Evaluation of the CBR program in Palestine – from the perspective of persons with disabilities themselves

"I can do everything…..but I don't get the chance"

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EXECUTIVE SUMMARY

This report documents an evaluation of the Community Based Rehabilitation program (CBRP) in Palestine that investigated the impact of the program from the perspective of disabled people and their families. The main objectives of the evaluation were to ascertain to what extent the CBRP has contributed to improving the quality of life of disabled people and suggest ways in which the program can more effectively meet the needs of people with disability.

In the evaluation, qualitative methods were utilised for data collection, mainly by conducting interviews and focussed group discussions with men, women and children with disabilities, in addition to interviews with local DPOs and discussions with CBR workers and field coordinators.

Despite the unfavourable political conditions the CBR program has managed to achieve a lot. The program has empowered individuals and parents, improved basic daily living skills and coping mechanisms, reduced stigma and isolation and increased social inclusion. People with disabilities are more respected in their families and have become more visible and more vocal. Many have also been able to access education and rehabilitation services.

In regard to the program's impact on the different aspects of quality of life, it had an exceptional impact on emotional well being and self esteem. It has also had a substantial but uneven impact on interpersonal relations, social inclusion and personal development.

It has had some impact on physical well being (access to medical treatment, rehabilitation services and assistive devices), especially in Gaza and Central Region.

However, the CBR program has had limited impact on self determination and influence, material well being and rights. The evaluation also shows that the least impact has been made on the quality of life of persons with hearing impairments and severe intellectual disability.

The strategies that were most successful to achieve the positive changes were: the moral support, getting the family to understand and deal with the disability, breaking the isolation and helping to change the attitudes in schools and communities. Children also praised the inclusive summer camps.

The report provides a detailed and critical description of program achievements and areas for further improvement as perceived by the disabled people themselves. Proposals made by the interviewees covered areas such as income generation, practical assistance (transport to and from school, technical aids), day care and special education classes for children with intellectual disabilities, youth clubs etc. Voices were also raised for increased coverage by the CBR program. It is presently reaching approximately 50 % of the target population.

The report concludes with a number of recommendations to improve the impact of the program. The recommendations are classified into three groups: program-related recommendations, advocacy and policy recommendations and management and organization recommendations. The report finally suggests that it is time for the CBR program to review its objectives, structures, strategies and working methods. A workshop

is proposed to be organised early 2006 to review the program and formulate a plan for the coming 5 years. Both CBR workers and representatives of the service users should be part of such a planning exercise.

1. Background Information

Since 1990, the Community Based Rehabilitation program (CBRP) in Palestine has been part of a long-term strategy aimed at strengthening the rehabilitation sector as a whole in order to address the needs of disabled people. The Norwegian Association of Disabled (NAD), in partnership with Swedish Diakonia, has since 1994 provided financial and technical support to 17 non-governmental organization (NGO) partners that implement the CBRP with the aim of promoting social inclusion of Palestinian children and adults with disability. CBR has since been adopted as a national strategy. The CBRP is one of six inter-related components that comprise the Rehabilitation Program (RP) supported by NAD/Diakonia in Palestine. These components are:

1. Community Based Development Program
2. Development of the rehabilitation referral system
3. Lobbying, advocacy and networking
4. Policy development
5. Capacity Building, research, documentation and development
6. Regional cooperation

The CBRP is active in more than 200 localities, covers 60% of the population of the West Bank and Gaza, and has reached more than 35,000 disabled persons and their families since its inception. The program's network of NGO partners have organized themselves into five Regional Committees that have responsibility for planning and implementing the CBR program, and for coordinating the work at both the community and regional levels.

A number of studies and program reviews carried out by external consultants have described the CBRP's accomplishments and documented that it has had a major impact on the rehabilitation sector in Palestine. These studies include an external impact evaluation of the CBRP (Arne Eide/SINTEF Health, 2001), a study that examined the effect of the program in terms of promotion of democratic norms and the empowerment of civil society (Democracy, Human Rights and the Palestinian Civil Society, Ann Kristin Brunborg, 2001), and a working paper that assessed the degree to which the program enhances gender equity and equality (Promoting the Status of Gender, Dr. Lamis Abu Nahleh, 2003). In addition, a study (Towards Inclusive Education for All in Palestine, Pia Karlsson/Institute of Public Management, 2004) was undertaken to consider the short-term outcome of the implementation of the Ministry of Education's national policy on inclusive education, which is supported through policy development component of the RP.

While the studies mentioned above have considered the effectiveness of the CBRP from a number of different aspects, none of them have focused solely on the 'user perspective'. Therefore, this evaluation has been conducted to investigate the impact of the program from the perspective of disabled people and their families.

2. Objectives of the evaluation

The main objectives of the evaluation are to:

- Ascertain to what extent the CBRP has contributed to improving the quality of life of disabled people.

- Assess the degree of involvement of persons with disabilities and their families in the CBRP.
- Identify the program's strengths and weaknesses as perceived by disabled people.
- Suggest ways in which the program can more effectively meet the needs of disabled people.

3. Scope of the evaluation

The evaluation has focused on obtaining and analysing ***the perceptions of disabled children and adults and their families*** on the points outlined below:

1. To what degree has the CBRP impacted on/improved the following aspects of **quality of life**[1]:
   a. Emotional well-being and self-esteem
   b. Interpersonal relations
   c. Social inclusion
   d. Empowerment, influence, self determination
   e. Material well being, self-reliance,
   f. Personal development
   g. Physical well-being
   h. Rights - Confidence and trust in society to fulfil its human rights obligations

2. When investigating these aspects of quality of life improvements special attention should be given to:
   a. To what extent do disabled people and their families **participate** in the CBRP?
   b. How do persons with disabilities perceive the accessibility of **rehabilitation specialist (referral) services**?
   c. To what extent do children with disabilities feel accepted in **school** and to what extent do they think that the learning environment meets their needs?
   d. How do disabled people perceive the effectiveness of DPOs/self help groups in advocating for the rights of/effect positive change for disabled people?

3. Which **aspects of the CBRP** are perceived as the most useful?

4. Methods for data generation

Data has been generated in the following way:

a. Material from previous evaluations was carefully studied and the authors of the SINTEF evaluation and the Gender Study were contacted
b. The report Health and Segregation – the Impact of the Israeli Separation Wall on Access to Health Care Services, July 2005 – provided very useful background information.
c. Interviews were held with 25 individuals with disabilities. These individuals were selected from a stratified random sample of 130 persons in each of the 5 regions.

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[1] The 8 domains defined in the IASSID Consensus Document and used in the WHO study "CBR as we have experienced it – voices of persons with disabilities themselves"

The individuals interviewed were selected to be representative of gender (50 % females 50 % male), age and disability type. The interviews were semi structured[2] Children interviewed were also asked to draw pictures to illustrate what makes their lives good and what makes their lives sad. Interviews with young children and persons with severe communication impairments were held with the assistance of the care givers (often the mother or sibling) and complemented with observations.

d. Focussed group discussions were organised with 15 groups of persons with disabilities. In each group 5-7 people participated. The groups were organised separately for women, men and children/youth. The focussed group discussions followed the same structure as the individual interviews. The children and adults participating in the group discussions were also selected from the stratified random sample of 130 persons in each of the 5 regions, but were not the same as the ones selected for the individual interviews. They were selected to be representative of gender, age and disability type. In total 90 individuals participated in the group discussions.
e. Interviews were held with local DPOs (The Union of Disabled People branches in each region as well as the Deaf Club in Hebron and the Organisation of Persons Injured by the Intifada in Gaza)
f. Discussions were also organised with staff in all 5 regions to hear from them what they thought would be the views of the persons served by the CBR program.
g. Finally, data was generated through observations during visits to homes, communities and schools.

The interviews and discussions carried out in Jenin, South and Gaza regions were done jointly by Ms Nilsson and Mr Qutteina. When interviewing female respondents a female translator was used. The data collection in Nablus and Central was carried out by Mr Qutteina alone. Responses and observations were recorded on tape (the joint interviews) and by taking detailed written notes. The responses have been analysed and categorised according to the 8 Quality of Life domains (as defined by IASSID). We have also analysed the findings in relation to gender, age and type of disability and looked at possible variations between regions and implementing organisations.

5. Limitations

Although being part of a random sample of 650 persons (130 in each of the five regions), representing all ages and disability categories, the selection of the 90 persons for the interviews and group discussions might have been positively biased as it was made by the CBR program staff. Persons with intellectual disabilities seemed to be less represented in the adult groups, possibly because it was felt that they could not participate in group discussions in a meaningful way. Also, for practical reasons, respondents were selected from the same cluster of villages to make transport to the meeting place feasible. In Gaza, all interviews and group discussions were carried out via video conference thus limiting the possibility of making personal observations and social interactions outside the interview situation.

Further more, information may have been lost or misunderstood due to the translation between English and Arabic during some of the interviews. The interviews that were held

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[2] Interview guide is attached

through the care givers are not necessarily representing the views of the person with the disability.

In order to limit the effects of these problems we verified our data by going back to the CBR program staff and to respondents to check for relevance and accuracy. We have also selected some of the respondents ourselves as a check up. For example, we looked especially for the views of hearing impaired and persons with intellectual disabilities as we thought there were some particular difficulties for these groups. We also interviewed representatives of the local branches of the disability organisations. In the case of interviewing the care giver we also complemented our impressions with observations of the interactions and communication efforts between the care giver and the child/adult with the disability.

We are satisfied that the views we have captured are fairly representative of disabled people who have been served by the CBR program.

In interviews and discussions we have focussed on the effects of the CBR program, but it has not always been possible for the respondent to isolate the impact of the CBR program from improvements that are related to the normal process of growing up and from improvements that are a result of other ongoing processes in the Palestinian society during the past 10 years. Apart from CBR, major factors contributing to improvements in the situation of persons with disabilities seem to be

a) the increasing number of Intifada related injuries that has made disability visible, “heroic” and less stigmatized
b) other organisations and agencies working to provide support and rehabilitation services to persons with disabilities – some of them implementing the CBR program as one of many different activities
c) the establishment of the Palestinian Authority with its various ministries (e.g. education, social affaires), district authorities and local councils

In general, however, the environment has worked against the CBR program. The overall situation in Palestine during the past 5 years has been that of negative development in all psychosocial and economic areas. Coordination and collaboration is hampered by restrictions in movement. Some referral services have been closed. Services remaining are often fragmented and uncoordinated. It is amazing that despite this the CBR program has developed and continues to have an important impact on the lives of people with disabilities.

6. The Context

In 2005, there were 3 762 005 Palestinians living in the West Bank and Gaza[3]. Around 2 % are reported to have a disability[4]. This means that there are at least 75 000 persons with a disability in need of various services. These services are organised at three levels[5]:

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[3] The Palestinian Central Bureau of Statistics (PCBS) – www.pcbs.org/Portals/_pcbs/populati/demd2.aspx

[4] The census of 1997 (PCBS) gives a figure of 1,9 % which is probably a low estimate.

[5] For more details, refer to “Health and Segregation – the Impact of the Israeli Separation Wall on Access to Health Care Services, July 2005”

Functional problem/difficulty	**%**

Visual	21.9
Hearing	18.5
Speech	28.6
Movement	44.6
Epilepsy/fits	8.1
Behaviour	4.3
Learning/intellectual	17.4

At ***primary level,*** services consist of outreach and CBR programs provided to communities by various organisations. The Central National Committee for Rehabilitation acts as an umbrella body for the CBR program, with an aim to set standards and coordinate activities of the various implementing NGOs. The CBR program covers 240 localities and has been in contact with 35 000 families since its inception. Presently the CBR program works actively with around 5 000 cases. Based on earlier assessments, priority is given to young children, women and people in smaller villages where services are scarcer. Every CBR worker is responsible for 50-70 active and follow-up cases. As cases are often active for a long time, often 5-10 years[6], it is difficult to add many new cases without adding staff. Compared to CBR programs in other countries, the coverage of the Palestinian program is remarkable. Still, most Palestinians with disabilities are not reached. The coverage of the CBR program is estimated at around 50 %.

Looking at the distribution of various disabilities covered by the CBR program it also seems that some disabilities are catered for more than others *(as indicated in the table from SINTEF study 2001*). Comparing these figures with the expected distribution of disabilities according to the census of 1997, there seems to be an over representation of persons with movement, speech and visual impairments and an under representation of persons with learning/intellectual difficulties and multiple disabilities. This study confirms that there is such a bias. The CBR staff tend to recruit persons and families whom they feel they can assist within the particular expertise of the NGO to which they are attached.

The secondary level offers intermediate services such as physiotherapy, appliances and speech therapy etc. There are around 114 such governmental and nongovernmental institutions in the West Bank (62) and Gaza Strip (52) that provide services to disabled persons. Thirteen of these institutions are under the supervision of governmental organizations. There is an urban-rural bias in the provision of secondary level services, with most institutions being concentrated in cities. The CBR program is implemented as an outreach program by some of these NGOs. They are referred to as partner organizations by the CBR program management. It was noted in the evaluation that many users do not differentiate between the CBR program and the implementing NGO. CBR is often seen as one of many programs carried out by the NGO.

Despite this, it seems that the CBR program has limited linkages with, and access to, other programs operated by the same NGO such as vocational training, psychosocial programs and provision/lending of technical aids. Quite a number of the CBR partners operate such parallel programs without ensuring that the users and workers of the CBR program benefit from them.

Tertiary level care is available at medical centers with facilities that offer sophisticated and specialized rehabilitation services for persons with disabilities. There are three such specialized centers in the West Bank; Khalil Abu Raya Rehabilitation Centre in Ramallah, the Jerusalem Centre for Disabled Children, and the Bethlehem Arab Society for Rehabilitation (BASR) in Beit Jala. In Gaza there is the El Wafa Centre, which provides specialized medical and rehabilitation services.

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[6] According to the SINTEF study there are variations between regions, but the mean figure is 5 years.

Due to the restriction of movements and financial constraints, many families cannot access the secondary level institutions and tertiary specialized centers. This has resulted in an increasingly difficult task for the CBR workers, whose role and training has focused on social counseling, daily living skills training and referrals.

7. The impact of the CBR program on quality of life

The eight Quality of Life domains defined by IASSID have been used to organise the statements from the respondents in meaningful categories. As some of the domains are overlapping and interlinked, the same statement can sometimes serve as illustration of several domains. The QoL domains must also be understood in the cultural context. We have tried to interpret them in relation to the situation of non-disabled peers of the same age and gender.

According to the interviews and group discussions the following can be concluded regarding the impact of the CBR program on various aspects of **quality of life**:

1. The CBR program had an exceptional impact on emotional well being and self esteem. It has also had a substantial but uneven impact on
   - interpersonal relations
   - social inclusion
   - personal development

2. It has had some impact on physical well being (access to medical treatment, rehabilitation services and assistive devices), especially in Gaza and Central Region¨

3. The CBR program has had limited impact on
   - self determination and influence
   - material well being and
   - rights

In some of these domains there are quite substantial differences in impact related to type of disability, gender and region/implementing organisation.

7.1 The impact on emotional well-being and self-esteem has been exceptional. A large majority of both women and men saw this as the most important result of the CBR program. It was verified by some very strong statements such as:

- I used to be isolated and lonely – but now I go outside and have many friends.
- I used to be in the darkness – but now I am in the light.
- I came from the dead to the living.
- I used to be a fish on the floor. Now I go to school and get 96 %.
- Before I was depressed and felt hopeless. Now my family accepts me and even asks my opinion.
- Being disabled does not mean not having a role in life – it means loving life.

- We were not treated like human beings. Our existence was denied. Now we are visible, we are demonstrating and celebrating. We have the right to education and free health services.
- Before we were not prepared to meet the society, now we are confident and even deliberate teasing does not hurt our feelings.
- I used to lock myself in my room, I didn't have the courage to think of having a social life.

Also parents reported that their emotional well being had improved. They felt relieved by the fact that somebody cared about their situation and helped them to find ways to cope. They also felt more confident to handle the family situation and the disability of their child. Many of the mothers reported that CBR workers helped out in all kinds of family difficulties – not only in areas related to the disabled family member. Although mothers report that life has changed for the better for them and their child, the CBR program has not managed to relieve them from carrying the sole responsibility for the well being and development of the child. In families, it is still rare to find fathers and brothers who take part in transport, education, training, sign language etc.

It was noted that for many children their disability was a minor emotional problem compared to the psychological traumas and the poverty experienced as a result of the occupation and military violence. When asked to draw pictures of situations that make them sad most children drew pictures of war injured children and Israeli tanks.

When children and young people described sadness linked to the disability it often had to do with the feeling of exclusion or abandonment:

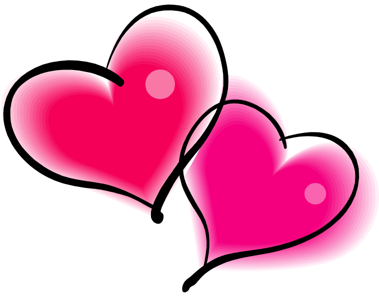
- I am sad when my cousins do not allow me to play football with them
- I am sad when I can't reach things that I want
- I am sad when my class mates and teachers just leave me in the classroom and nobody helps me to get home. I have frost bites on my hands from waiting for transport in the winter. Last week a stranger (male taxi driver) had to carry me.
- I would like to have an education but I had to leave school because I failed the exams and there was a lot of teasing.

Happiness is mostly linked to participation in social activities such as summer camps and other recreational activities, socialising with friends, etc. as this picture illustrates “Oh my god, all these people are my friends”

7.2 The impact on interpersonal relations has been impressive, especially within families and with peers in schools - although there are still areas of concern for some children and adults. Teasing and beating have been reduced and there is less pity. Many of the respondents report that the situation in the family has improved a lot. There is more understanding and the treatment is better and more supportive. Girls and boys often socialise with friends in school and the neighbourhood like others of the same age and gender. However, most children and young people reported that they mostly stay at home in their free time watching TV or playing with toys and that they socialise mainly inside the extended family (with siblings and cousins). Compared to other children of the same age and gender, there is still a tendency of over protection from parents and social attitudes that make it difficult to start and maintain interpersonal relationships. We also noted a few examples of abuse against children with disabilities inside families participating in the CBR program, mainly against children with hearing impairment and intellectual disabilities. Girls and women also tended to be more subjected to abuse. Some of the statements:

- There is less teasing now, and when there is I don’t care anymore.
- The family now understands our situation and believe in our ability.
- It is thanks to the CBR summer camps, really. People are not staring at me anymore. They know me now and don’t think about my disability. But when I go to my grandmother (in another village/community) it is different.
- I have two friends at school but I prefer to play with my dolls or the computer.
- My daughter is aggressive when people do not understand her. My sister in law complains all the time and then my son gets upset with his young sister and beats her. I have to keep her inside the house to protect her.
- My sister (with a visual impairment) is sleeping all the time. Nobody comes to visit her.

Concerning adults with disabilities interpersonal relations also include marriage and sex. The greatest wish of most people with disabilities is to get married and have a family, just like everybody else. It is a very important part of life and in Palestine it is a big emotional and social problem not to be married, especially for women. Some of the girls interviewed refused to wear hearing aids or eye glasses because of fear of not being married. Sometimes it is the parents who prevent them from using the aids. It is discouraging to note that women who have a disability seldom get married and women who were married before they got their disability often struggle a lot in their marriage. This is mainly a result of the expected gender based division of labour. Women are expected to carry out all home chores, raise kids, and even help them do their homework and a general view is that a mother with a disability might not be able to do this properly.



Men with disabilities sometimes manage to find a partner, especially if the disability is small or due to an Intifada related injury. However, we recorded plenty of examples of men who were prevented from marriage because of their disability. This sometimes also affected the siblings of persons with disabilities, who found that potential in-laws prevented them from marriage because of fear hat the disability might be inherited and therefore brought into their family. Sometimes marriage is prevented by financial constraints on the part of the disabled man.

There are very few examples of persons with disabilities marrying each other, which is more common in other countries. There were some reports in Ramallah but still they were exceptional cases. Only in Gaza there was any mention of advice on sexual matters to persons with disabilities (men with spinal injuries). Even this counselling is being offered by a medical professional and in a hospital rather than in the community. Discussing sexual matters in the community, even among men, remains very sensitive. Marriage and sex are difficult cultural areas to address and it is an area where the CBR program has not yet had much impact on attitudes and practices.

Some of the voices:

- I met a girl at the summer camp 8 years ago. We still love each other but our families refuse.
- Inch' Allah I will get married.
- The words "Inch' Allah" should be banned. It just means that it will never happen.
- I am lucky; my husband has not divorced me and not married another woman, despite my disability.
- I propose that the CBR program should collaborate with the disability organisations to support a collective marriage day for persons with disabilities.

7.3 The impact on social inclusion is also very positive compared with the situation before the CBR. The respondents talk about big improvements both on the family and community level. In the family many of the respondents verify that they are now included in family gatherings and social events. There is less pity and shame. Social inclusion has also gradually increased in communities as attitudes have improved. Respondents confirm that since they became visible in the neighbourhood and in schools, stigma and prejudice is reduced. However, many respondents point out that when they travel to other communities where they are not known, attitudes are still negative.

Many children report that they have been included in the local school or kindergarten thanks to the efforts of the CBR program. Physical adaptations are made and teachers are increasingly accepting the children in the class. Many children confirm that they are mostly treated well by teachers and classmates. This, however, is not always true for children who have communication or learning disabilities and for some reason - children in the Nablus area. Unlike children in other regions, the respondents in Nablus reported to have unsupportive teachers and a lot of teasing from class mates. A general problem in all regions is the academic challenges. Although socially integrated in schools, many children with disabilities still struggle with academic difficulties due to the traditional teaching styles in the Palestinian schools[7]. This affects their self esteem negatively and many children drop out from the educational system early - especially children with hearing problems and learning difficulties. It was echoed several times even by CBR workers that they are satisfied with the fact that these children at least go to school even if they are not learning anything at all. Some positive voices about social inclusion:

- The family used to deal with us as a subject for their pity and sometimes feel embarrassed because of us. But the program helped them to understand how to deal with us on equal basis.
- The disabled are even participating as everyone else in the Intifada. 80 persons with disabilities were killed by the Israelis in the Intifada (martyrs) and about 450 have been detained in Israeli jails.
- We used to prevent him (brother with intellectual disability) from sitting with others and talking to them. But the program made us understand that he should get the chance to interact with people in his own way and that we shouldn't feel embarrassed.
- Before, I was always at home. Now I have many friends in school and I do the same thing as other girls in my class.
- Before, my family was shy because of me. Now they don't care what others say.

However, negative social attitudes are still one of the main obstacles mentioned by many respondents. Among adults there are mixed feelings about the level of social inclusion achieved by the CBR program. Adults often find fewer possibilities of inclusion than children. While some have even been empowered and attend university and participate in local politics, some adults (especially women and persons with intellectual disabilities) are isolated in the home environment. They no longer go to school, they are no longer invited to summer camps or outings, they are not married, they do not have a job etc. Men with disabilities have sometimes found a role in the Intifada, where they are included on equal terms. In Gaza and in smaller villages many of the respondents indicate that there are still major obstacles in the social inclusion. Some of the concerns:

- I prefer to stay at home and watch TV and play with the computer. My cousins never want me to play football with them. It makes me sad.
- My sister sleeps most of the time and nobody comes to see her.
- I seldom go with my family to social events. I do not feel welcome. And it is a problem with transport. I don't want to be a burden.
- Social attitudes are the biggest problem. There should be more awareness.
- Just give us (persons with disabilities) the opportunity and see how we can be productive and successful. Thus we will not benefit ourselves only but all the society as well.

7.4 The impact on influence and self determination has been limited. Although empowerment is noted on the individual and family level this has not resulted in action on their part in terms of participation in community development, organising of self –help groups or engaging in advocacy and lobbying. We could not identify any self help groups or social clubs of parents or persons with disabilities in any the communities. Several adults with disabilities said they volunteer with the CBR but none said they had formed

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[7] Follow up study of inclusive education in Palestine, Pia Karlsson 2004

their own self-help group. The CBR teams explained that they promote the formation of community support groups from local councils, local institutions and influential people in the community rather than from families of disabled people. It seems that the political agenda of gaining influential persons to their side was more important for the CBR program as this will make life easier for the field workers. The CBR staff promoted the formation of community organizations in support of disability issues without giving a big role to disabled people themselves. Therefore, many such structures just couldn't last and in many cases were totally dependent on the good will of the mayor or school teacher rather than a strong self-organization of disabled people.

We also found that less than 50% of respondents have heard about the Union of Disabled People. Mothers and women were more uninformed than the men, although among the branch leaders interviewed three out of five were women. Almost nobody knew about the Deaf Clubs, not even deaf persons. Nobody talked about Associations of the Deaf or the Blind although these organisations apparently existed or were being formed. It does not seem to be a self evident part of the CBR workers job to encourage membership in disability organisations or the formation of self help groups, although in some regions this was more common.

Apart from the occasional membership in the Union and the Deaf Clubs, there was no evidence of collaboration between parents or disabled people outside the extended family. Only one parent (father) had engaged in advocacy activities together with other parents. It seems to be a strong cultural barrier within the Palestinian society against social organisation along lines other than kin relations. People group around blood relations rather than other interests as the family forms the main, if not only, form of social support. Many persons with disabilities expressed a need for interest and peer support groups. They want to socialise outside the family as many are not fully accepted or included as family members – and they need positive role models. Parents, however, showed very little interest in self help groups outside the family. They feel that problems can be handled within the family. There also seems to be a lack of initiative among some of the respondents. Even if they had wishes or ideas for joint activities, they rather wait for the CBR workers to provide these opportunities. Some of the statements:

- We used to have a CBR committee but it collapsed. People are only interested to participate if they can gain something from it.
- I don’t know about any other families with the same problems. We are managing within the family. But we participate if we are invited by the CBR.
- We really need a women’s group, but somebody must help us to start it.
- At the school for the blind, we inspired and helped each other a lot. It is important for young children to have role models.
- Just put us (disabled people) in the right place and see how we can be productive and successful. Thus we will not benefit ourselves only but all the society as well.

There seem to be a limited confidence by the CBR programs in the ability of persons with disabilities to do things for themselves. According to respondents, they are seldom supported by the CBR to start their own projects, link up with mainstream business or credit programs, access vocational training, seek employment in NGOs and government or form self help groups. It seems that the CBR program is concentrating mainly on individual and family counselling and referrals to schools and rehabilitation services. After 15 years of operation it is still very rare for a disabled person to become a CBR worker, not mentioning to become a decision-maker in the CBR program. Only in Jenin some of the CBR workers had disabilities themselves.

Despite this general situation, some persons with disabilities have been empowered on an individual level and become strong leaders in the disability movement. Some of them have developed a good working relationship with the CBR program (especially in Nablus and Jenin) but some feel that the CBR program sometimes speaks on their behalf and does things that an organisation of persons with disabilities could be better placed to do, such as

- counselling, role modelling and daily living skills
- advocacy and lobbying

Unless partnerships are formed around these activities, resources from donors shared and persons with disabilities employed there is a risk that the CBR program will be seen as a competitor rather than a supporter by the branches of the Union.

7.5 The impact on the material well being and self-reliance has been very limited. We met very few who had managed to get a job or an income. Some of the statements:

- I can do everything…but I don't get a chance. I have a university degree, I speak English and I have a car. But all doors are closed. My parents discourage me from trying to get a job. And they refuse to help me to get married. Just because of my CP.
- My house is full of embroidery and handicraft. What else can I do? I need to sell it to get an income. Can you help?
- Other women pick olives to get some extra money. I have rented out my wheelchair to get some income. It means I am stuck at home but at least I get something.
- My father has left the family and married another wife. He refuses to pay anything to my mother. They are not divorced so we can't get support from the authorities. What will become of us? I am losing hope of ever having an artificial leg.

To some extent the situation reflects the general economic depression in Palestine (unemployment rate of 60%), but also the limited opportunities of persons with disabilities. The central region (Ramallah) seems to offer a slightly better situation. We met quite a few persons holding important positions in this region. The new legislation states that 5 % of the jobs should be reserved for persons with disabilities, but neither the government nor companies or NGOs seem to have a proactive strategy to achieve this.

Many respondents felt that the situation was hopeless and did not even mention work as part of their dreams or plans for the future. The dreams were mostly related to being able to complete studies, getting a family, having peace (or being a martyr), getting a wheel chair, Braille machine, or a computer. More women than men mentioned the need for income generating activities or a job. Perhaps their financial security is less that that of the men, in particular if they remain unmarried.

However, poverty was mentioned as a major obstacle in the lives of almost all the persons interviewed. The poverty prevented them from getting transport to get to school, from getting technical aids or medical treatment and even from getting married. Many respondents mentioned the high cost of diapers as a very big problem. The disability grant in Palestine is 90 NIS (130 NOK) per month, which is not nearly enough to cover the extra cost of the disability.

7.6 The impact on the personal development has been substantial. The program has provided training in daily living skills and made referrals to schools. The number of children with disabilities who are being integrated in regular schools is impressive. Some youth have been assisted to attend university studies. Many respondents report amazing improvements in daily living skills, communication skills and academic skills[8]. Parents are often eager to show how much the children have learnt. We observed that the progress to a large extent depends on the commitment of the mothers (sometimes father), who are taking responsibility for the daily support and training.

Some positive voices:

- I never thought I would have a chance to learn in school, but now I attend school and do very good there
- They used to tease me when I was younger and I didn't manage in school at all. The teacher gave me passing grades because she felt sorry for me. The CBR helped me to go to the school for the blind. Now I am back in an ordinary school and there is no teasing. I do better in school than my classmates.
- CBR helped me in school and encouraged me to study and now I am the only blind person working in the media.

Some young people with disabilities have been able to attend higher education (University) but very few reported to have any vocational skills or training. Those who did mentioned that they got the training by YMCA in Beit Sahour – near Bethlehem or by Life Gate in Beit Jala. Very few mentioned the CBR program as being helpful in regards to vocational training or apprenticeships. While in other countries vocational training is more common among disabled people than academic studies it seemed to be the opposite among the respondents in this study. Some possible explanations could be

- In the Palestinian society academic education has a very high status while vocational training has a low status, especially when the training focuses on the same traditional skills, such as embroidery for women, bamboo work and baskets for the blind - things that do not have prospects for marketing.
- The focus on university education might reflect the bias by the CBR program on people with less severe disabilities, who need only little help to be integrated into universities (most of them have a physical disability) at the expense of persons with more severe disabilities who have more difficulties in the labour market.

We also identified some barriers and shortcomings in relation to the personal development of persons with disabilities.

- Most children with intellectual and multiple disabilities have still no proper stimulation or training. They remain in the home and depend on the support the mothers can manage to provide. Some are sent to institutions.
- Further more, the school system is not yet conducive for different learning styles. There is little support for children with special needs in the classroom[9]. For deaf children and children with learning disabilities the situation is worse.

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[8] Also confirmed by the SINTEF evaluation
[9] Also confirmed by Study by Pia Karlsson, 2004

- There are sometimes reluctance among students and staff to welcome a child with a disability. It requires a lot of persistence from both CBR workers and parents.
- There are also practical obstacles with accessibility, transport and personal help to get to the toilet etc. A big problem seems to be that of transport to and from school.
- Vocational training seems to be an option that is seldom promoted. It seems that University is the only option considered, even when academics is not the strength of the person.
- Traditional views and prejudice sometimes direct the field of training. For example most of the blind adults are looking at training in Islam and religious matters.

Some of the concerns mentioned:

- I usually go to the toilet in the morning and then I pray that I can manage until I get home.
- I don't go to school because if I do they move the classroom to the bottom floor. Then my classmates will be very disappointed. The bottom floor is only for the small children.
- Transport is the major problem. I never know if I will be able to go to school and come back. I miss a lot of classes.
- She studies twice as much as her sisters. She never watches TV. Still she only got 63 % at the end of last term. She cried and cried for a whole week. It is difficult for her because she can't hear the teacher.
- We had to bribe the other children to accept him in the class.
- It was only because the headmaster is my cousin that they accepted her in kindergarten.

7.7 The impact on the physical well-being is varying a lot between regions and individuals. Some are happy with the medical/rehabilitation treatment and the technical aids, while others report to have big problems. The level of satisfaction seems to depend mostly on the accessibility of medical and rehabilitation services[10]. In many parts of the West Bank it seems that specialist services are either unavailable or unaffordable, despite the public health insurance. Restrictions on movements hinder people from reaching services and some services have closed down.

The fee system of NGOs providing rehabilitation services seems unpredictable and difficult for families to understand. The quality of services is also varying between NGOs. Technical aids seem to come in as sporadic donations from various countries and are distributed according to principles that are not clear and known to families and CBR workers. Some have managed to get wheel chairs through companies, YMCA, Medical Relief or from the Gulf States. We did not see any locally made appliances. There is no proper supply or maintenance system for hearing, seeing or moving equipment. Spare parts are difficult to come by since equipment come from various parts of the world. We could observe that many children and adults were using appliances that were broken or unsuitable.

We also noted that very few blind persons use a white cane. There seems to be a stigma around using it and many prefer walking with a friend or

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[10] There was a fear from the CBR workers that many of their clients might have hopes for magical cures, but we found that this was rarely the case.

relative. It was also noted that many hearing impaired persons were fitted with hearing aids although this did not help them much in improving their situation as their hearing loss was too big. In some cases the hearing aid was giving problems rather than help.

We also met some who were still in need of surgery or medical treatment. However, the complaints about lack of medical treatments were less than those about technical appliances such as wheel chairs, artificial limbs, crutches, braces, etc. Surgeries and specialist treatments was mostly done in Jerusalem or abroad (Gulf countries or Iran).

In Gaza and the Central area (Ramallah) the supply of technical aids and medical services seem to be much better than in other regions, although there are complains about fragmentation and competition between agencies. Medical and rehabilitation services were often mentioned by respondents in these regions as the major and most important contribution by the CBR program.

Some positive voices:

- The CBR saved her life. They helped us to get the heart operation. She wasn't given priority because she has Down Syndrome.
- The CBR helped me to get the eye glasses – now I can read without a problem. But I only wear them in school because I don't like the way I look.
- I got a very nice wheel chair but it was not through the CBR program. I got it from the mobile phone company.

One boy is praising his hearing aid "I am happy because of my hearing aid, so I can hear my friends and the teacher". This young boy is one of the few children who new about and was a member of the Union of Disabled People. He is drawing himself and a friend going to a meeting of the Union to illustrate something that makes him happy.

Some concerns about the physical well being:

- She is using her grandmother's hearing aid. We couldn't afford to buy new ones. She needs two of them and they cost 3 600 Shekels each.
- I need medicine for my epilepsy, but the tablets are too expensive. My friend gets tablets for free but I don't know where.
- I (mother) have to read everything to him from the school books; he can only read big letters. I have never heard about a magnifier, what is it like? We were told that he needs a cornea transplant. I do not think it can be done in Palestine.
- I really need a Braille machine; it is impossible for me to take notes at school only using an old cassette recorder. I am afraid I will not pass.
- My only wish is for an artificial leg. My pack is in pain and I can't walk. I have waited for many years now. I am begging the CBR worker but my mother is not sure.
- My highest wish is for an electric wheel chair. I am a 17 years old man and I always have to be carried. How can I go to University and be part of society if I have to depend on somebody to carry me?

7.8 The impact on the rights of persons with disabilities is quite small. The program has, in collaboration with the Union of Disabled People, contributed to the creation of the new disability law which is guaranteeing persons with disabilities certain rights. Among other things it stipulated that 5 % of the employments should be reserved for persons with disabilities. However, the law is not implemented and confidence and trust in society to fulfil its human rights obligations is almost nonexistent among persons with disabilities. Less than 50 % of the respondents had heard about the disability law. Very few knew about its contents.

The respondents were not referring to the government at central or local levels as bodies that could do something about the situation of persons with disability. On the contrary they were referring to numerous disappointments and experiences of bureaucracy, especially within the Ministries of Education and Social Affaires (MOSA). Corruption was also mentioned. There is a general feeling that disability issues were low on the priority list – and getting lower. Support and service provision from NGOs and foreign donations seemed to be the most common idea of how the rights of persons with disabilities could be fulfilled in the future. Some voices:

- The government have more pressing priorities and problems
- Our government is new and division of responsibilities is not yet clear.
- MOSA could close down – they are not doing anything.
- Disabled people have no voice in the Legislative Council and the government.
- The law is just a piece of paper.

Most of the respondents acknowledged that the CBR program has contributed a lot towards the improved attitudes in society by assisting persons with disabilities to become visible and self confident. They also confirm that the CBR program is doing well to empower and support disabled persons and their families to a certain level and also to influence legislation and policies. Although a lot is said on paper about the rights of people with disabilities, in practice little is done by the responsible authorities. Doors are still often closed when it comes to the right to health care, work, education and marriage etc. Not even the CBR program is always doing what they preach. Some examples;

- In some regions persons served by the CBR program are called “cases” as if they were objects not human beings
- there seem to be a limited confidence by the CBR program in the ability of persons with disabilities to do things for themselves and they are seldom in the forefront in CBR community committees or in organising activities
- after 15 years of operation it is still very rare for a disabled person to become a CBR worker, not mentioning to become a decision-maker in the CBR program – mostly they remain volunteers

Not more than 50% of the respondents knew about the Union and even fewer were members. These members are often men and women with higher education, living in urban areas. The majority have mobility limitations. The branches have very little funding and no employees. Board members work on voluntary basis and often have other jobs. Many of the branches are still weak, lack strategic plans for their operations and have not yet been able to get organised as a strong national force. The status of the Association of the Deaf and the Blind is unknown by respondents. Nobody knew about a parent organisation. While some Union branches feel that collaboration with the CBR program is good some feel that there is a competition for influence and funding. Some feel that disabled people themselves are now empowered and better placed to take the lead in advocacy and policy development issues, while the CBR should take on a supportive backseat role.

8. The most important interventions

The CBR work often involves complex tasks such as building long lasting relationships with families, challenging established attitudes, providing social counselling, giving basic daily living skills training and advice related to the specific disability and making referrals to education and specialist medical/rehabilitation services. Home visits are made regularly under long periods of time, often many years. In many communities social activities are also organised (camps, outings etc) to promote inclusion. The CBR worker often becomes a friend of the family that is trusted also as an advisor in other family matters.

The CBR interventions seem to vary a lot depending on

a) the needs of the individual and his/her family (including type of disability)
b) the focus and level of community orientation of the NGO implementing the CBR program,
c) the CBR staff professional background and gender
d) the availability of referral services

Despite this, more than 90 % of respondents – both men and women alike - in all regions (except Gaza) agreed that the most useful interventions of the CBR program were first and foremost the ***moral support***. The most useful interventions were

a) The moral support, raising the self confidence and breaking the isolation
b) Getting the family to understand an deal with the disability
c) Helping to change the attitudes in schools and communities

Among the parents, mothers mainly appreciated the moral support of another woman/friend. They often mentioned that the CBR worker assisted them with all kinds of family problems – not only those relating to the disability. Fathers more often mentioned the practical support and the referrals as helpful. The home visits seemed to be a very effective way to build relationships and to provide the support. Many families wished for more frequent visits. Among children, the summer camps were often mentioned as one of the most important interventions.

Some of the voices:

- It was definitely the moral support that helped me most!
- It really helped me to know that somebody cared about my problems. I was not alone.
- The home visits encouraged me a lot. I wish (name of CBR worker) could come more often.
- The most important was convincing my family that I should be allowed to go out and go to school.
- Being there to stand with us is the most important thing.
- The most important was that (name of CBR worker) talked to my husband and mother in law. They didn't understand about the disability and were making impossible demands.
- When I had a problem in school (name of CBR worker) went there to discuss with the head master and the teachers.
- The practical advice was very important. It helped me to deal with the disability better.

The organising of ***social activities*** was also highly appreciated. Almost all children and young people praised the integrated summer camps and indicated that they had contributed a lot towards breaking isolation and changing of attitudes in the communities. Children and youth wished for more social events and social centres/clubs.

It is encouraging to see that the interventions that are most appreciated by the respondents are among those that the CBR program staff is giving highest priority according to their self assessment.→

Main inputs by the CBR program according to staff[11]	***%***
Persuading the family to receive assistance	94,3 %
Increased parent awareness/understanding	94,9 %
Change attitudes and behaviours in family	94,7 %
Referred to local service	90,1 %
Medical assessment	73,7 %
Community integration	72,4 %
Referring to regional service	53,5 %
ADL training	51,3 %
Simple instructions	41,1 %
Physiotherapy	37,4 %
Movement training	35,4 %
Mobility training	32,3 %
Training household activities	23,9 %
Admitted to school	22,0 %
Speech training	21,1 %
Day care centre	18,0 %
Vocational training	14,6 %
Referred to national service	9,0 %

It is however a bit strange to notice that in this list, there is nothing about the most important interventions mentioned by the respondents, namely the moral support to the individual (not only to the family), the counselling and persistent encouragement provided to individuals to build self esteem and self confidence. It might mean that this type of intervention has not been receiving the proper attention and recognition as a specific and important task in

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[11] SINTEF evaluation 2001 – page 47

itself. It could be that such personal relationships have not been considered as "professional ".

Other interventions that cannot be found in the list, but we found to be of great importance to the users were:

a) social activities such as summer camps, outings and meetings (called community integration in the table?)
b) provision of assistive devices and physical adaptations in homes and schools (hidden in the table?)

It is also clear that "making it possible to go to school" and "practical daily living skills" were ranked much higher by the respondents than by the CBR staff.

The respondents in Gaza and the Central region more often mention the material support (eye glasses, wheel chairs, adaptations of buildings) and the referrals for medical and rehabilitation treatments as the most useful intervention. Reasons for this could be that the referral system and accessibility of assistive devices is better in Gaza and the Central region and/or that the moral support is less developed in these regions. The situation in Gaza seemed different in a number of ways. Quite a number of the respondents in Gaza did not remember the CBR program either because it was a long time since they had been in contact or because they could not differentiate the CBR program from the NGOs providing rehabilitation services (or assistive devices). Respondents often mention other organisations as the ones assisting them (e.g. the Kindergarten for deaf children, Red Crescent, YMCA etc). It could also be that the CBR workers in Gaza have a different background (nurses) and gender (men). The CBR program seemed to be less visible in Gaza than in the West Bank. This might be due to the fact that the CBR program in Gaza is composed of about 5-6 different NGOs, while in the West Bank it is usually two NGOs per region[12].

It is quite common in all regions that people do not differentiate the CBR program from the NGO. In Gaza YMCA was praised; in Kharas village, Hebron, we heard a lot of praise for the Health Work Committee and in Jenin the DPO representative praised the Medical Relief and Diakonia because he thought we are representing these two organizations.

An interesting observation was that a number of respondents in the Jenin region claimed that the fact that the CBR worker was a person with a disability him/herself had been a very important source of inspiration and empowerment. "If she can do it, I can do it!" It was also observed that the exposure of persons with disabilities in society has contributed more than information and lectures to reduce stigma and prejudice in communities. The use of role models for empowerment of individuals and for influencing attitudes in the communities could be further explored.

9. Proposals from the users

When asked about what type of interventions that are missing in the CBR program, many respondents mentioned "***more frequent home visits***" and ***"more CBR workers"*** in order to

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[12] Regarding the reasons for the differences in Gaza please refer to page 13 in the SINTEF evaluation. These differences were confirmed by this evaluation.

be able to make more visits. Other areas where many respondents wished for interventions were:

- assistance to find income generation and job opportunities, perhaps by linking to mainstream initiatives, lobbying for the 5 % and job coaching
- assisting with transport to and from school, lobbying government and transport companies to provide or perhaps organising joint ventures where families can pool
- assistance to get assistive devices/technical aids such as wheel chairs, Braille machines, tape recorders, diapers, artificial limbs etc, perhaps by setting up a disability fund with the help of the Gulf states and/or by lobbying for improvements in the present systems
- creating special classes in ordinary schools for slow learners or hearing impaired so that the teaching methods can be adapted
- organising more social activities in villages
- help to start youth clubs and women clubs, especially for persons with disabilities
- arranging community meetings around important family topics
- finding ways to relieve the pressures on mothers by involving other members of the family to share the responsibilities
- creating day centres in villages for children and adults with severe disabilities to relieve the families at least for a few days per week and create meaningful, developmental activities outside the home for this group (there are already premises in most places that could be used and relatives could be trained as care takers/teachers and take turns)
- increasing the coverage of the CBR program (many respondents knew people who were not supported by the CBR – even in the same family)

10. Summary of achievements and challenges

Despite the unfavourable political conditions the CBR program has managed to achieve a lot. The program has empowered individuals and parents, improved basic daily living skills and coping mechanisms, reduced stigma and isolation and increased social inclusion. People with disabilities are more respected in their families and have become more visible and more vocal. Many have also been able to access education and rehabilitation services.
According to the interviews and group discussions the following can be concluded regarding the impact of the CBR program on various aspects of ***quality of life***:

The CBR program had an exceptional impact on emotional well being and self esteem. It has also had a substantial but uneven impact on

- interpersonal relations
- social inclusion
- personal development

It has had some impact on physical well being (access to medical treatment, rehabilitation services and assistive devices), especially in Gaza and Central Region

The CBR program has had limited impact on

- self determination and influence
- material well being and
- rights

The strategies that were most successful to achieve this were

- The moral support, raising the self confidence and breaking the isolation
- Getting the family to understand an deal with the disability
- Helping to change the attitudes in schools and communities

The moral support was rated as the most important factor of all. This would indicate the communication and counselling skills should be an important factor when employing and training CBR workers.

The CBR program has impacted a lot on areas that can be influenced locally by the CBR program through counselling, information, training or advocacy while areas that require government input or economic investments (e.g. medical services, technical aids, school system, jobs etc) has not been influenced as much. This is to be expected of a program that takes its starting point in community work. The CBR program has done a lot within its mandate and power.

However, in order to move ahead the CBR program must address some general challenges

- the school system does not manage to meet the needs of children with disabilities who are referred there by the CBR program
- the medical/rehabilitation referral system, especially provision of technical aids, is fragmented, unpredictable, sometimes inaccessible and/or unaffordable and without quality control
- the economic and political situation makes collaboration and development of national systems difficult and creates additional psychological problems and poverty (puts disability on a lower place at the national agenda)
- cultural practices and parental control hampers further improvements in the lives of persons with disabilities (approximately 10%[13] refuse to collaborate and many do not support their child adequately)
- the involvement of the family is crucial, but mothers are carrying a too large part of that responsibility alone
- the practical obstacles such as lack of transport, lack of proper technical aids, and lack of toilet facilities hampers further inclusion
- income generation opportunities for persons with disabilities are almost non existent
- the disability movement is still week and struggles to find its role for general as well as disability specific issues
- the disability grant is not nearly enough to meet the extra costs experienced by persons with disabilities and their families (for medical treatments, appliances, diapers etc)

Many of these challenges cannot be solved by the CBR program alone, but by making strategic alliances most of them could be addressed.

The CBR program also needs to look at some of its own methods and structures. The major challenges seems to be

a) The situation of deaf/hearing impaired persons and persons with severe intellectual or multiple disabilities has not been improved much by the interventions of the CBR program

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[13] Estimate by CBR staff

b) The coverage of the CBR program is not sufficient and the methods have remained the same for a long time without being reassessed

The QoL of children and adults with ***hearing impairment*** have often not been helped by the interventions of the CBR unless their hearing impairment could be substantially corrected by hearing aids. These deaf/hearing impaired children and adults remain socially excluded, without reading and writing skills and with few interpersonal relations. Attending classes, without being able to follow what is said, lowers self esteem and emotional well being and creates frustration among these children. Little effort has been given to assisting families to access sign language skills or schools for the deaf. In the list of inputs listed by the CBR program, sign language training is not even included as an option[14]. There is emerging recognition of this problem. The need for and usefulness of sign language is even reflected in the fact that most these persons already develop their own signs with peers or family members without being able to develop a systematic signing strategy for communication. Even for people without hearing a problem, using gestures and signs while talking is a very important part of the body language – a crucial element in interpersonal communication.

Children and adults with ***severe intellectual disabilities*** have also experienced a limited impact in their lives. Although parents have been helped to cope better with the situation and some progress has been made as regards to daily living skills, these children remain isolated in their homes or are sent to institutions. There are no day centres or parent driven social activities for this group. Developing such centres was raised as a demand by quite a number of respondents.

An area of concern is that the methods of the CBR program have not developed much in the 15 years of existence. It remains in the same place, run by the same organisations, ***providing the same services that are becoming a routine***. Coverage is not increasing. Over such a long time, the program has not yet involved disabled people in decision-making, which is a condition for empowerment and improved quality of services. Even CBR workers are not empowered in many instances. We found out that many do not have any idea of the budget of the CBR program or the policy for providing services[15]. Decisions are made by directors, who are usually males and not that close to the community.

11. Recommendations

Many of the strategies used by the CBR program have been good and have been praised by the respondents. The CBR program should keep good interventions strategies such as the summer camps and the home visits. In order to further develop its capacity and impact there are some areas that could be improved. Taking the findings of this evaluation into consideration, including the proposals from the users, the evaluators recommend the following:

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[14] SINTEF evaluation page 47

[15] We asked the staff about the annual budget for various activities and how much was available per year to assist persons to get assistive devices. They did not know.

11.1 Program related recommendations

1. The CBR program could improve its support to deaf and hearing impaired children and adults. The misconception that deaf and hearing impaired persons should not use sign language must be opposed. Sign language is a precondition for learning a spoken and written language and a precondition for proper learning in school. Hearing aids are effective only for some and even then sign language can help to improve communication. Sign language is also a very effective complement in communication with many children with intellectual disabilities.

   The CBR program should consider formalising a joint project with the Norwegian Deaf Association and SIGNO to

   

    a. Collaborate with the Deaf Clubs to offer sign language training to parents and CBR workers
    b. Collaborate with the Deaf Clubs to lobby the government to start separate classes and schools for deaf children. Encourage teacher training in sign language and arrange study visits for teachers of deaf and intellectually impaired children to Norway/Sweden. The CBR program should lobby for this with the inclusive education program at the Ministry of Education.
    c. Collaborate with Deaf Clubs to arrange summer camps and social activities for the deaf
    d. Employ deaf CBR workers to work as role models and supporters to deaf children
    e. Assist and encourage the formation of local Deaf Clubs
    f. Assist and encourage the formation of a national association of the deaf in Palestine

   The proposal to formalise the collaboration with SIGNO requires active involvement and support by Atlas Alliance.

2. The CBR program could improve their support to children and adults with severe intellectual and multiple disabilities. There is a need for day care and stimulation for this group outside the family. This would be helpful both as a relief to the family and for the improved QoL of the persons concerned. The following could be some of the options:
    a. To encourage families to start a self help groups (5-10 families) where the families meet to discuss how they could be of assistance to each other. Perhaps they can jointly start some activities for their children or just meet for social and peer counselling reasons.
    b. To encourage the establishment of training classes, day centres and relief services for this group. These could be community based centres. These do not necessarily need to be organised on daily basis. As a start, this can be for 2-3 times per week and using a local facility so that no large costs will be involved.
    c. To promote the establishment of a parent association. Invite parents for study visits to NFU or FUB (parent organisations in Norway and Sweden)

    d. To provide training for CBR workers in how to deal with severe disabilities (autism, alternative ways to communicate, feeding problems etc) by having seminars and practical case studies around these issues.

   The proposal to formalise the collaboration with NFU requires active involvement and support by Atlas Alliance.

3. The CBR program could strengthen the Union of Disabled people by
    a. Actively assist them to recruit members as part of the rehabilitation work
    b. Undertake the summer camps and outings as a collaborative effort with the local branch
    c. Always partner in advocacy matters
    d. Invite board members of the Union branches to all CBR staff training events and to annual evaluation and/or planning events

4. The CBR program should consider employing persons with disabilities as CBR workers and directors. As shown in the Jenin area this has significantly contributed to the success of the program. Role models with disabilities inspire persons who feel depressed about their situation and also contribute to the changing of attitudes among family and community members. The CBR program should make it a proactive strategy to employ, train and promote persons with all types of disabilities. This should not be limited to the availability of applications by disabled persons but rather a goal that can only be achieved if the program works on it proactively.

5. The CBR program should recognise that counselling and psychosocial support is one of its most valuable interventions. These skills could be further developed by specific training in these areas. The program should collaborate with programs within and outside the partner organisations to develop its competencies. Many organisations, including the CBR program partners, are developing programs to address psychosocial/mental health needs of Palestinian children and youth who are affected by the occupation and the ongoing violence. The CBR program could tap on and piggy back these initiatives. While doing so the CBR program must be careful not to loose its focus on children with disabilities. The CBR program should consider
    a. Getting expertise from ex Yugoslavia where numerous organisations have worked on the collective war traumas of children and youth. Individual counselling is found not to be sufficient (Contact Norwegian Save the Children for contacts and support to Hi Neighbour in Bosnia and CPA in Croatia)
    b. Further training of CBR workers in counselling an psychosocial work
    c. Collaborating with other groups providing such service in the same localities – these are numerous and include Ministry of Health, Ministry of Education, Ministry of Social Affairs, UNICEF, UNRWA and too many local NGOs. These programs do not provide special attention to children with disabilities and coordination with them is crucial in order not to unnecessarily duplicate activities or increase the burden on the CBR staff.
    d. CBR workers need debriefing and support to cope with their duties. There should be a day every second week for such “loading of the batteries” and

personal counselling. We heard of situations where the CBR worker had to go outside to cry because there was so little that he/she could do.

6. The CBR program should look into the possibilities of improving their support to income generation for persons with disabilities. Despite of a generally difficult situation with an unemployment rate of 60 % there are many things that could be done to improve the situation of persons with disabilities. Some ideas:
    a. Mapping of government and company positions to identify suitable jobs for persons with various disabilities. Advising persons with disabilities how to prepare and apply for these positions. Writing recommendation letters, when appropriate.
    b. Supporting apprenticeships in various trades (bakery, stone cutting, mechanical repairs, poultry etc). Sensitising companies and NGOs about disability and the law.
    c. Linking persons with disabilities to NGOs providing small scale business training and loans (there are many). There are ones that even focus on supporting women in setting up private enterprises – such a project is funded by the World Bank. Sensitising these NGOs about disability and the law.
    d. Using the network of the family of the person with a disability to find income generation opportunities.
    e. Referrals to existing vocational training opportunities, while abolishing the traditional trades such as embroidery and basket-making.

7. CBR workers need to work also with fathers, in-laws and siblings to relieve the mothers of the pressure.

11.2 Advocacy and policy recommendations

8. The CBR program could, through the regional CBR committees, address the issue of provision of technical aids and rehabilitation services. There needs to be clear guidelines and procedures for cost sharing, supply, repairs and quality of services. The feasibility of establishing a production/repair centre for wheelchairs and other technical aids could be investigated as it could also create jobs. There are detailed manuals guiding such initiatives. In the wake of government insurance, a technical aids fund could be established. In collaboration with the Union of Disabled People, the CBR program could lobby rich Arab States to contribute to such a Disability Fund.

9. The educational authorities should be lobbied to develop a strategy for special needs education, including the role of the special schools, the resource centres and support teachers of the inclusive education program etc. Small units for children in need of extra support are needed in all regular schools. Major donors (UN/Development Bank etc) could be approached to address these issues as part of their support to the Palestinian educational system.

11.3 Management and organisation recommendations

10. The CBR program could increase the coverage by establishing locally-powered CBR structures in some villages and then move to new areas to replicate the same structure. These could be run by disabled people themselves together with CBR workers from the area.

11. The CBR program needs to challenge its partners to treat CBR as a crosscutting program. Agreements between CBR and partners need to include commitments concerning access of CBR workers and users to all training programs, assistive devices, and medical treatments etc. provided by the partner. Partners also need to be challenged to employ persons with disabilities, at least to the 5 % level of the law. Partners also need to be challenged regarding their attitudes and the language used when talking about the users of their services. This can be dealt with through training provided by persons with disabilities and their organisations.

12. Using a local network of NGOs for implementation of the CBR program has been a good strategy under the political circumstances prevailing. There is however a need to discuss if and when the CBR program should be linked to the Ministry of Social Affaires (MOSA) and its district offices. Each implementing NGO has its own agenda and profile. The CBR program should ultimately serve persons with disabilities without having a bias for any particular NGO. The vision should be that the CBR program should cover all citizens and use all resources available. This is ultimately the responsibility of the government and stipulated in the law. Perhaps the time has come to establish a closer collaboration with the government social workers? Perhaps the regional CBR committees can be a link? It is proposed that

    a. An external consultant is hired to study the government's perception, vision and plans in regard to the disability issue. This could be organised as a follow up and dialogue around the implementation of the disability law. The consultant should work in collaboration with MOSA to assist them to define their role and make a plan for a possible take over of the responsibility of the CBR program. There is need for careful preparations for such a change as we cannot afford to run the risk of stopping NGO involvement (when donor support ceases) while the government involvement is at zero level. The initiative for such a consultancy must be initiated at the embassy level. Both Norway and Sweden have committed themselves to mainstreaming disability in their development assistance programs as indicated by the attached statement from the Nordic Ministers of Foreign Affaires.
    b. In order to build on the gained experience by NGOs and local communities, the government may develop a scheme to subcontract NGOs or hire individual CBR workers to provide the service, thus helping the programs to become more sustainable and more coherent under a standardized approach rather than simply taking over the responsibility from them.

13. Finally, it seems to be the right time for the CBR program to review its objectives, structures, strategies and working methods. A lot of things have happened in the environment (opportunities and threats), and quite a number of evaluations have made various proposals, including this one (strengths and weaknesses). All this can serve as important inputs when taking decisions about the future. It is proposed that a workshop is organised early 2006 to review the program and formulate a plan for the coming 5 years. Both CBR workers and representatives of the service users should be part of such a planning exercise.

ANNEX 1

Interview guide:

Respondent details
Age:
Sex:
Region:
Years in CBR project:
Latest contact with CBR:
Functional limitation:
☐ Seeing/Visual
☐ Hearing
☐ Speech
☐ Movement
☐ Epilepsy/Fits
☐ Strange Behavior
☐ Learning difficulties
☐ Other, namely:

☐ Questions answered by parent/care giver, namely:

1. What kind off support did you get from the CBR project?

2. Which was the most important support activity?

3a. Has the support from the CBR project improved your life situation *(the person with a disability)***?**
☐ Yes, definitely ☐to some extent ☐to a very small extent ☐ No

3.b What has improved?

4.a Has the support from the CBR project improved your life situation as a parent/care giver *(if caregiver is participating in interview)***?**
☐ Yes, definitely ☐to some extent ☐to a very small extent ☐ No

4.b What has improved?

5. a How do you feel about your life today?

5. b How was your life before you became part of the CBR project?

6.a Has the CBR affected your relationships with others in the family (mother, father, siblings, children, spouse, in laws)? Explain!

6.b How is your situation in the family now ?

6.c Are you participating like others in family activities?

6.d Are you treated unfairly or overprotective compared to others?

7. a Has the CBR affected your social life? Explain!

7. b What do you do in your free time?

7.c What do others of your age do?

7.d What kinds of activities are difficult for you to join?

7.e Do you have friends outside the household? Who?

7. f Are you invited to join community activities along with others? When/what?

7. g What about marriage (now or in future)?

8. Has the CBR project helped you to manage your personal daily living activities better (moving inside, dressing, eating, toilet etc) today? Explain.

9. Has the CBR project helped you to improve your health situation (less pain, less fits, less psychiatric problems)? Explain how.

10. Has the CBR project helped you to reduce your physical difficulties (seeing, hearing, talking, sitting, walking, moving)? Explain how.

11. Has the CBR project referred you to get medical/rehabilitation treatment or technical aids from an organisation, institution or hospital?

a. From where *(name of organisation/institution)*:__________________

b. What did you get? ________________________

c. Did your family have to pay?________________________

12. Are you still in need of medical/rehabilitation treatment or technical aids? If so, why can't you get the treatments or technical aids you need?

☐ I don't know where to get the services
☐ The services/treatments are too expensive
☐ The services/treatments are not available where I live
☐ I don't have transport
☐ Other:_________________________
☐ N/A

13.a Has the CBR project helped you to improve communication in the family, school, with friends? *(hearing impaired)* **How?**

13. b Do you still have problems to understand teachers or friends?

13.c Do you use sign language? Palestinian/private?

14. What kind of education do/did you attend?

☐ regular class
☐ special class/unit in regular educational setting
☐ regular class with younger students
☐ special education school for _________________________students
☐ university
☐ vocational training
☐ other ___________________
☐ none

☐ N/A *(did not have a disability at the school age)*

15. If none, why not?

16. How would you describe your situation at school (academically and socially)?

17. Has the CBR helped you to get skills for income generation? If so what?

18. Has the CBR helped you to get work or income? If so what?

19. How has CBR affected the situation in your community? What was it like before?

20. Is there and active CBR committee in the community? If so what does it do?

21. Do you know of the Union of Disabled people? ☐ yes ☐no
If yes,
a. Are you a member? ☐ yes ☐no
b. Do you take active part in the activities of the union? ☐ yes ☐sometimes ☐hardly ever ☐no
c. What is your opinion about the Union?

22. Do you know of other self help groups/clubs of disabled people? ☐ yes ☐no
If yes,
a. which group/club:____
b. Are you a member? ☐ yes ☐no
b. Do you take active part in the activities of the group/club? ☐ yes ☐sometimes ☐hardly ever ☐no

23. Do you know about the disability law and the rights of disabled people?
☐Yes ☐No Comment______________________________________

24. What are the most important results of the CBR project?

25. What is missing in the CBR project?

26. What are your biggest problems at the moment?

27. What are your dreams for the future?

ANNEX 2

COMMUNIQUE BY THE NORDIC MINISTERS RESPONSIBLE FOR DEVELOPMENT COOPERATION

At their meeting in Copenhagen on the 25th of August 2005, the Nordic Ministers of International Development Cooperation stressed the importance of increased efforts to ensure that people with disabilities are a priority in international development co-operation.

The ministers reviewed progress made in this field since the Nordic conference on Disability and Development Cooperation in Copenhagen year 2000. It is evident that substantial progress has been made, not least in the implementation of programmes through Nordic Disabled Peoples Organisations (DPOs). In priority fields, such as education, great efforts in the endeavour to include people with disabilities have been made.

It is, however, evident that more could be done, including taking full advantage of ongoing Nordic co-operation in the United Nations and in the international development financing institutions as well as looking into the possibility of further joint initiatives linked to bilateral development cooperation.

The Nordic country governments give their full support to the work in the UN on the Comprehensive and Integral Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities. Nordic governments support the participation of developing countries in the process where 140 countries are actively engaged. Nordic governments also support the initiative of the Global Partnership on Disability and Development where the World Bank has taken the role as coordinating body.

The achieving of poverty reduction goals will not be possible if disability concerns and disabled people are not included. This is self-evident as disabled people and their families constitute a large proportion of poor people. Therefore the disability dimension needs to be mainstreamed in relation to major development frameworks such as the UN Millennium Declaration, the MDGs, PRSPs and the OECD Poverty Reduction Guidelines.

The Nordic Ministers are encouraging development agencies and relevant research institutions in the Nordic countries to include the rights and living conditions of disabled people in development research. They also underline that continued support to organisations for and of people with disabilities is an important part of getting this issue high on the agenda at global, regional and country level.

The review of Nordic progress support the view that it is necessary to make more concrete and consolidated plans if mainstreaming is to be achieved. The Nordic countries therefore have decided to work together to identify arenas where Nordic cooperation can lead to increased efforts. The main focus would be on increasing mainstreaming efforts, though targeted approaches could be applied when appropriate. As women with disabilities often face double discrimination, gender issues need to be included. The relevant ministries in consultation with Nordic DPOs will review the common activities and arenas of cooperation identified at the next Nordic Development Ministers meeting.

Evaluation of the CBR program in Palestine – from the perspective of persons with disabilities themselves

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