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Planning for your cerebral palsied child's future:
educational needs

Jennifer Chalmers

Paper presented at the third symposium on cerebral palsy
Singapore 1989
When I was asked to present this paper I asked myself "How many students with Cerebral Palsy are there at N.U.S. or indeed at any other Tertiary Institution or Junior College?" In an attempt to find the answer, I tried phoning the registrars and public relations officers of several of these institutions to ask whether physically handicapped wheelchair bound students were accepted in any programmes and whether there were facilities such as ramps, wide doors, hand rails and toilet provisions. I struck a very polite blank: "Just a minute I'll put you through to .....", "Could you please phone this extension .....", "May I take your name and phone number and we will call you back", "That is dealt with by .... but he's not available just now " I still don't have my answer but I suspect there are very few students enrolled in tertiary programmes in Singapore. This need not be so.

In New Zealand where I come from tertiary institutions are now required to make physical provisions for and access available to disabled students. I personally know two physically disabled students, one on crutches and the other wheel chair bound who attend Auckland University and another two women with cerebral palsy who are teachers, one working with physically disabled children and the other with a normal class.

How can this be achieved in Singapore? One answer is through Parent Advocacy. What is required is a heightening of public and political awareness of the needs of the disabled and allocation of resources to improving physical, financial, educational and post-school training provisions. In countries which have legislated to provide for the needs of disabled people, great strides have been made and doors opened to disabled people. From developments over the last 2 years here in Singapore, largely arising from recommendations by the Advisory Council on the Disabled, it seems this country is progressing in the same direction. While there are other advocates for the disabled, it is mainly up to parents to take the initiative in ensuring that their child's impairments and disabilities do not handicap them unnecessarily. It is parents who must take responsibility for procuring appropriate support and services for their children so that they are able to achieve their potential. They must do this through public advocacy and by actively working to provide for needs either by their own efforts or by seeking quality programmes.
Remember this: A person may have an impairment or a disability but they are not handicapped until they encounter a problem which cannot easily be surmounted. So, a child with Cerebral Palsy in a wheelchair becomes educationally handicapped when he is refused admission to a school because there are no ramps or wide-doored toilets, or because the Principal is not receptive to the idea.

Do not settle for less than the best for your children. Do not allow impairments and disabilities to become handicaps. Not all children with Cerebral Palsy can qualify for degrees nor can all so-called normal children, but do not let your children be condemned to a life of limited educational opportunity and narrow horizons just because they have a physically disabling condition. As you know Cerebral Palsy is neurologically based but does not always manifest itself in both impaired physical and intellectual functioning. Many children given adequate support can make their way within the general education system. For others, however, there is more involved than responding to the obvious physical impairment. As well as their physical disability there is often an accompanying learning difficulty requiring specialised diagnosis and special school teaching. Therefore, educational planning for a child must be carried out on an individual basis as must be the providing of appropriate developmental experiences.

There are however some tasks which are common to parents of children with cerebral palsy especially if they wish to maximise the life potential of their child and ensure they develop in a positive, encouraging environment. The following tasks are adapted from suggestions made by David Mitchell (1983):

1. **Parent Tasks in Infancy**

1.1 Deciding whether to pursue intensive medical care where the new infant's life is at risk.

1.2 Deciding whether to keep the child or to seek institutionalisation, adoption or a fostered placement.

1.3 Accepting the reality of the handicapping condition.

1.4 Understanding and coming to terms with one's reactions to Cerebral Palsy.

1.5 Comprehending the nature of Cerebral Palsy, its causation and developmental possibilities.

1.6 Maintaining or enhancing one's usual self concept.

1.7 Establishing a positive loving parenting relationship with the infant.

1.8 Understanding and coming to terms with the reactions of family, friends and associates.
2 Parent Tasks in the Pre-school Years

2.1 Making contacts with other families with cerebral palsied children.
2.2 Becoming familiar with and accessing appropriate support services.
2.3 Establishing useful working relationships with particular professionals.
2.4 Coping with the reactions of the broader community.
2.5 Becoming familiar with the needs of cerebral palsied persons and their families.
2.6 Acquiring advocacy skills.
2.7 Establishing a 'balanced' family and personal life which includes the cerebral palsied child.
2.8 Developing competence in facilitating the cerebral palsied child's physical development.
2.9 Coping with the day-to-day tasks of caring for the cerebral palsied child.
2.10 Providing a stimulating learning environment.

3 Parent Tasks during the School Years

3.1 Investigating schooling options and assessing their suitability.
3.2 Participating in decisions relating to educational placement.
3.3 Establishing a working relationship with professionals (including teachers) to ensure continuity of appropriate in-home and out-of-home programmes.
3.4 Accepting prolonged dependence of the child, but fostering independence.
3.5 Helping the cerebral palsied child and the community to adapt to each other.
3.6 Helping the child understand his or her cerebral palsy.
3.7 Compensating for deficits in experience which could handicap the child and limit his/her school progress.
Parent Tasks during late Adolescence

4.1 Accepting that the cerebral palsied person has a right to maximum self determination while at the same time recognising dependency needs.

4.2 Understanding and accepting the cerebral palsied person's possible need and wish for close and enduring relationships outside the family.

4.3 Accepting that the cerebral palsied person may want to live outside the family home.

4.4 Becoming familiar with legal rights of persons with cerebral palsy.

4.5 Providing support for and participating in decisions relating to tertiary education, vocational training and work placement.

4.6 Ensuring satisfactory future provisions for the cerebral palsied person after one's death.

An important task of parents at all levels of their child's development is planning and providing appropriately for a child's present and future educational needs. In doing this parents should keep in mind three key principles: Individualisation, Normalisation, Augmentation.

1 Individualisation
Cerebral Palsy is an umbrella term which subsumes a range of conditions within which children differ markedly in their needs so it is very difficult to generalise about educational implications of the disability, rather an approach should be adopted in which educational services provided should be dependent upon a systematic analysis of each child's behaviours and needs. The parent needs to seek that placement which is most suitable for his child.

2 Normalisation
In terms of lifestyle provisions and educational placement decisions a parent ought to seek the environment or setting which is the least restrictive possible that is, one which does not handicap the child unnecessarily and at the same time is the most normal possible based on his needs and abilities.

3 Augmentation
The parent should do what he/she can to support the child in his/her learning environment. This usually means providing extra support of a physical, experiential, emotional or educational nature to help compensate for any handicapping conditions which the child is exposed to.
In real terms this means the parent ought not discount the possibility of mainstreamed placement, tertiary education or even open employment. Instead they should consider all possible alternatives at all levels from early intervention to secondary and post secondary education and in terms of occupational training and placement. What they must seek is effective service delivery from birth to adulthood.

The full range of alternatives at each age level needs to be considered. Placement decisions must relate to whether the child will benefit maximally from the environment and experiences provided and not be handicapped unnecessarily by it physically, socially, emotionally or in academic learning terms.

In sequence from most closed and restrictive to most open and normalised placement the alternatives during early pre-school to tertiary and post-school years are as follows:

**Restrictive**
- Residential/Institutional care
- Home/Family care
- Special Day Care Center
- School or Unit for Multiply Handicapped children
- Special School for Cerebral Palsied children or Training Unit/Workshop for Physically Handicapped people
- Special Satellite Unit in normal school

**Open**
- Mainstream placement in normal school or open employment

In terms of movement from one level to the next, as far as possible the principle of moving the child towards the more normal open environment as soon as he/she is prepared and ready to cope with it should be followed - i.e. placement in the restrictive or narrow environment should be for the purpose of developing those pre-requisite skills necessary for more open placement later on.

What else can parents do to help individualise, normalise and augment the educational and general development of their children? The school teachers or supervisors of programmes he/she is enrolled in cannot be expected to do everything. As I argued earlier parents must be active advocates who individually or by joining together as a group push for and acquire the necessary provisions at both the micro level and the macro level. It is the parent who is able to pay one to one attention to the child's needs. The parent should try to compensate for the child's disabilities by making sure communication and physical aids and other necessary assistance are provided. They also ought to try to increase and maximise the learning opportunities the child experiences to prevent the disabilities from becoming life long handicaps.
Some examples of the type of learning environment the parent should provide during infancy, in the preschool years and while the child is of school age are proposed below:

1. **In infancy** do not wrap the baby in cotton wool and shelter him or her from the world. In order to learn the baby needs:

   - propping to see
   - people and things to look at
   - voices and sounds to hear
   - tactile and sensory experiences
   - motor experiences which develop physical skills
   - people to talk to and who talk to him
   - toys to play with
   - opportunities to explore his/her world

   and most important of all, responsive parents who provide the love, care and attention necessary to develop positive self-esteem.

2. **As a pre-school child** the child with cerebral palsy needs all those educational and developmental experiences other children have and need such as:

   - outings with the family like picnics, rides on buses or MRT, shopping trips, visits to people's homes, birthday parties, etc.
   - play experiences, for example water and sand play, blocks and constructive toys, painting and drawing, dolls, cars, trucks and puzzles
   - picture books shared with and stories read to him
   - social experiences with other children both handicapped and non-handicapped. This may include attendance at both an early intervention programme to help provide for special needs as well as attendance at a pre-school which provides a normal social and learning environment

   encouragement and a need to communicate with people. If expressive language and speech development are delayed speech therapy, signing and even communication boards should be introduced. At the same time effort to develop receptive language must be made by talking, questioning, explaining and generally maintaining a high level of interaction with the child

   - to assist independent mobility and provide physical support the child may need specially designed seating to hold him upright and free his hands for manipulative and exploratory play, a low trolley to lie on and push around, a walker and a baby buggy.

3. **At school** whatever the placement made, special school or mainstream, the child must experience success and doing things for himself. This avoids development of "learned helplessness" and promotes a feeling of "I can" that is most necessary to healthy self concept development. In order to gain access to a wide range of school facilities and participate in and benefit from most school activities the child needs placement in an environment where:
independent mobility is facilitated by traditional as well as motorised mobility aids and by ensuring that access to classrooms and facilities like the library and toilets are possible. Provision as appropriate of ramps, handrails, widened doorways, and space for storage of specialised equipment and furniture is essential.

- Communication assistance is provided for children who cannot use pens and pencils. Items like electronic typewriters and word processors must be regarded as standard equipment and for those with speech difficulties the most suitable rather than the cheapest of the standard or electronic communication devices needs to be selected in order to maximise communication efforts. This will necessitate training in the selected communication system for both the child and his/her teacher.

- Curriculum adjustments are made where necessary. Although the child should, as far as possible, participate in all curriculum areas and extra curricular activities some programme modifications may need to be made in PE, art/craft and technical subjects. However, provision of teacher aide or volunteer support can open the door to many experiences previously considered beyond the cerebral palsied child.

- Social acceptance is experienced. The cerebral palsied child has the same need for peer and adult acceptance as any other child if he/she is to develop to his/her full potential in a social and emotional sense. Studies indicate that integration does not necessarily result in social acceptance of the child. The physical disability may make it difficult for the child to establish effective social relationships (Anderson, 1973). However, one study showed that where the non-disabled children were prepared in advance for the integration there was greater social acceptance of the disabled child (Allen, Wilton and Ballard, 1978).

- If the child is mainstreamed, the principal, teachers, other pupils and parents are receptive to the placement of the child. The principal if he is sensitive to special needs can project a positive attitude to both staff and pupils. Teachers will need appropriate skills, knowledge and attitudes with advance access to expert advice on management of the condition in the classroom, background information on the child, confidence that they can cope and a reduced work load. Although an attitude of willingness is important teacher training in education of pupils with special needs is crucial. Pupils require preparation to accept a special child. This may mean social awareness and skills development and a period of gradual familiarisation with the special child and his needs. Other parents will need to be reassured that the integration of a physically disabled child into the class will not disadvantage their own child in an academic sense but will be of advantage in a social sense in terms of developing social awareness, responsibility, tolerance and empathy.
- there is individualised programme planning. In order to provide special or regular school teachers with information about the children in their class and to help monitor their progress systematically individual records which contain detailed information about the child's health and physical condition, current and relevant past treatments, as well as providing a cumulative record of school progress and social adjustment need to be initiated early. Perhaps this could be started by parents in consultation with the pediatrician and then be maintained by all those working with the child. These records can form the basis of discussions between parent and teacher or teacher and speech therapist, etc. They should be available with parent permission to all professionals and agencies working with the child.

- supplementary support is provided as necessary to the child in the form of speech, occupational or physio-therapy and remedial teaching. As far as possible this support should disrupt the regular school programme as little as possible. For mainstreamed children it should take place out of school hours so the child enjoys maximum exposure to the total school programme.

- there is close co-operation and communication between home and school. Parents should become "friends of the school" actively supporting it in whatever way they can whether by attending functions, helping with class outings or projects, supporting fund raising drives or helping make classroom materials. On the other hand the school should encourage active parent involvement by informing them about proposed new programmes, advising them how they can assist in their child's education, inviting them to participate in various activities and reporting regularly on the child's progress.

In order to achieve the ideal educational conditions outlined above additional resources are needed in Singapore in terms of finance, trained personnel, up to date equipment, etc. Although improvements in government funding are currently forthcoming, parents and other advocates for cerebral palsied children must continue their efforts to provide not only material support but also to promote a social and emotional climate in which it is accepted that disabled people have the same rights of access as other people to education and training which develops them to their full potential whether this is at university level for the intellectually able or in a special day centre for profoundly multiply handicapped people.
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