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'Ask us what we need': Operationalizing Guidance on Disability Inclusion in Refugee and Displaced Persons Programs

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Persons with disabilities remain one of the most vulnerable and socially excluded groups in any displaced community. Barriers to accessing humanitarian assistance programs increase their protection risks, including risk of violence, abuse and exploitation. Women's Refugee Commission has been supporting the United Nations High Commissioner for Refugees and implementing partners to translate guidance on disability inclusion into practice at field levels through the provision of technical support to eight country operations. In the course of the project, WRC has consulted with over 600 persons with disabilities and care-givers and over 130 humanitarian actors in displacement contexts. Key protection concerns identified include a lack of participation in community decision making; stigma and discrimination of children and young persons with disabilities by their non-disabled peers; violence against persons with disabilities, including gender-based violence; lack of access to disability-specific health care; and unmet basic needs among families of persons with multiple impairments. Suggested strategies to further advance disability inclusion in humanitarian programming include: strengthening identification of protection risks and case management services for persons with disabilities; facilitating context-specific action planning around key guidelines; and engaging the disability movement in advocacy on refugee issues.

Keywords: Refugees; Disabilities; Displacement; Protection

Introduction

Worldwide, an average of 23,000 people are displaced daily – they leave their homes to seek safety and protection elsewhere, either within their own country or across borders into other countries (UNHCR, 2013). The World Health Organization (WHO) estimates that 15 percent of any population will be persons with disabilities (WHO and World Bank, 2011). There may be even higher rates of disability in communities that have fled war or conflict, as people acquire new impairments from injuries and/or have limited access to health care. Hence, there may be over 6.7 million persons with disabilities among the 45.2 million people forcibly displaced worldwide as a result of persecution and conflict (UNHCR, 2013).

The Women's Refugee Commission (WRC) seeks to advance the rights and dignity of refugees and displaced persons with disabilities through advocacy, research and capacity development initiatives to support disability-inclusive refugee policy and practice at

international and country levels. Towards this goal, the WRC has conducted research with populations affected by crisis and conflict to understand the needs and capacities of persons with disabilities (Women's Refugee Commission, 2008a), produced guidelines for humanitarian field workers on disability inclusion (WRC, 2008b), and advocated to the United Nations High Commissioner for Refugees (UNHCR) for greater attention to inclusion and access for this group in humanitarian programs.

Current literature recognizes that persons with disabilities are one of the most vulnerable and socially excluded groups in any displaced or conflict-affected community (The Sphere Project, 2011; WHO et al., 2013; International Federation of Red Cross and Red Crescent Societies, 2007; Kett et al., 2009; Kett et al., 2010). In 2008, the WRC undertook a six-month research project to assess the situation of persons with disabilities among conflict-affected populations in Ecuador, Jordan, Nepal, Thailand and Yemen. Findings demonstrated that persons with disabilities were hidden in shelters, overlooked during needs assessments and not consulted in the design of programs. They reported difficulty accessing humanitarian assistance programs, due to a variety of societal, environmental and communication barriers, increasing their protection risks, including violence, abuse and exploitation (WRC, 2008a).

There is now growing evidence that rates of violence may be 4-10 times greater among persons with disabilities than their non-disabled peers (WHO et al., 2011: 59). This has significant implications for the physical protection of persons with disabilities in situations of displacement, where community structures and social norms are altered (Inter-Agency Standing Committee, 2005). Women, children and older persons with disabilities are particularly vulnerable to discrimination, exploitation and violence, but they may have difficulty accessing the very support and services which could reduce their risk and vulnerability (UNHCR et al., 2011).

The *Convention on the Rights of Persons with Disabilities* (CRPD) requires states to ensure that persons with disabilities are protected in situations of risk or humanitarian emergency, and that international cooperation is inclusive of and accessible to this group (UN, 2006a). In humanitarian action, 'protection' is centered on the safety, dignity and integrity of the human being, and encompasses a wide range of activities 'aimed at ensuring full respect for the rights of the individual in accordance with the letter and spirit of the relevant bodies of law, i.e. human rights law, international law and refugee law' (Slim et al., 2005: 33).

In 2010, the UNHCR Executive Committee adopted a *Conclusion on Refugees with Disabilities and Other Persons with Disabilities Protected and Assisted by UNHCR* (UNHCR Executive Committee, 2010). This conclusion calls upon states, UNHCR and its partners to ensure the protection of persons with disabilities in refugee and displacement contexts, and their operational guidance on *Working with Persons with Disabilities in Forced Displacement* goes further to highlight that 'exclusion of persons with disabilities during displacement can be inadvertent or purposeful: in either case, nevertheless, it is discriminatory' (UNHCR et al., 2011: 4). This guidance is aligned with and supports the implementation of UNHCR's *Age, Gender and Diversity Policy* which details the organization's wider commitment to a rights-based approach, and highlights that effective protection can only be achieved by considering equality of different groups in the community, and promoting their participation 'in decisions that affect their lives and the lives of their family members and communities' (UNHCR,

2011).

Since 2011, the WRC has been partnering with UNHCR on the global roll out of its guidance on *Working with Persons with Disabilities in Forced Displacement* through field assessments and the provision of technical support and training to UNHCR country offices, implementing partners and disability organizations. This paper presents the key findings of field visits to refugee and displaced persons contexts in eight countries– India (New Delhi), Uganda, Thailand, Bangladesh, Nepal, Ethiopia, Philippines (Mindanao) and Lebanon – and discusses promising approaches to operationalizing guidance on disability inclusion in these humanitarian contexts.

Methodology

The purpose of field visits was two-fold – firstly, to conduct an assessment on access and inclusion of persons with disabilities in humanitarian programs, and secondly, to strengthen the capacity among UNHCR staff, implementing partners and local disability organizations to include displaced persons with disabilities in their programs.

Country operations were selected with feedback and facilitation from the UNHCR Division of International Protection in Geneva. Principles which guided selection of country operations were an interest in disability inclusion expressed by the UNHCR country office staff; geographical diversity; operational setting (for example, urban, protracted, camp, emergency response); and potential links to other priority strategies or initiatives of UNHCR (for example, the child protection framework; sexual and gender based violence strategy; education strategy). See Table 1 for a summary of the countries, operational contexts, and activities undertaken during the field visits.

Table 1: Summary of project sites

Country	Operational Context	Activities undertaken
India	New Delhi – Urban setting	Consultations with Afghan, Burmese and Somali refugees with disabilities and their families (29 participants). Interviews with humanitarian actors (5 interviews). Three-day workshop (26 participants).
Uganda	Kampala – Urban setting Hoima – Camp setting	Consultations with Somali, Eritrean, Rwandan and Congolese refugees with disabilities and their families (48 participants). Interviews with humanitarian actors (5 interviews). Two and half-day workshops in both Hoima and Kampala (55 participants).
Bangladesh	Cox's Bazar – Protracted camp setting	Consultations with Rohingya refugees with disabilities and their families in two camps (90 participants).

		Interviews with humanitarian actors (2 interviews). Three-day workshops in both Cox's Bazar and Nayapara refugee camp (78 participants).
Thailand	Mae Hong Son – Protracted camp setting	Consultations with Karenni refugees with disabilities and their families (26 participants). Interviews with humanitarian actors (14 interviews). Three-day workshop (42 participants).
Nepal	Damak – Protracted camp setting	Consultations with Bhutanese refugees with disabilities and their families (66 participants). Interviews with humanitarian actors (16 interviews). Two-day workshop (45 participants).
Ethiopia	Jijiga – Camp setting	Consultations with Somali refugees with disabilities and their families in three camps (142 participants). Interviews with humanitarian actors (17 interviews) Three-day workshop (33 participants).
Philippines	Conflict affected Mindanao - Internal displacement setting (rural)	Consultations with persons with disabilities and their families in conflict-affected communities (81 participants). Interviews with humanitarian actors (27 interviews). One-day workshops conducted in three priority municipalities for the Humanitarian Action Plan for Mindanao (68 participants).
Lebanon	Emergency response for Syrian refugees – Urban and rural settings (non-camp)	Consultations with Syrian refugees with disabilities and their families (127 participants). Interviews with humanitarian actors (48 interviews). Three-day workshops conducted in both Northern and Eastern Lebanon (50 participants)

Consultations undertaken in the scope of this project included group discussions with participatory activities and semi-structured interviews with persons with disabilities and care-givers, as well as interviews with humanitarian actors, to identify their perspectives on:

(i) Key protection concerns of persons with disabilities affected by displacement;
(ii) Gaps and approaches to disability inclusion in humanitarian programming; and,
(iii) Potential strategies to strengthen access and inclusion for persons with disabilities.

Group discussions and interviews were undertaken by the WRC Disability Program Officer, with support from UNHCR staff and partners. A risk assessment and strategies to mitigate

these risks was documented by WRC staff as part of the field visit methodology, and then implemented in the different contexts according to UNHCR protocols and recommendations. Participants gave verbal informed consent following a briefing about the purpose and scope of each activity, which included interpretation into local dialects and sign language. In some cases, visual aids were also employed to demonstrate how information would be used in reports. All participants were advised of available services and given information on how to access these services, and individuals requiring additional support were followed-up by UNHCR staff.

Persons with disabilities and their families were identified and invited to participate through UNHCR staff and partner organizations working with displaced communities. Persons with disabilities were defined as 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others' (UN, 2006b: 4). More detailed instruction was given to partner organizations about identifying persons with disabilities based on activity limitation and drawing on the work of the *Washington Group Questions on Disability* (Centers for Disease Control and Prevention, 2010).

A total of 609 persons with disabilities and care-givers were consulted in 37 group discussions and 28 interviews across the eight countries. Over half (56 percent) of participants were women. All group discussions and interviews with refugees were conducted through an interpreter using local dialects or sign language.

Efforts were made to include a diversity of persons with disabilities. In most settings, group discussions were conducted with men and women separately to gather more specific information about their different concerns. In several settings, transportation or an allowance was provided to facilitate access for persons who may be unable to walk to the location of the group discussions. In some contexts, smaller groups were formed and participatory activities were employed, such as drawing and photos, to stimulate discussion and elicit the perspectives of children, adolescent girls and youth with disabilities, as well as persons with intellectual disabilities. Smaller groups were also employed to gather information from deaf persons using sign language.

Home visits were conducted to interview individuals with disabilities who were unable to attend the group discussions. This approach was most commonly employed for persons with multiple impairments unable to move from their shelters, and those with mental disabilities[1] who were more comfortable participating in a familiar environment. Home visits also provided an opportunity to assess the standard of living of persons with disabilities and to understand better the challenges to access and inclusion which they face in the community.
Humanitarian actors were identified for interview through UNHCR staff and referrals from key informants. These participants included representatives from UN agencies, non-governmental organizations (NGOs), disabled people's organizations (DPOs), and national and local level government bodies. A total of 134 interviews were conducted in the eight countries during the course of the field visits.

Information gathered in both the group discussions and interviews was then analyzed for common themes crossing all contexts in key domains, including protection concerns, gaps and approaches for disability inclusion in humanitarian programming.

Workshops on disability inclusion in programs for refugees and displaced persons: Over 390 humanitarian actors attended workshops in these countries. Workshops were designed for UNHCR country offices, partner organizations and host country disability organizations. Workshops supported participants to:

- Recognize protection concerns and capacities of refugees and displaced persons with disabilities;
- Apply the CRPD and the UNHCR guidance on *Working with Persons with Disabilities in Forced Displacement* to their programs and sectors;
- Identify strategies to promote access and inclusion for persons with disabilities in key activities of their programs and;
- Design action plans to promote disability inclusion in their work sectors in collaboration with key stakeholders.

Limitations

In some contexts where there were refugees from several countries, groups were based on nationality, and time limitations prevented further disaggregation, including by sex. These mixed groups may have been less likely to express concerns about sensitive issues such as sexual and reproductive health and gender-based violence (GBV). In Bangladesh, cultural factors and a lack of privacy in the community, also posed limitations for discussions on such topics. Despite these limitations, participants did share information relating to these issues.
The vast majority of deaf persons participating in consultations used a form of unofficial sign language, requiring familiy members to interpret for them. This may have biased responses from individuals and/or affected the accuracy of information conveyed. Although persons with intellectual and mental disabilities were consistently engaged in all contexts, care-givers were often spoke on their behalf. Field staff also relied on information from care-givers of some persons with multiple disabilities. The presence of UNHCR staff in group discussions and interviews may have also biased responses from refugees, but was an important component to developing staff capacity to conduct future consultations with persons with disabilities in participatory assessments and country operations planning. It also facilitated the identification and follow-up of protection concerns expressed by individuals with disabilities.

Findings

Consultations in the different countries identified the following common protection concerns for persons with disabilities, as well as gaps and approaches to promoting disability inclusion in humanitarian programming.

Protection concerns of persons with disabilities

The most common protection concerns reported by persons with disabilities and their care-

givers across different contexts were a lack of participation in community activities and decision making; stigma and discrimination, especially among children and youth; emotional, physical and sexual violence; lack of access to disability-specific health care; and unmet basic needs among families of persons with multiple impairments. I shall outline these in the subsections below.

Participation in community activities and decision making

Persons with disabilities are still rarely included in refugee committees and associations, or consulted by the refugee leadership in community decision making processes. Informal associations and groups of refugees with disabilities are increasingly present, particularly in camp contexts, providing a vehicle for consultation with persons with disabilities on their needs and ideas. In many contexts, however, the procedures linking these groups to formal decision making mechanisms required strengthening, so that refugee leaders and organizations would consult with them on a regular and ongoing basis:

> *You are the first person to talk to us. Even for us who formed an association, they don't talk to us, ask us what we need. (Participant in group discussion with men with disabilities and male care-givers in Ethiopia)*

There may be added challenges in consulting with persons with disabilities in displacement settings where people are geographically dispersed. In situations of internal displacement, such as conflict-affected Mindanao, grass-roots groups of persons with disabilities were largely inactive due to repeated episodes of displacement, making it difficult for local leaders and humanitarian organizations to locate, mobilize and consult with persons with disabilities in planning processes. Similarly, refugees with disabilities in Lebanon remain scattered across the country posing challenges for meaningful information dissemination and consultation in refugee programming.

Another important finding relating to participation was that very few refugees and displaced persons with disabilities had contact with DPOs which play a critical role in advocating for the rights of persons with disabilities. The host country DPOs consulted in this project demonstrated a lack of knowledge and awareness of the situation of refugees and conflict-affected populations. Only two DPOs interviewed in Lebanon had significant contact with refugees. In all other countries, DPOs had almost no contact and/or information about conflict-affected and refugee populations. Hence, DPOs were neither actively engaged, nor invited to contribute their expertise to these humanitarian responses.

Persons with disabilities and their care-givers reported a number of other barriers which may hinder their participation in community activities and meetings. Parents and care-givers of persons with multiple disabilities reported being unable to attend community events, as they have to remain at home to care for their family member. Persons with disabilities in some camp contexts also reported that even if they are invited to community activities, they may not fully participate because of a lack of confidence:

> *Even I don't feel confident and a little ashamed to go amongst people. Usually when there is an event, we sit together at the back. (Interview with a man with disabilities in*

Thailand)

These findings demonstrate the importance of comprehensively analyzing and addressing barriers to participation in both community and programmatic activities, including environmental, communication, attitudinal and policy factors (CBM, 2012).

Stigma and discrimination of children and young people with disabilities

Children with disabilities and their care-givers across all countries reported that children with disabilities are often teased and discriminated by their non-disabled peers, both in and out of school. Parents, children and young persons with disabilities all reported that this behavior made them reluctant to attend school:

> *Other children tease them in the school. Children with intellectual impairments get the most problems from other children – they get demoralized. When they take the child to school, he is discriminated and starts hating the children, teachers and then mother because she keeps sending him to school. The mother even gets demoralized. (Participant in group discussion with female care-givers in Ethiopia)*

Care-givers and humanitarian actors consulted in the project percieved that separate and specialized education was needed for children with disabilities to prevent them from being 'bullied' by peers and to optimize their learning potential. In many countries where refugees and displaced persons are hosted, there is also a focus on separate or 'special' education for children with disabilities. This poses challenges to the ensuring Article 24 of the CRPD for refugees, which requires that supports are provided to facilitate the participation and optimal learning of children with disabilities in the general education system (UN, 2006a). In some urban settings children with disabilities were accessing 'special education' with support from local NGOs. In the camp settings, however, children with disabilities faced multiple barriers in accessing education, with the exception of the Karenni refugee camps in Thailand where the Jesuit Refugee Service had integrated community awareness raising through Parent – Teacher Associations and capacity development of teaching staff to promote inclusive education.

Adolescents and young persons with disabilities reported being excluded from social networks and community activities. In New Delhi, adolescent boys described how they feel *'rejected'* and *'bad and sad because, I don't have many friends'*. Girls and young women with disabilities highlighted that they are often excluded from activities with other girls, and social stigma reduces their confidence to engage in such networks:

> *We're not the same as other girls – they wander around, wear beautiful clothes and go to the market. We don't feel like girls, we are different…. In the school we are separated from other girls – they talk ill of us. (Adolescent girl with disabilities in Ethiopia)*

Hence, girls with disabilities are less likely to build friendships and social capital which has been identified as an effective mechanism in reducing vulnerability of adolescent girls to GBV and other protection concerns (Women's Refugee Commission, 2013b).

Violence against persons with disabilities

Persons with disabilities in all contexts reported experiencing different forms of physical and psychological violence perpetrated by members of their communities and families, as well as by strangers.

Sexual violence was mentioned by women and girls with disabilities in all countries, although the level of detail varied according to context and culture. The risk of sexual violence may be more significant in urban settings and new displacement contexts where there is less cohesion in the community and where community-based protection mechanisms are weakened. Concrete examples shared by women with disabilities and care-givers, suggest that adolescent girls with intellectual disabilities and women with mental disabilities, may be more vulnerable to sexual violence in these contexts due to a lack of knowledge about GBV and personal safety, which means that they may be more easily targeted by perpetrators. Community perceptions that persons with disabilities will be unable to physically defend themselves from a perpetrator or effectively report incidents of violence, was also described as a factor which increased vulnerability of women and girls with disabilities. Extreme poverty and lack of basic needs was proposed in group discussions to increase the risk that women and girls with disabilities may be abused and exploited, or resort to survival sex and prostitution:

> *If you have a disabled girl, you always worry – a man might come and give her money. She takes the money to get food and he will ask for something back – she will end up pregnant. (Mother of young woman with disabilities in Ethiopia)*

Finally, in two contexts, women with disabilities said they may not report cases of GBV, nor access services, due to the negative attitudes of service providers who may question their credibility:

> *They tell me to go away and to not be violent towards (these) people' (Woman with psychosocial impairments living in conflict affected Mindanao when asked about the response of police to her reports of 'molestation')*

Although less prominent, there were reports in most contexts that men and boys with disabilities also experience physical and/or emotional violence and abuse in their families and communities. Men with disabilities in several camp contexts reported having their eye glasses, wheelchairs and other devices stolen or damaged by members of the community. Family and community members may also perceive that men with disabilities are unable to fulfill the roles expected of men in their society, which makes them vulnerable to neglect and emotional abuse within the extended family in some settings:

> *Most of these men here [in the group discussion], even their wives have left them because of disability ... The wife will say they are suffering because you can't get water and carry things – things the family needs. When we discuss with the woman's father, he says you deceived her by becoming disabled. (Man with disabilities from Shedder camp, Ethiopia)*

Dependence on care-givers, isolation and a lack of contact with community networks also exposes both men and women with disabilities to different forms violence inside the home. Detailed examples of physical and emotional violence, as well as exploitation, being perpetrated by care-givers and/or extended family members inside the home towards adults with disabilities were identified in three camp contexts. As described by a deaf Bhutanese refugee in Nepal:

> *To outsiders everything looks fine, but actually they are neglected, beaten and abused by the family. (Participant in group discussion with deaf women living in Nepal)*

In some settings, for example in Lebanon, families of girls and women with intellectual disabilities, were using negative coping strategies such as physical restraint to prevent the individual from going outside or from hurting themselves and others in the household. Limited independent living options for refugees and displaced persons with disabilities in both camp and urban contexts, adds to stress and neglect in extended families and crowded shelters, and limits the options available for persons with disabilities requiring assistance with daily care and mobility.

Access to disability-specific health care

Persons with disabilities have a right to access not only the same health services as others, but also disability-specific health services such as therapy and rehabilitation, assistive devices and specialized surgical or medical interventions, which would enable them to 'attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life' (UN, 2006b: 19). The *World Report on Disability* highlights that persons with disabilities have greater unmet health needs than the general population due to a variety of barriers, including affordability of health care and transportation, limited availability of specific services, environmental barriers in facilities, and a lack of skill or knowledge among health professionals (WHO and World Bank, 2011).

Refugees and displaced persons with disabilities face additional challenges in accessing disability-specific health services in host countries. Limited availability and poor quality was reported as a concern by persons with disabilities and care-givers in all countries and contexts in this project. In group discussions and interviews, they expressed that primary health care facilities were not able to meet their disability-specific health needs and that they wished to access more specialized services in urban centers. When this was unavailable, or still perceived inadequate, they also requested access to care in other countries, through resettlement programs.

In most camp settings, rehabilitation and assistive devices were available through disability-specific service providers, but refugees reported that devices were difficult to maintain, and took a long time to repair. In a few cases, this resulted in interrupted school attendance, particularly for adolescents with disabilities. Specialized surgical and medical interventions were also only available following referral to secondary and tertiary health facilities in urban centers. Access to such services was sometimes complicated by a lengthy approval process from health providers and/or UNHCR, and often required prolonged stays or repeated visits,

resulting in families being separated for periods of time and interruption of school attendance for children with disabilities.

In urban contexts such as New Delhi and Kampala, the biggest barrier to accessing health care was money to pay for transportation to the health centers and hospitals. Participants also reported loss of income in households, as family members may have to accompany persons with disabilities to health appointments, and therefore be unable to work.

Consultations with persons with disabilities in Lebanon included a large number of Syrian refugees with new disabilities as a result of war injuries. Due to the size of the refugee population and significant resource limitations, most disability and health service providers were only able to provide life-saving interventions for persons with new injuries, and there was a significant gap in provision of longer-term care and rehabilitation services (UN, 2013). Some refugees reported paying for surgical and rehabilitation services out of their own funds, depleting what limited savings they had available to them and adding to the financial strain on them and their families. Many others reported having only limited social and physical support upon discharge from hospital, followed by prolonged periods of time isolated in their home. This increased their vulnerability to protection concerns, including neglect and abuse, but also had a significant impact on their psychosocial wellbeing, as described by this adolescent girl, now unable to walk as a result of a war-related injury:

> *She is unhappy about the way she was kicked out of the hospital–they told her that a new injury should take her place and gave no recommendations about what should happen next…When her husband is away, she has time to think about her situation and she feels very sad – she feels very negative about this situation. (Interpreted interview with an adolescent girl with new physical disability in Lebanon)*

A study of health care in humanitarian settings conducted by Mirza (2011) also identified that disability-specific services were rarely part of the 'basic bundle' of health services delivered in humanitarian programming. Addressing the disability-specific health needs of refugees and displaced persons with disabilities, is therefore limited not only by the availability and quality of these services in the host country, but also resource limitations. This often raises questions about 'distributional ethics', particularly in countries where the cost of specialized surgical and medical interventions are high. Refugees and asylum seekers with disabilities also face additional challenges in accessing service outside the 'basic bundle' due to complex referral or approval processes, which are linked to their refugee status in host countries (Mirza, 2011).

Transportation to services and programs

Persons with physical disabilities reported that distance and a lack of affordable transportation limits their access to services and programs, most commonly education and health services. In most camp settings, there are no transportation services available. Children and young persons with disabilities must rely on wheelchairs and other devices to move long distances to school facilities. In some settings such as Thailand, the terrain makes the use of wheelchairs for such distances unrealistic. In urban settings, transportation is available, but persons with disabilities and care-givers expressed concerns about the cost. In all urban settings, however, there were processes for refugees with specific needs to seek transportation

allowances from UNHCR and its partners. A lack of affordable transportation may also result in increased vulnerability to exploitation, and in many camp contexts persons with physical disabilities reported giving money or proportion of their rations to people who assist them to transport rations between the distribution sites and their homes.

Needs of persons with multiple impairments

Group discussions, interviews and home visits highlighted the unmet needs of persons with multiple impairments and their care-givers in seven out of the eight countries. Persons with multiple impairments are often unable to leave their homes or shelters and may require full assistance in toileting and bathing. Care-givers expressed that this makes their living conditions worse than other refugee households. As such, they have an increased need for basic supplies such as soap, water, cloth or diapers, and mattresses compared with other refugee families, to ensure personal hygiene and care.

Care-givers also expressed concerns about their own psychosocial well-being, as they must stay at home with their family member and have little contact with other community members or activities. They also experience 'worry' about who will care for their family member if they were no longer able to be a care-giver, due to a lack of support networks and social protection:

> *The most scary thing is what will happen after I pass away – who will take care of her like me. (Mother of young person with disabilities in Thailand)*

Approaches to disability inclusion in humanitarian programming

There is now an increased commitment in the humanitarian community to promote the rights of persons with disabilities in humanitarian action as demonstrated through the growing body of standards and guidelines that consider persons with disabilities and/or disability issues (The Sphere Project, 2011; WHO et al., 2013; UNHCR et al., 2011; Handicap International, 2005). Consultations with humanitarian actors in this project highlighted different approaches to inclusion of persons with disabilities currently being employed in humanitarian programming. These approaches are presented below as 'disability-specific initiatives' targeting persons with disabilities, and 'mainstreaming (or disability inclusive) initiatives' (CBM, 2012).

Disability-specific initiatives

Out of the 134 humanitarian actors consulted in this project, 22 were delivering services targeting the specific needs of refugees and displaced persons with disabilities. Disability-specific services being delivered in the different sites included physical rehabilitation and assistive devices (Lebanon, Ethiopia, Nepal and Thailand); sign language training (Nepal); representative organizations of refugees and displaced persons with disabilities (Kampala and Ethiopia); livelihoods and skills training (Nepal and Lebanon) and special education (New

Delhi and Thailand).

In some sites, disability-specific programs and activities were not effectively linked to community inclusion. Community members, as well as humanitarian actors, often deferred to the organizations delivering these services, rather than consulting directly with persons with disabilities and adapting their activities to promote inclusion:

> *We have places for them – Disability Centers. Since they are in a different section and looked after by a different organization, the CMC (Camp Management Committee) works with those organizations. (CMC member in a refugee camp in Nepal)*

Bangladesh had no disability service providers operational in the camps at the time of the field visit, but UNHCR had taken a lead role in coordinating awareness raising activities for the International Day of Persons with Disabilities, as well as conducting a survey and distributing wheelchairs to children. There were also significant gaps in community-based rehabilitation services for persons with disabilities displaced in conflict-affected Mindanao, with most services being located in urban centers. In these settings, it is even more critical for existing implementing partners to adapt their programming to meet both the basic as well as specific needs of persons with disabilities.

Mainstreaming (or disability inclusive) initiatives

In many contexts, humanitarian actors were adopting strategies to promote access and inclusion for persons with disabilities in mainstream humanitarian activities. Examples of such approaches included establishing partnerships with host country DPOs to implement community center-based activities (in Lebanon); including staff from disability programs in HIV/AIDS training (Nepal); ensuring a quota of persons with disabilities in UNHCR participatory assessments (Ethiopia); adapting rapid assessments to include questions on persons with disabilities (Mindanao); inclusive education (Thailand); and organizations appointing focal points for persons with disabilities (Uganda and New Delhi).
The vast majority of these initiatives, however, were isolated examples, largely led by motivated individuals within the engaged organization, and had not yet been institutionalized within organizational systems and processes. In Lebanon, however, UNHCR requested technical support on disability inclusion early in their operations planning, identifying the needs of persons with disabilities and promoting more systematic inclusion from the outset of their response.

Data collection on persons with disabilities and monitoring inclusion

Collecting, collating and analyzing data about refugees with disabilities and their needs can assist in humanitarian planning and programming, but also monitoring access and inclusion in programs. UNHCR's global registration database (proGres) is one of the most centralized portals of such data in refugee contexts, and is disaggregated for different types of disability and other specific needs. It is completed primarily at point of registration and then updated throughout UNHCR's contact with an individual and their family. UNHCR data ranges from

2 to 7.5 percent prevalence for disability in the refugee populations in Lebanon, Bangladesh, Ethiopia and Nepal. These figures are lower than global estimates, suggesting that there may be some gaps in identifying persons with disabilities and/or recording this information accurately in current databases.

Organizations delivering disability-specific services use different definitions of persons with disabilities, and the data they collect largely reflect those accessing the services of that organization. As a result, this data does not reflect the diversity and needs of the disabled population for the purposes of wider country operations planning. Finally, very few organizations delivering mainstream services are disaggregating their data for disability to determine if persons with disabilities are in fact accessing their programs and activities.

Discussion

Literature suggests that persons with disabilities and their families are more likely to experience poverty than those without disabilities (WHO et al., 2011; Mitra et al., 2011; Palmer, 2011). Exclusion, stigma and discrimination reduces their social, economic and human development opportunities (CBM, 2012). They may experience economic deprivation due to reduced income generating capacity, additional needs and expenses related to their disability, and increased care-giving responsibilities within households (Palmer, 2011).

Persons with disabilities and care-givers consulted in this project describe protection concerns resulting from a range of compounding factors which disadvantages them in comparison to other displaced persons, as well as other persons with disabilities in the host country. Conflict and displacement increases the risk of new impairments and/or deterioration in existing impairments, due to injuries, poor access to health care or inadequate rehabilitation services. These impairments, in interaction with the complex attitudinal, environmental, communication and policy barriers inherent in a displacement context, hinder their participation in social and economic opportunities compared with others. For example refugees with disabilities may experience discrimination in the already limited income generation opportunities which are available to refugee populations in host countries. Care-givers of displaced persons with disabilities, especially in new displacement settings, may also find it difficult to work or participate in community activities due to changes in social support networks which might have previously assisted with care-giving. Despite having less access to financial resources and economic opportunities, refugees and displaced persons with disabilities have needs which may carry additional costs for them and their households, such as transportation, as described in urban contexts; health and medical services, as demonstrated among persons with new impairments in Lebanon; and even extra soap, clothing and blankets for persons with multiple disabilities, as described by their care-givers in many contexts. In this way, displaced persons with disabilities and their households may experience a cycle where ‘disability and poverty reinforce and perpetuate each other’ (CBM, 2012: 6), exposing them to ongoing, complex and intersecting protection concerns.

Persons with disabilities consulted throughout the course of this project demonstrated such concerns, with unmet needs crossing both the medical and social dimensions. There is still,

however, a tendency for humanitarian agencies to refer the vast majority of persons with disabilities to service providers for health, rehabilitation and provision of assistive devices, sometimes failing to recognize other factors. These factors might include children being out of school, living in substandard shelter, being single parents or care-givers or single women with disabilities, the latter requiring a more comprehensive assessment and referral to a variety of other non-health-related services.

Case management provides a critical entry point to assessing the protection risk and vulnerability of persons with disabilities, and the provision of timely and coordinated support to persons with specific, complex and/or multiple needs. It also serves as a guide to prioritized service delivery in resource limited settings (WRC, 2013a). In response to this finding, the WRC developed and piloted a training package on *Individual Case Management – Identifying and Responding to the Needs of Persons with Disabilities* for case managers currently engaged in the Syrian refugee response in Lebanon (WRC, n.d.).

A variety of guidelines on disability inclusion are now available for humanitarian actors (CBM, 2012; Handicap International, 2005; WRC, 2008b; UNHCR et al., 2011). These guidelines are largely principle-based and require field actors to define more detailed action plans which are specific to programs, contexts, and priority needs or gaps.

In each country in this project, the WRC conducted workshops designed for UNHCR country offices, partner organizations and host country disability organizations, supporting them to apply existing guidance on disability inclusion in their given operational context (WRC, n.d.). Findings from consultations with persons with disabilities and humanitarian actors in each country, were used to adapt workshop objectives and content. In some contexts, workshops were adapted to focus on a specific sector. For example, in Nepal, the workshop focused on *Disability Inclusion in Gender-Based Violence Programming*; and in Mindanao one-day disability awareness sessions were conducted with local government units. All workshops utilized participatory methodologies to promote collaboration and sharing of knowledge between stakeholders, and facilitated action planning to translate largely principle-based guidance into tangible actions at field levels.

These workshops also served as a positive vehicle to bridge the gap between persons with disabilities and humanitarian actors, and promoted their participation in program planning and decision making. Persons with disabilities consulted in group discussions, were asked to appoint representatives to share their protection concerns and suggestions for change in the workshops. This approach highlighted their skills and capacities, and potential to contribute to programs and activities like other community members:

> *We are delighted as we have got a workshop with disabilities. Things we liked (were) participation of persons with disabilities; they are honored as human beings in the workshop; (and) group discussions with all to solve problems. We want this type of workshop in the future in the camp. (Representative from the Camp Management Committee in Bangladesh)*

Finally, the disability movement and DPOs can also play a critical role in bridging the humanitarian – disability divide. Despite many host countries having ratified the CRPD, refugees and displaced persons with disabilities may be excluded from CRPD

implementation and monitoring processes. In some contexts, DPOs have the potential to provide capacity building to grass-roots groups and peer support to individuals with disabilities. Host country DPOs may also direct humanitarian actors towards disability-specific services and/or advocate for refugees to access national disability policies and programs. WRC has been raising awareness with host country DPOs through their participation in workshops, and is now providing sub-grants to DPOs for follow-up activities in priority countries. This is complemented by global advocacy in partnership with UNHCR and DPO partners at key human rights events, such as the Conference of State Parties to the Convention on the Rights of Persons with Disabilities.

Conclusion

Women's Refugee Commission has supported UNHCR, its implementing partners and disability organizations to translate guidance on disability inclusion into practice at field levels through the provision of technical support to eight different country operations, including camp and urban refugee contexts, internal displacement and emergency response. In the course of the project, WRC has consulted with over 600 persons with disabilities and care-givers and 130 humanitarian actors. Refugees and displaced persons with disabilities have played a central and active role in this work, contributing to group discussions and presenting their perspectives and ideas in workshops with humanitarian actors.

Refugees and displaced persons with disabilities experience complex and intersecting unmet needs in humanitarian contexts which increases their vulnerability to protection concerns, including violence, abuse and exploitation. While considerable and commendable progress has been made in the humanitarian community on disability awareness and there are increasing examples of strategies to promote access and inclusion in selected humanitarian activities, there is still a gap in systematic inclusion across all humanitarian organizations and programs.

Notes

[1] In this paper, 'persons with mental disabilities' is used to reflect the interaction between mental impairment and attitudinal and environmental barriers which contribute to disability as described in the *Convention on the Rights of Persons with Disabilities*. It refers to persons with mental health conditions, mental health users and/or survivors of psychiatry, or persons with psychosocial disabilities.

Further notes

The WRC conducted follow-up field assessments to two country operations in late 2013 to investigate progress in the implementation UNHCR guidance on *Working with Persons with Disabilities in Forced Displacement*, positive practices and ongoing challenges, as well as the outcomes for refugees and displaced persons with disabilities. A report documenting these

findings and recommendations to further advance disability inclusion in humanitarian action can be accessed at: http://womensrefugeecommission.org/programs/disabilities/research-and-resources

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