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IMPROVING ACCESS AND SUSTAINABILITY****Strengthening the role of WASH
and disabilities in Bangladesh***M. Snel, K. Bostoën & A. Biran (The Netherlands)***BRIEFING PAPER 2015**

In 2014, the London School of Hygiene and Tropical Medicine and IRC obtained a grant from the Australian Development and Research Awards Scheme) to research accessibility to sanitation in relation with disabilities in Bangladesh and Malawi. The project, aims to obtain prevalence of disability related problems on access and accessibility to sanitation and reflect on a mitigation strategy to be rolled out beyond the project. Initial findings based on the survey are: To address the problem of adapted sanitation facilities, a general mobility problem needs solving first; to discuss solutions, social barriers around both sanitation and disability need to be lifted by all relevant stakeholders. To address suitable solutions in a cost-effective and up-scalable way, a dialog between provider and user seems to be the best way forward in Bangladesh. At the same time, self-assessment by the disabled does not always result in the most appropriate solution.

Introduction

This paper focuses on Bangladesh where the project is led through a collaboration between BRAC and IRC in collaboration with local disability organisations. In order to address disability in a strategic and cost-efficient way, basic data is needed. The paper is to reflect on some of the results of a baseline study conducted by IRC and BRAC to measure access and accessibility to and practice of water, sanitation and hygiene (WASH) services for persons with a disability.

Context

The prevalence of disability is believed to be high within Bangladesh for reasons relating to overpopulation, extreme poverty, illiteracy, lack of awareness, and above all, lack of medical care and services. Although disability is a major social and economic phenomenon in Bangladesh, there is very little reliable data available on this issue, especially in the absence of a comprehensive national survey on persons with disabilities.

The objectives of the Bangladesh disability part of the study focuses on:

- develop and pilot simple survey questions for collecting quantitative data on the nature and extent of WASH access and accessibility problems experienced by people with disabilities;
- disseminating these questions to relevant stakeholders in the WASH and disability sectors;
- collecting data on the extent and nature of WASH access and accessibility problems experienced by people with disabilities at two sites;
- piloting and evaluating potential activities to mitigate the WASH access and accessibility problems experienced by people with disabilities; and
- disseminating learning about the effectiveness and feasibility of potential mitigation activities.

Disability and poverty inevitably reinforce each other (Werner, 1999; WaterAid, 2010; WEDC and WaterAid, 2012, 2013 and 2014). Poor nutrition, and living conditions, limited access to health care, poor hygiene, bad sanitation, inadequate information about causes of impairment, war conflict and/or natural disasters create disabilities of which as many as 50% are preventable (Jones, 2013, 2005a, 2005b, Jones et al. 2009; WHO & World Bank, 2011). Disability, particularly of the head of household, exacerbates poverty

of the whole family due to increased expenses, lack of income from the care-taker and lack of opportunities due to social exclusion. It has been estimated from 10 to up to 20% of the poor in developing countries are disabled, which is significantly higher than the commonly assumed 7-10% people with disabilities in the general population (Trevett and Luyendijk, 2012; WaterAid, 2013; Wilbur, 2010). Disabled access to WASH has been raised as an issue but little is published on the nature and scale of the problem.

Disabilities and WASH as a service: initial data findings from Bangladesh

We carried out a cross-sectional survey to provide data to stimulate discussion around planning of a more inclusive WASH programming. In January 2014, a baseline study was conducted by IRC and BRAC to measure access and accessibility to and practice of water, sanitation and hygiene (WASH) services. As definition for disability the Short Set of Questions on Disability by the Washington Group on Disability Statistics are used.

The basis survey was done using QIS. QIS or Quality Information System is a survey method aimed at combining promotion and collection of information in a participatory way with a focus on behaviours (Mushtaque, Chowdhury, and Bhuiya, 2004) while the information on disability was added to the survey using regular survey questions. The survey was a 3-stage multi-cluster survey covering 3600 households in the BRAC WASH III area. It was the first time that BRAC has collected information on disabilities in relation to sanitation. One of the aims of the study was to assess the prevalence of the problem. The following were some of the initial results:

- Only 43 households expressed that at least one person in their house faces a problem to defecate autonomously which in percentages is only 1.2%. (39 households (HHs) with one in four HHs with two people that struggled to use the sanitation facilities autonomously);
- During a workshop, disability organisations were asked about this figure which seems low, as disability in general in Bangladesh is estimated around 10%.

There are, according to the disability organisation collaborating with BRAC, many reasons for the low reporting. Firstly, many disabled people do not necessarily see their disability as a problem they can or are willing to openly discuss, but rather as something they have to deal with themselves by trying not to be a burden to their family. In terms of administering the survey, this may have entailed that a number of households simply did not acknowledge that there was someone in their household with a disability. Another problem was the definition of having a disability problem. As sanitation is something required for every living person, households often solve this problem themselves (although not necessarily in an acceptable form) and therefore many respondents did not feel any connection with this question. It should be cited that all households which reported disabilities either have their own latrine or use their neighbours' facilities and a last proportion do not have sanitation in this intervention area.

One of the aims of the survey was to see if a focus on disability alone was not too narrow for this research as many people with non-specific medical reasons might also struggle with autonomous access and accessibility. The data confirmed that most access and accessibility problems are health related, as stated in the survey shown in Figure 1.

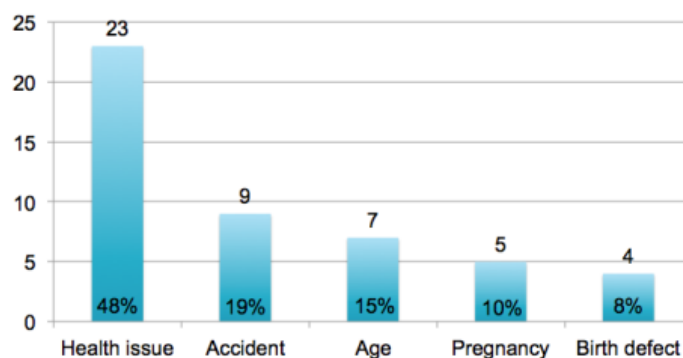


Figure 1. Main reason for reduced autonomy in the use of sanitation facilities

Almost one third of the interviewed people were above 70 years old, which is the official health expectancy (BBS, 2014). This might indicate that age related health issues are a serious contributor to problems on access and accessibility to sanitation. However children and adolescents are not excluded from having access problems. While physical mobility is the main cause of access and accessibility problems it is by no means the only issue. What is unclear from the survey is whether the problem with access to sanitation is due to a physical problem only or if these are related to some design criteria. In order to get more clarification on this issue, some further participatory research is currently being undertaken.

For the moment, based on the initial survey results, there is a discrepancy between the mitigation strategies currently employed by individuals and those desired as expressed in the BRAC WASH survey. Questions related to strategies around design of the sanitation facilities were not included as their description was too abstract for respondents to clearly understand. This data will be collected later in focus group discussions and interviews. What was clear, however, is that the individual coping strategies suggested the need for wheelchairs, tricycles and spectacles, which go well beyond the sanitation spectrum of the BRAC WASH programme. This, however, reinforces the need for collaboration with organisations specialised in work on issues around disability.

Based on this initial analysis of finding, there was a BRAC meeting held in September last year. In this meeting the fact that only 1.2% of the surveyed population felt they might have a problem with sanitation in relation to disabilities led to various discussions. One was on how those with a disability cope with access and accessibility to sanitation. For example, when an organisation specialised in disability came to deliver a wheelchair, as requested, they often discover that other solutions would have been more appropriate e.g. a specific crutch would have been a far more suitable solution if the problem had been better described in the first place and if the person requesting the help would have had better insight into a wider variety of specific solutions. Often the disability problem is defined by the solution and not by the problem. E.g. I need a wheel chair instead of I have a lower leg amputation. Defining the problem based on possible solutions restricts such description to the solution known by the disabled person expressing them. So the problem of disability and WASH is seen by the disability organisation as less a problem of technical solution and one of open discussion and understanding of the many various solutions available to physical disability problems. The same is the case with solutions for adapted hygiene and sanitation facilities, which required an open, dialogue between provider and user and can often be solved by determination and imagination.

The organisation suggested that any intervention chosen in the next stage of the research should be simple, reproducible and based on an open communication between all stakeholders.

Discussion and initial conclusions

Related to the initial BRAC survey findings and based on background literature, there is still need for more accurate national data on the type, severity and causes of disabilities in adults and children in Bangladesh. Definitions used for estimating disabilities are often unclear and when defined often not comparable between surveys. In our project this was solved by applying the definitions used by the Washington Group on Disability Statistics (UN Economic and Social Council, 2013).

However problems relating to the perception around disabilities and the reluctance to discuss sanitation might hamper estimating the extent of the problem more than accurate definitions.

While surveys allow estimating the prevalence of disability related problems to WASH access it does not provide the richness of information required to design mitigation strategies. They require more qualitative methods which are currently planned in a next phase of the project.

At the same time, there is sufficient data to justify a range of mitigation strategies and interventions for prevention of disabilities, for rehabilitation and for inclusion and participation of people with disabilities.

Focussing on the problem on sanitation problems we assume that disability people have for example experienced the access problems to their sanitation facility. This implies that they can all reach their sanitation facility. However the initial findings show that in our case there was a general mobility problem in simply reaching the sanitation facility so questions related to sanitation access and accessibility issues proved difficult to answer meaningfully. The idea in this project is to collaborate with disability organizations on the ground to solve both general mobility problems and WASH related accessibility problems.

The next step in the process is to do a quasi-RCT in which the intervention will be refined based on the above finding supplemented with finding from on-going qualitative work. The aim is to see to what extent simple advocacy messages and the stimulation of communication between various stakeholders

in particular sanitation providers and the disabled clients can improve access to WASH services by people with a disability.

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