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35th WEDC International Conference, Loughborough, UK, 2011**THE FUTURE OF WATER, SANITATION AND HYGIENE:
INNOVATION, ADAPTATION AND ENGAGEMENT IN A CHANGING WORLD****Principles and practices for the inclusion of disabled
people in access to safe sanitation:
a case study from Ethiopia***J. Wilbur, UK***REFEREED PAPER 1069**

Disabled people represent the largest socially excluded group and most live without access to basic sanitary services, which can exacerbate impairments and poverty. Nevertheless, they are often excluded from development intervention and research. In response, WaterAid in Ethiopia designed a pilot project to meet the needs of disabled people within their service delivery work. Learning gained through the project informed WaterAid's global equity and inclusion approach. In 2010, a formative evaluation of WaterAid's pilot project in Ethiopia was conducted, along with an extensive review of relevant literature, including an assessment of four case studies of World Vision's projects, semi-structured interviews and participant observation. This paper gives an overview of the research and draws out key principles and practices for development organisations aiming to empower disabled people.

Introduction and background

The Millennium Development Goals (MDGs) do not explicitly mention disability (UNDP, 2000). However, approximately 10% of the world's population live with a disability: this is the world's largest minority (UN, 2006). The World Bank estimates that 20% of the world's poorest people are disabled and are regarded as the most disadvantaged within their own communities (UN, 2006). In 2002, it was estimated that five million Ethiopians had a disability (MOLSA, 2010). Some consider this an underestimate due to ranging definitions of disability and the exclusion of disabled people in censuses, as their presence is often unacknowledged in the community (UNICEF, 2009; Yeo, 2001). Social discrimination is entrenched in cultural beliefs and customs – it is commonly assumed that a disabled person has been attacked by a *likift*, 'devil spirit' (Tesfu and Magrath, 2006). Consequently, many families do not seek medical attention, which can exacerbate the condition. Disabled people and their families are also isolated and ostracised from community life because of fear and misunderstanding.

WaterAid is an International Non Governmental Organisation (INGO) that is committed to providing clean water, safe sanitation and hygiene education to the world's poorest people. It works in 26 low income countries; one of which is Ethiopia. In 2006, WaterAid in Ethiopia conducted research into understanding the barriers that disabled people face when accessing safe water and sanitation (Tesfu and Magrath, 2006). The informants were members of Fana, a Disabled People's Organisation (DPO) located in Butajira town in Ethiopia. In response to a call for proposals for 'innovative' projects from WaterAid headquarters, the Ethiopia team submitted a successful bid to pilot accessible toilets and showers within the Fana building. This ensured that WaterAid in Ethiopia's initial research was not an extractive process. Instead, this pioneering project applied learning from the research to respond to the target groups' needs. Experiences from this project informed WaterAid's global approach to addressing social exclusion; the organisation now aims to conduct 'inclusive development' (Gosling, 2009).

In 2010, a formative evaluation of WaterAid in Ethiopia's pilot project in Butajira was conducted, along with an extensive review of relevant literature, semi-structured interviews and participant observation

(Wilbur, 2010). This paper gives an overview of the evaluation of the Butajira project and draws out key principles and practices for development organisations aiming to empower disabled people.

Description of the study

This research aimed to draw out key principles and practices for development organisations undertaking inclusive development. The research objectives were to: 1) investigate the impact of disability and social exclusion on a person; 2) evaluate the extent to which WaterAid in Ethiopia's project has assisted disabled people to make the transition from a state of social exclusion to empowerment; 3) identify principles and practices for future work with disabled people by WaterAid and other development organisations.

Methods applied

An extensive desk based review of relevant literature was carried out. In terms of the field work, empirical data was gathered through semi-structured interviews and participant observation. Transect walks with two wheelchair users were conducted within the project area and around their homes to understand environmental barriers.

Description of WaterAid's project in Butajira

Butajira town is located in the Gurage Woreda (district), Southern Nations, Nationality and People's Region (SNNPR). WaterAid worked with Prognyst (a local NGO) to address the needs of 62 members of the Fana DPO. DPOs are organisations with disabled people as members; their main activities include raising awareness for disability issues and promoting the rights of disabled people. WaterAid and Prognyst worked with contractors to construct two accessible toilets and showers within the Fana building located in Butajira town (Tesfu, 2008). These facilities are designed for, and used by, disabled and non disabled people living in and around Butajira town. This project has an income generation component as a fee is charged for using the showers. The project was completed in May 2009 and it is now operated and managed by the Fana management committee who live in the Fana building.

Selection of respondents

Informal telephone interviews were initially conducted with key sector specialists. Primary data was collected over two weeks in Addis Ababa and Butajira town in Ethiopia. During that time, a total of 25 individuals were interviewed. As Fana members were the project's target group, six informants were selected from that organisation. Purposive sampling was conducted: a gender balance, varying levels of confidence, as well as a cross section of ages, impairments and positions within Fana were targeted to ensure findings represent a cross section of the respondents' power levels. Two family members who care for disabled people were interviewed separately to triangulate findings. Two non disabled community members, who use the toilets and showers, were interviewed to assess the project's impact on attitudinal barriers. Three WaterAid staff and two Prognyst staff were interviewed, as well as representatives from other NGOs – Handicap International, Cheshire Foundation and World Vision in Ethiopia.

Analytical framework

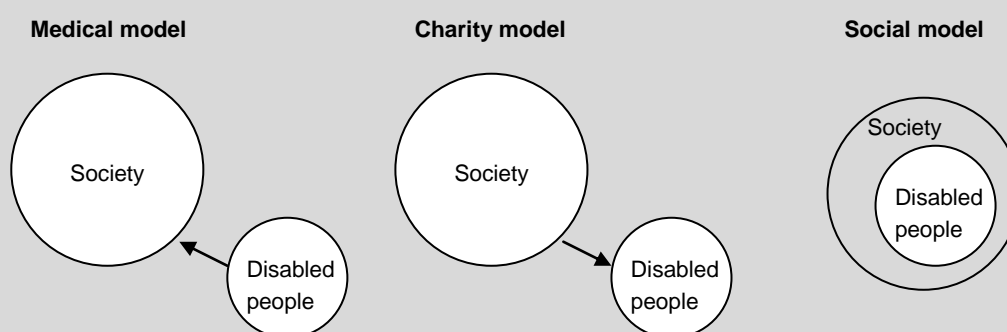
This research applied a framework for the analysis of field data which incorporates relevance (the extent to which the project design is consistent with the needs of the users' requirements and wider issues) and effectiveness (the extent to which the objectives are realised on the ground) (IFAD, 2009). The framework also includes the social model of disability (Box 1). Due to resource constraints, it did not include efficiency (how economically resources are converted into outputs) or sustainability (the likelihood that interventions will have lasting impacts).

Key concepts and the conceptual framework

Within this research, poverty includes social exclusion: a state of limited social solidarity and inequitable access to formal services (Foley and Chowdhury, 2007). Social exclusion displays the complexity of poverty beyond material living standards. This research focuses on a specific form of social exclusion: disability, and a specific service: sanitation. In this context, **sanitation** means toilets with hand-washing facilities. **Disability** is defined as 'the loss or limitation of opportunities to participate in everyday life due to social and physical barriers' (Yeo and Moore, 2003).

Box 1: Conceptual models of disability

Disability has traditionally been framed by the **medical model**, which focuses on the impairment, with intervention geared towards rehabilitation and provision of corrective devices to 'integrate the disabled person into society' (Shakespeare and Watson, 2002). The **charity model** also assumes that disabled people cannot contribute to society without external assistance. This has led to a proliferation of projects aimed at disabled people, such as the establishment of 'special' schools and income generation projects for disabled people (ibid). In contrast, the **social model** of disability treats disabled people as integral to society (Hurst, 1999). Rather than concentrating on the impairment, it recognises that barriers to full participation are societal and threefold: environmental, attitudinal and institutional. Consequently, society needs to adapt to enable disabled people to participate more fully in society. This includes access to rehabilitation and corrective devices where necessary.



Source of diagrams: World Vision (2007)

Environmental barriers relate to inaccessible transport and buildings and can be split into natural (distance from toilets and/or open defecation areas and terrain) and infrastructure (narrow entrances to latrines, lack of space, slippery floors and steps) (Jones and Jansz, 2008). **Attitudinal barriers** include negative traditional beliefs linked to a lack of information about the cause of disability. This can lead to low status, harassment and isolation of the disabled person (Tesfu and Magrath, 2006). Dependence on carers and limited social contacts also decrease disabled people's self esteem, so they are less likely to seek employment and attempt to assert their rights. **Institutional barriers** involve discriminatory legislation, policies and strategies; a lack of consultation with disabled people in policy influencing and practice intervention, as well as a lack of information on accessible toilet design options (Jones and Jansz, 2008).

In this context, **development** means addressing societal, environmental, attitudinal and institutional barriers, so that disabled people can move from a state of social exclusion to greater empowerment. The World Bank (Guernsey et al, 2006) define **inclusive development** as the result of combining three components:

1. **Inclusion:** Disabled people are recognised as participants in all development activities so they must be included in all phases of the intervention.
2. **Equity:** Every person, regardless of their age, gender, disability or ethnicity, benefits from an so that they can participate in civil, political, economic, social and cultural aspects of life.
3. **Access:** Ensuring that disabled people do not face barriers in the built environment. This includes transport and infrastructure, as well as access to information and communication.

It is often claimed that **participation** leads to the 'empowerment' of disadvantaged groups (Chambers, 1994a). However, it is a highly contested concept; if power dynamics within the focus groups are not understood, participation can gloss over power relations and further entrench inequalities (Chambers, 1974). **Empowerment** is also an extensively debated topic as organisations and individuals apply different meanings to 'power' (i.e. levels of influence), so the aim of empowerment differs (Mayoux and Johnson, 2007). To gain a more nuanced understanding of power, Mayoux and Johnson define four types of power relations: power within, power to, power with and power over (2007). **Power within** indicates an awareness

of choices, the potential for change and the confidence in one's ability to achieve that change. For instance, if a disabled person is aware of accessible toilet designs (power within) and knows who to target to request the accessible toilet, they have the **power to** direct their own existence. If a group of disabled people who all want accessible toilets demand their rights, they have **power with** each other to achieve change through joint action. An increase in the individual and collective power of disabled people can result in a reduction of **power over** the disabled people by others. In this research, empowerment is when disadvantaged people take control of their lives and their resources to become agents of change (Thomas, 2000).

Analysis and findings from the empirical data

The impact of disability and social exclusion on a person

All six Fana informants stated that not being able to use a safe, clean and private toilet was degrading, dangerous and extremely arduous. As entrances to toilets are invariably too narrow for wheelchairs to enter, all respondents who could not walk unaided, used their hands for support to drag their bodies on the floor to reach the toilet. AB explained that she did not go to the toilet during school time because it is inaccessible and unhygienic. As a result she experiences abdominal pain. She said, "The toilet at the school is not clean. I get out of my wheelchair outside and then I am coming on my hands. When I saw some dirt in the toilet I didn't use the toilet – I go back to my class. If I was not disabled I could go to the toilet anywhere. It is very painful not to go to the toilet". Forty percent of respondents (67% of the females interviewed) stated that they were ashamed to be seen crawling and how dirty they became. These findings support the literature review: **environmental barriers** force some physically disabled people to crawl on the floor to use a toilet or defecate in the open. This has implications for health and safety and negatively affects people's self esteem.

One female informant explained how her low status, isolation and exclusion within the household and community led to low self worth, "There was a big discrimination by the society and I was staying at home. My family sent my sisters and brothers to school but they are keeping me at home because they are ashamed of me. I am hiding myself too". All respondents disclosed that their families believed their impairment was caused by an evil spirit, which led to 80% of respondents being treated by traditional doctors in the first instance. Treatment included bathing in holy water and massaging the affected limbs with butter. A lack of proper medical treatment due to limited knowledge about the cause of disability could have worsened the impairment. The empirical findings support the literature review: **attitudinal barriers** reduce self confidence and the ability to assert rights.

Respondents who are independently mobile, educated and confident to voice their opinions in public attend district government meetings to promote the need for accessible infrastructure. However, the situation may reflect the urban context rather than the wider situation in Ethiopia. With 84% of the population living in rural areas (FDRC, 2007) the Ministry of Labour and Social Affairs (MOLSA, 2010) assumes that the majority of disabled people reside in rural areas where there is a severe lack of public services (eg basic healthcare and education). Hence the empirical data did not support the findings in the literature review in relation to **institutional barriers** as respondents were aware of their rights.

The extent to which WaterAid's project has assisted disabled people to make the transition from a state of social exclusion to empowerment

WaterAid in Ethiopia applied the charity model within its project. This is not uncommon in organisations that are beginning to focus on meeting the needs of disabled people within their development interventions. WaterAid concentrated on disabled people's impairments and therefore only focused on addressing access to the sanitation facilities (environmental barriers). It did not aim to address the attitudinal or institutional barriers which limit disabled people from fully participating in society (Box 1). This was in response to the priority placed on addressing those aspects by the Fana informants during WaterAid in Ethiopia's initial research (Tesfu and Magrath, 2006).

The management committee, who live in the Fana building, reported significant benefits due to their close proximity to the facilities. One member explained, "With this [WaterAid] project I feel that I am born again. I use toilet and shower freely; I am free and I am very happy by this project". However, the project did not effectively address the **natural environmental barriers** as the majority of Fana members live outside Butajira town. One unemployed informant has to either pay for another person to push him to town, or rely on good will. Another lives two kilometres away and has to travel 40 minutes over rough and hazardous roads in his wheelchair to reach the Fana building (Image 1). Consequently these informants'

sanitary practices remain unchanged. One informant continues to rely on his carer and AC defecates in fields behind his home (Image 2).



Image 1



Image 2



Image 3

Environmental barriers in relation to infrastructure also remain. As well as the entrance to the Fana building being too narrow, the entrance to the toilets and showers are also too narrow for wheelchair users; the corridors and cubicles are too tight to allow a person to turn with ease and the toilet has no light (Image 3). One respondent stated that she uses the light on her mobile phone when inside the toilet cubicle whilst also using her hands to balance.

Attribution can be claimed for addressing **attitudinal barriers** within the wider community as the project raised awareness of disability issues. The Fana management committee are also providing a service for non disabled people; this shows non disabled people that disabled people are capable of earning an income. One non disabled person commented, “I feel very happy when [disabled people] are working and get money by themselves because they are not begging on the street. That is a big thing and I appreciate them”.

Institutional barriers include limited consultation with disabled people within policy and practice, as well as a lack of information on accessible toilet designs options. WaterAid only involved the Fana management committee in the planning, implementation and management of the project. No informants outside the management committee were aware of accessible toilet designs. All respondents stated that they would have valued the opportunity to feed into the development intervention. One was highly frustrated by the situation saying, “Only some people are benefiting from that organisation. I was not included in the project; I was not asked about it. Fana did not tell me any information”. WaterAid did not address institutional barriers effectively within the project. WaterAid did not fully analyse the power dynamics within the DPO prior to intervention and instead, gave the most powerful group the legitimacy to act on behalf of the target group by only engaging the management committee. Arguably this has reinforced power relations.

Recommendations for development agencies working in the water, sanitation and hygiene sector

Drawing on the literature review, findings from the empirical research and the analysis of the World Vision case studies, the following recommended principles were developed:

1. **Mainstream inclusive development in all areas of work rather than targeting disabled groups as a stand-alone activity.** Intervention should be designed within the social model of disability to address environmental, attitudinal and institutional barriers.
2. **Conduct a stakeholder analysis that incorporates an assessment of power, age, gender and impairment during the project planning phase.** Other aspects can be added as appropriate; these can include ethnicity, religion and caste.
3. Recognising that full participation is unrealistic within resource constraints, **invite strategic participation that spans the power dynamics** detailed within a stakeholder power analysis (High,

2003). This means that target groups are not treated as a homogenous unit, which means that the most socially excluded can participate in the development intervention.

4. **Make ‘empowerment’ more specific, measurable and achievable.** Using the information gained from the stakeholder power analysis, develop activities which aim to improve specific power relations. Table 1 gives examples of activities.

Table 1: Putting principles into practice		
Power relations	Aim (Mayoux and Johnson, 2007)	Proposed activities for development agencies working in the sanitation sector
Power within	Increase confidence and voice	<p>Conduct strategic participation across the horizontal and vertical power relations of target groups.</p> <p>Construct accessible toilets; arrange and facilitate meetings between local groups (DPOs, government officials, teachers, religious leaders) and facilitate a discussion of disability issues with the longer-term view of supporting the DPO to lead the process independently.</p>
Power to	Increase skills, knowledge and resources	<p>Provide training on improved hygiene practices, operation, maintenance and management of facilities; publicise accessible latrine designs.</p> <p>Conduct meetings in accessible buildings and adapt communication styles (eg use sign language) to ensure it is accessible for all.</p>
Power with	Build networks and capacity for coordinated action	<p>Raise the public’s awareness of political processes and procedures to be targeted for change.</p> <p>Support local groups to use the media to raise public awareness of disability issues and the effects of social discrimination.</p> <p>Facilitate links with other DPOs so activities can be coordinated and their collective voice strengthened.</p>
Power over	Changing attitudes and behaviours of the powerful and changing discriminatory and unequal institutional structures and policies	<p>Provide continuous training for staff so that the social model is applied and staff do not slip back into the charity/medical model.</p> <p>Support the government to incorporate inclusive toilets into their standardisation of designs.</p> <p>Integrate disability issues within Information, Education and Communication (IEC) materials used at schools, clinics, hospitals and at religious events to raise the understanding of the cause of impairments.</p>

Conclusion

This research demonstrates the challenges of adopting inclusive development, but it also shows that addressing the environmental, attitudinal and institutional barriers within society is vital so that disabled people can participate fully in society. If this approach is not adopted, organisations risk excluding disabled people from their interventions. As all development interventions have unintended consequences, it is vital that organisations scrutinise concepts and approaches which they are committed to. This includes understanding power relations within the target group and acting to challenge unequal relationships to ensure that ‘empowerment’ and ‘participation’ do not remain rhetorical.

WaterAid in Ethiopia was one of the first WaterAid country programmes to pilot accessible toilets within the Butajira pilot project. This was a very courageous step. The team also opened their doors to allow internal and external stakeholders to review the project. This willingness to share learning gained through the Butajira pilot project has shaped WaterAid’s global approach to addressing social exclusion within its work (Gosling, 2010). The WaterAid team in Ethiopia have committed to mainstreaming inclusive development within all areas of their programming (WaterAid, 2010). They are also working towards

incorporating the activities included in Table 1 within the Butajira project in order to address the three societal barriers.

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