

The Rapid Assessment of Disability – Informing the Development of an Instrument to Measure the Effectiveness of Disability Inclusive Development Through a Qualitative Study in Bangladesh

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ABSTRACT

Purpose: *The Rapid Assessment of Disability (RAD) questionnaire was developed to provide governments and development agencies with an appropriate instrument to determine the prevalence of people with disability within their target populations, and to design and evaluate the effectiveness of disability inclusive activities in addressing their priorities and needs.*

Method: *The RAD questionnaire was developed using two conceptual frameworks: the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and the International Classification of Functioning, Disability and Health (ICF). Existing instruments were reviewed to inform the structure and content of the RAD questionnaire. The RAD questionnaire that was developed for field testing in Bangladesh comprised both a household questionnaire and a questionnaire for individuals within each household, with 5 sections: 1) Demographic information, 2) Assessment of functioning, 3) Awareness of rights of people with disability, 4) Well-being and quality of life, 5) Participation in the community.*

Prior to field-testing the RAD questionnaire in Bangladesh, a qualitative study was conducted to ensure the relevance of the questionnaire in the context of a developing country. In-depth interviews with 9 people with disability and a focus group of 8 parents of children with disability were conducted in Dhaka, Bangladesh.

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Results: *Qualitative findings highlighted factors relevant to the lives of people with disability in Bangladesh, including discrepancies between the awareness and attainment of rights for people with disability, the wellbeing of people with disability and their families, as well as numerous barriers to full participation in their community. While the findings confirmed that the design and content of the questionnaire reflected all these aspects, some changes were made to the items in the questionnaire to ensure that it reflected the views of people with disability from the context of a developing country.*

Conclusion and Implications: *This qualitative study was an important step in the development of the RAD questionnaire as it helped to achieve its aim - namely, to establish the prevalence of disability and to assist in the design and evaluation of disability inclusive interventions in the setting of a developing country.*

Key words: *Questionnaire development, disability, developing countries*

INTRODUCTION

Article 32 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) states that all international development programmes should be inclusive of people with disability (United Nations, 2006). Despite this, and a growing body of evidence on the relationship between disability and poverty, thus far people with disability have not been adequately included in development activities (Department for International Development (DFID), 2000; World Health Organisation and the World Bank (WHO & WB) 2011).

In response to the increasing awareness of the need for disability-inclusive development, several governments and international donors, including the Australian Agency for International Development (AusAID) and implementing agencies, have developed policies and made broad commitments to mainstream disability across their development programmes. However, while programme implementers increasingly understand why development activities need to be inclusive of people with disability, there is limited knowledge and experience of how this is to be done (Noe & Paul, 2006; CBM, 2008). Contributing to this challenge are factors such as limited internationally comparable data on the prevalence and trends of disability across and within countries and limited experience of how to include people with disability and their priorities across the programme cycle of development activities (Noe & Paul 2006; WHO & WB, 2011).

The Rapid Assessment of Disability (RAD) questionnaire aims to address these challenges. The intention is that it can help monitor a population's progress towards achieving the disability inclusive goals of the UNCRPD. The RAD questionnaire has been designed to establish baseline data on disability prevalence and its impact on people's lives, and to support the design, implementation and evaluation of disability inclusive development activities in low and middle income countries. The RAD questionnaire was developed for 3 age groups – one each for children aged 0-4 years and 5-17 years, and one for adults. This paper describes the development of the adult version (≥ 18 years) of the RAD questionnaire, with a focus on findings from the qualitative interviews and a focus group conducted to align the relevance of the RAD to people with disability in the context of a developing country.

METHOD

The conceptual frameworks guiding the development of the RAD are the UNCRPD and the International Classification of Functioning, Disability and Health (ICF), which was developed by WHO (2001). In line with the principles in Article 3 of the UNCRPD, the research was designed to be inclusive of people with disability at all stages of the process, including representation from Disabled Persons' Organisations (DPOs) on advisory committees (UN,2006) along with academics and experts in disability inclusion. Drawing on these frameworks and the expertise of advisory committee members, the research team identified major domains which would potentially meet the objectives of the RAD. These domains included: 1) socio-economic factors; 2) assessment of functioning to determine prevalence of disability; 3) wellbeing and quality of life; 4) awareness of the rights of people with disability; and 5) barriers and facilitators to participation of people with disability in their community. Ethics approval was obtained from the University of Melbourne Human Research Ethics Committee (Australia), the Royal Victorian Eye and Ear Hospital Human Research and Ethics Committee (Australia) and the Ethical Review Committee at ICDDR, B (the research partner in Bangladesh).

The next step was a review of existing disability-related questionnaires to identify existing measures of disability and the lived experience of disability (Goujon et al, 2013). The UNCRPD and literature from the development sector such as the World Health Organisation's Community Based Rehabilitation framework were also reviewed to help identify sectors and services relevant to disability inclusive

development (e.g. education, health, water and sanitation) and potential barriers to access for people with disability (e.g. environmental, attitudinal and legal barriers) (UN, 2006; WHO, 2010).

Individual items from the identified instruments were grouped under the main ICF domains that provided the best conceptual fit for the item, i.e. body structure and functions; activity limitation and participation restriction; and environmental/contextual factors. These groups of items were then assessed for content concordance with the five RAD domains identified by the research team and re-grouped under the relevant RAD domains. As there was considerable overlap in the content of a number of items grouped under each domain, the research team used sets of items that best covered the objectives of the RAD; this also helped to maintain the integrity of the existing instruments. It was also important to ensure that the RAD questionnaire was not heavily focussed on health conditions and was relevant to development initiatives seeking to address the participation of people with disability.

Gaps in the ability of existing instruments to measure important factors relevant to disability inclusive development included measuring awareness of the rights of people with disability and measuring participation in aspects of community life and the barriers to this participation. Workshops, involving the research team, people with disability and experts in the field, were conducted to generate new items to address the gaps. These new items were then grouped under the relevant RAD domains.

Revisions were made to items from existing instruments and to newly generated items so as to ensure: 1) consistency in structure and language of all items; and 2) items were phrased using positive terminology to avoid the potential for any negative psycho-social impact on questionnaire respondents.

Proxy versions of items were developed for those who were unable to provide responses. The household questionnaire contained 15 items adapted from the World Bank's Demographic and Health Surveys (DHS) Wealth Index (Grosh & Glewwe, 2000; Falkingham & Namazie, 2002; Rutstein & Johnson, 2004; ICF International, 2011). Household characteristics used to estimate a wealth index included source of water, having electricity, sanitation facility, roof, wall and floor materials, plus asset indicators including durable goods and ownership of the house, land and cattle.

RESULTS

The draft RAD questionnaire consisted of two questionnaires: a household questionnaire to assess household demographics and socio-economic status - to investigate associations with poverty, for example - and an individual questionnaire to collect data across five sections:

1. Demographics – comprising 25 items including age, gender, nationality, ethnicity, religion, marital status, education (if not completed, the reasons why), literacy, occupation or reasons for not being employed. Individuals are also asked about health conditions, including the type and cause, and self-perceived impact on daily living as well as information on any assistive devices used.

2. Assessment of Functioning - The purpose of this section is to identify people experiencing prolonged (6 months) functional limitations as a proxy for risk of disability. From a total of 18 items, 11 items address difficulties in functioning in 6 domains: vision, hearing, communication, mobility, gross and fine motor, and cognitive. Six items address difficulties in psycho-social functioning, and a final item asks whether a person has difficulty interacting with others due to appearance. In accordance with the ICF, items ask participants to report on their own perception of functioning when using assistive devices available to them (e.g. seeing, even if wearing glasses) (WHO,2002; UN, 2006). Participants are asked about difficulties in each domain to which they respond ‘yes’ or ‘no’. If the response is ‘yes’, they are then asked “how often” with choices being ‘some’, ‘most’ or ‘all the time’. Those who respond ‘most’ or ‘all the time’, and matched controls for age and gender would then continue with the other 3 sections. Items are drawn from a number of existing questionnaires (Table 1).

Table 1: Assessment of Functioning

	Item Source					
	WCG	ALS/PRS	WHO DAS II	PS	ICF	K6
Rapid Assessment of Disability						
<i>In the last 6 months have you had difficulties...</i>						
... <u>seeing</u> , even if wearing glasses?	<input type="checkbox"/>	<input type="checkbox"/>			<input type="checkbox"/>	
... <u>hearing</u> , even if wearing aid(s)?	<input type="checkbox"/>	<input type="checkbox"/>			<input type="checkbox"/>	
... <u>moving around inside your home</u> , even if using assistive device(s)?	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>		

... <u>moving around outside your home</u> , even if using assistive device(s)?	<input type="checkbox"/>	<input type="checkbox"/>		
... <u>using your hands and fingers</u> (e.g. pickup up small objects or closing containers) even if using assistive device(s)?	<input type="checkbox"/>	<input type="checkbox"/>		
... with <u>self-care</u> (e.g. washing yourself, dressing, eating food) even if using assistive devices?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... <u>concentrating</u> on an important task or activity?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... <u>remembering</u> to do things that are important to you (e.g. keeping appointments, paying loans)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... <u>learning</u> how to do new things (e.g. something you have never done before)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... <u>understanding</u> others (e.g. when people communicate with you)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... <u>communicating</u> (for example, understanding others or others understanding you)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... <u>interacting with others</u> in the community due to your appearance (e.g. some people have skin problems, or look different to other people)?	New Question			
<i>In the last 6 months have you felt...</i>				
... so <u>sad</u> that nothing could cheer you up?	<input type="checkbox"/>			
... <u>nervous</u> ?	<input type="checkbox"/>			
... <u>restless</u> ?	<input type="checkbox"/>			
... <u>hopeless</u> ?	<input type="checkbox"/>			
... like <u>everything is hard to do</u> ?	<input type="checkbox"/>			
... <u>worthless</u> ?	<input type="checkbox"/>			

WCG - Washington City Group; ALS/PRS - Activity Limitation Scale/Participation Restriction Scale; WHO DAS II - WHO Disability Assessment Schedule; PS - Participation Scale; ICF - International Classification of Functioning, Disability and Health; K6 - Kessler 6.

3. Awareness of the Rights of people with disability - The purpose of section 3 is to obtain information about the awareness of the rights of people with disability. Sixteen items informed by the UNCRPD were generated by the research team, in consultation with the advisory committee, to obtain information about the awareness of the rights of people with disability (UN, 2006).

Table 2: RAD Section 2 - Awareness of Rights items

Rapid Assessment of Disability	Item source UNCRPD
<i>Do you think you are entitled to...</i> ...access the information needed in your everyday life? <i>Yes</i> <i>No</i>	Articles 9 and 21
... live in a safe home environment?	Articles 16, 19 and 23
... go to school/study?	Article 24
...work?	Article 27
...access to health care?	Article 25
... access to assistive devices or personal equipment that you need?	Articles 20 and 26
... get protection from the police if needed?	Article 13
... get legal support to tell your side of the story?	Article 12
... look after your personal care (e.g. washing yourself, dressing, etc)?	Article 19
... initiate and maintain relationships?	Article 23
... participate in decision making which affects you?	Article 21
... participate in decision making which affects your family?	Article 23
... participate in decision making which affects your community?	Article 19
... be treated as equally as everyone else?	Preamble
... get married?	Article 23
... have children?	Article 23

4. Wellbeing and Quality of life – The purpose of section 4 is to assess individuals' perceptions of their wellbeing, including quality of life. Twenty items for the wellbeing section were sourced and selected from existing questionnaires (Table 3) to assess these perceptions.

Table 3: RAD Section 3 -Wellbeing

Rapid Assessment of Disability	Item source				
	WHO QOL	PS	ALS/PRS	WCG	WHO DAS II
<i>In the last 6 months, how often...</i>	<input type="checkbox"/>				<input type="checkbox"/>
... have you been satisfied with your <u>health</u> ?					
Never					
Sometimes					
Most of the time					
All of the time		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you been satisfied with your <u>sleep</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you been satisfied with <u>yourself</u> ?	<input type="checkbox"/>				
... have you been satisfied with your <u>sex life/intimate relationships</u> ?	<input type="checkbox"/>				
... have you been <u>confident</u> to try to learn new things?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you <u>enjoyed life</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you felt <u>respected</u> in the community?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... has your opinion counted in <u>family discussions</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you been <u>comfortable with your bodily appearance</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you felt your life has been <u>meaningful</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you felt <u>safe</u> in your daily life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you been able to <u>maintain family relationships</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>
...have you been able to <u>make new friends</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you been able to <u>maintain friendships</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you been able to <u>deal with people you don't know</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you been able to <u>deal with persons of authority</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...have you been able to <u>take care of yourself</u> as much as you would have liked?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

...have you been able to <u>take care of your household</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you been <u>living in the same conditions</u> as for the rest of your household?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you had the <u>opportunity to help other people</u> (e.g. neighbours, friends, relatives)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

WHO QOL – The World Health Organisation Quality of Life – BREF; PS – Participation Scale; ALS/PRS - Activity Limitation Scale/Participation Restriction Scale; WCG - Washington City Group; WHO DAS II – World Health Organisation Disability Assessment Schedule

5. Participation in the Community - The objective of section 5 is to understand participation of people with disability in aspects of public and community life, and to identify and prioritise barriers to participation across several domains. Items were informed by the UNCRPD, the ICF checklist, and the CBR framework (WHO, 2001; UN, 2008; WHO, 2010) and existing questionnaires (Table 4). Participants are asked if they have been able to access each of the domains “as much as they would like” to which the responses are ‘yes’ or ‘no’. If the response is “no” they are then asked the reasons, and if more than one is given they are asked to specify which barrier has limited them the most.

Table 4: Access to the Community

Rapid Assessment of Disability	Item source						
	ICF	CBR	UNCRPD	WHO DAS II	ALS/PRS	WHO QOL	PS
<i>In the last 6 months, how often...</i>							
...has the information that you needed been readily available?							
...has the layout of places in the community made it easy for you to access them?							
...have you been able to use transport needed in your everyday life?							
... have you been able to <u>participate</u> at school as much as you would like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>		

... have you been able to <u>participate</u> in work activities as much as you would have liked?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you been able to access <u>health care</u> as much as you needed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you been able to participate in <u>community decision making</u> as much as you would have liked?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you been able to access <u>assistive devices</u> that you needed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you been able to access <u>rehabilitation services</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
...have you been able to live in a suitable home environment as much as you would like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you had access to safe drinking <u>water</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you been <u>prepared in case of a natural disaster</u> ?	New question generated by research team			
... have you been able to gain <u>police assistance</u> ?	New question generated by research team			
... have you been able to gain <u>legal assistance</u> as much as you needed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you been able to participate in <u>recreational activities</u> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
... have you been able to participate in <u>religious activities</u> as much as you would have liked?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ICF - International Classification of Functioning, Disability and Health; CBR – WHO Community-based rehabilitation: CBR guidelines; UNCRPD – United Nations Convention on the Rights of Persons with Disabilities; WHO DAS II – World Health Organisation Disability Assessment Schedule; ALS/PRS - Activity Limitation Scale/Participation Restriction Scale; WHO QOL – The World Health Organisation Quality of Life – BREF; PS – Participation Scale.

Section 5 – Response categories (example structure, this structure applied to all domains)
<p><i>In the last 6 months,</i> ...have you attended any school? Yes No</p>
<p>If yes, ... have you been able to <u>participate</u> at school as much as you would have liked? Never Some of the time Most of the time All of the time</p>
<p>Which of the following <u>barriers</u> have hindered your participation at school? Lack of learning materials in suitable format Physical access to school Not being included in school activities by teachers Not being included in school activities by fellow students Cost of attending school Other (please specify)</p>
<p>Which of the following <u>barriers</u> affected you the most? Lack of learning materials in suitable format Physical access to school Not being included in school activities by teachers Not being included in school activities by fellow students Cost of attending school Other (please specify)</p>

Prior to finalising the RAD questionnaires for field testing in Bangladesh, a small qualitative study including in-depth semi-structured interviews with people with disability and a focus group with parents of children with disability were conducted. This was undertaken to ensure that the RAD questionnaire was applicable to people with disability living in low and middle income countries. The interviews and focus group were conducted in May 2010 by the Bangladeshi research team at ICDDR, B in collaboration with the Centre for Disability in Development (CDD), at 2 sites in Bangladesh - Tongi, an urban area in Dhaka, and Narshingdi, a rural district in the Dhaka division.

Interview and focus group participants were purposively recruited through the network of CDD. Two female and two male Field Research Officers of ICDDR, B with previous work experience in qualitative methods and fluency in English and Bangla were trained to conduct the interviews and focus group. Potential

participants were approached by the FROs and provided with information about the study. Written consent was obtained from them and they were assured of confidentiality. Efforts were made to ensure equal representation of male and female participants from rural and urban settings, with various types of impairments (vision, hearing, physical and communication impairments and people with mental illness).

All participants were 18 years of age or older.

Participants in interviews and the focus group were asked a series of open-ended questions focussing on perception of rights of people with disability, wellbeing and quality of life, and barriers and facilitators to participation in the community, such as education, health services and livelihoods. Guidelines for the semi-structured interviews and focus group were initially developed by the research team in English and translated into Bangla. The interviews and focus group were audio recorded, transcribed in Bangla and translated into English. Members of the research team then analysed the transcripts to identify individual statements describing a single element of lived-in experience of people with disability. These statements were entered into Microsoft Excel (Version 2003, Microsoft Corp.) and coded according to the main topic, using open coding. Individual statements were mapped onto questionnaire item(s) that best captured the meaning of each statement to determine if or how well that theme was addressed by the questionnaire. This helped to identify items that were potentially redundant or irrelevant, and those that needed to be included in the case of themes that may have been missed or were under-represented. The research team then discussed the implications of the findings for the RAD questionnaire, and revised it accordingly.

In all, 9 people with disability took part in qualitative interviews and 8 parents of children with disability participated in a focus group. Interviews took approximately 45 minutes and the focus group lasted for approximately 1.5 hours. The average age of the 9 interview participants was 26.6 years (range 22- 40 years) with more male participants (n=6, Sex Ratio=2) available for interviews. Only 1 participant reported having received any education. Five of the 9 participants reported no occupation (Table 5). The participants for the focus group were parents of children with disability (n=8), the majority of whom were mothers. Their children were between 3 and 8 years of age, and experienced a range of disabilities.

Table 5: Demographics of Interview Participants

Variable	N=9
Age in years Average (range)	26.8 (22-40)
Gender Male Female	6 3
Marital status Married	4 (3 male, 1 female)
Setting Urban Rural	4 5
Education No education Primary Not known	5 1 3
Occupation No occupation Farmer Beggar Ironing shop	5 2 1 1
Type of impairment Vision Hearing Physical Psycho-social Intellectual	2 2 2 2 1

Findings from the qualitative interviews and focus group are presented under the relevant sections of the RAD questionnaire. Many of the findings however were cross-cutting and have significance across all sections. (Note: As described in Methods, the qualitative study did not explore self-assessment of functional limitation, which is assessed in Section 2. Therefore, these results are presented across Sections 3, 4 and 5 of the RAD.)

Section 3: Awareness of the rights of people with disability - The findings indicate that a number of participants were aware of the rights of people with disability, particularly in terms of education, marriage, livelihood and ability to live as equal members in the community. However, a discrepancy was highlighted

between participants' awareness of their rights and their ability to exercise these rights, particularly with reference to education. For example, one participant observed that while everyone has the right to education, her daughter was denied this right through the actions of teachers. Many violations of the rights of people and children with disability, including the right to a safe living environment and to be treated on an equal basis with others, were also voiced.

The right to marry, for men and women with disability, was a strong concern identified among the participants. Due to the lack of livelihood opportunities, men with disability were seen to be dependent on their families, thereby reducing their prospects of making a good marriage. For women, concerns ranged from the expectation that women with disability require a large dowry, often not affordable by their families, and the fear that girls with disability would experience violence after marriage.

Findings also suggest that their marriage prospects are reduced further by persistent fears and perceptions in society that people with disability might produce offspring with disability. Fears regarding marriage also related to broader parental anxiety regarding their child's future after the passing away of the parents and marriage of siblings (Table 6).

Table 6: Sample of responses relevant to the RAD Section 3 – Awareness of rights of people with disability

Item domain	Sample responses	Source
Right to live as part of society	<i>"We disabled persons want that we can lead our life in a suitable manner. We do not want to beg, we want to live like other people in the society in an equitable manner, so no one can ignore us. This is the main right of people with disabilities."</i>	Male interview participant with physical impairment
	<i>"These children have rights to live in society."</i>	Focus group participant, parent of male child with disability
Right to education	<i>"She has rights to go to school but the teachers stopped her from going to school."</i>	Focus group participant, mother of female child with intellectual disability

<p>Right to live in a safe home environment, and right to be treated in the same way as others</p>	<p><i>“Another family has an intellectually disabled child; she is always kept on the dirt floor, neglected. Her father says ‘I will be happy if she dies.’”</i></p> <p><i>“Disabled (persons) have number of problems, they are ignored in the society, they are ignored by relatives, they are ignored by their brothers and sisters, they are ignored by the mother as well. They feel ashamed to recognise us as their near relative.”</i></p>	<p>Focus group participant, mother of female interview participant, intellectual disability</p> <p>Male interview participant with vision impairment</p>
<p>Right to marry</p>	<p><i>“There is another problem we are facing regarding the marriage of our sons and daughters, other people declines to make marital relationship in our family because of the disabled son. Because they apprehend that they (family members without disability) may also give birth to a disabled baby.”</i></p>	<p>Focus group participant, parent of a child with disability</p>

The findings confirmed that collecting data about awareness of participants’ rights across all areas of life such as the right to a safe living environment, education and, in particular, right to marry, were important themes. However, the right to live in society as an equal member was a theme which was added, as it had not been included in this section of the questionnaire. Further, after analysing the results of Section 4 on well-being, it was decided to add an item on the “right to Government social welfare services” as this emerged as an important theme. The phrasing of questions was also amended after the qualitative study, as the Bangladesh research team raised concerns that there were leading questions.

Table 7: RAD Section 3 – Changes to the Awareness of Rights section after the qualitative study

Section 3	Changes
<p><i>Are you aware of the rights of people with a disability?</i></p> <p>Yes</p> <p>No</p> <p><i>I am going to ask you what rights you think people with disabilities should have. Right to...</i></p>	<p>Structure and response category changed for all items (not directly because of qualitative findings)</p>
<p>...access Government social welfare services?</p>	<p>Item added post qualitative study</p>
<p>... live as part of society?</p>	<p>Item added post qualitative study</p>

Section 4: Wellbeing and Quality of life - When asked about themes relevant to the wellbeing and quality of life of people with disability, a number of participants expressed positive experiences of living with disability and acceptance in the community. However, several responses indicated that people with disability felt they were perceived as a burden on society, the government and, in some instances, their own families. The ability to live independently also arose as a common theme, with respondents expressing their reliance on others for day-to-day activities such as crossing the road and going to work. Communicating with others was also a function that required support from others and this was reported as impacting on both the wellbeing of individuals and their families.

Participants often highlighted the importance of family, consistent with the centrality of family in the Bangladeshi culture. Parents of children with disability expressed great concern about the wellbeing of their children due to the stigma and discrimination they experienced. Parents discussed the ‘disabling world’ in which children with disability are unnecessarily segregated and mistreated. For instance, some parents described experiences of derogatory language being used in the playground towards their children with psycho-social disability (Table 8).

Findings also indicated that parents felt having a child with a disability increased the levels of anxiety in their lives. One mother said she had difficulty participating in activities outside the home, including work, because she could not leave her child alone, thereby impacting on the family’s income which caused stress. Other families reported difficulty in providing the support required to educate their child with disability, especially if they had several other children.

Table 8: Sample of responses relevant to the RAD Section 4 – Wellbeing

Item domain	Sample responses	Source
General well-being	<i>“Though I have no eyesight, I do not feel any problem. Maybe I cannot earn my bread on my own; if I go somewhere, being blind, if ten people do not help me, at least one man will help me.”</i>	Male interview participant with vision impairment
Respected by community	<i>“They (people with disability) are a burden for their society...they are a burden for you and for the government as well.”</i> <i>“They addressed him as ‘Mad’ and beat him. If our children go to play with other children they mimic our children.”</i>	Male interview participant with physical impairment Focus group participant, mother of a male child with a disability
Importance of family	<i>“Every family member loves her and no one uses rough words with her. When guests come to our house some families hide this kind of disabled person but we do not. We allow her to mix with others and stay with guests.”</i>	Focus group participant, mother of a child with disability
Parental concern	<i>“Now I am alive so I can take care of him, but when I will die what will happen to him?”</i>	Focus group participant, mother of a child with disability

The findings confirmed that questions in the Wellbeing section of the RAD largely covered experiences likely to impact on people living with disability and their families, by addressing themes which the study participants identified as key areas of wellbeing such as self-perception of health, enjoyment in life and respect in the community. An item asking how often a person received the help needed to complete daily life activities, and an item asking if the main person helping them was a member of their family, were added (Table 9). These additions reflect that the capacity of the family to support individuals with disability and the ability to live independently arose as important themes throughout the qualitative study.

Table 9: RAD Section 4 – Wellbeing section - changes post qualitative study

Section 4	Changes
<i>In the last 6 months, how often.....</i>	
... have you been satisfied with your <u>intimate relationships</u> ?	Changed from “sex life/intimate relationships”

<p>... did you <u>get the help you needed</u> to complete daily life activities?</p> <p>Is the main person helping you a member of your family?</p> <p>Yes</p> <p>No</p>	<p>New questions</p>
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Section 5: Participation in the community - Participants were asked to discuss access to a range of domains related to participation in community life, such as education, health services and livelihood, in order to capture barriers and facilitators to their participation. Findings are reported under the relevant domains.

Education – This was the most commonly discussed domain by all participants, revealing a strong desire for improved participation in schooling. The main barriers to education included negative attitudes from teachers and students, as well as institutional barriers. While one mother stated that her child was restricted from attending mainstream school, another wished there were specific training centres for these children. Other participants reported barriers to education including fees, especially when the family has other children to educate, cost of transport and physical access to schools.

Livelihood – While several respondents reported involvement in various livelihood areas including business and handicrafts, others reported many barriers to accessing meaningful and paid employment, leading to feelings of sorrow and worthlessness. Some parents felt that despite their family members with disability wanting to work, they had not been given the opportunity to develop skills to participate in the work market or to self-manage their finances. Some respondents also reported not applying for work as they felt they would be rejected because of their disability.

Health services – Participants generally reported positive attitudes and good treatment by health professionals, yet barriers to services were still evident, with the cost of treatment reported as the major barrier. Some participants reported that due to unaffordable services, healthcare that could have improved their condition was forgone. Participants also expressed their need for assistive devices such as hearing aids, to improve their quality of life. Several barriers to accessing devices were discussed. Assistive device services are inaccessible to people living in rural areas of Bangladesh due to the distance from a major city where the services are located, cost of services and apparent selection bias by

providers. Participants reported that very few NGOs that are accessible to people with disability in remote areas offer assistive devices as part of their programmes.

Social welfare services - While some participants were aware of services provided to people with disability by the Government and NGOs, they reported barriers to accessing those services. Rural participants perceived that only people living in urban areas could receive such support. The need to bribe officials to gain access to government services was also mentioned as a barrier.

Religious activities - Participants also highlighted the importance of religion in the Bangladeshi culture and discussed participation in religious activities. While one participant described the local temple as welcoming towards the child with disability, others reported experiences where negative attitudes of religious leaders and attendees had prevented participation in religious activities.

Table 10: Sample of responses relevant to RAD - Participation in the Community

Item domain	Sample response	Source
Access to education	<i>"General schools don't admit our disabled children. I think if our children will go to general school, they would learn many things with other students."</i>	Focus group participant, mother of a child with disability
	<i>"She gets pleasure when she goes to school but she can't go. Teachers are neglecting her. Students laugh at her. They said, why have you sent her to school?"</i>	Focus group participant, mother of a child with a disability
Access to livelihood	<i>"I am a blind man, I cannot work, if I could work and earn money, I would have not been neglected by the people."</i>	Male interview participant with vision impairment
Access to health services	<i>"My child needs an operation, then he will talk. I need 1500 taka for the operation. I can't manage the money so I can't do the operation."</i>	Focus group participant, mother of a child with disability
Access to social welfare services	<i>"I know that the government helps the disabled persons a lot but we have not received any sort of help from the government."</i>	Male interview participant with physical impairment
	<i>"There is a social welfare office in this area... There is a peon (office attendant) in the office, he is very corrupt man. I could not reach to the officer by passing the peon."</i>	Male interview participant with hearing impairment
Access to religious activities	<i>"Once he went to mosque but the religious leader said to go out. He also said if my son goes to mosque then everybody's prayer will be spoilt. I don't know whether his prayer was accepted or not by Allah."</i>	Focus group participant, father of a male child with a disability

The findings confirmed that the design of Section 5 of the RAD questionnaire largely included community domains such as education, healthcare and, religious activities, which appear to be important for people with disability in Bangladesh (Table 4). However, as a result of the qualitative study, new domains including “Government social welfare” and “Disabled Persons’ Organisations” (DPO) services were added, reflecting their importance to participation in the community for people with disabilities.

The qualitative findings also confirmed that most types of barriers to participation mentioned by the participants had been included in the RAD questionnaire, including lack of accessible information about available services, physical access, and negative attitudes of teachers, families and service providers. New barriers such as ‘difficulty getting to and from facilities’ such as schools or health centres and the ‘financial cost of accessing services’, which is further accentuated by the need to bribe officials, were included in the RAD questionnaire because they emerged repeatedly as issues for participants. These barriers were added as standard response categories across all domains. Finally, given the importance of family support for people with disability as displayed throughout all sections of the study, an additional barrier, ‘family has difficulty assisting you’, was also added as a standard response category.

Table 11: RAD Section 5 – Additions to Participation in Community after the qualitative study

<p>Which of the following have limited your participation in school? Which of these has limited your participation in school activities the most?</p> <p>Lack of information about school Lack of learning materials Physical access to school Negative attitudes towards me at school Cost Difficulty getting to school from home Difficulty for my family to help me Other (please specify)</p>	<p>Additional response categories (in bold) added to all domains</p>
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... have you accessed <u>Government social welfare services</u> as much as you needed?	New item added
... have you accessed <u>Disabled Persons' Organisations</u> as much as you would have liked?	New item added

DISCUSSION

The RAD combines the measurement of prevalence of functional limitations in populations and the assessment of the impact of disability, using the social model of disability, to reflect the true experience of disability as an interaction between a person and the environment. The qualitative study provided a valuable opportunity to consult with people with disability, ensuring that their views were reflected in the RAD questionnaire. Moreover, this component of the RAD project yielded valuable insights into the quality of life and barriers to access and participation in the community for people with disability in Bangladesh.

The qualitative findings confirmed that the themes that emerged during interviews and at the focus group had been largely addressed in the rights and wellbeing sections of the RAD questionnaire. In particular, the need for a question regarding the right of people with disability to get married was also confirmed, as marriage is very important in the Bangladeshi culture.

In terms of participation in the community, the qualitative findings confirmed that the design of the questionnaire, based on the ICF and UNCRPD, appeared to largely reflect the domains of community life that were important for people with disability in Bangladesh. For instance, as consistently described in the literature, without access to appropriate education, people with disability have fewer opportunities to find meaningful employment. This reduces their ability to access economic resources and live independently (USAID, 2009; WHO & WB, 2011). However, the qualitative findings also identified access to social welfare and DPO services to be important domains for participants, and these were added to the questionnaire. Difficulty in accessing public transportation is reported in the literature as excluding people with disability from services such as education and healthcare (Grewal et al 2002; WHO & WB, 2011). Cost, ability of the family to assist, and difficulty in getting to services were constantly reported by participants as barriers to participation, and were subsequently included in the questionnaire as response options.

These changes were made to the questionnaire for field testing in Bangladesh to evaluate the psychometric properties of the RAD. Following this, the RAD will be tested in Fiji for cross-cultural relevance.

CONCLUSION

While the qualitative findings confirmed that the design of the RAD questionnaire did include the themes and priorities of people with disability, some items were modified or added to better reflect the needs of people with disability in Bangladesh. Therefore, this qualitative study was critical in the development of the questionnaire and can help it to achieve its purpose of assisting in the design and evaluation of disability inclusive development interventions. As an appropriate tool for development organisations, it is hoped the RAD questionnaire will ultimately contribute to the evidence in relation to disability and development, and promote inclusion of people with disability in the setting of developing countries.

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