

Meaningful rights-based engagement with Organisations of People with Disabilities

Laisa Veretiⁱ and Lucy Danielⁱⁱ

2024

This 'Disability equity and rights: Challenges, opportunities, and ways forward for inclusive development' publication was prepared under the DFAT – CBM Inclusion Advisory Group Disability Inclusion Technical Partnership, an Australian aid initiative implemented by CBM Inclusion Advisory Group and the Nossal Institute for Global Health at the University of Melbourne.

This publication has been funded by the Australian Government through the Department of Foreign Affairs and Trade. The views expressed in this publication are the author's alone and are not necessarily the views of the Australian Government.

This essay represents the views and experiences of the Pacific Disability Forum (PDF) and does not necessarily represent the views of all OPDs globally.

Background

People with disabilities have the right under Article 4.3 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) to be consulted and actively involved through their representative organisations in decision-making processes that affect them, including in relation to the development and implementation of policy and legislation. Article 32 of the CRPD further recognises that international cooperation should involve partnership with organisations of people with disabilities (OPDs). The past decade has seen increased awareness among development actors of the need to meaningfully consult and engage with the disability movement.ⁱⁱⁱ This significant achievement should be acknowledged.

The development sector's increasing engagement with OPDs, however, is bringing challenges for OPDs. Intentional strategies must therefore be established to balance the development sector's increasing awareness and impetus to be informed by the disability movement, with improved practices that better ensure such engagement benefits OPDs themselves. This includes respecting OPDs' time and agency to invest in their own priorities. Donors should not just request programs or partners consult with OPDs, or only quantify the number that do so. Focus should equally be placed on the quality of a program or partner's engagement with people with disabilities. This should be accompanied by guidance for development practitioners on how to do so according to a rights-based approach.

Opportunities and challenges

Resourcing restraints faced by OPDs

OPDs cover an enormous range of roles, projects, and responsibilities, from political lobbying, conducting accessibility audits, providing referral services, fostering relationships with local non-government organisations (NGOs), and running trainings to name a few. Some OPDs may cover a diverse range of disability types, significant geographical areas, and population numbers.

OPDs commonly face significant resource constraints. They are, at times, entirely or substantially run by volunteers. In countries where people with disabilities face systemic barriers to accessing education, it is not uncommon for OPD staff and members to have no or minimal formal education. This implies OPDs will be drawing on diverse skills sets when delivering activities such as report writing, training, meetings, or administration. They are often direly under-funded.^{iv} Funding that is provided may often be conditional and not allow for flexibility where unforeseen circumstances arise, such as in the event of a natural hazard disaster or an urgent consultation request. This places significant strains on the OPD.

Competing demands on OPD's time and misaligned priorities

Development actors in low- and middle-income settings are increasingly requesting the involvement of OPDs within mainstream programming in line with the principle of 'nothing about us without us'. While this is positive, it also needs to be recognised that development actors are working across a plethora of sectors and cross-cutting issues. This can range from programming design, delivery, and review to policy development and data collection. Given the large amount of work across sectors needed to achieve equity and uphold rights for people with disabilities, and the limited resources of OPDs, many OPDs will have to make strategic decisions to prioritise their work and activities.

Anecdotally, we often hear that to progress systematic change for disability equity and rights, an OPD's priorities should be focused on advocacy and monitoring implementation of the CRPD, for example CRPD ratification, passing of disability laws and provisions for funding, and access to assistive technology. This is not the same as being involved in mainstreaming disability throughout development programs, for example through consultations. Ideally, OPDs would be in a position to respond to every request for engagement. However, in reality OPDs have limited time and resources and have to make difficult decisions about where to place their focus. Even if an opportunity to engage with a mainstream development program does not align with an OPD's priorities, the OPD may feel that they need to accept the invitation due to the power imbalance between themselves and the organisation inviting them. This is particularly the case with a donor or potential funder. This tension between the mainstream consultation opportunities and the priorities of OPDs is rendered worse by the fact that mainstream development actors often do not offer OPDs payment for their time, services, or participation in consultations. This is despite OPDs contributing their expertise and taking time away from other work opportunities and priorities.

Tokenistic engagement

The CRPD Committee has noted that despite progress, there is much work to do before Article 4.3 on the involvement of people with disabilities in decision-making processes is realised.^v The International Disability Alliance (IDA) commissioned a global survey to measure progress, gather learnings, and identify where to improve in this regard. The survey found that while there is increasing participation of people with disabilities through their representative organisations overall, this remains insufficient by Article 4.3 standards. Moreover, OPDs are dissatisfied with their level of involvement in consultations. While OPDs increasingly participate, their contributions are not adequately taken into account. The IDA survey reported negative experiences about participation processes, such as being denied reasonable accommodations resulting in exclusion, or being invited to 'legitimise a process, without their views being adequately considered.'^{vi} Findings showed OPDs had very limited opportunities to shape donor policies, with roles limited to either attending events or conferences or receiving donor funds to implement.^{vii}

The experiences reported by OPDs within the IDA survey align with anecdotal reports from OPDs across the Pacific. Again, uneven power dynamics are at play, such as tokenistic engagement with development investments extracting OPDs' limited time without providing substantial opportunities to meaningfully shape the investment. As noted, it can be difficult for OPDs to turn down such opportunities. Meanwhile an OPD's presence 'legitimises' the process from the development actor's perspective, so the power imbalances and social norms remain undisturbed.

Accordingly, the focus of the development sector needs to be not only on the quantity of programs that engage with people with disabilities and their representative organisations, but also the quality of such engagement. Particular consideration needs to be given not only to the involvement of OPDs but to ensuring OPDs can meaningfully influence decision-making processes. Doing so involves careful consideration of the power imbalances between OPDs and development actors, particularly donors, who are seeking their engagement.

Reliance on OPDs for mainstreaming efforts

At times, there is confusion about the role of development actors and OPDs regarding the mainstreaming of disability inclusion. The Pacific Disability Forum's view is the role of OPDs in mainstream programs is best focused on engagement in strategic decision-making and consultations to help mainstream disability inclusion in programs. However, some development actors appear to outsource their responsibility for disability inclusion to OPDs rather than mainstreaming disability inclusion in their own work. OPDs are, therefore, expected to deliver disability inclusive programming as an implementer. Offers of funding support to OPDs may be tied to the OPD implementing disability inclusive program activities. Again, due to power imbalances and the need to accept funding opportunities, it can be difficult for the OPD to turn down such requests. It needs to be firmly understood across the development sector that mainstreaming of disability needs to be a responsibility of development actors themselves with OPDs involved as advisors.

Mainstream development stakeholders have an important role to play in promoting disability inclusion to ensure the success of disability equity across all programs and investments. Disability inclusion is the responsibility of all duty bearers and development actors, meaning that all stakeholders, including donors, must drive the disability inclusion agenda themselves. This means raising the need for disability inclusion in dialogue with partners or other stakeholders when they identify that disability inclusion is not being prioritised or when disability inclusion efforts are not following good practices.

Narrow approaches to organisational strengthening

An emerging strategy to engage and resource OPDs has been to provide 'organisational strengthening' support. While not clearly defined, this generally involves providing funding and activities to assist OPDs to develop strong organisational systems and functions, including governance, organisational policies, financial processes, human resources, monitoring and evaluation systems, data collection and risk management. Ideally organisational strengthening is a transformational journey to improve OPD's leadership, strategic direction, efficiency, and effectiveness. In practice, organisational strengthening support to OPDs is often focused on compliance and due diligence. This support assists OPDs to better meet partner assessments, risk management and legislative requirements, that are involved with receiving significant donor funds. Providing organisational strengthening to OPDs to meet these requirements is essential for the sustainable growth and development of OPDs.

When compliance and due diligence become the sole focus of OPD organisational strengthening support, we can end up with small, grass roots, Global South civil society organisations (CSO's) being funded to meet complex requirements of Global North development actor's own making. Again, power dynamics, the need to follow funding rather than priorities, and OPD's time being taken up with development actor's activities are all at play. This is not to undermine the importance of compliance and due diligence requirements. It is important to reflect, however, that OPDs are unique organisations, differing to typical program partners that donors or international NGOs may otherwise be funding. They are CSO's, run by people with disabilities who have faced systemic discrimination, primarily for the purpose of advocating for the rights of people with disabilities. They do not have the same organisational history, scale, structure, or purpose as other program partners, and should not be expected or treated as if they do. The challenge and the opportunity here is to take the necessary aspects of compliance and due diligence and the transformational aspects of capacity development and to align these proportionately with the unique aspects of OPDs. Organisational strengthening needs to be tailored to the needs and pace of the OPD in question.

Looking ahead to 2030: ensuring rights-based engagement with OPDs

Discussing these challenges with OPD engagement does raise risks in that development actors might become hesitant to engage with OPDs. This is due to concerns about doing so incorrectly or the misassumption that the above challenges suggest engagement is not necessary. To be clear, the

answer to resolving these challenges is not to step back from engagement with OPDs. But neither will these issues be resolved by simply continuing to ask programs to keep consulting with OPDs and counting how many do so. Rather, progress requires emphasising meaningful rights-based engagement with OPDs.

Rights-based engagement firstly means involving OPDs in strategic decision-making opportunities systematically throughout investment and programming life cycles, not merely consultations at the initial design or final review stages. It also means development actors establishing transformational partnerships with OPDs to ensure their programs and policies are aligned with, and informed by, OPD's priorities and that OPDs are strengthened and empowered through the relationship.^{viii} This approach would also involve ensuring the way development actors engage with OPDs is respectful of *all* rights of people with disabilities under the CRPD. It is not only the right to be consulted under Articles 4.3 and 32 that need to be considered, including rights to accessibility (Art 9), reasonable accommodation (Art 5), freedom of expression and opinion (Art 21), standard of living (Art 28), equality and non-discrimination (Art 5), and the advancement and empowerment of women with disabilities (Art 6). In all interactions with OPDs, development actors should be aware there is a significant power imbalance between themselves and the OPD and that the OPD has many competing demands on their time.

In relation to providing organisational strengthening to OPDs, while dedicated funding for this is welcomed, it must be delivered across the broad spectrum of organisational capacity development that would benefit OPDs. For example, providing leadership skills and professional development opportunities to staff members, in parallel to funding activities for due diligence and compliance. Activities delivered through organisational strengthening programs should be designed on a case-by-case basis and be responsive to the individual OPD's needs, their own priorities, their capacity to grow and develop, the pace at which it is sustainable for them to do so, and be reflective of OPD's advocacy focus rather as a service-delivery partner. Furthermore, development actors should examine the extent to which they can assist OPDs to become donor compliant by reducing their own requirements to be proportionate and cognisant of the unique scale and profile of OPDs, rather than necessarily requiring OPDs to meet the standard of compliance expected of all program partners. The Australian Government's new International Development Policy sets a positive example here in committing to seek to reduce the barriers faced by local partners (such as OPDs) to be engaged in Australia's development program by increasing program flexibility.^{ix}

To ensure progress towards disability inclusion by 2030, it is crucial these recommendations are incorporated into global development practices. Doing so will require adaptations within donor and investment's funding arrangements. For example, providing core funding and capacity building to OPDs as a part of consultative roles and ensuring monitoring and evaluation frameworks focus on *how* OPDs have been consulted and supported rather than only looked at *if* they have been.

ⁱ Pacific Disability Forum. Lead/corresponding author: Larisa Vereti, Laisa.Vereti@pacificdisability.org

ⁱⁱ CBM Australia Inclusion Advisory Group. daniel@cbm.org.au

ⁱⁱⁱ For the purpose of this essay, 'development' refers to the international development and humanitarian sector.

^{iv} International Disability Alliance. 2020. Increasingly Consulted, but not yet Participating: IDA Global Survey on Participation of Organisations of Persons with Disabilities in Development Programmes and Policies, 2020. International Disability Alliance, Geneva. https://www.internationaldisabilityalliance.org/sites/default/files/ida_global_survey_complete_report_final.pdf

^v Committee on the Rights of Persons with Disabilities. 2018. General comment No. 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, Para 8.

[docstore_ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPrICAqhKb7yhsnbHatvuFkZ%2Bt93Y3D%2Baa2pjFyzWLBu0vA%2BBR7QovZhbuyqzjDN0plweYI46WXRJJ6aB3Mx4y%2FspT%2BQRy5K2mKse5zjo%2BfvBDVu%2B42R9iK1p](https://www.internationaldisabilityalliance.org/sites/default/files/ida_global_survey_complete_report_final.pdf)

^{vi} International Disability Alliance. 2020. Increasingly Consulted, but not yet Participating: IDA Global Survey on Participation of Organisations of Persons with Disabilities in Development Programmes and Policies, 2020. International Disability Alliance, Geneva. https://www.internationaldisabilityalliance.org/sites/default/files/ida_global_survey_complete_report_final.pdf

^{vii} The Development for All policy was explicitly noted as an exception to this – see page 64 of International Disability Alliance: International Disability Alliance. 2020. Increasingly Consulted, but not yet Participating: IDA Global Survey on Participation of Organisations of Persons with Disabilities in Development Programmes and Policies, 2020. International Disability Alliance, Geneva. https://www.internationaldisabilityalliance.org/sites/default/files/ida_global_survey_complete_report_final.pdf

^{viii} Best practice would aim towards ‘transformative’ engagement with OPDs. Building towards such engagement takes time. A first step is to ensure all consultations with people with disabilities and OPDs are rights-based. From here, development actors should progress to building transformative relationships with OPDs. Relevant resources for guidance on engaging with OPDs include: Water for Women. 2022. Partnerships for Transformation: Guidance for WASH and Rights Holder Organisations.

<https://www.waterforwomenfund.org/en/news/partnerships-for-transformation-guidance-for-wash-and-rights-holder-organisations.aspx>; CBM-Nossal Partnership for Disability-inclusive Development and Research for Development Impact Network. 2020. Research for all: Making Development Research Inclusive of People with Disabilities. <https://rdinetwork.org.au/wp-content/uploads/2020/06/RDI-Network-R4All-Accessible-PDF-1.pdf>; Gibson C and Bokoff, J. 2018. Deciding Together Shifting Power and Resources Through Participatory Grantmaking. <https://learningforfunders.candid.org/content/guides/deciding-together/>

^{ix} Australian Government Department of Foreign Affairs and Trade. 2023. Australia’s International Development Policy. <https://www.dfat.gov.au/publications/development/australias-international-development-policy>