

CHAPTER 9

Parents' Role in CBR

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SUMMARY

This chapter describes our activities and perceptions as parents of children with disabilities. It presents case studies of the organisations with which we are involved and relates the lessons learnt from these experiences, to the development of CBR programmes. Our organisations perceive CBR as the de-centralisation of responsibility and resources to community level. The key focus in this process is working, living and sharing with persons with disabilities. This serves to enhance participation and consequently, promotes CBR as a participatory strategy in community development initiatives. Parents realise that a collaborative approach by all stakeholders is the best.

INTRODUCTION

The experience of having a child with a disability has stimulated us to establish and become part of parental organisations. These organisations aim to provide support for groups of parents who have children with impaired functioning. Both these organisations relate to specific impairment groups, namely children with hydrocephalus and children who are deaf/blind. Both organisations address the needs of our own children, together with others. The first hand experience we have gained, has put us in a unique position of knowing about the problems of establishing and running such organisations, about how parents feel when

they have a child who is disabled, about the sort of barriers and problems they are likely to have to face, and about the strategies that are effective in combating these realities.

CASE STUDIES

1. The Association for Spina Bifida and Hydrocephalus, Uganda (ASBAHU)

ASBAHU was started in 1995, by parents of children with one, or both conditions. It was the brainchild of Mr. and Mrs. Sekatawa who had two consecutive daughters with hydrocephalus. Mr. Sekatawa is the Director of ASBAHU, while his wife serves as co-ordinator for the association. The association was born as a means to counteract the then prevailing negative attitudes exhibited by some medical personnel, educationists and society at large, towards children with Spina Bifida and/or Hydrocephalus. The affected individuals and their families experienced a lot of stigma, loneliness and isolation, often being treated as 'outcasts' in their own communities. Even the traditional cultural support system of the extended family seemed unsupportive. Since unity is strength, parents of ASBAHU came together under the old African Philosophy of, '*I am, because we are*'. They chose interdependence over independence. ASBAHU is a registered charity and membership is open to all well-wishers on payment of a membership fee.

The activities of the organisation centre around the following areas:

- Awareness creation using the media (radio newspapers, video recording etc).
- Identification and mobilisation of new parents with affected children, followed by treatment at Mulago Hospital or CURE Christian Hospital in Mbale. Initially, Mulago was the only option and due to pressure and bureaucracy, some parents were overcome by frustration, which led them to abandon their children. Now the situation has improved with the addition of the second hospital facility.

- Counselling of new members by the experienced members about on-going projects, treatment, care, etc.
- Providing moral support and encouragement to parents, urging them to maintain contact with ASBAHU's social workers.
- Keeping constant contact with similar and other interested associations/organisations at local, national and international levels.
- Researching and training in the management and support of affected children/adults.
- Creating advocacy and lobbying, by holding regular conferences, seminars, workshops and meetings with opinion leaders and policy makers.

Achievements

The achievements over the last 6 years have included the improvement of medical services for this group of children through improved acquisition of shunts and better access to surgical interventions. It has also involved increased dissemination of knowledge and information, through sensitisation of community members, policy makers and opinion leaders. It has organised meetings using role models (adults with the conditions, who have attended school and are now leading independent lives), and the publication and circulation of regular newsletters.

Future Prospects

Possible future activities of the organisation include:

- Opening an ASBAHU centre at Kabowa, to provide a venue for keeping children in constant contact with social and medical personnel, who will make regular visits to the centre. The centre will also be used as a collection point for children, before they are taken for surgical intervention and as a convalescent centre for children after surgery.
- Participation in the 13th International Conference for Spina Bifida and Hydrocephalus in Dar-es-Salaam, Tanzania.

- Organising a two-week study tour to Britain and USA for 8 ASBAHU social workers.
- Opening up a school with the assistance and advice from sister organisations like the Uganda Parents of Children with Learning Disabilities (UPACLED), to provide services that can address the special needs of these children.

2. Uganda Deaf/Blind Parents Association (UDBPA)

UDBPA was started by five parents of deaf/blind children in 1998, and registered as an NGO in March 2002. Ms Olive Bwana B.Tibekinga is chairperson and Ms Suzan Luyiga is the treasurer. After attending a regional conference sponsored by SHIA, in Nairobi, Kenya, parents saw that there was a great need to come together, share experiences and try to find solutions to problems faced by parents and their disabled children in day-to-day life. As we were sharing experiences at the conference, we realised that each parent thought she/he was alone with such a problem. This inspired us to start the Association, so that parents can be helped in one way or another. This is based on the appreciation that if one does not become critically aware, then one cannot fight one's way out of an oppressive situation. This Association is based at Uganda School for the Deaf at Ntinda in Kampala.

Aims and objectives of UDBPA:

- To facilitate parents who have deaf/blind children, with professional assessment and appropriate therapy.
- To promote awareness among the public about deaf/blindness education and facilities given to them.
- To consider the future of deaf/blind adults.
- To plan, identify and find ways of mobilising sources of income by advising members on methods of setting up income generating projects.
- To identify more deaf/blind children and establish more units in the country.

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- To train parents and guardians on how to care for the deaf/blind persons.
- To promote guidance and counselling.

Activities:

- Counselling and guiding both parents and deaf/blind persons.
- Home visits to families who cannot bring children to school due to lack of funds, distance, type of disability etc.
- Training parents to help their children live an independent life.
- Training parents to run income-generating projects.

Achievements:

UDBPA has recorded some achievements since they started.

- The Association is registered as an NGO and has grown strong.
- They have a unit at Iganga High and Ntinda School for the Deaf.
- A poultry project has been started at Iganga High.
- Parents have attended workshops in Uganda, Kenya and Tanzania.
- The chairperson (Olive B.Tibekinga) was elected the regional parents' representative in 1999, for a two-year term.
- The chairperson attended a world deaf/blind conference in Lisbon –Portugal, July 2000.
- A vocational training unit was established. UDBPA is happy to inform that its students Emaringati and Ojok are doing very well and thank the headmaster of Ngola school, Mr Morrissy, for work well done.

Future plans:

UDBPA hopes to hold a regional conference (East Africa) in Uganda, in March 2002, with the help of SHIA, and to start an animal husbandry

project at Ntinda School for the Deaf, once funded. In this project it is intended to train parents in animal husbandry.

PARENTS' CONTRIBUTION TO CBR DEVELOPMENT

Parents' potential contribution to CBR development is enormous, but in this chapter, five possible areas will be explored, where their efforts could make a significant difference.

1. Overcoming ignorance

We all know that CBR has a major role to play in the education of the community, about disability. Ignorance is a big obstacle, many people with disabilities are in their present situation because they did not know what to do at the time when, the 'enemy' attacked them. Community members need to know how to prevent disabilities. They need to know how to care for, respect and communicate appropriately, with people with disabilities. Parents can make a major contribution towards sensitising families in these areas, by sharing their own experiences. They can encourage other parents to include their children in everyday activities, by providing a sympathetic, listening ear to the families' difficulties. They can also facilitate referrals to medical and social services. Their contribution in these areas can strengthen these aspects of a CBR programme considerably.

2. Promoting sustainability

The sustainability of an individual's independence relies heavily upon setting up the structures and support, which will enable him/her to acquire daily living skills and provide the opportunity for education and employment. Parents can facilitate this process by establishing NGOs, finding ways of sustaining individual PWDs, and making relevant connections between PWDs and prospective educational opportunities and employers. People tend to underestimate the capacity and capability of PWDs to carry out productive activities, for which they can be financially rewarded. They need the opportunity to practise any newly acquired skills and this is where parents can also be very supportive.

3. Promoting the validity and relevance of CBR activities

Essentially, PWDs and their families are the customers and consumers of CBR programmes and one of the objectives of any organisation is to satisfy its customers. In order to do this, the customers need to be involved in the identification of what is required and how it can be best achieved. In practice, this means that PWDs and their families need to be involved from the very beginning in any initiative so that their perspectives, wants, hopes, needs, fears and deep seated knowledge of the barriers, can form the design of an initiative, from the very beginning. Their participation is then required throughout the project, to keep the monitoring process relevant and to ensure that the project develops in a way, which will continue to benefit the 'customers'.

4. Parents' role in promoting education

Parents have a very powerful role to play in the promotion of the inclusion of disabled children within mainstream educational settings, as well as working towards the development of special provisions that children, both, within mainstream settings and in special settings, require. Their role is again one of raising awareness and providing the drive and inspiration needed, to initiate and sustain programmes with a lifetime of interest and commitment.

5. Raising gender awareness

Disabled girls, appear to be at a double disadvantage in many societies and Uganda is no exception. CBR programmes need to be very sensitive to the situation faced by disabled girls and women, which includes facing both physical and mental abuse, rape and exploitation. It is difficult for others to imagine what they have to learn to face, such as the problems that arise from menstruation, pregnancy and labour. Culturally, girls are expected to get married, have children and create their own homes. In Uganda, and I believe in many African societies, it is very painful (for parents and PWDs) to know that marriage is almost completely out of question. The worry is also that if you do get married, will you (or your child) be able to live up to the expectations required, and if you do not, what will happen to you?

As the parents of disabled children, we feel that the following soul searching questions are worth pondering upon.

- What are my weaknesses?
- What are my strengths?
- How do I feel or react when someone talks about disability?
- Am I able to talk or discuss disability freely?
- Do I have positive or negative attitudes to disability myself?
- How do these manifest themselves?
- How can I move the situation in a positive way?

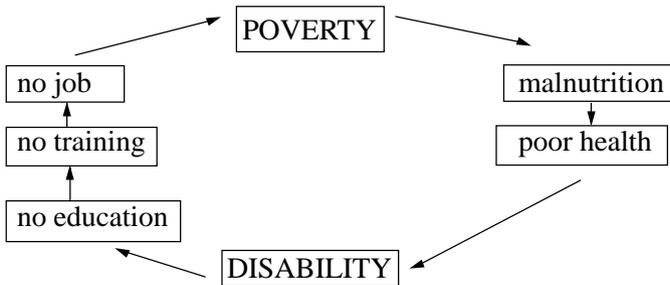
The following are real situations that parents and their disabled children have to face.

- They are disabled.
- They have no job. No one is interested in employing a disabled person.
- They feel rejected.
- They cannot do things like their brothers and sisters and friends.
- They cannot marry easily and have their own children.
- They do not go to school like other children.
- They do not know what their future holds and they are frightened
- The parents are not sure how long they can look after them, especially in being able to meet their emotional, physical and financial needs. (The world is big but to some disadvantaged people, the extent of their world is as small as just a house or a room, since their opportunity to interact with others, is so limited.)

Understanding that this is what preoccupies disabled children and their parents, goes a long way in establishing support services that are meaningful.

PARENTS' ASSOCIATIONS IN RELATION TO POVERTY

For families with disabled members, poverty is a dangerous but inevitable companion. It encroaches on their lives directly and frustrates participation and self-actualisation. Disability often affects families that are already poor, and parents in remote rural locations often feel that they are so poor that they have nothing to offer. It takes a lot of persuasion to encourage them to participate in the activities of parents' associations, since they feel trapped in the vicious cycle where, poverty is taken as a function of disability and vice versa.



CONCLUSION

It can be seen from the above, that PWDs and their families are a tremendous resource to any CBR programme. They really know what the effects of environmental conditions are on themselves and they almost certainly understand those same effects on their peers with disabilities. They have a better knowledge of what it means to be disabled in society, in the family and in the nation. They know the costs, both in emotional and financial terms, they know and understand the pain. This knowledge and experience is invaluable to CBR programmes and the most effective way of acquiring it, is to employ disabled people as CBR workers.

Understanding and empathy, cannot generally be taught to other people who do not have a disabled child, or a disability themselves. It is something acquired through experience. This is why PWDs and their

parents are an essential and invaluable element of any CBR programme or CBR work force. They contribute essential understanding and empathy, which cannot be obtained by any other strategy.

Additionally, their involvement also serves to improve the quality of life of PWDs and their families, as it gives them confidence and improved self-esteem. They find that they are needed, their expertise is wanted and valued. It reduces the sense of isolation and loneliness. So, by their participation in CBR programmes, they not only help others, but they also help themselves.

There are many fears and questions, unresolved issues, unpredictable situations, personal experiences and unexplained phenomena. There are natural situations, as well as man-made constraints. But, the situation of persons with disability is obviously such that it places them among the disadvantaged groups, often deprived of very basic human needs, including love and a desire for life. The greatest challenge for us all is the challenge of learning to live together and it is this challenge, that CBR programmes need to address, through promoting participation as a viable strategy in Africa.

Participation should be understood in its broadest dimension including the basic elements of making direct contributions, whether material, physical or professional knowledge, or simply in the form of organisation of a delivery system or the employment of PWDs. But the approach however, ought to be based on the principle of working with, and for, PWDs and their families. Participation is in itself, empowerment.

The parents of these organisations do not claim to have found solutions to the problems most children face, but there is a saying that if you have to wash an elephant you have to start somewhere. So they have made a start. They realise that in order for CBR to have the desired impact, there is a need for a collaborative approach. It is important for governments, local communities, NGOs, parents, teachers and other professionals, to join efforts and together participate in the rehabilitation, education, social and economic integration, of the affected individuals.