Rohingya refugees with disabilities: Prevalence, meaningful access, and notes on measurement

CONTEXT AND INFORMATION GAP

During the last four decades, Rohingya refugees have been fleeing in successive waves to Bangladesh, seeking safety from systematic and ongoing persecution in Rakhine State, Myanmar. Since August 2017, an estimated 745,000 Rohingya refugees have arrived in Cox’s Bazar, Bangladesh, increasing the total number of Rohingya refugees to more than 905,000. In response, national and international organisations have been delivering humanitarian assistance alongside the government of Bangladesh and UN agencies. A core component of the humanitarian 2019 Joint Response Plan aims to address the meaningful and dignified inclusion of all vulnerable groups, including persons with disabilities who may have suffered greater consequences of forced displacement, during and after their flight, due to potential heightened vulnerability.

Global commitments outlined in the Charter on Inclusion of Persons With Disabilities in Humanitarian Action, an initiative emerging from the 2016 World Humanitarian Summit, highlight the importance of collecting disability-disaggregated data to meaningfully include persons with disabilities in planning, implementation, and monitoring of humanitarian programming. Information is available on displaced and vulnerable Rohingya communities in central Rakhine through the Sittwe profiling exercise conducted by the Joint Internally Displaced Person Profiling Service (JIPS). However, in the context of the Rohingya refugee response, comprehensive data on this population group has not previously been conducted in a systematic fashion. Previous surveys have provided estimates on household-identified disabilities, while others have provided an in-depth analysis of service gaps and challenges in localised areas such as Jadimura (Camp 27).

This brief therefore aims to support the need for evidenced-based inclusion mainstreaming and planning across multiple sectors, through the provision of response-level findings systematically collected through the Washington Group (WG) Questions, which have emerged as one of the key methods for surveys and censuses to identify persons at risk of participation restrictions. In addition, this brief highlights considerations and limitations regarding the methodology of disability measurement in the context of Cox’s Bazar, drawing on lessons learned from recent assessments.

METHODOLOGIES

Questions on disability and functional difficulties were integrated within multiple in-depth sectoral assessments conducted by REACH in 2019: an Education Needs Assessment in February 2019 and a WASH household survey in May 2019. This brief compiles findings on the disability components of these assessments to provide a more focused overview.

For all assessed households, WG questions were asked by proxy rather than directly for each individual member, with one adult respondent providing information on behalf of all household members. Households were selected through a simple random sample of shelter footprints stratified by camp boundaries. In order to capture the experiences of female and male refugees, respondents were interviewed by an enumerator of the same gender, with enumerator teams split evenly between women and men. Both assessments were conducted in 33 of 34 refugee camps in Cox’s Bazar district.

- **WASH Household Survey**: Information on disability was collected using the Washington Group Short Set (WGSS) questions and therefore encompasses all individuals aged five years and older. The WGSS questions focus on the presence of difficulties in six core functional domains: walking, seeing, hearing, cognition, self-care and communication. All refugee households in the 33 camps were eligible for participation in the assessment.

- **Education Needs Assessment**: Information was collected using the UNICEF/WG module on child functioning, which includes a wider variety of questions inclusive of emotional functioning, with different variations for children under five and children aged 5-17. Households with at least one individual aged 3-24 were eligible for inclusion in the survey, and surveys were conducted with self-identified primary caregivers.

The WG modules ask respondents to classify each individual’s level of functioning according to a four-point scale ranging between “no difficulties” and “cannot do at all”. For both assessments, individuals reported as having “a lot” of difficulty or being completely unable to perform a task in any one of the six domains were classified as having a disability (disability-3 thresholds as per WG guidance). Findings in this brief are presented at the overall response level and can be generalisable to all refugee households living in these 33 camps with a 95% confidence level and a 2% margin of error.

**DISABILITY PREVALENCE**

14% of households have at least one individual with a disability

| 60+ years | 34% |
| 18-59 years | 5% |
| 12-17 years | 1% |
| 5-11 years | 2% |

The above estimated disability rates are drawn from the WASH household survey from May 2019. Current rates of disability appear similar to the JIPS profiling exercise conducted in Rakhine state in 2016/17, where individual disability rates were estimated to be between 2.5 - 2.9% in the Muslim villages and camps. However, disability rates may not be directly comparable, as the JIPS profiling focused on the population living in and around Sittwe township in Central Rakhine, while much of recent displacement into Bangladesh was a result of violence in northern Rakhine state.

Rates of disability in the Rohingya refugee camps are lower than global estimates likely due to the young demographics of the population. As per the trends found in the 2014 Myanmar census cited in the JIPS report, disability rates start to rise after the age of 40. UNHCR currently estimates that less than 2% of refugees living in Cox’s Bazar camps are 60+ years old, and assessment findings indicate that this population is disproportionately affected by disability. No significant differences in rates of disability were found between male and female individuals.

1. Inter-Sector Coordination Group. September 2019 Rohingya Response Situation Report.
4. Kutupalong registered camp was excluded from all three assessments due to ongoing security concerns.
6. The 2011 WHO/World Bank report on Disability estimates that roughly 15% of individuals lives with a disability globally.
7. RRRC/UNHCR population data and key demographical indicators. 15 August 2019.
Among the 5% of individuals over the age of five reported as having a disability, the most common functional difficulty was related to mobility, followed by vision/sight and self-care.

% of all individuals reported as having difficulties in each assessed functional domain

Among individuals with physical or cognitive difficulties identified by the WASH household survey, 34% were reported as having been able to access support services in Bangladesh (e.g. specialised equipment or rehabilitation services). The format of a household survey did not allow this finding to be further explored to understand individual or household preferences to address this reported gap in support for affected individuals. Additional research would be required to inform programmatic decisions to increase the regularity of support, introduce more targeted and/or expansive services, or community-centred approaches.

The remainder of this section outlines some specific challenges reported to affect persons with disabilities through the sectoral assessments. However, as these assessments were not specifically designed to capture the holistic in-depth experiences of persons with disabilities, they do not purport to cover the full range of information required to assess equitable and meaningful access to all services, social and community networks, and other dimensions required to lead a dignified life.

Water, Sanitation, and Hygiene (WASH)

A higher proportion of individuals with disabilities were reported to face difficulties accessing all WASH-related facilities - water points, latrines, and bathing facilities - compared to individuals without disabilities. The assessment captured problems accessing communal, shared, or self-made latrines only (and excludes single household latrines). More than half of individuals with a disability were reported to face difficulties related to water access. The most frequently reported challenges for all individuals - long waiting times, facilities being too far, overcrowding, or the path being too steep - may all have compounding effects for persons with disabilities.

% of individuals reported as facing problems accessing facilities

Finally, individuals (over the age of five) with disabilities identified through the WASH assessment were significantly more likely to be reported as having diarrhoea in the two weeks prior to data collection (17%) as compared to individuals without disabilities (7%).

Education

For children within the 3-5 and 5-14 age groups, those with functional difficulties were reported to be attending learning centres at a lower rate than their peers without functional difficulties. This trend was more pronounced for attendance rates for children aged 3-5, underscoring disparities in inclusion beginning during early childhood development. In the below chart, children with a disability refers to individuals who were reported as having non-emotional functional difficulties, including seeing, hearing, walking, self-care (or fine motor control for children aged 3-5), communication, learning, remembering, and concentrating.8

% of children reported attending temporary learning centres (TLCs) at least four days a week in the month prior to data collection

Children aged 15-18 were reported as attending learning centres at low rates regardless of reported ability levels, indicating that limited coverage of age-appropriate curricula are likely more critical impediments to attendance at this level.

As part of the assessment, 22 focus group discussions were conducted, four of which were with parents of boys and girls with disabilities. During these discussions, 76% of respondents stated that learning centres were a good introduction to education, with the majority of respondents indicating that they were beneficial in terms of social inclusion and self-confidence.

% of individuals reported as feeling unsafe accessing or using facilities

8. Information was also collected on children with emotional functional difficulties, such as controlling behavior and for children 6-18 accepting change, making friends, anxiety, and depression. The exclusion of emotional difficulties in this brief is largely to maintain consistency with findings resulting from WGSS. Assessment findings indicate that children with emotional difficulties were reported to access educational facilities at a higher rates than their peers with other disabilities, but still lower than children with no difficulties. More information can be found in the dataset and/or report from this assessment.
discussions, parents cited a number of specific barriers constraining their children’s meaningful participation at learning centres, highlighting the fact that they needed to accompany—and sometimes physically carry—their children to learning centres each day. Parents expressed feeling unable to accompany their children consistently, especially during the rainy season. Participants in all four discussions highlighted bullying at learning centres as a consistent issue faced by their children with disabilities. Several parents spoke specifically about their children experiencing both verbal and physical abuse from other children, and the negative impact this had on their children’s willingness to attend classes. A smaller number also reported that, due to being unable to access specialised support, their children would grow frustrated at their inability to progress at learning centres, leaving parents struggling to persuade them to attend.

In these respects, it is important to note that only 26% of staff surveyed at learning centres during this assessment (February - March 2019) reported receiving training on supporting children with disabilities, suggesting that staff and volunteers may not be fully-equipped to handle some of the issues raised above. Further, only 14% of assessed facilities were wheelchair-accessible, which may signify limited mainstreaming of physical adaptations.

**DISABILITY MEASUREMENT IN THE COX’S BAZAR CONTEXT**

A comparison of disability prevalence estimates in the context of Rohingya refugees living in Cox’s Bazar indicates that asking the WGSS questions by proxy for each individual household member resulted in higher rates of reporting as compared to estimates using other methodologies. The WGSS questions for each individual produced an estimated 14% of households with a member with a disability, higher than the following:

i) The fifth round of the UNHCR/REACH Settlement and Protection Profiling assessment, conducted in July - August 2019, adapted the WGSS questions to ask whether any household member faced difficulties in each of the six domains. This approach produced an estimate of 9% of households with at least one individual with a disability, suggesting that questioning WGSS questions at the household level may not fully capture the presence of individuals with disabilities, as compared to an individual-level approach to measurement.

ii) Findings from assessments that ask respondents to report on “disability” more generally, without specifying specific domains of disability also tend to lead to lower estimates of disability. The UNHCR Key Demographic Indicators dataset estimates roughly 5% of Rohingya refugee households with an individual with a disability, and the recent Joint Multi-Sectoral Needs Assessment estimates roughly 10% of Rohingya refugee households with an individual requiring assistance to complete daily activities.

However, the estimated 14% of households with a member with a disability may still represent a lower bound on possible disability prevalence among the Rohingya refugee population. While WG questions are specifically designed to avoid stigmatising language, considerable stigma is reportedly attached to disability—especially psychological disability—in Rohingya communities. Meaning respondents may be reluctant to discuss disabilities among individual household members. Additionally, as outlined in a review of using WG questions in humanitarian and development contexts, the ideal and most dignified measurement for disability requires speaking directly to individuals regarding their own levels of ability in each functional domain. Evidence suggests that collected data on individuals by proxy, while deemed acceptable by the Washington Group, can result in under-reporting. Finally, it should be noted that disability is a complex concept and the WG questions are designed to identify most, but not all disabilities. Disabilities that may be harder to measure, including among younger children under five, would not have been captured through the WGSS.

**NEXT STEPS**

A targeted disability assessment could deepen understanding of the lived experiences of Rohingya refugees with disabilities, which is currently still incomplete. Potential areas of focus could encompass perspectives of specific needs, barriers, and challenges for affected individuals and their family and community members, while also exploring key gaps and areas for improvement for service and information providers. A focused study on this population should speak directly with individuals with disabilities and apply WG measurement tools directly, in order to more closely capture their experiences in a dignified way, instead of through proxy.

For other future assessments seeking to incorporate disability within their analysis, the WGSS of six questions should be asked per individual, wherever time and resources allow. In addition to methodological considerations previously outlined, this approach allows for more accurate and meaningful analysis to understand specific sectoral needs or barriers through the ability to incorporate age, gender, and other diversity characteristics. Regardless of whether the measurement approach is at the individual or household level, special consideration should be given to the choice of terminology to mitigate stigma surrounding “disability” within this community.

Finally, additional work with the affected community to validate or contextualise existing disability measurement approaches could mitigate potential barriers to reporting and could help to estimate the level of under-reporting or additional gaps in knowledge associated with current methodologies.

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