



# THE ROLE OF OPDs AND THEIR LEADERSHIP IN RELATION TO THE CBID STRATEGY

This module describes the general roles of Organizations of Persons with Disabilities (OPDs) and their Leadership in five areas as described below. The OPDs play a significant role in supporting persons with disabilities in their development including supporting them to being leaders, professionals, and change-makers through active engagement within and outside the OPDs programme. The module seeks to impart knowledge and skills to OPDs and their leadership to ensure they exercise the five roles to bring a positive paradigm shift to OPDs themselves and their members in advocating their rights as part of a CBID strategy to meet the articles of the UN CRPD.

## 1. Advocacy

The main role of an OPD is advocacy and education. It covers five areas:

- (a) Advocate for the presence of assistive device systems within government structures
- (b) Collaborate with other stakeholders to ensure existing schools are inclusive of pupils with disabilities
- (c) Advocate for improved rehabilitation services for persons with disabilities
- (d) Raise awareness of the inequalities and poverty that exist for persons with disabilities
- (e) Advocate, educate and collaborate to make existing loan providers programmes accessible to persons with disabilities.

The description is covered in detail in the advocacy module.

## 2. Building capacity of persons with disabilities

Many people with disabilities in many countries including Zanzibar are unaware of their rights, and their potential for inclusion. They have frequently been excluded from most areas of society and have low self-esteem and confidence. OPDs play a vital role in identifying, and educating persons with disabilities and their parents/carers on their rights and potential. Other capacity building areas should be on economic/livelihood empowerment, self-advocating, leadership, gender roles and safeguarding.

## 3. Partnering with other development organisations

Partnering with other development organisations and government on programmes can ensure the greater participation and inclusion of persons with disabilities into mainstream national and international development initiatives.

OPDs can advise local and national government and development agencies on how to make their programmes accessible, and can also raise awareness of those activities to their membership to increase inclusion. As with CBID programmes generally, OPDs should be involved in all parts of the programme cycle in any development collaboration.

Examples of areas where collaboration can be very valuable are for OPDs to link CBID with international crosscutting issues such as HIV/AIDS, COVID-19, Climate Change, health, education, and livelihoods which address both women and girls with disabilities who face challenges in those areas.

If an OPD has a role in any aspect of service delivery, it must ensure it is separate from, and does not compromise, its advocacy role. For example, a government department might provide funding for an OPD to train people in disability awareness, or provide technical support, but it must still retain its independence to challenge Government where persons with disabilities rights are being compromised.

## 4. Networking with other OPDs and CSOs and SHIJUWAZA

Zanzibar has specific disability OPDs as well as general ones, and an umbrella federation: SHIJUWAZA. The OPDs have in common that their members all face barriers in society, and this is an area where OPDs can become much more powerful if they combine their efforts to challenge the barriers that face them.

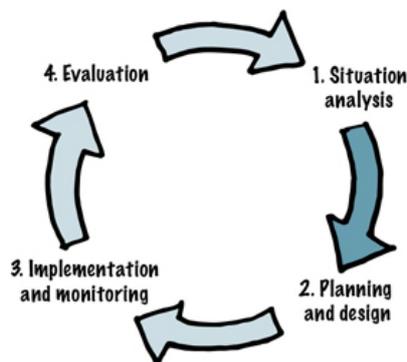
For example, all OPDs want their members to be registered as persons with disabilities, and to have the right to vote, and to access healthcare, education and livelihood opportunities. OPDs may be specific disability organisations or cross disability organisations: they can all identify people with disabilities through their fieldwork and refer people to other OPDs as needed.

OPDs can also collaborate with each other and with SHIJUWAZA to conduct disability sensitization workshops for government and non-government agencies. However, it appears that each OPD is working independently and there has been limited joint programmes in place that would strengthen networking and reduce donor funding competition between OPDs and other CSOs.

## 5. Networking with community members and media

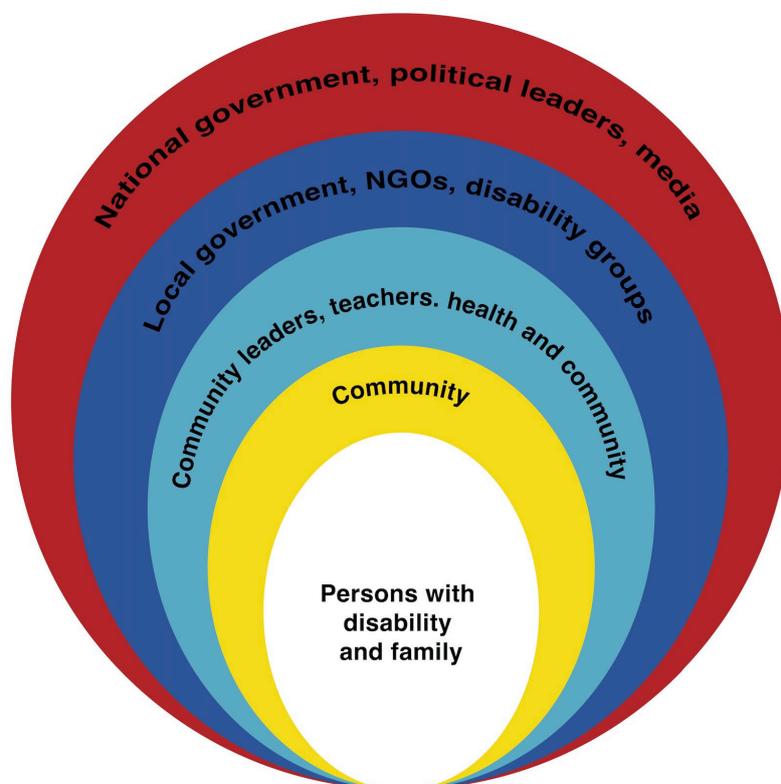
Networking also involves educating community members and the media about disability related rights, and relevant laws. This means developing social media and communication skills such as how to write a press-release, and how to use social media sites, and community forums to deliver messages to the public and discuss disability agendas.

## The roles of OPDs and other Stakeholders in CBID



CBID is about achieving the rights of persons with disabilities as outlined in the UN CRPD. They are at the heart of all CBID programmes. OPDs should be the drivers of CBID programmes: ensuring they are addressing the rights of persons with disabilities at all stages of the CBID programme cycle shown above: situation analysis, planning and design, implementation and monitoring, and evaluation. They can also be powerful advocates for CBID.

At each stage OPDs work with a variety of other CBID stakeholders outlined in the diagram below from the CBR Guidelines. The Guidelines also suggests the main roles of each stakeholder and these have been adapted and expanded in the tables below. Development partners are not shown separately in this CBR Guideline diagram but could be NGOs, disability groups, or for example UN agencies.



### **Persons with disabilities and their families**

Their roles may include:

- playing an active role in all parts of the management of the CBID programme
- participating in local CBID committees
- being involved by volunteering and working as CBID personnel
- building awareness about disability in their local communities, e.g. giving information on specific disabilities
- Identifying barriers and advocating for their removal
- Understanding their rights and advocating for their achievement
- Self-protection against GBV and any other kind of social abuse

### **Community members**

CBID can benefit all people in the community, not just those with disabilities. CBID programmes should encourage community members to:

- participate in training opportunities to learn more about disability
- change their beliefs and attitudes that may limit opportunities for persons with disabilities and their families
- address other barriers that may prevent persons with disabilities and their families from participating in the life of their communities
- lead by example and include persons with disabilities and their families in activities
- contribute resources (e.g. time, money, equipment) to CBID programmes
- help address the causes of disability
- provide needed support and assistance for persons with disabilities and their families where needed
- protect people with disabilities against any kind of GBV and social abuse.

### **NGOs and civil society**

The roles and responsibilities of NGOs and civil society organizations and groups will vary depending on their level – international, national, regional or community and may include:

- developing and implementing CBID programmes where there is limited government support
- providing technical assistance, resources and training for CBID programmes
- supporting the development of referral networks between stakeholders
- supporting CBID programmes to build the capacity of other stakeholders
- facilitating regional and international experience sharing amongst CBID practitioners and policy makers
- support pilot, catalytic projects modelled for sharing and replication and scaling up
- mainstreaming disability into existing programmes and services
- supporting the evaluation, research and development of CBID.

### **Organisations of persons with disabilities (OPDs)**

Their roles and responsibilities may include:

- representing the interests of persons with disabilities
- advocating and lobbying for action to ensure that governments and service providers are responsive to these rights, e.g. implementation of programmes in compliance with the UN CRPD and the Persons with Disability (Rights and Privileges) Act No. 9. 2006
- direct involvement in the management of CBID programmes
- providing advice about the rights and needs of persons with disabilities
- educating persons with disabilities about their rights and opportunities
- provision of information in accessible formats about services to persons with disabilities
- monitoring the implementation of disability programmes
- tracking of national budgets and expenditure reports
- facilitating networking and resource sharing among OPDs
- training relevant NGOs in disability mainstreaming.

### **Government**

Disability issues should concern all levels of government and all government sectors, e.g. the health, education, employment and social sectors. Their roles and responsibilities might include:

- taking the lead in the management and/or implementation of national CBID programmes
- ensuring that appropriate legislation and policy frameworks are in place to support
- upholding the rights of persons with disabilities as per ratified UN protocols
- developing and funding a national policy on CBID, or ensuring CBID is included as a strategy in relevant policies, e.g. rehabilitation or development policies
- providing human, material, and financial resources for CBID programmes
- ensuring persons with disabilities and their family members are able to access all public programmes, services and facilities
- developing CBID as an operational methodology or service delivery mechanism for providing rehabilitation services across the country.
- To develop and implement disability inclusion policy and programmes.

## Key concepts of disability integration, mainstreaming, and inclusion

The terms disability integration, mainstreaming and inclusion are often used interchangeably but they have different meanings:

**Disability integration** is about providing certain features and arrangements which allow some persons with disabilities to access and participate in their environment in limited circumstances or in reaction to a stated need. Or – it is the intermixing of groups or persons with disabilities that were previously segregated. This approach is reactive rather than proactive – it integrates the person with a disability into an already established structure.

**Disability mainstreaming** is the consideration of the different conditions, situations and needs of persons with disabilities in all policies and programmes at the stages of planning, implementation, monitoring and evaluation.

It is not about adding a disability component but is a strategy that ensures that the concerns of persons with disabilities are an integral dimension in any policy or programme design, implementation, monitoring and evaluation. Mainstreaming is a question of rights. When persons with disabilities are mainstreamed in different settings, such as education and employment, they are operating in a more natural context. For example, mainstreaming children with disabilities in education allows for their specific learning needs to be provided for in a regular classroom rather than in a special education classroom.

A major challenge to mainstreaming is negative attitudes. Stigma and discrimination are founded on fear and lack of knowledge and by creating inclusive environments we start to break those barriers down. There remains widespread lack of understanding of the abilities of persons with disabilities as well as their needs and rights. Low self-esteem of persons with disabilities is another factor, as well as high illiteracy and poverty levels.

Mainstreaming is a method to promote inclusion and address barriers that prevent equal and full participation. It aims to ensure that persons with disabilities have the same rights as others.

**Disability inclusion** provides all of the features and arrangements that allow all persons with disabilities to access and participate in their environment in advance of any stated need. It is proactive and anticipatory. The goal of inclusion is to facilitate an environment in which no one is, or feels, left out as a result of their difference. The environment is designed to fit the person.

## Teamwork in disability mainstreaming

Disability mainstreaming in Zanzibar requires the collaboration of Government, DPOs, service providers, people with disabilities and their families, as well as other players, each fulfilling a specific role:

**Government** is responsible for ensuring the rights of persons with disabilities in line with its national laws and policies as well as international instruments to which it has committed, such as the UN CRPD and the Sustainable Development Goals (SDGs).

**DPOs** are the voice of persons with disabilities and it is their role to identify their needs and identify the barriers to their inclusion. DPOs represent the views of persons with disabilities to decision makers and develop the skills of their membership to advocate and negotiate for the achievement of their rights.

**Service providers** are responsible to provide services in line with the demands of rights holders as well as in provisions of government policies and guidelines.

**Family members** also play a critical role in disability mainstreaming by supporting their family member with a disability to achieve their potential, and to be included in all aspects of Zanzibar life and society, and advocating for their rights in every situation.

**Community members** have a huge role to play in mainstreaming disability issues into community programmes to ensure people with disabilities achieve their potential.

## Scenarios to illustrate the Key concepts of disability integration, mainstreaming, and inclusion

### Integration

*A small village school built in Zanzibar had about 50 students. None of the children had disabilities but one day, Lulu - one of the young girls at the school - had a car accident and was paralysed. Lulu needed to use a wheelchair. Her family were supportive and wanted her to finish her education. They met with the Head Teacher at the school who agreed to make a ramp next to the steps at the main entrance and to organize for one of the toilets to be modified so that Lulu could continue her classes. The timetable was adapted so that none of her classes were held in the block which was only accessible by a flight of steps, and when it came to lunchtime her friends helped her to get up the three steps into the separate lunch area.*

### Mainstreaming

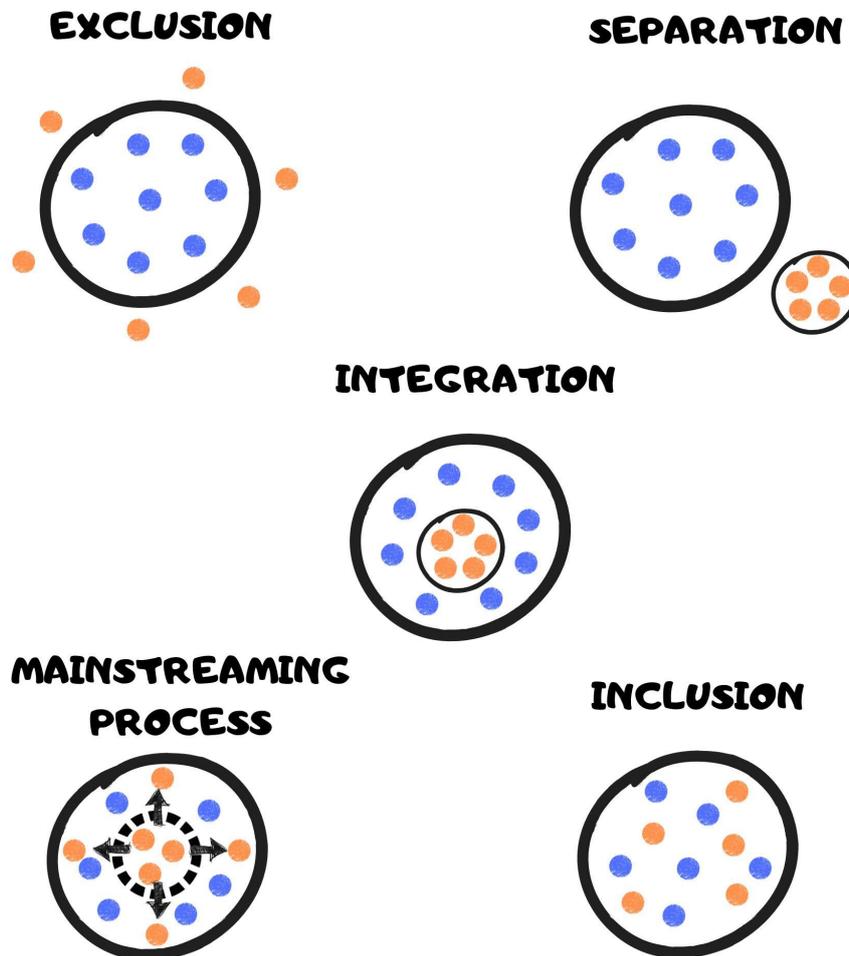
*A small village school in a rural area of Zanzibar had about 50 students. When one of the children, Lulu, had an accident and needed to use a wheelchair, the school realized that changes were needed to accommodate Lulu and other children with disabilities in the community. While she went through her rehabilitation, they added a ramp to the side of the school to make the classrooms which were only accessible by a flight of steps fully accessible. They also combined two of the toilets in each block so that there was a large accessible toilet in every area of the school. Some new adjustable height desks were purchased to ensure that all children, including Lulu, who needed a higher or lower desk could sit comfortably. Staff, pupils and parents were given more information about disability too. The changes also encouraged other children with disabilities to apply to the school because it was now fully accessible to them.*

### Inclusion

*A small village school is planned in rural Zanzibar. The design takes into account the rights and needs of people with different disabilities by consulting widely and taking a rights-based approach in line with strong national and international laws and conventions. From the start all of the areas of the school are accessible with ramps, large bathrooms that are easy for everyone to use, lighting that helps people with poor vision see the board well, clear signs to assist people with hearing disabilities, and other features that ensure that children with disabilities have their needs met. Staff, pupils, and parents are educated on disability issues and the curriculum meets the needs of different students. When one of the children, Lulu, had an accident and needed to use a wheelchair the school was already fully accessible for her needs and the staff and pupils welcomed her back. Lulu already had friends in her class and community with disabilities which also meant she wasn't nervous about returning to school.*

The chart below gives a graphic illustration of the differences between exclusion, separation, integration, and inclusion.

It also shows the process of Mainstreaming, which can help us move towards inclusion from any of the three areas: exclusion, separation, or integration.



### Sources

Ref 11: Training planned for “Training of Trainers” Course Under Disability & Start-Up (DASU) Project WHO Guidelines

World Vision, Lorraine Wapling, Kevan Moll, Sue Coe, *Practical guidelines on disability inclusive programming*