UNPRPD FUND
Partnership on the Rights of Persons with Disabilities

MEANINGFUL PARTICIPATION

OF MARGINALIZED AND UNDERREPRESENTED PERSONS WITH DISABILITIES

GUIDANCE NOTE
2024

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TABLE OF CONTENTS

Executive Summary i

Essential Requirements for Engaging Marginalized and Underrepresented Persons with Disabilities in Programming ii

1. Introduction 1

2. How to include underrepresented and marginalized groups in Global Disability Fund Programmes 4

3. Advancing the Rights of Marginalized and Underrepresented Groups in Global Disability Fund Programmes 8

4. Addressing Intersectional Discrimination Experienced by Marginalized Persons with Disabilities in Global Disability Fund Programmes 15

5. Recommendations 16

Annexes 17

- Annex I: Rights priorities of underrepresented and marginalized persons with disabilities 17
- Annex II: Resources 22
- Annex III: Perspectives from marginalized persons with disabilities on intersectional rights and addressing multiple and overlapping forms of discrimination 24
- Annex IV: Including People with Intellectual Disabilities: Learning from Self-Advocates by Down Syndrome International and Inclusion International 26

EXECUTIVE SUMMARY

This guidance note provides technical guidance to UN organizations implementing Global Disability Fund (GDF) programmes on how they can advance the rights of marginalized and underrepresented persons with disabilities more effectively in joint programming. It supports UN organizations in designing, implementing, and monitoring joint programming that address the rights priorities of underrepresented and marginalized persons with disabilities including Deafblind persons, persons with intellectual disabilities, persons with albinism, persons with psychosocial disabilities as well as persons with disabilities marginalized on the basis of their disabilities and other identities (such as sexual orientation, gender identity or expression, indigenous origin, migrant status, age, racial minority status etc.) It offers guidance for all GDF programmes on designing, implementing, and monitoring initiatives that address the systemic and structural barriers to inclusion faced by marginalized and underrepresented groups, while also identifying and closing gaps in policies, services, and systems. The guidance serves as a comprehensive roadmap for how GDF programmes can outreach to and engage with OPDs representing marginalized and underrepresented persons with disabilities ensuring accessible and inclusive engagement processes and decision-making mechanisms. Finally, it outlines the rights priorities of marginalized and underrepresented groups and their recommendations for more equitable engagement and meaningful participation in decision-making and priority setting.

The guidance draws upon the expertise of global and regional organisations representing marginalized and underrepresented persons with disabilities including: the World Federation of Deafblind persons, Inclusion International, Down Syndrome International, Transforming Communities for Inclusion, World Network of Users and Survivors of Psychiatry and Global Albinism Alliance along with national and local level organisations representing diverse constituencies.

Sections 1 and 2 provide an overview of GDF's approach to addressing the rights of marginalized and underrepresented persons with disabilities with practical guidance on how to outreach to and include marginalized and underrepresented groups in programmes. Sections 3 and 4 outline the 3 policy and systems changes needed to ensure full participation of marginalized and underrepresented persons with disabilities and address multiple and overlapping forms of discrimination. Section V provides recommendations for UN organisations, donors and decision-makers. The annexes include detailed overview of the rights priorities of marginalized and underrepresented as well as key messages and recommendations. Annex IV was developed by Inclusion International and Down Syndrome International in collaboration with their members and outlines the priorities of persons with intellectual disabilities (self-advocates). Below is an overview of the essential requirements for engaging marginalized and underrepresented persons with disabilities in programming. It can be used as a checklist to help in designing, planning and implementing inclusive programmes.

ESSENTIAL REQUIREMENTS FOR ENGAGING MARGINALIZED AND UNDERREPRESENTED PERSONS WITH DISABILITIES IN PROGRAMMING

1. **Identification:** Map national and local organizations representing marginalized and underrepresented persons with disabilities (e.g., Deafblind persons, persons with intellectual disabilities, persons with psychosocial disabilities, persons with albinism, little people, refugees with disabilities, LGBTQI+ persons with disabilities, and indigenous persons with disabilities). Where formal organizations are absent, engage regional or global bodies (e.g., the World Federation of the Deafblind[1]), informal networks, self-help groups, or family organizations. Collaborate with broader rights movements, such as those advocating for Indigenous or LGBTQI+ rights to gain support in identifying marginalized persons with disabilities and partner with larger OPDs like national umbrella organizations to identify and support these groups.
2. **Set criteria for inclusion in multi-stakeholder mechanisms:** Develop criteria for inclusion of marginalized and underrepresented persons with disabilities in multi-stakeholder coordination and decision-making mechanisms within the Global Disability Fund programme. Ensure marginalized groups are supported to engage in these multi-stakeholder spaces to influence and shape policy and services.
3. **Set deliberate outputs in programming:** Design outputs that ensure marginalized and underrepresented persons with disabilities, through their representative organizations are meaningfully engaged in all stages of the programme cycle. This includes developing outputs for capacity building, working in partnership and data collection and monitoring disaggregated by disability type and other factors. all. This ensures programming reflects the full diversity of the disability community so that immediate interventions and long-term, systemic changes to implement the CRPD reflect the rights priorities of all persons with disabilities.
4. **Ensure accessible and inclusive processes and budgets:** All programme plans, information and communications must be available to all. This involves allocating time to understand the information access barriers of diverse groups so that Fund programmes do not exclude anyone. For example, providing tactile interpretation for Deafblind individuals, Easy-to-Read information, accessible transportation, individualized support, engaging support persons and ensuring physical accessibility of all programme facilities.
5. **Learn the rights priorities of underrepresented and marginalized groups:** Consult with marginalized and underrepresented groups to learn about the barriers they face, and their access needs to be able to participate. This information is crucial for designing programmes that include their perspectives and address needs meaningfully. It is also important to understand specific accessibility requirements of diverse groups so that engagement processes are fully accessible throughout the Global Disability Fund programme.

1 World Federation of the Deafblind: WFDB – The World Federation of The Deafblind; see Annex II for a list of global and regional organizations representing marginalized and underrepresented groups of persons with disabilities.

1 INTRODUCTION

The Global Disability Fund's approach to meaningful participation and engagement with underrepresented and marginalized groups

GDF defines underrepresented groups as persons with disabilities that have less visibility and representation in the disability movement including persons with intellectual disabilities, persons with psychosocial disabilities, Deafblind persons, persons with albinism, little people, persons with multiple disabilities. GDF defines marginalized persons with disabilities as those who experience marginalization on the basis of their disability as well as other intersecting factors and identities, such as age, gender, sexual orientation, gender identity or expression, ethnic minority status, race, migrant or refugee status, Indigenous origin, location, and socio-economic status etc. In addition, the Global Disability Fund acknowledges that in diverse local and national contexts, other specific groups may be identified as marginalized. Therefore, the Global Disability Fund recommends applying this guidance to the local context and consulting with local stakeholders to identify marginalized groups.

All persons with disabilities face discrimination and exclusion throughout the world. Persons with disabilities from underrepresented groups such as persons with intellectual disabilities, Deafblind persons, persons with albinism or persons with psychosocial disabilities, experience even greater marginalization and exclusion. Barriers to participation are exacerbated for persons with disabilities when multiple identities or characteristics intersect, such as age, gender, race, ethnic origin, sexual orientation and other identities or characteristics. For marginalized and underrepresented groups, poverty, exclusion, and limited access to resources and services are intensified when national laws, policies, and systems fail to adequately address their rights, priorities, and essential services and support needs. Furthermore, the lack of representation of marginalized and underrepresented groups of persons with disabilities in national civil society structures means their voices and perspectives are less visible in national advocacy efforts, despite crucial advocacy efforts made by OPDs. The The Global Disability Fund (GDF) supports programmes that make coordinated and deliberate actions by UN agencies, development and humanitarian actors, donors, state institutions and wider civil society to address the priorities of marginalized and underrepresented groups. GDF supports UN agencies, national duty-bearers, service providers and civil society actors to build meaningful partnerships with marginalized and underrepresented groups to ensure inclusive decision-making processes and national reforms that reflect the diverse priorities and needs of all persons with disabilities.

Center the perspectives and priorities of marginalized and underrepresented groups in policy making and programming

Persons with disabilities, and their representative organizations, continue to be sidelined from policy making and programming leading to decisions made on their behalf, disempowerment, and broader social exclusion. Organizations representing more marginalized and underrepresented groups have had even less access to decision-making spaces, resources, and capacity building opportunities. Ensuring the rights of marginalized and underrepresented persons with disabilities means their perspectives and expertise must be included in policy and systems changes needed to accelerate CRPD implementation and advance the rights of all persons with disabilities. This is also central to achieving the Sustainable Development Goals and realizing the 2030 Global Goals within the Leave No One Behind framework.

By centering those most marginalized in development, humanitarian action and climate action programming, UN agencies and their Global Disability Fund programme partners including government and civil society have an opportunity to dismantle the multiple and overlapping barriers to participation. This also ensures programmes, systems and services are responsive to and inclusive of the diversity of the disability community, including those groups that are more marginalized and underrepresented.

Engagement through partnership and inclusion in decision-making

The Global Disability Fund is committed to partnership building with underrepresented and marginalized groups. This is built into the Fund's Strategic Operational Framework through three cross-cutting approaches[2]; partnership with organisations of persons with disabilities (OPDs), gender equality and diversity. Persons with disabilities, through their representative organizations, are critical partners in Global Disability Fund programmes and they play decision-making roles in policy and systems changes that impact their lives. To do this effectively and meaningfully, participation must be inclusive of the diversity of the disability movement ensuring all priorities and perspectives are heard and duly considered. It is imperative that programmes engage the diversity of the disability community to leave no one behind. This approach will also ensure that programmes are designed to address multiple and overlapping forms of exclusion, effectively leading to longer-term and more systemic change.

Global Disability Fund programmes can be most effective in addressing the rights of diverse groups by engaging with OPDs representing marginalized and underrepresented persons with disabilities and forming partnerships and inclusive decision-making processes. When such organizations do not yet exist, efforts should be made to solicit missing perspectives through consultations, qualitative data collection, discussions with national, regional, or international OPDs, outreach to informal groups such as self-help groups representing marginalized and underrepresented groups. Meaningful participation and partnership with marginalized and underrepresented groups must encompass capacity building and inclusive and accessible modalities for engagement.

Methodology

For this guidance note, the Global Disability Fund Technical Secretariat carried out in-depth interviews with global and regional organizations of underrepresented and marginalized persons with disabilities. Through this qualitative data collection process, the Technical Secretariat gathered the rights priorities of marginalized constituencies and recommendations for how to engage groups more effectively at the national level. In particular, the Technical Secretariat engaged with global and regional members of the International Disability Alliance. The consultations also included marginalized groups that are not formal members of the International Disability Alliance working at national and regional levels. For the scope of this report, the Global Disability Fund gathered input from Deafblind persons, persons with intellectual disabilities, persons with psychosocial disabilities and persons with albinism. The Global Disability Fund also interviewed organizations representing multiply marginalized groups including indigenous peoples with disabilities and persons with disabilities from the LGBTQI+ community.

The Global Disability Fund also engaged Inclusion International and Down Syndrome International to carry out in-depth consultations with self-advocates in different regions of the world. This collaboration was crucial to ensure the priorities of people with intellectual disabilities were clearly outlined and to facilitate accessible, inclusive data collection processes. Through these efforts, self-advocates were also able to articulate how UN agencies, donors, and other development stakeholders can better support self-advocates and strengthen the self-advocacy movement (see Annex IV).

The Global Disability Fund acknowledges that there are marginalized and underrepresented constituencies beyond those specifically mentioned in this document. It recognizes that the identities of persons with disabilities globally are diverse and multifaceted, and that the complexity of their experiences and priorities cannot be fully encapsulated in this guidance note. This recognition underscores the importance of an inclusive and comprehensive approach to addressing the rights of all persons with disabilities.

2 These cross-cutting approaches are built into GDF Fund's Governance, Strategic Operational Framework, Programme cycle, monitoring and evaluation, knowledge management and learning. See GDF Fund's cross-cutting brief: GDF Strategic Operational Framework: Briefing on Cross-Cutting Approaches

It should be noted that in doing a literature review on disability and diversity to understand how disability intersects with other identities and factors, there are very few available resources. When resources do exist, the focus is largely on disability and gender intersections.

Understanding the diversity of the disability community

There are approximately 1.3 billion persons with disabilities in the world.[3] These 1.3. billion persons with disabilities are not a homogenous group; they represent diverse disability groups with diverse backgrounds, experiences, and identities. There are diverse disability groups, and some are less represented in the disability movement and at greater risk of exclusion and marginalization such as Deafblind persons, persons with intellectual disabilities, little people, persons with albinism, persons with intellectual disabilities, persons with psychosocial disabilities, persons with albinism and persons with multiple disabilities. Identity factors such as sex, age, gender identity, gender expression, sexual orientation, religion, socio-economic situation, geographic location, migration status, indigenous origin etc. affect their experiences exercising rights, accessing services, and being included. At the same time, these groups may not be well represented within the disability movement or other civil society movements.

In most contexts, the disability movement is led by OPDs representing various disability groups (organizations of blind persons, organizations of deaf persons, organizations of persons with physical disabilities etc.) with a focus on the access of requirements and rights of these specific groups. National federation structures or national umbrella organizations representing many different OPD members aim to advocate for cross-disability issues. There are a growing number of disability-led organizations that are cross-disability representing different disability groups focusing collective advocacy on disability inequality.

In many contexts, the dominant structure of the disability movement is led by certain disability groups leaving many constituencies underrepresented at local and national levels. This includes persons with intellectual disabilities (self-advocates)[4], Deafblind persons, persons with psychosocial disabilities, persons with albinism, little people, persons with autism and persons with multiple disabilities. There are few organizations at the national level representing these constituencies, and they are underrepresented in leadership roles within disability-led organizations.

At the global and regional levels, the International Disability Alliance, an alliance of global and regional organizations of persons with disabilities, includes underrepresented constituencies such as: the World Federation of Deafblind, Inclusion International, an organization of people with intellectual disabilities and their families, Down Syndrome International, a global network of people with Down Syndrome and their families, World Network of Users and Survivors of Psychiatry, an organization of persons with psychosocial disabilities. See here for the list of global and regional level organizations.

Persons with disabilities with intersecting identities such as persons with disabilities from the LGBTQI+ community, indigenous peoples with disabilities, persons with disabilities who are ethnic minorities, children and older persons with disabilities are often less visible in the mainstream disability movement as well as other human rights movements. The lack of visibility and representation of marginalized persons with disabilities limits the prioritization of rights issues impacting these groups.

There are some OPDs that take an intersectional approach representing other identity factors such as race, gender, age, indigenous origin, sexual orientation, gender identity or expression. For example, in Nepal, there is an organization of indigenous women with disabilities advocating at the national level for the rights of these communities. In Fiji, there is an organization representing persons with disabilities from the LGBTQI community. For more about the disability movement and role of OPDs see the Global Disability Fund's guidance: Guidance note on effective and meaningful participation of persons with disabilities through their representative organisations in GDF joint programming

3 See: Global Report on Health Equity for Persons with Disabilities. Geneva: World Health Organization; 2022. License: CC BY-NC-SA 3.0 IGO. Available at: https://www.who.int/publications/i/item/9789240063600

4 The terms self-advocacy and self-advocate come from a movement by people with intellectual disabilities and their families when they no longer wanted other people to advocate on their behalf. The term self-advocate will be used throughout the guidance to refer to people with intellectual disabilities.

2 HOW TO INCLUDE UNDERREPRESENTED AND MARGINALIZED GROUPS IN GLOBAL DISABILITY FUND PROGRAMMES

Underrepresented and marginalized persons with disabilities continue to face egregious human rights violations such as institutionalization, forced or coerced medical treatments, violence and abuse and lack of access to justice services and support. It is critical that Global Disability Fund programmes ensure the rights of marginalized and underrepresented groups in national policy, law, and systems reforms. By excluding their rights priorities and services and support needs in national reforms, governments risk creating long-term discriminatory and exclusionary policy frameworks that perpetuate harmful and stigmatizing practices. For example, if inclusive education policy reforms do not consider the specific access and support needs of deafblind learners, deafblind students will continue to be left behind with greater risk of dropping out of the education system. In humanitarian action and protection programmes, coordination mechanisms must address the increased risks of violence persons with intellectual disabilities face. Similarly, when countries reform sexual and reproductive health rights policies, policymakers must include the barriers marginalized women with disabilities face in accessing these services.

This section of the guidance provides a practical overview of the key steps that can be taken to ensure the rights of marginalized and underrepresented groups are addressed in programming, outreach, and partnerships.

How to identify, outreach and include underrepresented and marginalized groups

Across various settings, there are few formalized organizations of marginalized and underrepresented persons with disabilities. According to the World Federation of the Deafblind (WFDB), there are still only a small number of national organizations of Deafblind persons in lower- and middle-income countries. When organisations do exist, they are seldom represented within the membership of national umbrella structures.[5] Similarly, persons with albinism are significantly underrepresented in civil society. According to research carried out in 2008, there were fewer than an estimated 30 groups of persons with albinism globally. In the past 15 years, that number has more than quadrupled, with the greatest growth occurring in Africa.[6]

Organisations of self-advocates and their families are structured differently in different contexts; they may be affiliated with family or advocacy organizations, or they may be led by self-advocates. However, in many countries, there may not be a strong self-advocate movement and the voices of people with intellectual

5 Tarczay, Sanja, President, World Federation of the Deafblind, Zoom interview, April 5, 2024.

6 Antoine Gliksohn, Executive Director, Global Albinism Alliance, Zoom interview, April 8, 2024.

disabilities may not be well represented in the disability movement at the national level.[7] For persons with psychosocial disabilities, there are a growing number of representative organizations formed at local and national levels. However, they still face barriers to participation in wider civil society structures.[8] Marginalized persons with disabilities such as indigenous persons with disabilities, LGBTQI+ persons with disabilities or persons with disabilities marginalized based on other non-majority identities are even less visible in mainstream disability movements.

The lack of representation of underrepresented and marginalized persons with disabilities within national bodies such as national disability umbrella structures, makes it challenging for donors, governments, UN agencies and other stakeholders to engage with more marginalized constituencies. This also makes it challenging to identify organizations at the grassroots level or those that are more informally structured. Interviewees suggest that if no organizations represent marginalized and underrepresented groups at the national level or within the national disability umbrella body, UN agencies should directly engage with organizations, including informal structures and networks, that represent these groups, rather than relying solely on the national umbrella organization. If it is challenging to identify groups or networks of underrepresented or marginalized groups, WFDB recommends contacting regional bodies or global level OPDs. For example, if there are no national organizations of Deafblind persons, there is an East Africa Deafblind organization based in Uganda working with Deafblind groups in Kenya, Uganda, and Malawi. In cases where there aren't regional or national organizations in place, it is important to contact global level organizations like WFDB, Global Alliance for Albinism (GAA), Inclusion International, Down Syndrome International, World Network of Users and Survivors of Psychiatry (WNUSP) or Transforming Communities for Inclusion Global (TCI)[9] to help identify organizations working in nearby countries or regions. Additionally, consulting at the national level with members of national umbrella structure to help identify informal or newly established groups. For example, WFDB recommends consulting with Deaf Associations or Blind Associations who may know of Deafblind groups within.[10]

For outreach to marginalized persons with disabilities such as indigenous persons with disabilities, UN agencies should consult indigenous peoples' organizations who can help identify indigenous members with disabilities. Similarly, to engage on the rights of LGBTQI+ persons with disabilities, interviewees recommended reaching out to mainstream LGBTQI+ organizations or organizations working on HIV/AIDS or sexual and reproductive health rights to see if they can identify members with disabilities who are willing to engage with other stakeholders. Disability activists who identify as LGBTQ+ have suggested that there is animosity from the mainstream disability movement in the forms of homophobia and transphobia.[11] However, there may be other civil society organizations that persons with disabilities from marginalized groups may be participating in beyond the disability movement such as LGBTQ+ groups.

It is important to consider safely and security of persons with disabilities working at the intersections of disability rights and other human rights issues such as LGBTQI+ rights, indigenous peoples rights, SRHR or gender equality in restrictive contexts. This is especially important when people do not openly identify as LGBTQI+. Safely engaging marginalized individuals requires collaborations with organizations that are familiar with their lived experiences, the potential risks they may face, and appropriate strategies to minimise these risks. Privacy and security considerations should be made to ensure no one is placed at risk through the identification and outreach process. The Global Disability Fund Technical Secretariat can also be a resource for connecting to organizations of marginalized persons with disabilities in different regions.

7 From consultations carried out by Inclusion International and Down Syndrome International with self-advocates and their families as part of the research for this guidance note. More detailed findings are available in Annex IV.

8 Daniel Mwesigwa Iga, Acting Chair of World Network of Users and Survivors of Psychiatry, Zoom Interview, April 3, 2024.

9 TCI Global is a post-CRPD movement of persons with psychosocial disabilities and its cross-disability supporters. It is a membership-based global OPD.

10 Tarczay, Sanja, President, World Federation of the Deafblind, Zoom interview, April 5, 2024.

11 Joint interview coordinated by AMERTA REKSA KAYANA (ARK) Foundation, Indonesia with Pelangi Disabilitas Yogyakarta, Indonesia (Rainbow of Disabilities Yogyakarta), and Perhimpunan Warna Disabilitas (Association of Colorful Persons with Disabilities) Indonesia, April 12, 2024, Zoom interview.

When working with underrepresented groups such as persons with intellectual disabilities, autistic persons, deafblind persons, or persons with psychosocial disabilities, it is critical to ensure that the representatives with whom you engage represent the constituent group. It is important to engage with members directly rather than staff and caregivers/personal assistants without disabilities from making decisions or speaking on their behalf. Ask if the OPD is composed of and represents the views and opinions of the underrepresented group, despite having support from staff without disabilities (even extensive support from parents or persons without disabilities). For example, are they responsible for decision-making regarding finances, policy positions, and organizational priorities?

Drawing from the Global Disability Fund's experience[12] it is important to consider key factors that will enable more fruitful engagement. For Global Disability Fund programmes, these are the essential enablers for meaningful engagement with OPDs.

- Ensure clear and accessible **communication** being clear about goals, objectives and intended outcomes, clarity of expectations, roles, and long-term plans
- **Inclusivity** – providing equal access to opportunities, resources, and information (understanding how to fully include people in processes and not exclude anyone)
- **Accessibility** – providing access to diverse persons with disabilities including physical, information and communication (e.g., Sign Language interpretation, tactile interpretation, Easy-to-Read and Easy-to-Understand[13] information and communication) as well as individualized support needed to access processes (such as personal assistance and accessible transportation)
- **Transparency** about the process and the mechanisms for engaging and decision-making
- **Build trust and responsibility** to work together and fulfil agreed roles
- **Capacity building** to bridge the gap and ensure participation is meaningful not just tokenistic
- Establish a place at the table for **priority setting** and ensure that **follow-up** is planned beyond consultations

Accessible and inclusive planning

It is crucial to allocate resources and plan for inclusive outreach and engagement with marginalized and underrepresented groups. Accessibility needs and reasonable accommodations can vary widely among individuals. Therefore, it is essential to schedule time to consult with diverse groups to understand their specific access requirements and how best to meet them. Addressing complex accessibility and support needs requires thorough planning and sufficient time. Additionally, programmes should allocate adequate budgets to ensure ongoing, inclusive engagement throughout the program cycle. Incorporating these considerations from the outset is vital to dismantling barriers to access and promoting inclusive engagement from the outset.

One challenge UN agencies may face is identifying accessibility services to provide needed support. For instance, it might be the first time PUNOs are arranging for Easy-to-Read translation services or mobility guides and interpreters for Deafblind individuals. A helpful approach is to consult organizations that represent these groups to obtain recommendations for service providers and support personnel. Another valuable resource are national, global, and regional OPDs representing more marginalized groups to provide resources and guidance on accessibility.

12 The importance of pre-conditions for engagement are also highlighted in the 2022 global survey on OPD engagement by the International Disability Alliance, OPD Engagement in Development and Humanitarian Action: Global Disability Summit (GDS) Discussion Paper, 2022: Global Disability Summit (GDS) Discussion Paper, 2022 (internationaldisabilityalliance.org)

13 Learn more about Easy-to-Read and easy-to-understand communication and other tools at Listen Include Respect guidelines on how to include people with intellectual disabilities: Listen Include Respect | Intellectual Disability

Participation and representation in decision-making and agenda setting

It is essential to engage grassroots organizations and marginalized groups at all levels of policy discussions and national development reforms. To do this it is important for the UN and other development stakeholders and donors to build bridges with grassroots organizations representing marginalized groups of persons with disabilities[14]. Marginalized persons with disabilities understand the issues they are facing and can outline their priorities for achieving a more inclusive society and provide expertise on how to be more inclusive and accessible. Facilitating dialogues with marginalized groups allows government, UN, and other stakeholders to better understand their challenges and the cause for the barriers they face. Global Disability Fund programmes can provide dedicated spaces to transition the engagement process from identifying problems to generating meaningful solutions. Given the unique experience of marginalized and underrepresented persons with disabilities, they are uniquely positioned to propose inputs on workable solutions.

Voices and perspectives of persons with disabilities are often left out of priority setting at the national level on policies, systems and services that impact their lives. For example, persons with psychosocial disabilities at the grassroots level are often left behind in poverty eradication efforts and their organizations are excluded from development processes.[15] For persons with albinism, the critical rights issues they face such as trafficking, torture, ritual killings, and lack of access to life saving health services are still not on the global agenda.[16] Global Disability Fund programmes can design targeted interventions that meaningfully include marginalized and underrepresented persons with disabilities in priority-setting processes and national policy dialogues.

When consultations do engage persons with disabilities, they are often not provided adequate information, accommodations or be carried out using accessible modalities to enable marginalized and underrepresented persons with disabilities to have agency and provide inputs. This leads to presence without voice and voice without influence. In research conducted on engagement of marginalized communities in global health research, researchers found that those most marginalized who often experience greatest health inequities, were listened to least within health priority setting.[17]

It is important that the engagement process does not stop with creating space at the table for marginalized persons with disabilities to share input. Follow up is essential so that communities feel they have been heard and their input made a difference.[18] For example, follow up support could be built into Global Disability Fund programmes to help build the capacity of smaller more grassroots constituencies of persons with disabilities in engagement in sub-national decision-making processes on issues affecting their lives. It is also important to foster these relationships to get to know one another and build trust ensuring stakeholders representing marginalized disability communities are listened to and that they have the information they need to be able to contribute to priority setting processes.

14 This means consulting beyond national level OPDs such as national umbrella structures and developing connection with local grassroots organizations and structures beyond the capital and informal groups

15 Daniel Mwesigwa Iga, Acting Chair of World Network of Users and Survivors of Psychiatry, Zoom Interview, April 3, 2024.

16 Antoine Gliksohn, Executive Director, Global Albinism Alliance, Zoom interview, April 8, 2024.

17 Bridget Pratt, Towards inclusive priority-setting for global health research projects: recommendations for sharing power with communities, Health Policy and Planning, Volume 34, Issue 5, June 2019, Pages 346–357, https://doi.org/10.1093/heapol/czz041

18 See: Engaging Marginalized Communities: Challenges and Best Practices | icma.org

3 ADVANCING THE RIGHTS OF MARGINALIZED AND UNDERREPRESENTED GROUPS IN GLOBAL DISABILITY FUND PROGRAMMES

Underrepresented and marginalized persons with disabilities continue to face egregious human rights violations such as institutionalization, forced or coerced medical treatments, violence and abuse and lack of access to justice services and support. It is critical that Global Disability Fund programmes ensure the rights of marginalized and underrepresented groups in national policy, law, and systems reforms. This requires an understanding of the rights issues marginalized and underrepresented groups face in their specific local and national context. It also requires comprehensive reforms to the legal and policy framework that address the rights of marginalized and underrepresented groups to ensure long-term systemic change. It also means designing programmes that address the multiple and intersecting forms of discrimination marginalized and underrepresented persons with disabilities face in all objectives and activities as well as to plan targeted programming.

The following section is organized by the essential pre-conditions to inclusion that cut across sectors. These fundamental building blocks are needed to ensure the inclusion, autonomy, and dignity of all persons with disabilities.

Equality and non-discrimination

As defined in the CRPD, disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation on an equal basis with others. Disability-based stigma and discrimination is rooted in ableism which is based on social and cultural norms and beliefs that define persons with disabilities as inferior. Ableism differs depending on gender, type of disability and other social factors with biases towards specific disability groups (such as persons with psychosocial disabilities, persons with albinism and persons with intellectual disabilities) resulting in higher levels of stigma and discrimination.[19]

Other aspects of a person's identity such as ethnicity, gender, sexual orientation, socio-economic status, indigenous origin etc. can contribute to multiple and overlapping forms of discrimination and stigmatizing attitudes and beliefs.[20] For example, there are multiple rights issues at stake for indigenous persons with disabilities ranging from respect and understanding for collective rights of indigenous peoples, self-determination, and protection of linguistic rights to Indigenous languages as well as the rights enshrined in the CRPD.[21]

19 Timmons, S., McGinnity, F., & Carroll, E. (2024). Ableism differs by disability, gender and social context: Evidence from vignette experiments. British Journal of Social Psychology, 63, 637–657. https://doi.org/10.1111/bjso.12696

20 CRPD Committee, General Comment no. 6 (2018) on equality and non-discrimination, Session 17, 26 April 2018, CRPD/C/GC/6: CRPD/C/GC/6

21 Pratima Gurung, President of National Indigenous Disabled Women Association of Nepal, April 12, 2024, Zoom Interview.

As revealed through in-depth interviews with organizations of underrepresented and marginalized persons with disabilities, harmful stigma and discriminatory practices and beliefs continue to threaten their life, liberty and security through violence, targeted killings, forced institutionalization, forced or coerced sterilization and deprivation of decision-making. All interviewees highlighted the importance of reforming the legal and policy frameworks to fully implement CRPD Article 5 (Equality and Non-Discrimination) to prohibit disability-based discrimination and recognize denial of reasonable accommodations as a form of discrimination.

If the legal framework does not expand anti-discrimination protections to include underrepresented and marginalized persons with disabilities, it puts these groups at greater risk of exclusion and discrimination. For example, if the legal and policy frameworks do not address the deeply engrained stigma and discrimination against persons with albinism, harmful beliefs and practices that enable violence, including torture and ritual killings, will continue, especially in contexts where the physical appearance of persons with albinism are hyper-visible. Similarly, widespread stigmatizing beliefs about persons with psychosocial disabilities perpetuate inhumane practices such as shackling, chaining or confining them, depriving them of their liberty for long periods of time.[22]

Equal rights before the law

Persons with disabilities throughout the world are denied their rights to equal recognition as persons before the law. This strips them of the right to legal capacity and to make their own decisions about their lives such as having a bank account, entering a housing contract or getting married. Persons with psychosocial disabilities and persons with intellectual disabilities are disproportionately deprived of these rights and placed under substitute decision-making mechanisms such as guardianship or conservatorship and denied the right to make their own decisions about their lives. Interviewees explained that even when legal capacity has not been formally taken away, families and community members often prevent members with disabilities from making their own decisions. For persons with disabilities, having access to supported decision-making services is essential to protect marginalized and underrepresented groups from being deprived of their right to decision-making and choice.

How this can be addressed in Global Disability Fund programmes

Equality and non-discrimination: In designing Global Disability Fund programmes, consider the national legal and policy framework and how underrepresented and marginalized groups are protected. It is also important to analyze if the legal and policy framework is discriminatory of certain disability groups. For marginalized and underrepresented groups of persons with disabilities, consider the rights protections to be addressed by the legal and policy framework:

- Anti-discrimination laws must be broadened to ensure the definition of disability is wide, thereby extending protections to persons with disabilities in all their diversity. This should be done in consultation with OPDs and adapted to the national context.
- The anti-discrimination legal framework must recognize multiple and intersecting forms of discrimination for persons with disabilities with multiple and overlapping identities such as LGBTQI+ persons with disabilities, indigenous persons with disabilities, women, and girls with disabilities etc.[23]
- The right to equal decision-making before the law must be recognized for all persons with disabilities with supported decision-making services in place in line with CRPD Article 12 (Equal Recognition Before the Law)
- Laws that deprive persons with disabilities of their legal capacity and personhood must be reviewed and repealed or amended

22 Human Rights Watch, Living in Chains: Shackling of People with Psychosocial disabilities Worldwide, 2020: Living in Chains: Shackling of People with Psychosocial Disabilities Worldwide | HRW

23 See: CRPD Committee, General Comment no. 6 (2018) on equality and non-discrimination, Session 17, 26 April 2018, CRPD/C/GC/6: CRPD/C/GC/6

- Measures must be in place to ensure persons with disabilities have support to exercise their legal capacity
- Disability discriminatory laws and policies across sectors should be systematically reviewed and amended including laws on education, equal recognition before the law and mental health and remove derogatory and stigmatizing terms such as 'persons of unsound mind' or 'mental retardation' and set in place a human rights understanding of disability within anti-discrimination and human rights frameworks
- Address the right to life, security, and protection from torture and inhumane treatment including ending infanticide and targeting killings of persons with disabilities, particularly groups disproportionately impacted by violence such as persons with albinism, persons with disabilities of diverse SOGIESC, persons with psychosocial disabilities, persons with intellectual disabilities, women with diverse disabilities, indigenous persons with disabilities etc.
- Invest in dispelling stigma and discrimination and the root causes of harmful beliefs, social and cultural norms about underrepresented and marginalized persons with disabilities as critical part of instituting systemic reforms to ensure persons with disabilities can exercise their human rights to participation and be free from violence, exploitation, and abuse

Accessibility

Accessibility is essential for persons with disabilities to live independently and participate in society equally. It is one of the fundamental principles upon which the CRPD was founded. For marginalized persons with disabilities with complex accessibility needs, it means providing technology, products and services to remove barriers to participation. For Deafblind persons, for example, they may need tactile communication, assistive devices or technology and live assistance (such as a guide and a Deafblind interpreter). For persons with intellectual disabilities, they may need a support person or personal assistant and Easy-to-Read communication and information. For an indigenous person with disabilities, they may need accessible transportation which could be challenging to procure in rural or remote areas. They may also require Sign Language interpretation in an indigenous language to participate in a meeting or at work.

How this can be addressed in Global Disability Fund programmes

Consider if there are opportunities to influence ongoing legal and policy reforms on accessibility standards, public services and infrastructure laws, information, communication or technology standards, or public transportation protocols and plans. Consider the following key reform aspects to effectively address the legal and policy framework:

- Accessibility standards should be developed at the national level, with enforcement mechanisms, and adopt the principle of universal design as this will consider the diversity of the access needs[24]
- These diverse accessibility needs of marginalized and underrepresented persons with disabilities must be factored into legislation to ensure the right to access, on an equal basis, to the physical environment, transportation, services, information, and communications including Information and Communications Technology (ICT) and other services provided to the public, in both rural and urban areas
- Within local development planning and city planning processes, engage marginalized and underrepresented persons with disabilities to understand their diverse access needs and how to shape accessible planning

CRPD compliant budgeting

To ensure governments are fulfilling their CRPD obligations, the overall public finance management and budgeting system must ensure that maximum available resources are used to implement the CRPD. For marginalized and underrepresented persons with disabilities who face greater barriers to participation and have limited access to

24 See: CRPD Committee, General Comment No.2 Article 9: Accessibility, 11th Session, 22 May 2014, CRPD/C/GC/2, CRPD Comm GC 2

resources, CRPD-compliant budgeting is a vital tool for establishing policies, services, and systems that promote inclusion and equal opportunities.

To achieve CRPD compliant budgeting, the planning and execution of public budgets must comply with the provisions of the CRPD including:

- Central and local government public budgets plan equitably for all persons with disabilities including underrepresented and marginalized groups across all ministries and levels of government
- This must be done with the meaningful engagement of representative organizations of all persons with disabilities with specific attention to the most marginalized groups[25]
- Training and capacity building for public authorities to understand the CRPD, to assess if sufficient public funds are spent to realize the rights of all persons with disabilities including marginalized and underrepresented constituencies[26]

How this can be addressed in Global Disability Fund programmes

Design initiatives to support governments to understand current public spending on disability and assess gaps with initiatives such as:

- Carrying out a disability budget analysis to assess how public finances contribute to the realization of the human rights to all persons with disabilities in line with the CRPD
- Use this analysis to also address if there is public spending on programmes and services that are in contradiction of the CRPD or if spending creates additional barriers for persons with disabilities
- Assess how public finances could be mobilized across sectors
- Analyze if there are investments made to support inclusion of underrepresented and marginalized groups[27]

Accountability and governance

Accountability and governance systems in place to implement the CRPD must account for the diversity of the disability community to ensure effective national implementation, monitoring and coordination across sectors. Inclusive evidence and data on persons with disabilities is an essential part of effective national implementation efforts. However, the disability data gap for both qualitative and quantitative data is acute when it comes to marginalized and underrepresented groups of persons with disabilities perpetuating their exclusion from equity and development planning and data driven policy making.[28]

The Washington Group on Disability Statistics[29] provides sets of questions to be used in national surveys and censuses. These question sets are critical tools for filling the disability data gap. However, the Washington Group questions do not cover every disability aspect of disability and certain groups, like persons with psychosocial disabilities, or persons with disabilities with multiple and overlapping identities, are not captured such as persons with disabilities of indigenous origin or LGBTQI+ persons with disabilities.

25 Center for Inclusive Policy, Inclusive CRPD Budgeting Brief. Clarification needed: Inclusive, Disability Responsive or CRPD compliant budgeting? May2019, available at: Inclusive-CRPD-budgeting-Brief_1006_-web.pdf

26 Center for Inclusive Policy, Inclusive CRPD Budgeting Brief. Clarification needed: Inclusive, Disability Responsive or CRPD compliant budgeting? May2019, available at: Inclusive-CRPD-budgeting-Brief_1006_-web.pdf

27 See: Center for Inclusive Policy, Inclusive CRPD Budgeting Brief: Inclusive-CRPD-budgeting-Brief_1006_-web.pdf

28 See: Disability Data Initiative - Advancing the Rights of Persons with Disabilities (fordham.edu) The Lancet Global Health, Volume 9, Issue 8, e1028 Disability: measurement matters - The Lancet Global Health

29 See: and Washington Group Questions: Question Sets - The Washington Group on Disability Statistics

How this can be addressed in Global Disability Fund programmes

Build disability inclusive data into the programme objectives to:

- Work with national statistics offices and other relevant actors engaged in national level data collection and research to raise awareness on the importance of using Washington Group questions in censuses and surveys
- Build capacities of national statistics offices to collect disability disaggregated data in national and sub-national data collection processes using the Washington Group questions and analysis
- Support research co-led by organizations of marginalized and underrepresented groups
- Support national and sub-national data collection processes to understand the situation of marginalized and underrepresented persons with disabilities through both quantitative and qualitative data

Service delivery

Access to rights-based services and support that are designed to meet the needs of diverse disability groups and to persons with disabilities with multiple and intersecting identities is an essential pre-condition to participation on an equal basis in education, work, and employment amongst other areas of life. Yet for many underrepresented and marginalized groups of persons with disabilities, services and support systems are not designed to respond to their diverse needs and when they do exist, they are not readily available, accessible or affordable.

Mainstream services, as well as disability specific services and support, must be designed to respond to a diversity of people, including those most marginalized. They must be available, accessible, and affordable at national and local levels. For example, policy and systems reforms must address the specific services and support needs of persons with intellectual disabilities to live independently, make decisions with support, have access to support persons of their choice, and access education and work. Without taking these rights into consideration, the risk is that funding could be directed to segregated systems such as residential institutions or segregated forms of education. For persons with psychosocial disabilities, their welfare will be regulated through outdated mental health policies focused on 'curing' or 'fixing' the person's disability through medical procedures and practices that are often inhumane, violent, and done without their consent. Instead, the focus should be on developing mental health/psycho-social support services within the community.

Mainstream services as well as support services must be designed to be disability and gender responsive, accessible and enable full participation including social protection and other benefits. For example:

- Access to quality health skin cancer screening, prevention, and treatment services for persons with albinism
- Eye health services that are responsive to the unique needs of Deafblind persons
- Community mental health services such as counselling and support that are available and affordable
- Violence protection and prevention services that address the pervasive threats faced by underrepresented and marginalized persons with disabilities such as women with albinism, indigenous persons with disabilities, persons with psychosocial disabilities
- Sexual and reproductive health services address the multiple and intersecting barriers marginalized persons with disabilities face in accessing services such as persons with disabilities from the LGBTQI+ community

In addition to disability responsive mainstream services, support services must be designed to address the specific needs of underrepresented and marginalized persons with disabilities to live independently in the community. For example:

- Support services to live independently in the community designed to support Deafblind persons (such as personal assistance or accessible transportation services)
- Supported decision-making services for persons with psychosocial disabilities and persons with intellectual disabilities

- Deafblind interpreter and mobility guides
- Support services available in rural and remote areas where indigenous persons with disabilities live

Access to education services and support

- Learners with intellectual disabilities are provided individualized support measures at school, as well as the facilitation of accessible communication modes and methods, and delivery of education using communication modes relevant to the individual learner
- Students with diverse disabilities, including Deafblind learners, persons with intellectual disabilities and students with albinism, have access to assistive devices and technologies, and access to live assistance
- Students with disabilities are provided extra individual support they need in the classroom with peers with and without disabilities including students with intellectual disabilities
- Students with disabilities, including marginalized and underrepresented groups, are not excluded or placed in separate, segregated education settings
- Teachers are trained to teach in ways that match diverse learning styles
- Anti-bullying campaigns are carried out in schools and communities to ensure all students with disabilities can learn and feel safe in the classroom including learners with albinism

Access to work and employment services and support

- Supported employment programmes are widely available to support persons with intellectual disabilities to work in the open labor market
- All persons with disabilities are included in vocational training and access to mainstream entrepreneurship opportunities and skills training that are inclusive and accessible with the support and accommodations needed to succeed
- Persons with disabilities, including marginalized and underrepresented groups, are not placed in separate work or employment settings outside the mainstream labor force such as sheltered workshops
- Employers and vocational training institutes have the tools and awareness to ensure workplaces are inclusive and accessible to diverse persons with disabilities including Deafblind persons, persons with intellectual disabilities, persons with albinism, persons with psychosocial disabilities and persons with disabilities marginalized based on multiple identities

How this can be addressed in Global Disability Fund programmes

- Legal and policy frameworks must recognize diverse types of disabilities, such as Deafblindness, to ensure that systems and services are designed to address their unique needs including in social protection systems (such as personal assistance and interpreter services specifically designed for Deafblind communication or skin cancer prevention programmes designed for persons with albinism)
- Disability determination systems must align with a rights-based approach to accessing services in which the definition of disability is in line with the CRPD and eligibility for services and benefits move away from the medical model
- Availability of support and services that meet the needs of diverse persons with disabilities such as supported decision-making, particularly for persons with intellectual disabilities, personal assistance services to live independently in the community, interpreter services for Deafblind persons, communication services for easy-to-understand language translation for persons with intellectual disabilities. These diverse services must be fully accessible, affordable and available national to local level

- Services and support must be designed to enable life in the community in which diverse persons with disabilities can exercise autonomy, dignity and choice in the care and support they receive
- States should invest in community services and de-institutionalization reforms including all forms of congregate care such as psychiatric facilities and wards in hospitals and residential institutions. In the transition to community care, states can provide interim services such as mobile services, home visits and outreach
- Multiple and intersectional approach to support and care that is disability inclusive and gender responsive[30] so that services and support are designed to address multiple and overlapping forms of discrimination marginalized persons with disabilities experiencing in accessing services including sexual and reproductive health services and gender-based violence protection and prevention

For services that prevent and protect from violence, exploitation or abuse

- Ensure access to gender-based violence prevention and protection services are inclusive and accessible to all persons with disabilities including access to judicial processes to report violence, abuse or torture seek redress from the legal system
- Ensure services addressing prevention and protection from violence, abuse and exploitation address the specific forms of violence, abuse and exploitation disproportionately impacting persons with disabilities such as persons with albinism, LGBTQI+ persons with disabilities, persons with psychosocial disabilities, persons with intellectual disabilities etc.

30 Catalina Devandas Aguilar, Report of the Special Rapporteur on the Rights of Persons with Disabilities, Human Rights Council Thirty-fourth session, A/HRC/34/58, December 12, 2017: A/HRC/37/56

4 ADDRESSING INTERSECTIONAL DISCRIMINATION EXPERIENCED BY MARGINALIZED PERSONS WITH DISABILITIES IN GLOBAL DISABILITY FUND PROGRAMMES

It is important to also understand the marginalization faced by persons with disabilities experiencing intersectional forms of discrimination and exclusion based on their disability and other identity factors. States need to acknowledge the different layers of identities within the disability community. Persons with disabilities comprise a very heterogeneous group with a wide range of impairments as well as identity markers such as race, colour, sex, sexual orientation, gender identity, language, religion, national, ethnic, indigenous or social origin, age and other status.

In designing Global Disability Fund programmes, participating UN organisations need to address the different barriers and access issues faced by marginalized persons with disabilities. These intersecting forms of discrimination and exclusion should be analyzed during the situational analysis to support PUNOs in designing initiatives that respond to them. Information on how to identify, outreach and engage organizations representing marginalized persons with disabilities is in Annex I.

Global Disability Fund interviewed organizations of persons with disabilities from the LGBTQI+ community and an organization of indigenous women with disabilities. While this sampling of experiences is not inclusive of all marginalized persons with disabilities, it provides insight on the intersectional barriers marginalized groups face and their priorities for more inclusive movement building and policy making. To read the in-depth case studies from the interviews with marginalized persons with disabilities, see Annex III.

Key rights and access issues experienced by marginalized persons with disabilities:

- **Multiple and overlapping stigma and discriminatory practices and beliefs:** Stigmatizing and discriminatory attitudes on the basis of disability and other non-majority identities (e.g. persons with disabilities of diverse sexual orientation, gender identity and expression and sex characteristics (SOGIESC) create major barriers to accessing public health services including HIV/AIDS testing, prevention and care services
- **Conflicting rights protections:** Depending on the national context, while certain rights are safeguarded under the CRPD, the legal and policy framework can be restrictive of the rights of other identities, particularly those of LGBTQ+ persons or other identities that face opposition (e.g., indigenous peoples, religious minorities, displaced persons or refugees without legal status etc.) and prevent persons from enjoying their rights to live a life free from discrimination as equal members of society
- **Lack of intersectional policy making:** National dialogues and policy making on human rights and development issues do not consider the intersection of disability rights (e.g. national policy making on SRHR or HIV/AIDS)
- **Civil society movements lacking intersectional approach on disability rights:** Civil society movements lack an intersectional approach on disability around key issues such as LGBTQI+ rights, indigenous peoples rights, climate change or gender equality.
- **Constituencies with multiple and interesting identities not well represented in disability rights movement:** Disability rights organizations not adequately including constituencies with multiple and intersecting identities such as persons with disabilities of diverse SOGIESC or other persons with disabilities with multiple identities

5 RECOMMENDATIONS

Design targeted initiatives to address the rights of marginalized and underrepresented persons with disabilities: Most donors and development stakeholders engage with national level OPDs and there are greater barriers to accessing donor networks and information for smaller, grassroots level organizations and organizations of marginalized communities. As a first step, UN agencies should consider targeted interventions to support and engage marginalized communities that include funding for capacity building and support for leadership building. Funding modalities should be adapted to ensure communication and application processes are accessible and that requirements for funding are proportionate to the size and capacities of OPDs.

Foster long-term strategic partnerships with underrepresented and marginalized groups: UN agencies and other development stakeholders should prioritize supporting longer-term strategic partnerships providing continuous funding to marginalized and underrepresented persons with disabilities to help build capacities and provide institutional support over time. For grassroots organizations of marginalized and underrepresented persons with disabilities, support for administrative set up and organizational registration can unlock barriers to more meaningful partnerships and civil society engagement. Addressing barriers like technological access and civic literacy are also vital to enabling their meaningful participation in national policy reform.

Support multi-stakeholder coordination with representation from marginalized and underrepresented groups: Funding and support for inclusion in multi-stakeholder coordination and decision-making mechanisms is an important lever for amplifying the rights priorities of marginalized and underrepresented persons with disabilities. Promoting greater participation and voice of underrepresented and marginalized groups with other civil society actors, including the disability movement, can help build solidarity and cohesion. For instance, supporting coalition building between organizations of indigenous persons with disabilities and indigenous people's rights organizations can help advance the rights of indigenous persons with disabilities in climate action.[31]

Invest in long-term capacity building for organisations and informal structures of marginalized and underrepresented groups: Building the capacities of organisations of marginalized and underrepresented groups to participate meaningfully in national and local priority setting, policy reform and systems and services change can be transformational for groups historically sidelined from decision-making. Building the capacities of these groups to participate empowers groups to advocate more effectively, shape more inclusive policy solutions and hold decision-makers accountable for equitable outcomes.

Build the capacities of government and public authorities on the rights enshrined in the CRPD and how they apply to the diversity of the disability community: Government, public authorities, UN agencies and civil society need stronger technical understanding of disability rights enshrined in the CRPD to operationalize disability inclusion and facilitate fully accessible processes for all persons with disabilities.

31 Global Disability Summit Discussion Paper 2022, International Disability Alliance: Discussion Paper on OPD Engagement - Global Disability Summit

ANNEXES

ANNEX I

Rights priorities of underrepresented and marginalized persons with disabilities

Rights priorities of persons with intellectual disabilities

Inclusion International and Down Syndrome International worked jointly to gather the rights priorities of persons with intellectual disabilities from various parts of the world, while also drawing on experiences and resources from their networks. They led accessible consultations with nine self-advocacy organizations representing persons with intellectual disabilities and their families from Bangladesh, Brazil, Croatia, Egypt, Ethiopia, Lebanon, Kenya, Malaysia, and the United States. To ensure an accessible process, each group nominated a self-advocate to represent their organization in the interviews. For the interview sessions, self-advocacy group facilitators or support persons were present to assist self-advocates as needed. These support persons provided guidance while remaining impartial. They were able to add, their thoughts or opinions after the self-advocate had shared theirs. Ten people with intellectual disabilities were interviewed in total (six women and four men).

Interviewees emphasized that central to the rights of persons with intellectual disabilities is the self-advocacy movement—where individuals speak for themselves to demand change. This human rights advocacy, led by persons with intellectual disabilities, is essential for advancing their rights and building more inclusive movements. Globally, the self-advocacy movement is at various stages: in some countries, there are well-established organizations led by self-advocates, while in others, advocacy efforts are primarily connected to groups led by parents and family members. Families and organizations of families continue to play an essential role in supporting persons with intellectual disabilities to understand their rights, build the skills to self-advocacy and become empowered. The role of families must be understood and supported so they can work with their relatives with intellectual disabilities. Greater support from donors and UN organizations is crucial for advancing this movement and strengthening self-advocate and family-led organizations.

There are many rights issues important to persons with intellectual disabilities, but one of the most fundamental is the right to decision-making. In many cases, persons with intellectual disabilities are denied legal capacity and placed under guardianship (or other substitute decision-making mechanisms), preventing them from making choices about their own lives, such as managing a bank account, signing a housing agreement, or entering a relationship. Self-advocates demand the recognition of the right to legal capacity through the development of “supported decision-making” models and policy reforms. Supported decision-making enables persons with intellectual disabilities to express their ‘will and preference” through their support or trusted person. Without this recognition of the right to decide, persons with intellectual disabilities will continue to be denied their rights in all other areas of life.[32]

32 Committee on the Rights of Persons with Disabilities, General Comment No. 1 Equal Rights Before the Law, Eleventh Session, CRPD/CGC/1, May 19, 2014: CRPD CGC1

In addition, persons with intellectual disabilities outlined the importance of support to live independently in the community with access to mainstream services. Most persons with intellectual disabilities continue to live in isolation either in segregated residential institutions where they are at risk of abuse and human rights violations or within their families with little access to the care and support, they need to live independently.[33] Services such as affordable accessible housing, accessible transportation, and personal assistance to help persons with intellectual disabilities live in the community and participate on an equal basis are not yet available in many contexts. As explained by a self-advocate from Kenya: *"The most important right is individual living and living by yourself."* Persons with intellectual disabilities should have choice and control over where they live and who they live with.[34]

Sexual and gender-based violence are significant issues for women with intellectual disabilities yet this is often an invisible issue within gender-based violence prevention and protection programmes and campaigns. Women with disabilities are more likely than other groups of women to face gender-based violence in their homes and communities.[35] Forced and coerced sterilisation and contraception are widespread amongst persons with intellectual disabilities and psychosocial disabilities and the risk of these practices is much higher in residential institutions.[36] In many countries, these practices are still legal despite years of campaigns by persons with intellectual disabilities.

Persons with intellectual disabilities also face high rates of exclusion from mainstream education and employment which has lasting impacts on their lives. When they do access schooling, it is often in segregated educational settings. Significant reforms are needed to ensure persons with intellectual disabilities have access to inclusive education and employment with accommodations and support they need to succeed.

Persons with intellectual disabilities also experience worse health outcomes than people without disabilities. Some common factors preventing access to services include high rates of stigma and discrimination by healthcare professionals, inaccessible information and communication and the denial of the right to make informed healthcare decisions.[37] To read more about the rights priorities of persons with intellectual disabilities through the consultations Inclusion International and Down Syndrome International carried out, see Annex IV: Including People with Intellectual Disabilities: Learning from Self-Advocates.

Rights priorities of Deafblind persons

The World Federation of the Deafblind (WFDB) is a global OPD made up of 75 national and associated member organizations from 62 countries. According to global research conducted by WFDB, Deafblind persons represent up to 2% of the world population. They are a diverse yet hidden group, and are more likely to be poor, unemployed, and have low education outcomes.[38] As a world federation representing Deafblind persons, their president, Sanja Tarczay, outlined the critical rights priorities for Deafblind persons that are essential for ensuring participation on an equal basis. Legal recognition of Deafblindness as a unique disability is critical and without this legal recognition, governments do not address the rights and needs of Deafblind persons in policies, laws, systems, and services. It is a key barrier to support and services. For example, in many contexts, there are still no personal assistance services or interpreter services specifically for Deafblind persons.

33 Catalina Devandas Aguilar, Report of the Special Rapporteur on the Rights of Persons with Disabilities, Human Rights Council Session Forty-third session, December 17, 2019, A/HRC/43/41: g1934654.pdf

34 Based on consultations with self-advocates and their families carried out by Inclusion International and Down Syndrome International as part of this guidance note. See Annex IV for more information.

35 Inclusion International, Learning Brief on Gender Based Violence for Girls with intellectual disabilities, 2024

36 Life After Violence Report, Inclusion Europe 2018 See also: Catalina Devandas, Report of the Special Rapporteur on the Rights of Persons with Disabilities, General Assembly Seventy-second session, July 14, 2017, A/72/133: n1721463.pdf

37 See WHO Global report on health equity for persons with disabilities

38 World Federation of the Deafblind, Second Report on the Situation of Persons with Deafblindness: Good Practices and Recommendations for Inclusion of Persons with Deafblindness, March 2023: WFDB Global Report 2023 – WFDB

The WFDB explained that the lack of legal recognition of Deafblindness often forces Deafblind persons to choose between services that address blind persons or those that support Deaf persons based on which of the two sense is more significantly impacted. However, services and accessibility measures do not often meet the specific needs of Deafblind persons. For example, available sign language interpretation services do not meet the needs of Deafblind persons because interpreters have not been trained on Deafblind communication (such as tactile communication), orientation, mobility support etc. Deafblind women experience multiple and overlapping forms of discrimination accessing services. Services and support must be designed to be gender responsive and meet the needs of Deafblind persons.

Access to education and employment are also critical issues. Access to adequate services and support that respond to the diverse needs of Deafblind persons is a pre-condition to accessing education, work, and employment. Without these services and support, Deafblind persons are excluded, they are not visible, they are left behind and their rights to participation are violated. This has multiple impacts on the lives of Deafblind persons from not having the support they need to live independently to limiting their participation in the formal and informal workforces. This has major limitations on the possibilities of Deafblind persons to effectively engage in advocacy within civil society as well.

Rights priorities of persons with psychosocial disabilities

For this section of the guidance, Global Disability Fund Technical Secretariat interviewed Transforming Communities for Inclusion (TCI), a global organization of persons with psychosocial disabilities and the World Network of Users and Survivors of Psychiatry (WNUSP). WNUSP is a global forum of users and survivors of psychiatry with member organizations and individuals from different regions of the world and its mission is to ensure the human rights of persons with psychosocial disabilities and the full implementation of the CRPD around the world. "Users and survivors of psychiatry" are self-defined as people who have experienced madness and/or mental health problems, or who have used or survived mental health services.[39] TCI is a post-CRPD movement of persons with psychosocial disabilities and cross-disability supporters. It is a global membership-based organization of persons with disabilities with the aim of ensuring the human rights of persons with psychosocial disabilities as enshrined in the CRPD to reclaim dignity, autonomy, independence, and the right to live in the community.[40] TCI works with members at the national level to support movement building and the establishment of organizations of persons with psychosocial disabilities. The focus of TCI's advocacy work is on transforming communities to be inclusive at national and community levels.

Tackling stigma and discrimination and the root causes of harmful beliefs about persons with psychosocial disabilities is a major barrier to inclusion and to instituting systemic reforms to ensure persons with psychosocial disabilities can exercise their human rights to participation. In many contexts, there are oppressive mental health laws in place that serve to perpetuate stigma and discrimination stripping away a person's right to decision-making and using derogatory and dehumanizing terminology such as "persons of unsound mind." Many persons with disabilities are denied their right to legal capacity in all contexts around the world. This is particularly acute for persons with psychosocial disabilities, persons with intellectual disabilities, autistic persons and persons with dementia.[41] For WNUSP and TCI, it is imperative that persons with psychosocial disabilities are seen as equal before the law and can exercise their right to legal capacity with mechanisms in place for supported decision-making so that persons with psycho-social disabilities can be supported to make their own choices with a support person or system they choose.

39 For more information on WNUSP see their website at: World Network of Users & Survivors of Psychiatry | Advocating for the human rights of persons with psychosocial disabilities worldwide. (wordpress.com)

40 For more information on TCI Global see their website at: TCI Global – Transforming Communities for Inclusion (TCI) (tci-global.org)

41 Catalina Devandas Aguilar, Report of the Special Rapporteur on the Rights of Persons with Disabilities, Human Rights Council Thirty-fourth session, A/HRC/34/58, December 12, 2017: A/HRC/37/56

In addition, WNUSP and TCI highlighted the importance of independent living, de-institutionalization and community support services and inclusive systems to enable persons with psychosocial disabilities to live in the community with autonomy, dignity, and choice. Persons with psychosocial disabilities around the world continue to be deprived of their liberty and placed on congregate care settings such as residential institutions, mental health wards in hospitals or psychiatric facilities which are sites of grave human rights violations including forced treatments, violence, abuse and torture such as the practice of shackling or placing persons with disabilities in confinement. Independent living is a critical rights issue so that persons with psychosocial disabilities can live in the community in a place of their choice, with the support of their choice.

Having services such as counselling, therapy, and support groups within the community at the local level is critically needed. These are the reforms governments should invest in rather than building residential institutions or psychiatric hospitals. Currently, in many parts of the world, de-institutionalization reforms are led by medical and psychiatric institutions and stakeholders. Reforms led by stakeholders within the medical and psychiatric industry only serves to keep the medical model of disability in place that segregates persons with disabilities into institutions and which is in contradiction with the CRPD and the human rights framework.[42] A medical understanding of disability is predominant in state approaches to disability which focus on prevention, cure, or segregation from society over access and inclusion.[43] For persons with psychosocial disabilities amongst other marginalized groups, this has manifested in harmful practices such as institutionalization and forced or coerced medical treatments.

This medical understanding has historically determined social and political approaches to disability, privileging prevention and cure over access and inclusion in policy making towards participation and community inclusion.[44] Both WNUSP and TCI stress the importance of access to mainstream services and community inclusion as integral to shifting the paradigm on mental health towards rights based, person centered support available in communities where people live. Having access to mainstream services such as general health services, social protection, vocational training, and education is critical for persons with psychosocial disabilities. To achieve these rights, governments must ensure comprehensive independent living reforms are built into the legal and policy framework with adequate financing. It is fundamental to transform cultural and social norms to move from the medal model to community inclusion.[45] For example, governments are allocating funding to improve institutions. Funding could be reallocated to community services and care but when states do not understand the implications of institutionalization and medicalized approaches to disability, reforms are in contradiction to the CRPD.

These fundamental rights are enshrined in many human rights treaties and while all of the articles of the CRPD are fundamental to ensure the rights of persons with disabilities to live in the community, CRPD articles 12 (Equal recognition before the law), 15 (Freedom from Torture or Cruel, Inhuman or Degrading Treatment or Punishment), 17 (Protecting the Integrity of the Person) and 19 (Living Independently and Being Included in the Community) are most critical for enabling the change of paradigm and 25 (Health) particularly as this article protects free and informed consent.

Rights priorities of persons with albinism

Speaking with the Global Alliance for Albinism (GAA), founded in 2020 to advance the human rights of persons with albinism and support capacity building of leaders and their organizations, they highlighted the grave human rights violations persons with albinism face including persecution, trafficking, torture, and death, most of which goes unreported. The right to life, security and protection from torture and inhumane treatment are critical human rights priorities for persons with albinism. In many contexts, there are superstitions and myths about persons with albinism that put their lives and security at risk such as the belief that their body parts bring good fortune or that sex with a woman with albinism cures AIDS/HIV. OHCHR has documented cases

42 Daniel Iga Mwesigwa, Interim Chair of World Network of Users and Survivors of Psychiatry, April 3, 2024, Zoom interview.

43 Catalina Devandas Aguilar, Report of the Special Rapporteur on the Rights of Persons with Disabilities, Human Rights Council Forty-third session, A/HRC/43/41, December 17, 2019: g1934654.pdf

44 Catalina Devandas Aguilar, Report of the Special Rapporteur on the Rights of Persons with Disabilities, Human Rights Council Forty-third session, A/HRC/43/41, December 17, 2019: g1934654.pdf

45 Waqar Shahid Puri and Richa Sharma-Dhamorikar from the Transforming Communities for Inclusion (TCI) Secretariat, TCI Global, April 22, 2024, Zoom interview.

of killings, ritual killings, dismemberment of body parts and trafficking for ritual purposes. These grave human rights violations include infanticide and abandonment of children with albinism.[46] Most of these rights violations have been reported and documented in Africa. GAA explained that the multiple and intersecting forms of discrimination against persons with albinism is more acute in Africa as reported by members.

The other area of focus for GAA and its members is the right to health and access to services that respond to the specific needs of persons with albinism such as skin cancer protection and prevention. Skin cancer is one of the leading causes of death for persons with albinism in sub-Saharan Africa. There is a lack of education and awareness on risks of skin cancer, a lack of access to prevention measures and states are not addressing the issue to ensure affordable access to skin cancer prevention in Sub-Saharan Africa. Additionally, persons with albinism experience lack of access to assistive devices and learning materials tailored to their low vision.[47]

Issues of stigma and discrimination are also critical to dismantle the harmful myths and culture beliefs around albinism as well as ensuring they are not discriminated against or excluded in accessing services, education, employment, healthcare etc. and so they can participate on an equal basis. Barriers to education were highlighted by the UN Independent Expert on Persons with Albinism citing rampant reports of bullying, stigma, discrimination, lack of access to reasonable accommodations and assistive devices as contributors for low retention and completion rates in education.

There is a severe underrepresentation of persons with albinism within civil society globally. Before 2008, fewer than an estimated 30 groups of persons with albinism groups existed globally. In the past 15 years, that number has more than quadrupled, with the greatest growth occurring in Africa. To support this gap, the Africa Albinism Network (AAN) was established in 2021 by the former UN Independent Expert on Persons with Albinism. They work to support advocacy led by persons with albinism and to develop an African plan of action for the rights of persons with albinism. Organizations of persons with albinism face large capacity gaps and lack of access to funding as many of the organizations are in their nascency.

46 Office of the Office of the United Nations High Commissioner for Human Rights, Human Rights Council 24th session, 12 September 2013, A/HRC/24/57: United Nations see also: United Nations Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, in collaboration with the Witchcraft and Human Rights Information Network & its member-organizations, concept note on elimination of harmful practices related to witchcraft accusations and ritual killings, March 2020: Concept note on the Elimination of Harmful Practices related to Witchcraft Accusations and Ritual Killings | OHCHR

47 Muluka-Anne Miti-Drummon, Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism, Human Rights Council fifty-fifth session, March 2024, A/HRC/55/45: g2402413.pdf

ANNEX II

Resources

Global and Regional Organisations of Underrepresented and Marginalized Persons with disabilities:

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Transforming Communities for Inclusion: TCI Global – Transforming Communities for Inclusion (TCI)

Africa Albinism Network: Homepage - Africa Albinism Network

Global Albinism Alliance: Global Albinism Alliance

World Network of Users and Survivors of Psychiatry: World Network of Users & Survivors of Psychiatry | Advocating for the human rights of persons with psychosocial disabilities worldwide.

Inclusion International: Home - Inclusion International

Down Syndrome International: Down Syndrome International

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Mirna Cunningham and Paul Kanyinke Sena, *Report of the Permanent Forum on Indigenous Issues, Study on the Situation of Indigenous Persons with Disabilities*: E/C.19/2013/6

Muluka-Anne Miti-Drummon, United Nations Independent Expert on the Enjoyment of Human Rights by Persons with Albinism (2024), *Report of the Independent Expert on the Enjoyment of Human Rights by Persons with Albinism*, A/HRC/55/45: g2402413.pdf

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ANNEX III

Perspectives from marginalized persons with disabilities on intersectional rights and addressing multiple and overlapping forms of discrimination

Case study: Interview with organizations of persons with disabilities from the LGBTQI+ community

Pelangi Disabilitas Yogykarta (PDY) is a newly established organization of persons with disabilities from the LGBTQI+ community with the support of a mainstream LGBTQI+ rights organization in Indonesia. The organization was founded to respond to rights of persons with disabilities of diverse sexual orientation, gender identity and expression and sex characteristics (SOGIESC). For persons with disabilities of diverse SOGIESC in Indonesia, there is little to no access to information and communication on sexual and reproductive health rights or LGBTQI+ rights. In addition, for persons with disabilities completing their education outside the mainstream system (such as special education settings, Deaf schools or schools for the blind) there is almost no access to comprehensive sexuality education (CSE).

Persons with disabilities of diverse SOGIESC experience multiple and overlapping rights violations. One of the main rights issues faced by PDY members is around the stigma and discrimination they face in accessing public health services. They are discriminated against based on both their disability and sexual and gender identities. The government has ratified the CRPD and implemented changes in the national law and policy framework. However, there are distinct regulations against LGBTQI+ persons so while the CRPD protects rights on the basis of disability, the anti-LGBTQI+ regulations restrict and prevent persons from enjoying their rights to live a life free from discrimination as equal members of society. Both persons of diverse SOGIESC with and without disabilities face similar forms of rights violations such as homophobic attacks, anti-LGBTQI discrimination and hate speech including from political leaders.

In terms of access to SRH services, the information, communication and physical infrastructure at service centers is largely inaccessible. Members of PDY have experienced stigma and discrimination by service providers refusing to provide services under the assumption that persons with disabilities are asexual or by not providing information or communication in accessible formats. PDY members have experienced refusal of care by providers questioning their sexual identity by making derogatory comments such as, “how can a person with a disability be from the LGBTQI+ community?” When it comes to national discussions on issues related to SRHR, gender and sexuality, there is no intersection with disability rights. National dialogues and policy making around issues related to SRHR, gender and sexuality are not intersectional and disability is left off the agenda. For example, after 40 years of HIV programming in Indonesia, there was no specific outreach to persons with disabilities.

At the national level, the disability movement is not engaging with the LGBGQI+ community and there is no known representation of persons with disabilities of diverse SOGIESC in the disability movement. Even at the district level there is little to no collaboration between movements. Interviewees experienced different forms of discrimination when trying to engage across movements and constituencies. For example, several interviewees faced homophobic discrimination from within the disability movement where they were prevented from becoming members on the basis of their sexual orientation. Another interviewee experienced ableist bullying from a mainstream LGBTQI+ organization during a meeting to establish cross-movement connections.

In Indonesia, there are very few organizations representing persons with disabilities of diverse SOGIESC. Interviewees stressed the importance of establishing organizations at the intersection of disability and LGBTQI+ rights because there is no representation in either movement. PDY began by building a support group as a first step and in 2023 they started the process to establish an organization reaching out to donors that work at these intersections.

At the same time, doing outreach to identify persons with disabilities of diverse SOGIESC can be risky especially when people do not openly identify as LGBTQI+ and/or live in restrictive contexts. PDY began to identify potential members by reaching out to organizations of persons with HIV/AIDS and asking if they had members with disabilities. From there they carried out focus group discussions and identified a larger group of persons with disabilities of diverse SOGIESC.

In the early stages of forming a grassroots organization, PDY got support and mentorship from more established civil society organizations active in LGBTQ rights. PDY collaborated with Amerta Reksa Kayana (ARK), an organization focused on HIV/AIDS issues in Indonesia. Through this collaboration, ARK served as a fiscal sponsor to PDY to help them access funding while providing guidance on establishing and registering an organization. This collaboration provided cross-issue learning for ARK as well prompting them to carry out an assessment on how accessible HIV questionnaires are within disability communities.

Case study: Interview with National Indigenous Disabled Women's Association of Nepal (NIDWAN)

NIDWAN is an organization of indigenous women with disabilities established formally in 2015 to address their underrepresentation both at grassroots and global levels collectively. NIDWAN works for groups with multiple and intersecting identities to support cross-movement collaboration and intersectional advocacy in Nepal with a focus on indigenous women and girls with disabilities.

Structural forms of discrimination are embedded historically and systemically for indigenous peoples in Nepal. Among indigenous peoples, there are higher rates of disability linked to poverty, violence, and greater exposure to environmental degradation and extractive industries such as mining.[48] For indigenous women and girls with disabilities, poverty, marginalization and exclusion are compounded when gender, indigenous origin and disability intersect. These multiple and overlapping forms of intersectional discrimination create structural barriers to resources, services and support. There should be targeted legislation and public policy that address intersectionality such as protection of the linguistic rights of indigenous women and girls with disabilities to education in their mother tongue and ensuring anti-discrimination frameworks looking at gender and disability also address cultural differences such as indigenous origin.

In order to create the structural changes needed, grassroots activists representing marginalized groups need to be in power and decision-making spaces to address intersectional rights priorities of indigenous persons with disabilities. Meaningful participation and representation of marginalized groups is essential in both the disability movement and indigenous people's movement and promote more intersectional advocacy. Civil society movements themselves struggle to be intersectional and in some cases, human rights movements replicate forms of structural discrimination against women and indigenous peoples in Nepal. In Nepal, indigenous persons with disabilities are struggling to gain recognition or leadership roles within the disability movement making it challenging to engage in national policy change.

At the national level, when addressing disability rights, most donors, development actors and humanitarian agencies in Nepal engage with and support the national disability federation. This creates a barrier for smaller organizations representing persons with disabilities with multiple and intersecting identities that are not represented by umbrella structures. It is important for donors, development stakeholders, humanitarian and climate action actors to have targeted interventions to support specific marginalized groups such as indigenous women with disabilities and provide them with long-term flexible funding to help build their institutional capacity over time.

48 Mirna Cunningham and Paul Kanyinke Sena, Report of the Permanent Forum on Indigenous Issues, Economic and Social Council 12th Session, Study on the situation of indigenous persons with disabilities with a particular focus on challenges faced with regard to the full enjoyment of human rights and inclusion in development, E/C.19/2013/6, February 5, 2013: Etpu

ANNEX IV

Including People with Intellectual Disabilities: Learning from Self-Advocates by Down Syndrome International and Inclusion International

Introduction

This paper is about including people with intellectual disabilities, in particular self-advocates.

The paper has been written by a combined team from Down Syndrome International and Inclusion International, including staff members with intellectual disabilities.

Down Syndrome International and Inclusion International are organisations of persons with disabilities and members of the International Disability Alliance. Their combined membership includes over 350 organisations worldwide.

Down Syndrome International is the global network representing people with Down syndrome and their families, and Inclusion International is the global network representing people with intellectual disabilities and their families.

This paper includes:

- How we wrote the paper
- Self-advocacy and organisations of persons with disabilities
- Key rights for persons with intellectual disabilities
- Barriers to participation for persons with intellectual disabilities
- Programme development checklists
- What to do if there are no self-advocacy organisations
- Case Study 1 - GoVoter project
- Case Study 2 - Toward Inclusive Social Protection in Lebanon project

How we wrote the paper

Interviews with self-advocacy groups

The team interviewed nine self-advocacy groups from Down Syndrome International and Inclusion International's networks. Below is more information about self-advocacy. The groups were from Bangladesh, Brazil, Croatia, Egypt, Ethiopia, Lebanon, Kenya, Malaysia, and the USA.

Each group nominated a person with an intellectual disability from their self-advocacy group to represent them (except the organisation from Kenya, which brought three people). Ten people with intellectual disabilities were interviewed: 6 women and four men.

Self-advocacy group facilitators or supporters were also present for the interviews. In total, 9 group facilitators or supporters were interviewed: seven women and two men. Their role was to support the persons with an intellectual disability in answering the questions, but they were allowed to add their thoughts afterwards.

We sent questions in advance so the self-advocates had time to go through them with their support persons and prepare their answers. The interviews were semi-structured, meaning each had the same questions, but we asked some extra follow-up questions.

Findings from Listen Include Respect consultations

The section also draws upon findings from consultations that Down Syndrome International and Inclusion International ran with self-advocates around the world when creating the Listen Include Respect guidelines.[49] These consultations took place in 2020 and 2021 and included an Easy Read survey in multiple languages and over 50 group consultations in countries around the world.

Experiences and resources from our networks

We also drew on the experiences of participants in projects and programmes from the Down Syndrome International and Inclusion International networks, as well as the resources and information provided by the two networks.

Self-advocacy and organisations of persons with disabilities

The self-advocacy movement

Self-advocacy is when people stand up for themselves and others, speaking out for their human rights. In the past, people with intellectual disabilities often had no control over their own lives, and this is still true for many today.

The self-advocacy movement began as a response to this, with people with intellectual disabilities joining forces to demand change. They formed groups and organisations to fight against discrimination and exclusion.

The self-advocacy movement is at different stages around the world:

- In some countries, there are well-established self-advocacy organisations.
- In some countries, there are only self-advocacy groups that are linked to family organisations.
- In some countries, there are only individual self-advocates speaking up, either on their own or as part of other organisations.

People with intellectual disabilities need training, support and opportunities to become self-advocates. A self-advocate from Brazil told us:

> "Our self-advocacy group was created 13 years ago with a small group of people with intellectual disabilities who barely knew about their rights. Over time, the group grew, and we learned about our rights, the importance of having autonomy, and places of social participation that we could engage in."

Organisations of persons with disabilities

The Committee on the Rights of Persons with Disabilities defines organisations of persons with disabilities as those *"that are led, directed and governed by persons with disabilities"*. They are organisations that represent people with disabilities, and the majority of members have disabilities. One example is self-advocacy organisations,

49 Listen Include Respect guidelines for inclusive participation: https://www.listenincluderespect.com/

where self-advocates with intellectual disabilities lead the organisations.

The Committee also recognises organisations that include family members or relatives of persons with disabilities, where they promote *"the autonomy and active participation of their relatives with intellectual disabilities"*.

There are many of these kinds of family organisations in Down Syndrome International and Inclusion International's memberships. These organisations have a majority of leaders and members who are either people with intellectual disabilities or their family members.

The Committee lists both of these as examples of OPDs, and it is important that family organisations are recognised as OPDs and included in consultations.

For example, in our interview with a self-advocacy group in Kenya, we learned that the group was started by a family-led organisation, which now brings together self-advocates and family members advocating together.

OPDs that represent people with intellectual disabilities exist at different levels, including:

- Local OPDs - represent people in one town, district or state.
- National OPDs represent people across a whole country and can sometimes be networks of local OPDs. Examples are the Down Syndrome Society of Bangladesh and the Kenya Association of the Intellectually Handicapped.
- Regional OPDs, which represent people across a whole continent or region, are normally networks of national OPDs. Examples include the Asia Pacific Down Syndrome Federation or Inclusion Africa.
- International OPDs representing people around the world, including regional and national OPDs. For example, Down Syndrome International or Inclusion International.

Key issues for persons with intellectual disabilities

It is very important to consult with self-advocates when designing any project or programme to understand the specific human rights issues that must be addressed. We know from people with intellectual disabilities that they face discrimination and are denied key human rights, including the right to make decisions in their lives, the right to live and be included in their communities, and the right to access education, health care and employment on an equal basis with others. While The UN Convention on the Rights of People with Disabilities (CRPD) elaborates on the rights of people with disabilities, there is clear evidence that these rights continue to be denied in many countries and contexts.

The Right to Decide

People with intellectual disabilities are often denied the right to make decisions in their everyday lives: decisions about their own health, financial and property decisions, and decisions about where and with whom they live.[50] Informally, this happens because service providers, families, and others in the community presume that people with intellectual disabilities cannot make decisions about their own lives. Formally, they are limited from opening bank accounts, signing contracts, and other legal processes because of substitute decision-making (e.g., guardianship) laws.

A self-advocate from Croatia said:

> **"Legal capacity is a major issue. Without it, we can't make our own decisions or even access basic services like banking or housing. This needs to change."**

Recognition of the right to *"legal capacity"* requires support for self-advocacy, shifting perceptions of families, supporters and communities about people with intellectual disabilities, and the development of *"supported decision-making"* models and policy reforms. This concerns all people with intellectual disabilities, including

50 Independent but not alone, Inclusion International, 2012

people with high support needs. People with disabilities should be supported to express their *'will and preference"* or have the *"best interpretation of their will and preferences"* through their support or trusted person. Without this recognition of the right to choose, people with intellectual disabilities will continue to be denied their rights in all other areas of life.[51]

Living and being included in the community

People with intellectual disabilities are often denied the right to choose where and with whom they live; they are denied the support they need to live and be included in their communities, and they are denied access to mainstream services and programmes in their communities.[52] Many are still in segregated living (institutions which are called many different things), where they live away from their families and communities and are at risk of abuse.[53] The majority of adults with intellectual disabilities live at home with their families. Those families do not receive support to advocate for or provide care to their family members. The result is that people with intellectual disabilities experience isolation and exclusion from the community and often live in poverty.[54]

A self-advocate from Kenya said:

> "The most important right is individual living and living by yourself."

People with intellectual disabilities should have choice and control over where they live and who they live with. They should have support systems that help them to live in the community, including:

- Social protection
- Human support with everyday tasks and being independent, such as a personal assistant
- Assistive technology, such as tools or apps that support with communication
- Accessible transportation
- Accessible and affordable housing.

These support systems should be rights-based and appropriate for the individual's needs while promoting control, choice and dignity.

Family and Relationships

Many people with intellectual disabilities are denied their sexual and reproductive rights, including the right to marriage and relationships. This can be due to discriminatory laws, social norms and bias.

Forced sterilisation and contraception without consent are severe problems for people with intellectual disabilities around the world. In many countries, this is legal despite years of campaigns by people with intellectual disabilities. Women with intellectual disabilities are much more likely than other groups of women to face gender-based violence in their homes and communities.[55] The risk of forced sterilisation and contraception without consent and other forms of violence is much higher in institutions.[56]

Inclusion in Education

People with intellectual disabilities are often denied access to any form of education; where they do have access

51 UNCRPD General Comment 1 on article 12

52 UNCRPD General Comment 5 on article 19

53 UN Guidelines on closing institutions, easy to understand videos

54 Inclusive Communities= Stronger communities, a global report on article 19

55 Learning Brief on Gender Based Violence for Girls with intellectual disabilities, 2024

56 Life After Violence Report, Inclusion Europe 2018

to education, it is often without the support they need and is usually segregated.

This has lasting consequences for their lives. A self-advocate from Egypt gave an example of how he struggles with reading and writing due to his poor-quality education. He tried to go back to school as an adult, but there were no accommodations made for him, and he had to stop.

In an inclusive education system, all children learn together in the same classroom. Each student receives the support they need, and teachers adapt their methods to suit everyone's learning style. Every child feels safe, included, and valued in their school and community.[57]

Access to Healthcare

People with intellectual disabilities face worse health outcomes than people without disabilities.[58] Healthcare systems need to change to make sure people with intellectual disabilities can access quality care that meets their needs.

Causes of poor health outcomes for people with intellectual disabilities vary from country to country, but some common ones include[59]:

- 'Diagnostic overshadowing' - where health providers wrongly diagnose health problems as being related to their intellectual disability, missing diagnosing a health condition.
- Discrimination by healthcare providers, for example, being denied treatments based on their condition due to negative attitudes of professionals.
- Inaccessible information and communication around health, for example, written information about treatment or verbal communication during an appointment.
- Health professionals talk to parents or supporters instead of the person, resulting in symptoms being missed and misdiagnosis.
- Denial of the right to make healthcare decisions by families or health professionals. This includes a failure to give support to make informed decisions.

Consulting with self-advocates during programme design will help identify exactly what needs to change where they live to improve healthcare. For example, the self-advocate from Brazil described the need for better training for healthcare providers to prevent discrimination against people with intellectual disabilities.

Employment

People with intellectual disabilities have very low levels of employment, and often, those who are employed are in segregated settings, such as sheltered workshops, with low pay and bad working conditions.[60]

Inclusive employment means people with and without disabilities work together as equals, with everyone getting the support they need. All workers are valued, treated fairly, and paid the same for their work.[61]

A self-advocate from Malaysia said:

> **"We are often placed in low-paying jobs or segregated workplaces. We need more inclusive employment opportunities that respect our abilities and ambitions."**

57 General Comment 4 on article 24

58 WHO Global report on health equity for persons with disabilities

59 DSI global consultation about health equity

60 General Comment 8 on article 27

61 Inclusive workplaces toolkit

Barriers to participation for persons with intellectual disabilities

When creating the Listen Include Respect guidelines, Down Syndrome International and Inclusion International asked people with intellectual disabilities about the barriers they face when participating in organisations, including in projects and programmes.

These barriers were again raised in the interviews. Below are summaries of the barriers, with examples from the interviews. The programme development checklists below offer suggestions for addressing these barriers during programming.

A lack of awareness and understanding about intellectual disability can lead to discrimination, stereotyping, segregation, and exclusion. For example, a self-advocate from Bangladesh said:

> "Our community needs to be more open and understanding. Too often, people with intellectual disabilities are seen as incapable, but when given the right support, we can achieve so much."

Inaccessible information and communication. This can cause people with intellectual disabilities to feel excluded and ignored. For example, a self-advocate from Brazil said:

> "One of the biggest barriers is communication. If information isn't provided in an Easy Read format, we're left out of the conversation. This needs to be addressed at all levels, from local services to international organisations."

Not providing reasonable accommodations. Some people need adjustments to how things work so they can be included. Organisations should provide these reasonable accommodations.

Poor support. People with intellectual disabilities may need support to understand information, learn new skills or tasks or make decisions. People with intellectual disabilities often have poor support, which stops them from taking part.

A lack of time. The lack of time organisations provide is a barrier. People need more time to understand and do their work.

Exclusion from decision-making. People with intellectual disabilities are often excluded from places where decisions are made, like governance, leadership and staff teams. This means that their voices are not heard and so decisions are often taken that do not respect and promote their rights.

Lack of budgets or resources to support inclusion. Money is a key barrier to inclusion. People with intellectual disabilities and their families may struggle with any extra costs. Organisations do not budget for the costs of inclusion.

PROGRAMME DEVELOPMENT CHECKLISTS

Below are checklists on planning projects and programmes, inclusive budgeting, and project evaluation. They are based on the 'Projects' section of the Listen Include Guidelines.[62] Please refer to these for more details and information.

Planning projects and programmes

1. **Before the project starts, think about what stops people with intellectual disabilities from participating in your projects.** Consider barriers like inaccessible information, lack of transport money, limited access to technology, and community discrimination. Think about these challenges before planning.
2. **Check your planning tools.** Review tools like budgets and work plans. If they're too complicated, people with intellectual disabilities can't participate. Use simpler tools and ask for their input to make them more accessible.
3. **Create standards for your project.** Ensure everyone agrees on what "inclusion" means. Use accessible language, align with Listen Include Respect principles, and make sure deadlines are fair.
4. **Involve people with intellectual disabilities in design.** Include them from the start to ensure the project is truly inclusive. It's easier to plan for barriers early on.
5. **Plan your time and budgets well.** People with intellectual disabilities may need extra support. Involving them in planning will help you remember this.
6. **Train project partners.** Work with self-advocates to provide inclusion training. Ensure all partners understand inclusion, participation, and accessibility.
7. **Include people with intellectual disabilities in project management.** Their involvement will keep the project accessible. Run meetings according to inclusive guidelines.
8. **Use accessible language in all planning, meetings, and information about your project.** Always use easy-to-understand language. This ensures everyone, including people with intellectual disabilities, can participate.
9. **Check your ways of working.** If using existing materials, make sure they're adapted for inclusion. It's easier to create inclusive materials from the start.
10. **When planning how to monitor and evaluate the project, include people with intellectual disabilities.** Involve self-advocates in planning evaluation tools that are accessible to everyone.

Inclusive budgets

Money can be a significant barrier that stops people with intellectual disabilities from getting involved in project work. Inclusive organisations consider the costs needed to ensure everyone can participate.

1. **Plan for extra time and costs.** People with intellectual disabilities may need more time to understand roles or activities, such as splitting training into smaller sessions—budget for additional staff hours to support this.
2. **Cover Upfront Expenses.** Think about:
    - Paying for transport if people need to attend meetings or training.
    - Reimbursing taxis if public transport isn't accessible.
    - Providing meals for longer events.
    - Covering data and tech costs for online participation.
    - Compensating those who lose a day's work to participate.
    - Paying expenses in advance, especially for those without bank accounts or for underfunded organisations (OPDs).

62 Listen Include Respect guidelines for inclusive participation: https://www.listenincluderespect.com/projects

3. **Pay Self-Advocates.** Self-advocates bring valuable skills to projects. To model inclusion, pay them for their work, whether they're advising, training, or building networks. If they work for an OPD, compensate the organisation for their time.
4. **Budget for Support People.** Support people are essential for participation. Budget for their seats, meals, and transport. In some countries, you may also need to budget for their time.
5. **Make Project Resources Accessible.** Most project materials aren't accessible by default. Budget for making them inclusive, like using easy language and inclusive trainers. Pay consultants with intellectual disabilities and OPDs to help.
6. **Use Existing Budgets Wisely.** Look for ways to use existing budgets for inclusion. For example, a communications budget can cover plain language reports or accessible videos with captions.
7. **Train Staff on Inclusion.** Budget for training staff on inclusion, using the Convention on the Rights of Persons with Disabilities (CRPD). Self-advocacy groups often offer these trainings, which should be included in the project budget.
8. **Plan for Other Reasonable Accommodations.** Depending on the group, you might need additional accommodations like:
    - Multiple support people.
    - Accessible venues for wheelchair users.
    - Translation and interpretation services.
    - Captioning for meetings.

Consult with organisations of people with intellectual disabilities to understand these costs.

Evaluating projects

1. **Involve people with intellectual disabilities in planning how to monitor and evaluate the project.** Engage OPDs and self-advocates in your M&E planning. Make sure all internal communications are easy to understand so everyone can participate.
2. **Present outcomes and activities in an accessible way.** Avoid complicated spreadsheets and frameworks. Use narrative formats or work with someone with an intellectual disability to create more inclusive templates.
3. **Make your M&E plan easy to understand.** Use narrative formats instead of complex documents. Combine activity and monitoring plans in one place to avoid confusion.
4. **Build in extra time for participation.** Start M&E planning early and allow more time so people with intellectual disabilities can fully engage. This might take longer but will lead to better, more inclusive tools.
5. **Use accessible evaluation tools.** Ensure surveys, interviews, and focus groups are accessible to everyone, including people with intellectual disabilities. Accessible tools are easier for everyone to use.
6. **Involve people with intellectual disabilities in adapting the project.** If something isn't working, involve people with intellectual disabilities in finding solutions. They know best what works for them.
7. **Share results and learning in accessible formats.** Make sure the results and learnings are shared back with communities in an easy-to-understand format, such as videos or plain-language reports.

WHAT TO DO IF THERE ARE NO SELF-ADVOCACY ORGANISATIONS

If there are no self-advocacy organisations, here are some tips for how to still involve people with intellectual disabilities:

- Work with family organisations of persons with disabilities to see if they have a self-advocacy group or individual self-advocates who can take part. Value the voices of family members, too.
- If there are no self-advocacy organisations or family organisations, reach out to other organisations that work with people with intellectual disabilities to get help reaching individuals with intellectual disabilities, such as other OPDS, NGOs, or service providers. Recognise that these organisations may need support to build the capacities of people with intellectual disabilities to become leaders.
- Reach out to regional or international networks that represent people with intellectual disabilities, who may be able to support you to link up with local self-advocates. For example, Inclusion International and Down Syndrome International.

Consider how the project or programme can support the self-advocacy movement in your country. For example:

- Support the establishment of a self-advocacy group with funding and technical support. This could be done together with a family organisation.
- Support self-advocates from other countries or regions to come to the country to train people with intellectual disabilities to become self-advocates.
- Support people with intellectual disabilities in your country to attend conferences, events or training workshops where they build their self-advocacy skills.
- Support self-advocacy groups to register and get established as organisations.

CASE STUDY: SUCCESSFUL ENGAGEMENT WITH SELF-ADVOCATES

Introduction

Engaging an organisation of self-advocates at the national level is not just about making adjustments to ways of working. It's about understanding and respecting the principles of self-advocacy,[63] ensuring participation and collaboration in a way that empowers the members.

The following case studies of two members of Inclusion International explore effective strategies and best practices for identifying and engaging such an organisation, focusing on national-level projects. The case studies include recommendations on effectively identifying and engaging with self-advocates.

Background: The Project and Organisation of Self-Advocates

Case Study 1 *- The Go Voter project is a long-term national initiative in the U.S. focused on voting rights and access for people with disabilities. It is a partnership between SABE (Self Advocates Becoming Empowered), a national self-advocacy organisation, and NDRN (National Disability Rights Network), the national protection and advocacy organisation. SABE is a national self-advocacy network representing people with intellectual and developmental disabilities (IDD) across the USA. SABE has a mission to ensure that people with disabilities are treated as equals and given the same decisions, choices, rights, responsibilities, and chances to speak up to*

63 These principles are outlined in the section What is Self-advocacy? in Inclusion International's global report Self-Advocacy For Inclusion

empower themselves, have opportunities to make new friends and learn from their mistakes. SABE operates with a decentralised structure, with regional chapters across the country; SABE is led by a national board of self-advocates elected by members.

***Case Study 2** - The project Toward Inclusive Social Protection in Lebanon was about implementing social protection programs for people with disabilities. The project's goal was to implement social protection in Lebanon. LASA (Lebanese Association of Self-Advocacy) is one of eight Organisations of People with Disabilities (OPDs) who work in consortium and were selected to work on this project in Lebanon in partnership with the International Labour Organisation (ILO) and UNICEF. LASA has a mission to empower self-advocates to defend their rights. LASA is based in Beirut and has around 30 members. LASA has connections across Lebanon with other organisations that work with self-advocates and people with intellectual disabilities. LASA is led by an elected board of self-advocates, supporters and family members.*

Identifying the Organisation of Self-Advocates

***Case Study 1** - NDRN identified SABE as a key organisation due to its wide structure, diverse membership across the country, and autonomy as a self-advocacy organisation driven by people with lived experiences. SABE is well-recognised within the self-advocacy community and by other stakeholders in the disability sector nationally.*

***Case Study 2** - LASA was identified as a partner by ILO and UNICEF as one of the members of the OPD consortium in Lebanon. The consortium has worked together for many years. LASA is a well-established OPD in Lebanon that represents people with intellectual disabilities. LASA's work focuses on advocacy and has worked closely with the ministries of Lebanon, including the Ministry of Education and, in this case, the Ministry of Social Affairs. Although the group is relatively small and based in Beirut, LASA has been part of national projects and has collaborated with organisations working with people with intellectual disabilities and their families across the country.*

The first step in engaging a self-advocacy organisation is to understand the landscape of organisations that represent people with intellectual disabilities (OPDs) and groups of self-advocates at different levels in the country—local, regional, and national. During mapping, it is essential to understand what self-advocacy is and is not. In self-advocates, you should look for awareness of rights and inclusion, leadership and decision-making, and confidence in sharing ideas and experiences. Self-advocacy is not the same as a leisure group or a vocational skill training group, although self-advocacy groups can grow out of these groups.

The self-advocacy movement looks very different in different contexts. National self-advocacy organisations may be independent, like SABE, but they could also be affiliated with family or advocacy organisations. Local OPDs that are not self-advocate-led may also run groups and ensure self-advocacy leadership by supporting self-advocates to be active in advisory groups or employed by the organisation.

Partner organisations can work with local groups or individuals without a national group. For example, as with LASA, a partner organisation can support a local self-advocacy group to engage, train and empower others across the country.

It may be the case that there is no self-advocate movement in the country. People with intellectual disabilities are amongst the most marginalised and excluded in the community and have few opportunities to connect with others. Individual self-advocates may not have met and organised.

If there is no self-advocacy movement, it may be a good idea to work with other active self-advocacy groups in the region or with regional and international OPDs that have self-advocacy programmes. Self-advocacy training works best when a peer leads it. It is important when supporting new groups to develop that the self-advocates' decision-making and autonomy are respected, the CRPD informs the curriculum and activities, and the principles of "nothing about us without us" are always respected.

Developing partnerships

Case Study 1 *- In the engagement with SABE, NDRN reached out and introduced the project goals. Early meetings focused on understanding the goals. NDRN and SABE ensured co-creation in the project from planning to execution. This included jointly setting objectives, defining roles, and agreeing on outcomes. State-level groups of self-advocates and Protection and Advocacy agencies worked together. Self-advocates at a local level were not immediately comfortable working with lawyers. It was important for the group and agency to understand each other and overcome attitudes. Awareness training and building relationships by meeting and working together helped this.*

Case Study 2 *- In LASAs case, the partnership with ILO and UNICEF was essential in building trust. Before the start of the project, there were focus groups with OPDs to understand the issues. The consortium of OPDs met with ILO and UNICEF to discuss the project and the implementation plan. As the project plan was developed, there was time for changes based on LASA members' feedback. LASA felt that the partnership was successful because there was open communication and mutual respect throughout the project, and the consortium of OPDs, ILO and UNICEF valued self-advocates contributions. The expectations of each partner were clear, and each partner understood one another's capability, creating an environment of respect and inclusion.*

Effective engagement begins with a foundation of trust and respect. Organisations working with self-advocates must recognise self-advocate leadership and approach work as equal partners. Avoid tokenistic engagement by ensuring that the self-advocacy group is involved in shaping the work from the outset and not brought in at the last minute to give feedback, as is often the case. This may require extra time and resources; for example, self-advocates may need extra time and more meetings to understand goals and plan activities, and additional resources may be necessary to ensure local activities are accessible and reach people.

Partner organisations, including those working in consortiums, are responsible for listening, understanding the barriers and adjusting to work collaboratively. Often, groups work with supporters or staff without intellectual disabilities who may also be able to guide; for example, SABE and LASA have advisors or supporters who help with contracting, writing reports and following through with actions. Whilst supporters are a vital part of self-advocate work, partner organisations need to ensure decision-making is by self-advocates.

Enabling Participation

Case Study 1 *-The GoVoter project activities included developing a voting rights toolkit, developing a programme for state-level self-advocate training, and a survey to collect the experiences of voters with intellectual disabilities, which contributed to state and national-level advocacy activities on voting issues. Self-advocates were part of all decision-making and had leadership roles throughout the project as project leads and co-trainers. Self-advocates co-created all materials. Planning meetings and training activities on a national and state level were conducted to accommodate the needs of the self-advocacy groups. Supporters were included in all meetings and communications and could support self-advocates in understanding and responding to actions. The national-level project team ensured there were capacity-building activities for the state-level groups, which, in addition to the voter training, included stipends for local self-advocacy groups that led and participated in training and relationship-building between self-advocates and the local protection and advocacy agencies.*

Case Study 2 *- The key activities that LASA ran during the project were training about social protection to build awareness and understanding of self-advocates of a new and complex topic. The training took place over five months and went into detail on the different pillars of social protection. The self-advocate training was designed to be accessible, and interactive methods were used, including role-playing exercises and drawing. An accessible booklet was produced to support self-advocate learning, and members were given the opportunity to ask questions and have discussions over WhatsApp when not together in person. Most of this training was led by LASA, including a self-advocate trainer. When partners from UNICEF and ILO led sessions, LASA supported them by running training about accessible communication for people with intellectual disabilities. In the second phase, LASA ran focus groups with self-advocates to collect input on what social protection initiatives were most important to them and to create clear recommendations for the final report to the Lebanese government.*

Working closely with self-advocates will help the partner organisation understand the barriers that might prevent full participation, whether physical, communicational, or attitudinal. Training about intellectual disability and accessibility led by self-advocates can make a big difference in understanding the adjustments organisations can make to enable participation. Luckily, there are lots of resources available that explain the barriers and recommend approaches inclusive organisations take. Many self-advocacy groups and OPDs run awareness training, and there are also international resources like Listen Include Respect, which gives guidance.

SABE has a strong network to rely on to engage with local project activities. However, as discussed, this is not always the case. The partner organisation can offer support to enhance the organisation's capacity and reach but also provide training or resources that strengthen their work and look for opportunities for them to connect with the broader advocacy movement, For example, equipping self-advocates with tools to engage in policy discussions, sending self-advocates to conferences and events that give them a platform, and providing links to other national or international organisations that may help them expand further.

Sustaining Engagement

Case Study 1 *- The GoVoter project has been ongoing for 20 years, with regular meetings between NDRN and SABE. The organisations meet three times a year to review work plans and activities. The project's longevity has allowed for the development of trust and understanding between the organisations, enabling them to navigate challenges, capitalise on opportunities and adapt to circumstances and as situations change. For example, state-level training moved from in-person to online over the years and so became accessible to more people. While sometimes burdensome for SABE, the annual grant renewal process has provided a mechanism for adapting to changing needs and contexts.*

Long-term engagement has helped achieve key project goals. Over the years, the partnership has:

- *Developed resources, including a voting rights toolkit and state-level self-advocate training programs, hotlines and online tools for voters with disabilities*
- *Conducted surveys to gather data on the experiences of voters with intellectual disabilities*
- *Increased awareness of voting rights for people under guardianship*
- *Improved accessibility of voting locations and processes*
- *Enhanced collaboration between self-advocacy and advocacy groups*

The ongoing commitment to this work has been instrumental in creating lasting change and improvements in voting rights and accessibility for people with intellectual disabilities.

Case Study 2 *- For LASA and their OPD partner organisations, securing government endorsement of their work was crucial for sustainability. The government accepted the project and made small changes to the strategic plan. A commitment from various UN bodies ensured continued financial and technical support. Representatives from the OPDs, including LASA, were appointed as a consultative body to the Ministry of Social Affairs. They were tasked with engaging the relevant organisations and their members before making key decisions. LASA also continues to collaborate with ILO and UNICEF to further the implementation of social protection measures. People with disabilities were in the project from the beginning to the end, and LASA believes that this will continue, ensuring that self-advocate voices remain at the forefront. LASA feels like the project has significantly raised awareness among self-advocates across Lebanon about the importance of social protection and its relevance to their lives.*

Effective engagement goes beyond a single short-term project. Sustained partnerships allow for trust and understanding between partners. Over time, this trust enables skill development, more effective problem-solving and innovation. It provides the opportunity to address systemic issues. Sustained engagement allows the time needed to observe, measure, and understand the true impact of activities, as has been the case with the GoVoter project and as has started with the Social Protection Project. Time and long-term engagement allow for improvements based on lessons learned and the flexibility to adapt to changing needs.

Tips and Recommendations from Case Studies

1. Understand and respect self-advocacy principles. Engage self-advocates as equal partners, avoiding imposed agendas.
2. Map the landscape of organisations representing people with intellectual disabilities in your country.
3. In the absence of a national self-advocacy movement, engage with OPDs, family organisations, or service providers, but recognise that these organisations may need support to build the capacities of people with intellectual disabilities to become leaders.
4. Ensure accessibility from the start, considering physical, communication, and attitudinal barriers.
5. Recognise that self-advocates often hold their own answers. Support them in articulating these and create environments where their voices are heard.
6. Support self-advocacy organisations' growth and sustainability through resources, training, and platforms for national-level amplification.
7. Prioritise and fund projects that ensure the participation of self-advocates and people with intellectual disabilities, who are often marginalised in cross-disability work.
8. Aim for sustained, evolving collaboration beyond short-term projects to adapt to changing needs and contexts

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