

Trends in the Field of Habilitation of the Cerebral Palsied

By F. M. TRAGOTT VORWERG.

A short time ago, I completed a world tour of centres for the cerebral palsied. The advantages of present day air travel are such, that I covered over 100,000 miles in 20 countries. Not only did I enjoy a "world's eye" view of facilities for the cerebral palsied, but I was able to examine these facilities, exchange views with hundreds of people dedicated to the many fields of work in Cerebral Palsy habilitation and discuss the work we ourselves are doing in South Africa.

It is impossible in an article such as this to describe all I saw, or discuss at length the wealth of knowledge gained by such a unique experience. However, a few general impressions may be of interest.

Of outstanding importance is that those working for the Cerebral Palsied belong not only to their own local community, but to an international family, the members of which want to help each other. All over the world, there are those who want to share our problems, add to our knowledge, and are keenly interested in what we are doing in the Union.

We have long known of advances in our work in such countries as the United States and in Australia. One was elated and humbled to hear of work being done in many backward areas (e.g. Asia) for the Cerebral Palsied. Elated at the high standard of knowledge of professional workers and humbled, because limited facilities in medicine, health, social welfare and education in poorly developed countries have presented formidable obstacles which have not prevented progress.

The concept of cerebral palsy habilitation has changed. It is now universally accepted that treatment and education are only the first stages of a complete programme for the cerebral palsied. Education which does not lead to economic independence or a useful daily life is wasteful and in many respects a failure.

In all countries, realistic thinking and planning are replacing the over-optimistic generalisations which marked the initial development of work in our field. The days of fancy slogans telling us that all the cerebral palsied can become "normal citizens", if given treatment, are passing. This misguided publicity led parents to expect the impossible and filled them with hopes which were beyond realisation. There is much bitterness and

heart-break as a result. Professional workers with enthusiasm and great emotional impetus to be leaders in a new field of work, find, instead of expected miracles, acute frustrations and innumerable problems which still remain unanswered.

It is quite wrong to call the cerebral palsied the "world's forgotten children." No other form of handicap has received so much attention of recent years or created so many controversies.

Many of the cerebral palsied have received years of skilled training in all aspects of habilitation. Despite this, they remain severely handicapped in locomotion, hand function, speech and scholastic ability.

Pioneering efforts, initiated in every instance by parents, were almost entirely devoted to children with cerebral palsy. This is understandable. These children, however, are now almost grown up. The question arose—everywhere I went: "What happens to the children leaving cerebral palsy centres who need vocational training, or care which will provide a useful daily life?" In particular, parents are demanding some assurance that their children will have understanding care if they require it, when they (the parents) are no longer living. We have this problem in South Africa, and it is occupying the full attention of the Cerebral Palsy Division of the National Council for the Care of Cripples, who hope the establishment of a Village Settlement will be the answer.

Vocational training and employment placement of the cerebral palsied was a main topic of discussion everywhere. Australia, New Zealand, the United States, Canada and Great Britain have initiated special programmes to deal with this. From all reports received it is evident that the number of cerebral palsied who can be placed in the open labour market is pitifully small.

A few remarks regarding the therapies. It is almost universally accepted that physio-occupational and speech therapies are essential services in the cerebral palsy unit. However, I visited centres where occupational therapists were not employed from choice. Such therapy was shared by the physio-therapist and the teacher and, I may add, very successfully. Then, too, it was very noticeable in vocational workshops in the United States, that the occupational therapist was often conspicuous by her absence. Training was being

initiated and carried out by personnel direct from the fields of industry, commerce and the like. Frequently, these people had had little or no previous association with the handicapped and yet were achieving startling results.

A point put to me was that for years, the cases concerned had been managed by therapists with continual attention to their handicaps. In these workshops, the handicaps are taken for granted. In an environment geared to the function of a normal factory or office, the client is concerned with his worth as a potential employee, his output as a worker, his training to do a job, *despite any handicaps*.

More important, with new feelings of personal worth and the realization that economic independence might be within reach, improvement in skills developed almost spontaneously, and these without the specific technical attention of doctors and therapists.

In the field of physiotherapy, no one system has been evolved for the treatment of cerebral palsy. The most progressive centres are guided by the needs of the individual patient. Thus, he may respond to one single method or parts of many methods, or even to just the personality and common sense of a therapist with only her general training and perspicacity to guide her.

It is heartening to find that those whom we accept as authorities in this field are not quite so hide-bound as of yore. Each is beginning to accept the ideas of others.

Many physiotherapists are asking if there is not such a thing as "too much physiotherapy" for the cerebral palsied. Some centres are experimenting on reducing the time given to treatment. It might be significant that in one centre, where great stress was laid on physiotherapy of a specific type (to the extent that I felt it was a discipline) there was a large number of behaviour problems among the cases. The fact that great emphasis was laid on the use of braces and appliances with consequent restriction of movement could also be a causative factor.

However, I visited only one cerebral palsy centre for children where physiotherapy was not available. Parents took their children to the local hospital after school hours for treatment. Medical officers reported no adverse effects from this arrangement, while the education of the children benefited through less interruption in the schooling programme.

The essential place of physiotherapy in the habilitation programme is beyond dispute. Physical improvement in the severely handicapped cerebral palsied case under treatment is slow and rarely spectacular. Those parents who doubt the value of physiotherapy services should see as I did the

chronic deformities developed over the years in adult cerebral palsy cases who had not had the benefit of treatment and training. Born at a time when no services were available, these men and women, fine and intelligent people, are today so deformed and handicapped as to be inmates in a home for custodial care.

Lack of adequate communication in speech and writing is universally recognized as one of life's greatest handicaps. The speech therapist is of vital importance in the cerebral palsy habilitation scheme. It is significant that all countries report a shortage of trained speech therapists. One no longer hears of "speech defects" but of "language disorders" which covers a much wider field. The ability to speak and have understanding of the written and spoken word touches on all subjects in the schooling programme. Consequently, the speech therapist plays an important part in the teaching of reading, writing and arithmetic—all aspects of language development. Teachers and speech therapists must work closely together, more so than we have expected in the past. In New Zealand where this is fully realized, students for speech therapy courses must be qualified teachers before they are accepted for training and this is also the case in parts of Australia.

Such "teacher-therapists" are not concerned only with speech defectives as we accept the term, but are making important contributions towards solving educational problems of so-called "normal" children in the ordinary schools.

The employment of therapists in schools for the cerebral palsied by official bodies (such as government education departments) shows a varying degree of control. This varies not only from country to country but frequently from province to province within those countries. In the schools (these are better designated as habilitation centres) the controlling body is the Education Department. Such departments accept full responsibility for educational staff (teachers). Many will not accept the therapists on the same basis. It was not unusual to find that teachers are paid by an official department with accepted privileges, such as pension schemes, vacation pay, etc., while therapists have to be paid by a voluntary organization who impose their own conditions of service. Sometimes two official departments are involved: eg. Education and Health—in which conditions of service have little in common. It is unsatisfactory as it leads to feelings of resentment and is not conducive to good teamwork.

This leads to another point—What constitutes "teamwork" in the cerebral palsy unit? I visited many centres and was met with the remark—"Teamwork is the basis of our success." I found on investigation that a wholistic concept of teamwork did not exist. Certainly there was a good

team of doctors, another of therapists and another of educationalists. Unfortunately the teams never met together. In one instance, the "medical" teams (employed by voluntary agencies) and the "educational teams" (employed by a State department) only communicated with each other in writing. Many teachers complained to me that they were regarded as only a "necessary evil" in the habilitation programme and there was lively discussion on this point at the Pan Pacific Conference in Sydney.

In the educational sphere, the most noteworthy progress is shown in the development of special techniques for teaching the brain-injured. Here the United States leads the way, but valuable research is being done in Great Britain and France. May I add with pride that the work which has been carried out at the Forest Town Teaching School for Spastics in Johannesburg for several years is equally meritorious.

The controversial question of criteria of admission to cerebral palsy schools is not quite the contentious issue it used to be. Where state departments control or subsidise schools for the cerebral palsied, the I.Q. level of admittance is high, in most places no less than 80. Children who do not fall within this "educable" category are catered for by the voluntary cerebral palsy associations. The best of these organizations do not run "centres of ineducable children" but "assessment centres." Here children benefit by long or short term treatment and training and dependent on the result, placement may be made. This solves the great problem of the "border-line" case, gives the benefit of any doubt to the child, and makes possible, after careful training and observation, a more accurate placement.

In South Africa, most attention has been directed to "educable children." Throughout the world, voluntary cerebral palsy associations have not left out the "other children." Many of the so-called "ineducables" prove otherwise if given time and opportunity. It is not out of place to remind such organizations that if they are working for the cerebral palsied, the funds they raise should be utilised for the benefit of all the cerebral palsied who may need assistance and not for a selected group with this condition. Many of the schools in Australia have separate units for the non-educable children. The staff are paid and facilities provided

by the cerebral palsy associations. With typical Australian terseness, they are called "minding groups" and provide a much needed service. It should not be forgotten that the parents of the so-called ineducable cerebral palsied child need help to lighten an almost unupportable burden.

A brief mention of one or two outstanding impressions in closing:—the importance of careful diagnosis and medical assessment. South Africa has much to learn here. Treatment and education of cerebral palsy cases MUST begin at the earliest possible age. The Department of Education, Arts, and Sciences are to be congratulated on the work being done here for the pre-school group. Great Britain could learn from this.

There are enormous sums of money devoted to cerebral palsy work in progressive countries overseas. Because of this, there are better facilities for the training of staff, and equipment is plentiful and of a much higher standard than that obtainable here. While it is accepted that specially designed buildings make for better working conditions, they are not an absolute essential. I saw units which ran the gamut in accommodation—from disused garages, dark basements, old houses to the most modern buildings of special technical design. Let me forever dispel the idea that only a single-storey building can be used. In Great Britain, such a building is hard to find and in France, one centre operates on several floors of a block of business offices. In all these places, a high standard of achievement is evident.

There is no one country which can offer perfection in every aspect of cerebral palsy work and the State-aided schools in the Union can hold their own with any I saw overseas.

It was an honour for me to be able to describe what we are doing in South Africa, as part of a great international movement. Regardless of colour, race, creed, politics or geographical boundaries, men and women throughout the world are united in a common cause: to improve the welfare of the cerebral palsied; to find the cause of the condition and its prevention.

To all those interested in this work, I bring good wishes and warm greetings in many languages from many friends valuable to our cause.