CBM Australia self-help group enquiry

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What is the self-help group enquiry about?

Developing and supporting self-help groups is a strategy used by many of CBM Australia's field partners. In community based inclusive development, they are seen as a key way of working towards empowerment of people with disability.

This enquiry was initiated to look at the different ways in which self-help groups are being used and supported, and whether there are factors that need to be addressed to ensure that they function well, are inclusive and sustainable.

This is a small-scale enquiry that involved looking at case studies from six partners that employ self-help group development for a range of purposes and in a range of geographical locations. A questionnaire was used by project officers with each of the six selected projects, and the resulting information was analysed by a group from CBMA's International Programs department, with key areas of learning identified from this discussion.

Findings are not comprehensive or conclusive and there is not one model for success. Instead we aim to draw some useful tips from partners' experiences.

What do we mean by self-help groups?

According to the WHO Community Based Rehabilitation Guidelines, "self-help groups are informal groups of people who come together to address their common problems. While self-help might imply a focus on the individual, one important characteristic of self-help groups is the idea of mutual support – people helping each other. Self-help groups can serve many different purposes depending on the situation and the need. For example, within the development sector, self-help groups have been used as an effective strategy for poverty alleviation, human development and social empowerment, and are therefore often focused on microcredit programmes and income-generating activities".[1]

This definition broadly fits with the examples of self-help groups seen in CBM Australia funded field programs, though in CBM's programs groups often have purposes other than livelihood development.

Self-help groups are discussed here as being distinct from disabled people's organisations (DPOs), though sometimes self-help groups may eventually become part of DPOs or be referred to as DPOs when they form networks as part of umbrella organisations. For the purposes of this enquiry we adopt the approach used in the Community Based Rehabilitation Guidelines, where "...self-help groups are considered to be groups that are established locally, operate on an informal basis, and are focused on addressing the needs of their own members, who may include people both with and without disabilities, e.g. family members. Disabled people's organisations are identified as organisations that are more formally structured, and have majority control by people with disabilities. They usually work on a larger canvas, advocating for human rights and influencing policy and resource allocation".[2]

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[1] Taken from Page 37 of World Health Organisation (2010) Empowerment Component: Community based rehabilitation guidelines document (PDF, 3.71MB)
(http://apps.who.int/iris/bitstream/10665/44405/5/9789241548052_empower_eng.pdf)

[2] Taken from Page 52 of World Health Organisation (2010) Empowerment Component: Community based rehabilitation guidelines
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Types of self-help groups in our programs

CBM supports programs involving self-help groups with a variety of different, and often very specific purposes. These include:

- Income generation/ livelihoods access.
- Advocacy and awareness of rights.
- Parent support.
- Mutual social support/ peer support.
- Working in groups for affordable access to medicines.
- Support with implementing individual rehabilitation plans.
- A combination of purposes.

The structure of self-help groups, and what sustainability looks like, will differ according to these purposes. Self-help groups developed by CBM's partners may be disability specific (comprised of people with disability and/or their family members) or also include members of the community without disability.

Examples from the following partners were considered for this enquiry.[3]

Partner organisation	**Location**	**Main focus of self-help groups**	**Disability specific or includes others**	**Linked with other groups**
Good Samaritan Foundation (Tanzania)	Tanzania	Diabetes education, collective purchase of medicines	Includes people with and without disability	No
CODAS Caritas Garoua	Cameroon	Awareness of rights, social support, income generation	Disability specific	No
Centre for Disability in Development	Bangladesh	Awareness of rights, advocacy	Disability specific	Yes
NORFIL Foundation	Philippines	Parent groups for support and advocacy	Disability specific	Yes
Cambodian Development Mission for Disability	Cambodia	Income creation, advocacy for inclusion in local development	Mostly disability specific (occasional exceptions)	Yes (now also trialling agricultural cooperatives)
Nav Bharat Jagiriti Kendra	India	Promotion of rights and economic inclusion	Includes people with and without disability	Yes

[3] Plus one small example used from Parivartan, India, though not included in the enquiry.

Self-help groups: good practice for CBM supported programs

What follows are key considerations to keep in mind when looking at proposed or existing self-help group approaches in our programs. These are things we should be alert to when supporting project planning and implementation, monitoring or evaluating. The considerations are grouped under three areas:

- For self-help groups to function well
- For self-help groups to be inclusive
- For self-help groups' sustainability

As there is obviously overlap, these are loose groupings.

Considerations for self-help groups to function well

1. Invest in group leadership

Supporting development of leadership in self-help groups (group leaders/ leadership committees) is essential to building strong self-help groups. Where leadership is weak, often it is because leaders either do not understand or do not have the confidence or capability to fulfil their role, or that those identified as leaders do not identify with the group and so are not motivated to work towards a common purpose. Poor leadership or mismanagement can lead to distrust and unwillingness to continue participating in a group.

By way of example of investment in leadership development, Centre for Disability in Development in Bangladesh provides training for at least two potential leaders from each self-help group. They initially conduct community surveys and identify potential members (one male and one female) from each potential self-help group to participate in training on rights, leadership, advocacy, effective communication and self-help group management. This is supported by guidelines for group processes (see 4 below).

2. Ensure the necessary support people are identified to support group development

CBM partners' experiences have highlighted the importance of having key committed (and resourced) people in place in a project team to support self-help groups to develop and progress. Ideally these are consistent people, and could be CBR workers, hospital staff or DPO members, depending on the nature of the project.

Consistency of people can be more challenging in some contexts with high turnover or changing responsibilities of staff, such as government hospitals. It is important to ensure stakeholders with influence are engaged and involved in decision making, and so understand the need for this consistency, where possible.

In some cases projects may need to invest in training or up-skilling of staff, either in broad skills to support self-help group organisational development, or in specific areas that relate to the focus of the groups (e.g. advocacy skills, how to link with experts in livelihoods).

As well as working to bring together often disparate groups, training, guiding and supporting them in their activities, there is an important role for these key people in sensitisation. This includes being able to work with people to see their ability to contribute, to encourage action and independence of individuals and groups, and to facilitate connection of individuals to self-help groups. In some cases where there is a history of passive receipt of "aid", encouraging active participation can be challenging.

For example, In Cameroon, CBM's partner CODAS Caritas Garoua is implementing a community based rehabilitation program, with self-help groups of people with disability being an important component. When self-help groups are set up in locations with a history of NGOs, churches, and missionaries taking a welfare approach, the population has come to expect and rely on handouts rather than being active. People with disability come to groups expecting to receive material distributions. This leads to challenges developing sustainable activities with the groups. A lot of sensitisation is required through CBR workers to change the mentality of people with disability in these situations, to a situation where they are ready to be active and to contribute. Great gains have been made with some groups successfully moving beyond immediate self-interest and towards group goals. Key to this has been appropriate and strong support by equipped CBR workers. Achievements include groups operating independently of CBR workers with their own savings, peer support and increased self-esteem, renting land as a group and farming groundnuts as a collective income generation activity, and broader acknowledgement of rights of people with disability.

3. Financial transparency helps build trust

Together with investing in leadership, transparency around financial management builds trust. Self-help groups need clear roles, responsibilities and guidelines for the management of funds. In the Kilimanjaro Diabetic Program, there were initially issues because of a lack of structure for how to keep the money that people were contributing to purchase medicines and glucose testing strips in bulk. The project realised a need to register the clubs with local authorities and open bank accounts. The project also had to be very clear about why they were collecting funds in the first place for medicines that were supposed to be free. (The reality was that funds generation was to address a resource shortage – there were either not enough consumables or private hospitals were trying to make a profit, meaning people needed to spend more money, or go without).

Alternatively, in self-help groups in the Community Based Rehabilitation Project in Cambodia, groups would have three people who were revolving the management of the funds, to ensure a shared responsibility and transparency.

4. Ensure self-help groups have operational guidelines

There is a benefit to organisations having clear guidelines around how self-help groups operate; only some projects have this in place. Having clear guidelines means group members (and project staff) can have a shared understanding of roles and responsibilities, procedures can be transparent, and members have a reference point for accountability.

CBM's partner Centre for Disability in Development (CDD), Bangladesh, has been working with 12 local NGOs to develop self-help groups of people with disability, and has clear operational guidelines for group processes. These guidelines cover group formation and running and were mainly developed by CDD, with self-help group members and field staff of partner organisations sharing their practical experience to enrich the content. These guidelines have later been reviewed in a participatory process involving the self-help groups and field level staff.

Another partner, CODAS Caritas Garoua, Cameroon, has not had operational guidelines, but has identified the need for more guidance on how to specifically support self-help groups, particularly around guiding groups through different stages towards autonomy, to assist groups to recognise progression and also to assist CBR workers in their support for groups.

5. Consider what motivates people to join and participate and work with that

Expectation of shorter term tangible benefits is a common reason why people join self-help groups, with some of the advocacy focus emerging later. Sometimes people's more immediate needs may need to be met, as well as confidence developed, before they may be ready to work towards longer-term, more strategic goals. A project may involve developing self-help groups for advocacy purposes, but there are usually other areas to progress through before members are in a position to advocate. Likewise, even within groups, people may have different motivations. Involvement in a self-help group may be the first opportunity for a person with a disability to socialise outside of their family, so building confidence can be a key achievement that should not be underestimated.

An evaluation of a project in Jharkhand, India found that women and men (generally) had quite different motivations for joining and participating. While some men shared mixed opinions (some were primarily interested in the income generation aspects and some in the social aspects), women were consistently interested in the social aspects of meeting. In several villages women shared that before, they would talk to each other as they walked to different locations, such as collecting water or as they passed each other's houses. Joining self-help groups provided them with a legitimate reason to meet together, share and support each other on specific issues. This is supported by in-laws due to the savings which have contributed to families avoiding having to use loan sharks for emergency situations. This perhaps reflects the existing norms in the project area where men are more focused on income-earning work and often women are expected to focus more on care giving and community roles. Focusing on these priorities is an important entry point for the project to engage with people.

Considerations for self-help groups to be inclusive (easy to join and participate)

The success of self-help groups (particularly in terms of groups that are as inclusive and accessible as possible) relies on how **easily people can join and participate** in a group, with many factors affecting participation in our programs.

1. Consider impairment type and participation

Self-help groups sometimes include people with only one type of impairment. This could relate to how potential members are identified, or perceptions and attitudes about different types of impairment. Linking with DPOs is one important strategy for identifying and communicating with people with disability, but it is important to keep in mind the reach of those DPOs, so that partners developing self-help groups don't reinforce exclusion of people with certain types of impairment.

Good Samaritan Foundation in Tanzania have primarily worked with DPOs that focus on physical disability, to ensure people with disability who have diabetes are accessing clinics for assessment and able to engage with diabetic clubs (self-help groups). In terms of those with disability joining the clubs, most had physical disability (e.g. wheelchair users) and by working with DPOs for physical disability specifically, the project could be seen to be perpetuating the focus on physical disability that we see in many projects. It was explained that in Tanzania, there may be a predominance of DPOs representing people with physical disability and with albinism, possibly making it more challenging to connect with people with other types of disability. If this is the case, then projects that include self-help group development need to consider other strategies for identifying and communicating with people with disability. E.g. ensuring information, education and communication campaigns that use a range of modalities to be accessible; linking with other service providers that may work with people with other types of disability etc.

Other partners have also described challenges with including people with a broad range of impairments. For example, CODAS Caritas Garoua in Cameroon's self-help groups mainly include people with mobility impairments despite sensitisation by the project. Possibly this is because this type of disability is most accepted, and in this context psychosocial disability is still not considered by many as a disability, therefore prejudice still exists. Mental health activities in the project's region can be built upon to encourage inclusion of people with psychosocial disability within self-help groups, enabling more diversity of representation.

2. Consider budgeting for transportation of people with mobility impairments

CDD in Bangladesh have made a lot of effort towards inclusion of a broad range of people in self-help groups, but still found that some people with disability were missing out on participation. This continues to be a particular challenge that they are working to address. Each self-help group intentionally plans how they will ensure inclusion and as part of this, some groups budget for transportation for people with severe disability, from the savings of the group, to enable their participation.

3. Use strategies to enable those who cannot attend to be represented and informed

Our partners in both Cameroon and Bangladesh have been using strategies to ensure that people unable to attend are still able to be represented and informed about what is happening with their group (this works best when people live locally to one another and so ties in with point 7 below). Strategies include:

- A member going to talk with the person unable to attend
- Arranging for family members to attend the group with or on behalf of the group member unable to attend.
- In Bangladesh, Centre for Disability and Development self-help group operational guidelines allow for two care givers to join each group (one carer of a child with disability and one carer of a person with severe disability).

4. Consider savings expectations and participation

In some cases where self-help groups have an emphasis on savings, people avoided joining new groups because they were unable to regularly contribute the expected amount to savings. And where people were joining established groups, they were expected to match the existing savings already contributed by other members. Additionally, some successful groups that had been saving for some time did not want new members they considered to be high risk. An evaluation of one project found this meant the poorest missed out and the project may have been unintentionally increasing inequality at village level. There were also issues for women with disability accessing household funds to contribute, potentially leading to further exclusion.

In the case of the Parivartan project in India, some strategies have been considered to address these challenges, including identifying people excluded and finding ways to link to pensions/ social protection; starting groups with lower monthly savings requirements; and awareness raising with self-help groups about the need to consider ways to support others in the community. Mahila mandals (women's groups) have taken on more of a role of promoting inclusion, campaigning for pensions etc. for women with disability.

Where savings is a focus, there could also be some benefit from looking at aspects of the Village Savings and Loans Association (VSLA) model where people can purchase "shares" and contribute differing amounts from each other and differing amounts per meeting.

5. Consider gender and participation

Some projects have faced challenges with the gender make-up of groups, and found that addressing this has increased active participation.

A CBM project in Jharkhand, India, identified the importance of considering gender. In the project area, women and men had very different opportunities to access and benefit from development activities. Initially, the project had mixed gender self-help groups only. Men were taking out most loans and women said they weren't interested in loans. When a women-specific self-help group was started though, the uptake of

loans by women in the women-specific group was much higher compared to the women in mixed groups. As a result, the project has developed more women-specific self-help groups. This is a strong reminder that gender dynamics cannot be taken at face value.

CODAS Caritas Garoua in Cameroon recognised the limited involvement of fathers of children with disability in parents' self-help groups, as children are often seen as the responsibility of the mother, and groups seen as informal activities. They restructured group times to attract fathers who were working, and sent formal letters to invite them. As a result, participation of fathers in these groups is much higher and they are now increasingly recognising their role and responsibilities in caring for their children with disability.

Good Samaritan Foundation in Tanzania has also identified the need to look more carefully at how they attract men with diabetes to be involved in the diabetic self-help groups. It was found that men often tend to ignore diabetes management, follow up less on treatment at the hospital, and were less likely to join groups. Part of this was around the language used when talking about diabetes. The Swahili word for "be sick" has been used when talking about diabetes, but this word also means "pain". As pain is not a typical symptom of diabetes, the condition is being ignored, and so men were less likely to see the need to do something about it on an ongoing basis.

6. Capitalise on people's routines

For some types of self-help groups, it can help to schedule meetings when people are likely to be in a location anyway. For example, in the Kilimanjaro Diabetic Program, group meetings were scheduled to coincide with diabetic retinopathy screening sessions, thus enabling many people to find out about and join a group more easily.

When scheduling meetings it is also important to consider timing in terms of length, frequency, time of day and seasonal considerations and make sure that they meet the needs of potential members. Meetings need to be short enough to be manageable for people with other responsibilities at home or in paid work, and at a time of day that is convenient for people travelling from further afield.

7. Make groups as local as possible

Group members being spread over a larger geographical area or a number of villages can lead to challenges for participation of people with some types of impairments. CDMD in Cambodia initially tried to establish self-help groups that were disability specific but found that, when spread over multiple villages, they often had some members unable to attend due to accessibility and mobility challenges. As a result they focused more on forming groups with all members living in the same village or nearby. This can have implications in terms of the possibility of developing disability specific self-help groups, with it being more realistic to form groups with members both with and without disability, in order to attract adequate numbers of people.

Considerations for self-help group sustainability

1. Sustainability seems to be greater where self-help groups are linked together

Experience with some of our projects is that it has been helpful to have a phase out plan from the start of the project that is clearly communicated and involves a structure or linking together of self-help groups. These linked federations/apex bodies can have a real benefit, as can collaborating with DPOs.

The way this has been addressed by CBM's partner Centre for Disability in Development (CDD) in Bangladesh, has been through the development of apex bodies. CDD has invested strongly in developing leadership skills in self-help groups and knowledge about rights and how to advocate for rights to be met. 108 self-help groups have been developed with 12 coordinating groups called "apex bodies" that consist of representatives from each self-help group. As well as the individual groups advocating at a local level, the apex bodies have been able to plan together to advocate at a higher level. Self-help groups and apex bodies also maintain close links with existing DPOs in their communities and sometimes jointly initiate advocacy and lobbying for greater inclusion of people with disabilities. In this context, the self-help groups and apex bodies have a common objective/ focus and work from a rights based approach. DPOs are varied, from a specific impairment group focus, to income generation, to rights and empowerment, so how they collaborate depends on where they overlap.

This collaborative approach has resulted in a range of successes, such as three people with disability elected to local councils, 74 people with disability included in a range of local council committees, and 20 councils having developed disability inclusive action plans and budgets for inclusion in 2015-16. In addition, neighbouring councils to the project areas have budgeted for disability. Twelve of the 108 self-help groups formed were developed through support of existing groups and other marginalised groups have been seeking support and information from the self-help groups. Awareness raising has led to the community contributing to creating an accessible environment at five schools and people with disability themselves have been accessing grants, credit, formal and self-employment.

2. Representation at the various levels of government is required to achieve outcomes

Project planning should include consideration of the intended aim of developing self-help groups, so that groups and their structures are developed to best be able to achieve these aims. If it is planned that the groups will together influence a certain level of government, they need to have their groups represented at those levels (local, state, national etc.). This could be through the development of peak bodies, apex bodies or umbrella organisations.

CBM's partner NORFIL has used another approach to developing linkages between groups. In Batangas (as well as other provinces) NORFIL's approach has involved first identifying barriers for children with disability and their families. Once initial needs are being addressed, they then go on to establish local parent groups . A few local parents become volunteers and, once there are enough members, they then create a higher

level municipal core group, called AKAPIN – or peak body – with representatives from different parent groups.

By having a representative peak body at municipal level, there has been a good basis for working with local government units to advise on addressing the needs of people with disability through the different government programs. The AKAPIN members have been able to have representation on Disability Advisory Committees that have been set up in local municipal councils.

3. Sustainability of self-help groups will look very different in different contexts

Given the broad range of purposes for self-help group development, it is important to consider what sustainability will look like in a specific program context, recognising that there is not one model for success. For example, where self-help groups are being developed to be able to advocate to government for their rights to be met (in collaboration with other self-help groups), sustainability may involve ensuring the ability to function with minimal support from implementing organisations. Meanwhile, a self-help group developed for affordable access to medicines may require strong linkages with a hospital.

For example, CBM's partner Good Samaritan Foundation has been working to reduce impairment from diabetes in the Kilimanjaro, and now Arusha, regions of Tanzania. An evaluation found that a key factor in the success and sustainability of the work has been the formation of diabetic clubs. These are a type of self-help groups in which people with diabetes have together been saving successfully for bulk purchasing of medicines and glucose testing strips, and participating in education and awareness raising. In this case, sustainability is about the ongoing role of local hospitals in supporting clubs; ensuring they function and are integrated into the health system.

4. Expectations of self-help groups and implementing partners need to be aligned

It is also important to consider whether expectations of self-help groups and the organisations involved in setting them up, are realistic. CBM's partner NORFIL in the Philippines has established a model with a high level of sustainability, but has found that when they phase out of an area, some groups have stopped because they have found expectations of the community work they were expected to continue too high, especially when they have other responsibilities; working or at home caring for children with disability. This is a reminder of the importance of alignment of expectations of groups and implementing partners.