

## Participation of the parents



*An I.G.P. (income generating Project) for the family of a mentally retarded child in India. The effect of such projects is mainly on a substantial level; it is important that the mentally retarded child/youngster participates in the income generating activities at his home.*

Many books and articles have been written on the importance of local participation when activities in the community are planned. The same applies of course to the participation of parents with disabled children when one of their children is in the course of rehabilitation. We prefer not to write another long and theoretical article on this subject but rather make some short remarks: - the family should in the first place understand the disability of their child: what is the cause; what is the prognosis, what can or cannot still be done, etc. - it is important that the family recognizes the *remaining abilities* of their child. There is sometimes a tendency from a family to make their disabled child your problem. It is important to be aware of that and to make it clear

that the family remains responsible.

Once they understand, they are more likely to start accepting the child.

Your role as mediator is of course very important to help the family understand and accept. With the family you could discuss the possible rehabilitation options in your area: medical, educational, vocational, economical and social: what could be relevant for this particular child. -There should always be some sort of participation from the part of the parent's family: the how and what will differ from case to case. We trust on you as a mediator to judge as to what they might contribute: you know the circumstances of the family. In some cases there will be a financial contribution; in other cases this may not be possible but the family can contribute in time e.g. by travelling with the child or in other ways of support. It does not matter how small the contribution is, but it should always be there and it should of course be reasonable with regard to the realistic possibilities and means of the family. - Please, remember that you as a mediator always keep the overall financial responsibility. You spend the money according to the needs, and the money we send should never be given to the family. Another important aspect of family participation is the organisation of parent groups:



*An I.G.P., showing a shop at home.*

It has been proved very useful to organise meetings with parents of disabled children. These meetings are best organised in different villages and for small groups in order to avoid too much travelling for the parents. The reports we receive from mediators who are organising these parent groups are very positive in the sense that it creates much more understanding and awareness. The possibility to share feelings, ideas and problems is important for parents; moreover it is also an occasion for you to provide some education and information on e.g. health or disability topics.

### **Integrated education for children with a disability**

It is well-known that special educational facilities for disabled children are often not available. We would like to share with you the contents of a letter we received recently from someone who worked for many years in Africa:

*"Rehabilitation in school, family and village"*

Father Mtuwana enrolled his daughter as pupil of the village school. The headmaster did a step back and took a good look. Yes, he did see it rightly. That girl was blind. Sir, the headmaster spoke, your daughter should go to a special school. We don't accept any blind children here. But I am paying school fees just like the others, Mtuwana said. Still we are not allowed to admit your daughter here, the headmaster persisted. Then you

must tell me, Mtuwana said, which law prohibits her to be admitted. Indeed, there was no such law.

Well, then my daughter will stay here. Mtuwana turned round, leaving the headmaster in despair. Mtuwana was firmly determined to give his daughter an education that would be as normal as possible and therefore she should go to a normal school. Thus somewhere the first step was made to what is called nowadays integrated education for the visually handicapped. Blind children are living at home with their parents and their brothers and



*Parent meetings to discuss and share problems are also good opportunities for mediators to provide information and raise awareness in the community*

sisters. They are going to the same school as other boys and girls in their neighbourhood. We seem to rediscover that handicapped children are in the first place children and that in many cases their handicap may be overcome. A great advantage of this approach is no doubt that a much larger number of handicapped children will be able to find their way to school. After all, special institutes have only a limited capacity. Also here counts: full is full. In the rural villages in Africa there were many parents of disabled children who knew nothing of the existence of special schools. They did not know either what to do with such a disabled child. So they would keep it at home and often they would hide it.

### **In for a penny, in for a pound**

No doubt it is a big step forward if more and more disabled children could get education. Then the question arises: what will happen when these children have finished their school. Are chances equal in that case too? That question is all the more conclusive if one considers that industry has hardly developed as yet and that thousands and thousands of perfectly healthy children who have just finished school, are scrambling to conquer a place on the labour market. People promoting the aforementioned approach of education were very well aware that it is of little or no use to provide disabled children with proper education, just to let them slip away in a vacuum afterwards.

### **Village industry**

In order to equalize the chances for handicapped people to participate in the labour process as much as possible, possibilities for village industry offer sometimes opportunities. Trainings were organised ranging from village carpenter, tailor and dressmaker to tinsmith and gardener. Everything aiming to set up a "petty one-man village enterprise". More and more handicapped people turned up asking for help.



*Small Income Generating Projects (I.G.P.'s) for disabled youngsters are important. The after-care and guidance form the mediator are essential to make an I.G.P. successful. The photo shows a young disabled man repairing shoes on a market.*

Centralized facilities for training proved to be insufficient. Institutional extension was not only costly in buildings but also in personnel. Besides, every institute would soon turn out to be too small afterwards. Therefore, a training on village level was chosen, a training in the village itself. Among the artisans of the village, people went in search of volunteers who would be ready, completely unsalaried, to train handicapped men or women. And by a miracle volunteers did turn up. Now one can see in a simple far-away village a village craftsman transferring his know-how to a handicapped fellow-man. This is how, somewhere, rehabilitation started on village level. This letter illustrates clearly the relevance of this approach and we welcome your response on similar experiences or on experiences where you come to a different conclusion! The (economic) prospects

for disabled youngsters are difficult and deserve much attention as part of a total rehabilitation plan for individuals.