Disability Inclusion Helpdesk, February 24

Evidence digest focus issue: Movement building and Disability Inclusion

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Guest blog: Inclusive Social Movements - Juan Ángel de Gouveia

In our latest guest blog, we have the privilege of conversing with Juan Ángel de Gouveia, the esteemed president of the Latin American Network of Organizations of People with Disability and their Families, better known as RIADIS. Founded in 2002, RIADIS operates across 20 Latin American countries, boasting a network of approximately 70 organizations of people with disabilities dedicated to championing the rights of people with disabilities. Join us as we gain insight into the journey of understanding and promoting an inclusive social movement.

What does an 'inclusive social movement' mean to you?

An Inclusive Social Movement holds immense significance to me. This extends beyond the scope of just people with disabilities. It encompasses women, children, older individuals, and indigenous people, emphasizing equal opportunities for all to impact public policies and advocate for intersectional perspectives. In essence, the inclusive social movement strives for a world where everyone has an equal voice and opportunities.

What are some of the barriers to building an inclusive social movement, particularly around inclusion of people with disabilities?

The prevailing attitudes and personalities within the local community present significant barriers. There is a lack of awareness regarding disability issues among the majority, and the prevailing mindset towards individuals with disabilities extends not only within my community but also to neighbouring communities.

Although most countries worldwide agree with the global convention for people with disabilities, the Latin American governments frequently cite budgetary constraints as a barrier to their inclusion in policies and programs. Governments often view the perceived high costs of providing accessibility and reasonable accommodation as deterrents. Even when individuals with disabilities express interest in participating in policy processes across various sectors for inclusive representation, governments consistently point to budget limitations for accessibility and reasonable accommodation as the primary impediment.

What works in terms of building inclusive social movements, particularly promoting collaboration between organisations of people with disabilities and other civil society groups? Please could you provide some examples from your own experience?

To foster effective collaboration, it's imperative to establish a comprehensive workplan. The disability movement and organizations should consistently partner with inclusive organizations, working jointly to plan and execute projects and programs. This collaboration is vital for genuine and impactful participation in public policy spaces. At RIADIS, our active collaboration with UN agencies involves research and investigation across various areas, including the circumstances of refugees with disabilities in Latin America. The involvement of people with disabilities in consultations is pivotal for finding solutions to improve the situations of disability refugees in this project. Proposals are also presented to state governments and UNHCR agencies.

In Venezuela, my engagement in numerous projects with UNICEF demonstrates the success of collaboration, particularly in projects focusing on the inclusion of children and young people with disabilities. This underscores the significance of organizations working with organizations of persons with disabilities (OPDs), governments, and international cooperations to share best practices. While challenges such as accessibility barriers exist, these can be overcome through training and capacity building, empowering individuals to better understand and participate effectively.

How do you see the role of international Donors in supporting inclusive movement building and supporting localisation?

Unfortunately, Latin America faces a scarcity of international corporations and donors supporting the disability movement. This contrasts with regions like Africa and Asia, where substantial international cooperation and budgets exist for people with disabilities. In Latin America, the available budget is notably limited, making it challenging to address the diverse needs of the disability community. Currently, only Nicaragua, Honduras, Guatemala, Venezuela, Colombia, Bolivia, and Peru receive limited funding from international donors, creating a complex and constrained process.

Having actively engaged with various projects, RIADIS has produced reports detailing the current situation of people with disabilities in Nicaragua, Guatemala, Venezuela, and Honduras. While we strive to form alliances with the international community focusing on Latin America, securing support remains challenging. Unfortunately, Latin America has only five international donors, including Handicap International, Humanity and Inclusion, ASB Germany, CBM International, and CBM Global, engaging with disability organizations in select countries. However, budget constraints, particularly for Humanity and Inclusion, pose challenges for comprehensive disability programs. Similarly, while CBM International and CBM Global support disability organizations in specific countries, the assistance remains limited, underscoring the need for more extensive and substantial support.

Many organizations of persons with disabilities (OPDs) in Latin America operate on a voluntary basis. This is due to insufficient budgets for projects and programs across the region.

If you had one key message to share about inclusive social movements – what would it be?

The primary focus should be on collaborating to establish a socially inclusive movement. Achieving a truly inclusive movement is impossible without international cooperation, which should prioritize intersectional efforts for accessibility and inclusion of disability organizations, both in Latin America and globally. This unity is key to substantial support, leading to improved realities and greater inclusion for people with disabilities in the Latin American region and worldwide. Increased funding for OPDs is also crucial to bolster their efforts.

The latest evidence and guidance on disability inclusion and inclusive movement building

Research

Programmatic contexts

A **report by Humanity & Inclusion in July 2023** examines the inclusion of people with disabilities in Nepal's humanitarian sector and response to climate change. A section of this report focuses on inclusion of people with disability in climate change related advocacy, as well as relationships with other stakeholders in this space. It notes that that persons with disabilities individually are generally not participating in local climate action, with over 80% of people with disabilities surveyed indicating they never having participated in climate discussions in their community. A small number of disability activists and organisations of persons with disabilities (OPDs) are involved in climate policymaking, with a majority feeling that the issue is too vast and overwhelming. This is attributed to a lack of knowledge transfer, inadequate opportunities for meaningful participation, and a lower prioritisation of climate issues compared to human rights topics like health and education within public structures. It provides several recommendations to NGOs and other local stakeholders in terms of including people with disabilities: including building links with OPDs, ensuring project activities are disability inclusive, disaggregating data by disability, and raising awareness among staff.

In May 2023, Disability Debrief published a blog entitled: '**Do we practice what we preach? The discrimination we face while advocating on disability.**' This blog highlights the implicit attitudes, inaccessibility, ill-treatment and outright discrimination faced by people with disabilities in spaces and organisations which are meant to be inclusive. The author, Peter Torres Fremlin, shares how their career with international organisations working for a better

world has been 'profoundly shaped by exclusion and discrimination.' This includes accounts of workplace-based discrimination and harassment.

The Inclusive Futures programme published a report in March 2023 on **Partnering for Disability Inclusion**, which looks at how local authorities, non-governmental organisations and organisations of people with disabilities can form effective partnerships to strengthen disability inclusion. It is based on learning from the Inclusive Futures Programme, using desk reviews and key informant interviews. Key messages include: the need to build shared understanding from the start (including of the project, its partners and disability); and the need to agree on roles and responsibilities of each partner to promote collaboration and shared decision-making. The report provides three examples of what can be achieved using partnerships between local authorities, NGOs, and OPDs, including: strengthening government tools and services for inclusion; advocating for inclusive policy implementation; and using partnerships to remove physical barriers.

Protests

A **blog published by Disability Debrief in March 2023**, discusses the experience of people with disabilities as part of political protests in Peru. The author, Andrea Burga, notes that people with disabilities are not often perceived able to have their own opinions, or that simply they are apolitical. She notes that physical protests calling for rights is not always inclusive for people with disabilities, and especially when the 'police are shooting tear gas and pellet guns.' The author notes the importance of online spaces for people with disabilities to use their voice and demand their rights. However, online spaces are also not always accessible, for example by not being screen reader-friendly or accessible for D/deaf people.

OPD engagement & other civil society movements

In January 2023, Inclusive Futures also published two discussion papers which summarise outputs from three peer-to-peer roundtables with international non-governmental organisation (INGO) project officers and organisation of persons with disabilities (OPD) officers from the Inclusive Futures consortium. Participants discussed their direct experience about what has and has not worked well, to help build meaningful partnerships for a disability-inclusive project.

The first of the two papers is entitled '**Creating meaningful and successful partnerships between INGOs and OPDs: key values and attitudes.**' It explores the deeper discussions, values and approaches required for a successful and meaningful partnership, identifying six key points:

- Prepare for the partnership to be transformative
- Start with understanding
- Respect an OPD's relationship with community
- Build a mutually beneficial partnership
- Use the partnership to challenge disability stigma
- Remember that 'one size does not fit all' contexts or situations.

The paper expands on each of these ideas individually.

The second paper published in this series is called '**A guide to building meaningful and successful partnerships between INGOs and OPDs: What we've learned from the Inclusive Futures programme.**' This paper features nine areas of agreement between participants in the roundtable, including:

- Start with shared vision and values
- Respect OPDs as expert organisations
- Share power, leadership, ownership, and responsibility
- Agree roles and responsibilities
- Dedicate resources and budget to OPD engagement
- Seek diverse inclusion
- Identify strengths and capacity challenges
- Link your project to policy
- Prepare for transformation and learning.

Guidance, Training and Case Studies

In March 2023, Oxfam launched an **Inclusive Language Guide**. The guide takes a critical look at the language used around inclusion, and whether it 'reinforces or disrupts our analysis of how poverty takes hold.' This guide features a section on disability inclusion, and provides examples of language to use and avoid – as well as exploring some of the reasons and criteria. This tool could be useful for organisations or movements seeking to create inclusive spaces and meaningful engagement of people with disabilities and OPDs.

A **report by CARE in September 2023** highlighted a number of case studies on how different civil society groups are working towards more inclusive humanitarian response in Fiji. The report showcases the work of Fiji Disabled People's Federation, as well as its collaboration with the Rainbow Pride Federation and Save the Children Fiji, to create more inclusive responses to climate-related disasters in the country. It notes that while each agency has specific areas of work, they recognise the universality of human rights and the importance of intersectionality in their advocacy (which forms a core part of their overall advocacy approach). This approach represents a type of collective power that aims to ensure no one is left behind.

The latest evidence and guidance on disability inclusion: Other topics

General

In December, the **FCDO hosted a webinar with women OPD leaders**, speakers from Inclusive Futures, to discuss how non-governmental organisations (NGOs) and donors can meaningfully engage with OPDs to deliver disability-inclusive development projects. The

webinar explored experiences and learnings, successes and challenges encountered in collaboration between OPDs, governments, donors and INGOs.

In November, a **roundtable was held to present findings** from a study entitled 'Nationwide Assessment of Water, Sanitation and Hygiene (WASH) situation of persons with disabilities and older people in Bangladesh.' The findings presented were based on a population-based cross-sectional study conducted from November 2022 to October 2023 – and identified a prevalence The key findings of the study reveal an overall disability prevalence of 8% in Bangladesh, with males at 7% and females 9%. The study goes on to explore experiences of barriers faced by people with disabilities in accessing WASH services. There are specific findings on the barriers faced by women with disabilities, including that 12% of females with disabilities required assistance for changing and disposing of menstrual products which can elevate the risk of urinary and faecal incontinence among individuals with disabilities. This issue emerged as a particular concern for those with communication limitations.

Research Practice

The Institute of Development Studies (IDS) delivered **a presentation** on what inclusive participatory research tells us about people with disabilities' lives. It draws on research within the FCDO-funded Disability Inclusive Development (DID) programme. The speakers share reflections on designing and using inclusive participatory research methods in Kenya (on inclusive pre-school education) and Bangladesh (livelihoods and skills development). Captions are provided.

The IDS also produced a blog on **five critical considerations for participatory research and inclusive education**. The blog draws on the above-mentioned two projects in Kenya and Bangladesh and focuses specifically on the research process, rather than the findings from the research. The five critical areas it discusses are safeguarding, ethics, collaboration, trust, and play-based creative research methods for engaging children and understanding their perspectives.

Further guidance was published by IDS in an article on **'Disability inclusive research: What is it and how can we do it?'** This guidance note provides general tips on disability inclusive research, as well as guidance for each stage of the research process.

Data

In November, the Disability Inclusive Development (DID) Helpdesk published a **query on safe and ethical data collection on disability inclusion in Gender Based Violence (GBV) programming**. The resource provides guidelines on safe and ethical data collection on disability inclusion in GBV programming, challenges and risks associated with data collection, and case studies of how well this has been done in programming. French and Portuguese language versions are forthcoming.

Digital

UNICEF published 'How to improve digital inclusion and accessibility for girls with disabilities,' a guide which highlights best practices in inclusion and accessibility of digital solutions for persons with disabilities, particularly girls. It aims to support developers and implementers of digital products and services to ensure that girls and young women with disabilities can benefit from digital services and platforms. It is structured around 10 tips, each of which are explained in detail. These tips are:

1. Work with disability allies
2. Respect disability etiquette
3. Include girls with disabilities in consultations
4. Host accessible events
5. Learn about girls with disabilities' digital use
6. Develop accessible and relevant digital content
7. User test with girls with disabilities
8. Build girls with disabilities' digital skills
9. Ensure inclusive launch and marketing
10. Inclusive monitoring and evaluation

Additional resources, links and case studies are also provided in the document.

Health

A blog by Sightsavers was published on Healthy Futures, entitled '**Ensuring no one is left behind on the path to universal health coverage.**' As part of the Universal Health Care Day in December, the blog highlights the role of disability inclusion in achieving universal health care. It outlines various initiatives by Sightsavers on the following issues/topics: health equity for persons with disabilities; promoting access to sexual and reproductive health and rights; inclusive family planning; neglected tropical diseases; inclusive data; and an accessibility standards toolkit for health care facilities in low- and middle-income countries.

Humanitarian response

In September, the Inclusive Futures programme launched a report on '**Including women and girls with disabilities in development and humanitarian projects**.' The report features learnings on successes, adaptations, and failures from the Inclusive Futures programme – all drawn from a content analysis of project reports from across the work of Inclusive Futures for the period April 2020–May 2023. It features practical examples which illustrate nine key findings in terms of what works, what needs to change, and what should stop in terms of meaningful inclusion of women and girls with disabilities.

In December 2023, **UN Youth and UNFPA published a checklist** to ensure the meaningful engagement of young persons with disabilities in humanitarian action. This checklist aims to provide guidance on how to ensure meaningful participation of young persons with

disabilities in local humanitarian response. The expected users are humanitarian actors, especially those working in the field.

In December, the International Organization for Migration (IOM) **published a report** about persons with disabilities in the aftermath of the earthquakes that struck Kahramanmaras on 6 February 2023, affecting 11 provinces in Türkiye's southeast region. It is based on consultations with representatives of Organisations of Persons with Disabilities (OPDs). The report provides an overview of the impact of the earthquakes on persons with disabilities, the earthquakes' response for persons with disabilities, the impact of the earthquakes on OPDs, and OPDs' involvement in the response. Findings show that persons with disabilities encountered difficulties in accessing health services, rehabilitation, assistive devices, and psychosocial support, as well as basic items, hygiene supplies, and sanitation facilities. Gaps were evident in addressing persons with disabilities' unique needs and vulnerabilities, and the report also identifies challenges faced by subgroups including women and children with disabilities. The report concludes with useful recommendations for local authorities and non-governmental entities.

In October, the UN Office of Disaster Risk Reduction (UNDRR) published **the 2023 Global Survey Report on Persons with Disabilities and Disasters**. The survey aimed to identify if persons with disabilities are prepared for potential disasters, whether early warning and risk information is available and accessible, if persons with disabilities are aware of disaster risk reduction (DRR) plans at national and local levels, and if persons with disabilities are participating in DRR decision-making and planning. This report includes findings from the survey and a set of recommendations that are intended to provide insights and direction on the remaining seven years of the Sendai Framework implementation. The results of the survey show limited progress in disability inclusion over the past 10 years, with no significant differences across the regions reviewed. The report's recommendations emphasise the importance of ensuring appropriate preparedness measures, improving access to risk information, and investing in disability-inclusive DRR, including direct resourcing of OPDs in recognition of their leadership and contributions to achieving the Sendai Framework outcomes.

A discussion paper published in December on '**Children and Armed Conflict (CAAC) Mandate and Children with Disabilities in Armed Conflict.**' The paper examines the impact of armed conflict on children with disabilities and provides recommendations for making the CAAC mandate more inclusive, aiming also at informing policy discussions on conflict-affected children. Key areas of action are outlined in the report, including: strengthening of data collection on children with disabilities in the framework of the monitoring and reporting mechanism on children and armed conflict; consultations with persons with disabilities, including children, and the organisations that represent them; and the provision of training and other capacity building efforts on disability inclusion would all contribute to enhancing the protection of children with disabilities in armed conflict.

Social protection

A blog published in October looks at '**The path towards inclusive social protection for people with disabilities in the Pacific.**' It discusses the limited coverage of people with disabilities in the context of the globally endorsed social protection floor approach. It outlines a range of barriers to social protection faced by people with disabilities and provides examples of initiatives to make mechanisms more inclusive and expand coverage. For example, it notes that inclusive programmes are universal, highlighting that testing may be a cause for exclusion. Other schemes were found to target a broad range of age groups, and two schemes being compatible work, enabling people with disabilities to access economic opportunities.

Disability inclusion policy news

The Third Committee (Social, Humanitarian and Cultural) of the UN General Assembly (UNGA) approved a draft resolution "**Implementation of the Convention on the Rights of Persons with Disabilities and the Optional Protocol thereto: situations of risk and humanitarian emergencies**" by consensus (document A/C.3/78/L.53/Rev.1). By its terms, the General Assembly would emphasise that accessibility is a precondition for persons with disabilities to live independently and participate in all aspects of life. It would urge States to enable their meaningful participation and representation in humanitarian action, conflict prevention, resolution, reconciliation, reconstruction, and peacebuilding.

About the Disability Inclusion Helpdesk:

The Disability Inclusion Helpdesk provides research and technical assistance on disability inclusion to the UK Foreign, Commonwealth, and Development Office as part of the Disability Inclusive Development Programme. All our published reports are available on **our website**. Contact us via: **enquiries@disabilityinclusion.org.uk**