



NOTHING ABOUT US WITHOUT US!

Cooperation with
organisations of persons
with disabilities in
community programmes

A learning guide



Women with disabilities in Bolivia founded their own DPO to fight for their rights.

Executive summary

Providing insights into some of the roles of organisations of persons with disabilities and the merits of their involvement, this paper shall help us and others in our learning. It shall also help to increase our own transparency and accountability towards the people and communities we serve.

The paper presents and analyses good practices of DPO involvement in Light for the World programmes and shows successful ways of supporting DPO empowerment. It is based on interviews and focus group discussions with organisations of persons with disabilities (DPOs for short), other project partners and Light for the World programme colleagues in Bolivia, Ethiopia, Mozambique, Northeast India and South Sudan.

“As a DPO, we know the needs of the people with disabilities. It’s personal for us.”

Mr. Armando Conduane
President of the DPO ADEMO
Beira, Mozambique

DPOs – a rising force

Definition of DPOs

DPOs are representative organisations of persons with disabilities, which are “rooted, committed to and fully respect the principles and rights recognised in the Convention. They can only be those that are led, directed and governed by persons with disabilities. A clear majority of their membership should be recruited among persons with disabilities themselves. Organisations of women with disabilities, children with disabilities and persons living with HIV/AIDS are organisations of persons with disabilities under the Convention.” (CRPD General Comment No 7, para.11¹)

DPOs might represent one particular group of persons with disabilities or various types of disabilities. Either way, they consist of members with lived experience and unique expertise on how to best provide support for persons with disabilities.

Information on the various roles, functions, objectives and types of organisations of persons with disabilities can also be found in General Comment No 7 of the Committee on the Rights of Persons with Disabilities.

According to the World Report on Disability, 15% of the global population are persons with disabilities. 19.2% of women and 12% of men have disabilities. With a constituency of more than one billion people and the still prevailing issues of discrimination and invisibility, persons with disabilities are entitled to strong representation. The human rights-based approach to development includes participation as one of its central pillars.

Empowerment of women and men, girls and boys with disabilities is among the central objectives of Light for the World. We work in partnership with representative organisations of persons with disabilities (DPOs) in our mandate areas and on all levels of our work.

1 <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/GC.aspx>

The CRPD², including its General Comment No 7 on participation, tells us why it is important to involve DPOs in the work for persons with disabilities and for inclusive societies. The 2030 Agenda for Sustainable Development, with its motto of “leaving no one behind” and specific goals such as SDG 10 “Reducing inequality within and among countries”, also provides strong arguments for the participation of the most at risk and marginalised social groups.

“Nothing about us without us” is the slogan of the global disability movement, which illustrates that persons with disabilities and their representative organisations must be meaningfully included in decision making. As an organisation dedicated to ensuring that persons with disabilities can fully exercise their rights, Light for the Word is committed to upholding this motto. We believe that involving DPOs in development work is not only the right thing to do, but that it is necessary to have the deepest impact.

“In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations.”

Article 4.3, Convention on the Rights of Persons with Disabilities (CRPD)

2 <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>

The roles of DPOs in programmes on Disability Inclusion in Community Development

DPOs play a variety of roles in their countries and communities in representing the interests of persons with disabilities and in efforts to fight discrimination and reduce inequality. In the research for this paper, the following roles have been identified as major ones.

Disability Inclusion in Community Development

Light for the World supports programmes aiming at Disability Inclusion in Community Development. Combined with targeted advocacy, it is an approach within general community development to trigger systemic change and the sustainable realisation of the rights of men and women and girls and boys with disabilities.

It means working with communities to become inclusive while also offering targeted support to persons with disabilities. At community level, a broad range of topics is relevant for persons with disabilities for which the Community Based Rehabilitation (CBR) approach and the CBR Guidelines 2010³ provide practical strategies: From inclusive and accessible health care to inclusive education and economic empowerment, social inclusion and participation.

With this two-pronged inclusive approach, in which the involvement of DPOs is critical, we also witness how attitudes change: From the notion that an individual should be rehabilitated to fit into society to the vision of inclusive communities where every individual has the equal right and opportunity to participate. In short: Communities must change to fully accommodate marginalised groups.

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3 <https://www.who.int/disabilities/cbr/guidelines/en/>

DPOs as experts: How the expertise of persons with disabilities enriches community development

As persons with lived disability experience, DPO members bring valuable perspectives into programmes. This includes contributing their knowledge to programme design and implementation as well as planning and facilitating trainings on inclusive development, accessibility and related topics.

In **South Sudan**, the knowledge of DPOs fed into a sequence of trainings for humanitarian and development organisations organised by Light for the World. Members of the umbrella organisation of DPOs, the South Sudan Union of Persons with Disabilities, played a key role in planning and holding the trainings. The DPOs had witnessed a severe lack of representation of and support for persons with disabilities in a visit to an IDP (internally displaced people's) camp. The trainings then provided information on disability mainstreaming in programmes, such as:

- Identification of persons with disabilities;
- Understanding of barriers which persons with disabilities face;
- Accessibility audits;
- Accessible communication and materials;
- Setting up inclusive meetings and ensuring inclusion in any project activities.



“We come up with ideas, but we need support to implement them effectively.”

Seme Lado Michael
South Sudan Union of
Physically Disabled Persons

By holding these workshops with DPO members as trainers and speakers, the message was much more convincing to the NGOs who participated. “Nothing about us without us” was at the heart of these initiatives, recognising that doing a disability mainstreaming training without persons with disabilities would be futile. Also, the DPOs gave very positive feedback, saying that they appreciated being involved while learning skills at the same time.

After the first batch of trainings, ten DPOs came together to develop plans for their involvement in programmes in IDP camps across the country. Their actions ranged from the provision of sign language training, mobility and orientation for blind and partially sighted individuals, to making use of the DPOs' own networks and resources in helping children and adults with disabilities.

DPOs as changemakers and influencers: Increasing the impact of community development programmes through advocacy

DPOs have an important role to play for their members, persons with disabilities and the entire community vouching for and communicating to them the value and positive impact of programmes. They also lobby for change directly through their advocacy, being highly familiar with the barriers and challenges which must be tackled. DPOs have a clear grasp of what works and what does not work to change perceptions on disability. They can use these strengths to influence attitudes on disability in their communities and towards the government.

In **Northeast India**, the village level DPOs showed how much influence they could have on the local government. Once empowered and educated on their rights, DPOs were able to mobilise and collectively raise awareness around disability towards the authorities. Government officials had rarely been in contact with persons with disabilities before and were thus unaware of their rights and needs.

Due to their awareness raising campaigns, the DPOs soon began to see change. Policies which so far only existed on paper – such as job quota of 3-4% for persons with disabilities in a company’s workforce – were finally getting implemented. They also focused on improving the existing disability certificate which enables persons with disabilities to access government-provided pension and medical care. Having received assistance in navigating the system, the DPOs are now supporting more and more persons with disabilities in obtaining these certificates and getting the services they are entitled to.

“I believe it is unawareness, not stigma.”

Kezhaletto Zecho

President of Nagaland State
Disability Forum
Northeast India

Another achievement of their advocacy efforts, which the DPOs shared in the interviews, was the appointment of a woman with disability as State Disability Commissioner of the Northeast Indian state of Nagaland. The former State Disability Commissioner was mostly unaware of the challenges of persons with disabilities and had never actively supported persons with disabilities. When the local DPO wrote a letter to the government calling for the appointment of a person with disability to the post, the government complied. The new Commissioner is now actively involving the DPOs in her work and takes up their concerns.

In **northern Ethiopia**, in Gondar, we saw another example of how DPOs became empowered and increased their influence on government. DPO members were informed about their rights through a Light for the World funded programme and began attending district council meetings and influencing planning and decision making.

In Gondar, Light for the World has a unique partnership with the University of Gondar, implementing a programme on Disability Inclusion in Community Development. The ultimate goal of this collaboration is a disability-inclusive society in North Gondar. The programme contains elements such as awareness-raising on disability inclusion towards officials, rehabilitation services for hundreds of persons with disabilities and training workshops on disability mainstreaming.

The University of Gondar learned that there were some well-established DPOs in Gondar city, but very few in the rural areas where 83% of persons with disabilities live. Outside the city, people did not have a mechanism to come together, advocate for their rights and raise their concerns towards the local government. Hence, from 2004 onwards the programme began facilitating the formation of local level DPOs in remote areas and by now, DPOs in 24 districts have been formed.

Dr Solomon Mekonnen, executive director of the programme at University of Gondar, stressed three elements which contribute to strong DPOs.

1. **Information and awareness-raising:** Women and men with disabilities in the rural areas were often unaware of their rights and opportunities, having never been educated about them. Muluke Akanaw, a woman with a physical disability from Gondar, assumed she didn't have the rights to work in her community. She was shy and afraid of the insults that would come her way if she tried to find employment.
2. **Capacity development:** Local DPOs expressed the need for support in strengthening their capacities. After identifying what these needs were – education, infrastructure, budgeting, setting up income generating activities, understanding legislation, advocacy, etc. – tailor-made trainings were provided.

“Now, I’m empowered, I talk in front of people, I’m not scared because I’m aware of what my rights are as a woman with a disability!”

Muluke Akanaw
from Gondar

- Fostering empowerment by building advocacy skills:** Initially, fear kept DPO representatives from attending district council meetings, but with initial support from the programme, the trainings they had received, and the empowerment they felt by knowing their rights, they began confidently attending these meetings. As persons with disabilities raising their own concerns to the district council, they were also more likely to make an impact than if it were field workers or others speaking on their behalf. Through their seat at the table they already secured free education for all children with disabilities, free or cost-reduced medical care and housing for their poorest constituents.

“We have our voices heard!”

Mr. Georgis
 chairperson of a DPO in
 Ambo, Ethiopia



Mr. Georgis, DPO chairperson in Ambo, on his way to a meeting.

Dr Solomon stressed that strengthening DPOs at the local level and connecting them to decision makers is key for sustainability, because having the government’s involvement in inclusion in all sectors will lead to systemic change. Mr Georgis from the DPO in Ambo agreed:

“It is the responsibility of every sector to consider inclusion of persons with disabilities as their mandate!”

DPOs as implementing partners: Involvement of DPOs in the management of community development programmes

Persons with disabilities are usually the beneficiaries in programmes on Disability Inclusion in Community Development, but they can also have a more active role in programme management and implementation. DPOs are equipped with knowledge, skills, and personal insights to address barriers to inclusion, which others might miss. They can draw from their own experiences in accessing services and improve programmes accordingly.

Having DPOs at the helm of a project signals to their communities that

- persons with disabilities are valuable members of any community and must never be excluded;
- persons with disabilities, if given trainings and opportunities, are well-equipped to lead and implement projects;
- the project has merit for the community;
- systemic inclusion of persons with disabilities and accessibility is a must.

An example from Beira, Mozambique, illustrates this:

ADEMO, the Association of Mozambicans with Disabilities, is the country's oldest DPO and a long-standing partner of Light for the World. It was established after Mozambique's independence to promote political, social, economic and cultural inclusion of persons with disabilities. In 2013, ADEMO took on an implementing role in one of Light for the World's projects on Disability Inclusion in Community Development. ADEMO became fully responsible for administration, coordination, and implementation of the project. By taking over the project, the organisation was able to bring change through direct support in the community. It led to change in attitudes towards persons with disabilities and their standing in the community, as several positions in the project are held by persons with disabilities: The project coordinator, accounting assistant, board members and three voluntary community field workers.

Leo Pechem, programme officer for Light for the World in Mozambique, explained:

“The comparative advantage of having ADEMO implement this programme is that they come with a network of many other DPOs that can provide technical support and expertise. And they have a vested interest that other persons with disabilities are equipped with the resources and services they need – not only to survive, but to thrive in their communities. ADEMO has strong knowledge of the policies and practices affecting persons with disabilities which feeds into their community work too.”

When asked what this programme would be missing without ADEMO, Mr. Armando Conduane, president of the DPO, said:

“We, people with disabilities, know the needs of the people with disabilities. It would be a completely different programme [without us] because we know how to work with people with disabilities.

Our DPO’s mandate is to empower and integrate other persons with disabilities. For us it’s personal. It’s what guides us and working with Light for the World allows us to increase the self-esteem of other persons with disabilities.”

“We are feeling more strengthened as an organisation. Everyone in the community knows about us now.”

ADEMO members participating in a focus group discussion



Two ADEMO field workers during a home visit in the community..

From project client to team leader – Puleze’s story

Underlining the example of a DPO as implementing partner, is this individual story of community supervisor Puleze Miguel Luís.

Some years ago, ADEMO was doing house-to-house visits to identify persons with disabilities who could benefit from their programme. They met Puleze, a young man with a physical disability, in his home and he shared his story:

Puleze had been kept at home for the first fifteen years of his life. Although his mother showed him some basic physio, he did not know any proper exercises that would help him make progress towards walking on his own. At age 11, he had learned to stand up by balancing against a wall. At age 15, his uncle took him in and he finally got the opportunity to attend school. When he was in secondary school he was forced to drop out because of lack of money. It was at that point that he met ADEMO and got structured support from the programme. Within a year, he learned to gain balance and walk on his own. Later on, he started working in different jobs. Having recognised his great skills and commitment, ADEMO hired him as field worker who supports clients with disabilities in their rehabilitation and access to the community. In his fifth year he got promoted and became a team leader.

Puleze described his situation before he started working with ADEMO. He felt stigmatised by the community and found things very difficult. Now that he is so involved in the programme, those same people come to him asking for advice. His enthusiasm for his work clearly shows: “When someone gives me an assignment, I do it. I’m dynamic, always on time, I am committed!”

DPOs as links to individuals with disabilities: How DPOs are further increasing the reach of programmes on Disability Inclusion in Community Development

Local DPOs usually know very well where persons with disabilities in their communities live and can connect programmes to people and people to programmes.

They might know of individuals and families in need of services or are aware of a person who is kept at home because of prejudice and fear. In short, DPOs have an important role of linking programmes with communities.

Puleze's story and the example of ADEMO clearly show the impact which is possible if DPOs are involved in the identification and support of persons with disabilities in their communities, rehabilitation and services. The empowerment stemming from conquering challenges and becoming a leader in the community was tangible as well. Puleze and his colleagues have influenced the attitudes of many.

Dr Solomon from the Gondar programme in Ethiopia stressed that "we can't leave anyone behind, but we need support getting there". DPO members often know about other persons with disabilities and can help field workers to locate them and provide resources and services. As the DPO chairperson in Ambo, Mr Georgis said: "We all want to be productive and contribute our skills and help other persons with disabilities in our communities". Working together – DPOs and community development organisations – can help make this a reality.

DPOs as catalysts of entrepreneurship: How DPOs empower persons with disabilities to start their own businesses

Persons with disabilities have the right to a livelihood just like everybody else and should not be confined to certain occupations because of their disability. They can create their own businesses and contribute to their local economies. DPOs, with their knowledge about the many skills and talents represented within their constituency, can facilitate this entrepreneurial spirit.

A project in Ambo, Ethiopia, gives more details how this might look in practice. In 2013, the NGO "Vision Community Based Rehabilitation Association" (VCBRA) and the Ministry of Labour and Social Affairs provided financial and

technical assistance to the local DPO Furtu Rekina. Trainings and meetings were organised to equip the DPO members with new capacities around business and income generation, regulations, policy and legislation.

The training participants learned about their right to decent work and income. They began identifying options for their association to economically empower its members. Together they established their own Ambo Abdi Saving and Credit Group. VCBRA provided them with their first grant which, albeit small once divided, was enough for several members to start small businesses.

Then they connected to a local credit union, collectively saving money to become a member and access more funds. Initially, the group faced discrimination from the credit union, but thanks to their training, the DPO members were able to insist on their rights and get a loan. While expanding their businesses, they also learned about saving and they opened their own bank account. By now, the number of people benefitting from this saving group has more than doubled. From being hairdressers, to renting out bicycles, to owning grocery shops, the members have proven that they can manage successful businesses and act as role models for others.



Accessibility sign
in an IDP camp in
South Sudan.

DPOs as changers of the status quo: How women with disabilities challenge social norms and fight discrimination

People who get organised in groups and organisations are often more capable of challenging and changing the status quo, such as the prevalence of discriminating gender norms:

In **Cochabamba, Bolivia**, the first organisation of women with disabilities, called “La Asociación Manuela Gandarillas” was founded in early 2017 by the activists Rose Mery Guarita and Patricia Cadima. The two women took this step after male DPO members were unwilling to recognise the important work of Rose Mery Guarita at the UN in 2016, presenting the views of persons with disabilities about Bolivia’s progress in implementing the CRPD.

From the beginning, the association has been supported by Light for the World’s partner IIMS (Instituto de Investigaciones Medico Sociales). IIMS works on strengthening public policy and lately has begun working with DPOs to support their organisational strengths. The members of Manuela Gandarillas learn about organisational development, empowerment, community work, addressing the media etc. and use their new skills to fight the barriers and discrimination they face.

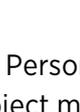
Manuela Gandarillas has made links with other organisations too, especially other women’s associations, to address issues such as gender-based violence. Having a safe environment to talk about women’s experiences is something that was sorely missing. Being able to work on these issues in coalition with other women’s groups further strengthens them and enables them to work towards challenging socio-cultural norms.

How Light for the World and others can partner with and support DPOs

In this publication, we identified some of the many roles which DPOs play in projects and partnerships: As experts, influencers, implementing partners, role models and entrepreneurs they are critical in the process of making societies and programmes inclusive.

Based on the interviews, there are several measures Light for the World and other development organisations can take to enable DPOs to meaningfully play these roles.

Enabling participation in programmes

In **South Sudan**, we worked with the DPO umbrella  for years, providing training on the Convention on the Rights of Persons with Disabilities, national policies, organisational development and project management.

With such support, DPOs are able to contribute their wealth of knowledge and lived experience into partnerships, trainings, projects and overall community development. Light for the World and its partners can actively enable participation and make others aware of the need to involve DPOs.

Enabling participation in decision making

Hearing from people who have personal experience with barriers and discrimination gives a much stronger impression than getting such information from others.

DPOs are well positioned to share personal challenges and cases from their community. It is important to provide accessible, inclusive and safe spaces to address discrimination and grievances. Equally important is working together on actions for necessary changes. Light for the World and others can sensitise decision makers to always include persons with disabilities in consultations, meetings and information. This also includes demanding that meeting venues, communication and information are fully accessible.



“We don’t just work for people with disabilities, but with people with disabilities.”

Sophia Mohammed
country director of Light for the World South Sudan

Providing skills and capacity development training or investment

All too often, persons with disabilities are not given the opportunity to lead on initiatives or receive funds and loans for entrepreneurial activities because of prevailing prejudice and wrongful assumptions about their capabilities. With the right support, DPOs can implement Disability Inclusion in Community Development programmes effectively and with added value. The project with ADEMO in Mozambique and on income generation in Ethiopia showed how the community changed by seeing persons with disabilities in the lead.

Light for the World and other organisation can facilitate DPO involvement in such initiatives by offering support such as skills training or organisational development.

Supporting movement building, gender equality, diversity and inclusion

Persons with disabilities are often marginalised by society. And, many individuals experience intersecting discrimination because of other factors such as gender, religion, ethnicity, or age.

Coming together and building momentum and collective energy to challenge the status quo is much more powerful than fighting alone. Disability and development organisations like Light for the World can assist by connecting DPOs to new allies, for example to mainstream women's organisations or partners with expertise in movement building, organisational development and campaigning.

Conclusion

The work on disability inclusion requires recognition of the aspirations and capabilities of persons with disabilities. The collective and unified voices of persons with disabilities are presented in their organisations – the DPOs. These representative organisations play many different roles in development work and in holding their governments accountable in policy making, budget allocation, or programme implementation. Governments and all other development partners must recognise that persons with disabilities are entitled to speak for themselves and shape their communities. Gaining empowerment and removing barriers to inclusion, persons with disabilities and their organisations not only impact their own lives, but influence the whole community to become more inclusive and human rights oriented.

For disability and development organisations such as Light for the World, ensuring meaningful participation and working with DPOs goes beyond a stand-alone strategy. Rather, it is an indispensable element of the rights-based approach and contributes to sustaining the development work we do.

Abbreviations

ADEMO:	Associação dos Deficientes Moçambicanos – Association of Mozambicans with Disabilities
CBR:	Community Based Rehabilitation
CRPD:	Convention on the Rights of Persons with Disabilities
DPO:	Organisation of Persons with Disabilities (originally: Disabled People’s Organisation)
IIMS:	Instituto de Investigaciones Medico Sociales
SDGs:	Sustainable Development Goals
VCBRA:	Vision Community Based Rehabilitation Association

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