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**Humanitarian
Exchange**

Disability inclusion in humanitarian action



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The Humanitarian Practice Network at ODI is an independent forum where field workers, managers and policy-makers in the humanitarian sector share information, analysis and experience. The views and opinions expressed in HPN's publications do not necessarily state or reflect those of the Humanitarian Policy Group or ODI.

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Editorial



The theme of this edition of Humanitarian Exchange, co-edited with Sherin Alsheikh Ahmed from Islamic Relief Worldwide, is disability inclusion in humanitarian action. Persons with disabilities are not only disproportionately impacted by conflicts, disasters and other emergencies, but also face barriers to accessing humanitarian assistance. At the same time, global commitments and standards and the IASC Guidelines on the inclusion of persons with disabilities in humanitarian action all emphasise how persons with disabilities are also active agents of change. Disability and age-focused organisations have led on testing and demonstrating how inclusion can be done better. Yet despite this progress, challenges to effective inclusion remain.

As Kirstin Lange notes in the lead article, chief among these challenges is humanitarian agencies' lack of engagement with organisations of persons with disabilities. Simione Bula, Elizabeth Morgan and Teresa Thomson look at disability inclusion in humanitarian response in the Pacific, and Kathy Al Jubeh and Alradi Abdalla argue for a 'participation revolution', building on learning from the gender movement. Tchaurea Fleury and Sulayman AbdulMumuni Ujah outline how the Bridge Article 11 training initiative is encouraging constructive exchange between humanitarian and disability actors. The lack of good, disaggregated data is highlighted by Sarah Collinson; Frances Hill, Jim Cranshaw and Carys Hughes emphasise the need for training resources in local languages and accessible formats; and Sophie Van Eetvelt and colleagues report on a review of the evidence on inclusion of people with disabilities and older people.

Kirsty Smith analyses the findings of a review of a DFID programme in north-east Nigeria, while Carolin Funke highlights the importance of strategic partnerships between disability-focused organisations, drawing on her research in Cox's Bazar. Sherin Alsheikh Ahmed describes Islamic Relief Worldwide's approach to mainstreaming protection and inclusion, while Pauline Thivillier and Valentina Shafina outline IRC's Client Responsive Programming. The edition ends with reflections by Mirela Turcanu and Yves Ngunzi Kahashi on CAFOD's SADI approach.



Editorial photos

Top left and right: Humanitarian actors and DPO representatives at the Bridge CRPD-SDGs training on Article 11
IDA/Federica Settini 2019

Bottom: Mansehra District, Pakistan: a student enjoys improved access to education after assistive devices and accessibility ramps are provided at her school
HRDS/Afzal

As always, we welcome any comments or feedback, which can be sent to hpn@odi.org.uk or to the **HPN Coordinator, 203 Blackfriars Road, London SE1 8NJ.**

Disability inclusion in humanitarian action

Inclusion of persons with disabilities in humanitarian action: what now?

Kirstin Lange

The past few years have seen substantial progress on inclusion of persons with disabilities in humanitarian action. The World Humanitarian Summit in Istanbul in 2016 was a key point in recognising that persons with disabilities face a double jeopardy in humanitarian emergencies in that they are both disproportionately impacted by conflicts, disasters and other emergencies, and also face barriers to accessing life-saving humanitarian assistance. These challenges, now widely documented and acknowledged at the most senior levels of the humanitarian system, resulted in the establishment of an Interagency Standing Committee (IASC) Task Team, with the responsibility for drafting guidelines on inclusion of persons with disabilities in humanitarian action.

The IASC Guidelines on inclusion of persons with disabilities in humanitarian action were officially launched in November 2019, marking another important milestone in the promotion of the rights of persons with disabilities affected by humanitarian emergencies. This article explores the question of ‘what now’ for disability-inclusive humanitarian action – what is needed for the Guidelines to be translated into concrete change for persons with disabilities in countries most impacted by humanitarian emergencies.

Developing the guidelines

The process of developing the guidelines was arguably as important as the product itself, as it brought organisations of persons with disabilities (OPDs) to the table alongside humanitarian actors. The guidelines were developed through a highly participatory process, which, through regional consultations, ensured that OPDs from across the world were at the centre of defining standards for disability-inclusive humanitarian action. The expertise of OPDs was essential to understanding the key challenges to be addressed in the guidelines, and for developing rights-based approaches to addressing the risks persons with disabilities face in humanitarian crises.

Issues and challenges

While OPDs were central to the development of the guidelines, there remains a substantial gap in their

engagement in humanitarian action at field level. For the guidelines to be implemented and disability-inclusive humanitarian action strengthened, a number of issues will need to be tackled.

The first involves a shift in thinking to recognising persons with disabilities, not only as beneficiaries of humanitarian assistance, but also as key actors in the response. Such a shift is in line with the broader priority of accountability to affected populations, which emphasises partnership with people affected by humanitarian emergencies, rather than a top-down approach, providing aid to passive populations. It also requires an understanding by humanitarian actors of the knowledge and experience of OPDs as essential to the delivery of an inclusive humanitarian response that is better for all. On a more practical level, there is a need for capacity-building of OPDs, both building knowledge of the humanitarian system and enabling access to the financial resources required to engage meaningfully as an actor in the response. This in turn is linked closely to the localisation agenda, and efforts to strengthen localisation therefore must be fully inclusive of persons with disabilities.

The second key development needed in order to promote implementation of the Guidelines and strengthen disability-inclusive humanitarian action is capacity-building of humanitarian actors at field level. The humanitarian system is demonstrating a strong commitment to the rights of persons with disabilities. Humanitarian Needs Overviews (HNOs) and Humanitarian Response Plans (HRPs) for 2020 are evidence of the increasing recognition of the vulnerability of persons with disabilities in humanitarian emergencies, and the need to do more to ensure their inclusion in humanitarian response. However, what those HNOs and HRPs also demonstrate is a gap in understanding of the specific factors that place persons with disabilities at heightened risk, and the concrete actions needed to make humanitarian response more inclusive. Following the launch of the guidelines, there is a need now for attention to shift from global frameworks to operational support at field level, to ensure that humanitarian actors



Wheelchair user moving through Zaatari Camp, Jordan
Unicef

are equipped, not only with the knowledge of ‘what’ disability inclusion entails, but also the resources to address the ‘how’.

The third key development is to more systematically integrate disability inclusion into key global agendas and ensure that it does not remain a separate stand-alone work stream. It is increasingly being recognised that disability inclusion is a central component of a number of key priorities in the humanitarian system, including improving accountability to affected populations, protection mainstreaming and strengthening localisation. Further, disability inclusion is closely interlinked with gender equality, age-sensitive programming and mainstreaming of mental health and psychosocial support. A more coordinated approach is needed in the humanitarian system, where these multiple agendas are not seen as competing but rather as linked, with common objectives around ensuring that humanitarian action is effective in reaching the most marginalised people and engaging them as equal partners.

Reference Group on Inclusion of Persons with Disabilities in Humanitarian Action

With the launch of the IASC Guidelines in November the mandate of the Task Team responsible for developing them ended. While specifically focused on development of the guidelines, the Task Team, also provided an important forum for bringing together OPDs, NGOs and UN entities. The end of its mandate therefore also left a gap in terms of mechanisms for engagement between OPDs and humanitarian actors at a global level, at a time when this engagement is particularly important in order to support implementation of the Guidelines and maintain the momentum that had been built around this

agenda. In February 2020, at the Humanitarian Networks and Partnerships Week (HNPW), this gap was addressed through the launch of the Reference Group on Inclusion of Persons with Disabilities in Humanitarian Action. The Reference Group, co-led by an OPD, NGO and UN entity (currently the International Disability Alliance, CBM and UNICEF), aims to provide a forum for coordination on strengthening disability-inclusive humanitarian action, including to support implementation of the guidelines.

The work plan for the Reference Group for 2020–2022 reflects the three key challenges identified above, with separate work streams established for operational support, mainstreaming into global processes and support to OPD engagement. These three work streams will be advanced through coordination between OPDs, NGOs and UN agencies, and through engaging with other key humanitarian coordination mechanisms, including IASC results groups and associated entities, as well as the cluster system and other inter-agency processes. It is hoped that this work will further advance the gains made on inclusion of persons with disabilities in humanitarian action, especially translating these to field level, to reach persons with disabilities affected by humanitarian emergencies.

For more information or to engage with the Reference Group on Inclusion of Persons with Disabilities in Humanitarian Action, contact the co-chairs (Elham Youssefian, IDA; Christian Modino Hok, CBM; and Kirstin Lange, UNICEF) at rg.disabilityinclusion@gmail.com.

Kirstin Lange is a Disability Inclusive Humanitarian Action Programme Specialist at UNICEF and Co-Chair of the Reference Group on Inclusion of Persons with Disabilities in Humanitarian Action.

Pacific people with disability shaping the agenda for inclusive humanitarian action

Simione Bula, Elizabeth Morgan and Teresa Thomson

Not everyone experiences humanitarian emergencies in the same way. We know that people with disabilities are disproportionately impacted. This is not due to inherent vulnerability; it is the result of existing inequalities that are compounded by crisis and exacerbated by the way that humanitarian assistance is traditionally designed and delivered. This is well recognised: Article 11 of the Convention on the Rights of Persons with Disabilities (CRPD) promotes equitable approaches to inclusion in situations of risk and humanitarian emergencies, and the Sendai Framework calls for a disability perspective in all Disaster Risk Reduction (DRR) efforts.¹ However, even as the Sendai Framework was being agreed in 2015, people with disabilities in Vanuatu were absent from response and recovery activities in the aftermath of Tropical Cyclone Pam. This article considers the critical role of Organisations of Persons with Disabilities (OPDs) in humanitarian action, and how the Pacific Disability Forum (PDF) Regional Capacity Building (RCB) programme's focus on a shared vision for the disability movement has led to significant improvements in inclusive DRR, response and recovery.

Context: disability exclusion in humanitarian settings

Disability inclusion within the humanitarian sector is a relatively new area, and the situation of people with disabilities is still often overlooked in preparedness, response and recovery efforts. Disability inclusion across DRR, prior to disaster, is often limited. Preparedness information is often unavailable in accessible formats, so many people with disabilities are less aware and prepared for a disaster. Research shows that 60% of people with disabilities in Vanuatu did not have information on what to do in an emergency before Tropical Cyclone Pam hit in 2015.² People with disabilities are also often left out of community disaster management and risk reduction; a UNDRR survey of over 5,000 people with disabilities across 137 countries found that 85% had never participated in these processes.³

During disasters, poor or no consideration of physical accessibility means that people with disabilities may be unable to flee or evacuate safely with the rest of the community. Even if they can leave their home, long distances or difficult terrain may make it virtually impossible to reach shelter. Evacuation centres themselves may not be accessible due to stairs and other barriers; 74% of women with disabilities and 50% of men with disabilities reported barriers to access during Tropical Cyclone Pam in Vanuatu.⁴ Evacuation centres are public spaces, and gender norms mean that many women feel unsafe and lack the privacy they need. Women with disabilities in general are three times more likely to experience physical, sexual and emotional abuse compared to their non-disabled peers.⁵ While there is limited information on the situation for women with disabilities in emergency settings, this likely compounds the safety and security concerns women with disabilities may have in relation to evacuation centres. The implications of exclusion when disaster strikes are dire. Tropical Cyclone Pam injury rates among people with disabilities were 2.45 times higher than for people without disabilities.⁶

In the aftermath of disasters or humanitarian crises, when local responders and other actors begin to mobilise, people with disabilities are often overlooked and inadvertently excluded. Emergency food, water and health services are often inaccessible, and the standard set of food and non-food items often does not take into account the differing needs of people with disabilities, such as adapted feeding implements and assistive products, and additional continence and menstrual hygiene support. Accessible distribution points may also be inaccessible; after Tropical Cyclone Winston in Fiji these were located far away, location information was inaccessible and there was no support for people with disabilities to carry supplies back to their original location. OPDs played a limited role and were left out of key decision-making processes, which meant that the priorities and needs of people with disabilities were often overlooked.

1 UNDRR, Sendai Framework for Disaster Risk Reduction 2015–2030, 2015 (www.undrr.org/publication/sendai-framework-disaster-risk-reduction-2015-2030).

2 Nossal Institute for Global Health, CBM Australia, Oxfam in Vanuatu, Vanuatu Society of People with Disabilities, Vanuatu Disability Promotion and Advocacy Association, Ministry of Justice and Community Services, Vanuatu National Disaster Risk Management Office, *Disability inclusion in Disaster Risk Reduction: experiences of people with disabilities in Vanuatu during and after Tropical Cyclone Pam and recommendations for humanitarian agencies*, 2017 (https://mspgh.unimelb.edu.au/__data/assets/pdf_file/0011/2567576/WEB-DIDRR-Report-14112017.pdf).

3 UNDRR, *Living with disabilities and disasters: UNISDR 213 survey on living with disabilities and disasters – key findings*, 2013 (www.unisdr.org/2014/iddr/documents/2013DisabilitySurveyReport_030714.pdf).

4 Disability inclusion in Disaster Risk Reduction.

5 UN Special Rapporteur on Violence against Women, its Causes and Consequences, Ms Rashida Manjoo, *Report on violence against women with disabilities*, 2012 (http://www.ohchr.org/wp-content/uploads/2013/12/UN_SR_Report_2012.pdf). See also Ortoleva, S. and Lewis, H., *Forgotten sisters: a report on violence against women with disabilities: an overview of its nature, scope, causes and consequences*, 2012 (<http://hdl.handle.net/2047/d20002563>).

6 Disability inclusion in Disaster Risk Reduction.

Challenges to meaningful participation of OPDs

Since Sendai and the experience of Pam and Winston, humanitarian agencies are realising that effective disaster preparedness and response in the Pacific must include people with disabilities. Meaningful and direct engagement is key, in order to understand particular barriers and preferred strategies for removing these barriers, and to harness what people with disabilities can bring to disaster preparedness and humanitarian action.

People with disabilities are experts in their own lives, and humanitarian actors need to be able to access this expertise. OPDs can act as a conduit between humanitarian actors and people with disabilities. However, many people with disabilities face enormous barriers in accessing education, obtaining formal employment and accessing funding opportunities. This means that many OPDs lack human resources and core organisational funding. Many OPDs in the Pacific have only one or two paid staff members and rely on volunteers.

While inclusion in disaster preparedness and response is a key priority for people with disabilities and many OPDs, it is only one of many competing priorities for resource allocation. This means that humanitarian actors need to work with OPDs in a way that does not swamp the organisation, but builds core capacity and enables further resources to be allocated. OPDs in the Pacific, including PDF, consider this approach vital to their work.

A coordinated vision for the Pacific

In 2017 PDF, supported by CBM Australia, brought together 14 member OPDs from Pacific Island nations to develop a vision and coordinated priorities for disability-inclusive disaster preparedness and response. The strategy was developed as part of preparation for the roll-out of the Australian Humanitarian Partnership (AHP) Disaster READY programme,⁷ focused on disaster preparedness in the Pacific. National-level OPDs recognised that requests for technical input would increase as part of this programme, and wanted to ensure that they had dedicated staff with the time and mandate to engage, and avoid taking OPD leaders and other staff away from other priorities.

The result was the *PDF Disability Inclusive Preparedness for Response Strategy*, which sets out six key change areas that need to be addressed for inclusive and accessible humanitarian action. OPD capacity and resourcing is central. Having OPDs leading their own decision-making rather than always being pulled in the direction of other partners is a key goal of the strategy.

Figure 1 The six change areas of the PDF Disability Inclusive Preparedness for Response Strategy

Change area 1

Disabled people's organisations (DPOs) are well resourced, coordinated and mobilised to lead and oversee the success of the PDF Pacific Disability Inclusive Preparedness for Response strategy at regional and national level, with technical support provided

Change area 2

Government-led preparedness for response processes (including legislation, policies and coordination mechanisms) are fully inclusive and able to meet the needs of people with disabilities

Change area 3

Mainstream preparedness for response actors have policies and practices in place to ensure full inclusion of people with disabilities

Change area 4

Preparedness for response processes for individuals, households, communities and churches are inclusive of people with disabilities

Change area 5

All services and processes operating as part of preparedness for response are inclusive of and accessible to people with disabilities

Change area 6

Disability inclusive approaches to disaster preparedness for response are based on evidence drawn from inclusive research and MEL processes

⁷ See www.australianhumanitarianpartnership.org/preparedness. AHP Disaster READY is currently being implemented in Fiji, Vanuatu, the Solomon Islands, Papua New Guinea and Timor-Leste.

A catalyst for change

The strategy has proven to be the catalyst for a raft of changes that are redefining how people with disabilities are engaged in humanitarian access and inclusion efforts in the Pacific. PDF, national OPDs and CBM Australia have together leveraged the momentum and resourcing available under the Disaster READY programme and are building a more sustainable model of disability mainstreaming that has the rights and priorities of people with disabilities at its centre.

Human resources

Through the process of strategy development, OPDs realised that human resources and technical capacity were key for building their work in this area. PDF and CBM Australia successfully advocated for funding for one full-time staff position dedicated to disability-inclusive humanitarian action in each national OPD in the five countries where Disaster READY is currently being implemented. Mainstream actors pay for these roles through a 'Shared Services' contribution model, and can tap into their expertise in disability inclusion, as well as learn from the lived experiences and perspectives of people with disabilities.

Confidence and capacity

The PDF and CBM Australia RCB programme prioritises funds to strengthen the capacity of people with disabilities and their representative organisations, so they can become more confident at applying their lived experience of disability and their knowledge of disability rights and inclusion principles to disaster preparedness and response issues.

To support OPDs while localised capacity is built up, a 'triangle team' has been developed. National OPDs are at the 'pointy end' leading engagement with humanitarian agencies in-country, with PDF and CBM available to

support as needed and able to facilitate cross-country learning. This ensures that national OPD staff develop the skills and confidence to respond directly to requests for support. PDF and CBM provide the OPDs with development tools and training and mentoring support so that they can participate with confidence in community to national-level forums and broker relationships with mainstream actors. The programme also enables the five national OPDs to share resources and divide work among themselves to ensure the widest possible reach.

Participation and representation

This has resulted in improved partnerships with the mainstream humanitarian sector. OPDs are no longer seen as merely sub-contractors or implementers who can tick the disability box for mainstream organisations, and they are more confident engaging with humanitarian actors on their own terms. PDF has leveraged funding to establish a Preparedness for Emergency Response Unit with four staff to enable better engagement with regional cluster mechanisms.

In turn, OPDs are accessing humanitarian sectoral knowledge and the opportunity to influence the work of others. A key message is the importance of accessibility, not only of the built environment but also in terms of information, communication, transportation and services. As a result of this clear advice, national-level humanitarian partners are now seeing the importance of paying for reasonable accommodations to ensure that people with disabilities are included – and meaningfully engaging – in preparedness forums and activities.

Impact: inclusive response during recent crises

Tropical Cyclone Harold tore through several Pacific Island countries in April 2020. This time, due to the capacity development efforts of the PDF RCB programme, local OPDs were well-placed to coordinate an inclusive response,



Members of the Fiji Disabled People's Federation sub-national DRR resource teams during their training in Suva, Fiji. Pacific Disability Forum

mitigating barriers and connecting with hard-to-reach communities. Through a collaborative effort, the Vanuatu Disability Promotion and Advocacy Association (VDPA) and the Vanuatu Society for People with Disabilities (VSPD) quickly mobilised to join post-disaster needs assessment teams and check what help people with disabilities in affected areas needed. VDPA staff have been sharing this information with all organisations to make sure the cyclone response and recovery reaches everybody.

OPDs in the Pacific are also playing a crucial role in providing an inclusive and accessible response to Covid-19. They are distributing emergency food packages and hygiene supplies to their members to ensure that basic needs are met, given current limitations to livelihood activities. OPDs are also sharing the lived experiences of people with disabilities and helping shape public health messaging so that it is disability-inclusive.

Lessons learned and conclusion

- **OPDs play a critical role in humanitarian action and must be involved in decision-making.** They are best-placed to articulate the lived experience of people with disabilities and leverage local networks to identify and communicate with people with disabilities before, during and after disaster.
- **OPDs themselves should determine exactly what their roles should be.** Time and space should be prioritised upfront to develop a clear vision and strategy, so that OPDs drive the direction of disability-inclusive response.
- **Partnerships are vital to enable disability inclusion and mutual learning between OPDs and humanitarian actors.** A long-term capacity-building approach is needed so that humanitarian actors can access the valuable perspectives of people with disabilities, and OPDs can increase their understanding of humanitarian issues.

This article demonstrates how, by articulating a shared vision and priorities, the PDF and CBM Australia RCB programme has enabled OPD participation in humanitarian response and recovery in the Pacific. In the past, PDF and OPDs in the Pacific felt pushed aside or drawn into delivering on the priorities of others, and that disability inclusion efforts were often tokenistic. By taking the time to focus first on defining a strategy for the disability movement in the Pacific, OPDs were able to identify their resourcing and capacity development priorities, and direct their energies to these areas, in turn allowing them to provide quality disability inclusion advice and better influence the mainstream humanitarian sector.

This article also highlights the direct impact these efforts have had on inclusive DRR and recovery. The cost of exclusion during past disasters was significant and, while considerable work remains to be done, recent responses have moved beyond a one-size-fits-all approach, and humanitarian agencies are now seeking the perspectives and priorities of OPDs to better meet the needs of diverse community members. The work being done to ensure Pacific OPDs are at the decision-making table and feel confident to provide their disability inclusion perspectives to mainstream humanitarian stakeholders has, in the words of one national OPD member, ‘given us the power, not to do everything alone, but to share a vision that others can support us in achieving’.

Simione Bula is Regional Coordinator with the Pacific Disability Forum, and is currently leading the implementation of the Regional Capacity Building programme described in this article. **Elizabeth Morgan** is an Advisor with the CBM Global Inclusion Advisory Group. **Teresa Thomson** is a gender equality and intersectionality practitioner and founder of Paper Cup Consulting.

‘A participation revolution’: creating genuine dialogue and partnerships between humanitarian actors and the disability movement

Kathy Al Jubeh and Alradi Abdalla

A ‘participation revolution’ was one of the key commitments coming out of the 2016 World Humanitarian Summit (WHS). Under the Grand Bargain, the most influential humanitarian donors, UN agencies and international NGOs, representing some 70% of humanitarian sector revenue, undertook to ‘include people receiving aid in making the decisions which affect their lives’. It was also a commitment to keep humanitarian action ‘as local as possible, as international as necessary’. But what do these commitments mean in practice? How do they translate into genuine

participation, control and decision-making by all people with disabilities impacted by humanitarian crises, especially in the context of a worldwide pandemic? And what can be learned from work to mainstream gender equality within humanitarian aid?

Given that people with disabilities are one of the most under-served populations and the least included in humanitarian decision-making, significant change is undoubtedly needed. A wealth of reports from the disability movement on the impact of the



Humanitarian actors and DPO representatives at the Bridge CRPD-SDGs training on Article 11
IDA/Federica Settimi 2019

coronavirus pandemic speak to the increased isolation, discrimination and exclusion that persons with disabilities face daily, especially women with disabilities and under-represented groups. There is major concern that the important gains the disability movement has made in developing and low-income countries are in jeopardy from both the direct and indirect impacts of Covid-19. If ever there was a time to reassess how to create more equitable, inclusive systems and achieve a participation revolution, it is arguably now, at this time of pandemic.

The outbreak of the Covid-19 pandemic and its subsequent spread to almost every corner of the world has, in a short space of time, up-ended traditional ways of working, unmasked systemic discrimination, destabilised economies and markets and deepened already entrenched inequalities. At the same time, what was considered impossible has almost overnight seemingly become possible: flexible home working; drastic reductions in national and international travel, with subsequent reductions in fossil fuel pollution; the largest increase in income safety nets and renewed discussions around an equitable universal basic income; and increased support for more local markets. These are all policies and practice that people with disabilities, the women's movement and environmentalists have been

advocating for decades: to develop more people-friendly, climate-friendly, inclusive and resilient ways of working.

A time for change

As the world heads into the most significant economic recession in decades, business as usual is no longer an option. Across the globe, households, local businesses, global conglomerates, municipalities and national governments are finding new ways of working; change is not only possible, but essential. However, many of the changes being implemented by governments are temporary, born out of necessity to meet short-term needs. They are not necessarily rights-based, and do not intentionally address longer-term policy commitments to promote participation and achieve systemic change and equality for all.

Even so, this time of change could open up significant opportunities for humanitarian agencies to seize the moment, using the Covid-19 response to help ensure more inclusive participation and engagement of people with disabilities and their representative organisations at all levels.

Over the past four years, since the WHS, there have been Important gains that have created a strong basis

for longer-term, systemic change, not least the wide endorsement of the Charter for Inclusion of Persons with Disabilities in Humanitarian Action; the development of IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action; and UN Security Council Resolution 2475, to protect persons with disabilities in situations of conflict. Critically, all of these normative documents have demonstrated a substantive shift away from traditional medical and ableist paradigms that view persons with disabilities as vulnerable, homogenous recipients. In line with Committee on the Rights of Persons with Disabilities (CRPD) jurisprudence, they recognise persons with disabilities in their wide diversity, as active agents of change, as rights holders and as valued actors, with relevant lived experience to shape, monitor and hold humanitarian actors to account.

However, while this groundwork is important, these commitments still largely remain at a formal, international level. The degree to which they have filtered down to practice at field level is still negligible. For example, the fact that the Grand Bargain Annual Report of 2020 did not mention disability once speaks volumes to the challenges, including the low priority given to disability, low awareness and capacity, negligible investment and low levels of consultation with and participation of disability movements.

Compared to gender mainstreaming, disability inclusion, despite some recent progress, is still a long way from being properly understood and embedded as a legal and professional imperative by humanitarian actors. While it would be unthinkable for mainstream humanitarians to undertake gender analysis without consulting affected women and girls, or to not allocate specific resources to ensure that humanitarian action directly addresses and mitigates potential gender-based violence, equivalent steps for persons with disabilities are still not yet standard. This disparity is disappointing, but it also offers opportunities to learn from the gender movement.

Learning from the movement to mainstream gender

The development of the first IASC gender handbook in 2006, more recently updated in 2017, was an important turning-point in raising awareness of and capacity on gender mainstreaming. This was followed by the establishment of the IASC Gender Marker, initially piloted in 2009 and updated in 2018 to the Gender and Age Marker. This basic mandatory requirement for funding across humanitarian assistance has resulted in higher levels of reporting, with relevant data disaggregation across all humanitarian projects to increase accountability. While this still does not guarantee quality, or that standards are being met, it does ensure greater visibility and ability of local communities to hold humanitarian actors to account. In addition, this has led to increased resourcing of capacity and engagement of

women-led organisations to help translate policies into practice and support locally led capacity development initiatives, and increased the number of women working in humanitarian agencies. This is still a work in progress in terms of including women in leadership positions, who are still not near parity with male counterparts.¹

These elements combined are supporting gender-responsive programming and increased investment in, ownership of and responsibility for gender equality as a core humanitarian responsibility. The same is now required for disability inclusion, for women, girls, men and boys with disabilities, recognising that most people with disabilities will have other characteristics that compound multiple discrimination, such as age, race, ethnicity, gender identity, faith and sexual orientation.

In many ways, the IASC gender handbook has laid a good foundation for the inclusion of disability in humanitarian response. It recognises disability as a critical intersectional discrimination that needs to be addressed, and which calls for, where possible, data disaggregation and analysis of programming on the grounds of disability. Unfortunately, the caveat – ‘where possible’ – in the handbook has often led to lack of engagement with women, girls and youth with disabilities. This has fed into a perception that disability inclusion is a separate or specialist issue, and one which is either too difficult to manage, or the responsibility of specialist agencies. This view further reinforces ableist attitudes and a medical approach that views persons with disability solely through the lens of health. Although there is wide recognition that persons with disabilities, of all gender identities, face much greater levels of abuse, violence and exploitation than their non-disabled peers, especially during crises and in displacement, mainstream agencies still do not automatically consider this as a core immediate responsibility. Hopefully, the recent IASC Guidelines on inclusion of persons with disabilities will provide practical support to equip mainstream actors on disability inclusion, as the gender handbook did on gender equality.

The more recent introduction of an OECD DAC disability marker, albeit not yet mandatory for official development assistance (ODA), could be another catalyst for change, as was the Gender Marker in its time. However, it is not clear that a separate marker for disability from the gender and age marker will be helpful. Will it support mainstream agencies to engage directly with disability movements to support disability inclusion, or will it only serve to further silo people with disabilities as the responsibility of specialist agencies?

Recognising the challenges

Much will depend on efforts to create inclusive spaces for participation. Currently, the majority of work to address disability inclusion has been through established

1 Black, A., Henty, P. and Sutton, K., *Women in humanitarian leadership*, Deakin University, Humanitarian Advisory Group, 2017 (http://devpolicy.org/2017-Australasian-Aid-Conference/Papers/HAGWomeninLeadership_Final_email%20and%20web_120217.pdf).

formalised processes, such as rapid needs assessments, response plans and evaluations. These are all processes constrained by limited time and budgets, and as such are rarely conducive to open dialogue and reflection. This often results in humanitarian agencies taking short cuts, bypassing local Disabled Persons' Organisations (DPOs) and consulting internationals from disability-specific agencies. Furthermore, although localisation efforts are improving partnerships with local agencies, formalised systems are still predominantly coordinated or managed by humanitarian surge teams, which often come to a disaster response with limited understanding of the complexities of local contexts, languages and cultural norms, much less the disability situation.

The shift to more localised responders, putting as much resource as possible into local national teams, will also not necessarily create a safe space for dialogue on issues of disability inclusion. Like their international counterparts, national responders do not always have an understanding of the complexity or diversity of local disability movements, much less trusted relationships with these groups. Furthermore, at times of crisis, what disability networks that do exist may equally have been disrupted by the crisis.

This therefore demands more forward thinking around how relationships can be nurtured between humanitarian, development and DRR practitioners and disability movements, including formal organisations of persons with disabilities, self-help groups and more ad hoc disability peer support networks. It also requires more coordinated approaches across mainstream and disability-specific agencies, local governments and UN agencies to jointly create space for disability movements to engage and lead on framing the issues that are the priority for people with disability during emergencies.

Creating the space for genuine dialogue

If we want a participation revolution, and want to open up more innovative dialogue that allows for meaningful participation, we need genuine spaces and opportunities, both formal and informal. This requires the creation of spaces where the traditional power dynamics of donor and recipient are upended. A potential space for this kind of dialogue is the formation of the third workstream on DPO engagement as part of the Reference Group to promote inclusion of persons with disabilities in humanitarian action. This workstream is developing a workplan, and there is an open invitation to all DPOs working in, or interested in working in, humanitarian crises to join humanitarian actors in taking forward the IASC Guidelines.

Effective participation requires, not just resourcing, making disability a mandatory marker and creating opportunities for engagement – but also creating genuinely safe learning environments. Much of the reluctance to engage with persons with disability stems from a fear of failure, of unwittingly doing harm. With so many taboos, stigma and deep layers of entrenched

unconscious bias on all sides, it is hard to create trusted spaces for dialogue where risks can be taken and humanitarian practitioners and disability activists can open up, challenge each other's views, share expertise and question often deep-seated bias. In order to create a critical mass in favour of inclusive humanitarian action, humanitarians need disability activists, just as disability activists need humanitarian partners. Creating the space where we can learn to work differently, especially during the current upheaval triggered by Covid-19, is critical, as is recognising that, while none of us has all the answers, together we are more likely to find good solutions.

A genuine participation revolution is still possible

Fourteen years after the adoption of the CRPD, it is time to build on the Grand Bargain commitment to realise a participation revolution that includes the disability movement as active partners with humanitarian actors. This will require us to overturn outdated mindsets, ways of working and ways of thinking. If we are to achieve



Humanitarian actors and DPO representatives at the Bridge CRPD-SDGs training on Article 11
IDA/Federica Settimi 2019

localisation and genuine partnerships with local actors, those actors must include persons with disabilities and their representative organisations in all their diversity. The implementation of the IASC Guidelines, the Inclusion Charter, the Sendai Framework and the SDGs cannot succeed if we do not recognise and engage the rich diversity of the lived experience of persons with disabilities.

In answer to learning from the gender movement, efforts towards disability inclusion have to be much more open and inclusive, with the intent to work in a way that is inter-disciplinary and cross-sectoral, with all stakeholders. The great power of the disability movement lies in its diversity and its ability to make connections: their multiple identities as indigenous people, youth and women, as ethnic minorities, farmers, union members, faith leaders and much more. This depth of experience and connectedness to wider local, regional and global constituents should allow for a more inclusive integrated approach that no longer looks at issues in isolation.

Useful further references

For a good analysis of current funding of international aid targeting disability see [Development Initiatives June 2020 report, Disability-inclusive ODA: aid data on donors, channels, recipients](#)

For clear rights based approach to Covid-19 response see [Toward a Disability-inclusive Covid-19 response: 10 recommendations from the International Disability Alliance](#)

For a good example of research undertaken by DPOs on the impact of COVID on their membership see the World Blind Union: [Amplifying our voices: our lives, our say](#)

For a good analysis of how Covid-19 has exacerbated inequalities see Save the Children's global report: [Protect a generation: the impact of Covid-19 on children's lives](#)

For clear recommendations on how to build more inclusive and equitable responses see the Cities for All Learning Series [Equity and access in times of pandemic](#)

If you would like to engage in the third workstream of the Reference Group to take forward DPO engagement to promote opportunities for inclusion of persons with disabilities in humanitarian action please register or email rg.disabilityinclusion@gmail.com.

Kathy Al Jubeh is Senior Advisor Inclusive Development – Capacity Development Lead at CBM Global and co-chair of workstream 3 of the IASC Reference Group. **Alradi Abdalla** coordinates the Training of Trainers programme of the Bridge CRPD SDGs initiative.

Bridge CRPD-SDGs Global Training on Article 11

Tchaurea Fleury and Sulayman AbdulMumuni Ujah

The IDA-IDDC Bridge CRPD-SDGs Global Training on Article 11 was the first-ever global training initiative on Article 11 of the Convention on the Rights of Persons with Disabilities (CRPD) to bring together Disabled Persons' Organisations (DPOs) and humanitarian representatives. The training, held in Lebanon over eight days of intensive immersion, from 20–27 June 2019, brought together leaders from the disability movement and experienced humanitarian actors in a safe space for open dialogue and constructive exchange, exposing participants and facilitators to each other's work and encouraging genuine peer learning and mutual accountability. The aim was to build stronger relationships to help realise CRPD Article 11, the Sendai Framework and the Charter on Inclusion of Persons with Disabilities in Humanitarian Action.

The initiative brought together 38 participants and facilitators – half of them women, and a third from under-represented groups of people with disabilities – from 31 countries across five regions, using four languages, three national Sign Languages and 12 interpreters. The objective was to pilot a capacity development mechanism that could foster dialogue, cooperation and exchange between disability activists and humanitarian actors, creating a safe space for relationship-building, genuine learning and peer exchange that would ensure

mutual recognition of the value to humanitarian actors of disability movement learning, and vice-versa.

The Bridge CRPD-SDGs Initiative had a strong impact on my knowledge and supported me in my advocacy and technical activities, widened my knowledge on the CRPD and helped me on how to instrumentalise it. For instance, I was able to work with the Humanitarian Innovation Fund (Elrha) – reviewing CRPD-compliance of applications on humanitarian interventions. I worked with the Leprosy Mission in Nigeria and HAND – a local partner of CBM – on how to make inclusive responses on their work. Again, I acted as advisory member of the International Rescue Committee on disability inclusion, supporting on how humanitarian actions can be further inclusive of persons with disabilities. Currently, I am the ADF Project Officer for the Inclusion Works Project in Nigeria.
(Sulayman AbdulMumuni Ujah)

This was also the first attempt to put together a joint learning curriculum aimed at meeting the needs of the two constituent groups. Designed over two years by, with and for persons with disabilities and their representative organisations and humanitarian and development actors, the organisers held three separate workshops to create,



Humanitarian actors and DPO representatives at the Bridge CRPD-SDGs training on Article 11
IDA/Federica Settimi 2019

Box 1 Under-represented groups

The International Disability Alliance understands the term ‘under-represented groups’ to mean persons with disabilities who enjoy less visibility in decision-making processes. The disability movement, like other social movements, is not homogenous. Some groups have traditionally been included less in participatory processes, have been harder to reach or face higher barriers to participation. They include, among others, persons with deafblindness, persons with intellectual disabilities, persons with psychosocial disabilities, persons with autism or deaf people. It can also include those who may be less engaged in decision-making, such as women, children, older people and indigenous peoples, as well as people from diverse faith, ethnicity, caste, class, sexual orientation or gender identity minorities. This understanding may differ in different countries, culture and contexts.

review and validate the curriculum. Humanitarians were keen to have practical and immediate answers on how to deliver inclusive humanitarian programming, but were not necessarily interested in understanding the detail

of how the CRPD underpins a rights-based approach to humanitarian programming, or the ways in which disability movements would like to be engaged in humanitarian action. For their part, disability activists wanted an easy handbook showing how the humanitarian infrastructure, programmatic decision-making and programme processes work, with a straightforward road map of where and how they can engage to address CRPD non-compliance in humanitarian systems.

Overall, the training was evaluated as extremely positive. Both DPO representatives and humanitarian actors evaluated the inclusive facilitation styles and tools of the Bridge CRPD-SDGs Article 11 initiative as unique. But there were challenges. The curriculum was heavy for humanitarian actors, and a preparatory day was requested in future training, as well as a more consolidated pre-reading pack to better orient participants on the basics of the CRPD. Participants from DPOs said that they would have liked more time to understand the humanitarian system and infrastructure, and would have liked more pre-reading on this. Another challenge was to ensure a balance between humanitarian actors and DPO representatives. The planned ratio of 2:1 was not managed, as one humanitarian had to cancel at short notice and another’s visa was delayed. Both had significant relevant experience that would have created

more intensive exchanges. Many of the humanitarian participants also felt that they would need more senior leadership buy-in from their agency, and that, in addition to the training, there was a need for shorter immersion opportunities to engage decision-makers within humanitarian agencies to help them understand the importance of shifting humanitarian processes and systems to be more inclusive of, and accessible to, persons with disabilities.

The great impact of Bridge CRPD-SDGs was that I was best equipped to deliver capacity-building of organisations of persons with disabilities, mainstream organisations, and government organisations to ensure disability-inclusive DRR. Also working with NGOs for post-disaster response e.g. rebuilding livelihoods.
(DPO participant)

The secret ingredient of the curriculum was in fact the participants themselves: as many good capacity-development programmes show us, it is the wealth of knowledge and experience that participants bring that provides the richness and the space for learning within and beyond the curriculum, particularly, in this case, with such a diverse group.

Humanitarian action was already my area of work but participating in Bridge CRPD-SDGs Article 11 allowed me to connect DPO members with multiple projects my organisation is implementing, from accountability to affected populations to early childhood development and family violence.
(Humanitarian participant)

The results of the training show how humanitarians and disability activists can create genuine mutual learning that is both challenging and rewarding. All participants valued the opportunity to learn alongside each other, and very much appreciated the informal learning spaces that the training opened up.

The great impact of Bridge CRPD-SDGs was the change that our community of refugees with disabilities experienced after sharing with them the knowledge that I got from the Bridge Uganda and talking with UNHCR, OPM, Inter Aid Uganda as Implementing Partner of UNHCR. Refugees with disabilities started to be involved in different programmes and projects and are being involved in decision-making and consulted before all projects and programmes regarding persons with disabilities and refugees. Not only that the number of refugees with disabilities who are resettled, and resettlement programme has increased compared to before the Bridge Uganda and I and our community are very proud of that step.
(DPO participant)

The Article 11 training tried to create an environment where everyone's expertise was valued and shared equally. This was in contrast to typical humanitarian or rights-based training, where one specialist group or another are in control of delivering often very prescribed

Box 2 Video testimonies

For personal individual video testimonies please click on the hyperlinks below

(Please note subtitles are available for all videos)

Interview with [Agnes Abukito](#), Inclusion Support Team to the Bridge CRPD-SDGs Module 3.

Interview with [Jessica Kay](#), Save the Children.

Interview with [Rahma Mustafa](#), Sudan National Union of Persons with Physical Disability.

Poem by Elizabeth Ombati from the World Network of Users and Survivors of Psychiatry (WNUSP) and IDA Bridge CRPD-SDGs Fellow and facilitator, on the themes touched upon from the beginning of the training week until Day 4.

Interview with [Sulayman AbdulMumuni Ujah](#) from the Joint National Association of Persons with Disabilities, Nigeria, on the last day of Bridge Module 3 on CRPD Article 11.

training. Bridge Article 11 created a space where both areas of expertise – of humanitarian action and of applying the CRPD – were valued and could be drawn upon. No one group was dominant and no hierarchy was created, so that sessions, exercises and simulations allowed for reflection and peer exchange and learning.

The training was helpful at the professional level, but it had a huge impact at the personal level. Thank you, trainers, organisers and facilitators for such valuable lessons. I have not felt/learned something like this in many years. It entirely changed my perspective on how I look at the humanitarian/development field. I reflected on how the world we are living in is designed to accommodate the needs of persons who do not have disabilities; I was able to not only identify this but to look at it as a structural problem. I took many learnings from the training including that all is about involvement of persons with disabilities. Based on the outcome of this training, we would amend our call for proposals to put conditions in place for implementing partners to include consultation and involvement of persons with disabilities at the community level prior to land release and to accommodate rights and needs of persons with disabilities for risk education.
(Humanitarian participant)

Through this experience, IDA and IDDC realised that, for genuine participation and learning to take place, we all had to be ready to let go of any pretence that any of us, including the facilitators, have all the answers. People can be supported by guidance and tools, but this can never equate to the power of learning where people directly and openly share lived experiences: the painful

mistakes, the successes, the embarrassments and the totally unexpected.

As a result of being part of the Bridge CRPD-SDGs Article 11 training, I was confident to advocate to the government on humanitarian issues, on the necessity for priority attention of persons with disabilities in disaster risk reduction and emergencies cases such as during election violence, flooding and fire outbreak in the community where persons with disabilities were affected. I also gave some first-hand awareness and education programmes to the community on early alert and quick evacuation for persons with disabilities.
(DPO participant)

The Bridge CRPD-SDGs Global Article 11 is a multi-actor initiative. Different actors and agencies are welcome to support joint capacity-development work with DPOs and humanitarians to create stronger relationships and engagement for an inclusive humanitarian sector. For further information, see our flyer and webpage. The Bridge CRPD-SDGs Coordination team (Tchaurea Fleury, Amba Salelkar and Alradi Abdalla) would be happy to discuss the initiative, its history, results and ways to engage.

Tchaurea Fleury is Director of Capacity Building, International Disability Alliance, based in Geneva.
Sulayman AbdulMumuni Ujah is the National Project Officer for the International Disability Alliance through the Africa Disability Forum's Inclusion Work/Organisations of Persons with Disabilities engagement in Nigeria.

Ensuring disability counts in humanitarian programming: addressing the data gap

Sarah Collinson

The past five years have been pivotal for advancing disability inclusion in the humanitarian sector. While the raft of new global declarations, standards and guidelines have brought global attention to this issue, work on the ground has been led by disability organisations to address gaps in practice. One of the weakest links in current practice, however, remains a lack of data about people with disabilities. Most humanitarian actors lack even the most basic information about numbers and needs of people with disabilities and the threats and barriers they face in accessing services; they are also unsure how best to go about collecting and using this data.

At present, people with disabilities are estimated to represent 15% of the world's population;¹ however, this figure is often higher among populations affected by crisis. In the case of Syria, for example, a recent survey found that 27% of people aged 12 years and over have a disability and, in some governorates, the majority of households were found to have at least one or more member with a disability.² If people with disabilities are not visible in the data and systems underpinning humanitarian programmes, the institutional imperatives to pay attention to their needs and to ensure or account for their inclusion is weakened.³ This represents a profound challenge to the impartiality of humanitarian action.

More inclusive and impartial programming will depend on agencies collecting and using a combination of both statistical and qualitative data which, when analysed

Box 1 Varying concepts of disability affecting disability data

Traditionally – and in many administrative data collection systems – disability has been approached as a binary ‘yes’ or ‘no’ matter (i.e. when answering the question ‘do you have a disability?’). This leads to significant under-reporting of disability prevalence due to stigma and differing understandings of what is understood as a disability.¹

By contrast, universal models of disability – such as the model underpinning the WHO's International Classification of Disability (ICF) – approach disability as a continuum, in line with the Convention on the Rights of Persons with Disabilities, which stresses that ‘disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others’.²

1 Ibid., p.70; and DFID Humanitarian Investment Programme (2019) Guidance on strengthening disability inclusion in Humanitarian Response Plans (https://reliefweb.int/sites/reliefweb.int/files/resources/Guidance_on_strengthening_disability_inclusion_in_Humanitarian_Response_Plans.pdf), p.15.

2 WHO & The World Bank (2011), p.4.

1 WHO and World Bank (2011) *World report on disability*. Geneva: WHO, Chapter 2 (www.who.int/disabilities/world_report/2011/report/en/).

2 Humanitarian Needs Assessment Programme for Syria (2019) *Disability: prevalence and impact: a nationwide household survey using Washington Group methodology*. HNAP for Syria. (www.globalprotectioncluster.org/wp-content/uploads/Disability_Prevalence-and-Impact_FINAL-2.pdf).

3 Holden, J., Lee, H., Martineau-Searle, L. and Kett, M. (2019) *Disability inclusion in humanitarian programming*. Disability Inclusion Helpdesk Research Report No. 9. London: Disability Inclusion Helpdesk (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/833579/query-9-evidence-humanitarian-response1.pdf).

together, can provide a full picture of the number and circumstances of people with disabilities. The IASC Guidelines on inclusion of persons with disabilities set out four main types of information collection and analysis on people with disabilities that agencies need at each phase of the programme cycle to support the delivery of quality inclusive humanitarian responses:

1. identifying the population of people with disabilities;
2. analysing the risks they face and the factors that contribute to those risks;
3. identifying the barriers that impede them from accessing humanitarian assistance; and
4. understanding their roles and capacities in the humanitarian response.⁴

This may seem a significant challenge, particularly given the operational pressures and constraints that organisations contend with in crisis response situations. But there is growing consensus on some of the most appropriate instruments and approaches to support disability data collection, sharing and use among humanitarian actors.⁵

Identifying the population of people with disabilities: quantitative data collection

A number of recent studies have successfully used the Washington Group Short Set of Disability Questions (WG-SS) to collect population-level quantitative data. The WG-SS is a widely-used and internationally endorsed set of six targeted questions on individual functioning to identify people with disabilities in a given population group (see Box 2). By integrating the WG-SS into existing surveys, humanitarian organisations can:

- understand the prevalence of people with disabilities to inform strategic planning frameworks;
- measure and monitor access to services by people with disabilities, with potential for further disaggregation by sex, age or other relevant characteristics to highlight potential barriers for specific groups; and
- disaggregate programme indicators by disability to better understand the situation of people with disabilities and the effectiveness of humanitarian programmes.

A key source of evidence supporting a widening endorsement of the WG-SS use in humanitarian programming is a UK Aid-funded study led by Humanity & Inclusion (HI) from 2016 to 2019, in collaboration with



Cover graphic for the HPN Network Paper *Addressing the disability data gap in humanitarian action*

the Washington Group, which tested and assessed the WG question sets through action research with a range of operational partners in Syria, Jordan, the Philippines and the Democratic Republic of Congo.⁶ The project supported a range of humanitarian actors⁷ working in different sectors⁸ and contexts⁹ to integrate the WG-SS questions into their existing practices and explored the practicalities and utility of the questions for generating useful and reliable data on disability among affected populations. The findings of the HI project are strongly corroborated by further indicative evidence emerging from other organisations' use of the WG-SS in a range of development and humanitarian settings.¹⁰

While the challenges should not be underestimated, there is little doubt that, when the WG-SS Questions have been used, the reliability of quantitative data on people with disabilities has been significantly improved (see, for example, Box 3). As concluded by HI, if, through the use of the WG-SS, disability prevalence is found to be orders of magnitude higher than previously assumed, this should directly impact programme planning and implementation and may raise potentially far-reaching

4 IASC (2019) *Guidelines: inclusion of persons with disabilities in humanitarian action*.

5 Including the IASC Guidelines; ECHO - European Civil Protection and Humanitarian Aid Operations (2019) *The inclusion of persons with disabilities in EU-funded humanitarian aid operations*. DG ECHO Operational Guidance (February) (https://ec.europa.eu/echo/sites/echo-site/files/dg_op_guidance_inclusion_gb_liens_hr.pdf); and DFID Humanitarian Investment Programme (2019).

6 Available at: <https://humanity-inclusion.org.uk/en/projects/disability-data-in-humanitarian-action#9>.

7 Including UN agencies, INGOs, local NGOs, government agencies and disabled people's organisations (DPOs).

8 Including multi-sector, food security and livelihoods, WASH, protection, health and disaster risk reduction.

9 Including sudden onset emergencies, displacement and refugee emergencies, protracted crisis and disaster-prone contexts.

10 For information on this HI project see <https://humanity-inclusion.org.uk/en/projects/disability-data-in-humanitarian-action>. Further information on other organisations' use of the WG-SS, see Collinson, S. (2020) *Addressing the disability data gap in humanitarian action*. HPN Network Paper 85, Box 5.

Box 2 Disability measurement and monitoring using the Washington Group Short Set of Questions on Disability

Not all people have the same understanding of what disability means. Therefore it is important that the questions used to obtain disability data are appropriately designed and implemented.

The Washington Group Question sets are intended to facilitate the comparison of data on disability cross-nationally. They are derived from the WHO's bio-psychosocial concept of disability and its International Classification of Functioning, Disability, and Health (ICF).¹

The Short Set of Questions on Disability (WG-SS) is designed to be used in conjunction with other measurement tools within a larger survey or registration process to enable disaggregation of other population measures (e.g. age or sex) by disability status. The focus on functioning and the brevity of the tool² mean that it can be relatively easily used in a variety of settings, including, potentially, humanitarian response contexts.

The questions intentionally do not use the word 'disability', but instead ask people how much difficulty they have performing basic universal activities in each domain (walking, seeing, hearing, cognition, self-care and communication) with answers categorised into 'no difficulty'/'some'/'a lot'/'cannot do it at all'. Disability is determined, according to the WG-SS, as anyone having at least 'a lot of difficulty' on at least one of the six questions.

The WG-SS will identify most but not all people with disabilities. Longer 'Enhanced' and 'Extended' question sets include questions on mental health/psychosocial functioning,³ and the Washington Group has developed a Module on Child Functioning in conjunction with UNICEF to identify a fuller range of childhood disability for children and youth aged 2–4 and 5–17.⁴

For further details see: www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/.

1 The Washington Group has developed a number of tools including four main question sets: the Short Set of Disability Questions, an Extended Set (expanding on the six short set questions with 39 additional questions on different aspects of functioning, including psychosocial functioning, fatigue and pain), an Enhanced Short Set (including the Short Set and three additional questions on anxiety, depression and upper body functioning), and the Washington Group/UNICEF Module on Child Functioning (specific to the needs of children aged 2–4 and 5–17). Additional sets of WG-related questions are also in development but not yet fully validated, including questions on participation and alternative questions on psychosocial disabilities.

2 The WG-SS is estimated to add approximately two minutes per survey.

3 For a detailed consideration of prevalence data on psychosocial functioning in conflict-affected contexts, see: Charlson, F. et al. (2019) 'New WHO prevalence estimates of mental disorders in conflict settings: a systematic review and meta-analysis' *The Lancet* 394(10194): 240-248 ([www.thelancet.com/journals/lancet/article/PIIS0140-6736\(19\)30934-1/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(19)30934-1/fulltext)).

4 For further information and resources on the Module on Child Functioning, see: <https://data.unicef.org/resources/module-child-functioning/>. See also Mactaggart, I., Cappa, C., Kuper, et al. (2016) 'Field testing a draft version of the UNICEF/Washington Group Module on child functioning and disability. Background, methodology and preliminary findings from Cameroon and India' *Alter, European Journal of Disability Research* 10(4): 345-360 (<https://doi.org/10.1016/j.alter.2016.09.003>).

questions about how organisations understand and operationalise disability inclusion.¹¹

Assessment data on the situation and needs of people with disabilities

The Washington Group Questions do not on their own provide a framework for needs or vulnerability and capacity assessments, nor do they inform organisations about the specific barriers that people with disabilities face or the enabling factors that help them in crisis response situations.

A fully inclusive and mainstreamed approach to disability-responsive programming will depend to a great extent on carefully adapting mainstream assessment tools to incorporate the collection of data on persons with disabilities.¹² Focused attention must be given pre-crisis at both headquarters and operational levels both to modify the assessment frameworks appropriately and to put in place the necessary awareness-raising and training to ensure a quality and mix of data to inform inclusive responses.

While the constraints on disability data collection and use are very real in the earliest stages of an emergency response, at later stages, and particularly in protracted

11 Humanity & Inclusion and Leonard Cheshire (2018) *Disability data collection: a summary review of the use of the Washington Group Questions by development and humanitarian actors*. London: Humanity & Inclusion and Leonard Cheshire; and Humanity & Inclusion (2019) *Data on persons with disabilities in humanitarian action: collecting quantitative data with the Washington Group Questions*. London: Humanity & Inclusion.

12 ECHO (2019)

Box 3 Varying disability prevalence rates reported among Syrian refugees in Lebanon with and without using the WG-SS

In 2013, UNHCR data reported that 1.4% of registered Syrian refugees in Lebanon had disabilities, based on self-identification against its own categories covering a number of impairments: physical (moderate and severe), mental (moderate and severe) and visual, hearing and speech impairments.¹

Using the WG-SS, a joint HI and iMMAP assessment found a disability prevalence of 22.9% in Lebanon, with 59.9% of sampled households including at least one member with disabilities, compared with only 14% of households identified in a previous vulnerability assessment.

Source: *Humanity & Inclusion and iMMAP (2018) Removing barriers: the path towards Inclusive access disability assessment among Syrian refugees in Jordan and Lebanon: Lebanon report* (https://d3n8a8pro7vhmx.cloudfront.net/handicapinternational/pages/5144/attachments/original/1537200833/Lebanon_Removing_Barriers_2018_Report_Final_web.pdf?1537200833)

1 Cf. HelpAge International & Handicap International (2014) *Hidden victims of the Syrian crisis: disabled, injured and older refugees* (<https://reliefweb.int/report/syrian-arab-republic/hidden-victims-syrian-crisis-disabled-injured-and-older-refugees>).

crises, time and resources should not pose a significant barrier to collecting assessment data. Where staff have been sufficiently prepared through prior training and sensitisation in disability inclusion, agencies should not face significant methodological barriers – the same methodologies routinely used in vulnerability, needs and protection are needed for disability-focused assessments. As detailed in new guidance on strengthening disability inclusion in HRP, existing assessment frameworks and methodologies can be modified fairly easily to include attention to people with disabilities and the intersectional risks that they face.¹³

Data and information on programming barriers and enabling factors affecting inclusion

Wherever assessments have focused on the needs of people with disabilities, findings highlight significant accessibility and inclusion barriers in humanitarian

programmes that substantially compounded the risks, threats and vulnerabilities experienced by people with disabilities. A recent evidence review¹⁴ uncovered multiple factors limiting and excluding people with impairments from accessing humanitarian services and programming. Furthermore, a 2013 rapid participatory assessment of the situation of people with disabilities among IDP populations in Northern Iraq found that most service providers were passively excluding people with disabilities and identified minimal active inclusion.¹⁵

It follows, therefore, that humanitarian actors need data about their own responses and the institutional barriers and enabling factors within mainstream humanitarian programming to successfully deliver more inclusive programmes. Service accessibility audits and assessment have a key part to play, as does performance monitoring using disability disaggregated data (based on the WG-SS). As highlighted by the IASC Guidelines, donors also have a key role in requiring humanitarian actors to disaggregate data by disability (and sex and age), to deliver results frameworks that include specific outputs or outcome indicators for people with disabilities, and to use resource tracking markers to identify projects that are disability-inclusive.¹⁶

Conclusion

As the quality of the data on people with disabilities in crisis contexts has improved, it has started to reveal that the numbers, needs and barriers affecting people with disabilities are far greater than previously recognised. This challenge has become even more urgent in the context of the Covid-19 pandemic, which introduces a new and potentially devastating intersecting factor of vulnerability for crisis-affected populations.

The needed step-change in disability data collection and analysis and wider strengthening of disability inclusion will not come about simply because the data shows that it should. Substantial investments are needed to equip and resource systems and staff, as well as effective coordination among humanitarian actors in collecting, sharing and using this data. More robust accountability frameworks across the system will also support better inclusion of people with disabilities in humanitarian responses going forward. Humanitarian actors must adopt a fully inclusive approach to the collection of this data and to the decisions and practices informed by it, ensuring that people with disabilities are fully involved at every stage.

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13 DFID Humanitarian Investment Programme (2019) *Guidance on strengthening disability inclusion in Humanitarian Response Plans* (https://reliefweb.int/sites/reliefweb.int/files/resources/Guidance_on_strengthening_disability_inclusion_in_Humanitarian_Response_Plans.pdf): this includes the Multi-Sector Initial Rapid Assessment (MIRA), the Needs Assessments for Refugee Emergencies checklist (NARE/UNHCR), the Vulnerability Assessment Framework (VAF/UNHCR), the Humanitarian Emergency Settings Perceived Needs Scale (HESPER/WHO), the Displacement Tracking Matrix (DTM/IOM), and the JIPS Essential Toolkit (Joint IDP Profiling Service).

14 Holden et al. (2019), op cit.

15 Handicap International [Humanity & Inclusion] (2013).

16 IASC (2019), p.27.

A review of disability and older age inclusion training – what works, what doesn't and what needs to be done

Frances Hill, Jim Cranshaw and Carys Hughes

It is estimated that people with disabilities and people over 60 years of age make up more than 15% and 11% of the world's population respectively.¹ This means that, of the 201 million people affected by disasters and in need of international humanitarian assistance in 2017, just over 30 million were people with disabilities and 22 million were older people. Given this, it is essential that inclusion is prioritised in humanitarian practice.

Progress on inclusion among humanitarian NGOs is, however, patchy and limited – with larger organisations able to invest in a system-wide approach leading the way. Over the past few years, the Age and Disability Capacity Programme (ADCAP), a multi-stakeholder partnership of eight agencies working on these issues, has done a great deal to raise awareness of the need for greater inclusion in all aspects of humanitarian interventions, providing a model, training, toolkits, templates and guidance on best practice.

Inclusion training study

As part of a wider gap analysis around Disability and Older Age Inclusion (DOAI), a top-line scoping study focusing on training was commissioned by HelpAge International as part of the Elrha Humanitarian Innovation Fund's Thematic Working Group on Disability and Older Age Inclusion in late 2019. The study sought to scope out the DOAI training landscape, highlight gaps and identify what type of training participants felt had more impact, greater reach or better outcomes. The study does not claim to be comprehensive (in the time available, we identified 42 training initiatives and conducted 15 interviews). It was designed instead to present a sample and cross-section of some of the training currently being offered, available in the public domain and within a selection of humanitarian agencies. The aim is to provide donors, grant-makers, Organisations of People with Disabilities (OPDs) and Older People's Associations (OPAs), as well as other agencies engaged in the humanitarian sector, a sense of what type of training initiatives are most effective, where resources can be accessed, and what the gaps in provision are and what could be done to fill them. Using desk and online research and key informant interviews, we built a matrix of which training addressed each of the Humanitarian Inclusion Standards to get a sense of either over- or under-provision. The report is designed to be a living document that it is hoped will grow into a useful resource on inclusion-relevant training.

Box 1 Types of training

- Face-to-face – usually workshops over several days.
- E-learning (self-directed) – short courses of between 30 minutes and three hours.
- E-learning as part of a wider curriculum – again, short courses under a curriculum umbrella containing a series of shorter elements.
- In-house – not publicly available, with the aim of being more embedded at all levels within an organisation and with greater awareness of intersectionality rather than a single-issue disability focus (such as CAFOD's SADI approach (see p. 43 in this issue).

Challenges

1. Lack of sufficiently disaggregated data.
2. Coherence and communication.
3. Staff turnover and lack of institutional memory.
4. Not enough training materials or guidance in local languages.
5. Role of local and national government agencies.
6. Role of caregivers.
7. Political will.
8. Gaps in provision.
9. Mental health and psychosocial needs are very poorly addressed across the board.
10. Lack of resources.

Findings

The report identified four principal types of training and 10 challenges (see Box 1, and refer to the report itself for a more in-depth analysis around each of the 10 challenges).² Here we discuss those challenges that are currently more overlooked than others. For example, data disaggregation has long been acknowledged as a major constraint to identifying older people and people with disabilities and addressing their specific disability needs, whereas to be truly effective at the OPD level, resources need to be translated into or co-created in local languages and accessible formats – a resource-intensive process that donors frequently overlook.

1 Age and Disability Consortium (2018) Humanitarian inclusion standards for older people and people with disabilities (www.helpage.org/resources/publications/?ssearch=standards&adv=0&topic=0®ion=0&language=0&type=0).

2 See www.elrha.org/researchdatabase/review-of-training-for-the-inclusion-of-people-with-disabilities-and-older-people-in-the-humanitarian-sector/.

Box 2 The ADCAP 'model'

Training was conducted using the 'Inclusion of Age and Disability in Humanitarian Action' resources. This took the form of a two-day workshop drawing on resources produced by RedR: a Learner's Workbook, a Training Handbook and a Training Slideshow.

Eight inclusion advisers were recruited into each of the eight ADCAP agencies (Islamic Relief Worldwide UK, Islamic Relief Pakistan, Christian Aid International UK, Christian Aid Kenya, Kenya Red Cross Society, CBM Kenya, HelpAge International Pakistan and Concern Worldwide Pakistan). The advisers were supported through e-learning modules and webinars developed by DisasterReady.org, as well as face-to-face training of trainers to help them identify barriers and opportunities, influence and manage change and, crucially, develop organisational action plans.

The advisers then went on to lead training and change processes within their own and partner organisations. This involved carrying out organisational assessments identifying areas where policies on inclusion were weak, and recommending areas for improvement. Coaching and mentoring support was provided to and by the advisers during this process.

One of the key summaries of good practice (4.8 develop inclusion competency of staff involved in humanitarian action) recommends that organisations adopt the ADCAP Inclusion Advisor model using ADCAP's tools, training and face-to-face training of trainer models to embed inclusion within their organisations. This is a resource-intensive model, and so needs buy-in from senior managers wishing to move beyond a tick box approach and see this as a 'have to have, rather than a nice to have', as one of our interview respondents put it.



Barangay Catmon risk map
NASSA/CARITAS Philippines

Discussion

In the humanitarian sector, the inclusion agenda is mainly being taken forward by key individuals within organisations focusing on a particular group, such as older persons and persons with disabilities. There is limited buy-in from colleagues in other departments (programmes, finance, human resources), other aid organisations, donors, governments of crisis-affected countries and UN agencies.

Although departmental silos exist within most organisations, it is possible to overcome them. One member of the ADCAP programme, Islamic Relief, did this by sensitising, training and building the capacities of staff at different levels, aiming to integrate inclusion throughout all departments. The organisation gradually built a cadre of champions who now sustain this work. Once monitoring and evaluation staff were involved it was relatively straightforward to reframe the organisation's work for more nuanced data disaggregation to reflect the more detailed reality of people with disabilities and older people in order to bring about more effective humanitarian action – whether disaster risk reduction (DRR), response or recovery (see Box 2 for more detail on the ADCAP model).

There is a need both for humanitarian agencies to be more inclusive, and also for 'inclusion specialist' organisations to be more aware of humanitarian policies and practice in order to identify key points during the humanitarian cycle where their input would be most effective. Much of the training we identified focuses on disaster risk reduction (DRR), rather than actual humanitarian response, so this is one area that could be strengthened. The ADCAP model has the potential to bring about greater coherence in terms of inclusion

sensitivity and awareness, but does not address the need for inclusion specialist agencies to be more aware of the policies and practice of humanitarian response.

One interviewee suggested that, while it may have been necessary in the past to focus on a single issue or identity category – such as disability or older age – we now need to view inclusion through an intersectional lens, recognising that each individual has multiple intersecting and overlapping identities and characteristics, including age, (dis)ability, gender, sexuality and ethnicity. This dovetails well with the trend towards more user-centred programme design.

Communication and training materials

Communication and training materials need to be contextualised and translated into local languages to improve understanding and uptake of inclusion principles and approaches. HelpAge International Pakistan has worked to reach communities in remote areas by advertising for positions via text message and developing communication guidelines in local languages. This helped staff to better understand the barriers faced by people with disabilities and older people in these communities. However, this is also a resource-intensive activity, and many interviewees noted that most inclusion materials were only available in English, with a few recently available in French and Arabic.

Role of local and government agencies

Not involving the government/state sector was seen by some as the biggest obstacle to mainstreaming and sustaining inclusion work. The Special Talent Exchange Programme (STEP) in Pakistan included government actors and promoted inclusion within the country's National Disaster Management Agency (NDMA) from the outset. This brought inclusion standards into government practice, particularly in DRR work. However, there is a concern that, once the two-year funding window is closed, and with continuous staff turnover, momentum around inclusion mainstreaming within the NDMA could falter. If each inclusion drive culminates in the funding of a one-off, one- to two-year INGO project, the agenda will certainly struggle to gain traction across the sector.

In most countries, NDMAs need more information and analysis about the specific and various needs of people with disabilities and older people in preparing for, and responding to, emergencies which particularly affect these groups. In some cases, once a person with disabilities reaches the age of 60, they are then viewed as an older person and treated accordingly. Their specific disability becomes invisible to the systems in which they find themselves, so a more holistic, user-centred approach of intersectionality is required. One initiative in the Philippines has started to do this (see Box 3) – working in a highly inclusive and participatory way at Barangay level and digitising the results so that local front-line responders know which households are most vulnerable.

Box 3 Case study: NASSA/CARITAS Philippines

NASSA/Caritas in the Philippines has mapped over 260 Barangays in enormous detail – both physically and digitally – down to the number of livestock and forms of livelihood, as well as identifying households with people with disabilities and older persons. This provided information as to where the most vulnerable elements of the population were, enabling them to be reached first. It was also an important innovation in getting local government departments to engage and see the value of such detailed data sets for DRR.

'I saw it as an urgent need for us to be able to provide baseline demographical data to our partners, especially those in the local government units. You see, our public officials would readily believe something when presented with imaginable data sets' (J.D. Melendrez, MEAL Officer, Caritas Palo, Philippines).

In India, it is at the District, rather than the community level, where there is a lack of awareness around inclusion issues and their importance for a more resilient society as a whole. For example, one interviewee noted that 'at the local level the frontline responders are "street smart"; they know what needs doing and have a rough idea where the more vulnerable might be', so are able to act more immediately and effectively. District-level governments have decision-making power in allocating resources, so raising awareness at this level could enable more funds to be more effectively directed towards inclusion activities. One assessment of how older people were affected by floods in Kerala highlighted a lack of data within local government on the number, location and overall condition of older people, hampering efficient evacuation. Had local district institutions completed vulnerability maps, such as those conducted in the Philippines described above, a more targeted and effective response could have been implemented.

In Gaibandha in Bangladesh, CBM piloted a model for disaster risk reduction, which integrated work with all relevant stakeholders building on existing, embedded structures of organisation already in place, believing this to be a more sustainable approach. As there were no OPDs in Gaibandha, and most people with disabilities lived in isolation and rarely participated in community life, interventions were implemented at three levels: household, community and municipal. Self Help Groups (SHGs) comprising household participants selected representatives to participate in the community-based Ward Disaster Management Committees (WDMC), ensuring a coherent, highly participatory and inclusive structure. Different types of training for each intervention level were built into the programme. SHGs, for example, received training on disability rights, relevant legislation, government structures and how to lobby and advocate.

Inclusion will not happen unless it is sufficiently resourced, and those funding DRR, response and recovery programmes need to recognise and act on this. Different means of communication are required, and older people and people with disabilities are harder to identify because of stigma or a desire not to be labelled, or are kept out of sight by other family members and care-givers. Changing long-established forms of provision and making allowances for different types of disability or for older people needs both time and money. Introducing inclusive measures at the start of a programme is cheaper than retrofitting, and some donors are now asking specifically how inclusive programmes are, with reporting against these and separate sections in grant funding proposals. However, many of these requirements refer to people with disabilities and not older people, where there is a real gap. There also needs to be a shift towards more integrated reporting that moves away from inclusion as a tokenistic add-on, to be ticked in a box on a form. This problem is not specific to the humanitarian sector, and is common in development-oriented proposals and reporting.

One of the main gaps we found was around data, which is a well-recognised and acknowledged problem. Data collection depends on organisations' front-line staff. If these staff are not sufficiently trained in how to work with communities to identify people with disabilities and older people, if they cannot communicate with them or if they have culturally embedded biases and prejudices, this is a major block to understanding the scale of the issue, and formulating an effective DRR or response strategy. By involving people with disabilities and older people and enabling them to express their needs and requirements, a more coherent approach can be designed. It is important to note that effective communication is not just about language – it can also require different types of organisations with different operational cultures and values seeking to understand each other. As in many other areas, programmes should be owned and funding streams controlled by local and national organisations and integrated with local and national government agendas. They should build on existing community infrastructure, rather than being dictated and designed by those not affected by the issues that need to be addressed.

Conclusion

A series of recommendations emerged from the findings:

1. Donors could provide an additional percentage, over and above programmatic costs, for inclusive capacity-building within their grantees' organisations.

2. Build up a community of practice to share learning and experiences of, in particular, the larger agencies implementing the more intersectional/user-centred approaches.
3. Provide a portal for all inclusion training resources as a 'one-stop-shop'.
4. More resources to be made available at a local level.
5. Increase awareness of humanitarian structures, policies and processes on the part of inclusion-specific agencies.
6. Assessing the reality and identifying during which phases of the humanitarian cycle the humanitarian inclusion standards can be operationalised most effectively.
7. More emphasis on the barriers faced by older people.
8. More research around the role of care-givers as both enablers and obstructers.
9. People with disabilities and older people design and facilitate training for greater transformative change.
10. Follow up training with organisational change processes.

While everyone working on these issues acknowledges that not enough is being done, some areas – such as the lack of resourcing and inadequate data disaggregation – have received more attention than others. Findings from our report highlight that sustainable change needs a combined approach which is demand-led from Southern OPDs, includes locally owned approaches to population mapping, and integrates with national government disaster response agencies. There needs to be a recognition among INGOs that inclusion has to become part of their core business, whatever their focus. This means embedding sensitisation and training programmes into every staff member's induction processes – from field level to HQ. Inclusion has to move away from being retrofitted as an add-on with a few mandatory tokenistic hour-long online courses, towards the normal way INGOs, national NGOs and local community organisations conduct their work. Donors have a vital role to play, and many are starting to incorporate inclusion criteria into their programmes. However, it is not enough to insist that organisations embed inclusion into their programmes; donors need to recognise that this takes time and resources, and should make funds available for all organisations to train and sensitise their staff at all levels, not just as part of a particular funded project or response.

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What does the evidence say? A literature review of the evidence on including people with disabilities and older people in humanitarian response

Sophie Van Eetvelt, Dr Manjula Marella, Lana Logam and Dr Alex Robinson

In 2016, the Grand Bargain recognised the need to increase effectiveness in the humanitarian ecosystem through better use of evidence. Humanitarian actors are increasingly recognising that evidence from quality research should be central to decision-making at all stages of humanitarian response.¹ At the same time,

there has been increasing attention on who is excluded or 'left behind'. Numerous surveys and reports tell us how people with disabilities and older people are often overlooked, and their rights and agency not recognised.² It is now widely acknowledged that people with disability and older people are disproportionately impacted by



Members of Organisation of Persons with Disabilities-OPDs (wearing khaki vest) delivering hygiene promotion session for community members of Mantikole Village in Sigi, Central Sulawesi. Local OPDs are ASB Indonesia and the Philippines main partners in delivering inclusive humanitarian assistance particularly in WASH services, including for the tsunami and earthquake affected community in Central Sulawesi, Indonesia.

Credit: Dwi Oblo/ASB Indonesia and the Philippines

1 See <https://evidenceaid.org/resource/evidence-based-humanitarian-action-is-the-humanitarian-sector-serious-about-evidence-geneva-28-march/>

2 Holden, J. et al., *Disability Inclusion Helpdesk Report No. 9*, 2019 (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/833579/query-9-evidence-humanitarian-response1.pdf); HelpAge, *Missing millions: how older people with disabilities are excluded from humanitarian response*, 2018 (www.helpage.org/newsroom/latest-news/millions-of-older-people-with-disabilities-risk-being-excluded-from-humanitarian-assistance-new-helpage-report-reveals/); Light for the World, *Aid out of reach: untold stories from people with disabilities*, 2020 (www.light-for-the-world.org/aid-out-reach-untold-stories-people-disabilities).

disasters, conflict and humanitarian crises. However, while much has been done to promote rights-based inclusion in humanitarian response, the inclusion of people with disability and older people remains an under-prioritised or emerging area of work.

As part of a commitment to supporting problem-led and evidence-based innovation, Elrha's Humanitarian Innovation Fund (HIF) commissioned a Gap Analysis on the inclusion of people with disability and older people in humanitarian response. The study aims to understand the evidence base on inclusion and contribute to more effective and inclusive response. The work has been led by the Nossal Institute for Global Health at the University of Melbourne, supported by Arbeiter-Samariter-Bund's Office for Indonesia and the Philippines (ASB).

The first of two reports from the Gap Analysis, published in July 2020, summarises the findings from academic and grey literature reviews.³ The second and final report, which will include the findings from all components of the Gap Analysis, will be published in September 2020.

Method

For the initial report, reviews of academic and grey literature drew on systematic review methods. Reviews were conducted separately for people with disability and older people to ensure that a wide body of evidence was identified. Only articles published in English between the start of January 2010 and the end of January 2020 were included. More than 23,000 articles were identified from a range of databases; 337 full-text articles were screened, and 74 were included in the final mapping.

A thematic analysis was completed to organise and map the articles. Both disability and older age articles were mapped across two sets of categories. The first set is based on the Humanitarian Inclusion Standards for Older People and People with Disabilities (HIS).⁴ The second is based on humanitarian sectors or areas of work, including shelter, water, sanitation and hygiene (WASH) and health. This provided a practical overview of how evidence is distributed across areas of humanitarian practice and facilitated the identification of key gaps. We also hope that, by aligning to existing standards, this review will aid coordination and collaboration to address the gaps.

Summary of disability evidence mapping

Overall, disability articles were widely dispersed across the nine HIS. Most of the disability articles were from peer-reviewed journals (35 out of 46). No evidence was identified under building resilience and preparedness through humanitarian action (HIS 3) for people with disability. Very little evidence was identified on the meaningful participation of people with disability (HIS 4), inclusive mechanisms for feedback and complaints (HIS

5) by people with disability, and coordination of inclusive humanitarian assistance (HIS 6). By sector, very little evidence was identified on disability inclusion in WASH in humanitarian settings and in camp management. No evidence was identified relating to disability inclusion in food security or logistics.

Most disability articles related to access to humanitarian assistance (HIS 2), followed by organisational learning for inclusive humanitarian assistance (HIS 7). By sector, most articles related to communications and to health. Limited evidence was found on data and identification of people with disability (HIS 1), on staff and capacity (HIS 8), or on managing resources for inclusive humanitarian assistance (HIS 9).

Summary of older age evidence mapping

Fewer articles were identified on the inclusion of older people in humanitarian response compared to the inclusion of people with disability. Most articles addressing the inclusion of older people were from peer-reviewed journals, with the exception of those on access (HIS 2), which were mostly from grey literature.

As with disability, no evidence was found on building resilience and preparedness through humanitarian action (HIS 3); on the meaningful participation of older people (HIS 4); on inclusive mechanisms for feedback and complaints (HIS 5) by older people; or on organisational learning for inclusive humanitarian assistance (HIS 7). As with disability, most older age articles related to access to humanitarian assistance and accessibility (HIS 2), followed by managing resources for inclusive humanitarian assistance (HIS 9). Limited evidence was identified on data and identification of older people (HIS 1), coordination of inclusive humanitarian assistance (HIS 6), and staff and capacity (HIS 8) respectively.

Most articles addressing the inclusion of older people did not have a specific sector focus. Those that did looked most frequently at shelter, camp management, communications and health. Very little evidence was identified for food security, logistics or WASH. In comparison to the sectors identified for disability, no older age articles were identified under protection.

Key findings

This article provides a summary of overall findings. Please refer to the full report for more detailed findings, including under individual HIS categories.

The current evidence base on the inclusion of people with disability and older people in humanitarian response is highly diverse in terms of research topics, approach, quality and scope. Evidence is spread broadly and there is little depth of quality evidence for any sector under

³ The initial report is available at: www.elrha.org/researchdatabase/gap-analysis-humanitarian-inclusion-disabilities-older-people-literature-review/.

⁴ Age and Disability Consortium (CBM, HelpAge, Humanity & Inclusion), *Humanitarian inclusion standards for older people and people with disabilities*, 2018 (<https://reliefweb.int/report/world/humanitarian-inclusion-standards-older-people-and-people-disabilities>).

any HIS. Despite growing awareness of the importance of inclusive humanitarian response, there is limited evidence that people with disability and older people are being included. There is also limited evidence on institutional barriers to the inclusion of people with disability and older people in response, or on why known inclusion principles and approaches are not being widely adopted.

Most of the literature notes an absence of inclusive interventions and little critical analysis on the use and effectiveness of existing inclusive approaches. There is also no clear evidence on the positive impacts or outcomes for people with disability and older people resulting from inclusive humanitarian response. No evidence relating to the costing of inclusion or cost-benefit analyses on interventions was found, and there was limited evidence on the effective use of data to improve inclusion in humanitarian response.

Although a large number of articles argue for the importance of inclusion, the humanitarian sector generally has an outdated understanding of disability and tends to approach it from a medical, rather than a social or rights-based, perspective. The medical model of disability focuses on the individual and their impairment, in contrast to the social model, which emphasises the removal of barriers in society to ensure inclusion.

The disability literature notes the importance of engaging with representative organisations of people with disability (OPDs). No mention of an equivalent mechanism or approach to engaging with older people was identified. Humanitarian actors may also assume a link between social standing and older age. There is evidence of a tendency to identify, and coordinate with, 'elders' who may not represent older people more broadly. There is also a lack of nuanced understanding and critical analysis of the diversity of older age beyond 60.

Overall, evidence on the intersectionality between disability and older age, and other identity characteristics, was limited. A few articles addressed specific groups, such as women with disability, but there was little detailed gender analysis and almost no evidence analysing how other characteristics, such as race, ethnicity or class, may interact with disability or older age.

Finally, with the exception of Deaf researchers, there was a lack of research led by people with disability or older people themselves.

Where are the gaps?

The gaps in evidence identified in the literature reviews indicate where additional research, resources and policy could be targeted. Distinct gaps were found for individual HIS categories; further information can be found in the full report. Here we provide some highlights we feel are particularly relevant for further research and potential for innovation.

Under HIS 1, on data collection and identification, a key evidence gap was around the identification or development of data collection tools to measure barriers to participation in response. The focus to date has been on tools, such as the Washington Group Questions, to identify individuals with disability. However, these tools alone provide little information on participation or the barriers that prevent it. There was also a lack of evidence comparing people with disability with people without disability. Aside from diagnostic health tools, no tools to identify the specific needs of older people in response were identified.

The largest number of articles related to access and accessibility (HIS 2) for both disability and older age. However, these tended to be broad in nature and lacked specifics. Little evidence was found on the access and particular support needs of people with disability or older people of different ages. Further gaps included understanding the long-term sustainability of interventions initiated during response to improve access. There is also a need for more effective strategies to promote independence for people with disability and older people when established support networks and systems are disrupted or absent.

No articles were found on building preparedness and resilience through humanitarian response (HIS 3).

In terms of meaningful participation (HIS 4), an important gap is understanding the roles of, and challenges experienced by, representative organisations of people with disability and older people in facilitating participation. One of Elrha's current challenges is looking to support innovative mechanisms for meaningful participation and innovative methods to assess its effectiveness. Leadership or partnership with an OPD or Older Person's Association (OPA) is mandatory for this challenge. We hope this innovation challenge may contribute to filling the evidence gaps on meaningful participation and the roles of OPDs and OPAs.

HIS 5 is dedicated to inclusive mechanisms for feedback and complaints. There is a key gap around how, and in what circumstances, to apply existing and emerging technologies to improve people-centred feedback mechanisms. Similarly, more understanding is needed on how the social (human interaction) aspect of technology-based systems may affect adoption and use by people with specific information access needs.

There was very little evidence on coordination of humanitarian assistance under HIS 6. Gaps included understanding how OPDs and people with disability may most effectively contribute to coordination mechanisms to improve inclusion, and where key entry points may be. There is also limited evidence on the role and effectiveness of formal and informal coordination mechanisms in improving inclusion for older people and people with disability in response at all levels.

From the nine articles identified on organisational learning for inclusive humanitarian assistance (HIS 7), key gaps include the effectiveness of approaches to ensuring disability inclusion in response beyond voluntary commitments, for example consideration of mandatory codes of practice at international or national levels. Additionally, more evidence is needed on how to overcome institutional perceptions that inclusion is the responsibility of specialist agencies, and that barriers to inclusion are only physical.

Under HIS 8 on staff and capacity, there are gaps in understanding the effectiveness of different approaches to training and capacity-building for inclusion. Alternatives to formal training, such as mentor and resource networks, are not well-explored. There are gaps in the provision of training on the specific needs of people with diverse disabilities and older people, in addition to inclusion in general.

Lastly, on managing resources (HIS 9), key gaps include assessing the advantages of deploying multidisciplinary teams with shared responsibilities for inclusion of people with disabilities and older people across sectors. This is in contrast to individual or sector-specific focal points for inclusion. In general, there are significant gaps in understanding the costs and resourcing requirements to effectively ensure inclusion in specific sectors, and that specific needs are met.

Reflections on the evidence

While there is increasing awareness of the need for inclusion, practice continues to lag behind. This is despite the increase in publications, including guidelines, on the inclusion of older people and people with disability in humanitarian response in recent years. Further, there is a growing body of evidence on the impacts of humanitarian crises and disasters on older people and people with disability. Yet the inclusion of people with

disability and older people is still not common practice in humanitarian action.

The evidence highlights a need to look beyond general approaches to improving access and consider what institutional or structural changes may be required across the humanitarian system. Examples include shifting the understanding of humanitarian actors towards social and rights-based approaches to inclusion; increasing staff skills and capacities beyond raising awareness on the importance of inclusion; and mandating, and requiring accountability for, the allocation of resources at all levels of management and coordination. Viewed across sectors, the evidence clearly points to this being an emerging area of work, and supports the need for increased investment in inclusive practice and related research.

This article provides a summary of findings: further detail is available in the full report. The second report will build on the evidence from the literature reviews and explore the extent to which humanitarian actors and other stakeholders are using available information and resources. We intend for this research to become a foundational resource to ensure that the innovation we support is problem-led and addresses gaps in evidence. We hope the wider humanitarian community will similarly benefit from these findings.

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'He who lives in the attic knows where the roof leaks': lessons from a disability audit in north-east Nigeria

Kirsty Smith

Despite the humanitarian principle of impartiality, by which assistance is meant to be provided based on need, much humanitarian support still does not reach those worst affected by crises. The needs and capacities of people with disabilities and older people continue to be systematically overlooked by the humanitarian system, with low levels of awareness and limited capacity among humanitarian actors and inadequate action plans or budgetary allocations by implementing agencies.

Recognising this, the UK Department for International Development (DFID) commissioned CBM and Nigeria's Joint Association of Persons with Disabilities (JONAPWD) to carry out an audit of four humanitarian projects funded through the five-year North East Nigeria Transition to Development (NENTAD) programme, designed to support the transition from humanitarian aid to early recovery programming.¹ As such, the programme offers a particularly interesting angle through which to

¹ More details of this DFID-funded humanitarian response programme can be found at <https://devtracker.fcdo.gov.uk/projects/GB-GOV-1-300432>.



David Undie, a person with disabilities, using an accessible hygiene facility in Nigeria
United Purpose/Jason Florio

explore the barriers preventing people with disabilities from being included in and benefiting from responses in a post-humanitarian setting.

Using the lens of the recently published Humanitarian Inclusion Standards (HIS), developed by the Age and Disability Capacity Programme (ADCAP) in 2018,² the review sought to assess the extent to which people with disabilities and older people were systematically and consistently included in the response provided by DFID's NENTAD partners. The findings and subsequent recommendations were published in three documents: a partner-focused report with organisation-specific recommendations which implementing partners could use to develop workplans with CBM support; an anonymised report with summary findings relevant for

all humanitarian actors in Nigeria; and a policy brief for use by all humanitarian actors seeking to provide a more inclusive response.

Frameworks for inclusive humanitarian response

The UN Convention on the Rights of Persons with Disabilities (UNCRPD), the Sendai Framework for Disaster Risk Reduction 2015–2030 and the Humanitarian Disability Charter provide a clear legal and policy framework underpinning the commitment of the humanitarian community to include persons with disabilities and older people. Articles 11 and 32 of the UNCRPD³ require that persons with disabilities benefit from and participate in disaster relief, emergency

2 The Standards seek to address gaps in understanding the needs, capacities and rights of older people and persons with disabilities, and to promote their inclusion in humanitarian action at all stages of the project cycle. For more details see: www.helpage.org/what-we-do/emergencies/adcap-age-and-disability-capacitybuilding-programme/.

3 See for instance *International agreement on the rights of disabled people* (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/345108/easy-read-un-convention.pdf) and *Handbook on the human rights of persons with disabilities*, July 2010 (HI) (www.internationaldisabilityalliance.org/UnderstandingtheCRPDHandbook).

response and disaster risk reduction strategies. The Sendai Framework⁴ reinforces the message that disability inclusion is crucial in all phases of humanitarian response, including disaster risk reduction – preparedness, prevention and mitigation – along with disaster relief, rehabilitation and recovery. In addition, it uses disability-inclusive language and introduces the principle of an inclusive ‘Build Back Better’ approach, which uses the reconstruction and recovery period as an opportunity to address and rectify vulnerabilities and exclusions in communities. The Charter on Inclusion of Persons with Disabilities in Humanitarian Action⁵ commits to ensuring non-discrimination, fostering participation, developing inclusive policies and guidelines, developing inclusive responses and services and improving cooperation and coordination. Yet despite these overarching frameworks, there is often little clarity on how to develop inclusive policies, systems and processes, and a subsequent lack of practical application.

Nigerian context

In Nigeria, disability is not seen as a human rights issue but viewed in terms of charity and welfare.⁶ As in many African societies, the traditional response to social care needs, where care is provided by family and (social or religious) community members, is being challenged by rapid and profound social change. The government is struggling to fill the gap, and limited resources, inadequate management and a lack of legislation mean that social care provision is not available to persons with disabilities. There is also a high degree of exclusion and stigma associated with disability,⁷ with charity and medical approaches to disability still highly prevalent at all levels of society.

The exclusion of persons with disabilities is further exacerbated by a complex humanitarian context and insecurity in the north-east, which has been the scene of hostilities between military forces and non-governmental groups since 2009. The international humanitarian response has been slow; the large-scale response now in place dates from late 2015. Security has often overshadowed other considerations for implementing agencies, diverting time and attention away from developing inclusive practices more widely.

Findings of the review

DFID is committed to ensuring that humanitarian action leaves no one behind and is fully inclusive, as described in the fourth pillar of its disability inclusion strategy.⁸

However, the findings of the NENTAD review make it clear that more action is urgently needed. Additional funding and capacity, the development and implementation of organisational policies and advance preparation are all vital to assist frontline actors and communities affected by armed conflict, disasters and other humanitarian emergencies to coordinate, plan, implement, monitor and evaluate essential actions for disability inclusion across all sectors of humanitarian response.

Despite genuine openness to inclusion on the part of NENTAD partners, basic understanding of inclusion is often lacking, and misconceived and negative assumptions around disability are common among humanitarian actors. This is compounded by high staff turnover, particularly related to temporary emergency surge deployments. In north-east Nigeria, where none of the humanitarian organisations operating today was present prior to the outbreak of the current crisis, mainstream organisations often struggle to find disability expertise at field level. Most staff have had little exposure to humanitarian principles, disability inclusion or the international policies described above. There is an urgent need for capacity-building, developing knowledge and understanding on disability issues among staff in mainstream humanitarian organisations, communities, service staff and government workers. Preparedness is essential, which means investing in the capacities of humanitarian staff and organisations representing of persons with disabilities before a crisis occurs.

This may require donors to support technical advisory resources within implementing partners and their own country offices, with responsibility for cross-cutting issues such as disability inclusion. This function may be funded through a combination of core funding and cross-charging across multiple projects. In addition, after a period of some agencies investing heavily in developing policies and tools on inclusion, it is critical to invest equally in the promotion and dissemination of these tools so that they are embraced by all staff, including senior leadership.

The cluster system and key humanitarian coordination agencies should be engaging with specialist local and international agencies in their responses. In north-east Nigeria there has been very limited attention paid to disability inclusion across the humanitarian clusters, and there is a need for opportunities for humanitarian stakeholders to share challenges and good practice. This participation could be organised through regular liaison with organisations of people with disabilities (OPDs).

4 The Sendai Declaration is here: www.unisdr.org/files/43300_sendaideclaration.pdf. The Framework has seven targets and four priorities for action. It was endorsed by the UN General Assembly following the 2015 Third UN World Conference on Disaster Risk Reduction.

5 The Humanitarian Disability Charter is available at: <http://humanitarianandisabilitycharter.org/>

6 See the full report commissioned by DFID in 2008 and realised by the Leonard Cheshire Disability and Inclusive Development Centre with the support of JONAPWD: *Scoping study: disability issues in Nigeria* (<https://studylib.net/doc/13390397/scoping-study--disability-issues-in-nigeria-final-report>).

7 E. Etieyibo and O. Omiegbe, ‘Religion, culture, and discrimination against persons with disabilities in Nigeria’ *African Journal of Disability* 5(1), 2016 (<https://ajod.org/index.php/ajod/article/view/192>).

8 As well as the DFID strategy on disability inclusion (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/760997/Disability-Inclusion-Strategy.pdf), the NENTAD Business Case mentions two commitments on disability. See also DFID’s *Humanitarian guidance note: ageing and disability in humanitarian response* of November 2015 (<https://inclusion-international.org/wp-content/uploads/2015/11/DFID-Humanitarian-Guidance-Note-Ageing-and-Disability-in-Humanitarian-Response-copy.pdf>).

Strengthening collaboration between mainstream INGOs and disability-specific agencies, as well as OPDs, could bring a mutual learning exchange and contribute to more effective and inclusive aid delivery.

Women and men with diverse disabilities should be active participants in the humanitarian response, including opportunities to assume leadership roles, as they understand the context, can identify their needs and know their own capacities – ‘He who lives in the attic knows where the roof leaks’.⁹ However, most OPD members do not have experience of working with INGOs in humanitarian contexts, and may not be confident interacting and engaging with them, leading to misunderstandings and making cooperation uncertain and complicated. Current initiatives to strengthen OPDs do not go far enough, and have not equipped their members with the required skills for taking up leadership roles in humanitarian response. The Bridge Training Module on Article 11 of the CRPD (see pp. 13– 16 of this edition)¹⁰ is a step towards addressing this gap. Humanitarian coordination agencies should consider working with the International Disability Alliance (IDA) and the International Disability and Development Consortium (IDDC) to ensure that this training, or similar, continues to build the skills and confidence of participants with disabilities to ensure that their voices are heard in decision-making.

Data collection, particularly disaggregated data on gender, age and disability, has the potential to identify adaptations and address barriers that could exclude persons with disabilities, as well as identifying intersectionalities that might lead to double discrimination. Implementing partners need support to ensure disaggregated data is not only generated but also used in an appropriate and robust way. The ground is currently incredibly fertile for DFID and other donors to provide practical, context-specific technical support to partner organisations. Partners have made some progress in this area, but need further guidance. The appointment of dedicated Humanitarian and Development Disability Advisors within donor country offices would be a very valuable step in providing technical support, which could focus on networking to share learning experiences, translating Washington Group Questions¹¹ into local languages and forming links with organisations experienced in the area.

A twin-track approach to disability inclusion removes the barriers that prevent the full participation of persons with disabilities in mainstream humanitarian programmes at the same time as addressing their

immediate, specific needs (such as replacing assistive devices or the provision of specific medical services). Donors applying the twin-track approach need to build inclusion considerations into funding mechanisms to ensure a disability-inclusive approach to budgeting. This supplements mainstream humanitarian funding with a complementary disability pool fund for empowerment work and capacity-building with OPDs, plus cross-cutting adaptations and accessibility measures to ensure equal access to the response. This could be articulated in the Humanitarian Response Plan (HRP).

Building on recent positive policy developments in Nigeria, such as the signing into law of the Discrimination Against Persons with Disabilities (Prohibition) Act 2018, there are opportunities to change attitudes, reduce stigma and raise awareness of the rights of people with disabilities. The review revealed that stigma and exclusion remain a common experience for people with disabilities, and this is reinforced during conflict and emergencies. It is not only the attitudes of family members, caregivers and members of the community that may contribute to the marginalisation of persons with disabilities, but also the attitudes of humanitarian workers, staff in public services such as schools and health centres, as well as policy-makers and grant allocators in government departments. NENTAD partners have implemented awareness-raising programmes with public sector workers and advocacy initiatives seeking to change infrastructure. By showing good examples of inclusion, local partner staff can build awareness among decision-makers and civil servants regarding inclusive approaches, including the need for accessible public spaces.

Humanitarian response cannot achieve its purpose of providing assistance and protection to all people according to need, and without discrimination, if it continues to exclude the needs and capacities of some of the most vulnerable and marginalised people in the world.¹² The north-east Nigeria example shows that each key stakeholder in the humanitarian community – donors, implementing agencies, coordination bodies and government agencies – has a vital part to play, but that this must be in partnership with persons with disabilities and their organisations. Working together can make humanitarian assistance inclusive and accessible, and as a result impartial and effective. Investing in disability inclusion ahead of time helps address the challenge of limited capacity and knowledge, the lack of policies and structures and inadequate financial architecture prior to a crisis.

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⁹ Nigerian proverb.

¹⁰ For more information about the BRIDGE training see IDA’s website: www.internationaldisabilityalliance.org/bridge-art-11-global-training-call.

¹¹ See www.washingtongroup-disability.com.

¹² The IASC Guidelines on inclusion of persons with disabilities in humanitarian action (2019) outline actions that humanitarian actors must take in order to respond to the needs and rights of persons with disabilities who are most at risk of being left behind in humanitarian settings. See <https://interagencystandingcommittee.org/system/files/2019-11/IASC%20Guidelines%20on%20the%20Inclusion%20of%20Persons%20with%20Disabilities%20in%20Humanitarian%20Action%2C%202019.pdf>.

Strategic partnerships and disability-inclusive humanitarian action: the Rohingya refugee response in Bangladesh

Carolin Funke

Following the influx of 745,000 Rohingya refugees into Cox's Bazar in Bangladesh in late 2017, hundreds of international and national organisations set up operations to provide protection, food, water, shelter, education, health care and other essential assistance. Most initially overlooked the rights and specific requirements of persons with disabilities. Distribution points, safe spaces for women and children and service and sanitation facilities in the camps are difficult to access or operate for people with physical impairments. Buildings have steps and narrow entrances and latrine blocks are too narrow to accommodate a support person. Stigma and discrimination within the Rohingya community mean that persons with disabilities rarely leave their improvised shelters and are in effect invisible, exacerbating their vulnerability and exposing them to increased protection risks, exploitation and abuse.

Against this background, disability-focused organisations play a vital role in promoting the inclusion of persons with disabilities. In the early phase of the crisis, these organisations mainly delivered targeted assistance, for example assistive devices and rehabilitation services. Since 2019, however, cooperation with mainstream organisations has increased; coordination mechanisms include persons with disabilities in their activities, partnerships have been established with UN agencies, and consortia projects with international and national NGOs are building capacity and promoting sustainable changes in organisational practice. In 2018, Humanity & Inclusion (HI), CBM, the Centre for Disability in Development (CDD) and HelpAge International founded the Age and Disability Working Group (ADWG). From this year the ADWG is operating under the Protection Working Group led by the UN High Commissioner for Refugees (UNHCR). A formal collaboration framework specifies the conditions of the cooperation between the working group and the ADWG, and grants the ADWG observer status within the working group task team.

Although it is still too early to evaluate the long-term impact of these partnerships, they have the potential to facilitate the inclusion of persons with disabilities and contribute to change in humanitarian practice. Field research in Cox's Bazar in 2020 reveals notable progress in data collection and analysis, the removal of physical barriers and the participation of persons with disabilities in the humanitarian response.



Women's Skill Development Centre for women with and without disabilities
Carolin Funke

Data collection and analysis

In 2020, the protection working group declared the inclusion of older persons and persons with disabilities a core priority. However, important data gaps on disability persist, including disability prevalence and the needs of and barriers faced by persons with disabilities. The 2019 joint government–UNHCR registration exercise, for example, relied on a binary 'yes-no' question to estimate the proportion of persons with disabilities in the camps. Not surprisingly, it found that just 1% of refugees have a disability, a figure which clearly contradicts global estimates, according to which persons with disabilities represent 15% of any population.¹

In an effort to address this data gap, the protection working group and the REACH Initiative,² in partnership with the ADWG, have prepared a joint needs assessment. Using quantitative and qualitative data collection methods, the assessment aims to identify the specific requirements of persons with disabilities in the camps and capture the voices and experiences of persons with disabilities and older persons in a holistic and dignified fashion. The intent is to further understand the safety and dignity of persons with disabilities across all age groups, ensure meaningful access to multi-sectoral services and assistance and foster participation and empowerment within community and humanitarian spaces. The ADWG

1 Rohingya Refugee Response/Bangladesh: Joint Government of Bangladesh – UNHCR Population Factsheet as of March 15, 2020 (<https://reliefweb.int/report/bangladesh/rohingya-refugee-responsebangladesh-joint-government-bangladesh-unhcr-population-0>).

2 The REACH Initiative conducts and facilitates field-based assessments in more than 20 countries to provide timely information and in-depth analysis from contexts of crisis and enable efficient aid planning and response. See www.reach-initiative.org/who-we-are/.

will provide training to enumerators and technical support to the project team to ensure that the methodology, tools, data collection process and analysis and use of the data is inclusive of persons with disabilities, including hard-to-reach groups such as deaf persons and persons with autism. The results of the needs assessment are expected in the second half of 2020.

Outside of the ADWG, disability-focused organisations support UN agencies and NGO consortium partners in the collection, analysis and use of disaggregated data. In training sessions, participants from different sectors and levels of the response learn how to apply the Washington Group Short Set of Questions, and how to use this data for inclusive programming.

Removal of barriers

Widespread misconceptions among humanitarian workers in Cox's Bazar lead to incorrect assumptions about how to remove environmental barriers for persons with disabilities. As one respondent from an international NGO explained:

We always think about someone with a wheelchair. Hence, most of the time, the response is 'Let's build a ramp!' But a ramp will not be helpful for people with different types of disabilities.

To overcome these misconceptions and provide UN agencies, international NGOs and their national and local partners with the necessary skills to address physical barriers, HI, CBM and CDD hold one-day coaching and training sessions for field staff and managers from various sectors of the response, including WASH, protection, nutrition and site management. Facilitators provide participants with a generic orientation on disability inclusion, explain different conceptual models of disability and outline national legislation and policies on disability inclusion. In group work, participants identify barriers and risks for persons with disabilities in their respective programmes, and identify ways to address them. Based on feedback from the facilitators, participants then develop project indicators for continuous monitoring. Subsequently, mainstream organisations establish a disability-inclusive action plan, which ideally reflects these indicators, and partners share their progress and seek advice in regular meetings. Close monitoring of programme indicators and camp visits by experienced project managers and technical officers from disability-focused NGOs minimise implementation gaps and reduce the risk of design errors and construction defects, and in this way help ensure that newly built facilities are accessible for everyone.

Overall, the training sessions and subsequent technical support have been well-received by the project partners,

Box 1 Donor-recipient partnerships

Under these partnerships, HI, CBM or CDD receive funds to provide targeted assistance to persons with disabilities in the camps and/or host communities, while simultaneously strengthening the capacities of the donor agency (a UN organisation) and its implementing partners. Most of these partnerships evolve from financial relationships, by which the disability-focused NGO acts as a service provider. With the establishment of the UN Disability Strategy in 2019, however, UN agencies are increasingly moving away from merely financial relationships and reaching out to disability-focused organisations in order to strengthen their own capacities and that of their mainstream partners on disability inclusion. This means that staff from different departments and sectors of the response participate in large-scale training and coaching sessions. One UN agency is particularly active in reaching out to disability-focused NGOs and has become more disability inclusive. Several departments and implementing partners have benefitted from training and coaching. Subsequently, one department redrafted its community feedback mechanism to make it more accessible for persons with disabilities. Several departments have established inclusive action plans, which will form the basis for a mission-wide, multi-sector action plan, starting in late 2020.

though participants have indicated that the training would be more effective if sessions were longer than a day. While training is often preceded by short site visits, some participants believe that an in-depth pre-assessment by the training facilitators could provide detailed information about inclusion gaps in project activities, which could be integrated into the training.

Besides training and coaching for humanitarian staff from UN agencies and NGOs, the ADWG also raises awareness on contextual factors that can lead to the exclusion of persons with disabilities, and advocates for inclusive humanitarian assistance in coordination and working groups. During the Covid-19 crisis, for example, the ADWG, in partnership with the Protection Working Group, published a joint Covid-19 Guidance Note on making the response age- and disability-inclusive. The Note enumerates the factors making older persons and persons with disabilities more susceptible to the virus, and provides recommendations on how to reduce the risk of infection for these groups.³ However, there is no evidence that the humanitarian community in Cox's Bazar regularly uses the Guidance Note in the response.

3 ADWG and Protection Working Group, 'COVID-19 guidance note', 7 April 2020 (www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/documents/files/protection_sector_adwg_covid-19_inclusion_guidance_note_12_april_2020.pdf).

Meaningful participation and empowerment of persons with disabilities

The government of Bangladesh treats the crisis as a short-term challenge and does not permit the formation of organised groups in the camps, including organisations of persons with disabilities (OPDs). Persons with disabilities living in host communities have not had the chance to make their views and opinions heard either. According to a representative of an OPD, there are only 12 such bodies in the district and they do not operate in the areas where refugees have settled. OPDs comprise Bangladeshi citizens and do not necessarily reflect the concerns of refugees. Disability-focused NGOs recognise this problem and are trying to support OPDs. The ADWG, for example, invited OPDs to join in 2019. However, until the government allows the Rohingya to fully exercise their rights and permits the establishment of OPDs in the camps, this problem will be very difficult to address.

Humanitarian organisations have become more deliberate in reaching out to persons with disabilities to increase their visibility in the humanitarian response. Thanks to intensive sensitisation efforts on inclusive humanitarian action, more and more organisations involve persons with disabilities in community meetings and focus group discussions. Some respondents indicated that this was resulting in programme adaptations. For example, one organisation had established a women's committee to encourage the participation of women in the refugee response. Initially, consisting of 100 members, the organisation subsequently expanded the committee to include 10 places for women with disabilities, to give them the chance to address specific issues and report unmet needs.

Remaining challenges and benefits of strategic partnerships

Overall, humanitarian workers have become increasingly aware of the importance of and need to include persons with disabilities in their interventions, in line with human rights approaches and in accordance with international frameworks. At this stage, however, there are still important data gaps on disability, widespread misconceptions among humanitarian staff on how to remove persistent barriers, and a lack of participation of persons with disabilities in the humanitarian response, in the refugee camps and in host communities.

Without a doubt, these challenges are hard to address. Organisations in Cox's Bazar are grappling with numerous structural challenges, including extremely short funding cycles, frequent staff turnover, restrictive government regulations that also entail a high administrative workload for NGOs and limited information-sharing among organisations and across organisational structures. These challenges prevent organisations from developing holistic, long-term approaches on disability inclusion, impede the effective coordination of disability-inclusive activities, and reduce the time available to humanitarian workers to participate in coaching and training sessions.

Box 2 NGO consortia

Consortia are a special form of cooperation between organisations with the same donor. These organisations come together as partners, operate within a single financial and reporting framework and share the same objectives. The general idea behind the formation of consortia is to reduce duplication of humanitarian services, increase the geographic coverage of interventions and share and complement existing expertise among the members. In Cox's Bazar, disability-focused organisations joined consortia with international and national mainstream NGOs to strengthen their capacity on disability mainstreaming. Within these projects, disability-focused organisations offer technical support and training to other consortium members operating in different sectors (e.g. health, nutrition, WASH, education, protection) and across different camp areas. With support from HI, CBM and CDD, mainstream NGOs learn to collect and analyse disaggregated data, and how to use it for inclusive programming. Thanks to these consortia projects, some mainstream actors have successfully remodelled or rebuilt their service facilities and included persons with disabilities in their programmes. One women's skill development centre, for example, offers training for women with and without disabilities, and children with disabilities benefit from inclusive learning materials and the removal of environmental barriers in learning facilities.

Strategic partnerships with disability-focused organisations cannot eliminate the structural challenges inherent to many humanitarian responses. Even so, research in Cox's Bazar shows that they can contribute to a response that is more disability-inclusive, mainly because they allow disability-focused NGOs to work with a specific set of partners in a structured and coordinated way. Technical assistance and capacity-building at various levels and in different sectors can help mainstream actors absorb any negative effects when staff trained on disability inclusion leave a given location. Strategic partnerships also facilitate regular knowledge exchange between departments and sectors, and thus encourage communication and reduce information silos. They allow disability-focused organisations to closely monitor the implementation of inclusive action plans and help reduce implementation gaps.

The ADWG, in close cooperation with the Protection Working Group, is at the forefront of promoting change in organisational practice. It advocates for equal and safe access to participative processes; facilitates the collection, analysis and use of gender-, age- and disability-disaggregated data throughout the response; raises awareness on contextual factors that can lead to exclusion; and builds capacity for inclusive humanitarian programming among members of coordination and sectoral working groups. In summary, strategic

partnerships seem better equipped to meet the growing demands on disability-inclusive humanitarian action than previous ad hoc approaches.

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Bazar was carried out between 12 January and 6 February 2020 under the project 'Phase 2 – Leave No One Behind! Mainstreaming Disability in Humanitarian Action'. The project is implemented jointly with HI Germany and CBM Germany and funded by the German Federal Foreign Office. The author would like to thank Danielle Richard (HI) for her valuable comments on earlier drafts of this article.

Lessons from Islamic Relief Worldwide's integrated approach to mainstreaming protection and inclusion¹

Sherin Alsheikh Ahmed

In crisis settings persons with disabilities are more likely to lose their lives and livelihoods than people without disabilities.² This is due, in part, to the policies and practices of humanitarian actors, where a focus on a blanket approach can exclude persons with disabilities from assistance and protection.

No longer seen as the domain of specialist agencies, a wide variety of development and humanitarian agencies have committed to improving disability inclusion. At the 2018 Global Disability Summit (GDS), Islamic Relief Worldwide, along with dozens of other state and non-state actors, made a series of commitments to tackle critical issues such as exclusion from education, livelihoods, stigma and discrimination and engaging with organisations of persons with disabilities (OPDs).³

In 2020, Islamic Relief carried out an internal review to assess progress towards these commitments and document positive and challenging practices on disability-inclusive programming to identify opportunities for learning. Conducted with limited resources and based mostly on secondary data, project documentation and key informant interviews with representatives from across the IR Family, this was not a rigorous assessment of Islamic Relief's capacity and performance in relation to disability inclusion. Rather, the review represents a light-touch stocktake, focusing on eight areas with the most practical implications for IR programming. (The review did not cover other organisational functions, such as human resources or governance, which have a strong impact on inclusive programming.)

Background

In recent years, Islamic Relief has sought to improve its performance in relation to disability inclusion, alongside

other cross-cutting issues such as safeguarding, gender justice, child protection and conflict sensitivity, through an integrated approach to mainstreaming protection and inclusion in programmes. Building on momentum generated by investment in technical capacity through the DFID-funded Age and Disability Capacity Programme (ADCAP) (2016–18) and then through two thematic projects supported by the Swedish International Development Cooperation Agency (SIDA), IR has developed human resource capacity in the form of protection and inclusion Officers/Coordinators in about a dozen country offices.

Islamic Relief Worldwide (IRW) also developed an operational framework on Protection & Inclusion (P&I). The framework has six elements:⁴ intersectional analysis (based on data disaggregation on age, gender and diversity), attention to negative effects, adapted assistance, adequate participation, accountability and adequate capacity. This framework, which is based on the principle of Do No Harm and key elements of protection mainstreaming, provides a link between IR's protection-specific policies⁵ and the programming standards of the IHSAN accountability framework,⁶ which is itself based on the industry-wide Core Humanitarian Standard.

The findings of the review will provide the basis for Islamic Relief's future efforts to improve its policies and practices relating to disability inclusion in humanitarian and development programming. This article presents some of the review findings in relation to IR's commitments to disability inclusion, namely: collaborating with OPDs for programming and capacity-building; tackling disability-related stigma and discrimination; and the intersection of gender and disability.

1 This article is based on a review of disability inclusion in Islamic Relief programmes drafted by Tom Palmer and finalised by Sherin Alsheikh Ahmed.

2 Katsunori Fujii, 'The Great East Japan Earthquake and disabled persons'. Japan: Disability Information Resources.

3 See <https://www.internationaldisabilityalliance.org/commitments>

4 Bhardwaj, R., *Leave no one behind in humanitarian programming: an approach to understanding intersectional programming*, Islamic Relief Worldwide, November 2018.

5 For example, the Safeguarding Policy (2018), the Gender Justice Policy (2016) and the Child Protection Policy (2015).

6 The IHSAN accountability framework is an internal tool based on CHS and other widely used accountability tools.

Table 1 Focus areas for Islamic Relief’s internal review of disability inclusion

A) Focus areas – programme processes	GDS commitments	CHS/HIS*
A.1) Collaborating with DPOs for programming and capacity-building	Commitment 3	Standard 4
A.2) Improving staff knowledge on rights-based approaches to disability	Commitment 4	Standard 7&8
A.3) Collecting and analysing data on men, women, boys and girls with disabilities	Commitment 11	Standard 1
A.4) Including men, women, boys and girls with disabilities in feedback and complaints processes	Commitment 1	Standard 5
B) Focus areas – programme content		
B.1) Tackling disability-related stigma and discrimination	Commitment 5	Standard 2
B.2) Building infrastructure that meets universal design criteria	Commitment 6	Standard 2
B.3) Including men and women with disabilities in livelihoods programming	Commitment 8	Standard 2&3
B.4) Targeted programming which addresses access to services and empowerment of men, women, boys and girls with disabilities	Commitment 7	Standard 2&3
C) Cross-cutting		
C.1) Intersection of gender and disability	Commitment 12	Standard 2&4

* CHS: Core Humanitarian Standard; HIS: Humanitarian Inclusion Standards for older people and people with disabilities

Review findings

Collaborating with OPDs for programming and capacity-building

Engagement with OPDs is a critical component of effective and inclusive programming. However, the review found that, at a Country Office level, OPD engagement varied, from limited (for example targeting of persons with disabilities for seasonal distributions) to some very significant engagement. For example, in 2020 IR Niger coordinated with the national OPD federation to identify over 1,000 persons with disabilities to receive Ramadan packages.

The most notable engagement with OPDs has taken place in Chechnya, Palestine/Gaza and Bangladesh. IR Russia has partnered with OPDs since 2012, when it began a series of projects with the Chechen Union of Hearing Impaired People to establish a Development Centre for Hearing Impaired in Grozny to provide access to free training services and opportunities to study Islam. IR Palestine/Gaza has collaborated with the local OPD network (with support from the INGO Humanity &

Inclusion) to conduct accessibility audits of venues for community-based activities. It has also involved OPD representatives in the baseline assessment for a recently initiated project on education and in the design of their current cash for work project. This engagement ensured that IR Palestine achieved a more complete understanding of the barriers facing persons with disabilities in accessing education and employment, and the accommodations required to ensure their inclusion.

IR Bangladesh has been supported by Humanity & Inclusion to make connections with local OPDs in Rangpur and Dhaka to support the inclusion of persons with disabilities in a number of livelihood projects. The OPDs provide orientation sessions for adults with disabilities to help them understand IR’s livelihood support and identify potential participants. IR Bangladesh is now planning further projects in collaboration with OPDs and Humanity & Inclusion.

At a global level, IRW is building and strengthening relationships with IDA and Inclusion International



A workshop carried out by a person with physical disability to Islamic Relief Gaza staff addressing lessons learnt about disability inclusion Islamic Relief Gaza

to map out and identify areas of mutual interest for collaboration focusing on mainstreaming disability in all efforts towards localisation, in accordance with the Grand Bargain and in response to both ethical and practical drivers, underlined by the Covid-19 global pandemic.

Tackling disability-related stigma and discrimination

There is significant evidence to show that the negative attitudes and misconceptions of family members, neighbours, community leaders, service providers and staff represent the most significant barriers to inclusion of persons with disabilities in humanitarian programming.⁷ However, the disability review showed that, of all its commitments to the Global Disability Summit, Islamic Relief has acknowledged that disability stigma and discrimination is one of the major challenges it needs to address through its programmes. Some country offices undertake ad hoc activities, for example integrating messages relating to disability inclusion in orientation sessions for protection committees (IR Niger, IR Malawi) or holding events and producing videos for the annual International Day of Persons with Disabilities (IR Palestine, IR Pakistan).

Disability-related stigma affects IR staff, as well as the communities we serve. Persons with disabilities are often perceived as intrinsically ‘vulnerable’, requiring handouts or specialised health services. Even when disability inclusion is internalised as part of Islamic Relief’s mandate, progress is limited by an overly generalised

approach which has yet to deliver the specific measures required to remove attitudinal, physical and institutional barriers, and ensure dignity, autonomy and accessibility for persons with disabilities.

To fully engage staff, overcome negative perceptions relating to disability and build confidence around inclusion, IR realised that it is necessary to conduct a consultative and participatory process to develop its own internal policy. Currently, IR is exploring ways to ensure that the policy articulates an Islamic perspective on disability inclusion as a foundation for a faith-sensitive approach to disability mainstreaming, within Islamic Relief and beyond. IR is aiming to finalise a policy that is grounded in the values of the organisation and linked to the frames of reference to which staff are accustomed (Islamic perspectives, faith-sensitive approach, global strategy, CHS). The policy would provide a firm foundation from which to generate further organisational change and to translate policy commitments into systematic practice, such as developing a faith-sensitive approach to promoting the rights of persons with disabilities in humanitarian and development programming (with a focus on combating stigma and discrimination).

Faith and faith-based institutions are very often a source of hope, empowerment and resilience for crisis-affected communities.⁸ However, in many traditional societies religious beliefs are also a source of stigma, discrimination and prejudice, which lies at the root of social exclusion, diminishing resilience and exacerbating

7 DFID, *Disability inclusive approaches to humanitarian programming: summary of available evidence on barriers and what works*, 2019 (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/833579/query-9-evidence-humanitarian-response1.pdf).

8 Lutheran World Federation and Islamic Relief Worldwide, *A faith-sensitive approach in humanitarian response: guidance on mental health and psychosocial programming*, 2018 (<https://interagencystandingcommittee.org/mental-health-and-psychosocial-support-emergency-settings/documents-public/faith-sensitive-approach>).

crisis-related protection risks, particularly for people with disabilities.⁹ ‘Disability is often blamed on: misdeeds of ancestors; misdeeds of parents; misdeeds of the person with disabilities; supernatural forces such as demons/spirits; witchcraft; or punishment or fate from God’.¹⁰

Even the most detailed guidance on inclusion of persons with disabilities in humanitarian action, such as the 2019 IASC Guidelines and the 2018 Humanitarian Inclusion Standards, provides only cursory instructions to address stigma through engagement with faith leaders. And the evidence is scant on the role of faith leaders in community-based approaches to tackling disability-related stigma and discrimination, or the value of prayer and religious contemplation to the mental health wellbeing of persons with disabilities.

Humanitarian actors do not have the knowledge or tools to respond to the relationship between faith and the protection of persons with disabilities in crisis settings, either to leverage the positive aspects or to mitigate the negative ones.

Responding to the intersection of gender and disability

In its commitment to intersectionality, Islamic Relief recognises that it cannot deliver disability-inclusive programming without understanding and responding to the different situations of women, men, girls and boys with disabilities, affected as they are by multiple and compounding discrimination on the grounds of both their gender and disability. This is reflected in the prominent position of intersectional analysis and disaggregated data as key pillars of IR’s Protection & Inclusion framework.

The Gender Mapping Audit 2020 highlights the need to strengthen work on gender and disability:

- Age, gender and diversity analysis should also consider barriers to participation and meaningful access.
- Gender justice in humanitarian and development settings must be rooted in meaningful participation of women and girls in decision-making, including women and girls with disabilities, and in support of local women-focused CSOs, including organisations of women with disabilities.
- Setting targets disaggregated by sex, age and disability will strengthen accountability and encourage better data to inform more inclusive and protection-sensitive programming.
- Addressing the gendered needs of women and girls with disabilities requires a twin-track approach to inclusion¹¹ combining the following components:
 - Mainstream programmes and interventions designed for the whole population, which are

inclusive of women and girls with disabilities (in terms of both access and participation).

- Targeted programmes and interventions which address the specific risks and requirements of women and girls with disabilities (in terms of both needs and empowerment).

No humanitarian agency can claim to have fully adopted an intersectional approach to protection and inclusion. It is a challenge to break down the walls between the thematic or demographic siloes into which technical and programmatic teams are organised. With finite resources and an expanding list of cross-cutting issues, it is tempting to try to prioritise and give prominence to certain demographics over others. However, intersectionality requires that we take a more nuanced approach based on multi-dimensional protection risk analysis and integrated multi-sector responses implemented in partnership with multiple stakeholders representing the diversity of the populations we serve.

Conclusion

The review found that actions are required to accelerate progress across all nine focus areas/commitments on disability inclusion. However, it is also important to recognise where progress has been made, particularly in relation to engagement with OPDs, accessible infrastructure, inclusive livelihoods and targeted programming.

As a theme cutting across not just programmes, but all organisational domains, disability inclusion is subject to many of the same institutional challenges which limit progress in other areas, such as gender justice, localisation, sustainability, safeguarding and systems-level impact. These challenges are the result of tension between valued aspects of IR’s identity (e.g. fast response, direct implementation, large scale, high visibility for private donors, engagement with local leaders) and the drive to increase IR’s impact through long-term, evidence-based programmes which meet technical standards and respond to the changing role of INGOs by transferring power to communities through localisation and meaningful participation.

These challenges have limited IR’s progress towards meeting its commitments to disability-inclusive programming. IR should consider working with OPDs in humanitarian action. There are clear guidelines and examples to follow, but greater OPD engagement will necessitate mobilising resources for capacity-building of local organisations and a shift to a robust partnership model.

Improvements in disability data will require reducing reliance on community leaders as key informants and

9 IDA, DFID and Government of Kenya, *Global Disability Summit – Dignity and Respect for All: creating new norms, tackling stigma and ensuring non-discrimination*, 2018 (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/726179/DFIDHandouts_Dignity_Respect_V6.pdf).

10 Rohwerder, B., *Disability stigma in developing countries*. Brighton: IDS, 2018 (https://assets.publishing.service.gov.uk/media/5b18fe3240f0b634aec30791/Disability_stigma_in_developing_countries.pdf).

11 This is consistent with the formulation in the new IASC Guidelines on inclusion of persons with disabilities in humanitarian action (<https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/iasc-guidelines>).

increasing primary data collection, using methodologies that take account of the low visibility of persons with disabilities. The availability of external tools and training on disability data and ongoing development of internal digital data management systems will help facilitate this. The momentum provided by high-level prioritisation of complaints mechanisms to improve safeguarding can be an opportunity to improve informal feedback processes as well.

Finally, IR realises that inclusion and rigour of analysis and accountability will be boosted by recent progress

to improve project cycle management tools and processes. Resourcing should not be an excuse as donors expect project budgets to include costs relating to inclusive MEAL as well as accessibility and reasonable accommodations. Change will also require nurturing a working culture that encourages staff to learn from failure, reflect critically and apply their creativity.

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Walking the talk: a participatory review of the IRC's feedback mechanisms

Pauline Thivillier and Valentina Shafina

For many years, persons with disabilities have reported a lack of access to basic humanitarian services. We also know, as a humanitarian community, that older persons, women, girls, boys and men with disabilities are at particular risk of discrimination, exploitation, violence, including sexual and gender-based violence, and exclusion from support and services in humanitarian contexts. At the same time, 92% of humanitarian actors have acknowledged that persons with disabilities are not properly included in humanitarian responses.¹ Despite a growing body of tools and guidance, humanitarian actors still lack the capacity to understand how disasters and conflict affect the lives of persons with disabilities, as well as how their own responses can be adapted to better address their needs.

The recent UN Flagship Report on Disability and Development 2018² shows that persons with disabilities continue to face barriers and are under-represented in decision-making processes. Due to poor identification, registration and access to feedback and complaints mechanisms, persons with disabilities are often under-identified and no information is collected on the barriers they face. To address this gap, the UN report calls on states to ensure the implementation of accountability mechanisms in accordance with the UN Convention on the Rights of Persons with Disabilities (CRPD). The recently published Inter-Agency Standing Committee (IASC) Guidelines on inclusion of persons with disabilities in humanitarian action³ also emphasise that mechanisms for accountability must be accessible to persons with disabilities and must consider their requirements.

IRC Client Responsive Programming

Participation of and accountability towards all people we serve – our clients – is central to the International Rescue Committee (IRC)'s strategy and our work on Client Responsiveness. The IRC's approach is described in our Client Responsive Programming Framework,⁴ which maps out how the IRC delivers on high-level goals and commitments, such as within the IASC Results Group 2 on Accountability and Inclusion, the Grand Bargain and the Core Humanitarian Standard (CHS). The IRC implements Client Responsive Programming throughout all aspects of programmatic decision-making by putting in place the mechanisms to collect, analyse and respond to client feedback, and to use that feedback to inform our decisions. The IRC has also identified and invested in a number of critical internal and external enabling factors, which support the process of consultation and collaboration with clients and communities.

A CHS Self-Assessment, conducted in 2018, highlighted areas for improvement for the IRC, including consultation with marginalised groups and data disaggregation (including by disability). At the same time, IRC staff were requesting additional guidance and support on how to engage clients with disabilities, and how to respond to their feedback.

To address these challenges, the IRC initiated a two-year project (April 2019–March 2021) in north-west Syria and Tanzania, funded by the Swedish International Development Cooperation Agency (SIDA), to strengthen the inclusion of persons with disabilities in the IRC's Client Responsiveness approach. By being more inclusive of

1 *Disability in humanitarian context: views from affected people and field organisations*, Handicap International, 2015 (<https://handicap-international.ch/sites/ch/files/documents/files/disability-humanitarian-context.pdf>).

2 *Realization of the Sustainable Development Goals by, for and with persons with disabilities*. UN flagship report on disability and development 2018 (www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2018/12/UN-Flagship-Report-Disability.pdf).

3 See <https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/iasc-guidelines>.

4 For more on the IRC's Client Responsiveness Framework, see www.rescue.org/resource/irc-client-responsive-programming-framework.



Mansehra District, Pakistan: a student enjoys improved access to education after assistive devices and accessibility ramps are provided at her school
HRDS/Afzal

Figure 1 IRC’s feedback cycle and eight enablers

The feedback cycle



The eight enablers

- A. Defining roles and responsibilities
- B. Data management
- C. Defining internal and external systems and pathways
- D. Leadership
- E. Resourcing Client-Responsive Programming
- F. Managing risks
- G. Internal and partner organisations development and capacity building
- H. Coordination and collective actions.

Source: adapted from IRC

persons with disabilities, the IRC also aims to strengthen institutional and global standards and publish tools and guidance to ensure that the views of persons with disabilities are included in accountability mechanisms.

Scoping study

To evaluate existing guidance, tools and methods through which the IRC collects feedback and supports clients’ participation, we completed a desk review of inclusive feedback mechanisms during the first year of the project. We then carried out a series of consultations with experts in inclusion and Accountability to Affected Populations (AAP), IRC staff in the pilot locations and

clients with disabilities, to identify opportunities and gaps around inclusion of persons with disabilities in feedback mechanisms. The scoping study was structured according to the principles established in Article 3 of the CRPD.

To ensure a participatory and collaborative process, we established an Advisory Committee to guide, support and promote the project throughout all its phases. The Committee includes representation from mainstream and disability-specialised INGOs, research institutions, organisations working on quality and accountability and, first and foremost, Organisations of Persons with Disabilities (OPDs), which constitute over 50% of the committee. The IRC developed a process for the provision

of reasonable accommodation⁵ during interviews and consultations, following the guidance provided by the IASC Guidelines.

This is the first time that this range of organisations has worked together in a project on disability-inclusive AAP, with the expertise of persons with disabilities themselves at the centre. The Advisory Committee helped to shape the scoping study criteria and provided insights on feedback and complaints mechanisms regarding disability inclusion. The IRC interviewed nine members of the Advisory Committee, and reflected their inputs in the consultation process, scoping study and recommendations.

Several members advocated for increasing the accessibility of informed consent language and forms that can be processed by persons with disabilities during the consultations, to ensure they were truly participatory.

Informed consent is often provided through family members. Each adult person should be able to provide free and informed consent if communication is made accessible ... You can use easy-to-read language, and large fonts in documents. Some people may need more time, so sharing the forms in advance or making time enough to read them, and giving the option to reach back if there are questions or concerns around the interview. (Advocate for the rights of women and girls with disabilities; female; visual disability)

We addressed this recommendation by developing an easy-to-read Guidance and Consent Form, which was used in the remaining consultations. Interview and focus group discussion guides were developed for each of the consultations, including easy-to-read versions produced with the Lebanese Association for Self-Advocates, a member of the advisory group with experience in this area.

Gaps and good practice

This thorough engagement with OPDs, IRC staff and clients with disabilities provided the IRC with extremely valuable reflections on the Client Responsiveness approach, as well as broader sector practices on AAP initiatives and good practices implemented in the pilot countries. Key findings highlighted the need to:

- 1. Deepen understanding of rights-based approaches to disability**, including concepts such as universal design, accessibility, discrimination and reasonable accommodation. Current services and strategies to respond to feedback collected from persons with disabilities reflect an understanding of disability that is closer to a medical model, focusing on a person's health condition and impairment rather than the rights-based model, which focuses on the interaction of this condition/impairment with a multitude of

influencing factors in the environment. When a client with a disability cannot access a service or feedback channel, reasonable accommodations to address individual situations of lack of access should be provided. However, in practice staff with inadequate training tend to think the issue lies with the client. This means they assume that addressing the barrier by providing reasonable accommodation is not the IRC's responsibility, or if it is, they assume that it falls to another team with more specialised expertise (e.g. protection, health or a specialised disability partner organisation). Although anecdotal evidence of reasonable accommodation was reported by the north-west Syria team, this is not provided in a systematic way and the scoping study highlighted that inclusion and accessibility for persons with disabilities needs to be further mainstreamed across all sectors. Going forward, we will develop content on disability inclusion to include in the existing tools package on Client Responsiveness and in-person training guides. In one case, an adult man with a disability reached out to the IRC asking about a livelihoods project he had heard about and, when asked if he could access the centre where the activities take place, he replied that he could not reach that area due to difficulties with his mobility. A team was sent to his household to make an assessment there, and he could then join the programme with additional support provided to reach the training centre.

- 2. Strengthen data collection, including disaggregation of data by disability and age.**

Findings show that data collected as part of Client Responsive Programming is only disaggregated by sex, without systematic disaggregation by age and disability, and analysis does not look at barriers to access for persons with disabilities. Field staff reported during interviews that, without disaggregated data, they cannot verify how efficient efforts to ensure inclusive design of the Client Responsive Programming have been in ensuring accessibility. Systematically collecting data on age and disability status would enable monitoring of access to and use of feedback mechanisms for persons with disabilities, as well as identifying preferences, risks and barriers to access. Up-to-date standards recommend, at a minimum, disaggregation by sex, age and disability, recognising that these factors are present in any given population and can provide valuable information on who is at heightened risk.⁶ Standardised tools also exist to collect data on disability status, such as the Washington Group questions.⁷ In the second year of the project, we will further integrate and strengthen the use of the Washington Group questions in feedback forms and registry.

- 3. Introduce a regular assessment of safety and accessibility of the IRC's feedback and complaints mechanisms and strengthen collection of data**

⁵ Reasonable accommodation requires individuals and institutions to modify their procedures or services (accommodate), where this is necessary and appropriate, either to avoid imposing a disproportionate or undue burden on persons with disabilities or to enable them to exercise their human rights and fundamental freedoms on an equal basis with others.

⁶ For example, The Sphere Standards, pp. 13 and 56: see <https://spherestandards.org/>.

⁷ Available at www.washingtongroup-disability.com/.

on barriers and enablers to ensure that persons with disabilities can provide feedback, and that their views and priorities are understood. Available and up-to-date legal frameworks, standards and guidance suggest going further than data disaggregation and collecting information on environmental, attitudinal and institutional barriers, as well as enablers. In interviews, IRC staff and external experts recommended integrating practical information on accessibility in all Standard Operational Procedures (SOPs) for client feedback mechanisms, and developing a method and tools to assess the accessibility of the channels being used (including identifying physical, information and attitudinal barriers). Field practices in both the Tanzania and north-west Syria Country Programmes addressed this gap to some extent by having dedicated SOPs for child-friendly mechanisms (including children with disabilities). The north-west Syria programme has developed leaflets, a video and a song to encourage the use of the feedback mechanism. In Tanzania, a question on identifying children facing barriers to accessing services is included in the guidance for child-friendly focus group discussions. During the project we went further and developed an accessibility assessment tool in collaboration with the north-west Syria Country Programme. It is worth keeping in mind that a standardised method for collecting information on barriers in humanitarian action is not yet available. Results of the audit highlighted that women with disabilities experienced challenges accessing safe transportation which prevented them from using feedback mechanisms. This was integrated into a planned safety audit, resulting in a 'Safety and Accessibility Audit' tool. This recognises that accessibility is a factor that can increase or decrease the level of safety of a service. The assessment tools used for this audit will be further refined during the second year of the project.

- 4. Develop methods to identify programmatic changes related to accessibility** based on analysis and use of feedback from clients with disabilities. Client Responsiveness includes an established process to ensure clients' feedback is responded to and addressed in a timely manner, and there is a requirement to ensure that programmatic changes are made. When it comes to disability, interviews with field staff highlighted that decisions on how feedback is analysed and what type of programmatic responses are implemented is based on staff knowledge, and there is a lack of guidance on how to address problems of access and barriers reported by persons with disabilities. This means that changes are happening on an ad hoc basis. The use of disaggregated data and data on barriers is essential to put in place mitigation measures to address risks and barriers as highlighted in available guidance (including the IASC Guidelines on inclusion of persons with disabilities in humanitarian action) and reinforces the rights-based understanding of



Child-friendly communication on the IRC's feedback mechanisms
IRC Syria

disability. A contingency budget line is necessary to ensure programmatic adaptation based on feedback from clients with disabilities, and to address individual situations of lack of access. Around 3–7% of the budget is recommended in existing standards and guidance and by experts in key informant interviews.⁸ During the first year of the project, we developed a short guidance document with tips on inclusive budgeting to support staff in understanding the principles required, dedicating budget for accessibility and reasonable accommodation, and finding ways to use this budget. This document will be further refined during the second year of the project.

- 5. Improve communication with clients with disabilities** to demonstrate how feedback influences programmatic decisions. The current approach to Client Responsive Programming has dedicated recommendations on closing the loop to encourage IRC staff to communicate back with IRC clients how their feedback has been used, the types of response put in place as a result, and creating room for discussion on what has been decided. The north-west Syria Country Programme has developed an internal communication newsletter called Client voices. The newsletter, shared via email with Country Programme staff, identifies examples where feedback from

8 Including the IASC Guidelines (p. 29).

clients has made a positive difference. For example, complaints from potentially eligible clients that were not included in a cash and voucher programme led to the disbursement of additional funds to assist some of them. Going forward, we will proactively monitor the participation of clients with disabilities in this process, with data disaggregated by sex, age and disability, by engaging OPDs and communicating back to them the outcome of their feedback.

[Clients with disabilities] feel more secure and they know they are part of the solution, of finding a solution. In the Bekaa Valley, for example, their feedback helped to have money to get a lift in a clinic. A lot of people got to benefit from this, and this changed as well the perception of the population of older people and people with disabilities.
(NGO disability and older age advisor, female)

By adapting our approach to Client Responsive Programming based on the findings of the scoping study, the IRC aims to produce guidance and tools that can be used by the humanitarian sector overall to

improve and promote inclusive feedback mechanisms. However, as reflected by the participatory approach taken in this project, gaps and challenges will not be addressed by guidance and tools alone, but will require a shift in how international agencies make programming decisions, moving away from a top-down approach. At the IRC we have renewed our commitment under our new organisational strategy – Strategy 100 – to putting our clients at the centre of everything we do. Informed by consultations with our clients, partners and frontline staff, the IRC’s new strategy emphasises the need for stronger involvement of clients in driving improvements to programme quality, describing a set of ambitions to strengthen our responsiveness to clients’ priorities and preferences, and more meaningfully engaging them in decision-making about the programming we deliver.

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SADI – CAFOD’s safe, accessible, dignified and inclusive approach

Mirela Turcanu and Yves Ngunzi Kahashi

In the last two decades, we have seen a proliferation of approaches to enhance protection and reach all people affected by crises, including accountability, protection mainstreaming, gender mainstreaming, safeguarding and inclusion of older people and people with disabilities. Over recent years, CAFOD has worked on a joined-up approach, bringing together these workstreams and putting intersectionality at the core. The result has been the development of SADI, an approach that can be applied to any type of programme to ensure that it prioritises the safety of programme participants, that traditionally marginalised groups are enabled to access and participate, and everyone’s inherent dignity is respected in all interactions. SADI is particularly relevant for preparedness, helping organisations take actions ahead of emergencies and ensuring they are able to deliver a high-quality and safe response when the time comes.

The approach operationalises concepts such as inclusive community engagement by focusing on particularly vulnerable groups, including older people and people with disabilities. It is helping to mainstream meaningful participation and accessibility, and reasonable adaptations, and challenging the belief that anything related to disability is the area of specialists only. It does so by enhancing the capacity of staff and partner organisations on inclusion through training and one-to-one support, promoting the use and analysis of sex, age, disability and diversity (SADD) data, promoting

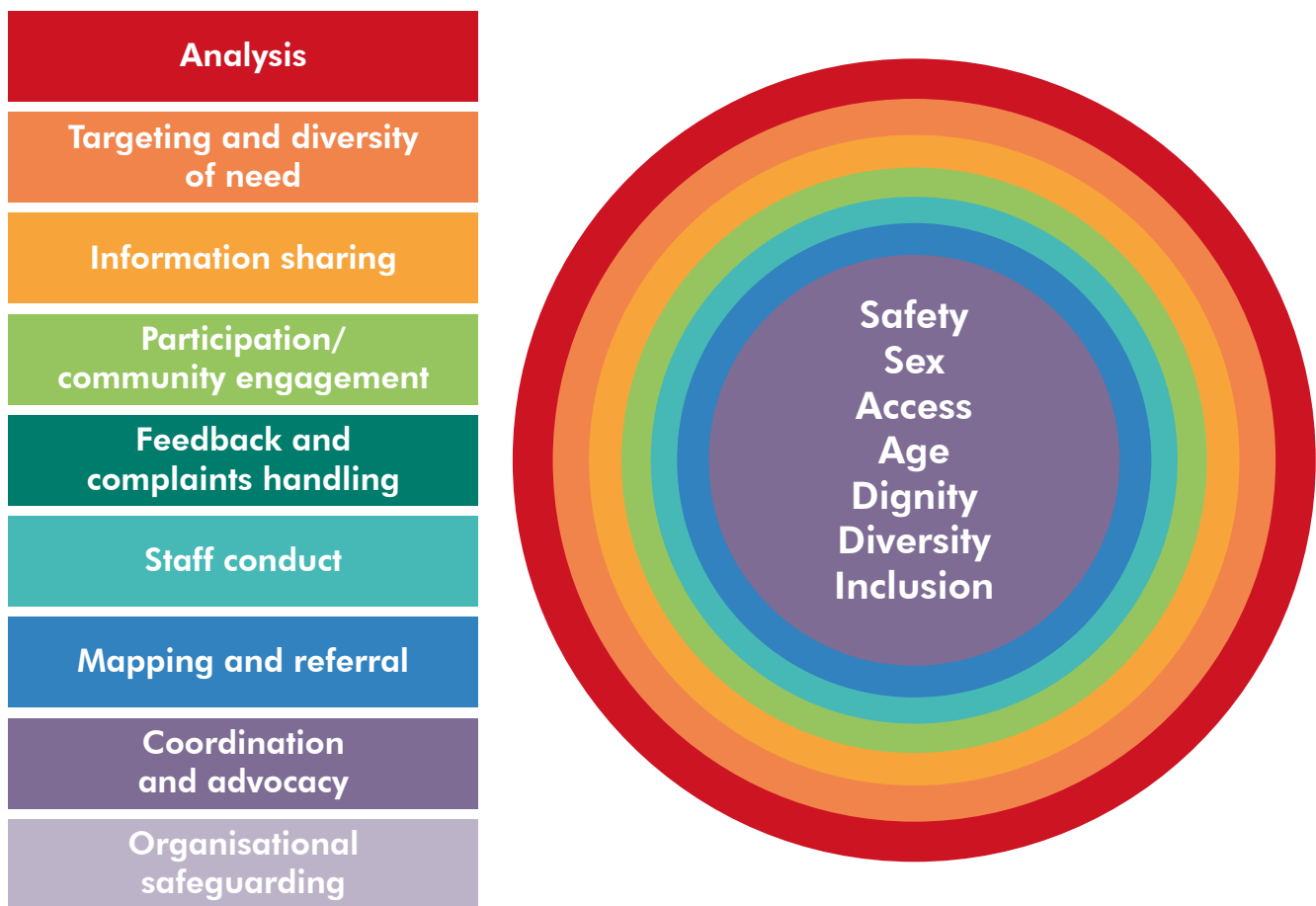
the development of practical tools that help staff in the field implement guidelines, as well as capturing their voices in improving them, and not least promoting the set-up of supportive, inclusive structures and processes to enable a culture of accountability to communities in all their diversity.

What is SADI?

SADI is not about *what* an organisation does, but about *how* it does it. It is an approach, a framework and a toolkit, built on intersectionality – the understanding that one’s experience of conflict and poverty, as well as privilege and opportunity, is defined by not one but many intersecting identities, determined by one’s age, gender, physical ability and membership of various locally defined domains of diversity and exclusion, including religion, race, ethnicity and displacement status.

SADI builds on the Protection Mainstreaming Package developed by the Caritas Inter-Agency Protection Mainstreaming Working Group (PMWG). It goes further, however, in integrating organisational safeguarding and building in an integral ecology perspective. It can be applied as a self-assessment tool, to guide programme design processes and for quick reference. The framework underpinning it has nine core components (see Figure 2). Each component has a statement of good practice, indicators to establish a programme’s level of adherence,

Figure 1 The SADI framework



Source: adapted from CAFOD

and guiding questions to support practical application and understanding.

Why is SADI important for our work?

- Implementing safe, accessible, dignified and inclusive programming is central to delivering **quality programmes**.
- SADI supports **accountability** by addressing power imbalances and responding to the diverse voices of people in the communities served, with attention to those who are traditionally excluded, such as women, youth, older people and people with disabilities.
- SADI is benchmarked against good practices for **safeguarding** in international development work.
- It recognises the fundamental relationship between human development and environmental protection, thus adopting a **holistic approach** to people and the environment.
- Finally, **inclusion** has gradually grown to be a central focus of our work, and SADI provides the bedrock on which we can build, ensuring that everyone understands adaptive programming and is aware of the diversity of needs within communities, and that our ways of working promote the inclusion of people who might be traditionally excluded.

How does it work?

The nine components, taken together and approached in an intersectional way, are about operationalising inclusive programming. Weaved through each component is the SADD-SAD approach, which requires an analysis of how sex/gender, age, disability and other relevant domains of diversity and exclusion will impact on the safety, access and dignity of diverse groups.

Homing in on the analysis component, the SADD-SAD approach ensures an inclusive data collection process and the collection of SADD- disaggregated data, which can provide information on power dynamics and existing capacities, and on the domains of diversity and exclusion in the local context. This in turn helps break down the idea of a homogenous community, bringing into focus the diverse groups within that community, and their needs, vulnerabilities and capacities.

Bespoke practical tools are being created and adapted at each component level. One example is an inclusive protection risk analysis tool. In a first stage, the programme team, ideally in collaboration with representatives of diverse groups in the community, assesses the risks relevant to their context, under categories such as sexual and gender-based violence, exclusion and lack of access to services and safeguarding,

Figure 2 SADI components

Analysis	Understanding the capacities and vulnerabilities of different groups in the community, what protection and safeguarding risks they face and how our programme interacts with them. How do we consider the environment?
Targeting and diversity of need	Consideration of sex, age, disability and other diversities in a context. Understanding the data collection and disaggregation: who is asked what, by whom and how? How can we adapt programming for different groups?
Information sharing	Participation links strongly to a sense of dignity. Who participates in our projects and how? How do we ensure meaningful participation from different groups?
Participation/ community engagement	What information do we need to share about our organisation and our projects? How do we share it to ensure access for different groups?
Feedback and complaints handling	A safe and responsive mechanism should be in place to handle sensitive and non-sensitive complaints, designed in consultation with different groups in the community.
Staff conduct	Is a code of conduct in place that meets best practice and is it consistently applied? How are staff and volunteers supported to do their jobs well? How do we consider personal well-being?
Mapping and referral	Mapping the local context for making referrals is critical in any programme and for complaints handling. How can we respond to disclosures safely in the field?
Coordination and advocacy	Which protection actors can address concerns raised outside of our programming? How can we coordinate and advocate for the protection of different groups?
Organisational safeguarding	What systems are in place to support safeguarding in the organisation? E.g. safeguarding policy, safe recruitment, management oversight and organisational learning.

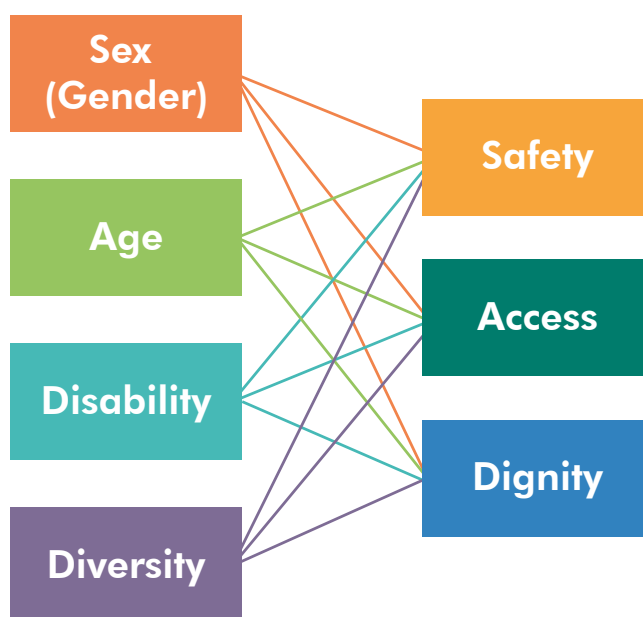
Source: adapted from CAFOD

and whether the proposed project design may directly or indirectly increase those risks. This is followed by a reflection on whether specific groups such as people with disabilities or older people may be facing exacerbated risks, what capacities they have to mitigate them and, crucially, what adaptations can be put in place to enable full safe, accessible and dignified participation.

The organisational safeguarding component focuses on the internal systems and policies that need to be in place to deliver safe programming. These cover areas such as safe recruitment, safeguarding policies, staff training and safe and responsive mechanisms for handling sensitive complaints. A safeguarding profile is developed in dialogue with local partners to assess and record what measures are in place and draw up a plan to address safeguarding challenges.

Rolling out SADI was a multi-level process, which required assembling a distinct team to design a product that marries global best practice with internal ways of working, the investment of time and resources across the organisation and strong leadership. A steering committee, bringing together department heads across the organisation, provided critical organisational buy-in and governance. In a first stage, more than 300 people participated in week-long SADI training sessions globally. Following these workshops, local partner organisations

Figure 3 SAD-SADD analysis



Source: adapted from CAFOD



Picture books show how to engage with CAFOD DRC's partner organisation, Centre Olame, to provide feedback and complaints
Centre Olame

and CAFOD teams developed action plans to work on over the following months. The establishment of an internal programme development and MEAL fund was a key component. Where the action plans revealed areas needing further investment, partner organisations could apply for grants as well as access technical expertise. Another key component was the establishment of a SADI focal point network. In each country programme, one person was identified to be further upskilled in the various tools that form SADI, to continuously support the team and partners locally, induct new staff members into the SADI approach from the start and, perhaps most critically, lead on the contextualisation process.

An example from the field: the Democratic Republic of Congo experience

Implementing SADI across all country programmes is an ongoing process, with tools still being designed and adapted, people still being trained and brought on board with the approach, and a continuous process of reiteration.

One of the most valuable lessons has been recognising the importance of encouraging and facilitating a process through which SADI can further develop and adapt to the local context. In the Democratic Republic of Congo (DRC), for example, CAFOD DRC worked with a local partner organisation, the Centre Olame in Mwenga, to establish an inclusive feedback and complaints mechanism as part of an initiative to engage the community in the Ebola

response. As we see now with Covid-19 as well, risk communication and community engagement will only work if supportive, inclusive structures and processes are put in place to ensure that people, particularly those who may be disproportionately disadvantaged, such as women, girls, children, young men, persons living with disabilities and older people, take a lead. As part of the response, picture books in Swahili explored the 'how' of engaging with the organisation to provide feedback and complaints, using gender-, age- and disability-inclusive displays. This encouraged people with disabilities to participate in the project committee, and contributing to the programme helped them to feel empowered, included and valuable in their community. According to the Centre Olame: 'The feedback we receive is ... a way for us to improve ourselves and allow others to improve the way they work and integrate into the community. Feedback and complaints can also allow us to change the strategy of our interventions and adapt them to the customs and habits of the communities we serve'. Being inclusive was at the core of dispelling rumours, engaging in a continuous dialogue that spoke directly to the specific questions people in small communities had, and helped stop the spread of the disease in target areas.

To support the age, gender and diversity analysis and promote the inclusion of people with disabilities, in DRC CAFOD partner organisations started using the Washington Group questions to improve the quality of SADD data. However, through this process

it became apparent that it can be difficult to identify and calculate the number of persons with disabilities in a target population, to some extent because targeting in many humanitarian projects happens at the household level, whereas global-level guidelines tend to be at an individual level. Equally challenging has been to move inclusion as practice away from a numerical and statistical approach. The focus often rests on disaggregated data, instead of adaptations, a process that requires either more flexible budgets, which account for 'reasonable accommodations', or an openness to introducing such programme adaptations at a later stage. It became apparent that it was necessary to develop localised and context-based guidance and tools, building on global ones.

This process identified gaps in the targeting process. In early 2020, CAFOD DRC secured a grant from the Start Fund to create a tool to facilitate a consistent approach to targeting and data collection. As inclusive community participation was the starting point of the design, the tools and processes coming out offer exciting opportunities to reach people in all their diversity by including variables relating to groups with specific needs. The tool combines social vulnerability criteria

with food consumption scores and material vulnerability, enabling programmes to better capture intersectionality. The approach integrated 'data-driven' targeting with consultations with diverse groups at each stage of the process. Selection committees included representatives of women's associations, associations of people with disabilities and the elderly. We are now looking at how to broaden the scope of this work and use the learning from it to improve targeting practices in other regions where CAFOD partners operate.

Concluding remarks

Inclusion of groups such as older people and people with disabilities requires a shift in the way we work, where we place our attention and the processes and tools we use. Mainstreaming inclusion cannot come at the expense of other workstreams, such as gender mainstreaming or safeguarding. With its focus on intersectionality, SADI is one attempt to do this.

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