Lessons learned on inclusion of people with disability in the ICCO Gaibandha Food Security project for Ultra Poor Women

Paulien Bruijn

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Center for Disability in Development
ICCO Kerk in Actie
The Leprosy Mission International Bangladesh
The Leprosy Mission International England & Wales
The Leprosy Mission International Netherlands
LIGHT FOR THE WORLD Netherlands

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Listen to the story of Molida & Hena

Five years ago, Molida and her sister Hena were selected by a fieldworker to be participant of the Food Security Project for Ultra Poor women in Gaibandha district. Together with the other beneficiaries in their village, they formed a women group. In the women group they received training on healthy food, how to start their own vegetable garden, and how to generate their own income. Molida and Hena both have a hearing impairment, so communication with their group members is not always easy. But with the help of a community member who is able to speak the local sign language, they are able to come along very well. At the beginning of the project Molida and her sister, who live in their brothers house, received a couple of chicken. They did very well and soon were able to eat and sell eggs and give a few hens to another group member. In return they have both received a goat from another beneficiary. With the profit they made, they were able to rent a plot of land and started growing pumpkins. Their group members helped them to convince the owner to rent the land to them. Besides that, they also started keeping ducks. Molida and Hena are very happy with their own income, they are no longer fully dependent on their brother.

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Why inclusion of people with disabilities?

Poverty creates disability and disability creates poverty. People with disabilities are often among the poorest of the poor. The World Bank estimates that disabled people make up to 15-20% of the poor in developing countries. In Bangladesh most people with disabilities live in the rural areas. The most vulnerable are women and children with disabilities. The prevalence of disabilities in children below 18 years can be estimated to 6% and for the age group above 18 years the prevalence to about 14% or corresponding to 3.4 million children with disabilities and 10.2 million adults with disabilities in Bangladesh. While in dire need of assistance, people with disabilities, and sometimes also their families, are often excluded both from their communities and from development initiatives. The result is that people with disabilities sink deeper into poverty.

The reason why people with disabilities often do not participate in development projects is not their impairment or functional limitation. Inadequate policies, negative attitudes and lack of accessibility often prohibit their participation. The WHO World Report on Disability (2011) addresses this problem and calls for inclusion of people with disabilities in mainstream programmes:

"People with disabilities have ordinary needs – for health and well-being, for economic and social security, to learn and develop skills, and to live in their communities. These needs can and should be met in mainstream programmes and services. Mainstreaming not only fulfills the human rights of persons with disabilities, it is also more effective"[i].

According to WHO, people with disabilities have poor health outcomes, have lower educational achievements, are less economically active and experience higher rates of poverty. It needs no further explanation why this group of people should be included in a food security project that aims to reach ultra poor women and their households.

The UN Convention on the Rights of Persons with Disabilities that came into force in 2008, obliges states, but also development organisations to include people with disabilities in all development programs (article 32) and humanitarian relief (article 11).

The Char Livelihood Programme in Bangladesh has done a research on health and disability and their findings also underline the importance of inclusion of (households with) disabled persons in livelihood programmes, especially when they focus on women headed households. They conclude:

"Food insecurity is higher amongst households with a disabled head, as shown by their greater dependency on food coping strategies." [ii] They also mention that the *"Incidence of disability in female-headed households was nearly threefold that of male headed households, whilst disability incidence in males was slightly higher than amongst females."*

FSUP Gaibandha project

Inclusion of persons with disabilities and leprosy in mainstream development programs is a relative new concept in development. This new trend is a result of the ratification of the UN Convention on the Rights of Persons with a Disability, which underlines the rights of persons with disabilities to be enrolled in development programs. The Gaibandha Food Security Program is one of the first programs that mainstreams disability on a large scale. The project is implemented by seven local partner organizations (RDRS, GBK, UST, GUK, CDD, CCDB and TLMB) and supported by ICCO Kerk in Actie, The Leprosy Mission Netherlands/England & Wales, Light for the World, the Netherlands. The European Union is funding the project for 80%, while the Northern partners contribute the remaining 20%.

The Food Security Project in Gaibandha was implemented in order to improve the food security situation of 40.000 women headed households. The 40.000 direct beneficiaries are organized into 1600 women groups. The women groups together form a federation. The women received training and assets to perform their own income generating activities (IGAs). They also received inputs to start their own homestead gardens. The IGAs range from chicken, goat and beef rearing, to tailoring, shop keeping and fishing. The Heifer principle is used in this project, so each women has to give off-spring from the received animals to another group member. By using this principle, all group members will get two different IGAs during the project. Next to the income generating activities, the women received training on health and hygiene, disaster preparedness, but also on how to get access to government safety nets. A disability and leprosy team provided health education to the women groups about the prevention, detection and treatment of disability and leprosy. The team also provided rehabilitation services to the beneficiaries and the family members with a disability.

When the project was designed we aimed to include at least 20% households with a member with a disability. Based on the information available in august 2013, 21,4% of the households in the project have a disabled member. This is more than the target of 20%. The high incidence of disability amongst the target group is not a surprise. There is a strong link between disability and poverty. People who live in poverty are more vulnerable to get a disability. From the stories of the participants becomes clear that many of the disabilities could have been prevented by an early and appropriate treatment. Lack of money and lack of information are often the reason for a late and inappropriate treatment.

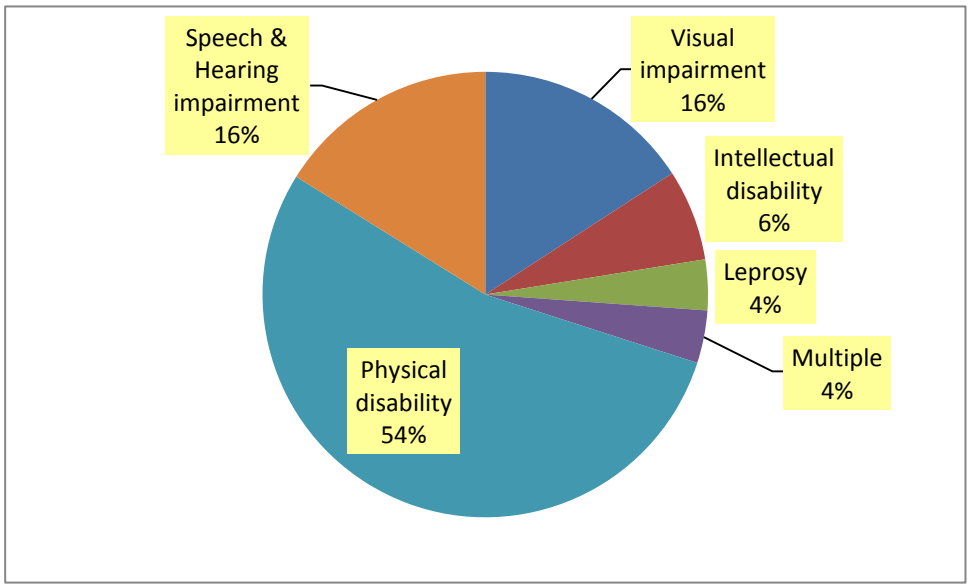
Table 1. Support provided by the disability/leprosy team – up to august 2013

	People with a disability	People with minor impairments or treatable diseases	**totals**
Direct beneficiaries	3792	3207	**6999**
Family members	4781	877	**5658**
totals	**8573**	**4084**	**12657**

9,5% of the direct beneficiaries are women with disabilities (3792). The direct beneficiaries are the women who participate in the women groups and are enrolled in the income generating activities.

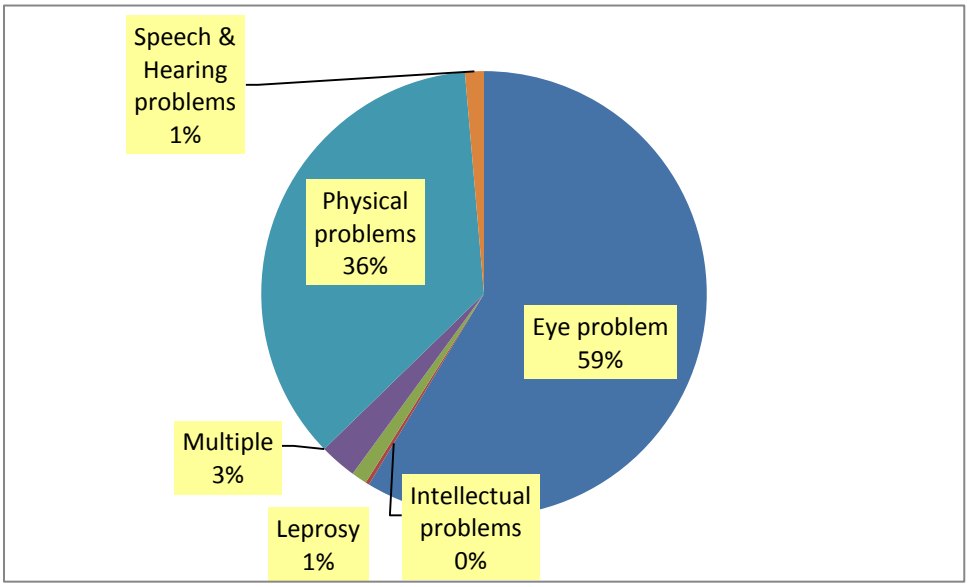
Not all people who were assessed by and received services from the disability/leprosy team have a disability. Some of them only have minor impairments or treatable diseases. So in the table below we make a distinction between people who have a disability and the people who received services, but do not have a disability according to the definition of the WHO.

Figure 1 Type of disability



The most common type of disability in the project are physical impairments (54%). 16% of the people with disabilities have visual impairments and 16% of the people have speech & hearing impairments. People with intellectual disabilities only constitute 6% of the total.

Figure 2 Type of health problems of the people with minor impairments or treatable diseases



From the people with minor impairments or treatable diseases, 59% had eye problems. Many people with cataract underwent an eye operation and got their vision back. Also quite some people received glasses, which greatly helps people to perform their daily activities. In this group there are also a lot of women who received physiotherapy for chronic low back pain.

Lessons learned from disability mainstreaming

In April 2013 an internal evaluation took place on the disability mainstreaming process within the FSUP Gaibandha project. This report reflects the lessons that we have learned about disability mainstreaming so far. The report follows more or less the chronological order of the project cycle. In September a study will take place on IGA & disability, focusing on the relation between disability and the selection and performance of the beneficiaries in their IGAs. Besides that, we are still finishing a study on the impact of the project on the households with a disabled family member, where we look more into the stigma, social inclusion and empowerment of people with disabilities. By the end of the year the information from the three studies will be put together in a bigger publication.

Summary of the lessons learned about mainstreaming disability in the FSUP project

1. Invest in building up disability mainstreaming networks long before any call for proposals is expected.
2. Inclusion starts right at proposal writing! It is unlikely to expect that people with disabilities will automatically be included in a project if there are no specific strategies formulated in the proposal to enhance their equal participation.
3. Make sure that your selection criteria do not exclude people on the basis of age or disability.
4. Inclusion of people with disabilities isn't very costly. But you have to reserve budget in advance.
5. Having accurate data on disability during proposal writing is essential to make a good planning for your project. All data collected should be disaggregated for people with disabilities; otherwise it will be impossible to measure equal participation. Include disability inclusion indicators in the M&E framework right from the beginning.
6. Training of staff is the most crucial part of the inclusion process, because the major barrier that prevents people with disability from participation in projects is the attitude of development practitioners
7. Accessibility needs to be taken into account in all aspects of the programme, right from the beginning. Undoing inaccessibility later on is more costly and less efficient.
8. There's no need to organize special training for people with disabilities. The women with disabilities could participate in all income generating activities and reached the same results as beneficiaries without disabilities.
9. Make sure people with disabilities have access to disability specific services, such as physiotherapy, medical care or assistive devices. Refer to other service providers or hire specialists who can provide these services within the programme.
10. Don't forget that the provision of rehabilitation services is only one aspect of the inclusion process. Social inclusion and the removal of barriers within the project and society is equally important.
11. Sensitization of the women groups on disability and Leprosy is important for the social acceptance of the women with disabilities and leprosy in the group.
12. Inclusion of people with disabilities is not a one time activity in a single project. It can only be sustainable if organisations incorporate the inclusion of people with disabilities throughout all programmes and incorporate it in the systems and structures of their organizations.

Consortium development

The FSUP project was jointly developed and implemented by one British and three Dutch Development NGOs and their 7 local partner organisations in Bangladesh, each NGO with their specific task and role: ICCO and it's partner organisations had a lot of experience on food security, income generation & women groups; TLM and their local partner brought in expertise on leprosy, disability specific service delivery and health education; and Light for the World and their local partner CDD brought in knowledge and skills on capacity building for inclusion of people with disabilities. Before the call for proposals came out, the three Dutch Development NGOs already worked together within a bigger alliance. So mutual trust was already established and a basic understanding on inclusion of persons with disabilities was already present within the consortium. This was a prerequisite for developing such a joint proposal, as it would not have been possible to form a consortium from scratch and develop a joint proposal in the short period of time that was available after the call came out. Therefore if organisations wish to join or form consortia, in order to facilitate the inclusion of persons with disabilities, we advice them to invest in building up disability mainstreaming networks long before any call for proposals is expected.

The consortium made it possible to include people with a disability (including leprosy) in this huge food security project, proving it to be an effective way to mainstream disability. Most development organisations don't have the skills and knowledge to meet the needs of people with disabilities, therefore the involvement of TLM, Light for the World and CDD added value to the experience and capabilities of the other organisations involved. Conversely disability-specific organisations do not usually have the capacity to implement such large scale development programmes alone and may lack sectorial expertise. So the cooperation between disability-specific organisations and mainstream development NGOs in this way has been proven an effective way to ensure access of persons with disabilities to development initiatives.

The practice of consortia in social development interventions is relatively new, so there were some initial misunderstandings and tensions over power relations; not surprising considering the local NGOs had previously seen each other as competitors. It took until the second year until really good working relationships were in-place between the different Bangladeshi implementing partners and project implementation was proceeding efficiently. Although some of these issues will be lessoned among consortia partners that have had previous experience of working in a consortium. When developing a consortium, it is therefore important to be very clear about the roles and tasks of each organization, as well as mechanisms and frameworks for working together. In the case of disability mainstreaming it is important thatall partners need to understand that the inclusion of people with disabilities is an integral part of the project and is a joint responsibility.

When two organisations bring in a similar kind of expertise, such as knowledge on disability and on leprosy, as did TLM-Bangladesh and CDD within the FSUP, there is potential for duplication and confusion, so the definition of efficient and clear task divisions is important before the project starts. In a new project we would make a clearer distinction between disability specific service delivery and the capacity building activities that are needed to mainstream the topic, such as staff training and community awareness.

Proposal writing

The call for proposals that was given out by the European Union for the FSUP project did not specifically mention the inclusion of people with disabilities, for five years ago this was not yet common practice amongst institutional donors. The ratification of the UN Convention on the Rights of Persons with disabilities encouraged institutional donors to specifically ask for the inclusion of persons with disabilities in their calls. However, even without being explicitly mentioned, the inclusion of persons with disabilities easily fitted within the guidelines for applications, as they stated:

"The overall objective of the Food Security programme 2007 in Bangladesh is to improve food security in favour of the poorest and the most vulnerable and contribute to achieving the first Millennium Development Goal (MDG). (…) *The programme is designed to support innovative interventions targeting the most disadvantaged ultra-poor to overcome the root causes of poverty and food in-security in a sustainable manner, taking into consideration the reduction of long term risks*."

Despite the absence of disability inclusion criteria in the call for proposals, it was no problem to accommodate the inclusion activities and budget in the proposal. Some organisations are reluctant to include disability in a proposal if the donor does not ask for it, because they are scared that their proposal is not competitive enough. This fear is often unjust. In our case the EU highly valued our efforts to include this marginalized group when they appraised our proposal.

ICCO's FSUP is one of four projects that make up the EU's FSUP programme. The implementing agencies of the three other projects are WFP, CARE, and Islamic Relief. The Gaibandha FSUP project is the only project that actively included people with disabilities. There is no data available about the exact number of people with disabilities who participated in these other projects, but the numbers are low according to the people involved. WFP evaluated their FSUP project and concluded:

"Exclusion criteria actively prevented the selection of women over the age of 49 years, and selection practice prevented the participation of the majority of disabled or chronically ill women."[iii] To prevent this kind of exclusion WFP Bangladesh advises to *"Incorporate strategies to identify and provide additional support for disabled, chronically ill, and other vulnerable women in the project plan."*

The WFP lessons learned report commended the approach of the Gaibandha FSUP, but it is an opportunity lost that only one out of four project of the FSUP programme included a significant number of people with disabilities. If people with disabilities would have been specifically mentioned in the guideline for applications this would not have been the case, as it would have encouraged all the applicants to actively include them and to collect data on their inclusion. Excluding people with disabilities is usually not a matter of ill-will, but more often a matter of overlooking a group of people. A proactive approach by institutional donors would greatly stimulate the inclusion of this marginalized group of people in all kinds of development projects, but even more importantly in food security and safety net programmes, which are designed to reach the poorest and most vulnerable people of society.

A good comparison to a project that did not specifically seek to accommodate people with disabilities as did the Gaibandha FSUP, but that did do a survey on health and disability amongst their beneficiaries, is the *Char Livelihoods Project (CLP)* funded by the British (DFID) and Australian

(AusAid) Governments. Like FSUP it also focused on providing livelihoods to ultra-poor people in the North Bengal region of Bangladesh including riverine areas of Gaibandha District. The project didn't formulate equal participation measures, but only adopted a policy not to exclude people with a disability. The outcome is that only 3% of their direct beneficiaries were people with a disability.[iv] This is a significantly smaller percentage than achieved under the FSUP Gaibandha project where 9,5, of the women participating in the women groups have a disability .

The lesson that we draw from this is, that it is unlikely to expect that people with disabilities will automatically be included in a project if there are no specific strategies formulated in the proposal to enhance their equal participation. Inclusion starts right at proposal writing!

Selection criteria

Beneficiary selection criteria for development projects often implicitly or sometimes explicitly exclude people on the basis of age or disability, as was also illustrated by the quote from the WFP Bangladesh report above. Within the FSUP Gaibandha project we deliberately choose to include elderly women and women with disabilities, so we made sure that the criteria were not excluding them. However, after the second year we needed to broaden the admission criteria to make sure more women with disabilities, with leprosy or women with a disabled husband could be enrolled. This amendment was needed, as although very vulnerable ultra-poor, they were not necessarily women heading a household. Many women with disabilities are fully dependent on their families and never got the chance to start their own family or household. Additionally, women with a disabled husband were initially excluded because they are not women who are nominally heading the household, but they are functionally heading the household, for the husbands with a disability were usually either unable to gather any or sufficient income. So practically the women with a disabled husband were in the same situation as the single women heading their households. The criteria regarding women with leprosy or women with a husband with leprosy was also relaxed so that ultra-poor within these categories were fully included within the project.

It is not suggested that having a disability or a disabled husband (or other family member) should automatically lead to enrolment in food security programmes, as some people with disabilities are actually economically comfortable. However, when enrolling beneficiaries economic status should not be the only criteria; but social status, level of participation in the community, position in the family/household and the resilience of person with a disability (or the caretaker of the person with a disability) should also be considered. One should also take the extra (health) expenses into account that people with disabilities often have to make. To prevent problems with enrolling persons with disabilities in programmes, it is suggested that a clause be added to the selection criteria that states that people with disabilities (and caretakers of disabled people) get priority to participate in such projects and that selection criteria will be used more flexibly to ensure equitable participation of people with a disability.

Beneficiary selection process

Apart from discriminating criteria, people with disabilities are often further excluded from development programmes by the beneficiary selection practices. As project staff or communities

often use unofficial criteria when beneficiaries are selected: such as "ability to learn", or "fit enough to generate income". .People with disabilities are often considered not able to meet these levels. Disabled people themselves frequently internalize the message that they can't perform and do not consider themselves as potential project beneficiaries. The WFP lessons learned report also mentioned this problem:

"Disabled and chronically ill women were not excluded specifically by selection criteria, but selection practice, and even self-exclusion played a role." Project staff were told by some community members that certain individuals were ultra-poor but "not in a position to manage an IGA". Project staff themselves only considered disabled women who were deaf/dumb or had some mental disabilities. Despite this, all staff reported that they felt there was scope for other women with disabilities to participate in similar projects if they were provided with the support to do so.[v]

Even within the FSUP Gaibandha project, where inclusion of persons with disabilities is a prominent part of the programme, some problems were encountered at the beginning of the selection process, with few project staff reporting that they were using the unofficial criterion "ability to learn". The only way to overcome such problems is to make sure that all the project staff are trained on the rights and abilities of persons with disabilities, before they start selecting project beneficiaries (see staff training below for further discussion).

Planning and budgeting for inclusion

People often think that inclusion of persons with disabilities in development projects will be very expensive and is frequently given as a reason for excluding this group of people. However, existing literature estimates that the extra costs of including people with disabilities is only between 1-7% of total project costs. Within this food security project the costs of inclusion of persons with leprosy & disability are 6%[vi] of the total project budget. This amount falls within the mentioned range, but is relatively high as in this project rehabilitation services were provided not only to project participants, but also to their household members that had a disability. In projects where people are referred to other service providers for their rehabilitation needs, the costs can stay lower, around 1-3%, for then the only extra cost incurred will be for training of staff and for making project activities accessible.

When preparing the budget, organizations should be aware that providing rehabilitation services can create a lot of extra, unforeseen demand. Although very legitimate by nature, this needs to be anticipated in terms of flexibility in staffing and resources. Having accurate data on disability during proposal writing is essential to make a good planning for your project. Triangulation of data on disability & leprosy during proposal writing is very important to set realistic targets. We assumed that there would be many more people with leprosy, but this was not the case, so we needed to adopt our planning & budget later on. On the other hand the need for eye surgeries was much higher than initially anticipated. If reliable data are not available before hand, it is important to collect good baseline data early in the project. This can be done by an early diagnosis of all people with disabilities enrolled in the project. If these data are available it is possible to plan according to the real need.

Prerequisite is that organisations and donors are flexible in changing the budget division after the first year. The provision of rehabilitation services should always be demand driven and not target driven.

Monitoring inclusion

Including specific and holistic disability indicators in the M&E framework is an important step in the disability mainstreaming process. All the data collected should be disaggregated for people with disabilities; otherwise it will be impossible to measure equal participation. The collection of disability data from the FSUP project has been a struggle at times. This is not merely about the logistics of actual collection of data but also about how disability is defined, and who should be included within the category of 'people with disability? We learned that everything starts with a clear definition of disability and a good assessment of the people with disabilities. It is also important to record the severity of the disability, and to have indicators to measure the inclusion process.

In retrospect under the Gaibandha FSUP there was too little focus on the monitoring of the inclusion process. Indicators to measure inclusion were not developed, or developed too late. For example the Group Development Agents could have been more involved in the monitoring of the inclusion process within the women groups. This should have been included in the design of he M&E framework. Then staff could have been trained to collect the data right from the beginning. We also paid too little attention to the monitoring of the disability mainstreaming process at project and organisational level. When the FSUP project started disability mainstreaming was a very new topic, we simply were not aware what areas should be monitored. With the experience we have now, it is much easier to set up a sound monitoring framework.

Overall, we have learned from the FSUP project that the M&E framework for inclusion of people with disabilities should be clear right from the beginning and should be an integral part of the overall m&e framework. Disability should not be an add on to the existing framework, but disability and inclusion should be truly mainstreamed.

Capacity building for inclusion

Training of staff is the most crucial part of the inclusion process, because the biggest barrier that prevents people with disability from participation in projects is the attitude of development practitioners. People with disabilities are often overlooked in the designing of development projects and not considered as part of the target beneficiary group.

The project staff of the FSUP Gaibandha project admit that when they started working for the project, they were sceptical about inclusion of people affected by disability. They report that they thought it would be difficult to include them and that people with disabilities would not be able to generate their own income. After training however, the staff were motivated to work on inclusion and after having seen the good results of the inclusion process, they were really convinced of the capabilities of persons with disabilities. Staff training should include the following topics: understanding the concept of disability, rights and capabilities of persons with disabilities, how to remover barriers that block participation, and clear instructions on their role in the disability mainstreaming process.

In the FSUP project we started with training the field workers and trained the higher management at a later stage, but in retrospect it would been better to start with training the higher management right at the beginning of the project, as it is very important that they are able to support the fieldworkers in the inclusion process. We also learned that staff training is needed throughout the whole project period in order to refresh their knowledge and to deal with staff turnover. Furthermore ideally the project proposal writers should be already trained on disability before they even start designing a project, for this will enable them to remove the barriers that block inclusion of

persons with disabilities at the design stage. It is recommended that organisations who are willing to include people with disabilities in their projects, should organise a short training workshop on disability mainstreaming for higher management and proposal writers, even before a call for proposals comes out. As once a call comes out, time is too limited for training workshops.

Considering the FSUP overall program, with four projects being implemented simultaneously while only one project specifically designed for disability mainstreaming, the opportunity to exchange best practices to address disability issues in the other projects has been underutilized. We hope this publication will make up for this pitfall.

Inclusion in all project activities

The direct beneficiaries of the Gaibandha FSUP project were organized into women's groups where they received training and developed income generating activities. The field workers of the project, called group development agents (GDAs) played a crucial role in the inclusion process. They have sensitized the women in the women's groups on disability and made sure the women with disabilities were included in all women's group activities. The GDAs referred the beneficiaries with disability specific needs, to the disability and leprosy agents, who provided these services within the FSUP project. The GDAs were also involved in the non-technical follow up of the clients with a disability, such as monitoring the use of their devices and the progress with their income generating activities.

Social acceptance in women groups

Sensitization proved to be important for the social acceptance of the women with disabilities in the group. 'Name calling' was a particular problem at the beginning of the project, but this improved after the orientation on disabilities. For some women with disabilities it was the first time that they were addressed by their names in the community and not by their disabilities. The social acceptance of the women with disabilities in the group was not a problem. They request to be treated like everyone else and receive assistance from their group members where needed. The election of women with disabilities as group leaders and even federation leaders were a good indicator of increased social acceptance, also the women affected by Leprosy were accepted in the groups and able to participate on an equal basis. We didn't notice a difference in stigma between people affected by leprosy and people affected by other type of impairments. More information about stigma and social inclusion will be provided in the impact study.

> *"Sukina, a women with spinal deformity, is chosen by the other member of the group as a leader because she can speak and understand very well and better than other beneficiaries. (..) At the beginning she got a lot of attention because of her disability, but now the focus is on her because she is a good leader."*
>
> Polin, Group development Agent

Inclusion in income generating activities

The women with disabilities received the same kind of income generating activities, as women without disabilities. However, they received priority for the shop keeping & tailoring, since these trades are considered very suitable for people who have difficulties in taking care of animals or doing farm work due to physical limitations. The success for women with disabilities in income generation were found to be equal to the success rates for women without disabilities. Some GDAs even reported that women with disabilities were more serious about their IGAs and are able to achieve better results than women without disabilities, because they did not want to ruin the only chance that they had received so far. Where women with communication or learning difficulties needed support in some aspect of managing their IGAs, the FSUP involved family members or neighbors in the trainings. This worked very well, because the family members can effectively support the women with disabilities in performing their income generating activities.

> *"Before Sukina got the IGAs she had troubles with her husband and her children but when she became a beneficiary in the group and she got hens and chickens then children started thinking: "my mother can do something" and Sukina's husband saw that Sukina was earning. So the relationship changed a bit. But since she got the second IGA and since she is doing very well in her small shop, now she is not only respected and seeing as smart by the children and husband but by the whole village."*
>
> Polin, Group development Agent

Earning own income proved to be a very empowering exercise for women with disabilities. They are often seen as a burden to the family, but once they are able to contribute to the family income they get a more respected place in their families and communities. So the income generating activities did not only improve their economic status, but also their social status and their self-confidence.

A separate study on IGA and disability will be carried out by the FSUP project shortly, which will provide more quantative data about the results of the women with disabilities in doing their IGAs and will also help us to learn from the IGA selection process.

Inclusion in Disaster Risk Reduction

Disability was also included in the Disaster Risk Reduction activities and the water and sanitation services of the project. In case of floods or other emergency situations, people with disabilities are often forgotten and left behind. This is not only a very dangerous situation, it is also traumatizing for people. So when the communities prepared their evacuation plans and conducted evacuation drills, they also paid attention to the evacuation of people with disabilities. Flood shelters, latrines and tube wells were made accessible for people with disabilities, with access ramps up to the shelters. Some federation leaders with disabilities were also member of Disaster Management Committees that were formed. This is a good example of where people with disabilities' needs can be addressed without extra costs due to its consideration in the design phase of the project.

> *"Years ago the water rose even at our home. I stayed for the whole day inside the house. I kept on waiting until they came to help me out. It is better to die, than remembering those times".*
>
> Sobita, project beneficiary with a physical disability.

Accessibility

One of the barriers that prevent people with disabilities from participation are environmental barriers, such as: inaccessible buildings, offices, latrines, and flood shelters. For people with hearing or visual impairments, sometimes information is not accessible. If disability is mainstreamed in a project, these barriers need to be removed. During the design phase of the Food Security Project, not enough attention was paid to accessibility. This resulted in offices and flood shelters that are inaccessible for people who are using wheelchairs. This could have easily been prevented by using Universal Design standards during construction works. CDD also has developed a disability friendly design for flood shelters, housing and toilets.

> *I have seen a flood shelter with an access ramp which would be too steep for a wheelchair user to go up without assistance. The adjacent toilet was of the squat type, without any room to put in a movable toilet chair. The toilet was also not attached to the flood shelter meaning someone who wished to use it during a severe flood would need to go down the steep ramp, through the water and up the steps. This is regrettable for an attempt was made to make shelters accessible but they did not always attain the required standards. Better designs were available, but these were not circulated at the beginning of the project.*
>
> James Pender, Programme manager, TLM England & Wales.

More could also have done to provide training materials in accessible formats. So, an important learning point is that accessibility needs to be taken into account in all aspects of the programme, right from the beginning. Undoing inaccessibility later on is more costly and less efficient.

Disability specific service delivery

When people with disabilities are included in development programmes, automatically the demand for disability specific interventions, like physiotherapy or assistive devices, comes up. Generally, there are two ways to respond to these needs: organisations can refer beneficiaries to other service

providers or they hire specialists who can provide these services within their own programme. The first option fits well for small projects in areas where these services are available and affordable. In the context of Gaibandha, service delivery within the project was the best option, because there were no large scale disability specific services available at that time in most locations.
As a result of lobby and advice from CDD, the government of Bangladesh is currently setting up disability resource centers in Gaibandha and in other locations throughout the country. So in future projects it may be possible to link to government facilities for disability specific service delivery.

When starting a disability inclusive project the sustainability of the disability specific service delivery needs to be taken into account right from the beginning of the project. Because continued access to rehabilitation care, after the project has ended, is really important for people with disabilities. People should know where to go when their wheelchair breaks down, and where to go if they are in need of more physiotherapy. So in the design phase already an exit strategy needs to be formulated. In the case of the project in Gaibandha the government disability resource centers will take over and both CDD and TLMIB remain active in Gaibandha district the coming years.

Within the FSUP Gaibandha project, service delivery was done by the Leprosy and Disability Agents, the Disability Agents and Physiotherapists of TLMB and CDD team. This team assessed the beneficiaries with impairments and decided what kind of assistance would be needed for them. It is important to note that not all people with disabilities are were need of rehabilitation services or devices. For many people with disabilities could participate in the project without any disability specific interventions. However, there is always a group of people who can really improve their functional abilities by physiotherapy, medical treatment, or who can improve their mobility with the help of devices. In some cases, people can even fully recover from their impairments. The provision of these services can have a very positive influence on the performance of peoples' income generating activities. However, it should always be taken into account that the provision of rehabilitation services is only one aspect of the inclusion process. Social inclusion and the removal of barriers within the project and society is equally important.

Alam, the husband of Shevali, got injured long time ago playing football. He hurted his spinal lumbar. At that time he ignored the pain, but the pain started to get worse with the time. After 15 to 20 years he slowly lost his movement in his legs completely. Alam has got physiotherapy from the project. Shevali got also a training on how to give her husband physiotherapy. Alam is completely cured and he can move like every ordinary man. "I never have thought that my husband will ever be able to stand and now he is pulling riksha in Dhaka"

Shevali, project beneficiary

From the design of the project until the last day of implementation, it is important to communicate to the staff and to beneficiaries that the rehabilitation services are a means to an end. The services are provided to enable the beneficiaries to improve and support their economic situation and their social inclusion. The rehab services should not become a goal in itself, it should always be supportive to the overall goal of the project.

Leprosy

Within this project there was a lot of attention on people affected by leprosy. In the end the number of people affected by Leprosy was much lower than initially expected, although with 910 people a significant number were reached. The main reason for this is that the targets set at the beginning of the project were too high and not underpinned by accurate data. In the last 20 years the Government of Bangladesh and NGOs have been very successful in their fight against Leprosy. The people in Gaibandha are much more informed about the treatment and early detection of Leprosy, and the incidence of leprosy has gone down. In the FSUP project there was a lot of specific attention on Leprosy. In future programmes it would be better to integrate early detection & treatment of Leprosy within the overall disability intervention. Leprosy is a cause of disability and does not necessarily need a different approach than the other causes of disability. However, it is important to make sure that the stigma related to leprosy is addressed in a project and that ample attention is paid to early detection and treatment of Leprosy. In this regards an important output of the FSUP project was the training of the staff of the non-disability focused NGOs in the consortium in the identification of leprosy symptoms allowing them to refer cases as well as better understanding of the disease leading to a reduction of stigma and fear towards people affected by leprosy who were beneficiaries. Furthermore the fact that leprosy affected people were included within a mainstream development programme alongside those with other or no disabilities , in itself helped facilitate inclusion and a reduction of stigma. The acceptance of leprosy affected people within the village federations and within the communities targeted was impressive, for stigmatization and exclusion of people affected by leprosy is still the norm in Bangladesh. In the FSUP project we didn't notice a difference in stigma between people affected by leprosy and people affected by other type of impairments.

Sustainability of disability mainstreaming

Inclusion of people with disabilities should not be treated as a one time activity in a single project. It can only be sustainable if organisations incorporate the inclusion of people with disabilities throughout all programmes and incorporate it in the systems and structures of their organizations. Starting with inclusion in one project however, can be a good starting point for organisations to mainstream the topic throughout their whole organization. The organisations who implemented the FSUP Gaibandha project are now very motivated to include people with disabilities in their other programmes as well. This is another benefit of the consortium as the training and example presented to the staff of other NGOs by TLM-Bangladesh and CDD, has helped them to understand the importance of including people with disability within their interventions. This could be further maximized through a short capacity building programme for the management of the implementing organisations, focused on disability mainstreaming at organisational level.

The FSUP Gaibandha project will end by the end of the year 2013, but the federation and the women groups will continue their work to improve the livelihoods of it's members. In the last project year the federation leaders have received extra training to ensure sustainable attention for the needs and rights of people with disabilities. During the trainings the federation leaders for example learned about the safety net structures of the government for people with disabilities and how they can help their members to get access to these provisions.

Endnotes

[i] World Report on Disability. WHO, 2011. Page 264.
[ii] Char Livelihoods Programme: Reducing Extreme Poverty on the Riverine Islands of North West Bangladesh 2010. The Health/Disability Status of CLP Cohort 2.1 Core Participant Households
[iii] Food Security for the Ultra Poor. Lessons Learned Report 2012. WFP Bangladesh. Page 11.
[iv] Char Livelihoods Programme: Reducing Extreme Poverty on the Riverine Islands of North West Bangladesh 2010. The Health/Disability Status of CLP Cohort 2.1 Core Participant Households
[v] Food Security for the Ultra Poor. Lessons Learned Report 2012. WFP Bangladesh. Page 11/12
[vi] Based on the real expenses up to 2012 and the estimated expenses for 2013

For more information please contact Paulien Bruijn:
p.bruijn@lightfortheworld.nl