

Twenty Years of Community-Based Rehabilitation in Guyana 1986-2006

AN IMPACT ASSESSMENT



Dr. Sunil Deepak – AIFO/Italy (2006)



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Acronyms Used in the Report

ADD	Action on Disability & Development
AIFO	Italian Association Amici di Raoul Follereau
CBID	Community-Based Inclusive Development
CBR	Community-based Rehabilitation
CIDA	Canadian International Development Agency
DPO	Organisation of Persons with Disabilities
EBD	East Bank Demerara
GCBRC	Guyana CBR Committee (national)
GCBRP	Guyana CBR Programme
IDCE	Institute of Distance & Continuing Education
NCD	National Commission on Disability
OPD	Organisation of Persons with Disabilities
ToR	Terms of Reference
VSO	Voluntary Services Overseas
WBD	West Bank Demerara

1. Introduction

Guyana community-based rehabilitation (CBR) programme started in 1986. The Italian non-governmental organisation Amici di Raoul Follereau (AIFO) has been associated with Guyana CBR programme since 1989. This report is about an impact assessment of 20 years of the CBR programme in Guyana conducted by an AIFO consultant in 2006.

CBR programme in Guyana has been a subject of many studies and evaluations over the past twenty years. The decision to conduct an assessment of impact of the Guyana CBR was taken by AIFO. The impact assessment did not concern itself with problems or successes of the specific programme activities, but rather it aimed to look at the bigger picture, by focusing on "*lasting or significant changes*" in relation to persons with disabilities in Guyana and the role played by Guyana CBR programme in bringing about those changes.

With its limited population, most of which lives in the narrow coastal areas of the country and an on-going CBR programme managed by the same national institutional and non-governmental partners over the past 20 years, it was felt that Guyana provided an ideal location to understand medium-term impact of the CBR approach on persons with disabilities and their families.

1.1 COMMUNITY-BASED REHABILITATION (CBR)

CBR is a community development strategy that aims to enhance the quality of life for people with disabilities and their families, and ensure their inclusion and participation in the community. CBR was initially launched by WHO as a strategy to increase access to rehabilitation services at the community level for people with disabilities, but it has evolved into a much broader and multisectoral approach to community-based inclusive development.

CBR aims to achieve rehabilitation, equalization of opportunities and social inclusion by involving people with disabilities in community development processes. It presents an opportunity to operationalize the recently approved (Dec. 2006) United Nations Convention on the Rights of Persons with Disabilities (CRPD).

CBR is implemented through the combined efforts of people with disabilities, their families, disabled people's organizations (DPOs), other community stakeholders including nongovernmental organizations (NGOs), and relevant governmental bodies, particularly those responsible for health, education, vocational and social services. It uses a grass-roots approach to guide development priorities.

CBR is also known as **Community-based Inclusive Development (CBID)**.

1.2 OBJECTIVES OF IMPACT ASSESSMENT

AIFO's Board of Directors asked for an impact assessment of the GCBRP focusing on achievements of CBR programme over the past twenty years, with particular emphasis on the following:

- Impact on the policies and practices of institutions in Guyana
- Impact on the lives of children and adults with disabilities

- Impact on the civil society & organisations in Guyana

A draft Terms of Reference (ToR) was prepared by AIFO and shared with partners in Guyana for their comments and suggestions. On the basis of these comments, a modified ToR was finalised (Annex 6).

1.3 METHODOLOGICAL CONSIDERATIONS

The following considerations were made while deciding the methodology to use for this impact assessment in Guyana.

It is not easy to clearly mark the boundaries of terms like 'Output', 'Outcome' and 'Impact' when applied to social interventions. For this Impact Assessment, the following meanings were given to these terms - the term 'Output' measures effort of the intervention and indicators for its measurement are related to implementation of activities; 'Outcome' relates to effectiveness of intervention and indicators for its measurement are related to use of outputs and sustained production of benefits; and finally, 'Impact' measures change and the indicators for its measurement are related to difference from the original problem situation. (Oakley, Pratt & Clayton, 1998).

Thus, “Impact” is understood as “the effects of an intervention that can be attributed uniquely to it, *i.e.*, with the influence of confounding effects from other sources controlled or removed” (Rossi, Freeman & Lipsey 1999). Since, “removing” the influence of confounding effects from other sources in communities and national regions is not possible, in social (or community) development programmes, assessment of impact can only be made with some degree of uncertainty. Such programmes do not take place in a social vacuum, and it may be impossible to distinguish the effects of the programme from other influences such as political changes, competing programmes, parallel initiatives, economic changes, or changes in rules and regulations. (Eide A. H., 2006)

While the common approach to impact assessment is based on the ideal of experimental design, it follows from the character of a community development programme that alternative approaches will be needed. The judgements of experts, programme administrators, key personnel or participants (users, clients) are acceptable alternatives when conditions for applying a classical experimental design are absent. (Oakley, 1999)

From the early 1980s, new methods of enquiry have emerged which attempt to make people and communities subjects and active participants, rather than objects of impact assessment. In contrast approaches to the evaluation of social development have built on historical and anthropological ideas and see evaluation as negotiation of diverse opinions and perspectives. This later approach, in combination with participatory methods, thus seeks to understand the opinions of various interest groups, especially those whose views are not normally heard. (Roche C., 1999)

1.4 METHODOLOGY USED FOR IMPACT ASSESSMENT IN GUYANA

As suggested by Rosche above, the present impact assessment focused on "*significant or lasting changes in people's lives, brought about by a given action or a series of action*" through opinions of various interest groups and negotiation of diverse opinions and perspectives.

This impact assessment included:

(1) A review of reports and studies from different sources related to Guyana CBR programme.

(2) Interviews with key stakeholders identified by the GCBRP during a field visit of the consultant in Guyana from 23 October to 6 November 2006.

For measuring the "change", this impact assessment was carried out in two phases - an initial review of documents and reports and a second phase of field visit in Guyana. The initial document review compared the situation related to different aspects of disability among clients, stakeholders of Guyana CBR programme as well as among other institutions of civil society through an examination of different project documents and studies produced by Guyana CBR programme over the past 17 years (newsletters, formal project reports, research studies, formal evaluation reports, etc.). A list of documents and reports consulted for the impact assessment is provided at the end of this report.

For the field visit, the consultant visited all the regions of Guyana where CBR programme is



or was active, meeting present and past clients and their parents, present and past volunteers, representatives of institutions, representatives of civil society organisations, etc., both as individuals and as groups, and conducted semi-structured interviews. Annex 1, presents an overview of field visits, interviews and consultations, Annex 3 presents the programme of field visits and Annex 4 shows the areas visited on the map of Guyana. (Image left: Individuals who took part in a group discussion about the impact of CBR in Essequibo).

Overall, during this impact assessment, the consultant interacted with:

- About 100 disabled persons and families (either individually or in small groups, including about 30 home visits);
- About 100 CBR volunteers and ex-volunteers;
- 20 representatives of Governmental and non-governmental organisations and institutions.

As suggested by Roche above, this impact assessment combined participatory methodologies by giving voice to persons involved at different levels and ways with CBR programme with the negotiation of different opinions among different stakeholders for coming to a shared vision about the accomplishments and challenges of CBR in Guyana.

2. Context of Guyana CBR Programme

2.1 BRIEF HISTORY OF CBR PROGRAMME IN GUYANA

The implementation of CBR programme in Guyana can be divided into 4 phases as explained below.

Initial Phase: The Community-based rehabilitation (CBR) programme in Guyana targeted at children with disabilities was initiated as a pilot initiative in 1986 in two coastal locations, by a group of individuals including parents of children with disabilities. This pilot initiative involved training of volunteers, which was organised in collaboration with the Institute of Distance and Continuing Education, of the University of Guyana and Ministry of Education. (O'Toole B., 1995)

In 1990, this pilot initiative was expanded through a joint project of two European organisations - Action on Disability & Development (ADD, UK) and Italian Association Amici di Raoul Follereau (AIFO, Italy), co-funded by the European Commission. During this period the basic foundations of a new voluntary organisation composed of parents of children with disabilities and community volunteers were laid in Guyana, which became one of the national partners for the field-implementation of this CBR project.

A Second Phase of expansion and consolidation of CBR programme in Guyana supported by AIFO-Italy and co-funded by European Commission covered the period from 1994 to 1996. National Rehabilitation Commission of Guyana was the formal Guyanese counterpart for this project as the newly created Guyana CBR organisation composed of parents and community volunteers was still not a formally registered organisation. During this phase, Guyana CBR Committee (GCBRC) became a registered and formal non-governmental organisation and the de facto Guyanese counterpart for managing this project. This phase also saw the setting up of “small loans and income generation activities” in the CBR programme and the programme was expanded to an internal part of the country (Rupununi, region 9).

The conclusion of the second phase of CBR programme also saw internal divisions among some components of GCBRC. There were leadership issues and some key persons decided to stop their collaboration with Guyana CBR Programme (GCBRP). In many areas of the country, community volunteers also left the programme. Thus, it was a period of transition and instability. At the same time, during this period GCBRC became a stronger organisation firmly rooted in the local communities.

A Third Phase of expansion and consolidation of CBR programme in Guyana supported by AIFO-Italy and co-funded by European Commission covered the period from 1999 to 2002. This project had two specific components –

- (a) an institutional component related to setting up of a vocational training centre, strengthening of services for the provision of technical and orthopaedic appliances and training of rehabilitation assistants (in collaboration with the Ministry of Health of Guyana);

(b) a community-component linked to consolidation of CBR activities in different regions of Guyana (managed by GCBRC).

During this phase, there was greater emphasis on collaboration with Ministry of Health of Guyana. At the same time, the activities of GCBRP were uneven as in some areas the exit of volunteers created new gaps while new groups and volunteers started in other parts of the country. Over the last decade, the CBR programme also enlarged its focus from children with disabilities to all the persons with disabilities, including adults.

The 4th Phase, after 2003 till now, can be seen as a period of consolidation and the strengthening of the democratic processes in the GCBRP organisation and its community activities.

During 1990-2006, in between the formal projects covered by increased level of support with co-funding from European Commission, a smaller level of funding has been assured annually by AIFO to facilitate the basic functioning of GCBRP. In this period, GCBRP has also received contributions and support for specific activities from many other quarters such as VSO, CIDA, ADD, BCCP, USAID, etc.

While reading this report, it would be important to remember that the term GCBRP means (1) A CBR programme which is being implemented in the communities in Guyana; (2) As well as, the national organisation implementing this programme, which is a democratic organisation formally registered in line with the national laws.

2.2 SIGNIFICANT MACRO-LEVEL EVENTS IN GUYANA DURING THE LAST 20 YEARS

There were many important macro-level changes in Guyana over the past twenty years that affected the way the Guyana CBR programme has developed and evolved. This list of contextual factors refers to 3 issues identified as significant by the key stake-holders during the interviews and group discussions.

2.2.1 Emigration of trained personnel

It is said that more Guyanese live outside Guyana than inside the country. The issue of emigration and influence of diaspora living in developed countries, came up repeatedly during this visit. For example, during one discussion it was mentioned that "*there are no trained orthopaedic technicians in the Ptolemy Reid orthopaedic workshop, because they have emigrated and now there are only untrained persons who have learned on the job.*" Emigration of Guyanese persons to other countries, especially to north America, affected both trained personnel working in the rehabilitation services as well as community volunteers trained by the CBR programme.

The difficulty of retaining the trained health personnel had prompted the Ministries of Health and Education in setting up of new training courses that aimed at the preparation of mid-level professionals with multiple skills, who may not easily find standard employment opportunities outside Guyana. One such example was the training of multi-purpose rehabilitation assistants with 18 months of training, touching on aspects of physiotherapy, occupational therapy and speech therapy.

It also had some positive impact on lives of persons with disabilities. For example, receiving remittances from family members settled abroad allowed persons with disabilities to live in

newly renovated and comfortable looking houses, even while their own level of economic independence remained low or limited.

Possible emigration of different stake-holders involved in the project at different levels, remains a key area, that needs to be constantly kept in mind while planning any initiative.

2.2.2 General Development & Improvement of life conditions of Guyanese

In terms of infrastructures, roads, transport, connectivity, housing, etc., the country presents a number of improvements as compared to the situation twenty years ago. Partly this may be due to funds sent by the diaspora settled in developed countries. During the discussions, many persons expressed satisfaction over the improvements in their own life conditions.

There has also been some improvement in per capita Gross Domestic Income (GDI) in Guyana, though yet, this improvement does not reflect in some selected health related indicators. For example, in 1985 infant mortality was 33 per thousand and average life expectancy was 69 years. (O'Toole B., 1995). More recent data from World Health Report 2006 shows some deterioration: infant mortality 64 per thousand and average life expectancy 63 years. (WHR, 2006).

On the other hand, per capita GDP was 670 USD in 1982, 590 USD in 1994 and had increased to 4,439 USD in 2004. This discrepancy between increase in GDP and deterioration of some health indicators can be explained in terms of Human Development Index (HDI). The Human Development Report (HDR) 2006, shows that Guyana has lagged behind other countries in Latin America and Caribbean in terms of HDI.

2.2.3 Evolution of Political System & the Multi-Racial Society

Guyana is a country of different ethnic groups and racial tensions have been a significant issue in the recent past. Immediately after independence, for about three decades the political power was with PNC party dominated by persons of African origin. Since the last fifteen years, the power is with PPP, dominated by persons of Indian origin.

During some discussions, especially with persons of older age groups, individuals felt that racial tensions continue to be significant issue and persons of different racial origins in Guyana have not yet found a way to live in harmony.

On the other hand, some persons expressed optimism about the recently concluded elections that were not marred by the usual violence and expressed hope that perhaps "*we are on the way to peaceful co-existence*".



Discussions with younger persons also brought out awareness of their own unique Caribbean identity that goes beyond the confines of African or Indian origins and is uniquely Guyanese. (Picture above right: Children in a CBR resource centre in Corentyne)

Discussions with many individuals often brought out more nuanced stories of mixing of races and cultures of persons over generations, that may not be apparent in clearly demarcated boundaries of ethnic profiles and classifications.

In addition, discussions with Amerindian persons, who are a minority, brought out their marginalisation from the racial discourse, that "*sharing of power between the persons of African or Indian origin will not change things for us and we need to look after ourselves.*"

At the level of the GCBRP, these racial differences are considered as important in different ways as these might influence access and participation of individuals in the CBR activities. In terms of beneficiaries, GCBRP reaches to persons of different ethnic and religious groups. However, in terms of community participation through volunteers, in terms of ethnicity, persons of African origin are in majority, especially women. In terms of religion, persons of Muslim origin are a very small minority among the volunteers.

However, GCBRP is very much aware of racial divisions in Guyana and actively endeavours to promote an inclusive model that respects diversities and embraces all the different groups of persons in all its activities, as beneficiaries, as community volunteers, as regional committee members and at the national GCBR committee.

3. Impact of GCBRP on National Policies and Services

The Impact Assessment showed that globally, Guyana CBR programme organisation has played a key advocacy role in putting disability and rehabilitation issues in the national agenda, in shaping up national policies and in influencing the organisation of services aimed at persons with disabilities. On the other hand, its impact on improving the level of services available for persons with disabilities has been more limited, presumably due to limited national resources (especially, financial and human resources).

3.1 NATIONAL COMMISSION ON DISABILITY AND THE NEW LEGISLATION ON DISABILITY

Guyana CBR programme has been one of the prime movers advocating for greater awareness in national policy on disability issues and has contributed to setting up of the National Commission on Disability (NCD) in 1997 and especially in advocating for greater and more active role of the Commission in the past few years.

Guyana CBR programme (GCBRP) organisation is an active member of the NCD, contributing to debates and insights about the needs of persons with disabilities and issues related to human rights and equal opportunities, for the drafting of the new national legislation on disability, that keeps into account the newly approved UN Convention of Rights of Persons with Disabilities. This new legislation is now going through the drafting process for submission and approval at the National Parliament.



NCD is a Presidential commission that was first commissioned under the ex-President Ms. Janet Jagan. It has 15 members coming from the main stakeholders including different ministries, DPOs, human right organisations and GCBR. NCD had replaced an earlier National Rehabilitation Commission.

Ms. Hamilton, chair-person of NCD, acknowledged the importance of the contribution of Guyana CBR programme in setting up of NCD with the following words: *"The work done by GCBRP has been fundamental in creating awareness about disability issues in the country. GCBRP has done active advocacy even before NCD was started and was an active supporter of the National Rehabilitation Commission."* (Picture above left: Ms. Hamilton, chair-person of NCD with Ms. Geraldine Halls & Ms. Gwendoline Glasgow from GCBRP Board during the Impact Assessment visit of the consultant in Guyana).

GCBRP promotes and actively participates in disability related initiatives in Guyana. For example, recently, through its network of CBR chapters in different regions of the country, Guyana CBR programme (GCBRP) has been collaborating with NCD for conducting surveys and collecting information on disability issues in different regions. This information collection is very important for having some baseline information and for planning of future strategies and activities.

2.2 CREATING AWARENESS ABOUT DISABILITY AMONG KEY STAKEHOLDERS

Creating critical awareness about disability issues among the key stakeholders has been a priority for GCBRP. It has been successful in reaching out to the different Government ministries and departments in creating awareness about issues related to persons with disabilities and about its own work and ensuring that accessibility of the different programmes and services to persons with disabilities is kept in mind.

A statement from the Minister of Health, Honourable Mr. Leslie Ramsammy, illustrates this high level of confidence in the activities of GCBR, *"I know the CBR programme very well. Every month, I give one day of my salary to CBR programme in West Berbice, that can tell you what do I feel about this programme! Support to CBR programme comes from all the Government. President himself gave support from his fund for the construction of CBR resource centre in Essequebo region."* (Picture



right: Meeting of the consultant with the Health Minister Mr Ramasammy, second from right, during the impact assessment).

While the project has been successful in reaching persons and institutions that have a direct stake and interest in disability and rehabilitation issues, it has faced difficulties in reaching other civil society institutions, especially those that do not have a direct interest or stake in these issues. Representative of USAID in Georgetown, one of the partners of GCBRC, expressed this difficulty in the following words, *"They [GCBRP] can do much more to promote their image and encourage other persons to join them. They can work more on making their work more transparent and avoid conflict of interests. Persons with disabilities are still hidden and there is much more scope for reaching out. Barriers are there and much more can be done. Involving business community can be a strategy because if they adopt a programme, they can pay the costs. Some radio and TV programmes are free and they can also be tapped into."*

2.3 PROVISION OF REHABILITATION SERVICES THROUGH MINISTRY OF HEALTH

Guyana faces a serious challenge in terms of retaining trained health professionals, as most of the trained professionals tend to emigrate to other countries. At the same time, the country has a limited population to justify continuous training of new professionals, as this places a large burden on national resources.

For this reason, since 1999, the Ministry of Health in Guyana has decided to create a new category of intermediate rehabilitation professionals, the rehabilitation assistants, who receive training for 18 months and whose training curriculum contains elements of physiotherapy, occupational therapy and speech therapy. These workers, do not have a degree which is recognised outside Guyana.

Through rehabilitation assistants and their collaboration with CBR groups in different regions, rehabilitation services are gradually being extended to cover 9 out of 10 regions of the country, for providing referral support to primary health care services.

This training of Rehabilitation Assistants was initiated as a part of the AIFO supported CBR programme funded by European Commission (1999-2002) and ever since, is coordinated by the national resource person Ms. Geraldine Mason Halls, who is also National Advisor to GCBR. This has allowed a greater networking and collaboration between the rehabilitation assistants and CBR groups at peripheral level.

Though there are some critical issues in relation to coverage and supervision support of rehabilitation assistants, discussions with the CBR volunteers in the communities showed that they do play an important role in the present scenario of rehabilitation services in Guyana.

2.4 PROVISION OF ORTHOPAEDIC APPLIANCES AND MOBILITY AIDS

As for rehabilitation assistants, an earlier AIFO supported project co-funded by European Commission (in the period 1994-96) had contributed to the strengthening of National Orthopaedic Laboratory in Ptolemy Reid Centre in Georgetown by providing training of personnel, raw materials and equipment for production of orthopaedic appliances and mobility aids. However, the emigration of all the formally trained personnel has left a void in these services that has been filled by personnel lacking formal training. Thus, the national institutional services for the provision of orthotics and prosthetics have been limited.

On the other hand, the local production of simple appliances and aids at community level, was never a strong component of GCBRP and continues to be an episodic rather than a planned activity reaching all the regions. GCBRP collaborates with national orthopaedic centre and if the country receives orthopaedic appliances from any sources, GCBRP collaborates in identification of persons with disabilities who can benefit from these, and helps in their adaptation and training of the users.

Thus, in terms of supply of and access to the orthopaedic appliances and mobility aids, the impact of GCBRP has been relatively limited.

2.5 PROVISION OF SPECIALIZED REHABILITATION SERVICES

Specialised rehabilitation services such as orthopaedic-surgery, plastic surgery and reconstructive surgeries, etc. are quite limited in Guyana. These are also not a focus for the GCBRP and over the past twenty years, only a very small part of AIFO's supported resources were targeted at this area.

The AIFO supported project co-funded by European Commission (1999-2002) did provide some short-term training of hospital personnel, and GCBRP occasionally tries to find support for visits to neighbouring countries for persons requiring specialised interventions, overall, the impact of this has been very limited, as can be expected from a programme focusing on communities.

Thus, persons with severe disabilities in Guyana requiring specialised rehabilitation interventions, often do not receive adequate services. During the visit, the consultant met some of these persons, such as children with progressive genetic conditions.

2.6 PROMOTING EDUCATION OF DISABLED CHILDREN AND YOUNG ADULTS

GCBR project has a special focus on promoting education for children with disabilities. School teachers have always played an important role among the CBR volunteers and even when they stop volunteering, they continue to support inclusion of children with disabilities in regular schools, especially in the nursery schools.

For primary and higher education of disabled children in regular schools there are physical barriers for children with mobility-related disabilities. Therefore, the project also supports them through informal education and coaching at resource centres for children of older age groups.

Another way in which GCBRP promotes education at national level is through the collaboration with Institute of Distance and Continuing Education (IDCE), including the certificate course for CBR volunteers recognized by Ministry of Education. Mr. Francis Glasgow, director of IDCE says, “*IDCE has the goal of promoting education in the country and it finds a synergy with the community level activities of GCBRP.*”

Thus in terms of education, GCBRP has played a significant role in improving the access to formal and informal education for children and adults with disabilities in its project areas, as well as for other persons from the communities through the volunteer training programme.

2.7 VOCATIONAL TRAINING AND JOB PLACEMENT

In terms of vocational training, job placements and economic empowerment, the project has activities in two different directions – in the regions and through the setting up of a national vocational training centre.



Through the different regional groups, the project has provided opportunities for vocational training courses to persons with disabilities, families and volunteers at the regional resource centres. A certain number of persons have also benefited from loans for starting their own commercial enterprises. Though these activities have helped some persons to become economically independent, in most cases their impact has been limited and are perceived as “*I have some support*” rather than economic self-sufficiency. For example, a beneficiary of loans from

GCBRP for making and selling handicrafts said, “*It gives us some income and keeps us busy but I can’t live on these earnings, I have to look for other ways to earn more money.*” (Picture above left: Open Doors vocational training centre)

As part of the CBR programme co-funded by European Commission (1999-2002), AIFO collaborated with Ministry of Health for setting up of a vocational training centre, “*Open Doors Vocational Training Centre*”. At the end of the project funding in 2002, this centre was taken over the Ministry of Health that is paying all the costs and “Open Doors” continues

to function, even if it is mainly accessible only to residents of Georgetown as it does not have possibility of providing hostel for disabled students coming from outside the city.

The Health Minister, Mr. Leslie Ramsammy said, *“We cannot continue to create new separate services and centres for persons with disabilities. We have regional technical training institutes in our country, we need to work with them so that they can also accept some persons with disabilities and organise services that answer the needs of disabled persons like the wheel chair repair services.”*

Thus, vocational training, job placements and economic empowerment activities of GCBRP are largely positive and sustainable, even if their impact has been somewhat limited.

2.8 CONCLUSIONS

Considering that GCBRP is a civil society organisation based on participation of community volunteers, its overall impact on national disability and rehabilitation strategies and policies has been significant.

Even other support from AIFO to Ministry of Health for training of the new rehabilitation professionals (rehabilitation assistants) and setting up the Open Doors vocational training centre has had positive impact. It is also positive that these additional activities with other institutional partners in Guyana, continued to maintain links with GCBRP.

4. Impact on persons with disabilities, their families and their organisations

The Impact Assessment showed that in the last twenty years, Guyana CBR programme has touched the lives of a large majority of disabled persons living in the country in some way, directly or indirectly. It has played a significant and direct role in promoting empowerment of many children and adults with disabilities.

4.1 EMPOWERMENT OF INDIVIDUALS AND THEIR FAMILIES

This is the greatest area of impact of the CBR project in Guyana. In countless small and big ways, the project has been instrumental in fighting the isolation of disabled persons and their families, giving them opportunity to meet others, learn about the possibilities and to change the outlook from that of closure, isolation and barriers to those of fighting for rights and promoting changes & improvements.

Even when the community volunteers of GCBRP cannot find any answers for the lack of different institutional health, education, social and cultural services for persons with disabilities, they almost always managed to create opportunities for increasing awareness, contact with others and sharing of experiences and ideas. During the meetings, most persons with disabilities and parents of disabled children identified this as the most important impact of CBR programme on their lives.

Mr. Sahadeo in Anna Regina summed up this feeling in the following words, *“For me CBR had a great impact. From 1977, when I became paralysed, till 1994, I was completely isolated and closed in the house. Then CBR programme volunteer came and helped me to overcome my isolation, to go out and mix with other persons. My whole life changed because of this.”*

4.2 PROMOTING ECONOMIC INDEPENDENCE

While the project had some activities for promoting income generation in the past, specific funds for providing loans through GCBRP were provided in two periods. Economic empowerment of persons with disabilities and their families through small loans for income generation activities was one of the objectives of the project during 1994-96 & then 1999-2002.

During the discussions in the communities, many persons who had benefited from the loans expressed appreciation about this aspect of the programme, and how the loans had helped them to become economically independent.

At the same time, discussions about the management of this activity showed that there were some problems in repayment of loans and in 2002, a new decentralised management system was introduced for it.

In addition, over the past few years, the number of requests for new loans from the GCBRP had decreased to less than 10 requests per year and project was unable to use the funds kept aside for the loans, underlining the difficulties in these activities.

4.3 DISABLED PERSONS' ORGANISATIONS

From the very beginning CBR project in Guyana initiated collaboration with national level Organisations of Persons with Disabilities (DPOs or OPDs). However, at that time, national level DPOs were facing lot of difficulties and were not functioning properly. Over the past years, GCBRP has focused on creation and strengthening of local level DPOs in different regions. Most of the time, persons involved in DPOs are also active members of CBR programme. Through this grassroots level participation in the regional and national DPOs, they have been strengthened. (Picture right: Andrew and Berti from East Berbice regional DPO during the discussions at the CBR resource centre).



For example, Mark Archibald is blind and is the president of the regional DPO group of West Berbice. Their organisation is formed by persons with different disabilities. They started as an informal part of the local CBR group but are now making links with the national level DPO. Mark says, “*We recognise the important role played by CBR that has helped me to become aware of the situation of different disabled persons and how we can fight for their rights.*”

Discussions with DPO representatives during the visit showed that often persons did not have a clear idea of differences between the roles of a DPO and CBR group. This might have been partly because GCBRP, by involving persons with disabilities and their family members in different decision making and implementation roles at different levels in the organisation, often acts as a DPO in some ways, though it is also engaged in service delivery and has a much wider base in the community including the representation of health, education and social professionals. Through GCBRP, persons with disabilities in the communities, were also linked with other civic organisations.

Thus, the impact of GCBRP on the DPOs, while being recognised as complementary and positive, was more complex and nuanced.

4.4 SUPPORTING PERSONS WITH DISABILITIES TO ACCESS DIFFERENT SERVICES

GCBRP supports children and adults with disabilities to access different services. These include home visits by volunteers to share knowledge and skills with the parents and other family members, especially in terms of greater autonomy of disabled persons for their daily living activities.

Often, interactions between CBR volunteers, persons with disabilities and family members takes place in **Community Resource Centres (CRCs)**, which are local spaces identified with the support of the community, where collective activities of GCBRP take place. For example, in one area the CRS was a room at the house of a CBR volunteer while in another area, it was a room in the local primary school.

Other forms of support for accessing different services includes advocacy with the regular schools for the inclusion of disabled children and for finding solutions to barriers, support to children with learning difficulties in the resource centres, support for visits to specialised rehabilitation services in the hospitals, organising visits and consultations of the rehabilitation assistants to the resource centres, organisation of training courses, advocacy with social services for receiving social welfare support, getting certificates for facilitating access to public transport, etc. Such activities directly benefit persons with disabilities and their family members. (Picture left: A volunteer Patricia Williams with Iony Chattoor during field visits)



Thus, the CBR programme contributed in different ways to improvements in health, rehabilitation, education, social and participation outcomes in the persons with disabilities, however those outcomes cannot be counted only as “impact of GCBRP”.

The discussions with CBR volunteers and GCBRP regional committee members showed that they tended to count only the children and parents regularly coming to resource centres as the direct beneficiaries of GCBRP. They did not count the persons to whom information or advice was provided or those who were facilitated to visit different specialised services. Thus, in terms of data, there was an under-representation of the individuals actually benefiting from GCBRP activities.

4.5 PERCENTAGE OF DISABLED PERSONS DIRECTLY BENEFITING FROM GCBRP

Estimates of numbers of persons with disability in Guyana vary widely. A 1996, report had estimated their number to be around 12,000 (1.5% of the population), while a disability survey carried out by GCBRP for National Commission on Disability in 2006, had chosen a sample based on an estimate of about 50,000 disabled persons in the country (around 6% of the population).

It is not easy to find out the total number of persons who benefited directly from GCBRP in the past twenty years. The information from the first decade of GCBRP was lost during the phase of transition and instability between 1996 and 1999, when many persons involved in programme management had left the programme and Georgetown office was relocated.

Even otherwise, at the regional level the GCBRP is followed by a part time coordinator with the support of community volunteers, some of whom have a very high turn-over, so that record keeping is not easy. During the Impact Assessment, discussions with the groups of volunteers, regional committee members and coordinators, during which the question of “*how many persons with disabilities your group has directly helped over the past ten years*”, frequently brought out confused answers.

Among the different regions of Guyana, among the GCBRP committee members, there was no common definition of a “*direct beneficiary of GCBRP*”. As mentioned above, volunteers tended to count only the children regularly visiting the local resource centres as “*persons benefiting from the CBR programme*” and did not count other persons who may have received occasional support, information or advice from them.

In 1996, a comprehensive evaluation had calculated that GCBRP was reaching to 286 children with disabilities. Recently collected data showed that 486 persons with disability were receiving some direct support from the CBR programme during 2006. This information is too limited to measure the exact number of persons who have directly received some benefit from the CBR programme in Guyana.

There are other measures that provide additional information. For example, during the past twenty years, about 1,500 community volunteers have been trained by the GCBRP, each of whom had networked, at least for a certain period, with different persons with disabilities in their communities. In 2006, there were about five hundred regularly or occasionally active CBR volunteers in the coastal areas of Guyana where the population density is higher. Some of these volunteers have been working with the GCBRP for many years, some for more than a decade.

The nature of direct benefits received by disabled persons varied hugely. Some disabled persons needed more support and attend the CBR services and activities regularly, for example at the resource centres, at summer camps, etc. and these persons are counted in the project data. Others, may not require regular services but for them key information provided by GCBRP can play an equally important role in improving their quality of life, but are not counted in the project data. During this Impact Assessment, the CBR volunteers were asked about the number of persons they directly supported - they tended to count only the persons who were receiving regular support.

For example, during a visit to a school, a head-mistress at a nursery school said, *“I was a CBR volunteer for a number of years but then I could not give any time to CBR as I had other things to do with family, so I stopped being a volunteer. Then, for many years, I lost contact with CBR programme. However, I never forgot the importance of including disabled children in the school system and I have kept on encouraging families to send their disabled child to the nursery school.”* When asked about total number of disabled children she had helped in accessing the nursery school, she thought that she must have helped about 20 disabled children over the past decade.



She said, *“It is so much easier to accept children with disability in the nursery schools but as these children grow older, it usually becomes more difficult for them to continue in the school system.”* (Picture above left: CBR volunteers Carmen, Norma, Harmoine & Indrani during a home visit in East Berbice region)

Though GCBRP had contributed to the education of these children, these were not part of the data collected by the programme.

Keeping all these issues in mind, it would be reasonable to assume that each volunteer in the coastal areas during their period of collaboration with GCBRP reached an average of 5-6 persons, while in the interiors, probably they reached less persons. This means that over the past 20 years, GCBRP must have had a direct impact on at least 5 to 6 thousand persons with disabilities and/or their families.

The data related to activities of GCBRP for the year 2006 (Annex 5) showed that there were 245 persons collaborating with its community level activities and there were 485 persons with disabilities receiving regular support. Among them 52.7% were females and 47.3% males.

Among those 485 persons with disabilities, 11.9% had vision related disabilities, 24.1% had hearing and speech disabilities, 30.7% had physical or mobility related disabilities, 18.7% had learning disabilities and 14.4% had multiple or other disabilities. There were no persons with mental illness, convulsions or leprosy among them.

In terms of age of those 485 persons with disabilities – 44.5% were in the older age group (more than 36 years), 28.2% were young adults (16 to 35 years) and 27.4% were less than 15 years of age (including 14.6% who were less than 5 years old).

4.6 CONCLUSIONS

In terms of impact of the GCBRP on persons with disabilities, their families, their organisations and local communities, we can conclude that impact of GCBRP was considered as significant and positive by the beneficiaries. Its biggest impact is in reducing isolation and exclusion of individuals with disabilities and their family members and in facilitating their access to different kinds of services.

Through creation of the local resource centres in communities, it has helped in improving the visibility of persons with disabilities and their families.

Data from 2006 shows that the GCBRP reaches both males and female persons with disabilities. It also reaches persons of different age groups and persons with different kinds of disabilities.

There was no reliable information about the exact number of persons who had benefited directly from the GCBRP during the past twenty years, but it was estimated to be between 5 to 6 thousand persons (between 0.07 to 0.08% of the total population of Guyana, estimated to be around 700,000).

5. Impact of GCBRP on the Civil Society

Guyana CBR programme (GCBRP) is run by Guyana CBR (GCBR), a Guyanese registered non-governmental organisation. GCBR is a grassroots-based, democratic and participatory organisation formed by school teachers, parents, disabled persons, housewives, other persons, who all come together as “CBR volunteers”.

In 2006, there were 245 formal members of GCBR including 28 persons with disabilities or family members, 98 community members, 54 health workers, 57 school teachers, 7 social workers and 17 other professionals.

Through involvement of community members and different kinds of professionals as CBR volunteers, GCBRP has been an important vehicle for involving civil society in Guyana in issues related to disability and rehabilitation.

5.1 PARTICIPATION AND TRANSPARENCY IN GCBR

GCBR is organised nationally through the regional groups, each of which has its own Regional CBR Committee. Delegates from each regional committee and regional coordinators are part of the National CBR committee, which meets regularly and has different opportunities during the year to come together for an active and participatory decision-making process of the organisation. Such opportunities include monthly meetings, annual retreats, summer camps, annual national conference, etc.

Dr. Janice Jackson, who has facilitated the annual retreats of representatives from regional teams over the last few years, said, *"There is a sense of ownership of the organisation in the regional groups, though, this sense of ownership is not uniform, some have it much more. Every year, there are new persons in the annual retreat and I notice an increased voice for the persons with disabilities. I can't say about the ground reality, and about their work in the communities, but every year I meet 50-60 persons representing the office, national committee members and regional representatives, so it gives me a good overview of their organisation."* (Picture right: A meeting with CBR group in East Coast region during the Impact Assessment)



The national GCBR committee has been able to meet the challenge of a difficult transition period. In 1997-98, they took over the project leadership. Since then, it has become a registered organisation and in spite of all the challenges, it has been able to set up a democratic and participatory structure. Even the critics of the GCBRC recognise its growth.

For example, Ms. Natalie Ramotar, one of the first volunteers of CBR in New Amsterdam region almost 20 years ago, confessed that she is no longer very active in CBR activities, and added, *"Today there is more ownership and participation in the GCBRP."*

National level CBR committee now exists for a number of years and has annual elections. Though the composition of the national committee has been regularly changing with new representatives from different regional committees, it continues to re-elect Mr. Gregory Glasgow as the committee president for the past 6-7 years. Discussing this with the national committee, they explained, *“GCBR has membership base at community level and members come through regional committees to the national level. We feel it is democratic and participatory and we do not see any need for changing the president. If the same persons can continue in the role, they acquire competency and it is good to have a competent person in the role.”*

The President Mr. Gregory Glasgow himself talked of relinquishing the office. He said, *“Now the persons from regions are stronger. They need to develop other skills beyond commitment. Building the credibility of the organisation takes a long time but now it is there and it is possible to change.”*

In terms of national coverage, the internal areas, especially Rupununi represents a challenge because the level of participation of the regional CBR committee in this region is completely different from all the other areas where GCBR is active. In Rupununi, the large distances, the sparse population, and the lack of infra-structures like roads, telephones, etc. make the participation and consultation more difficult and costly.

As GCBRP looks at future planning and development, including other internal areas, they feel that it needs to seriously review the possibilities of increasing participation from these isolated and difficult to access areas.

5.2 NATIONAL PARTNERSHIPS AND NETWORKING

In terms of national partnerships and networking, at national level GCBR is well integrated and represented with both Governmental and non-governmental organisations and bodies. Their relationship with the Ministry of Health and Ministry of Education has already been mentioned earlier in this report. It also plays a key role in strengthening of organisations of disabled persons (DPOs or OPDs).

In terms of international partnerships and networking, GCBR is considered as a reliable and consistent partner by a number of international organisations present in Guyana including Pan American Health Organisation (PAHO/WHO), USAID, Voluntary Services Overseas, etc. Through these different organisations GCBR has been able to broaden its donor base and has successfully completed the different assignments.

In circles outside the disability field, probably GCBR is not very well known but to all the major stakeholders in disability and development issues in Guyana, it is well known and has built up a positive and efficient image.

5.3 COMMUNITY PARTICIPATION & VOLUNTEERS

GCBRP works with an extensive base of unpaid community volunteers. Though some of the initial volunteers are still continuing to collaborate with the programme, during recent years, many of the younger volunteers have had a very high turn-over. In addition, the period of transition and instability between 1996 and 1999, also saw many volunteers and key persons from the regions leaving the programme and CBR activities were limited in a few areas.

The gradual revival of GCBRP after 1999, has brought back many old volunteers as well as new persons. A key factor in attracting persons to volunteer for GCBRP includes the possibility of receiving a training certificate, which is recognised by Institute of Distance and Continuing Education of the University of Guyana. However, having this certificate also means that after completing the training, the volunteers leave the project. A key factor in ensuring continuity as CBR volunteer seems to be the presence of a disabled person in the family of the volunteer. (Picture left: group of new volunteers in East Coast)



According to the comprehensive evaluation carried out in 1996, during the first decade of the programme a total of 227 community volunteers were trained in the coastal areas and additional 987 persons were trained in the interiors. According to more recent data, there are 255 active volunteers in the CBR programme. Thus, it would be safe to say that over the last twenty years, GCBRP trained about 1500 community volunteers.

5.4 COMMUNITY SUPPORT FOR GCBRP

Apart from the community volunteers, other aspects of GCBRP denoting involvement and participation of civil society are related to resources mobilised by the programme, especially in the regions. For example, five of the seven regions involved in GCBRP have a regional resource centre. All these resource centres were initiated in buildings provided by the local communities for the use of GCBRP. Gradually many regions have been able to mobilise local resources and support from the local government for acquiring land and constructing their own resource centres

Mobilising of local institutions and enterprises in providing resources for GCBRP varies in different regions but is an important part of the activities at community level. (Picture right: CBR group in the resource centre in East Bank Demerara)



In 2005, GCBRP conducted a participatory exercise at regional and national levels to come up with national and regional strategic action plans called “Creating together an enabling environment”. The overview report of the strategic plan underlines that, *“The strategic planning process has been driven, owned and developed primarily by persons with disabilities, their family members and other caregivers.”*

The overall vision of GCBRP sees it as an agent of change who *“will mobilise action in communities through a network of capable and committed volunteers”* in five areas of work – (1) organisational development, (2) advocacy & awareness raising, (3) community-based action, (4) improving access to education and (5) volunteer training, action and retention.

5.5 CONCLUSIONS

As far as impact of GCBRP over the past twenty years on the civil society is concerned, it has been able to involve and mobilise important resources from the local communities across different regions, in terms of volunteers, buildings of resource centres, schools, etc.

At the same time, Guyana CBR committee has become a formal organisation, with a democratic and participatory network in the regions.

GCBRP has also promoted creation and strengthening of organisations of persons with disabilities (DPOs).

Thus in terms of involvement and engagement of civil society in Guyana, GCBRP has been very successful.

6. Data About Persons with Disabilities in Guyana

The interviews and discussions with persons with disabilities, their families and with other key stakeholders during the Impact Assessment showed a positive impact of CBR programme in Guyana over the past twenty years.

However, there is another key question – is there any objective data to show that GCBRP has made a difference? Has the GCBRP made a difference to the lives of persons with disabilities which be measured through statistical data?

6.1 WHAT KIND OF DATA CAN SHOW THE IMPACT OF GCBRP?

Through GCBRP, community volunteers visited home and provided information to the families about different services and opportunities available in the country for persons with disabilities. They also promoted greater autonomy in activities of daily living, inclusive school education and social participation. Through the local resource centres, they provided support for learning, play, summer camps and social participation. Through their interventions with rehabilitation assistants, school teachers and social workers, they facilitated access to different services and institutions.

All these activities of the GCBRP should be reflected in the disability surveys. Areas of the country where CBR activities started first, should show a better impact. For this we need regional data about persons with disabilities, so that we can compare the data from regions covered by CBR programme with the regions where CBR programme did not reach. Ideally, we would also need baseline data before the start of CBR programme to assess its impact.

No survey or baseline data about persons with disabilities from the different regions of Guyana could be identified which could be used for comparing the situation twenty years ago and today.

6.2 GUYANA NCD DISABILITY SURVEY REPORT 2006

In the period October to December 2005, the National Commission on Disability of Guyana carried out a survey about the needs of persons with disabilities in 4 sample regions. The report from this survey was published in 2006. Unfortunately, it provided only composite data and the data sets from the regions could not be accessed. Thus, this report did not provide specific information that could be used to assess the impact of GCBRP.

This survey was carried out by volunteers of GCBRP in 4 regions – region 4 (Demerara and Mahaica), region 6 (East Berbice and Corentyne), region 7 (Cuyuni Mazarini) and region 9 (Upper Takutu Essequibo). GCBRP was well-established in the coastal areas of region 4, 6 and 9 and it had also reached some interior parts of region 9 (Rupununi area around Lethem).

The sample-sizes for this survey reflected the population-sizes in the 4 regions – 903 persons in region 4; 484 persons in region 6; 50 persons in region 7; and 50 persons in region 9. A total of 1485 persons with disabilities were interviewed. They included persons with

different kinds of disabilities including vision, speech & hearing, physical & mobility, learning and multiple disabilities. They did not include any persons with mental illness, epilepsy and leprosy related disabilities.

A questionnaire with 22 questions based on the Washington Group recommendations about functional difficulties was used for this survey. The survey excluded children with disabilities below 4 years and in the age group 18-25 years. Since the sample from region 7 was relatively small, we can think of the findings of this survey as an indirect reflection of the impact of CBR.

For example, the survey report shows that only 15% of the persons with disabilities of different age groups had never been to a school. Around 61% of school-going persons were in ordinary schools, 29% in special schools and the remaining 10% in “other education”. However, the report does not mention what percentage of 4 to 18 years had been to a school and for how many years?

Looking at the tables, it seems that there were 485 children in the 4 to 18 years age group, out of which 58% were going to school at the time of the survey and 42% were out of the schools. However, there is not enough information to judge how many of those 42% had been to school and for how long.

6.3 CONCLUSIONS

The Minister of Health of Guyana acknowledged the importance of GCBRP with the following words: *“Government has a critical responsibility towards persons with disabilities but at community level, GCBRP has an equally critical role to play and without GCBRP the situation of persons with disabilities will be very difficult.”*

However, no specific objective data could be identified to support this acknowledgement.

7. Conclusions

The Impact Assessment showed that Guyana CBR programme had made a significant impact on the lives of persons with disabilities and their families in Guyana in many different ways, both directly and indirectly.

According to the United Nations' Human Development Report 2006, Guyana is at 103rd place in the world, placing it as one of least developed countries in Latin America and Caribbean. The country has to meet huge challenges with a very limited resource base. Keeping these limitations in mind which impact the availability and quality of specific national services for persons with disabilities, GCBRP has been able to participate actively in and influence the definition of national policies and strategies related to those services. It has played a strong advocacy role in making institutions aware of the needs and has helped in shaping the national response to those needs.

The on-going discussions on the definition of "CBR Guidelines" at the World Health Organisation have identified four specific fundamental principles of CBR – participation, inclusion, sustainability and self-advocacy. We can use these four fundamental principles to review the Guyana CBR programme:

- ◆ Participation: Review of reports, documents, etc. and discussions with different stakeholders show that GCBRP has made impressive efforts to promote active participation of the different stakeholders in all the different phases of the GCBRP's work. Its work with strengthening of organisations of persons with disabilities at community level merits special attention.
- ◆ Inclusion: GCBRP also scores high on inclusion as it has consistently searched for inclusion of all the different groups of persons with disabilities along with networking and collaboration with governmental and non-governmental partners for mainstreaming and use of existing services rather than trying to create parallel services.
- ◆ Sustainability: The programme is well embedded in the local communities, who feel ownership about the programme and mobilise local resources from their own efforts. Even additional new infrastructures created through European Union supported projects, have been taken over by the Government of Guyana and continue to function.
- ◆ Self-advocacy: GCBRP is working in close cooperation with persons with disabilities, promoting the spirit of "Nothing about us, without us" and having persons with disabilities and their family members in key leadership roles at peripheral, regional and national levels, who take an active role in all its decisions and activities.

In terms of persons with disabilities and their families, it has played an important role in promoting empowerment of individuals and strengthening of organisations of persons with disabilities at grassroots level.

Finally GCBRP has developed into a robust organisation based on principles of participation and democracy, with a well organised structure that starts at grassroots level and through regional committees reaches up to national level. It is recognised and acknowledged by all the major national and international bodies as a significant stakeholder in disability issues. This is all the more impressive as this capillary organisation is composed mostly of the persons from simple backgrounds.

Though the exact numbers of persons who have directly benefited from GCBRP's support over the past twenty years, are not available, probably it is around 5-6 thousand persons. Indirectly, the impact of its work has probably touched the lives of most persons with disability in the country. GCBRP has been able to network with institutions and mobilise human and material resources through active involvement of communities for its work.

All these are significant achievements for any organisation, even more so for a community-based organisation that is dependent on unpaid community volunteers from poor communities. Having said that, it is important to remember that there is a huge unmet need of services and support for persons with disabilities and that is a challenge for GCBRP to extend and improve its activities.

8. Acknowledgements

As the consultant for conducting this impact assessment, I, Dr Sunil Deepak, would like to express my deep gratitude to all the persons, organisations and officials in Guyana, who were so warm to welcome me, always willing to share their ideas, comments and feelings. My thanks to all those persons linked to GCBRP and CBR Committees who opened the doors of their homes to share their lives and all those who walked or travelled for miles to attend meetings. It was a great privilege for me to listen to your stories and experiences. I thank AIFO/Italy for having this opportunity. Finally, my special thanks to Ms Geraldine Mason Halls and Ms Gwendoline Glasgow for accompanying me in this visit and for your insights, patience and friendship.

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This part of the report provides more details about discussions, thoughts and feelings of different individuals as well as institutional representatives during the field visits. It is not exhaustive in the sense that it does not provide details of all interviews and discussions but a selection has been made to present the diversity of views expressed. This part of the report is based on notes taken during those discussions and interviews. The consultant visited Guyana from 23 October to 6 November 2006.

IMPACT OF CBR PROGRAMME ON NATIONAL LEVEL POLICIES AND SERVICES

1. Views of other organisations (both Governmental and non-Governmental)

Ms. Sara Bienemann, VSO volunteer, is a trained psychologist and occupational therapist, she says, *"The commitment, time and effort of the community CBR volunteers is a big resource and also a problem area. In spite of family problems, responsibilities, work, etc. so many persons work with CBR as volunteers. It is very important contribution. New volunteers can be enthusiastic and contribute strongly. At the same time, attrition rate is high. Persons change, their commitments change, their circumstances change so they leave and sometimes activities stop. So, this is also a challenge."*

Regarding her own specific skills, Ms. Bienemann explained that she is participating in the training of volunteers and is preparing a training manual for the Guyana CBR programme. She says, *"I can't transfer my own specific skills of occupational therapist to the volunteers, they do not have the background and capacity for it. CBR programmes focuses on social aspects of disability, issues of rights, education, etc. but there is not much focus on medical rehabilitation aspects. Links with Ministry of Health are therefore very important. The presence of a rehabilitation assistant is a big support but they are not present in all regions. So, I need to decide on the skills that cannot do any harm for teaching them to the CBR volunteers."*

Mr. Francis Glasgow, head of IDCE (Institute of Distance & Continuing Education, Guyana University) has taken over this role recently. GCBRC has a long history of collaboration with IDCE. The volunteer training programme of CBR programme is recognised by IDCE as part of adult and continuing education and this recognition helps in identifying community volunteers, since the training provides them with a certificate they can use for their careers. IDCE has the goal of promoting education in the country finds a synergy with the activities of GCBRP. IDCE also has regional coordinators and one of their regional coordinators is a wheel chair user, who has come to IDCE through the CBR programme. CBR training certificate also helps the volunteers to access university education. During the last session, graduation session of CBR volunteers was held together with other persons who had completed IDCE training, so it gave a moral boost to the CBR volunteers that they were like other persons completing IDCE training. CBR programme also helps IDCE by promoting awareness among communities about the education opportunities available through IDCE.

Ms. Hamilton, head of the National Commission on Disability (NCD) and Chief Planning Officer of Ministry of Education on GCBRP: *"CBR is a success story. There are some areas*

that CBR programme needs to strengthen such as extending the programme to other regions. She feels that "volunteers of the CBR programme feel ownership for the programme, they also feel empowered. GCBR is one of the few organisations working in a sustained way with disabled persons for promoting development. There are some others engaged in some advocacy, some who organise activities like sports day but they work in an ad hoc way and there is no sustained effort. But the CBR programme is not present in all regions and they should extend to cover all regions as there are areas where persons with disability are marginalised. It is true that extending in all areas is not easy and there are many challenges."

Ms. Hamilton mentioned the different activities that CBR programme has been doing for promoting inclusive education. For example in region 3, 12 schools participated in inclusive education training. It is important that all new schools in Guyana ensure accessibility to children with disabilities.

NCD has produced two documents, a policy document for the period 1995-2000 and a strategic plan for the period 2003-07. The second documents gives example of the GCBR programme to support collaboration with NGOs. Ministry recognises that it has monetary resources while GCBR is strong in human resources.

Another example of collaboration between NCD and the GCBRP is about a community survey on disabled children carried out in 4 regions of Guyana. CBR coordinators and volunteers played a significant role in carrying out this survey and helping the Ministry to conduct this research. NCD conducted a consultation for preparation of a policy document in 1997 and wanted to develop a legislation from that policy, thus new consultations were held to understand the views of the communities and once again, GCBRP played a significant role in this survey.

Ms. Hamilton feels that the best impact of GCBRP is through its nurturing of human resources. Other organisations that went through some difficult times, just broke up but not GCBR, it continues to grow, its annual meetings are still bringing so many persons from all over and people have been empowered by this programme. Different Guyanese DPOs are no longer working but GCBR is trying to build up DPO groups at community level.

NCD is a Presidential commission under the ex-President Ms. Janet Jaggan and has 15 members coming from the main stakeholders including different ministries, DPOs, human right organisations, GCBR, etc. Commission is not an umbrella organisation, its role is to give advice to the Government on policy, and to monitor the implementation of policies. It receives funds from Guyana Government and from UN bodies and has a small secretariat with two persons, both of whom are persons with disability, Karen and Tiffany. At least one of them have had strong links with GCBRP.

Ms. Inge Groenewegen from the Guyana office of Voluntary Services Overseas (VSO): VSO has an official partnership agreement with GCBRC. The collaboration was very satisfactory and thus this agreement was renewed. While the DPOs are in Georgetown, majority of persons with disabilities are in the regions, where the CBR programme works, so it was logical to work with GCBRC as the volunteers from VSO are working in the regions. At the same time, the regions do not have the capacity to absorb the volunteers, so they are attached to GCBRC office in Georgetown and travel regularly to the regions. The VSO volunteers are involved mainly in training activities.

Initially VSO started activities in Guyana by collaborating mainly with Ministry of Health by providing volunteer physiotherapists, speech therapists, occupational therapists, etc. but they had a strategic review and decided to also work directly with persons with disabilities and focus on social components, legislation, DPOs, etc. For example the collaboration of the two deaf volunteers with the CBR programme was very satisfactory.

In terms of challenges, VSO feels that GCBRP needs to develop other leaders and persons who manage communications, so that duties can be shared, as the persons presently managing GCBR are getting older and they need to delegate. The issue of brain drain and emigration is a critical issue, so that really capable persons leave the country. CBR's strength has been the capacity to identify persons with limited formal education and give them responsibility.

Among the different programmes run by NGOs in Guyana, GCBR stands out as a strong NGO. Generally speaking civil society in Guyana is weak and thus the achievements of GCBR are even more impressive. It's strength has been to establish links with Ministry of Health and Ministry of Education. The two deaf volunteers from VSO, were allowed to work with teachers in special needs programme and thus Ministry of Education recognised their contribution. Because of its long track record, a large number of past GCBR volunteers have been able to gain acceptance from the Ministries for employment.

For VSO volunteers coming to work in Guyana, working with community volunteers of GCBR means that everything is slower and more gradual but generally speaking they are very positive about their experience of working with GCBR.

Dhaniram Singh is officer for National Development Commission (NDC) in Queenstown, Essequibo Coast. He knows the CBR programmes and says, *"It is a great programme and it is doing important work for changing the lives of persons with disability. If we can help the programme in any way then we are willing because we know that this is a genuine programme, actually working with persons and promoting development. NCD gave all the support to the CBR programme for the making of their resource centre."*

Ms. Barbara Lawrence is head of the National Rehabilitation Programme in the Ministry of Health. Barbara said, *"Ministry collaborates with the CBR programme at regional level. We have mid-level rehabilitation workers, they work closely with the CBR programme and volunteers. The training of these mid-level rehabilitation workers was started as part of a AIFO project. As we do not have trained physiotherapists and emigration of trained persons to other countries is a problem, so we aimed to train a mid-level rehabilitation worker who has skills in physiotherapy, occupational therapy and speech therapy. After the initial support from AIFO, the Ministry has continued its support for this course. So far three batches of students of about twenty in each batch have been trained. Even if this course is not recognised outside Guyana, still it helps our students when they apply for studies abroad so we have lost some students and we need to train more. We also need some trained physiotherapists to supervise the work of mid-level workers, so we are sending 6 persons to Cuba on a scholarship and after training they will have an obligation to serve in Guyana for five years."*

In terms of the work of National Disability Commission, Barbara said, *"CBR is one of most organised groups of disabled persons. They are a pioneer. If we need to consult and seek advice, we often refer to CBR. Most disabled persons recognise CBR programme as an opening, as a window of opportunity. Ministry and GCBRP need to work even more closely. Our Ministry is dependent on expatriates like the volunteers from VSO, who work*

in hospitals and schools. Role of rehabilitation professionals from VSO for the school programme is very important and teachers look forward to these visits as they have limited or no training on how to deal with disability."

Regarding the National Orthopaedic Workshop that received equipment through AIFO and EC project, Barbara says, *"Emigration is a big issue in Guyana. Both our trained technicians have left and now we have staff that has practical experience but not formal training. The equipment is still working well and is used. We need to bring in someone who can provide practical training to our orthopaedic laboratory personnel."*

Finally, regarding collaboration between GCBRP and the Ministry, Barbara said, *"GCBRP should strive to work even more closer with Ministry and ask for support from the Ministry because it is providing services that are the responsibility of the Government. Ministry is also supporting the NCD and the Open Doors vocational training centre."*

Mr. Arthur Lewis is the new director of the Open Doors Vocational Training Centre under Ministry of Health. Open Doors Centre shifted to its own new building in August 2006, built by New Horizon, an organisation of American Marines. The Open Doors Centre was started as part of an AIFO project co-funded by European Commission in 2001. When the project funding finished, the centre was taken over by the Ministry of Health that guarantees its continued functioning. Besides training, Open Doors also promotes employment for its students by providing them with job attachments in well-known companies so that trainees get self-esteem. From the last batch of 19 students, 9 found an employment. For this reason, period of training has been increased from 12 to 18 months. The carpentry workshop of Open Doors is in the David Rose School for Handicapped Children Compound. Funds for all the equipment had come from AIFO and EC project.

Regarding the activities of the centre, Mr. Lewis says, *"Many students come with little or limited formal education. The age range of the students applying for the courses is also very wide. At present, one of our trainees is 42 years old. Companies were more diffident initially but now they accept our trainees. At present, there is no law in the country for giving employment to persons with disabilities so companies are not willing but in the new legislation that is being readied, such a provision will be there. Right now, there are four courses, each with 10 students so we have a total of 40 students. We received about 100 applications. We do not provide any stipend or food during the training period. We have discussions with VSO to see if we can get more volunteer instructors. Our teachers need training on business management so that they teach it to the students. Without GCBRP, we would not have existed and they continue to collaborate with us. They sent us two deaf instructors on sign language and that has been very much appreciated. From the annual conference of the CBR programme, I get new ideas for enhancing our work. Some of our students come from CBR, but as we do not have accommodation it is a challenge for students coming from outside Georgetown. We provide transport from city centre."*

Dr. Leslie Ramsammy is the Health Minister of Guyana and he knows the CBR programme very well. He says, *"I know the CBR programme very well. Every month, I give one day of my salary to CBR programme in West Berbice, that can tell what I do feel about this programme. Support comes from all the Government. President himself gave support from his fund for the resource centre in Essequibo. We are thinking of converting the old rehabilitation centre in New Amsterdam into a day care centre for elderly persons and disabled persons. We want to give priority to those persons who are in difficult situation and do not have families to support them. We need to be careful in the way we organise the services so that we support the families and do not take away from them their role and*

responsibility of taking care of disabled persons. Sometimes people bring a person to a centre but then they are not willing to take back these persons and do not even come for visiting. We need to avoid this and so we must create an environment where people do not give up."

In terms of changes in the community attitudes about persons with disability, the Minister explained, *"I went to the Para Olympic sports meet organised under Rotary and it was good to see that parents were there proud of their children, earlier they were hiding them. We need to bring out the things into open. Providing services like wheel chairs and organising service for repair and maintenance of wheel chairs is needed. However, we cannot continue to create new separate services and centres for persons with disabilities. We have regional technical training institutes in our country, we need to work with them so that they can also accept some persons with disabilities and organise services that answer the needs of disabled persons like the wheel chair repair services. Open Doors centre is limited to Georgetown and it cannot answer the needs of the whole country. We have so many buildings and they are not used all the time, half the time they are just empty but we keep on making new buildings. This is wrong and wasteful, especially as we have limited resources. These are more bureaucratic issues. The disability legislation is almost ready and will be tabled in the parliament and CBRP has played important role in making this legislation."*

Dr Hedwig Goede, Health Systems and Services advisor at Pan American Health Organisation (PAHO) office in Georgetown, came to Guyana 2 years ago and about the CBR programme he said, *"GCBRP has done lot of work and it has faced different challenges, but it has shown that you can work successfully at community level. It is a good example to show to other countries. The Guyanese health system is undergoing lot of changes and the country needs to strengthen the surveillance system as the information is scattered and difficult to put together. Among the different challenges, emigration is a big issue but in spite of it, Guyana has been able to provide free universal health care services, even if the coverage is limited. Lately health care facilities have improved and more specialist care services are today available. Country's production of medicines is good and is seen as a social need, so it is not being used for making money, which comes more from over-the-counter drugs. To counteract the effects of emigration, Ministry of Health has been training mid-level workers in community dentistry, rural midwives and rehabilitation assistants. However, for these mid-level workers, the supervisory component is lacking."*

Ms Merle Sobers started as a volunteer and now works as a Rehabilitation Assistant in West Bank Demerara. She tells about her experience, *"I came through the church. We had received a letter from GCBRP asking for volunteers, so I decided to give it a try and filled up the form. Lot of persons had applied and they chose 30 of us. Only when I started doing the course did I realise that there were so many disabled children and adults in the community. After that I applied for the training of rehabilitation assistant and I am working in the rehabilitation services of the Ministry of Health. I also collaborate with the GCBRP and provide support to different groups of persons with disabilities on two afternoons per week at this CBR resource centre. For some persons going to hospital is costlier so they prefer coming here."*

Ms. Gloria Richards Johnson, Mr. Hubert Robertson and Ms. Daune Pratt of USAID Guyana office is an implementing organisation for USAID and is supporting a project on governance in three areas - civil society, justice & ethnic political conflicts. They explained, *"Guyana has deeper, hidden tensions and though the present situation is apparently calm, it may not last. Civil society organisations have an important role in our*

work, they are one of the guarantees of our work. We admire GCBR, we have been to their annual meetings and we have seen the wide and varied participation they evoke in their constituencies. They have done admirable work with the National Commission on Disability. They help raise the voice of persons with disabilities who are neglected. We deal with them also as a receiver of grants and we like that they can use the grant properly and they help us in our mandate of promoting citizen participation. In our opinion, GCBR is a fairly mature learning and development organisation. They work in a responsible manner for grant management, the accountability is good, they follow the objectives that are decided together and if there are any changes, they discuss them with us."

In terms of the challenges, the team from USAID office noted, "They can do much more to promote their image and encourage other persons to join them. They can work more on making their work more transparent and avoid conflict of interests. Persons with disabilities are still hidden and there is much more scope for reaching out. Barriers are there and much more can be done. Involving business community can be a strategy because if they adopt a programme, they can pay the costs. Some radio and TV programmes are free and they can also be tapped into. But you would need a specific person in the office to look after these issues."

Ms. Janice Jackson is a trainer and a member of "Circle of Friends of CBR", an informal group of persons from Guyana who support the GCBRP. Janice facilitates the annual retreat of groups at the beginning of each year with the aim of promoting individual and collective self-development. She has also been involved in the workshop on inclusive education in West Bank region. About the changes in GCBR over the past years since she has been associated with the programme, she says, *"I know about the teams in different regions. I think that there is more openness and awareness of possibilities for the CBR. Doing the exercises of strategic planning with the groups helped them to understand, how important they are to the organisation. There is a sense of ownership of the organisation in the regional groups, though this sense of ownership is not uniform, some have it much more. Every year, there are new persons in the annual retreat and I notice an increased voice for persons with disabilities. I can't say about the ground reality, about their work in the communities but I meet 50-60 persons representing the office, national committee members and regional representatives, so it gives me a good overview."*

About areas for improvement, Janice says, "We need to have more emphasis on having persons with disabilities in the forefront. In the organisation, we need persons who are articulate and are assertive, they can change the society. GCBR also needs to document its experiences and share them with others, also in terms of documenting the experiences of persons with disabilities."

2. Voices of Persons with Disabilities and Their Families

Mr Leon Walcott is a wheelchair user and is involved in CBR programme since 2001 as member of fund-raising committee and as editor of the CBR newsletter. He is a journalist by profession. About the CBR programme he says, *"CBR has become so ubiquitous in Guyana. From the point of view of persons with disabilities, CBR is very influential programme, much better than just giving handouts, it is more like a mother hen with her brood. The programme attracts dedicated persons who step forward to volunteer for GCBR shows the kind of image and attraction the programme has."*

On the impact of CBR programme in the country, Leon says, "GCBR has been strong on advocacy. If we think of the legislation that has been drafted, it is a success of GCBR also,

as we were in the forefront to get this bill. We played a very active role. In any meeting, you can see that more than 70% of persons are those who have come through CBR programme."

In terms of the impact of GCBR on his own life, he adds, *"I am very proud to be part of CBR volunteers, I call myself a disability advocate. I spoke with other disabled persons earlier also but my views were based on ignorance and lack of knowledge, even if I was a teacher. I think that communication is very important and we need to do much more. We also need a building of our own, a larger place and we can do much more."*

Finally, about his newsletter, Leon explains, *"Two copies of newsletter are produced. Information comes from all over Guyana from different CBR groups and I also collect information from other Caribbean countries. Newsletter is printed in 500 copies. It is distributed through the CBR groups."*

Mr. Jainarain Lal lives in Anna Regina, the main centre of Essequibo region. He had polio when he was 5 years old. As a young man he had a fight with his father and left home to work with a cousin on making furniture. Today he owns his own business and employs two persons, is married and has two daughters. He was among the first persons to receive a loan through the CBR programme for starting his own business. He dreams of selling the present house and buying a new, bigger place and to expand his business. He has already repaid the loan and did not have to ask for another loan. He feels that the loan system is very good and useful, it helps to make everyone equal by giving opportunities to persons with disabilities.

Mr. Sahadeo is a wheel chair user from Anna Regina in Essequibo. He is also among the first group of persons who received a loan through the CBR programme. About the impact of CBR programme on his life he says, *"For me CBR had a great impact. From 1977 when I became paralysed, till 1994, I was completely isolated and closed in the house. Then CBR programme came and helped me to overcome my isolation, to go out and mix with other persons. My whole life changed. The loan programme has also been positive for me, even if I have difficulties in repaying the last loan."*

Ms. Purnwati has a movement disability. She has been to Trinidad on a scholarship to learn garment making and has been to Kenya through a VSO scheme. She has also received a loan for chicken-rearing and is thinking of setting up a tailoring unit for making school uniforms for children. She is secretary of the DPO of Queenstown and is involved in fund raising and skills-training activities. About the loans she explains, *"The decision for awarding a loan is taken by the regional CBR committee. To get a loan the person must be member of CBR programme for at least two years and we ask two members of CBR to sign as guarantors. The committee discusses if the business proposed is feasible or not before making a decision."*

Ms. Karen Hall is disabled and is project officer for the National Disability Commission in Georgetown. Karen tells about the links between the work of the commission and GCBRP, *"There are two project officers, I and Tiffany. Both of us have background in CBRP. Tiffany was trained in the first batch of Open Doors centres as it was established under the AIFO-EC project. I was in contact with the CBR programme in East Bank and used to go around to meet persons with disabilities, I couldn't do much but at least we could talk. I started school very late, when I was 13 years old and that was my mother's initiative, she contacted different organisations. I was good in the school and it was a novelty, as I was the only person with disability there. I did an accountancy course and later went to university in the faculty of education. In those years, I was close to CBR programme, went to some*

meetings, learnt about advocacy work. Later, I got the scholarship for studying development in Canada and AIFO provided funds for my thesis on GCBRP. Now I am working with the NCD and the new disability legislation is being prepared, so it has been a long journey."

Shahzar's Mother: In the West Bank Demerara, the mother of a 7 year old Muslim boy with intellectual disability explained, "My son's name is Shahzar. CBR programme has made a lot of difference to him. Initially I did not want to come here and bring him here, so volunteers used to come to our house. Now I bring him here two times a week. We also went to an exchange visit to see how persons in other areas live and what activities they are doing. He now mixes with other children."

Darshini's Mother: Darshini is a five years old girl, youngest of 3 children living in West Berbice. Her father is a fisherman. Between Darshini and her elder brother, there is a gap of fifteen years. Darshini was born at 7 months, her mother tells, "*I came from a poor family. I had studied in the primary school. My children were grown up, my eldest son is now 22 years old. My eldest daughter died in an accident. When I found that I was pregnant, I felt that my dead daughter has come back. When the labour pains started, I had to wait for the bus to go the hospital and as I was coming out of the bus, Darshini was born. She did not cry immediately and she was sent to the big hospital in Georgetown where they put her in an incubator for 8 days. Her lips used to become blue. After she came home, after a month she has strange rash on her skin and her hair fell off. Now she has problem with her left leg, it is short and she cannot open it properly. They operated her at the ankle but it did not make any difference. So she can't put her foot down and can't walk. We don't know what to do?"*

Ms Maurice Daniels is 61 years old in West Berbice and for the last 4 years she is on the bed after a stroke that left her right side paralysed. Maurice cannot speak but she can make sign with her left hand. Jennifer, her grand-daughter tells, "*When I come back from school, I take care of my aunt. I have learnt how to turn her around so that she does not get bed sores. I give her liquid things to eat. I change her pampers. I help her to sit near the window so that she can look outside as she cannot go down the stairs to meet other persons."*

Thiona's Mother: Shalon Mercy, mother of 5 years old Thiona lives in West Berbice and she told about her daughter, "*Thiona was born in the maternity hospital but there were some problems, even if the nurse continued to say that everything was fine. Thiona had convulsions and she was not breathing properly so we took her to hospital in Georgetown. They put her in the incubator for a week. Now she can turn by herself, but she cannot sit. She follows with the eyes but does not speak. A CBR volunteer has started to come and has told me to come to the resource unit."*

Mr Alexander lives in Mahaicony, he is sixty years old, and he tells his story, "*I was in the army for seven years and travelled all around Guyana. My wife left me when I was in the army. Then I came to work in the rice-mill for some time, I did many jobs, I even worked for a company constructing the road. Last year, I was out with my son and suddenly I started to feel weak, as if I can't stand. Slowly it has got worse. I am afraid of falling. I can't stand without support, so I was just sitting at home and not going anywhere. CBR volunteer has told me to support myself with this bench and do regular walking so that I can keep the strength in my legs."*

Ms. Patricia Williams is a wheelchair user and she lived in Leonard Cheshire Home since 1972, one of the first residents of the home. She went to a special school for a few years and

then learned other skills like embroidery. Growing up, she was employed at the home as an assistant to take care of other inmates and received a salary but continued to live in the home. In 2001, she decided to rent a house not very far from LC Home and is now living independently. She says, *"In the Home I have lot of friends but I prefer living on my own even if it is harder. I have good relations with my neighbours and they come to see me. In many ways, CBR programme has accompanied me in my journey. I know Gwen from the CBR for such a long time. CBR programme helped me to go out, to socialise with other persons. I participated in training courses, workshops, summer camps, etc. Housing is such a problem in Guyana for persons with disabilities as they always make the house on first floor and if you can't climb the stairs, it is so difficult. CBR programme has helped persons in finding suitable housing. Even elderly persons have same problem. I am not very much into meeting with other disabled persons, but I like my friends from CBR programme."*

Ms. Jennifer Summers was a school teacher in East Coast and after an accident at school, she hurt her back. CBR programme gave her a loan to start a chicken-rearing business. She explains, *"I get about 120 to 250 baby chickens. I also give them sugar water with vitamins when they are young. If it rains or there is wind, you need to make proper protection for them in the cages. Once I had lost 300 baby chickens after a strong rain. I have got the cages built up higher from the ground, so that if floods come they will not be damaged. Normally they cost 100 G\$ each but around Christmas the prices go up to 120 G\$ per baby chicken. Their feed costs me around 3000 G\$ per week, to this you to add the cost of vitamins and supplements so that costs, another 500 G\$ per week. They need 6 to 7 weeks to grow. I got a first loan of 60,000 G\$ and repaid it. CBR programme has been very good to me and they are my friends. I know that some persons were not so lucky like me. In the last floods, some persons lost everything they had earned from the chicken rearing."*

Mr. Hemal in East Coast is secretary of the East Coast organisation of disabled persons (DPO). About the influence of CBR programme he says, *"I joined the programme in 1997. Ever since my accident in 1983, I was isolated at home, I did not go out, I did not do anything. With CBR programme, I came out, I started to socialise, to make friends. I went to summer camps, I did literacy classes, I like meeting new persons and telling them about CBR and bring them to the programme. As DPO, we are involved in advocacy activities."*

Ms. Shirley was born blind and she was eight years old when her father died. Her mother was afraid that someone might hurt her daughter, so slowly Shirley stopped going out of the house and slowly even the neighbours forgot about the blind child. She was "discovered" by the CBR programme in 1995 after almost 12 years of isolation and ever since has taken an active role in the CBR programme. She says, *"I have visited all the different regions of Guyana. I know lot of persons."*

DISCUSSIONS WITH MEMBERS OF GCBRP COMMITTEES

1. Perceptions from the National CBR Committee Members

Ms. Leila Eastman feels that finding a *building* is a challenge for GCBRC. If more space is available, they can have more volunteers from VSO for working on deaf issues.

A larger building can be a solution for displaying and selling the products of our income generation activities. The present building does not have accessible bathrooms and toilettes, spaces are also not easily accessible. A larger building developed as a business centre can be

support for our income generation. Naturally with larger building, expenses for maintenance will also increase.

Ministry of Health has been supportive of this idea. They had proposed to provide some land to GCBRC however the area was not easily accessible so GCBRC is still exploring this idea of finding a land and making a new building for GCBRC.

Some of the CBR groups have had success in mobilising support for having their own building.

Essequibo CBR group got the land from the region and then funds from President's fund to make the building. They need to find the funds to maintain this centre as everything costs. Since it is in a rural area and finding funds for rural areas is more difficult.

Region 6 also got a centre through CIDA. Region 5 has already got the land and President has promised to give them funds for making the building. In East Coast the CBR group has talked to a number of agencies and they are still trying to get land. East Bank had a building but now they are operating from a community centre given to them by local authorities.

Region 3 also had a resource centre provided to them by local authorities but it was damaged during floods. They have approached the President, who has promised to help them, so they have reopened their resource centre. President had also promised them 500,000 G\$ for maintenance but it has not been easy to access these funds.

High attrition rate and drop out of *volunteers* is a problem. Finally they have started to implement the new strategy for curbing the high drop out of volunteers by insisting that the certificate from IACE (Institute of Distance and Continuing Education) will only be given after they work for one year with the project. This strategy was discussed some years ago but only recently it has been implemented. We need to wait and see the impact of this strategy.

There are persons who have been volunteering for 10 years or more and they continue. At the same time, there are persons who want some training and then leave.

Another aspect is that persons who worked as volunteers and who have left, can still continue to contribute in significant ways to the activities of GCBR. For example, one ex-volunteer became principal of a school, while another has become officer in social services and both the persons, even if no longer volunteers, contribute significantly to CBR work through their support to CBR initiatives.

Other ways to strengthen volunteer loyalty is through award schemes, supporting them for personal development by other training courses, providing them with references for finding a job, etc.

Programme is able to involve as volunteers, persons from different ethnic groups making up the Guyanese society. This is another value of the GCBRP by promoting working together of different ethnic groups. Persons accept that GCBR does not any political agenda but has real desire to improve the society.

Finding a job for persons with disabilities is very difficult. Advocacy is an important area to develop.

Patricia Thomas has been a volunteer from East Bank for past 8 years and is now the treasurer of GCBRC. She feels that CBR has helped to developed the lives of many disabled persons and hopefully more persons can be helped to develop in future.

Earlier two deaf volunteers from VSO were very useful, created lot for awareness on deaf issues and promoted the creation of deaf clubs in some groups. They conducted courses on sign language. Important in showing that deaf persons can be functioning part of society. GCBRC played a key role in the success of this initiative and without the presence of CBR at community level, they couldn't have worked with deaf persons and achieved so much.

Only GCBR invites sign language interpreters for all its meetings. Improving access is still a big problem. Transport is a big difficulty, so organising a meeting becomes so difficult. Access to buildings is another difficulty. National policy on access is still in draft stage.

Montgomery or Monty, works with GCBR as sign language translator and is the coordinator of the USAID funded Advocacy Project , he said, "*GCBR has changed my life. I learnt the sign language and now I can use this skill for my career.*"

2. Discussions Regarding Changes in the Leadership of GCBR

One person had played a crucial role in development of CBR programme in Guyana - Dr Brian O'Toole. During 1996-97 Dr O'Toole left the programme and the programme management was taken over directly by the national CBR Committee. This was a major crisis period for GCBRP and for a couple of years, the activities of CBR programme faced different obstacles, and a number of persons involved with the programme in different capacities left it.

During discussions with persons involved with the programme from pre 1996 period, the name of Dr O'Toole was raised up occasionally. Majority of the persons raising the issue felt that CBR programme has been able to build up its strength by involving new persons and by sharing of responsibilities. At the same time, some concerns were expressed that the different roles played by Dr O'Toole have not been considered and replaced by other persons, such as his role in networking links between different groups, making them feel as part of one programme.

3. Impact of Income Generation activities

Terrence Dhainy, initially a volunteer from East Coast, is the coordinator for income generation activities at the GCBRC office feels that income generation activities have improved a lot of persons lives.

At present there are 31 active loans, of whom 13 are with persons with disabilities, 9 are for family members of disabled persons and 9 are CBR volunteers. Among all these persons who took loans, 4 are serious defaulters (2 disabled persons, 1 family member and 1 volunteer), 3 of them for quite a long time with old loans. One loan is defaulting as the person died. Over the last few years, there were about 10 loans but this year only five loans till November 2006. About 80 to 85% loan repayment is there.

Mr. Dhainy started as a volunteer in East Coast area, 8 years ago. After two years he became a part time loans coordinator at GCBR office. One year later, the job was made full time. During the first 4 years, there were lot of problems with loans, especially with loans in Rupununi, where people felt that loans where actually handouts and they were not supposed

to pay them back. So they decided to stop the loans programme for one year and to review it.

As availability of funds varies so amount for loans is not always same. In the recent past more focus on training of new volunteers so loans were less. However in spite of it, the requests for the loans are not many and the reasons for this are not clear.

Terrence did not get any specific training for running the loans programme but his different skills help in dealing with persons making different business proposals. He has been involved in training of new volunteers in Berbice and East Coast on the theme of loans and income generation. Trainee volunteers are told about rules of loan schemes, criteria for accepting loan applications, how to fill application forms, etc. There is no systematic way of capacity building of persons taking loans on making business plans, running a business, financial planning, etc.

It is possible to get loans from banks but usually banks do not wish to give loans to persons with disabilities.

The funds for the loan scheme are managed separately in a bank account, separate from the GCBRP budget funds.

Ms. Marvis in Sand Creek village in Rupununi region had taken a loan of 60,000 G\$ for opening a shop. She repaid most of her loan but not the last part of 5,000 G\$ and regarding this she explained, *"There was no communication. Earlier, I was paying back the loan to the loan coordinator but then he stopped coming. They told me that I have to give the funds to the coordinator in Lethem, but I did not get any feedback if the money was reaching the national coordinator or not, so I just stopped."* Regarding the success of her business she says, *"It is a small income. The cost of transport to Lethem for buying things and bringing them to Sand Creek is high. In the end the margin is small, but still it is an important help to run my house."*

Ms. Carmen, mother of a boy with intellectual disability and a CBR volunteer from the first group in Essequibo has taken three loans for her own business and has repaid all the three loans. The first loan was for 40,000 G\$, second was for 60,000 G\$ and the third loan was for 100,000 G\$.

Mr Sahadeo is a wheel chair user from Anna Regina in Essequibo. He is also among the first group of persons who received a loan through the CBR programme. His first loan was for 40,000 G\$ (about 200 USD) and he used it to open a pastry shop, and he repaid it. Two years later, he received a second loan to expand the pastry business and he repaid it. Finally, he asked for a third loan of 80,000 G\$ to start a business of dealing with CD-Roms but this business has not worked out and he is late in repaying this loan.

4. CBR Regional Committee in Essequibo Area

CBR started in 1993 and so far four batches of volunteers have been trained for a total of about 100 persons. Out of all these persons, 24 are still working with the project. Training course for a batch of 20 new volunteers is going on. There are still some old volunteers who started in the first batch like Paulette and Morny.

Ms Morney Brandon is a CBR volunteer and chair-person of regional CBR committee. Morney, a mother of 4 grown-up children is divorced, lives with her old mother and teaches

in a nursery school. She tells about her own experience in the GCBRP, *"I am second of 10 children, 8 brothers and 2 sisters. I wanted to be a nurse but when I finished my school, I had to start working and it was not possible to go for nursing training and thus became a school teacher. I heard about CBR from Brian O'Toole and I agreed to join the one-year training. At that time in the school, I had a child with Down syndrome, I worked with him and he is now grown up and in USA. It was something that gave me lot of satisfaction. I also supported many other disabled children. Then I took up job at department of education and there was a lot of work, there was no free time so I left the CBR programme. It was a very frustrating period of my life. I came back to CBR in 2005. I am involved in raising funds. We did a hot dog sale together with the DPO, and I am very motivated. Then we had elections of regional committee and they asked me to become the chair. My special skill is to be able to relate to small children and people are comfortable with me. I think that in my role as volunteer, I have been in contact with about 50 disabled children. I feel that community recognised my work and appreciated it. Not all volunteers are involved equally, some do not take responsibilities and do not come to meetings regularly but there are some who are very regular."*

Initially the CBR programme in Essequibo was only with school teachers and CBR volunteer training was given only to school teachers. Other volunteers worked with CBR but they did not get any training. Now the CBR programme here is in a transitional phase. So they have a wide base of volunteers, but not all of them are trained. They feel the need to conduct a refresher training course for old volunteers also.

Ms Orsilla Wilson and Ms Carol Weithers (*two new volunteers of Essequibo*): Orsilla has five children and one of them is blind. Carol had epilepsy since she was 17 years old and she has two children, and she also has a nephew who has speech disability. Both of them have been training for six months and even if they have not completed the training, they already have experience of working for a long time with disabled children. Carol participated in DPO training camp as a resource person. In the past, Carol's sister was chair-person of the regional CBR committee.

About the impact of CBR programme, Carol explained, *"My nephew who had speech disability, he received a scholarship through the CBR programme to study in Trinidad for one year and now he is in USA. Training is not necessary to become a CBR volunteer. When you show commitment and collaborate with the programme, then you are a CBR volunteer, whether you have done a formal CBR course or not. I started collaborating with the CBR programme in 2000. The training course is giving me new skills. For example, now I understand about different kinds of disabilities and can identify them."*

Regarding the ethnic differences in Guyana and their impact on CBR programme, Orsilla and Carol explained, *"For CBR programme, there are no differences if you belong to a particular ethnic group or religion. We work with everyone. However, it is true that it is harder to involve a Muslim child in CBR, even more so if the disabled child is a girl. Now Muslims are building their own schools so that will make things even more difficult. In East Coast they have a Muslim man involved in the CBR programme but he does not like that women are in the top role, so he talks only to men. It has been very difficult to involve Muslim women in the CBR programme activities."*

Mr. Riccardo Banwari (*Probation and Social Services officer of Essequibo*): He has joined the service recently. He knows that there is a CBR programme and the resource centre but does not know about the different activities. He is aware of the public walk organised by GCBR for promoting awareness about disability issues and agrees that networking and

learning about other programmes is important as these relate directly with his work as social services officer. His department is involved in distribution of mobility aids, support for vulnerable situations like support for housing, transport, disability certificates and financial assistance for the very poor. They also work on issues of violence and sexual abuse, also in relation to persons with disabilities.

Other Considerations from Essequibo CBR volunteers and disabled persons:

Initially the programme started with a focus on nursery school teachers. From the second batch of volunteers this policy was changed. Among the CBR activities, summer camps are considered as key activity to identify and bring new persons into programme. 15 persons get the opportunity to benefit from the summer camp, for one week each year. During this week, the person is assessed in different ways, counselling can be given, it is also a moment of staying with others, sharing and learning. Ministry of Health collaborates with the camps in providing a medical check-up and assessment. However, for the past two years there have been no camps and this has been missed. Regional committee identifies the persons who will participate in the camp. About 1.8 million G\$ are needed for the summer camp and usually these funds come from community donations.

The CBR workers, when they identify a new child with disability, they contact the family and if needed, visit the school to talk with teachers. Sometimes, parents deny that their child has any problem and do not want anything to do with CBR so it requires patience and repeated visits to convince them that their child is safe and can go out and mix with other children. In Essequibo, the CBR programme collaborated with National Disability Commission, to conduct a survey and during this survey lot of new children were identified. Many of them were hidden inside the house. For example, Pinky a disabled girl was identified in a Muslim family, who is still isolated as in spite of repeated visits, the family does not agree for her to go out. Sometimes, volunteers need to work together in couples. Ever since the programme started probably the programme has touched the lives of about 1000 children and adults with disability.

Mr. Paul is a volunteer and a retired mechanical operator. He has played a crucial role in facilitating the land for construction of the new resource centre of CBR programme in Queenstown. He says, *"I was invited to a meeting by Geraldine. I saw that the building we had for CBR resource centre was not accessible, so I proposed that we need a new building. I found about different rules and regulations, how we can ask the Government for some land, etc. This was in 2001. I contacted Paulette, the CBR coordinator in Essequibo and she agreed. We then worked together and asked the Government to give us the land. Initially they did not know about our organisation. Then we found that this land had been leased to an organisation called Friendly Barriers and we discussed it with them. They agreed and so they joined CBR. District chairperson was very supportive and helped us to get the lease. We collected funds from different donors. We heard that President was coming to Essequibo so went as delegation to meet him and ask him for support. Finally in March 2006 our dream came true and our building was completed."*

Plans for the resource centre in Queenstown: The CBR committee in Essequibo thinks that resource centre can play a more active role in providing vocational training courses. To help in the maintenance of the resource centre, they also think of starting some paid courses, this will help them to take some paid teachers for the training. They also want to strengthen their links with IDCE and hope that IADE will sponsor some of their activities. They have space for hosting a few persons to stay there for the training.

5. Discussions with Persons Associated with GCBRP in West Bank Demerara

Ms. Kay Henry and **Ms. Audrey Hunte**, two volunteers of the East Bank CBR programme explained their activities, *"Right now we have 41 children of whom about 20 children come to us regularly. Bougainville community centre is our resource centre. About the volunteers, the project had 35 volunteers trained in 1997 and another 36 persons during 2002-03. From all those persons about 10 persons are still working actively with the programme as volunteers."*

Children and parents are asked to come to the resource centre where different activities like vocational training, support for children for their studies, learning general skills, etc. are carried out by volunteers. The group also participates in national level activities. The programme also promotes inclusive education and has trained school teachers in 10 schools in making simple aids, teaching techniques and making ramps and rails for improving access of buildings to disabled children. The building has been provided to them by Neighbourhood Development Council (NDC). They also had exchange visits and special events like kite flying, etc. They have a special play-ground for the children who come to the resource centre.

One of the children with a physical disability that they were following, went on to university and is now going to Cuba on a scholarship. Another disabled child followed by them has finished university and is now head of a nursery school. They plan to do another volunteer training course in 2007.

Among the *challenges* faced by GCBRP in West Bank, the two CBR volunteers mentioned the difficulties in getting the commitment of volunteers and the difficulties linked to the building. The centre is not very far from the river and during high tide and heavy rainfall, water seeps in. In addition, during 2006 there were floods so lot of water entered the building and spoiled furniture and activities. No one from West Bank ever received a loan, though some of them had applied but they did not satisfy the basic criteria. During the rainy season, all the roads become very bad so people cannot come to the resource centre.

Ms. Audrey is a school teacher and a parent of a child with epilepsy and a CBR volunteer. She came in contact with the CBR programme in 1997 and explained her views about the impact of CBR programme as well as the activities in West Bank, *"CBR programme is useful in my roles as a parent, as a volunteer and as a teacher. The skills I learn with the programme, I can use them at home, in the community and in the school. My son is now 28 and he started having epilepsy when he was 10 years old but his father did not have any patience with him. I am the secretary of the regional CBR committee. I participate in annual conferences of CBR, my school is part of the pilot schools for enrolling children with disabilities and I attended the workshop on inclusive education. For parents, a big obstacle is to find funds for transport to come to the resource centre. For example, I know of a church group that has 6 disabled children, but it is too far for them. Time is another issue for the parents. Ours is a poor area. Sometimes children come hungry to school, in other instances, the environment at home may not be good, so the resource centre becomes an escape."*

Ms. Kay Henry is also a CBR volunteer and she says, *"I was very shy when I joined the CBR programme in 1997. Slowly as I started working with children with disabilities, I opened up and became less shy. I first started to work with a child on a wheel chair, who later on could walk without wheel chair and this gave me lot of satisfaction. Before, working with GCBRP, I didn't know that there were so many disabled children who need support and services."*

6. Discussions with Persons Associated with GCBRP in East Bank Demerara (EBD)

This CBR group operates from a resource centre based in Diamond community centre.

Ms. Donna, a volunteer in EBD explained, *"We were in another building for 13 years but there were problems and we came here. We have many income generation activities like sewing, making table clothes, bed sheets, tie and dye, crafts, making hammocks, cake sale, raffles, etc. We also go to the community for creating awareness and for providing information to persons with disabilities about the CBR programme. We have a programme for learning Braille. We have literacy programmes for both children and adults and we also have a drama programme. We get some support from the Diamond distillery factory for our insurance needs. Presently we have about 18 persons who go to the community on every Monday morning to visit persons with disabilities. None of our volunteers at present have got any CBR training and we are finalising 25 volunteers for a training course, so after their training, our work should improve. As there is no CBR resource unit in Georgetown, persons from Georgetown can go to EBD or to East Coast."*

This is one of the oldest CBR groups in Guyana and persons like **Ms Jocelyn Moore**, **Ms Sharon Harris** and **Ms Ruth** have been with the programme since 1989-90. Regarding the changes in these years, the group explained, *"In the old times, when Brian was there, we used to get food and snacks during meetings and we received 1,500 G\$ per month, the transport was paid, so it was easier to work. These days all these things are gone."*

Ms. Patricia Thomas, one of the old volunteers at EBD explained about the loans she received from the CBR programme, *"In 2001, I received a loan of 60,000 G\$ for setting up a chicken rearing business. I set up a pen. It was successful and I repaid the loan. Then I took a loan of 100,000 G\$ and I expanded to 200 chickens and it was also successful. There were floods and water came in the pen but fortunately I had already sold my chicken by that time so I did not suffer any damage, but other persons had problems. This year, I am aiming for 250 chickens for Christmas. Another person who has a child with disability, she also had chicken rearing business and she had already repaid the loan, but she lost her chicken in the floods so now she does not have money to restart her business. Another disabled woman got a loan for starting a small shop, that gave her a small profit, but not enough to be able to support her family and children from that income. So, the benefits of the income generation activities and the loans are variable."*

7. Discussions with Persons Associated with GCBRP in Kuru Kururu

Kuru Kururu is an area behind the international Timheri airport. The area is very large extending for about 20 miles. **Ms Yvonne Smith** is the chair-person of the CBR group. The Kuru Kururu group was started by **Ms Cleopatra Critchlow**, Coordinator who came here from East Coast. She thought that it would be useful to start CBR here as there were no support services for persons with disabilities. GCBRP asked her to do a survey so she wrote to the churches in her area to ask for their help and collected the information about disabled persons in the area.

They have a resource unit given to them by Neighbourhood Development Council in Kuru Kururu. 20 volunteers from the area were trained 3 years ago, who are presently working with about 100 disabled persons. Five of the volunteers are school teachers and they are lobbying with Government authorities for inclusion of disabled children in the schools. They use the CBR vehicle for visiting some disabled persons at homes, once a month. Every

Tuesday they meet at the resource unit for activities like literacy classes, crafts, sign language learning, physical education, indoor games, etc. For example, for literacy classes, presently 8 disabled children are coming, who are not going to any school because the schools do not accept them because "*they do not have trained teachers.*" Diamond in EBD is too far away to send the children to the special school situated there. Two teachers have been trained as CBR volunteers and they support children for literacy activities in the resource unit.

Only one child attends the sign language classes presently. There are four other deaf persons but they have problems in coming to the resource unit as they cannot pay the transport costs, so they cannot benefit from sign language classes. One of the volunteers who attended the six weeks of sign language course is now teaching it to other volunteers so that this activity can be expanded.

The volunteers carried out awareness raising in schools of Kuru Kururu. They spoke to children and teachers about different disabilities, early diagnosis and early intervention. Regarding the income generation from the crafts and sewing activities, the group agrees that it is not very good at generating income as only some of their own members can buy the things they make. They do not get any large orders for their materials and are planning to organise a fair to publicise their products.

Ms. Ingrid Frank, another volunteer organises the physical education activities for doing simple exercises. Nine volunteers are part of the drama group that writes its own plays on different themes for raising awareness.

Among the challenges faced by the group, the limited financial resources is the biggest issue. GCBRP can provide them with limited resources, so they also go out to local business community to ask for more support. Transport is another area of challenge as part from the costs, often drivers do not stop or slow the vehicle when they see a disabled persons or an elderly person. In spite of all these difficulties they get lot of persons with disabilities who come to the resource centre regularly since "this is the only structure existing for us in the whole area and at least here we feel wanted. It is fun to come here. They organise parties and games for us. This is the only opportunity we have to go out, to be with people, to be with friends."

8. Discussions with Persons Associated with GCBRP in West Berbice

Ms Gloria Lindo is the president of the CBR group in West Berbice. The CBR resource centre is in Lovely Lass community centre, about 10 miles from Mahaicony where Gloria lives. Volunteers in West Berbice were trained in 2001-02. They have good collaboration with the rehabilitation assistant at the hospital in Fort Wellington, who was a volunteer with the group before her training as rehabilitation assistant. So for all issues of medical rehabilitation, they send the persons to Fort Wellington. The activities of the volunteers at Lovely Lass include organisation of sports, home visits, promoting socialization of persons with disabilities so that they go out and meet with other persons, promotion of inclusive education, advocacy for improving the physical accessibility of schools, literacy classes, parent support groups, some income generation activities such as picture frame making, floral decorations, etc. They received 10 wheel chairs from the "Food for the Poor" programme that were distributed to persons with disabilities. They also have an arrangement with a dentist who provides free voluntary services for persons referred by CBR programme once per month.

CBR group also collaborates with other health programmes such as vaccination and nutrition programmes. They receive pamphlets from "Food for the Poor" programme for distributing them to bed-ridden persons. 12 persons in this area received loans from CBR programme, of them two persons have problems with repayment.

Neighbourhood Development Council has donated land to them for building their own resource centre. President has promised to give 9 million G\$ donation to them for their building. Dr Leslie, the Health Minister, gives them one days salary per month. A new group of volunteers has just completed training.

Mr Mark Archibald is blind and is the president of the DPO group of West Berbice. Their DPO is a mixed group with persons with different disabilities. They started as part of CBR group but are now making links with the national DPO. Mark recognises the impact of CBR that has helped him to become aware of the situation of different disabled persons and how they can fight for their rights.

9. Discussions with Persons Associated with GCBRP in Rupununi

CBR programme in Rupununi initiated around 1994 and the approach adapted was different from that in other regions of Guyana. As Rupununi is a vast area with a very small Amerindian population scattered in distant villages where the availability of different public services was extremely limited, CBR focused on each village promoting the creation of a village team of a health workers, school teacher and a community volunteer. During 1996-97, with the difficulties related to change in the leadership and limitation of funds, some of the key persons associated with the programme in Rupununi left and the activities faced severe limitations.

Mr. Jude Isaac, health coordinator of Sand Creek sub-district explained, *"From the original groups of persons, only a small number of persons continues to be involved in CBR. We did not have new training-courses. Here distances are so big and transportation difficulties are there, so it is not easy to get together all the persons from whole of Rupununi. Regional coordinator is based in Lethem, she can't go out to all the places, because she has other responsibilities and funds are limited. Only recently did we have some training courses, so persons from different villages came together."*

Ms. Julie Loris, a teacher in Potarinau village under Sand Creek sub-district explained, *"Our total population is 575 persons. We have this hall for our school. Here we have 205 students from First till 9th grade and we are five teachers. The classes are divided by blackboards. After 9th standard, if children want to study more, they have to go to Lethem. All our teaching is in English but we also teach the oral Amerindian Waipashana language. We have five children here who are disabled."* All the five children had movement disability and none of them had ever been to any other medical services.

Potarinau is about 15 km from Sand Creek village where the sub-district hospital is based and where Jude works. The nearest big hospital is in regional headquarters, Lethem, about 80 km away, but even in Lethem, there were no rehabilitation professionals. For any rehabilitation services, persons need to go to Georgetown or cross the river and go to Brazil.

Sand Creek has a population of 740 persons. During the visit in Sand Creek, 14 persons with disabilities, majority of them children, were interviewed. Only one child had been to a rehabilitation professional in Brazil, the remaining 13 persons had never been seen by any

rehabilitation professional and the support from CBR programme had been mainly in terms of social support and going to school, and not for simplified home rehabilitation exercises.

10. Discussions with Persons Associated with GCBRP in East Coast

East Coast has one of the more dynamic groups of CBR with lot of activities in this region. Their resource centre opens three days a week. Their original resource centre was offered by **Ms. Gwendoline Glasgow**, mother of a child with disability, it is undergoing repairs and for the time being they are in a temporary resource centre in Haslington, offered by one of the CBR volunteers in her home.

In the meeting held at the resource centre there were about 40 persons including disabled persons, parents and a few volunteers. Many of the disabled persons were also members of the East Coast DPO.

Patricia Malay, secretary of the East Coast CBR committee is also chairperson of the local DPO. During the visit, many disabled persons talked about the changes brought in their lives by the CBR programme, in terms of coming out of their homes and mixing with other and now, helping in organisation of activities for fund raising, organisation of a bus service for going to the church, distribution of food and clothes, organisation of medical assistance, etc.

This group is also very well represented at national level and many persons of the group take an active role in the functioning of the organisation, giving their time and commitment. Two years ago a survey was conducted in East Coast and they identified 1500 persons with disabilities. They plan to have their own building for their resource centre close to the main road so that persons with disability can access it more easily.

Ms. Doodmattie Singh is the *regional education advisor* for East Coast region. She is very much aware about the CBR programme and says, *"Teachers of East Coast are not trained in special education, they do not know how to work with disabled children. In region 3, teachers from all schools were placed in CBR programme and they became capable of identifying different disabilities and could accept disabled children in their classes. This was during 2002-03. They also did some work on income generation."*

Regarding the promotion of inclusive education in East Coast, Ms. Singh added, *"Ministry of Education is now trying to train all the teachers on working with disabled children. We wanted to organise a workshop on this theme but there were insufficient funds to do it. If resources are available, we will be happy to support that teachers of East Coast are trained by the CBR programme. We have Diamond school in our region, where we have students with physical disabilities and hearing disabilities, etc. We support our teachers from the schools to go for upgrading training but they change to other courses, they do not come back. Head of Diamond school is an ex-volunteer of CBR programme. Another teacher is parent of a disabled child and she was also CBR volunteer. In the nursery school close to this office, the head mistress is an ex-volunteer of CBR. These ex-volunteers are very supportive of education of children with disabilities in their schools and classes."*

Ms. Ionie Chatoor, accompanying the evaluator for the field visits, is one of the CBR coordinators in East Coast and also the head mistress of a nursery school in the region.

In a nursery school, **Ms. Darmalingam**, mother of 4 year old **Balmitra** described her son as "slow learner" and explained, *"My son sometimes wets himself, so it is a problem for the class. Fortunately, it does not happen every day, it happens sometimes. When he first*

started coming to the nursery school, he was very difficult to control, he could not focus his attention on anything, but now he can trace letters, he paints and sings, he reads. It is good that this school accepted him."

Ms. Chatoor introduces thirteen years old **Haresh Ryan**, who lives with his old grandmother and younger brother Kishen. Haresh was a student of the nursery school. However, growing up, he started getting weak in the legs and now cannot walk. Through the CBR programme they have been able to get him a wheelchair. However, Haresh cannot go to school as the primary school has stairs. **Kishen Randel**, the younger child is also showing similar symptoms. Some relatives from their mothers' side also had similar problems so they all think that this is due to some hereditary disease. Haresh was taken to a hospital in Georgetown but they were told that nothing can be done for him and they did not go back.

Dennis Masalamani is 26 year old CBR volunteer. His right hand was crushed in a traffic accident and amputated, and he received an artificial hand from Ptolomey Reid centre for which he paid 250,000 G\$. Dennis collaborates with CBR programme as a photographer. At the same time, he is works as volunteer with Haresh Ryan.

Dr. Leslie Carter is the *regional medical officer* in East Coast. About the CBR programme he says, *"I was trained in Cuba in 1982. I am always happy to collaborate with the CBR programme, I tell them that whenever you have a problem, come and see me. I will help as much as possible. In terms of specific services for persons with disabilities, now it is possible to operate children with cleft lip and palate. These operations are done by an orthopaedic surgeon. We do not have any trained physical medicine specialist in Guyana."*

Ms. Jean Frasier is a nurse at the East Coast *regional health centre*. About her links with CBR programme she says, *"My grand-daughter was born with one leg shorter than the other, so I know the CBR programme for a long time. A couple of years ago, I also gave a lecture to the CBR volunteers. It is a useful programme that helps persons with disabilities. I even went to their big meeting in Georgetown. They are doing very well. I saw a programme about them on the television."*

There is a batch of 23 *new volunteers* in East Coast who are undergoing training from the CBR programme. The evaluator met the new volunteers for discussions. The volunteers come from a variety of backgrounds including some housewives, a pastor, some students, parents or relatives of persons with disabilities, teachers, etc. The persons also vary greatly in age, from a young 21 year old student to an above-fifty grandmother.

11. Discussions with Persons Associated with GCBRP in Corentyne East Berbice

The CBR group in East Berbice has a new resource unit in its own building, made with the contribution of CIDA. Before they were in a nursery school. They have had training for three batches of CBR volunteers so far. The activities include literacy classes, income generation activities, daily living skills, etc. The resource centre accepts all the children that are not accepted at other schools and is open five days a week.

Ms. Norma Cummings, an old volunteer of the group and a special education teacher, works with these children. Presently about 50 children come to the resource centre regularly. Older children and adults are organised in a disabled persons' organisation (DPO).

The CBR group also collaborates with a non-governmental organisation focusing on HIV/AIDS. **Ms. Sharon**, the *rehabilitation assistant* in Corentyne, also comes to resource

centre and every Wednesday does home visits. She visits an average of 15 persons during her visits to the resource unit.

The *Corentyne DPO* has links with national level DPO. **Trisha**, one of the children coming to resource unit participated in national games and won a medal in 100 meter race. 12 persons from the group have received loans so far and are involved in activities like poultry farming, garment making, catering, etc. The loan repayment was a problem so a training was conducted to inform persons about the loan scheme.

Andrew and **Berty**, both young men are wheel chair users and run a workshop for repair of wheel chairs. They wanted to do vocational training but since there is no hostel facility in Open Doors vocational training centre, this was not possible.

Ms. Carmen Davis is mother of a boy with disability as well as a CBR volunteer. About her experience in CBR, Carmen says, *"The programme has been very useful for my son. I could see him improving daily and when they said that he was a smart child, it made me feel good. He can handle music systems and does it in very orderly way. He has found a special affinity for music. Music is there in many children with disability and I feel that we should be using it more. The teacher in the resource unit needs assistance from us parents as she has so many children with disabilities in the class. We also need some financial support. I want to appeal to parents to come and participate in the CBR programme."*

This was followed by a discussion on ordinary schools versus the special schools, as some persons felt that Corentyne resource centre may be promoting that disabled children should be sent here rather than to ordinary schools. Some parents said that they feel more comfortable with the resource unit as teacher is very qualified and sympathetic. Others felt that resource unit can be a temporary place for children who have been isolated and have never been to school before, so that they can prepare themselves and get ready for going to ordinary schools. Some persons felt that children can benefit by going to ordinary schools and then coming for extra support to the resource unit.

Ms. Natalie Ramotar in New Amsterdam has been associated with the CBR programme for a long time. She was in the first group of volunteers in 1991, though in recent years, she has not been very active. In terms of impact of CBR programme in Guyana, she said, *"The greatest strength of CBR has been its capacity to raise the profile of disability in the country. Today people are more aware and persons with disabilities are more visible."*

About the areas of challenges for the programme she said, *"A stronger partnership with Ministry of Health and Ministry of Education is needed. CBR alone cannot take over and provide everything, it will be too much for CBR programme. Organisational management also needs to be strengthened, Brian was good at that. After he left, there is more ownership and participation, but management also needs to be strengthened. Income generation is another area that is not very successful. DPO component also needs to be strengthened. Perhaps, right now it is important to consolidate its work rather than spread into new areas."*

Mrs. Mala, mother of 5 years old **Lukram** says, *"I have two older children, who are all right and they have no problems. Lukram was born slightly early and when he was born, he did not cry and was put into incubators for 2 weeks. He has been slow in everything. He was almost 4 years old before he started to stand and walk. Since September 2006, I am taking him to resource unit. He is making good progress. He tries to speak now and wants to eat by himself. He is going to the resource unit daily."*

12. Discussions with Members of National CBR Committee

The general view was that NCBRC in Georgetown is just a linking place. Important work, in terms of working with children and adults with disabilities and facilitating different services, is done at regional committee levels. Networking at national level is important to know what is happening where. There is No CBR group in Georgetown and only the NCBRP office is there. DPOs are also based in Georgetown, so NCBRC is useful for linking with them.

The Consultant had raised the question about GCBRC president, who is the same person from the beginning. The members explained that GCBRC has membership base at community level and members come through regional committees to the national level. They feel it is democratic and participatory and they do not see any need for changing the president. They said that if the same persons can continue in some roles, they acquire competency and it is good to have a competent person in the role of the president.

President Mr. **Gregory Glasgow** himself talked of relinquishing the office. He said that *"Now the persons from regions are stronger. They need to develop other skills beyond commitment. Building the credibility of the organisation takes a long time but now it is there and it is possible to change"*.

Ms. **Geraldine Mason Halls**, national consultant for the GCBRP is also in charge of training of mid-level rehabilitation workers (rehabilitation assistants) under the Ministry of Health. She explained, *"For the last 9 years, we have been able to introduce a 7 weeks training module for 4th year medical students. This module includes six weeks of field visits to different structures and services involved in rehabilitation including Open Doors centre and CBR programme in a region. I coordinate this training module. Thus there are 15-20 new medical students each year, who learn about CBR. During their field work, they also do research on issues such as attitudes and behaviours."*

Regarding the image of GCBRC in the country, Ms. Halls said, *"We recognise that we can do much more in terms of our public image. Previously we were doing work with schools using puppets and we were much more present on the television and these activities have not been as visible in the recent years. We need to work much more also with newspapers and the other media about how to deal with and how to present disability issues. We also need to work much more with Government officials."*

Discussions Regarding Inclusive education: In Essequibo, the CBR programme started in 1993 in collaboration with school teachers. 32 nursery school teachers including Ms. Morney, Ms. Dana, Ms. Carmen were trained, who took an active role in CBR activities. Mr. Llyod, the present chair of the DPO, was one of the facilitators for this course. The main focus of the programme was to get these children into ordinary schools. Many children, not all, were accepted in the nursery schools but when they finished the nursery, they were not accepted in the primary schools. The primary school teachers felt that they needed special training to deal with disabled children. Now the national teachers' training course provides some training on working with disabled children and some teachers can specialise in special needs, but even without the training all teachers do have some knowledge. However, even with the law that says all children must go to school, not all teachers accept disabled children in their classes.

Slowly with time, many nursery school teachers involved with the CBR programme, have left the programme as the CBR activities sometimes clashed with their other meetings and

activities. Also as officials were changed, the new persons did not know about CBR and were less supportive. Still, the persons who had worked with CBR programme, they retain some sensitivity towards disabled children and help whenever they can.

Discussions about Involving Other Organisations in CBR: Two deaf volunteers came through VSO. Two new volunteers may come through VSO for working with the deaf persons. The new volunteers will work with literacy, recreation and counselling related activities.

Rotary International of Georgetown - for past 8 years it has been sponsoring the sports day for children with disabilities. They wanted to work with disabled children but without the CBR network, they could not have done it. This activity allows CBR to bring 400 children from the country to participate in the sport activities.

Mr. Terrence Dhainy said, *“Other agencies find GCBR attractive but because our space is limited, we can't accept all their volunteers.”*

Discussions about Long Term Perspectives of GCBRP: Ms. Halls said, *“With AIFO's support CBR programme has been unique in offering long term support. Many other projects start and finish, persons receive some support and then activities stop. In case of GCBRC, the activities have been ongoing so that persons who came in the programme as children could be followed to the adulthood.”*

DESK REVIEW: IMPACT OF GCBRP

The desk review looked at the different evaluations of the CBR programme in Guyana conducted over the past 20 years, ever since Brian O'Toole and Geraldine Mason Halls started the CBR programme with a small number of volunteers and school teachers in a community in 1986. Over the years, it expanded and reached many other regions of the country, especially in the coastal areas. During 1996-07, one of the original founders, Braian O'Toole, left the programme due to differences with GCBRC and this was a difficult period for the programme.

The desk-review presents some key findings mentioned in the earlier evaluation reports, which influenced the different phases of this programme.

1. EVALUATION REPORT ON THE CBR PROGRAMME IN GUYANA (B. Gautron, 1993)

Initial project (1986-88): The two years pilot project was completed in June 1988. The project introduced a CBR programme to twenty-six volunteers and twenty-five teachers who, in turn, worked with fifty-nine disabled children and their families.

The pilot project was assessed by independent evaluators and was found to have been effective in a number of ways. Children with disabilities progressed significantly, parent's attitudes towards them changed considerably and the community got involved in all stages of the project, its design, implementation, management and evaluation. (p. 4)

Present project (1991-93): The objective of the programme is to assist the development of 300 children with disabilities who are presently receiving no help for their disability. (p. 4)

Strengths of the programme include the following: High degree of mobilization from people in the community; The sense of partnership between volunteers from the Health and Education sectors; A comprehensive training has been developed; The political support is important (from the First Lady, from the Ministries of Health and Education...).

Weaknesses of the programme include the following: Limitation of the programme which meet just a few percentage of children with disability at the moment; Lack of appropriate supervisors and of management at the local level; Weaknesses in the referral system and difficulty to build on when there is lack of services. (p. 8)

2. OFFERING HOPE: AN EVALUATION OF THE GUYANA CBR PROGRAMME (J. Miles & L. Pierre, 1994)

That impression is that the Guyana CBR programme is making what earlier generations would have called a miraculous difference to the lives of the children and families affected by it. (p. 1)

Extrapolating from this base line to the whole population (of 750,000 persons), it can be assumed that the total number of disabled children in Guyana must be in the region of 8,400....the number of children so far reached by the programme, 300 is only 1/33 of the probable total.. (p. 2)

The programme should examine the reasons for gender imbalances in the respective volunteer forces, and should seek ways to enlist more men into the volunteer force on the coastlands and more women in the Rupununi. (p. 11)

The proportion of Christian to non-Christians among the respondent from coast and inland volunteers was 21:8. .. it would seem that there is a marked disproportion of African-Guyanese among the volunteers...the programme should examine the reasons for what seems to be the under-representation of Indian and non-Christian volunteers...for the sake of increasing the aggregate yield of volunteers ... the authors of this report see no reason to believe that the work of a volunteer is any more effective if she/he is matched to a family of her/his own ethnic group or religion...amongst the non-Christian volunteers responding to the coastal areas questionnaires none were Muslims. (pp. 13-14)

So the relevant question is whether, given the general scope of the programme, the services are reaching predominantly the children and families most in need in economic sense ... two thirds of all the female and male heads of households represented in the questionnaire sample had received only primary education. All the fathers or other male heads of households in the sample were in manual or other unskilled or semi-skilled occupations ... taken together, these data, illustrative of limited education, lowly occupations, and large family size, demonstrate that the families concerned belong typically to the poorer socio-economic strata. (pp. 15-16)

The proportion of African, Indian and 'mixed' families among CBR coastland clientele - 11:15:4 - are very much what would be found in the general population... the programme is therefore found to be highly effective in reaching a representative cross-section of the population, ethnically speaking. The above figures for ethnicity are echoed in the proportions of Christians and non-Christians ... but as with volunteers, a marked under representation of Muslim families is noted. (p. 16)

Two thirds of the children served by the programme are under 10... the most commonly occurring single impairments were hearing and speech impairments, followed by specific deformities of limbs or extremities not related to more general or complex impairment, and by Down's syndrome... In only seven cases out of the thirty families covered by coastland parent questionnaire had the family either sought or received may help or intervention before CBR. (p. 17)

The kind and degree of changes observed in the children, and the precise significance of those changes, will obviously depend upon the kind and degree of impairment(s), as well as upon the chronological or developmental age of the child, the length of the intervention period, the quality of the volunteer, and the responsiveness of the family; so that it is difficult to generalise about the changes - except to say that there were observed changes in virtually all cases, often of a most dramatic and decisive kind... We find the ability now to perform basic personal functions which improve self-esteem and relieve the burden on other members of the family: to bathe themselves, to dress themselves, to groom themselves, to feed themselves, and to use the toilet by themselves. (p. 21)

(In Rupununi) Some difficulties have been experienced in the formation of teams and in getting their work started; but in other cases, encouraging results have already been recorded, in terms of parents who had not previously done so, bringing their disabled children to clinics, ameliorations being effected in some disabled children and enthusiastic community responses ... (p. 36)

3. A DECADE OF HOPEFUL STEPS IN GUYANA - A PARTICIPATORY, COMPREHENSIVE EVALUATION OF THE CBR PROGRAMME IN GUYANA (Hoffmans T. & De Roos V., 1995)

The quality of training is generally rated high by the volunteers... with the use of locally produced training materials, over a thousand people have been trained by the programme. The background variables of families who are participating in the CBR programme are an exact representation of the average Guyanese population. From the evaluation, it appears that most of the parents have noticed positive changes in their disabled child as well as in themselves as a result of the programme... When looking in the areas where CBR is implemented then the coverage is about 9%, which is not very high. A reason for the low coverage can be due to the fact that the preliminary focus of CBR was on children, whereas most of PWDs in Guyana (70%) are older than 15... The programme has catalysed the establishment of several "disabled people organisations" and provides benefits for able bodied persons. Also, the programme receives support from several Governmental and Non-Governmental organisations. (p. iv-v)

A key element of the CBR programme in Guyana are the resource centres. Each coastal area has one or more resource centres, which are run by the regional CBR committees. Most of these units are situated in a village school, which has been made available for training sessions, meetings, and as a resource centre for the programme... In the Rupununi region of the southern interior the programme attempts to develop a wider range of services related to child-development in general... Workshops have been conducted to provide a basic introductory training for volunteers and other members of the communities which is similar to the training sessions on the coastlines, but embrace a wider range of topics, such as literacy, numeracy, nutrition, parenting, family budgeting and community development... the training is under the auspices of IACE. (pp. 16-17)

In 1996, the project was active in five geographical areas (Berbice, East Coast Demerara, East Bank Demerara, Essequibo and Rupununi) with 286 parents of disabled children, 267 volunteers and 15 regional coordinators. (p. 29)

For many parents (30%) an important merit of the CBR was that they learned how to cope with their PWD (person with disability)... About a quarter (28%) of the parents said that they learned to accept their PWD.. Eighteen percent said that they now know how to help their child. (p. 47)

Many parents (34%) believe that their child can become more independent than would have been possible when it had not participated in the programme. Another change is that 30% of the mothers realise that their child has abilities. Some mothers mentioned that their child can do schoolwork (11%) and home work now (8%). According to 22% of the mothers, their ideas of what their child is capable of doing have not changed. (p. 48)

During the evaluation, percentages of persons with different disabilities benefiting from the CBR programme was calculated and showed the following distribution: movement (21%), visual (4%), speech & hearing (33%), learning (11%), convulsions (2%) and multiple (30%). (p. 66)

More than one-third parents answered that the attitudes of the community towards the PWDs has changed. .. It was also noticed by 26% of the parents that there is more contact and communication between PWDs and the community. A number of parents (12%)

mentioned that the community is more willing to assist the parents with their PWD. A third (34%) has not noticed any changes in the community. (p. 72)

The regional coordinators gave various examples of the impact of the CBR programme has on the wider community. For example, the impact is also evident from the wider developmental role it has within the community. Several Disabled People's Organisations (DPOs) have recently been established... These DPOs evolved out of CBR, and look at the needs and rights, and serve as a meeting place, for adult disabled persons. Also the SCOPE Women group has evolved out of CBR. This group aims at creating awareness of the rights of PWDs. Another effect of CBR is that the Community Health Workers and teachers are now more aware of PWDs, and have increased the level of commitment to their work with PWDs. (p. 73).

It is remarkable that almost all the volunteers are female... in contrast to the families who represent the Guyanese society, the volunteers are most of the time Africans and adhere to Christian faith. The question here is: what does it matter? Maybe it is an aspect related to the culture. The authors believe it is more important that the people who are to be reached (the PWDs and their families) are a cross-section of the society than the people who bring about the change (the volunteers). (p. 90)

During conversations it became clear that a lot of volunteers formerly thought that they could not mean anything to the society, they mentioned things like, "I was just a housewife, now I know that I have qualities and can really mean something for the people in one way or another." So CBR did not just "use" the volunteer as a medium but made a tremendous impact on the community (volunteers) as well. (p. 90)

The collaboration with the University of Guyana and Ministry of Health has led to several training programmes for health workers, doctors and teachers. By means of these training programmes doctors, health workers and teachers will be more aware of PWDs in their community and in their work, they will know how to deal with PWDs and how to offer appropriate help. (p. 99)

Until now 401 disabled children have been reached, which is four times as much as was aimed for in 1991... there are about 12,000 PWDs living in Guyana; considering the fact that the focus is only on children (this group accounts for 30% of total number of PWDs), CBR has reached about 11% of the total disabled children. (p. 110)

4. STRENGTHENING OF REHABILITATION SERVICES IN GUYANA - A PARTICIPATORY EVALUATION (Schneider E., 2002)

In the context of Guyanese society and the social discrimination toward people with disabilities, the Vocational Training Centre (VTC) provides an example of the capabilities of people with disabilities and has a positive effect of impacting social consciousness and awareness. This was acknowledged by all counterparts – the Ministry of Health and all personnel of the VTC. (p. 6)

Rehabilitation Assistants (RAs) are Guyana's creative response to meet the challenge of strengthening and expanding the quality, range and accessibility of rehabilitation services by providing trained health workers in the areas of physical, occupational and speech therapy. They function as multi-disciplinary technicians at secondary and tertiary level health services, and can provide training, education and referral support to community level activities. (p. 15)

A short course in fundamental principles of rehabilitation medicine was carried out in 2001. It was a four week course designed to provide general medicine physicians and other health workers with the rehabilitation principles for traumatic brain injury, stroke, spinal cord injury, and amputations... Dr. Newman's course established a multidisciplinary team to improve referrals. The course also taught new techniques and treatment for early weight bearing in lower extremity amputations which is associated with better prosthetic outcomes. It also identified ways to treat and prevent such problems as bedsores which occur frequently in the hospital setting. (p. 21-22)

The six month upgrading course on speech therapy and occupational therapy for rehabilitation assistants took place in 2002... The impact of the course in occupational and speech therapy for rehabilitation assistants is very concrete. There is now speech therapy available in a number of different regions which clearly has an impact on the quality of services. There are kits for speech training, resource manuals, and other materials available in each region. (pp. 21-22)

On the national level, there are nine members of the NCBRC Board. There are five ordinary members who are persons with disabilities or family members; and four supporting members, who are community members who are supportive of the objectives of the organization. The ordinary and supporting members are elected annually to sit on the board by the CBR Regional Commissions. As such the majority of persons on the Board are persons with disabilities and their family members... In addition, the structure includes the National Advisor to the CBR programme, Geraldine Maison-Halls. (p. 24) There appears to be a strong relationship between the regional CBR and committees and disabled person and their families.(p. 30)

A major accomplishment in this period of the project is the reappearance, after an absence of three years, of the CBR quarterly Newsletter called "Hopeful Steps" which is edited and produced by persons with disabilities. It serves as an important forum for information, networking and highlighting the accomplishments and activities of the different program components of CBR. (p. 26)

Disabled persons organisations (DPOs) in general acknowledge that they have emerged from the CBR program experience and structure, but are now moving to a greater level of autonomy. The mechanism in place thus far is that the DPOs conceive, create and implement local projects with the technical assistance, training and funding from the NCBRC once the proposal is approved. This has permitted a level of advancement and development that is recognized and appreciated by the DPOs, but is still based on an affiliated status with the CBR rather than an autonomous status. (p. 34)

In Essequibo the DPO has about 70 members with varied disabilities... In Berbice, there are about 100 members. In East Coast Demerara there are about 35 members. (p. 35)

5. EVALUATION OF CBR COMPONENT OF THE PROJECT "STRENGTHENING OF REHABILITATION SERVICES IN GUYANA (Gordon S.J., 2003)

(In Essequibo coast, region 2) Two PWD's from this region were granted scholarships and successfully completed their studies. Both of whom have been given the opportunity to utilise their skills, the young man did woodworking and the RCBRC organized several

training sessions at which he was the resource person. The other person did two programmes simultaneously – Food Preparation and Garment Construction. She has established a business through the credit scheme. School aged children with disabilities attend regular schools, and volunteers visit schools to sensitize the children about providing support to children with disabilities in their school. The volunteers also visit parents to encourage those who are reluctant to send their children to regular school. (p. 7)

The RCBRC receives fair support from agencies within the Region such as the Regional Administration, who would provide transportation and other skills whenever called upon. Similarly other agencies e.g. churches, service organisations and the business community would assist when requested, but no attempt has been made to create permanent partnerships with other organisations and groups in the Region. (p. 9)

(In region 3, West Demerara) 12 schools are involved in a pilot project to mainstream children with disabilities, the committee has embarked on a series of activities to ensure the smooth implementation of the project. Activities undertaken for the inclusive education, by the committee members, volunteers and coordinator include sensitisation of school teachers at the pilot schools, sensitisation of school children, presentations at PTA meetings to encourage parents to work with their children to accept those who are differently able. (p. 14)

Parents of children with disabilities also indicated a number of positive aspects of the programmes. One parent said that her child now uses her foot to write and colour, and she now makes signs to draw your attention since coming to the Center; another parent said that she is now able to go out and leave her child with other persons, which she could not do before. (p. 15)

The East Bank Regional CBR Committee is intended to cover the entire East Bank of Demerara as far as Moblissa, which is a distance of over 50 miles... The East Bank, Region 4 Community Rehabilitation Committee services 61 persons with disabilities, 34 of whom are young adults between the ages 16-35... It is apparent that this RCBRC has many problems in terms of its management. During the focus group discussion, there was considerable dissent and contradiction, in fact one of the participants was very outspoken and said there has to be more cooperation between members of the committee, coordinators and volunteers. Her comments were confirmed by most of the key informants interviewed. Their comments included – lack of consultation among committee members, no cooperation, persons are not allowed to speak freely. (p. 18)

Persons with Disabilities have expressed positive feelings about the CBR programme, according to them it has provided them with new skills, to access loans for self-improvement, the opportunity to socialise and has helped them to recognise that they are not the only one with a disability. (p. 21)

(In region 5, west Berbice) there are approximately 150 PWD's registered with this committee with 40 volunteers, 4 of whom were trained in 1997, and thirty six persons completed their training as volunteers in 2002. The RCBRC is managed by a committee of 9 persons and a Regional Coordinator. The committee's responsibility is to plan programmes while the Regional Coordinator is responsible for overseeing the implementation of the programmes. The volunteers teach children with disabilities, working with DPO's to reduce 'shut' in behaviour. The Committee has not outlined specific activities for volunteers and as a result, the volunteers only attend meetings and are not motivated. (p. 27)

The group operates a Resource Unit in temporary facilities at Lovely Lass but they have acquired a plot of land and they are hoping to acquire funds from SIMAP for the construction of the Resource Centre. The present building is located a fair distance from the public road and persons in wheel chairs cannot get across the bridge. To compound this problem, most of the disabilities in this region are associated with movement, so as can be expected, the major problem facing PWD's is transportation, since many of them have no source of income and in addition, many buses do not take them. For these reasons, attendance at the Resource Centre is low. (p. 28)

The PWD's interviewed indicated that they have benefited from CBR in many ways, they are better able to socialise with other people, the opportunity to obtain loans, and they have been able to attend training courses. They would however wish access to aids such as walkers, spectacles. Members of the community interviewed had heard about CBR through the television and the "grapevine", but did not know about the Resource Center. They all suggested that the RCBRC should have sensitisation sessions and workshops in the community, not only to make more community members aware of CBR, but to encourage more persons to become involved. (p. 29)

(In region 6, east Berbice) the Resource Centre also serves as a "sitter" for adults with disabilities because it operates daily. At the Resource Centre, there are 2 volunteers who provide academic sessions for 20 children who have disabilities. One day each week, there are parent education sessions, at which they are taught craft, and have educational sessions through talks and videos. The Centre also provides Literacy and Numeracy training for members of DPO's and Parents of children with Disabilities. Therapy sessions are also provided by the Rehabilitation Assistant in the area. (p. 31)

(In region 9, Rupununi), one view of the present operation of CBR is that there are no visits, guidance or activities since the departure of persons such as Dr. Aidun, Dr O'Toole, the Dutch volunteers and Juliet Solomon. The other group was of the view that the persons of Region 9 would now have the opportunity to be more involved in the decision making and therefore have little need to depend on other persons to plan activities for them or give them directions. (p. 38)

The South Central Sub District includes Sand Creek, Potarinau and Shulinab. It has a facilitator and three committee members who lead small CBR groups in each village. There are 12 persons with Disabilities in this Sub District and has approximately 18 support persons including 11 volunteers, most of whom have not been trained. In this area, there is considerable involvement of health workers, probably due to the fact that the facilitator is a health worker. (p. 40)

CBR activities in the Rupununi seem to have come to a complete halt. Much of the energy seems focussed on griping about the problem with the vehicle. Training activities, though they may include Persons with Disabilities are for the general public. The RCBRC does not meet as often as it should and though facilitators may have been trained as volunteers, they have had no training as facilitators, and consequently, some of them seem unsure of their responsibilities and role and because many of the present facilitators were CBR members during the period when there were full time CBR coordinators, they expect that the same structure and functions apply. (p. 42)

6. GUYANA CBR PROGRAMME, ANNUAL REPORT 2003

There was disappointment in terms of the limited number of applications for new loans, however, there was a noticeable increase in the level of repayments during 2003. Efforts will be intensified in 2004, to increase the number of applications for new loans and to broaden the range of the micro-enterprises. (p. 7)

As a follow-up to efforts made over the past few years, a more structured plan was put in place to facilitate the development of an autonomous Disabled People Organisation. The representatives at the meetings were tasked with the responsibility of increasing the membership at the local level. It was felt that as the numbers increased, it would then set the stage for the establishment of a strong and effective national network of DPOs. Meetings were held on a quarterly basis to allow persons with disabilities to share and discuss issues that affected them, identify common strategies to deal with the issues and to work towards the formation of a National Disabled People Organisation.. A steering committee was elected to do the preparatory work for the establishment of the National DPO. A draft document was produced with the philosophy, goal and objectives of a national DPO movement and a constitution was drafted. (p. 6)

The launching of the National DPO Network is a major achievement of persons with disabilities and much credit should be given to Patsy Mallay for her determination in getting the Network established. Capacity building of the local and national committee will need to be continued so that the DPOs can become strong self-advocacy groups. There is need for continuing dialogue between the GCBRP and the DPO Network, so that roles and responsibilities can be clarified and conflict situations minimized. (p. 7)

The analysis revealed that each regional CBR committee is a unique organisation, with some similarities and common problems. However, one issue has been highlighted, that despite the fact that the national CBR programme has coordinated the development of a vision, goals and objectives, these guidelines seem not to have been communicated effectively to the other stakeholders involved in the CBR in the regions or to have been internalised by the RCBRCs members who were involved in the creation of the vision. (p. 21)

PROGRAMME OF VISITS OF THE CONSULTANT (2006)

- October 23 Arrival in Georgetown
First meeting with Ms. Geraldine Mason Halls, national advisor of GCBRP & Ms. Patricia Thomas (Treasurer, National GCBR Committee)
- October 24 Second meeting with Ms. Geraldine Mason Halls, national advisor of GCBRP
Ms. Patricia Thomas, treasurer GCBR national committee and office staff of GCBRP
Meeting with VSO volunteers Sarah (medical rehabilitation) and Jim (advocacy)
Mr. Francis Glasgow, Acting Director, Institute of Distance & Continuing Education (IACE)
Ms. Evelyn Hamilton, Chairperson, National Commission on Disability (NCD) & Head of Planning Dept. Ministry of Education
Ms. Inge Groenewegen, Disability Programme Manager, Volunteer Service Overseas (VSO)
Mr. Leon Walcott, journalist, editor of CBR News
- October 25 Visit to Essequibo (Region 3) – visits in Saddle, Anna Regina & Queenstown; meetings with coordinators of CBR programme, new volunteers, old volunteers, persons with disabilities, parents, regional administration, regional development council, social services, home visits (Ms. Morny Brandon, Ms. Orsilla Wilson, Ms. Carol Weithers, Mr. Reccardo Banwarie, Mr. Ali Bachs, Mr. Ariel, Mr. Jainarain Lal, Mr. Sahadeo, Ms. Purnawati, Ms. Carmen, Mr. Weasley, Ms. Dana, Ms. Paulette Dainty, Mr. Lloyd Lewis, Mr. Paul, Mr. Andy de Silva, Mr. Dhaniram Singh and others)
- October 26 Visit to Open Doors vocational training centre, meeting with Mr. Arthur Lewis (Director)
Meeting with Ms. Barbara Lawrence, Director, National Rehabilitation Services
Meeting with Dr. Leslie Ramasammy, Minister of Health
Meeting with Dr. Hedwig Goede, Health Systems & Services Advisor, Pan American Health Organisation (PAHO)
Meeting with Ms. Karen Halls, programme officer, National Disability Commission
Meeting with Mr. Emmanuel Goring, expert, European Union
Visit to West Bank Demerara CBR Programme (Region 2) – meeting with coordinators, volunteers, persons with disabilities and parents at the resource unit in Bagotville (Ms. Audrey Hunte, Ms. Kay Henry, Ms. Hazel Agard, Mr. Coleridge Delph, Mr. Joe Singh, Ms. Sharon, Ms. Donna, Ms. Samantha, Ms. Tanya, Mr. Shahzar, Ms. Sattar Mohamed, Ms. Merle, Mr. Derek and others)
- October 27 Meeting with Ms. Garladine Mason Halls, National Advisor GCBRP
Visit to USAID office and meeting with Mr. Hubert Robertson (Grants, Monitoring & Evaluation), Ms. Gloria Richards Johnson (Deputy Chief), Ms. Daune Pratt (Civil Society)
Meeting with Ms. Sarah Bienemann, Occupational Therapist, VSO volunteer

- Visit to Diamond Community Centre and CBR resource unit in East Bank Demerara (Region 4) and meeting with coordinators, volunteers, persons with disabilities, parents, DPO representatives (Ms. Harmonica Walcott, Ms. Jeane Danny, Mr. Learoup Rupart, Mr. David Burnett, Mr. Philippe Carris, Ms. Gayatri Devi, Ms. Jocelyn Moore, Mr. Robert Pits, Ms. Sharon Harris, Ms. Donna, Ms. Patricia Thomas, Ms. Ruth and others)
- Visit to CBR resource unit in Kuru Kururu and meeting with coordinators, volunteers, persons with disabilities, parents (Ms. Yvonne Smith, Ms. Ingrid Frank, Ms. Pam Smith, Mr. Anthony Bascom, Ms. Easter Bascom, Mr. Vishnu, Mr. Winston Swapan and others)
- October 28 Visit to CBR programme in West Coast Berbice (region 5) – home visits to persons with disabilities (Ms. Darshini, Maurice Daniels, Thiona Merey, Ms. Alexander & Mr. Lloyd), visit to CBR recourse unit at community centre Lovely Lass and meeting with coordinators, old volunteers, group of new volunteers, persons with disabilities, parents, president of DPO and rehabilitation assistant (Ms. Gloria Lindo, Ms. Iris Cully, Ms. Lalita, Mr. Banarasi, Ms. Sheling, Ms. Elisabeth, Ms. Wandara, Ms. Rohini, Mr. Chandrapaul, Mr. Ramnauth, Ms. Veronica, Ms. Evelyn, Mr. Mark Archibell, Ms. Sharon, and others)
- October 29 Rest
- October 30 Journey to Lethem – Rupununi (Region 9), meeting with Mr. Jude Isaac, coordinator at Sandcreek, visit to Lethem hospital and meeting with Dr Aidoun
- October 31 Journey to Potarinau village, visits to nursery and school, meeting with disabled children in the school, meeting with teachers (Ms. Julie Thomas, Ms. Jane Rodrigues, Ms. Nita Isaac, Ms. Forna Isaac, Ms. Mary Anne, Mr. Ciril, Mr. Generis and others); journey to Sand Creek village, meeting with Tushaw (village head), meeting with persons with disabilities and parents at the Sand Creek hospital (Ms. Marvis, Ms. Mary, Ms. Wiannicia Winters, Mr. Ernstein Spencer, Mr. Dixon Spencer, and others), journey back to Lethem
- November 1 Discussions with Mr. Terrence Dhamy (coordinator income generation activities National GCBRP)
Journey Lethem to Georgetown
- November 2 Meeting with Ms. Janice Jackson, trainer and member of Circle of Friends of CBR
Meeting with Ms. Leila Eastman, Administrator, GCBRP office
Visit to CBR programme in East Coast – visit to a nursery school and meeting with headmistress (an old ex-volunteer of CBR); meeting with Ms. Doodhmattie Singh, regional education officer; visit to another nursery school, meeting with headmistress Ms. Ionie Chattoor (also CBR coordinator), meetings with disabled children and parents (Ms. Nirmala Praseud, Mr. Balmitra Dharmalingam, Mr. Haresh Ryan, Mr. Kishen Randael, Mr. Dennis Masalamani and others); visit to East Coast hospital and meeting with Dr. Leslie Carter and nurse Jean Frasier; visit to Ms. Patricia Williams at Leonard Cheshire Home, member of DPO; home visit to Ms. Jennifer Summers, beneficiary of loan for chicken rearing; visit to East Coast resource centre and meeting with coordinators, volunteers, DPO representatives, disabled persons, parents (Ms. Shirley Singh, Ms. Patricia Malay, Mr. Shelton, Ms. Mabel, Mr. Himel, Ms. Nicola Alichand, Mr. Providence, and others); visit to new volunteers training programme

and meeting with students (Indrani Shahav, Amba, Jocelyn, Michael Pastor, Nina Bacchus, Norma, Stanely and others).

- November 3 Visit to CBR programme in New Amsterdam and Corentyne (Region 6), meeting with Natalie Ramotar, teacher for deaf children and trainer for CBR; home visits to persons with disabilities (Luk Ram, Charles Sanders, Shalini, Parvati and Joel Mandal); visit to resource unit of Corentyne and meeting with coordinators, volunteers, rehabilitation assistant, persons with disabilities, parents, representatives of DPO, teacher for literacy unit (Ms. Norma Cummings, Ms. Sharon, Mr. Andrew, Mr. Berty, Ms. Carmen Davis, Ms. Jane, Ms. Myrna Trotman, Ms. Meylene Welch, Mr. Rod and others).
- November 4 Meeting with the National Committee of GCBRP
- November 5 Final meeting with Ms. Geraldine Mason Halls, National Advisor of GCBRP and Mr. Gregory Glasgow, President of National Committee of GCBRP
- November 6 Departure from Georgetown
- November 7 Arrival in Bologna and end of mission

Map of Guyana and Places Visited By the Consultant during the Impact-Assessment (Marked with red dots)



Persons with Disabilities Involved in CBR Activities in Guyana in 2006

		CBR ACTIVITIES REPORTING FORM										
		Project Number		Project Name/Country						Year		
		3.24.90.02		GUYANA						2006		
TOTAL POPULATION COVERED BY PROJECT:												
2. PERSONS WORKING FOR CBR ACTIVITIES AT COMMUNITY LEVEL												
										M	F	TOTAL
2.1 Disabled persons or family members as community volunteers										12	16	
2.2 Other community volunteers										15	72	
2.3 Community Health workers										9	36	
2.4 Local schools teachers										15	45	
2.5 Social workers										1	6	
2.6 Doctors, nurses, physiotherapist and other professionals										2	15	
2.7 Other community level workers										2	9	
TOTAL										56	199	255
3. ALL DISABLED PERSONS DIRECTLY BENEFITING FROM THE PROJECT ACTIVITIES												
Type of Impairment	Children				Young Adults		Adults		TOTAL		GRAND TOTAL	
	Age 0-5 Yrs.		Age 6-15 Yrs.		Age 16-35 Yrs.		Age +36 Yrs.		M	F		
	M	F	M	F	M	F	M	F	M	F		
Visual	5	6	3	5	0	0	19	21	27	31	58	
Hearing & Speech	8	9	11	9	27	33	9	11	55	62	117	
Physical	7	8	6	7	15	15	41	50	69	80	149	
Leprosy												
Convulsions												
Mental illness												
Intellectual	6	9	5	6	12	17	19	17	42	49	91	
Multiple/others	7	6	5	5	11	7	13	16	38	34	70	
TOTAL	33	38	30	32	65	72	101	115	229	256	485	

Terms of Reference for Impact Assessment

AIFO/Italy came in contact with Guyana CBR programme in 1989 and the first collaboration started in 1990. In this period, twice the project received co-funding from European Commission, while in the remaining periods, AIFO's support to CBR programme came exclusively through its own resources.

Over the past decade and a half, CBR programme in Guyana has received lot of recognition at international level. The programme had been object of different studies, verifications and evaluation visits. Programme run initially under National Committee of Rehabilitation was taken by Guyana CBR Committee. Programme is also characterised by varying degrees of collaboration with Government of Guyana for some specific activities.

Considering this long collaboration, the Board of Directors of AIFO has asked it to carry out a visit for assessing the impact of Guyana CBR programme focusing on its achievements. At the same time, the visit should provide indications about future directions of collaboration with AIFO.

For this purpose a mission of Dr Sunil Deepak from the Scientific Activities department of AIFO/Italy is planned in Guyana for a period of two weeks in October 2006 (probably from 8 to 22 October 2006).

Issues for the visit of Dr Deepak

Dr Deepak's visit will focus on four main areas:

- Impact of CBR programme on persons with disabilities and their families - This will look at number of persons who have benefited from the CBR programme in the past decade and a half, kind of persons who have benefited, their socioeconomic status, their kinds of disabilities, severity of disabilities, kinds of benefits received, etc. This will be done by looking at project reports, records and registers, kind of data collected by GCBRC, meetings with disabled persons (adolescents and adults), meetings with parents of disabled children.
- Impact of CBR programme on the communities - this aspect would be useful to know the opinions of volunteers, community leaders, authorities, schools, partners, etc. about impact of CBR programme.
- Impact of GCBRC - what kind of organisation is GCBRC, how do its partners in Guyana see it, how vital, robust and participatory it is, where does it see itself going, etc.
- What are views of stakeholders of Guyana CBR programme about its future directions of development.