected school and medical unit at Blacktown was a disaster, culminating in an 'Education Draft Assessment Specification'. We could not agree with this, because it took us back to where we started nearly thirty years before, in 1945.

Following the planning of the Allambie school, we confirmed an application for reservation of land in the Blacktown area for future development. This would enable us to build a school and medical treatment unit, together with residential hostels and other facilities. Our plans called for an area of four hectares.

In 1973, the Education Department wrote to us, expressing the view that they would now be in a position where they could go ahead with the erection of a Blacktown school without cost to us, on the assumption that the school would be used by us and the Crippled Children's Society, and would be within easy reach of normal children's classrooms so that there could be an interchange of visits between handicapped and non-handicapped classes. No discussion took place as to whether the CP children would be included in the same classes as other diagnostic groups, and there was no discussion on questions such as responsibility for transport, provision of therapists, and medical supervision.

We received a formal notification from the Secretary of the Department that the Education Department agreed in principle with the proposal of a school for Blacktown. It would be done by the Education Department, and the Department of Public Works would consult with The Spastic Centre of New South Wales and the New South Wales Crippled Children's Society concerning building design and facilities.

Plans went ahead throughout 1974 and 1975, until 1977, when the Children in Institutions Educational Conference presented us with a 'Blacktown School for the Physically Handicapped Educational Specification'. A sixty-page report, but it boiled down to the fact that this was a school at which the CP child would take his place in the classroom among a very wide range of other handicapped children, particularly among the following: muscular dystrophy, spina bifida, skeletal deformities (eleven in number), disabilities following accidents and burns, brain damage in connection with road accidents, hemiplegia, quadriplegia as a result of accidents, emotional development, cardiac conditions, asthma, hemophilia, epilepsy, congenital bowel problems, and others. This specification was introduced as follows: 'Even with the area of physical handicap, there is a wide range and variety of disabilities. Major research, particularly in Europe and in England, shows that all types can be adequately handled in a single complex ...' a conclusion which we challenged.

Mr Willis, as Minister for Education, welcomed a grant of \$10.8 million to help the State's handicapped children. This would be \$7 million to provide additional facilities for education for handicapped children and to upgrade existing facilities. There would be, Mr Willis said, a grant that would enable the recruitment of additional staff, including 130 classroom teachers, and there would also be an increase in general auxiliary staff, expert consultants and social workers. The discussions went on until October 1978, when we realised that The Spastic Centre could no longer be concerned with the projected Blacktown handicapped school.

We believed that the success of the Mosman school demonstrated what can be done by CP pupils, and we would not go back to a multi-handicapped school in the complete absence of any factual basis. The Department had modelled many strategies in their brief on both medical and educational assumptions that are contradicted by internationally recognised medical and paramedical personnel, psychologists and educationists. Our decision to withdraw from the project was primarily because most of our children lack intelligible speech and would be swamped by the other pupils who did not have this handicap. Our cerebral palsied children and adults currently maintain a level of purpose in education, and social and vocational growth as a direct result of the specific and specialised treatment and training programmes provided at our Centre. We are unwilling to forego the systems that have been instrumental in attaining these developments.

This is especially so since a wide range of disabilities will be catered for in the proposed school. If this is the case, then may we ask — "What hope will there be for the yet unborn, cerebral palsied child of tomorrow?"



The completed school for 100 cerebral palsied children and the W. C. Allen medical treatment unit.

Children at the newly built school at Croudace Bay, Newcastle in 1983 - built after 10 years procrastination.



Surveying the land at Croudace Bay. Cliff Morrow, Jack Cotterill, Ron Keers, Phil Roberts.

Part Four

The Solution - Adults

At the 6th Medical and Educational Conference of the Australian Cerebral Palsied Association, held at Sydney on 21 October 1961, the opening address was made by Professor Charles R. B. Blackburn, Professor of Medicine, University of Sydney.

He said, 'Professionally I thought along these lines — habilitation or rehabilitation of the individual child — the means used to determine the needs so that the ends achieved must be foreseen. The ultimate integration of the individual child depends upon the total capacity of the brain to respond and upon the people helping ... The manner must therefore be based on an early accurate assessment of the individual. Therefore, early accurate assessment is the key to successful habilitation and integration of the patient, though it can be very, very difficult. Now, on that very great day when the child integrates the elements of awareness into the concept of its own individuality, it is on the threshold of the greatest problem that confronts mankind. It is not only a question of the individual acting in relation to other individualities ... it says, What am I doing? What have I done? What shall I do? and this in relation to other individualities with which I can come in contact. We have integrated our deliberative actions into a scheme of contact appropriate to the ego in relation to other egos. Cogito ergo sum — I think, therefore I am.

A puppy has an appeal to practically everyone, though the pup grown into a dog may evoke the opposite feelings. A dog can be taught to beg for tidbits, and this pleases the teacher. I do not think that the husky has any real appreciation of the dignity of labour. We are habilitating the human organism, so we may be able to say cogito ergo sum, not teaching dogs tricks. We must keep emotionalism out and aim at integrating the person: the thinking, aware personality.'

Remember "Pygmalion", "My Fair Lady"? Eliza Doolittle cries in anguish — 'What is to become of me?' What is to become of me; not what shall I do. She is aware of what has happened — Eliza has disintegrated in part into a strange environment not her own, and she has nothing to lean on; she is stripped of her protection, which has been replaced by a thin veneer of culture.

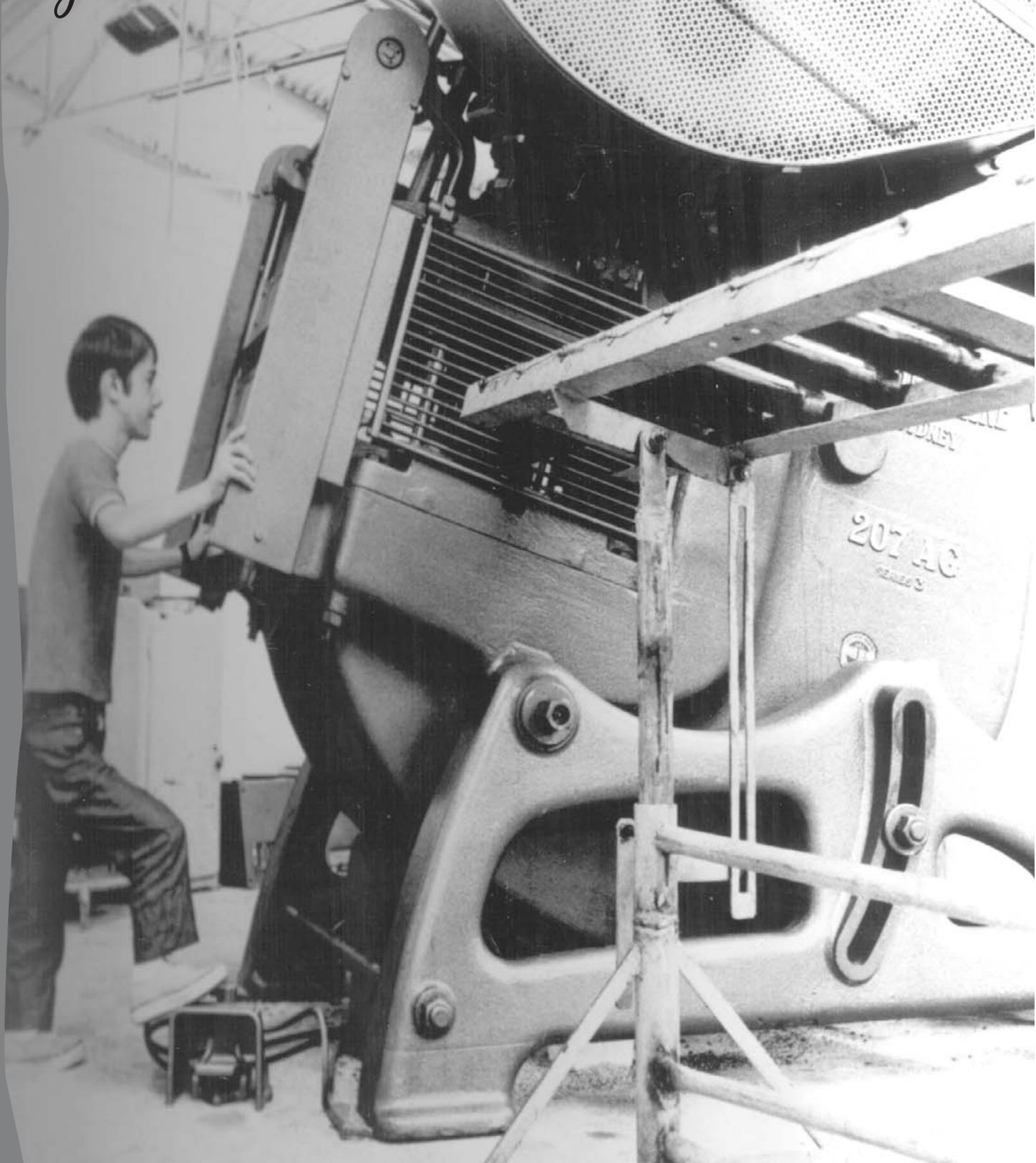
Our rehabilitated children might think like Eliza Doolittle. Not today, not next week, but in 1970 or in 1990. Can the question, What is to become of me? be answered when we have gone, when the therapists and parents have gone. There must be an answer to this question provided the doctor himself says, 'What am I doing? What should I have done? What shall I do?'

What happens with spastic children after they become adults? I am sure you know, but I have asked people around the hospitals and they did not know. We cannot leave the story like Shaw did in his original play without an ending, and must follow the musical playwright and ensure a happy ending, or else we are just becoming meddlesome — we are teaching tricks.

An integrated individual properly adjusted to his environment is contented, and this is a positive thing in the person who can say — cogito ergo sum — I think, therefore I am.

Early accurate medical assessment is the key to successful integration of the individual child.

*"The most exciting project
yet... Centre Industries"*



Centre Industries Establishment

1961

When Professor Blackburn prepared the foregoing address, he did not know that we were in the process of answering his question — 'What happens to spastic children after they become adults?'

Centre Industries was established just four weeks earlier, with an establishment of forty adult cerebral palsied and forty-five able bodied workers. Now it has grown to two hundred and ninety CP employees and three hundred able bodied workers. So our rehabilitated spastic child can no longer echo Eliza Doolittle's plea — 'What is to become of me?' — in the years ahead.

In considering a plan for the rehabilitation of disabled people, it is necessary to question the concepts upon which this work is based. Some of these concepts are built on attitudes, long since abandoned in other fields of social activity. Some are the end result of ad hoc compromises made over the years, then crystallised into widely varying policies which, because they exist, are accepted — but little understood. A great deal is expended on rehabilitation in the public relations field in all countries, but it is doubtful whether the results have justified the effort, or the cost. Perhaps we have been wasting our energies in the wrong direction. Let us dispose of the shibboleths and rethink the real issues.

First, what is a disabled person? How do we define somebody who is 'severely' handicapped? How severe? Where is the dividing line? All experts in the field draw the line in a different place and for different reasons, most of which are concerned with decisions for admission to a training programme or a disabled person's pension. For example, in Australian legislation a person may receive an 'invalid' pension provided he has less than the specified income and if he can be certified as 85 per cent permanently incapacitated. Obviously, if a person is permanently incapacitated he cannot be capacitated. Secondly, how is the 85 per cent assessed? Nobody knows how, except that some person has made a subjective and probably questionable judgement.

Engineers have been left out of the general field of rehabilitation which is strange, because professionally they have been taught to understand and to measure work. A major part of their life is in work training and there is no difference except in the time-scale in training unskilled able bodied workers and training unskilled workers who are everything but able bodied. It is the same learning process, superimposing a newly learned skill over a lower functional ability.

For the disabled worker, the degree of previous dysfunction is unimportant to his success. What is important is the learned skill which can be utilised by the engineer by machine modification as required. Again, it is an engineering process.

When we started in Sydney in 1945, we had no experience and no precedents to guide us in the treatment of the cerebral palsied, but we were confident that by providing door to door transportation, intensive medical therapy and daily schooling, we would achieve our immediate objectives — giving these forgotten children their rightful place in the community.



Fathers' work gang. Preliminary work. Steel mats with a concrete floor and, inevitably, bricks stacking.



Putting the second steel trusses for the roof into position.

The principle of free treatment was established with the corresponding obligation on parents to provide unpaid rostered labour — mothers working two days each week as aides, and fathers two days monthly on building extensions and equipment. This principle still applies, although parents' labour has since been reduced. Forty years later the number of children and adults under treatment has grown to over one thousand, and the improvement in those is self-evident.

To meet the needs of rural families, who could not obtain treatment unless the family moved to the city, we built the Country Children's Hostel for one hundred children, and planned to incorporate in it a small specialised hospital for orthopaedic and neurological work. With the abatement of poliomyelitis and with the advances made in the work done in the orthopaedic field by the great metropolitan hospitals, it became unnecessary to go ahead with the hospital scheme. The hospital wing was subsequently turned into a residential hostel for young adults.

The quality of our schooling, orthopaedic work, and the various therapies had developed to a high standard, when in 1949 we were honoured by a visit from the great Dr Earl R. Carlson. He pricked our complacency somewhat by asking how many cerebral palsied we had in employment, and we had to admit that we had not even got around to thinking of employment at that stage. It was still far below our mental horizon.

During the next ten years, however, it became a question of immediate importance. Our children were growing up and it was now evident that, although many had done so well that they could be transferred to normal schools, we would still have a large number who could never graduate to normal employment without intensive development and training.

With sixteen years of intensive school and medical therapy behind us, we had a group of young heavily handicapped CP still at The Spastic Centre School at Mosman. They were unhappy because they could make no plans for their future. Therapists had done a good job as far as stabilisation of posture was concerned, but the teachers' educational methods were hampered by the CP lack of hand function, and defective speech. In the meantime they were fiddling their lives away with felt dolls and raffia work, and we needed to get them into some form of productive work training.

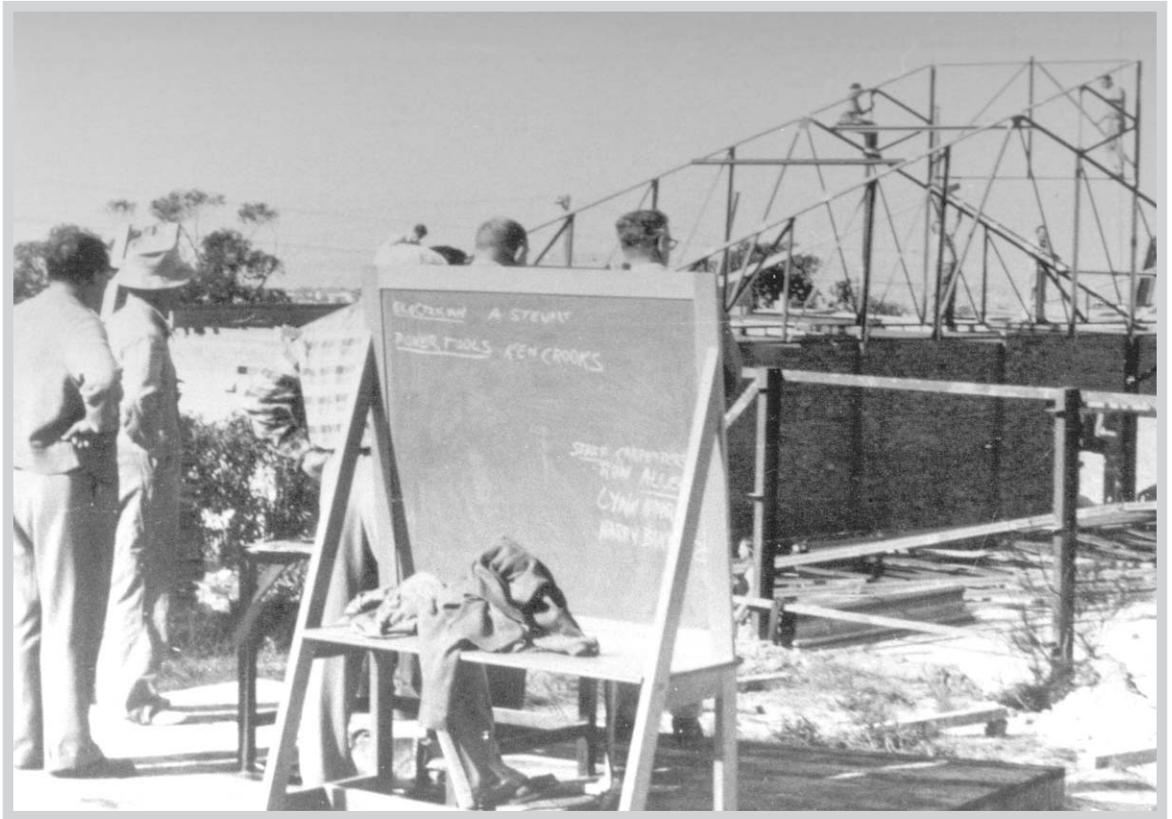
We did some preliminary planning on sheltered workshops on the usual standard lines. We envisaged an organisation that would enable the CP handicapped to engage, after training, in some profitable industry. We envisaged a system in which a CP worker would perform a part of a process, which would enable him to contribute to a finished article on an assembly line.

In 1950, we manufactured the first splints in Australia using clevis engineered ankle, knee and hip joints. As effective orthopaedic bracing for our children was not available in Australia, we had already developed a large, well equipped splint shop, and were planning the production of our own wheelchairs. That was the real start of our workshop.

We planned to erect a building for a workshop at Allambie Heights, adjacent to the Country Children's Hostel. We were perpetually short of funds, so we resorted to our well-tryed use of weekend voluntary labour and donated building materials for our proposed building, which we named Centre Industries. To attract the attention of the public, it was to be a 'barn raising' edifice, to be completed in the one day. I called upon my friend the honorary architect Mr Bob Pollock, with a copy of our plans, and told him of our intention. He had supervised the Mosman School and medical treatment buildings and the Allambie Country Children's Hostel - work spanning up to ten years. So I was not surprised when he called a halt on our projected factory building. He said that he would be pleased to do it for us, but added that his blood pressure could no longer stand the sight of my 350 voluntary labourers swarming over the building site, especially on a Sunday.

This was before the advent of ready mixed concrete, so our preparatory concrete work had to be mixed on the site. Steel frames had been manufactured elsewhere and we carted them to the job, with sheeting for the sides and roof. So all was ready for a Sunday building bee. We had sent out a call to all parents and the Service Clubs, Football Clubs, the Army, Scouts and building workers. Three hundred and fifty of them turned up for the day. The mothers of our CP and their friends made tea in unlimited gallons and sandwiches, cakes and scones. Alcohol was strictly banned on the job, but three 28-gallon kegs were cooling, under wet bags, waiting for the signal that the day's work was over.

The structure was steel framed columns, supported by angle iron trusses, for the saw-tooth roof structure. The trusses were supported by four metre wooden purlins. After the steelwork was erected, our agile footballers swarmed up and lifted the heavy purlins on rope slings at each end. Sometimes a purlin slipped out of the loops holding it and crashed twenty feet onto the concrete below. Fortunately, there were no casualties, with the exception of a rigger who clambered up on top of a steel column four metres high. He crashed on the concrete floor with the column beneath him. My heart was in my mouth as we took him to the Matron of our hostel for first aid treatment, but no bones were broken, and she festooned him with bandages. Before long he was back on the job again, minus his bandages and making light of his injuries.



The one day office. Control was established by microphone and loudspeaker.
Aub Stewart *i/c* electricians; Ken Crookes *i/c* power tools; Ron Allen *i/c* carpenters; Len Thomson *i/c* riggers.



The second span erected.

Here is how a country newspaper reported our 'barn raising' event:

'E DAY, which is Erection Day for The Spastic Centre.

Here on this high and windy hill looking over the sweep off Manly's northern beaches, the first stage of the new project takes shape — an industrial building, that is more than it at first appears. For this building is a monument to the kindness and warm fellow feeling of a group of ordinary people who gathered and laboured without payment to erect it. On a sunny Sunday in May, nearly 350 people swarmed all over the site, and in one day's frenzied activity erected the whole of the major fabric of the 1200 square metre building.

Some have brought their tools — these are tradesmen who have worked throughout the week and are now prepared to forego their Sunday relaxation. Others operate equipment borrowed from their employers and from friends - mobile cranes, welding equipment; power drills, ropes and slings. Some are bosses, now a little rusty from wearing a white shirt and building from an office desk. They are experiencing an unaccustomed satisfaction in working alongside their men again, perhaps even putting on an act, to show that 'the old man' has not forgotten the days when he could work harder, and better, and faster, than anyone else on the job. The majority of these big-hearted voluntary workers are unskilled - accountants, doctors, bank clerks — fathers of handicapped children — as well as riggers, carpenters and steelworkers, all prepared to follow a common lead and 'give it a go'.

All of the steel frame of this building was erected in this one grand morning's work. Roofing and other tradesmen moved in and finally left more than just a factory building. They have built more into this building than they knew — more than just sweat and idle time. They have themselves contributed some of their generous happy-go-lucky friendliness, their ready extension of a helping hand, their cynical refusal to believe good of themselves. More than steel, concrete, bricks and fibro, they built in something of themselves; something of their courage and their generous openheartedness, their disrespect for convention in dress and in behaviour.

For when the lights go on and the building takes on its new life as a busy factory workshop, people who without this help would never find a job, will be taught to earn their first pay envelopes. These are the 'impossibles' — the heavily handicapped cerebral palsied, or spastics, whose multiple handicaps bar them from holding any normal job. They will be trained within these walls to hold a skilled productive job, instead of wasting away on the desert island of a fortnightly invalid's pension. Who wants a pension, if you can earn a living for yourself?

These are people, who previously were destined for a quiet chair in an unobtrusive corner, from which they could watch their life slide by, missing altogether the satisfaction and joy of independence. They are normal happy young people of good intelligence, locked away behind the personal prison of their unruly muscles. They have been educated; they can be taught many skills. Medical care and modern science can prevent deformities previously inevitable, but who will take a risk and employ them without specialised job training?

That is why The Spastic Centre has entered into this, its most exciting project yet — Centre Industries.'

The 'knock off' was signalled by the State Minister for Labour and Industry, Mr J. J. Moloney, M.L.C., blowing upon a borrowed police whistle at 4.45 p.m. and the beer supply lasted until 8.30 p.m.

We did not expect government assistance, nor did we get it. We finished the building on the allotted day, without killing anybody, completing the steel frame, roof, gutters and side walls. This was the first stage of the building; now it is twelve times larger at 14,000 square metres.

Regrettably, another eight years had passed before the first item of Commonwealth legislation was effected in 1968 for subsidised workshops for the handicapped, and twelve years before Commonwealth Government subsidy became a real factor in The Spastic Centre's budget in 1971.

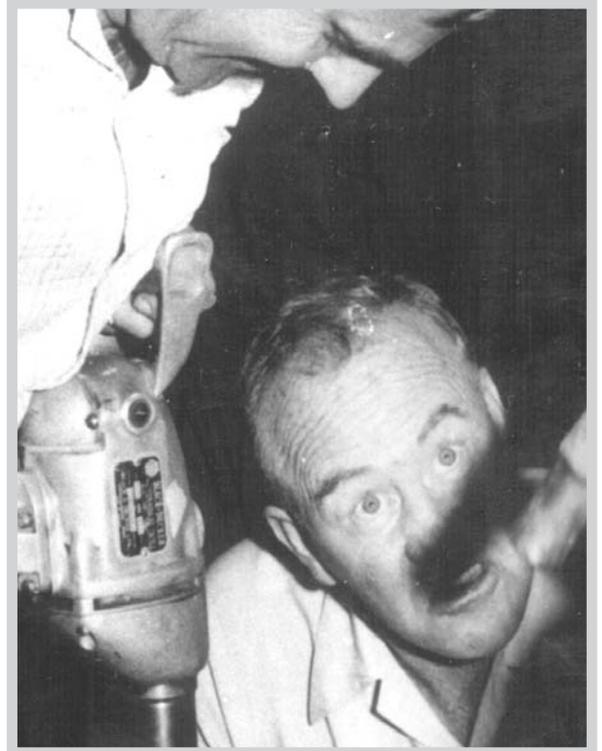
The Governments of all states provided significant funding for their spastic organisations, with the exception of New South Wales. It is not for the want of asking for assistance from this funding source. It is perhaps ironic that we who led the march for medical treatment and education for the cerebral palsied, and helped to establish sister organisations in all other states, should not be recognised financially in our own State.



The fathers were amateur riggers for the day. Dick Temple, Jack Rayward, Sid Ryan and George Taylor.



Bernie Stanton and Dick Temple.



Geoff Strong.

Centre Industries was established as a CP adult training unit for The Spastic Centre of New South Wales. It did not require a separate corporate identity apart from The Spastic Centre. The name was registered under the Business Names Act, but the Board of Directors controlled the whole organisation. As the Chairman of the Board since its inception in 1945, I assumed day by day control of Centre Industries from its commencement, until I retired in 1980.

With the building completed, we looked for a suitable Manager who would assume responsibility of a combined factory and splint workshop. Among the applicants was a young production engineer, Mr Bruce Hume, whose qualifications looked to be too good for our limited requirements. But he explained that he was short on management experience, and I did not think that he would stay the distance. He left us fourteen years later, leaving behind him a unique legacy. As a professional, he was able to combine his undoubted engineering competence with the rehabilitation of CP trainees, to a worthwhile degree. The factory management team included the medical and therapy aspects and engineering services. It was a mix that had never been tried before.

The philosophy of Centre Industries had not been tested in Australia or overseas, because rehabilitation worldwide was wedded to the sheltered workshop approach, and people were horrified at the idea of mixing a labour force of able bodied among a heavily handicapped CP workforce. Added to this, the operation was to be on a strictly commercial basis, aiming for profitability in the area of telecommunications manufacture. It had for its objective, the same measure of efficiency generated by our manufacturing and rehabilitation departments, as in an engineering work situation.

We discussed with Mr Hume our project of combining manufacture of wheelchairs and splints and braces with whatever extraneous work we could arrange on a job production basis. He raised the question of line engineering production work, but we pointed out that as a charity, we did not have access to the finance that would be needed for manufacture and marketing. We did not possess the staff nor the expertise required, in sales or in distribution. Quite rapidly, my negative assumption was proved totally wrong.

In Australia the year 1960 was marked by the end of the postwar economic boom. The oversupply of black and white TV sets and of refrigerators entailed some form of rationalisation to meet the severe financial losses of manufacturers in this industry. Mr Hume had mentioned that Pope Electronic Industries, where he had worked, was shortly closing down and we could pick up the secondhand machinery and obtain the labour quite cheaply. Among the reorganisation of this company structure was a division which manufactured telephone exchange relay sets. This was a project that interested me very much, because it offered secondhand machinery and an ongoing production business with the Australian Post Office (A.P.O.) as the principal customer. (A.P.O. was replaced by Telecom in 1974).

Privately, I thought that, no matter what the price was, it would still be beyond our reach. Urged on by Mr Hume and by Mr Israel (who was a technical expert in the same company), we inspected the plant. Immediately the 'penny dropped' in my mind's eye, and I could see the CP operating each machine on the production line. I left convinced that that was the pattern we should follow in some form or other, because it had everything in its favour — technology, simple machines, equipment and one major customer, the Commonwealth Government's Australian Post Office Telephone Department. I was convinced that we should plan on getting into the light engineering business, with new plant and equipment, should it prove necessary and should the Pope deal fall through. We had no money — as a matter of fact, in 1960 we were forced to make an appeal to the public under the title 'Operation Desperation'.

From our earliest years we had decided against fiscal reserves, put aside 'for a rainy day'. We felt that, for the CP, it was raining now and until our children were fully serviced, it would be our job to get them whatever they needed. On this basis, we first spent our money and then scratched around to find the funds we needed later. I was convinced that we needed the Pope bid for the future of Centre Industries. The fiscal arrangements were a headache, but we could worry about that tomorrow.

We put in our bid immediately with Mr Moore, the N.S.W. Manager of Pope Industries. He said Sir Bertram Pope, his principal, needed to have a decision before the end of that month (September 1961). So that gave us fourteen clear days to develop our strategy. From there, the story ran like a modern takeover saga, but with a David and Goliath touch.

A competitor was in the field. He was Sir Arthur Warner of Electronic Industries, a Melbourne manufacturer. Sir Bertram Pope was in Adelaide, 1300 km away, but time was pressing, so I went to Adelaide to open negotiations directly. On the way back in the plane next day, I glanced idly through the newspaper, and there on the financial page was a paragraph announcing the sale of Pope Electronic Industries in Sydney to Sir Arthur Warner of Electronic Industries. That firmed my decision that we would go ahead in any case.

The labour force of Pope Electronics amounted to fifty people. They had been placed under notice of dismissal on the following Friday. I arranged to offer them a job at Centre Industries, and forty-five accepted the offer. Then we sent them off for a two-week preliminary holiday while we sorted things out. We could not successfully approach the A.P.O. Engineering Branch until we

were able to start production. We could not start production until we had an arrangement to meet a bank loan. We could not have a bank loan until we had a contract of sale, signed by the Director General of the Post Office. The contract of sale depended upon the acceptance of the Public Tender Board. So it was a question of breaking into that circle of impedance.

While our labour force were on their enforced vacation, a subsidiary of Sir Arthur Warner's Electronic Industries was doing a recruiting drive among the dismissed Pope Industries staff. They had found that forty-five of their people gave evasive answers about going up the coast, or their brother needing help in a garage, or something else again. It did not take them long to find out that these people were already on Centre Industries' payroll.

As Pope Industries had taken over the Telephone Exchange 2000 Type Relay Set from the previous manufacturer (Thom and Smith), when they had gone out of business, and because they had taken over the experienced engineering staff, there was no need for effective engineering documentation. All the documentation and the skills were in the engineers' heads. This was an interesting situation, because Sir Bertram had the machines and stock and badly needed the money, but the machines were useless to Sir Arthur Warner unless he could get the experienced labour to man them, and we had the labour under contract to us.

Meanwhile, we had a series of talks in Melbourne with the Director General of the Post Office, Mr Frank O'Grady, and with Mr Evan Sawkins; I was accompanied by Mr Bruce Hume and Mr Bert Israel. They were very interested in our project, and were especially interested in the portfolio of photographs depicting the CP condition of some of our prospective employees. They could not give me an answer immediately, but said that they would not be averse to the entry of a third supplier to keep the others lower in their tendered prices.

The next call was to the Government Tender Board, headed by Mr Tom Skelton and supported by the Treasurer of the A.P.O. He referred to my lack of working capital, and advised me personally that they were very fearful of a charity organisation being involved in the manufacture of telecommunications equipment for the A.P.O. They feared that we could not manufacture according to the terms of the contract, which set price, delivery and quality restrictions. In my reply, I stressed the point that we were determined, as a new business, to fulfil every condition of the order, and I was confident that we would not ask for any latitude that would not be requested from a competitive manufacturer.

My next problem was to see the Commonwealth Bank Manager for New South Wales, to whom I boldly announced that we already had a promise of \$80,000 worth of work under outstanding contracts with the P.M.G. Department. If we had a loan of \$100,000 we could buy the necessary plant. Would he back us? He was interested in the proposal and quizzed us about management and technical expertise. He promised to analyse our submission and expected a favourable response within a few days.

I then had a series of talks with Mr Moore, the Sydney General Manager of Pope Industries. He said The Spastic Centre organisation would always have his support, but, in its own interests, he would most strongly advise against the projected manufacture of the 2000 Type Relay Set. It was a dicey thing anyway, but it demanded more skill and technical expertise than we had to offer. I gave him an evasive answer.

Then, with five days to go, Sir Arthur Warner rang me from Melbourne. He said he had been informed that we had 'locked up' the Pope Electronics labour force, and that we were not in the position to use them for some time, so he offered to take them off our hands until we were ready. I brazened my way out of that by saying that we already had work for them and we wanted them for our own projects. That made him hot under the collar and he said, among other things, that he had never personally wanted the Pope Electronic deal at all, but that was part of the rationalisation scheme which he had worked out with Sir Bertram Pope.

I then said, 'Would you like me to take the Telecommunications Division over from you?' He blustered a bit, saying he could not take that sort of money from a charity. I countered that by describing the rehabilitation aspects that we expected to flow from our entry into the field of telecommunications. I referred to his statement that he was not really interested in Pope Electronics and then I said, 'I have the authority to take your place in this deal for Pope Electronics, under the same conditions, and the same terms of payment, as your contract with Sir Bertram Pope. If you, on your part, have the authority to accept it, we can go ahead immediately'.

By querying his authority to accept anything that he did in the Company of Electronic Industries, I clinched the deal. You can imagine that I wasted no time in going to the Pope Industries General Manager and saying that Sir Arthur Warner had agreed to Centre Industries taking the place of Electronic Industries in their deal with him, under the same conditions and terms of payment. I said, 'We will have a cheque for \$40,000 this day week, and the balance on delivery of the plant, tooling, stores and raw material on valuation, but no goodwill is to be involved'.

That left the A.P.O. to tidy up. So I went down to Melbourne again with Mr Moore, the Manager of Pope Industries, and Mr Hume and Mr Israel. The A.P.O. Director General, Mr Frank O'Grady, Mr Evan Sawkins and Mr Skelton accepted the proposal of the



Centre Industries rear view.



transfer of the undelivered contract, approximately \$80,000, from Pope to Centre Industries, subject to Pope Industries' signature on the contract, which was duly signed that day.

Then I had to get the approval of the Manager of the Commonwealth Bank, the loan at that time having crept up from \$100,000 to \$160,000. In the light of the contracts we already had in hand, the machinery and the inventory, they were well secured. And after listening to a lecture on capital investment and the need for establishing a reserve, I had no compunction in leaving that to the future.

My wife, as the Honorary Superintendent of The Spastic Centre, was attending an international conference on rehabilitation in Vienna. I hurriedly penned a letter off to her giving her the details of the negotiations to date, but by the time I had her reply we had the contract signed and sealed. Fortunately, she was most enthusiastic about the whole project. Throughout these negotiations I had kept the Board fully informed and, when the time came to sign the contract, there was only one negative vote among nine others, and that was on technical legal grounds.

Quite deliberately, we did not involve Dr Burton-Bradley, our Medical Director, in the scheme, because we wanted to be free to take advantage of any gains by way of increased maturity of the adult CP, and their response to the work environment. It was years later before the medical staff and teachers accepted Centre Industries as a place of employment for their cerebral palsied pupils, because in their minds it carried the stigma of working in a factory.

I think that this was my fault, but I was imbued with the idea that a completely new start should be made with the working adults. We did not want them to be cast back into the same mould as older children. We wanted them to grow up and be their age! To use the Mister and Miss classification instead of Tom and Phyllis. We advised them to be responsible for their own medication and finally, we needed to reinforce their morale with the knowledge that they were mature handicapped adults, working for their living and that they were no longer entitled, as children, to hide behind their mothers' skirts. For that reason we opposed the mothers' voluntary labour in Centre Industries. We recruited our own staff of doctor and therapists, not because they were better than those working with the children at Mosman and the Country Children's Hostel, but because they were relatively inexperienced in handling cerebral palsied people, and we wanted to take advantage of the new-found maturity of the adult CP and of the morale engendered by working for a living.

We stressed that this was a workplace. We would keep them, irrespective of their physical capacity, as long as they tried. If they wanted to spread their wings in outside industry, we would give them every support, and if it did not work out there would still be a place for them at Centre Industries.

We could not forecast what our problems of training were likely to be, but were conscious of the fact that if we did not persist in a training schedule (in spite of lack of progress), the CP workers might give up their struggle, and, more importantly, our engineers might be provided with the open-ended alibi, against further rehabilitative effort.

So we broke new ground by challenging the validity of the sheltered workshop approach to the work training and employment of heavily disabled, young adult cerebral palsied.

All in all, that tidied up our saga, and we met the October 1 deadline for our contract with Sir Bertram Pope, and were in full production by 15 October 1961 . . . with the real purpose of our job ahead of us. On 5 December, eighteen CP trainees moved in and a further group of twenty-two were delayed until the following February. Sir Bertram Pope gave us a personal donation of \$10,000 to help us on our way.



Ray Caffrey

Centre Industries Operations

1961

What can we do for the very heavily handicapped cerebral palsied young adults, other than go through the motions of giving them a pseudo-academic training, that leads nowhere, and wait for the years to sap their dreams and desires? By this time, perhaps we too will have grown old enough to rationalise our apathy, to swallow our personal guilt, and to quickly switch the conversation to our marvellous programmes for the mothers and their young babies.

But we can do something for the most heavily physically handicapped. Do not let the assessment people talk you out of it! They can be trained, they are capable of work, they can compete in industry, they are responsible and they can contribute, economically, to their own training costs.

It is fashionable today to decry the dignity of work and to look forward to a bright world of tomorrow, when only footballers, racehorses and computers will be required to work. We, and all of our cerebral palsied, will lie on the grass and enjoy eternal leisure.

However, that day is not yet here! The ability to earn money is still a measure of man's independence. In these circumstances, the disabled cerebral palsied is clearly entitled to work for his economic freedom and he is entitled to compete for his labour against the able bodied applicant. The question of its attainment is related only to training time and effectiveness, but it can, and it is being done here, every day!

In industry, there is no difference in principle in teaching new hand skills to an inexperienced housewife with normal hand function, from teaching a cerebral palsied person with grossly affected hands. The divergence is in greatly extended time, in the provision of intensive, but normal, engineering techniques of work study, ergonomics and discipline. The incentives for both are identical - first, money in the pay packet, and second, the social advantages of being an IN member of a large heterogeneous workforce.

We thought that the brace shop would be the right foundation for the establishment of our sheltered workshop. However, we had some serious misgivings. If our prime objective was to place our cerebral palsied out in industry in future years, a closed sheltered workshop would improve their skills but not their maturation, nor their employability. A jobbing shop by the very nature of its operation had serious weaknesses. It would not provide any effective costing, or efficiency control, and it did not lend itself readily to long term job training, including matching the work abilities of able bodied workers.



A.T.U. Adult Training Unit about 1965



Handpress Line. Ian Russell and Adrian Lynch operating a powerpress in the background.

If cerebral palsied workers were to compete with able bodied workers in outside industry, as we hoped they would, why could not the same principle be applied to our plant? Why should we not eliminate the segregation of our trainees, by the introduction of able bodied workers? If we were able to set up a diversified production line, we would be able to inject our cerebral palsied into particular jobs that were within their scope, as soon as their training had reached the required level of efficiency. This would provide automatic control of productivity, measured against the output of the able bodied workers.

Apart from the entry of electronics, this planned programme has stood the test of twenty years.

The objectives of Centre Industries are as follows:

- To train our adult cerebral palsied in a normal working environment.
- To provide an able bodied workforce which is essential to working normality.
- To make a commercial profit as an essential component of cost control, and therefore efficiency, in manufacture and work training methods.

To carry out our objective we need:

- An up-to-date plant suited to our needs and to that of our customers, engineering structure and supervision.
- Therapy supervision to ensure that the CP training programme is not harmful to health and to provide maintenance therapy.
- The health of the individual remains the responsibility of the local general practitioner, or the nursing home.
- Transport door to door is essential from the home or hostel.

The rehabilitation department provides the services that are needed to effect work training of the CP. The engineers, therapists and other staff members co-operate in training the cerebral palsied in the skills needed for production: Postural changes as required; design of the workbench or machine to meet individual needs; provision of jigs and fixtures, test rigs or supplementary appliances, electric wheelchairs and posture seats in buses; assessment testing - functionally and psychologically; adult education tailored to fit the working needs of the CP. It includes primary, secondary and technical education, including those who, for various reasons, may be considered incapable of working; audio/visual work training procedures; computer data preparation, operation, systems analysis, programming; the design, manufacture and testing of a range of mechanical and electronic equipment designed for the heavily handicapped CP. This represents the future in technology for the assistance of the individual handicaps.

Additionally, we need the services of our Spastic Centre Research Unit:

To be able to quickly transpose their findings on research into servicing our present generation of CP in our schools and in Centre Industries; EMG biofeedback; eye control; speech control; hand function control. In order to provide The Spastic Centre as a whole, the design and manufacturing facility of a range of mechanical, electro-mechanical, or electronic machines applicable for the classroom and therapy needs of the cerebral palsied child and junior adult.

In 1947, The Spastic Centre of New South Wales was legally constituted as a non-profit company limited by guarantees, and exempt from the payment of income tax because of its charitable purpose. In 1961, we established Centre Industries by registering its name under the register of business names, and its organisation was just another division of the parent body, The Spastic Centre of New South Wales.

Since its inception, I was the Chairman and Honorary Treasurer of the Board of Directors of The Spastic Centre, and my wife was the Honorary Superintendent, and, with the advent of Centre Industries, we formed a sub-committee of the Board to act in a management role in the new, and we hoped, profitable venture.

As Managing Director, the management of Centre Industries devolved to me. In 1948, after the war, I rejoined Burroughs Ltd, resigned in 1970, and established my own consultative service, specialising in computer installation in the cane accounting of the sugar industry in Australia and Fiji. Mr Bruce Hume was appointed the General Manager, Mr Bert Israel as Sales Manager, and Mr Jack Blackler, a quadriplegic, was engaged to look after the training and the welfare of the cerebral palsied. My initial idea was for the General Manager to be responsible for the manufacturing and commercial business aspects and for Mr Blackler to be responsible for the CP work training and welfare. It was wrong in concept and did not work out the way it was planned.

There is a need for a great deal of new thinking in the whole field of rehabilitation of the physically handicapped. Most of us are physically handicapped to some degree, at various stages of our working life. If we count those of us on some public occasion,

we will probably find a few potential coronaries, half a dozen ulcers, a few arthritic backs, a hernia or two, some bronchitis or asthma and probably a few others. These are invisible handicaps, which we learn to handle because we have to live with them. Through adaptation, we can learn to handle our workloads, in spite of our difficulties. Why then are we so surprised to find people whose handicaps are more obvious, because they are visible, handling their work problems in the same manner? They deserve no special credit for this. They need to get on with the job, as you do.

In Europe, there is a current attitude that the community should be able to afford to provide for its disabled as passengers, without requiring anything from them. The argument is that their lives are already hard enough, and that everything should be done to meet their needs without contribution. In any case, what can people so heavily disabled do to help themselves?

We believe the opposite to be the case. We believe that the handicapped people in general, and the CP in particular, need employment. Not only because of the income, which gives them independence, but also they need work as a discipline of living. They need the competition of the able bodied, and they need the social atmosphere of the workplace in which they share.

To answer those who say that it is wrong to subject people so badly handicapped as these to the disciplines of work, and that the community should shoulder the burden of their care, we say the community can never shoulder the real core of the rehabilitation of the severely handicapped CP - it is made up of many things apart from money. Independence, discrimination, education, mobility, speech and a self-sufficient lifestyle. Most of all, the patronage and the hurts inflicted by others, on whom they are forced to depend for their physical wellbeing.

A survey by the American Department of Health, Education and Welfare estimates that the cost of bringing a young CP through various therapies surpasses \$100,000. In lifetime institutionalisation, public cost may approach \$750,000 over the person's lifetime. This is a tremendous loss to the State and the Commonwealth of both those economic and human resources.

We are dealing with the work training of the adult CP, and it is important to realise that we are operating in an entirely new dimension which is not merely an extension of the physical treatment and education appertaining to childhood. They are adult, and must be treated as such, despite the tendency to regard them merely as older children.

The adult CP has finished with growth but not with maturation. He is the product of imperfect educational environment when, because of his handicaps, he has missed out on so many things that are important stimuli in his progression towards maturity. The adult CP present different problems in corrective surgery, which now has divergent objectives. In the physical therapies we can measure the results of treatment without being confused by the changing patterns of childhood growth and development. In education, maturation has engendered new objectives and new interests from the stimulation of the adult world. We can capitalise on these new drives by providing incentives that were insufficient for attaining the goals of the school child.

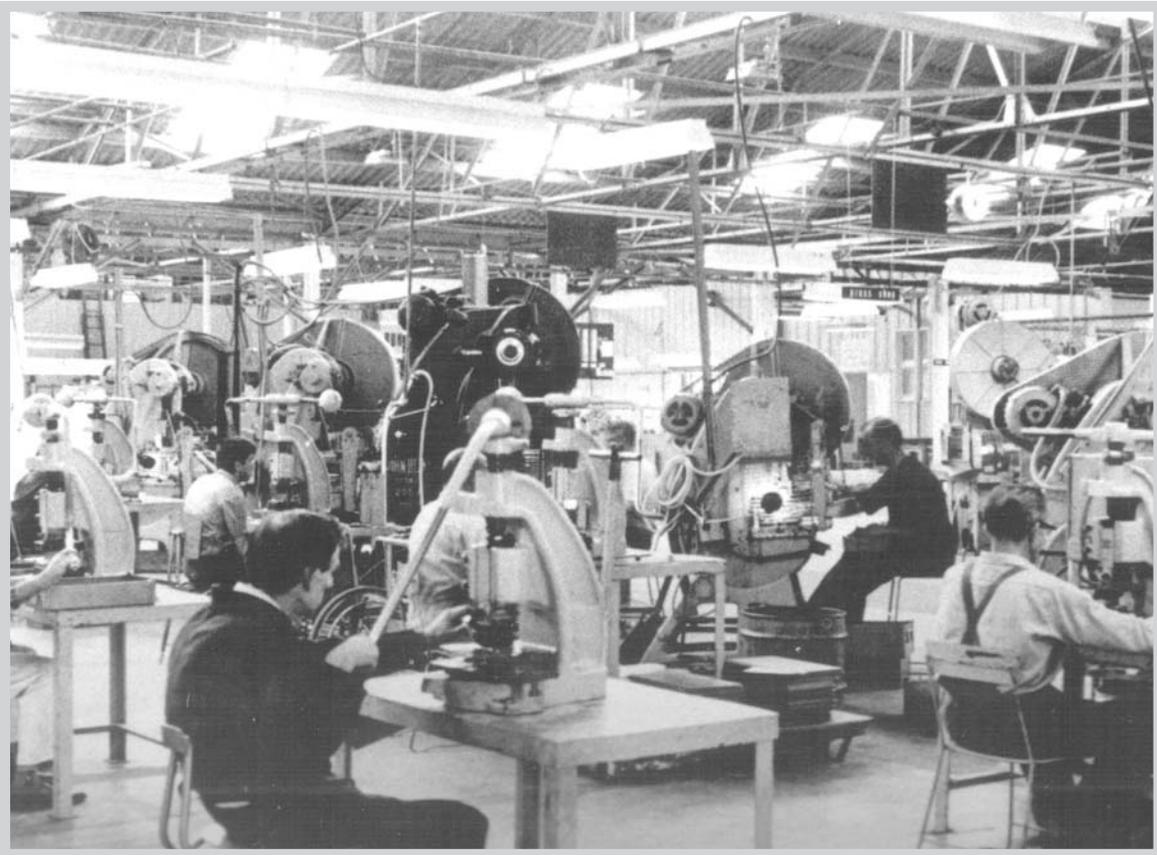
It is easy to wash our hands of their problems of lack of experience in the adult world, by labelling CP, as a group, as 'unrealistic' in their aims and attitudes. We must accept this label as more precisely defining our own lack of understanding of the problem. These young people want to work, and are happy and excited by the demands made upon them. While they have difficulty in matching the output of the able bodied, their physical output is far greater than that of an able bodied worker, because of their increased muscular activity, but they have resources that enable them to meet work tolerance demands. More importantly, they have a stamina and a tenacity that keeps them trying beyond the point at which we might capitulate.

In an extract from an article in the 'International Labour Review' Mr Norman Acton, Secretary General of Rehabilitation International, had this to say on the fundamental values of employment for the disabled people, including the cerebral palsied:

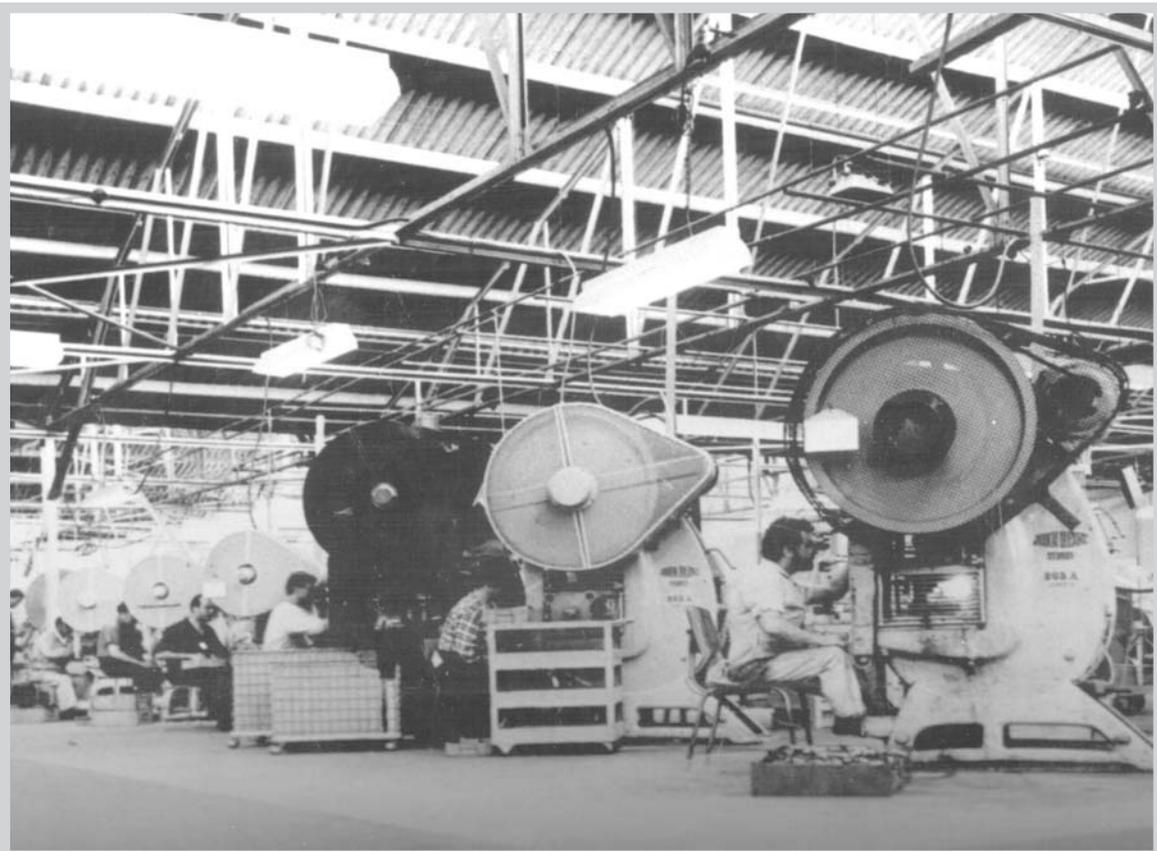
'Why is employment an essential goal for persons with disabilities? In most societies, its importance derives from four interacting economic and psycho-social pressures or needs.

In the first place, most handicapped individuals and their families need the income that can be obtained from gainful employment. The majority of families with disabled members are like the majority of other families in that their economic resources do not permit them to survive without current income. Beyond that, studies in many countries disclose a high correlation between the incidence of disability and of poverty. In addition, the presence of a disabled member in a family increases its basic operating costs. Special equipment, medication, transportation and other services may be required, help may be needed to care for the handicapped member, and many other exceptional items appear in the budgets of such families. Governments can, and some do, help satisfy some of these unusual requirements, but rarely to the extent of eliminating the need for the extra income which the disabled family member could produce.

The second need relates to the value placed by most societies on productive and gainful employment. "Work satisfies fundamental human needs of developing and enriching life", says an official Swedish report.



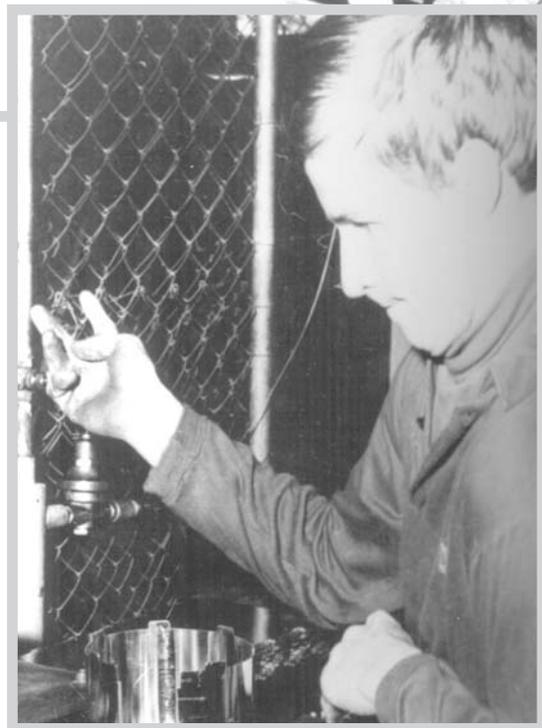
Handpress line



Powerpress line



Coil winding department in 1968. A staff of 32.
Lindsay Dalmon was assistant to the foreman.



Leslie Christian

The Constitution of the Polish People's Republic states in article 19: "Work is the right, duty and a matter of honour of every citizen". Nearly every statement of human objectives in nearly every culture assigns a high value to work as a part of the complete life. Thus when an individual is disabled and, as a result, is not working, he is judged to be failing to meet one of the principal standards of behaviour of his society. He is perceived as being inadequate, incomplete - and he so perceives himself. Productive employment is, therefore, widely regarded as a crucial component in a rehabilitation program. Its attainment usually means that the program has succeeded.

The third element in the importance of vocational rehabilitation is the need to integrate disabled persons in the normal flow of life in their societies. Together with the family and the school, the place of work is an arena in which social relationships are formed, social skills are developed, and social status is confirmed, increased or lost. Without the opportunity of taking part in those processes, a person with a disability is severely hampered in the quest for genuine integration in society.

A fourth value of suitable employment lies in the fact that it gives a regular structure and discipline to living. Studies disclose the depressing effect on all people of day after day passing by without the challenge of tasks to be performed. It is much worse for those who, because of a permanent disability, must look forward to months without being needed and a lifetime of boredom and loneliness. Work is not the only solution, but it is an important one.

From the nature of the needs referred to above, we may draw some tentative conclusions about employment for disabled people and the criteria it should satisfy. To help meet the economic need that usually exists, employment should be gainful. To satisfy the culturally determined work ethic by which most people have been conditioned, the employment should be perceived as being productive and at a level that, in keeping with the individual's capabilities, represents achievement. To help facilitate the social integration of the disabled individual, the job should be in a setting where other people are also working. And, to give some form and discipline to life, the employment should be regular and continuous. As is true of the population at large, there are among people with disabilities those who have only some or even none of the needs enumerated here. For the overwhelming majority, however, life can be improved greatly by effective action to provide employment corresponding to the above criteria.'

We did not know whether people as heavily handicapped as adult CP would want to work or whether they could do a full day's work within normal hours, in addition to travelling time daily. Whether they could be trained to operate machines, or whether their use of a wheelchair precluded them from assembly work at the bench. We did not know whether normal safety measures could preclude entry to metal working machines because of their unsteady gait and athetoid arms and hands. Their muscular spasms, eye involvement, deafness and lack of speech, presented additional training problems. Due to their muscular spasms, cerebral palsied workers have to compete beyond their physical abilities and this is where morale enters the picture, as it does in every avenue of work and sport, when physical demands are made.

We attempted to equalise the CP disadvantages at the work bench, by application of normal engineering practice, which enables the trainee, no matter how severely physically handicapped, to enjoy the same rights and privileges as his able bodied peers. This includes his right to maintain the dignity, and independence, which we cannot win for him, no matter how much we may wish otherwise, but which he must achieve by his own efforts. We reject the concept that a heavy physical handicap automatically absolves a person from all responsibility to contribute to the community he shares. It must be emphasised that the physical loss of function is not the most important loss; the loss of self-esteem is intrinsic to dependence, and is correlated with the patronage of family and society. These are the real disabilities and they generate the greater hurts. They can be evaded with a wages pay packet, never with a welfare handout.

The able bodied provide objective standards of productivity, and set normal work and social patterns. Working alongside the able bodied, the disabled trainee can see at first hand, and in proper perspective, the required objectives of production and quality. From the outset, trainees are exposed to a competitive working world in their own plant, and are supported by the provision of rehabilitation and training facilities, at the workbench. Our economic survival is dependent upon our ability to be as efficient as any other industrial undertaking.

A major group of our CP lacked mobility, hand function and speech. That they were highly intelligent added to their frustration, as it did to ours. They could converse with their own families and among their fellow CP, because they had learned to communicate with them by gestures and attenuated speech, but could not speak intelligibly to a stranger. They were dependent



Beverly Read left, operates a screw press.



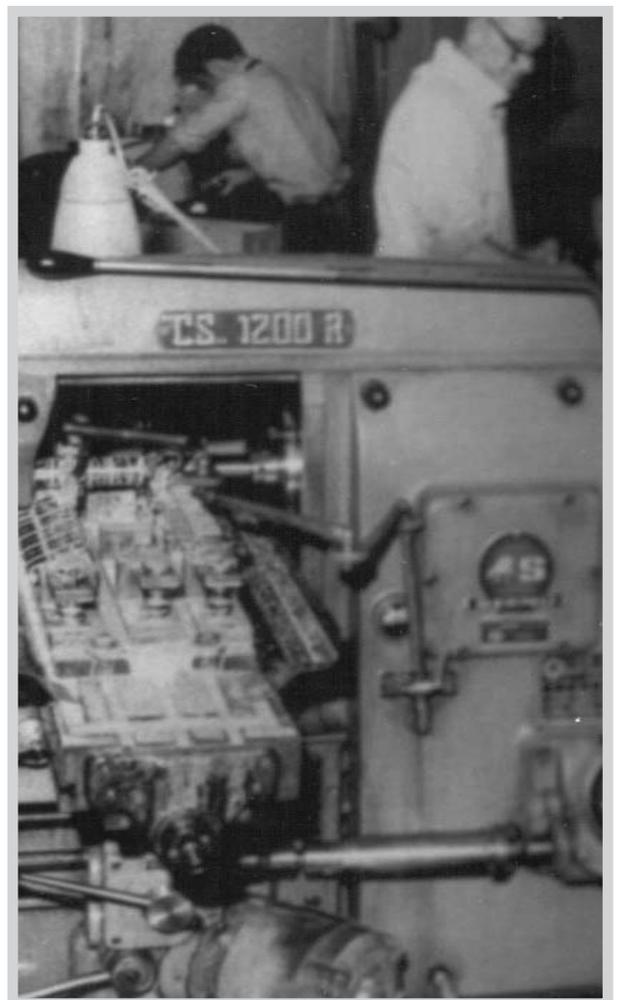
Ian Russell operates the 100 ton powerpress. The component is returned to die by a spike held in his right hand. 85% efficiency.



Ian McKenzie uses his left forearm to feed a strip of leatheroid into a handpress.



Robert Bland has achieved an efficiency rating of 55%



A general view of the tool room.

upon spelling out the alphabet letters on a 'point board'. The alpha-board was operated in a variety of styles, depending on physical ability. The head probe used a mechanical finger, others moved the board under their chins or a fist, some used the movement of their eye or their feet. We were looking for simple mechanical answers. Today, twenty years later, the problem has become relatively simple with electronic controls.

We had an initial group of about twenty CP of the Rh group, and we accepted their deafness as a lack of speech; consequently, our training in auditory perception was limited. We know better now, but those were early days in the treatment and training of the adult CP.

I think that the reader might see an anomaly developing in my insistence that integration is right for the adult CP population of Centre Industries, because it provides a normal working environment. Our adult CP need to provide a social interchange with the able bodied workers and the medical therapy staff.

Why not extend integration to the schools? It could certainly be helpful if the minority in the classrooms could be provided, among their able bodied peers, with specially trained teaching staff, bearing in mind that the CP need a relationship of one to one with the teacher. Equipment too, lags far behind the level required by the CP pupil. The need for intensive therapy during school hours, and the needs of the multi-handicapped for speech, eye control, deafness and hand function, spell out the difference. It should be desirable, but we could not risk turning over to the Department of Education, even though they, at least, are trying to do the job with inadequate facilities. Over the experience in CP education, we have established that the average CP child does not fit in with his classmates in a multi-handicapped classroom, because of his speech deficit which permeates the whole of his special curriculum requirements.

In Centre Industries, the first year was spent in finding our feet. We did not know what the CP trainee could do, what their limits were, or whether there were physical limits at all.

The breakthrough came soon enough. In 1962, Mr Jack Blackler, on a vacation in the country, had a traffic accident when he collided with a kangaroo, and both his paralysed legs were broken. This took some months to heal, because of the absence of muscle tone. Mr Hume was therefore forced into the picture, and he approached it professionally as an engineer. His first question was, "How much longer must we keep those in Centre Industries?" pointing to a group of heavily handicapped CP. I said, instantly and firmly, "You've got them for ever, so you had better get cracking and do something about them". I must confess I did not know what he should do, but he assumed, on the basis of my twenty-five years of experience of cerebral palsy, that I knew all the answers. I did not, but used my Scotch poker face to some effect.

The upshot of this discussion was that Mr Hume demanded an expensive high speed movie camera, for taking, frame by frame, analyses of CP at work. He found, predictably, that the more work he put into his methods development, the bigger the output of the CP, as it would be for the able bodied worker.

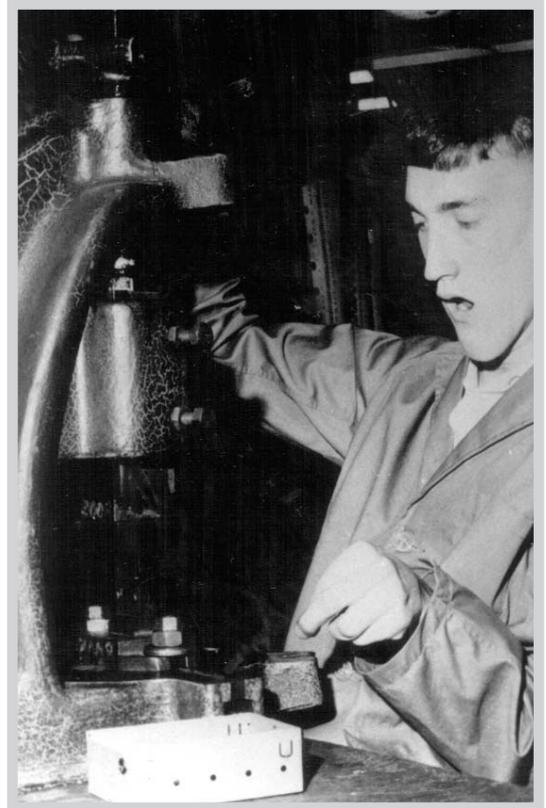
What we were doing was applying the principles of normalisation, as we had learned to do in our school at Mosman. Treating the normal person first, and then finding an answer to the defined problem of the handicap itself. In Centre Industries, it was then a simple question of adjusting the machine controls to the CP trainees' physical capacity.

When we started Centre Industries, it was assumed that people as heavily handicapped as our CP could not respond to training anyway. We knew better - in our classrooms at school, the educational progress of the children was in direct relationship to the hours of work that our doctors, therapists and teachers had given them. I had no doubt that the adult CP would do equally well, given the opportunity to start a new working lifestyle.

Work training was started in the Machine Shop because there we could find an acceptable engineering method around the problems of a lack of hand function. Power presses were operated by a foot pedal and the finished component part was taken away by gravity or by air control. The larger components were removed by the operators' fingers, but the safety fence operated a brake automatically on the press. So a CP worker could safely remove it, taking his own time. Later, following training, and the use of a wheelchair and designed worktable, our CP were successfully integrated into assembly lines in the factory, into the accounting department and into the office.



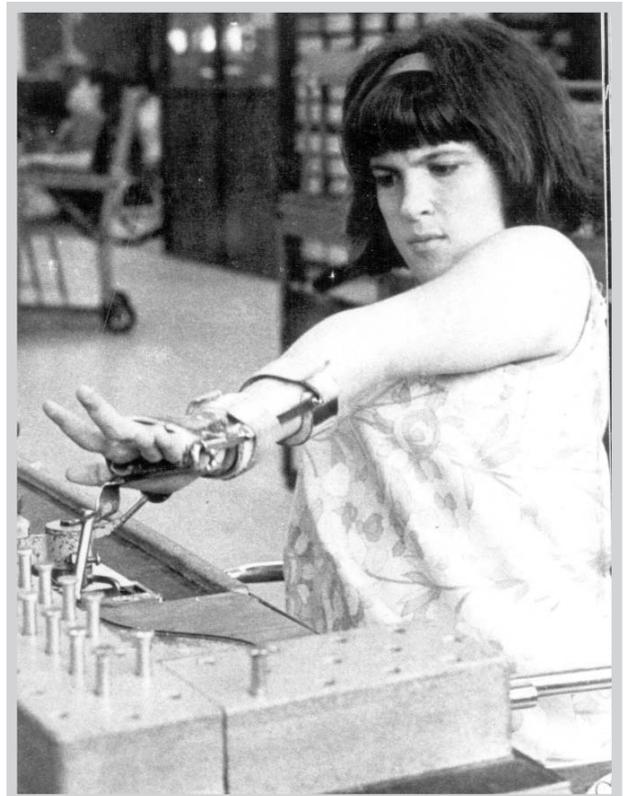
Howard Davidson operates an automatic press. Note that the lever has been extended for his wheelchair operation



Adrian Lynch operates a large handpress which involves control finger movement to place a component in the die.



Danny Hingston operates a semi automatic moulding machine.



Carmella Kirkman assembling a core and cheek in an automatic press. Note that the hand splint provides a fork for the component part.

In 1963, at the Ninth World Congress of the International Society for Rehabilitation of the Disabled at Copenhagen, The Spastic Centre was awarded the regional prize, in the Reader's Digest International Rehabilitation Award, for its establishment of Centre Industries as an industrial work training unit for adult CP.

In presenting the award, together with a cheque for \$500, the President of the Society explained that the award was made for distinguished service in developing and expanding community rehabilitation programmes for the handicapped. The award was open to all societies concerned with the rehabilitation of the disabled. There were 130 entries from all over the world and the Selection Board had a most difficult time in deciding on the winning projects.

In discussing the award, I said that the recognition of their work implied by such an award was of tremendous encouragement to the CP trainees now working in the project. In this field of rehabilitation morale is more important than muscles, money, or even medical treatment. All are essential, but the amount of spirit with which the trainees attack their job is assisted tremendously by any recognition given of their efforts. Due to its comparative isolation from the overseas countries of Europe and America, we in Australia have been forced to develop our own solutions to many of our problems. In the case of Centre Industries, this has evolved as a distinct advantage. It has allowed us to approach the work training of our severely disabled from a new and opposite standpoint of competitive employment, instead of the traditional sheltered workshop approach. The engineering principles we adopted for the training and employment of our disabled are the same as those used in normal industry for the employment of able bodied workers.

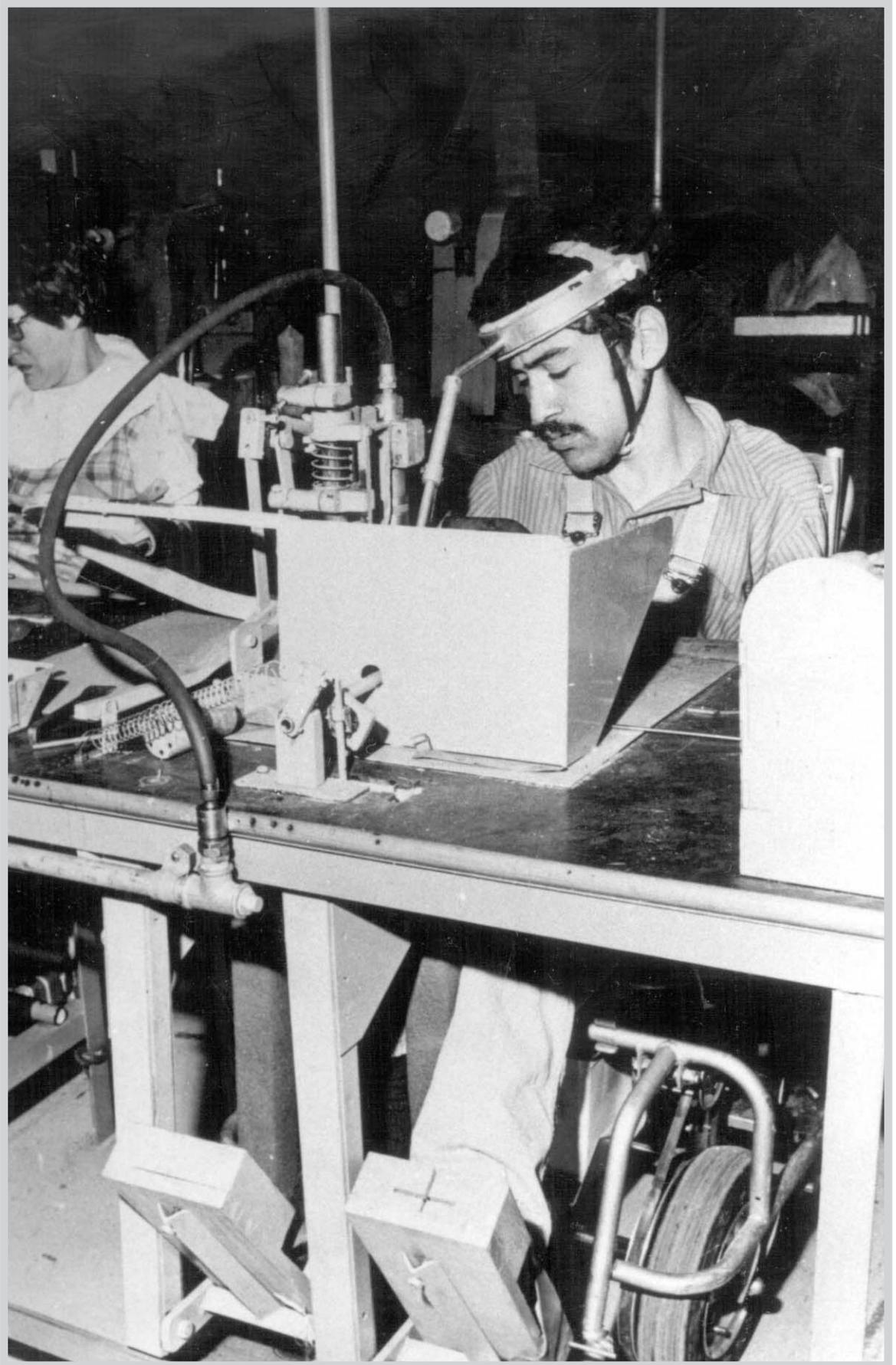
We believe that the sheltered concept does not provide the training nor the reinforcement of morale necessary for the CP handicapped person to successfully compete in the outside unsheltered economy. The sheltered workers are trained in a negative environment, where every allowance is made to their disability, but little training is given in mastering their handicaps. You cannot blame the workers in this environment for believing that they are permanently and hopelessly disabled. Everyone says so. Each handicapped adult needs the reinforcement of a group. If he stands alone, he is vulnerable. It is essential that his chance be not denied him because of the severity of his physical disablement. If we concentrate on what they can do, what they cannot do becomes irrelevant. This is why we have no time limits on the period that we will keep a CP trainee, because we refuse to allow our staff to dispose of what they may regard as an insoluble problem by simply discharging him. We do not believe that there are physical handicaps that are totally beyond the reach of our Job Training Programme.

The severity of the handicap is not the determining factor in the ultimate productivity of the severely disabled person. What is of far greater importance, is the learned skill that can be overlaid, above the initial physical handicaps. The training procedure necessary to attain that skill is a normal problem of Methods Engineering. The Centre Industries engineering design competence is the key factor in the success of its rehabilitation programme.

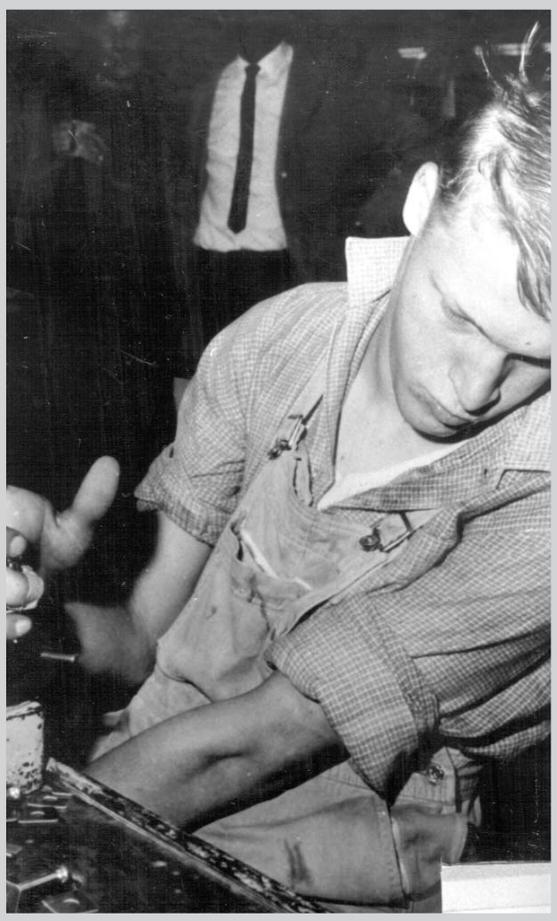
We are not concerned with the elements of rehabilitation per se, and the various processes of assessment, medical therapy, conditioning, guidance, job training, methods study and placement. Sometimes we lose sight of our human objective in the application of scientific method. A disabled person is merely another worker who has an incidental handicap, and we should treat him as such. Only after all the normal rules of dealing with him as an able bodied person have been applied should we delve into that special bag of tricks that we call rehabilitation, and find additional measures needed to make him employable. The goal of Centre Industries is work!

In job training, the therapy that is prescribed by the medical service must be aimed at the physical target of the moment. The objective is to operate a lever in a certain position, through an ascertained range of movement, against a specified resistance. This calls for correlation between therapist, design engineer and the training staff. Carrying out this purpose effectively requires the setting up of an efficient manufacturing complex, equipped to an engineering level that enables it to compete successfully with open industry in engineering standards, efficiency, quality, price and delivery. The able bodied worker is essential to the eventual rehabilitation of the cerebral palsied worker, because he offers a normal working environment and freedom to compete. In our industry, we will probably have an equal ratio of cerebral palsied workers and able bodied workers.

The very heavily disabled can be trained to work effectively in spite of the severity of their handicap, but this is an engineering, not a medical problem. To bring real work and associated profitability into our rehabilitation, the able bodied worker, with his strength and fine finger movement, supplements the work of a handicapped worker, allowing each to do the job to which he is best suited. This imposes on the whole organisation, rigid standards of efficiency and performance, which are necessary for our economic survival. It is even more essential that the same standards of efficiency and technical know-how be applied to our rehabilitation procedures, because here we are dealing in our CPs' lives, not mere production dollars. The physically disabled are highly motivated workers, with better than average attendance and safety records, and the forward thrust of technology in engineering, and electronics, obviously works to their advantage. Their employment means more to them than it does to somebody who can shop around for employment elsewhere. Their disability may even, in the future, be turned into a possible advantage, by higher vocational and technical education. The application of production 'know-how' may well offset the production line advantage of nimble fingers, which the able bodied employee now enjoys.



Martin Fox operates an adaption drill with automatic feed and foot control.



Daryl Bennett using one band Bakelite washer being mated in this press operation



Joy Stanton drilling code plates with a foot pedal and gravity feed.



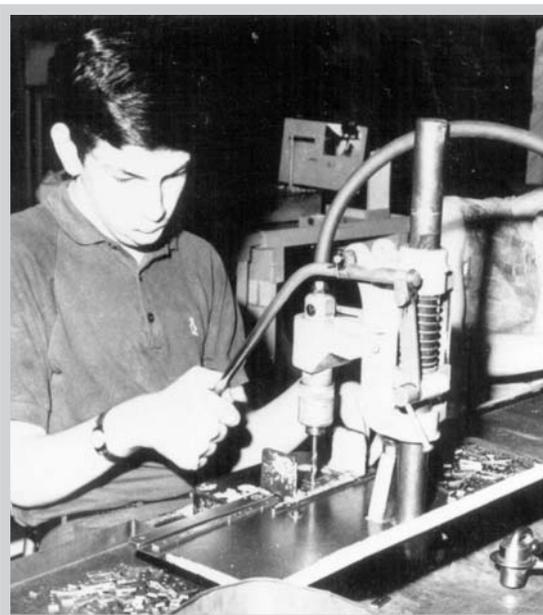
Brian Freestone operates a drilling machine that has been adapted to an automatic operation of feed and displacement.



Dr James F. Garrett, Deputy Chief of Health, Education and Welfare, Washington examines the work of Dennis Staback using his athetoid hands.



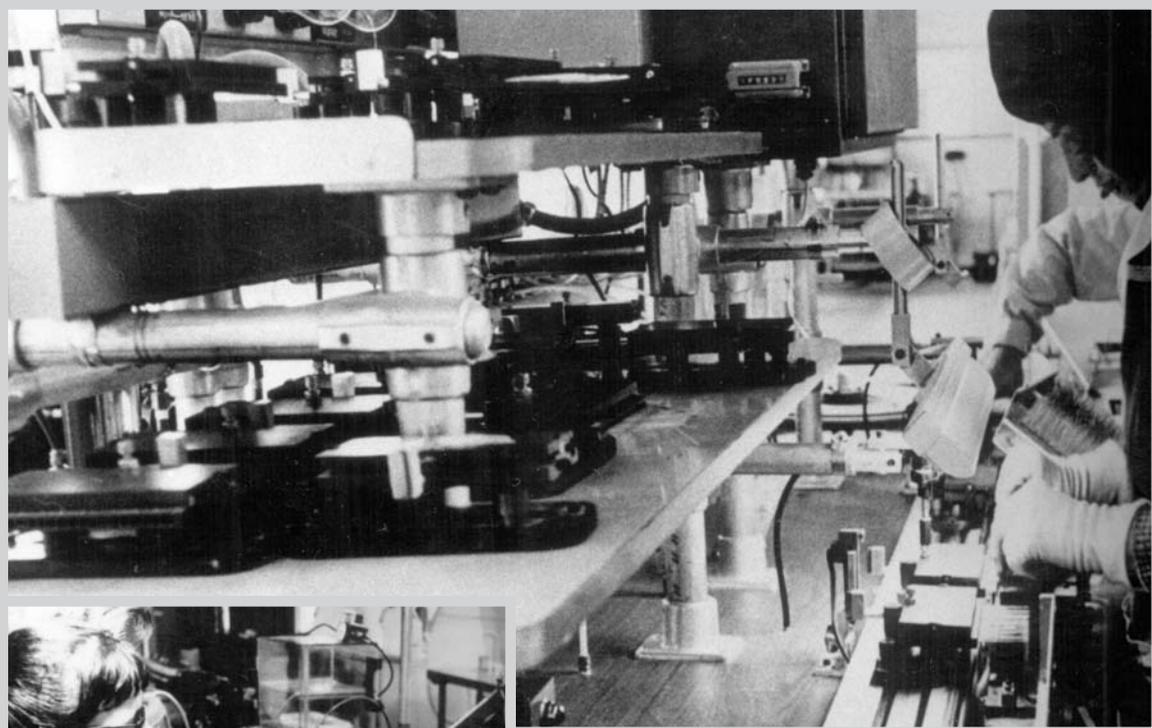
A general view of the A.T.U. in 1968.



The speed up line in the drill section operates four stations in line.



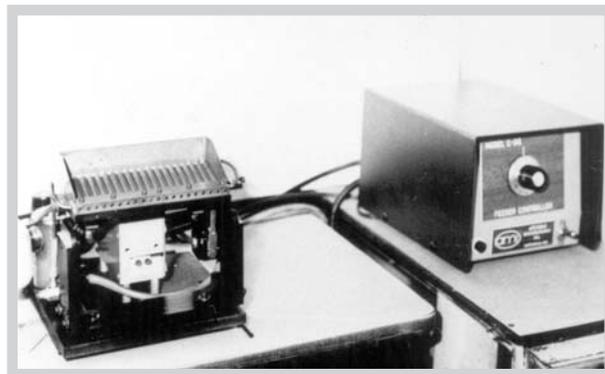
Gold plated telephones assembled for Telecom by Michael Guilfoyle and Lyndal Newton.



Loading the automatic etching of the Al4 diode.



Loading the slug and wire. Rosemary Street.



The pellet machine puts one pellet each space

We use the standards of the real world and pay our trainees at able bodied piecework rates for their work, after applying the normal industry standards of quality control. To employ able bodied workers within the same factory provides the disabled with direct competition and standards of production and quality control that are realistic and match those whose jobs they are competing against. We recently had a complaint from the government that we had discriminated against an able bodied worker. This is an accolade for which we have been searching!

Centre Industries operates in the commercial, profit-oriented world of business, competing on an equal basis for its contracts and meeting the challenges of cost, quality and productivity without favour and certainly without fear of competitive industry. A profit-oriented manufacturing organisation must be efficient to survive. If it cannot produce at a competitive price, delivery, or quality, it goes out of business.

Engineering is the key to rehabilitation, and the engineering work approach is fully backed by medical and therapy staff operating from the factory floor, where they control posture and work place design. They are supported by an in-house vocational education classroom instruction, which is made necessary because the barriers of architectural design and speech problems, bar all but a minority of CP from Technical College classrooms or other adult education facilities.

A committee of trainee CP operates within Centre Industries as a management liaison group. They attempt to obtain a solution to problems as they arise within the department and, if necessary, refer those that remain unsolved to higher levels of management. Their role is to protect the trainees, to advise top management, and to gain experience to develop their own skills

in management, as a step to the future. The independence training for the CP must be carried through to self-help in toileting, dressing, hair care, make-up and feeding, in the home and at work. Methods engineers, trainers and the occupational therapist are responsible for finding an acceptable answer in designed gadgetry for individual usage.

By mechanising the work station, and manually transferring work between stations, we are able to provide a large diversification of jobs, with sufficient variety to cover the ultimate residual skills of two hundred and forty CP workers, irrespective of the degree of physical handicap. This leaves a residue of fifty CP workers who take their place in the Intensive Training Department. These will stay until we find a solution to their problems. It is important to the staff that we never give up in trying for an alternative.

It is a normal function of engineering to match man and machine, and in the case of the CP this does not differ from the normal problems which industry has always faced. The able bodied worker uses only a small percentage of his total physical potential in the course of his employment, and supervisory or technical staff probably even less. This leaves tremendous areas of technological production exactly tailored to the physical limitations of each disabled individual. The concentration is on residual abilities. Rehabilitation is merely a logical extension of methods engineering.

With Mr Hume's interest in the adaptation of machines that were needed for training of the cerebral palsied, it became apparent that machine adaptation would enable many CP to operate normal production machines, in spite of their handicaps. The introduction of airpowered drills, tapping and counterpresses, enabled the trainees to achieve modest but significant productivity. At the same time, others found suitable employment in the operation of capstan lathes, milling and special purpose machines, spot welders and power presses. Later, the scope of work grew to include cable forming, spring set assembly and plastic extruding plant.

Mr Hume accepted an invitation to an International Seminar on Function and Assessment in Weisbaden in 1966, and, from the ground work he achieved there, he was invited to Copenhagen to see Dr Michaelsen, who had a typewriter with relays mounted over each key; this he thought would be a communication breakthrough. Mr Hume went on to London and was at the Bobath Centre for two weeks. He returned to Australia via New York, where he met Dr James Garrett of Health Education Welfare U.S.A.

Mr Hume did not see anything in Europe to excite him apart from the new Bobath physiotherapy and Dr Garrett, who was able to convince him that the services of a psychologist at Centre Industries were essential. So he came back to Sydney, fully determined to press on with Centre Industries, to see how far we could get, as soon as possible. He immediately appointed Mervyn Taylor, an experienced methods engineer, and Wilfred Jones, imported from Sherrards in England, to take up the position of Rehabilitation Manager.

Mr Taylor shared in the initial MODAPTS development work which grew out of Mr Hume's interest in the development of the CP trainees. This enabled them to do surprisingly well in some unexpected areas. If the hands of some athetoids were anchored to the machine's operating lever, their control was immediate; when it was removed they continued to move their arms or hands as if they were flying. That led to the idea of an elbow brace, with a friction retard built in, as an extra-skeletal brace. It did not work, but in the process of finding out the reason for its failure, he enlisted the aid of an electronics technician. His name was Peter Neilson, who was technical assistant to Professor James Lance of the Neurological Department of the University of New South Wales. With Mr Neilson's evident interest in the neurology of the CP and Professor Lance's encouragement, Mr Neilson declared that as a researcher in neurology, he would make cerebral palsy his life's work. We, in turn, encouraged him further with a three year scholarship at the University of New South Wales. Mr Neilson was already a graduate in Electrical Engineering, and a Science graduate. He was awarded his Ph.D. in 1972 with his thesis on the Action Tonic Stretch Reflex. Peter Neilson was responsible for setting up The Spastic Centre Research Unit in Prince Henry Hospital, under the aegis of the University of New South Wales and under the control of Professor Lance.

In 1966, Dr Suzette Blight was appointed Medical Officer of Centre Industries, under the direction of the Medical Director as far as operations or drug administration were concerned. We had been using the physiotherapists from the Country Children's Hostel for Centre Industries, but we needed to have our own therapists engaged on adults, rather than trained children's physiotherapists. From that stage, Dr Blight recruited our own physiotherapists and occupational therapists.

We invited Dr Garrett to visit us in the following year. During that time, he established that the psychologists in training at the two Sydney Universities had passed through the psychology classes without any reference being made to handicapped people. He suggested — and this was later taken up by the psychology head of Sydney University, Professor Richard A. Champion, and with Professor Gordon Hammer of the University of New South Wales — that we should sponsor a senior lecturer from Sydney University, Miss P. Leahy. The two universities then set programmes in the diploma year of psychology to include subjects related to the handicapped. Dr Garrett provided introductions to Universities in the U.S.A. The Spastic Centre funded a scholarship of \$2500 for that purpose.

In the following year, we recruited a psychologist at Centre Industries, Mrs Cecily Katz, who stayed with us for some years.

As work studies, methods development, and engineering design facilities already exist in Centre Industries, the functional physical assessment is provided for the CP worker by the engineering staff rather than by a psychologist. MODAPTS (Modular Arranged Predetermined Time Standards) suits our needs for an effective measurement of muscles of the hand. It is a relatively simple system of time standards, used by us as a multi-function test battery of measurement. Not only for pre-determining potential times, therefore productivity of a trainee, but more importantly to provide for the cross-matching of CP disabled person and the machine, to measure the positive value of increases in efficiency obtained by therapy, surgery or job training, and the control of the trend of rehabilitative policy and the testing of its effectiveness.

Work has been described by the industrial engineer as a sequence of motions logically performed, in a definite order, to produce the desired effect on the work piece, or the placement of the body members. An important criterion of the MODAPTS system is that the productivity of the CP is not dependent on the speed of performance of a motion. Rather, the difference between operator speed is accounted for in the manner of the method in which they do the task. Thus, given sufficient learning or instruction, the difference between the very best and the very poor operators will be negligible. Where the differences are not negligible, then there are other sources of variables which need to be located. It is the location of such variables precluding a disabled operator from performing a normal task that we must discover. It does not allow us to predict performance but, used in association with psychometric standard tests, it offers a satisfactory profile of trainees at work. MODAPTS was adapted and developed by Centre Industries; it has been used successfully by the Ministry of Labour in the Japanese Government for classifying the degrees of handicaps needed for the operation of its quota system, under their new legislation (1976) for the handicapped. This followed a computer study undertaken by Professor Yoshimi Yokomizo of Waseda University Engineering Faculty in 1975, when he established that the MODAPTS test battery was validated for the able bodied worker and by paraplegics, quadriplegics, and cerebral palsy subjects, all of whom were found stable in their own division of handicap.

For over twenty-three years from 1945, we at The Spastic Centre had battled our way forward without Commonwealth Government aid. During that time, we had established the first school for 210 CP children, 760 outpatients, associated medical and therapy assistance, a home transport service with 33 mini buses, a splint engineering division, a Country Children's Hostel for 100, a small school and clinic at Newcastle, and lastly, Centre Industries, a commercially oriented engineering plant employing 230 CP and 607 able bodied workers. In the absence of government aid, we built our own buildings with weekend volunteer labour and donated materials - 7000 square metres in brick and concrete and 2500 square metres in lighter materials. The State Department of Education paid the salaries of the twenty-one teachers employed, as, under the Education Act, they were obliged to do.

Now we had a chance of doing something really worthwhile for our cerebral palsied – Mr Sinclair in 1968 replaced Mr Robertson as Minister for Social Services in the Commonwealth Government. He was charged with the responsibility of administering the new legislation, which gave us an opportunity, previously lacking, for services affecting the CP handicapped. At a conference held in Canberra and presided over by Mr Sinclair, we became aware that his interest was real and sincere. We presented him with the three thorny problems that would have the effect of barring any Social Services subsidy from Centre Industries under the 1968 Sheltered Employment legislation, which was framed on the pension entitlement for aged persons and invalid persons. Centre Industries, at that time, had been going for eight years, and we did not like being called a 'sheltered workshop', but we took the view that our CP were obviously entitled to Government subsidy no matter what name was applied to it.

We made our first application to the Director General of Social Services, and it 'went round the traps' in the State and Head Office until finally we tracked it down to the Minister. At a meeting with Mr Sinclair, I stated that the work we were doing at Centre Industries should be fully supported because of our rehabilitation measures and training, which were far in advance of anything Social Services were doing in Australia.

Firstly, the regulations under which the Director General had made his determination - that a 50 per cent ratio level of able bodied workers should be the deciding factor as assessment of subsidy claims - in my view were completely wrong. Our able bodied workers were engaged in making profits for the advancement of the CP trainee, and reducing pensions paid by the Department of Social Services. We were a non-profit company, and any profits we made were turned back into additional facilities for training.

If the legislation did not permit a subsidy, I would not be averse to drawing a chalk line down one side of the machine shop and putting the CP trainees into a sheltered workshop on one side of the chalk line and the able bodied unsubsidised workers across the other side of the line. I pointed out to the Minister that if our CP could not be trained on machines over one side of the chalk line it would defeat the objectives of the legislation. The purpose of the regulations was to make sure that the handicapped people had adequate facilities. The more able bodied workers we employed the less the future demands on Government finance.

Mr Sinclair accepted my arguments at face value and instructed the Department to place us in the same legislation area as sheltered workshops.

Later we had talks along similar lines with Mr Cox, State Director of Social Services, and the Director General of Social Services in Canberra, Mr Hamilton. I repeated the same argument I had had with the Minister, and Mr Hamilton agreed to subtract from our ratio of able bodied people a sufficient number for commercial purposes, and that affected able bodied cleaners, engineers, administrative staff, supervisors, drivers and others. That gave us:

Total Able bodied	569	Disabled CP Workforce	272
Less Commercially Employed	248	Plus Other Disabled	50
Net Able bodied	321	(Not CP)	322

Secondly, at that time the invalid pension was made available to parents as warrantors and not to the invalid pensioners themselves. The parents had felt the need for protecting the pension at any price, and looked upon employment as the thick end of the wedge that would work against them. The Minister gave his ruling that the pension would be restored immediately in case of need.

Thirdly, we wanted to regard the pension and the additional earnings from Centre Industries as part of a weekly pay packet, from an incentive viewpoint. With the Minister's assistance, we hammered out a proposal which he accepted. Under this scheme, the Sheltered Employment Allowance (SEA) came into effect. Centre Industries paid the pension entitlement weekly as part of the pay packet, and then we recovered our prepayment from Social Services two weeks later. That meant that the CP was paid according to his earnings, including the pension and a bonus on productivity, which was calculated on the piecework rates of the able bodied.

The Department of Social Services (now the Department of Social Security), has been very good to Centre Industries over the years, because they could appreciate at first hand, the value of what we were attempting to do. They had some departmental experience in manning their Mount Wilga Rehabilitation setup, but we had a ten year advantage in rehabilitation techniques.

The whole trouble lies in the pattern of legislation that has been built up, like a patchwork rug, of whatever shapes and colours were available in their legislation bag. It is high time for a new look at the whole situation. The workshop area is not the only one. The legislation in 1975 led to subsidies being paid to profit-making nursing homes. That was the basis on which elderly people were exploited in the homes under cover of a charge for profit. Institutions such as The Spastic Centre were included in this legislation with a blanket assistance to nursing homes. No differentiation was made between an elderly person who needs bed care, and an active, working, handicapped person who needs hostel accommodation and some services, such as assistance in feeding, toileting, dressing and nursing care.

The Commonwealth Health Department assumed control of the legislation and left it to the State Health Department to control it. This led to a plethora of negative rules and regulations; for instance, you cannot have a kitten in a Children's Hostel and you cannot have a double bed for married people although twin beds are permissible, provided you do not have a coverlet to extend over the two.

All too frequently individual rights are downgraded and obscured to the point where they are effectively denied. With our nursing homes the inspectorial staff have a dual role. They are auditors from a financial view of cost control - this is accepted. They also have a much more important role - to see, on behalf of their charges, that they get the services to which they are entitled. We would welcome the inspectors wholeheartedly if they showed signs of cooperating in a team spirit for the benefit of our individual CP, but I think there is a pre-occupation with how not to do it, rather than how to do it. Thus, they ignore the rights and particular needs of the individual person they have been established to serve when they make rules and regulations, which seldom fit the individual case. One cannot be sure as to whether their interpretation of the rules may not mask a personal prejudice.

May I say that we have nothing but praise for the Commonwealth Social Services, Health Departments and State Ministers and highly placed officials of the State Health Department. They have encouraged us to the very limits of their powers. My strictures are reserved for the lower grade officers who have not reached the same standard of competence.

Mobility equates with independence. Most cerebral palsied do not have sufficient hand control to operate the manual wheelchair, therefore battery powered electric operation is essential. The wheelchair driver is entitled to go where he wants to and when, whether it be canteen, toilet or elsewhere. Work discipline is administered through the normal factory channels of chargehand, foreman and supervisor, for the able bodied and the CP worker. Lack of mobility cuts the severely disabled CP off from his contemporaries - socially, economically, and from the achievement of independence.



Beverley Black assembling the A14 diode onto a PVC Board.



Beverley Massey is a one handed operator who achieves 100% of the A.B. rate.

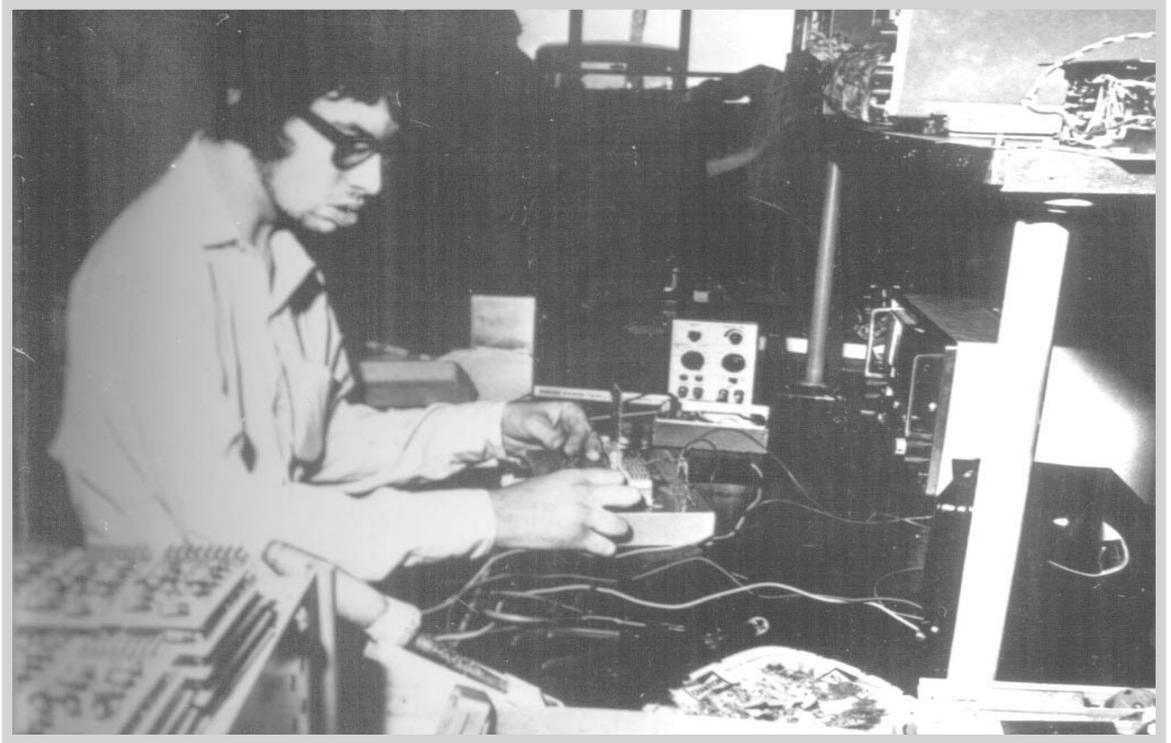


Una Holibone in the cable forming section.



Lyndal Newton engaged in cable forming.

The development of an electrically operated wheelchair was commenced by Centre Industries engineers in 1967. This involved extensive research into providing a low cost unit and achieving maximum stability and manoeuvrability, greatest ease of handling and minimum maintenance. The requirements were for the chair to be 'custom built', with correct postural seating, and to be operated by the most severely disabled. The doctor and the physiotherapist share the responsibility for design changes in posture necessary in the individual case, and for adjustments needed. The development of this chair is an achievement and a major contribution to assisting the disabled. We made ninety of these chairs in the next three years, after which we were forced to discontinue the manufacture because of the downturn in Centre Industries' profitability. Research is now planned to develop a similar type of chair for small non-walking children. There is a certain argument about the provision of an electric, or electronic, wheelchair for the very young child, as to whether it is desirable or not. Will it affect their desire to walk, will the stimulus of the chair be affirmative or negative? I can only base my own conclusions on the more than one hundred wheeled vehicles



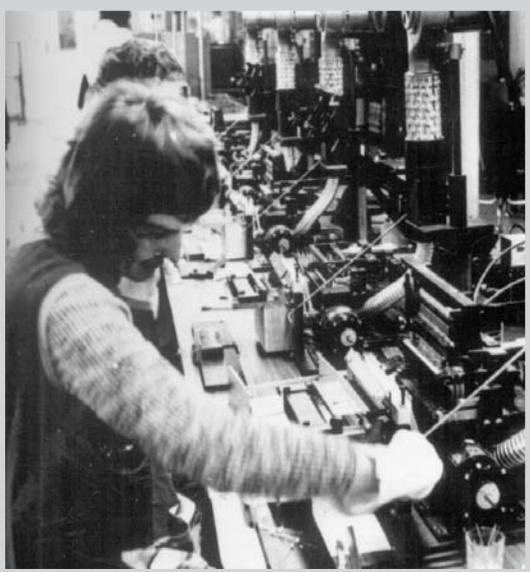
Alan Bimson, a qualified operator in the electronic laboratory



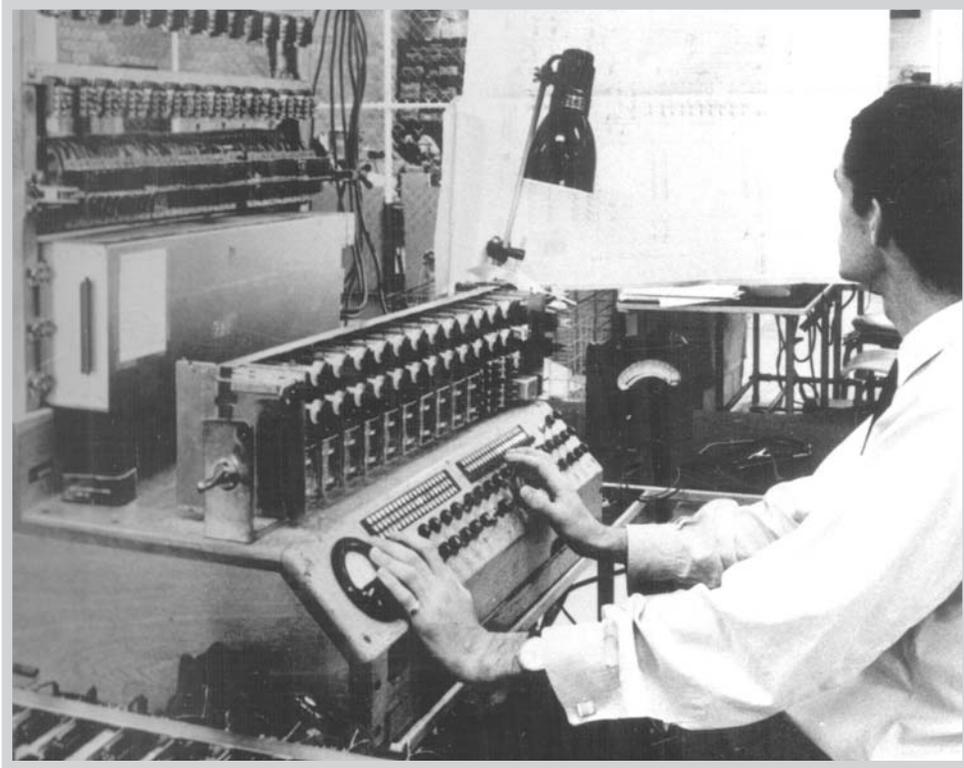
Talia Jacks tinning operation on the A15 diode.



The glassification line.



Harry Ashton is a CP Quality Control Officer.



L.M.E. combination test unit applicable to L.M.E. Xbar sets or 2,000 switching sets.



John Morgan operated a Capstan Lathe for 13 years.



Traffic route test inspected by Mr Sanders of G.T.E. All 35 were manufactured by C.I.



Testing in Modapts operation.



Lorraine Hemmings on the drill line.

surrounding our Mosman and Allambie Schools in any day - tricycles, three-wheelers, trucks, pushers and manual wheelchairs operated by pushing with the feet. I think the power wheelchair would merely take its place among the group. The manual wheelchair, because of its light weight, is convenient for auto transport, and there is no difficulty in surmounting steps and kerbs as is the case with the heavier electric wheelchair. It is important to realise that the 'pusher' of a manual wheelchair abrogates his role as a helpful friend when he responds to the communications of other people, instead of allowing the CP enough time to acknowledge a greeting, or instruction, or some other element of conversation directed at him. The CP in a manual wheelchair must accept the responsibility of demanding, first to be seen, and then to be heard. They are not inarticulate furniture, to be moved while the conversation level takes place above them and beyond their conversational reach. The 'pusher' should be mute, not helpful in speech unless the CP demands it. This applies to parents, who are the worst offenders of all, and to the doctors, dentists and nursing staff in their own hospitals and surgeries. It even applies to staff within our own organisation.



Betty Rowe with her electric power control wheelchair (on right). Phyllis Kyle with the "L" Plate is learning to control with her feet (on left).



Harry Ashton assembling yoke onto 3,000 class relays.



A mildly athetoid with good hands operates the paint spray gun.



Office Staff in the early 1960s. Betty Rowe, Jan Lot, Di Hart, Sharon Greig, Ron Spokes and Vivian Bruell.

That is why the 'pusher' should be gagged, because, for the CP, it is on those vital occasions that the doctor, or dentist, or shop assistant, all of whom are busy people, would prefer to speak to the 'pusher' rather than waste time on the slow speech of a CP. On these occasions, the CP is entitled to express himself unassisted, for he is, in the final analysis, the holder of the money purse.

The 2000 Type Relay Set for the telephone exchange was our first manufactured product. In 1961, we were told by the A.P.O. (Australian Post Office) when we started that it only had a limited life. Our three commercial competitors were tooling up for the new LME Crossbar manufacture, which was then standard equipment in the A.P.O. exchanges. So, while they tendered for all the 2000 Type Sets available on the A.P.O. order schedule, we were able to meet their competition in price, delivery and quality.

Our sales rose from \$0.3 million in 1962 to \$2.2 million in 1966, and our net profits were \$4000 and \$138,000 respectively. This was after providing \$122,000 for the transport of our CP and rehabilitation training costs. The five years' results fully justified our business activities, but they more than justified the rehabilitation training given to our one hundred heavily handicapped CP workers.

For the next eight years to 1973, our sales had progressively increased - \$2.2 million to \$4.4 million, and we had \$2.4 million accumulated operating net profits which was satisfactory in relationship to our profitability. Our costs of transport had risen from \$50,000 to \$225,000 and the costs of rehabilitation had risen from \$100,000 to \$440,000 and they were destined to get worse over the next decade.

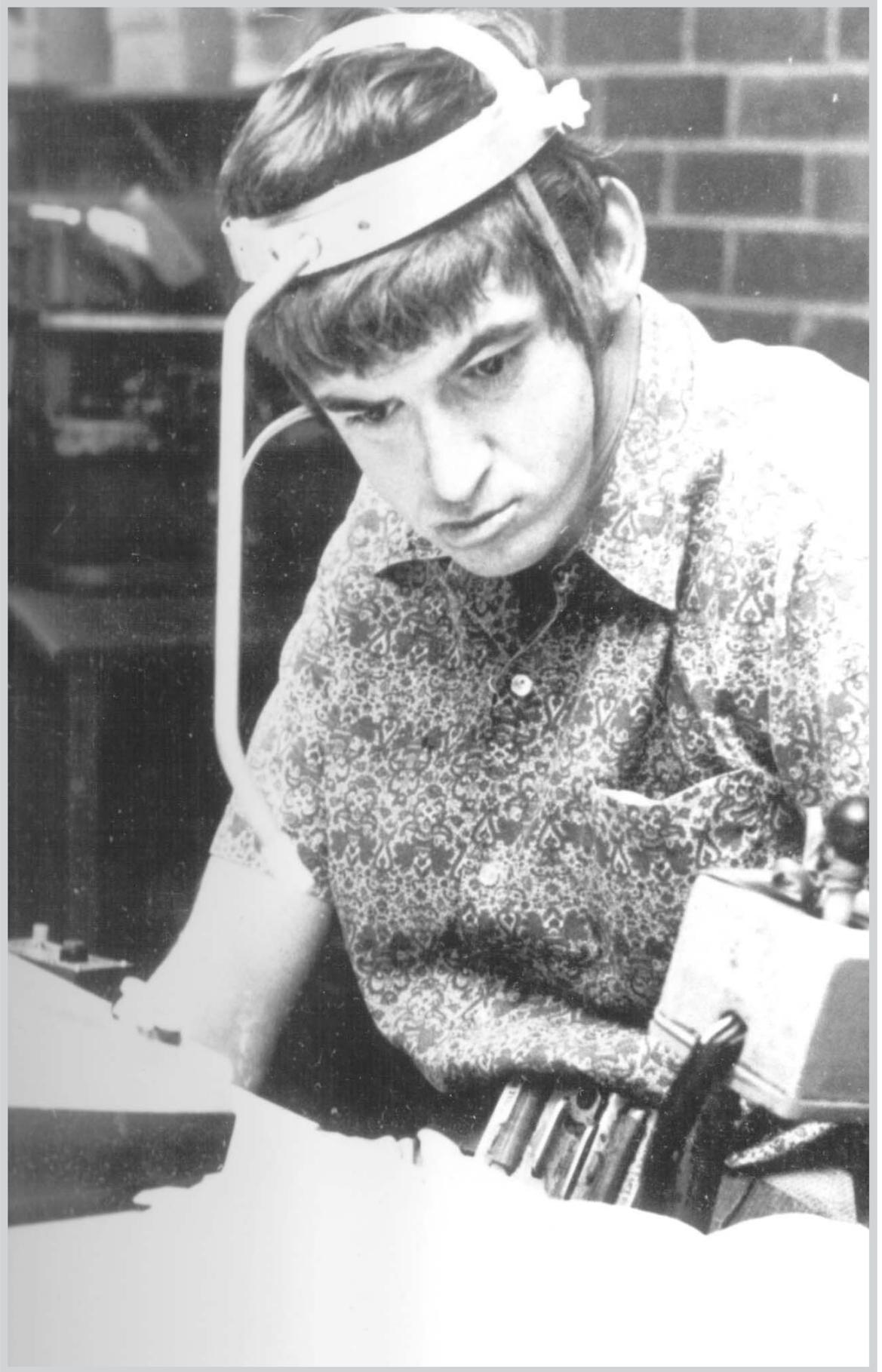
At that time, our sales were confined to the manufacture of Telecom orders for 2000 Type Relay equipment for telephone exchanges. We are now the sole Australian manufacturer of this ubiquitous relay, and its life span is by no means over today. Still we worried about the future prospects of the 2000 Relay system. In 1968, with the sponsorship of Mr Evan Sawkins and our friends in the A.P.O., (assisted by the President of the L.M.E. Company in Stockholm, Mr Malte Patricks), we arranged for a licence to manufacture their A.P.O. designed RAF crossbar sets. Mr Israel and Mr Holborow were sent to Sweden on a technical fact-finding mission. My wife and I, accompanied by Mr Pike, a Director of Centre Industries, followed up their visit in 1969 to arrange for the purchase of \$70,000 worth of secondhand L.M.E. tooling which they had on hand from the closure of the L.M.E. Danish factory. With Mr Patricks' sponsorship, we also succeeded in a quest for five L.M.E. closely guarded Combination Test Units, which were essential to our production efficiency of the new crossbar sets. They were very sophisticated electrical push button devices, which are still in use in the 1980s, despite the movement into electronics and the micro chip. We were very lucky to get them. In 1970, the manufacture was commenced of the crossbar sets, and other products were added, such as high speed relays, teleprinter subscriber units, and traffic route testers.

With those difficulties over, we started a major expansion of Centre Industries, which at that time occupied 4000 square metres. The proposals for the building extensions were provided by the Department of Social Security under their Sheltered Workshop provisions, which came into effect that year and provided a subsidy on a basis of \$2 for \$1. These were proposals that the Minister, Mr Ian Sinclair, had piloted through the sheltered workshop area, and were to give us more than treble the size of our existing floor space. It was to be a brick two-storey building, with provision for air conditioning which was demanded by the A.P.O. because of the dust and salt content of the air, contiguous to the shore. The building contained the new L.M.E. switchgear, which became a significant part of our manufacturing programme for the next ten years. It was equipped with a large elevator capable of handling eight wheelchairs. This space increase meant that we were able to transfer the whole of the office staff (including the Honorary Superintendent, the Public Relations and the Transport) from Mosman, to the top floor of the new building.

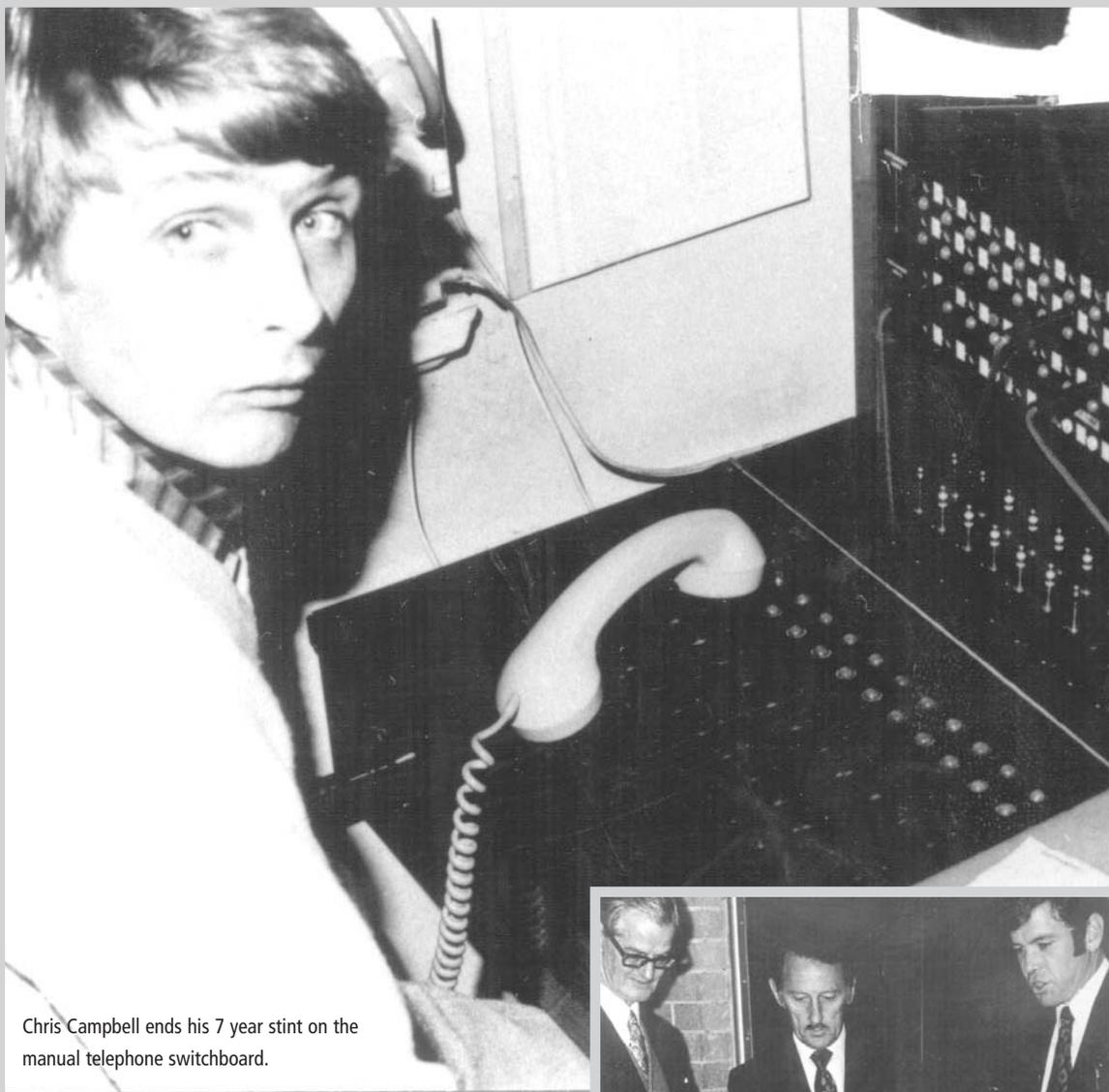
In 1970, we had a visit from Her Majesty the Queen and Her Royal Highness Princess Anne, which went off very smoothly. The weather was glorious and all the CP children from Mosman School were there, amongst a crowd of cheering public.

The Government having at last brought into their legislation the Sheltered Employment Assistance Act, the Director General of Social Security appointed Mr Hume as a consultant to the sheltered workshop scheme. We assented to this because it gave us access to the Social Security Rehabilitation Department and it envisaged extension of his work for some days only per month. This was at the time when we received the first subsidies under the Workshop Scheme, which amounted to \$120,000. Our costs for the adult training unit, medical, therapy and transport amounted to \$240,000.

In 1967, we became concerned about the problem of adult education for those heavily handicapped CP who had difficulty in learning to read, despite their apparent intelligence. They included a number of the Rh deaf group and others devoid of speech. Additional education was necessary for the lost generation of those intelligent CP, for whom primary and secondary education was deficient in hourly content, and in the quality of teaching. No matter whether the teachers, or the support given them in the



Brian Juleff, EDP input section.



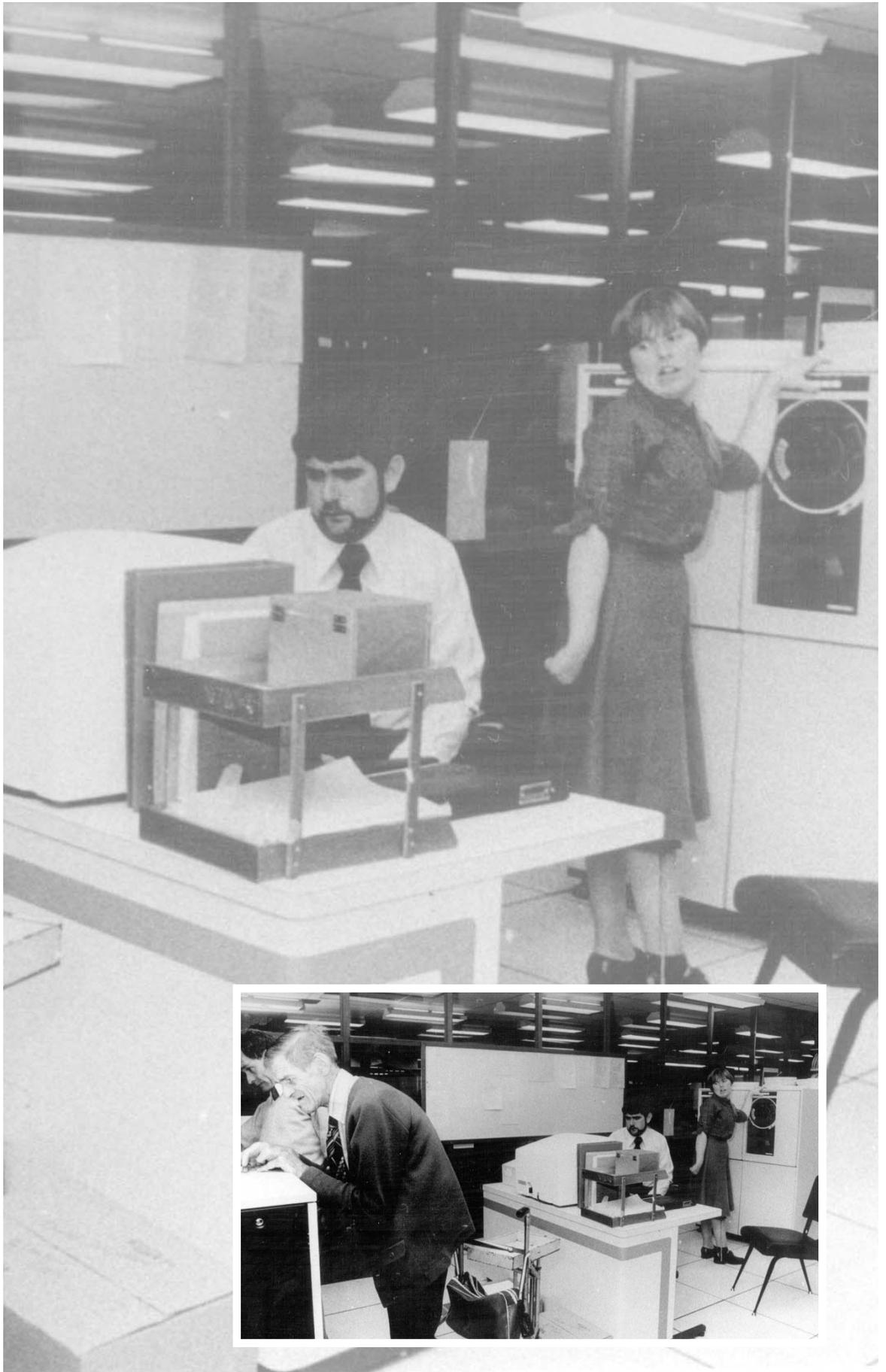
Chris Campbell ends his 7 year stint on the manual telephone switchboard.



John Baldwyn



Jenny talks to Mr Sanders, the General Manager of GTE for the Pacific (middle). Neil McLeod (left) and Mr Bruce Hume, G.M. (right)



EDP Programming Section. Left to right: Lindsay Dalmon, Lindsay Sinclair, Geoff White and Maria Tsoukalidis.

past, were at fault, we must make it up to them with increased standards of adult education for all students at Centre Industries. We formed CENTACS (Centre Technical and Academic Courses) for continuing adult education. Originally, we offered three hours of lectures after hours, and ninety people participated, over a wide range of subjects. Then two years later, we decided that, because of the transport problem, it was economically sound to provide the CENTACS facility during working hours.

As adults, the CP appreciate the importance of additional education, and respond with a more mature outlook towards the effort required of them. Participants are paid at their average earning rates for the production time lost. Subjects are dictated by management, and progress is closely monitored. The rate of illiteracy and numeracy has been reduced and the higher technical skills increased. This is especially apparent with those whose speech and hand function is affected.

By concentrating on remaining physical and intellectual abilities, instead of on apparent physical handicaps, we have been successful in upgrading our CP trainees to levels of high technology. Our computers are operated 90 per cent by CP workers. They provide all the input data, comprising a monthly total of 231,000 key strokes on 13 VDUs. Six write the computer programmes on four VDUs, and three process operators are employed. In this context, their lack of normal hand movements, their inability to walk, or their speech limitation, does not prevent them from competing successfully against the able bodied computer staff.

A rough measure of the general level of disability could be gauged from the fact that, of our 290 CP in 1976, 151 trainees required assistance in feeding in the canteen, and in toileting, yet the average productivity based on able bodied standards was over 41 per cent. Or, expressed differently, our 194 disabled trainees earned \$317,200 at able bodied piecework rates, and the saleable value of their production was \$740,000. We admit a broad range of CP disabilities, which includes all who have finished their final year in our schools, and includes some with a quite low IQ level.

In Centre Industries, we took part in testing the able bodied operators on behalf of the A.P.O., and Professor David Ferguson of the Commonwealth Department of Health, for telegraphist's cramp or tenonitis of the wrist and hand. Originally, this complaint was confined to the operators of the old fashioned keys on which telegraphists recorded their messages, but at the time we came into the picture they were using teleprinters. We could not understand why typists did not contract the same cramp. At the same time the cramp was endemic in Centre Industries amongst our own wirers, who used pliers continuously in their work. The survey, which lasted over a period of twelve months, took into account the position of the operator, from the standpoint of ergonomics. These are worth restating:

'There has been unceasing interest and application by engineering staff and medical personnel to the task of suiting the handicapped trainee to his work and suiting the work to the trainee. The majority of these trainees have been severely disabled, some with little or no hand function, so that Centre Industries, of necessity, has developed a research area where the practice of ergonomics has become an intensely interesting and rewarding experience.

Ergonomics is concerned with the worker's well-being as well as his efficiency. The health and dignity of the disabled worker are of as vital importance as productivity.

Any work situation makes demands upon the worker. The amount of effort they create will depend upon the demands of the work being carried out. How the worker stands up to the load will depend on his physical, perceptual and mental capacities. In the severely disabled worker, there are limitations resulting in a reduced work capacity in those areas affected. It is the function of the ergonomist, and all those working in the rehabilitation of the severely disabled, to utilise the worker's residual capacities to their best ability.

The posture of the disabled worker will need careful assessment and, if necessary, corrective seating. This is essential in the severely physically disabled worker who is sitting in a wheelchair with canvas back and seat for the whole of his working day and usually for his leisure hours too. In some disabilities there is an inability of the worker, to change his posture by movement, which an able bodied worker is constantly doing to relieve muscle fatigue.

Research has been carried out into the design of correctly dimensioned chairs, tables and equipment for our disabled employees. Wherever possible the design of work benches has been made standard for able bodied as well as disabled workers. With this uniformity of design throughout the factory, disabled workers are able to replace able bodied workers or vice versa at any work bench situation.

Irrespective of degree of handicap, motivation is the most important single factor operating in the successful rehabilitation of the handicapped. Two principles are involved: to build up the residual capacities of the disabled worker, and to suit the job and environment to the disabled worker.'

Telecom was moving away from electro mechanical relays into electronics, and that meant we would be out of business within ten years if we failed to join them. In 1969, it became apparent that we must do something about widening the technical facilities of Centre Industries, to be able to cope with the new technology. S.T.C. already had a large contract for the computer control of their trunk lines exchange and L.M.E. were already looking at the prospect of eventually replacing their electro mechanical registers with electronic controls.

Our perennial lack of working capital is because we are a wholly owned, non-profit company limited by guarantee; we do not have access to normal sources of funding, from shareholding or debentures. On the credit side, we do not pay company income tax, and do not face shareholders' dividend payments, all of which enables us to compete on equal terms within the competitive framework of Australian industry. This means that we must import technology from overseas by offering them, in exchange, an entry into the Australian market.

In 1969, in company with my wife and Mr Reg Pike (a member of the Board), I attended an International Rehabilitation Meeting in Dublin, at which I delivered a paper on Centre Industries, which was well received. Then, leaving my wife and Mr Pike to finish the conference, I flew to Syracuse, New York, to put in train a proposal to manufacture a G.E. (General Electric) type of semiconductor (the A14/15 diode), and flew back to Dublin two days later.

Dr Donnalley, the General Manager of the semiconductor division of G.E. was completely surprised that a public charity in Australia should be in the market for the manufacturing of a sophisticated device like this, and I had to do some hard selling on our capacity to handle the technology. At Centre Industries, we were using a quarter of a million such devices in our contracts for the A.P.O., and G.E. had estimated that the Australian usage would be 10-12 million units per year, all of which were imported and subject to a duty of 34 per cent. Our orders from the U.S.A. were dragging nine months from the order date.

The G.E. organisation was just getting a first whiff of manufacturing competition for their semiconductors in Japan. They were interested in our proposal in limiting the Japanese imports into Australia, by setting up a G.E. promoted factory in Australia. We, of course, could not finance the tens of millions of dollars needed for the research and development that would have been involved, but we were very much interested in getting a window into G.E.'s semiconductor technology, without cost to us.

G.E. was a large business empire, and it was two and a half years before we got the G.E. management approval for the project, by which time the worldwide famine in semiconductors had been largely overtaken. In our first year, G.E. and L.M.E. of Sweden were having a legal battle, because of the wording of the G.E. Licence to a subsidiary company of L.M.E. It spilled over, and RIFA, the subsidiary, set up a plant to manufacture the A14/15 device in Australia. That further reduced our Australian sales market, but the exercise had been very well worthwhile from the CP rehabilitation point of view, because it allowed us to come to grips with the new technology. The CP were heavily involved in production, printing, and more importantly, in quality control of the finished product.

Let me give some idea of the technology involved. One batch we exported into Canada was rejected; their laboratory tests disclosed the presence of silicon. It took us five weeks to track down the trace of silicon, because there was none present in our production, and electronic testing did not disclose it. The search finally came down to the plastic sponge in which they were packed for export. The manufacturer of the sponge had used a substitute guillotine because his own had broken down and the sub-contractor had used a trace of silicon when cleaning the blades of his knife. When you are dealing with single atoms of contamination, you must have this sort of quality control.

I was interested in this project because it offered new advanced work for our CP, with production machines, electronic test machines and computerised sorting of the finished product. G.E. warned us that the expected life of the A14/15 would be about ten years. In fact, we closed the line down at nine years. In those years more than half our workers in this department were CP. Originally, I was afraid to place the CP into that working environment because of the danger of acid burns, so we took every safety precaution we could and I finally decided that we could not deny the job to any CP person who applied for it. We did not have an acid burn during the whole nine years of its life, and the safety showers we provided in strategic locations gathered spiderwebs and dust since they were first installed.

In 1973, we had been engaged on a similar partnership with G.T.E. (General Telephone and Electronics), a telephone and telecommunications giant. They had been successful in winning from the A.P.O., a contract for microwave equipment, and that gave us the chance of funding into that technology for Centre Industries.

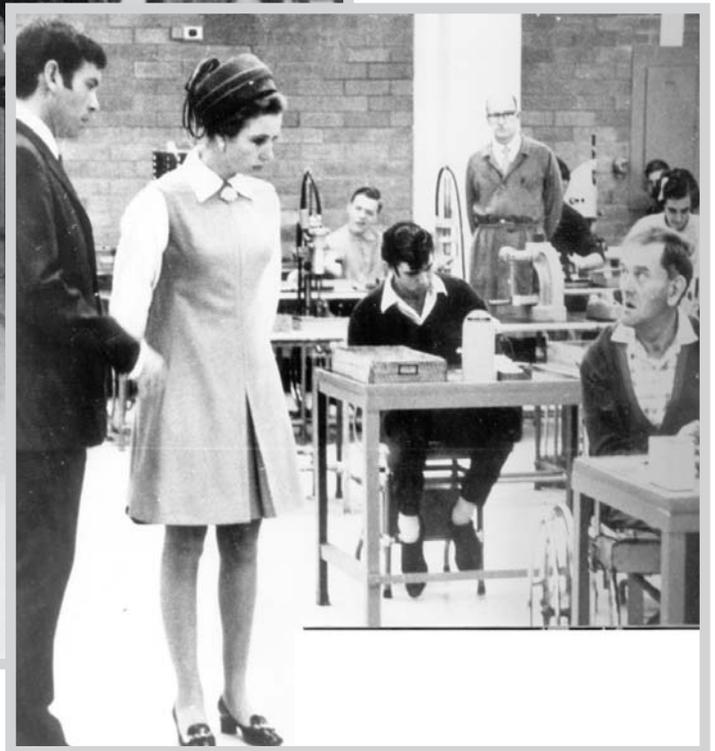
Before the negotiations had commenced, G.T.E. startled us by enquiring what was the sellout value which we had placed on Centre Industries. They explained that we could still use the project for the employment of CP in a separate annexe, and that this would give us the money which we could use in our welfare projects. They had looked on \$6 million as an asking bid. That did not solve our long term objective of providing paid work for our CP on an ongoing basis. We placed an alternative before them - if they would pay for the erection of the necessary building, we would man it with our organisation and split the profits at fifty percent.



Her Majesty The Queen visits Centre Industries with Her Royal Highness Princess Anne.



Her Imperial Highness The Shah Banou of Iran questions Brian Julef about working with a head probe.



H.R.H. Princess Anne talks with Teddy Laws. Bruce Hume, G.M., Howard Davidson, Wilfred Jones, ATU Manager and Wendy Benjafield.

The President of G.T.E., Mr William Bennett, came to Sydney and, following an inspection visit to Centre Industries, told us he was satisfied with what he had seen. He immediately gave us a summarised version of the terms of agreement, written on half a sheet of quarto paper. When it came to the question of splitting the profits, one of his managers raised the point that we had not provided for any losses, but Mr Bennett made the classic remark, 'There are not going to be any losses'. So that meant we were in the microwave business.

Following on that visit, I, Mr Hume and a couple of Centre Industries engineers, made an inspection of the huge G.T.E. plant in Chicago, which covers forty acres in extent under the one roof. They have their own fire station in the centre of the plant, and the supervisors ride motor cycles around the aisles. Another project was involved in our discussions. This was the HQA telephone relay, for which they established an offshore factory in Spain, and looked forward to a similar factory in Centre Industries in Australia. Mr Bennett had warned his senior officers to be very careful in seeing Centre Industries would not be hurt by its association with G.T.E.

As a special curtain raiser to our two new projects - the manufacture of the A14/15 semiconductor for G.E., and the G.T.E. contract for the manufacture of microwave assembly - we had an opening ceremony at which we entertained 150 manufacturers, Telecom officials and Centre Industries rehabilitation supporters. Mr Alf Byrne represented G.E., and Mr Arnold and Mr Sanders from America represented G.T.E. The building was opened by Mr E. F. Lane, Director General of Posts and Telegraphs, when he said, "I am told that advanced technology holds the key to the rehabilitation of the heavily disabled. The technical interchanges involved in setting up these two highly complex operations to manufacture semiconductor products for the General Electric Company, and microwave equipment for G.T.E., introduces a degree of sophistication in Centre Industries' engineering capability that will be vital to the success of our spastic trainees, in the hard years they have ahead of them. It is of equal importance to Centre Industries that our disabled trainees should have this opportunity of returning the community's investment in their training by increasing, in no small measure, the productivity of the Shire, the State and the Commonwealth".

Mr Byrne, in the course of his address told a story new to me, about the Prime Minister of Japan asking Mr Truman, then President of the United States, if he could borrow three American Generals, after the occupation. Mr Truman asked which three he was thinking of, and the reply was, "General Electric, General Telephones, and General Motors".

One year later Mr Bennett asked me to speak to the leaders of their legal department, because the original terms of agreement had now blown out to sixty-four pages of fine print, but it was not acceptable to us in its present form. I suggested modifications that I considered necessary, but by the time the building was completed and production started, G.T.E. had lost their Telecom contract to Siemens, and the A.P.O., with a change of plans, had decided against the radio microwave technology in place of cables. So we were back to square one, without a formal ratification of the contract. We erected the building as an extension of Centre Industries, but we were refused Government subsidy because of G.T.E. participation.

We got a year's work out of the microwave project, but we still had the building which we could put to good use, and had a contingent liability of \$300,000 which was part of the cost of the building.

That was sad, but it did give us some experience in microwave technology, and it gave us the use of the factory space we needed for the expansion of the LME crossbar lines. We carried the contingent liability on the balance sheet for a number of years, hoping that G.T.E. might have need of our production services in Australia, but following upon Mr Bennett's retirement, it was finally written off by G.T.E.

Application was made to the Department of Social Security for a subsidy on the building extensions and specialised machinery, valued at \$200,000, for the G.E. project. It was refused on the grounds that they might have done something for rehabilitation of the cerebral palsied, but at the same time they would not have entered into partnership with us unless there was a profit in it for them.

Each year has seen a steadily increasing number of CP requiring physiotherapy, and in 1980, a total of 170 CP were receiving a regular treatment programme. The objectives of the physiotherapy department are related to the CP employed at Centre Industries, and can very broadly be defined as increasing the productivity of the CP at the workbench, maintaining their level of function, and preventing the development of postural deformities. In addition to the neurological deficits affecting CP adults, are the degenerative body processes, which are no respecters of the human body, be it able bodied or handicapped. With our steadily aging CP population, these processes are becoming increasingly noticeable, with involvement of the cervical and lumbar spine, hip, knee and ankle joints in particular. In addition, those with atypical walking patterns are experiencing increasing difficulty in walking as they grow older. A survey carried out by the physiotherapy department in 1978, revealed that 100 CP employed at Centre Industries had foot problems requiring immediate podiatry attention. Of the 53 with hearing loss, 30 wore hearing aids. Some of the balance should, or could, have been wearing hearing aids.

In 1971, I attended by invitation of the New York Cerebral Palsy Committee, a seminar on the Centre Industries Workshop. In the year following I attended an I.M.C. meeting in Paris aimed at bringing together specialists in cerebral palsy and parents.

In September 1972, we were advised by our own therapists that they had joined a Union and, although we were not a party to the agreement, the arbitration committee judge awarded fourteen months retrospective pay for the therapists, amounting to a liability of \$62,000. We were under no legal obligation to pay, but our refusal would have meant that we would sacrifice the expertise of our major therapists, which was needed desperately for our children's sake. Therefore, we had to go along with the submission. The Award covered those people who had left our employment during the fourteen months, but we ruled that they were ineligible to share in the Award. Upon application to the Premier of New South Wales, Sir Robert Askin, the Government eventually provided \$24,000, which was the first money we had received from the State Government.

The GE10 computer was installed by Honeywell in 1972, marking the entry of our CP trainees into the computer world of the future. The installation was completed in 1976, when a second computer system was installed. There are thirty people employed in the computer services department, using two Honeywell Model 58s which are run on shifts over twenty-four hours. The applications run on the computers are: manufacturing system consisting of inventory management, product data management, material requirement planning, costing, purchasing; accounting system - general ledger, creditors, payroll.

We are now on the threshold of a major change from metal fabrication to electronics, via the printed circuit board (the PCB). For the first time, technology is moving towards rehabilitation. The able bodied operator with dependence on deft finger movement can be replaced by a trained cerebral palsied person. That is already happening on our assembly lines, and the process will be increased as the test units come into production. Of particular importance to our future is the rapid technological movement in the field of telecommunication, toward processes which favour handicapped workers. In a computer oriented production world, they can offset the limited function of their muscles by superior technical education, and better product and process knowledge. The new technology in the electronics field of telecommunications has simplified our problems still further, by reducing the production gap between the physically handicapped and the able bodied worker. The entry of the microprocessor and associated technologies places a higher premium still on aptitude and intelligence. Morale is still more important than muscle strength, and productivity depends more on drive than dexterity. For those smaller numbers whose intelligence is impaired, technology can still help, by the marriage of sophisticated production methods with relatively simple bench work.

Our programme for work training and employment of the disabled has been achieved without any increase in costs to our customers, and without prejudicing in any way required standards of quality and delivery. The additional costs of training disabled workers, of machine modification, and transportation from and to their homes, are funded separately by allocation of earned profits, and by limited Commonwealth Government subsidy. They are excluded from commercial operating costs.

The Fujitsu Company, one of the largest of the Japanese companies, was interested in finding an Australian manufacturer for the FETEX-100 systems. In 1979, this company had sales of \$2 billion, including telecommunications, computers and components. The FETEX-100 was an all-digital switching system, and it involved us in monitoring the terms of the tender and making sure that it contained all of the alternatives that were available in the standard contract of the A.P.O. We previously had been involved in Telecom's search for a number of different schedules. They were the TCP telex exchanges, PABX equipment, revised prices of the FETEX-400, Fujitsu microprocessor, digital data network, rural radio, facsimile, telephone instruments for O.T.C. and the Venus packet switching system. We had spent upwards of twelve months on this project, and we were optimistic until the tender came out and we were unsuccessful. In the following three years our association yielded a sale to Telecom of \$100,000. Getting to know the top people in Fujitsu may be worthwhile in the future, because we could still be in line for A.I.P. (Australian Industry Participation policy) on any future Telecom orders, particularly in digital networks, optical transmission equipment and Fedex facsimile.

In 1974, we had a visit from Her Imperial Majesty, the Shah Banou of Iran. She was tall and slender with lustrous brown eyes, was impeccably dressed and impressed me mightily. She inspected Centre Industries quite thoroughly, and said she was interested in the work we were doing for the heavily handicapped. She headed the welfare work of her ministry, and was particularly interested in putting the handicapped to work, as we had done in Centre Industries.

In Iran, the Empress controlled twenty-five educational, cultural, welfare and health organisations. Her interest was such that she was familiar with the most advanced methods for the rehabilitation of the disabled.

Following the visit, my wife and I were awakened about midnight with a call from Government House, where the Shah and Shah Banou were staying. The caller apologised for waking me, but said the Shah Banou was attending the ballet in the Opera House,

and after supper she had expressed the wish to see my wife and me at Government House at nine the next morning prior to her departure. We were on time, as you can imagine, with all sorts of questions lying unspoken in our minds. We were given cups of coffee, sitting on gilt chairs in an otherwise empty sitting room. Then the Shah Banou entered and presented my wife with a solid gold filigree cigarette case, set with her initials in diamonds, from her personal possessions. She thought it would be a suitable prize through which The Spastic Centre could raise money for our CP children.

We said thank you for such a lovely gift, and then said our goodbyes. As we were leaving, an official from her retinue handed me a large envelope, unsealed, which I placed in my pocket, thinking it was a notebook or something special from Iran. We opened it in the car, and nearly fell over when one hundred notes, each comprising one hundred U.S. dollars, erupted. The \$US10,000 felt so nice and warm in my pocket, over my heart, that I was loath to surrender it to the cashier of The Spastic Centre. It was the only time that I felt really, very wealthy.

From 1962 until 1973, our accumulated operating profits were \$2.4 million, and we were able to fund our adult training unit costs, including transport, with profit after adult training unit, medical, and transport costs of \$440,000. Government subsidy, which started in 1971, helped to the tune of \$399,000. So, even without subsidy we were able to pay our way to a figure of \$155,000.

With the newly elected Labor Ministry, under Whitlam, in December 1972, the economic climate was unfavourable, then in 1974 runaway inflation struck us at 11 per cent. We lost our General Manager, Bruce Hume, who had been offered a position with a major group of companies which he felt he could not refuse given the salary offered and the status this would give him. The newly commissioned Telecom, successor to A.P.O., cancelled 50 per cent of their orders. The newly appointed General Manager knew production engineering, but did not know CP workers and rehabilitation, and he lacked experience in fiscal matters as applying to Centre Industries. The Centre's accounting staff with their time honoured standard costs, under inflation conditions were no longer to be relied on. The Christmas payout of \$450,000 could not be met - this was four weeks annual vacation pay plus 17½ per cent holiday loading, in addition to the payment for ten public holidays during the year, and the provision of sick pay.

Therefore, I was faced with a personal decision. I took pride in the fact that I had worked entirely in an honorary capacity at The Spastic Centre and Centre Industries for thirty years, and I wanted to continue in that way. Should I abandon my consultative practice in the sugar industry, which I had set up after resigning from the Burroughs Company in 1970 - if I took a salary from Centre Industries, I would automatically forfeit the Chairmanship of the Board of The Spastic Centre which I had held since 1945, and of Centre Industries, which was my joy because it was largely my personal creation. In the interests of The Centre, I took the only course open to me.

So we set to work. In 1974, The Spastic Centre and Centre Industries stood at the crossroads of politics, finance and technology. Inflation and wage rises leapfrogged each month, and our expenses ate into our profits. In financial terms, we were facing a hard decision. We could not afford to spend money on our medical centres, schools and two residential hostels, because, on the basis of free treatment, we were looking at \$3 million annual costs, and only the money from donations from the public to balance the budget. In Centre Industries we could, in the worst event, discharge all of our able bodied workers, but that would leave us with three hundred CP on our hands for whom we could not disclaim responsibility. It would cost us much less if we were able to retain the work output of the able bodied employees and reduce the anticipated yearly losses to that extent.

We determined that we would trade out of the difficulty. That was a bold decision, but it worked. It is still not over, but during the past nine years we have not sacrificed services to our CP children or adults, and that is something we can be proud of. Many businesses of our size went to the wall. The progress that we should have made in these years has, of course, slowed down substantially.

With guarantees from the Minister for Social Services, Mr Hayden, and Mr Enderby, we managed to find loan accommodation until after February 1975; otherwise we would have been forced to postpone the Christmas vacation until Easter - it was a close-run exercise. The Commonwealth Bank bent the rules for us, as far as they were able, and continued to do so over the next nine years, despite the changing staff of the Bank's administration. We paid interest for their accommodation at a high rate - Centre Industries in the nineteen sixties used to look for a gross profit of 20 per cent over all, and we were paying the Bank an overdraft close to that rate, but it could not be continued indefinitely. Of course it works both ways - with an organisation like ours we did not have access to debenture or shareholders funds, so we were restricted to bank overdraft rates to finance our manufacturing inventory.

The following two Treasurer's Reports to the Board of Directors for the critical years of 1976 and 1977, will give you some idea of the bind we were then in:

'This year of 1976 has been one of extreme difficulty in balancing the restriction of Commonwealth funding against the firm policy of your Board that, in spite of all difficulties, there should be no curtailment of

services to our cerebral palsied children or adults.

It has fallen to the Honorary Superintendent and her Public Relations staff to bridge the financial gap, a gap which in this year has been widened by the inability of Centre Industries to regain the profitability lost for the first time in 1974.

On the credit side, there have been some very encouraging achievements. For the first time we have obtained partial Commonwealth funding toward the operating costs of our vital Mothers and Babies Programme. The Miss Australia Quest celebrated the Sydney Finals at the Opera House, and brought in an all-time record for the year. Centre Industries achieved a record order from Telecom for \$2 million for X-bar equipment, for 1978 production. For the future Centre Industries, in conjunction with SAGEM of France, will manufacture electronic teleprinters estimated to lift CI sales by an average of \$4 million per annum, over a long term contract.

Because Commonwealth Social Security funding has been pegged to about the same dollar value for the past three years, inflation has reduced substantially the prospect of undertaking any major capital expenditure. It is expected that this position will continue for at least the next three years, and in addition there is a very real danger that our rising costs will attract further cuts from Health and Social Security Departments, in reducing their own budgets, in compliance with the Government's anti-inflation policies. We can see no prospect this time of being able to undertake Benjafield House, the Newcastle Unit, or Blacktown School. We see as our next priority the central kitchen and laundry as an essential pre-requisite to the badly needed alterations to McLeod House, expected to yield further accommodation for twenty or more children. As we all know, these additional beds are badly needed.'

And in 1977 I reported:

'The efforts of Centre Industries management, since the destructive cuts in Telecom orders in 1973, have been to retain and expand within limits all of our services to our 273 CP workers. At the same time, to build a manufacturing team with the expertise to enable it to survive and to grow in the new manufacturing technology of the future.

The alternative, of course, would be to abandon the operation and turn it into a sheltered workshop. But that would merely mean competing with our own CP children for the additional Spastic Centre funds required.

In these circumstances your Board has determined on the necessity of swallowing the unexpectedly heavy losses incurred in the past year, in the firm expectation of recovering them from developmental operations now commencing to bear fruit.

Previously CI has been largely a light engineering plant, producing electromechanical telecommunications switching equipment. Within ten years that equipment will be superseded, and to survive we must change over to the new solid state technology of electronics.

This suits us very well, because it is work entirely suited to handicapped workers and, quite as importantly, it provides us with a technical window into the new applications world of the microprocessor.

This technology offers our school CP pupils, particularly those without effective speech and with limited hand movement, an effective communication developmental bridge that is essential to their future. We are engaged on building a whole family of modular electronic devices for the children in our schools, and are delighted with the results already obtained.

In 1976, we set about obtaining partnership arrangements with large overseas multinationals who could provide the Research and Development needed for the enhancement of our future sales to Telecom and other Government Departments.

We have now entered into manufacturing agreements with an extensive French group, SAGEM, who have been successful in their tender for the new generation of electronic teleprinters, and we are now making the necessary arrangements for the initial deliveries to be made from CI from January 1979, at the rate of some 4000 per annum. Our share of the work will rise to about 60 per cent by 1982, and the contract should continue for many years ahead. This contract will not get us out of the wood immediately, but we now have a solid base for future development and are confident of the future.

This is not to say that 1978 will be easier. In the work training area we have expanded our services by restarting the Centre Industries Technical and Academic Courses (CENTACS) which we provided in 1972-73 after working hours. We do not feel that our trainees can benefit fully from study after hours in view of the long distances travelled. So under the new scheme courses are arranged during paid working hours in subjects determined by management. The existing schedule of courses includes Management, Computer Applications, Microprocessor, Cobol Programming, Elementary Japanese, together with basic training in literacy and numeracy for non-readers. Even in today's financial climate, the results have justified the additional costs.

We have also removed the comparative isolation of our medical and rehabilitation services by locating them all on the factory floor. This has improved substantially the cooperation between the engineers, therapists, psychologist and teachers, and should improve the concentration on the individual problems of each trainee.'

The SAGEM sub-contract provided the electronic expertise that we needed for its work value, and a breakthrough into the technology of the future. For our severely handicapped CP workers, it offered them speech, higher education, and all manner of other electronic training. Centre Industries' ability to take part in such advanced equipment as SAGEM teleprinters reflects strongly the reputation for expertise encouraged over the years within our plant.

Negotiations between SAGEM and Centre Industries commenced in May 1975, when preliminary enquiries were made at Centre Industries in Sydney, and I visited SAGEM in Paris. The visit was timely because the investigating engineer of Telecom, who was reporting on the future tenders for an electronic teleprinter, was in Paris at that time, and he knew Centre Industries' capacity. SAGEM then carried out a thorough investigation into potential Australian associates and manufacturers. In June 1977, the General Manager of Centre Industries, Mr Holborow, and I moved into Paris for three weeks. We had closely investigated Centre Industries' cost structure and, as far as we could gather, it matched the requirements of SAGEM precisely. It was a business game of chess in which we attempted to estimate SAGEM'S cost structure and they were intent on learning ours. Day by day, for three weeks, we slaved away from 8.00 a.m. to 6.00 p.m., and then Mr Holborow had figures he had to update, for each morning session. It was the last day, and we announced that we would be flying home the next day, when, on cue, it all came together. All remaining points were quickly resolved, and we signed the preliminary contract between us. We had previously examined, in the SAGEM factories, all manufacturing and quality control techniques, methods and practices concerning the teleprinter.

This association with SAGEM allowed Centre Industries the opportunity to become more diversified and broader based as a manufacturer; equally, the opportunity to expand its capabilities in the electronic and microprocessor technology. The comprehensive final agreement was signed on 8 December 1977.

We invited all the members of the SAGEM team to a final dinner party to be attended by members of the Board who were in Europe investigating residential hostels for our adult CP. We met at the Lasserre Restaurant in Paris. For your interest, I have notes of my speech at that dinner on 25 June 1977:

'Firstly I welcome our guests, and in order to tell you something about their backgrounds, I first introduce to you M Raboux and his wife Mme Raboux. M Raboux is the proprietor of the mighty SAGEM concern. He is a noted fisherman and a mountaineer and, in his spare time, has developed the SAGEM teleprinter, the world's first fully electronic machine of this kind. This is why this dinner party is arranged between Australia and France, bringing together so unlike organisations as a public charity, interested in the technology of electronics to provide muscles for our children, from Australia on the underside of the world, and the space age group of SAGEM.

Then we come to M Naigeon, and here is a man who can answer all of your questions about atomic energy matters, ranging from Madame Curie, without whom we may not have had electronics. And Mme Naigeon, his wife, can answer all questions about M Naigeon.

M Labergerie is Mr Raboux's most valued assistant. As a matter of fact, when M Raboux was laying on a bed of sickness in the early part of 1975, Mr Labergerie was responsible for removing the seven veils which covered the exotic body of the TX20 teleprinter.

M Alain Revion - his ownership of SAGEM sales territory extends to a great deal of Europe, the Far East and Australia; he is very rich in SAGEM'S real estate. Of course, in Australian eyes, the Far East should be the

Far North, and this includes Europe as well. Mme Revion puts up with these absences, so long as SAGEM'S sales territory does not include the isle of Tahiti

M Passemard owns all of SAGEM'S hidden technical secrets. Mr Holborow is being very very respectful to him. Mme Passemard owns all of Jean Claude's hidden secrets.

Michel and Claudette Bonnet operate a Centre for one hundred handicapped children at Marnes-La-Coquette (which I can never pronounce), and are old friends of ours. According to tradition, we first met in New York City.

Your hosts - a Study Group of Members of the Board of Directors of The Spastic Centre of New South Wales, who are in Paris at this time to investigate the residential accommodation of physically handicapped people. They are: My wife, Audrie, who is the Honorary Superintendent and the Chief Executive of the Board of Directors. She represents the soul and conscience of The Spastic Centre. She is very small, but very, very fierce.

Mrs Ness Gibbons, a member of the Board, who is responsible for administering a residential unit comprising one hundred handicapped children from the rural districts.

Mrs Daphne Martin, also a Board member, who administers a residential unit for adult handicapped people, and also deals with the social problems of Centre Industries.

Mr Jack Cotterill, a Board member and a builder who, in his spare time, controls the transport system with forty-five mini buses which transport 450 children and adults daily, over a city radius of forty kilometres. Mr Cotterill only flew into Paris from Australia this afternoon, so he thinks that this is a normal Parisian breakfast party.

I would like you to know that we have discovered one very important thing. We have discovered a way of making our Directors all work full time without paying them any salary. I do not like to suggest it to you, but it would offer a fruitful field for SAGEM to investigate.

In conclusion we have Charles Holborow, the General Manager of Centre Industries, who has accepted the challenge of getting the TX-20 SAGEM teleprinter off the ground. It is truly a formidable responsibility, but he carries the confidence and good wishes of all Board members in the task he has been given.'

The dinner accomplished its purpose, and Paris was equally kind to us. She put on a Festival and fireworks display on the river Seine. We had to wait an hour for a taxi, and when it came the driver was equally kind and regaled us with bawdy songs in French all the way back to the hotel.

Over nearly forty years, The Spastic Centre of New South Wales has operated in Sydney, and over half of these years Centre Industries, has developed comprehensive assessment and training programmes, and now has a facility to support the gainful employment of 290 CP people, in areas comprising process workers, computer operators, programmers, data input, VDU operators, planning, laboratory, quality control, cleaning, supervision, stores, accounting costing and estimating. We should have increased our CP population by an additional one hundred, but the economy did not support it.

What have we proved? That we can obtain significant productivity from the most heavily handicapped. That this is worthwhile in terms of personal worth and satisfaction. That world to people otherwise condemned to rust in front of television for ever. That engineers are as essential to such a programme as doctors, and so are accountants and most other professionals. That able bodied workers and handicapped can be mixed easily and profitably in one production line, that unions and governmental officials, outside manufacturers, and the public generally will weigh in and help anybody who is prepared to 'give it a go' and help himself, and that the community at large appreciated this. The SAGEM teleprinter that you have in your Australian office is made by Centre Industries under a subcontract, with a staff of 290 CP and 394 able bodied workers. This year's production target is 4000 units. This is particularly important for the heavily cerebral palsied worker, because they lose out in the labour market. Not because they cannot work, but because we concentrate on their obvious physical handicap, when we should be looking at their residual abilities.

In 1983, Centre Industries' sales totalled ten million dollars. From a taxpayer's point of view, Centre Industries is all profit. It will repay its subsidies to Social Services in reduced pensions, but it is of equal importance that our CP workers should have the opportunity of returning the community's investment in their childhood training at The Spastic Centre by increasing, in no small

measure, the productivity of the Shire, the State and the Commonwealth.

In 1966 we had 95 CP trainees:

Graduated into outside industry	7
In manual wheelchairs	43
Crutch walkers	12
Defective speech	81
Hearing defects	29
Normal hand	17 out of 88 persons
Impaired hand	159
Independent walkers	41
In electric wheelchairs	-

In 1984 we had 293 trainees:

Not known	
133	
38	
36 - no speech	
64 - speech difficulties	
57 - hearing loss	
40 - wearing hearing aids	
83 out of 293 persons	
503	
70	
51	

The severity of the handicap is not the determining factor in the ultimate productivity of the severely disabled person. What is of far greater importance is the learned skill that can be overlaid on the initial physical handicaps. The training procedure necessary to attain that skill is a normal problem of engineering, and the Centre Industries engineering design competence is the key factor in the success of its rehabilitation programme.

Changes will soon be on us again, as Telecom increasingly installs electronic exchanges. We at Centre Industries are facing this fresh challenge by diversifying into new products and new markets. It is broadly our intention to stay within the telecommunications field, for we have gained much experience from Telecom and the many companies, which have been associated with us.

In the present unemployment situation in Australia, the CP worker should exploit his advantage competitively, against the able bodied person. The only chance of doing so is to ensure that, when the economic picture changes, the handicapped CP is better equipped, in technical education and job experience, than his able bodied competitor. Otherwise, it is back to a pension for everybody, and the physically handicapped share of this is swamped by politics.

The CP rights carry with it a corresponding demand for responsibilities.

That the disciplining the work place demands greater levels of production from the A.B. and C.P. working together. Otherwise Centre Industries is redundant.

Letter from Eita Yashiro,

Member of the House of Councilors, Tokyo, Japan, 1976.

I had an opportunity to travel to Australia last November for the first time as a Japanese wheelchair-bound Dietman. One of the richest crop of the trip was that I could visit Centre Industries, where I met many CP workers. I would not forget their faces sweating at their jobs in the huge grounds of the factory.

In Japanese society the discriminative way of thinking – shown by the saying ‘no need to water a dead tree’, likening the severely handicapped to a dead tree – is old fashioned but still deep seated. A sense of the principle of ‘productivity first’ in the age of high economic growth also stops increasing employment opportunity of CP people.

In such a situation, I have been thinking of realisation of better environment in which anyone can use his utmost ability and devote himself to the job of his choice. The visit to Centre Industries brought me an impression that I got an answer of the problem I had put on myself. Centre Industries finds out remaining physical capacity in each person and deals with the measure of self-independence by full use of his possible physical ability.

What I was impressed most is machinery and devices modified and improved in order to enable every worker to use his own ability enough to make a contribution. They are well-considered in every part. If the user cannot use his hands, he operates them by his feet, and if not his feet, he does by other capable parts of the body. That is, it is not a man that adjusts himself to machinery, but it is machinery that adjusts itself to a man. The orthodox way of thinking of human initiative is carried out here. Then I was firmly



Lindsay Dalmon, Senior Systems Analyst

reconvinced that no one is unable. And when I saw vivid eyes with rejoicing in their labour of CP workers at Centre Industries, I felt my conviction becoming stronger.

Of course, in Australia the financial support by the disabled pension is superior beyond the comparison with that of Japan. But what I want to learn most is that the pension takes the role of a jumping board toward self-independence. If there is no effort to extend working places for the physically handicapped, and if there is no national consensus that everyone owns the right and responsibility to make an independent living, payment of the pension would be a minor and passive policy.

I most sincerely tender my congratulations to the present success of Centre Industries brought by CP people's endeavour of self-independence, Mr Neil McLeod's passion and other various factors, and I hope your lasting prosperity in the future. I myself, in co-operation with many Japanese colleagues, wish to strive for self-independence and welfare of the Japanese physically handicapped, learning from Centre Industries as a textbook.

With my best wishes for your sound health and every happiness.

LINDSAY DALMON

Lindsay Dalmon, aged forty-one years, was one of the original intake to Centre Industries in 1961. Lindsay says: 'My 'career' as a spastic began in Perth, Western Australia. At that time, very little was known about abnormal births but it was obvious from early infancy that I was not normal. My parents sought advice from doctors and specialists concerning my condition but were not given much help or encouragement. As a matter of fact, the leading child specialist advised them to put me in a home and forget about me. Luckily, they never took his advice or I wouldn't be doing what I am today.

Mum and Dad read about a Centre which had been started for spastic children in Sydney by Mr and Mrs McLeod,

so they decided to take a gamble and bring me to Sydney. I was six years old and had only just started to walk. Not many people can boast that they remember their first steps. I climbed out of my pedal car, let go with my hands and ran around a rose garden in the middle of a lawn, then fell flat on my face, laughing my head off.

When we arrived in Sydney, I was told that I would be accepted at The Spastic Centre. Like all kids just going to school for the first time, I was nervous and apprehensive, but before I left the interview Mrs McLeod said to me, "We have ice cream every Monday", and that won me over. I was eager to learn and I received treatment at the same time as doing schoolwork. I was not walking at all well, and it was not until The Centre started working on me that I showed any improvement. I was greatly intrigued when I was told that I would be getting my first pair of irons. I could not work out how they put them through my heel without hurting me, of course, when I got them I realised they were put in the heel of the boot, not through my foot.

During five years of constant physiotherapy, speech and occupational therapy, I made steady progress physically and, at the same time, progressed well in the schoolroom. At this point, I cannot stress too greatly my appreciation for the untiring efforts of the medical staff and teachers for their patience and understanding in helping me to progress in such a way, and in fact I considered myself very fortunate that The Spastic Centre was there at a time when I most needed it.

I completed primary school, and then it was decided to try something new – correspondence school – under the supervision of The Spastic Centre teacher. All my high school work was done on a typewriter, using one finger. After three years of hard work, and a lot of encouragement from my teacher and others involved I was successful in passing my Intermediate Certificate in six subjects. I could have continued my education by attempting to do the Leaving Certificate, but the general opinion of the doctors and teachers was that it would involve a great deal of effort and be of little benefit to me, as there was no possibility at that time of using this education in employment. I had come to what seemed to be a dead end. Then Centre Industries was established – just at the right time, when most of the CP who had been with the Centre from its inception needed something more than The Spastic Centre had previously been able to give them – that is, useful employment!

It was a bold venture, having spastics working alongside able bodied people. I started at Centre Industries at its inception in 1961 and was put to work as a storeman. It was a very hard but interesting time, learning to work and get along with able bodied persons. At first, there was a feeling of doubt and strangeness on both sides, but it was interesting to watch this change to one of complete acceptance as fellow workmates. While working in the store, I was trained in normal factory procedures as I, like all the other CP, had not even been in a factory before, let alone work in one; I also learnt how to accept people and get them to accept me. One difficulty I had was overcoming a communication problem. My speech is not good, but is understandable if people will take the time to listen. It took some time for the normal employees to learn that I had something to say, if they were prepared to concentrate a little harder, on what I was trying to convey. This was, and still is, a major problem faced by myself and most other CP.

After five years as a storeman, I was given the opportunity to become a charge hand in the Coil Winding Section. I found this job a great challenge as it meant being responsible to a foreman for the running of a fairly large department of thirty workers. It was a job that I enjoyed and it further increased my self confidence. I remained in this position for seven years. At the end of this time, I began to get itchy feet, feeling that I needed to do more. It was at this time that the management of Centre Industries began talking about computers. I think that this was what I had been waiting for and was fortunate enough to be included, together with several other CP, to take a course on computer familiarisation with a view to establishing an electronic data processing department. While attending this course, it was confirmed that Centre Industries would be purchasing a computer and I would be further trained as a computer operator. I was in my element.

I have now been operating for twelve years, and I am responsible for computer operations. This involves anything to do with the actual running of the computer, including work loading, logging and routine maintenance. We soon had another computer installed, for which I am also responsible. Then in 1980, the mainframe computer, a Facom M140F replaced the Honeywells, and I had the chance to switch to the programme department. In 1984 I was promoted to Systems Analyst. I enjoy this work immensely. I am very grateful to Centre Industries, which has made this possible for me.

I consider myself very fortunate in being able to take part in the Social Welfare Exchange Program between Japan and Australia in 1978. Thanks to the McLeod Society of Japan and their many helpers, for me it proved to be both a rewarding and very interesting experience.



It was the first time I have visited a foreign country and I have memories of a lovely country full of warm and friendly people. It was also the first time I have had the opportunity to meet and communicate with handicapped people of another country. It did not take me long to realise that although we live thousands of miles apart, being handicapped, we share many problems and we also share a common desire to be accepted into the normal community. I would have liked to have been able to spend more time with the handicapped.

I have so many memories of our trip. Doctor Takahashi and the wonderful children at his centre. It reminded me so much of my school days at The Spastic Centre. Doctor Ohta and Terry Teramota who looked after us so well all the way through Japan, Mrs Yoshida who was asked for such strange things as an iron and ironing board. She was wonderful. There are so many other people I think of constantly. I will always remember our trip to Tendou and the night of Koyo-en. I enjoyed very much the hot springs and the traditional Japanese meals. When I woke up the next morning, I spent about five minutes looking for my shoes before I realised that they would be waiting for me at the front door.

The highlight of the trip for me, was my first sight of Mount Fuji with its perfect cone shape covered in snow. It was fantastic, so much better than any picture I have seen.

I thought the organisation of our trip was amazing. When I saw our itinerary, I wondered how we would get through it all, but everything seemed to go smoothly, but I did enjoy our free days, especially the two or three in Kyoto. I was feeling very tired after the heavy schedule early in our trip, and these gave me time to recover. I was very excited at all the gifts I received, and now I have small bits of Japan all through my family's house in Sydney.

My mobility is not good enough to use public transport, and I have been driving my own car since 1959. This has made a great difference to my life, more than an able bodied person would realise, and now I am able to go anywhere, at any time, rather than rely on other people.

Another activity I enjoy is golf. I always felt everyone should play a sport if possible, and golf happens to be the only game suitable. Mind you, I am no Gary Player, but I am able to enjoy eighteen holes with able bodied people. Dr Reye once said to me, "Golf is a good game for CP as it is the only game where the ball is initially at rest". However, I find it most annoying when the ball remains 'at rest'.

In summing up, the big message to be learnt from Centre Industries is that CP, and of course other handicapped people, do have something to contribute to society. Centre Industries has been, and will continue to be, one of the best ways this can be demonstrated. By working alongside able bodied persons, CP can show they are able to participate in a normal way of life, given the opportunity. With the advance of technology in computerisation and other sophisticated equipment, they are able to compete even more successfully regardless of whatever physical disability they have.

My job means a great deal to me. Firstly, it gives great satisfaction being able to take my place alongside able bodied people and make a meaningful contribution to the job in hand. It enables me to use whatever mental ability I may have. I cannot imagine not having a job to go to. I would be bored stiff. It makes my blood boil when I hear, almost daily, of these damn unionists going on strike over petty little things, when I am so happy to be able to work, and there are many other handicapped people who would love to be able to work, if given the chance. Secondly, and of course importantly, my job makes me financially independent.

I was born a CP and I don't know anything else! To me, it's normal. There are many other things that an AB can do that I can't, but as I've never been able to do them, I really don't miss them. This doesn't mean I wouldn't like to be able to do them, and this does lead to a good deal of frustration. I hope this does not sound contradictory. All I can really say is that I try to make the best of what I am able to do. My lifestyle has been moulded by my handicap, and this is the only lifestyle I've had. I really don't have a long-term ambition at the moment, I just try to make the best of opportunities that come along. I have often thought, however, that I'd like to learn to fly, but my speech is not good enough to use a radio transmitter. I am planning to get married early next year, so that I will have to accept a more responsible lifestyle.'

GLEN BRAY

Glen Bray is now the Office Manager of the Costing Section at Centre Industries. Glen tells us: 'I was born late in 1946. During a difficult birth, I suffered brain damage which was to inhibit my natural mobility later in life. At the age of about six months, it was noted by a local doctor that there was something wrong. He explained that by this age my neck should have stiffened. From then on there were visits to numerous doctors, one of whom told my mother that I would never be able to learn to do anything in the normal way. He added that when I was seven years old, I would have to be admitted to a mental institution.

Finally, my mother took me to see Dr Burton-Bradley. She was the first doctor who knew what my troubles were, and shortly afterwards she was able to have me accepted by The Spastic Centre at Mosman. When I started there on a daily routine, I was only three years old. At that stage, I did not realise just how fortunate I was to be there, that in the years ahead I would have the very best of treatment available from doctors and therapists.

Throughout my school life, The Spastic Centre was the only school I attended. During my years at Mosman, there were many goals achieved. I went from a three year old who could not even sit for long, to a boy walking on crutches at the age of seven. This was done with many hours of treatment and quite a few disagreements. It was decided to tie the crutch onto my right hand as my fingers were not strong. This proved very successful and a short time later I was mobile. From almost the start, I was able to do mathematics better than any other subject in the school curriculum.

At ten years of age I started to become less dependent on my crutches. This was encouraged and aided in my treatment periods, and I could soon walk around indoors with only an occasional fall. It was about this time that I developed a great interest in cricket. I remember sitting down on Saturday afternoons watching the 1st Grade games with my parents. We always followed Bankstown. In the winter, it was soccer and later, rugby league. I was thrilled when it was decided that school sport would be played every second Thursday. We would come to school on our regular buses then change to another bus which would take us to Mosman oval. Here the boys were divided into four teams – the lesser handicapped into two teams and the more heavily handicapped into two teams. Sports played were cricket in summer and soccer in winter. I'm told the soccer match between the more heavily handicapped had to be seen to be believed – I never saw it as I was always in the middle of it.

Other great times I remember were when the school holidays came around and we were invited to stay at the Hostel. This was really the only time we got together as a class, as the children came from all over New South Wales. This was unlike other schools where the children could play together before and after school.

As time passed, school commitments took over more and more of my time. By now I was walking better, so I had to catch up on my school work. I had previously been taught to type with one finger in occupational therapy, and this was how I coped with my lessons. In 1962 I started with my lessons being supplied by the correspondence school, under the supervision of the teacher at Mosman. The highlight of that year was in the half-yearly examination when I topped the correspondence school with a mark of ninety-three in mathematics. I went on to pass Forms 2 and 3, and in the School Certificate in 1965, I gained passes in six subjects – English, Maths, Science, Geography, French and Commerce. Relating back, my geography teacher suggested I should buy a typewriter that could spell!

With school days coming to an end, the question of work arose. It was then I really discovered how difficult it was for a handicapped person to obtain work in society. It is almost impossible.

As I lived in the western suburbs, I was not looking forward to the three hours travelling per day to and from The Spastic Centre. So this left me with another field to conquer, the thing I wanted most – to learn to drive. I gained the necessary medical clearances but my parents were not too happy about my learning. I finally won, but it was to be a driving school and my mother decided there was to be no easy way out – I was to learn on a Holden with manual gears. Four or five driving instructors came and went until one finally stayed and saw it through. A short time before my driving test, my instructor realised I would need a car with a left-hand hand brake. I managed this, and passed my test at the first attempt. I was extremely pleased with this effort as most of my relatives had needed two attempts.

Meanwhile, I had started work in the Training Unit at Centre Industries. Here I stayed six weeks before being moved to the office in February 1966. Since then, my job has not so much been changed, but added to. I am now in charge of four CP, and together we compile efficiency reports for all CP and AB. The figures we compile

are used by the foremen in the factory as they show who produces what and how efficiently it is done. The calculations are also needed in the entering up of certain accounts and working out gains or losses. When my normal work is up to date, I am sometimes required to do some costing. I find both jobs very interesting and quite different.

I have various other interests and activities. I enjoy listening to pop music, watching cricket and football, going to films, playing chess and driving my car. I am a member of the Canterbury-Bankstown Leagues Club Chess Club. Last year I played in the 'C' Grade Team which tied for first place in the metropolitan grade matches. This won me a pennant which is proudly hanging on my bedroom door. I also received a trophy from my Club for the most improved player for 1976, and two books for being the second highest scorer in 'C' Grade.

If I had to name the thing which made the biggest improvement in my way of life, I would have to say it was learning to drive. It has given me an independence which I never could have achieved otherwise. I was very lucky to have a mother who made sure I carried out all instructions.

In conclusion, I would say The Spastic Centre has been the basis of my life, for here I received the very best treatment and training possible. It must be emphasised that The Centre cannot do everything – it is up to the individual to also play his part.'

MARIA TSOUKALIDIS

Maria Tsoukalidis, twenty-eight years old, is a competent operator in the E.D.P. Section of Centre Industries. In 1978, she was a member of the Welfare Exchange Group which visited Japan. Maria says:

'A single minute, to most people, may not mean much. For me, that minute almost took my life but, instead, has given me a life full of determination and courage to achieve the most normal life possible.

My determination began the day I was born. My birth would have been perfectly normal, except I did not receive oxygen for that minute. I was then placed in a humidicrib for three weeks. When I was twelve months old, my parents became concerned about my development and took me from doctor to doctor. I was unable to sit alone or support my head. It was soon discovered that I had cerebral palsy, and would be handicapped for the rest of my life. At that time my father was working with a man whose daughter was spastic and he suggested to Dad that he take me to The Spastic Centre.

My long association with The Spastic Centre began when I was two, when I became an outpatient there. Mum used to take me once a month to the Centre for treatment. I was put into long calipers and at the age of four I began to walk. Dad built long walking bars in the back yard, and there I spent many hours trying to walk. As well as this, I had a standing box which became my play pen. Mum would put my calipers on and I would play for hours in my box. My brothers were always teaching me how to play games, always trying to educate me.

I started school at the Centre when I was four. At first I was in the nursery, which was full of games, mystery and friends. Then I started my primary lessons. I was never able to spend a full day in school as my day was interrupted with treatment. During my day I was given speech therapy, occupational therapy and physiotherapy. I was taught to overcome most of my problems and was given exercises to improve my balance. In speech therapy, I spent many hours trying to overcome breathing problems which affected the output of my speech, and in occupational therapy I was taught a wide range of activities, from knitting to learning to dress myself.

After primary school, I was given the chance of doing secondary school work. At first I found this hard, as I was enrolled with the State Correspondence School and received all my lessons in note form. I soon became used to this, and studied for my School Certificate, which I achieved in 1974.

When I was eight, there was great excitement at school. A Brownie Pack was formed, from which a Girl Guide Company was developed. I was lucky enough to be asked to join. Brownies were a lot of fun, but it wasn't until I joined the Girl Guides that I began finding out for myself how exciting it was to establish relationships with non-handicapped people. This was brought about by weekly meetings with physically able Girl Guide Companies. Two of my handicapped friends worked towards the rank of Queen's Guide, the highest award in Guiding, which they achieved. This was then the goal I set for myself. I wanted to prove to myself that I could do the same as other Guides. It was a lot of hard work but also much fun. I attended camps, cooked dinner, and worked for the



Maria Tsoukalidis, at the console of the Honeywell computer in 1973.

'Save the Children Fund'. The most challenging activity was camping. In 1972, I was invested as a Queen's Guide. This was the proudest day of my life. I stood with four hundred non-handicapped Guides that day. This gave me a tremendous feeling of equality. I shall never forget stepping up to the Governor of New South Wales, Sir Roden Cutler, and receiving my Certificate with the others.

Since the beginning of 1975, I have been employed at Centre Industries. The C.I. bus stops outside my home each day to take me to work. At Centre Industries I began work in the Training Unit where I worked through a variety of tasks such as drilling holes in code plates and making 'U' plugs for the 3000 type relays used in telephone exchanges, in order to learn skills for future placement in the factory.

Despite the fact that I have been impeded over the years by several periods in hospital for extensive orthopaedic surgery, I feel I have at last achieved a level of social maturity. I have observed in present day society, feelings of dissatisfaction and inconsideration for other people. We are all too familiar with young people complaining that they don't know what they want to do. I, as a physically handicapped person, knew exactly what I wanted to do – learn to use my hands more efficiently, to be able to walk more steadily, and to achieve a worthy place in today's workforce.

In 1978, I had the good fortune to be chosen as a member of a small group to represent Centre Industries at a Cerebral Palsy Seminar in Tokyo. This involved an extensive tour of Japan, visiting centres for cerebral palsied people, hospitals, workshops and nursing homes. With the help of a highly efficient interpreter, I was able to have involved conversations with fellow cerebral palsied people, realising that we share the same problems. I always hoped to meet someone who had the same handicap as myself. I did once, and was lucky enough to be seated with her for lunch. With the help of Terry, our interpreter, we were able to hold an interesting conversation. We talked about our different types of work and social lives. I became aware, however, that we in Australia are greatly advantaged. It is common here in today's society to see handicapped people travelling far and wide, participating in athletic contests overseas, enjoying the sports of indoor and outdoor bowling, and participating in chess competitions.

In relation to my job at Centre Industries, two computer operators are employed. I am one of them, and we are both physically disabled. In March 1980, Centre Industries acquired the latest design in computers, a FACOM M140F. FACOM's modern facilities have proven to be much more appropriate for use by physically handicapped people, one of its special advantages being that the operator can comfortably work from a wheelchair. At present we are engaged in the processing of The Spastic Centre's and Centre Industries Financial Control System, which includes the payroll for employees. In addition to this, we process a complete manufacturing system which includes Inventory Management, Inventory Accounting, Materials Requirement Planning, Standard Costing and Manufacturing Control.

At this stage of my life, I feel I am in a most fortunate position. It is not just that I have a challenging and stimulating job, but that also I feel that I am making a real contribution in the Australian workforce.

I would like to mention here the pleasure and satisfaction I am enjoying during my leisure time from rug making, knitting and needlepoint. The creation of many pieces of handwork has been most rewarding.

While it is most gratifying to see the advances which have been made regarding ramps, handrails and toilet facilities in many public buildings, I hope this will continue and be extended. I would like to see the physically disabled person accepted in his own right as 'a person', not stared at as an object of pity, or our wayward movements or defective speech mocked by insensitive people. I would like to see children and young people especially encouraged to accept us all as 'people'.

I would like to offer some advice to handicapped people: Please don't be shy or embarrassed by your handicap.

My job means independence and dignity. I regard my job as part of Australia's workforce. If I wasn't disabled, I would hope to be a member of the computer industry. As I know nothing different, I consider myself as a 'normal' person, but I have to work twice as hard to achieve goals that would be easy for the able bodied. My handicap does not affect my lifestyle very much at all. I am able to do most activities able bodied people do. I am lucky – I have a wonderful family who accept my handicap and let me stand on my own two feet. My ambition in life is to be accepted by all people for the person that I am.'

CLARE WALKER

Clare Walker is twenty-nine years old and is a FACOM computer programmer. Clare has worked in the computing section of The Spastic Centre for five years. She started as a punchcard machine operator, and today is responsible for programming. She has no use of her hands, and she operates the FACOM computer via a VDU keyboard, with a head probe. She can speak, but speech is limited to a few words because of her associated spasms, probably originated with her athetoid arms, that are held down. She operates her Jyro wheelchair with the same head probe.

For Clare, the electronic era has provided not only an educational medium but also a highly valued vocation. The fact that Clare's hand function is severely impaired has not prevented her entering a truly competitive work situation. It would be true to say that Clare's work is very demanding, for not only is she called upon to use her intelligence constantly and to muster up the physical strength and endurance to use a head probe all day, but Clare must also accept the responsibility that goes with her job. Although Clare makes it look easy, a head probe makes considerable physical demands on a person, and to be able to use one as accurately and for as long as Clare does is a commendation to her desire to achieve and succeed. As she is a very determined lady, she will go on with her present programming schedule but we are looking ahead to what her job will be in five years' time, when she can supplement her programme with her individual mental shortcuts.

At the same time Dr Neilson has Clare in his ATR laboratory twice a week to see whether he can correlate her functional control from the biofeedback results, from the muscle spasm and uncontrolled athetoid movements. It may be of interest to you to learn that at weekends, Clare spends her free time exchanging her wheelchair for a horse, and she does not need her wheelchair when she goes sailing in her catamaran with her brother on Sundays.

Of her job at Centre Industries, Clare says, 'My job is very important to me, because without it I'd go off my brain! It offers stimulation, friendship and job satisfaction. To me, being a spastic is the norm, but it affects my lifestyle in that it makes me dependent on other people. The fact that I cannot use my hands means I have no privacy;

for example, everyone knows what I have in my handbag. And because of my handicap I am denied time by myself, something which everyone needs.

However, in spite of this limitation, my ambition is to enjoy life to the full!’

Note: Clare has announced her engagement to Geoff White, another programmer and, as well as continuing in her work at C.I. she has enrolled at the Sydney University as a first year psychology student for two days a week.

MICHAEL DAVID

Michael David is twenty-five years old. His life has been a constant struggle, but now he has a promising career in front of him as a programmer. Michael describes life and his work in the following way:

‘Programming may be more difficult than driving a car, but certainly much easier than flying an aeroplane.’ This was the first thing we were told by our lecturer at the introduction lecture on computers at the course in which I was enrolled. In the past, there were many periods of my life which were much harder, and where my adjustment and advancement was not as easy as it was this time. In order to make myself understood clearly, I have to tell you about my past.

I was born in Russia with some disabilities. At the age of four, I began to walk and three years later I attended normal school. It was difficult for me to follow and to concentrate during lessons, because I was unable to write as fast as other students did, but with help I could continue to study until my family decided to emigrate to Israel.

We went to Israel when I was nine years old. In the beginning, I went to a special school, where I was taught Hebrew and slowly prepared to go to normal school. At this stage, I must admit that it wasn’t easy for me to be in a class with pupils who had no physical difficulties. I had to face not only the problems of ordinary students, but I also had to battle with special difficulties such as concentration during lessons and writing. To overcome those difficulties, I had to work very hard and try to give everything I had to keep up with other students in the class. My school career was successful and I continued to attend school until coming to Australia.

When we arrived here, I had to face new and old problems. A new language and new environment, in addition to my special disabilities, were my major difficulties. My hearing problem was more intensified as I did not know the language. In spite of the fact that I have been given hearing aids in order to hear better, I still suffer great difficulty in communicating with the people surrounding me. After our initial stay here I was enrolled at Vaucluse High School, and had some success, particularly in mathematics. I had difficulties in other subjects, and because of that I was sent to a special school for migrants, where the main object was to learn English. My progress at that school was satisfactory and my English improved reasonably. I had to decide whether to return to school and study for a High School Certificate, or to pursue a career. At that stage it was difficult to make up my mind, because I was worrying about my success in both fields. After obtaining the opinions of other people and being given the opportunity to join Centre Industries, I decided to join this organisation in the hope that I would be able to acquire a profession there.

It was three years ago when I started to work in C.I. My very first job was to do simple office work. I used to get bundles of invoices which I had to sort out. I did this work for a week only, because it was difficult for my hands to sort a great number of documents. I had to get used to an office environment, and did not possess enough knowledge of English. After the first week of my employment at C.I., I was transferred to the Computer Section. Due to the results of aptitude tests, which I did at the Education Department as well as at C.I., I was hoping to become a computer operator, but I had to wait until training was available. My next job was as a punchcard operator in the Computer Section. I was very pleased with myself and tried to work as hard as I could. I felt at that stage I could utilise myself much more effectively, if I would be given the opportunity to do so. I was waiting for the right time. In the meantime, my interest in computing increased and I began to read some books about it. I have to admit that at that stage my aim was still to be a computer operator.

After two years of working as a punchcard operator, I was told by my E.D.P. manager that I had all the potential to become a computer programmer. I was very happily surprised by his acknowledgement. I knew that I had to go a very long way before I achieved my aim, and if I did not work hard my dream would not be realised. I started to read a lot more about computer programming and, with the help of an English teacher in C.I. and friends in the E.D.P. department, I was able to prepare myself for a computer programming course.



I attended a course for people who have any interest in the computer field generally and particularly for those who wish to become programmers. The first days were very hard because of my special difficulties which I have mentioned already, mainly hearing, concentrating and writing. I worked hard, applied myself as best I could and, with the help of the staff and students, I was able to improve my knowledge in that subject, and after two or three weeks I had almost no worries. Writing was the only difficulty which neither myself nor anybody else could help, so it took me very often four to five times as much time as it took the other students to write a programme. I knew that I must help myself in this matter, and the fact that I started to like to work with computers made it more enjoyable to work, sometimes until midnight. The students, including myself, used to make mistakes sometimes, because of misunderstanding the specification, and carelessness. I was unable to think of all the possibilities that existed in a particular problem. Therefore, I studied very carefully and tried to solve the problems by myself. I began to ask other students' advice and tried to remember their solutions. After four months of hard work, but a very enjoyable time, I managed, as did most of the other students, to finish the course successfully, and most of us were able to find jobs in the computer industry.

I was back at C.I.'s computer section, facing very serious problems of acclimatisation to new type of work that I had to do. Suddenly, I felt that in spite of the fact that I made progress in programming, I was seriously affected by my special difficulties, such as slow writing, unable to concentrate for longer periods during working time and as a result of having problems in English and unable to hear well, I could not understand other people, or was misunderstood. At that stage, I had the feeling that I needed some help, because I had very little experience in computer environment, and I was very shy and did not want to ask questions at all. After a few weeks I had some very serious problems in my first programme that I did in C.I., leaving myself with no choice but to ask for help, and discovered nice and helpful staff people with whom I have been working. I won't forget how they were trying to help me find solutions to my problems and explained how to use the hardware facilities available. After studying their suggestions, I developed my ways of writing programmes, and also adapted myself to standards of the systems that they have been using. After a short period of time, I found a way of facing and overcoming my special difficulties, so instead of writing new programmes I simply copy an existing one and alter it to comply with the requirements of the specifications, and as a result of finding the solution to my writing difficulty my concentration has improved considerably. Instead of spending time and effort in writing, I can use the time much more effectively in solving programme problems. In order to improve my English, I enrolled in a correspondence course and slowly I feel that I can express myself better than I did in the past. Overcoming those problems not only improved my ability at work, but increased my interest in my profession. The fact that I have been able to enjoy myself during work has also affected my progress at work, and has been the cause for trying to work hard. I must be thankful to The Spastic Centre for giving me, as well as other disabled people, the right opportunity and supporting me in my progress.

I can say that my dreams of the past are reality now. My success gives me a lot more support to try to improve my ability in every way, because my aim is to work as any able bodied person in the workforce, and I hope my computer knowledge, education and experience will enable me to do computer work in the computer industry.'

GEOFFREY WHITE

Geoffrey White, aged thirty-one years, walks with crutches, yet drives his own car. After commencing work in the Training Unit, he was transferred to E.D.P. Programming in 1973 and progressed so well that in 1978 he was transferred to full award conditions. Geoffrey says, 'Many people attribute to disabled persons the qualities of great determination and inner strength. While I have known many people during my life who have possessed these qualities, I make no claims to having them myself. I believe I have reached my current employment position through a combination of good fortune, a certain amount of natural ability, but most of all through having the help and encouragement of the right people at the right time. Something which all of us need.

When I was born in October 1952, the doctors declared that it would be only a matter of time before I died, as I had been born with cerebral palsy. Doubtless their prognosis was correct, however, I sincerely hope that the 'time' does not come for another fifty years or so.

I did survive those early days, and at the age of three or four was taken to see and, more importantly I suppose, be seen by, an orthopaedic specialist. He put me in a brace to straighten and strengthen my back, and in boots and calipers in the hope that I could be taught to walk. It seems difficult to believe, but as recently as the mid-

fifties the existence of organisations such as The Spastic Centre and The Crippled Children's Society was not widely known. As the Northcott School for Crippled Children at Parramatta was closer to our home at Epping, my parents decided to try there first. Although I was not quite five at the time, I still remember the interview with the social worker at Northcott. There was a minimum I.Q. requirement and one of the questions she asked me was, "What colour is your jumper?" I replied without hesitation, "It's not a jumper! It's a cardigan!" Despite this, I was enrolled, and spent all of my school days at Northcott.

The days spent at Northcott were not only taken up with regular school work. Time off was regularly taken from the classroom, in order to undergo physio, occupational and speech therapy. I am fortunate in having a right hand which is capable of performing most of the normal functions, and a left hand which is good enough to be used in most of the day to day tasks which require two hands. I am also more fortunate than many people with cerebral palsy in that, providing I am relaxed and giving some thought to my speech, I have little difficulty in communicating with others.

At the age of six, with regular physiotherapy and a lot of encouragement, I began walking unaided. Slowly, unsteadily, and only on level surfaces, but unaided. My walking improved gradually until, when I was nine, my doctor performed an operation on my right leg. I was off my feet for some time after this and never regained the confidence or stability that I had previously had. I tried various walking aids, including walking sticks and a full length caliper, but it wasn't until I was fourteen that I found true mobility in the form of a pair of 'ring-top' crutches. These are a sort of hybrid, a cross between the conventional full length crutch and the Canadian crutch which fits around the arm just below the elbow.

After four years, I managed to scrape through my School Certificate examination. However, the tedium of correspondence lessons, combined with the lack of any clear goals and a long stint in hospital for more orthopaedic surgery, put paid to my ambitions of gaining my Higher School Certificate. By the middle of 1972, at the age of nineteen, it was being suggested that I should look for employment, and Centre Industries was cited as my best chance.

I was not happy to say the least, and initially stayed at C.I. only because there seemed no alternative. Fortunately for me, my commencement at Centre Industries coincided with the creation of their E.D.P Department. Within six weeks of starting work, I was given an IBM Aptitude Test and was offered a position in the new department.

I attended a course in Mini-Cobal Programming for the G58 Series computer, with its very small (5K Bytes!) basic central memory capacity.

The arrival of our first Honeywell G58 computer in November 1973, unfortunately coincided with yet another trip to hospital for more orthopaedic surgery. I was installed as a full time operator. For a few months during the middle of 1975, I was made Senior Operator, while the other operator was involved in a system design project. Upon his return, we started working staggered shifts, and in early 1976 we upgraded our original computer and bought a second G58. A third operator had been trained.

My only formal training had been the two week course in 1973, and although I had dabbled in programming in my spare time, I was by no means confident as to my ability. In fact, I only agreed to this proposal because I did not like to think of what the alternative might be.

With a lot of help and encouragement, particularly from our Systems Analyst of that time, I began my programming career. Upgrading our computers had meant a switch to 'full Cobol'. I made the transition from Mini-Cobol by constant reference to the Cobol manual. On one occasion I modified a 'Gesal' programme, Gesal being the assembler language used on the G58 computer. The programme is still working, rather more slowly than it used to, but without the previous 'bug'.

I have worked on most of the systems operating on our G58s including Manufacturing, Purchasing, Engineering and Financial Systems. Although concentrating more on the 'non-Financial' systems, I was responsible for the detailed specification, and most of the programming, of a new Creditors System transaction 'module'.

In 1978, Centre Industries won an important contract to modify, then assemble, and eventually manufacture, a French designed teleprinter for Telecom, our biggest customer. Due to problems with disc-pack capacities on our 58s, it was decided that we would create an entirely separate data base for the Teleprinter Project. Due to my overall knowledge of our manufacturing systems, particularly from the operations side, I was given a fairly free hand in setting up this 'second system'. I was responsible for determining the number of disc-packs required,

allocating files to packs, calculating file sizes and 'initialising' those files. On the programming side, I carried out many of the modifications, ranging from simple heading changes to include the word 'Teleprinter' through to changes in Purchase Order Categories and the manner in which they were processed.

It had seemed like the 'elusive dream', but in March 1980, Centre Industries took delivery of a FACOM M140F computer. While not in the "state of the art" class (no laser printer), it is a modern and very powerful system. Our Honeywell machines have a central memory capacity of 10K bytes each, can only handle single 'batch' job processing, and all virgin input is via punchcard. Compare this with the current 1.5 megabyte memory capacity of the M140F, multi-tasking and the capacity for interactive processing. There are no card readers, all source input being through visual display terminals, of which we have nine, six in Data Entry and three in Systems and Programming.

The course was an introduction to the operating system, and dealt largely with Job Control Language. I have since repeated this course and twice attended a series of courses on Data Communication Programming and Systems Design. So far, I have written only four or five batch programmes, am lost with all but the most simple JCL statements, and get a real thrill out of getting a Systems Utility programme to work. I am presently tackling my first Data Communication programme.

There is a tendency for those in the computer industry to change jobs fairly frequently. This can cause problems for the disabled employee, particularly if he or she is restricted to one place of employment, either through physical restrictions or lack of self confidence. The departure from your daily life of somebody with whom you have declared a close relationship can be very hard to accept. An obvious counter to this problem is for the disabled person to have a reasonable number of friends outside their work environment.

The most obvious benefit from my job is the income I receive, which is essential in the quest to obtain a degree of independence in my way of life. It also enables me to demonstrate, to myself as well as others my ability to compete on more or less equal terms with able bodied people and make a contribution to the workforce. The knowledge that I am an integral part of a team, working towards common goals, is also of great importance to me.

There are often occasions when my inability to do, or difficulty in doing things that other people take for granted, can be very frustrating. Coping with the misinformed attitudes of many people in the community is also a fact of day to day life. Ever tried playing soccer on crutches? Neither have I. I guess there are things in everybody's life that they would like to do but cannot. It is just that for me, the 'can't do's' often seem to outweigh the 'can do's'. When going somewhere new there is always the question of accessibility; when trying something new there is the worry of whether I will be able to cope.

However, I think the real answer is my handicap affects my lifestyle only as much as I let it. My ambition in life is to find the goals which mean something to me and to reach as many of them as possible. Independence and equality are fundamental parts of any goal!

GREG PIKE

Giving the viewpoint of a handicapped worker, Greg Pike, aged thirty-five says: 'I would like to outline my experience in entering industry before expounding my own personal views on this topic, as I feel much of my own feelings at that time would be shared by the majority of the disabled.

At the age of eighteen, with secondary education behind me, I faced the problem of employment. Having attended The Spastic Centre school, a logical source of employment was Centre Industries, where I commenced in January 1967 as a trainee in the Training Unit.

From this transitional area, I was transferred to a drill line. This was my introduction to working side by side with the able bodied worker. I achieved satisfaction in the challenge of producing the same work rate. After six months in this section, my next position was the millroom, where the work was physically harder. Here I found myself unable to maintain the rate of the AB worker.

This was a period of much frustration for me, and when it was suggested that I may prefer to transfer to the Electronic Laboratory, I readily accepted the challenge. In this section, with full encouragement from my departmental head, I developed an interest in electronics. This prompted me to take the appropriate technical training. I completed this course in 1977, being the first candidate to complete the Electronics and

Communications Certificate without writing one exam, this being due to my physical disability. I had to enlist the aid of a writer, who had to sign a Statutory Declaration which had to state that he or she had no more than a layman's knowledge of the subject.

After three years in the Laboratory an opening arose for a Quality Control Officer in the Semiconductor Division, and I was appointed to this position in 1972. At that time, I had reservations about how the AB workers would react to a CP person being in control, but I soon realised these reservations were unfounded. My staff accepted me as an individual, and I managed to maintain a very efficient department.

During this time, I completed my electronic course as well as a Quality Control Course, which added to my general qualifications and put me in direct conflict with my immediate superior. In 1978, the position had deteriorated to such an extent that I had no option but to leave, as all job satisfaction had long since disappeared. I have now joined the self-employed, participating in a company with my father and brother; although it has nothing to do with what I had been trained for, my training stands me in good stead for the challenge of running a small business.

For the disabled person from a previously sheltered environment to be thrown into competition with industry workforce, difficulties and frustrations can follow, as has been my experience. In my opinion, this arises from initial feelings of inferiority which are instilled in the disabled person, either through early experiences in childhood, or from realisation of physical limitations. In order to overcome this obstacle, preliminary training of the disabled person is essential.

In my own case, the frustration created in the millroom was neutralised by the encouragement given to me while working in the laboratory. This motivation enabled me to accept challenges, which I would not until then have considered. It is my belief disabled people need greater motivation and guidance in order to develop their capabilities. To accomplish this end, they should be encouraged and praised when they succeed in overcoming barriers. Higher goals should be set, and if the occasion arises, they should be allowed to shoulder responsibility.

I feel it is very important to educate the disabled and welcome responsibility, because this generates a feeling of pride, satisfaction and high morale in their job. I remember the first job assigned to me in the laboratory was the design of a printed circuit board. This facet of laboratory work was completely new to me, but I did not allow this problem to defeat me, and within a few weeks the task was completed. I was highly elated at this success and realised this exercise served as an indication of my potential.

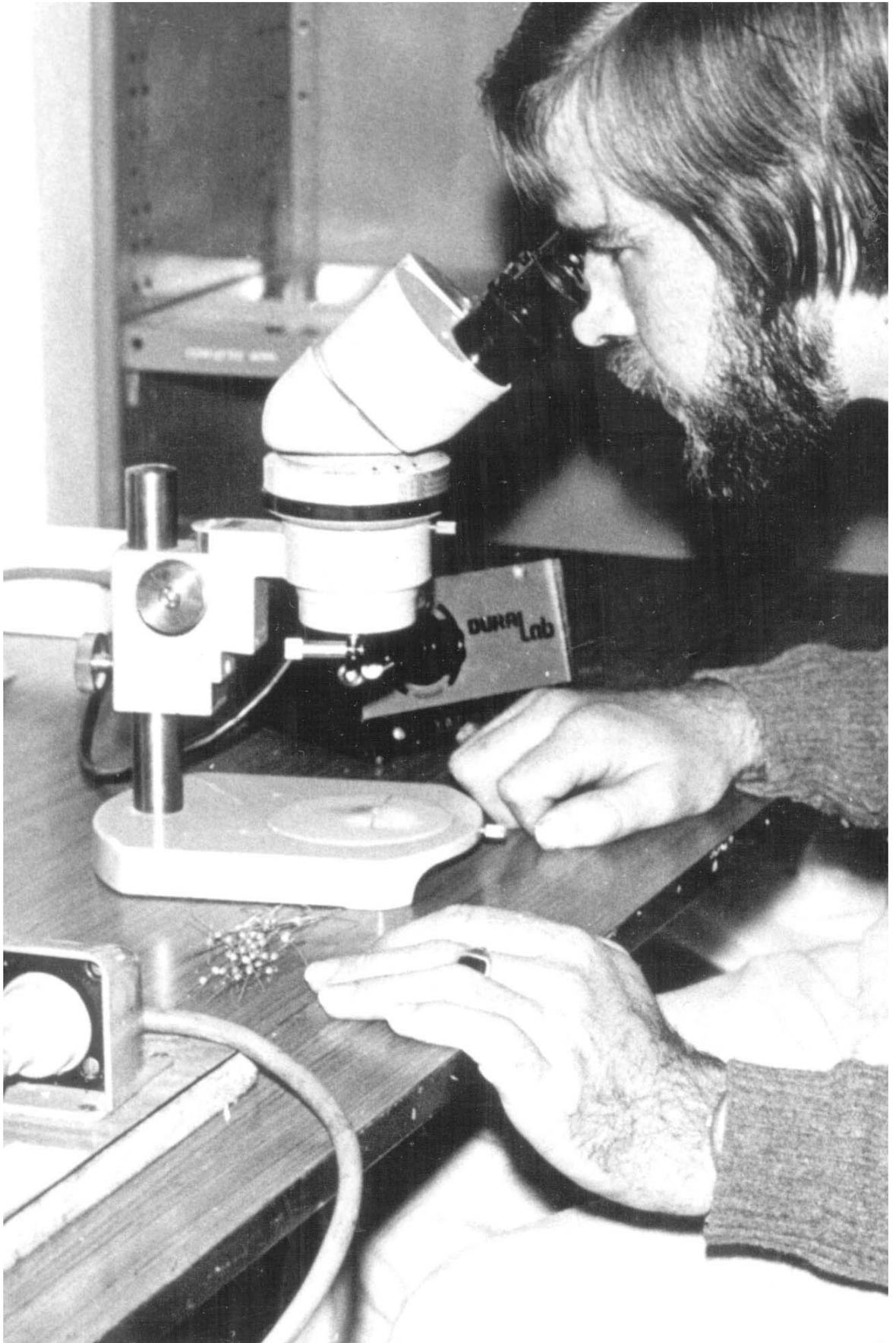
We all know the thirst for learning is a very demanding force in everyone, whether it be to learn about history, cars, ships, our job, or sex, an active human mind is always searching for more knowledge. One of the key factors in motivation of any person is education as to WHY he is doing WHAT he is doing. The disabled person is no different. In fact, he is probably more eager to learn about his job than the average worker.

I think more disabled people should strive to improve their capabilities in industry through tertiary education. With assistance of the government, this could be implemented by means of such aids as extended time in examinations, oral examination papers, use of calculators and typewriters.

The fact that I have always been treated equally, both at home and socially, has helped me to adjust to the industrial atmosphere. Interaction with the able bodied is the best working environment for the CP person to compete, but a greater sense of fulfilment can be earned by endeavouring to reach the highest goal possible. As someone once said: "A quitter never wins and a winner never quits".

We live in a very exciting era, with man taking giant steps in science, medicine and social reforms. In the last decade, we have seen an American walk on the moon, a South African transplant the human heart, and the western woman liberated from her so-called bondage. It gives me a very proud feeling to know that here in Australia we are one of the leaders in the world of rehabilitation, with places such as Centre Industries, which I understand was the first of its kind in the world to attempt the integration of disabled and able bodied people into a productive workforce.

Let us hope that with the help of the Australian people, this ideal will one day reach fruition. There is a lot of work ahead and in the present economic climate where unemployment is rising, let us hope that this ideal will be kept alive by keeping the handicapped in employment, and not to sacrifice what has been achieved to satisfy a selfish minority. For, in the words of one Australian writer, we truly live in a 'lucky country' – let us hope it stays 'lucky'.



Greg Pike, Quality Control Officer for the G.E./A14 diode operation.

Advanced Education 1972

We have been searching for the Holy Grail of cerebral palsy for the past forty years. Our search has embodied all the many pathways of education and medicine that have emerged in those years.

From the antibiotics of the war years – to the CAT scan of the nineteen seventies. From the RH blood groups, the radical orthopaedic surgery, splinting of the nineteen fifties – to the neurophysiology of the nineteen sixties and seventies. Last of all, from the Mothers and Babies Programmes of early treatment – to engineering and employment of cerebral palsied in Centre Industries in the nineteen sixties and seventies.

We were always conscious of our total inadequacy for this search, but as long as our children, with all their tremendous handicaps, were prepared to fight on, we could do no less. Like all parents, we were searching for a magic answer. Microtechnology is not magic, but for the CP it is an excellent substitute!

Everybody can work. There are no limits by the severity of physical handicap that education, training and adaptation cannot meet. This leaves a problem that can be solved by the use of standard techniques of technical engineering and rehabilitation therapy. In factory work, however, the CP workers are competing with their impaired hands against the sinews of able bodied workers – they can be more faithful, work harder, be more careful, have fewer rejects, but in the final analysis they cannot work as fast.

What they can do, however, is to compete where they are not handicapped, substituting intelligence for hand function. Competing with 'know-how' at sophisticated levels, and aided by advanced education.

At The Spastic Centre our children are surrounded by the loving care of their parents, but babies grow up very quickly to be adults, and this is an adult world. Spastic babies are children for the first twelve years of their life, and then they face fifty hard years of survival as an adult. They are fated to spend the later years of their lives without the assistance and care of their aging parents. They must prepare in advance for an independent lifestyle, before it inevitably happens.

For the adult handicapped CP, especially, daydreams are an essential ingredient of future success in mastering the disability, daydreams in which they perceive the certainty of attaining a chain of small successes, set against the risk of sustaining a heavy defeat in the first major adult objective, that of work. Learning is not dependent on age. If you have the motivation you can do anything, but you need the discipline of employment to drive you along. Equal in importance is the need for intensive adult education, to make up the gaps in CP education which has been erected by his slower-paced learning, due to defective speech and other handicaps and the hours lost by surgery and therapy.

Unemployment and lack of opportunity to participate in life's activities, socially or educationally, may be difficult for many of the able bodied who are out of work, but this, surely, cannot be compared to the frustration suffered by a CP who is seriously disabled,

when faced with permanent uselessness. Even though social and cultural values are ignored, and human happiness and independence do not have a dollar value, on economic grounds alone, the CP must be given their chance.

Previously, we thought that walking was the principal target of the CP medical therapy. Now we realise that lack of speech is the major hurdle. Most of the CPs are unable to speak intelligently to a stranger, but can make themselves understood among their familiars. They may have limited hand function, and they may need to use a head probe instead of their hands; they may be deaf or hard of hearing, but our heavily handicapped CP have proved that standard industrial training practices may validly be applied to the handicapped. In Centre Industries, our CP trainees have been accepted without difficulty in the normal world of the able bodied worker.

Since 1948, we had been using three old IBM electric typewriters in our schools, and an electric Burroughs bookkeeping machine adapted so it printed alpha letters instead of figures because our CP children had difficulty in using a manual typewriter keyboard. In 1958 when portable electric typewriters came on the market, Miss Brereton used them for our CP children who were unable to form the letters by hand. In 1963, our speech therapist, Miss Grace Ellis, at our Mosman school had the idea of using a clockface with moveable hands upon a face of alpha letters. It was a fairly primitive idea, and at Centre Industries we improved its function, by an arrangement of relays to point to the letters in question. Then we added a light for an indicator, and arranged for its return to the 'home' position when the appropriate letter was struck on a pressure switch. We finally evolved a device, based upon the electricomechanical relay, and were successful in designing and manufacturing the Clockface Selector. This provided the mechanism, which replaced the electric keyboard as a means of operating a power driven typewriter. The next step was to electronically replace the keyboard of the typewriter or microcomputer altogether.

In 1968, we started to inject adult education into the CP area. We set up CENTACS (Centre Industries Technical and Academic Courses), a school operating from the shop floor, aimed at improving the low standard of adult CP education in the past years.

We were unable to use existing Technical Schools because of stair traffic, slow speech, and the absence of special staff and transport arrangements. We thought that the Technical Schools could assist us in our planning and also the provision of teaching staff. However, they displayed a callous disregard, saying that they had limited funds to meet their own Departmental needs. A submission to the Board of Adult Education met a similar fate.

At Centre Industries, we were then on the threshold of a major change from metal fabrication to electronics, via the printed circuit board. It was steadily becoming apparent that we had gone as far as we could go in mechanical answers to our rehabilitation problems. For the first time in history, engineering technology was moving towards rehabilitation of the physically handicapped CP, and we hoped to share in that. The future of CP people is changing rapidly by the introduction of microtechnology - we must educate and train them to meet the new challenges of the electronic field. Technical education for the able bodied is important - for the cerebral palsied it is vital. These are intelligent people whose control of various muscle groups is impaired, and who may have associated difficulties in speech and hearing. Some may have no hand movement at all, but can walk, others in a wheelchair, can rely on a head probe or a switching device operated by their foot. Most have been debarred by their disabilities from a normal education.

We set ourselves the task of entering a dynamic world of electronics in 1971, with a proposal to manufacture the A14 and the A15 diode for the General Electric Company in America. Correspondingly, in 1972 the General Telephone and Electric Company engaged Centre Industries to manufacture radio microwave units for Telecom. These two projects were well worthwhile, because they encouraged our CP to take a role in the microtechnology of the future, and introduced them to the printed circuit board (PCB).

Then in 1975, negotiations commenced between Centre Industries and SAGEM for production of the SAGEM teleprinter by Centre Industries under sub-contract. Australian production started in February 1979, with an annual target of 4000 TX-20 teleprinter units.

The importance of the new technology is to understand the implications, particularly for the severely handicapped CP. Cheap, simple and readily available Micro devices are already on the market. It is our responsibility to make use of them in education, at primary and technical levels, in the problems of speech, deafness, hand function, work training and functional assessment. Today, our CP can operate a wider range of devices, due to the introduction of a variety of sensors, which activate the equipment by responding to light, heat, or friction, setting off an electronic impulse. So that a single nod of the head, or even the blink of an eye, provides the signal to operate the equipment. Very many of the longstanding communication problems can be solved by the increased use of computers, display screens and appropriate sensors. This opens up a new world to the CP. For these, microtechnology offers not just hope, but real opportunities to change their whole lives.

Unfortunately, in 1974 in Australia, we were entering upon a ten year cycle of increased inflation and unemployment and economic doldrums. So those years, which should have been rewarding years for many of our CP charges, have been eroded by the economic locusts.

At Centre Industries, apart from the production work of the factory, we have had outstanding results from the introduction of CP into our computer department. In 1974, we installed a Honeywell punched card computer, which gave a tremendous boost because it appealed to the more heavily handicapped, who were unable to achieve productivity in the factory lines for want of an effective hand function. Because of the CP success in adapting to computer usage, we duplicated the Honeywell installation in 1976. Today twenty CP workers service the Facom M140F, a computer installed in 1980; it is pleasing to note that these are among the most heavily handicapped. It has proved to be a most important step in rehabilitation of the cerebral palsied. It removes the card punching, and subsequent card reading and sorting, and replaces it with the VDU (visual display unit) which is used for programming and data input. It is a joy to operate, because it is built with every operating control at wheelchair level, including the tape machines and the Hi Speed Printer.

We know that our cerebral palsied are capable of being 'stretched' beyond the demands that their past work performances have made upon them physically, and intellectually. We know that they react well to the challenge. We are prepared to plan on the assumption that they can do more and better work than they have previously accomplished, that they will continue to be happier and more responsible, under an increasing load of work and responsibility in the future.

May I reiterate that the development of the space age technology of electronics has made a wonderful world possible for everybody, but for the CP it has proved to be a vital component of the real rehabilitation in education, neurophysiology, and employment. We have not made use of it as we should have done because of its high cost, and every day's delay means, in humane terms, a day of further unnecessary imprisonment for the CP person.

Can I now take a peep into the future that affects every CP worker: At Fujitsu Laboratories in Japan for the first time in the world was fabricated a new type of transistor, called a High Electron Mobility Transistor – HEMT. Fujitsu assess the speed characteristics of the conventional transistor thus – a Silicon Field-Effect Transistor, SIFET, possesses the speed of a motor car, 50 km per hour; a GaAsFET has the speed of a Bullet train, 250 km per hour. A HEMT device has the speed of a Boeing 747, 1000 km per hour; this will be used in computer logic elements and memory about 1985.

Fujitsu are also applying the HEMT techniques of Molecular Beam Epitaxy, MBE, to developing microwave and fibre optics semiconductor devices. They are also making a major effort in the field of Josephson junctions, to introduce computers with switching speeds, more than ten times faster than today, but it will also have power dissipation characteristics less than one-thousandth of today's computers. The Josephson computer will be as small as a shoe box and will be housed in a special refrigerator, because it must operate at minus 100°C.

Corresponding advances are being made in software. The computer will need no special language or code on the part of the operators – just normal speech or written characters. It will translate, say, from English into Japanese and, instead of a written programme or sets of instructions on how to solve a problem, it will create its own software or solution path to fit the data given to it.

How does this hyperbole affect our CP, at present working in the computer section? Five CP have been trained to programme the mainframe computer and one has recently been promoted to Systems Analyst. Two share the responsibility of operations, and even the most heavily handicapped CP can provide on-line computer input for data preparation. As they do not have the deft fingers of the able bodied, they use a head probe, or one finger control, to insert information. All the data preparation for the whole organisation is handled unassisted by cerebral palsied operators.

Microelectronics can help CP with special needs. It includes educational programmes for the classroom, speech, deafness and hand function, and is limited only by our lack of foresight. Microelectronics cannot replace the skills of the trainer in planning the learning programme. This is a highly complex and critical aspect of special education; microelectronics serve in this process, they cannot replace it. If we employ the computer as a servant, we have to be clear in the orders we give it. Technology is compatible with a personal caring approach. It will be used by the teacher and therapist only as an extension of their own skills.

Centre Industries has an electronics laboratory with all necessary facilities. So when a CP is faced with a lack of hand function, we can replace the conventional keyboard with a circular scanning device which is our own design. It includes all the figures and letters of the alphabet, and appropriate control functions are ranged in a circle, each illuminated by LED lights. These are divided into eight sectors, each of which has eight positions. So that two operations of a switch can give each one of the sixty-four digits. This has opened up avenues for many CP, previously denied communication through lack of ability to use a conventional keyboard.

If hand function permits, a simple pressure pad switch is required for the input to the typewriter or microprocessor. Deaf people can use the scanner, but the hard of hearing pupils have successfully used it by making use of a tonal variation for the sector and the final digit.



In eighteen year old Adam Rennie's case, exhaustive tests were carried out to find a muscle in his body which we could use on a biofeedback basis, to replace his lack of hand function. The researcher detected an imperceptible movement controlling the base of his left little finger – a muscle flexor of 5 mm was enough. The biofeedback switch detects changes in electrical potential in a muscle of Adam's hand. An electrode is attached to either side of the muscle and a third acts as an earth. The change in electrical potential is detected by the electrodes, so that when he moves his finger imperceptibly the switch is operated. Adam has an additional problem; his neck goes into a spasm to the right (TNR) and he can no longer see the scanner. Adam is completely without speech, so he must carry a picture of the scanner in his mind. He has been using this switch for almost two years. The switch was developed by the Action Reflex Laboratory at Centre Industries. It is anticipated that in the near future, a voice synthesiser will be attached to the scanner so that Adam will be able to hear immediately what letter he has typed and, if necessary, correct it. The electrodes and a biofeedback meter were all he needs to communicate with his world. This is a practical application of the biofeedback principle. His speed of input is automatically handled by the computer, so he can work up to high speed on a good day and, when he tires, the speed of input is automatically slowed down.

Kim Brierly operates the same scanner using a touch switch. Kim is twenty-six years old, with very limited speech, which she makes up for with a brilliant smile. Prior to the development of the scanner, she was unable to type at all. Kim uses her chin to operate the switch and must put a lot of effort into typing even a single word. However, the effort is worthwhile for both Kim and Adam, for without the biofeedback switches and the scanner, they would not be able to express themselves very well at all. Despite the fact that Kim and Adam are severely handicapped, both are quite active intellectually, and it is only through the use of this electronic equipment that they are able to further develop their intellectual skills and demonstrate their abilities and knowledge to the world around them. They quite admirably demonstrate the possibilities being made available today at Centre Industries. Both of them are very severely handicapped, and electronic technology is offering them a future very different from the one they both would have dreamed of years ago.

The scanner can also be attached to the computers, enabling very handicapped people to carry out their own academic pursuits or recreational activities without requiring a person to act as a scribe or assistant.

Dennis Stabback who, like Kim, has limited speech, uses his head probe with a conventional keyboard. Dennis uses a word processor disc to prepare the news journal that is distributed throughout Centre Industries. Dennis is thirty-four years old and has been taking considerable advantage of this piece of equipment over the last few months. The word processor disc enables Dennis to independently correct and edit his own work. Without this piece of equipment it would be necessary for Dennis to constantly require the services of another person to assist him with his work. Unlike Kim and Adam, however, Dennis has the head probe to type on a conventional keyboard. The value of this independence to a man of Dennis's intellectual ability cannot be overstated. Independence, that allows a person to sever some of his reliance ties with other people, is an immeasurable gift. He operates his electric wheelchair with his head probe, fitted onto a cup on the joystick. Dennis also uses a Cannon communicator to communicate with people; his communicator enables him to type a message and provide his 'listener' with a written copy of whatever he has typed. Once again, Dennis uses his head probe to operate the communicator. For Dennis, not having hands that he can use, and not being able to talk, does not prevent him from communicating and pursuing his interests as a reporter and editor of the Centre Industries monthly journal. Not being able to speak gives him far more time to listen to what other people are saying. Time to understand, and reflect on what has been said.

At Centre Industries, by using modern technology in their own training school and in their production line, they have been able to utilise the disabled workers' productive abilities. It is most important to train them to work in the technological arena. These people demonstrate the marvellous opportunities that electronic technology now offers to the heavily handicapped.

Thus we take pride that our CP are exploiting, instead of being exploited by, the very technology which many people fear.

In the short time that microprocessors have been available, two streams of development have emerged. On the one hand, the microprocessor has permitted the creation of sophisticated devices such as the modern teleprinter or teaching aids for the handicapped, while on the other hand it has provided comprehensive business systems which can handle the requirements of a small business, or be used on a departmental basis by larger organisations.

We have an interest in both fields, since we can see a large number of aids for the handicapped which can be created around the microprocessor, and at the same time we see that handicapped people might well be trained as computer operators around the small business system. In both cases, the need will exist for programmes to be written, and this would provide another avenue for the employment of the handicapped.

Since the formal mathematical education of many disabled people is poor, we are attempting to introduce general programming concepts by teaching the high level language 'BASIC'. This gives the student the opportunity of operating the computer for himself right from the start of the course. Once the student has become aware of such programming concepts as conditional branching,

sorting and looping, we intend to move him on to the use of MPL (a subset of PLI) and perhaps to Assembler. We will train operators to use the system in such a way as to be part of the factory production control network. In addition, the machine can be used as a training aid with the educational packages already written.

In the longer term, we believe that microprocessor-based aids will play a major role in the rehabilitation and comfort of the handicapped. This technology forms part of the learning environment, or as an aid to communication in a variety of ways, but the appeal for the CP lies in its motivational qualities. This mode of teaching attracts an interest in learning. A trainee who has bypassed the normal education because of his lack of hand movement, or speech, or through deafness, benefits substantially from adult education. But I wonder if people generally, and politicians in particular, realise just what this technological revolution means for the CP; if its real potential is appreciated. Do we care sufficiently to explore its potential, for other than personal gain?

Apart from education for those adult CP who missed out on primary school levels in the nineteen fifties and sixties, we must, for the future, provide work training and employment of CP trainees in electronic technology, microprocessors, testing production machines, and computer data control. We must assume advances in speech, in hand function with biofeedback, Action Stretch Reflex training and, for the deaf, education in speech therapy by signs and symbols, and aided by electronics.

God's gift of technology can help to adjust the balance, but there is still a long, long way to go. We have not yet seen a person whose physical handicaps are so great that he could not be significantly improved by applied treatment and technology. If we concentrate on what they can do, what they cannot do becomes irrelevant. Microtechnology is here, let us take advantage of it. We may not succeed in restoring the hand of a CP to its fullest function, but there is nothing wrong with the spastic's intelligence. It is the mind with which we shall deal in the years to come.



Hooked wire electrodes into 19 muscles of the face and tongue provided a simultaneous computer recording of cerebral palsy speech

Neurophysiology

In all the clever affairs of man, a consistent pattern runs through his search for knowledge and for better ways of doing a set task.

First there is the steady accumulation of learning, based on the results of years of work and the experience of many other people.

Then there is a continued modification and adaptation, made possible by the use of new techniques, and then a steady forward march again to new objectives.

But sometimes there occurs a lightning flash which illuminates the whole field, and a breakthrough is established which will affect all future work in that particular area.

Within the compass of this chapter, I can only give a brief resume of the direction our research patterns are trending. Our funds are necessarily limited, and require us to carefully equate the value of a dollar spent on a research project with the demands of CP children's therapy and adults' work training procedures. We could advance the argument that all therapy and surgical operations are a waste of time; that we could spend the money more effectively, if we concentrated on the next generation, in finding why cerebral palsy happens in the first place. The Spastic Centre exists only for its present CP children and adults. Therefore, the levels of medical therapy and social maturation must be considered first, and only then can our research programmes be done, on a shoestring, depending upon the interest and the fibre of the people involved. We owe our Director of The Spastic Research Unit, Dr Peter Neilson, and all his staff, a lot!

For this chapter, I have asked Dr Neilson to give me a resume of his work during the eighteen years that have elapsed since he accepted the challenge of researching the reasons for 'spasm' of the muscle of cerebral palsy.

We know full well that there are no magic wands in research, or in therapy generally. What we have put in, necessarily limits what we can expect to get out, in effort, or in finance. Part of the problem is to interpret the findings of the research into the neurophysiology of the muscles of the cerebral palsied, into the associated areas of therapy, where we are dealing with abnormal muscle groups affecting posture and movement. We hope that the development of better muscle and speech training facilities, associated with better educational techniques and more advanced work training, would give the CP, in the years to come, a much better opportunity of making use of their undoubted intelligence.

The Spastic Centre of New South Wales has an active policy of encouraging both basic and applied research into cerebral palsy. Since The Spastic Centre was established in 1945, conservative therapy and management has reduced the consequential orthopaedic defects of this condition, probably about as far as this approach can be taken. Research into the neurophysiology of the basic problem of abnormal muscle tone has contributed little to its control. However, we continue to hope that it will do more in the immediate future.

The term 'cerebral palsy' implies damage to parts of the brain concerned with the control of movement. This damage can occur before, during, or shortly after birth. Cerebral palsy does not imply epilepsy perceptual problems, behavioural problems or mental retardation. All of these terms including cerebral palsy, are covered by the more general term 'brain damage syndrome'.

Cerebral palsy is only the motor component of the brain damage syndrome. Individuals with cerebral palsy often have diffused brain damage, however, many display multiple aspects of the brain damage syndrome, together with cerebral palsy. Nevertheless, it is important to realise that even severely disabled individuals with cerebral palsy are not necessarily mentally retarded.

As a result of damage to motor control centres of the brain, cerebral palsied persons often display bizarre postures and stereotyped facial expressions. They frequently have difficulty with swallowing and drooling is common. They may develop deformities of bones and joints, particularly as the ankle, hip, hand and neck muscles may become physically shortened, a state known as 'muscle contracture', and have a limited range of movement.

Individuals with cerebral palsy (CPs), often display writhing, sinuous involuntary movements, particularly of the hands and fingers, as well as tremors. These involuntary movements are referred to as the involuntary movements of athetosis. Their attempt at volitional movement is usually uncoordinated, slow and clumsy, and often non-functional. Their speech is frequently unintelligible and is referred to as 'dysarthric speech'. They suffer from intermittent spasms or vigorous involuntary contractions of muscles, which often lead to deformities of joints and ligaments, requiring surgical correction. Automatic postural responses are often abnormal. Attempts to move the limbs of a CP individual are opposed by active contractions of the muscles, producing a feeling of rigidity and tightness, referred to as 'rigidospasticity'.

A newborn cerebral palsied baby may have all of the infantile reflex responses of a normal newborn, and so it is often difficult to make an early diagnosis. As the weeks and months go by, however, normal motor development is not observed. The motor development process is slowed down and in many cases, the motor milestones are not reached. It is usually possible, within the first two to three months, to make a diagnosis of cerebral palsy, although cerebral palsied babies are often not diagnosed until towards the end of the first year.

CP children retain many of the so-called primitive or infantile reflex responses, and also display abnormal or pathological reflex responses. If a severely disabled CP child is placed on his back, he may display a whole body extensor spasm, so he forms an arching bridge between his heels and the back of his head. If the same child is then rolled onto his stomach he may switch into a flexor spasm, in which his knees are brought up towards his chest and his head is flexed forward. Rotation of the head can produce reflex movement of the arms and legs, the so called 'tonic neck reflexes'

What are the causes of these problems? What are the neurophysiological mechanisms which underlie these motor disabilities of cerebral palsy? What can be done to ameliorate these problems? If we recognise that brain damage is irreversible, what can be done to ensure that an individual CP leads a life in which he can achieve his full potential and contacts with others, in which he has a minimum deformity and requires a minimum of medical or surgical intervention?

Before these questions can be answered, we must develop an understanding of the underlying neurophysiological mechanisms responsible for the various motor symptoms of cerebral palsy. Little is currently known about these mechanisms; the prevailing therapy techniques recognise the major problem as being associated with abnormal postural reflex control. In the Bobath method, the CP child is encouraged to remain in postures opposite to those in which he is normally pushed by reflexes. He is encouraged to inhibit the reflexes, so he can remain in so-called 'reflex inhibiting postures'. The focus of Bobath therapies on reflex inhibition and proprioceptive neuromuscular facilitation (PNF), is one reason for starting our research programme with an investigation of reflex behaviour and reflex mechanisms. Another reason was that, as shown at the beginning of the century, there already existed an animal model for rigidospasticity. Although it is now appreciated that the decerebrate animal is not a good model for human rigidospasticity, this research provided motivation for us to begin our research programme with an investigation of stretch reflex behaviour in cerebral palsy.

At the beginning of our studies, the twitch contraction produced by tapping the tendon with a reflex hammer was the best known illustration of the stretch reflex. The tendon jerk had been used for many years by neurologists to test the integrity of spinal circuits. The H-reflex, an electrical equivalent of the tendon jerk, had also been studied. Instead of tapping the tendon with a reflex hammer, an electrical stimulus is applied to the nerve to evoke a stretch reflex twitch contraction of the muscle. The characteristics of this electrical tendon jerk reflex have been much studied and were well known at the beginning of our research.

It was generally believed by neurologists that rigidospasticity, assessed clinically by asking the patient to relax while passively moving the limb back and forth about the joint and feeling the resistance to movement, was caused by an exaggerated sensitivity of the same stretch reflex circuit responsible for the tendon jerk reflex. Patients with exaggerated resistance to passive movement usually have brisk tendon jerk reflexes. It was argued, therefore, that the hypersensitive tendon jerk stretch reflex circuit was also responsible for the exaggerated resistance to passive movement.

There were some neurologists, however, among them Professor James Lance, head of the Department of Neurology at Prince Henry Hospital (The Spastic Centre Research Unit is one of the laboratories within this Department), who were not satisfied with this explanation of rigidospasticity, because they often saw rigidospastic patients with no brisk tendon jerk reflex responses, or vice versa. The best example is observed in cerebellar patients, who display a so-called 'pendular' knee jerk. These patients are hypotonic; their limbs feel loose and floppy. Nevertheless, a brisk tendon jerk reflex response can be elicited in these patients. The foot swings forward, driven by the hypersensitive twitch contraction of the tendon jerk reflex, and then swings back and forth

like a loose pendulum, because of a lack of muscle tone. Due to these observations, Professor Lance recognised the importance of an experimental finding in our laboratory, which later became known as the Tonic Vibration Reflex. We found that when vibration was applied to a muscle, it suppressed the tendon jerk reflex responses. As soon as the vibration was removed from the muscles, the tendon jerk reflex responses reappeared. At the same time, however, the vibration evoked its own sort of reflex response which consisted of a slowly augmenting tonic contraction of muscle. This differential effect indicated that there were two reflex mechanisms – a phasic reflex mechanism, which produced the tendon jerk reflex responses, and a tonic reflex mechanism that was excited by vibration and produced a sustained contraction of the muscle.

This provided the first experimental evidence that two or more stretch reflex mechanisms exist in human muscles, and provided a possible explanation for the observed dissociation between the sensitivity of tendon jerk reflexes and the level of rigidospasticity assessed clinically. However, the characteristics of the Tonic Vibration Reflex do not correlate well with clinical measures of rigidospasticity. Nevertheless, the differential effect of vibration on phasic and tonic reflex mechanisms demonstrated in the original experiment emphasised the possibility that other reflex mechanisms may exist which are responsible for rigidospasticity.

The problem now was to find those reflexes. It was decided to study the electromyographic characteristics of tonic stretch reflexes by slowly moving the limbs backwards and forwards about the joint, in the same way as during clinical assessment of rigidospasticity, while recording joint angle movements, thereby measuring the magnitude, amplitude, and velocity of stretch applied to the muscles, and at the same time using electromyography to record the reflex contraction patterns of the various muscles operating across the joint. In brief, the results of these studies showed that if a normal subject is asked to relax while his limbs are moved passively back and forth by an examiner, there is no abnormal resistance to the movement and no reflex contractions of muscles, and the joint feels loose. When this test is applied to a CP patient, however, there are reflex responses in the muscles, and there is an abnormal resistance to the movement. The resistance is associated with abnormal asynchronous bursts of reflex contraction, which occur at various times in different muscles operating across the joint. In any one muscle, an asynchronous burst of EMG activity is usually produced during the early part of the stretching cycle. For example, if one were stretching the limb backwards and forwards rhythmically, say at 1 – 2 Hz through about thirty degrees change of joint angle, every time the movement swings into the stretching phase a burst of EMG activity is recorded from the muscles being stretched. The muscles then remain silent for the rest of the stretching cycle. Such reflex contractions could be responsible for the feeling of tightness experienced in rigidospastic patients. In CP patients there is a velocity threshold of muscle stretch, below which no reflex response is produced in any of the muscles. As the velocity of stretching is increased above the velocity threshold, the size of the EMG burst increases in proportion to the velocity. It was thought that this might provide a method of quantifying the amount of rigidospasticity in a muscle. If the size of the EMG reflex response is graphed against the velocity of stretch, then both the threshold and the slope of the straight-line relationship provides a measure of the degree of rigidospasticity. The lower the velocity threshold, the more spastic the muscle, and the steeper the slope, the more spastic the muscle. This method of assessing spasticity has since been used by a number of researchers investigating the effects of drugs on rigidospasticity.

At The Spastic Centre Research Unit, we were still not convinced, however, that this method of studying tonic stretch reflexes revealed the physiological mechanisms responsible for rigidospasticity and disruption of voluntary movement in cerebral palsy. The prevailing clinical idea was that abnormal postural reflexes in cerebral palsy disrupt voluntary movement. That is, abnormal postural reflexes compete with the voluntary system for control of muscles, and the reflexes dominate because of their hypersensitivity. The reflexes push or pull the patient into various postures – reflexively splinting him in those postures, thereby disrupting control of movement. Thus, the stretch reflexes responsible for disrupting control of movement in cerebral palsy must be those abnormal reflexes operating in competition with voluntary movement. The tonic stretch reflexes described above were measured while the subject was attempting to relax. It seemed highly probable, therefore, that a different stretch reflex mechanism might be activated when the subject attempted to voluntarily contract muscles.

Another line of reasoning also indicated that we should attempt to measure stretch reflex responses during voluntary activity. The tonic stretch reflexes described above were not observed in normal relaxed subjects, but only observed in movement-disordered patients, such as spinal injured patients, hemiplegic patients, CP patients, Parkinsonian patients and patients with cerebellar damage. This had led to the view that the tonic stretch reflex was a pathological phenomenon. It seemed to us that pathways for such complex stretch reflex mechanism were unlikely to exist within the nervous system without there being some reason for their existence in terms of normal mechanisms. Although there were no tonic stretch reflex responses present in normal subjects when they were relaxed, it seemed likely that the tonic stretch reflex mechanisms might be activated during voluntary activity.

For both of the reasons mentioned, it was decided to investigate tonic stretch reflexes while the subject was voluntarily active. This requirement considerably complicated the measurement analysis technique. When a muscle is being contracted voluntarily, a sustained EMG signal is produced, which consists of an interference pattern of electrical spikes. When a stretch is applied to the muscle, the tonic stretch reflex response is also indicated by a burst of electrical impulses in the EMG, mixed with the

background activity. Consequently, we have the problem of extracting the tonic stretch reflex responses from the background activity. This can be achieved by using an averaging technique in which the reflex responses to a series of stretches are averaged together. Only the part of the EMG activity consistently present in each response averages up; the irregular varying background activity averages to zero.

More sophisticated computer analysis techniques, employing cross-correlation and spectrographic analysis, have been developed for technological applications such as seismographic analysis. These procedures have the advantage, that not only can they solve the problem of separating reflex EMG responses from the background activity, but also they provide a mathematical description of the transmission characteristics of the stretch reflex pathways. Consequently, at the Spastic Centre Research Unit, we developed computer programmes to perform this cross-correlational and spectrographic analysis procedure, and applied these programmes to analysis of EMG signals and joint angle signals recorded from normal and cerebral palsied subjects during sustained voluntary activity.

Large tonic stretch reflex (TSR) responses were clearly present in normal subjects during voluntary activity. The very process of voluntarily contracting muscle seemed to activate the TSR circuits associated with that muscle. These TSR responses recorded during voluntary activity in normal subjects were very powerful responses, producing large swings in the contraction of the muscle. A small displacement of five to thirty degrees at the joint can drive the muscle through almost its full range of contraction. The responses were certainly large enough to be of functional importance during movement. The computer analysis procedure provided detailed technical specifications of the closed-loop transfer function transmission characteristics of the reflex loops involved in generating the responses. This was exactly the knowledge we needed to investigate the behaviour and the functional role of these tonic stretch reflexes during voluntary movement.

We had discovered a new and powerful TSR, brought into play during voluntary activity. We had revealed a muscle control mechanism that was involved in the pathological process responsible for the generation of rigidospasticity in cerebral palsy.

The next step was to study TSR during voluntary activity in CP subjects. Although the TSR responses were grossly abnormal in CP subjects, TSR pathways were also functionally reorganised in CP during voluntary activity. Although CP patients displayed TSR responses when they were trying to relax, when the same CP subjects voluntarily contracted muscles, the TSRs were reorganised. The reorganised responses were more sensitive to stretch, the responses were much larger, and the timing of the responses was completely different from that measured when they were relaxed. In other words, both the magnitude and timing of the TSR responses measured during voluntary activity were completely different from the TSR responses measured in the same CP subjects attempting to relax. It was clear that we were studying a different reflex mechanism during voluntary activity from that studied in the same CP subject at rest. *We coined the terms 'Resting Tonic Stretch Reflex' and 'Action Tonic Stretch Reflex' to differentiate between these two types of reflexes.* An important consequence of this discovery was that the rigidospasticity assessed clinically in CP subjects (by asking them to relax and passively moving their limbs back and forth about the joint and experiencing the resistance to the movement) was very different from the rigidospasticity experienced by the CP person himself when he attempted voluntarily to move his own limbs. In other words, the rigidospasticity experienced by a CP individual during voluntary movement was quite different from the rigidospasticity assessed by the clinician with the subject at rest.

The functional importance of the difference between the resting TSR, and the action TSR, in cerebral palsy was further emphasised by the results of a double-blind drug study conducted to assess the efficacy of the drug Phenoxybenzamine in controlling the involuntary movements of athetosis. Results of this investigation revealed that the drug Phenoxybenzamine Veldopa suppressed resting TSR responses and was effective in reducing rigidospasticity as assessed clinically. The drug had no influence, however, on the action TSR responses and produced no improvement in functional control of movement as assessed by visual pursuit tracking tests. This differential effect of the drug Phenoxybenzamine on resting and action TSR responses provided further experimental evidence in support of the hypothesis, that additional reflex circuitry is brought into play by descending neural activity during voluntary activity. It also supports the notion that it is the action TSR and rigidospasticity assessed during voluntary activity that is important with respect to functional control of movement in cerebral palsy, rather than the rigidospasticity assessed clinically when the CP patient is at rest.

Action TSR studies were performed on two groups of CP subjects. The first group was predominantly spastic, the second group was predominantly athetoid. Results showed that the characteristics of the action TSR in CP subjects are grossly abnormal, with distinct and significant differences between the spastic and athetoid groups. Action TSR characteristics were also investigated in cerebellar patients and found to represent yet a third type of abnormality. The abnormality seen in different motor-disordered patient groups was found to be consistent with the clinical picture of the disorder.

Nevertheless, results of these studies of action TSRs in CP indicated that the disorder of action TSR transmission was not so much a disorder of the stretch reflex circuits. This indicated that the pathophysiological mechanisms responsible for rigidospasticity and

spasm in CP would be found, not in the stretch reflex circuits themselves, but in the parts of the brain involved in descending control of reflex transmission. *In our search for the neurological course of rigidospasticity and spasm, it was now clear that we should investigate the brain mechanisms involved in descending control of action TSR transmission.*

Normal subjects are usually not conscious of descending control of stretch reflex transmission. In fact, when you think about it, almost all of the mechanisms that are involved in producing a voluntary movement are not available for conscious examination. We are usually not aware which muscles we are contracting, let alone what nerve signals we are sending down which motor nerves. Reflex transmission control seems, subjectively, to be an automatic path of voluntary movement. Presumably, if the descending control systems were damaged in CP, the individual CP would be unaware he was inappropriately tuning reflex transmission. The consequences of faulty descending control would be experienced, however, as spasm and rigidospasticity.

There are two important reasons for asking the question, 'Can reflex transmission be brought under conscious control?' Firstly, if it were possible to teach CPs to switch off defective stretch reflexes, this would be equivalent to suppression of rigidospasticity and spasm. This would represent an important advance in therapy for CP, particularly with respect to prevention of muscle and joint deformity. The second reason for asking this question is, that if we could teach normal subjects consciously to control reflex transmission, we would be able to study the associated changes and this would give us some idea of the range of normal descending control and of its functional significance during voluntary movement. We would then be able to recognise abnormalities of descending reflex transmission control in CP.

One of the first things we studied concerning the nature of this descending control of TSR transmission, was the effect of changing the level of voluntary contraction of the muscle. Able bodied subjects contracted elbow muscles to various proportions of a maximum contraction while transmission characteristics of the action TSR were measured. We found a systematic change in the characteristics of the TSR with changes in contraction level – as the contraction level increased, sensitivity of the TSR increased. We also found a systematic change in the timing of the reflexes with changes in contraction level – as the contraction level increased, the phase lead of the EMG responses ahead of muscle stretch increased. It was thus demonstrated, that descending control of TSR transmission is not a simple switching of the reflexes on or off, but a graded control in which the sensitivity and the timing of the stretch reflexes change in proportion with the contraction level of the muscle.

We repeated this experiment with a group of CP subjects, and found that graded descending control of reflex transmission was absent or at least disrupted in CP. As soon as a CP contracted the muscle, the descending TSR control acted like a switch and an abnormal action TSR was switched on. When a CP subject produced even a small voluntary contraction, the TSR was switched on with an abnormally high sensitivity, and then remained switched on, despite subsequent changes in contraction level. A clear abnormality was thus demonstrated in the descending control of stretch reflex transmission in CP. Normally, the sensitivity of the TSR increases in proportion with the level of contraction of the muscle, but in CP subjects the TSR has high sensitivity even at relatively low contraction levels. In other words, in CP, the descending control of reflex transmission does not appear to be coordinated with voluntary control of muscle contraction as it is in normal subjects. This is consistent with the notion that stretch reflexes compete with, rather than cooperate with, voluntary signals for control of muscle contraction. But, does the sensitivity of the TSR in normal subjects always increase or decrease in proportion with the contraction level of the muscle, or can the sensitivity vary independently of the contraction level? Independent control of sensitivity would greatly increase the adaptive control capabilities of the nervous system, and would indicate the existence of additional brain mechanisms involved in coordinating reflex transmission with voluntary activity. This is an important question to answer, since it helps define the brain mechanisms, which when damaged in CP, lead to faulty descending control of TSRs and hence to rigidospasticity and spasm.

To resolve this question, we developed computer programmes to provide an on-line visual display of both the sensitivity of the reflex, and the contraction level of the muscle. We then asked normal subjects to try and hold the contraction level constant as indicated on one of the visual displays, and to attempt to reduce the reflex sensitivity indicated on the other display. We used this biofeedback training method to discover whether or not it is possible for the central nervous system to vary the sensitivity of tonic stretch reflexes independently of the contraction level of the muscle. Within one hour's training, ten of the eleven normal subjects tested were able to reduce the sensitivity of the TSR three to fourfold while holding the contraction level constant at 30 to 50 per cent of a maximum contraction. This was an exciting result. It demonstrated the potential of using biofeedback to teach

CP subjects consciously to suppress rigidospasticity and spasm. *It also indicated the existence of complex central mechanisms involved in descending control reflexes that could be damaged in CP. Almost nothing was known about this mechanism.*

What is the functional significance of descending control of reflex transmission during voluntary movement? How is the descending control system disrupted in CP? An important clue to the role of descending modulation of reflex transmission was noticed during the biofeedback experiments. Despite the fact that subjects held the contraction levels of the muscles constant, the stiffness of the limb, as experienced by the experimenter, felt looser when the stretch reflex sensitivity was set low than when it was set high.

Following this observation, we performed a series of experiments, in which the mechanical force-displacement characteristics of the elbow joint were measured, while the contraction levels of the muscles were held constant. The elbow joint was shown to be mechanically equivalent to an inertia restrained by both stiffness and viscous elements. In other words, the mechanical characteristics of the elbow resembled those of an automobile suspension system with a spring and a dashpot damper. As the descending influences controlling the transmission characteristics of the stretch reflex pathways varied, the stiffness and viscosity of the equivalent spring and dashpot damper varied. These data showed that the stiffness and viscous mechanical characteristics of the elbow are determined predominantly by the involuntary tonic stretch reflex contractions of the muscles. Moreover, both the stiffness and viscosity can be varied by the nervous stem controlling the descending modulation of interneurons involved in stretch reflex transmission. In turn, the sensitivity and timing characteristics of the stretch reflex pathways determine the stiffness and viscous characteristics of the joints. This data provide compelling evidence in support of the hypothesis that the central nervous system normally tunes the mechanical stiffness and viscosity of the skeletal joints by modulating the transmission characteristics of the TSR pathways within the central nervous system. The data supports the view that brain damage sustained in cerebral palsy disrupts descending modulation of TSR transmission, and thereby produces abnormal stiffness and viscosity of the joints, which is experienced clinically as rigidospasticity.

We now had to determine whether or not conscious control of stretch reflex transmission could be taught to severely disabled CP individuals. Benefits, such as reduction in spasm, reduced muscle tightness, increased range of joint movement and prevention of muscle and joint deformities would ensue. According to the prevailing views, if a CP could learn this descending control of TSRs there might be an unmasking of the unrelying voluntary control ability, which would otherwise be 'splintered' by spasm and rigidospasticity. Even if it took years for a CP to learn to control TSR transmission, the benefits would be more than worth the effort.

Firstly, we conducted a pilot study. Two intelligent adult CPs volunteered to work with us for two weeks. Using the biofeedback visual displays, they attempted to hold the contraction level of the muscle constant while decreasing reflex sensitivity. After two weeks training they were able to produce small but significant changes in stretch reflex sensitivity. This finding indicated that it is possible for a CP to learn consciously to suppress spasm and rigidospasticity. It also indicted, however, that training would be difficult and slow. A training period of one or two years might be required to learn to control rigidospasticity, and perhaps a lifetime of continuous retraining to maintain the skill. Nevertheless, the technique had such exciting potential it was considered worthwhile setting up a training programme. Accordingly, an Action Reflex Training room was established at Centre Industries and a small group of adult CPs volunteered to attend the training room for one hour each working day. We provided biofeedback displays of muscle contraction level and reflex sensitivity, and we recorded progress in learning to self-regulate TSR transmission, that is, spasm and rigidospasticity. We also employed a visual pursuit-tracking test to assess functional control of movement; movement of the elbow was used to control the vertical movement of a response marker on a visual display screen. The task for the subject was to move the elbow in such a manner that the response marker followed a slowly moving stimulus marker on the display. Movements of both stimulus and response markers were recorded and analysed. This provided detailed objective measures of the CPs functional control of elbow movement, since we knew exactly the movement the CP was trying to make and had precise measures of the movement actually made. It also provided an objective description of inappropriate and involuntary movements at the elbow, and enabled us to describe three types of movements, which characterise the involuntary movements of athetosis. This work led to the discovery of the so called 'athetoid action tremor', a vigorous tremor or bursting in the contraction of athetoid muscles which varies irregularly at frequencies between 2 - 4 Hz, and is uncorrelated in agonist and antagonist muscles.

After twelve months training, all of the CPs in the group succeeded in controlling action tonic stretch reflex sensitivity independently of contraction, and showed a reduction in the amount of spasm and rigidospasticity. The training led to a reduction in muscle tightness and increased the range of movement in the joint.

This experimental result is clearly of great importance with respect to therapy, particularly with respect to prevention of muscle contractures and joint deformity. It demonstrated that the damaged brain in CP has sufficient plasticity to acquire, given appropriate training, some inhibitory control over reflex transmission. This is an essential first step in any therapy programme, not only to reduce muscle tightness and prevent deformity, but also to unmask underlying functional control of movement

From a scientific point of view, however, we still have the problem of tracing these descending signals into the brain and finding which parts of the brain are involved in modulating reflex transmission, and what goes wrong with those parts of the brain in CP.

A problem in assessing rigidospasticity in CP was revealed by this data. We found that reflex sensitivity can be influenced by the size of the stretch applied to the muscle. Although we had been carefully controlling the contraction levels of the muscles and

the velocities of the stretch, we found that the sensitivity of the stretch reflex increased as the magnitude of the stretch was decreased. This is very important in clinical assessment of rigidospasticity, because, as the rigidospasticity of the joint decreases with training, there is a tendency for the examiner to move the limb (which now feels looser) through a larger range of movement at a lower frequency. Consequently, the dependence of TSR sensitivity on the magnitude of stretch confounds the measurement of rigidospasticity and therefore must be taken into account during future design of spasticity meters. We had not controlled the magnitude of stretch during the tests with the first group of CP subjects, so we found it necessary to start a new group of CP subjects, this time with contraction level, velocity, frequency and magnitude of stretch all carefully controlled. For this second group of CPs, we obtained the same results as with the first group, but of course the data was no longer confounded by the effects of changing the magnitude of stretch. *Within twelve months, all the subjects learned to self-regulate spasm and rigidospasticity. The limb felt loose, and involuntary contractions of the muscles were reduced.*

We are continuing to experiment with the use of EMG biofeedback training to teach CPs to self-regulate spasm and rigidospasticity. We are attempting to determine which particular aspect of training is most responsible for the observed improvement. During training, CPs learn to contract the muscles being studied without producing contractions in neighbouring muscles. They learn to relax the muscle (which is different from reflex sensitivity control during active contraction), and they learn to sustain a voluntary contraction with a minimum of involuntary fluctuation. Any or all of these skills could be contributing to the observed improvement. We are also experimenting with the use of EMG biofeedback training with four to seven year old CP children at risk of developing contracture of the calf muscles and deformities of the ankle joints. The question being investigated is, Can the tightness of the calf muscles be reduced sufficiently to prevent or even reverse the development of muscle contractures in children?

Another important result was obtained from our studies of action reflex training in CP. Although treatment of spasm and rigidospasticity is an essential component of therapy for CP, results from the biofeedback training studies indicate that spasm, rigidospasticity and involuntary contractions are not the primary cause of motor disability in cerebral palsy. All of the CPs in the training programme succeeded in reducing spasm, rigidospasticity and involuntary contractions of the elbow muscles, but their ability to control elbow movements, as assessed by pursuit tracking tests, remained very poor. It seems that the lack of functional control is caused, not so much by abnormal reflexes competing for control of muscles, but by a fundamental inability to formulate an appropriate sequence of motor commands to achieve a desired movement. This is an important deviation from the traditional explanation for motor deficiency in cerebral palsy. The notion of a movement programming defect as the primary cause of disability in cerebral palsy was further supported by our work on the contraction patterns of lip, tongue and jaw muscles during speech in CP.

CPs often lack functional control of the speech muscles and their speech is often unintelligible. The only form of communication is frequently via a point board. Such a communication barrier makes education, and psychological development in general, very difficult. The lack of communication resulting from dysarthric speech can be seen as one of the major handicaps in CP. But what is known about the physiological mechanisms underlying control of speech? What goes wrong with these mechanisms in CP? A review of speech science literature showed that the prevailing explanations of the cause of dysarthric speech in CP could be classified into five different theories: weakness of speech muscles, rigidospasticity of speech muscles, release of primitive and pathological reflexes involving speech muscles, imbalance of approach and avoidance reflexes influencing the speech mechanism, and disruption of speech by involuntary contractions of the speech muscles.

We decided to use hook-wire electrodes to record EMG activity from lip, tongue and jaw muscles during a variety of speech and non-speech tasks in both normal and CP subjects. The CP subjects involved in this study all had severely dysarthric speech. The EMG activity from up to nineteen lip, tongue and jaw muscles was recorded simultaneously onto a 14-track FM tape recorder, providing a library of tapes.

Many important findings have come from this data, but the result we found first, and perhaps one of the most important, was the discovery that TSR responses are not present in lip and tongue muscles, although clearly present in jaw muscles. This was true both in normal subjects and CPs, which implied that rigidospasticity cannot be present in lip and tongue muscles, and therefore, contrary to the prevailing view, rigidospasticity of lip and tongue muscles cannot be responsible for the dysarthric speech of the CP subjects. This challenges the notion that lack of motor control in CP is a consequence of a competition between reflexes and a relatively normal voluntary control system. *It would appear that one cannot attribute the lack of intelligible speech in CP to the presence of rigidospasticity in speech articulator muscles.* This of course, is an amazing conclusion, especially in the light of speech therapy aimed at CP, which often includes many hours of oro-facial desensitisation in an attempt to reduce the spasticity of these muscles.

The subjects were nevertheless grossly abnormal. This indicated that the abnormal contraction patterns of muscles in CP are not necessarily produced by abnormal TSR behaviour, and indicated an abnormality in the central mechanisms responsible for

programming motor commands. This result is most important, because it clearly challenges the notion that lack of movement control in CP is the result of a competition between a relatively normal voluntary control system and an abnormal reflex control system. *This result was the first clear pointer to the conclusion that the primary movement disability in CP results, not from reflex abnormality per se, but from abnormalities in the voluntary control system itself.*

This conclusion is consistent with results from the action reflex training programme discussed earlier. After many months of training, our CPs were able to reduce spasm and rigidospasticity of the elbow and their limbs felt loose. There was no dramatic improvement in functional control of movement as assessed by visual tracking tests. Movement control was poor and remained poor, despite reduction in spasm and rigidospasticity. So, although spasm and rigidospasticity are important symptoms of CP, they are not the symptoms most responsible for the movement disability of CP. This is not to say that treatment of rigidospasticity is unimportant; voluntary movements cannot be made while muscles are in spasm, and consequently reduction of spasm and rigidospasticity is a necessary step towards improving functional control of movement, but it is not sufficient. *Even if problems of spasm and rigidospasticity were eliminated, CPs would remain seriously disabled, because of an inability to transform desired perceptual goals into appropriate motor commands to achieve them.*

Detailed examination of the EMGs recorded from lip, tongue and jaw muscles in the CP patients during speech, showed that each CP had an idiosyncratic abnormal pattern of muscle activity. There were, however, a number of features in common: they all used an excessive number of inappropriate muscles, the muscles contracted to excessive levels and the contractions were prolonged compared to normal subjects, but the details of the coordination of the muscles, the timing patterns of muscle contractions were quite different from one CP to the next. Nevertheless, even in athetoid CP subjects who display pronounced involuntary movement, it was found that each individual produced the same abnormal pattern of muscle contraction every time he repeated a particular syllable.

The results of these studies provided evidence that the primary cause of the motor defect in CP was an inability of the damaged nervous system to programme the appropriate sequence of motor commands to produce a desired movement.

It was time to switch all attention to the brain mechanisms involved in programming voluntary movement. We studied the literature relevant to voluntary control of movement in the physiological, psychological, behavioural, sports science, work load and ergonomic fields, and in the process have collected a library of reprints which are now stored at The Spastic Centre Research Unit. We decided that pursuit tracking provided the most powerful experimental method of investigating voluntary control of movement. We already had some experience with visual pursuit tracking, and developed computer programmes for analysis of such data. In visual pursuit tracking, the subject operates a control in order to move a visual response marker on a display screen, and attempts to keep the response marker aligned with a continuously moving target or stimulus marker also on the display screen. This test has the advantage that the experimenter knows exactly the movement of the control that the subject is trying to produce, and also has a precise measurement of the movement actually produced, and so is in a position to assess the accuracy and speed and appropriateness of the voluntary movement responses. From our own tracking experiments, and studies of the voluntary movement research literature, we knew some things about the behaviour of the voluntary control system. We knew, for example, that the maximum speed at which one can track a moving target is considerably less than the maximum speed at which one can move the limb. In other words, while the maximum speed for voluntary movement is limited by the mechanical properties of the limb and the maximum forces that can be generated by the muscles, the maximum speed at which one can track a moving target is limited by the time taken by the nervous system to analyse sensory information and programme an appropriate motor response. The maximum speed of tracking is less than 2 Hz, while the maximum frequency at which one can move the elbow, for example, is 4-6 Hz. We also knew that the voluntary control system updates movement programmes intermittently, in the sense that a reaction time interval is required to detect input and initiate an appropriate motor response.

The concept of intermittent motor programming is of fundamental importance to an understanding of brain mechanisms involved in voluntary movement control.

In essence, it implies that central mechanisms require a finite interval of time (related to reaction time) to analyse sensory information and formulate a desired movement response.

Once the desired response has been programmed, it is transferred to other parts of the brain concerned with response execution, thereby freeing the central mechanisms concerned with movement programming, enabling them to commence work on programming the next response. Thus, while muscles perform continuous contractions during the execution of movements, the underlying sequences of motor commands prepared by the central motor programming mechanisms are updated only intermittently and, once formulated, the motor programmes are executed in an open loop fashion; that is, they are performed, for at least a reaction time interval, without being modified by feedback from the evolving response.

A range of evidence exists in support of intermittency in movement programming, including our own work showing intermittent

updating of correction responses, following unexpected changes in the sensitivity of the control in a visual pursuit-tracking task. The most compelling evidence for intermittency comes, however, from double stimulus reaction time tasks and studies of the so-called psychological refractory period. It is as if a central mechanism is busy programming the first response, and consequently the second stimulus has to be held in short-term memory until the first response is programmed.

Thus we have a picture of voluntary control, in which the central nervous system requires a reaction time interval of about two hundred milliseconds to analyse sensory information and programme an appropriate response. While the response is being performed, central mechanisms can analyse sensory feedback from the movement, detect errors and, if necessary, programme a correction response. Consequently, movement programmes can be updated intermittently at reaction time rates.

Equally important to an understanding of the brain's movement control systems, is the observation that voluntary control is highly adaptable. A newborn baby has to learn to move, and there is a natural time course for development of motor skill.

This implies that the voluntary control system is a learning machine. This learning ability underlies the voluntary control system's adaptability. For example, a child can continue to perform complex skilled movements despite changes due to body growth. The nervous system is able to compensate for changes in mechanical loads applied to the limbs. For example, one can move an arm and point to objects in three dimensions, then pick up a heavy weight and move the arm in exactly the same way, compensating for the heavy weight. One can put on a pair of heavy boots and walk just as well as without heavy boots, even though completely different muscle contraction patterns are required. The voluntary system can learn the characteristics of external systems, so we can learn to operate tools, drive cars and sail boats, and so on. Moreover, we can rapidly compensate for changes in the characteristics of these external systems. The voluntary control system can also adapt for a variety of surgical changes. For example, the nervous system can learn to control movements following surgical relocation of muscles and nerves. The nervous system can often recover function following damage to descending tracts in the spinal cord, and even following damage to the motor cortex itself. The wearing of prism glasses, which invert images, at first disturbs movement control, but after a week or two, adaptation occurs and the subject sees images normally and can control movement skillfully. Clearly, adaptability is a key feature of the voluntary control system.

Apart from intermittency and adaptability, one other factor strongly influenced our thinking about the nature of the movement programming deficit in CP. After many years of studying motor ability and motor disability in CP, Beatrice Le Gay Breerton, a psychologist at The Spastic Centre of New South Wales, presented the following insight into the mechanism of motor disability of CP at a Spastic Centre Conference.

She proposed that a CP child may have difficulty in performing a task, such as drawing a square, because, although he appreciates the task involved and could readily find a similar square, he is unable to transfer this appreciation into appropriate movement.

She suggested that the difficulty experienced by a CP in performing a voluntary movement is analogous with the confusion experienced by an able bodied person in drawing a square when the hand and pencil can only be seen reflected in a mirror.

Based on the above observations, we proposed the following Sensory-Motor (S-M) Model Theory of voluntary movement control. Volitional movement is programmed at a cortical level in terms of the desired perceptual consequences of the movement and transformed in subcortical circuits into an appropriate input to the motor cortex to produce the movement. The transformation of desired perceptual consequences into appropriate motor commands is based on previous learning of the relationships between central motor activity and the resulting perceptual consequences of the movement. In other words, the nervous system continuously monitors its own motor commands, and computes and stores internal models of the relationships between motor commands and their perceptual consequences. These internal models are used during voluntary movement to transform desired perceptual consequences into appropriate motor commands to achieve them. The continuous updating of internal models enables the voluntary system to adapt and compensate for changes in muscle control systems, limb mechanics, and/or external systems.

We suggest that periventricular lesions in the deep white matter of the brain, produced by ischemic and haemorrhagic lesions in the newborn CP, prevent the nervous system from monitoring its own motor activity and therefore prevents the learning of internal sensory-motor learning essential for transforming movements planned in terms of desired perceptual consequences into appropriate motor activity. Thus a CP might know precisely the movement he wants to make, but his nervous system is unable to transform this appreciation into appropriate motor commands, just as suggested by Le Gay Breerton.

Pursuit tracking tests and the computer analysis technique developed at our laboratory provided an experimental approach for studying adaptability of voluntary motor control in CP. We first investigated tracking performance in a group of spastic and a group of athetoid adult CPs and found that they moved only at low speeds, had long time delays, and produced a large amount of movement unrelated to the motion of the target. An interesting observation was that although this residual movement might

be regarded as involuntary movement, and certainly included the involuntary movements of athetosis, the spastic group produced a larger amount of residual movement than did the athetoid group. This led us to the notion of 'inappropriate voluntary movement' rather than 'involuntary movement'. Spastic CPs do not display involuntary movement when they are at rest, but when they attempt to make a voluntary movement, the contraction patterns of their muscles are inappropriate and the voluntary movement is disrupted. This distinction between involuntary movement and inappropriate voluntary movement we consider to be important.

When an operator first begins visual tracking, let us say he uses a joystick to control the position of a response marker on a display screen, and tries to drive the response marker so it will track or follow a target marker, he must first calibrate himself. That is, he must learn the relationship between movement of the joystick and the resulting movement of the response marker on the screen. According to our S-M Model Theory of movement control, this calibration procedure represents the CNS learning an internal model of the relationship between movement of the joystick and the resulting visual deflection of the response marker on the display

Visual tracking experiments with normal subjects demonstrated that acquisition of skill is represented, to a large extent, by the subject learning the relationship between movement of the control and the resulting deflection of the response marker.

We investigated how quickly normal subjects could adapt following sudden changes in the relationship between movement of the control and the resulting movement of the response marker. Normal subjects tracked sudden steps of the target from one position on the screen to another. After practice, sensitivity of the joystick was suddenly and unexpectedly increased, so the same movement of the joystick produced a bigger movement of the response marker on the screen. We found that after the target jumped, there followed a reaction time interval, and then the subject initiated a fast movement of the joystick appropriate for the old joystick sensitivity. Consequently, the response marker would overshoot the target. A second reaction time interval would follow before a new response was initiated which, 70 per cent of the time, was appropriately adjusted for the increased sensitivity of the joystick.

In other words, subjects could detect a change in sensitivity of the joystick and adaptively adjust their internal model within one or two reaction time intervals.

Generally speaking, we found that the operator adjusts his characteristics so he behaves like the inverse or reciprocal of the characteristics of the system he is controlling; in engineering terms, he behaves like an inverse model of the external system. The nervous system learns the relationship between the kinaesthetic and visual sensory information by monitoring feedback during the movement, and then uses the information in programming succeeding responses.

If we assume that the same neurological mechanisms involved in learning to control an external system (such as a visual tracking system), are involved in learning to control the movement of one's own body and in adapting for growth and for changes in mechanical loads on limbs, then we can develop a theoretical view concerning the brain mechanisms involved in programming voluntary movement and what goes wrong with those mechanisms in cerebral palsy. One can argue that in order for the nervous system to learn to control the movements of the body's mechanical systems, it must establish an internal model of the relationships between the tensions generated in muscles and the resulting movements of the body parts. These relationships include reaction forces due to the body's inertia, visco-elastic properties, Coriolis forces and the effects of gravity. Just as the nervous system can establish internal models of the relationships between kinaesthetic and visual information representing the relationships between movement of the control and the resulting deflection of the response marker in a visual tracking test, it can establish internal models of the relationships between proprioceptive information describing the tensions generated in the muscles, and proprioceptive information describing the resulting movements of the body parts. Furthermore, the nervous system can also establish internal models of the relationships between central motor activity in the motor cortex and the resulting tensions generated in the muscles. In other words, just as the nervous system can learn the inverse characteristics of the external system in a visual tracking task, it can learn the inverse characteristics of the body's biomechanics and of the body's neuromuscular control systems. The same adaptive mechanism involved in learning to control an external system is involved in learning to control movements of the body. This view accounts for the nervous system's ability to compensate for changes in mechanical loads on limbs, for changes due to growth, surgical relocation of muscles and nerves, and damage within the nervous system itself.

The Sensory-Motor Model Theory of voluntary movement control can be summarised as follows: Movement is programmed initially at a cortical level in terms of the desired perceptual consequences of the movement. It is then transformed at a sub-cortical level, via an internal model of the external system, into desired body movement as represented by sensory information detected by joint receptors, muscle spindles and skin receptors. The desired body movement information is then transformed by an internal model of the body's biomechanical system into the desired pattern of muscle tensions, as detected by Golgi tendon organs, required to produce such a movement. The desired pattern of muscle tensions is then transformed via an internal model

of the body's neuromuscular control systems into appropriate motor cortex neural activity to generate the desired muscular tensions and produce the desired movement. The nervous system must learn the internal models (this learning represents acquisition of motor skill) and maintain their accuracy by monitoring sensory feedback of the motor commands, muscle tensions, body movements and exteroceptive consequences and by computing and updating the internal models of the relationships between these sensory signals. Furthermore, it is proposed that the movement programming defect in CP is consistent with the notion that brain damage in CP disrupts internal feedback of motor commands, thereby preventing the nervous system from forming an accurate internal model of the body's neuromuscular control systems. Consequently, during movement programming, the damaged nervous system experiences difficulty in translating desired muscle tensions into central motor activity capable of producing those muscle tensions. As a result, the nervous system generates inappropriate motor activity and this constitutes the primary disability of cerebral palsy.

The notion of the motor programming deficit in CP being a motor learning defect, caused by disruption of internal feedback of motor commands preventing the nervous system from establishing an accurate internal model of the body's neuromuscular control systems, is consistent with the observation that diagnosis of cerebral palsy only becomes possible as the CP falls further and further behind in normal motor development and fails to reach various motor milestones. Clearly, the movement deficiency in CP is an expression of a motor learning defect. CPs know exactly what they want to do, they know what movements they need to make to achieve the goal, and they can compute the muscle tensions required to achieve those movements, but they cannot compute the central motor cortex activity needed to produce the muscular tensions required to produce the movement. In other words, they have a breakdown of voluntary control at the level of learning the relationships between central neural activity in the motor cortex and the resulting tensions generated by the muscles.

All of this of course is speculation; a hypothesis is to be tested experimentally. If it is confirmed, it will represent an important new direction in our understanding of the mechanisms responsible for the motor programming disabilities of cerebral palsy. *It will shift the emphasis of therapy away from spasm, rigidospasticity and involuntary movement and focus it on motor learning and lack of motor adaptability as the primary cause of disability in cerebral palsy.*

A neuroanatomical picture, relevant to understanding the mechanisms of cerebral palsy, is beginning to appear in the neonatal intensive care and neurodevelopmental research literature. This picture is consistent with the Sensory Motor Model Theory presented above. In the developing brain there is an area of brain tissue which lies at the boundary between two different blood supply circuits; one blood supply circuit originates on the surface of the brain and radiates inward. If the developing brain is deprived of oxygen in some way, say by haemorrhage or occlusion of the blood supply vessels, so that there is a massive drop in the amount of oxygen reaching the brain, this vulnerable area of the brain at the boundary of these two blood supply systems is the region most likely to be damaged. This region is deep in the white matter of the brain, and is referred to as the periventricular white matter. It includes those nerve fibres which pass through the internal capsule of the brain on their way to the spinal cord. Brain sections at autopsy and brain scans of babies with brain damage have shown a patchy mottling degeneration within this white matter, which is referred to as leukomalacia – the sort of lesions which commonly occur when babies survive an anoxic insult of the developing brain. The blood vessels in this region of the developing brain are particularly thin and are vulnerable to damage in premature infants. Haemorrhage in this region is common and bleeding often extends into the ventricles.

The idea that the lesions responsible for motor disorder in CP are located in deep white matter in the internal capsule is consistent with the traditional explanation of cerebral palsy; that is, lesions disrupt the nerve fibres which transmit motor impulses from the brain to the muscles. Hemiplegic spasticity due to stroke is commonly associated with haemorrhage into the internal capsule and damage to the descending motor fibres, but CP is only superficially similar to stroke hemiplegia and the muscle contraction patterns observed in CP indicate a motor programming defect not observed in stroke patients.

Recent reviews of the neuroanatomy and neurophysiology of the deep structures in the brain known as the basal ganglia, thalamus, and cerebellum, in the nervous system section of the recently revised Handbook of Physiology, indicate that movement programming involves subcortical circuits which project from the cortex through the basal ganglia and cerebellum and back to the motor cortex. These circuits involve multiple pathways concerned with control of different body parts. The multiple pathways through the basal ganglia are not concerned with control of the forces generated by muscles per se, but rather are involved in specifying the parameters of limb movement, the speed and direction of movement of the limb as a whole. This is consistent with the notion that the subcortical circuit through the basal ganglia behave like an internal model of the external system which transforms desired perceptual goals into a neural code representing the body movements required to produce those perceptual consequences. For example, in a visual tracking task, the basal ganglia would transform the desired visual displacement of the response marker into the hand movement required to operate the joystick. Next, the information flows through the subcortical loops through the cerebellum and back to the motor cortex via the thalamus. In these subcortical loops, the desired body movements are transformed into the required patterns of tensions to be developed by the muscles and then the desired patterns



of tensions are transformed into the appropriate central neural motor activity (central motor commands) to activate the neuromuscular control systems. In other words, the subcortical loops through the cerebellum, behave like internal models of the body's biomechanics and neuromuscular control systems. The transformations involved in these loops represent learned relationships between perceptual consequences of movement, kinaesthetic sensations of movement, patterns of tensions developed by muscles, and central motor cortex neural activity. All of these transformations involve flow of neural signals from the cortex through the basal ganglia back via the thalamus to the pre-motor cortex, to the cerebellum, and back via the thalamus to the motor cortex. In other words, as best as we can tell from neurophysiological and neuroanatomical research, the nerve fibre pathways involved in transforming desired perceptual consequences of a movement into appropriate motor cortex activity to produce the movement, include the very pathways in the brain which are most vulnerable to damage by lack of oxygen in the developing brain.

The location of brain lesions in CP determined in one field of research, and the function of the neural circuits in which those lesions are located from another field of research, are consistent with the nature of the motor learning disability observed in CP in yet another branch of research.

Thus the pieces of the jigsaw of CP so far assembled, suggest that the primary motor disability in cerebral palsy results from haemorrhage or ischemic lesions in the deep periventricular white matter of the developing brain.

This white matter includes nerve fibres involved in the subcortical circuits through the basal ganglia and cerebellum involved in transforming desired perceptual consequences of a movement into appropriate motor commands to produce the movement. As a result, a CP can appreciate precisely the task he wants to perform, but is unable to translate this appreciation into appropriate motor commands to perform the task, just as suggested by Le Gay Brereton. As a consequence, the nervous system generates inappropriate motor commands, which are communicated to muscle control systems through intact descending pathways producing the powerful, but inappropriate, muscle contractions typical of CP.

Notice, this view differs from the traditional explanation of CP, which asserts that motor commands are disrupted by lesions in the descending pathways from the motor cortex to the muscles.

According to this new point of view, lesions in the periventricular white matter disrupt internal feedback of motor commands. Although the motor learning mechanisms receive sensory feedback from muscles, tendons, joints, skin, etc., it has no feedback of the motor commands which produce volitional movement, and so it is unable to learn the characteristics of its own neuromuscular control systems. The damaged nervous system can compute the muscular tensions required to produce a desired movement, but is unable to translate these desired tensions into the appropriate central motor activity needed to produce the movement. The inappropriate activity, which is formed by some compensatory mechanism, leads to inappropriate contractions of muscles and inappropriate reflex behaviour. Notice that this view implies that CPs have difficulty in controlling the tensions of individual muscles, rather than in computing the appropriate patterns of tensions to be developed across groups of muscles. In other words, strictly speaking it is not a problem of muscles coordination per se, but a problem in controlling the individual muscles within a coordinated pattern.

If these experiments, which will require some years to complete, are successful, we will have provided experimental evidence in support of the notion that the primary motor programming defect in CP results from disruption by brain lesions of internal feedback of motor commands, thereby preventing the nervous system from establishing internal models of the body's own neuromuscular control systems. We will also have obtained learning curves demonstrating the extent to which improvement in functional control of muscle contraction level can be obtained by appropriate EMG tracking training.

These data will then form the experimental basis for establishing new therapy techniques, aimed not only at reduction of spasm, rigidospasticity and involuntary movement, and prevention of development of deformities, but also continuing that training to acquire improved functional control of muscles.



Una Holibone



A suit of Samurai armour presented to The Spastic Centre by Dr S. Yamada of Okinawa.

Japan Takes up the Challenge

'I was instrumental, in my capacity as a Member of the Council for the Handicapped in Japan, in advising the Ministry of Labour about the working of Centre Industries in Sydney in Australia. The Minister of Labour, Mr Hasegawa, on my advice, set up legislation for profit-making Model Workshops, utilising Centre Industries as a pattern.

The numbers of the Model Workshops had grown to nineteen in 1976 and by March 1984 there were 252. I kept in touch with Centre Industries yearly for the last twelve years and in 1976 I formed the McLeod Society of Japan with hundreds of Japanese members who had visited Centre Industries on my recommendation.

I am certain that the Centre Industries philosophy has permeated the rehabilitation circles in Japan, and not only for the physically handicapped but, more importantly, for the cerebral palsied, as it put new heart into the parents of children with that dreaded affliction.' – Dr Takeo Noda

The Credo of the McLeod Society of Japan 1976

'We, human beings, strive for unwavering independence of spirit. For the physically handicapped, this independence must be achieved through rehabilitation to the utmost limits of their ability.

If we concentrate on what they can do, what they cannot do becomes irrelevant. No matter how severely they are handicapped, they certainly have the strength and will to guide their own destiny. It is essential that their own meaningful life not be denied. Let us go forward, challenging the new horizon's boundless goals, based on this common credo for the independence of the cerebral palsied and severely handicapped.

And let us propagate our credo to the whole world and join the wisdom, hands, and hearts of the people of the world.'

During the post-war period until 1960, Japan's economy was wholly based on export trade, but the idea was growing that the people of Japan should have some share of the market for themselves, and this embodied a change in the lifestyle of the Japanese family. Most of the domestic market would have been saturated in the sixties, except for those disadvantaged people who could not share in the general wealth.

The year 1970, brought to a close the age of Japan's rapid economic expansion and its fast transformation into a society of consumption oriented, economic prosperity. The high rates of growth began to create problems with the limited natural resources available, so that in the seventies they followed a more stable and slower path of economic growth. Then the concern of the Japanese people turned toward providing broader social welfare programmes, and creating a better living environment and more satisfying life mode. This in turn produced an impetus on welfare legislation for the physically handicapped, mentally handicapped and the aged.

In 1965, I attended the Third Pan Pacific Rehabilitation Conference in Japan with my wife. We assumed the typical tourist philosophy, being not yet aware of Japanese culture. Living in a western style hotel did not advance our knowledge of the people, apart from photographing the prevalence of kimonos and doll-like babies carried on their mother's backs, and the usual temples and shrines. That knowledge came later in the seventies.

Before the Conference, we had a preliminary meeting in Sydney with Dr George Pollock, an orthopaedic surgeon from Edinburgh, and Professor Guy Tardieu of Paris, both of whom were interested in cerebral palsy and were en route to the same Conference in Japan. They were very interested in Centre Industries. Professor Tardieu had done some interesting work with the use of alcohol

injections on muscles, to temporarily block their use while undergoing the spasms of cerebral palsy. He was interested in Centre Industries because he was dealing with his CP under laboratory conditions, whilst we had them in a working situation. Dr George Pollock had spent some years in Japan as a medical graduate and had not been back for twenty-five years. At the Conference, he delivered a paper on the new concepts in the treatment of the orthopaedic and related physical and medical management of the patients with cerebral palsy. Professor Tardieu delivered a paper on a critical study of the physio-pathological aspects of athetosis.

My wife delivered a paper at the Conference describing the measures that The Spastic Centre had taken in Sydney to provide the CP with daily transport, education, medical treatment and employment training. She described how it was started and had been maintained for twenty years by a group of parents. She said:

'I understand, as the mother of a handicapped daughter, many of the fears of mothers and fathers. Our children can be given a definite programme of work, well supervised medically and educationally. The training is prescribed by the Medical Director and carried out by the doctors with the schoolteachers, therapists, social workers and parents making up a team.

Mothers see the children at home and at work. The close contact with other parents provides them with companionship. They gain from one another's child's success or failures. The children of mothers who, for health reasons have been exempted from work at the Centre, do not make the same progress.

Since we started Centre Industries, there has been a remarkable change in the parents' outlook. I have seen most fears being changed to hope and, as the project prospered, to confidence. They were worried less about their living care. Adult CP are working to overcome their handicaps with a determination that they had never shown as children. Once money was something that they knew little about; now it is something to strive for and expend carefully. Boys are saving up for cars, and girls are taking care of their appearance as carefully as any girls in their age group.

The love of parents for CP children is a wonderful thing. It creates tremendous drive to do something to help the child overcome his handicaps. In return they receive such rich emotional rewards that, from time to time, I feel sorry for people who do not have a CP child - they miss so much.'

I was a discussant with Dr Sato, Director of the Habilitation Center for the Disabled in Hiroshima. Dr Sato knew that many sufferers of CP are in a serious condition and the counter measures for their welfare have become quite an urgent problem. He said there was a shortage of physiotherapists and occupational and speech therapists, and the families were facing an economic, as well as an emotional, problem. No action was being taken to solve the problems. Some of the CP in employment were moderate or mild cases. Dr Sato said, "Generally speaking it is better to choose simple and crude works when we select employment for the CP. That is not of course, however, to say that the goal will never be attained without the support and co-operation of the community."

I made a number of points in discussing Mr Sato's paper:

In cerebral palsy, restoration of the patient's right to a normal place in a normal society is possible only if normal facilities are made available. We tend to lose sight of the main objective and continue to isolate them in sheltered workshops or homes and other places in the interests of efficiency. We have lost sight of our objective and we should return to it again and again, at every stage of treatment and ask - is this going to place him further away from the normal social placement?

I applauded the degree and breadth of Dr Sato's approach to the problem, and said:

Here we are dealing not only with the degree of physical handicap, but a whole complex of intellectual, emotional, social, family and the physical variants, which together make it impossible for us to be certain of our assessment. I believe that there is only one valid form of work assessment and that is a trial on the job over an extended period. I quarrel with only three points in Dr Sato's address. I cannot agree that it would be right to restrict the employment of the CP to crude, simple works. I do not believe that home grants are the answer. I think these people need the discipline of a group of spastic workers. I believe in the integration of handicapped and able bodied in the same work situation.

As delegates, we were interested in visiting all available facilities in Tokyo, but we could not find any CP among the people in their workshops and we had to seek them out at the back of the room. Discussing this aspect with the guides, they said, "If it is spastics you want, you should visit a treatment unit set up for one hundred six-year-old spastic children." The following day we found it

outside Tokyo in a former rice field. It had been opened just a few months. It was equipped with every conceivable toy and therapy aid imaginable, but they were hamstrung because they had only just established a training school for physiotherapists and were dependent upon visiting tourists who were therapists from America. They were going through the same problems we had faced twenty-five years earlier.

On that trip we called in at Hong Kong, Bangkok and Singapore. The problems of Asia making any progress in the care of the CP could be equated with the level of poverty everywhere apparent. The United States and the United Nation were exporting rehabilitation expertise on a package basis to the developing nations of Asia and Africa, but it was many years premature. They had first to overcome the problems of sufficient food, basic hygiene, environmental disease and medical assistance. Welfare would come later, and among all the programmes of welfare, western style rehabilitation would be last on a very long list; and last of all must necessarily be the cerebral palsied.

In 1972, a Pan Pacific International Rehabilitation Conference was held in Sydney, attended by 2,500 delegates from overseas countries. Due to our experience in the work training of the severely handicapped CP, we felt disappointed that we had not been invited to participate actively in the Conference, and that Centre Industries was not on the visiting list of the delegates. I had spoken unofficially with Mr Norman Acton, the Secretary General of the International organisation, on my visit to New York about that time. I said that we proposed to put on an unofficial three-day lecture and inspection tour of our vocational work in Centre Industries whilst the International Conference was being held in Sydney.

We had many visitors at Centre Industries on the first day of the Pan Pacific Conference. The next day we had approximately 200 and finished with 300 in the audience on the third day. There was a group of Japanese people at the Conference who were completely fascinated with the idea of training CP among the able bodied workers in a profit-making commercial undertaking. The delegates returned to Japan and organised a seminar to visit Centre Industries one month later, to be further informed on the philosophies and principles of treatment. It was attended by representatives of the Japanese Ministry of Labour and people immediately concerned with rehabilitation. It was led by Mr Takeo Noda, a consultative member of a panel set up by the Ministry of Labour for the Technical Guidance of Model Factories, and Executive Director of Japan Charity Plate. They explained that they had scoured the world for a working model of a rehabilitation factory. They found what they were looking for in Centre Industries, because we were dealing with the very heavy physically handicapped CP. If it worked for the spastics in Centre Industries, with all their physical difficulties, it must offer a pattern for Japanese physically handicapped people.

The annual Japanese tours of Centre Industries that started in that year brought us in closer touch with the Japanese people themselves. Our contacts with the Japanese parents of the neglected cerebral palsied assisted the process, because we had been down the same road twenty-seven years before. The Rehabilitation Directors and Government administrative officials attending the seminars were able to talk in their own language of costs/benefits, of labour, buildings, assessment and servicing.

Most of all they were able to see our CP at work, in spite of their athetoid waving arms and grossly affected hands, more than half in wheelchairs, using the same machines as the able bodied workers – power press, drills, counter boring, welding and lathes – to make a highly technical telecommunication product for use in the telephone exchange system.

Then we took the Japanese delegates of the Ministry of Labour to Canberra, where they met the Minister for Social Services, the Honourable W. G. Hayden, which was opportune, because Mr Hayden was in the process of reviewing our own legislation aimed at subsidies for the sheltered workshops.

Shortly afterwards, a policy decision by the Labour Ministry of Japan was formulated, to establish a model factory for employment of the disabled. These were to be profit-making commercial undertakings, with land provided by the Government, and supported by a long term loan at low interest rates. They were to have more than 50% physically handicapped employed on a permanent basis, and the loans from the Government were confined to capital and could not be used for operating expenses.

In 1973, Professor Tatsuo Ohtsuka of the University of Doshida led a particularly active group in Japan, to establish in our honour, the Japanese Center Industries. It was set up to provide work training and employment for handicapped people, including CP, on a printing, advertising and computer basis. Mr Yoshihiko Watanabe was to be Managing Director, and among the others participating were the President, Professor Tatsuo Ohtsuka, Mr Seijun Sato, President of the Chiyoda Gravure Printing Company, and Mr Takeo Noda. Professor Ohtsuka had asked Mr Hume and me to participate in the naming ceremony, saying "It has given us a great spiritual uplift and encouragement. We are especially gratified that you make such long trip, taking time out from your own affairs to visit us. We have planned to exchange plaques between your Centre and Japan Center Industries. We have been searching for a propitious time to establish Japan Center Industries. September has been the month for promoting the employment of the disabled by the Ministry of Labour in Japan. The reason we have for wishing to exchange plaques can be understood by

the reading of the Center Industries' Credo." We were in New York at that time in connection with our G.E. and G.T.E. deals, and had arranged to fly to Tokyo on the return trip.

In 1973, when Mr Hume and I arrived in Tokyo airport at 5.00 p.m. local time, tired after a direct flight from New York, I should not have been surprised at what greeted us. I had remarked to Bruce that it would be nice to have a free evening, presuming nothing would be prepared for us until the following morning. I had underestimated Mr Noda – as we picked up our luggage we were confronted with a handwritten banner worded 'MCLEOD AND HUME – WELCOME TO TOKYO'. All the luggage was spirited away and we were ushered into a hire car with its traditional linen seat covering and a white-gloved chauffeur. Then Mr Noda produced three copies of a two-page itinerary he had prepared for our visit. I exchanged glances with Bruce when I saw that we would have only ten minutes in our hotel for a welcoming party in the lounge of the hotel twenty minutes later.

Introductions were made, and we were again in the hire car en route to the ceremony at the Hie Shrine, conducted in the Japanese manner. The shrine was constructed in the 10th century, and is famous for celebrating the union of lovers and other close ties between people. In the car I was filled in on the details of the ceremony, the manner of holding a sprig of palm, and the way it was to be returned to the High Priest as a gift. It was quite a moving ritual, but I was uncomfortable moving around in my socks, and the stools we sat on were about 30 cm high, so I must have looked odd with my knees on a level with my mouth. Then it was over, and the High Priest in his robes posed for photographs on the steps beyond the shrine. At the ceremony I said, "This shrine is ten centuries old, and my country, Australia, is still in its first century of nationhood. We the young and the old – the large and the small – are joined together in a simple ceremony in signing a credo that links us together in a common purpose."

The next day we had a meeting for one hundred specially selected people, including Masao Endo, Secretary of the Division of Employment Security, and Dr Fumihide Koike, Chief Director of the Japanese Society for Rehabilitation of the Disabled. I gave a lecture on productivity of the heavily handicapped, followed by Mr Hume on development of the hidden abilities of the CP and their training and activities in practice. That was followed by a reception given by Mr Motome Ikezumi, President of the Japanese Society for Rehabilitation of the Disabled. I said:

'Let me now run through the list of differences from the conventional type of sheltered workshops that make Centre Industries a more effective training unit. We use a production engineer to head our operation because that is the kind of business we are in. It is easier to train an engineer in rehabilitation, than to make a production man out of a rehabilitationist. We do not segregate our trainees in a group of disabled people. We cannot yet place people as heavily disabled as this in outside employment, so it is logical to bring able bodied workers into our own factory. We do not believe in the principle of sheltered workshops. Our CP trainees compete openly for their jobs against the able bodied at the same workbench, operating the same machines, at the same rates of piecework pay. We provide the additional training as the trainee requires it, and we modify the machines accordingly.

Somewhere, there is an answer to every individual problem of adaptive training, no matter what degree of physical handicap we are faced with. It is our engineer's responsibility to find that answer, no matter how long it takes or what it costs. We consider that medical supervision, including physiotherapy, speech and occupational therapy, as well as technical education, must be available on the factory floor rather than provided from outside sources. Advanced technology offers the heavily handicapped a release from unsuitable menial work not otherwise possible. Today's employer buys expertise, experience and efficiency in his labour rather than skilled hands and fingers. Mobility is essential. You cannot breed an attitude of independence if you cannot even push your own wheelchair to the toilet or canteen. We now have seventy electric wheelchairs in action and hope to introduce a mini-model in our pre-school groups next year. All cerebral palsied desperately need some means of communication. Every child who lacks effective speech should be equipped with a small electronic readout that will provide him with a word by word display. The technology for making this already exists here in Tokyo. Only the cost is holding it back.

Above all, the disabled person is entitled to an equal opportunity at the workbench. This can only be provided by adequate training facilities. This brings him personal dignity that is associated with worth and independence. He is entitled to live his life as others do; to marry and have the joy of children, to experience the sorrows, the happiness, the snubs and the defeats of daily living – and why not – he is a normal person too – something we all too easily forget.

However, our work for the very young child is equally important, because this is where the work of Centre Industries really starts – with the babies under one year of age. The preventive work we are now doing on some four hundred mothers and their very young babies can, we hope, make a Centre Industries totally unnecessary at some future time.

To summarise: Rehabilitation is good business for the CP because it offers him a new life. It is good for his family because it gives them a freedom that they have not known before. For the community it gives the CP the right to share in the economic cost of his own training, and for the Government it is more than good business, it is a wonderful business.'

Then we flew to Oita airport in Kyushu with Dr H. Nakamura, whose motto in Japan Sun Industries is: 'The handicapped who were tax spenders become tax payers. The handicapped themselves are eager to make the best of their remaining function.' Japan Sun Industries had 250 handicapped workers and embodied residential apartments and the factory in the same building. When we saw it first, they were doing amazing work with the more lightly handicapped disabled, but it has now gone beyond Centre Industries in wealth and facilities, though not in the degree of handicaps being rehabilitated. Its aim is to contribute to the progress of the labour, will, and ability of the handicapped, to analyse and study the concerned field and cultivate the human resources with their impediment for the rehabilitation.

We were given a private party in a tea house. This was our first experience of surrendering our coats, including wallets and all possessions, to the geisha girl, and donning kimonos. Shoes had to be surrendered as we entered. The party ended about 9.00 p.m. and our host, Dr Nakamura, decided on a 40 km trip to his mountain home. This was in the traditional Japanese style, with a bath fed by steam from the volcanic slopes. We engaged in the ritual soaping before the shower, which was a prelude to the bath proper, then to bed, with a futon bed over the Japanese tatami mats. It was 4°C in the mountains. We lost no time in getting our clothes on before breakfast.

In the course of lectures that I gave in Tokyo and Beppu, I came to realise that the path we had followed in establishing The Spastic Centre was not necessarily the only way. I had said in my talks to parents that the only way to get facilities for your child was to go out and get money by public donation and, if necessary, build it yourself. I was surprised when a mother took me up on that matter. She said, "That is not the way we would do it in Japan. Here we put pressure on the Government to get it for us, and in the meantime we will wait for our turn." She was supported by the other parents, but I could not at first understand. It was my introduction to the Japanese 'way' – political obedience but never servility.

We went to Sun Industries in the morning and back to Tokyo that night, where we met Mr Noda with an amended itinerary for our last day in Tokyo. Bruce said later that we would be taking coffee in a cafe, or lunch in a hotel, and a hand would come through the potted palms with four copies of Mr Noda's newly amended itinerary. I think that was stretching it a bit.

We had a sukiyaki party hosted by Dr Koike, and Dr and Mrs Karel Bobath. Dr Bobath is a London neurologist who, together with his wife, set up the physiotherapy programmes of the Bobath treatment that has done so much for the cerebral palsied people. The party included: Miss Chieko Akiyama, a TV commentator, Mr Seijun Sato, the President of the Chiyoda Gravure Printing Company, and Mr Takeo Noda.

Mr Noda had a previous appointment on our last night in Tokyo, so he deputed John Watanabe as his 'night manager'. His job was to show us the night life of Tokyo ... we got back to the hotel in the early hours of the morning, having further advanced our knowledge of Japan

In the ten years association with Mr Takeo Noda, I have got to know him quite well as a friend, and the culture gap has been accepted by each of us. It takes some time to break down the reticence of the Japanese, and it took many years to be invited to his home in Tokyo – this is the final social accolade.

I had first met Mr Noda at the Pan Pacific International Conference in Sydney in 1972, and he returned a month later with a team of Government and rehabilitation people. He marshaled his team into working groups from 9.00 a.m. to 6.00 p.m. for four days, and then there was a session in the hotel each night to reconcile their notes and prepare questions for the next day to be answered by us. He exhausted us with his questions, but it was apparent that the answers he received confirmed his previously arrived at conclusions, that Centre Industries was the philosophy he wanted for his model factory programmes.

Mr Noda had sponsored annual visits of about twenty to thirty groups of rehabilitationists to Centre Industries yearly for the next ten years, and in addition there was a constant stream of Japanese visitors over the summer months.

In 1976, Mr Noda visited us in Sydney for the purpose of ascertaining whether we would accept an invitation, if made by the Japanese Government, to carry out a programme of lectures designed to set the basis of new Work Training legislation to be brought into effect in Japan, broadly based on their interest in our Centre Industries concepts. Following the Sydney visit of the 1973 work study group, the Japanese legislation for the control of 'model training factories' was administered by the Minister of Labour, where the training of the handicapped takes its rightful place among that of apprentices, technical college students and able bodied workers. In 1976, the Ministry of Labour advanced still further with new legislation, designed to make it worthwhile for industry to accept handicapped workers, first by setting a quota, and then by subsidising additional costs and setting a tax levy for non-compliance.

The position then was that eighteen 'model factories' had been set up or were in process, and there were a number of 'welfare factories' financed mainly by Prefectural Government. With the exception of one outstanding factory employing severely retarded, and one large productive factory employing a large number of lightly handicapped, all the Japanese factories were below our Centre Industries' standard, although they were well above the standard of our sheltered workshops.

With my wife, I visited Japan in 1976, the trip being planned by the three hundred and fifty members of Japanese Rehabilitation Study Groups who had worked at Centre Industries Seminars over the preceding four years, to form a 'McLeod Society of Japan' for the purpose of promoting the Centre

Industries type of factory training in Japan. This was duly inaugurated on the first day of our visit, which was selected as Fathers' Day in Japan. We tried to persuade the organisers that they would serve their purpose better if a more Japanese name for the Society was given; but they felt that 'Mac-kee-odd' was sufficiently Japanese. More importantly, McLeod was already associated in their minds with the philosophy of training the heavily handicapped, which was the thing that they particularly wanted to publicise.

The McLeod Society of Japan is a structure to exchange ideas, training facilities, technical know-how, research and development material, and later perhaps to exchange selected trainees. They have much to offer in the realms of production, especially in electronics.

For the present, they can learn from us. Very soon, we will gain far more than we contribute to the common pool. We can only gain in the future from this close association, which puts at a practical level what the Prime Minister, Mr Takeo Miki, had been discussing in their Treaty of Friendship and Co-operation, which was signed during our visit.

Mrs McLeod's report on the first forty-eight hours in Tokyo:

'On arrival in Tokyo we were met at the airport with great ceremony and conducted to our hotel. Here we were excused for one hour to have a shower and unpack. We then met in the next room for a day-long briefing of our itinerary, particularly that part of it which related to the formation of the McLeod Society of Japan. We finally finished the day at 7.58 p.m. Whilst we were both extremely tired, we felt that every effort was being made by everyone to ensure that everything that could be done to make sure that no hitch occurred was in fact being done, and they were reassuring themselves as much as explaining to us.

The next day we were free until eleven, when Mr Suzuki arrived to give Mac some practice in a few sentences which he was to speak in the Japanese language. We lunched in our room and at 1.00 p.m. went out for the big occasion. Prior to our entrance they showed 'This is Your Life' to the audience. As it was a Sunday, only 150 people could be present in the hall for fire precaution reasons. No other hall was available. However, Mr Noda overcame the problem by having another fifty or sixty as helpers. He explained that there could be scene shifters, doormen, cleaners, or tidy-uppers – this is quite legal and enabled him to add to the number in the audience.

We made our very self-conscious entrance, feeling like a couple of aged outmoded pop stars attending a teenagers' performance. Professor Ohtsuka led the procession and everyone clapped and we bowed to the left and right, feeling uncomfortable, but trying to look dignified as Spastic Centre representatives. The proceedings opened with proclamations by our hosts. A message from the sponsors – McLeods – and then the reading of the Credo sentence by sentence, Mac in English and Professor Ohtsuka in Japanese, then we all signed it. We then had an interval while pictures were taken and then Mac gave his speech. This was very good and dignified and, as I had taken care to look at his feet beforehand, this time he did not have odd socks on. Then came my turn to speak, and after Mac's scholarly presentation, I felt stupid. However, I did my usual bit of talking about the children and parents and it was well received. The Professor was pleased and asked me to give the same talk in Kyoto. As if I could! He told Mac Japanese men don't cry, but he cried, so I guess we achieved something.

After the proceedings finished, we went to another floor in the same building for a party. This started with a toast, one country to the other, and some more speeches. Then we drank and ate, except that I didn't get time to more than sip a drink. So many people wanted to talk. You just can't be photographed, talk and eat all at the same time. Mac was having the same problem at his part of the room and was positively besieged. Then they presented us with a gift to commemorate the occasion - in the one glass case, a very old gentleman with long white beard and rake, and a very old lady with a straw broom. I knew the years

had passed, but this was faster than I thought. It was explained that great thought had been given to the selection of the gift. This was to wish us a long, healthy, happy life of one hundred years or more. Mac gave a hilarious speech of thanks which had all the Japanese in fits of laughter as he went through the actions of sweeping. They all loved it, and him.

After the general guests left, we sat down with an inner group to eat the leftovers. We returned to the hotel to have another meeting until about 9.00 p.m. It was a long day, but Mr Noda was very happy with it, and the McLeod Society of Japan had been formed.

Next day we went to see the Minister of Labour, Mr Hasegawa, who is quite tall and very handsome and distinguished looking. We took our Minister of Labour's introductory letter, but Mr Noda explained that it was not nearly important enough for us to just present a letter in an envelope. So the letter was framed under glass with a translation and the envelope on the back of the frame. We were received with great formality and great dignity and complete cordiality.

We, and especially Mac, had been fully briefed by Mr Noda about what areas to touch on, and Mac did a marvellous job.

The Minister told us of the manifold reports, which he had received from all the different types of people who had visited Centre Industries. He said Japan has great reason to be grateful to Australia for teaching them our thinking on employment and training, as carried out at Centre Industries, that nowhere in the world had anything like it been seen, and there was a debt of gratitude to be paid to us and they wanted to join with us for our common objectives of welfare. He told the Japanese, who were with us as we were leaving, that as well as all the past reports about Centre Industries, in the past two days on two occasions other people had spoken to him about the work both Mac and I had done. He also said that having met Mac, he too was as impressed with his demeanour and bearing as all the other Japanese told him that they were.

The Japanese people do seem to love and respect Mac, who teases them and jokes with them, which they enjoy. The dinner to be given by the Minister of Labour, will not now take place until later in the tour as the Australian Prime Minister's visit has caused some problems for them in having everyone available at the one time.

We leave Tokyo tomorrow for visits to two model factories and then we stay at Hotel Mount Fuji where the manager has insisted on us being his guests. We are to have a formal Japanese dinner tomorrow night.

I had my hair washed and set this morning. Cost \$25.00, but every hair was washed at least eight times. My scalp feels raw, and if a hair fell out I would scream with pain. At least I look like a lot of Japanese women from the back, although I differ from them in the front view. I also had a manicure, and this entailed a massage up to and past the elbow joints. If my sleeves had not been so tight heaven only knows what would have happened next.'



Takafumi Takahashi M.D. Director of Seichi Takuto-Ken and Chairman of the McLeod Society of Japan.



Mr Sodanori Iwasaki from the Prefectural Government of Hiroshima with Miss Australia 1970 Shirley Young and Judith Geppert, operating a press.



Professor Yokomizo of Waseda University, Tokyo.

My wife has already mentioned an official visit to the Minister of Labour, Mr Hasegawa, attended by Mr Dosho, Administrative Vice Minister, Ministry of Labour, Mr Masao Endo, Director General of Employment Security, Mr Saburo Mochizuki, Director of Employment Service, Council Member of Labour Ministry, and Managerial Councillor of Model Factories. I thanked the Minister for receiving us and outlined Australian-Japanese reciprocity in welfare. I congratulated the Minister on the forward looking Model Factory legislation and new legislation to be implemented the following October, which was planned to encourage industries and community participation. The Minister said the spirit of the Act is significant - factories will be required to employ handicapped subject to a levy; 1.5 per cent of workers employed must be handicapped, 1.7 per cent in Government employment, on a certificate of handicaps, provided by the Minister of Labour. The Centre Industries MODAPTS Test Battery would be used in assessment. I requested details of the legislation. The Minister responded and promised to have it translated and forwarded. I then presented the framed letter from the Honourable A. A. Street, Minister for Employment and Industrial Relations, and the Minister commented on the Japanese translation on the back. He recalled the visit of two of his senior officers – Mr Matsushita and Mr Ujiie – to Sydney and Canberra in 1973, and the value of their subsequent report to him. The Minister promised to write suitably to Mr Street and suggested that pressure for advancement in legislation in Australia should be obtained by pressure 'from all sides'.

Miss Yoko Kojima, Ph.D., a member of the National Council on Employment of the Disabled, the Ministry of Labour, had this to say:

'One factor is the increase in disabled manpower, shifted from the enlarged school population. Up to now, seriously disabled children were either institutionalised or kept at home, bound by an official permit excusing compulsory elementary and secondary education. In recent years however, parents in a civil rights movement appeared in some local government offices, rejecting and objecting to this negative permit system.'

Japan was hit by the oil crisis in the early 1970s. In the following years, the total economic situation became tight and expansion has been greatly slowed down. Consequently, business lost its power to absorb new manpower. Even non-disabled young labour forces faced the risks of unemployment. This pressure was much stronger on the disabled manpower. Numerous disabled persons were discharged from jobs that they had obtained at the time of the high production period preceding the oil crisis. Further, the smaller employers, with employees numbering less than three hundred, were taking more than their fair share of the disabled, but the disabled proportion was appreciably worse in larger factories employing more than that number. So it was obvious something had to be done in the larger plants, which absorbed six million workers out of a total work force of ten million.'

We visited two Model Factories. Nihon Rikagaku is located in a heavily populated industrial suburb about 20 km from Tokyo centre. It employs seventy-one mentally handicapped and twenty-six able bodied workers. The city bought the land and handed it over at cheap rental. The National Government provided a special loan; \$20,000 for initial assets. The factory produced dustless chalks in all colours for schools, blackboard erasers, moldings, and assembles cassettes for Pioneer tape recorders, and gaskets for the Nissan motor engines. They propose to level off the employment of the mentally handicapped at 150 over a five year period. The workers are all assessed at minus 50 IQ. No transport is provided – each of the handicapped workers uses public transport. I requested a sample of a complicated route handled by a grossly mentally retarded of about twenty years old. He leaves home at 6.30, walks to Kanazawa-Hakkei station in fifteen minutes, catches a train to Yokohama central, changes for a train to Jiugaoka station, changes again for a train to Futago-Shinchi station, and then walks fifteen minutes to the factory. This boy works at the end of the chalk line filling cartons of chalks with sawdust and sealing the cartons with adhesive tape. The factory is quite profitable and expects to increase its market and numbers of mentally handicapped substantially in 1977. The general impression left by this visit was that severe mental retardation is no bar at all to profitable operation, and there was no evidence of 'lack of concentration' which, in this factory at least, is a complete myth; a surprising and very heartening demonstration.

The second Model Factory was Musashino Denshi Kogyo Co, on the foothills of Mount Fuji, which employs fifty handicapped, forty part-time handicapped workers and forty-six able bodied. Most of the handicapped are paraplegics who can buzz around in manual wheelchairs. The two factory foremen are wheelchair paraplegics. All machine operators have good hands, but some single amputees are placed in one-hand operations. Most live in residential accommodation, single-storey on factory premises. In the main, they produce machined solid aluminium and aluminized plastic knobs in about 450 models for Pioneer and other manufacturers of hi-fit radio and similar equipment. Productivity is high, the cramped work space engenders a 'beat' that makes our machine shop appear leisurely in comparison. The Factory is profitable and competes successfully with its product, which has been exclusive until recently. MODAPTS assessment is used. Test equipment is our design, altered in some details and chrome plated, which makes it look much more impressive.

The President of the Company, Mr Kimura, an Executive Director of The McLeod Society, entertained us royally. In the boardroom we were seated on two white linen-covered chairs which had last been used five years before by the Crown Prince and Princess Michiko. His Board presented us with a painting of Mount Fuji, and a young athetoid worker presented an envelope containing ¥3,400, which he had collected from his workmates for The Spastic Centre. We heard a week later that he only had ten minutes free at lunchtime to get around among his supporters. He was still seeking out and telling each one individually how he had made a speech and had been kissed by Mrs McLeod. The Japanese do not kiss – too embarrassing!

We were entertained for dinner that evening and next. We were driven on a 'free' day up the Fuji Mountain to the 5th stage and climbed just out of the tree line. Very inspiring - especially as Fuji-san appeared magically out of the mists just for us whenever we removed a camera lens cap. She averages appearances on only two days in the month of June, so she was very kind to us.

Our second memorial lecture was given in Kyoto, attended by 200 at the Crippled Children's Centre, Fukushi Kaikan. The welcome dinner, Japanese style, in a tea house with geishas, was attended by about twenty guests, including Professor Ohtsuka, Professor Yokomizo and the Director of Welfare Services for Kyoto Prefecture, who visited Sydney the following August and asked for help in understanding his handicapped people's problem. Audrie said, 'I cannot match my western awkwardness to the geishas with their graceful movements in the dance, but I can do pushups.' She accordingly demonstrated and instructed Professor Ohtsuka, and the geishas present, in the fine art of pushups!

We visited Professor Goto, an ENT specialist, Director of the Red Cross Hospital, Dr Fujita, Vice Director and Lecturer at Kyoto University and Dr Takeshita, pediatrician, Medical Superintendent and in charge of a separate cerebral palsied hospital for heavily handicapped, who is particularly interested in problems of muscle function in cerebral palsy. We discussed the Peter Neilson project with Professor Goto, an elderly but extremely bright and interesting man who says that, like most doctors, he has applied himself to the correction of medical problems and now wishes that he had worked at preventing them from happening in the first place. Dr Fujita asked for permission to retain a copy of Neilson's summary and will have it analysed and discussed thoroughly at next week's Kyoto University seminar, and will forward a questionnaire asking for further details. We had a very well spent morning because of the interest and evident keenness of the three doctors concerned. Professor Goto has spent his lifetime, he says, unsuccessfully trying to understand the problems of speech. Dr Fujita is a neurologist and by reputation a good one.

In Kyoto, we inspected a CP hospital for heavily handicapped. The hospital comprised two units each of twenty-seven handicapped cerebral palsied. The first was set up in the normal way with activity rooms and some attempt made in physical training. Facilities are primitive, and there is little stimulation. In Japanese style, all activities are floorbound, and this works against attempts to improve mobility. Plenty of evidence of fixed deformities and no plasters, braces or physio aids in sight. The second group were far worse physically, and included half their number moribund in cots at midday. They had the appearance of never being taken out of bed, and displayed complete lack of interest in their surroundings. Sufficient foot, leg and hand deformities were evident to make one weep. The whole place gives the appearance of acceptance of the impossibility of improving the condition of CP, so badly physically and perhaps grossly mentally handicapped, and cries out for a visit from one of our doctors. Fortunately we may well be in a position to discuss this unit and its problems with Mr Morita, the Director of Welfare at Kyoto City, if he comes as promised to Sydney in August. The immediate problem is one of funds, because the present Matron cannot change much in the existing unsuitable buildings, equipment, and perhaps staff, although she appears to be anxious to upgrade the work. At present, finance is obtained from the Central Government on a limited basis aimed at training the patients to the stage where they are progressed to crippled children's schools. Unfortunately, these are not progressing, so funds otherwise available are reduced.

I had trouble in getting my wife to leave the hospital – there was so much that was crying out for attention – and we left there with heavy hearts. We could not, of course, prejudice our status as friendly visitors. All we could do was to say that we regarded these children as treatable, in the hope that that designation would be remembered.

We then visited Hiroshima, where we lectured to a group of twenty-six experts, drawn from the Prefecture and voluntary bodies. This lecture followed the pattern of the others given in Tokyo and Kyoto, as a plea for the heavily handicapped to be accepted as individuals; to believe rather than pay lip service to the concept that they are not different from us and that they can contribute significantly to their own rehabilitation in both costs and organisation. It stirred up a lot of interest and questions, and these were continued through the reception which followed. The morning of the following day was spent in Hiroshima Peace Park Memorial, which shows without embarrassment or hostility only too clearly what happened to 400,000 people one bright, sunny morning in 1945.

We next visited Sun Industries at Beppu. I had been there three years earlier. It is a welfare factory, which gets funds from the Central Government Department of Welfare, and the Prefecture. They are not repayable, long term, low interest loans, as they are in the case of Model Factories administered by the Central Government Department of Labour. The effect of this is that Sun

Industries is very well endowed financially. Since our last visit about two years previously, a large multi-storey residential block, a full-sized basketball court with audience gallery, and an indoor heated Olympic standard swimming pool have been added. Production is mainly woodwork – small shrines and floor heaters which we saw previously, extended to high class lacquered cabinets and hand carved wooden medallions for adornment of furniture, and steel rules. The Sun Company is licenced by the Department of Weights and Measures for the manufacture of steel rules, which operates at a high level. At the molding machines, we met the handicapped daughter of Mr Ibuka, the Sony President who is interested in Sun Industries, as also is Miss Akiyama, the TV and radio social welfare commentator, who we met at The McLeod Society inauguration and later, at the Ministry of Labour reception. There is an assembly and test operation on Sony calculators. The assembled PCBs and keyboards are supplied, and they produce 20,000 per month. Final assembly – motorised wheelchair, with ten pushbuttons, which operate by ultrasound and open doors, drawers, curtains, and bring cupboards within reach in a fully mechanized kitchen. A machine with tape numerical controls has been purchased for programmed drilling operations and a pipe bending machine for continuous production. One useful idea is a hydraulic work platform for wheelchair workers, which elevates the platform to any convenient height. It can be freely rotated, enabling four workers to operate without moving their wheelchairs, which are used in the assembly of motorised wheelchairs. The wheelchair is quite light, with geared power to each wheel controlled by a joystick. A Sun designed mechanical quadrant fitted to the castor wheels acts like a segment of a large wheel, enabling the chair to mount a 10 cm kerb without difficulty.

They have all the expensive facilities for elaborate physical testing, including EMG, treadmill and friction loaded devices with oxygen analyser, and rely on assessment as the minimum standard needed to be able to work on a process line.

We lectured to therapists, teachers, parents and crippled children and care centre administrators from Oita Prefecture and North Kyushu, together with Sun Industries staff. We had to gallop from the lecture room to pick up our train, but on balance we seemed to have stirred them successfully. We would have liked to see more heavily handicapped involved in this factory. It is doing work which is necessary and desirable for the lightly handicapped, but it has all of the facilities to lead the field with the heavily handicapped, which in Japan, in 1976, was an untouched area of work training.

In Fukuoka, we visited the Dai-Ichi Koso Co. Ltd Model factory. This is a rather surprising unit employing thirty deaf handicapped and twenty-six able bodied in the production of very high class western style kitchen furniture for domestic and hotel trade. The designs are mouth-watering by any standards, and the deaf are not handicapped at all by their disablement. They are paid on productivity and in two departments out of four the handicapped average slightly higher wages than the able bodied workers. The President, Mr Yamashita, employs deaf workers because in his youth his employer was deaf. He was treated so well by him, that he feels he must repay his kindness by fostering the employment of the deaf. This he is doing very well.

Back In Tokyo, we lectured on vocational training at Centre Industries to the National Institute of Vocational Research. This is part of the Sun Plaza, a community youth centre operated by the Department of Labour, aimed at providing social training and cultural activities for young people.

Attendance was one hundred, including thirty-five vocational research staff, ten Ministry of Labour officials, fifteen training and employment officers of the Department of Labour, and Prefectural officers. The talk was successful, but translation reduced the effective time, leaving insufficient time for questions and discussion. To our surprise and embarrassment, they showed their appreciation by a gift of ¥40,000 to The Spastic Centre.

A welcome party organised by the Minister of Labour was attended by the Vice Minister Mr Dosho and twenty-two officers of the Department. It was followed by a private dinner, Japanese style, in Tea House at Firefly Gardens. The fireflies were a new experience for both of us. The pathways into the Gardens were dark and screened by trees. Suddenly, turning a corner, the whole sky was filled with myriads of fireflies in criss-cross clouds, rising and falling and rising again. Their light was so strong that I could clearly see my wife's face, and it continued ahead for a least one hundred metres. Mr Noda referred to it as 'a Japanese circus'.

We were hosted by senior officials of the Department of Labour, including Mr Endo the Director General, Mr Ujiie, the Director Public Relations Division, Mr Matsushita, Deputy Director Ministry of Labour, Legislation Division Labour Policy Bureau, Department of Labour, Mr Mochizuki, Director Employment Service Division, Department of Labour, Mr Nagasaka, Executive Committee McLeod Society of Japan, Mr Noda, Executive Director Japan Charity Plate, Secretary General McLeod Society, Member Consultative Committee Technical Guidance Model Factories, Mr Kimura, President, Musaschino Electronics, Executive Committee McLeod Society, Professor Ohtsuka, Doshisha University, Professor Yokomizo, Waseda University; Professor Hayashi, Shizuoka University, and Dr Suzuki, Griffith University, Brisbane – all of whom had visited Centre Industries on a number of occasions.

We then made an official call on the Australian Ambassador, Mr M. Shann who received us very graciously and apologised for not accepting the invitation to The McLeod Society inaugural ceremony. He said that he was personally interested in the promotion

of Australian-Japanese relationships beyond those of Toyota cars, and iron ore. The Treaty of Friendship and Co-operation had already provided the setting up of a Government sponsored Foundation which would have money to spend in this area. He was very interested in our Japanese-Australian interchange. We had been ahead of Government policy in carrying out this exercise privately for the past four years and he promised his full support.

Mr Shann noted the date of the arrival at Centre Industries, of the August Japanese visit of 140 welfare officials, with a view to their official recognition by City, State or Commonwealth official circles. The Australian Information Service team were already waiting on our return, and filmed a C.I. documentary for Tokyo TV and material for the Japanese newspapers and other media.

When Professor Yokomizo visited Centre Industries in 1973, he obtained photographs and assessment operational details of MODAPTS, a test battery for the CP developed by Centre Industries. He has developed the computer system by long term validation studies conducted on eight different types of handicapped ranging from able bodied to cerebral palsied. His tests show a significant stability in MODAPTS assessment scores in relationship to normal able bodied performance and the deviation by diagnostic groups is also stable. On the basis of this work he has obtained approval for the use of the MODAPTS system as a basis for classification of degrees of certified assessed handicap under the new Department of Labour legislation which requires a definitive measure of handicapped workers' degree of disability. In short, while we have developed a unique tool of assessment in adapting MODAPTS into the realm of rehabilitation, we have not progressed it beyond the original manual classification.

In 1974, we took Mr Noda to Canberra to meet the Minister for Social Services, and after our visit he expressed an interest in the Australian War Memorial, particularly the mini-submarines that were exhibited there. I was ill at ease about this, because the submarines were blown in half in the explosion on Sydney Harbour, but Mr Noda and Dr Takahashi were extremely interested, without any embarrassment, because Mr Noda said that his father had designed the optics of that submarine.

Over the years, I picked up bits of Mr Noda's background in casual conversation. He was of a Samurai family and he said that that meant in kindergarten he was in the front row – but that he would sooner be in the back away from the teacher. He was a Naval trainee pilot during the war, but fortunately for him the war ended before he qualified.

Mr Noda told me that he had not always been involved with rehabilitation work. Originally, he had set up the Japan Charity Plate, a charitable institution. The reason he had done this was that his eldest son had a serious accident, falling on the steel spikes of a fence. The doctors thought that he might have sustained brain damage, and Mr Noda made a vow that, if his son recovered uninjured, he would make welfare work his life's vocation.

After the war was over, two of Mr Noda's friends did a welfare course at University under Professor Ohtsuka. They were having some difficulty in translation of some technical papers, so they enlisted a junior economics student as an interpreter. There was a feeling that they were putting too much work in the student's hands, and wanted to recompense him for his time, but he refused because he had a spastic sister – and that was Mr Nagasaka. In the late 1970s, the Board of Trade posted him to Sydney. The other friends were Professor Yokomizo, who was responsible for the MODAPTS computer conversion, and Dr Takahashi, who established a children's hospital at Sendai.

Mr Noda said that he had been in Australia twelve times since his first visit in 1972. People often asked him questions about Australia, but he could not answer the questions because the only part of Australia he knew was Centre Industries and his hotel.

I have put a lot of detail into our visits to give you some idea of the friendship that was formed with the Japanese people altogether, apart from culture and language problems. I made three later visits to Japan with my wife, and I added a fourth one on business with the Fujitsu Company. On these visits, we had extended our range to Sapporo in Hokkaido in the far north, to Oito in the south island of Kyushu.

In 1978, we needed to show the Japanese what were the degrees of handicap that we were talking about in our many lectures. 'Severely' handicapped and 'heavily' handicapped mean different things to different people. They had seen our people at work on their visits to Centre Industries. Now we embarked on an exchange visit between Japanese students and our CP workers in Centre Industries. Our objective was to demonstrate that cerebral palsied could be trained for a place in the workforce, in spite of their physical infirmities. We needed to convince the Japanese people that the spastics were just as intelligent as normal people, but they lacked the means of expressing their thoughts by speech or hand movement. Both of these deficiencies could now be overcome by medical therapy, engineering and electronics; mobility had already been achieved by the powered wheelchair.

Now they needed to be shown that the cerebral palsied could take their place in a highly technical sphere. We took a team of five adult CP along with us – two of them were working in the EDP section as programmers and operators, one hemiplegic man was a switchboard operator, another, my daughter Jennifer, was in control of twenty-two able bodied female aides and operated her own Personal Independence Programme, and the fifth was a man working as an engineer's typist. We also took along two



Prime Minister of Australia, Mr Malcolm Fraser, greets Japanese visitors of The Fespics Games in Sydney.

nurses from our Venue Burges House. Three of the CP were in wheelchairs and two were walking with difficulty. Only one could speak intelligibly to a stranger, but they were an object lesson which paid dividends. They were required to make speeches and present gifts to the Governors of the Prefectures and the Mayors of the cities they visited. In spite of their problems, they behaved admirably, but, most of all, they were clothed in the normal fashion of their age group and that had an immediate effect on CP people in Japan, because they had not expected our people to be so well dressed. Lindsay, one of our group, in talking to a group of Japanese CP, said, "If you are a spastic you must present well, more than an able bodied person, in order to gain respect." This message sank in.

At a reception in Kobe two years later, my wife had remarked on the improved presentation of the CP group. She admired a pretty dress worn by a young girl in a wheelchair. The girl explained that this was the first time she had gone into a shop, unescorted, and selected a dress without assistance from anybody, and paid for it herself out of the money she had earned.

On our visit to Sapporo in 1978 the Governor, Dr Dogakinai, took pride in the dinner that he gave us because every item of food and drink was from the Island of Hokkaido. This island is under heavy snow seven months of the year, and when I mentioned wine I was given two bottles of Hokkaido wine, one of red and one of white, which were equal to anything I have tasted. To get the utmost yield from the sunshine, the grapes were trained over a canopy three metres from the ground, so the bunches hung down from an arboreal ceiling.

Further down the coast we visited Mr Iwati's Nishitage Work Campus at Sendai. Mr Iwati had visited us at Centre Industries two years before. In those two years he had built the workshop building and staffed it with seventy adults. He had residential buildings for married and single people and he was, at that time, involved in a printshop for the severely handicapped spastics. He had done all that in twenty-four months. What impressed me most was that he was working with twenty handicapped people doing data processing for a local firm, under contract, and using sixteen VDUs and a tape concentrator. In another section he was adapting the skills of the swordmakers of past centuries to modern use, by capitalising on the hand engraving of shotguns for the American sporting market. In 1981, he had doubled his staff of handicapped people and had increased it further with handicapped people too old to work, who were given an 'active' nursing home atmosphere.

I visited Dr Takahashi's hospital for crippled children in 1976 and in 1978. On that latter visit, the children were assembled and the selected girl welcomed us on behalf of the hospital, and then in conclusion she added that she always thought all foreigners had big noses. In 1981, I was astounded by the advancement in Dr Takahashi's medical work. Six years previously, most of the children were in beds – now 75 per cent were up on crutches and in wheelchairs, including the smallest ones in the Mothers and Babies Programme that he said he had borrowed from The Spastic Centre. He had completed a new modern school since our last visit and had a staff ratio slightly more than one to one of the children.

Instead of making a speech to the children, I had said I would give them a foreign language lesson. In lieu of saying 'Sayonara' in Japanese, I drilled them in 'Australian', saying 'I'll see you later.' The children picked this up so quickly, that when we were leaving we were besieged by a hundred mobile crutches and wheelchair children shouting as only small children can, "See you later! See you later!"

The year marked the high point in Japan. Dr Takahashi established more firmly than ever his hospital and school in Sendai, with emphasis on early treatment. Mr Iwati extended his workshop facilities at Sendai. Dr Kinbara established the Nojigiku-Ryoiku Centre at Kobe, again with emphasis on early treatment. The National Vocational Rehabilitation Centre was established in Saitama Prefecture, not, in my narrow view, with enough cerebral palsied trainees. Dr Nakamura of Sun Industries had started work on the heavily handicapped CP. Dr Nishimura had established the Rehabilitation Workshop for Physically Handicapped in Hokkaido with laundry facilities, equaling Centre Industries in annual sales budget. In 1979, the Model Factory target was sixty plants engaged in light engineering projects, and their target rose by twenty-five per year over a five year period.

Japan was on the way with the customary Japanese thoroughness!!

In 1981, we made a further tour at the invitation of The McLeod Society of Japan and then called it a day.

Altogether, over one thousand Japanese people have visited Centre Industries in the past ten years. In those ten years we have learned a lot about the Japanese people and their culture. Whether we were at Centre Industries or in Japan, we received great politeness, which very soon made way for a sincere friendship for the people who were working in the same field of rehabilitation as ourselves. I think we were privileged because we were able to get beyond the shell of western culture, with which everyone surrounds himself, and dig deeper into the hearts of Japanese parents, whose children had suffered the same tortures as ours. We were not specialist welfare workers to provide a scientific technical course on social justice. Our appeal was primarily to other

parents and their cerebral palsied children, and to adults, and the Japanese responded wholeheartedly.

I was especially glad to see that two hundred handicapped visitors to Centre Industries in 1984 comprised a predominance of Assemblymen from a wide list of Prefectural Governments, because they are the planners. The women's groups were there and youth groups of high school students with their promises to be more aware of the handicapped in their midst.

When we lectured in Japan or Sydney I never failed to make the point that they were learning about rehabilitation of the cerebral palsied from us, but it would not be long before the position was reversed and we would be learning from Japan. There are two measures responsible for this: they are the advanced Japanese legislation programmes affecting the physically handicapped over the past ten years, and our depressed economy over the past decade from 1974 until 1984, when we stood still and were satisfied with economic survival.

We have always believed the answer to cerebral palsy lies, specifically, in electronics – for education and mobility for the very young child, the school child and for the working adult. Electronic speech is just around the corner. Computer software can replace metal working machines, this will have the effect of equalising the competition between the able bodied person and the heavily handicapped cerebral palsied, in just a few years from now.



Leader of the Japanese official visits in 1975 Dr S Yamada of Okinawa, and Miss Taruko Akita was the interpreter.





The contract was signed between Civil and Civic Company for the Construction of the adult hostel.
Jan Lott and Elizabeth Pumpa are seen in the background.

Venee Burges Hostel 1974

Letter One:

'Please help me. I'm getting more and more depressed every day and I'm taking drugs that don't help. I get worked up easily, so much so I couldn't go through with the operation. There must be something wrong with my mind. I hate myself more and more, for being a CP. Why should I be forced to miss out on so many things in life? Why can't this place provide a hostel where I can live my own life and not be tied down by aging parents or be forced to live in a hostel for kids?

I don't think you fully understand the problems some CP have to face. Look, all I know is that something inside me has changed. I don't know what it is, either environmental factors or just going through a difficult age. All I know is that life for me at the moment is very frustrating and difficult. And above all I suffer from depression most of the time. Please note, I have gone off the Librium. Would an antidepressant drug help?'

Letter Two:

'I hope this letter is better than the last one, and it will give you a better insight into my problem. You may pass this letter on to anyone who wants to know more about the problems a lot of CP have to face today.

I think, unlike some CP, for a year or so I have been able to live an unsheltered life because I had to stay at the hostel when my mother was ill. When through things beyond my control, I started living at home again, I was not prepared to be 'Mum's little boy' any more, more or less secluded from the outside world. However, if a young man who is handicapped to the extent where he has to rely on someone to feed, bath and dress him, namely his aging parents, he becomes more and more agitated because he is forced to miss out on a lot of pleasures in life.

Centre Industries gives me a tremendous feeling of satisfaction by giving me a chance to serve the community. And The Spastic Centre has educated me. But The Spastic Centre and Centre Industries have only fulfilled a part of my life, mainly due to public ignorance by not providing funds in order that accommodation be provided for myself

and others like me. Thus I am forced to live only half the life I should be living.

To face up to the fact that I am handicapped is very difficult. I have learned to live with it; but like everyone else I have 'desires'. A normal person can satisfy them in one way or another, but at the moment I cannot do that altogether, I'm not just speaking in terms of sex and love, although these things play a big part. A lot of the things people take for granted, such as going to various places, even simple things like going shopping or to the local pub.

These things I cannot do because I'm forced to live with my parents, whom I am totally dependent.

I have tried to organise my interests in life without involving them. I should be able to get acquainted with people, seeing that there are so many at Centre Industries, but I can't as everyone is so busy.

I understand when the Adult Hostel Complex is built there will be someone to organise social activities, and I'm hoping these future extensions to the Centre will help to give me so many of the things I've been missing out in life, and like any normal person, I would like to be able to live my life as I see fit.'

AFTER SEVEN YEARS OF STRIVING TO FIND THE MONEY NECESSARY TO PROVIDE A PLACE WHERE THESE VERY HEAVILY HANDICAPPED, INTELLIGENT PEOPLE CAN LIVE THEIR LIVES AS THEY WANT TO – AND AS THEY ARE CLEARLY ENTITLED TO – OUR FIRST ADULT HOSTEL IS AT LAST COMPLETED AND NOW HOUSES FIFTY VERY HAPPY, VERY HANDICAPPED PEOPLE WHO CAN FIND NO OTHER PLACE IN THE COMMUNITY.

OUR JOY AND PRIDE IN THIS PROJECT ARE, HOWEVER, SHARPLY MODIFIED BY THE REALIZATION THAT IT ALL CAME TOO LATE FOR THIS LAD – BRIGHT, INTELLIGENT, INTERESTED IN MUSIC AND BOOKS. HE COULD NOT WAIT ANY LONGER, AND YEARS BEFORE IT WAS OPENED HE DIED – PROBABLY BY HIS OWN HAND.

In 1967, Mrs Audrie McLeod and Mrs Venee Burges were assigned by the Board of The Spastic Centre, the task of reporting on a plan for the living accommodation of the adult cerebral palsied. The Board was conscious of the fact that the facilities in the McLeod House Country Children's Hostel were unsuitable as adult living accommodation because they were geared to the requirements of children only. The delegates visited thirty-three units in the United States, eighteen in the United Kingdom, three in Holland, eight in Denmark, eight in Norway, seven in Sweden and one in Italy. Their conclusion was that many of the things they had seen were applicable to some aspects of our own problems, and that, worldwide, there was no effective accommodation or work for the heavily handicapped adult cerebral palsied.

We envisaged a hostel aimed at accommodating fifty workers already employed at Centre Industries, whose parents, for a variety of reasons, were unable to care for their children at home. In planning for the living accommodation of the adult cerebral palsied, it was necessary to consider two important factors: satisfying the needs of the people who were to live with us, and providing a training medium to prepare as many as possible to achieve independent living in the general community.

In a letter to the Director General, Department of Social Services in June 1972, we wrote:

'We have recently submitted to your Sydney Office an application for subsidy, under the Sheltered Employment Assistance Act, for a Hostel to accommodate forty-nine severely handicapped cerebral palsied persons who are employed at Centre Industries and who, because of the severity of their handicaps, will probably remain in this hostel accommodation throughout their working lives. It would be impossible for them to obtain outside accommodation with the level of personal service they would require.

In spite of the fact that these people are so heavily handicapped, because they are young and energetic, they do not believe that the facilities available in this hostel should be geared to the kind of sedentary life, which may be more suited to the elderly inmates or a nursing home.

Most of them will be in motorised wheelchairs, therefore the hostel must be designed for wheelchair access, not only to rooms, but to cupboards, washroom vanity tables and showers. In addition, wheelchair footpaths must be provided to enable them to take themselves to and from work, without the need for engaging outside assistance. These people also require independent access to other sporting and social amenities, provided elsewhere in the complex.

To provide an efficient design, it is necessary to provide new standards of space, plumbing, circulation and social activities within the hostel . . .'

In the past, due to the fact that most of the adults living with us were invalid pensioners, the weekly charge had been extremely small. Now that these people were being trained in employment at Centre Industries and their earnings were increasing, we needed to adopt a more realistic attitude, making our weekly charges more in line with those applicable in the community generally. Unless we did so, we would find that our adults would always have a false conception of living costs. It was our duty and responsibility to teach them to budget their money, firstly for the essentials of living and secondly, for expenditure on those things which would give them a more comfortable and happier way of life.

The hostel design is similar to a motel, with four six-bed dormitories and thirty single bedrooms. The single rooms have connecting toilets and bathrooms for every two rooms, and that applies to the dormitories too. The minimum size of a one-bed bedroom is approximately fifteen square metres, in order to provide the bed with alternative access. In special circumstances we need access to both sides of the bed. From later experience we have found this minimum too small for long-term occupancy, having in mind the wheelchair space and the accumulation of the occupant's separate personal pursuits. We would prefer twenty-one square metres. Other furniture comprises a bedside table, dressing table or desk, chair and wardrobe, and the space permits turning of a wheelchair.

A bathroom entered direct from the bedroom is a more desirable arrangement than a bathroom accessible from common corridor. This can best be planned by locating a bathroom between two bedrooms, the occupants of which having sole use of this bathroom. The advantages of this arrangement are, in the first place, as assistance is generally required from hostel staff in bathing and toileting, more privacy is obtained, less space is required for wheelchairs, less travel from bedroom to bathroom, and it expands the personal living area of a person beyond one room. The minimum size of a bathroom containing a toilet, shower and basin is approximately 50 per cent smaller than that required for the bedrooms.

The provision of outdoor recreation areas is most important. Access to these areas is planned at several points in the hostel, to restrict travel from bedrooms to a minimum. These areas can be developed with screen walls, gardens, barbecues, into smaller sections which provide for group or individual enjoyment.

The Spastic Centre's first adult hostel for the cerebral palsied, the Venee Burges Hostel, was opened by the Honourable L. J. Waddy, O.B.E., D.F.C., M.L.A., Minister for Health, supported by Mr R. Dowell, Director of Social Security, and Sir Vernon Treatt, K.B.E., M.M., Q.C.

The opening of this building, named in honour of Mrs Venee Burges, a dedicated voluntary worker since the inception of The Spastic Centre, marked a further phase in plans to help spastics from birth to their final retirement. Over the years they will have received treatment and therapy, special schooling, on the job training and, above all, will have known social contact and the dignity of working alongside and using the same machines as able bodied people.

Mrs Burges paid tribute to the late Mrs Florence Deaton, who had worked with her for twenty-nine years as a volunteer, and to Mrs M. Joule, who was responsible for the attractive drapes already installed.

In the course of his speech, Mr Waddy said, "This is the first of four buildings planned for orphaned spastics and those whose parents are too old or too ill to look after them. This single-storey brick and tile hostel houses fifty-seven young adults working

in nearby Centre Industries, the rehabilitation division of The Spastic Centre of New South Wales. They are part of the workforce of 271 spastics, who share a normal working environment with a further 500 able bodied people. Each unit has been designed to meet the individual needs of the occupants, with wide doorways and special shower and toilet fittings for those confined to wheelchairs. Great attention has been paid to details such as extra light switches and special shower and cistern fittings to enable easy operation for the most heavily handicapped. Those who can do so, walk, others wheel themselves or travel in electric wheelchairs along wide cement paths and ramps to their place of work in Centre Industries. Medical and therapeutic services are close at hand in Centre Industries during the day, when those requiring treatment have their regular appointments."

Sir Vernon Treatt, President of the Appeal Committee, said, "The Spastic Centre has now become a national institution, recognised by its activities and contributions to human happiness. Milestones achieved since the 1945 inception of The Spastic Centre are: 1947 – voluntary weekend labour built first part of Spastic Centre at Mosman. A school and therapy block. 1950 – two more floors added and the building extended at Mosman, using voluntary labour; 1954 – the inception of the Miss Australia Quest by the Australian Cerebral Palsy Association. 1957 – completion of the Country Children's hostel at Allambie Heights, built by voluntary labour; 1961 – Centre Industries established. Using Sunday voluntary labour, 350 workers erected 1200 square metres in one day. 1966 – the Baby Training and Management Clinic began. 1967 – Newcastle Treatment and Training Unit opened. 1969 – major extensions to Centre Industries complete. 1971 – further extensions to Centre Industries. The Action Appeal was launched under the Chairmanship of Sir Vernon Treatt. 1972 – the Allambie Medical Treatment Centre and School complete. And now, 1974 – Venee Burges Adult Hostel opened."

Voluntary help and the determination of parents to help their heavily handicapped children, the foundation on which The Spastic Centre has been built, today remains the main factor in its continued development. The Spastic Centre believes that the men, women and children in its care have the right to live a normal life in a normal environment, and the Venee Burges Hostel has helped to achieve this aim. It is a happy place, people with disabilities, relaxed workers, who know that because of the generosity of people in general, they can look forward to the future as productive members of society.

Mr R. Dowell, Director of the Department of Social Security, said the hostel represents the very successful participation between voluntary organisation and State and Federal Governments. In 1967, a subsidy of 2:1 on employment for people in sheltered workshops came into effect. The number of those employed in Centre Industries was: 1967 – 64; 1973 – 223.

The Social Security Department contributed to the Hostel the maximum subsidy, at that time consisting of \$5,200 per person, at a building cost of approximately \$11,000 per room, which The Spastic Centre assumed.

On that day, I made the following points to the assembled guests:

'This hostel, beautiful as it is, is no Country Club for spastics. It is a serious experiment in independent living for the heavily physically handicapped, and if it has cost twice as much per person as the Commonwealth now allows, it is still inadequate as to space and facilities for its purpose.

Twenty years ago we built the Country Children's Hostel. In those twenty years we have learned a great deal about cerebral palsy. Then we planned it to supplement a highly specialised orthopaedic hospital, which we proposed to establish in the fourth wing. Now we know that orthopaedic surgery has only a small, if important place in our treatment schedules.

But the Country Children's Hostel is out of date, and we will have to substantially rebuild it to enable it to serve its proper function.

In 1961, we started Centre Industries as a model for something better than mere sheltered workshops. With the aid of the Department of Social Security, we have established that the quality of the rehabilitation work at Centre Industries clearly shows that the most heavily handicapped can compete with able bodied workers in highly technical fields in industry.

We will have to convince our legislators that the quality of rehabilitation done on the most seriously disabled counts as much as the numbers of more lightly handicapped pushed through the pipeline.

We quarrel with the legislation that equates a hostel for children or a hostel for active young adults with nursing home requirements, or with regulations for the conduct of private, profit-making nursing homes. Rigid regulations framed for another purpose are inappropriate to our work. We are dealing here with young people who want to live their own lives in their own way, and I complain that those regulations now applying are not in the best interests of these young adults.

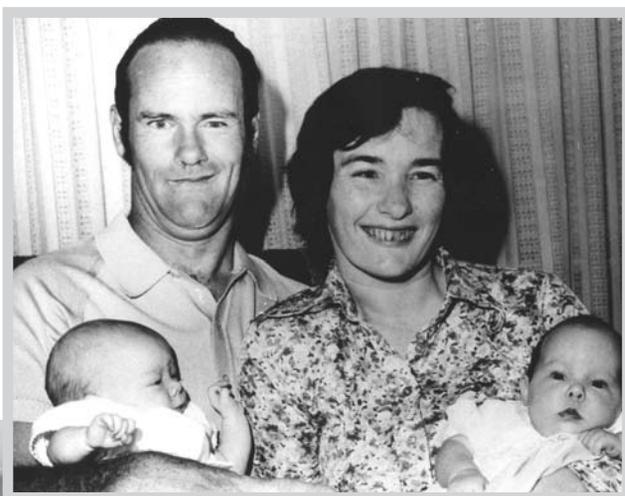
The Country Children's Hostel and the Venee Burges Adult Hostel are places of long term residence for heavily

handicapped cerebral palsied children and adults. They are energetic young people who have their lives ahead of them, and their interests are the same as those of any normal person of the same age group. They are not sick, they are well. They do not want to occupy a bed in the daytime, they want to go about their affairs as best they can on their own feet, on crutches or sticks, or in a wheelchair. But they are heavily handicapped, requiring physical assistance in feeding, drinking, toileting, bathing, dressing and undressing and administration of medication. These requirements of services have been, and must continue to be, at the background of the Venee Burges Hostel. The real objective of the place is the lifestyle of the CP person, and the services must not impede that objective.'

THE FIRST TWO WEEKS AS SEEN THROUGH THE EYES OF JENNY McLEOD:

I entered Venee Burges Hostel on my first afternoon in my electric wheelchair, and I was at home almost immediately. There was a very happy and warm atmosphere about the place. After unpacking and having a cup of tea with my parents and some friends, I saw my parents off at the entrance. Then back to the duty room because it was time for my pills. At this time I delivered all my medication to the Sister in the duty room. However, she did have some trouble in understanding what pills I took and the times I took them. Fortunately Dr Blight was present, and when my medication had been disposed of she asked if I preferred a bath in the morning or at night. I said the mornings were better, but I would fit in with the staff situation. I had a long talk with her about this, because she was trying to please me, and I was trying to please her and the staff. Dr Blight stressed that she wanted to make it a 'home away from home', with everything to suit us, like breakfast in bed, baths when we wanted them, and so on. She was really being very kind and helpful.

By this time it was our 'happy hour' as Colin named it, which is a drink with everyone just before dinner. Everybody was so happy. It was wonderful to see Bill and Carmella sitting talking at the table, and Bill helping Carmella with her food just as a matter of course. There was an air of excitement and complete happiness. There were some wonderful people helping us, not only the nursing staff from our previous hostel, and I think that for the first meal this was a great help, as they knew us so well. Before dinner Ingrid helped sort through the drawers in my bedroom. I sat at her table with the other young people. To make it even more enjoyable, the people who



To Mr and Mrs John Morgan – twins.



The completed hostel is surrounded by two miles of virgin bush and has a commanding view of the City.

helped us with our food sat with us and ate their dinner. This meant a lot to us all, because it was more relaxed and more like home. This, I feel, is very important because it creates a social atmosphere where we have to talk, as well as having to eat our meal, with the least possible mess.

After dinner I went to my room, turned on my light, closed my three doors and sat, thinking – this is all mine. Everything in this room is going to be mine. This sounds a bit selfish – what I really meant was that this may be my room for the rest of my life. Then I got all my night gear out and waited until someone came to put me to bed. I was going to do a lot of waiting over these first few weeks, so I decided not to watch the clock, but just take my time and not worry, which I did. Finally I got into bed, fairly late for me, and I experienced another 'first' ... the smell and the feel of new bed linen.

The next thing I knew, the door opened, the light went on, and a big 'Mumma' type of Sister came in – I found out later she is Spanish – and introduced herself, saying "You are down for a bath; where is it?" I pointed to the shower and she went over. "No bath here pet, will you have a shower?" I told her that I couldn't sit in a showerchair and I had to have a bath. However, she did not understand my speech, and asked me again if I would try the chair. By this time, I was thoroughly awake. She went to the door, saying she would have to get the male aide to help me into the chair. I spent the next few minutes pulling down my nightie and wondering how I could get out of the situation. When the Sister returned with the showerchair and the male attendant I said, "Sister, I do not have a chance of sitting in that chair." The male aide, who I recognised, asked if I would prefer a bath, and I said, "Yes." Then he said, "I think it may be better if you waited, Sister, until the other girls come on at six o'clock to bath Jenny." So I breathed a sigh of relief, and eventually at six another Sister from the nurses club came and bathed and dressed me, which took about forty minutes because she did not know me; then she put me into my wheelchair.

I had been woken at 5.45, so by breakfast time I was still a bit 'under the weather'. I got Sister to leave my bag on my little chair, and after cleaning my teeth she left me. I found my makeup in my drawer and put half of it on, but couldn't get the rest of it out of my bag, so I left it. Then I did a few other things, like washing a glass and putting it in my cupboard, turned off my light and went out. Gee, that was a lovely feeling! Then to breakfast – appetising bacon and eggs. But my pills were not right, so that I wasted time whilst getting them.

At breakfast, someone had spilt coffee all over Ingrid's blouse, so I told her that I would help her remove it. Ingrid had the next bedroom to mine – she is a severely handicapped athetoid. So after getting my pills, I went up to Ingrid's room and we both struggled to remove her blouse, with me trying to undo five little buttons and Ingrid holding the blouse down. After about half an hour, I managed to get two buttons undone, which was enough for Ingrid to get the blouse over her head. It was a struggle, but we made it, and then she put a jumper on. There was not the staff available, so we just had to do it ourselves, and it felt good! I stayed with Ingrid until she got her jumper on, then I went and had a talk with Mr Fisher and Peter about things like meals and their times, staff positions, where they would come from, outings, and so on. We did this every morning in these first two weeks.

Venee Burges Hostel is about two hundred metres from Centre Industries, and we approached it along a wheelchair pathway through the gardens and gum trees. It was a beautiful drive in an electric wheelchair when the sun was shining, with the multi-coloured flowers and the magpies singing their morning welcome.

We were located at the edge of one hundred hectares of bushland, so there was no shortage of bird life. The vociferous kookaburra outside my door, the grey and pink cockatoo and the yellow-legged plover on the lawn, the flight of clamorous lorikeets in the wattle trees, and the distant calls of crows and currawongs. I had never seen so many birds.

The second night it was raining. It was lovely to arrive into a warm place and make my way to my room, to be stripped of my wet weather gear, have some lipstick put on, and off to the lounge room where everyone was gathering for our 'happy hour'. The dinner was very nice, and it was relaxing to have the people who were helping us sit down to have their meal with us. This meant an awful lot to me and to the others, because it was the type of thing that you would enjoy in your own home. I'm all for this, even though it presents big staff training problems.

Just after dinner, I was asked by Sister if I would like a nice leisurely bath that night, because they would not have the necessary staff in the morning. So after some talking around the subject I said I would have my bath at night,

until there was more staff in the mornings. By 7.30 that night there was no one around, so I decided to go to my room and get things ready for my bath. I had tried to pull my bedspread off, but couldn't. I got things out of my drawers, put my hairnet and showercap on, and tried to open my bottle of face cream, but couldn't do that. So I called on Brian, a neighbour, and got him to loosen the top, then I was right, only the cream went everywhere. I cleaned up most of it. Then I waited a long time for my bath. Eventually I got into bed.

I had trouble getting the right pills for quite a while – I guess it was because they were new staff not used to giving one individual so many tablets. So, I just told them what I needed and eventually I gained their trust. By the second week, they generally had the medication right. Another nice thing was that with my bedtime pills the Sister would come in while I was having my bath, and either stay or leave them with me. That meant that I didn't have to wait up for them.

Nothing was a problem to them. If I needed some other medication they would go and get it without any fuss or complaint. They were all wonderful and still are.

In that first week, we were very badly off for staff, both morning and night, so you didn't know who was coming in your door next. There were rumours in the early days of that first week that the staff from the Children's Hostel were not permitted to come down to assist. Gradually, one or two did come down, as well as some staff from Centre Industries. So, although we were late for work, we had a lot of fun, because you had to tell each person what you wanted, over and over again. As I said, time didn't mean much at that stage. You were woken up at different times, so you just had to take your time at breakfast because you didn't have anyone to help you, as most of the staff were dressing other CP. I went back to my room after breakfast to have my wash, clean my teeth and put on makeup, then Peter, Mr Fisher and I had a talk, so I came up to work at about 9.00. Most of the other girls went back to their rooms for different reasons, the same when we arrived down at night.

There were two English women who worked in the evenings in McLeod House who had put in transfers as soon as Venee Burges House was started, but were turned down because the Matron wanted totally new staff. The third evening they arrived at the hostel and I knew they had plans to stay, so I thought I had better do some training. I got one of them to help with my dinner, knowing that anything I said would be repeated to the other one. I told her that we liked them to sit down with us while helping us with our meal. I told her about this as I was having my sweets, which she liked, so she went straight to the other woman and told her. I told her about us setting a time for our baths and showers, but I did this all in a slow subtle way, and she accepted it. So I did this with most of the new staff. Whether I did the right thing, I do not know. I thought if I told these things it would create a better understanding of what we wanted them to do.

By the weekend I was tired and looking forward to a little sleep in. As I drifted off on the Friday night, I was thinking about this. However, the next thing I heard was a male voice, shouting, and each door opening. At the top of his voice he was saying, "Get up! Breakfast is on in half an hour." He was waking all the wing up, especially the boys. This was at 6.00 am, so everyone was up in arms. I could hear Colin telling him off for going into Bev's room and waking her. He opened my door, and I just pulled the bedclothes over my head and pretended to be asleep, hoping he wouldn't come any further, and he didn't. He just closed my door and I tried to go back to sleep, but it was impossible because he was still going to each door and shouting, "Get up! Get up!" So I just waited for someone to come to dress me, which was about 7.00. Gee, I was mad! When Sister came in I asked her, very nicely, what was the idea. She missed the point of my complaint and said he may not have known whether my room contained a boy. I complained about the noise and she smoothed it over. I was to find out, quite a long time afterwards, that he was the son of one of the female aides, and she wouldn't come near me for a long time. I don't think Sister went to him then, but the same thing was to happen the next morning.

Breakfast over, I grabbed Margaret McColl and went to my room and had a quick wash and put my makeup on, as my father was coming to take me to the hairdresser at 9.30. Then Margaret changed my sheets, mainly because I wanted to take them home to be washed. We just made it. I went to the hairdresser and then went home until the late afternoon. When I got back everyone was very angry, because a Sister had done so many wrong things to five of the girls. It was like stepping into a hornet's nest. I cannot remember exactly what had happened, however, the things she had done were pretty terrible, like telling Ingrid she was only allowed to speak to her mother for one minute on the telephone. When the minute was up, she dragged Ingrid away from the phone! Other things were just as terrible, so we talked about it until we went to bed but without any conclusions being made. In fact, the more we talked, the angrier we became. By eight o'clock, there was nobody around, so

I went into my room to wait for a bath, and I had to wait a fair while for it, but eventually I got into bed. I think there were only two Sisters and one aide on.

On Sunday, I was awakened again by the man's voice, all along the hall, "Get up. Breakfast is in half an hour." He opened all the doors and banged them shut. Then he came to mine. He opened my door, and I'm afraid I was a little bit rude. As soon as he put on my light I said, "I like my sleep. Would you please put my light off and leave me alone?" He said, very quickly, "Only checking, love; Sister asked me to wake you." I just looked at him. He closed the door and went away. A few minutes later I heard him outside my room saying to another male aide, "Don't go in there mate," then he made a noise like a cat and they both went off laughing. When Sister came in to dress me I complained to her again. She apparently said something to him, after she dressed me, because he avoided me all day.

Sunday was very quiet except for lunch. It was supposed to be a barbecue, but it was windy and cold, so we had to have the food cooked inside, which was OK. However, just before lunch we were nearly all in the dining room when Sister came in and said, "You'll all have to imagine that you are sitting under gum trees with all the bush around you and the sun blazing down on you." She went on and on. When she went out we all burst out laughing. It was so silly and, the way she said it, anyone would have thought we were 'nongs'.

After lunch was pretty quiet. I guessed that people were tidying their rooms. About two o'clock, we were informed by different people that the heat was off. Something had broken down and we had no hot water and no heating, so the whole place was in an uproar. How were we going to have showers or baths or washes? How were we going to keep warm for the rest of the day and night? How was the staff going to function? Anyway, we did a slight freeze from then until about 7.00 p.m., when it was fixed. Mr O'Brien was there all the time, and he got the man from the boiler firm straight away. Sister was running around all afternoon putting extra blankets on all the beds. However, the rest of the afternoon was dead. I had dinner, and after wandering around for a while went up to my room. I was just getting undressed when the Sister, who was with me, was called away. I had a sheet over me. While Sister was away, the door opened and in came the man who awakened me the previous mornings. I gave him a dirty look, and he said, "Sorry" and walked out. I was fuming, so when Sister came back I told her. After bathing and putting me to bed she went to get my pills, and when she came back she told me that she had spoken to the man and had advised him of a new ruling. That from then on, a male attendant was not allowed to go into a female resident's room without a female attendant there with him. She was quite understanding about all of this, and quite prepared to work things out with all of us, and stay with it, until she got things right for us.

In the mornings you didn't know who was coming in to dress you, or at what time, but I didn't have to worry about male aides any more. So most days I just slept until the light went on. On the odd morning I woke up early, I used to pull my curtains back and watch the crows and kookaburras sitting on a fire hydrant, and the sun coming up. It was so lovely to be able to pull my own curtains over in bed.

During the second week, there was a more permanent staff, but you still didn't know who was coming through your door. This made it interesting, but also a challenge. They didn't know you, or what clothing to put on or take off. You had to talk to them without knowing their names, and keep on talking, so they would get to know all about you. Gradually the CP sorted the staff names out, and they returned the compliment.

I found it took me up to two hours in the mornings to get toiletted, dressed, and have my breakfast. Then go back to my room and have my teeth cleaned, and wash and makeup and be at the front door, to go to work at Centre Industries. This wasn't every day, but it was about seven out of ten. At night it took me at least three-quarters of an hour to have a bath, and get to bed with the light turned off.

A meeting was held with Mr Barry Fisher and John Morgan. They talked about the Committee and explained the function of it, urging people to go to the Committee or to themselves with any problems. Then we talked about other things which the Committee had discussed the night before. It was a good meeting, because Barry made us think. He went over the things which we had discussed, so we all would know exactly where we stood. It was a very lively meeting, and I think we all felt much more secure, and much more settled.

The meeting ended at 8.15, so the staff didn't shower or bath anyone that night. We were angry about this because we thought there were enough staff to do that in the time. However, I found out the next morning that there were only three female attendants on and one Sister on after nine, so Peter and I spread the news around, though we still felt there had been time to do some of the residents' baths.

As the week went on, we got more organised. Such as, we would name the time for our baths or showers with a female attendant, and she would come at that time or as close to it as she could. I always got out the things for my bath, except when they were not within reach, or I wasn't feeling too well. I think the other girls would do the same. It was quite a thrill to get things out of a drawer by myself, even though I dropped things at times. Then I'd call one of the other residents to pick it up for me – the spirit of 'help each other' was very strong. It still is.

As we were dealing with nurses and aides who had little experience of cerebral palsy, I typed a paragraph containing some hints on helping when I spasmed, and I kept several copies in the drawer of my dressing table to hand out when necessary.

'When I spasm all over badly, the first thing to do, other than a Valium, is to put my head forward on some pillows on the bed. If that does not work, try to bend me up on the bed, turning me over on my right side in a foetal position and hold me hard in that position until I relax. This is hard work so you may need some help. If you hold my head forward and my knees up you may find it easier.

Feeding me when I am spasming - occasionally I can't chew or swallow, food or drink, unless you put my head right forward. If you hold my chin up firmly all the time when I am eating or drinking, this may work. If it doesn't, it is best to leave the meal until later. Usually I would skip it altogether because it is too hard for me.

If I don't smile, it is not intentionally, as I find it very hard on these occasions to control my face muscles, except for the wink, which means 'yes' or a head shake which is 'no'. Thank you. Jenny.'

The girls decided to give Bev Chivers, on the next Saturday afternoon, a surprise shower tea on her engagement to be married - only for the girls and a few friends of Bev. So as Saturday approached, there were more and more whispers and quiet talking, and the hope was that Bev didn't find out. On the Friday night, I told Sister that I wanted to be woken at 7.30. There wasn't any sound in the morning, so I slept until that time, which was lovely. I got up and had breakfast, then went to the hairdresser, and on the way back picked up some cakes. We had tons of food, which Barry and his wife prepared after lunch, and as the time drew near, excitement mounted. After I was ready, I went down to see if I could help. I got the chairs fixed, and then I went in and out of the kitchen carrying food. However, there was a problem – the aides had got Bev ready too early and we had to keep her in her room, so we had to send people in to talk to her. When we were all settled about twenty minutes later, we shut the dividing doors and Bev came in. It was a lovely party, and Bev didn't suspect a thing! Everyone joined in. I nearly dropped a dish of biscuits, but they were rescued. We didn't have much dinner that night. The boys did though!

It was so wonderful to be able to sleep in the next morning; not very late, about eight o'clock. Then a very quiet day – we didn't have many staff.

On the Monday I was supposed to go home, but my parents had a meeting, so I spent another night at the hostel. During the day a friend rang at work and asked if they could come to the hostel that night. So I bought some chips from the canteen, got John Morgan to arrange for a couple of tins of beer, then went into my room to prepare things. Then a quick tea, back to my room to get some makeup on, and down to the front door to wait. Eventually they came, and I took them around the hostel quickly, because people were getting ready for bed. Back in my room I sat them down, and in a couple of minutes John brought the drinks along. I told Phyl and Don where the glasses were and I gave Howard the chips, which I had put into a dish. We just talked. I couldn't help thinking what a difference it was from my previous life at the Children's Hostel. It was so lovely to have your friends in private, and to entertain in your own room. They stayed just on an hour. Then I saw my first visitors off at the front door, and went back to my room where the girls bathed me and put me into bed. Funnily enough, it was one of the earliest nights I had in those two weeks.

Reading through this account, I seem to be complaining about the staff and the organisation, which I don't mean to be. My object was only to point out some of the difficulty that I personally experienced. They have done magnificently with untrained staff, when we consider the difficulties of fifty CP, each with their physical handicaps, personalities and severe lack of speech, trying to turn them into a living family, in two weeks.

SPASTIC
CENTRE



Jannifer McLeod meets The Empress of Iran, Shah Banou, Fara Diba,
accompanied by Audrie McLeod.

Jenny Continues Her Story 1961 – 1982

I was thirty years of age when the engineers at Centre Industries developed a push-button electric wheelchair.

Since then, I've had an entirely different life. It was surprising and unexpected, but funny in a way, because after I got my licence to drive myself unaccompanied by my OT trainer, I felt so lonely. I had never been alone in my life. I always had someone pushing me in my wheelchair. It affected my speech too, because the pusher, probably unwittingly took over the conversation with a third party. Now I was on my own, sink or swim. I had to make myself understood without the pusher's help.

When my father told me I would be working in a factory, I was horrified, and told him quite definitely that I would not work there. This I kept on saying for months and months. Early in 1960, a shell of a factory building was erected by 350 men one Sunday, near the Country Children's Hostel. In time, I accepted my fate, as I knew there would be nothing else to do. I was not happy. On 5 December 1960, the Adult Group, which had increased to eighteen, moved into Centre Industries; I was a bit sad because I was ill that day, which meant I couldn't say goodbye to my friends at Mosman.

What a first day! We just sat in a front room, which was the canteen, all day. People kept popping their heads in and out of the doors. The factory workers couldn't take their eyes off us during the meal breaks. We had two occupational therapists and two aides, but even they didn't know what to do. By the end of the day we felt like wet rags. The next day was different. We were in the factory all facing the wall, with the able bodied at the back of us. When I complained about being put in front of a blank wall, I was told the 'big boss' had said that everyone was to sit the same way. We didn't talk - that was a rule. I thought this was silly, but I wasn't game enough to say anything. However, if the same thing happened today, I'd be saying what I thought.

I should explain here, that the instructor who was in charge of the CP Training Unit was a quadriplegic from an accident on the football field. He had been in touch with us at Mosman. Mr Blackler was a nice man, but he didn't quite understand about CP problems. So he and I clashed a lot.

My first job was folding boxes, and my first pay was twenty cents a week, of which I was very proud. I found by the time the morning was over, with the thump, thump of the big machines, the smell of oil, the other general noise, the repetitive work and my own physical condition, I was so tired that it took me all my time to get through the rest of the day. I was even going to sleep at the dinner table at night. So after a while, I asked if I could stay in the canteen and type, which I eventually did. Some days I would fold twenty boxes and other days over a hundred, depending on my spasming and the way I felt. This led to a new type of handsplint because the old one was too big.



In those early days of Centre Industries, the CP were in a sort of difficult position because we didn't know where we were going. We were somewhat segregated from the able bodied, and we didn't know about factory life, and we missed the protection of Mosman. I felt I had to spend some time in the Training Unit each day, just to watch what was going on and to see that the CP were treated properly. We had a CP committee, with two young men and myself, to see to the needs and the welfare of the CP and liaise with Management on their behalf. This Committee is still going, with the same basic ideas. However, the members have changed, apart from me.

Those first six months here at Centre Industries were difficult. We were doing little jobs like counting and sorting, folding things. Then fate had a hand in it - Mr Blackler had a car accident and was off work for four months. This meant that the General Manager, Mr Hume had to take over the Training Unit, as well as his other duties. Within a few weeks, some CP were put onto machines, small presses and other jobs, both in the Training Unit and out in the factory. This was a terrific morale boost for us, mainly because we were working amongst the able bodied, who did their best to understand us, but really they did not at the time.

I was given some flat silver things with holes in them which I later found out were called 'springs'. I was to learn a whole new language, like 'dies' that were not dyes you dye a dress with - they were part of the machinery - and 'cheeks' and 'cores'. A 'cheek' was a square bakelite flat thing, which the 'core' would go through, then be pressed together in the machines.

After the first week, I wanted to surprise my father because he didn't know about me working on a hand press, slotting springs, or so I thought. So I fixed it with Mr Hume that he would bring father around on a set route. However, being my father, he came the opposite way, so I didn't make the impact I wanted. My new handsplint made work easier, but by lunch time I'd had it, and it took a full hour at lunch to unwind and relax, and in the afternoon I used to type.

I learnt that you were 'told' not 'asked' to do things, which I hated. I felt that the work was driving me up the wall. It was a whole new life; no longer the protected atmosphere of Mosman School, nor the familiar faces popping in and out of the door. Instead, the grease and oil and the smell of it, and being among able bodied strangers made it seem worse.

Mr Hume didn't know much about CP, and as I didn't know anything about factories, it merited an exchange of thinking; he taught me about factories and I taught him about CP. We worked well together and I settled down. I worked in the Training Unit in the morning, keeping my eyes on the welfare of the CP, then after lunch I typed in the canteen.

Although I talked to them about the problems, I never have and I never will use my parents' name for my own purpose or influence. Due to this, I was sometimes a lone wolf. I will never forget my first pay, which was the grand sum of twenty cents. I spent it all on sweets in the canteen. My pay went down the next week to ten cents. When I asked why, I was told that my production had gone down. It went up and down so much that I never knew what was going to be my pay envelope each week, but I didn't really worry about it. After Christmas we had a further intake of CP, making about thirty altogether.

One afternoon, about two weeks after we began working at Centre Industries, I was left on the toilet at about 3.30 pm. I waited and I waited for the two aides to come back to me. As you can well imagine, there was a lot for the aides to do with about twelve girls. At 3.45 pm I started to call out. In those days everyone stopped work at 4.30 pm and the aides went off at 4.15 pm so by four o'clock I was panicking a little bit, and trying to attract the attention of the women in the factory. We had a very small toilet block, and the noise of the machines was very loud. I was getting in more of a panic, which made it harder for me to yell for help. I was wondering what I would do overnight, and as I got more frightened, I lost my voice entirely. By 4.25 pm I was in a great old state, and managed a few yells, but still no one heard me. Then as the women went out, one by one, I really thought I was there for the night.

I was thinking what I could do. I couldn't move myself because I was braced from my feet up to my neck in aluminium splints. There was no way I could move myself at all. I had support under my arms but that was all, and by this time they were aching. So what could I do? I kept making noises, but there was dead silence except for a couple of voices, outside in the factory. I knew I was to go to the hostel instead of to my home that night because my parents had a meeting. I thought the people at the hostel might ask questions as to where I was,

but then, I wasn't too sure that they knew I was to be at the hostel. I knew I wasn't expected at home.

I yelled, then I started crying. I heard a woman come in to wash her hands, and I thought this would be my last chance, so I tried to yell and the sound would not come out at first. I continued yelling for quite a while and, as she was on her way out, she heard me. She came in, got me off the toilet and fixed my clothing. By this time I was so glad to have someone with me, and to realise that it was all over.

My rescuer did not know how to tilt my chair up on the back wheels to wheel it; I tried to tell her, over and over again. Finally she understood what I was saying and wheeled me up to the front door. By this time everyone knew what had happened. The Sister from the hostel had come down to find me, but she did not know, then, the drama that had gone on before.

The next morning I came down to work and was laughing about it all, until I saw one of the aides crying. She felt terrible, so I tried to calm her down. The other aide was very upset too, so I tried to make them laugh about it, but all they could do was cry.

From then on, there was a bell put in the toilet wall, but not where a CP on the toilet could reach it. It rang in the General Manager's office. We used to bump it on occasions, and we had a message from him not to ring it. Anyway, later the bell was moved outside, and this experience taught me a big lesson, which I used later.

I was always watching for things to do with the welfare of the CP - I was like a watchdog. If a problem came up I would take it to the Committee, and we would take it up with the management. Gradually, things got better for us. Early the next year, I asked the Board if I could have six weeks in which to make the toileting situation a little bit better for the girls. I told them that if they were not satisfied at the end of six weeks, I would be perfectly happy to drop it. They gave me the okay and every opportunity and facility that they could.

There were a number of CP who couldn't balance themselves on a toilet seat without an attendant to support them, and this affected the bodily relaxation necessary. Among these, was a girl named Joy. I decided to do something about her myself. I developed a chair with hinged padded arms which could swing out while the aides were lifting the girl onto the toilet. A padded back was fitted, and a seatbelt securely fastened at the back, so that the aides could leave her unattended. The hinged sides were locked back in position when she was seated. This was my first success, and the girls were very happy. It made the aides' work much easier. A pull cord switch was later added to ring a bell for attention. I then had bars made for the two other toilets. I should perhaps explain that we had a very small toilet block. It had four very small cubicles, and three larger ones, ranging in size. A row of basins stood outside the toilet block. There was a separate locker too, and off that, a rest room.

As those six weeks went on, I found most of the girls could help themselves quite a bit with their washing and make-up and pulling themselves up on the wall bars to go to the toilet. So I gently eased some into doing what they could to help the aides. I encountered some interference from therapists, who thought they knew more about this problem than I did, but they weren't remotely interested until I started.

By then, it went so far that a couple of members of the Board had to be brought into it, because in those days, I just didn't have the confidence to deal with it myself, although I tried to. By the end of that six weeks I was accepted, but I still had a long way to go. I filed my first report, which was the hardest thing of all to do. I didn't know where to start, so I just told my own story.

As that year went on, I felt myself becoming more and more involved with training and encouraging the girls to do things. The aides could not always be with me, which was a bit of a strain because, with a girl up on the bars I was scared, knowing she might topple over at any stage. The girls were scared too, but nothing serious happened, and this was the start of the biggest thing I have ever attempted. I was still very unsure of myself, so I looked for help in my decision making from everyone. Fortunately, I had many good friends and my mother and father to see me through this period, but it lasted a long long time. In fact it took me up until a few years ago, when I really knew what I wanted out of life and have become more and more confident. I think my increase in speech has helped me too.

At this time also, my sister Robin was engaged to be married, and as my wheelchair was so uncomfortable, we decided to make a whole new one for the engagement party.

Expansion of the factory involved a new toilet block so, knowing what some of the girls needed, I had the



plumbing fittings improved in design more than the previous block, in order to give the girls more of an opportunity to be independent. I insisted on coloured things, every shade I could think of, so that the girls would want to do more because of the feminine appearance.

There were three toilet blocks built, one after the other at Centre Industries. Being me, I got myself involved, because I wanted certain things for my Personal Independence training, such as the toilets, basins and taps put in the right positions so that the girls had the full benefit, to make us as independent as possible. I drove the builders and architects crazy because I insisted on certain things, which they thought were not necessary, such as space in the cubicles for motorised chairs to be able to move around, as well as more space for the aides, who must operate from either the left or the right hand side, depending on the physical involvement of the individual CP.

In bed one night, I designed a back-to-front toilet, that is a toilet facing the wall, with bars in front of it instead of on the side wall, so that the girls could just go in and pull themselves up on the bar, without having to turn around on the toilet seat. When I explained to the builders what I wanted, they threw up their hands in horror and said it could not be done. But I was so sure it would work I would not give in, so finally they relented, still saying, "It won't work." However, it did, and several CP girls have become totally independent using it.

For someone like me, with slow speech and not being able to move myself around, because I didn't have my motorised chair in those days, it was terribly difficult to deal with all that went into the building of the washrooms. The architects and plumbers involved were the experts, but they did not realise the importance of things like pipes under basins being put as close to the walls as possible, so that wheelchair steps could go under the 'S' bends, the basins and toilets being placed in the right position, away from the walls so that a CP in a wheelchair can reach the taps or plugs, and toilets placed behind doors for reasons of privacy. All those little things that would make the CP girls more independent. It was a difficult time for me and I got most of the things we needed.

In the washrooms we have every type of tap, every type of cistern, shelves that let down and up, as well as bars on the walls. This means that the girls can learn to be more independent, especially when they go out into another job away from Centre Industries. It does help in their own homes as well; also this is important when they go out to a friend's home, or go to the pictures, or go somewhere else where they do not have as much help.

From the time I started helping the girls to do personal things for themselves, as simple as taking something out of their own handbag, or getting onto the toilet, or have a wash and doing their own make-up, I began to become more and more involved with these detailed problems. So many of us, including myself, had never ever turned a tap on or off, used a key to unlock a door. So I drew up a programme for some of the girls who I thought would benefit from this help. I started with four girls, and now I have twenty-five for half an hour a week, with an aide who is there for safety reasons and to give any help if required.

Some of the girls do not like this much, because they've always had things done for them, and they think it is a bit of a waste of time. Usually, once they've successfully accomplished one thing, they want to try something else. The more handicapped ones seem to enjoy it more; they often do better and are more willing to try, whereas the less handicapped demand much more help. When the girls come to Personal Independence for that half-hour period, I find out what they can do. During the rest of the week, the aides try to help them carry it through.

Fortunately, I have McLeod inventiveness. We have a large safety pin on the plug to make it easier to get in and out, a piece of ribbon on the end of a zipper on a purse, a powder puff with elastic on one side so the girls can hold it and not drop it. The soap is in a net holder so that the soap doesn't slip out of the girls' hands, but other girls don't need the net. We also have several types of lipstick holders, and many other things to help the training of the girls.

The girls might have an idea and we try it out first. If it doesn't work we think up something else - it's a two-way thing. We gradually withdraw these things, then the girls find their own way of managing. I do encourage this as I feel the girls have a right as adults to air their own opinions. The female aides are a vital part of Personal Independence because they carry out the girls' training during the week.

For the few girls who are able to go right through their training and go to a normal toilet without help, it means they can go out anywhere socially, or go into employment and be totally independent. This takes many years to achieve, but when it does happen it gives a lot of satisfaction, both to the girls and to me.

After each session of Personal Independence, I dictate what each girl has done and I write a Yearly Report to the management. Personal Independence is not an easy job by any means and, like everything else, it has its ups

and downs, but it is rewarding to see the least little improvement in anything the girls do, no matter whether it is big or small, and the glint in their eyes when they achieve something, makes it worthwhile. As the years went on, more and more CP were coming here and I was in the Training Unit in the morning, because I was interested in all CP, especially the very handicapped ones.

As well as training the girls, I also train more than twenty able bodied staff aides in the way to carry on the Personal Independence training. This means I must be as close to them as I can.

The aides are handpicked by our Senior Aide and myself, and over the years we've had so many come and go. In this job, I've learned to work with people. I'll never forget how hard it was to sack someone. The things that went on inside of me when I had to do it still upset me, but not now to the same degree. Unfortunately, over the past five or six years I've had to withdraw from the factory job in the Training Unit because I've had so much else to do. I still go in there as often as I can. However, there are other Committee members working in the Training Unit, and we work together much more than ever.

Together with my other activities, there was the CP Committee work to do. Unfortunately, I had many arguments with the Committee. I was always, and still am, very stubborn on the things affecting the CP that I feel should be attended to, but others who were less handicapped did not see the things that I saw in the same way. So some of the original members of the first Committee, after about three years, resigned, and management then appointed two boys, two girls and myself. Eventually after some years that, too, broke up, and our present Committee was appointed. They are very good at their job because they care, and also we had a bigger voice with Mr Hume. This made it a lot easier for me, mainly because I've got most of the same drive that is necessary in this kind of work.

About 1963, I asked our doctor if I could leave my leg braces off, to which she agreed. This started to make my legs, which were like matches, a lot stronger and it did help the spasms. What joy to be free at last of the ugly aluminium braces, with their leather kneecaps and, most of all, the clumsy boots. Now I could wear pink shoes with a party dress.

This started me thinking casually about this need for physiotherapy in the factory, because the doctor thought that some physiotherapy would loosen up my muscles. Eventually we did get one physiotherapist, but inevitably she left to get married about a year later. We then got a full time doctor at Centre Industries, and she recruited four physiotherapists and a male occupational therapist.

Back in the period from 1954 to 1958, there had been more and more meetings at night for my mother and father and, as there was no one to care for me at home on those nights, I went to the hostel. It was called McLeod House because my father was so involved in building it. It took about five years to build, using voluntary help and fathers at weekends. I often went there during the building with my father, because someone very special to me at that time was helping to build it. It has four wings, one for the boys, one for the girls, and one for the treatment rooms. The fourth wing was designed to be a hospital wing, because we felt that outside hospitals did not understand the nursing needs of a CP child or adult, especially as most of them had little speech. However, later arrangements were made for post-operative nursing at our own hostel, so then we didn't need our own hospital wing. That wing was later converted into an adult residential wing. I used to sleep in the girls' dormitory. I found it most embarrassing to be undressed in the dormitory, and then have to be carried out in the hallway to go for my bath. The building was centred around the children whom I loved, and I would take every opportunity to go and play with them.

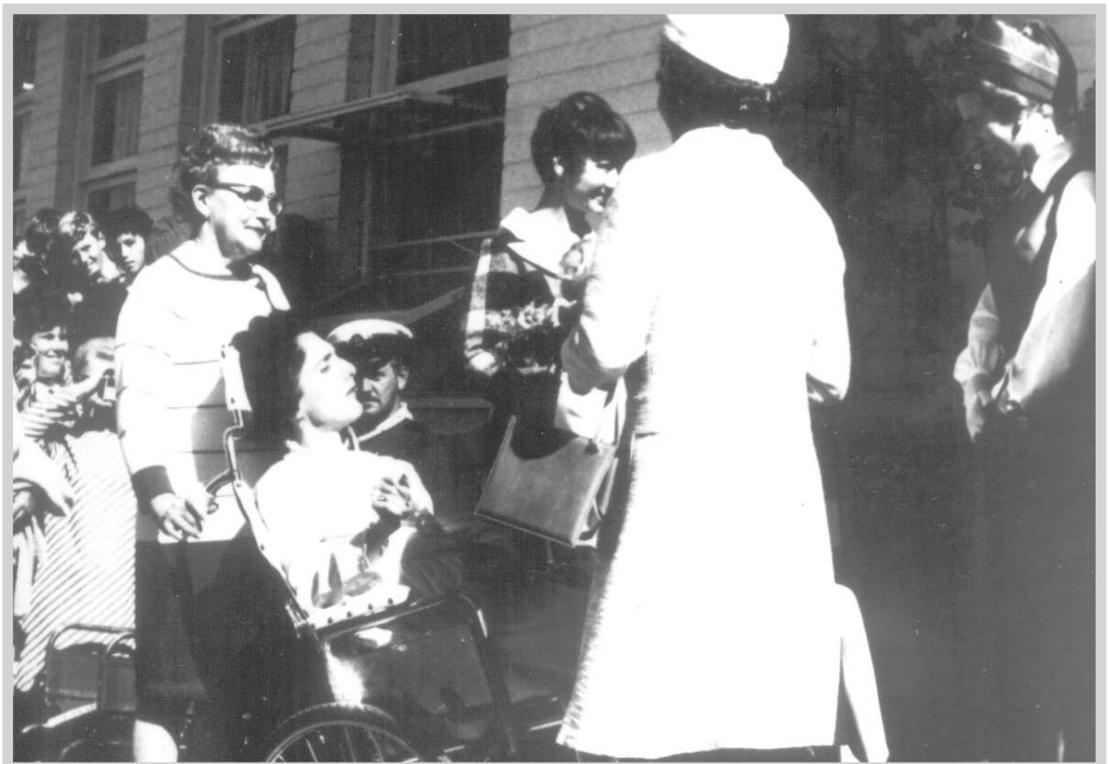
The nursing routine got me down a bit, though, because it was geared around the children. We had to get up very early in the morning, and then wait at night until all the children were bathed and toiletted before we could be bathed. Also, we were treated like children by the staff and we were very regimented. When the hospital wing was converted to the adult wing as a trial for another hostel, we had a bit more freedom. Although there were rooms along the corridor, I was still in the dormitory, mainly to be a self-appointed watchdog again for the heavily handicapped girls. One thing I found was that we could not sleep in at the weekends because all the beds had to be made, and all the other things had to come first before us, which was pretty tiring. They used to ask me why I looked tired all the time.

Robin's wedding was lovely, and I got myself a big brother, which I'd always wanted. Ron treats me like a sister; no pity, no giving in, and is marvellous in every way. In fact, the first words he said to me when they came out of the church were 'Hello sister.' From that day on, I always knew that if ever anything happened to my mother and father, Ron would see that I was looked after. I would never ever live with them, because I believe they and I have separate lives to lead.

In 1965, we had a visit from an orthopaedic surgeon from Edinburgh, Mr George Pollock. He examined my neck and said there was nothing structurally wrong with it and expressed the view that the muscles needed building up. He said the collar actually impeded the muscular control of my head. That gave me some hope of getting rid of my hated collar, which I had worn for eighteen years. I started taking the collar off for five minutes every day, gradually increasing it to longer until, after eight years of hard labour with a lot of physiotherapy and a great deal of perseverance, I was able to leave it off altogether. The year I took it off my mother was ill, so I was able to relieve her of the task of taking it off when I got home.

In 1969, an American surgeon was here on a Fulbright scholarship, showing some of our doctors his methods of orthopaedic operating on CP. My mother wanted Dr Silver to see my right hand, which was still in a leather splint. This had stopped me using the hand since I was sixteen. She had to talk me into seeing him. I told her flatly I would not have another operation, ever - 'Only if I was dying. But I did go over to Mosman, and Dr Silver did have a look at my hand. My thumb was contracted into my palm much more than it had ever been. He told me just what they could do and he talked to me quite a long time, telling me what the operation would involve. He said to me, "You're an adult, you can decide yes or no, it's up to you."

So over the next three or four weeks I just put it aside in my mind, thinking of it occasionally. Then Dad suggested that he see Dr Silver with me, and over to Mosman we went. Dr Silver went right through the procedures again and again, and told us just what they would do. On this day there was another doctor with him and also our Medical Director, and they were talking quite a bit, with Dr Silver holding the floor. Someone said, "We haven't asked Jenny yet if she wants to have the operation." So I thought a moment or two. I had nothing to lose, so I said, "I'll give it a go."



Jennifer McLeod meets H.M. Queen Elizabeth and H.R.H. Princess Anne.



Audrie McLeod



Jennifer McLeod



Jennifer McLeod

Two days later, I found myself in Lewisham Hospital, which is a Catholic Hospital, with kindness that I didn't know existed in a hospital. I had a special Sister who I knew very well. She used to come in the daytime and stay with me most of the day.

On my first day I thought they were going to take X-rays, or be dramatic or something like that, but it didn't happen that way at all. Everything was so calm, after my last experience in hospital. Late in the afternoon, a Resident came in to check me over, and asked if I'd had mumps and measles and all that, then he asked me how long I had been like this. My nurse, who had a quick wit, said two weeks, and he did a double take. He didn't know what to say, the poor boy, so we fixed him up with the right information. But there is something missing in a doctor's education when he does not know about cerebral palsy at first hand.

The next morning I woke up about five o'clock and was given a cup of tea. Everything was so quiet, it made me feel calm, and everyone was so pleasant too. They wrapped my arm up and wheeled me to the theatre, and I waited outside for about five minutes, when Dr Silver came out and the other doctors too. He said to me, "Do you still want to go through with this?" So I said, "I'll give it a go. If you're game, I am."

The anaesthetist knocked me out, but it seemed ages, and just as I was going out, a nun in a white habit came behind me and put her hands on either side of my head. When I woke up the nurse was there, and they took me down to my room. My hand was in plaster, and Dr Silver had told me I'd feel uncomfortable. That night, every time I pushed the bell someone was there with an injection. Then both doctors came to see me, on the Saturday, which I thought was rather nice, and Dr Silver loosened the plaster a bit. For the rest of the day I was all right, and the following day I went home. I would have liked to stay longer, which I told the Sisters, and they just laughed.

Five weeks later, Dr Silver took the stitches out, and the plaster off. I think that was the worst part of it. Then he gave me a lecture and said, "What we have done for you is to restore the hinge of your thumb to its original position. That is all that a surgeon can do. We cannot give function to your right hand - that is a job for you and your physiotherapist to do. You can't expect to overcome ten years of disuse of the muscles of your hand overnight. You must be patient, but not too patient. You must exercise your hand every hour of the day for six months or a year, until you get back the function you lost at sixteen years of age!" I took his advice, and after a lot of intensive work on my hand I was able to get some function from it. Today I can do things with it just as I did when I was younger. Which is great!

I was wholly set on having an electric wheelchair, but first we had to design and make one that I could handle with my limited finger control, and that was two years hence. As Centre Industries grew, I and other CP were pushing to get motorised chairs, because our hands are not good enough to wheel a manual chair. We got a couple of different chairs on loan from another company, but they were not suitable. In fact, I took one home and wrecked the house by climbing up the wall, because my hand couldn't let go of the joystick. Then Mr Boyce, our occupational therapist, tried to get me a couple of comfortable seats and backs, because I have a persistent backache, but when we tried them out they were uncomfortable. His theory was that if you were comfortable in your chair, it would make it a lot easier to manage the controls, and I agree with that fully. In the meantime, they had developed six motorised chairs, which disappointed me a little bit because I was jealous - they were the joystick type, which I couldn't control.

I was still sitting in a very heavy wooden chair that I'd had for ages, and which had to be tilted to move me. It was awfully hard for everyone, including me. I didn't like to be stuck in the one spot for too long, although I was used to it, nor did I like having someone pushing this great big chair, although it was comfortable for me. Eventually, after about three years of trying to get the right control and the right seating, Mr Blackler came up with the idea of using an aircraft seat, which was just right. It had everything I needed, including an ashtray! Then I finally got a press-button control from an engineer, who thought about it a lot before actually designing it, because he was scared that I'd be hurt, if it went phut!

Once I got the controls and the chair itself with a few adaptations, we started training. We began in the gym, with chairs in the middle so I could get the feel of it. After a while, we ventured halfway into the factory. Each day we would go a little bit further, until we got to know where the awkward spots were. Mr Boyce used to close his eyes quickly sometimes, especially when I went under a ladder, with a man on it, fixing a light. People used to ask me why I never smiled when I was driving, but my whole concentration was on the chair. Half an hour was all I could take. We both ended up back at the gym with taut faces. It took me half an hour before I could

do anything else. I can still see and hear Mr Boyce saying, "Go to your right, go to your left, charge them Jenny, charge them!" I was so scared of bumping the able bodied, especially when they jump over you, but Mr Boyce said not to take any notice. It took me about six hard months to get over this fear.

One day I was feeling good, so I led Mr Boyce up into the lift, pressed the lift button and got out on the next floor. Mr Boyce was having kittens. I went in and out of the desks without touching many, then I led him back down to the gym, again with not a word spoken and his face as white as a ghost. He said to me, "Would you mind telling me next time where you're going? I nearly had a heart attack!" I said, "I did it on purpose; I wanted to try it out." Anyway, two months later I got my L plate licence, which gave me permission to go unaccompanied anywhere in the factory.

In 1966, the first Adult CP Conference was held in Perth. It was the first adult conference held on various aspects of our lives. Four CP, including myself and CP from other States, attended this week-long conference. On the way, we had a look at the Spastic Centres in other States, so we would know about them before we arrived. We reached Perth a week before the actual conference, which was to be held at the Perth Spastic Centre Hostel. As I was getting into the Spastic Centre bus on the tarmac of Perth's airport, I thought to myself - that's funny, no family - then all of a sudden people were streaming across the tarmac, waving and shouting. Hundreds of them were all over the place and all over me, saying, "I'm your cousin; I'm your aunt; or I'm your uncle so-and-so." They all followed us to the motel, and we had quite a gathering in the two rooms adjoining each other.

That whole week was spent in getting to know all members of both families, most of whom I hadn't met since I was a baby. They took us everywhere. I really enjoyed it so much, as up until then I'd just known my family by name only. I was able to leave my collar off some of this time, during the family gathering, which made me feel like anyone else

They had 'McLeod Night', when the McLeods gathered all together. I can remember when I was about two, that one of my cousins who was then a fairish little boy, used to bring me sweets from his tuck shop at kindergarten, and when he too came in there was a hushed silence and I said to Alan, "My God, you've changed!" He had a dark beard and moustache and dark hair. Nevertheless, I still thought of him as a little boy who used to bring me sweets.

Then they had a 'Mell Night' - my mother's family - and the place was packed full of people. I've never been so crowded in my life. All of them were a bit shy, and scared of me, but they managed to get over that. By the end of the two weeks there I could put a name to most of them.

When I got back home I again threw away my communication board. We can blame the four weeks' concentration on my speech, unassisted by my parents, or staff at home in Sydney, who were ready to assist me.

Just before Christmas of that year, we had a tiny little bundle of pink skin arrive in my sister Robin and Ron's household. They took my mother and me down for her first inspection. Every time she moved, someone would say, "Look at that - look at that!" Melissa was all ours, and no one was more proud than her father. Two years later a sparkling, fat little baby boy called Christopher came, but I had learned my lesson with Melissa about not nursing her. Not that anyone could, as she would scream blue murder if anyone apart from Robin or Ron touched her.

When she was just walking, my mother put a chocolate on the shelf in the kitchen, and Melissa would take mother's finger and lead her to the chocolate. This worked wonders in establishing a contact between them. Christopher proved to be a totally different baby, and I made a point of nursing him, so he used to come to me much more readily. Even now, he still sits on my lap and we have a great old talk and he nearly covers the whole of me. Then Jeremy came, and he was different too.

The years have been most eventful for me. What with meeting Her Majesty the Queen of England, Her Imperial Majesty the Shahbanou of Iran, going on a cruise with two friends and loving every minute of it, especially Suva, where we had an Indian taxi driver who was determined to show us everything. He stayed with us most of the day and evening, and he lifted me in and out of the car about eight or nine times during this period. I even found myself being carried into a Fijian Village and placed on a mat on the floor of a hut. It was a lovely day. I found the sea was just as I'd imagined, and completely relaxing.



Two years later, I was off again. This time it was to a seminar in Holland on leisure time activities for handicapped people; we wanted this for our nursing homes. The seminar turned into the motivation of life, which we didn't get much out of because we were the only country who thought work was the motivation of life, so we were a little alone. Still, it was a good experience.

We stopped off at Rome and London and Singapore, and went to see Spastic Centres in these places, which was good experience because it showed us how lucky we are. I learnt a lot from that trip about travelling, people, and fun, and it also gave me a lot more confidence. I know now what I will need when I make my own trip around Europe in the future.

Over the years there have been many changes. Mr Hume left, which was a blow to me, because I knew I could go to him at any time about little things. Since this happened we have had three other General Managers. The place has expanded, not in building size, but in moving departments to give maximum work space. A new complex has been built on the factory for all rehabilitation departments, like physiotherapy, occupational therapy, doctors' rooms, assessment and MODAPTS, and so many other professionals, including our CP Committee room, which will be manned in time when we get more members. The idea was to pull the rehabilitation, therapy, medical, teaching and training staff out of a detached 'clinic' environment and to involve them more directly in the work of the CP in their working environment on the factory floor, and to get some more handicapped CP in our training area. This I have waited for for twenty years. I have always said these people should not be left to vegetate but should be able to go into the factory and feel just like anyone else.

Now, we have an intensive training programme going for those fifty very handicapped CP, and all the rehabilitation staff are involved.

In 1974, we built our adult hostel, the Venee Burges Hostel. It was geared to be a residence for working adults, and we made full use of our new freedom, instead of being treated as older children in the Country Children's Hostel. We were invited to select all our own furnishings and wallpaper. Now we are in an adult atmosphere, we stick together more. We have four dormitories and twenty-eight single rooms, and when I come down from work I know I'm home as soon as I reach the front door, with my own personal bits and pieces, in my own room.

I was called upon to design the toilet areas in our Venee Burges Adult Hostel. I've thought of taking a course in plumbing, but decided it would be too dirty. However, with all the building of the washrooms, I have gained a lot of experience, which I would never have had. At the same time, it has given the CP and other handicapped people more independence.

I have been responsible for the female aides since 1962, with access to and directions from the General Managers of Centre Industries. Over those years, I have been responsible for selecting and interviewing new staff members and dispensing with those who proved to be unacceptable.

I have set up a programme of staff training so that anybody knows their responsibilities and duties. My objective is to instill upon my staff that they are responsible for caring above anything else. They must encourage the CP as much as they are able, to provide personal independence and not to do things that impede it, even though it might take a while longer. We look for people to be interested in the day-to-day work of the department and to be interested in the people. The two major aspects of their work are feeding and toileting.

Feeding - In every way, to keep food off mouths, faces, clothing, table and wheelchairs. This applies to morning and afternoon teas, and lunches. They must maintain the dignity of the person being fed. They must understand why we are doing that in a certain way; it leads us to encouragement for personal independence. The head must be on the mid-line as much as possible. We feed them slowly and carefully. We make sure that they eat enough food.

Drinking - Arrange straws, glasses, paper cups appropriate to the person so that they have the drinks they require, no matter how long it takes. The male CP are fed by the seven male aides. I do not supervise the male aides, but we have a close contact with the head male aide. In addition, there are thirty male CP fed by female aides at lunch, morning and afternoon tea. In warm weather, I send around jugs of water and plastic cups to the benches throughout the factory, so as to keep the dignity of the person under control and prevent an untrained person slobbering a drink over face and clothing.

We have over one hundred lunch orders to be prepared each morning after the chef has advised the menu. The aides collect the food and drink and bring it to the table already cut at a separate serving table, or at the table as required. If there is any doubt about the way to feed, then I go to Mrs Northern, speech therapist, and she helps with the problem.

Toileting - I have been responsible for the design of the female toilets, including the back-to-front toilets, adjustable bars, adjustable seating in the toilets, which are designed with the heavily handicapped in mind. The waste drains of the washbasins have been changed so as to avoid hindering the passage of wheelchair foot supports. Approximately sixty of the female CP have to be serviced entirely. Thirty female CP need to be assisted with dresses and personal needs; the aides help them with hands and face washing, makeup and clothing tidiness. There are approximately thirty who are totally independent. Due to the peaks of traffic, some delays may be experienced corresponding with arrivals and departures, pre-lunchtime and after lunchtime.

Caring - We insist on personal care. That demands time, and we wait for the person. Some people are slower in toileting and some people are slower in feeding, and all of them are entitled to talk. This makes the aides' job harder, but they must be trained to wait. If you have a person whose speech is impaired, it is more important for him to get the message across, irrespective of time taken to wait.

The care taken by our aides could be qualified by the things they do outside working hours. These include telephone messages, shopping, accompanying CP on social outings, visits to their homes for a meal, and the warmth that they exhibit in their personal relationships.

Personal Independence (P.I.) - I have not included my Personal Independence Programme, because I regard that



Father of the Year 1979

as being a plus to my real responsibilities. It might be said that my P.I. Programme is a lot of work for such a little result, but for the persons themselves they don't regard it that way at all. It is just the first step to being able to do things for themselves, instead of relying on other people.

My interest has always been geared to the severely handicapped CP because this is my role in life. This has been very close to my heart for some years. I feel very strongly that the severely handicapped should have the same opportunities to get into the workforce as any other handicapped person, even if it takes years to get there. No one should be sitting around without help to reach a goal just because there is no one working with them to achieve something. Some people think that because a person is heavily handicapped and cannot move or speak that they are retarded, and treat them like children, whereas most CP are intelligent and it is frustrating and degrading to be treated as a child. I desperately hope that these very handicapped CP will be able to be transferred from the training area to the factory, even if it takes ten or more years. Most people want to learn, especially after their ordinary schooling so they can go to University or Technical College, but this is not possible for us because those places are not built for the handicapped, nor are they staffed for us.

Recently, the speech therapist started a communication programme for both deaf CP and others who cannot speak. We believe communication is the most important facet for us in both our work and leisure. Everything is being done to help in this sphere of communication.

We have a very good physiotherapy department, with ten physiotherapists and six aides to help them. As I have had a lot of physiotherapy over the years, I have become very interested in the different techniques, especially the Bobath method, which is mainly relaxation and positioning in the correct way, aiming at keeping that position. This is for adults, but for a CP baby the Bobath treatment aims to get the baby into a pattern of movement which any other baby would use, such as head control, crawling, sitting, and standing. This means a lot to me, mainly because, had I not been born like I was, these babies would not have the opportunity of this treatment and all that the Centre offers.

In 1978, I was invited by the McLeod Society of Japan to take my place in a welfare student exchange programme. It was designed to show to the Japanese rehabilitation world that spastics were capable of working, even though they were heavily handicapped. We were a team of three males and two females. Two of us were in wheelchairs full time, and one half-time, depending on the length of walking to be done. All were employed at Centre Industries – in computer operations, computer programming, a telephone switchboard operator and an engineer's typist. I was, of course, the Supervisor of a team of twenty-two able bodied aides for the feeding and toileting of our 150 CP girls at Centre Industries.

Japan is a mixture of big bustling cities, quiet countryside with rice paddy fields wherever you look, and a background of extremely beautiful mountains. When we visited Mount Fuji, she unveiled herself of her mist and cloud, and on her summit she wore a halo of fresh snow. She had a dress of autumn leaves coloured orange, yellow, red and green wrapped around her. The mountains around her too were covered with mist and cloud, but Fuji held me spellbound, especially as it was my first sight of snow. Sharp contrast to busy, noisy, fast moving Tokyo, which is beautiful in its own way, with 12,000,000 people in it.

All the places we visited were so different, both in scenery and customs; for instance, people bowed more in some places than others. The roadways are narrow and just fitted our bus and another car; the pine trees as well as other types of trees covered the hills. Little houses covered every bit of land available both in city and country.

However, it is the people who make Japan; their hospitality was like no other I have experienced. From when we arrived in Tokyo until we left, everywhere we went there was a multitude of people to help us in any way they could, which was overwhelming at times. I was particularly impressed with the young people who took us everywhere, smilingly and willingly. One day in particular stays in my mind, when we were travelling in our bus and I was sitting in my wheelchair. My head was wobbling, and a young man who was holding my chair although it was strapped down, said to me, "Are you all right, or would you like me to hold your head?" I said, "No thank you, it is all right." Then about two minutes after this I happened to look out the window of the bus, and he unobtrusively had his arm on the bar of the bus just so I wouldn't bump my head. Another day I went into a big shop and as the young man who was wheeling me didn't speak English at all, I pointed to wherever I wanted to go and he took me straight to the place. After the first hour, we had communication.

The older people were just the same, only in a different way, they were very charming and would do anything to make us feel at home.

When we went to each Prefecture or city we had to meet Mayors, Governors, and other important people, and present them with various papers and gifts - and present them in the right manner. They were so friendly and put us at our ease. Even so, I shook a bit!

At our first reception in Tokyo we were late because the bus was late in picking us up from the hairdresser. My mother and father were already there, and as we went into the reception and found our places everyone clapped, and by the time I got to my place it took me all my time to control my tears. That night each one of us had to make a speech. This was the same at each reception. Everywhere we went, we were showered with gifts, which was quite overwhelming.

We had a Japanese night in Sendai where we got ourselves into kimonos. We had a Japanese meal and entertainment, then all except myself had a spa bath, a massage, then toppled into bed on the floor. This was quite an experience.

Another funny experience was when we went on the Bullet Train, because the train stopped for only one minute to let everyone on with our large amount of baggage, three wheelchairs and about a dozen or more people. We just made it, but getting off we did it in twenty-five seconds, thanks to Mr Noda's faultless organisation. The Bullet Train is controlled by computers in Tokyo, so passengers are trained to get on and off very quickly. Mr Noda had our bus driven 400 kilometres to our destination the night before so it would be there on our arrival. Then he arranged for a team of three people to get on the train one stop before our destination. They had assembled all the suitcases in the following carriage, and had organised exit for our wheelchairs and our passengers and the thirty assorted hand luggage and parcels.

Another thing that impressed me, was that at each place we visited our hosts would come with us half way to the next place, and then they were replaced by our new hosts.

Right throughout the trip we visited a number of work places, nursing homes and schools for the handicapped. The work places were quiet rooms where people were making various components for many companies. However, there weren't many CP in these places, only hemiplegics, mainly paraplegics, amputees and a few other handicapped. I was a little disappointed in this. We didn't have time to make contact with these people at all. When we were asked why they were so quiet they said it was the Japanese way of working, which was interesting after being at Centre Industries.

In the main, the rehabilitation centres were big new buildings with everything in them, such as hydrotherapy with hoist equipment, occupational therapy department, operating room, other hoist equipment for the bath, ADL equipment including a wall with a stove and sink which moved up and down by a push of a button, and a toilet with the same thing. There was a Japanese bedroom with the same devices to lower the floor, because a Japanese bedroom always has a step up to it. They even have a dentist's room in one of these nursing homes, and a hairdressing room and so many other facilities. However, we didn't see any CP using these facilities at all.

Then we went into a big room half filled with CP, and we sat in front of them and exchanged names in Japanese. They asked us questions. In one such place, which had eight CP residents who were very very handicapped (some stretched out on beds or trolleys in extension spasm, with their heads turned to one side), my first impulse was to go and sit them up, but I didn't. We were asked how it felt to work. We looked at each other and we couldn't answer. These CP really touched me; I felt I had a bond with them, more so than others who were less handicapped.

The schools were just like ours in a way; the same children, happy little faces, and willing to show you what they could do.

We went to a place they used as an operation after-care hospital for CP and I happened to see a little boy in bed through a window, so I broke away from the party and went into the ward. I just felt I had to say 'Konnichi Wa' and he responded and pointed to his leg. As we were passing the ward again, he waved to me and broke into a gleaming smile when I responded. I carried that smiling face in my mind's eye for the whole of our tour. He just typified the children of Japan.

At the Sayonara Party we each made a speech. Murray stole the show because he gave the whole speech in Japanese! They gave everyone a candle in a silver foil base, then as Mr Noda, who was one of the chief organisers, finished his very moving speech, the lights were put out and the candles we held were lit. The whole room sparkled with the light of the candles. They formed a line on each side of the door, then they hummed or



sang a traditional Japanese song of Sayonara, which was quite beautiful, as we passed through the line of people to the door, and as each one of us got to the door we blew our candle out. This was quite unforgettable.

Although we had a very busy schedule we enjoyed every moment of it. We will never forget the kindness and hospitality we received from the Japanese people.

I've changed too. Not basically, but I am more positive. I am still in charge of the female aides, which is a very responsible position, and on several Committees, but my basic aim is to see that all CP get equal rights, and jobs, and recognition, like anyone else!

A spastic's life is what you make it. It has a beginning and an end, but it is up to us entirely to accept the facts of our lives.

Part Five

Conclusion

In any field of human activity, if you make progress little by little, then you can eventually achieve things that you never believed possible. When you are small, you think your Dad is very clever. You think, how will I ever grow up and be able to do all the things he does. Once you have grown up and look back, because you have learnt everything over a period of twenty years, it seems quite surprising that once you thought it would be difficult.

The way you teach children arithmetic is the way you can teach them to speak or to do other things, as long as you take it one simple step at a time and make sure they understand the first step before they progress to the next.

The cerebral palsied, if asked to step from handicap to normality would continually fail no matter how motivated they were. If asked to move a fraction at a time, in a very systematic way towards the goal of intelligible speech, they will be able to succeed fraction by fraction, so that eventually they will be able to utilise the basic neurological equipment they do have, to learn the essential movements necessary for intelligible speech.

Professor G Andrews

The Human Communication Laboratory of the University of New South Wales.



The first intake of children at The Spastic Centre Mosman

If you can't beat them, join them

Upwards of three thousand individual CP passed through our hands during the lifetime of The Spastic Centre, and all of them have a unique story to tell. Some of the stories have been lost by death or dispersal, and some others have been locked away in their inner consciousness behind the grey veil of their inability to communicate.

All are stories of a single, self-determined human being, confined behind the physical handicap of speech and hand function. The resultant thoughts, the memory and the motivation have been burning away, behind the faulty nerve barrier of communication, for all the years of their lives.

Now, comes the great moment – when the magic of electronics and language come together – the restrictions of communication are swept away and a torrent of words emerges – dispelling forever the stereotyped label of cerebral palsy.

DENNIS STABBACK

Dennis Stabback is thirty-six years old and uses a head probe or stylus with a conventional keyboard. Dennis is the athetoid who was responsible for sparking Dr Peter Neilson's interest in cerebral palsy in 1966. The General Manager, Bruce Hume, had noticed that Dennis could manipulate a Press when his hands were firmly attached to the operating lever, but was unable to operate it otherwise. This led to the investigation of the first experiment and ultimately the foundation of The Spastic Centre Research Unit.

Dennis says, "Until recently, I used a word processor to prepare the news journal that is distributed throughout Centre Industries. At the moment I am establishing a resource area, using a word processor and a data-based programme. The resource centre is to be an information base for both disabled and non-disabled employees of Centre Industries.

The word processor enables me to independently correct and edit my own work. Without this piece of equipment, it would be necessary for me to constantly require the services of another person to assist with my work.

The value of this physical independence to me cannot be overstated. Independence that allows me to sever some of my ties with other people is an immeasurable gift.

I also use a Cannon communicator to communicate with people. This enables me to type a message and provide the 'listeners' with a written copy of whatever I have typed. Once again I use my head probe to operate the communicator. Not having hands that I can use, and not being able to talk, does not prevent me from communicating and pursuing my interests.

Not being able to speak gives me far more time to listen to what other people are saying – time to understand and reflect on what has been said.”

GREG MOTT

Gregory Mott is a thirty-nine year old severely disabled athetoid working in Centre Industries D.E.P. section. His speech is difficult, dependent upon the listener's translation aptitude. He operates his electric wheelchair with the back of his right hand, and uses a head pointer for typing. Greg is a Past President of the Centre Industries Chess Club, and Chairman of the Cerebral Palsied Work Committee. He lives at home. Greg said, "I started at The Spastic Centre in 1946 at the age of two years. The Centre was operating out of an old white house at Mosman. When I commenced there were only about eight patients being treated, because there was not enough room and nobody knew about spastics.

By that, I mean doctors did not know how to treat them. Then a couple of years later, the parents decided to put up a new building. They had a lot of help from other people such as the Newtown football team and many other sportsmen. By this time, when I was three and a half, the physios had more idea what cerebral palsy was all about, and they were learning how to treat it. I was having physio, speech therapy and school work three days a week. The reason that I only attended the Centre three days a week was because I could not stand the travelling; my home was 20 km away, and the long journey there and back was a bit too much for me. In the early days the Centre had a couple of old Army ambulances and volunteer drivers. They used to pick us up, drive us to the Centre and then home again.

When I was five years old my physio had me sitting up with special supports. One year later she put a pair of skis on my feet. These skis, as they are called, are like a big pair of shoes. They are made out of wood and are pretty heavy. Now I had to learn to balance myself. I learnt how to do that after a lot of bruises, which I received when I fell over. The next thing was walking, and to everyone's surprise I took my first step with a lot of effort.

Then, to my dismay, I became very sick, and entered hospital. The doctors found that I had a hernia and they would have to operate. They said that if they did not, I would die. I had the best doctor in Australia, Professor Lorimer Dodds. He gave me a slim chance of coming through the operation, and it took about eight hours to repair the hernia, during which time two ribs were removed. I finally overcame that hurdle.

Now it was back to schoolwork, and in 1953 at the age of nine, I found that I had missed about two years of education. After my operation, the physio said that I would never walk again. My occupational therapist found that with a hand splint and an electric typewriter I could do my lessons. I finished primary school without much trouble. I graduated to first year and, to my surprise, I topped the class.

Then it was on to second year. My first year teacher asked me if I would be prepared to do correspondence work. Naturally I said yes. I like a challenge. The Correspondence School sent my work out every month. I finished the year with average marks. I went on to third year and at the end of that year, when the results came back, much to my surprise I found that I had come first in English, and over all out of eight normal pupils I finished second. This was in 1962, and I started work at Centre Industries in April that year.

The first day that I was at Centre Industries I was very nervous for some reason. Anyway, my job was to count out two hundred screws into a box. Then Friday came – pay day! I received twenty cents, which I thought was great at that time. I counted screws for about three years, then my boss gave me a go on a power press, stamping out contacts for telephone relay sets. I mastered this job after a couple of months. I stayed on that for years.

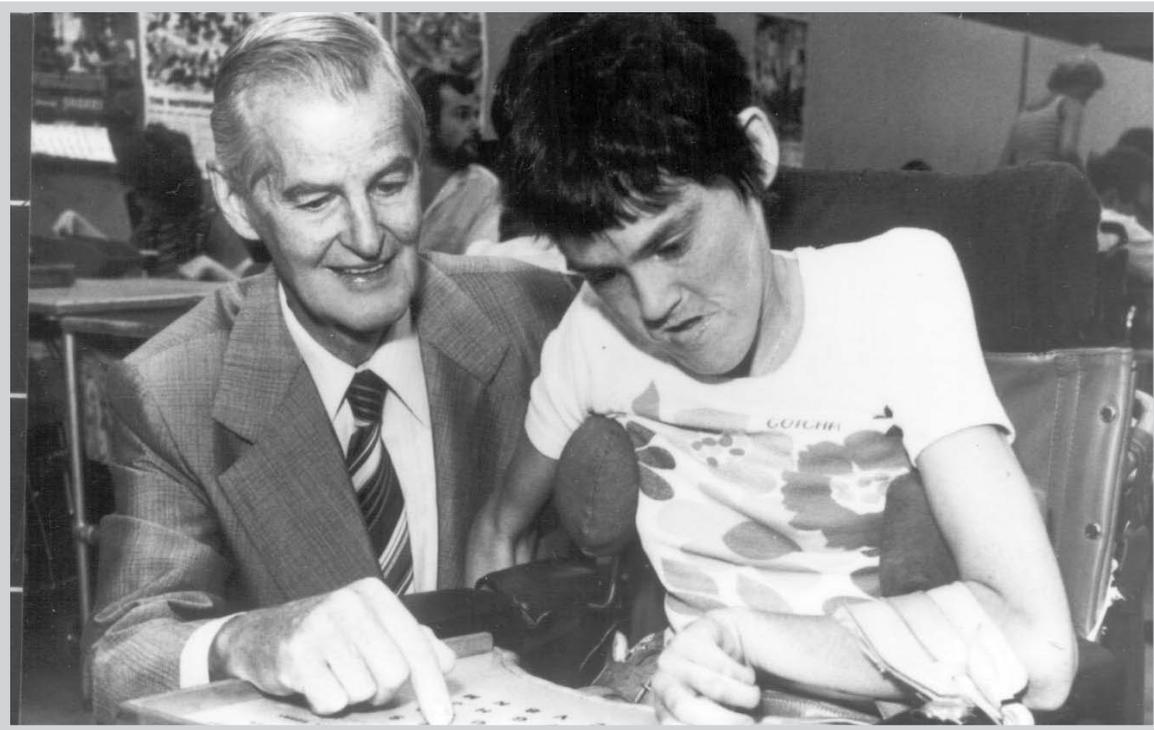
During that time, the engineers had developed a motorised wheelchair. I had my chance to drive one, but my chair had to be specially made. The physios and engineers designed it specially so that I could sit in it. The next thing was to drive it. I don't think the people in charge thought that I would be able to handle the chair, but if you are determined enough you will succeed, and boy, was I determined! After a few crashes and nearly running over the General Manager I proved everyone wrong! I could handle it!

About ten years later, I was asked if I would like to join the computer section, working out the rate of the keypunch operators. I said yes, but I found for some unknown reason I couldn't use a hand splint to type with like I did at school. I thought that I might be able to use a head piece, which is a band that goes around your head and has a pointer attached. Again, they said it would be too hard, but that determination I spoke of earlier came through and I learned to type with a head piece. So up to the computer section I went.

A year after I started there I was due for my long service leave. I had been saving for years to go to America with my brother. We didn't only go to America, we went to Hawaii, Tokyo (where Dr Noda introduced me to the night life and the bars), and then to Hong Kong. I had a ball. Then it was back to work.

Late in 1980, Centre Industries bought a new computer and six visual display units. Much to my delight I was chosen to operate one of these VDUs, and that is what I am doing now.

I haven't known any other way but being handicapped, therefore I have built my life around it. There is one thing that is very hard to get used to, and that is when I go anywhere people look at me as if I have just come from another planet or something – that really gets me going. My handicap doesn't have any effect on my lifestyle. Naturally I would like to have a better lifestyle, but I can't so that's that. My ambition in life is to succeed in my job and try to better myself in my work. Also I would like to go overseas again; I am in the process of saving for that now."



Kathleen Coppins with her point-board which was her sole means of communication until we discovered the Japanese electrical machine which had a printout on a tape.

KATHLEEN JOYCE COPPINS

Kathleen Joyce Coppins is unable to use an electric typewriter. She has battled against the reflex action of the tongue thrust through the whole of her life because of its effect on speech. Now, with her electronic speechmaster, she is able to communicate freely. She says, "I come from a family of eight. My mother and father are very good to me; they are very understanding. I have three sisters and four brothers and I love them all. I am a great auntie four times and an auntie fifteen times.

Being a disabled person as I am, that's not to say disabled people aren't the same as anybody else. We cry, we love. Yes, I have been hurt, but like anybody else I haven't learnt my lesson yet at thirty years of age.

I was about nine years old when they tried me in a red wheelchair. Dr Reye said if I could use it without letting my tongue spasm come out, I could have a wheelchair, so I had to show Dr Reye I could push myself and keep my tongue in. Well, all the physios and all the teachers were watching and helping me keep my tongue spasm in. Anyhow, Dr Reye said OK, you can have a red wheelchair.

When it arrived, I was home on school holidays. They sent the wheelchair home in bits, so Dad had to put it together, with a lot of bad words! But when I had that operation on my legs, and after six weeks in plaster, I was too long for my little red wheelchair and had to go into a larger one.

When I was about fourteen I used to get mad at my speech disability and I used to go in my bedroom at home and slam the door if I was in a bad mood, and I would cry. Now I think I know why I used to do that – I wanted to be just like my sisters and my brothers, doing the things that they were doing, like sewing and making some dresses and going out.

Now I have accepted my disability, it is a bit easier but even when I hear someone has been married, then I start to wonder what would it be like to be an able bodied person – really.

We used to have a wood fuel stove and Mum would make the most beautiful roast dinner with gravy, and the most beautiful apple pies and gramma pies that you ever tasted. I loved sitting and watching the flames dancing all round the walls. But when we had a new electric stove, the dancing stopped.

When I was young and Mum and Dad took me out, people would just stare at me as they pushed my wheelchair up the street. I often wonder what they thought. Mum used to say don't worry about them, they are little people.

As a disabled person, I find that making friends is a bit hard, though I have made a few very good friends at the hostel and at Centre Industries. When I meet new people, I can almost tell if they are going to be good friends by their reaction to me as a disabled person.

Such as Peter and Greg; they made friends by saying hello – without being afraid of me.”

PETER LOSURDO

Peter Losurdo as born in 1946, in a little village on the northern coast of Sicily. He said, “Before coming to Australia all I knew was that I had some sort of paralysis. In those days, and in the little village of my birth, cerebral palsy was unheard of. It was in Sydney that doctors diagnosed the problem. I am a cerebral palsied quadriplegic, and came to Australia with my parents at the age of three and a half. Six months after arrival, I attended The Spastic Centre, where I was put into the Kindergarten class.

The Centre has been my life. If my Mum and Dad hadn't come to Australia, I guess I would have been institutionalised. Back in the village, my Mother was told by her friends to drown me! I am very glad she did not heed that advice. I have four sisters, all younger than myself. We are a very close-knit family, and I enjoy a number of nieces and nephews.

I attended school until the age of sixteen years. I then went into the Training Unit at Centre Industries, and after two months went into the Drilling Section, where I worked for the next ten years.

Over the years I had surgery to the ankles, knees and groin, and at one time was in plaster for four months. Until about six years ago, I was using a walking frame, but now I accept the fact that I must reluctantly submit myself to a life in a wheelchair.

After working in the Drilling Section, I did timekeeping and undertook intensive work training for the handicapped. Then I was made Supervisor of the male aides, which is what I am doing today.

I was one of the cerebral palsied involved in Dr Neilson's research at The Spastic Centre Research Laboratory, which I found very interesting.

My main hobby is classical music. I have a comprehensive collection of recordings which I greatly enjoy. I live at Venee Burges Hostel during the working week, and spend weekends at home with my Mother, with whom I speak in the Sicilian dialect. I am told that mastering two languages has been a singular achievement for one whose speech is considerably affected by cerebral palsy.

My job gives me a sense of achievement being able to help my fellow cerebral palsied. It is rewarding to know that I am able to supervise the able bodied male aides of my department.

One of my most memorable moments, as Chairman of the Cerebral Palsied Committee, would be when I made a presentation to Mr McLeod upon his being named "Father of the Year". It took me days to get over that excitement!"

GREGG WAYNE GILLETT

Gregg Wayne Gillett is profoundly deaf. He uses an Apple computer for communication but his education is only just beginning. He types and writes, and his reading is minimal. He says, "I am twenty-seven years old. I have three brothers. Glen is twenty-eight, then me, Grant is twenty-four and Garry is twenty. My mother's name is Pat and my Dad's name is Don. I live in a home unit at Kensington. We have a swimming pool and a barbeque.

When I was a little boy, I went to school at Mosman Spastic Centre from 1961 to 1974.

Ten years ago I went to work at Centre Industries.

My interest is Stanmore Deaf Club. My best friend is John Windsor. He is deaf also. We go on outings every weekend, everywhere. John has a Sigma car. He lives at Maroubra. John picks me up at the Stanmore Deaf Centre for Youth every Friday night. We have all my friendly deaf people at Stanmore Deaf Centre.

I like football. My favourite team is South Sydney. For four months I played soccer for Centre Industries against all visitors. We played weekends at Dee Why. My friend George Krams is deaf also. He lives in Randwick.

My Dad and I go shopping at Doncaster Avenue, Kensington, for food every Saturday morning.

John, George, David and I will go on the tour bus to Perth, W.A. for the 8th Australian Deaf Games 1985-86 for one month, and we will stay in a caravan park. I have a new T-shirt with 'New South Wales' on the back.

Maybe I will win? Or lose? Time will tell . . ."

ADRIAN LYNCH

Adrian Lynch is now forty years old. He spent his earliest years on his parents' poultry farm at a suburb, which in those days was regarded as 'rural'. Adrian says, "I started at the Mosman Spastic Centre school when I was three years old. We lived so far distant that The Centre bus could not collect and deliver me at home, so my father drove me to and from a collection point each day.

Through the intensive training at The Centre, and the perseverance of my mother, I learned to walk when I was nine years of age. I have always admired the dedication of the teachers and therapists at Mosman.

I am interested in all sports and follow them keenly. I am a keen chess player and together with other members of the Centre Industries Chess Club, I have played in competition with other clubs throughout Sydney. Last year, overall, we won fifteen games out of thirty. I have recently been made a Life Member of the Chess Club. I listen to music a lot, both on the radio and on cassette. My preference is for 'middle of the road' music.

I am a regular attendant at Church, which is the real key to my outlook on life. My Christian beliefs sustain me, making it possible for me to accept my disability and be thankful for the many blessings that have come my way. I have spoken several times at Church gatherings, relating how I was able to overcome my disability by persevering in doing things that able bodied people did, and what other disabled people did, to compete with able bodied workers. I wanted to demonstrate that we do not want, or need, any pity.

Now I live at McLeod House, but go home when my mother's health permits.

A highlight of my life occurred when Her Majesty the Queen and the Princess Anne visited Centre Industries in 1974. At the time, I was lifting some wire onto a shelf in the coil winding section and Princess Anne spoke to me.

Having joined Centre Industries in 1963, I have been a witness to all the different phases of growth. Considering the level of my education, it amazes me that I have been able to work in various sections of the factory. I regard my job as important, to keep my mind occupied and to make me useful in the community. I am thankful that I can play a small part in helping the economy through the manufacture of our electronic components. I am a clerk in the Component Stores.

My main problem in being a spastic, is that I am unable to co-ordinate my muscles in everything I do. I am dependent on someone to cook and cut up my food and to do my laundry, as well as to assist with travel, as I am unable to use public transport, other than a taxi and taxi-buses. Despite this, I enjoy quite a degree of privacy, something which is not available to a lot of other handicapped people.

I was part of Dr Neilson's A.T.R. research programme for three years, concentrating on action reflex in my right arm. I enjoyed the work, knowing that it will help future cerebral palsied people.

My ambition in life is to be associated with the general public as much as possible, because I have found through experience, that it helps a great deal to forget one's handicap and enjoy life as much as possible, even maybe in a limited way.

It takes a very long time for the community to accept and understand that really one is a normal person, and needs no pity."

COLIN BARTON

Colin Barton is aged forty-three years. When very young he had surgery on the hips. Doctors told his father that he would never walk, but Colin was determined, and is an independent walker. He spent his childhood in the Crippled Children's Home at Campbelltown. At the age of sixteen years, he was obliged to leave there and so went to stay with his sister in the country. After this he was accepted into a mentally retarded unit of the Sunshine Home.

From there he was rescued as an intelligent cerebral palsied by The Spastic Centre and taken into the pilot country children's hostel at Mosman, and later transferred to McLeod House. At Mosman he met his future wife, Beverly,



John Baldwyn, Chris Nixon, Adrian Lynch, Dennis Stabback, Judy Geppert.



C.I. Chess Championship 1981. Dennis Stabback, Adrian Lynch, Robert Kenny, Greg Mott, Lindsay Sinclair.

also cerebral palsied, and after a twelve-year courtship, they finally married and moved in Venee Burges Hostel.

Colin joined Centre Industries in 1962, where he has been engaged in stores work, systems supervision, machine shop operations, and transferred to the E.D.P. Section in 1973.

He says, 'Over the years I saved my money to buy a car, which I did in 1968. I love driving and taking trips. Every weekend I take Bev out for a drive, sometimes quite long distances. Learning to drive was a great achievement, proving to everyone that it was possible for a handicapped person to drive.

My job means everything to me. Like everybody else, I need a job to pay my own way in life. When you are born a spastic, you virtually accept it from the outset, even though you have the same ambition as the non-handicapped. You just try harder to achieve what you can. One has always to live with one's disability. It was once said that everyone has a handicap.

My ambition in life is to keep on living!!'

LINDSAY SINCLAIR

Lindsay Sinclair, now aged sixty-three years, was born the eldest of a family of six children at Temora in New South Wales. His movements are slow, and he has difficult speech and limited hand movement. Describing his life, Lindsay said, "When I was born my parents did not expect to take me home. They had me baptised in the hospital. I was taken to many doctors, and when I was four a doctor operated on me. The operation was to transplant a nerve, but whether the operation did me any good it is hard to say. I started to walk when I was seven years old.

Some of my aunties suggested I would be better off in a home, but Dad would not hear of it. He felt that it was his responsibility to bring me up himself. For this I'm very grateful. I was brought up as a normal child. Of course, having sisters and brothers made a difference.

I learned to count when I was four. I used to take medication, which I liked and had to count up to a certain number before I got the medicine. One Christmas I received a slate with the alphabet on it. I just about knew the alphabet at the end of Christmas Day, and so my mother bought me two reading books. After I had finished these books, my brother brought books home from school, for me to read. Then I read my own books, which had been given to me, and also Dad's books. My brother Ron went to high school and when he came home for the holidays, I read his text books. I did sums on a slate, with a piece of limestone.

I lived on a farm for thirty-two years, and in town for eighteen years before I came to Centre Industries. I did all the odd jobs that I was able to do. I was not paid for anything I did, but to be able to do these jobs was a good enough reward for me.

When I was fifty-two years old my father died. I thought there must be something that I could do, so my sister-in-law wrote to The Spastic Centre. I spent over two years in the Training Unit. I felt I wasn't getting anywhere, so I asked to see the psychologist. I had some tests, and they found that I had a high I.Q. I was one of the group picked to study the computer. We met Monday afternoons with the systems analyst. There were blackboard lessons and books on computer programming. At that time I was working in the Machine Shop and not very happy with the amount of work I was doing, so I asked if I could study these books instead.

I was transferred to the Computer Section in 1973 as a Trainee Programmer. My supervisor says that, with all of my handicaps, I can compete with the able bodied programmer.

While I have no regrets not previously having a job, my present employment means a lot to me. I have been to places where I would not have been had I not had the programming job.

My job gives me an income, which makes me independent. Above all, it gives me a chance to prove to myself, and other people, that I am capable of doing a worthwhile job. Not being able to do all the things that able bodied people can do, I learned to appreciate the things that I can do. My ambition would be to work as well and as long as my health lets me.

It is what you can do, not what you can't do, that matters. Real enjoyment comes from doing things – a sense of achievement. The bigger the handicap, the bigger the achievement."

Summary

In nature there are neither rewards nor punishments - there are only consequences.

– Ingersoll

This is not a survey of the rapid growth of a new charitable establishment, born out of the heartache and bitter impatience of parents, unable to obtain treatment for their children. It does not tell of struggles against financial failure, official indifference and political evasion, nor of the difficulties in wartime and afterward of finding premises, obtaining and training qualified staff, breaking down the initial passive resistance of the medical profession, organising a transport fleet, erecting and equipping a building complex in the midst of severe housing shortage. And getting a large group of people of all classes, types and creeds, to work efficiently together, towards a common end.

Such a story might be told, but, interesting as it may be, the real story of The Spastic Centre is the story of its many thousands of children and adults.

In this volume, space considerations can only afford a representative sample of the dauntless and indomitable spirit that typifies our cerebral palsied.

We started The Spastic Centre in 1945 and Centre Industries in 1961. I feel very humble when I think of the years between; it should not have taken so long. All I can say is that in those years we have established a firm basis for our future work and can use our experience in all areas to plan much more effectively in medicine, education, work training, employment, neurophysiological research and the individual's independent lifestyle.

In 1945, we did not know whether the cerebral palsied child was educable. All the professional help we were offered said they were not. The years have proved how wrong they were. Similarly, in Centre Industries we did not know whether adults, as heavily handicapped as our cerebral palsied, could contribute to their own training from a commercial and manufacturing basis. Now, however, their ability to do so is unquestioned, even for the severely handicapped. The chapters of this book provide us with an invaluable record of the achievements of very many people from our staff and from the people outside our organisation. We are grateful for their participation and for their skilled achievements in our work. On behalf of our children, we offer them all our warmest thanks.

In 1945, in Australia, and indeed in most of the world there was no formulated body of medical, psychological, neurological or educational professionals experienced in the handling of cerebral palsied children. Physical treatment was largely based on successes obtained in poliomyelitis treatment, and had little relationship to the problems of the cerebral palsied.

It was wrongly assumed that mental deficiency was symptomatic, and that a continuing series of orthopaedic operative procedures was necessary in most cases, to combat the distortion of joints brought about by the increasing tension of the affected muscle groups.

Since that time the picture has changed dramatically. One common theme runs through the whole fabric of our medical treatment, education, work training and residential living. We now know what is required physically, medically and educationally. We know that the apparent physical disability is only the manifestation of secondary handicaps, which we should be able to

prevent. We know what we need to do in preventive work on the young baby, and are looking to medical science to further reduce the incidence of cerebral damage prior to the birth process.

Over this period of almost forty years, the life expectancy of the cerebral palsied has been extended from what was probably ten to twenty years, to a normal life expectancy.

Control has been established over the frequent epileptic fits previously experienced, and our orthopaedic surgeons are now able to predict, with some accuracy, the improvement they will obtain from the various surgical procedures, following the intensive physiotherapy and retraining programmes, now available to them.

We know that the physically handicapped baby, child or adult, is a normal person first and foremost. The neurophysiological anomaly is incidental to his basic needs as a complete person. First, they need the love and security of their homes and families, then they need such special services as are necessary to enable them to take their place in the normal world.

Mrs F.N. Kerr, Headmistress of our school at Mosman, set the pattern that has operated over the years, when she stressed the role which the school plays as part of the social education of cerebral palsied children who, along with their brothers and sisters, must be prepared for their future, whatever it is; whether it is towards independence economically or independence of spirit and of thought. School becomes the first major social group which the child contacts after he has left his home. The teachers' responsibility is to lead these children to an awareness of the wealth of knowledge, which is in the world and also an awareness of the beauty which exists. Teach the cerebral palsied child to think, but also teach him to see and feel.

As Dr John Foley of the Cheyne Centre, London, U.K., says: "Athetosis is a disorder of movement, not a disease ... The layman, untroubled by neurophysiological niceties, sees the problem simply – they can't sit, can't move at will, can't talk, and yet take everything in ... There is no other condition in which an intelligent individual may be obliged to spend a lifetime deprived of the ability to communicate or move, or in which there is such a discrepancy between motor intention and accomplishment. There is no other condition in which early prediction of ability is so often belied by ultimate achievement, if modern aids are provided from infancy."

Our search has embodied all the many pathways of education and medicine that have emerged in those years. From the antibiotics of the war years – to the CAT scan of the nineteen seventies. From the RH blood groups, the radical orthopaedic surgery, splinting of the nineteen fifties – to the neurophysiology of the nineteen sixties and seventies. Last of all, from the Mothers and Babies Programmes of early treatment – to engineering and employment of cerebral palsied in Centre Industries in the nineteen sixties to the present day.

We broke new ground by challenging the validity of the sheltered workshop approach to the work training and employment of heavily disabled, young adult cerebral palsied. We established Centre Industries for that purpose. To carry out this objective effectively required the setting up of an efficient manufacturing complex, staffed by competent able bodied workers and equipped at an engineering level that enables it to compete successfully in industry standards of engineering, efficiency, quality, price and delivery.

We emulated the mainstream of industry and, instead of a sheltered workshop, we insisted, for the first time, that the concept of Rehabilitation Engineering Support Services be accepted. This led to the modification of the work stations, machines, and hand tools, and was used to increase the productivity of our CP workforce. We have not yet seen a person whose physical handicaps are so great that he could not be significantly improved by applied treatment and technology.

Engineering principles and techniques are obviously applicable to the function problems of the cerebral palsied handicapped workers, in the same way that they have always applied to other workers in industry. Thus, the cerebral palsied worker is placed in direct competition with the able bodied employee. We employ an equal number of able bodied workers who are vital to the scheme, because they provide the CP worker with a normal working environment.

The incentives for both the able bodied and the cerebral palsied worker are identical – firstly money in the pay packet, and secondly the social advantages of being an 'in' member of a large heterogeneous workforce.

At Centre Industries, we have demonstrated the capacity of the heavily handicapped cerebral palsied to work in sophisticated electronics manufacture, using standard machine tools in direct competition with the able bodied. Our main frame computer is staffed by twenty cerebral palsied workers, in systems analysis, programming, operations and data input, with a similar number of VDU terminals.

The Centre Industries concept of rehabilitation engineering support has spread to Japan, where the Ministry of Labour has sponsored the 'Model Factory' scheme. They are for-profit companies, which the Government provides with low interest loans of 70% of the required capital. In 1984, there were 252 Model Factories employing thousands of severely handicapped persons. The

Model Factories must have a minimum of 50% handicapped workers, and the loans must be for capital and not used for operating costs.

In the United States, Centre Industries was established in Wichita, Kansas ten years ago. Additionally, ten centres are currently in a submission to the United States Senate, in answer to the President's call for improvement in the life of the 35 million severely handicapped Americans. Centre Industries in Wichita has proven a concept that is both morally and economically sound, says the proponent John F. Jonas.

The following gives a passing glimpse of the Speech and Education research work done by the dedicated team, headed by Miss Brereton and her supporting therapists, under the control of our Medical Director:

BASIC ABILITIES PLAN 1967 – Demonstrated the gains in perceptual thresholds, and ultimately in I.Q. levels, by extending the control and experience of the child beyond the limited and artificial environment imposed on him by his handicaps. This was followed by –

INTERACTION GAMES – 1969 – The neurological approach to treatment of severely handicapped children without speech, starting at the earliest possible age.

LEARNING ABILITY AND BEHAVIOUR 1972 – Physiotherapy can alter motor experience. Facilitated movement can replace passive movement. Abnormal motor experience is likely to influence learning ability and behaviour; modification of the motor handicap could produce a child who is more able and has better social adjustment.

SOUNDS AND SYMBOLS 1973 – For speechless cerebral palsied children. Prior to this, the conversation of children without speech, depended on their ability to spell. This frequently left them without an effective means of communication until ten years of age, or older, by which time the natural flow of language may have been inhibited. The three-and-a-half year old cerebral palsied child has little difficulty in working with these global concepts, or handling a vocabulary of over 1000 words.

MOTOR PLANNING – Miss Beatrice Le Gay Brereton in propounding "Motor Planning" showed remarkable insight in her "Study of Motor Disability in Cerebral Palsied Children" in the early seventies, planning the movement appropriate to the situation. And it was ten years later that Dr Neilson arrived at the same point by painstaking neurological experimentation.

Over the last forty years, my wife and I have worked as a team to build The Spastic Centre to its present heights, and it is fitting that all of the effort, strain and sweat should be crowned by the ultimate achievement of finding answers to the riddle of cerebral palsy, but it still remains enigmatic.

In 1966, we prevailed on Dr Peter D Neilson to take a scholarship to investigate the causes of muscular spasm in cerebral palsy. At about the same time we became very interested in a programme for the early treatment of cerebral palsied infants within the first year after birth – the Mothers and Babies Programme.

These two developments were critical to our understanding of the neurophysiological patterns of cerebral palsy. The results that have flowed in the wake of this have a direct bearing on the projects which are summarised here.

Dr P.D. Neilson is a unique blend of electronic engineer and science graduate turned into a neurophysiologist by his interest in cerebral palsy. He worked through the neurology of the cerebral palsied, upsetting previously held beliefs of the nature of the condition and the myths that had grown up behind the accepted medical therapies. Now, after eighteen years work, he is prepared to advance an entirely new therapy based on his neurophysiological findings

We are facing the eternal problem of equating the cost of a research programme with the demands for money to be spent on existing children. Therefore, Dr Neilson's work was done on a shoestring. To the best of our knowledge, it is a unique Research Unit created specifically to investigate the neurophysiological mechanism underlying the movement disabilities of cerebral palsy.

Considerable progress has been made in improving the world's understanding of the physiological mechanisms responsible for spasm, rigidospasticity, and involuntary movement in cerebral palsy. Research has also demonstrated that, by focusing training on specific problems, therapy can be devised to teach cerebral palsied to self-regulate spasm and reduce the amount of involuntary movement. Research, however, has led to the view that the primary cause of the motor defect is not spasm, rigidospasticity and involuntary movement, as is usually suggested, but an inability of the damaged nervous system to translate movements, in terms of desired perceptual goals, into appropriate sequences of motor commands to achieve these goals. Reduction of spasticity is an essential component of any therapy, since spasms can, and do, block voluntary movements and the spasm leads to deformities of muscles and joints.

The consistency of the 'Sensory Motor Theory' with observations of motor development in cerebral palsy, leads us to believe that



we are getting closer to the primary problems in cerebral palsy. This has produced a feeling of great excitement, and expectation, in those of us involved.

While we have climbed the foothills of the mountain range of cerebral palsy, we are still battling our way forward over the pass that will, we hope, provide a clear view of the plain beyond. If it only reveals another mountain, and then another, we will meet those difficulties when we get that far ahead. We know the general direction of our travel, and we have an electronic compass to guide us – that was something missing in 1945, when we only had personal intuition to show the way.

As to the future, we have heights to climb, which will carry our work far beyond existing levels. Starting with the babies, we are looking to increased preventive measures to reduce the total incidence of cerebral palsy, early treatment in the Mothers and Babies Programmes to reduce the severity of the action of impaired muscle groups on growing joints, more specialised teaching staff, with equipment designed to enable our children to obtain an education that really does equate with that of a normal child, more sophisticated electronic communication devices, more knowledge of the mechanism of speech, and some means of obtaining effective control of the muscular spasms of the cerebral palsied, apart from drugs, therapy and surgery.

We must keep abreast of the latest techniques: of paediatric, orthopaedic and neurological medicine, of educational techniques, of medical therapy, and rehabilitative engineering, especially as it applies to electronic and computer science.

Lastly, and perhaps the most important of all, we must obtain full economic and social self-sufficiency for the even more severely physically handicapped cerebral palsied person.

These are our minimum needs for the future.

Epilogue

Nureyev hoisted Dame Jenny high above his head. With all the grace and beauty of the world's prima ballerina, Jenny stretched her body to the limit. The pas de deux was perfect, and the ovation reverberated around the walls of the famous Bolshoi Theatre for a full fifteen minutes.

The Allambie Heights girl was pleased with her performance and, as usual, Rudolph was impeccable.

"Nureyev is my idol – he's beautiful," Dame Jenny told the press, as she and her partner left Moscow for Rome.

That is Jenny McLeod's favourite dream – but one she knows can never become a reality.

Jenny cannot walk.

The world of 'Swan Lake' – of pas de deux and pirouettes – will always be closed to her.

Jenny is a spastic – one of thousands of cerebral palsy victims whose bodies do not work properly, but whose minds do.

Dreams are far from being Jenny McLeod's only outlet in life – in fact, her achievements would make any able bodied person proud.

She looks forward to the day when cerebral palsy is defeated.

"I'm so glad for the babies of today – modern treatment now prevents them from being so severely deformed by cerebral palsy," she said. "There are still many spastics born in the world, and I call them half mine. So I do have a big family of babies of my own after all, don't I?"

After four years of struggle, Jenny has been able to discard the apparatus, which formerly supported her.

But the dreams will never be discarded.

"I am very interested in ballet, and if I'd been able to walk or dance I would have loved to have been a ballerina," she said. "I have seen Rudolph Nureyev on both occasions he's been to Sydney, and he is my idol. I think he's beautiful."

Jenny has danced with both life and death.

She will never dance with Nureyev – but she is a dame in every sense of the word.

"Manly Daily"

This epilogue is difficult for me to write. Let me start with an entr'acte – a telex dated 16 February 1981 to Dr Takeo Noda of Tokyo:

A personal request – my daughter Jenny is in trouble. The drug Lysivane which she has taken for twelve years has gone off the market without warning, and the recommended medical replacement drug affects her speech and throat spasms. May and Baker in England are the manufacturers and I wonder whether you might have surplus stocks available from the wholesalers in Japan. She requires 5000 (five thousand) 50 mg tablets to give her a weaning period of a year's supply so that we can establish a satisfactory substitute. My only excuse for worrying you is that she was getting on so well with Lysivane and establishing an independent lifestyle for herself. I have not got a lot of years ahead.

Then I sent a telex in similar terms to Mr Leslie Park of United Cerebral Palsy in New York, U.S.A., and to the International Cerebral Palsy Society in London.

After some weeks, Dr Noda provided a replacement supply of 1000 of the original Lysivane, which were marketed in Japan under the name Parkin and in the meantime, Mr Leslie Park sent us five bottles of Parisidol, which was the American equivalent.

But Jenny refused to take them because she did not want to go through the same process in the reverse direction and we couldn't blame her, so this was a reserve supply. Jenny improved on the Disipal over the next six months. Her speech seemed to be better than it was before, but this was offset by her extension spasms, which seemed to be worse.

Jenny says, "February 1981 started a disastrous year for me. It began one Monday, when the retail chemist returned an order for the drug Lysivane saying it was now off the market. I had just two tablets left, and then my spasm started. I went home early from work, and I couldn't make it the next day, nor for a month following. It affected my speech so I couldn't get a single word out, and my throat was gagging like fury so I couldn't get my food down. My father and a nurse took two hours for a meal, holding my chin up while I masticated my food.

Dr John Grant prescribed Disipal as a suggested replacement drug. This improved my throat spasm, but at the expense of my extension spasm in my legs and arms. It was a month before I returned to work and six months before I reached a similar standard of performance in speech and in control of muscular spasms as I had attained with my previous drug."

Then the lightning struck again:

'9 September 1981. Dr Takeo Noda, Tokyo, Japan. I regret to inform you that Jenny has developed a growth in her right breast. Following surgery, this involves cobalt treatment daily from the radiotherapy department for six weeks. In her favour, she has maintained her valiant determination to get back to work as early as possible. You may know the effects of the radio therapy are debilitating and make her excessively tired. Will you advise her Japanese friends of this, especially Dr Takahashi, Professor Yokomizo and Toshi Nagasaka. It is now eight months since I last appealed to your help on the Lysivane issue, and it has taken us this long on the new drug to get Jenny back to where she was. She has mastered this, especially in her speech which is better than normal. This is a stroke of fate which we must accept, but I cannot help but feel the unfairness of it all.'

And Dr Noda's reply:

'19 September 1981. I got your personal telex in regard to Jenny. It was the most shocking news that I heard from you during past years. I pray to God that she might keep her courageous independence and I will take any amount of trouble to help her. If you mind, would you tell me details about her? And I also want to know if you have possibility to come to Japan in this time for the November meeting of the McLeod Society of Japan. Please tell my heartfelt comfort to Audrie.'

This was the most terrible thing to happen to our lovely daughter Jenny. Our family and friends were devastated at the news. You can be logical in the control of your thinking, but controlling emotions is harder. I know that is the price all parents pay for having children - you must give a hostage to fortune for illness, or accident – but we thought we had paid the price with Jenny's cerebral palsy.

For forty years of her life span, she had battled her way through: an orthopaedic hospital at the age of five years, with the archaic gutter splints in bed every night, the pelvic control braces by day, which stretched already tight muscles even tighter, then a neck collar to support her head, and a corset with steel supports for her back. From the age of sixteen years, muscular spasms forced the abandonment of use of her right hand (which was her better hand) for ten years. With plaster casts used successively over the same period, she had to obtain control of her head, master the control of her electric wheelchair at twenty-four years of age, and improve her speech over the succeeding years. It does seem unjust that she should have to accept this physical burden and then to add the scourge of cancer – but there is no justice in life.

But Jenny was made of sterner stuff. So instead of saying, "Why did it happen to me", she said, "Through my life, I have been cast in the role of a leader of the cerebral palsied. My life has been devoted to a crusade for the rights of the cerebral palsied, especially for those who are heavily handicapped as I am, in The Spastic Centre, then in Centre Industries and finally in Venee Burges Hostel. Now I have been selected for the additional task of pioneering the path to success in the cancer treatment area."

She says, "I haven't got time to be ill", and refuses to worry about the future, saying, "If it happens, it happens, and we'll deal with that when it comes." She is more concerned with the twenty-two female able-bodied aides, who are her managerial responsibility. They had been getting inefficient in the feeding and toileting of the severely handicapped cerebral palsied in Centre Industries during her six months absence while she was undergoing treatment.

There were no tears – just a calm acceptance of the fate in store for her. The surgeon did not expect his patient, on the first day after the operation, to produce a questionnaire on her future cancer treatment with twenty-three questions which she had the nurse copy for her. Later he recalled that incident, saying, "Jenny is the first person who has ever asked me those questions."

My wife and I had a long-standing appointment in Japan, and on Jenny's insistence we made the trip when she had only a week of daily radiotherapy treatment left

The telexes tell their own story:

'Finished treatment not allowed to have bath for two weeks. All is well. Back to work maybe next week for half day. Have fun, love Jenny.'

'Your telex received. Sorry about your bath. Glad to know that you are planning to go back to work, but take it easy. We are now in Kobe. Doctor Takahashi and all the Sendai people send you their love.'

'Burrandong was wonderful had fun, bus trip OK. Johnsons were lovely asked me up next January. Feel good. Work tomorrow half day. Miss you. Hope things are going all right and Japanese are not working you too hard. See you soon, love Jen. PS. See Holecek on Friday, let you know any news.'

'Saw Holecek. Everything clear. Bath tonight. See you soon, love Jen.'

She is a beautiful creature. Her wheelchair holds her slight frame – she weighs only thirty-five kilograms and, in spite of her years, she is ageless. She looks like a faery child, aeolian and ethereal. Then she talks to you, and you become aware of the cutting edge in which she exhibits her mother's practicality, which manifests a fierce independence on behalf, not of herself, but of the other cerebral palsied for whom she has made herself responsible.

During the next twenty months, we were alert for the appearance of a lump that would presage more surgery. As the months wore on, we were able to comfort ourselves with the knowledge that the statistical survival rate for breast cancer was 86 per cent, and it was presumably working out for Jenny. But alas, in February 1983, the surgeon discovered a suspected cancer had spread to the other breast. Jenny was watching his face during her examination. His expression changed and hardened, so she was prepared for his verdict when it came. Another and larger operation followed, and daily doses of radiotherapy, extending over two months. We were bitterly disappointed.

Jenny was no stranger to hospitals, but the daily treatment with cobalt radiotherapy was a new experience. Her doctor was a young man, and they established a rapport on the first visit. I think he tried to treat her with professional detachment, as he said he could not get too close to his patients for obvious reasons. As the weeks wore on, his detachment melted, when Jenny wrought her own magic on him.

The treatment was given in a huge machine something like an X-ray machine. That was a problem, because the table of the machine was very narrow, to permit a 360° travel about the vertical axis of the table. Jenny suffered from a 'startle reflex', brought on by the high physio tables in her early years that had as a consequence established a fear of falling, when all of her muscles in spasm could roll her off the narrow table onto the floor. (Commencing in the nineteen seventies, all physio treatments were done on floor mats).

The time of each treatment was about thirty seconds, and it needed to be exactly set on the axis of the previous treatment. This was accomplished by marking the skin of the body with indelible colours – green, purple and red. So bathing was banned for the six weeks of treatment. During treatment movement is forbidden, and this posed a major problem for Jenny because she could not hold her arms in the required position for thirty seconds, without spasm of her muscles

The team had never had a cerebral palsied patient before and it was strange to them, but fortunately Jenny had gone prepared with straps and sandbags, so that she would keep perfectly still. No one could be in the room when the cobalt ray was activated. Jenny was locked in with the huge looming machine with its red position lights and with the large steel doors clanging tightly behind her. She said, "It is very lonely here, and thirty seconds seems thirty minutes, especially when your nose is itchy and your hands are tied down." The operator had a small window and a computer scan screen, but that was hardly enough to get rid of

the feeling of solitary isolation. Jenny tried to get her doctor to put music into the operation room, and pictures on the ceiling so that there was somewhere to look. But without success. The team of operators was extremely nice to Jenny, with their smiles and laughter that offset the depersonalisation of their equipment.

Jenny had saved her money since early girlhood for a holiday in Europe. Financially she never had a chance of doing that, but lack of money does not prevent you dreaming, and the intensity of dreaming would make some of it come true. She used to say that when she was eighty years old she would leave Centre Industries to look after itself. She would have saved enough to take off for Europe, and at eighty-four years she would return to Sydney and then she would simply 'pop-off'.

With the recurrence of Jenny's cancer, we feared that if she left it too long she may not be able to fulfil her life's ambition. So Jenny put in hand her selection of the people who were potentially her retinue of aides for her European trip. The Bank's travel agent and Jenny worked together refining her itinerary. Jenny insisted that she was the leader and paid all the bills for fares and accommodation.

Jenny made a deep impression on the handicapped groups during the Japanese Exchange Student visit in 1978, and wherever we went during this tour of Japan we were besieged with enquiries about her health, and loaded down with presents for her. One that won our hearts completely was presented to us by the handicapped workers in Mr Iwata's workshop north of Sendai. This present symbolised one thousand prayers for Jenny's recovery. It was in the form of strings of multicoloured origami folded cranes, which is a lucky symbol in Japan.

Jenny finished with the cobalt radiotherapy in May, and she planned the trip to commence on 15 July 1983, so in that eight weeks she had to prepare. The surgical operation was severe and the cobalt treatment was additionally debilitating, but she was adamant in her refusal to put off the July date. She did not say so, but reading between the lines, we realised she felt that if she postponed the trip she might not make it later on. Then, to make matters even worse, she had an excruciating attack of shingles, which the doctor said often attack patients whose resistance is below par. It lasted about eight weeks, and even when the blisters had broken it was getting perilously close to mid-July. We did not think that she would be able to make it physically. Her weight was down to 31 kg, but her dauntlessness was unimpaired

You can imagine what our feelings were like to see Jenny off in the Qantas flight QO5 for Rome. My wife and I were experienced travellers and aware of all the things that can go wrong on such a flight – loss of luggage, ill health of Jenny or her companions, theft of money or possessions, passport loss, and infighting of her companions on such a long intensive itinerary over six weeks. Fortunately our fears were unjustified.

Leaves from Jenny's diary:

'It was extremely hot in Rome. Fortunately I had fourteen hours of sleep on the plane. Saw the Pope among 5000 others. Luigi's breakfasts are something to write home about. The Trevi Fountain and The Spanish Steps are all in the same places.

We went on a five-day trip with mostly American tourists. The bus driver was fat, and lifted me onto his stomach and into the bus without any trouble. Florence, Assisi, Venice, Verona and Milan – they were all pleasant, and bring back happy memories. I have decided that when I am rich I am going to have a villa in Venice.

Then the flight over the Alps into Switzerland. Bright sunshine over the mountain and snowy peaks, and then the lakes. We explored them all, by cablecar, train, bus and steamer. We got ourselves stranded in mid-lake when a hailstorm hit us for half an hour.

A flight to 'Gay Paree' for my birthday the next day. When we got to my hotel room a bouquet of red, red roses was waiting there from Dr Noda of Tokyo, and some friends of my father sent an armful of flowers with an apology because they had left Paris for the coast. We had a birthday dinner on a floating restaurant in the Seine, and I happily left my year behind me. Now to prepare for the next.

I bought a frock in Paris, in fact two, and did not check the price until they were wrapped up. Then I had a heart attack when I converted francs into dollars. I have not been brave enough to tell my parents or friends how much they cost, but that is my secret, and after all, who has two gorgeous Parisian frocks in her wardrobe!

London was the next stop. The roses in Kensington Gardens and Trooping the Colour. The policeman on duty at the Palace who permitted me to enter the high fence so that I had a grandstand view, and more

shoes to add to those previously bought in Rome and Paris – fifteen pairs in all.

Then to Bonny Scotland. Edinburgh first and lunch with Mr George Pollock, who was the surgeon, who in 1963 visited Centre Industries, examined me and told me that I did not need the collar that I had worn for the past fifteen years.

The Military Tattoo in Edinburgh Castle – I had seen it on TV but this was the real thing; the skirl of the bagpipes and the Scottish uniforms and the massed bands of men marching.

We then hired a van and took to the Highlands, finishing our trip at Dunvegan Castle, the home of the MacLeods for six centuries. Big Kenneth MacLeod and his wife made light of the problems getting me and my wheelchair up to the Great Hall. It is approached by a winding narrow staircase as a protection against surprise attacks. I saw the Faerie Flag, which tradition says was reserved for use in a critical passage of history. Kenneth said it was last waved in 1745, when the clan was dispersed. We ended our last night of the tour of Scotland on the banks of Loch Lomond, with the moon and the mist reflected in the water.

There was always some unexpected person. For instance, at dinner in Edinburgh a man introduced himself as Derek MacLeod and said, "Let me welcome you to Scotland on behalf of the Clan MacLeod," and then stayed for an hour.

I was sad to learn of the death from a stroke of big Kenneth MacLeod shortly after I returned home. We only stayed two days in Dunvegan, but he was so kind and gentle as often a big man can be, and I felt that I had known him all my life.

Back to London for a week, shopping and sightseeing, and then back to Sydney.

I was surprised on our tour that everybody was kindness itself. Five airlines, starting with the Qantas attendant who stretched me out on three seats and made sure that I could sleep for fourteen hours. The bus drivers in Italy made certain that I was comfortable, and the wheelchair was waiting for me at comfort stops on the way. An elderly American tourist from the bus tour was always unobtrusively on hand with steps and stairs, and when on a water taxi in Venice he was on hand again to lift me into the bobbing craft one metre below ground level. The hotel staff could not do enough for us in Italy, Switzerland, Paris and London.'

'At Centre Industries I picked up the thread of my work again, I had been away during most of the year, and when I was in the middle of treatment I could not do justice to the management position. Following the year's end with the Christmas and New Year holiday break, I came back in 1984 jumping out of my skin, physically fit and in fine fettle. I had put on more weight, and as a result of my tour my speech was better than it had ever been.

Now I have three years of solid work ahead of me, bringing the cerebral palsied in Centre Industries up to their own physical capability, and maybe beyond it!'

I have stolen one of Jennifer's sayings for the title of this book –

'Nothing is Impossible'