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SCRIPTS PRESENTED BY STUDENTS AND STAFF

OF

THE PRETORIA COLLEGE OF OCCUPATIONAL THERAPY.

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CEREBRAL PALSIED.

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Presented in 1971 to the A.G.M. of the Cerebral Palsy Division of the National Council for the Care of Cripples in South Africa.

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I. A REVIEW OF THE SITUATION

Mrs. H.J.V. du Toit

To review the situation in respect of the cerebral palsied, let us take a long look back to 1946, and acknowledge the lions share that the National Council for the Care of Cripples have had in bringing about the extensive services which exist for the Cerebral Palsied today.

As I feel very privileged to have been propelled along with this early history, so dynamically shaped by your Council, I hope you will forgive me for mentioning my own involvement.

In 1948, a small group of us from Pretoria attended the first meeting in Johannesburg. The group consisted mainly of desperately concerned parents. Out of this meeting grew the facilities for finding, treating and educating the cerebral palsied children there.

In 1949, a counterpart of this meeting was held in Pretoria and these efforts resulted in the establishment of the first Pretoria School for the Cerebral Palsied at the "Kappie Kommando" where I opened the Occupational Therapy Department in 1951. This may in fact have been the first Occupational Therapy Department for the Cerebral Palsied in South Africa.

In 1952, the National Council for the Care of Cripples, organised a congress on cerebral palsy, at which I enthusiastically propounded theories in a paper entitled "The Problems of Home Treatment for the Cerebral Palsied". At that stage, I was looking after my first child aged two, and doing home treatments of the Cerebral Palsied. Some of my most treasured and satisfying contacts which I still have with individuals who, incidentally, also suffer from cerebral palsy, date from this time. I had then just returned from a year of specialised study and work in the field of Cerebral Palsy in England. Thus, through the mammoth efforts of parents and public, catalysed and guided by the National Council for the Care of Cripples, and implemented by Doctors, Therapists and Educationalists, we reach the present situation.

The Department of National Education controls, finances and operates the II centres catering for ± 1325 children, under a separate division for the neurologically disordered.

The centres are as follows:

Cape Town	Rondebosch, Vista Nova	:	130
Transvaal	Krugersdorp, West Rand	:	165
	Brakpan, Muriel Brand	:	135
	Pretoria	:	175
	Johannesburg, Forest Town	:	210
	"Nuwe Hoop"	:	75
	South Rand	:	75
Natal	Durban, Brown's School	:	180
Cape Province	Port Elizabeth, "Oos Kaap"	:	130
O.F.S.	Bloemfontein	:	45
			1,325

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There are other centres for mixed disability groups such as the Hope Home, Meerhof, Elizabeth Conradie, each of these would include a certain percentage of Cerebral Palsied, and bring the total of Cerebral Palsied receiving treatment, education or training into the vicinity of 1500.

The following centres exist for coloured and bantu:

The Cape Town one for Coloured Cerebral Palsied.

Mixed disability Bantu Centres at Umtata (Ikhwezi Lokusa).

Letaba and West Transvaal (Tlamelang)

The National Council for the Care of Cripples has a special and very dynamic Cerebral Palsy Division whom we have the pleasure of meeting this morning.

This division has, as I have said, from its inception acted as the catalyst for cerebral palsy services, stimulating and co-ordinating their growth. One of their contributions is to provide a channel for communication and interaction, and another to organise congresses and seminars.

Each centre has a Board of Management which consists of a certain percentage of people appointed by the Cripple Care Association, and a certain percentage appointed by the Department of National Education.

In addition, every school has a Parent Teachers Association which concerns itself with active Fund Raising for special projects not subsidised by the Department.

The quota of staff members to children in each centre is stipulated and adhered to by the Department of Education. It is as follows:

Teachers	1 to 10 children
Physiotherapists	1 to 20 children
Occupational Therapists	1 to 48 children
Speech Therapists	1 to 48 children

Occupational Therapy and Speech Therapy posts are classified together, so stated differently, it can be said: There is 1 Occupational Therapist or one Speech Therapy post to every 24 children.

It would, therefore, be possible to appoint 2 Occupational Therapists and no Speech Therapist to 48 children or vice versa.

Having described the situation, it is obvious that the acute problems which existed in 1948, have now been solved at a very high level.

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These problems were:

1. To define the size of the cerebral palsy problem in our country, and seek out the cerebral palsied.

2. To acknowledge that cerebral palsy is a neurological disorder which affects a sufficiently high percentage of the population to justify that financial responsibility be assumed by a State Department. This includes the provision of special treatment/education centres equipped with the specialised personnel and facilities to provide the many facetted programme required for the cerebral palsied.

3. To establish cerebral palsy directed training for the specialised medical, paramedical and educational personnel, who would be members of the team, and to sort out role definitions and decide on relative numbers.

These problems were solved in the light of the problems of the programme in its early developmental stages, but we have long passed this stage now, and the problems of an established service functioning at a level which can compete with those in the rest of the world, have now emerged.

Now that the backlog of completely untreated cerebral palsied, who obviously had an immediate and primary need for pure physical treatment, has been dealt with, are our problems still the same? If they are different - does the quota of personnel provided to solve the problems which existed in the stage of early development still apply?

Has there been a shift of emphasis perhaps from pure treatment and education, to incorporate motivation, preparation, evaluation and placement? Should we re-think the relative quota of personnel providing specialised services to the cerebral palsied. To answer this, let us look at the human products of our programmes.

Cerebral Palsied children are now being discharged from these highly specialised education and treatment programmes provided throughout the country at a rate of 50 - 75 individuals per year, and we must ask ourselves a new set of questions:

To what are they being discharged? How adequately are the specialised programmes equipping them to function in their reality? How much better able are they to live happily and successfully after the programme than they would have been without the programme? Is each child as able as he could be assisted to be, to live a happy and productive life?

I am convinced that we must now turn our attention to a new programme for the cerebral palsied child, one which will function <u>concurrently</u> with the two programmes which already exist.

1. the treatment of physical capacity with all its complex nuances of control of neurological dysfunction, and restoration of independent function;

2. the educational programme with all its pedagogical and academic implications.

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This third programme should stimulate the sequential development of creative expression, and lead to the preparation and evaluation of each child's work capacity, culminating in work and study prognosis before the child's discharge from the School.

I know that you have all been vitally concerned with these problems and with their possible solution. I sincerely hope that what we have to show you, and to discuss with you, will interest you and that it may perhaps in some small way contribute to a new approach to these complex problems.

II. A NEW PROGRAMME FOR THE CEREBRAL PALSIED WHICH MAKES PROVISION FOR THEIR EVALUATION, PREPARATION AND PLACEMENT.

Mrs. H.J.V. du Toit

It is clear that excellent work has been done, in identifying, educating (in the pedagogic sense of fostering and rearing) and treating the cerebral palsied child in special centres since 1946. In the process many problems have seen solved, and others have been highlighted. We are all concerned with what appears to be the most significant unsolved problem at this time, that of providing a programme for the motivation, preparation and evaluation of the cerebral palsied for employment, a programme which will lead to placement in approriate work or further schooling or training, in a rather ruthless uncompromising reality. A reality very different from the one of special care, which compensates for the child's disability and which is of necessity created in the centres.

It is no longer necessary to present a philosophical treatise on the merits of work, we know and accept that human dignity and selfworth are inextricably bound up with the opportunity to fulfil one's potential in appropriate work. We also know that it is economically sound not to waste work force particularly in a country suffering from a chronic manpower shortage.

We know that far too few of the cerebral palsied children are moving from C.P. centres into employment appropriate to their level of residual ability, or into further study or training. Somewhere along the line we are missing out on the key factors that lead the cerebral palsied child to a meaningful way of living after discharge from the centre.

I am obviously not presuming to offer answers, or to provide an infallible magic wand solution, but I would enjoy sharing with you the thoughts which have been concerning me since I started my professional career in the field of cerebral palsy in 1951.

At the moment the programme for the cerebral palsied child is enjoying attention from many sources. Committees, commissions and individuals are investigating problems and suggesting solutions. One is conscious of receptiveness to new thought, and a preparedness for the next phase in the development and growth of the habilitation services for the cerebral palsied.

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It is in this spirit that I respond to the invitation inherent in this dynamic situation to offer some thoughts.

At the moment there are two basic services provided for the cerebral palsied at each centre, one for education (with all its facets), and one for treatment with its medical and paramedical ramifications. The time allocated to the programmes in each of these two main areas, will vary for each child according to his particular educational and treatment needs and his potential to benefit from the selected programmes.

I submit that two additional programmes should be introduced which will fall under the broad classification of treatment, and be classified as additional Occupational Therapy Programmes. I hope that it will become clear why these programmes should be administered by occupational therapists as we go into more detail.

I believe that one of the additional programmes should be aimed at restoring and evaluating medical fitness for employment, further training or further study. This programme would be geared into the stimulation, in each child, of creative ability and would become preparation and evaluation for placement in the appropriate level of employment, continued study or training situations respectively.

I am convinced that every single child should attend this medical work fitness programme from the time of his admission to the centre, and that he should continue to attend this programme until discharge from the centre.

The other additional programme which I believe to be necessary is a job training programme which will be structured specifically for those children who cannot benefit from further academic study. This programme will absorb those children who have been withdrawn from the academic programme, and it will consist of training them to execute a single one-step job, or a routine sequence of simple steps in a job, which will correlate directly with the work expected from him in the appropriate placement.

These children would, in other words, be taught to perform the same single "job" or simple combination of "jobs", with varying content and to cope with the surrounding and related demands, which would simulate those required of him in the appropriate placement, be that a hobby activity in his own home, organised sheltered disability, low production, non profit making employment institutions, sheltered workshops, or repetitive type simple job, in the open Labour market.

How will these two additional programmes function?

I am sure that many of you are aware of the dissimilarity of the contribution made by occupational therapists in the different centres. In some cases the occupational therapist concentrates on the testing and treatment of perceptual impairment, in others occupational therapy is directed almost exclusively towards helping the child attain independence in performing selfcare and activities of daily living. In some the occupational therapist may treat specific symptomology by basing activity participation on Bobath principles.

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Ofcourse this diversity in the role and contribution of the various occupational therapists must be confusing to those of you looking in, and create the impression that occupational therapists do not have a clearly defined role.

However, a look at the quota of occupational therapists to children in the centres elucidates the main reason for this chameleonlike behaviour. There are so few occupational therapists that in each situation they are compelled to limit themselves to one or two of the 7 occupational therapy media, classified as the occupational therapy contribution by the South African Medical and Dental Council.

It is abundantly clear that if the occupational therapists cannot even adequately cover the existing basic occupational therapy programme, they will not be able to assume the responsiblity of the two additional programmes unless there is a radical increase in the quota of occupational therapists. I submit that this lack of posts is also partly responsible for the fact that occupational therapists have not up to the present time, been able to develop adequate preparation and evaluation for employment programmes.

A prerequisite, therefore, for the institution of these programmes, would be the creation of additional posts and facilities for their implementation.

Content of Evaluation and Preparation Programme:

The preparation and evaluation for work programme (medical work fitness programme) is specific and quite separate, it is concerned with the restoration or stimulation of the handicapped child's creative ability or motivation for work. It has been proved over and over again that intensive treatment/education programmes too often result in an over treated, unmotivated child.

Physical development precedes and stimulates every other facet of the child's development. Thus if the child, through physical disability, should experience discomfort, failure and endless frustration in his attempts "to do" things he will quite understandably and in self-defence tend to withdraw, and to assume a passive non-participating role.

In fact, as a result of his feelings of anxiety and of failure, which the child associates with effort, he almost inevitably builds up a resistive, actively negative, attitude towards task fulfilment.

It would be the purpose of this programme to counteract or prevent the growth of this negative pattern of behaviour. This will be done by providing the child with graded opportunities to participate in creative and independence activities, leading to recreational, social, and ultimately work related activities, the latter chosen to represent each of the relevant sociological areas of work.

The special contribution of the occupational therapist in this programme would thus be to stimulate the child's desire to participate actively in activity, to make it possible for him to do so, and to select those activities in terms of norms graded in respect of his developing psychical (psychological and spiritual) ability, and his residual and recovering physical ability.

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You all know that if this statement is not to remain just so many words, the programme will require the interaction of all the members of the education/treatment team. In fact I envisage this programme as the meeting ground of all disciplines and to succeed, the norms and principles elicited in this programme will overflow into all the other situations.

However, the programme will have to be structured and implemented by a particular member of the team, and I believe that this can only be the occupational therapist because it requires the combination of skills which together form occupational therapy.

Primarily a thorough knowledge of the child as a total developing being, the ability to understand, assess and treat physical and mental pathology and an ability to analyse and use the content of activity to lead the child to work readiness at his own level of ability.

I present a scheme which was developed at the Pretoria College of Occupational Therapy, and which we have used with success with cerebral palsied children with primary physical pathology at the Orthopaedic Hospital and children with emotional disturbances.

I will not discuss the treatment implications which includes the nature of the child's interaction with material, people and situations and the quality of his expressive response, task fulfilment and task grading at each stage of creative ability.

These are complex concepts which obviously cannot be covered in a casual lecture of this nature. However, they form an integral part of the three year training presented at our College.

STAGE OF PSYCHICAL DEVELOPMENT.	LEVELS	CREATIVE PARTICIPATION.	EMPLOYMENT POTENTIAL.
TONE		Predestructive Destructive	Total institutional care.
SELF-DIFFERENTIATION	Therapist directed.	Destructive	One step hobby-type activity
	Patient directed.	Incidental	low productivity non-profitmaking Home occupational
SELF-PRESENTATION	Therapist directed.	Incidental	Ditto
	Patient directed.	Explorative	Ditto
	Therapist directed participation	Explorative	Sheltered workshop 50% productive.

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PARTICIPATION	Passive participation	Explorative	Sheltered workshop
	Imitative participation	Imitative	Sheltered workshop Repetitive open labour market
	Active participation	Originative	Open labour market
	Competitive	Product-centred.	Open labour market Study Possible professional training
CONTRIBUTION		Product-centred	Ditto Professional + technical training Graduate+ post-graduate level
COMPETITIVE CONTRIBUTION		Abstract	Research and function at highest level.

I believe that the specific medical work fitness programme involving work preparation and evaluation would give a clear indication of the appropriate placement area for each child. These could be further study at a high school and University, trade, placement in a special progressive or terminal sheltered workshop, Home industry, or job training.

This programme would, by achieving this, give meaning to the handicapped child's future, and validate the long and expensive educational/treatment programmes offered by special schools.

Job Training Programme:

Additional Programme No. 2.

I have defined this programme as one which will absorb those children who are unable to benefit further from academic educational programme as offered by the particular school.

It is envisaged that this programme will consist of training these selected children to execute a single job, which will be correlated directly with a job, which it is known that they will have the opportunity in the open labour market, special placement workshops or which may lead to remunerative home employment, or at the lowest level, provide a satisfying hobby activity.

It is a very serious matter to remove any child from the obvious advantages which are implicit in what we understand under "Schooling". Schooling involves, apart from the psychological, pedagogical factors of adult concern, the possession of knowledge and skills associated with each "standard" of education, (particularly with the landmarks such as Std. VI, school leaving and matriculation).

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Therefore the introduction of job training programmes cannot be undertaken lightly, it requires responsible investigation, and systematic, practical research.

It is obviously not possible to do more than mention a few factors under the following headings:

1. Reasons for the introduction of a job training programme.
2. Method of selecting children for the job training programme.
3. Content of programme.
4. Placement out of the job training programme.

1. Reasons for the Introduction of a Job Training Programme

Because of the additional burden which multiple physical handicap brings to the Cerebral Palsied child, the Education policy should permit the children who do not have the academic capacity to benefit from the three R and school syllabus facets of the education programme to channelise his efforts into a training programme which will correlate directly with what life will hold for him after he leaves the School.

It seems logical that in cases where it known that intellectual or physical problems, will preclude an individual from using classroom skills, that he should use his time and energy to learn skills which will enable him to live a productive, satisfying, and where possible, financially independent life. It also seems logical that this channelisation should occur as soon as it can be known, with a reliable degree of certainty, that a child would benefit more from a job training programme than a school programme.

2. Methods of selecting children for the Job Training Programme:

I believe that when a medical work fitness programme (programme one, designed to prepare and evaluate each child) is introduced into a Cerebral Palsy Centre, then much of the information required to make the decision to transfer a child to the job training programme will emerge out of the concurrent treatment/evaluation procedures.

Moreover, I believe that the existence of a medical work fitness programme in a centre will orientate all the other treatment education programmes towards work or its closest equivalent and in so doing will orientate the personnel of the centre to observe each child in terms of these norms which will, in the process, become more defined.

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The information gleaned about a child's creative and work ability in programmes, must, if it is to succeed, infiltrate all other programmes and apart from giving direction to therapy and education, it will give direction to the "evaluation" of each child in every area. This information will accumulatively "Chrystallise out" a decision regarding the job training programme.

I believe that transfer to the job training programme should not be a "final break" decision, but should rather be based on more than one exposure to the "job training" programme. It may happen that a child may, through negative associations based on repeated failures in the classroom, become temporarily passive, non-receptive and mentally immobilised. This child, if exposed to other demands and stimuli, may become sufficiently re-stimulated to respond to renewed classroom demands.

Thus I think on the basis much like "a change is as good as a holiday" a few exposures (of sufficient time duration to be meaningful) to the job training programme and school programme respectively will lead to final confirmation of a decision one way or another.

The information gleaned about each child in the medical work fitness programme, plus the information contributed by each member of staff handling the child, including, of course, the psychologist for his specialised contribution, and finally, if necessary, information sought by actual exposure to the job training programme, followed by re-exposure to the school programme, should make it possible to decide at the earliest time which children would benefit maximally from a job training programme.

3. Contents of Programme:

(a) In preparing the child to perform the relatively simple and intellectually undemanding tasks, the surrounding qualitative factors of relating with materials, people and environment must be taken into account.

(b) There is little merit in instituting practical programmes if one is not, by doing so, going to ensure that the child achieves more success in and benefits more from, the practical situation than he did in the academic programmes. If a child merely substitutes failures in performing a practical job, for failure in reading, writing or arithmetic, nothing will have been achieved.

(c) The job training programme must relate to the child's future. Nothing will have been achieved if the child, as a result of this job training programme, is not able to live a more meaningful and productive life, than if he had not had this training.

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(d) Job training programmes must be meticulously planned and graded to build on the information gleaned in the medical work fitness programme, and to relate to a particular job, in a particular situation, in a particular Sociological work area.

4. Placement out of a Job Training Programme:

It is obvious that existing sheltered workshops cannot absorb the cerebral palsied. Therefore, it is essential that this matter receive attention so that a productive life at all levels may be offered each Cerebral Palsied Child.

However, nothing will be achieved by the haphazard erection and equipping of workshops. Workshops and their facilities must be based on statistics and must relate to medical work fitness programmes, job training programmes and work opportunities, in the community. It is hoped that every workshop will be truly transitional and that it will in practice allow not only for easy progression from one level of productivity to the next, but that it will, in fact, provide the stimulation and training which will utilise and upgrade each child's maximal residual capacity to work.

With the present lack of work preparation/evaluation facilities, there can be no real work prognostic procedure and without placement opportunities there would be little purpose for it, and I venture to suggest that without such a programme, much of the purpose of treating and educating handicapped children, is lost.

III. ACTIVITY PROGRAMMES IN THE PREPARATION OF THE CEREBRAL PALSIED FOR EMPLOYMENT.

Miss J.M. Farrell.

May I take this opportunity to express my appreciation to the National Council for the Care of Cripples in South Africa for its part in making these six months working with you in this country possible. It is a pleasure to see so many people here today whom I have already met, and to be able to thank you for making my time in the various parts of South Africa so pleasant and rewarding.

My experience with the cerebral palsied comes from working with those who have just left school, and are having difficulty with independent living, and also with those adults who, having remained at home unoccupied for a number of years, are seeking to gain greater independence.

The Commonwealth Rehabilitation Service in Australia has had quite a degree of success in bringing quite severely disabled cerebral palsied adolescents to a level of function enabling employment following discharge from school. Some patients, despite treatment in the centres, have only been able to manage employment under sheltered conditions.

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