

The use of appliances

There are various appliances for people with disabilities. The most common are:

1. Orthopaedic appliances:
 - a. Callipers, prostheses, special shoes.
 - b. Sitting and standing aids.
 - c. Mobility aids like: wheelchairs, tricycles, crutches.
2. Hearing aids (including the very essential ear-moulds)
3. Visual aids (mainly glasses)

Many books have been written about the various aspects of appliances. We would simply like to list some of the main observations and guidelines on the use of appliances:

The leading article of this newsletter will be mainly on the use of orthopaedic appliances. Regarding orthopaedic appliances, such as callipers and prostheses:

1. First of all there are three basic questions to be asked:
 - a. How does the individual mobilize him/herself at present, for example crawls on the ground, walks but must hold one leg, walks with a limp, etc.
 - b. What are the local conditions in the area inside and around the house level? Are the local paths and streets smooth or rough? What is the path and road like to the nearest school? etc.
 - c. How would it benefit an individual to have an appliance?
2. After proper assessment it is essential to involve the disabled individual (and the family of a disabled child) in the decision making.



It is important that the family not let the disabled person be separated from daily work and activities.



Instead, look for ways to let the disabled person help as best as she can.

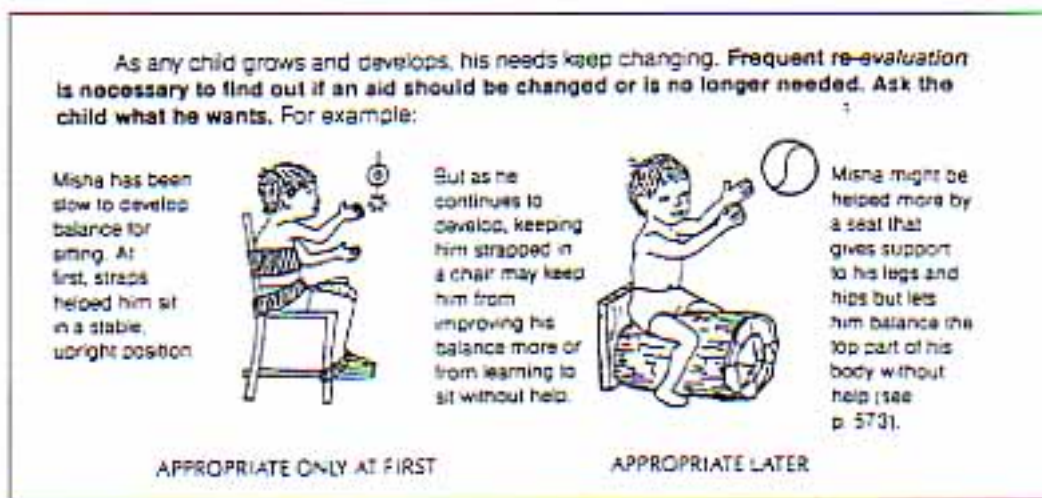
A realistic picture should be drawn with regard to the result that can be expected. To illustrate this just an example from the time I worked in Africa:

Agnes was a woman of about 26 years old. She had a severely paralysed leg due to polio and was walking with the help of a (self-made) stick while holding the paralysed leg with one hand. She was identified in her remote and rural village and brought to the hospital for a series of surgeries and a long-leg calliper and physiotherapy afterwards. The result (after months) was that she walked much more difficult than before. The worst of all was that she was now unable to carry water and wood on her head, because she was missing the balance she had developed before; she had three little children to care for. She was very unhappy of course with this "result" and she told us that she had understood that she would get "new and normal" legs after the surgery. The conclusion of this story is obvious!

If disabled children are involved it is very important to have the cooperation of the parents; they should agree and understand the relevance and they should also be involved in the after-care. Besides this the parents should -if possible- also contribute financially, no matter how little. You as mediator will be able to judge what contribution the family or the parents can make.

Shame is also an important element to be discussed first.

3. As a mediator you rely in general on the services available in your area. The right choice for a referral centre for the orthopaedic cases is therefore of utmost importance. Our correspondent can always try to help you to find a good referral centre. Experiences in many countries has taught us some lessons:



Orthopaedic surgeons and technicians tend to do what is technically possible: this is definitely NOT ALWAYS to the benefit of a child / person with a disability! The example of Agnes and unfortunately many other examples from all over the world are illustrating this. An orthopaedic appliance should in general have a functional goal: the mobility should be improved.

Another important issue for you to consider as mediator is that some orthopaedic centres may have their own financial reasons and interest for interventions: they are sometimes running a business and are eager to always increase their productivity.

4. So if a functional goal seems to be realistic and if the child and the family have been involved and agree, orthopaedic surgery and appliances may be provided. But there are still two other important preconditions: AFTER-CARE and FOLLOW-UP!!

After-care:

After fitting the appliances (of course the fitting must be as comfortable as possible, otherwise it will hardly be used, but this will mainly depend on the quality of the work of a referral center) the individual must be trained to use the appliance.

Follow-up:

- a. After returning back home, the mediator will do the follow-up. Is the appliance indeed functional and is it being used properly?
- b. Is the child (now) attending school?

c. *Is the adult now able to start with a vocational job training or to start certain income generating activities?*

Every appliance gets broken sometimes and needs repair or renewal; also for that reason it is important that the mediator (or his/her co-operator) keeps in touch with the individual concerned.

If follow-up is not possible there may be strong reasons not to intervene, because the result will only be positive on short time and will most probably not last long.

5. Some parents (or disabled people themselves) don't see the value of it; here the mediator could play an important role in trying to encourage and conscientize them. If parents are extremely poor this may be even more difficult: people may be tempted to sell the appliance. It is obvious that food and shelter are sometimes a higher priority!

Before deciding if a child needs surgery and/or special aids (and what kind), carefully consider the needs of the whole child within the family and community.

6. Another important aspect is that the circumstances at home should be considered before surgical correcting and / or the provision of appliances: a child may after correcting and fitting be able to walk on the plain ground or floor of the hospital, but in the difficult terrain at home this may be impossible, with the result that the child will never use the appliance and go back to the old state. A waste of money and energy! And last but not least unnecessary suffering for the child.

Regarding Wheelchairs and tricycles

Most of the remarks made above are also applicable here. For some people where surgery and appliances are technically possible, it is sometimes better to choose for a wheelchair or a tricycle:



Joyce from Zimbabwe

For example: Jean Marie. He is 19 years old and has paralysed legs and a deformity of the spine due to polio. To move around he is crawling. When the mediator met him, they went to an orthopaedic centre. They assessed him and suggested a series of at least three corrective surgeries on both legs. Afterwards he would have to walk with two long- leg callipers with a hip belt. He lives in a rural area. The future prospect is that he will be able to walk, but very slowly and only short distances. After discussions with his mediator, it was decided to leave the surgery possibilities and to opt for a tricycle. He is now being trained to become a shoemaker and will start his income generating activity soon.

In our newsletter no. 4 dated autumn 1990 we mentioned the book "Disabled village children" of David Werner (who is the director of the Hesperian Foundation, running a project in Mexico). This book is now available in English, French, Spanish and Urdu through us for mediators). The drawings from the previous and from this newsletter are taken from that book. Some ideas on the appropriateness or inappropriateness of different appliances are discussed in the book, especially in chapter 56 "Making sure aids and procedures do more good than harm". This chapter gives many excellent examples in story form and with pictures. Mr. David Werner wrote us a letter in response to our question on the relevance of appliances. We would like to share with you what he wrote.

"There is, of course, no easy answer to this question. The appropriateness of the particular need for an appliance depends not only on an unique combination of ability and disability of an individual child, but also on the particular situation in which the child lives.

For orthopaedic appliances (callipers and the like), as a general rule, we and many other groups have found that if the child is able to walk and get around fairly well without an appliance -- be it with a limp or helping to support one leg with a hand -- often that child will not want and will refuse to use callipers. However, if the child is unable to walk and drags herself around on the ground but has a potential for walking reasonably well with the callipers or callipers and crutches then the child is usually eager to have the chance to walk and will continue to use the aids provided. However for the same child, if walking with callipers and crutches is inordinately slow and painful and the child can move about faster crawling, many children prefer the latter. For such a child, a wheelchair is often the better choice - provided the environment is suitable to getting around with a wheelchair.

We have found that often young persons who become permanently disabled (for example, paraplegic) through an accident often at first refuse to accept the wheelchair because it is a symbol of serious disability - sometimes that they are still not ready to accept. In this case, the wheelchair becomes acceptable and appropriate when the person is able to accept the disability and ready to get on with life. We have seen many young people at PROJIMO (= the name of the project in Mexico -red.) who first reject to use a wheelchair and then, as they become involved in the activities of the program in helping others, are eager to move around quickly from place to place they change their minds and are very happy to use the wheelchair. In this context, they are not "wheelchair bound" but "wheelchair freed".



A functional rehabilitation plan was made for this Kenyan child after discharge from the rehabilitation centre.

So the appropriateness of a given need for an appliance depends not only on the physical and psychological needs of the individual, but also on environmental factors and on the person's own view of himself or herself.

It is very true that many of the aids and appliances provided to disabled children are not nearly as helpful as they might be, and sometimes they are actually counterproductive. What is so very important in figuring out what will help a child most is to involve the child herself in the process of figuring out needs, designing the equipment, testing and modifying it and sometimes then starting all over again. What is so very important is that the child be a partner in the process of development and testing of the appliance or equipment created for him or her"?

Special thanks for the following mediators whose reply contributed to this article Br. C. Chishiri (Zimbabwe), Dr. Nguyen qui Hung (Vietnam), Sr. Joan Pritchard (Brasil Dr. Sathis Chandran (India), Lilia Peralta de Ferreyra (Argentina), Rev. Jac. Ermers (Ethiopië), Rev. Father Lodewijks (Brasil), Sr. Maria Izabel Marques (Brazilië) Mr. David Werner (Mexico) and Sr. Angela (India).

Hearing aids

In the newsletter no 2 dated June 1989 we informed you about the SLF participation in a working committee in Holland with regard to the development of ear moulds. In our next newsletter we hope to inform you about the final result. In that issue we will also deal with the topic on "the relevance of hearing - aids". For this newsletter we restrict ourselves to the orthopaedic appliances. If any one of you would like to comment on that subject we would appreciate and welcome your contribution for the next newsletter very much.

How to make an individualized rehabilitation plan: a case to case approach

Although we are very reluctant to "classify" people (since every person is unique!) it is sometimes important, in order to clarify things and make it easier to develop a strategy. As you know, usually three main categories are used: motoric, sensoric and mentally handicapped. In our contacts with mediators, we would like to introduce NEXT to this a new classification: A. People with a (any) disability who have the potential to become independent (also economically) in life. B. People with a (any) disability who will always remain dependent on their family or others. For the first group the goal of rehabilitation would be to work on the "child development" medically, educationally and social ly. An individual rehabilitation plan can be worked out through you as mediator, hopefully finally resulting in an optimally integrated and rehabilitated person in the community. For the second group, the emphasis would be on the family-development aspect. Of course also here, like with individuals from the first group, opportunities to rehabilitate the child should be utilised. But also here individualised rehabilitation plans can be made. The main question should always be: what functional goal can be achieved? And if the person from this second group, who is severely handicapped, will always remain (at least to a certain extent) dependant on his family, it is important to make a family development plan: vocational /job training for the mother or father and enabling them to start income generating activities at home. This income generating activity at home will enable the family to take better care of the disabled family member. If ever possible one should try to let the disabled person "somehow" participate in the activities at home. The counselling and the after-care are again of paramount importance.

In our next newsletter we would like to share more about this issue: how to make individualised rehabilitation plans for people with a severe disability, with attention for both the child- and the family development aspect. We will illustrate this with some "case-histories" and we welcome your contribution very much!

Finally: short news and remarks

1. There are quite a number of mediators who are active in organizing parent-meetings and regional mediator meetings. Among the initiatives we would like to mention one from India Kerala:

*In the northern part of this state mediators are gathering regularly and also publishing a newsletter called "Lillian Voice". The initiative was taken by Sr. Alphonse Jaya, one of our mediators in Kerala. In the December '91 issue, information was published about referral possibilities for hearing impaired and deaf children and for vocational training centres in the area. The group is composed of 18 mediators, active in three regions in the northern part of Kerala (_ South - West India). A very good initiative: Congratulations !
After their meeting the following resolutions were published in the Dec. 1991 "Lillian Voice"*

- a. *The next gathering will be held in April 1992.*
- b. *The list of resource institutions for educational and vocational training and other useful information should be printed and circulated among the mediators.*
- c. *Whenever possible, useful and healthy sharing of the experts should take place among the mediators.*
- d. *The mediators should try to meet one another as frequently as possible to share their experiences to chalk our plans for improvement and for fellowship and prayer.*
- e. *A newsletter will be published half yearly or yearly.*

2. We would like to emphasize once more that the mediator is always responsible and accountable for the money. Please NEVER give the money in cash to the family, but "pay the bill". Please do not show the family our letter, because then they may claim the allocated amount while it is always our intention that you pay for what is needed; if there would be a surplus you should reserve this for a next case.
3. In relation with the above remark also the following: please try always to discuss with the family about a certain financial contribution. In general the assistance should never be a handout; It is important that everything has its price, because this applies also for the other family members without a disability.

Giving a contribution makes the rehabilitation process the responsibility of the family as well.

4. The SLF has decided to aim at co-operation and structuring the activities in areas, where a relatively big number of mediators are working A start has been made in Kenya, where Sr. Marcelle Morin has been appointed as our coordinator and consultant. Also in the Philippines an initial start has been made with Sr. Agnetia Naval. Next to co-ordination an important aim for these countries is to upgrade the quality of the work and to offer training to mediators. There are similar plans in some other countries for the next future.