Disability Equity and Rights: Challenges, opportunities, and ways forward for inclusive development

Essays on progress towards sustainable development commitments to leave no one behind

Nossal Institute for Global Health

THE UNIVERSITY OF MELBOURNE

Australian Aid

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inclusion advisory group

Pacific Disability Forum

IDA International Disability Alliance

Disability Equity and Rights: Challenges, opportunities, and ways forward for inclusive development

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Disability-inclusive development: Reflections on 2030 progress

Alex Robinson, Nossal Institute for Global Health[1]

Introduction

In 2015, governments committed to end poverty in all its forms everywhere and to ensure no one is left behind. This aspiration drew a line under previous global development frameworks by specifically addressing the inclusion of people with disabilities. In contrast to preceding frameworks, disability inclusion was emphasised and endorsed in the 2030 Agenda and Sustainable Development Goals (SDGs), the Sendai Framework for Disaster Risk Reduction 2015 to 2030, and the Paris Climate Agreement. This brought contemporary global development frameworks in line with the United Nations Convention on the Rights of Persons with Disabilities (CRPD), 2006. We are now at the mid-point of the 2030 Agenda and Sendai Framework.

The 2023 United in Science report finds we are only on track to meet 15% of the SDGs by 2030.[2] Limited progress has been compounded by lost development gains and rising inequality triggered by the COVID-19 pandemic.[3] The Mid-term Review of the Sendai Framework reports we will not meet risk reduction objectives agreed in 2015.[4] We are also off-track to meet 2050 Paris Agreement targets to limit global warming to 2°C, and ideally 1.5°C, above pre-industrial levels.[5] There is now a 66% likelihood that global temperatures will exceed 1.5°C in at least one of the next 5 years.[6] It is widely acknowledged that those most marginalised are most affected by these changes and our lack of progress. It is no longer simply enough to accelerate progress to achieve 2030 objectives: our efforts need to be 'supercharged'.[7]

With limited progress towards global targets, people with disabilities face ongoing disadvantage and inequity. We can expect this to be exacerbated by the disproportionate impacts of climate change, increased disaster risk, and persistent poverty and marginalisation. The optimism that surrounded disability inclusion in 2015 has been severely dampened.

Looking ahead to 2030

We asked a group of experts to contribute essays on what they see as key challenges and opportunities for achieving disability inclusion by 2030. This included individuals with lived experience of disability. This introductory essay presents a high-level overview and readers with specific sectoral or thematic interests should refer to the individual essays.[8] The essay topics and thematic areas covered are limited, non-exhaustive, and do not necessarily represent priority areas for all disability stakeholders. However, we are

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[2] World Meteorological Organization. 2023. United in Science 2023. Sustainable Development Edition. https://library.wmo.int/records/item/68235-united-in-science-2023

[3] World Bank. 2021. Poverty, median incomes, and inequality in 2021: a diverging recovery.https://documents1.worldbank.org/curated/en/936001635880885713/pdf/Poverty-Median-Incomes-and-Inequality-in-2021-A-Diverging-Recovery.pdf

[4] United Nations General Assembly. 2023. Main findings and recommendations of the midterm review of the implementation of the Sendai Framework for Disaster Risk Reduction 2015–2030. https://www.undrr.org/publication/report-main-findings-and-recommendations-midterm-review-implementation-sendai-framework

[5] World Meteorological Organization. 2023. United in Science 2023. Sustainable Development Edition. https://library.wmo.int/records/item/68235-united-in-science-2023

[6] Ibid

[7] Ibid

[8] Essay topics cover: Caregiving, deinstitutionalisation, digital technologies, disaster risk, early childhood development, elimination of violence against women and girls, inclusive education, organisations of people with disabilities, preconditions for inclusion, psychosocial disability, rehabilitation and assistive technology, and social protection.

confident the essays address important contemporary issues in disability-inclusive development and provide a timely and important point of reflection.

While the authors recognise progress has been made, the essays are not written as a point of celebration. Commitments have been made, progress is expected, and the overarching concern is that much remains to be done and, for some, there is a growing sense of frustration. The essays call for increased prioritisation, resourcing, and comprehensive action toward disability inclusion – they urge us to take stock and start working differently.

Disability inclusion then and now

In 2012, CBM with contributions from the Nossal Institute, published Inclusion Made Easy: A Quick Program Guide to Disability in Development.[9] The guide emphasised partnering with organisations of people with disabilities (OPDs) and applying a twin track approach. With the addition of collecting and using disability disaggregated data, these 3 principles have formed the mainstay of disability-inclusive development guidance and advisories over the last decade. While these principles hold true today, their adoption and application has been limited. Of deeper concern is that despite the wealth of guidance produced over the last decade, there remains limited evidence of positive impact on the lives of people with disabilities.

The objective of advocacy messaging in the run up to 2015 was to demystify disability and to counteract the view of many in global development that disability inclusion was overtly technical and complex. Non-technical solutions were needed to raise awareness, generate buy-in, and ensure disability inclusion in the 2015 frameworks. To this end, the advocacy was successful; however, we need to recalibrate and move the dial forward.

Figure 1. Evolving priorities for disability inclusion from 2015 to 2030

2015		2030
Generic guidance	Acknowledgment of progress	Specific / contextualised solutions
Recognition of the 'issue'	Increasing expectations	Engaging with complexity
Raising awareness	Sense of impatience	Delivering impact
Moral obligation		Legal requirement
CRPD informed		CRPD compliant (with recourse to other legal instruments)
Sector focused (with limited scale and scope)		Systems approach

[9] CBM. 2012. Inclusion Made Easy: A quick program guide to disability in development.
https://www.cbm.org/fileadmin/user_upload/Publications/cbm_inclusion_made_easy_a_quick_guide_to_disability_in_development.pdf

Sticky issues and working differently

Mainstreaming and disability specific interventions

In the run up to 2015, raising awareness of the importance of disability inclusion and recognition of the disadvantage that people with disabilities face was a significant achievement. However, the translation of this understanding into action has stalled. In practice, disability inclusion remains deprioritised, under-resourced, and typified by small-scale projects and investments of limited scale. The mainstreaming of disability inclusion in programs remains piecemeal with institutional responsibility outsourced to OPDs and disability-focused organisations. Or responsibility is deferred to an individual advising on social inclusion in its entirety. Relatedly, guidance on disability inclusion shows little progression. Standardised approaches are uncritically repurposed and applied across the spectrum of development programs and activities. While programs and sectors are becoming increasingly specialised, guidance on disability inclusion has remained generic.

Greater attention needs to be paid to integrating disability inclusion into programs and investments. This requires full recognition of the responsibility for mainstreaming held by program planners, managers, and implementers. However, if we are to leave no person with disabilities behind by 2030, this will not be enough. While increasing recognition of the need for mainstreaming is noteworthy, it has been at the expense of investment in disability-specific programs and interventions. We urgently need to recalibrate to ensure individuals with all levels of support needs, including high support needs, are accounted for, can participate, and are included. Including all people with disabilities requires acknowledgement that health-based interventions, including rehabilitation, assistive technology, and allied health services, are fully compatible with the Social Model of disability and rights-based approaches.

Equity as outcome

While there have been efforts to increase the participation of people with disabilities in programs and policies, these are not clearly resulting in equitable outcomes. This is, in part, due to siloed and sector-specific interventions. For example, equity in workforce participation between people with and without disabilities requires attention to inclusive education. Equity in education is, in turn, reliant on early identification of disability and access to inclusive early childhood development supports. These are complex issues with multiple influencing factors and illustrate the limitations of standalone interventions. To ensure equity, we need to better engage with complexity and apply a systems lens to challenge the constraints of traditional administrative and sectoral boundaries.

Equity will also not be achieved without addressing the underlying causes of exclusion for people with disabilities. Frustration with established approaches to disability inclusion and a lack of clear impact has driven the disability movement to reconfigure and reprioritise disability inclusion approaches with the objective of ensuring equity. This includes addressing 'pre-conditions for inclusion' as policy priorities for ensuring equitable participation in society. For the Pacific Disability Forum, these non-negotiable pre-conditions are accessibility, assistive devices, support services, social protection, non-discrimination, and community-based inclusive development.

Recent gender, disability, and social inclusion (GEDSI) approaches and the extent they are addressing intersectionalities are also a key equity concern. To date, GEDSI initiatives have been more reflective of a 'gender plus' approach. That is, a focus on gender with some reference to disability and possibly age. Rather than addressing intersectionalities across and between identity characteristics, approaches remain siloed within an overall

GEDSI framework. There is also the risk that some groups, such as people with disabilities, and some thematic areas, such as gender-based violence, are relegated to the background. On the one hand, combining responsibilities under a single GEDSI umbrella is a response to resource limitations and could play a constructive convening role. However, current GEDSI approaches and roles are likely to be challenged by the need to incorporate tailored and more technical disability inclusion solutions within programs. In response, we need to consider: who needs to know what and why? While disability inclusion is 'everyone's business', more nuanced consideration of what information is needed at different levels of decision-making and implementation would be helpful. Knowing where, and importantly how, to access expertise is key.

Issues of representation

An intersectional GEDSI lens can highlight diversity and the underrepresentation of specific groups of people with disabilities. At the same time, issues relating to representation persist. While not exhaustive, this includes charges of tokenism, 'box ticking', and insufficient attention to resourcing and power differentials levelled at development actors by OPDs. Some OPDs also acknowledge more needs to be done to ensure gender and age equality within their own work. Attention also needs to be paid to ensuring the voices of children and young people with disabilities are heard. This requires engaging with caregivers and directly with young people with disabilities themselves.

Caregivers and parents of children with disabilities are part of a wider disability and support ecosystem. There are two important considerations that relate to caregivers and representation. The first is the role that caregivers may play in representing children with disabilities and, in specific cases, facilitating supported decision-making by some adults with disabilities. It is noteworthy that children with disabilities and, for example, people with psychosocial disabilities are not well-represented by, or within, OPDs. Secondly, it is important that parents and caregivers have their own voice. Informal and unpaid care impacts on the economic security of households, the social participation of family members across generations, and the wellbeing of individuals with disabilities.

Justice and legal compliance

Inequity and violence against people with disabilities are persistent themes. This includes disproportionate exposure to specific forms of gender-based violence; physical restraint, institutionalisation, abuse, and neglect; stigma and prejudice; higher death rates in situations of risk and climate injustice; and persistent socio-economic disadvantage and exclusion. The CRPD has almost universal ratification by UN Member States, whether those countries are donors or recipient partners of development cooperation. The implication is that disability inclusion, and addressing inequity and violence, is now mandated under national law in most countries we work.

Members of the disability movement are increasingly turning to legal recourse whether that is under laws based on CRPD ratification or, where these are deemed insufficient, alternative legal instruments. For example, on torture in the case of rights abuses stemming from forced institutionalisation. A failure to acknowledge the gravity of CRPD ratification and the subsequent establishment and implications of national disability laws will increasingly expose implementing partners and investments to institutional, reputational, and financial risk.

Expectations and standards

At the global level, expectations have been set. That is, by 2030, we will leave no one behind. To 'supercharge' efforts, we need to rigorously translate this aspiration into development practice. A starting point is reconsidering equity as our principal objective. This will not be achieved by a reliance on accepted standards, inadequate resources, and current ways of working. We need to become comfortable with complexity, working across systems, and addressing the root causes of exclusion and injustice in our work. Towards this end, we hope these essays provide some points of reflection and inspiration.

Preconditions for inclusion in the Pacific

Laisa Vereti, Pacific Disability Forum (PDF)[1]

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

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Introduction

In 2016, the Special Rapporteur of the Human Rights Council on the Rights of Persons with Disabilities' annual report focused on disability-inclusive policies. The report described such policies as 'a prerequisite for the implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the 2030 Agenda for Sustainable Development'. The report proposed that the 'initial step' of a disability-inclusive policy framework must incorporate 3 aspects: a non-discrimination framework, accessibility requirements, and assistive technology (AT) and support services that support the autonomy and inclusion of people with disabilities on an equal basis with others.[2] The Special Rapporteur's call to action to policy makers was clear: 'take those three aspects into account when designing and implementing any public policy or program, as they are indispensable for addressing the specific demands and needs of people with disabilities.'[3] It is from this that specific preconditional aspects have been developed.

Like others across the disability movement and sector, at Pacific Disability Forum (PDF) we found the Special Rapporteur's conceptualisation of preconditions that are requisite for including people with disabilities in all programming and policies most useful. These increasingly began to be referred to as 'preconditions for inclusion.' At PDF we began to consider further preconditions critical to progressing the rights and needs of people with disabilities in our region. The Pacific has a strong regional identity as well as deep understanding of the unique experiences of our people with disabilities. We began to identify particular policy and programming areas within the Pacific that we considered to be additional prerequisites and indispensable for implementing the CRPD and Sustainable Development Goals (SDGs). We were concerned they may not be captured within the three 'aspects' or 'preconditions' outlined by the Special Rapporteur's report.

Preconditions to inclusion as defined by the Pacific Disability Forum

While keeping the Special Rapporteur's original aspects of non-discrimination and accessibility, we split her third category. There is a dire lack of both assistive devices and support services in the Pacific and the resourcing and policy considerations to support each area is quite distinct. Our concern was that consolidating assistive devices and support services under one precondition, as the Special Rapporteur's report had done, would not give either the attention they required for effective action towards realising the CRPD and SDGs. Therefore, we made assistive devices and support services 2 separate preconditions in our framework. We define support services as specific services provided to people with disabilities that support their direct participation and access to services, such as sign language interpreters, personal assistants, guide dogs, and peer support services.

We included community-based inclusive development (CBID) as an additional precondition. While CBID is not mentioned in the Special Rapporteur's report, it is a prerequisite to disability inclusion as it facilitates the 'last mile' delivery of national sectoral policies as well as encompassing specific activities, such as community awareness raising and resource mobilisation. This is vital in the Pacific where the distances between countries and population spread within countries and across islands pose unique challenges.

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[2] UN Special Rapporteur on the Rights of Persons with Disabilities. 2016. Report of the Special Rapporteur of the Human Rights Council on the rights of persons with disabilities, Catalina Devandas-Aguilar. https://undocs.org/en/A/71/314
[3] Ibid

We also included social protection as a further precondition in recognition social protection is widely recognised as fundamental to achieving social inclusion and the active participation of people with disabilities.[4,5] Social protection schemes are life changing for people with disabilities, addressing social and economic impacts in times of crisis, alleviating poverty, and enhancing productivity, independence, and social inclusion.[6] While mainstream social protection schemes are essential and people with disabilities must be ensured access to these, disability-specific benefits are also crucial to enable people with disabilities to pay for the extra costs associated with disability.

Other ways preconditions to inclusion have been understood

It is worth noting that other stakeholders have developed their own thinking around preconditions to inclusion and key aspects that should be named. We appreciate actors taking their own approach as appropriate to their own context, as we have done with our context. The United Nations Partnership on the Rights of People with Disabilities (UNPRPD) applies a preconditions to inclusion framework, naming equality and non-discrimination, inclusive service delivery, accountability and governance, accessibility, and CRPD-compliant budgeting and financial.[7] There could also be concerns that the term 'preconditions' may be misinterpreted by governments or donors as implying that progress on other aspects of disability rights and inclusion (such as mainstreaming) is less of a priority or does not need to progress until the preconditions are first met. While we respect this position, the usefulness of the preconditions framework makes it worth applying regardless. However, we emphasise that the preconditions should never be taken to suggest any lessening of urgency in other areas of disability inclusion work.

Challenges and opportunities

The past 5 years have seen mixed progress in relation to both the understanding of preconditions of inclusion and their achievement. Although the Special Rapporteur's report was released in 2016, and PDF has advocated for many years since, policy makers in the region have lagged in applying the preconditions to inclusion as envisaged by the Special Rapporteur or PDF. There have been pockets of progress under some of the 6 areas. The pandemic saw increased investment and development of social protection schemes throughout the Pacific, including the introduction of disability-specific benefits. There is an opportunity to continue to build on momentum to establish mainstream and disability-specific social protection schemes that follow the Special Rapporteur's guidance.[8]

There is also an opportunity in relation to AT and the World Health Organization's Pacific AT Procurement Study, 2020.[9] The study explored current challenges and strategies for strengthening the procurement of appropriate AT to increase access for people in the Pacific. Any future work in this sector should refer to this report, particularly regarding

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[4] United Nations Partnership on the Rights of Persons with Disabilities. 2023. CRPD Implementation. https://www.unprpd.org/crpd-Implementation

[5] UN Special Rapporteur on the Rights of Persons with Disabilities. 2015. Report of the Special Rapporteur on the rights of persons with disabilities. https://undocs.org/en/A/70/297

[6] Ibid

[7] United Nations Partnership on the Rights of Persons with Disabilities. 2023. CRPD Implementation. https://www.unprpd.org/crpd-Implementation

[8] UN Special Rapporteur on the Rights of Persons with Disabilities. 2015. Report of the Special Rapporteur on the rights of persons with disabilities. https://undocs.org/en/A/70/297

[9] World Health Organization. 2020. Assistive technology procurement study: technical report. World Health Organisation Regional Office for the Western Pacific, Manila. https://iris.who.int/handle/10665/334368

supply and economic efficiency. The report provides clear recommendations regarding how the region should proceed to strengthen provision of AT.

Huge challenges in progressing preconditions for inclusion remain. There has been a devastating loss of momentum around CBID in recent years. This has seen meetings and grass roots programming continuing but no systematic or resourced way forward for CBID at national and regional levels. A significant challenge is cross-departmental coordination as CBID does sit under any one ministry. There is a need for reinvigorated commitment by national governments in the Pacific to find CBID frameworks and resourcing models that work.

There has also been little progress on support services despite this being highlighted as a prerequisite to disability-inclusive policy frameworks since, at least, the 2016 Special Rapporteur's report. Formalised support services remain virtually non-existent across the Pacific. Again, there is an urgent need for commitments, frameworks and resources to ensure this vital precondition to inclusion is galvanised into action. Doing so would have a transformational impact on individuals with disabilities, their families and communities, not least because it would enable more effective engagement within other mainstream and disability-specific development programs.

Looking ahead to 2030

A strong focus of the development sector since 2015 has been on mainstreaming disability into development efforts to achieve the 2030 Agenda objectives and SDGs. There has not, however, been the necessary awareness or traction around the preconditions to inclusion since the Special Rapporteur introduced in 2016. It is now with increasing urgency that we are calling upon national governments and donors to apply and resource a preconditions to inclusion framework to their country policy and programming approaches. This is an imperative if disability inclusion efforts are to be effective in realising in rights of people with disabilities in the Pacific. The recommendations for progressing the preconditions for inclusion, as defined by PDF, are outlined below. These need to be followed if we are to make meaningful progress towards disability equity in our region by 2030.

Accessibility

- Regional Accessibility Standards on the Built Environment are under development. When publicly endorsed, adopt these within national regulatory frameworks.

- Train national delegations of professionals, OPDs, and government representatives (particularly at the sub-national level) on how to use and monitor the Regional Accessibility Standards on the Built Environment.

- Develop a regional process for monitoring the implementation of the Regional Accessibility Standards on the Built Environment by Pacific Island Countries, involving OPD representatives, government and other key stakeholders.

- Establish a regional taskforce to identify and mobilise action on strategic opportunities for accelerating accessible transport and infrastructure in the Pacific. This should build on the analysis and recommendations in the Pacific Regional Infrastructure Facility report *Improving Accessibility in Transport Infrastructure Projects in the Pacific Islands.*[10]

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[10] Pacific Region Infrastructure Facility. N.d. Improving Accessibility in Transport Infrastructure Projects in the Pacific Islands. https://www.theprif.org/sites/default/files/documents/prif_transport_report_web.pdf

- Commission a report to undertake a situational analysis and outline of information and communications technology accessibility standards for the Pacific. This could then be tailored by countries when developing their own national standards.

Assistive devices and technology

- Review existing tax regulations and promote exemptions or concessions for assistive products and technology across the region.

- Establish a regional procurement facility, in line with the recommendations of the WHO AT Procurement Study, to address the shortage of quality and affordable assistive products and technology across the region.[11]

- Develop support from national governments and partners for training of multi-disciplinary personnel related to assistive products and technology and integrated health and rehabilitation services to improve access and ensure safe and appropriate use by people with disabilities.

Community-based inclusive development

- Link CBID to disaster risk reduction through systematic mechanisms (such as national policies, international frameworks, and national and international funding allocations) to ensure risk reduction and risk prevention is sustainably embedded in CBID programming.

- Support an initiative to identify a new action plan and budget commitment to continue strengthening CBID in the Pacific. This should focus on key barriers, such as resourcing, improving coordination between government ministries, accessing regional and remote areas, and workforce planning.

Non-discrimination

- Ensure disability is mainstreamed into all other sectoral laws, particularly anti-discrimination legislation and policies.

- Include non-discrimination terms and provisions in partner and donor funding arrangements, including adequate provisions to address reasonable accommodation.

Social protection

- Support all countries in the region to adopt disability-specific support benefits and allowances based on regional good practices, including protecting the right to work, and embed these in relevant policies, legislation and budgets.

- Implement disability-inclusive mainstream social protection schemes, which protect the right to access specific disability support benefits and necessary family benefits.

- Develop social protection schemes that support children with disabilities and their families.

- Establish schemes that enable people with disabilities to access social welfare assistance automatically in the event of disasters, without having to provide evidence of hardship.

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[11] World Health Organization. 2020. Assistive technology procurement study: technical report. World Health Organisation Regional Office for the Western Pacific, Manila. https://iris.who.int/handle/10665/334368

Support services

- Recognising the dearth of support services in the region, commission a regional report to provide a situational analysis regarding what support services currently exist in the Pacific and how they enable daily living and inclusion for people with disabilities. Provide clear recommendations for next steps to deliver concrete and systemic changes required to progress this sector.

- Invest in a pilot program that can be scalable to implement the recommendations of this regional support services report.

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Rehabilitation and assistive technologies in disability-inclusive development and health systems

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Background

Rehabilitation and assistive technologies (AT) have been described by the Pacific Disability Forum and other disability representative groups as 'preconditions' for both disability-inclusive development, and equitable, responsive health systems that respond to population changes. In this paper, we build on this call from persons with disabilities to argue the critical and 'cross-cutting' importance of rehabilitation for everyone.

Disability inclusion, health systems strengthening, and humanitarian preparedness are interlinked themes in Australia's development agenda. Rehabilitation and AT are essential to all these areas. Political commitment and normative guidance are stronger than ever, but without an urgent, coordinated response, services will continue to lag behind the rapidly growing need.

Populations are growing, ageing, and living longer with more long-term health conditions. Chronic respiratory and motor sequelae of COVID-19 provided a stark example of the importance ongoing care after infectious disease. At least a third of all people globally experience more than one health condition. Global 'Burden of Disease' data suggests that up to one in three people overall may benefit from rehabilitation services,[2] while a recent Global Report on AT reports persistent unmet needs for AT.[3] In lower-income countries, as few as 3% of people can access needed products due to out of pocket costs, poor supply, limited knowledge, and fragmented systems.

While there is clear evidence of persistent unmet needs, and epidemiological transitions from communicable to non-communicable diseases are mostly well-understood, social trends are also changing and provide further impetus for re-thinking the right mix of health and social services. Families are getting smaller, more people are living in cities, and traditional family models for providing care and support to family members who are unwell, ageing, have difficulty functioning, or experience disability are becoming less common.[4,5]

Among the implications for population health and social cohesion, and how systems respond, is an urgent need to redress the shortage of rehabilitation and AT services.

In broad terms, rehabilitation and AT involve a range of services and professionals, spanning multiple systems including health, social services, education, and others. AT includes both products and services to support, adapt to, or recover from functional difficulties with the aim to optimise function, promote recovery, or facilitate participation.

In our region, the Pacific Disability Forum (PDF) has argued that access to AT is a 'precondition' for disability inclusion, essential for preparing for climate and population

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[2] Cieza A, Causey K, Kamenov K, Hanson S W, Chatterji S and Vos T. 2021. Global estimates of the need for rehabilitation based on the Global Burden of Disease study 2019: a systematic analysis for the Global Burden of Disease Study 2019. https://pubmed.ncbi.nlm.nih.gov/33275908/

[3] World Health Organisation and United Nations Children's Fund. 2022. Global Report on Assistive Technology. https://www.who.int/publications/i/item/9789240049451

[4] Seltzer J A. 2019. Family Change and Changing Family Demography. Demography 56(2), pp. 405–426. https://doi.org/10.1007/s13524-019-00766-6

[5] Schoeni R F, Cho T C, and Choi H. 2022. Close enough? Adult child-to-parent caregiving and residential proximity. Soc Sci Med. 2022. 10.1016/j.socscimed.2021.114627

changes, and progressing development goals.[6,7] The Pacific Framework for the Rights of Persons with Disabilities goals require development of vocational rehabilitation expertise and services, along with reasonable accommodations including assistive products.[8] Strategies for rehabilitation and AT, either as standalone strategies or embedded within health or disability strategies or both, are now common.

Rights for people with disabilities to access rehabilitation and AT are well established (including in the United Nations Convention on the Rights of Persons with Disabilities), and a recent World Health Assembly resolution bolstered political commitment for Member States to strengthen rehabilitation services and integrate them with health systems.[9]

Rehabilitation and AT have been an important part of Australia's development investments. From at least the late nineties, Australia has provided financial, technical, and other in-kind support to the rehabilitation of landmine and other unexploded ordnance (UXO) victim-survivors through Victim's Assistance (VA) support. Australia was one of the top 6 donors as recently as 2014 (OECD), but specific VA funding has declined.[10] Rehabilitation and AT, including through VA, previously dominated 'disability' investments. Recognising disability inclusion and disability rights, rehabilitation and AT have tended to be de-emphasised in favour of 'mainstreamed' approaches to inclusion for people with disabilities across all development, paradoxically reducing opportunities for rehabilitation and AT which are essential for inclusion.

While these issues continue to occupy an uncertain place in development investment – neither fully part of health systems strengthening nor disability inclusion, and with an uncertain place in humanitarian preparedness and response – the strategic opportunity to build on current progress will be missed.

Challenges and opportunities

Even as population trends have shifted and focus on non-communicable disease and injury demanded a greater focus on rehabilitation and AT, these services have been provided either through community-based rehabilitation or specialised rehabilitation services in larger, urban centres. In general terms, these have worked independently of each other and from the health system, resulting in a fragmented system of urban specialist rehabilitation centres and volunteer, community-based rehabilitation at primary or local levels.

Increasingly, national ministries of health and social affairs have recognised the urgent need to respond. The Global Report on AT was prepared to guide efforts to strengthen AT services. In rehabilitation, the World Health Organization (WHO) has supported many countries to assess and generate evidence-based plans to strengthen rehabilitation services and to better integrate rehabilitation in health systems. New evidence and

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[6] Pacific Islands Forum Secretariat. 2022. 2050 Strategy for the Blue Pacific Continent. Pacific Island Forum Secretariat, Suva. https://forumsec.org/2050

[7] Pacific Disability Forum. 2020. Guideline on Pre-Condition to Inclusion Persons with Disabilities – COVID-19. https://pacificdisability.org/wp-content/uploads/2021/03/Guideline-on-pre-condition-to-inclusion-for-persons-with-disabilities-1.0.docx

[8] Pacific Islands Forum. N.d. Pacific Framework for the Rights of Persons with Disabilities: 2016 – 2025. Pacific Island Forum Secretariat, Suva. https://forumsec.org/sites/default/files/2023-12/PFRPD.pdf

[9] World Health Organisation Executive Board. 2023. Agenda item 8: Strengthening rehabilitation in health systems. https://apps.who.int/gb/ebwha/pdf_files/EB152/B152(10)-en.pdf

[10] McMullan B and Davies R. 2016. Demining disaster? DevPolicy Blog. https://devpolicy.org/demining-disaster-20160819/

technical guidance to implement evidence-based systems responses is emerging and will guide the next generation of responses.

Opportunities

Combined efforts of Australian collaborators, such as NGOs, professional associations, research groups, OPDs and others, along with organisations and government partners in Asia and the Pacific are already working to strengthen rehabilitation and promote access to rehabilitation and AT. With stronger government commitment and a growing body of technical resources to support change, there is a strategic opportunity to re-focus investment on rehabilitation and AT, recognising their centrality to both disability inclusion and in responding to population health changes.

Below, three illustrative cases outline strategic directions to complement other areas of investment. The cases focus on three different entry points: procurement, capabilities, and health systems.

Technical support and procurement of AT

Robust methods to assess AT needs, and select and procure, as well as training local personnel to assess needs and provide simple products, are now available and being used around the world, but there are many opportunities to introduce these 'shovel-ready' approaches in Asia and the Pacific.[11,12,13]

A number of current and recent investments in the rehabilitation and AT space provide strategic entry points to coordinate efforts and implement the growing body of evidence and technical guidance at scale. Doing so has multiple benefits, including for disability inclusion, ageing, injury management, and managing NCDs including vision and hearing-related conditions.

WHO and Department of Foreign Affairs and Trade have previously commissioned a report on strategic entry points to strengthen AT procurement in the Pacific, which recommended, among other things, to:

- coordinate regional efforts and provide technical support, including through a specific AT facility
- develop a regional approach to AT procurement and supply
- coordinate AT workforce development initiatives.[14]

Promising technologies and experiences implementing them have enormous potential to improve how people access appropriate AT. Diverse fields like app-based communication solutions, centralised fabrication of specialist products and 3D-printing continue to evolve. At the same time, informal markets and ultra-low-cost solutions will remain commonplace,

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[11] Zhang W, Eide A, Pryor W, Khasnabis C, and Borg J. 2021. Measuring Self-Reported Access to Assistive Technology Using the WHO Rapid Assistive Technology Assessment (rATA) Questionnaire: Protocol for a Multi-Country Study. International Journal of Environmental Research and Public Health, 18(24). https://doi.org/10.3390/ijerph182413336

[12] World Health Organisation. 2021. Assistive product specifications and how to use them. . https://www.who.int/publications/i/item/9789240020283

[13] World Health Organisation. 2023. Training in Assistive Products. https://www.who.int/teams/health-product-policy-and-standards/assistive-and-medical-technology/assistive-technology/training-in-products

[14] World Health Organisation Regional Office for the Western Pacific. 2020. Assistive Technology Procurement Study: Technical Report. World Health Organisation, Manila. https://www.who.int/publications/i/item/9789290619178

highlighting the importance of whole-of-system emphasis, rather than focusing on just a few product types, or methods to produce and provide them. Overall, strategic priorities include to:

- leverage 'critical mass' of global efforts to generate evidence and implementation capacity in integrating rehabilitation and AT into health systems through strategic collaborations with organisations working in health systems strengthening

- contribute to pooled resourcing arrangements, such as ATscale[15]

- situate rehabilitation and AT as 'pre-conditions', which cross-cut health, social inclusion, education, livelihoods, disability inclusion, ageing, humanitarian response, and others.

- include high level indicators (drawing on WHO's Rehabilitation Indicators)[16] for rehabilitation and AT in health-related program designs.

Supporting rehabilitation and AT competency development

Providing appropriate rehabilitation and AT services requires adequate human and financial resources. This includes rehabilitation-specific professions, rehabilitation competencies among other health professional (doctors, nurses, etc.), and continuing to develop the role and capabilities of community-based inclusive development (CBID) managerial staff. Australia and its collaborators have strong capabilities and existing relationships. Strategic opportunities include to:

- generate political will to allocate resources and effort to grow the rehabilitation and AT workforce, including through opportunities for training and strengthening relevant professional groups

- support regional countries and partners to collect information about workforce readiness

- apply technical and logistic support to implement evidence-based approaches for building competencies among health workers in rehabilitation and AT. This includes building regional and national capabilities to design and implement locally adapted training and service design projects, potentially alongside or within existing health-sector investments, is a promising avenue to scale-up access to timely rehabilitation care

- continue efforts to strengthen rehabilitation and AT in a context of ongoing support to regional CBID investments.

Integrating rehabilitation and AT in health systems

Recognising that rehabilitation and AT have mostly been provided in parallel to health services by a mix of civil society (including international) actors, there is strong political commitment and growing evidence and guidance for greater action to integrate rehabilitation into health systems.

Practical solutions for estimating needs, evaluating current arrangements, and developing strategic plans are now available and in use. There is good guidance to prioritise

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[15] ATscale. N.d. Global Partnership for Assistive Technology. https://atscalepartnership.org/

[16] World Health Organisation. 2023. Rehabilitation Indicator Menu: A tool Accompanying the Framework for Rehabilitation Monitoring and Evaluation (FRAME). World Health Organisation, Geneva. https://www.who.int/publications-detail-redirect/9789240076440

interventions to address the most prevalent conditions, and to adapt and implement 'packages' within health systems. Understanding whether and how those interventions are taken up at scale, and how rehabilitation services are governed, financed, and sustained, are priorities for health systems research.[17]

Strategic opportunities include:

- strengthening rehabilitation and AT in regional health systems, including coordinating with WHO and in-country expertise in situation analysis, strategic planning and implementation strategies

- applying participatory methods to simplify assessment of rehabilitation and AT in local health systems[18]

- working with health systems actors to raise awareness of the need for and effective solutions to, strengthening rehabilitation and AT in health systems

- supporting organisations of people with disabilities to contribute to health systems reforms (both in general, and specifically related to rehabilitation and AT)

- supporting national and sub-national assessments of AT needs, workforce readiness, and local rehabilitation and AT arrangements using existing tools and methods

- supporting national and subnational health authorities to develop strategic plans (including through WHO's Rehabilitation Guide for Action)[19]

- providing technical and financial support for local service providers to strengthen disability inclusion.

Looking ahead to 2030

Recognising how population health and functioning is changing, modest integration of rehabilitation and AT in health systems, new global consensus and commitments to collective efforts, specific focus on rehabilitation and AT in both health-related investments and disability-inclusive programming is as important as ever.

Key messages

- Rehabilitation and AT are critically important to achieve both universal health coverage and disability inclusion.

- Access to affordable rehabilitation and AT are rights for people with disabilities, and pre-conditions for attaining other rights, as well as for inclusion.

- There is a growing and unmet need for rehabilitation and AT to respond to population changes including ageing, increasing prevalence of NCDs, chronic effects of infectious diseases, injuries, and changing patterns of social care.

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[17] Cieza A, Kwamie A, Magaqa Q, Paichadze N, Sabariego C, Blanchet K, et al. 2022. Framing rehabilitation through health policy and systems research: priorities for strengthening rehabilitation. Health Research and Policy Systems. https://pubmed.ncbi.nlm.nih.gov/36127696/

[18] Learning, Acting and Building for Rehabilitation in Health Systems. 2024. R-FIT. https://relabhs.org/r-fit/

[19] World Health Organisation. 2019. Rehabilitation in health systems: guide for action. World Health Organisation, Geneva. https://www.who.int/publications/i/item/9789241515986

- Australian stakeholders are uniquely positioned to convene expertise and partner with regional actors to strengthen rehabilitation and AT in both health and disability inclusion sectors.

- There are current global efforts and high level inter-governmental commitments to addressing the shortfalls in rehabilitation and AT.

- Emerging high-level commitments, including World Health Assembly resolutions in particular, reflect global consensus that rehabilitation and AT are essential health services and call for shared efforts to redress historic neglect of these issues.

- Emerging normative guidance provides stronger, evidence-based frameworks to integrate rehabilitation and AT into health and social systems.

Inclusive early childhood development in the Pacific

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Background

Optimal early childhood development (ECD) is widely accepted as critical not only for the outcomes of children, but for their families and society more broadly. Providing enabling environments for nurturing care and development in the first years of life, when children's brains are undergoing their most rapid change, ensures they can achieve their best possible physical, social, emotional, and cognitive outcomes. This applies equally to children with and without disabilities. The evidence shows that investing in ECD has intergenerational benefits for productivity and wellbeing that in turn promote societal economic growth, stability, and equality.[2] To this end, Sustainable Development Goal (SDG) target 4.2 seeks to ensure that 'by 2030 all girls and boys have access to quality early childhood development, care and pre-primary education so that they are ready for primary education'.[3] While action on ECD has gained global support, with just 7 years left to achieve target 4.2 there is still much to be done and children with disabilities are being left behind.

The Pacific region is home to approximately 1.7 million children under 5.[4] Considering recent estimates that 16% of the global population has a disability this translates to approximately 272,000 children with disabilities under 5 in the Pacific region who can benefit from inclusive ECD programming.[5] Safety, health care, adequate nutrition, responsive caregiving, and opportunities for early learning are all necessary for optimal ECD yet data indicates that young children with disabilities are far less likely to have access to these than children without disabilities. [6,7]

With the recent establishment of the Pacific Regional Council for Early Childhood Development (PRC4ECD), a multi-sector, multi-government body, to guide and strengthen approaches to ECD across the Pacific now is the time to ensure ECD activities across the region are disability inclusive.[8]

Challenges and opportunities

Inclusive ECD for school 'readiness'

The focus on development investment for children with disabilities to date has been on inclusive education for school-aged children. However, as illustrated in Figure 1, inclusive ECD starting from birth is needed to build the foundation for successful inclusive education.

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[2] World Health Organisation, United Nations Children's Fund, and World Bank Group. 2018. Nurturing Care for early childhood development: a framework for helping children survive and thrive to transform health and human potential. World Health Organization, Geneva. https://nurturing-care.org/ncf-for-ecd

[3] United Nations. 2015. Sustainable Development Goal – Goal 4. https://sdgs.un.org/goals/goal4

[4] Pacific Regional Council for Early Childhood Development (PRC4ECD). N.d. [Accessed 13 July 2023] https://pacific-child.org

[5] World Health Organization. 2022. Global report on health equity for persons with disabiltiies. World Health Organization, Geneva. https://www.who.int/publications/i/item/9789240063600

[6] World Health Organisation, United Nations Children's Fund, and World Bank Group. 2018. Nurturing Care for early childhood development: a framework for helping children survive and thrive to transform health and human potential. World Health Organization, Geneva. https://nurturing-care.org/ncf-for-ecd

[7] United Nations Children's Fund. 2021. Seen, Counted, Included: Using data to shed light on the wellbeing of children with disabilities. United Nations Children's Fund, New York. https://data.unicef.org/resources/children-with-disabilities-report-2021/

[8] United Nations. 2015. Sustainable Development Goal – Goal 4. https://sdgs.un.org/goals/goal4

Figure 1. Pathway to inclusive child health, education and development.[9]

While the growing global action on ECD is pleasing, much of it has excluded children with disabilities. Moving forward, achieving SDG target 4.2 of access to quality ECD *for all* requires mainstream ECD services and programs to be inclusive of children with disabilities, including health and nutrition programs, early childhood education and parenting support. But these need to be accompanied by programming to address the specific needs of children with disabilities, such as early detection, early intervention, and provision of assistive technology. Inclusive ECD programming from birth to school age promotes not only 'child readiness' for education, but also 'family and community readiness' to support and facilitate children with disabilities to access and meaningfully participate in education.

Until now, the focus of development programming on inclusive education has been on the readiness of education systems to include children with disabilities, not on the readiness of children and their families to access and utilise education. Investing in inclusive ECD will enable greater readiness of children and their families to attend school and benefit from inclusive education.

'Child readiness' in this context refers to children with disabilities having access to opportunities for physical, social, and cognitive development and participation with peers that 'prepares' them for school.[10] This requires effective systems for early detection of developmental disability and access to early intervention services (see Figure 1). Early intervention services support young children with disabilities to develop their independence and functioning across developmental domains (for example: communication, mobility, self-care) through advocating for the rights of children with disabilities, therapeutic interventions and parent education and support. Access to inclusive playgroups, preschool, or early childhood education programs, play and early learning further support the readiness of children with disabilities for school, while also facilitating 'community readiness' by setting a precedent and expectation for inclusion from the earliest stages of education.

'Family readiness' for inclusive education is facilitated by supporting parents or caregivers of young children with disabilities through social supports and protection. There is a growing evidence base of the feasibility and acceptability of peer-facilitated parent and caregiver support programs as a model of early intervention for children with

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[9] Olusanya B O, Yun Boo N, de Camargo O K, Hadders-Algra M, Wertlieb D, and Davis A C. 2022. Child health, inclusive education and development. Bulletin of the World Health Organization; 100(7), pp.459-461. http://dx.doi.org/10.2471/BLT.22.288103

[10] Nair M K C, Radhakrishnan R, and Olusanya B O. 2023. Promoting school readiness in children with developmental disabilities in LMICs. Frontiers in Public Health, 11. https://doi.org/10.3389/fpubh.2023.993642

developmental disabilities and their caregivers, including the pilot of such a program in Fiji.[11,12] Such programs have been found to increase parent and caregiver awareness of their child's rights and support needs, and in turn empower them to advocate for their child's inclusion and participation.[13] Family 'readiness' is further supported through provision of social protection or other forms of livelihood support for parents and caregivers of children with disabilities. The links between poverty and disability are well-established, and such financial support measures enable families to meet the direct and indirect costs associated with their child's disability, protecting the family unit from the economic, health, and social impacts of the disability-poverty cycle.[14]

Despite the evidence of what is needed to achieve inclusive ECD, including child and family readiness for inclusive education, many of these inclusive mainstream and disability-specific supports are lacking throughout the Pacific region. As the Pacific Regional Council for Early Childhood Development works to implement the 'Pasifika call to action on ECD' and ensure that every child in the region has access to the services and opportunities needed to reach their potential, there is an opportunity to change this.

In addition to inclusive ECD being vital for successful inclusive education and continuing Australia's positive track record in disability inclusive development, inclusive ECD intersects with other key development priorities of gender and climate change responsiveness.

Inclusive ECD and women's empowerment

Women continue to assume the primary caregiving role for young children, impacting their ability to participate in the workforce and contribute to household income generation. This is compounded for female caregivers of children with disabilities by a lack of alternative childcare options that are willing and able to appropriately care for children with disabilities.

While early childhood education or preschool services are becoming more common in many low- and middle-income countries, there is little evidence these are disability inclusive. Support for inclusive early childhood education and care services is key to enabling women to have equal opportunities for workforce participation. This support also contributes to 'family readiness' as described above. Further, female primary caregivers are more likely to face stigma, discrimination, and partner abandonment.[15] Inclusive services for young children with disabilities can alter such social norms and build both gender and disability equity.

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[11] Nanyunja C, Sadoo S, Kohli-Lynch M, Nalugya R, Nyonyintono J, Muhumuza A, et al. 2022. Early care and support for young children with developmental disabilities and their caregivers in Uganda: The Baby Ubuntu feasibility trial. Frontiers in Pediatrics, 10. https://doi.org/10.3389/fped.2022.981976

[12] Woolfenden S, Milner K M, Tora K, Naulumatua K, Mataika R, Smith F, et al. 2020. Strengthening Health Systems to Support Children with Neurodevelopmental Disabilities in Fiji–A Commentary. International Journal of Environmental Research and Public Health; 17(3). https://doi.org/10.3390/ijerph17030972

[13] Smith F, Perera S, and Marella, M. 2023. The journey to early identification and intervention for children with disabilities in Fiji. Int J Environ Res Public Health; 20(18). https://doi.org/10.3390/ijerph20186732

[14] Loucaides E M, Zuurmond M, Nemerimana M, Kirk C M, Lassman R, Ndayisaba A, et al. 2022. Livelihood support for caregivers of children with developmental disabilities: findings from a scoping review and stakeholder survey. Disability and Rehabilitation. 46(2), pp.293-308. https://doi.org/10.1080/09638288.2022.2160018

[15] Nair M K C, Radhakrishnan R, and Olusanya B O. 2023. Promoting school readiness in children with developmental disabilities in LMICs. Frontiers in Public Health, 11. https://doi.org/10.3389/fpubh.2023.993642

Inclusive ECD and climate change

There is increasing evidence of the significant impacts of climate change on young children with disabilities. Climate change disproportionately impacts both people with disabilities and children under 6 years of age.[16] The impacts of climate and other emergencies on young children include disruption and toxic stress impacting on brain development during a crucial period and thus their physical and mental wellbeing, while also impacting access to mainstream and specialist services. This serves to further increase risks of exclusion, violence, discrimination, institutionalisation, and risk of injury and death.[17]

As Pacific Island countries develop their multi-sector approaches to ECD, it is necessary that these systems and services are climate and disaster resilient. This includes mainstream and disability specific ECD programming and consideration of how these measures can contribute to reducing disaster risk and mitigating the effects of climate change on young children's development. Also required is contingency planning for service disruption during disasters, to ensure young children's development does not suffer.

Looking ahead to 2030

The following recommendations are made with a view to supporting governments in achieving SDG target 4.2 and ensuring children with disabilities are considered front and centre among *all children*.

Given the recent establishment of the Pacific Regional Council for Early Childhood Development and the opportunity this presents, the following recommendations are focused on the Pacific Island countries but are equally applicable to other countries beyond the Pacific.

- Provide support and advocacy to the Pacific Regional Council for Early Childhood Development to ensure children with disabilities are included in strategies and actions.

- Support the establishment of Organisations of People with Disabilities (OPDs) that specifically represent and advocate for children with disabilities and their families. For example, a specific branch of the Pacific Disability Forum (PDF) or a similar regional OPD for children who could support national level child focused OPDs.

- Support countries to evaluate current ECD programming for barriers to disability inclusion, and enablers of disability inclusion.

- Enable existing services to increase capacity and coverage including through supporting trials of service models such as telehealth and community-based peer-facilitated caregiver support programs. Also, by supporting workforce development initiatives, particularly in Pacific Island countries where the workforce is extremely limited.

- Support strengthening of routine developmental monitoring and referral systems in existing health systems to identify children with developmental delays and disabilities early, linking them into available services.

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[16] United Nations Children's Fund. 2023. Over the tipping point. United Nations Children's Fund, East Asia Pacific Regional Office, Bangkok. https://www.unicef.org/eap/reports/over-tipping-point

[17] United Nations Children's Fund. 2017. Situation Analysis of Children in the Pacific Island Countries. United Nations Children's Fund Pacific Office, Suva. https://www.unicef.org/pacificislands/reports/situation-analysis-children-pacific-island-countries

- Promote access to affordable inclusive early childhood education and care services (childcare) to support caregiver wellbeing and workforce participation for women.

- Consider how mechanisms for social protection and livelihood support for parents and caregivers of children with disabilities can be strengthened in the Pacific.

- Ensure inclusive ECD is considered in actions to respond to the impacts of climate change in the Pacific.

Disability-Inclusive and Resilient Education

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Background

Article 24 of the United Nations Convention on the Rights of Persons with Disabilities and its accompanying General Comment No. 4 enshrine the rights of people with disabilities to education.[2,3] The Cali Commitment to Equity and Inclusion in Education calls for accelerated efforts towards inclusive education, building on previous commitments including Sustainable Development Goal 4, the Salamanca Statement, and the Education 2030 Framework for Action.[4,5,6]

However, progress is slow. On average, children with disabilities comprise 15% of all out-of-school children, however this figure is much higher in some countries, such as Tunisia (30%) and Iraq (35%). Children with disabilities are less likely to be enrolled in school, have lower rates of attendance and transition to higher levels of education, and are less likely to complete education compared to children without disabilities.[7,8]

As a result, people with disabilities are more likely to experience lower learning outcomes. The literacy rate among people with disabilities has been estimated to be 54% compared to 77% for people without disabilities. This percentage is even lower for women and girls with disabilities.[9]

Disasters, so prevalent in many of the world's poorest countries, close schools and prevent learning, compounding inequities and inhibiting progress. As the climate continues to change, humanitarian emergencies become more common and severe, devastating infrastructure, derailing plans, pre-occupying ministries of education, schools, and communities in response efforts. Ultimately, disasters limit gains made by nations seeking to strengthen inclusive education systems. The COVID-19 pandemic resulted in school closures, learning loss, and psychosocial crises for students with and without disabilities. As education systems and schools struggle to deliver education that includes and benefits everyone and is resilient throughout pandemics and in a changing climate, people with disabilities are disproportionately disadvantaged. Lower education completion rates lead to reduced access to qualifications and fewer opportunities to find employment or to start a business.10 Consequently, people with disabilities have lower employment rates when compared to others, reinforcing the interconnectedness of disability and poverty.[11]

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[2] UN General Assembly. 2007. Convention on the Rights of Persons with Disabilities. https://www.refworld.org/docid/45f973632.html

[3] UN Committee on the Rights of Persons with Disabilities. 2016. General comment No. 4, Article 24: Right to inclusive education. https://www.refworld.org/docid/57c977e34.html

[4] United Nations Educational, Scientific and Cultural Organization. 2019. Cali commitment to equity and inclusion in education. https://unesdoc.unesco.org/ark:/48223/pf0000370910

[5] United Nations Educational, Scientific and Cultural Organization. and Ministry of Education and Science Spain. 1994. The Salamanca Statement and Framework for Action on Special Needs Education. United Nations Educational, Scientific and Cultural Organization, Paris. https://unesdoc.unesco.org/ark:/48223/pf0000098427

[6] United Nations Educational, Scientific and Cultural Organization. 2015. Education 2030: Incheon Declaration and Framework for Action for the implementation of Sustainable Development Goal

[7] United Nations Educational, Scientific and Cultural Organization. 2020. Global Education Monitoring Report 2020: Inclusion and Education: all means all. UNESCO, Paris. https://gem-report-2020.unesco.org/

[8] Mitra S and Yap J. 2021. The Disability Data Report. Disability Data Initiative. Fordham Research Consortium on Disability, New York. https://disabilitydata.ace.fordham.edu/reports/disability-data-initiative-2021-report/

[9] United Nations Department of Economic and Social Affairs. 2018. Disability and Development Report: Realizing the Sustainable Development Goals by, for and with persons with disabilities. https://www.un.org/development/desa/dspd/2019/04/un-disability-and-development-report-realizing-the-sdgs-by-for-and-with-persons-with-disabilities/

[10] World Bank and World Health Organization. 2011. World Disability Report 2011. https://apps.who.int/iris/handle/10665/44575

[11] Mitra S, Posorac A and Vick B. 2013. Disability and poverty in developing countries: A Multidimensional study. World Development, 41, pp.1-18. https://doi.org/10.1016/j.worlddev.2012.05.024

Challenges and opportunities

Strengthening inclusive education requires action on several fronts, and by a multitude of stakeholders at all levels. A Framework for Disability-Inclusive Education was developed by UNESCO, UNICEF, the Global Partnership for Education, and the United Kingdom's Foreign, Commonwealth and Development Office to support countries in undertaking an education sector analysis. It provides an approach for assessing and supporting education systems, from early childhood education to tertiary education, through a disability-inclusive lens .[12]

The framework is divided into 2 main sections: service delivery and enabling environment. *Service delivery* consists of 3 elements that determine the extent to which schools can offer inclusive education for children with disabilities: (1) Supply covers provision of adequate teacher training, making school infrastructure accessible, and ensuring availability of textbooks and learning materials for learners with diverse disabilities; (2) Quality refers to the establishment and delivery of a relevant, flexible curriculum, regular screening and assessment of children to identify learning needs, and provision of learning support systems, including provision of assistive technologies (AT), accessible learning materials or individual assistance; and (3) Demand covers the attitudes of school communities, staff and students, additional costs of AT and learning materials, and the availability of future benefits, including opportunities for employment and social inclusion.

The second section, *enabling environment*, refers to the operating context for inclusive education and includes legal, policy and planning frameworks, systems for data and evidence to support participation and learning outcomes of students with disabilities, leadership and management capacity and partnerships to enable inclusive education, and sufficient finance to support inclusive education. These elements of the framework are essential to establishing, maintaining, and improving disability-inclusive education. However, in addition, inclusive education systems and schools must also be prepared for and resilient in the face of emergencies. If they are not, gains in these domains can be washed away or stalled by disasters and pandemics.

In response to disasters, schools often close or temporarily relocate. Students may have lost their homes and/or family members and may be absent from school for long periods. As a result, some students do not return, and if they do, they may experience learning loss from having missed time at school. A study in Puerto Rico found that standardised test scores dropped following Hurricane Maria, and following a subsequent earthquake, dropped further.[13] Students with disabilities had even lower test scores. The dropout risk was high for all students, but especially for students with disabilities.

Recent evidence on the effect of the COVID-19 pandemic on educational outcomes points to smaller gains in academic abilities following the pandemic, especially in mathematical skills, and higher rates of students leaving school early.[14] Another study found that the mental health problems experienced by students with disabilities rose during COVID-19, with the introduction of remote learning and associated reductions in social interactions

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[12] United Nations Educational, Scientific and Cultural Organization, United Nations Children's Fund, and Global Partnership for Education, and UK Foreign, Commonwealth & Development Office. 2021. Education Sector Analysis: Methodological Guidelines. https://www.iiep.unesco.org/en/publication/education-sector-analysis-methodological-guidelines-vol-3-thematic-analyses

[13] Segarra-Alméstica E, Caraballo-Cueto J, Cordero Y and Cordero H. 2022. The effect of consecutive disasters on educational outcomes. International Journal of Disaster Risk Reduction, 83. https://doi.org/10.1016/j.ijdrr.2022.103398

[14] Kuhfeld M, Soland J, Tarawasa B, Johnson A, Ruzek E, and Lewis K. 2020. How Is COVID-19 Affecting Student Learning: Initial Findings from Fall 2020. Brown Center Chalkboard. https://www.brookings.edu/blog/brown-center-chalkboard/2020/12/03/how-is-covid-19-affecting-student-learning/

with peers and teachers.[15] Research from China found that students with disabilities faced 4 challenges during the pandemic: the requirements of students with disabilities were not considered in the design of education policies; technological strategies offered to students were not accessible; mainstream schools offering remote schooling options overlooked the education of students with disabilities; and parents were unprepared to support remote schooling.[16]

Learners with disabilities face increased educational vulnerability because of disasters. Reasons for this include the loss of accessible school infrastructure, loss of consistent emotional support from teachers who leave due to staff turnover, high sensitivity to changes in routine, loss of diagnostic data and documentation about their educational support requirements, limited access to required health or specialist services, loss of AT such as wheelchairs and hearing aids, and loss of support personnel including carers and sign language interpreters.

School closures in response to the COVID-19 pandemic exposed the fragility of education systems for learners with disabilities. Approximately 40% of low- and lower-middle-income countries did not take any measures to support learners at risk of exclusion during the crisis. While some countries put remote learning approaches in place, these were often not accessible to students with disabilities, potentially resulting in disproportionate learning loss.[17]

Inclusive education systems and schools must be resilient to disasters at all levels. There is a tradition of this in highly disaster-prone countries, such as Indonesia and the Philippines, and emerging awareness in Pacific countries, where inclusive school disaster preparedness plans are in place in many schools in 8 of 15 countries.[18] However, many schools in many countries still require disability inclusive disaster preparedness plans. Further, noting the high number of children with disabilities who do not attend school, disability inclusive disaster preparedness education is required in communities to ensure that children with disabilities participate in and benefit from drills and simulations.[19]

Education systems that proactively anticipate future challenges, developing contingency plans and providing necessary resources, can improve educational continuity for all learners, including those with disabilities. Schools must be built to withstand emergencies, and able to reopen and re-establish programs quickly to limit attrition and optimise the psychosocial health of all students. Additionally, schools that are empowered to visit students with disabilities at home, and be flexible with homework, attendance and uniform expectations can improve student retention and limit learning loss.[20]

Diverse learning models can support and enable ongoing learning during disasters including pandemics, such as hybrid learning models that utilise technology as well as

[15] Aquino K C and Scott S. 2023. Supporting Students with Disabilities during the COVID-19 Pandemic: The Perspective of Disability Resource Professionals. International Journal of Environmental Research and Public Health, 20(5) pp.4297. https://pubmed.ncbi.nlm.nih.gov/36901305/

[16] Jia L and Santi M. 2021. Inclusive education for students with disabilities in the global COVID-19 outbreak emergency: some facts and thoughts from China. Disability & Society. 36(7), pp.1186-1191. https://doi.org/10.1080/09687599.2021.1925226

[17] United Nations Educational, Scientific and Cultural Organization. 2020. Global Education Monitoring Report 2020: Inclusion and Education: all means all. United Nations Educational, Scientific and Cultural Organization, Paris. https://gem-report-2020.unesco.org/

[18] United Nations Children's Fund. 2022. Pacific Regional Inclusive Education Review. United Nations Children's Fund, Suva. https://www.unicef.org/pacificislands/reports/pacific-regional-inclusive-education-review

[19] Stough L M, McAdams D E, Kang D and Lee S. 2020. Disasters, schools, and children: Disability at the intersection. International Journal of Disaster Risk Reduction, 45(4). https://doi.org/10.1016/j.ijdrr.2019.101447

[20] Kuhfeld M, Soland J, Tarawasa B, Johnson A, Ruzek E, and Lewis K. 2020. How Is COVID-19 Affecting Student Learning: Initial Findings from Fall 2020. Brown Center Chalkboard. https://www.brookings.edu/blog/brown-center-chalkboard/2020/12/03/how-is-covid-19-affecting-student-learning/

face-to-face teaching and learning.[21] The ratio of technological to in-person teaching can change depending on the circumstances. However, technology infrastructure is required for this to work, including access to computers or tablets for children with disabilities, which are not always available in countries with limited resources.

Preparing for ongoing inclusive education in the face of disasters, including pandemics, requires collaboration between education stakeholders and others, including disaster management stakeholders, civil society organisations including organisations of people with disabilities, health stakeholders and communities. Stakeholder cooperation in the development of plans that benefit students with disabilities can result in referral networks and shared resource allocation. These networks and resources can enable the provision of social supports to improve the welfare of learners with disabilities and their families, stabilising home environments so that children can return to learning as quickly as possible. For example, social protection measures for learners with disabilities and their families can act as a safety net, mitigating shocks from disasters and promoting continued school attendance.[22]

Looking ahead to 2030

Enabling resilient disability inclusive education by 2030 requires the use of a disaster preparedness lens in planning, implementation, and monitoring. Applying this to the Framework for Disability-Inclusive Education may assist in building education systems and schools that are resilient to shocks and emergencies.

The first section within the framework on service delivery covers school-level delivery of inclusive education that benefits children with disabilities. The use of a resilience lens prompts the following recommendations. Teacher training must incorporate disaster preparedness and response approaches that include students with disabilities, and the use of disaster preparedness plans in their classrooms. Schools must ensure their evacuation facilities are accessible, including water, sanitation and hygiene amenities, and that information about evacuation is accessible to all. Learning materials must be prepared, made available and delivered in a range of formats (electronic and paper-based) in readiness for remote learning, necessitated by a disaster or pandemic.

Information regarding the diagnoses, learning needs and plans of children with disabilities could be located on paper and via electronic files that are backed up on a shared server, so that they are available even after a disaster. A tradition of using student disability data to inform planning and delivery of lessons must be established. Partnerships must be sought with health and civil society service providers, who may stockpile AT for distribution following a disaster.

The second section within the framework covers enabling environments. Application of a resilience lens in relation to this prompts the following suggestions. Ministry of Education policies and plans must incorporate measures to support disaster preparedness and climate change. An overarching national plan for disaster preparedness and climate change in education could guide school-level development of disaster preparedness plans. Government and school leaders must be trained in the importance of resilient disability-

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[21] Kuhfeld M, Soland J, Tarawasa B, Johnson A, Ruzek E, and Lewis K. 2020. How Is COVID-19 Affecting Student Learning: Initial Findings from Fall 2020. Brown Center Chalkboard. https://www.brookings.edu/blog/brown-center-chalkboard/2020/12/03/how-is-covid-19-affecting-student-learning/

[22] GLAD network. 2017. Promoting Disability-Inclusive Climate Change Action. https://gladnetwork.net/search/resources/secretariat-global-action-disability-glad-network-presents-issue-paper-and-guide

inclusive education and could be supported to establish partnerships with other government departments and civil society to enable access to supplementary support services, for example psychosocial support and social protection schemes.

As inclusive education approaches take hold around the world, much needs to be done to strengthen education systems and schools so that they are resilient as well as inclusive. Resilient inclusive education systems continue to benefit learners with disabilities during and after disasters and pandemics. Efforts must be implemented, monitored and successful practices should be shared to inspire and multiply effects around the world.

Meaningful rights-based engagement with Organisations of People with Disabilities

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Background

People with disabilities have the right under Article 4.3 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) to be consulted and actively involved through their representative organisations in decision-making processes that affect them, including in relation to the development and implementation of policy and legislation. Article 32 of the CRPD further recognises that international cooperation should involve partnership with organisations of people with disabilities (OPDs). The past decade has seen increased awareness among development actors of the need to meaningfully consult and engage with the disability movement.[3] This significant achievement should be acknowledged.

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

Opportunities and challenges

Resourcing restraints faced by OPDs

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

OPDs commonly face significant resource constraints. They are, at times, entirely or substantially run by volunteers. In countries where people with disabilities face systemic barriers to accessing education, it is not uncommon for OPD staff and members to have no or minimal formal education. This implies OPDs will be drawing on diverse skills sets when delivering activities such as report writing, training, meetings, or administration. They are often direly under-funded.[4] Funding that is provided may often be conditional and not allow for flexibility where unforeseen circumstances arise, such as in the event of a natural hazard disaster or an urgent consultation request. This places significant strains on the OPD.

Competing demands on OPD's time and misaligned priorities

Development actors in low- and middle-income settings are increasingly requesting the involvement of OPDs within mainstream programming in line with the principle of 'nothing about us without us'. While this is positive, it also needs to be recognised that development actors are working across a plethora of sectors and cross-cutting issues.

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

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

This can range from programming design, delivery, and review to policy development and data collection. Given the large amount of work across sectors needed to achieve equity and uphold rights for people with disabilities, and the limited resources of OPDs, many OPDs will have to make strategic decisions to prioritise their work and activities.

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

Tokenistic engagement

The CRPD Committee has noted that despite progress, there is much work to do before Article 4.3 on the involvement of people with disabilities in decision-making processes is realised.[5] The International Disability Alliance (IDA) commissioned a global survey to measure progress, gather learnings, and identify where to improve in this regard. The survey found that while there is increasing participation of people with disabilities through their representative organisations overall, this remains insufficient by Article 4.3 standards. Moreover, OPDs are dissatisfied with their level of involvement in consultations. While OPDs increasingly participate, their contributions are not adequately taken into account. The IDA survey reported negative experiences about participation processes, such as being denied reasonable accommodations resulting in exclusion, or being invited to 'legitimise a process, without their views being adequately considered.'[6] Findings showed OPDs had very limited opportunities to shape donor policies, with roles limited to either attending events or conferences or receiving donor funds to implement.[7]

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

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[5] Committee on the Rights of Persons with Disabilities. 2018. General comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention, Para 8.
docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhsnbHatvuFkZ%2Bt93Y3D%2Baa2pjFYzWLBu0v A%2BBr7QovZhbuyqzjDN0plweYl46WXrJJ6aB3Mx4y%2FspT%2BQrY5K2mKse5zjo%2BfvBDVu%2B42R9iK1p

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

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

process from the development actor's perspective, so the power imbalances and social norms remain undisturbed.

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

Reliance on OPDs for mainstreaming efforts

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

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

Narrow approaches to organisational strengthening

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

When compliance and due diligence become the sole focus of OPD organisational strengthening support, we can end up with small, grass roots, Global South civil society organisations (CSO's) being funded to meet complex requirements of Global North development actor's own making. Again, power dynamics, the need to follow funding rather than priorities, and OPD's time being taken up with development actor's activities are all at play. This is not to undermine the importance of compliance and due diligence

requirements. It is important to reflect, however, that OPDs are unique organisations, differing to typical program partners that donors or international NGOs may otherwise be funding. They are CSO's, run by people with disabilities who have faced systemic discrimination, primarily for the purpose of advocating for the rights of people with disabilities. They do not have the same organisational history, scale, structure, or purpose as other program partners, and should not be expected or treated as if they do. The challenge and the opportunity here is to take the necessary aspects of compliance and due diligence and the transformational aspects of capacity development and to align these proportionately with the unique aspects of OPDs. Organisational strengthening needs to be tailored to the needs and pace of the OPD in question.

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

Discussing these challenges with OPD engagement does raise risks in that development actors might become hesitant to engage with OPDs. This is due to concerns about doing so incorrectly or the misassumption that the above challenges suggest engagement is not necessary. To be clear, the answer to resolving these challenges is not to step back from engagement with OPDs. But neither will these issues be resolved by simply continuing to ask programs to keep consulting with OPDs and counting how many do so. Rather, progress requires emphasising meaningful rights-based engagement with OPDs.

Rights-based engagement firstly means involving OPDs in strategic decision-making opportunities systematically throughout investment and programming life cycles, not merely consultations at the initial design or final review stages. It also means development actors establishing transformational partnerships with OPDs to ensure their programs and policies are aligned with, and informed by, OPD's priorities and that OPDs are strengthened and empowered through the relationship.[8] This approach would also involve ensuring the way development actors engage with OPDs is respectful of *all* rights of people with disabilities under the CRPD. It is not only the right to be consulted under Articles 4.3 and 32 that need to be considered, including rights to accessibility (Art 9), reasonable accommodation (Art 5), freedom of expression and opinion (Art 21), standard of living (Art 28), equality and non-discrimination (Art 5), and the advancement and empowerment of women with disabilities (Art 6). In all interactions with OPDs, development actors should be aware there is a significant power imbalance between themselves and the OPD and that the OPD has many competing demands on their time.

In relation to providing organisational strengthening to OPDs, while dedicated funding for this is welcomed, it must be delivered across the broad spectrum of organisational capacity development that would benefit OPDs. For example, providing leadership skills and professional development opportunities to staff members, in parallel to funding activities for due diligence and compliance. Activities delivered through organisational strengthening programs should be designed on a case-by-case basis and be responsive to the individual OPD's needs, their own priorities, their capacity to grow and develop, the pace at which it is sustainable for them to do so, and be reflective of OPD's advocacy focus rather as a service-delivery partner. Furthermore, development actors should

[8] Best practice would aim towards 'transformative' engagement with OPDs. Building towards such engagement takes time. A first step is to ensure all consultations with people with disabilities and OPDs are rights-based. From here, development actors should progress to building transformative relationships with OPDs. Relevant resources for guidance on engaging with OPDs include: Water for Women. 2022. Partnerships for Transformation: Guidance for WASH and Rights Holder Organisations. https://www.waterforwomenfund.org/en/news/partnerships-for-transformation-guidance-for-wash-and-rights-holder-organisations.aspx; CBM-Nossal Partnership for Disability-inclusive Development and Research for Development Impact Network. 2020. Research for all: Making Development Research Inclusive of People with Disabilities. https://rdinetwork.org.au/wp-content/uploads/2020/06/RDI-Network-R4All-Accessible-PDF-1.pdf; Gibson C and Bokoff, J. 2018. Deciding Together Shifting Power and Resources Through Participatory Grantmaking. https://learningforfunders.candid.org/content/guides/deciding-together/

examine the extent to which they can assist OPDs to become donor compliant by reducing their own requirements to be proportionate and cognisant of the unique scale and profile of OPDs, rather than necessarily requiring OPDs to meet the standard of compliance expected of all program partners. The Australian Government's new International Development Policy sets a positive example here in committing to seek to reduce the barriers faced by local partners (such as OPDs) to be engaged in Australia's development program by increasing program flexibility.[9]

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

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[9] Australian Government Department of Foreign Affairs and Trade. 2023. Australia's International Development Policy. https://www.dfat.gov.au/publications/development/australias-international-development-policy

Disability and disaster risk

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Background

Disaster Risk Reduction (DRR) is an umbrella term that includes the reduction of existing risk and the prevention of future risk prior to, during, and following disasters. DRR can be considered the objective of Disaster Risk Management.[2] Contemporary DRR encompasses natural and human-induced hazards; biological hazards, such as COVID-19; and hydrometeorological hazards and climate risk. When our efforts to manage disaster risk fall short, humanitarian response becomes the option of last resort. Preventing disasters, crises, and pandemics from happening is the core concern of DRR.

Disability and disaster risk

It is only recently that disability inclusion has been prioritised in DRR. This is despite well-established understandings of the relationship between disability and risk in general. For example, we know people with disabilities are at increased risk of poverty, lower educational attainment, and poorer health outcomes compared to people without disabilities. Regardless, prior to 2015 there was limited engagement by the DRR community. Engagement with disability inclusion was further curtailed by claims of insufficient evidence to warrant the allocation of resources. These claims ran counter to some fundamental DRR truths. We know people with disabilities experience barriers and, as a result, increased risk of exclusion and inequity. Disasters, by definition, disrupt the fabric of societies and create more barriers. This increases the risk of loss, damage, injury, and death for marginalised individuals and groups as well as contributing to disability. We now have the evidence. We know that disaster risk, including the impacts of climate change, is disproportionately higher for people with disabilities.[3,4,5,6]

There have been three global DRR frameworks (Yokohama, Hyogo, and Sendai) that have shaped how we anticipate and respond to disaster risk. We have moved from single hazard approaches to recognise multiple hazards and cascading and compounding risk. The 2011 Great East Japan Earthquake is illustrative, with an earthquake triggered tsunami leading to failure of the Fukushima Daiichi nuclear reactors. Our language has also evolved and NATECH, or Natural Hazards Triggering Technological Accidents, are now a policy concern. COVID-19 also transported the language of preparedness, response, and 'building back better' into our homes. Borrowing from the financial sector, we now recognise that disaster risk can be systemic. Systemic risk refers to risks characterised by uncertainty, multiple origins, and complexity making systemic risk hard, or impossible, to predict.[7] To manage systemic risk, traditional approaches based on rigid or prescriptive preparedness and contingency plans are likely to be of limited use.

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[2] United Nations Office for Disaster Risk Reduction. 2017. Sendai Framework Terminology on Disaster Risk Reduction. https://www.undrr.org/terminology

[3] Fujii K. 2015. The Great East Japan Earthquake and Disabled Persons. Background to their High Mortality Rate. https://www.dinf.ne.jp/doc/english/twg/escap_121031/fujii.html

[4] Benigno M R, Kleinitz P, Calina L, Alcida R, Gohy B, and Hall J L. 2015. Responding to the Health and Rehabilitation Needs of People with Disabilities post-Haiyan. WHO Field Investigation Report. https://ojs.wpro.who.int/ojs/index.php/wpsar/article/view/357

[5] Doocy S, Robinson C, Moodie C, and Burham G. 2009. Tsunami-related Injury in Aceh Province, Indonesia. Global Public Health 4(2) pp.205-214. https://doi.org/10.1080/17441690802472612

[6] Pacific Disability Forum. 2022. Disability and climate change in the Pacific. Findings from Kiribati, Solomon Islands, and Tuvalu. https://pacificdisability.org/wp-content/uploads/2022/08/PDF-Final-Report-on-Climate-Change-and-Persons-with-Disabilities.pdf

[7] United Nations Office for Disaster Risk Reduction. 2019. Global Assessment Report on Disaster Risk Reduction. Chapter 2: Systemic risks, the Sendai Framework and the 2030 Agenda. https://gar.undrr.org/chapters/chapter-2-systemic-risks-sendai-framework-and-2030-agenda.html

There are parallels between how we understand disaster risk and disability. The Social Model of disability explains it is how societies organise themselves that creates disability, inequity, and exclusion. Foundational to contemporary DRR is the recognition that disasters are not natural. Nor are they part of an inevitable and unbreakable cycle of disaster event, response, recovery, and attempting to be better prepared the next time around. Disasters are preventable and, just like disability exclusion, arise because of the choices we make as individuals and societies.

Opportunities and challenges

Commitments and stalled progress

The Hyogo Framework for Action 2005 to 2015 made one passing reference to 'the disabled'. This was followed by Article 11 on 'Situations of risk and humanitarian emergencies' of the UN Convention on the Rights of Persons with Disabilities (CRPD), 2006. From a contemporary viewpoint, Article 11 reads like something of an afterthought and does not fully reflect the preventative stance promoted in Hyogo. Just as disability inclusion was not sufficiently prioritised by the DRR community, Article 11 is a product of a time when DRR was not high on the disability community's agenda. At the time of writing, an interpretive General Comment on Article 11 is being drafted. Despite the benefits of a more preventative approach to disaster risk and the accelerated impacts of climate change, inputs to the CRPD Committee remain largely focused on improving disability inclusion in humanitarian response.[8] The General Comment on Article 11 presents an important opportunity to refocus attention on 'situations of risk' more broadly and align with contemporary DRR understandings.

Despite a sluggish start, the DRR community has embraced a disability inclusive approach – on paper at least. The Sendai Framework for DRR 2015 to 2030 emphasises disability inclusion, accessibility, and includes designated roles for disability stakeholders. However, at the mid-point of Sendai, progress is behind expectations. The Mid-term Review of the Sendai Framework (MTR) finds member states are not on track to substantially reduce disaster mortality, the number of disaster-affected people, and disaster losses and damage by 2030.[9] Participation of people with disabilities in DRR processes remains low, and people with disabilities and other marginalised groups continue to be excluded from early warning and recovery. Pacific contributions to the MTR report a lack of resourcing for disability inclusion and the ongoing need to translate national policies into local action.[10] A 2023 UN Office for Disaster Risk Reduction study found little progress on participation by people with disabilities compared to 10 years earlier: worryingly, there were indications we may be moving backwards on some metrics.[11]

We now have substantive commitments to disability inclusive DRR, humanitarian action, and climate change at the global level. Global frameworks, alongside CRPD commitments, are being translated into national and sub-national policies and legislation. However,

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[8] See: https://www.ohchr.org/en/calls-for-input/2023/day-general-discussion-and-call-written-submissions-article-11-convention

[9] United Nations Office for Disaster Risk Reduction.. 2023. The Report of the Midterm Review of the Implementation of the Sendai Framework for Disaster Risk Reduction 2015-2030. https://www.undrr.org/publication/report-midterm-review-implementation-sendai-framework-disaster-risk-reduction-2015-2030

[10] United Nations Office for Disaster Risk Reduction. 2023. Midterm Review of the Sendai Framework for Disaster Risk Reduction 2015–2030. Thematic Report on Disability Inclusion in Disaster Risk Reduction in the Pacific. https://www.undrr.org/publication/thematic-report-disability-inclusion-pacific

[11] United Nations Office for Disaster Risk Reduction. 2023. Global Survey on Persons with Disabilities and Disasters. https://www.undrr.org/report/2023-gobal-survey-report-on-persons-with-disabilities-and-disasters

initiatives to increase the participation of people with disabilities in DRR programs are often limited in scale. Disability inclusion is too frequently more characteristic of an 'add-on' than a comprehensive and integrated approach. Despite this, the growth of small scale initiatives indicates awareness and an incremental response to changing societal expectations. It is also the case that people with disabilities and organisations of people with disabilities (OPDs) are taking action and filling gaps left by government and other DRR stakeholders. Initiatives by, and partnerships with, OPDs are important, but they should not divert attention from the duty of governments and DRR actors to deliver on inclusion and equity. While we are seeing examples of progress, they are islands amidst a wider sea of inertia. Disability inclusion initiatives continue to be under-prioritised and under-resourced and tied to short term projects with limited potential for sustainability or replicability: this limits opportunities for learning and fostering institutional change.

Understanding disaster risk

Sendai Framework Priority 1 on 'understanding disaster risk' provides a point of reference for considering disability inclusion. The intention is that a solid understanding of disaster risk, including the collection and use of data, is a prerequisite for effective prevention, preparedness, and response. The need to better understand disaster risk reminds us of the importance of reflection and evaluating actions and their impacts. This should not, however, become an excuse to repurpose old learnings as new knowledge. Understanding disaster risk must go beyond recognition of the disproportionate impact disasters have on people with disabilities and the need for accessible services and infrastructure. This was well-known, and advocated for, before Sendai. Today, it is hard to explain an inaccessible shelter or early warning system as a lack of understanding rather than an ongoing lack of prioritisation. Interventions that wilfully exclude, generate disaster risk for and within communities and run counter to fundamental DRR principles and the 2030 Agenda commitment to leave no one behind. Again, disability inclusion and exclusion are about the choices we make.

The theme of understanding disaster risk suggests areas for improvement. This includes the observation that guidance on disability inclusion has changed little over almost two decades – this is not specific to DRR. This guidance was developed to raise awareness and outline principles that could be generally applied. In principle, applying a twin-track approach, partnering with OPDs, and collecting disability disaggregated data are sound. However, when considered against how understandings of disaster risk have developed over the same period and the emergence of increasingly specialised sub-sectors, they seem overly generic and lacking in nuance. At worst, guidance on disability-inclusive DRR has stagnated. Relatedly, considerations of people with complex support needs in DRR have not substantively progressed.[12]

While general guidance was needed to raise awareness and generate buy-in for disability inclusion pre-Sendai, by its nature such guidance oversimplifies and obscures complexity. An unintended consequence is efforts to understand disaster risk have not addressed the elevated risk that people with complex impairments and high support needs experience. Recalibrating our perspectives to recognise both the complexity of disaster risk and of disability will require new approaches and solutions. For example, a rigid emphasis on personal preparedness may not be immediately helpful for individuals that rely on others to complete activities of daily living. Identifying and addressing complex needs also requires a rethink of one-size-fits-all approaches to disability data collection and use. While a

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[12] For an Australian example of preparedness to address individual support needs see: https://collaborating4inclusion.org/home/pcep/

proponent of the considered use of the Washington Group questions in DRR programming, there is reason for concern when one tool is considered the solution to all disability data needs.[13] Addressing complexity will also require new partnerships, collaborations, and access to expertise.

Looking ahead to 2030

Moving ahead there is a clear need to ensure disability inclusion in DRR is prioritised. This need is accelerated by growing climate risk. DRR legislation, including legislation relating to CRPD ratification, increasingly recognises the importance of including people with disabilities. It is no longer enough to simply consider disability inclusion in DRR as a moral prerogative or an issue for voluntary reporting under the Sendai Framework. Disability inclusion needs to be recognised as a legal requirement by decision makers, leaders, and managers. Organisations that do not ensure disability inclusion will increasingly face the institutional and reputational risks of non-compliance.[14] Prioritisation also requires the allocation of resources.

An important advocacy message in the run up to Sendai was that disability inclusion should not be viewed as an 'extra cost'. Instead, disability inclusion should be considered the cost of doing DRR properly and DRR interventions that exclude persons with disabilities underestimate the true costs of doing business. It is hard to identify budget allocations to disability inclusive DRR, but there are indications they remain woefully inadequate.[15] We continue to be constrained by the view that disability inclusion in DRR is one more focus area competing for funds, time, and resources. It is time to properly acknowledge that disability is a cross-cutting risk multiplier that increases disaster risk for people of all genders, ages, and social standing. Prioritising disability inclusion in DRR does not detract from other priorities and work – it elevates and enhances them.

Prioritisation of disability inclusion in DRR is evidently needed by 2030. On the one hand, we need to move to scale and expand coverage of standard, or established, disability inclusive practice. In this regard, there is little mystery – we know what needs to be done. However, driving this forward will require clearer direction and signposting from donors and host governments, including ensuring the legislative compliance of in-country programming and investments. On the other hand, we need to progress conversations and embrace complexity. Standardised solutions have a role to play, but they should not be mistaken for comprehensive solutions that address the diverse needs of all people with disabilities, particularly those with complex and high support needs. Just as the wider DRR community is grappling with the challenges of systemic risk, we need to become more comfortable with complexity in the design of disability inclusive DRR solutions. Growing interest in anticipatory action is a case in point and raises questions of the coverage of social protection, the inclusiveness of financial service providers, the need for

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[13] Robinson A, Nguyen L, and Smith F. 2021. Use of the Washington Group Questions in Non-Government Programming. International Journal of Environmental Research and Public Health,18(12). https://www.mdpi.com/1660-4601/18/21/11143

[14] Weibgen A A. 2015. The Right to be Rescued: Disability Justice in an Age of Disaster. Yale Law Journal. https://www.yalelawjournal.org/note/the-right-to-be-rescued

[15] United Nations Office for Disaster Risk Reduction. 2023. Midterm Review of the Sendai Framework for Disaster Risk Reduction 2015–2030. Thematic Report on Disability Inclusion in Disaster Risk Reduction in the Pacific. https://www.undrr.org/publication/thematic-report-disability-inclusion-pacific

contextualised disability data solutions for targeting, and consideration of the additional financial costs of disability.[16]

The commitment made in 2015 to leave no one behind signalled our ambition and is a call to action. By 2030, we need to have demonstrated we have done more than continued to raise awareness on the importance of disability inclusive DRR.

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[16] For a brief introduction see United Nations Office for the Coordination of Humanitarian Affairs. Anticipatory Action. https://www.unocha.org/anticipatory-action#:~:text=Anticipatory%20action%20is%20now%20commonly,impacts%20before%20they%20fully%20unfold.

Disability, digital information and communications technologies: challenges and opportunities for digital inclusion

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Background

The critical role of digital information and communications technologies (ICTs) in progressing equitable development for people with disabilities in Asia and the Pacific cannot be understated. When digital ICTs are accessible, affordable, and tailored to needs, they provide people with disabilities with vital tools and resources for living independently and participating equitably in social, economic, and political life. Digital ICTs need to be better considered as assistive technologies (AT) as they reduce individual functioning limitations. Innovations and improvements in digital connectivity are constantly evolving, yet barriers to people with disabilities accessing and using digital ICTs remain. This essay presents current challenges and opportunities for expanding the availability, accessibility, and inclusivity of digital ICTs for people with disabilities in the region.

Global commitments reflect the importance of ICTs for ensuring equitable and sustainable development for people with disabilities. Countries are obligated under the United Nations Convention on the Rights of Persons with Disabilities (CRPD) to take action to ensure ICTs are available and accessible for citizens with disabilities at minimum cost (Articles 4 and 9). The role of ICTs in progressing sustainable development for the benefit of all is underscored in Goal 9 of the Sustainable Development Goals (SDGs): 'Significantly increase access to [ICTs] and strive to provide universal and affordable access to the Internet in least developed countries by 2020'. In Asia and the Pacific, regional commitments around equitable access to ICTs for people with disabilities are reflected in the 2012 Incheon Strategy and more recently in the Jakarta Declaration on the Asian and Pacific Decade of People with Disabilities, 2023 to 2032.[2,3]

Expansion of and reliance on digital tools and resources for transmitting, storing, creating, sharing, and exchanging information has increased dramatically since 2015. With dependence on internet-enabled technology accelerating, key human development interventions, such as health care (telehealth), education (remote learning), and social services (online government service platforms) are trending towards online interfaces. While progress toward universal digital coverage is encouraging, bridging 'the digital divide' so people with disabilities are not left behind remains a significant regional challenge. This was highlighted during the COVID-19 response, with accessibility barriers to online platforms and digital information contributing to limited access to healthcare, education, employment opportunities and income support for people with disabilities in Asia and Pacific countries during the pandemic.[4] Accessible ICTs and digital devices are now recognised as preconditions and priorities for ensuring disability equity by the Pacific Disability Forum and by the United Nations Partnership on the Rights of People with Disabilities.[5,6]

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[2] United Nations Economic and Social Commission for Asia and the Pacific. 2012. Incheon Strategy to "Make the Right Real" for Persons with Disabilities in Asia and the Pacific. https://www.unescap.org/sites/default/files/Incheon%20Strategy%20%28English%29.pdf

[3] United Nations Economic and Social Council. 2022. Jakarta Declaration on the Asian and Pacific Decade of Persons with Disabilities, 2023-32. https://www.unescap.org/sites/default/d8files/event-documents/B2200897_L4_E.pdf

[4] Hillgrove T, Blyth J, Kiefel-Johnson F, Pryor W. 2021. A synthesis of findings from 'rapid Assessments' of disability and the COVID-19 pandemic: Implications for response and disability-inclusive data collection. Int. J. Environ. Res. Public Health, 18(18) https://doi.org/10.3390/ijerph18189701

[5] Pacific Disability Forum. 2020. Guide on pre-condition to inclusion of persons with disabilities – COVID-19 response. Pacific Disability Forum COVID-19 Update, Ref no. COVID-19_PDF_09.

[6] United Nations Partnership on the Rights of People with Disabilities. 2020. The preconditions necessary to ensure disability inclusion across policies, services, and other Interventions. http://unprpd.org/sites/default/files/library/2020-08/Annex%202%20UNPRPD%204th%20Funding%20Call%20Preconditions%20to%20disability%20inclusion%20ACC.pdf

With only modest and patchy focus so far on improving access to and quality of digital ICTs for people with disabilities in many countries there is an opportunity to support the development and implementation of strategies for positive and lasting change in this emerging area. Digital ICTs have transformative potential; however, without consideration of social inclusion and accessibility, they also risk perpetuating the exclusion and marginalisation of people with disabilities.

Challenges and opportunities

Progress in making digital ICTs accessible for people with disabilities has been slow, uneven, and inequitable. This is evident when comparing scores in the Digital Accessibility Rights Evaluation (DARE) Index, which measures country performances across disability inclusion outcomes in ICTs. Southeast Asia and Pacific countries scored on average 36 out of 100, compared with Australia which scored 80.[7] DARE index scores also indicate large variations between countries, with Indonesia (48) and the Philippines (53) scoring higher compared with Papua New Guinea (9.5) and Samoa (26.5).[8] Understanding the underlying challenges and opportunities for overcoming these disparities is important.

Access to affordable internet-enabled devices and broadband coverage is tied with geographic and socioeconomic factors within countries. Significant disparities remain in levels of access between urban and rural or remote areas and between higher and lower income populations. More likely to live in poverty and less likely to move from rural to urban areas for education or employment, people with disabilities typically have fewer opportunities and less capital to access and use digital ICTs. Broader systemic issues impacting on disability inclusion and equality, such as access to general education, employment, social security, mobility and transport, should therefore be considered as underlying barriers to digital inclusion.

Contributing to gaps in digital coverage are challenges in the availability and affordability of digital ICTs in low-resource and remote settings. Improvements in local digital infrastructure, such as for broadband internet and 3G–4G networks, are needed to support use of internet-reliant devices and software in rural and remote areas. Portability and offline capabilities of ICT devices themselves are critical for users living in areas with limited or unreliable internet connectivity. Cost is a significant barrier, with both retail cost and the extent to which people with disabilities are entitled to subsidies or government support to purchase assistive products both impacting on affordability. Country strategies for improving universal digital coverage often fall short of adopting approaches for improving accessibility and affordability of digital ICTs for people with disabilities. Global commitments around access to ICTs and AT are not synergised with national standards and planning objectives, with many countries lacking legal definitions of accessibility and AT that include ICTs.

Investment to increase coverage of digital ICTs in Asia and the Pacific is crucial. Reliance on market-driven incentives for innovation and scaleup of digital technologies has contributed to limited availability of consumer-friendly products in remote and linguistically diverse areas. This is evident in the development of language-based digital products, such as speech synthesis software and text-to-speech (TTS) systems. On the one hand, progress in speech synthesis product development is promising, with manufacturers

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[7] Narasimhan N. 2021. 'Digital accessibility in the Asia-Pacific Region', in Accessible Technology and the Developing World. Oxford Academic. https://doi.org/10.1093/oso/9780198846413.003.0006

[8] The Global Initiative for Inclusive ICTs. 2020. Country dashboards. https://g3ict.org/country-profile

incorporating more South and East Asian languages as part of multilingual TTS systems. On the other hand, less widely spoken languages, such as Indigenous and Pacific Island languages, and languages spoken in countries with less consumer purchasing power, such as Tok Pisin in Papua New Guinea, are not being prioritised for speech synthesis software development by global manufacturers. Most countries in the region continue to rely on importing digital technologies from overseas manufacturers. Increasing capacities to develop digital ICTs locally can reduce costs and encourage design of products to suit niche consumer needs.

Developing digital products in local languages has potential for high impact. When communication tools and resources are available in local languages, people from cultural and linguistic minorities rely less on lingua franca for communication and participation. This approach not only ensures greater digital inclusion for people with disabilities, but also protects the rights and traditions of minority ethnic and indigenous groups in line with the UN Declaration on the Rights of Indigenous Peoples.[9] There are signs of progress in this area; digital braille display devices, such as Brail Me, are examples of low-cost digital products becoming more widely available in Asian languages.[10] More investment is required to ensure wider coverage, particularly across Pacific Island communities.

Increasing access to ICT-specific education is another area with high potential impact. According to the World Bank's Digital Development Partnership, improving ICT education creates demand for accessible ICT products and equips end-users with the necessary skills and knowledge to use them.[11] Digital literacy in Asia and Pacific countries is low compared with other regions and is commonly confined to urban areas.[12] People with disabilities are disproportionately excluded from formal education and less likely to obtain vital skills and knowledge in digital communications. Education systems are often underprepared to support learners with disabilities in developing digital ICT skills and knowledge, and related learning criteria and outcome areas are often left out of national education curriculums.[13] Increasing digital literacy can give people with disabilities opportunities to work in the 'tech' industry and contribute directly to the design and quality assurance of digital ICT products, as well as contribute to OPDs' capacity to build skills and advocate on digital inclusion.

Digital ICTs and social media offer critical tools for enabling 'full and effective participation and inclusion in society' for people with disabilities. Harnessing this potential means ensuring digital and online spaces are safe, inclusive, and free from discrimination. Evidence shows people with disabilities, especially younger users, are more susceptible to cyberbullying than people without disabilities.[14] The negative impacts of disability stigma and cyberbullying are often considered as separate topics, with research into how people with disabilities experience cyberbullying and how online and offline discrimination impacts

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[9] United Nations. 2007. UN declaration on the rights of indigenous peoples. https://social.desa.un.org/sites/default/files/migrated/19/2018/11/UNDRIP_E_web.pdf

[10] Narasimhan N. 2021. 'Digital accessibility in the Asia-Pacific Region', in Accessible Technology and the Developing World. Oxford Academic. https://doi.org/10.1093/oso/9780198846413.003.0006

[11] World Bank Group. 2022. South Asia's digital opportunity: Accelerating growth, transforming lives, digital development partnership, accessed via: https://openknowledge.worldbank.org/server/api/core/bitstreams/4044c18e-d6ba-50aa-8e3f-efade3ca5ab1/content

[12] Taneja-Johansson S, Singal N. 2021. Pathways to inclusive and equitable quality education for people with disabilities: cross-context conversations and mutual learning. International Journal of Inclusive Education. https://doi.org/10.1080/13603116.2021.1965799

[13] Hoogerwerf E. 2021. Removing barriers to digital inclusion: Engaging stakeholders in rethinking policies and services. UN Commission for Social Development 59th Session Side Event: Overcoming the Digital Divide to Ensure Disability Inclusiveness 11 February 2021 (New York)

[14] United Nations Educational, Scientific and Cultural Organization. 2021. Violence and bulling in educational settings: the experiences of children and young people with disabilities. https://unesdoc.unesco.org/ark:/48223/pf0000378061

on use of ICTs still lacking. While most countries are signatories of the CRPD with dedicated anti-discrimination legislation, laws may not make explicit reference to online conduct. Strategies for addressing disability stigma should address problematic online behaviour and assume that people with disabilities are active users of, and benefit from equitable access to, shared digital spaces.

Looking ahead to 2030

The benefits of ensuring people with disabilities have easy and equitable access to high quality, affordable digital ICTs, regardless of where they live, is a major opportunity for enhancing disability inclusion and sustainable regional development. Achieving this will not be easy. Asia and the Pacific are culturally and linguistically diverse, with large populations living in rural and remote areas and in low resource urban centres. Innovations and improvements in digital technologies are constantly expanding the realm of possibilities for positive and negative impacts on disability inclusion. As reliance on portable, internet-enabled communications devices for everyday life increases, so do the stakes for bridging the digital divide so people with disabilities are not left behind.

The transformative power of artificial intelligence (AI) in shaping future opportunities for disability inclusion is already apparent and an example of things to come. While the same underlying challenges for digital inclusion apply, there are new challenges with AI. Lack of government control and oversight of the AI industry has sparked concern about advanced AI systems posing 'profound risks to society and humanity', including amplifying entrenched discrimination and biases, and further marginalising disadvantaged communities and diverse viewpoints.' [15,16] AI language models, such as Chat-GPT, have shown tendencies to perpetuate negative stereotypes about people with disabilities.[17] Bias in AI systems has the potential to impact negatively on equity, for instance fair employment. The outsourcing of job recruitment processes, such as job applicant screening, to AI firms is already a trend in global AI investment.[18] As with digital ICTs more generally, progress towards accessible and inclusive AI systems can be achieved through design considerations and setting appropriate regulations. Ensuring AI developers have access to accurate disability data and comply with updated inclusion guidance and regulatory frameworks will reduce the risk of bias and exclusion.[19]

Ensuring the widespread availability of digital ICTs that are accessible, affordable, and tailored to the needs of people with disabilities by 2030 must be a priority. This requires a multi-pronged approach. Digital inclusion cannot be seen as separate from disability inclusion more broadly. Addressing the underlying reasons for unequal access to digital ICTs between people with and without disabilities will have a big impact. This means increasing access to education, employment opportunities, and secure incomes. Improving digital literacy and digital coverage, including infrastructure and access to digital devices, is crucial for rural, remote and low resource areas. Improving the design and quality of digital ICT products so they are user-friendly and culturally safe will increase uptake,

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[15] Future of Life Institute. 2023. Pause giant AI experiments: An open letter, Mar. 22, 2023.

[16] Future of Life Institute. 2023. Policymaking in the pause: What can policymakers do *now* to combat risks from advanced AI systems? https://futureoflife.org/wp-content/uploads/2023/04/FLI_Policymaking_In_The_Pause.pdf

[17] OpenAI. 2023. GPT-4 Technical Report. https://cdn.openai.com/papers/gpt-4.pdf

[18] Benaich N, Hogarth I. 2022. State of AI Report. https://www.stateof.ai/

[19] European Commission. 2019. Ethics guidelines for trustworthy AI. High-level Expert Group on Artificial Intelligence. https://www.europarl.europa.eu/cmsdata/196377/AI%20HLEG_Ethics%20Guidelines%20for%20Trustworthy%20AI.pdf

particularly among minority and linguistically diverse groups. Working with countries to tackle these challenges should be a major priority for the next 7 years.

Eliminating violence against *all* women and girls

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Background

Violence against women (VAW) is a major public health issue and human rights violation. Globally, almost one third of women and girls aged 15-49 have experienced violence from an intimate partner.[3] Overwhelmingly, VAW is perpetrated by men, usually by a man known to the victim. The reasons for this are complex, but gender inequality is a fundamental driver of violence against women. Patriarchal systems around the world afford greater power, resources, and opportunities to men over women, creating a social context where women are systematically devalued making violence against them more likely.[4] Achieving gender equality is central to the 2030 Agenda.

All women experience gender inequality, but not in the same way, to the same degree, or with the same impacts. Some women are at increased risk of violence due to intersecting experiences of discrimination associated with different aspects of their identities. Women with disabilities experience violence driven by gender inequality, ableism, or both.[5] Consequently, compared to women without disabilities, women with disabilities experience higher rates of gendered violence, additional forms of disability-based violence, a wider range of perpetrators, a broader range of settings of violence, and more severe consequences of violence.[6] Despite Sustainable Development Goal (SDG) Target 5.2.1 being to eliminate violence against *all* women and girls, women with disabilities are often forgotten. Disability-inclusive VAW response services, primary prevention, and research must be prioritised to ensure no one is left behind.

Challenges and opportunities

The challenges and opportunities for eliminating VAW with disabilities lie across three priority areas: response services, primary prevention, and research. While disability inclusion across these domains remains a critical challenge, pockets of promising practice are building the evidence-base for inclusive approaches that uphold disability equity and rights.

Response services

VAW response services are essential for assessing and managing risk and keeping women safe. However, responses to women with disabilities experiencing violence are often inconsistent and do not meet individuals' needs.[7] A major challenge is many women with disabilities lack accessible information about their rights, available VAW services, and how to access them. This, alongside cumulative experiences of discrimination, can mean that women with disabilities may not recognise they are experiencing violence or may believe they have nowhere to go.

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[3] World Health Organization. 2021. Violence against women [fact sheet]. World Health Organisation, Geneva. https://www.who.int/news-room/fact-sheets/detail/violence-against-women

[4] Our Watch. 2021. Change the story: A shared framework for the primary prevention of violence against women in Australia (2nd ed.). Our Watch, Melbourne. https://www.ourwatch.org.au/change-the-story/change-the-story-framework

[5] Our Watch. 2022. Changing the Landscape: A national resource to prevent violence against women and girls with disabilities. Our Watch, Melbourne. https://www.ourwatch.org.au/resource/changing-the-landscape/

[6] Garcia-Cuellar M M, Pastor-Moreno G, Ruiz-Perez I, and Henares-Montiel J. 2022. The prevalence of intimate partner violence against women with disabilities: a systematic review of the literature. Disability and Rehabilitation, 17(1), pp.1-8. https://doi.org/10.1080/09638288.2022.2025927

[7] Thiara R K, Hague G, Bashall R, Ellis B, and Mullender A. 2011. Disabled women and domestic violence: Responding to the experiences of survivors. Jessica Kingsley Publishers, London.

When women do get to services, many service providers lack the resources to be disability-inclusive. Services may lack universal design features and reasonable accommodation, and workers may have limited knowledge of support services available to women with disabilities. Both VAW response services and disability services may lack understanding and support on the intersection of gender, disability, and violence, which can result in prejudicial attitudes or patronising over-protection.[8] This creates additional barriers to women getting the help, information, and choices they need. There are opportunities to create more inclusive VAW response services by focusing on three key domains:

1. Disability-mainstreaming. Disability-mainstreaming in VAW response services ensures women with disabilities are prioritised in organisational plans, policies, and procedures. This requires VAW response services to address the barriers that make it difficult for women with disabilities to access the service and information they need to support their decision-making. A practical way to address these barriers is through an accessibility audit, ideally carried out by representatives from a local Organisation of Persons with Disabilities, a member of a service's leadership team, and people with different impairment types. This involves moving through a service to identify access barriers (e.g. physical, communication, attitudinal) and implementing strategies to then improve accessibility. Additionally, organisational budgets should consider provision of targeted initiatives specifically for women with disabilities experiencing violence.

2. Cross-sectoral collaboration. Different parts of the VAW response, disability, and other service sectors have expertise to contribute to the safety of women with disabilities.[9] However, resourcing constraints, a lack of knowledge on available support services, and 'culture clash' between sectors can hamper effective multi-agency collaboration. Services working together, and with women with disabilities, through a process of reflection, engagement, and shared goal-setting may lead to more systematic, high-quality cross-sectoral collaboration.[8] This process should include time to foster trusting, respectful relationships, and bring parties together to learn from each other, such as through communities of practice.

3. Workforce development. To address prejudicial attitudes in the service system, both the VAW and disability sectors require training on the intersection between gender, disability, and violence, and how to collaboratively deliver appropriate services. As part of the W-DARE project in the Philippines, women with disabilities co-facilitated disability and gender sensitisation workshops for local government policy makers, sexual and reproductive health service providers, and VAW response services to raise awareness about the rights of women with disabilities and the barriers they face accessing services and information.[9] This training increased participants' knowledge of the needs of women with disabilities experiencing violence and increased their skills in providing appropriate services and making referrals.[10]

[8] Frawley P, Dyson S, and Robinson S. 2017. Whatever it takes? Access for women with disabilities to domestic and family violence services: Key findings and future directions. ANROWS, Sydney. https://anrowsdev.wpenginepowered.com/wp-content/uploads/2019/02/Disability_Compass-1.pdf

[9] Vaughan C, Devine A, Ignacio R, Lacsamana W, Marco J, Zayas J, et al.. 2016. Building capacity for a disability-inclusive response to violence against women and girls: experiences from the W-DARE project in the Philippines. Gender and Development, 24, pp.245-260. https://doi.org/10.1080/13552074.2016.1194031

[10] Vaughan C, Gill-Atkinson L, Devine A, Zayas J, Ignacio R, Garcia J et al.. 2020. Enabling action: Reflections upon inclusive participatory research on health with women with disabilities in the Philippines. American Journal of Community Psychology, 66(3/4), pp.370-380. https://doi.org/10.1002/ajcp.12468

Primary prevention

While building the capacity of the VAW response sector to deliver disability-inclusive services is critical, sustained investment in primary prevention is also needed to drive the long-term social change required to eliminate violence against women and girls with disabilities.[11] Primary prevention aims to stop violence against women with disabilities from occurring in the first place.

Disability-specific primary prevention interventions in high-income countries have focussed on teaching women with disabilities to recognise violence and abuse, and to develop confidence and self-advocacy.[12] While increased knowledge and skills are important, 'increased individual awareness of rights does not automatically lead to the attainment of these rights'.[13] Sustained change will not occur by placing the onus on women to keep themselves safe; rather, broader community interventions that target the drivers of violence against women with disabilities are needed.

Encouragingly, the recent *UN Trust Fund Special Window to End Violence Against Women and Girls with Disabilities* funded projects that not only supported women to recognise their rights, but also included multiple, reinforcing strategies that target the intersecting, ableist and gender discriminatory norms that drive violence against women with disabilities.[14] These primary prevention initiatives highlighted the importance of centring the agency of women with disabilities, fostering a multi-sectoral approach, and supporting interventions attuned to culturally-specific manifestations of gender norms and disability stigma. For example, formative participatory research by ADD International in Cambodia found an entrenched culture of silence surrounding the intersection of disability and gender, and beliefs that women with disabilities were 'burdensome' family members, as key drivers of violence against women with disabilities.[15] The research informed a primary prevention initiative using positive community role models to shift harmful social norms.

To prevent violence against women with disabilities in the long-term and reduce downstream pressures on the response system, sustained investment must prioritise ongoing research into what works, adaptable program implementation, and evaluation of primary prevention strategies. This is essential for building an evidence base for primary prevention that addresses the diverse realities of women with disabilities, upholding their human right to live a life free from violence.

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[11] Dunkle K, van der Hejden I, and Chriwa E. 2018. Disability and violence against women and girls: Emerging evidence from the What Works to Prevent Violence against Women and Girls Global Programme. UK Aid, United Kingdom. https://www.whatworks.co.za/documents/publications/195-disability-brief-whatworks-23072018-web/file

[12] Sutherland G, Hargrave J, Krnjacki L, Llewellyn G, Kavanagh A, and Vaughan C. 2024. A systematic review of interventions addressing the primary prevention of violence against women with disability. Trauma, Violence & Abuse, 25(2), pp.1235-1247. https://doi.org/10.1177/15248380231175932

[13] Palm S and Le Roux E. 2023. "They call me by my name": A synthesis review of the United Nations Trust Fund to end violence against women's special window on ending violence against women and girls with disabilities. United Nations Trust Fund to End Violence Against Women, New York. https://untf.unwomen.org/en/digital-library/publications/2023/03/a-synthesis-review-of-the-un-trust-funds-special-funding-window-on-ending-violence-against-women-and-girls-with-disabilities

[14] Ibid

[15] Strickler C and Sovann P. 2021. Preventing violence against women and girls with disabilities in Cambodia: A community mobilization model project. ADD International, Cambodia. https://untf.unwomen.org/en/digital-library/publications/2022/08/final-evaluation-preventing-violence-against-women-and-girls-with-disabilities-in-cambodia-a-community-mobilisation-model#view

Research

VAW research is critical to understand the scale of the problem, advocate for policy change, and inform appropriate VAW interventions. The World Health Organisation's advancement of a consistent, robust, and ethical VAW prevalence research methodology has achieved global recognition of VAW as a serious human rights issue. However, women with disabilities are often excluded from national VAW prevalence studies and other research because they are considered too 'hard to reach'. As a result, there are large data gaps about VAW with disabilities, making it difficult to develop policy, services, and programs that meet their needs and rights.

These gaps are not irresolvable, and there are ways to collect data to better understand VAW with disabilities. For example, the Washington Group Short Set on Functioning (WGSS) produces internationally comparable data by identifying people who report difficulties with seeing, hearing, walking, cognition, communication, and self-care.[16] While it has some limitations, the WGSS is a useful tool that can be incorporated into existing VAW prevalence surveys, allowing researchers to disaggregate data and compare the prevalence and experience of violence between women with and without disabilities. Sri Lanka's first VAW prevalence survey incorporated the WGSS and found women with disabilities experienced a much higher prevalence of physical and/or sexual violence compared to women without disabilities. Sri Lanka's First National Action Plan on Women, Peace, and Security now explicitly recognises the disability-based forms of violence that women and girls with disabilities experience.[17]

There are limitations with using existing VAW prevalence surveys to understand violence against women with disabilities. Existing surveys do not measure many forms of violence that women with disabilities experience (e.g. over or under-medication, withholding of assistive devices, forced sterilisation, dis-crediting and ridicule based on disability), and they do not fully capture the range of perpetrators and settings in which violence against women with disabilities commonly occurs. It is important that researchers continue to refine measurement tools and use different study designs and data collection methods, including qualitative methods, to understand how women with disabilities experience violence. Qualitative data can provide valuable information to inform policy and service development. Participatory methods, where women with disabilities are involved as co-researchers from design to dissemination, centre the expertise and agency of women with disabilities, and increase the relevance of data generated to women's priorities for change.[18,19]

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[16] Washington Group on Disability Statistics. 2020. The Washington Group Short Set on Functioning. Washington Group on Disability Statistics, Hyattsville

[17] Ministry of Women, Child Affairs and Social Empowerment. 2023. Women, Peace and Security: Sri Lanka's National Action Plan for the Implementation of the UN Security Council's Resolutions on Women, Peace and Security 2023–2027. Ministry of Women, Child Affairs and Social Empowerment. https://asiapacific.unwomen.org/sites/default/files/2023-07/lk-NAP-FINAL2023-eng.pdf

[18] Vaughan C, Devine A, Ignacio R, Lacsamana W, Marco J, Zayas J, et al.. 2016. Building capacity for a disability-inclusive response to violence against women and girls: experiences from the W-DARE project in the Philippines. Gender and Development, 24, pp.245-260. https://doi.org/10.1080/13552074.2016.1194031

[19] Vaughan C, Gill-Atkinson L, Devine A, Zayas J, Ignacio R, Garcia J et al.. 2020. Enabling action: Reflections upon inclusive participatory research on health with women with disabilities in the Philippines. American Journal of Community Psychology, 66(3/4), pp.370-380. https://doi.org/10.1002/ajcp.12468

Looking ahead to 2030

To continue momentum towards achieving the SDG target of eliminating violence against all women and girls, it is paramount that VAW policy and programming is attuned to the experiences and needs of women with disabilities. To promote more disability-inclusive VAW response services, primary prevention strategies, and research by 2030, there is a need to:

- build capacity of the VAW response sector to deliver accessible and appropriate services to women with disabilities by:

  - embedding disability-inclusion in organisational policies and procedures

  - promoting accessibility audits to address barriers to access information and services

  - providing resources to promote collaboration between VAW and disability sectors

  - increasing knowledge on the intersection between gender, disability and violence, disability-inclusive practice, and effective cross-sectoral collaboration (through activities such as running professional development, providing resources and referral pathways for staff, and appointing Disability Practice Leaders to guide practice and consultation)

- support organisations of people with disabilities and disability service providers to identify and respond to VAW and girls in a timely, effective, and appropriate manner

- prioritise primary prevention initiatives that encourage multiple, reinforcing strategies, multi-sectoral collaboration, and centre the agency and participation of women with disabilities

- engage in capacity building with governments and other funders to understand the cost-benefits of tailoring responses, developing workforces, and resourcing co-design

- build the evidence base for the primary prevention of violence against women and girls with disabilities through ongoing research, adaptable program implementation, and evaluation

- build the capacity of governments, practitioners, and statisticians in low-and-middle income countries to collect prevalence data about violence against women with disabilities in a reliable, safe, and ethical way

- ensure existing VAW datasets are disaggregated by gender and disability

- fund research using qualitative and participatory methods to gain a more comprehensive understanding of violence against women with disabilities and use these findings to inform VAW policy, programming, and the refinement of existing survey tools.

Beyond identity: unlocking the potential of intersectionality

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Introduction

There is increasing recognition that structural barriers and rights violations faced by people with disabilities must be addressed for the Sustainable Development Goals (SDGs) to be achieved. However, current efforts often focus on distinct identities, forcing resources and perspectives into discrete categories such as gender, disability, or the broader catch-all 'social inclusion'. This ignores the complexity of intersecting experiences of privilege and disadvantage. When gender is the lens, then people with disabilities are often overlooked. When disability is the lens, then women, gender diverse people, and ethnic minorities are overlooked. Such siloed approaches, where one lens takes precedence over others, risks excluding those most marginalised from development processes.

Intersectionality is a way of understanding how different forms of discrimination – such as those based on gender, disability, class, or race – overlap and interact to shape experiences of inequality and injustice. The resulting impacts are often more complex than those of a single form of discrimination experienced in isolation. It reflects what marginalised communities have always known: experiences of discrimination are intertwined and cannot be neatly categorised, because people's lives are not lived like that.[4]

Intersectionality is gaining traction within disability inclusive international development. The United Nations Convention on the Rights of Persons with Disabilities explicitly recognises 'multiple forms of discrimination' faced by people with disabilities.[5] While yet to be consistently conceptualised or applied in practice, key elements of an intersectional approach include:

1. identifying the underlying causes of various forms of discrimination in a given context (such as ableism, homophobia, transphobia, classism, colonialism, racism, sexism)

2. considering how these intersect to create privilege and disadvantage for different people

3. centring development processes and outcomes on the experiences, needs, and interests of people who are most marginalised and disadvantaged, and

4. prompting critical thinking and reflection around individuals and organisations' relationships to power and privilege, and whether they are upholding or challenging the status quo.

An intersectional approach helps to illuminate the rights of all people with disabilities, aligning with the SDGs' commitment to 'leave no one behind' by ensuring equal rights and inclusive development for the most marginalised.

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[4] Crenshaw K. 2015. Why Intersectionality Can't Wait, Washington Post, September 24, 2015.

[5] 'Intersectional discrimination' is further defined in Committee on the Rights of Persons with Disabilities. 2018. General comment No.6 on equality and non-discrimination. https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no6-equality-and-non-discrimination

Challenges and opportunities

Intersectionality is over-theorised and treated largely as a technical approach

Intersectionality is frequently perceived as overly theoretical, and its application in development practice tends to be top-down and bureaucratic, diluting its transformative potential. Narrow, quantifiable indicators for measuring development outcomes tend to frame inequalities as discrete technical problems. This diverts focus away from the systems that produce and maintain inequalities. Used properly, intersectionality is a powerful analytical and advocacy tool, especially for those with lived experience. It can be used to hold institutions accountable by exposing structural discrimination and the limitations of one-size-fits-all approaches. Bridging theory and practice is essential to keep intersectional approaches robust and uncompromised by 'indicator culture'.[6]

Need to move beyond 'intersecting identities'

Intersectionality is often understood only in terms of multiple intersecting identities. Kimberlé Crenshaw, who coined the term, notes that many applications of intersectionality simply multiply identity categories rather than provide structural analysis.[7] This focus on identity can lead to prioritising one group's experience of marginalisation over others, hindering collective movement building and equal outcomes. A more holistic conceptualisation of intersectionality should look beyond identity categories to recognise and critique interconnected systems of privilege and disadvantage to better illuminate the necessary interventions for transformative change.

Lived-experience as the starting point for understanding intersectional discrimination

With few exceptions, development actors have generally failed to engage sufficiently with people experiencing intersectional discrimination to understand how they would define it for themselves. Like early definitions of disability, where rehabilitation and medical experts dominated discourse until people with disabilities began to lead the discussion, intersectionality presents an opportunity for development actors to learn from those affected by intersectional discrimination. This perspective shift is crucial for developing credible intersectional approaches that challenge the dominance of Western ideas over traditional and Indigenous knowledge. Addressing this power dynamic allows for more inclusive development, enabling marginalised communities to shape their own narratives and drive meaningful change.

Rights-based approaches need to be specified and integrated

An intersectional approach is not a panacea for all challenges within disability inclusive development. It must be implemented in conjunction with a rights-based approach, grounded in the general principles and full articles of the CRPD. By connecting human rights to the various forms of discrimination that people with disabilities experience, and paying attention to specific measures, we ensure equality and non-discrimination for all.

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[6] Henne K. 2013. From the Academy to the UN and Back Again: The Travelling Politics of Intersectionality. Intersections: Gender and Sexuality in Asia and the Pacific, 33. http://intersections.anu.edu.au/issue33/henne.htm

[7] Berger M T and Guidroz K. 2009. A conversation with founding scholars of intersectionality Kimberlé Crenshaw, Nira Yuval- Davis, and Michelle Fine. The Intersectional Approach: Transforming the Academy through Race, Class, & Gender. University of North Carolina Press, Chapel Hill.

Principles to enable intersectionality in practice

Tools such as UN Women's Intersectionality Toolkit are available to support the application of intersectionality in development and human rights programming. This toolkit provides guidance and a set of core enablers to help explore who is left behind, why, and in what circumstances, supporting development actors to better incorporate an intersectional approach and identify key gaps and opportunities in their work.[8]

1. Self-reflection (reflexivity). We (as individuals and as part of organisations) all bring our own perspectives, biases, and assumptions to our work and this may play a role in perpetuating discrimination. It's important to always interrogate this and consider how this may influence how you engage with others and how you frame social issues. Reflect on what other perspectives there might be, who might be excluded from sharing their experiences, and what you can do to address this and enable others
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2. Dignity, choice and autonomy. Respect and uphold the dignity, choice, and autonomy of all people. This cannot be assumed, and decisions and perspectives should not be made on behalf of another person. Consider who does (and does not) have independence, full control over how they live their life, and the opportunity to directly share their experiences, rather than having someone speak on their behalf.

3. Power and relational power. Consider who holds power, who makes decisions, who is oppressed, and in what circumstances. Make sure you consider your own role and relationship to the way power is held and enforced, for example when engaging with organisations of people with disabilities (OPDs). Reflect on how those in power may or may not be held accountable.

4. Diverse knowledges. International development often favours Western academic and scientific knowledge over other forms. It is crucial to prioritise and learn from people with diverse knowledge and experiences who are typically excluded from 'expert' roles. Incorporating local and traditional knowledge and practice can significantly strengthen community-based supports for people with disabilities, especially in areas like support services and deinstitutionalisation.

5. Transformative and rights based. An intersectional approach should be transformative and rights-based, aiming to go beyond mainstreaming by addressing inequalities in resources, relationships, and social structures. Intersectionality brings attention to overlaps in these systems, such as how social norms and stigma interact to limit access to education for children disadvantaged on the basis of disability, gender, and ethnicity.

6. Time and space. It is important to reflect on how privilege and discrimination are experienced in the specific context and location you are working in as this shifts over time and is influenced by social positioning and location. For instance, gender discrimination varies across generations, and experiences of racism differ between countries. Similarly, understandings of disability have also shifted from a medical model to human rights model.

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[8] UN Women. 2022. Intersectionality resource guide and toolkit: An intersectional approach to leave no one behind. https://www.unwomen.org/en/digital-library/publications/2022/01/intersectionality-resource-guide-and-toolkit

7. **Accessibility and reasonable accommodation.** Accessibility and reasonable accommodation are critical for intersectionality. This includes budget, asking people what they need for full participation, and addressing physical, social, transportation, information, and communication barriers. Language translation, sign language interpretation, closed captioning, braille, easy-to-read formats, child-friendly and hybrid consultation methods are all considerations.

8. **Intersecting identities.** This prompts us to understand who is most marginalised, within already marginalised groups, learn about the intersecting and unique systems of discrimination and barriers they face, and centre their perspectives and priorities in a program or context. Remember that not all identities are visible or safe to disclose in some settings for marginalised individuals, and collection and analysis of intersectional data must prioritise adherence to rights-based principles.[9]

Looking ahead to 2030

By harnessing the above enablers and unlocking the potential of intersectionality for international development, practitioners can actively work towards equitable outcomes for all. Intentional strategies to progress this include:

Capacity development for donor staff

Transformative change requires capacity development on intersectionality with a focus on self-reflection, building relationships of trust, and understanding contexts. The focus should be first on cultivating a mindset where attitudes and ways of working are challenged, and subsequently on applying intersectional enablers throughout existing work processes at a policy, programmatic, or institutional level.

Shifting power through transformative approaches to engagement

Intersectionality requires transformative engagement processes, with the most marginalised actively framing social issues and shaping policy, research, and programs. This involves finding new ways to seek, listen, and learn from those experiencing intersectional discrimination, as well as 'turning the lens inwards', acknowledging our own roles as development practitioners in perpetuating power imbalance. Peer-to-peer consultations facilitated by trusted entities like OPDs can mitigate risks from unequal power dynamics between donor agencies and people with disabilities. Emphasising strengths-based approaches and avoiding tokenistic representation can further enhance the process.

Dedicating resources, time, and valuing expertise as part of intersectional GEDSI analysis

An intersectional approach to gender equality, disability and social inclusion (GEDSI) analysis is needed to map the barriers, experiences and priorities of those facing intersectional discrimination. This analysis must actively seek out and be informed by diverse and marginalised perspectives. This requires dedicated time and financial

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[9] UN Human Rights Office of the High Commissioner. 2018. A Human Rights Based Approach to Data - Leaving No One Behind in the 2030 Agenda for Sustainable Development. https://www.ohchr.org/en/documents/tools-and-resources/human-rights-based-approach-data-leaving-no-one-behind-2030-agenda

resources, including budget for accessibility and reasonable accommodation and adequate compensation for lived experience expertise. In the context of intersectional discrimination, it is crucial to allocate sufficient time to foster trust and create safety within development processes.

People with psychosocial disabilities

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Background

Representative organisations of people with disabilities recommended adoption of the term 'psychosocial disability' during negotiations of the UN Convention on the Rights of Persons with Disabilities (CRPD). The term reflects the paradigm shift advocated by the disability movement away from a biomedical model of mental health focusing on treating or curing impairments towards addressing the social and cultural components of psychosocial disability. These components include social and attitudinal barriers, like discrimination and negative stereotypes, that exclude people with psychosocial disabilities from community life or deny access to employment or social protection. Psychosocial disability describes people who face restrictions in the exercise of their rights and barriers to equal participation based on an actual or perceived mental health condition. The term applies to all people who experience psychosocial distress and related barriers and restrictions, regardless of their diagnosis and/or self-identification.

Opportunities and challenges

Rights abuses faced by people with psychosocial disabilities

People with psychosocial disabilities are one of the most marginalised and disadvantaged groups globally. They experience exceptionally high levels of violence and abuse, much of which is experienced in the communities in which they live.[3] Discrimination and prejudice towards people with psychosocial disabilities is pervasive, including in health, education, employment, programs and services. This manifests in higher rates of poverty and an estimated drop in life expectancy of 20 years for men and 15 years for women.[4,5,6] In most settings, people with psychosocial disabilities experience greater discrimination and barriers than people with other impairment types. Additionally, various areas of unique and complex breaches of their rights are not as widely experienced by other people with disabilities.[7] While all people with disabilities face risk of social prejudice and discrimination, misunderstandings regarding the nature and origins of psychosocial impairments remain common and perpetuate exclusion of and violence towards people with psychosocial disabilities.[8] The COVID-19 pandemic has deepened these layers of disadvantage.[9]

[3] Drew N, Funk M, Tang S, Lamichane L, Chavez E, Katontoka S, Pathare S, Lewis O, Gostin L, and Saraceno B. 2011. Human rights violations of people with mental and psychosocial disability: an unresolved global crisis. The Lancet, 378(9803), pp.1664-1675 https://pubmed.ncbi.nlm.nih.gov/22008426/

[4] United Nations Human Rights Office. 2017. Mental Health and Human Rights - Report of the United Nations High Commissioner for Human Rights. https://ap.ohchr.org/documents/dpage_e.aspx?si=A/HRC/34/32

[5] Ebuenyi D I, Syurina E V, Bunders J F G, and Regeer B J. 2018. Barriers to and facilitators of employment for people with psychiatric disabilities in Africa: a scoping review, Global Health Action, 11(1). https://pubmed.ncbi.nlm.nih.gov/29764342/

[6] Hjorth C F, Bilgrav L., Frandsen L S. Overgaard C, Torp-Pedersen, C, Nielsen, B, et al. 2016. Mental health and school dropout across educational levels and genders: a 4.8-year follow-up study. BMC Public Health, 16. https://doi.org/10.1186/s12889-016-3622-8

[7] World Health Organisation and World Bank. 2011. World Report on Disability. World Health Organisation, Geneva. https://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/world-report-on-disability#:~:text=World%20Report%20on%20Disability%202011,a%20figure%20of%20around%2010%25.

[8] Human Rights Watch. 2020. Living in Chains: Shackling of People with Psychosocial Disabilities Worldwide. Human Rights Watch, New York. https://www.hrw.org/report/2020/10/06/living-chains/shackling-people-psychosocial-disabilities-worldwide

[9] Knapp M, Cyhlarova E, Comas-Herrera A and Lorenz-Dant K. 2021. Crystallising the Case for Deinstitutionalisation: COVID-19 and the Experiences of Persons with Disabilities. Care, Policy and Evaluation Centre – Research at London School of Economics, London. https://www.lse.ac.uk/cpec/assets/documents/CPEC-Covid-Desinstitutionalisation.pdf

Transforming Communities for Inclusion (TCI), a global organisation of people with psychosocial disabilities, points to 3 key and grave issues in their 2018 'Bali Declaration'.[10] The first is institutionalisation of people with psychosocial disabilities – for more on this topic, see Essay on Deinstitutionalisation[11]. Human Rights Watch estimates hundreds of thousands of people with psychosocial (and/or cognitive) disabilities are shackled across 60 countries worldwide, in both institutional and home settings.[12] Institutionalisation today needs to considered within the context of growth within Asia and the Pacific of mental health laws allowing provision for forced admissions and treatment, as highlighted in the Bali Declaration.[10]

The CRPD protects an individual's right to make decisions about matters that affect them. Yet widespread practices and mental health laws remove legal capacity on the basis of mental impairment.[13] This can include removal of the right to own property, manage money, vote, marry, raise one's children, or refuse medical treatment, including refusal of sterilisation procedures or psychiatric medication or treatments. Representative groups have been advocating for the abolishment of these laws since before development of the CRPD. However, discrimination and a pervasive framing of the subject as a health rather than disability issue have prevented substantial progress being made. There is also poor awareness about alternatives to the prevailing medical approach, such as community care models and supported decision-making schemes that provide people with psychosocial disabilities the supports they require to make their own decisions on matters that affect them. This contrasts with, for example, having guardians appointed on their behalf.

The Bali Declaration's third priority area is the systemic discrimination and exclusion of people with psychosocial disabilities within development efforts. In particular, the Declaration highlights the multiple layers of discrimination experienced by women, children, people of diverse sexual orientation, gender identity and expression and sexual characteristics (SOGIESC), and Indigenous and other marginalised groups of people with psychosocial disabilities.[10] People with psychosocial disabilities are not only excluded as beneficiaries from development services and programs, but also as partners and decision-makers through representative bodies despite their rights under Articles 4.3 and 32 of the CRPD.[14] Due to systemic prejudice, people with psychosocial disabilities are significantly underrepresented within cross-disability OPDs and experience marginalisation even within the disability rights movement. Specialised OPDs such as the World Network of Users and Survivors of Psychiatry (WNUSP), TCI, and some emerging specialised OPDs and self-help groups exist. However, they are not given the consultation and attention they deserve on issues affecting their members.[15] UN agencies, including the World Health Organization, need to commit to continue to strengthen how they consult people with psychosocial disabilities and their representative organisations on key initiatives impacting their lives, including reforms to mental health legislation.

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[10] Transforming Communities for Inclusion. 2018. Bali Declaration. https://tci-global.org/bali-declaration/#:~:text=At%20a%20plenary%20meeting%20of,disabilities%20from%20the%20Pacific%20region

[11] https://mspgh.unimelb.edu.au/centres-institutes/nossal-institute-for-global-health/research/research-groups/the-state-of-disability-inclusion/transforming-lives-deinstitutionalisation-for-people-with-disabilities

[12] Human Rights Watch. 2020. Living in Chains: Shackling of People with Psychosocial Disabilities Worldwide. Human Rights Watch, New York. https://www.hrw.org/report/2020/10/06/living-chains/shackling-people-psychosocial-disabilities-worldwide

[13] See Stein M, Mahomed F., Patel V, and Sunkel C. (Eds.). 2021. Mental Health, Legal Capacity, and Human Rights. Cambridge University Press, Cambridge.

[14] United Nations. 2006. United Nations Convention on the Rights of Persons with Disabilities. https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

[15] For example, TCI members shared that they were recently not consulted on an upcoming UN resolution titled "General Assembly resolution on mental health and psychosocial support for sustainable development and peace". See further: TCI. 2023. Stop Psychiatrizing the SDGs. https://tci-global.org/stoppsychiatrizingsdgs/

Looking ahead to 2030

Focus on community-level inclusion

While there is growing recognition of psychosocial disabilities in international human rights frameworks, progress at national levels is slow and not at the pace required to see significant positive change by 2030. Firstly, increased attention needs to be shifted towards inclusion of people with psychosocial disabilities at the community level. This requires transformative approaches that engage with cultural understandings of psychosocial disability, examine community distributions of power and inequality, and redress past injustices such as harmful forced treatments, exclusions, and discrimination.

People with psychosocial disabilities have a vast range of attributes, capabilities, and strengths, so increasing involvement in their communities is mutually beneficial. Investing in a three-tier approach can ensure people with psychosocial disabilities are both supported and embedded within their communities. The first tier focuses on establishing 'community support systems', such as informal networks, self-help groups, drop-in centres, and informal support people that can assist with supported decision making, community clubs and peer support. The second tier focuses on 'community-based support services' that people with psychosocial disabilities require to live their day-to-day life. For example, social protection, personal assistance, crisis support, support in securing accessible housing, provision of assistive technology, and support to access mainstream services.[16] The third tier focuses on 'mainstream services' such as affordable housing, education, employment, vocational training and healthcare. Increased efforts are needed to deliver each of these tiers in the lead up to 2030. It is also crucial that development efforts focus on mainstreaming disability inclusion with specialised awareness and integration of psychosocial disability inclusion.

Deinstitutionalisation

Many of the Sustainable Development Goals (SDGs) cannot be realised while people with psychosocial disabilities remain institutionalised or shackled and denied their human rights. The SDGs will also not be achieved unless processes of deinstitutionalisation include adequate planning and provision of community-based supports, multidisciplinary psychosocial care, adequate housing, and supported decision-making models, as guided by the CRPD Committee's 2022 guidelines.[17] Another important aspect of deinstitutionalisation is supporting legal harmonisation processes. By 2030, there should no longer be any laws that override people with psychosocial disabilities' rights under the CRPD. This includes abolishing mental health laws that do not uphold people with psychosocial disability's legal capacity, as well as legal reviews for anti-discrimination and equal opportunity, for example within employment and insurance law, and establishing strong justice systems that are accessible for people with psychosocial disabilities.

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[16] For a discussion of what community-based support services should involve, see: CBM Global Inclusion Advisory Group, International Disability Alliance, Pacific Disability Forum, Transforming Communities for Inclusion. 2022. People with Psychosocial Disabilities in Disaster Events. CBM Global, Melbourne. https://cbm-global.org/resource/people-with-psychosocial-disabilities-in-disaster-events

[17] Committee on the Rights of Persons with Disabilities. 2022. Guidelines on deinstitutionalization, including in emergencies. https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including

Separate psychosocial support programs from mental health programs

Properly planning, resourcing, and implementing community-based psychosocial and community support systems requires governments and other stakeholders to recognise the distinction between psychosocial supports and services from mental health programs, and allocate separate funding streams to each of these. This distinction has long been advocated by the psychosocial disability movement as part of the paradigm shift from the biomedical model to the psychosocial disability model, and was recognised by the Human Rights Council's 2019 *Resolution regarding Mental Health and Human Rights*.[18] This urges states to ensure people with psychosocial disabilities have access to a range of human-rights based support and services, including peer support.[19] It also emphasises that states should promote and invest in a multisectoral approach that promotes community-based and person-centred services addressing underlying social, economic, and environmental factors.

Increased awareness raising

Despite the high-level directive from the Human Rights Council, increasing use of the term 'psychosocial disabilities', and better understanding of the social and cultural barriers experienced, most governments and organisations continue to channel funding primarily into mental health initiatives that follow a biomedical model of treatment and care. Accordingly, priority must be shown to raising awareness of psychosocial disability supports and services, particularly for national and international stakeholders. Focus should be on the nature of psychosocial disability along with appropriate services, policies, and mechanisms to ensure emphasis on the issues faced by people with psychosocial disabilities as well as their rights. Community awareness raising programs are crucial to removing attitudinal barriers that may exclude people with psychosocial disabilities from employment and participation in community, religious and social events, as well as across disability communities, including generalist OPDs.

Rights-based crisis support

People with psychosocial disabilities may need specific support in times of crisis. Any support provided at a time of crisis should be with the prior consent of the person. The Bapu Trust has developed a model that includes multifaceted strategies for providing crisis support based on many years working with people with psychosocial disabilities.[20] These strategies include putting in place a safety plan with the person; providing preferred support options, including a 'circle of care', which enhances social capital at times of greatest need; ensuring the continuation of basic needs; holding 'panchayats' (confrontation meetings) around disability exclusion; and supporting access to community justice systems and formal legal processes as needed.

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[18] Human Rights Council. 2019. Mental Health and Human Rights. https://undocs.org/Home/Mobile?FinalSymbol=A%2FHRC%2FRES%2F43%2F13&Language=E&DeviceType=Desktop&LangRequested=False

[19] Peer support services are provided by people with lived experience and give opportunities for people to receive support on issues that they consider important to their own lives in a way that is free from judgment and assumptions.

[20] Bapu Trust for Research on Mind and Discourse. 2020. About us. https://baputrust.com/

Appropriate social protection schemes

Many low- and middle-income countries have minimal social protection programs, and where these do exist, people with psychosocial disabilities often face higher barriers to accessing them. For example, people with psychosocial disabilities may encounter difficulties registering or demonstrating eligibility for benefits due to the 'invisible' nature of psychosocial disability, or due to fear around disclosing their disability due to prejudicial attitudes in society. Exclusion from social protection schemes place people with psychosocial disabilities under much higher stress and marginalisation, breaching their rights, and increasing their exclusion from society.

Partnership with representative organisations of people with psychosocial disabilities

All listed priority actions should be discussed, planned, and implemented in partnership with representative organisations of people with psychosocial disabilities. Partnership indicates inviting people with psychosocial disabilities to have active involvement with decision-making and respecting their right to state their views on matters rather than presuming what these will be, or the correct way forward. People with psychosocial disabilities should not be treated as mere informants during consultations but instead as the driving force. Investing in established and emerging psychosocial OPDs' core viability through ongoing flexible and other funding will sustain these priorities.

Transforming lives: Deinstitutionalisation for people with disabilities

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Background

Central to the disability rights movement, culminating in the development of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), was protesting 'against the service systems, medical professionals and social institutions that keep people with disabilities "captives of care"'.[4] Progress towards universal deinstitutionalisation has been slow. Many people with disabilities are continually denied the right to live independently in the community. They are segregated in health or social care institutions or held captive in homes where they are deprived of basic liberties such as being able to make decisions about their lives and participate in the community on an equal basis with others.[5,6]

The UN Committee on the Rights of Persons with Disabilities' Guidelines on Deinstitutionalisation calls on Member States to 'recognise institutionalisation as a form of violence'.[7] The Guidelines, together with the Committee's General Comment No. 5 on living independently and being included in the community, emphasise that institutionalisation is a discriminatory practice, involves de facto denial of legal capacity, constitutes detention and deprivation of liberty, and exposes people with disabilities to the administration of drugs and other interventions without free and informed consent.[8] As such, all disability-based institutionalisation is prohibited under the CRPD.

People with mental health issues and psychosocial disabilities, people with intellectual disabilities, and those with complex support needs make up the largest institutionalised groups. In the European Union alone there are an estimated 1.4 million people living in institutions.[9] The UN estimates that of 8 million children who live in institutions, 1 in 3 are children with disabilities.[10] People in institutions, particularly women and girls, experience greater rates of sexual and physical violence, forced sterilisation, neglect, substance abuse, suicide, human trafficking, and other forms of torture and violence.[11] The COVID-19 pandemic brought institutionalisation back into the public eye with higher rates of infection and morbidity than the wider population. Representative organisations of people with psychosocial and intellectual disabilities indicate that disability-based institutionalisation is one of the gravest issues affecting their constituents in Asia and the Pacific.[12]

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[4]Kayess R and Sands T. 2020. Research report: Convention on the Rights of Persons with Disabilities, shining a light on social transformation. https://disability.royalcommission.gov.au/system/files/2020-09/Research%20Report%20-%20Convention%20on%20the%20Rights%20of%20Persons%20with%20Disabilities%20Shining%20a%20light%20on%20Social%20Transformation.pdf

[5] Human Rights Council. 2019. Report on the deprivation of liberty of persons with disabilities. https://www.ohchr.org/en/calls-for-input/report-deprivation-liberty-persons-disabilities

[6] Human Rights Watch. 2020. Living in Chains: Shackling of People with Psychosocial Disabilities Worldwide. https://www.hrw.org/report/2020/10/06/living-chains-shackling-people-psychosocial-disabilities-worldwide

[7] Committee on the Rights of Persons with Disabilities. 2022. Guidelines on deinstitutionalization, including in emergencies. https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including, para.22

[8] Committee on the Rights of Persons with Disabilities. 2017. General comment No. 5 (2017) on living independently and being included in the community. https://documents-dds-ny.un.org/doc/UNDOC/GEN/G17/328/87/PDF/G1732887.pdf?OpenElement

[9] Mansell J, Knapp M, Beadle-Brown J, and Beecham, J. 2007. Deinstitutionalisation and community living – outcomes and costs: report of a European Study. Tizard Centre, University of Kent. https://research.kent.ac.uk/tizard/wp-content/uploads/sites/2302/2019/01/DECLOC_Volume_2_Report.pdf

[10] Committee on the Rights of the Child. 2019. United Nations Global study on Children Deprived of Liberty. https://www.ohchr.org/en/treaty-bodies/crc/united-nations-global-study-children-deprived-liberty

[11] Human Rights Council. 2019. Report on the deprivation of liberty of persons with disabilities. https://www.ohchr.org/en/calls-for-input/report-deprivation-liberty-persons-disabilities

[12] Transforming Communities for Inclusion. 2018. Bali Declaration. https://tci-global.org/bali-declaration/

Challenges and opportunities

Despite many states being in a process of deinstitutionalisation for over 50 years, processes are often not CRPD-compliant or are overdue and, in some contexts, institutionalisation may be increasing.[13] While a global issue, quantification of the problem is challenged by poor data collection and reporting, including a lack of reporting by privately run institutions and exclusion from mainstream surveys and censuses.[14] Several factors, often complex and interrelated, contribute to the persistence of institutionalisation of people with disabilities.

High levels of stigma, stereotyping and prejudice toward people with cognitive and psychosocial disabilities and lack of respect for their dignity and autonomy is common. People with disabilities are often treated as though they are objects of charity, unable to make decisions, or potential criminals. A lack of understanding of the rights of people with disabilities to live in the community persists.[15] Pervasive historical, colonial, legal, and attitudinal barriers fuel ongoing justifications and practices of institutionalisation. For example, the persistence of a medical model of disability which sees psychosocial disability as the purview of medical professions and as an individual and tragic problem to be lamented and 'treated'. The marketisation of mental health by the mental health industry and psychopharmacology curtails both will and preferences and is underpinned by colonial mindsets.[16]

Discriminatory laws and policies supporting institutionalisation are based on actual or perceived impairment. Some countries have adopted CRPD Article 19 into their disability or amended mental health legislations (e.g. India) without explaining the provisions through case or constitutional law. Such new laws also allow traditional coercive methods of disability-based institutionalisation. Within national human rights institutions (NHRIs) and women's rights commissions, the issue of 'mini-institutions', shackling practices, and human rights violations have been sporadically addressed by higher order courts. However, more is needed to find legal solutions and create legislation to free people bound under incapacity, guardianship, and commitment laws. There is a lack of awareness in judicial systems, law faculties and other technical agencies worldwide of the need to transform legal systems towards inclusion.

Mental health legislation continues to be a barrier to living independently in the community. Discriminative legislation is continuingly promoted and increasingly taken up in new contexts. In Peru, where good practice disability legislation exists, independent living is under threat by new mental health legislation developed without consultation with people with disabilities.

Confusion persists around what deinstitutionalisation entails and ineffective strategies for implementation. Efforts to deinstitutionalise without a comprehensive human rights foundation and commitment of public funds have resulted in different forms of

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[13] Committee on the Rights of Persons with Disabilities. CRPD/C/5: Guidelines on deinstitutionalization, including in emergencies. 2022. https://www.ohchr.org/en/documents/legal-standards-and-guidelines/crpdc5-guidelines-deinstitutionalization-including, para.22

[14] Economic and Social Commission for Western Asia. 2019. Barriers to Implementing Article 19: A Study on the Institutionalization of Persons with Disabilities in Select Arab Countries. https://e-inclusion.unescwa.org/sites/default/files/resources/barriers-implementing-article19-institutionalization-persons-disabilities1-en.pdf

[15] Kayess R and Sands T. 2020. Research report: Convention on the Rights of Persons with Disabilities: Shining a light on social transformation. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disabilities

[16] Clarke J. 2014. Medicalization of global health 2: the medicalization of global mental health. Global Health Action, 7(10) https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4028926/

institutionalised living arrangements in the community (trans-institutionalisation), such as 'small-scale' residential care facilities. These 'group homes' accommodate large groups of people making individualised attention and inclusion in the community difficult. This perpetuates segregation and lack of choice instead of promoting genuine community-based alternatives.[17,18] Funding plans for deinstitutionalisation that do not consider the needs of institutionalised children with complex disabilities or behaviours have seen children with disabilities left behind in institutions while other children returned to the community.

Market trends and competing interests have seen private psychiatric hospitals replacing state-run institutions. Private insurance systems have contributed to increased hospitalisation and discourage psychosocial interventions and alternative treatments. The dependence of psychiatric research and development on multinational pharmaceutical companies means it is difficult to generate evidence around 'competitive' alternatives and establish a balanced knowledge base for policymakers to draw on. Further, the low cost of hospitalisation in some areas does not provide an economic incentive to push for deinstitutionalisation.[19]

Many institutionalised people remain there indefinitely due to the absence of mainstream opportunities, support networks, and community-based services. The ongoing provision and funding of medical care through institutions, rather than in the community, means individuals and families are compelled to give up children or admit themselves to institutions to receive support. With the shift towards decentralisation in many states, there is risk transferring responsibility for deinstitutionalisation from national to local governments will result in reduced funding and issues with service coordination, consistency, and competence. A lack of reparations and redress mechanisms for those affected by institutionalisation to support people immediately following deinstitutionalisation also negatively impacts people with disabilities.

Donor funding can perpetuate the maintenance of institutional approaches. For example, donor funds are used to renovate and 'prop up' institutions in the short term, with the unintended impact of perpetuating their existence. There is also evidence of perception by states that deinstitutionalisation is a 'donor-led' project, thereby risking the sustainability of changes.

Despite the challenges, there are growing models of rights-based alternatives to institutionalisation supported by key human rights and legal frameworks. These include the CRPD, the Sustainable Development Goals, the UN General Assembly Resolution on the Promotion and Protection of the Rights of Children, and recently released UN Guidelines on Deinstitutionalisation, including in emergencies. These Guidelines detail the aspirational as well as immediately achievable actions to ensure the rights-based inclusion of people with disabilities and effective deinstitutionalisation. There is an opportunity to use the COVID-19 recovery process and the introduction of the new Guidelines to highlight the need to address deinstitutionalisation as a matter of urgency.

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[17] Siska J and Beadle-Brown J. 2020. Report on the transition from institutional care to community-based services in 27 EU States. https://www.researchgate.net/publication/341902653_Report_on_the_Transition_from_Institutional_Care_to_Community-Based_Services_in_27_EU_Member_States

[18] Committee on the Rights of Persons with Disabilities. N.d. Outcome of Regional Consultations for Eastern Europe and Central Asia on Deinstitutionalization. https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx

[19] Cortes C, Moller J, Dominguez I, Thomas F, and Ortiz, J. 2023. Moving psychiatric deinstitutionalisation forward: A scoping review of barriers and facilitators. Cambridge Prisms, Global Mental Health, 10. https://doi.org/10.1101/2023.03.28.23287810

Looking ahead to 2030

Underpinning key actions for the full realisation of the rights of people with disabilities is a commitment to transformative development. This means engaging with and challenging prevailing structures and systems that maintain the status quo and shifting decision-making power to those most marginalised and most affected by institutionalisation. For deinstitutionalisation to succeed, states, development partners, and communities must urgently address these key issues:

- establish a supportive legal environment and repeal discriminatory legal incapacity, mental health, and other disability-based detention laws and provide supported decision-making mechanisms

- foster enabling environments within communities to better support all persons with disabilities

- address entrenched negative attitudes and social norms about the capacities of people with disabilities

- mobilise public funds to mainstream inclusion and provide personal supports and community-based services.

Community-based programs led by people with disabilities, created within a human rights and integrated development framework in the Global South, demonstrate deinstitutionalisation is achievable now. Lessons from these programs and recent CRPD committee consultations suggest the following actions to support successful deinstitutionalisation.

Build capacity of DFAT staff and partners on deinstitutionalisation, including how to identify and prevent institutionalisation, with technical guidance for staff engaging in National reform. This includes an intersectional approach with attention to children, women, LGBTQIA+ people, culturally and linguistically diverse communities, people affected by leprosy, older people, people with dementia, and unhoused people. Provision of clear guidance and standards for programs and embedding expectations into contract negotiations and guidance would support communication of expectations to downstream partners. Enhanced safeguards, such as the European Checklist for EU-Funded measures, would help prevent funds being used to create or renovate new institutions .[20]

Support states to chart a clear vision and policy for deinstitutionalisation with the effective participation of people with disabilities in the design, implementation, and review of deinstitutionalisation efforts and decision-making processes.[21] For example, via funding situational analyses and needs assessments sensitive to contextual factors and with mapping of existing services, gaps and opportunities, and supporting the review, repeal, and reform of harmful legislation.

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[20] European Expert Group on the transition from institutional to community-based care. 2020. Checklist to ensure EU-funded measures contribute to independent living by developing and ensuring access to family-based and community-based services. https://enil.eu/wp-content/uploads/2022/03/EEG_Checklist.pdf

[21] Committee on the Rights of Persons with Disabilities. N.d. Outcome of Regional Consultations for Asia Pacific on Deinstitutionalization. https://www.ohchr.org/sites/default/files/Documents/HRBodies/CRPD/OutcomeRegionalConsultationAsiaPacific.docx

Prioritise investment in high-quality, individualised support and inclusive mainstream services in the community without delay. Support services should include personal assistance, peer support, caregivers for children in family settings, crisis support, communication, and mobility support, including provision of assistive technology, support in securing housing and household help, and other community-based services. Support should be available to access and use mainstream services, including in education, employment, social protection, justice, and health. People with disabilities, particularly people with psychosocial and cognitive disabilities in development, should be included in implementation and monitoring of mental health services and psychosocial supports. Investment in reparations and redress mechanisms, such as compensation packages, to support people immediately following deinstitutionalisation to live with adequate standard of living in open settings without fear of insecurity is essential.

Ensure social protection programs account for the additional costs of disabilities and include end of program outcomes for people with disabilities. People with disabilities should have access to disability allowances on an equal basis with others and information about housing and unemployment allowances, personal assistance, health care, vocational training, and social protection. Additionally, child protection and welfare systems should prioritise and address the needs of children with disabilities, including those with high support needs.

Raise national and community awareness on community inclusion of people with psychosocial and cognitive disabilities. Core funding for emerging representative organisations will amplify the voices of people with psychosocial and cognitive (particularly intellectual) disabilities by supporting their collective action.

Improve data collection and engagement of civil society. Establishing national monitoring frameworks for institutions, including indicators on children in alternative care, is crucial. Developing and publishing official statistics on this population group and monitoring progress is important, for example around implementation of child protection system reforms. Civil society can improve inclusion of people with psychosocial and cognitive disabilities and those with high support needs in programming and advocacy by developing and testing person-centred, community-based mental health and psychosocial services and offering choices as per the will and preference of people with disabilities. Incorporating action research will contribute to the evidence base in the Global South.

Dedication: Bhargavi Davar: A Global Leader in the Struggle for Human Rights

Dr Davar Executive Director of Transforming Communities for Inclusion (TCI) Global, passed away on May 22, 2024

Bhargavi was a staunch advocate for the rights of people with psychosocial disabilities.

In 1999, Bhargavi founded the Bapu Trust for Research on Mind and Discourse, inspired by her mother's experience of violence and discrimination in institutions. The organisation pioneered providing mental health services based on rights, focusing on community inclusion and peer support. Bhargavi co-founded Transforming Communities for Inclusion (TCI) Global, an international organisation representing people with psychosocial disabilities that now operates in more than 50 countries advocating for the rights and inclusion of persons with psychosocial disabilities worldwide.

Bhargavi dedicated her life to advocating for the rights of people with psychosocial disabilities and transforming mental health services and supports.

She was a trail blazer in the global disability rights movement, a champion of the UN Convention on the Rights of Persons with Disabilities (CRPD), and a mentor to many through initiatives like the Bridge CRPD-SDGs Training. Her relentless efforts to decolonise the mental health space have left an indelible mark on countries worldwide.

Bhargavi's insights and dedication helped shape a more inclusive society. Her legacy is one of courage, vision, and resilience.

Family-based care and support: the role of male caregivers

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Background

Caregivers can be an important resource in enabling people with disabilities to access services and community resources and to promote inclusion more widely. It is accepted, and supported by evidence, that caregivers play an important role in maximising the wellbeing of many people with disabilities.[3] This is especially the case for children with disabilities. Where a child has a profound intellectual disability, such as the child of one of the authors, the caregiver can in effect be the 'communication aid', equivalent to a sign interpreter, through which the person communicates their needs, desires, and preferences.

Globally, primary caregivers are predominantly women and girls. Caregiving by family members is informal, unpaid, and performed in addition to other roles that caregivers have, such as paid employment. Providing informal care over prolonged periods can result in caregivers experiencing burden and stress.[4,5] If the caregiver is stressed or isolated, or has poor mental health and minimal resources, the person with disabilities being cared for is less likely to maximise their potential and wellbeing. While recognising that women and girls provide the majority of informal caregiving in the family, this essay focuses on the under-researched area of male caregivers.

Opportunities and challenges

The stress that caregivers experience has been well documented in both low- and high-income settings. Caregivers experience high levels of negative mental health and social isolation; financial strain; the physical burden of caregiving; feelings of pessimism, exhaustion, and anxiety; cognitive and memory difficulties; and, consequently, reduced quality of life. These negative impacts are compounded by a lack of internal resources, such as information, skills and coping behaviours, and limited external resources, including finances, help from extended family, and formal supports.[6]

The economic impact of the additional expenditure and decreased income of caregivers is well known. These impacts provided justification for the National Disability Insurance Scheme (NDIS) in Australia whereby supports provided to people with disabilities and their families enable caregivers to engage in the workforce. In most countries, caregiving is unpaid and the economic contribution of caregiving is uncounted. Informal caregiving enables a person with disabilities to live at home rather than in institutional- or state-based care. Home-based care generally costs less and is often preferred by people with disabilities. The UN Convention on the Rights of Persons with Disabilities emphasises the right of people with disabilities to live in the community (Article 19) and the right of children with disabilities to family life (Article 23).

The role of caregivers is often overlooked in global development cooperation. Failing to engage with caregivers can further disadvantage people with disabilities, especially for

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[3] World Health Organization. 2004. The importance of caregiver-child interactions for the survival and healthy development of young children: A review. https://iris.who.int/bitstream/handle/10665/42878/924159134X.pdf?sequence=1

[4] Joling K J, O'Dwyer S T, Hertogh C M, and van Hout H P. 2018. The occurrence and persistence of thoughts of suicide, self-harm and death in family caregivers of people with dementia: a longitudinal data analysis over 2 years. International journal of geriatric psychiatry, 33(2), pp.263-270. https://doi.org/10.1002/gps.4708

[5] Murthy R S. 2016. Caregiving and caregivers: Challenges and opportunities in India. Indian Journal of Social Psychiatry, 32(1), pp.10-18. DOI: 10.4103/0971-9962.176761

[6] Joling K J, O'Dwyer S T, Hertogh C M, and van Hout H P. 2018. The occurrence and persistence of thoughts of suicide, self-harm and death in family caregivers of people with dementia: a longitudinal data analysis over 2 years. International journal of geriatric psychiatry, 33(2), pp.263-270. https://doi.org/10.1002/gps.4708

those with severe intellectual disabilities. The Committee on the Rights of Persons with Disabilities General Comment Number 7 highlights the importance of including caregivers and family members in consultations. Including caregivers is important where there is a risk of losing access to the voice of some people with disabilities, for example, where the caregiver may play a critical role in supporting communication.[7]

Without assuring appropriate representation of caregivers within the disability movement and related dialogue there is a risk of excluding people with disabilities who rely on supported communication through their caregivers. A recent study noted that people with intellectual or profound disabilities are underrepresented in organisations of people with disabilities (OPDs).[8] Reasons for this include limited mechanisms for supported decision-making or communication, a role commonly provided by caregivers for some people with disabilities.

Research has shown that female caregivers of children with disabilities are often marginalised and disempowered socially and financially.[9] This marginalisation has been associated with poorer wellbeing, health, and education outcomes for the child. Male involvement in the day-to-day care of a child with disabilities is often limited due to various factors such as paid labour, absence due to migration for work, societal norms and gendered domestic role allocations associated with caregiving. In some contexts, men may not be welcome to engage in personal caregiving due to cultural and traditional norms around gender roles in the family.[10] There has been limited engagement with the role of male caregivers in the literature and practice. The role of male caregivers in contributing to childhood development and wellbeing has been shown to be important; for example, male caregivers' participation in parenting programs in Japan was associated with positive outcomes on their child's behavioural problems and communication skills.[11]

Understanding the role and function of male caregiving in providing disability support in the family is essential for furthering women's empowerment. For example, the sharing of domestic loads, which are typically greater in the context of disability, increases opportunities for women to engage in paid employment outside the home. Studies also demonstrate more equitable caregiving for children with disabilities in a household can reduce potentially negative impacts on female caregivers, such as depressive symptoms and exposure to stress.[12]

Often it is the lack or absence of caregiving by men that is the focus of research and intervention with little attention paid to the positive aspects of caregiving by men to a child with disabilities' welfare. A negative portrayal with a focus on the shirking of responsibilities by men can perpetuate gendered inequalities. There is appreciable scope to better

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[7] Committee on the Rights of Persons with Disabilities. 2018. General comment No. 7 on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention. https://www.ohchr.org/en/documents/general-comments-and-recommendations/general-comment-no7-article-43-and-333-participation

[8] Banks L M, Eide A H, Hunt X, Abu Alghaib O, and Shakespeare T. 2023. How representative are organisations of persons with disabilities? Data from nine population-based surveys in low-and middle-income countries. Disability & Society, pp.1-17. https://doi.org/10.1080/09687599.2023.2215397

[9] Fisher P, and Goodley D. 2007. The linear medical model of disability: Mothers of disabled babies resist with counter-narratives. Sociology of Health & Illness, 29(1), pp.66-81. https://doi.org/10.1111/j.1467-9566.2007.00518.x

[10] Shorey S, and Pereira T L B. 2023. Experiences of fathers caring for children with neurodevelopmental disorders: A meta-synthesis. Family process, 62(2), pp.754-774. https://doi.org/10.1111/famp.12817

[11] Sato N and Araki A. 2022. Fathers' involvement in rearing children with profound intellectual and multiple disabilities. Journal of Family Nursing, 28(1), pp.57-68. https://doi.org/10.1177/10748407211037345

[12] Laxman D J, McBride B A, Jeans L M, Dyer W J, Santos R M, Kern J L, et al. 2015. Father involvement and maternal depressive symptoms in families of children with disabilities or delays. Maternal and child health journal, 19, pp.1078-1086. https://doi.org/10.1007/s10995-014-1608-7

understand and address the constraints to male engagement in caregiving for family members with disabilities in development research and programming.

Looking ahead to 2030

An important question that remains unanswered in low- and middle-income countries is: does the absence or exclusion of male or female caregivers hinder the child's development? Also, what additional impact does the absence of a male or female caregiver have when caring for a child with disability? In order to recognise this key component of childhood development and disability, new efforts need to be made to foster understandings and engagement of caregivers, including their own wellbeing.

It is critical to develop strategies for both male and female caregiver engagement, such that they have a comprehensive understanding of the care needs of children. Notably, engaging male caregivers in appropriate allocation of resources and creating a supportive social and family arrangement affords critical support to women and the family.

Ensuring gender equality and the social and financial empowerment of women in households with people with disabilities who require support or care requires us to work with men. We should take a strengths-based and co-design approach to understanding this dynamic and designing appropriate interventions for men. Such initiatives would involve looking at the whole family unit and dynamics in the care of children, including a focus on better supporting and promoting care by men, given male caregivers are often excluded from research and interventions.

We recommend the following to better ensure more equitable provision of care and support for people with disabilities by 2030:

1. Work with partner countries to generate co-designed, evidence-informed research and develop policies and programs to understand and support the role of male and female caregivers respectively in promoting the wellbeing and positive development of people with disabilities.

2. Encourage OPDs and community self-help groups to be actively inclusive of male caregivers, or to develop structures that facilitate the inclusion of men in caregiving roles in line with the principles of supported decision making.

3. Develop targeted, sustainable interventions to improve the health and wellbeing of male caregivers to optimise the potential of those for whom they care.

4. Invest in developing and delivering evidence-based positive parenting programs, such as those being co-designed in rural India,[13] and specifically tailored to meet the needs and challenges faced by male caregivers while promoting gender equality in caregiving roles.

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[13] Mathias K, Nayak P, Singh P, Pillai P, and Goicolea I. 2022. Is the Parwarish parenting intervention feasible and relevant for young people and parents in diverse settings in India? A mixed methods process evaluation. BMJ open, 12(2). https://doi.org/10.1136/bmjopen-2021-054553

Disability inclusive social protection

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Background

Social protection programs are especially important for people with disabilities who are more vulnerable to negative shocks and face greater barriers to social and economic participation. Evidence shows people with disabilities are more likely to be poor, have greater difficulty accessing health care, including a greater need for rehabilitation services, and have lower rates of education and employment and higher rates of being subject to violence.[3,4,5,6,7,8]

In the past, social protection programs took a charity approach to addressing these vulnerabilities or a wage replacement philosophy. Benefits were designed to provide a minimum level of consumption and/or to substitute for wages that were lost due to the inability to find or undertake livelihood generation.

The UN's Joint Statement on Inclusive Social Protection builds on the UN Convention on the Rights of Persons with Disabilities (CRPD) and establishes a human rights-based approach to social protection.[9] This entails:

- moving away from using 'incapacity to work' to determine program eligibility

- moving away from institutionalised care, to support for living in the community, for which social protection can play a vital role

- accounting for the extra costs of disability, which can vary dramatically in amount and type of expenditure depending on the nature of a person's disability. As such, a 'one-size-fits-all' approach is inconsistent with effective eligibility determination or to the design and delivery of benefits.

According to the Joint Statement, an inclusive social protection program should:

- ensure income security that enables access to necessary goods and services

- ensure coverage of disability-related costs and facilitate access to the required support, including services and assistive devices

- ensure effective access to health care, including disability-related medical care and rehabilitation, as well as HIV services

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[3] Mitra S and Yap J. 2021. The Disability Data Report. Disability Data Initiative. Fordham Research Consortium on Disability, New York. https://disabilitydata.ace.fordham.edu/reports/disability-data-initiative-2021-report/

[4] Banks M, Kuper H, and Polack S. 2017. Poverty and disability in low-and middle-income countries: A systematic review. PloS one, 12(12). https://doi.org/10.1371/journal.pone.0189996

[5] United Nations Educational Scientific and Cultural Organization. 2020. Inclusion and Education: all means all, Global Education Monitoring Report. https://unesdoc.unesco.org/ark:/48223/pf0000373718

[6] Mizunoya S and Mitra S. 2013. Is there a disability gap in employment rates in developing countries? World Development, 42, pp.28-43.

[7] Mitchell R J, Ryder T, Matar K, Lystad R P, Clay-Williams R, and Braithwaite J. 2022. An overview of systematic reviews to determine the impact of socio-environmental factors on health outcomes of people with disabilities. Health & social care in the community, 30(4), pp.1254-1274.

[8] Mailhot Amborski A, Bussieres E L, Vaillancourt-Morel M P, and Joyal C C. 2022. Sexual violence against persons with disabilities: A meta-analysis. Trauma, Violence, & Abuse, 23(4), pp.1330-1343.

[9] United Nations. 2019. Joint Statement Towards Inclusive Social Protection Systems. https://www.social-protection.org/gimi/gess/RessourcePDF.action?ressource.ressourceId=55473

- improve access to services across the life cycle, such as childcare, education, vocational training, support with employment and livelihood generation, including return to work programs

- account for the diversity of people with disabilities, both in terms of type of disability and other factors such as age, gender, and ethnicity.

Two fundamental issues relating to disability inclusive social protection are the determination of the nature of the extra costs facing people with disabilities and the mechanisms for assessing the needs of people with disabilities within a country's context.

Opportunities and challenges

Extra Costs

One challenge in designing inclusive social protection systems is addressing the extra costs of living incurred by people with disabilities. Research shows that these are highly significant.[10] Two households with similar levels of income – one with a household member with disability and one without – will not have the same standard of living. This is because the household with a person with a disability has additional needs. Accounting for the costs of these extra needs when drawing poverty lines yields significantly higher poverty rates for people with disabilities. Without these costs being met, people with disabilities are subjected to a reduced quality of life and increased barriers to participation in the economic and social life of their communities.
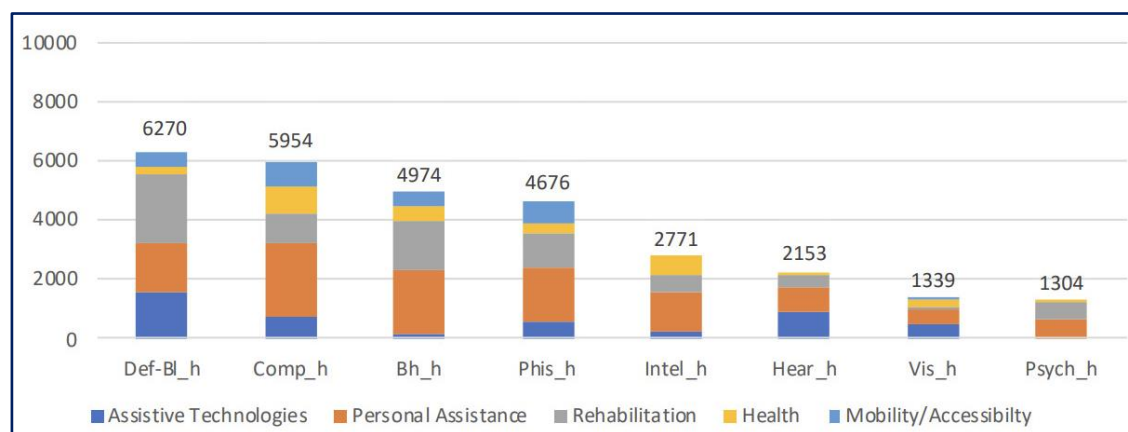
Extra costs vary significantly by type and degree of disability, as shown in Figure 1 below from a UNICEF study in Georgia that looked at disability costs among children.[11] This figure shows the monthly costs for children with high support needs by type of disability (Deaf-blind, complex medical, behavioral, physical, intellectual, hearing, visual and psychosocial). This includes the total monthly costs and how these costs are distributed by type of spending. Clearly a single size cash transfer would not align with how these costs are incurred. Further, any program targeted on a specific good or service – for instance, assistive technology or rehabilitation – would cover a very different percentage of total costs depending on a person's situation.

Methodologies have been developed to measure the costs required for equal participation between people with and without disabilities. In addition to Georgia, there is ongoing work in Peru and Tamil Nadu and upcoming work in Fiji and Nigeria. The approach of assessing the individual needs of people with disabilities and tailoring benefit packages to them is becoming more common in high income countries, such as in Australia, France and Ireland.

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[10] Mont D, Cote A, Hanass-Hancock J, Banks L M, Grigorus V, Carraro L, et al. 2022. Estimating the Extra Costs for Disability for Social Protection Programs. https://www.social-protection.org/gimi/RessourcePDF.action?id=57850

[11] United Nations Children's Fund. 2023. The Cost of Raising a Child with Disabilities in Georgia. https://www.unicef.org/georgia/media/8421/file/The%20Cost%20of%20Raising%20a%20Child%20with%20Disabilities%20in%20Georgia.pdf

Disability Assessments

To meet these costs, a needs assessment is required. The sophistication of this assessment will depend on the country context, for example the number and capacity of people doing such assessments. But they all serve the same function, which is to identify the difficulties people with disabilities have undertaking activities and the types of supports people with disabilities need to participate in daily life on an equal basis with others.

It should be noted that the determined needs (and associated costs) are those existing in the current environmental context with the current barriers in place. Meeting those needs, and reducing those costs, can be achieved both through providing individual-level benefits as well as introducing policies that eliminate the barriers that create those costs. For example, extra costs associated with transportation could be reduced by making public transportation more accessible. However, no matter how many barriers are removed, people with disabilities will have extra costs associated with their needs.

A responsive social protection system requires a disability assessment that adheres to a human rights-based approach. The assessment can help determine eligibility in obtaining legal disability status and collect information relevant to accessing services, particularly disability-specific support services that promote the inclusion and participation of people with disabilities. It is important that assessments go beyond eligibility determination to identify what goods and services a person with disabilities requires.

It is important that the assessment is accessible, affordable, reliable, comprehensive, and compliant with the CRPD. Furthermore, it must gather data on support needs of children, working-age adults, and older people with disabilities with the goal of enabling better case management and more effective referral to existing services. Additionally, this data should have relevant information that will inform decision-makers in developing policies and programs supporting inclusion and participation of people with disabilities in the community.

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[12] The disability subgroups listed on the x axis are identified as follows: Def-Bl (deaf-blind), Comp (complex medical needs), Bh (behavioural), Phis (physical), Intel (intellectual), Hear (hearing), Vis (visual) and Psych (psychosocial).

[13] United Nations Children's Fund. 2023. The Cost of Raising a Child with Disabilities in Georgia. https://www.unicef.org/georgia/media/8421/file/The%20Cost%20of%20Raising%20a%20Child%20with%20Disabilities%20in%20Georgia.pdf

The disability assessment system should be localised and designed to make it interoperable with other existing local and national data systems to maximise usage. For example, in the Philippines, all local governments are required to establish and maintain a Community-Based Monitoring System for developing and implementing social protection programs both at local and national level.

Various data tools exist (for example, the International Classification of Functioning, the Model Disability Survey, and early childhood care and development checklists) as well as assessment tools (the Functional Independence Measure, or FIM, in Fiji) and more expansive tools in high income countries (such as in France and Australia) that can provide frameworks for different components of the disability assessment. However, as stated above, the assessment must align with the capacity of the government to administer an assessment tool, the goods and services available in the country, and the nature of participation. A limitation in that capacity, of course, is not an excuse for not expanding social protection and/or making it more inclusive. Part of those efforts could be to increase that capacity, both to assess needs and build policies and programs that address them.

A recent pilot test of an assessment tool designed for the Philippines showed that for the disability assessment system to be truly localised, local knowledge and practices have to be incorporated throughout the development process. This increases the tool's validity and acceptability. The multi-stakeholders' group who should be involved in developing the disability assessment system includes local and national government agencies and offices, organisations of people with disabilities, health and allied professionals, special education teachers, and community-based workers such as child development workers. In the Philippines, multi-stakeholder group knowledge and practices contributed to the design of the system, including the content of the disability assessment tools, how the tools will be administered, accountability mechanism, and the mechanism for case management and referral to services. With real intention to use local knowledge and practices, the disability assessment system creates ownership resulting in a more suitable and acceptable system designed to address issues of accessibility, feasibility, and affordability in the local context, as well as ensure coordination and interoperability with other services.

Looking ahead to 2030

The recommendations below outline ways in which donors and governments can work together to make social protection systems more inclusive and promote the participation and wellbeing of people with disabilities.

1. Social protection system evaluation. Assist countries to evaluate their current social protection systems for compliance with the CRPD and the Joint Statement on Inclusive Social Protection, with recommendations on how to improve that compliance.

2. Extra Cost Studies. Support countries to undertake studies that estimate the goods and services required for equal participation, their availability and accessibility, and how the nature and extent of those costs vary over the life cycle by type and degree of disability and gender.

3. Disability Assessment design. Assist countries to develop disability assessments that identify the support needs of people with disabilities necessary for the delivery of those services. This must be driven in a way that is feasible given the current country context, which can also help with planning programs and policies to provide them.

4. Social protection system design. Based on the results of the above, offer assistance with reforming the social protection system to ensure it is CRPD-compliant and promotes the participation of people with disabilities.

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