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INNOVATION, ADAPTATION AND ENGAGEMENT IN A CHANGING WORLD****Inclusive sanitation: breaking down barriers***S. Ahmed, H Jahan, B. Bala & M. Hall, Bangladesh***BRIEFING PAPER 1132**

During implementation of WaterAid Bangladesh's current project it became evident that certain populations were unintentionally being excluded – people with disabilities were one of these groups. Social stigmas and access difficulties meant that they were not present in CBOs or hygiene promotional sessions and excluded from decision making activities, resulting in continued open defecation and other unhygienic behaviours. The linkages between poverty and disability are strong, with disability being both the cause and effect of poverty. Without specific activities to address the requirements of people with disabilities the cycle of poverty remains, further exacerbated by continued exclusion from services such as health care, education and water and sanitation. This paper concentrates on the barriers faced by people with disabilities in accessing water and sanitation services and explains how through WaterAid Bangladesh's recent initiative, a greater understanding on breaking these barriers is strengthening the future interventions.

WaterAid Bangladesh — achieving sustainable environmental health

WaterAid Bangladesh (WAB) has been working in Bangladesh implementing water, sanitation and hygiene promotion activities since 1986. In 2004 WAB started a 5-year DFID funded project called 'Achieving Sustainable Environmental Health' (ASEH) which aimed at reaching the poorest, geographically excluded people living in hydro-geologically difficult areas of the country. In little over 5 years the project has reached nearly 6million beneficiaries with safe and sustainable water, sanitation and hygiene promotional activities in both urban and rural areas. During the implementation of ASEH it became evident that certain populations were unintentionally being excluded from the project – people with disabilities were one of these groups (others include sex workers, tea workers, street sweepers, floating people). The standard models used by front line staff and engineers in awareness raising, building capacity, hygiene promotion and in the choice and installation of technologies were not addressing the specific needs of people with disabilities. Social stigmas and access difficulties meant that they were not present in meetings, CBOs or hygiene promotional sessions. Technologies chosen by the communities/households most of the time did not take into account the specific requirements of those with disabilities. In addition many other people such as the elderly, pregnant women, the sick and injured faced problems in accessing and using water and sanitation facilities and as a result returned to unsafe practices.

This paper concentrates on the barriers faced by people with disabilities in Bangladesh and how through WaterAid Bangladesh's recent pilot project these barriers are being broken.

Disability and poverty

It is recognised by many (DFID 2000, UNESCO 1995) that poor nutrition, dangerous living and working conditions, limited access to health care and education, poor hygiene and bad sanitation are some of the causes of disability. Sadly, these are also some of the conditions which are exacerbated by disabilities and which ensure that people with disabilities are usually the poorest, have low literacy rates, poor health and have poor access to services. Poor access to education, health care and employment, lead to social and economic exclusion – resulting in lack of opportunities to participate in community activities and decision making, families and difficulties in generating income and increasing the workload on caretakers.

Dependency on caregivers and families often has further knock-on effects. The caregiver who is normally female is overburdened with the additional duties, unable to fulfil the regular household duties which in some cases led to domestic violence. In other cases young girls are given the caregiver responsibilities, missing school to attend to the needs of a family member.

Disability in Bangladesh

The Government of Bangladesh estimates that there are approximately 14million people in Bangladesh with disabilities however, figures vary widely with reported prevalence between 0.77 and 0.47 - even this is thought to be seriously under reported (ActionAid 2004). Poor, uneducated people with disabilities find it difficult to work, with no opportunities for employment. They are often pushed to the large cities to enter into begging. Others are confined to the household, socially stigmatised, and 'invisible' in the community.

In recent years there have been some changes, with the inclusion of people with disabilities into national policies such as Poverty Reduction Strategy Papers and disability specific acts such as the National Disability Welfare Act 2001 and associated National Action Plan on Disability. However little action is evident.

WAB pilot project – sanitation for people with disabilities

During the ASEH programme it was recognised that in order to successfully achieve 100% sanitation and achieve the maximum health benefits, tailor made approaches to address the specific needs of elderly, pregnant women and people with disabilities were required. To address this WAB established a 1-year pilot project working with two partner organisations VERC - operating in rural areas and DSK - operating in slums in Dhaka. The objective of the pilot project was to build the capacity of WAB and partners, identify best methods of inclusion, create appropriate software materials and introduce appropriate and user friendly sanitation options prior to scale up. To address the people with disabilities in WaSH services at urban areas, a pilot was conducted in three slums (Beltala slum, Beguntala slum & Pabna House Goli slum) in Dhaka city. A total of 74 people with different type of disabilities were targeted in the pilot interventions including other peoples of nearby community. Facilities provided were different chambers with provision of various heights, space and others supports; bathing facilities having friendly sitting arrangement, available water facilities; water supply system with overhead tank; hand railing, access road with ramp through maintaining smooth & rough surface; rest place with sitting arrangement; Solar panel for support during power failure. In rural areas, pilot project on Activities with People with Disabilities (PWD) in Varshaw union under Manda upazila in Naogaon district and in Ouchpara union under Bagmara upazila in Rajshahi district. In Ouchpara union, a total of 51 PWD friendly latrine installation completed. In Varshaw union, a total of 92 PWD friendly latrine installations were completed.

Activities

Front line staff are those who are directly employed by WaterAid's partners and are responsible for field level implementation. They addressed the CBO members of VERC and DSK working areas, orientating them on the pilot project, assisting them in understanding the problems encountered by people with disabilities and the importance of including them in development projects. Front line staff organised courtyard sessions at easily accessible places and at a convenient times to inform people with disabilities and (where relevant) their caregivers of the pilot project. Individual household interviews were held at the homes of the disabled to better understand the specific difficulties faced by the individual in using sanitation.

The findings from the needs assessment and household visits were used to create appropriate materials for the dissemination of appropriate hygiene promotion messages and better identify the mobility needs of the people with disabilities in accessing and using sanitation.

Persons with disabilities were the key persons who sat with WaterAid and its partners to discuss about different aspects of technical options for their facilities. After knowing and discussing with the technical experts of WaterAid and partners they were able to choose for themselves which would be the most appropriate technology. Innovation was also encouraged, with individuals making modifications and designing more appropriate designs. Courtyard sessions were held, again at a convenient time and an accessible place with both the disabled person and caregivers encouraged to attend. WAB covered the cost of the latrine adaptation/aid with the household responsible for the labour and carrying costs and supplying the rings, slab and vent pipe (through government subsidies or self-purchase).

After installation, front line staff returned to each of the households to monitor use, cleanliness, hygiene behaviour.

A total of 145 people with disabilities got access through the pilot intervention, of whom 5 were mentally, 25 were visually, 88 were physically and 12 were multiply disabled. Apart from that, 72 elderly people and 15 pregnant women also benefitted through this intervention.

Barriers to sanitation services

In rural areas the main barriers which people with disabilities faced were regarding the institutional, structural/ergonomic availability and social barriers.

Lack of access, accessibility, and space constraints, lack of service availability and some additional supports were not considered with the conventional services. In addition that there was no technological provision or guidelines to address persons with disabilities in WASH services. There were problems regarding water supply, e.g. tube well based water point was difficult for physically disabled person. Water tap was easy for them to collect water; stair of platform prevented them to get easy access; access road/lane was not smooth for movement; and in rush period they had to wait. Difficulties related to sanitation were many including PWDs could not use latrine easily as no extra arrangement inside the latrine chamber existed for friendly use; stair of latrine prevented them to get easy access; PWDs needed more space in the chamber who used chair and required additional devices; carrying water inside the latrine was problematic; water supply inside the chamber was needed; and some of the PWDs could not use present lock- unlock system. Special type door locks (inside) were needed so that they could lock and unlock easily. Difficulties related to hygiene were mainly the lack special hygiene education and practices for PWDs; special hygiene education and practices were needed for PWDs; and hygiene education/practices were needed based on the individual condition.

Social stigma included different issues like; they were often neglected and ignored both by the family and the society; access to the facilities was dominated by the normal population; kept them isolated by the family and community.

Overcoming the barriers

Institutional/organisational barriers

In rural areas most households have their own latrine and are unwilling to share outside of the immediate family. Disabled people and their families are generally some of the poorest and do not have the finances to invest in a simple low cost latrine. Those who were unable to afford the latrine were encouraged and assisted in seeking support from the Union Parishad to claim national sanitation subsidies for which they are entitled. Through the encouragement and motivation they are now more capable of addressing local government bodies to claim their rights.

Structural/ergonomic availability

Latrine adaptation models/aids were not readily available on the open market – as in Dhaka. VERC faced some initial problems in finding suppliers for latrine adaptation/aids. After some time they approached a steel furniture workshop which had already constructed a few latrine-chairs designs which were being sold on the shop front. VERC consulted with the workshop to expand the range to address the requirements of the persons with disabilities. The workshop now provides 7 latrine aid models and has the flexibility to modify these where required by the individual needs.

Social barriers

People with disabilities were generally excluded from community activities, and often remained in the household as the families felt ashamed and embarrassed. Caregivers, mostly women and girls felt the disabled person a burden and incapable of contributing to the family. WAB and partners used focus group discussions and courtyard session with the disabled people, families and communities. Talking openly about individual latrine behaviours, the difficulties faced and requirements, enabled people with disabilities to be more involved in community decision making. By ensuring hygiene promotional sessions are relevant and accessible, people with disabilities and their caregivers were able to maintain good hygiene practices.

With disability friendly latrine adaptations (often much closer proximity to the house), disabled people were less reliant on their caregivers. This was seen as a big step in creating independence, self respect and empowerment. Individual latrines, made to their specification and demands created ownership, latrines were

kept clean, with families providing sufficient water for flushing and cleansing. In rural areas key messages which were emphasised were handwashing after defecation, safe water sources, water storage and food preparation.

In urban areas under the pilot project, sanitation options were available in the form of community latrines. The main barriers to accessing sanitation were environmental and structural/ergonomic.

Environmental barriers

Disabled people often face mobility barriers. In the cramped dirty conditions of the slums it is even more problematic to move around. Locating sanitation facilities is often difficult and dependent on space availability and as a result they are often located in undesirable locations.

Structural/ergonomic design

Disabled people's needs had not been accounted for in the initial designs. Problems included; steep stairs, unpaved access routes, no internal support, small latrine chambers inaccessible by wheelchairs or not permitting mobility inside, lock systems too high, water supply at distance.

In urban areas however, access to latrine aids were easier to access. Hospitals which specialised in disabilities in Dhaka had a wealth of supplies and different models. Associated social stigmas also appeared to be less.

Hardware interventions

Rural - WAB promoted the installation of latrines within or at close proximity to the house. 3-ring & slab were installed by the disabled person and their families at their own cost, approximately \$6-7. The disabled person/caregiver was able to choose the latrine option and WAB bore the additional expenses approximately \$10-12.

In rural areas WAB and partners implemented six different types of chair model which varied in height, width, arm support and pan shape (dependent on the specific requirements of the individual) and one model for visually impaired.

Urban - Space restrictions meant that in most places it was unfeasible to provide individual household latrines. Instead adaptations to the existing latrines have been provided by WAB to increase usability. Adaptations include; use of ramp, provision of handrail and support brackets and handles. All costs were borne by WAB (prices range between \$70-90), however the incorporation of these into the original design would be considerably less.

Materials developed

Hygiene promotion guidelines for persons with disabilities

Based on the experiences in the pilot project, Hygiene Promotion Guidelines for Persons with Disabilities aimed at partners' front line staff have been developed.

Hardware brochure: sanitation options for persons with disabilities

Based on the designs used in the pilot project a brochure of sanitation adaptations/aides has been compiled in a brochure. This will be used by front line staff and engineers to explain different models and their benefits and limitations to the disabled person.

Discussion

WaterAid took following initiatives for mainstreaming persons with disabilities in programme interventions:

1. Developed Hygiene Promotion Guidelines for people with disability
2. Develop Technical Guidelines on Suitable Sanitation Facilities for persons with disability
3. Trained WA and Partners' staff
4. Trained Community based Organizations (CBOs)
5. Identified and prepared list of persons with disabilities depending on their disability
6. Organized hygiene education sessions for persons with disabilities at household level
7. Organized sessions with CBOs/ local bodies for supporting persons with disabilities at greater extent.

Lessons learnt:

1. Ignorance during providing the services is the main barrier to ensure access of WASH facilities
2. Positive attitude towards disabled should be ensured
3. It is an important component of rights to get WaSH services
4. Hygiene promotion approaches and tools should be appropriate according to disability
5. Problems regarding disability should not be addressed in isolation
6. Engagement of persons with disabilities can contribute towards enhancement of ownership of facilities and increasing dignity.

Challenges that remain

- PWDs expressed that a minor problem arises while cleaning the bottom. The gap between pan and bottom part of the body is insufficient for proper cleaning.
- Poor families try to make them as earning source by engaging into begging
- They are treated as burden both by family and community
- Access to the facilities is dominated by general population.

The future — inclusion of all in the water and sanitation sector

Findings from the pilot project identified that 1) it was much more cost effective to incorporate people with disabilities and their needs during the planning stages, and 2) in most cases, through participation with/within the CBO and other community activities the social position of the person with disability was elevated. It is thereby essential that excluded populations be involved at all stages of the project cycle. The inclusion of water and sanitation facilities for excluded populations will be extended beyond the household and mainstreamed into activities ensuring facilities are available at schools and bazaars, encouraging and facilitating involvement in education and income generating activities.

Through the establishment and strengthening of disability organisations WAB aim to create a forum for excluded populations to raise their voices to demand safe water and sustainable sanitation as a basic human right, advocating for the inclusion of disability in national water and sanitation policies.

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