

# Involvement is more than just contribution

The role of parents or relatives in their child's rehabilitation process

## Introduction

In the contacts with mediators (i.e. by application forms and report) we stress the importance of the parents' contribution. In general everyone agrees that parents or relatives have an important role in the rehabilitation process of a child. You also write to us frequently about the trouble and efforts this requires. However, experience shows that it is not easy for parents to actually contribute. Also there is sometimes confusion about what is really meant by "parent contribution". This could refer to a financial contribution. However, this is not the idea. Although a financial contribution is always welcome, and it increases the parents' involvement, at the same time we have some more aspects in mind here.

In this newsletter we would like to illustrate this important issue with some examples. We hope this will be useful to you for further consideration. We realise that it is very difficult at times, though.



## Prathap

Prathap, a girl aged 18, lives in a rural area of India. As a result of malaria in the first year of her life her brains were damaged and she became severely handicapped. Prathap walks with much difficulty and she cannot use her hands properly. She understands reasonably well what is happening around her, although she can hardly talk.

At the occasion of the mediator's visit to Prathap's family, it becomes obvious that the parents do not understand why their daughter does not recover. "She used to be in good health!" Over the past

years all kinds of "healers" were consulted. Also the girl has frequent epileptic fits, making the parents believe that an evil spirit is putting a spell on their daughter. They love their child very much and in spite of their poverty they would do anything to have her cured.

## Tudzani

In the village where Tudzani lives people who benefited by the help of a mediator spread the word that 'something' can be done for children with a handicap. Consequently a 17 year old girl takes her little handicapped brother Tudzani to the mediator, asking for help. Tudzani can not walk and he is in a poor condition; the mediator makes an appointment to have the boy examined and some weeks later Tudzani is admitted to a rehabilitation-centre in a big city. Six months later Tudzani is discharged: in the meantime he can walk with crutches!

Some time later the girl comes back with her handicapped brother on her back: his condition got worse again and the appliances have hardly been used.

## What can we learn from this:

The two examples just described teach us several things:

- Prathap's parents are frequently seen by the mediator. It is important for the parents to stay motivated; there is the risk that the parents continue to expect eventual recovery of their child. guidance is very important here. If the mediator is not sufficiently qualified in this field, she may refer to a reliable expert. Our

advice here is to be cautious. All over the world there are people (doctors or physiotherapists) who advise operations or other treatment which may more harm than good. These people take advantage (financially-wise) of the ardent wish of the parents to have their child cured. There are even cases in which it is better to refrain from treatment, because the child's family situation is so difficult that treatment would not be functional.

- Fortunately Prathap could be treated with proper anti-epilepsy medication. Although this has led to a considerable improvement of her condition, complete recovery failed: her mental handicap remains and she can hardly walk. The parents must learn to cope with this, together with Prathap. Fortunately Prathap's father was rather good at carpentry: after being an apprentice with a local carpenter for some time, he can now, thanks to a starting capital that enabled him to some wood, earn a living for his family and even pay for Prathap's medicines himself now.
- In Tudzani's case the mediator sadly enough had no time to get to know the family situation. If possible it might be a good idea to seek co-workers who could make home visits. Such a visit would have made it clear that Tudzani's parents were not motivated to have him medically treated. After all, without the parent's involvement rehabilitation of the child is bound to fail.
- When Tudzani came home from the centre his parents found the callipers very strange; they had never seen anything like it before. After a few weeks a wound appeared on one of Tudzani's feet, preventing him to wear his callipers any longer. It is very important for parents to understand the reason why their child has to use a certain appliance and which exercises should be done. Also here applies that a home visit, in the framework of the necessary after-care, is the best way to discuss this. It also helps to take the specific living conditions of the family into account.

### **Parent groups**

- Prathap's parents have also started to cooperate actively in the organisation of a parent group. It turned out that there were six more families with handicapped children in and around their village. As a mediator it is very good to encourage the formation of parent groups. In general you can expect three types of problems in the discussions between parents:
  - a) Parents do not understand what is wrong with their child and it is difficult or impossible for them to accept that they have a child with a handicap. As a result it happens sometimes that parents neglect their handicapped child.
  - b) They have difficulty in coping day to day with behavioural problems of especially mentally retarded children.
  - c) They really worry about their child's future.
- Mediators who would like to set up a parent group and who would like to consult us please write to your correspondent here.
- Mediators who have experience with parent groups, please share your experience with us.

### **Finally**

For children like Prathap it is important to attend special education. Very often this is impossible, because there are no special schools in the area. An alternative could be a day-care centre, where children will be offered ADL training (Activities of Daily Life). It is essential again that the parents are involved as well.

*There may only be question of "parent participation" when we help the parents or family to help their child.*



Clearly the parents are responsible for their child's rehabilitation and the mediator (together with the Liliane Foundation) participates. The amount of our contribution is not that important and may range from 1 to 99%. It is only a contribution to the efforts of the parents though.

Another important point is that rehabilitation, particularly the social aspect and home care, should take place at the child's home. Regular contact between the mediator and

the family at home is vitally important. Mutual cooperation will eventually lead to successful rehabilitation for people like Tudzani and Prathap.

Once again we thank you very much for all your help.

With kind regards,  
**Liliane Foundation**