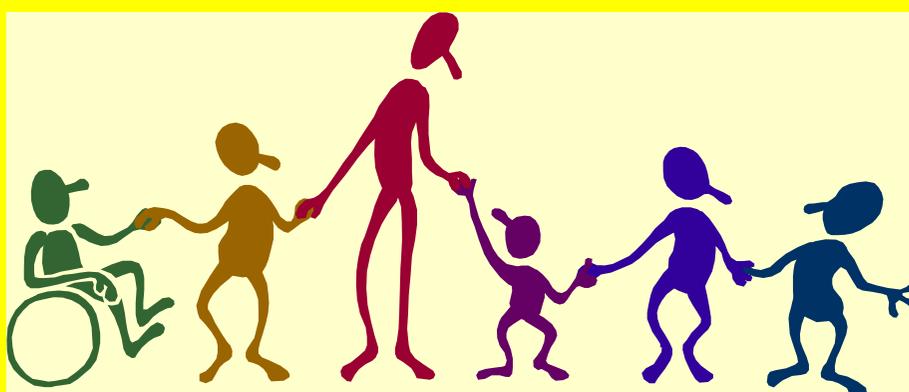


Part 2 - Country Reports

*Community-Based
Rehabilitation as we have
experienced it...*



*...voices of persons with disabilities
in
Ghana, Guyana and Nepal*



WHO
World Health Organization



SHIA
Swedish Organizations of
Disabled Persons International Aid
Association

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Foreword

This study on how persons with disabilities experience community-based rehabilitation (CBR) has been undertaken through the collaboration between the Swedish Organizations of Disabled Persons International Aid Association (SHIA) and the World Health Organization (WHO).

SHIA is a partner to the Disability and Rehabilitation Programme at WHO (WHO/DAR), and as such is very supportive of DAR activities in general, and the present study in particular.

Although there have been many previous evaluations of CBR carried out to a very high quality, this study is the first of its kind that is based on the experiences of the users of CBR themselves. In this respect it is unique and thus adds value to the other studies and evaluations of CBR.

The draft report was sent by WHO/DAR for comments to a selected number of professionals as well as WHO regional offices who expressed their appreciation. Based on these comments the text was revised by the authors. We wish to express our gratitude to Mrs Solveig Hargö Granér, who did the fieldwork that involved all interviews and compilation of data. Also, our thanks go to Mrs and Mr Annika and Lennart Nilsson who analysed the material and wrote the report. They have been exceedingly dedicated and committed in their efforts to complete this undertaking.

We hope that the report will be used as a source of inspiration and assistance to any CBR programme. It is through the participation and involvement of disabled persons in CBR programmes that their quality of life can be improved.

This report could also be used as an important background document for the International Consultation on Reviewing CBR in 2003.

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Secretary General
SHIA

Acknowledgement

We should like to extend our thanks to all persons in Ghana, Guyana and Nepal who have volunteered to express their most personal thoughts and feelings to help us understand the benefits and challenges of community-based rehabilitation (CBR). We have appreciated their frankness, openness and critical views. Without their willingness to contribute, this study would not have been possible. They have told their stories in the hope of being able to influence development and contribute to more efficient programmes in their country that will improve living conditions of persons with disabilities and their families. We hope that this report will do justice to what has been said and that it will lead to practical measures being implemented in many CBR programmes. As one person said "You spend so much time and so many resources quantifying and justifying what you are doing. But when is that going to help us?" We forward that question to the readers of this report.

Annika and Lennart Nilsson

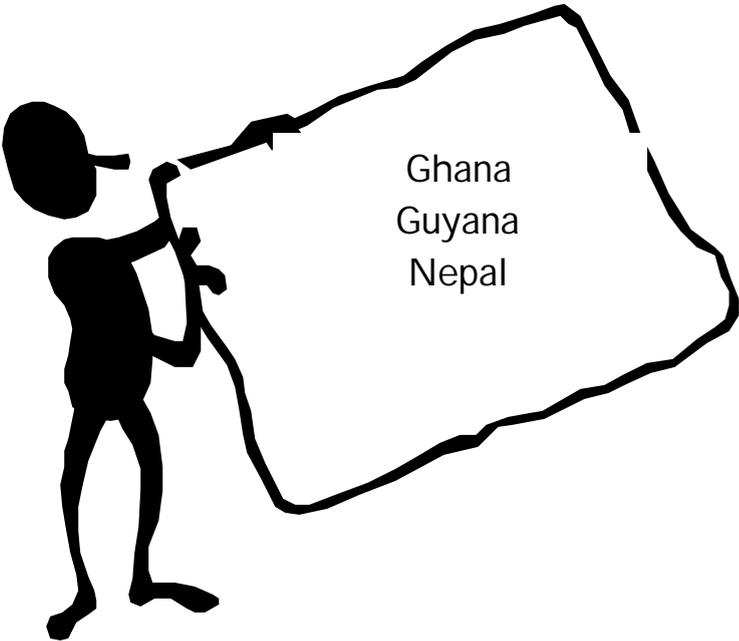
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GHANA'S NATIONAL CBR PROGRAMME

Background and organization

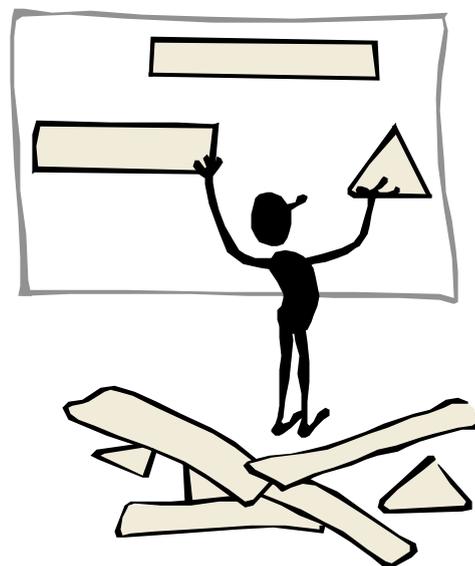
In 1992 the Ministry of Employment and Social Welfare initiated a national CBR programme for persons with disabilities in Ghana. The programme has been supported by two NGOs: the Swedish Organizations of Disabled Persons International Aid Association (SHIA) and the Norwegian Association of the Disabled (NAD), and by the UN agencies WHO, ILO and UNESCO. Financial support has also been provided by UNDP and AIFO.

The purpose of the CBR programme is to improve the quality of life of persons with disabilities. The major goals of the programme are:

- To promote the human rights of persons with disabilities by raising awareness and mobilizing resources in the districts and communities.
- To establish links between service providers in health, education, community development and social welfare.
- To strengthen associations of disabled persons.
- To develop a National Policy on Disability and appoint a National Advisory Committee on Disability.

The CBR programme is a collaborative effort between the ministries of Employment and Social Welfare, Health and Education. The programme is managed by a Programme Management team at the Department of Social Welfare and guided by a National Coordinating Committee, where ministerial staff as well as representatives of Disabled People's Organizations (DPOs) are represented. Implementation has mainly been applied through:

- Employment and training of district CBR Agents placed with the District Offices of Social Welfare.
- Appointment and training of community Local Supervisors who are engaged on a voluntary basis.
- Establishment of Community CBR Committees to ensure commitment and local ownership.
- Employment and training of district peripatetic teachers who support inclusive education in schools.
- Training of staff in health, education and social welfare departments.



Previous evaluations and reports

Previous evaluations and reports^{1 2} conclude some of the lessons learnt during the nine years of implementation of the CBR programme:

Coverage remains limited. At the end of 1996 only a few persons with disabilities, their families and communities were actually benefiting from the CBR programme. By the end of 1997 only 10 out of 110 districts had been reached and only 86 communities had been covered. According to the 1996 evaluation 41% of persons with disabilities in the communities targeted reported that the CBR programme had done nothing to improve their

¹ O'Toole B, Participatory evaluation, Ghana community-based rehabilitation program. Government of Ghana/ NAD/SHIA/UNDP, April 1996.

² Ghana national community based rehabilitation program — assessing needs and resources, NAD, 1999.

situation, while 17% reported that CBR had helped with income generation, 12% with skills acquisition, 11% with educating the community, 11% with advice and support and 8% with ADL training. Parents of children with disabilities were more positive. Only 3% reported that CBR had made no difference to the situation of the child, while 41% reported improvements in mobility and communication, 15% reported that the child was more independent and could do household activities, 14% reported that the child was more sociable and self-confident and 22% reported that the community was more understanding.

Inter-agency collaboration is weak. The 1996 evaluation report indicated little collaboration between governmental agencies and DPOs. Such collaboration is essential for the quality and the sustainability of the programme. In particular, the participation of the Ministry of Health is weak and needs to be strengthened.

Sustainability is a concern. The Local Supervisors cannot be sustained on a purely voluntary basis and without continuous upgrading of skills. Community involvement and resource provision to the CBR programme are limited. Many of the Community CBR Committees have stopped functioning because members see no benefit to being part of the Committee.

Lack of reliable data and information. The evaluation report highlighted the absence of reliable data on the incidence of disability and on the needs of disabled persons. This type of information is necessary when planning and budgeting programme activities for the entire country. It is also needed for evaluation purposes.

The 1996 evaluation team confirmed that health services, early detection, physical rehabilitation services and assistive devices do not seem to be an important part of the CBR programme. According to their observation there were no aids or appliances made or provided by the programme in the 32 villages visited, except for a set of parallel bars. The team also concluded that the major problems are poverty, lack of income, no water and no health facilities. These problems are shared by the entire community but exacerbated, perhaps 10-fold, when coupled with disability. The CBR programme needs to accept these realities, make CBR an integrated part of community development and give priority to apprenticeship schemes, training in income generation skills and credit rotation facilities.

The new CBR Programme model introduced in 1998 has tried to address these challenges by taking the following steps:

More in-depth information and reliable data on disability are now available in some regions. This will enable better district level planning and more accurate budgeting of services for persons with disabilities. It will also facilitate the deployment of resources to address the needs of persons with disabilities.

There is now more meaningful participation in the programme. There is an attempt to secure more meaningful participation of other stakeholders — both governmental and nongovernmental organizations. DPOs at the district and local levels are increasingly considered as a resource in planning, implementation and monitoring of the programme. DPOs are also essential for raising awareness and advocating the rights of persons with disabilities at these levels.

Programme ownership has shifted. The districts and the communities are supposed to have ownership of all CBR programmes and activities. The responsibility has been moved from specific CBR Committees to the existing, ordinary government structures at community and

district levels. These are the structures that have the overall responsibility for development issues in the area. The ownership issue is still being debated and is still not clear to all stakeholders.

Investment in capacity building is now a priority. In order to better address the needs of persons with disabilities, the CBR Programme model focuses on capacity building of stakeholders at district and community levels.

Quality of life analysis

According to the in-depth interviews and inquiry groups the following has been said about the impact of the CBR programme on quality of life.

“CBR gave us confidence and self-esteem”

Many of the interviewees report that the increased interest in the situation of persons with disabilities brought about by the CBR programme has positively influenced their self-image. People with disabilities have become visible and they have been able to attract the attention of the community, which has enhanced their status and emotional well-being. Typical statements were:

“I see myself as a role model to other persons with disabilities. I am prepared to volunteer to go to the communities to counsel parents of children with disabilities not to lock up their children at home or feel shy about the child and to encourage them to go out and join whatever goes on in society. I can also give disabled friends encouragement to feel self-worthy.”

“Previously, I felt very inferior but after I joined the CBR programme, through social education and counselling, I have been able to overcome that feeling and I am fully integrated into society. I can now assess myself with others and say that I can perform certain activities and tasks better than the able bodied.”

“I am now independent of my extended family; the room is well furnished and this has gained me recognition as a responsible person. This promotes my self-image and I am self-supporting.”

“It makes me proud that I am able to assist other women who are not necessarily disabled. With the help of the CBR credit scheme, I can provide all the members of the Association of Weavers with raw materials on credit.”

“If somebody calls me by my disability I talk to him or her. Now the name-calling has almost stopped.”

“I am relatively satisfied with the level of integration and always make sure that I try to involve myself in activities that would make people recognize me.”

“Actually my needs are no different from those in the community. The only difference is that I am blind. My wishes for the future are that I can take good care of the house and sponsor my children’s education so that they become better adults. I am confident that I can do that.”

“I have succeeded in establishing this carpentry workshop. I am ready to use my skills to train my unskilled colleagues at a minimal fee.”

“CBR empowered us as individuals and as DPOs”

Although the CBR programme started with little involvement from the DPOs this has changed over time. Many statements refer to the impact of the CBR programme on the formation and development of DPOs. Such DPOs have positively affected the interpersonal relations, social inclusion and personal development of persons with disabilities. They have also empowered people to claim their rights and influence authorities. To have an Association has been particularly important to deaf persons who have been able to meet and develop sign language and social skills. The following was said about individual empowerment:

“Before, we hardly knew each other. This has changed. When I got to know about the Association I realized there were others like me. I am always happy to attend meetings because of the companionship.”

“I have been able to get advice, companionship and play an advocacy role. I try to discourage my disabled colleagues from begging. Social acceptance cannot be achieved if some of us are begging or are involved in antisocial behaviour.”

“I am learning sign language from my colleagues in the Association (of the deaf). Then I want to learn reading and writing.”

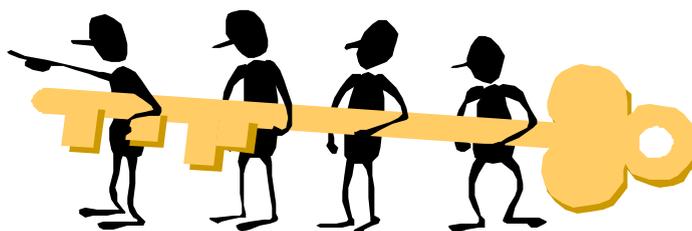
Representatives of the DPOs confirm the positive impact of the CBR programme:

“The CBR programme has been able to encourage DPOs to form a common platform on which they present common issues and chart a common course.”

“CBR has assisted the Association immensely since it has enabled us to get funds, and mobilize members. The three Associations (of the blind, the deaf and the physically disabled) work hand in hand in our district.”

“The CBR has helped the organization to identify people at the grass roots level because there are villages or remote areas, which the organizations have not reached. The CBR as it were has come to enhance the mobilization effort.”

“At the societal level some awareness now has been created and there is acceptance and recognition that persons with disabilities are part of the community and all services should be accessible to us. In communities where the CBRP is operating some initial acceptance is evident. A lot of persons with disabilities are now integrated in schools or apprenticed in trades. Some districts have been able to start some micro-projects such as soap and form projects in Akim Oda, and poultry and bee-keeping projects in Tano District and women’s activities in Bolga, not forgetting the Revolving Loan Scheme in the Techiman District. But I think the main thing is the enhanced empowerment of the organizations — the organizations have become a bit more formidable through the CBR programme.”



Although individuals and organizations have been empowered there are still limitations to their influence. Persons with intellectual disabilities and children with disabilities and their parents do not yet have an organization of their own and are seldom given the opportunity to have their views heard. The same is true for deaf persons and their Association when they do not have access to a sign language or to interpreters to facilitate communication.

Here are some of the views:

“The authorities still do not accept us. We need the CBR Agents as facilitators to make the authorities take us seriously.”

“I wouldn’t say that we are entirely (part of the decision making), because we still do not have the Disability Policy — the Policy is not legalized, and there is no Bill to enforce it. But since we were part of the Team that developed the policy, our input is there.”

“In the situation of the hearing impaired because they cannot verbalize their concerns, they are considered a disturbance. Often people make negative remarks: ‘The deaf people are coming’.”

“I am restricted because of my limited sign language. I would like more training. Because of the difficulty communicating with the authorities they have not taken it seriously about our needs.”

“Ownership of the CBR programme is with the government. Although the officials make a point of consulting us they control the funds. Funding should go directly to us. And we could fill some of the positions!”

“The Government still has its control, but I am sure when we have the Council of the Disabled in place, when it’s located and manned by a PWD as a liaison between us and the government, then we would be better empowered. There is nothing for us, without us!”

“If our branches at the district and community levels are stronger, they can better influence the programme. That is our new drive to develop our capacity at district level. That is why we want to be at virtually every district — but again, that takes resources.”



“CBR brought about social acceptance”

Numerous stories give evidence of how social acceptance and inclusion have improved. Typical statements were:

“Previously most people in the community did not want to associate with us, they always prevented us from going out and hid us from the sight of visitors. Now, we are able to interact with the community because they have been educated and we have been empowered.”

“I am now invited to family gatherings.”

“The level of social understanding has improved; we are able to interact with people and they do not make fun of us. There is gradual change of attitude toward us.”

“There is not much problem with social recognition and acceptance, since I am one of the recognized tailors in town.”

“I am well accepted by friends and at my work place. People know that I can’t hear so they draw my attention to oncoming vehicles.”

“As you move in the community, assistance in movement is provided willingly. The level of understanding of the blind has improved greatly.”

“Previously it was taboo for persons with disabilities to enter the Chief’s Palace: all this has changed now.”

“It has made most of the communities aware about disability issues, and to accept persons with disabilities like anybody else, because formally, persons with disabilities were perceived as ‘strange’; but with the introduction of the CBR programme, people’s attitudes have changed towards persons with disabilities. It has also educated the parents because parents thought that children with disabilities need not go out, but should be kept indoors and catered for. The perception was that if they were allowed to go out to play with other children, they would hurt themselves. With the introduction of the CBR programme, this trend has changed.”

“We have been recognized as a group and we have access to the District Assembly Hall for our meetings.”

“CBR increased self-reliance”

This study gives evidence of increased self-reliance in two distinct areas:

- ability to manage daily living activities and to help in family household activities
- ability to contribute financially to personal maintenance and to family needs

Self-reliance is intimately linked to self-esteem and social acceptance. According to the interviewees the CBR programme has contributed towards their self-reliance mainly by providing training in daily living skills and by providing loans for viable business ideas.



Typical statements were:

“Initially, I found it difficult to socialize and did not have any personal skills, such as putting on shoes was difficult for me. With training from the CBR programme I am now able to take care of myself and interact with people in the community.”

“CBR has helped through the loan. The revolving fund is for those of us who do not have much assistance from our parents.”

“When CBR was introduced we received a lot of support from the loans and training in activities of daily living. I used the first loan to buy raw materials. The second loan I used to buy a goat and some chickens. They have already reproduced. I am saving to buy a cow. It is customary to give the family of the bride a cow when you want to marry.”

“When I lost my sight I was worried about how I could get a husband and go to the farm like the others. My happiest day was when I learned to weave, which was the first step to earning an income. This was fulfilled when I received the first loan. Through the loan from the CBR programme I have been able to start a weaving trade and now I cater for my needs and assist others in my family.”

“CBR has not improved physical well-being”

Despite the focus on physical rehabilitation in the training of CBR community workers, this is an area where very little has been achieved according to the persons interviewed. Community workers are not confident enough to give appropriate advice, to design suitable technical solutions or to assist persons with communication difficulties and severe or multiple disabilities. Referrals systems on the other hand are few and far between and the costs are prohibitive. The following statements give some examples:

“I was taken to the hospital, but was not able to recover. I was given a walking pen but it was not helpful. Due to financial problems I could not purchase one that would be suitable. I am now managing without a walking aid. The CBR Agent gave me some training in an easier way to move about.”

“Due to financial problems, I have not been able to undergo medical treatment.”

“I don’t go to the hospital anymore because I can’t afford the medicine. That’s why I am having the pains.”

“I was provided with callipers and trained on how to use them. However, when I got back home, the landscape was not good enough since I was experiencing great pains. I now use a stick for walking.”

“There is no support for technical aids. The limb fitting centre, which is under the Ministry of Health, has all the materials but they are very expensive and when we complain they tell us that it is the tax on the raw materials and that the rate of exchange is unfavourable.”

“I know one person who was admitted to a centre doing orthopaedic services. But the places where these services are available are few and far between. And the cost of accessing these services is also a problem.”

“CBR struggles to ensure community commitment”

Many interviewees testify that communities have started to improve their attitudes towards persons with disabilities — but only as long as it does not demand time or money from the community. Some District Assemblies have agreed to sponsor school fees and to contribute towards income generation projects for persons with disabilities. Yet, most district and community leaders show little commitment when it comes to allocation of resources. Many CBR Committees are no longer functional and responsibility for the CBR programme has been formally shifted from the specific CBR committees to the ordinary local and district government authorities, which is a move towards achieving sustainability of the programme. People with disabilities and their organizations are now struggling to find ways to influence these bodies.

Typical statements from the interviewees were:

“The Community is very innovative with the social attitude. If I go to the District Chief Executive, he welcomes me wholeheartedly into his office and I am able to discuss a lot of issues with him. But when the discussion borders on financial commitment or support, the response is usually discouraging.”

“The CBR programme is supposed to be community based but the response here has been very, very discouraging. Would you believe that after launching an appeal in church you may receive approx. USD 1.80, which cannot even cater for the cost of transportation incurred to undertake the appeal?”

“Generally contributions come from individuals. We have not received any funds from the community or district bodies. Our needs are not a priority. Our plans of action are made known to the authorities but are always cut out of the budgets.”

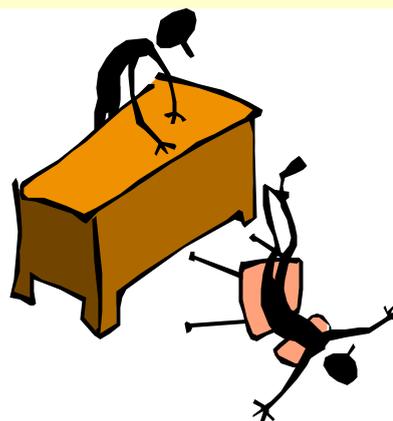
“The Local Supervisors (volunteers) cannot work under the existing financial situation. There are no incentives and no funding for travelling, meetings or training.”

“At first they indicated that they would join the project (authorities) but later on we realized their assistance was not forthcoming. So we decided to come together and help ourselves.”

“This is a CBR project but the very people who should support us disregard us. They used to attend meetings in the hope of obtaining some reward. Since that was not forthcoming they gradually withdrew their participation.”

“It all boils down to poverty. We can’t go to meetings just to talk when we are supposed to be in the field working. If at least you know you get something to eat at the end of the meeting or learn a skill.”

“Even though we recognize the responsibility of parents and communities, the CBR programme should complement these efforts as a last resort. Our community is not economically strong.”



Analysis of CBR programme initiatives

With respect to the impact of the different CBR programme initiatives the following can be concluded from the interviews in Ghana.

Awareness-raising

The major programme initiatives that have influenced the quality of life of persons with disabilities seem to be related to awareness-raising. The most successful ways of raising awareness are reported to be

- social counselling to families and individuals
- existence of role models, e.g. persons with disabilities, who are seen to be socially and materially “successful”
- information dissemination at community meetings by trusted persons
- empowerment workshops for disabled persons

A considerable part of the CBR programme is devoted to workshops and training for government officials. However, persons with disabilities did not mention this as an important strategy to achieve change. Increased knowledge alone does not seem to bring about change. It seems that training has to be combined with social or financial rewards for improved behaviour and with personal experiences and relationships with disabled persons to reduce prejudice.

Medical care

Access to medical care is reported to be limited. Early detection is poor and the treatments are not adequate due to lack of knowledge at the primary health care level and due to inaccessibility of the referral level. This, in combination with fees for medical care, excludes the majority of disabled persons. The perception of the CBR programme is that it is limited to activities that can be managed at community level. Medical care is not such an activity. The Ministry of Health needs to take an active part in the CBR programme to resolve this problem.

Rehabilitation and support services

In connection with social counselling the CBR programme has provided advice and training in daily living skills. This has contributed towards increased self-esteem and self-reliance. However, the skills of the CBR community workers are reported to be quite limited. Persons with communication difficulties and intellectual disabilities are often excluded because “they do not understand what we advise them”. Few persons report on having received assistive devices that are appropriate. Mostly, it seems that either the devices suggested are not suitable or that they are not affordable.

“Initially, under the CBR programme, that was the expectation; that logistic support and all other things would have to come from appropriate technology in the community. But like my sister was saying, it takes a bit of expert knowledge to be able to produce the appropriate thing. At the community level for example, if you want to develop crutches, you can easily develop them, but at the end of the day, because there might not be any cushion for the armpit area, the user may develop some lumps in the armpit. It might not be up to the measurement, so eventually the user might develop some curvature instead of straightening up. There has to be a measure of training in the provision of these services. Talking about passive exercises, such as physiotherapy in the house, if the person does not know a few things, the exercise might be more harmful than helpful. So there has to be some know-how in providing these services.”

Education

The interviews in Ghana give little information about the views of persons with disabilities regarding the impact of the CBR programme on their access to **basic education** — perhaps because there were few parents and children among those questioned. However, the following statements were given:

“The peripatetic teachers have been providing counselling and advice in the school and to other stakeholders. I think this has led to the integration of some of the children in school.”

“When I became disabled I stopped going to school. I wish I could complete my education. But I must work to support myself.”

“There are only two schools for the intellectually disabled children in Ghana.”

“My daughter was sent to my sister to attend the School for the Deaf. Later I found out that my sister had neglected her. She never went to school. Now she is trying to learn sign language from the Association.”

The experience of inclusive education varies greatly, depending on the person’s disability and on the resources and skills of the school. In some cases self-esteem and social inclusion improve when children with disabilities are able to attend classes with other children. There is a negative impact when prejudices are reinforced rather than eliminated. Many parents testify about such cases. Children with communication difficulties or children who need a lot of extra assistance often seem to be at a loss. Special learning environments need to be provided for these children. Success stories usually refer to children with physical disabilities and moderate visual or hearing problems who do not require extra support from the teacher.

Income maintenance and social security

Concerning **skills training** most of the interviewees reported to have acquired their skills by means of relatives or private initiatives — not through the CBR programme. Although the CBR Agents had facilitated some apprenticeships, lack of skills training opportunities was seen as a weak point in the CBR programme. It was suggested that a vocational training centre should be established in the district as part of the programme.

Concerning **employment** the situation is very bleak. With one exception, the interviewees did not know of any person with a disability who had regular employment. Some interviewees pointed out that, within the CBR programme itself, there were many positions where a disabled person could do an even better job than an able-bodied person. The 1996 evaluation confirms that the CBR programme at that time only knew of two employees with disabilities — in both cases acting as volunteer Local Supervisors.

Although many had benefited from the **Revolving Loan Fund** established by the CBR programme there was some dissatisfaction about the size and conditions for the loans. The following list was seen as the limitations to the present lending system:

- providing too small amounts
- limiting the loan to raw materials — not allowing investments in tools
- creating jealousy among the non-disabled population who could not access the loan
- not available to parents of disabled children

Lack of access to starting capital for tools and raw material is mentioned as an important problem. Many persons with disabilities who have acquired a skill cannot create a business due to lack of finance. In the absence of other options, some DPOs are now supporting their members with loans and skills training. Here are some of the statements:

“(Not getting a loan) is like standing with me under a tree and not giving the push to help me to climb.”

“Parents should be assisted to earn an income to maintain our children and ourselves. This would attract other parents. The Association (of the physically disabled) has started such a scheme with the assistance of ADD.”

“The CBR programme could not help but the Association assisted me with working materials like nails and wood to start the trade.”

“We made an appeal to an NGO in the Netherlands to get some tools.”

“Our weakness is that the size of loans is too small. If I were the CBR manager I would support the various DPOs with a credit scheme.”

When asked how they plan to finance their income generation activities (private and DPO activities) nobody among the interviewees believed that the resources could be raised locally. All of them talked about “sending proposals to NGOs” or “contacting individuals abroad”.

Accessing finance was seen as a general problem in the rural areas visited and many interviewees urged UNDP, commercial banks and the newly started Poverty Alleviation Programme to initiate lending operations in the area — accessible to everyone with a feasible idea.



The issue of control over the Revolving Loan Funds was also an issue. DPO representatives were adamant that they would be better suited to identify persons with viable ideas and to monitor and to support them in their businesses.

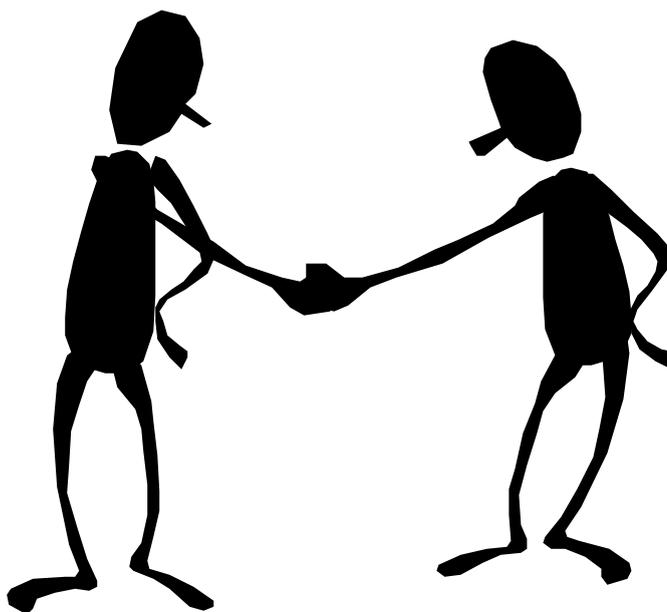
Government and community commitment

Ghana’s CBR programme is one of the few government driven CBR programmes aiming at national coverage. The commitment from the Ministry of Employment and Social Welfare has been substantial over the years. A national management team and District CBR agents are part of the structure that has been set up to implement the programme. UNDP has funded the programme from its country frame and UN agencies and Nordic NGOs have contributed. District authorities are slowly taking an interest in supporting the CBR programme. Despite this, the feeling of the interviewees is that government and community commitment is more moral than substantial. Families, communities and districts now increasingly accept children and adults with disabilities but they still do not see disabled persons as a priority when it comes to resource allocations. Structures such as the Local Supervisors and CBR Committees working on a voluntary basis cannot be sustained.

Support to DPOs

After a slow start the CBR programme is now reported to collaborate with and support DPOs both nationally and locally. Although the feeling is that persons with disabilities are still seen as beneficiaries rather than resource persons the support to DPOs in Ghana is much appreciated. The interviewees give many examples showing how the CBR programme has helped to mobilize members and to assist in the capacity building of the organizations. This has contributed to the improvement of quality of life of disabled persons because, through the DPOs, they have been able:

- To find companionship and social relations.
- To improve communication skills (especially in the case of the deaf).
- To start self-help programmes.
- To increasingly influence decisions in districts.



GUYANA'S CBR PROGRAMME

Background and organization

The Guyana Community-based Rehabilitation Programme (GCBRP) was started in 1986. It is a nongovernmental national organization with its headquarters in Georgetown. The organization is managed by a National Committee of nine members elected by the Regions, an Executive Committee, a part-time National Advisor and National staff at the headquarters. Operations in the regions are guided by Regional Committees. Regional Coordinators are responsible for the programme, including the management of Community Resource Units (CRUs).

There are two types of members in the organization — Ordinary Members and Supporting Members. The former consists of persons with disabilities and their family members; while the latter includes any person who is committed to the philosophy of the GCBRP.

Since 1989 the Amici di Raoul Follereau (an Italian NGO) and the European Union have been the main providers of funds to the programme.

GCBRP started as a small project and expanded to seven of the ten administrative regions of Guyana. The CBR programme aims at involving the community and the family in addressing the rights and needs of children with disabilities. It works with children with disabilities in four main areas: vision; hearing and speech; movement; and learning and focus on development of self-esteem and self-reliance of children with disabilities and their integration into the mainstream of society.

The organization has four major strategies:

Recruitment and training of volunteers. The intent of the programme is to maintain a cadre of capable and committed volunteers who can work in the communities. These volunteers receive a basic rehabilitation training of approximately 150 hours. Initially, the number of volunteers grew rapidly as the programme expanded to various regions. During the last three years, volunteer recruitment and training did not occur because of lack of funding.

Community-based Resource Units. The programme aims to establish CRUs as coordinating centres, e.g. places for skills training, socialization and networking, parent education and training. However, the main focus is on training in homes and on the living environments of children with disabilities, e.g. home-based basic rehabilitation services and coping skills, home and family support.

Income Generation Programme. The Income Generation Programme, which started in 1997, has been in response to the challenge of the economic circumstances of families of children with disabilities. The intent of the programme is to demonstrate the economic feasibility of a loan scheme and to use its results to advocate credit facilities geared to families and persons with disabilities. After three years in operation, the loan scheme has served 72 families, and has been considered a success in terms of repayment and benefits.

Disabled People's Organization Programme. Support has been given to the establishment of four Disabled People's Organizations (DPOs) in the regions in order to enable persons with disabilities and parents of children with disabilities to become self-advocates. The DPOs have their own structure and have begun to plan programmes to satisfy their specific needs.

However, because of the challenge of finances, transportation, leadership and management skills, DPOs have not yet been as visible as they would wish.

Previous evaluations and reports

The evaluation carried out in 1994³ reported that the GCBRP had made a major contribution to improving conditions for children with disabilities. The following improvements were reported:

- the family no longer pities the child
- the child is allowed and encouraged to be a more active participant in the life of the household
- the child is no longer hidden and closed out of shame or over-protectiveness
- the family is less ashamed and embarrassed
- the family shows more interest, understanding and acceptance of the child and renders more love, care and attention
- the parents feel happy and proud instead of being constantly worried
- the child and family relate and communicate with each other
- parents have hope about the children's future

The evaluation also mentioned some of the challenges:

- to involve the fathers
- to organize subsidized or free transport for disabled persons and their parents
- to provide skills training and loans for the children and youth with disabilities so that they can become self-reliant adults
- to use media more efficiently
- to seek alliances and alternative funding

According to the interviews in the present study these challenges are still being faced by the CBR programme. Furthermore, due to organizational changes and lack of funding in recent years, the activities and capacity of the CBR programme have declined significantly. In a WHO report from 1999⁴ the following observations were made:

- Volunteers need more training and incentives. Many volunteers have lost interest; others need to upgrade their skills.
- DPOs are weak and not involved. There are organizations for and of persons with disabilities in Guyana, but there is still no movement of persons with disabilities articulating a demand for rights. The CBR programme has not managed to mobilize and empower these organizations.
- Although there is a National Policy on Disability (and has been since 1997) and a Commission on Disability government departments remain passive. People with disabilities have been given low priority by health planners, and even less by development planners and policy-makers. Many of the training programmes, which used to be provided by government, have been curtailed and there is a lack of trained teachers in rehabilitation and special education.
- Rehabilitation services are not provided as part of the CBR programme and inclusive education depends on individual goodwill.

³ Miles J, Pierre L, Offering hope, an evaluation of the Guyana CBR program. AIFO, July 1994.

⁴ Florisse S, Report from a visit to Guyana, WHO, 1999.

- The CRUs are used in an ad hoc manner for meetings, skills training of parents, education for children and sign language classes.
- Positive results are mainly based on social counselling activities and the loan scheme.

Since 1999, GCBRP has been undergoing a process of restructuring and change. A visible result is its comprehensive programme plan covering the period 2000 to 2002. It is now on a development path with new funding from its international partner, AIFO.

Quality of life analysis

In Guyana all interviewees, except one, were parents of children with disabilities. The responses therefore reflect the perceptions of the parents, and not those of the children themselves. The interviews were made before the reconstruction of the organization and before the new programme plan was in place.



“CBR made us proud of our children”

Parents who joined the CBR programme describe how their attitude changed from being sad and ashamed to becoming proud of their children. These were the voices of some of the parents:

“I did not get involved at first since there was still some trauma in accepting that I had a daughter with disability. Friends and others ridiculed me. I was embarrassed and wanted to be in the background. It affected me just as it would affect other persons. With the persistence of the volunteer, I realized that there could be something good to be gained. My daughter may learn to do something good and in turn it will ease our responsibilities. Also we could learn to assist her development and that would help me personally, psychologically, emotionally in accepting the situation.”

“Since I started CBR, I am not depressed as I used to be — Oh, I have a child like this. By seeing other children and being involved my daughter has learnt a lot.”

“CBR has helped many parents, who have disabled children to come forth and not be ashamed of their children, e.g. when that parent first started coming, you could see that she was shy. But now that she (the mother) is more involved she is more open and comfortable and confident and she is now able to work better with her child.”

“We need parents’ involvement for CBR to succeed”

From being alone and frustrated at not knowing what to do or where to go, parents are now announcing that they are aware of many with disabled children. CBR has brought the parents together and they have started to communicate, exchange experiences and educate themselves. Parents have also realized that their involvement is needed for CBR to progress and for the right steps and decisions to be taken.

The following was said about parents' involvement:

“Since I have known about CBR I have learned a lot. I learnt that there are many other disabled children so that mine is not the only one and with my experience I can advise other parents. Because for 16 years I have had to deal with my child so I have a lot of experience. So that whatever I have learned from CBR I can share with younger parents how to keep the child entertained and not to keep him home so that he can get to interact with others. Before that I usually kept my child at home for fear that someone would laugh at him, only his parents could have communicated with him. It is really nice to be associated with CBR.”

“I think that the policy-makers understand that they cannot make decisions for us without consulting us who are in the situations and knows exactly the way it feels.”

“The parents of CBR have a bond because of the concern for their children. They are able to rise above the hurdles such as religion, status, race, etc. They just look at the common cause they are there for and because of the fact that the children have a lot to do with how you feel and because of this there is an emotional attachment to our kids. This has helped to create a bond amongst the group and there is trust we can say to each other how we feel with out any reservations, despite we have not know each other for a long time.”

On the organizational level parents seem to be influential in the CBR programme. They make up 50% of the regional and national committees. Decision-making, proposal writing and funding is decentralized to the members of the regional committees who take initiatives for action, such as finding land for building a resource centre, solving transportation problems, and organizing training programmes, workshops, camps, etc. It should be noted, however, that persons with disabilities themselves are completely absent from participation and decision-making positions. One would expect that after 14 years of operation of the CBR programme at least some young adults with disabilities would have developed into excellent candidates for employment, volunteering or executive positions in the regions.

A leadership crisis a few years ago greatly disempowered the organization and many parents left. The once-established CBR groups in the communities no longer function and many volunteers have lost interest due to lack of recognition, back-up and refresher training. However, democracy seems to be strengthened and the fighting spirit in the CBR programme is growing again:

“Things began to go amiss so we had kind of a breakdown. We were making proposals and we were not hearing anything. We would want to find out what was happening and we would be distracted because we were asked to do something else. We read between the lines that something wasn't right and eventually the national committee picked up on it and things were streamlined so we got on track again.”

“We had to pull ourselves together and decide that this thing cannot die because there are persons who are looking forward to our help. We need to move on. Persons with disabilities need to be oriented and socialized, live and take their rightful place in society. So we just decided: Let's do it!”

“CBR revolutionized the concept of social acceptance”

All parents have suffered difficult times regarding their own and the environment's acceptance of receiving a child with disability. Their stories vary and the attitudes seem to be more understanding and supportive the younger the child. One mother says, “CBR has helped me and, as I tell you, friends and neighbours they come into my house and encourage me.” Yet other parents have been given advice such as “Why don't you go and throw that thing away?” or “Carry him to the deaf and dumb school”. People in the community assume their own reasons and religious taboos for the cause of the disability, and their attitudes have made it difficult for some parents to accept the child. The general feeling was that the CBR programme brought about many changes in the social acceptance of children with disabilities:

“When the CBR programme started the community members got involved. Parents initially shy brought their children out and, as this happened, the false names that the children were called became a thing of the past.”

“CBR is good in the sense that it brought out so many other persons that had children with disabilities to understand that they had a place in society and that they should not be locked away and be kept indoors. CBR brought them out.”

“Self-reliance is a concern for the future”

Many parents testify that, based on advice from CBR volunteers, they increased interaction with their children, trained them in daily living skills and allowed them to try new things. As a result children are reported to have become more self-reliant in their homes and even contribute to household activities.

“CBR has made a difference in all our families' lives. From the inception when the child could not do anything for himself, it was very frustrating not knowing what to do and where to go for help and this is where CBR came into our lives. It has worked tremendously for other families and us.”

“She learnt how to do things for herself — bathing, go to the toilet, she can identify a bucket, cup, plate and understands instructions ‘go’, ‘come’, ‘no’, etc. I did learn how to teach her.”

“At home she helps with wiping, feeding the ducks, washing the dishes, making up the bed, folding the pillowcase, packing the goods, fetching the goods, etc.”

However, parents have many worries about the future of their children and some parents do not see how their children will manage to live independently as adults. The CBR programme has become a parent-oriented programme and has not focused enough on developing care facilities or vocational skills training for youth and adults. The programme has focused more on the skills training and income maintenance of the parents rather than on the future independence of the children. This was a concern already voiced in the 1994 evaluation.

“There was no improvement by our observation”

In this study, no children aged between 5 and 18 years have received early interventions. The stories below illustrate the level of medical care and help received by the parents.

“From since he was born (knew something was wrong) because when he was born he did not cry and I hear the nurse saying that something is wrong with this child and they had to rush him and put him in the incubator. When I start going to the hospital I look at him and see he looks different from the other children. His face was different. And then when he starts to grow, he can’t do anything, and just how you put him to lie down he would remain the same way and he didn’t turn and twist. And then we start taking him to doctors here in Essequibo and in Georgetown. Doctor says that something happen to his brain and he might grow it out and they can’t do any thing more. It took him about nearly two years before he could sit down and then he took about a next year before he could balance on foot and start walking.”

“We did not know from the beginning. Our child was born at the Public Hospital Georgetown. There was difficulty in the birth period and we did have a problem in getting the doctor to explain to us. We were told it was related to jaundice but subsequently everything would be okay. As time went by there was no improvement by our observation. At the paediatric clinic the doctors still said everything would be okay, she would develop. It was not until some years after we knew she was disabled. She had difficulty moving, keeping her head up.”

“It all depends on our dedication”

Parents feel that community involvement in the CBR programme is very limited. A father who joined the CBR programme at its initiation is convinced that “If anything should happen to the dedication of parents we would not be achieving much more”.

The involvement of government authorities has also been limited. The need for mobilization is urgent and future actions have been discussed. The need to involve the education and health authorities was stressed. One father, discontent with the lack of educational opportunities for his child, said: “We think the training (of teachers) should be continuous. We should form a group and go to the Ministry of Education and see how much support you can get”.

It is encouraging to note that the new plan of action for Guyana’s CBR programme has been developed as a collaborative effort with the Ministry of Health.



Analysis of CBR programme initiatives

The impact of the different CBR programme initiatives can be concluded from the interviews in Guyana.

Awareness-raising

The major programme initiatives that have influenced the quality of life of families with children with disabilities seem to be related to awareness-raising. The most successful ways of raising awareness are reported as

- social counselling and advice to families and individuals in their homes
- empowerment workshops for parents
- parents' meetings and self-help groups

Medical care

Access to medical care is reported to be limited: early detection is poor, the treatments are inadequate and the high costs exclude the majority of persons with disabilities. In this study none of the families had received adequate medical diagnosis, advice or treatments when the child was born. The only radical intervention reported, an operation, was not successful:

“When he was born his foot was turned in. He (a doctor) said that he would operate on him, to help him to walk. He did more damage. He made three (operations), one at the Georgetown Hospital and two at St. Joseph Mercy Hospital (private). We did get help (financial) from the Women's United Group (NGO). The CBR programme could not help with funding. They explained that CBR is about training of parents and guidance to assist the child with the disability, especially at home.”

Rehabilitation and support services

Rehabilitation and support services are provided by volunteers who make home visits and by the CRUs that serve as referral points for the communities. The efficiency of the home visits has declined as no new volunteers have been trained and old ones lose motivation. The efficiency of the units varies but common problems are:

- The units are mainly used by the communities in which they are situated because the cost of transportation is too high for families coming from far away. This means that the units are not accessible for the majority of families.
- The units do not seem to provide physical rehabilitation services for children as the professional back-up is missing.

However, the CRUs are appreciated for their social support, and skills training activities **for parents**. Some units also have classes for children who do not cope well in ordinary schools.

“We sit and plan what we are going to make, then we will talk about our personal affairs. We usually talk about our family, how you relate to your husband (no fathers are joining) and children and their behaviour. If I have a problem I might tell it to (name of a mother) and she will advise me what to do.”

“I did not know how to read and write properly, but coming here I improved on what I knew. I am learning all the time by reading.”

“It is very good, because they (the volunteers at the unit) have taught my son to spell and play games and have also taught the parents handicraft, needlework, knitting, etc., on Thursdays. I like the knitting and handicraft and I have been able to sell some work.”

“The unit in my area would be used to get the parents together and they would learn from each other and to give them the strength, by telling each other problems of their child. Sometimes parents come into contact and they assist each other. Like if one parent is working and the other is at home, she can bring her child and I would look at her child while she is at work and you have things like that.”

Parents discussed many aspects of the CRUs and some ideas were suggested to overcome the problems:

- To establish a unit in every community by using public spaces, such as nurseries or health centres.
- To invest in a CBR vehicle for transportation. One mother said, “The basic challenge is transportation. Getting a building is one but getting persons to the building is the other. Once we get rid of our transportation difficulty we don’t have any other problem”.
- To systematically use the units as training centres for children with disabilities who could not manage in an ordinary class.



A number of children have received physiotherapy treatment or sign language training. Volunteers, sometimes with professional guidance, train the children at home or at the resource centre. Parents have observed that neither the quality nor the quantity of interventions is sufficient. Their desire is to obtain the cooperation of qualified staff as an ongoing process.

“We (parents) would like to have qualified staff to use the equipment that we have because it’s only the volunteers that can use them; we need physiotherapists, occupational therapists, sign language teachers who can come to the centre, if only once a week.”

The CBR programme has no support services, e.g., no production of simple and inexpensive assistive devices using local material. The Ptolemy Reid Rehabilitation Centre in Georgetown is providing assistive devices and equipment. From time to time hearing aids are available. A problem is that the devices and equipment are not free of charge and many persons with disabilities cannot afford to buy what they need.

“Another problem we have is mobility aid. About six years ago we had to start paying for mobility aid. I thought that was quite ridiculous since a high percentage of persons with disability do not work. How could you pay for mobility aid when you do not work? Through that a lot of people have been hindered by not getting appropriate mobility aid. If you’re going to consider getting people jobs, I mean your boss will expect you to be on time daily and wants 110% from you. How can you give that if your crutches don’t have rubber? Or you have to pay \$20 000 just to change an instep. Also, your leg may not be durable enough for the road with potholes, mud and sand. Your chair is not a sports chair or a roadworthy chair. So there is lots of contributing factors that can overwhelm a person with disabilities when we try to live a life in society.”

Education

Parents hold their own views on education depending on the disability of their child and their individual experience. Educational opportunities for children and youth with disabilities are unpredictable and often dependent on the attitude of the personnel in the ordinary schools and the accessibility of alternative training. Through the CBR programme many teachers are trained volunteers, and they have achieved some knowledge on how to assist children with disabilities. The training has not lately been an ongoing process; many volunteer teachers have moved or been transferred, and children are integrated in classes where teachers have little knowledge of special needs. The classes count about 40–50 pupils, and many classes share a whole floor without partitions.

Concerning the acceptance of children with disabilities at ordinary schools, parents again have different experiences depending on the disability of their child, the school environment and the capacity of the teacher. Contradictory statements illustrate these varied experiences. Some of the parents told discouraging stories:

“My son started nursery school. There wasn’t any problem, because all the staff are volunteers who know the problem. But when he went to primary school there was this difficulty, like children hitting him, pushing him around and not allowing him to pass, etc. I spoke to the head teacher about how they should assist children with disabilities, instead of taking advantage of them. But the ill treatment continued with other children who are not in his class.”

“The educational programme was not geared for persons like that. All that is needed is a demonstration for the child to learn, e.g. mixing of two colours to get another. They (hearing impaired) could do the job much better than those listening and hearing could because they know that they have to show that they are able. No, so the person (the teacher) just did not want to have the student. The child is very sensitive. Children are aware when told off, or when you are not helping them as they think you should.”

“He did not get on very well (at school). The teachers did not pay any interest to him because he was not learning anything, and the children were beating and mocking him. So we just had to keep him home from school.”

Other parents experienced cooperation and understanding, and a supportive attitude at the schools:

“She gets on well (at school), she writes but she cannot read. She interacts with the teachers and children. She shows them when she wants something; the teacher also explains to her what is on the blackboard. I really try to find out how she is getting on at school. The teachers show me. Her father also goes there often. When she comes home she opens her book to show me and I help with whatever she cannot understand. If I do it different from the teacher she shows me instead. If I need some assistance I would sometimes write a note and send it (to school).”

“When my son went to school he was uncomfortable but as he moved from class to class with the same pupils they took him as their responsibility. Though the teachers had reservations, they had to adjust because the children were comfortable with him. In that way the whole school accepted him”.

Parents of children with hearing impairments stress the need for training in communication and sign language. This has been provided on an ad hoc basis at several CRUs. Here is the viewpoint of one mother:

“He (my son) attended all the schools from nursery to primary. He got on well, no one mocked him, he was well adjusted at school from the beginning and learnt to write and read a little. You could not tell how much he could hear, but by reading and visualizing he communicated, you know he understood. I am stressing about the training in sign language and communication. These areas are special and necessary in order to earn and become independent. They (the hearing impaired) should have ways in which they can express themselves and feel that they are understood.”



For some children with intellectual disabilities it is difficult to acquire a good start in life. In Guyana two different strategies have been used to organize training for these children:

- home-based training with the support of volunteers
- training at the CBR units

A mother receiving home-based assistance from a volunteer discovered that her son could learn new things and that he showed interest in learning.

“He learns a lot, he learns to colour. She (the volunteer) would draw shapes and he would know to pick them out, and he knows to count from one to ten, he knows the days of the week, he knows to match things. For these children to learn something they need training. I would like to at least know that in next five years when he is an adult, he must learn something he can make a living out of.”

In another area of Guyana, where there is a CBR Unit, the small children and those who cannot attend the ordinary school are invited to join classes three mornings a week. The parents are very happy about this opportunity for their children to gather, play, sing and learn and profit from special attention.

“It means a lot to me and my daughter, more so to her, since she is happy when she sees the other children. She can play, ride the cycle, she meets new children and communicates with others. She learnt how to do things for herself — bathing, go to the toilet, she can identify a bucket, cup and plate and understands instructions ‘go’, ‘come’, ‘no’, etc. I did learn how to teach her.”

In areas where the CBR programme has no resource centre or unit, the possibilities for parents to organize activities by themselves are limited, as illustrated in the following story:

“I went to the nursery school and the teacher and the headmistress told me that they cannot accept this child because she doesn’t have enough sense and the rest of the children will keep looking at her and they might be distracted seeing a child like this. I don’t know how it will end for a child like mine. I noticed she can learn (being trained by a CBR volunteer), she can do many other things, you know she would be livelier, more active (if she could go to school). Really I am trying my best but we don’t have the facility for children like her. Parents cannot afford to buy a place and make a school, we need assistance.”

Solving problems and finding solutions for a child depends on where you live and the attitudes in the local community. A child with a similar disability and family situation to the case mentioned above could have several options in another district: a supportive nursery school, a CBR unit with classes and a special school within the region.

Income maintenance and social security

The Income Generation Programme, which is part of the CBR programme, has helped parents to receive loans so that they can create a business to make a living and cope with the well-being of the child.

“Mothers that received loans are not working. They stay at home to take care of the child with disability. That mother can access loans on behalf of the child. You have to be a member of CBR to be eligible for a loan, attend meetings, be involved at the unit levels, pay early subscription.”

“I (a single mother) took the income generation (loan). More money was needed, if not my business would fail. I would not have stock. People do not ‘trust’ so you are not allowed to pay for goods after you have made a turnover (profit). You have to pay cash.”

In most cases the parents receive the loans and the skills training — not the child. As it is not possible for all children with disabilities to make their own living this may be the only solution. The income-generating activities that the parents start will hopefully give enough profit to provide a savings account for the future of the child. In Guyana social security provision is a family responsibility and parents describe precautions that they have taken.

“We (the parents) are making provisions for her (child with disability) in the event we are not around. We are building a house with a ramp, also the house cannot be sold, and she will live there until she dies. Also, ensuring that financially she is taken care of.”

However, parents need to accept and to support the independence of their children as much as possible. Ideally, the loans and skills training should firstly be given to them. There are few examples of parents taking on this responsibility but one father had the following story to tell about his son who has a hearing impairment:

“He has finished school and I am an electrician so he spends most of his time assisting me and I feel he is showing a lot of interest. I idolize in him for he is my first son and once I am around he would make it in life. I am doing my own work so I usually train him.”

“He also shows interest in poultry and I am planning to expand the business to maybe more than 50 heads of chickens. I got from the CBR a loan scheme and from the income we plug it back into the business. He was able to get his clothes, so he sees it as his business since he is gaining something from it. Whatever he needs he is able to buy it for himself, but we would manage the money putting aside how much capital he needs, etc. He buys the chicks at a day old and rears them, after which he sells them. He supplies two shops and the neighbours.”

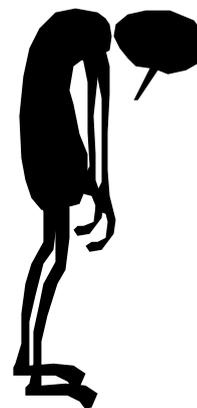
There are few examples of disabled persons themselves receiving support for income generation, as stated by this young person:

“I think the loans have done a lot for persons with disabilities to start their own business to improve their social and economical being. It is not easy for them (PWD) to obtain employment in Guyana — there are few agencies that employ.”

Government and community commitment

The progress and sustainability of the CBR programme seem to be based on the parents’ commitment and hard work. There is no sense of ownership of or responsibility for the CBR programme outside the organization itself. Despite the National Policy adopted in 1997, the government has not shown commitment in the form of resource allocation or supportive actions to promote the rights of children and adults with disabilities. Community contributions are generally moral and not material. As one person said:

“There are a limited number of persons and organizations that donate locally so they are worn out of giving.”



Support to DPOs

GCBRP has supported the establishment of DPOs in four regions. These DPOs are primarily organizations of parents and youths, and they are seen as arms of the CBR programme. The relation between GCBRP and DPOs did not seem entirely clear, as the following statements show:

“Yes, they (DPOs) have their own meetings, boards, etc. They usually decide what they want but the two units usually coordinate. It (the DPO) is registered under CBR because it is really an arm of CBR.”

“It is a good idea (Parents’ Organization) but the question is how many parents will come? But I guess that is where mobilization comes in.”

“There were meetings with all relatives of the disabled children and there we would decide on what needs to be done and make proposals, which then would be listed according to their priority. This really worked in the past. The reason why the group fell apart is that those who attend the meetings just go and return home without communicating the information to others or visiting others to share the information or progress that the unit is making or its goals.”

“At the meetings there would be a lot of plans made but after that there is hardly any action we need to be more active.”

“I think the DPO (the young people’s arm of CBR) caters for the growing children.”

These DPOs operate as branches of the CBR programme rather than linking up to existing (but weak) national DPOs. Strengthening of independent DPOs at national and regional levels does not seem to have been part of the CBR programme initiatives.

One young adult with experience of disability from childhood, involvement in GCBRP and participation in the young people’s arm of CBR added:

“What probably should be done is that the young people themselves in the DPOs should form strong advocacy groups and become watchdogs concerning the issues with persons with disabilities. For example, we have a policy document up. Yet new schools are being built without consideration of access for persons with disabilities. Had there been a strong young people’s group it would have gone and advocated. So in the next five to ten years anything they build would be accessible.

There’s also a need in Guyana for an organization for parents who have children born with multiple disabilities. The person who acquired the disability may have had the opportunity to go through at least primary school and their education maybe stopped at the point when they got the disability but they have some foundation. But when you’re born with a disability you’re totally neglected and a high percentage of us have never gone to school or have acquired working skills.

We tend to look at what we don’t have instead of what we can achieve. In Japan a parents’ organization actually did a sit-in and were asked by Parliament what could be done for them. That fighting spirit we lack in Guyana. A lot of us hide under the excuse that we cannot do this or that but if we really have that inner deep motivation we can rise above it. Most persons with disability are in the poverty zone and very few come out of it.”

NEPAL'S NDA CBR PROGRAMME

Background and organization

The CBR programme in Nepal is implemented by the Nepal Disabled Association (NDA), an organization founded in 1969 with the mission of enabling persons with disabilities to lead a life of dignity and self-respect. The CBR programme is one of five separate programmes undertaken by NDA. The others are: Special Education and Vocational Training; Ryder Cheshire Home; SOS Children Village; Nepal Orthopaedic Hospital.

The SHIA funded CBR programme started in 1991 and it is one of many CBR programmes in Nepal. The development objectives of the programme are:

- To improve the quality of life of disabled persons by providing rehabilitation services and opportunities for education, mobility, participation in community development and employment.
- To create an environment in the community where both the disabled and the non-disabled can mutually respect each other.
- To support persons with disabilities so that they can influence all activities carried out in their interest.
- To empower persons with disabilities to take leadership to run and to sustain CBR in the future.

The main programme initiatives to achieve these objectives are:

- To provide disabled persons with medical, vocational, educational, economic and social rehabilitation services in their own community.
- To support persons with disabilities to become functionally literate.
- To provide persons with disabilities with assistive devices, mobility and sign language in accordance with their needs.
- To raise public awareness on disability prevention and rehabilitation.
- To assist persons with disabilities in improving their community life through leadership training and counselling.
- To encourage disabled persons to form their own organizations.
- To train community people to implement CBR programmes on their own by using local resources.
- To orient and train CBR resource persons to ensure sustainability of the CBR programme.

The implementation is carried out through the formation of CBR Committees in the villages where there is a willingness to start a CBR programme. The committees consist of local leaders and professionals who work out plans and proposals and suggest a CBR local supervisor and a CBR fieldworker to be employed by the programme. NDA at central and district levels then trains these community workers and gives them technical back-up support. It is agreed from the start that the financial support and supervision will only continue for a limited time of 3–4 years, after which the programme must be locally sustained. The intention is for disabled persons, by that time, to have formed their own Disabled Organizational Development Group (DODG), which can take over the continued development of the programme. Training in leadership and fund-raising options is part of the programme.

The CBR programme has targeted 21 villages in 11 districts of Nepal (out of 75 districts and approximately 4000 villages). SHIA and the Ministry of Welfare and Social Services financially support the CBR programme. To date, approximately 2534 persons with

disabilities have been reached: 64% are men and 36% are women; 44% are physically disabled, 27% hearing impaired, 19% visually impaired and 7% intellectually disabled. The remaining 3% have other types of disabilities.

Previous evaluations and reports

Previous evaluations and reports^{5 6} conclude some of the lessons learnt during the 10 years of implementation of the CBR programme. In their report the NDA highlights the following constraints:

- There is still no national government policy on disability to guide NGO and government programmes.
- Absence of rehabilitation specialists outside Kathmandu creates problems in delivering the needed services.
- Existing health facilities are not sufficient.
- Superstition and prejudice still prevail against persons with disabilities.
- Community people prefer traditional healers to modern medicine.
- It is difficult to find local female social workers who can leave their household confines and participate actively in CBR programmes.
- Dominant ethnic groups deny disabled persons in the lower cast from socializing.

The evaluation report from 1998 found that:

- Self-esteem had increased among disabled persons, especially those who had an opportunity to attend school or to obtain training. Some of the women had gained confidence from income generation and participation in self-help groups.
- Self-confidence was noted among children who learned to sign, read and write. Sign language training has become a significant part of the programme in some communities — in collaboration with the Association of the Deaf. This initiative is impressive and has a substantial impact on quality of life for persons with hearing impairments.

However, the evaluation was concerned that:

- The programme reaches few persons with disabilities. In some of the targeted communities less than 40% of the disabled population are contacted.
- Persons with severe disabilities are seldom included. The majority of the persons benefiting from the CBR projects have small or moderate physical disabilities.
- Families indicated that there was little change in attitudes towards disabled persons. Changes in attitudes concerned those families where the person with a disability was now able to make a financial contribution towards the family.
- Few persons had access to appropriate assistive devices. None of the community CBR workers had any concept of how to make or to repair assistive devices with local resources.
- NDA needs to improve its organizational and management structures and to transform into an organization of persons with disabilities.

⁵ Evaluation report NDA/NHR/SHIA CBR Program Nepal, December 1998.

⁶ A Decade with CBR NDA, May 2001.

Quality of life analysis

The interviews in Nepal focus on the views of the women. The following describes their observations on the impact of the CBR programme on quality of life.

“It helps you grow strong inside”

Almost all the interviewees noted the positive impact on self-esteem:

“Since the participation in the training (leadership) I’ve confidence in myself. I’ve a feeling that now no one can push me backward or can’t be looked upon as a person without capabilities. The training has broadened my ideas and knowledge and it has helped me to build up determination to face every kind of challenge and made me enthusiastic to work to support my family and myself.”

“I used to be a very shy girl and felt hesitant to speak a word in front of 2–3 persons. This was because of the discrimination and the way non-disabled persons looked upon me. Since the programme was launched in this village we came to know about disability and learn to support ourselves through different trainings. Now I have confidence on me and I’m able to introduce myself in mass and speak my mind.”

“This programme not only helps to uplift the economic background of disabled persons but also helps them to grow strong inside.”

“Though I’m physically disabled, I’ve gained confidence that makes me think myself as a woman, a normal person rather than a woman with disabilities. I don’t forget my disability but I think this disability should not be an obstacle in approaching forward and it shouldn’t affect the capabilities and abilities of the mind. Had I taken myself as a disabled person I wouldn’t have been able to run the shop successfully and sewing dresses for the people.”

“I feel content and feel like disabled people also have an identity in this village. So I feel very happy.”



“We can fight for our rights”

The CBR programme has contributed to the empowerment of persons with disabilities and to the formation of Disabled Organizational Development Groups (DODGs) that are able to take on the responsibility for sustaining the CBR programme. Several DODGs have managed to raise funds — even grants from the village authorities — and have set up loan funds and accounts for subsidies to school fees, assistive devices and medical treatment.

These are the stories told:

“Before the CBR was launched in this village we didn’t know the number of disabled people living in this community. We only saw them and knew about their disabilities. But now we have strong relationship among ourselves. We can do everything according to our desires. We came to know that my disability is different from hers or his, but in one way or another we support each other, which we have learned through the CBR Programme’s guidance and support.”

“We can do everything through this DODG unity. We can fight for our rights in this community. If anybody hampers our way of progress we can tackle them and stop them from doing anything negative on our part. If somebody says ‘you are this or that’ we can go through this DODG and convince them that you should not say that.”

“Before this programme I used to think that I’m the only one with disability but after participation in various programmes I came to know other disabled people from Nepal itself and from foreign countries too like Ulla didi and Sonia didi from Sweden. Seeing them coming from a far land just to help other disabilities something clicked in my mind and I thought that disabled people could also do the work according to their capabilities and support themselves.”

“Whatever I’ve gained through programmes, I like to use to help other disabled persons. Being myself disabled, I know that disabled persons have some inferiority problems so they keep themselves at home not exposing their skills and talents in society. I’ll go to their places and give advice to them so that they can help themselves from not being a burden to their family by grabbing the opportunities, which they haven’t been able to see. I’ll use my knowledge to wash away their fears of being pulled down.”

The women also had specific ideas of starting a women’s group:

“We had many experiences in which we had to go to the village or district authorities with applications or proposals and as we are not able to read and write we had to ask men for their help. It was a very embarrassing moment as well as we’re not able to include all the things we’d liked to. So, it’s very important to have a separate group and women writing for the group.”

“It is a good idea to have a separate women’s group but in our community women remain very busy with their household activities so they are not able to attend the meeting. Most of the girls both disabled and non-disabled are married, and married women are very busy compared to unmarried ones.”

“Till now this programme is only for persons with disabilities but it will be more prestigious if we include non-disabled persons to the programme. Because in this village there are not only disabled women who suffer but there are non-disabled women who suffer equally and are tortured or left by their husbands. Such women live in very poor financial conditions; besides this they have responsibilities of growing up their children. This type of problem is especially with married women who have been left by their husbands. I think the programme should also be organized for them.”



“Revolution has come to the disabled people of this community”

Social acceptance and inclusion have improved greatly, although some prejudice still exists. The practice of calling persons with disabilities by nicknames (referring to the disability) has decreased dramatically. Acceptance is often linked to the ability to contribute to family income.

“Before the launching of the CBR programme in this village we used to sit at home idly doing no work. Neither had we confidence that we could do anything to support our family, nor our family believed in us that we could also be professional. But with the introduction of the CBR, we had vocational training; we built up confidence and started our own small business, which changed the attitudes and beliefs toward us.”

“There has been a vast change in attitude towards persons with disabilities. Before, the family with a disabled person was looked down on by the society. If the family had a member who was mentally weak, dumb, deaf or any kind of disability, the rest of the family members faced humiliation if they participated in any social activities. Because of the fear of being humiliated by the society, the family members did not take them to any kind of social events or during the festivals. Virtually going outside the house was banned for them. So the parents or family members were worried about their future but now the revolution has come to the disabled people of this community. Many families are getting support from their disabled family members.”

The women continued:

“Before the CBR Programme was launched in this village, the disabled people were teased and humiliated by the local people. These activities made them hesitate to go outside so they had no choice other than to sit at home idly. But since the CBR Programme started in this village there has been drastic change in the life of persons with disabilities. They gave trainings of different skilful activities to disabled people and made them capable to earn money on their own. Now the disabled children go to school where non-disabled children study. They are not teased like before but it’s not completely gone either.”

“They were many parents in this place who didn’t send their disabled children to school even though they could afford it because they worried about their children being humiliated and pulled away by the mass. Besides they thought the disabled children could not read or write. But with the CBR Programmes run in this place people got aware about the disabilities and the way to sort out the dependency problem of disabilities.”

“Yes, now we are much more confident that we are also a major part of this society. We are no weaker than non-disabled people in this community. We are equally as strong and can assist our family.”



“We can tell you some successful stories”

Self-reliance is generally linked to the ability to contribute to the family income but it also concerns mobility and personal hygiene. Most of the interviewees reported that self-reliance had increased as a result of the CBR programme. Many persons with disabilities had received loans to purchase chickens, ducks or goats, which gave them an income as soon as they could sell the offspring. Others had opened retail shops or tailoring businesses. These are some of the stories told:

“If the CBR Programme were not launched in this area I would have never come this far. I mean I would be staying at home the whole day depending on family for everything. I would be crawling on the ground, others staring at me and querying about my disability. But this programme has changed my life positively. Before this programme I had to depend on the family but now I can support them with my independent professions.”

“If I went outside people would stare at me and used to say that though I have a beautiful face and body it is just worthless, as I can’t walk. So they just pitied me but my parents love me and supported me greatly. Now, I can go a longer distance with the help of a wheelchair (from Sweden). And I can change cloths for myself during the period. I can wash them. I can take a bath without support of my mother, sisters or sisters-in-law.”

“Now I’m benefiting from this business and feel proud that I’m not dependent on my husband. Because in our society all women are dependent on men but in my case I’ve my own business raising the children by myself and I feel very happy about that.”

“Disabled persons should not sit ideally, instead they should be engaged in skilful activities so that they become independent and show to the non-disabled that disabled persons are also no less than them.”

“He beat me with an aloe plant”

Some of the interviewees had in fact improved their physical well-being through the CBR programme: the reason being that the CBR programme provides funding for medical treatment and surgery in specialist hospitals in the capital, Kathmandu. However, in most cases the traditional healer was the first option:

“I went to the healer for one year. He used to put some locally made medicine on my legs and also asked us to give sacrifices of animals like goats and chickens in some temples. But nothing helped my condition. Then I went to a hospital but the medication didn’t help me. I couldn’t stand on my legs and I was not able to bend them either. I used to work by crawling and sitting because the doctors and sisters had suggested to me that I wouldn’t be able to do anything and my condition would be degraded more if I sat idly. So I started doing things in whatever way I could.”

“Three blind persons got the medical check-ups from CBR and they got spectacles. Six people got surgical treatment. CBR has links with hospitals like HRDC and ADRA. These hospitals are especially for the surgical treatment of different kinds of deformities. The CBR office pays the hospital bills.”

“The traditional healer beat me with an aloe plant. It’s a common belief in the village that the people who are jealous of you, could put a spell on you and the person becomes ill or will have pain in the specific part of their body. So when such a person is bitten by an aloe plant the pain of biting is actually felt by the person who has put the spell. So they thought that somebody had put a spell on me. I was covered by a blanket and beaten by an aloe plant. It was very painful and I cried of pain, then my father told that if the pain were due to the spell or something like that I would not feel any pain. So we refused to get the treatment from the healer and he brought me back home. After that we went to the hospital. The doctor at the hospital scolded us because it was late for a good treatment. After 5 days I had surgery and stayed 2/3 months in hospital. When I came back home, the assistant of the doctor visited my home to clean up the wound. When I tried to walk I couldn’t. It was only possible by keeping my hands on my knees. I had to go to the hospital once in 6/7 days and I used to walk keeping my hands on my knees. Though I tried to walk properly I was not able to. At that time my sister wasn’t married and sometimes with the support of my father and sister I used to go for a check-up in the hospital. After going for the continuous treatment I was able to walk without any support. It took 2 years for the recovery.”

Stories vary about assistive devices and rehabilitation. Some people have received advice on how to do exercises — some have figured it out on their own — some are using locally made walking sticks or crutches. The central CBR office acts as intermediary to buy sophisticated supports such as wheelchairs from the market. A few people have received expensive equipment from Sweden. Unfortunately, such equipment cannot be maintained locally and it soon becomes impractical.

“It’s a good sign from government”

Although there is still no National Policy or plan of action in Nepal the interviewees could see some positive signs:

“Two or three years back we hadn’t seen any interest and effort from the government side shown in developing the condition of PWD but now we hear on radio and see on NTV, different kinds of programmes relating to disability being broadcasted. This shows that the government is also stepping towards helping persons with disabilities. We have also heard that from the coming-up census they are counting the population of disabled persons in Nepal. So, it’s a good sign from the government side.”

Although community commitment seems to decrease when support from NDA and international donors is phased out there are positive reports from the newly established DODGs that they increasingly manage to obtain grants from village authorities and that the interest they charge on the revolving loan funds can sustain some of their work in the future.

Analysis of CBR programme initiatives

The most appreciated CBR initiative in Nepal seems to be the loans that are given to support income generation activities. When disabled persons are able to contribute to family income their status, self-confidence and social acceptance increase. Other initiatives were also appreciated as indicated below.

Awareness-raising

CBR awareness-raising was mainly advanced at public meetings and during visits with the village leadership. These activities were considered valuable, as the following statements show:

“The most important thing is to bring changes in their (community members) attitudes towards PWD. We have to make them aware of the things that PWD can do to support themselves. We have to counsel them, giving examples of disabled people who are doing well in life.”

“The most valuable was when CBR representatives gave inspirational speeches in front of the village office. I don’t remember them all except one thing: they told us that disabled persons could do anything if they had good skills and financial support. They can be independent and can stand in competition with non-disabled persons in every field if they are given the opportunity and if the disabled themselves are confident and determined on what they are doing. At that moment I promised to myself that I would show my husband that there isn’t anything that I can’t do to support and bring up my children. Though I didn’t tell this to anybody I felt a strong determination within me that I can do everything whether it be men’s work or anything else.”

“I came to know that awareness is the most important over any other activities. In the first place we should be aware of the parents of disabled children and the teachers under the guidance of whom these children will find themselves.”

It was emphasized that the most effective way to influence attitudes and perceptions was through exposure of role models — persons with disabilities who were considered successful in life. Many of the women testified that the discrimination and ill-treatment of women was just as bad as discrimination and ill-treatment of disabled persons and should be equally addressed.

Medical care

The CBR programme has established linkages to specialist hospitals and has provided funds for medical treatment. This has led to the successful treatment of some disabled persons. However, the practice of using traditional healers as the first option for treatment is still the most common. This means that early interventions are few. As long as medical treatment is not free it will remain inaccessible for most persons with disabilities.

Rehabilitation and support services

The programme initiatives reported as most successful were social counselling, training in daily living skills and mobility and sign language training. The provision of physical rehabilitation services and provision of assistive devices was seen as a less important part of

the programme — maybe because of the low quality of these services⁷. However, it was seen as absolutely essential that the CBR programme continues to contribute towards the cost of purchasing assistive devices; otherwise they will be inaccessible for the large majority of persons in need.

Education

The interviewees do not mention access to basic education as the most essential CBR initiative. As one father said, “Education is not our first priority”. However, there was disagreement among the persons interviewed on this issue. One person said:

“Educating a child is very important whether he is disabled or non-disabled. Moreover, a disabled child should be educated even more than a non-disabled one because a disabled person cannot do field and other labouring work. So the easiest way for him to live independently is by being educated.

There are some parents of disabled children who don’t send them to school. Such parents should be counselled in the programme that your children should be educated, that’s the only way of making them a respected man in the society.”

Although it is appreciated that the CBR programme has successfully integrated children with physical disabilities into nearby schools, education is seen as a luxury by many. This successful inclusion of children has been made possible because of contributions by the CBR programme towards school fees, books and uniforms. Some of these children have already become important role models.

In one village the CBR programme managed to convince the school authorities to move a secondary school closer to the community to accommodate a girl with a disability. This was much appreciated by the community as it has benefited all children.

The CBR programme does not promote inclusion of children who are deaf, blind or intellectually disabled because the present school system is unable to give these children a fair chance and the relevant support. Instead, they assist these children to go to special schools or encourage the establishment of special units in the local schools. This was also the view of persons with disabilities themselves:

“Teachers should be trained specifically for students who are blind and deaf. At the moment we don’t have blind children because the teacher must know their way of reading and writing. If she doesn’t know about Braille then it’s worthless that any blind child goes to school. He won’t learn anything; it will only be like going and coming from school. Similarly in case of deaf children, teachers should also know about their sign languages. Then, only the deaf students can learn things well.”

⁷ Krefting L, Krefting D, Evaluation report NDA/NHR/SHIA CBR program in Nepal, December 1998.

Income maintenance and social security

The most appreciated CBR initiatives were vocational training and loans. For some people loans were given for the purchase of animals such as ducks, goats and oxen so that they could make an income from the offspring.

The CBR programme offered skills training to others. After the training a loan was provided as a starting capital for tools and raw materials. Although satisfied with the assistance from the CBR programme interviewees complain that the variety of skills training offered is too stereotyped (mainly tailoring and carpentry). They had other ideas:

“It’s better if we get other vocational training like fabric painting, knitting and candle making. Yes and it’s good if we get the training of incense making because people can benefit from this type of small business. There is nobody who is in this business at the moment in this community.”

They also express a need for training in business management for the self-employed.



Government and community commitment

The interviewees express a positive view about disability issues now being more visible on the national political agenda, in the media and in the village committees. The decentralization of some decision-making functions and of budgets to village levels (VDCs) has made it possible for community members to approach their communities to ensure commitment in the form of political priority and resource allocation.

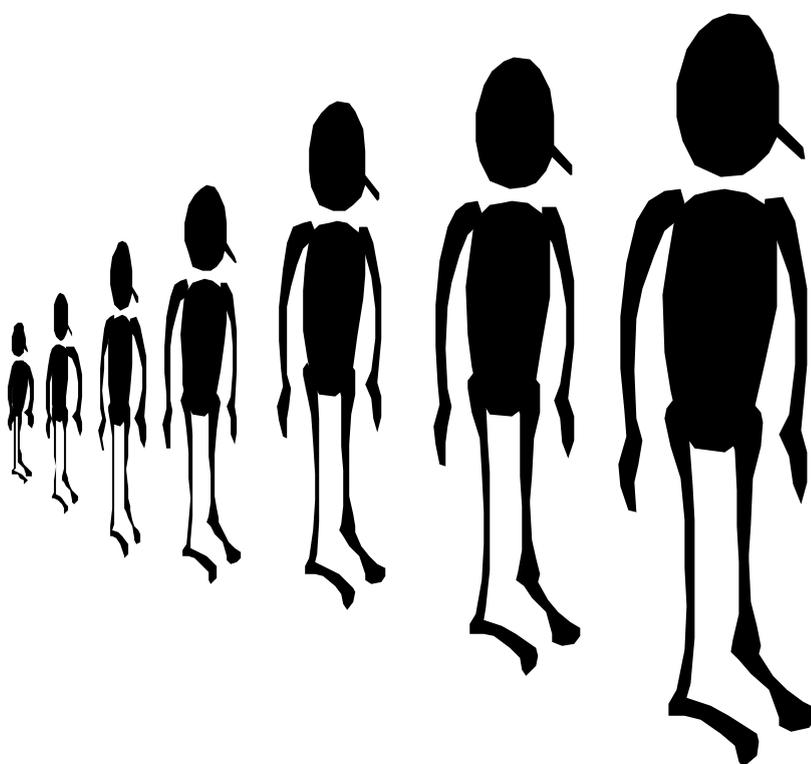
However, the village mandates are limited and the commitment must therefore be sought mainly on a district level. The CBR programme does not seem to have contributed to the involvement of the district authorities. These authorities have in many places expressed goodwill to prioritize disability issues. However, they have to relate to numerous proposals and ideas (sometimes contradictory or conflicting) from various NGOs, DPOs and CBR programmes, and therefore they remain confused as to the right way forward. Another problem is that the NDA CBR programme only targets one to three villages in each district, making it less interesting for the district authorities, which have the responsibility for approximately 50 villages.

Commitment at community level is declining as well. CBR committees (made up of community leaders and professionals) that were established in the communities to oversee the implementation of the CBR programme seem to have lost motivation at the same time as resources have stopped coming into the community. They have been replaced by the DODGs that are supposed to manage the continued implementation of the CBR programme without external resources and on a purely voluntary basis.

Support to DPOs

The CBR programme has inspired the formation of DODGs in 20 villages. The groups are expected to continue running the CBR programme independently in their villages and to forward the cause of persons with disabilities as much as they are capable, after the financial and human resource support of the CBR programme is phased out. Unfortunately, these DODGs are not linked to any major disability organization and therefore they will have problems in extending advocacy efforts beyond their own villages. Such links are essential to succeed in influencing education or health authorities or budget allocation at the district or national levels.

DPOs in Nepal have mixed feelings about the development of NDA into an organization that has much influence on policy development, as it is not an organization **of** persons with disabilities. This has made them reluctant to associate with the DODGs. NDA is also accused of assisting only persons with physical disabilities: the visually impaired to the Association of the Blind and the hearing impaired to the Association of the Deaf. A strong parents' movement has yet to emerge.



LIST OF ACRONYMS

ADD	Action on Disability and Development
ADL	Activities of Daily Living
ADRA	Adventist Development and Relief Agency
AIFO	Italian Association Raoul Follereau's Friends
CBR	Community-based Rehabilitation
CBRP	Community-based Rehabilitation Programme
GCBRP	Guyana Community-based Rehabilitation Programme
CRU	Community Resource Units (Guyana)
CWD	Children with Disabilities
DAR	Disability and Rehabilitation Programme at WHO
DODG	Disabled Organizational Development Group (Nepal)
DPO	Disabled People's Organization
DSI	Danish Council of Disabled People
ESCAP	Economic and Social Commission for Asia and the Pacific
HRDC	Hospital and Rehabilitation Centre for Disabled Children (Nepal)
IASSID	International Association for the Scientific Study of Intellectual Disabilities
ILO	International Labour Organization
INGO	International Non-governmental Organization
NAD	Norwegian Association of the Disabled
NDA	Nepal Disabled Association
NHR	The Swedish Association of Neurologically Disabled
NGO	Non-governmental Organization
NTV	National Television (Nepal)
PRA	Participatory Research Approach
PWD	Person with Disability
SHIA	Swedish Organizations of Disabled Persons International Aid Association
UN	United Nations
UNDP	United Nations Development Fund
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNICEF	United Nations Children's Fund
USD	US Dollar
VDC	Village Development Committees (Nepal)
WHO	World Health Organization
WHOQOL	World Health Organisation Quality of Life Assessment

