

Mentally retarded and brain-damaged children

On the front page a story is told about a child in Africa who is disabled by polio. 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, about children with physical deformities, about children with amputated limbs, who also deserve our attention and assistance. For most of these physically disabled children at least 'something' can be done, provided the (financial) means are available: treatment, surgery, appliances, education, and etcetera.

There are also many children who are mentally retarded or brain-damaged, or who behave in strange ways. For these children there is no surgery to be done. There is rarely any medicine that will help. There is no prosthesis or electronic aid that will make the brain work faster or more intelligently.

Special care



A group of us neighbors will take turns each afternoon in caring for Maria, so that you can have a rest and get other things done.

The special care and assistance for these children is to come from where they already are right there in their families. Mentally retarded children need much more of what all children need: love, attention, being talked to and listened to, being praised when they learn something new, hearing songs sung by mother or 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 if they make a mess the first ten times, until they have learnt how to do it.

The child within the family

The Liliane Foundation aims at reaching non-institutionalized disabled children. To be able to do this we work with people like you, local mediators, of whom we have over 500 now in many countries. Together with you we look for the best possible solution for the child, making use of the existing facilities in your area. Our policy is to work family-oriented: the child is first of all a member of his or her family. It's not easy to have a mentally retarded child in the family. Often, families may try to hide the child who is "different", who learns very slowly, who cannot do the things other children of that age can do. People sometimes say: "we do not know about such children here, we hardly ever seen one.

That already indicates the problem, because they are there, very often hidden from the outside world. In other cultures people have a much more positive way of looking at it. They say "God knows that this special child will need extra care and attention. He provides the family with special gifts enabling them to give even more love and attention. That family should be honoured by their community, because God entrusted to them this child with special needs". Even where such a positive view is not held, many families with a mentally retarded child have looked back on their life and said "We learnt a great deal from this child. We now understand something deeper about the meaning of life. This child taught us something new about love".

How can you help?

To give extra care and attention to the mentally retarded child is not enough, unless 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 or she has already learnt. Children of normal ability learn so much and so fast in their early years, that many parents are not even aware that the child is learning. They may think that, at a certain age, the child somehow automatically begins to speak. But in fact, the child begins by trying out different sounds, imitating what he hears, putting sounds together to make small words, receiving encouragement from older people, listening to words used in the family, trying to use these words again. This learning process goes on throughout childhood.



Dennis Lagradente from the Phillipines suffers from braindamage due to TB. He cannot walk or talk, but he can hear and understand. His special chair means a lot to him. Our Mediator is further helping him and his family with regular check-ups, medicines, nutrition, special toys and exercises that can be done at home and also with a piglet-selfsupporting project for his father.

More...

The learning process for the mentally retarded child takes place much more slowly. The child needs to spend more time trying out different sounds with encouragement from mother or brother, more time playing imitation games with older sister or grandfather, needs to get more raise every time she understands what is said to her or uses a word correctly. Much of what needs to be done with the mentally retarded child is already within the experience of 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 over a month. But it can be done and it is the family who can do it.

Does the family have time?

Just as these children need extra praise and encouragement, so their families will also need extra attention and encouragement, because it may not be easy to find time to do what is needed for the special child. You can perhaps help the family to understand that if it gives time now to help the special child learn ADL (Activities for Daily Living), like washing, toileting, dressing, eating), there will be very big savings of time later on. If they do not help the child now to learn ADL for himself, someone will have to give time to do these activities with him for the next 60 years.

Note: We acknowledge the valuable contribution of Mr. Mike Miles to the above article.

The mediator

As a Mediator you can help the family to benefit from any professional advice that may be available. When a child behaves strangely or learns very slowly, it is important that it should have a full check-up of hearing and visual ability, by a trained examiner. Even in European 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, all of which could have been helped years before if they had been noticed. However, apart from getting any professional advice, you can play a very important role in just listening to the family and helping them to see their special child in a more positive light.



Suggestions

In short, these are some suggestions of what you might do:

Even more than with children with "only" physical disabilities, family counselling is important. How does the family feel about their special child, do they understand what is "wrong" and what caused the child to be like this, do they know how to handle the child, do they accept the child?

Discuss with the family what could possibly be done for the child to improve its physical and/or social condition. Be careful not to raise expectations too high, but raise some expectations. Concentrate first on what the child can do, rather than a list of all the things she cannot do.

Discuss with the parents that special care and attention can improve the quality of the child's life.

Is referral to a hospital, therapist or doctor possible? Can the child be ADL-trained (Activities for Daily Living such as washing, toileting, dressing, eating)? Is it possible to somehow communicate with the child and/or play with simple toys? If for instance the child is always lying on the floor, could something be done to let the child sit with a simple sitting aid?

Role mediator

As a mediator you can play a very important role in the lives of these families. It is very often already an enormous relief for them to know that somebody is available, a friend who is willing to sit down and listen. When time is ready for it, you could 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 these things yourself you might consult someone who does (a nurse, a doctor or a therapist).

Counselling, 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 only (such as ADL-training) this should be done.

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

And if the family is poor this means an added economic burden in an already difficult situation. The mother will not be able to go out for work because she constantly needs to look after the child.

Small-scale income generating projects (IGP)

During a recent working visit to India, I met quite a number of special children who were locked up in a room during the day because the mother was forced to go out for 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) for the family. The proposal for an IGP may differ from country to country and from area to area. In India for example, it is very often a small window-shop, a cow or some goats, a sewing or tailoring machine. It might also be a chicken-project, shoe or radio repair, typewriting and so on. It all depends on the local circumstances and the possibilities that are there.



Maria Rosario Corral and her mother in their little shop at home. The mother needs to stay at home to look after her child. This IGP raises the income of the family so they can meet the needs of their special child.

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 learn us that counselling, therapeutic advice and possibly an IGP can improve the living conditions of special children significantly.

Parent groups

More or less in line with what has been written about the assistance for mentally retarded and brain-damaged children, we would like to emphasize the importance of trying to organize small groups of parents with disabled children. If you assist a few families with disabled children within a certain village or area, you could consider bringing them together. It is not absolutely necessary to form groups on the basis of the disability of the child; all types of disability can be involved. In such a gathering you can offer the parents a possibility to share their experiences, their sorrow and their frustrations. It could serve as a platform to look for possible solutions and common interest. You as mediator can use the opportunity to provide the parents (or caretakers) with some basic and relevant information with regard to disabilities and rehabilitation. People could listen to and learn from each other. Priorities as felt by the parents could become clear. These gatherings could also serve as an occasion for the disabled child to meet other children and to play with each other. In case minor costs are involved, such as for serving tea and coffee during the meeting, the Liliane Foundation is willing to pay for these through you.

A child is a child

This leads us to a matter on which you, as our Mediator, can advise us. We realize that in different countries and cultures, each with its own people and traditions, there may be a difference in how people look upon their children. In most western countries parents are in the lucky position to give their disabled child the best possible rehabilitation and (special) education so the child can develop its own capacities. However, in our society of individualism, much is still to be done to improve the acceptance and integration of our disabled children and adults, so that they will have a full and equal life. In developing countries the meaning of a full and equal life might well be based on different values. We would like to avoid that we get (or have) wrong ideas about what should be done to serve the child's interest. You, as our mediator, are in close contact with the families having a disabled child at home. You can communicate the feelings of parents towards a disabled child to us. You can also tell us what is most important to them. For instance whether it is the education of a disabled child that is important or is it better to give the child an opportunity to earn money and help raise the family income. But you may also advise us on other matters, such as the different opportunities that can be given to boys and girls.

What do you think?

Bearing the above in mind, we would appreciate receiving your view on how people in your area think about children. That is if you can find the time for it. In case you have your doubts about asking a particular kind of assistance for a particular child, please communicate your problem to us. We in SLF would like to keep in touch with your views, because we are here to share with children in many different communities and cultures. Children with disabilities are, first of all, CHILDREN. On behalf of all our co-workers here, I wish you courage and strength in your very good work.

Kees van den Broek

Project coordinator