

Children with brain damage

Introduction

In many countries, poliomyelitis is still one of the major causes of disability. However, if we look at all categories of disabilities, we must conclude that disability by polio is definitely not the only disability that counts. We all know about deaf and blind children, children with physical deformities, children with amputated limbs, all children who deserve our attention and assistance. For children with physical disabilities 'something' at least can be done,



provided the (financial) means are available: treatment, surgery, appliances, education, etc.

But, there are also many children with some kind of brain damage. For these children surgery is of almost no use and there is rarely any medicine that will help. There is no prosthesis or electronic aid that will make the brain faster or more intelligent.

With help and training, some children who have been considered retarded prove to be quite intelligent

This newsletter specifically deals with questions on how best we could help these children. It is important to know that about 60% of the children with brain damage have only a slight mental handicap or none at all. Often, people think that children with serious mobility impairment or speech problems have a mental disability. But this is by no means always the case. Two main categories may be differentiated:

- a) *children, affected by slight brain damage may attain a fair degree of independence*
- b) *children, affected by a more severe degree of brain damage have far less possibilities of development -but for instance , they may learn to sit if provided with an adapted sitting device and sometimes may be taught, with much effort, to eat by themselves.*

With both categories the brain damage cannot be cured, but efforts should be made to optimally use the possibilities that are available. Essential herein is the role and guidance of the parents. You can play a very important role by listening to the family and helping the



parents to see their special child in a more positive light. The family counselling is very important, even more so than with children who are 'only' physically disabled. How do the parents feel about their special child, are they aware what is 'wrong' and what has caused the child to become what he is, do they know how to handle the child, do they accept the child?

The baby can be so limp that her head seems as it will fall off. Or she may suddenly stiffen like a board, so that no one feels able to carry or hug her. Body stiffens like a

Every child and every situation is different. You will come across parents who look after their child with much patience and love. On the other hand, you will meet parents who hide their child out of fear or shame. For them, their child is a heavy burden. Therefore, it is important to focus your attention on the overall family situation first. The following questions will be of help to you:

- Do the parents and the other children understand what is wrong with the child?
- Do they expect the child to make a full recovery?
- With which parent or brother/sister does the child have a special relationship?
- Can the parents (financially) maintain their family?
- Can the family cope emotionally with the child's situation?
- How would the parents like to improve the quality of their child's life?
- Does the family get the support from the neighbourhood?

It is important not to raise any false hope with the family. They should know that there is no 'cure' for their child. Their child's development will always be slower and different than that of their other children. **But more important still, is that the parents should learn to discover what their child can do, rather than emphasizing what he/she can't do.** Please discuss with the parents that special care and attention can improve the quality of their child's life.



Child: Granny i'm thirsty
 Granny: There's water in the jug. Help yourself
 Granny: I put the jug close to the ground so that you can try!
 Child: I can't please granny!



Child: Look granny! I did it!
 Granny: I'm proud of you, pepe!
 Granny: Now please bring me some firewood.

Special care within the family

The special care and assistance for these children must come from where this also occurs: in their families. Children with brain damage need much more of what every child needs: love, attention, being talked to and listened to, being praised when they learn something new, hearing songs sung by mother or an older sister, being helped by big brother to put their shirt on not just once or twice but maybe 40 or 50 times with lots of patience and encouragement, being included in family outings, weddings, special occasions, being given every opportunity to try out new experiences, being encouraged to do things for themselves, even though they make a mess the first ten times, until they have accomplished it.

The Liliane Foundation aims at reaching out to non-institutionalized children with disabilities. To be able to do this, we work with people like you, local mediators, of whom we have about 1350 located over many countries. Together with you, we look for the best solution for the child, making use of the existing facilities in your area. It is our policy to direct assistance to the family situation: the child is foremost a member of his or her family.

How can you help?

To give extra care and attention to the child with brain damage is simply not enough, unless of course, the family knows how this care and attention should be directed. The aim should always be that the child should continue to learn something new and consolidate what he has already learnt. Children with normal ability learn so much and so fast in their early years that their parents are not even aware that the child is learning. Not a single child begins talking automatically. The child begins by trying out different sounds. He imitates what he hears and combines sounds together to form small words. He listens to words used in the family and tries to use these words again. This learning process goes on throughout childhood.

1. More...

The learning process for the child with brain damage is a much slower process, especially in the case of mental retardation. The child needs to spend more time trying out different sounds with encouragement from mother or brother. More time to play imitation games with older sister or grandfather. More praise as he understands what is said to him or he uses a word correctly. Much of what needs to be done with the child is already familiar within the family, but it needs to be given much more time, more repetition and more persistence. Things that the ordinary child learns after being shown once, the special child may need to practice 40 or 50 times. But it can be done - within the family bond.

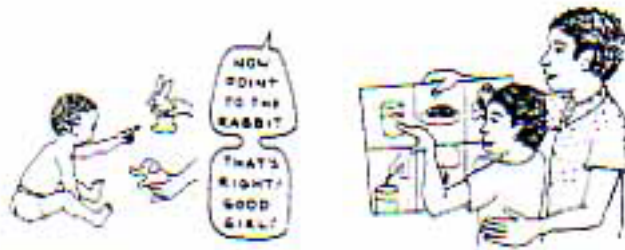
2. Referral

As a mediator you can help the family with professional advice. When a child behaves strangely or learns very slowly, it is important to have a full check-up for hearing and visual ability, by an expert. Even in western countries, some children are still labelled as 'mentally retarded' or 'problem behaviour', when in fact the original problem is one of hearing loss or poor eyesight.

3. Role mediator

As a mediator you can play a very important role in the lives of these families.

It is often already an enormous relief for them to know that somebody is available, a friend who is willing to sit down and listen.



When the time is right, you can give the family some background information about the disability of their child and what they can expect for the child's future. If you do not know this information yourself, you can consult someone who does (a nurse, a doctor or a therapist).

Now point to the rabbit. That's right! Good girl!

4. Possibilities of treatment

Counseling, listening and observation is of utmost importance. In some cases you may feel that you have to look for possibilities to get the child admitted in an institution for permanent and specialized care. Also, if there is a possibility to get the child temporarily admitted to a day-care centre for functional training (such as ADL - Activities for Daily Living - training) you should do this.

But in reality the majority of these special children will always remain at home, within the care of the family.

The nature of the disability of the child and the facilities available in your area strongly affect the possibilities for treatment. For instance, in some regions special education or day-care centres are available where basic skills (eating, washing etc.) can be taught. Maybe there are physiotherapy facilities in the vicinity where sitting, standing or walking devices can be purchased from a workshop.

If a child must constantly lie on the ground, could something be done to help him sit with the help of a simple sitting device?

When the child can be given physiotherapy there are two important aspects:

- the exercises that are done should have an obvious aim. This aim is mainly the improvement of a certain function like eating, sitting, walking, etc.
- it should be possible to do the exercises at home also, therefore, they should be taught to the parents as well.

It is important to avoid going on with certain exercises endlessly and out of routine, if no clear aim is set.



Instead of always feeding her yourself, look for ways to help her begin to feed herself.

Be very reserved with medicines and operations. We would advise you not to give medicines specifically in the case of spastic children, unless they are also epileptic or if medicines are required for reasons other than spasticity.

In general, we advise against surgery for spastic children, unless the child is able to walk a little already and if surgery would improve walking. A reserved attitude is also required in the use of orthopaedic appliances (particularly callipers). The main criterium is that interventions are only justified if they lead to functional improvement. When in doubt, ask for a second opinion. You may also write to us, then together we can reach an answer.

5. Small-scale income-generating projects (IGP's)

If the family is poor, it means an added economic burden in an already difficult situation. The mother will not be able to go out to work because she constantly needs to look after her child. It also happens quite frequently that children are kept locked up in a room during the day because the mother is forced to go out to work in order to feed the rest of the family. In these cases you can apply for help to the Liliane Foundation for small home-based Income-Generating Projects (IGP's) for the family. The proposal for an IGP may differ from country to country and from area to area. This is easier said than done. In order to ensure that the IGP becomes a success, we have the following criteria:

- Is the project in line with the interests of the parents?
- Can they, together with you, prepare a good plan?
- Is there any need for their services or products in the immediate surroundings?
- Can the parents also invest some money in the project?
- Are the parents willing to save up monthly sums to serve in due time as new investment in the project?
- Is the child in any way involved in the project?
- Are the parents motivated to work?
- Do you have time to counsel the project?



Arrow 1: board or plywood leaned against the table

Arrow 2: strap (if needed)

Arrow 3: wedge made from cardboard, foam, or other material

Another aim of the IGP will be to save up money for the child's future, for the time when his parents won't be there anymore. Then one of the other children should be willing to take over the care.

Examples of an IGP are: a small shop, a cow or a few goats, a sewing machine or a tailoring machine. It might also be a chicken project, a shoe or radio repair shop, a typewriter and so forth. It all depends on the local circumstances and possibilities.

Very often an IGP implicates that there must be a vocational training first, or at least some informal basic training, e.g. on how to keep simple accounts, how to care for a cow, to learn sewing or tailoring. The mediator plays a crucial role in discussing a proposal with the family and in organizing the necessary investments, guidance and follow-up.

By enabling one of the family members (in most cases the mother, but it could also be a brother or sister) to raise some additional income, the child will benefit as well. The experiences of mediators teach us that counselling, therapeutic advice and possibly an IGP can improve the living conditions of special children significantly.

Finally

Just like the fact that there are never two children who are exactly alike, this also certainly applies to children with brain damage. Should you wish to have more information about the cause and background then you may write to your correspondent and the information required will be sent to you - unless you are already in possession of David Werner's book 'Disabled Village Children', of which one chapter is especially dedicated to this issue.

A newsletter on the care for these special children can never be complete. We would like to hear about your experiences, so that we can refer to this important issue later. One of our mediators has chosen the slogan "to make the impossible, possible", especially for this category of children. It's with much patience and especially much commitment from the parents that help these children experience that they also count.

We wish you much inspiration in your work.