



Working with and through Organisations of Persons with Disabilities

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Acknowledgement

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Purpose, audience and objectives

Purpose	The full and effective participation of persons with disabilities is central to the realisation of their human rights and inclusion of all persons with disabilities in society. The Convention on the Rights of Persons with Disabilities (CRPD) sets a unique role for Organisations of Persons with Disabilities (OPDs) as key intermediaries to represent and channel the views and perspectives of persons with disabilities. This guide explores some guidance on ensuring a successful partnership with OPDs.
Audience	It is one of a series of short guides developed by Sightsavers, within Futuremakers by Standard Chartered , and specifically written with Youth Business International programme partners in mind. While advice included in the document is more targeted towards YBI's youth entrepreneurship programme, we have tried to make these relevant to all Futuremakers projects.
Objectives	<ol style="list-style-type: none">1. To build greater disability confidence of the reader and how partners can better include youth with disabilities in their Futuremakers projects.2. To give specific examples, advice and simple steps on how to adapt projects to be more inclusive of youth with disabilities.

Context

The effective and meaningful participation of persons with disabilities across all sectors of public life is at the very heart of the UN Convention on the Rights of Persons with Disabilities (CRPD). Governments, and not least development partners, are mandated to closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations in the development and implementation of legislation and policies concerning issues relating to persons with disabilities. Working with persons with disabilities through their representative organisations needs to be planned for at the start of a project. Effective development programmes need partnerships, particularly at local levels, and in the case of programming for youth, which put the inclusion of youth with disabilities and their representative organisations at the centre. Ensuring youth development programmes are inclusive is a shared responsibility amongst partners.

Definition of OPDs

OPDs are those that are: - rooted, - committed to and - fully respect the CRPD principles and rights. They are those that are: - led, - directed and - governed by persons with disabilities - with a clear majority of their membership recruited among persons with disabilities

themselves. OPDs are established mainly with the aim of collectively acting, expressing, promoting, pursuing and/or defending the rights of persons with disabilities.¹ The CRPD Committee² also draws a distinction between organisations of persons with disabilities (OPDs) and organisations ‘for’ persons with disabilities. Organisations ‘for’ persons with disabilities provide services and/or advocate on behalf of persons with disabilities.

Types of OPDs³

- a. Umbrella organisations of persons with disabilities. These are coalitions of representative organisations of persons with disabilities. Ideally, there are one or two at national level in many countries. Often and where they exist, the umbrella OPDs are largely known and recognised by the movement of people with disabilities in that country, the governments, as well as development partners. For example, in Kenya, United Disabled Persons of Kenya is largely recognised as the umbrella OPD and in Uganda, the National Union of Disabled Persons of Uganda (NUDIPU) is recognised as one. In Bangladesh, there is no one organisation of persons with disabilities recognised as an umbrella, and is, therefore, an example that there will not always be umbrella OPDs in every country that has ratified the CRPD.
- b. Individual organisations of persons with disabilities representing specific impairment groups. The existence of umbrella organisations should not hinder individuals or organisations of persons with disabilities from participating in consultations or other forms of promoting the interests of persons with disabilities.
- c. Cross-disability organisations are composed of persons representing all or some of the wide diversity of impairments.
- d. Self-advocacy organisations representing persons with disabilities in different networks and platforms. Generally constituted by persons with intellectual disabilities.
- e. Organisations including family members. The role of parents, relatives and caregivers in such organisations should be to assist and empower persons with disabilities to have a voice and take full control of their own lives,
- f. Organisations of women and girls with disabilities, recognise that women and girls with disabilities are a heterogeneous group.

¹ General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation and monitoring of the Convention.

² <https://www.ohchr.org/en/treaty-bodies/crpd>

³ **Guidance by the CRPD Committee in its General Comment 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention**

- g. Organisations and initiatives of children and young persons with disabilities which are fundamental for the participation of children and young people in public and community life as well as for their right to be heard, freedom of expression and association.

It is important to be aware that not all people with disabilities are members of an OPD, and not all impairment types are represented by OPDs in every area. In the case that you cannot connect with an OPD in an area, you can engage with individual persons with disabilities. You may then work together to support the creation of OPDs where possible.

Ensuring successful partnerships with OPDs

The following offers guidance on what may be important in ensuring a successful partnership with OPDs. It has been adapted from resources developed under Inclusive Futures⁴ and the International Disability Alliance.⁵

1. The need to have a shared understanding of a project. Understand what all partners agree on and the values they share. A strong foundation means that all partners are working towards a common vision.
2. Agree on roles and responsibilities of each partner. It may include establishing collaborative working through a steering committee, where decision-making is shared across partners. This broadly also involves sharing power, leadership, ownership, and responsibility. Clear communication sets and maintains expectations and roles for each partner.
3. Valuing OPDs as expert organisations. OPDs have a variety of skills, including knowledge and training on human rights including the CRPD and other national and global frameworks on equality and non-discrimination. They also draw on lived experience to add to their expertise.
4. Dedicate resources and budget for OPD engagement. This includes budgeting for reasonable accommodation, funding OPDs for their institutional strengthening among others.
5. Diversity. Partnering across the diversity of the disability movement taking into context among others local and urban contexts.
6. Identify strengths and capacity challenges to support what partners can be responsible for, and a plan for how a partner can strengthen their skills if there are

⁴ <https://inclusivefutures.org/how-to-create-meaningful-partnerships-between-ingos-and-opds/>

⁵ <https://www.internationaldisabilityalliance.org/blog/applying-crpd-standards-programmatic-processes-look-inclusive-programming-practice>

gaps. For example, we see that OPDs are increasingly taking up roles that may require additional technical expertise. It for example means that OPD partners can do participant mobilisations from their database, but in addition, OPD partners will for example take up other roles such as employer training on disability inclusion, supporting jobseekers taking different programmes such as soft skills trainings and co-leading Business and Disability Networks, among others. This therefore means the need to afford OPDs opportunities to strengthen their skills including relevant training opportunities.

Now that I know, what do I need to do?

- Include OPD representatives in the development of project proposals, clearly articulating their roles across all stages of the project, including resources to be made available for them
- Communicate clearly about the project at the grassroots for more OPDs to have the chance to engage
- Define the role of OPD representatives within the decision-making processes of the project, with a feedback mechanism to reflect how their inputs are being considered
- Define a mechanism for OPD engagement throughout the programme
- Establish open, accessible processes to enable OPDs to express interest to engage as partners. Define the level of partnerships so that OPDs can indicate interest based on the level of engagement they decide for themselves within the project
- Allocate adequate resources for meaningful engagement of OPDs, in consultation with them, including supporting staff time and enhancing operational capacities of OPDs
- Develop, along with OPD partners, clear guidelines for meetings and events that foster inclusion of a diversity of disability groups
- Establish feedback mechanisms to continuously enhance inclusion in project activities

Further reading

Applying CRPD standards to programmatic processes: A look at inclusive programming in practice

A guide to building successful partnerships between INGOs and disability

General Comment 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organisations, in the implementation and monitoring of the Convention

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