



Mainstreaming disability and making WASH programmes inclusive

*Sue Enfield
Institute of Development Studies
15 October 2018*

Question

What approaches have worked in mainstreaming the disability agenda in WASH programming.

For the purpose of clarity 'the disability agenda' is taken to mean access by children and adults with disabilities to mainstream (core) public services in WASH

Contents

1. Summary
2. Barriers to Access and Consequences
3. Practical Guidance for Inclusive WASH Programming
4. References

The K4D helpdesk service provides brief summaries of current research, evidence, and lessons learned. Helpdesk reports are not rigorous or systematic reviews; they are intended to provide an introduction to the most important evidence related to a research question. They draw on a rapid desk-based review of published literature and consultation with subject specialists.

Helpdesk reports are commissioned by the UK Department for International Development and other Government departments, but the views and opinions expressed do not necessarily reflect those of DFID, the UK Government, K4D or any other contributing organisation. For further information, please contact helpdesk@k4d.info.

1. Summary

Access to Water and Sanitation: a matter of right

There is a need for accessible inclusive WASH facilities at several levels:

- Personal (i.e. within the home);
- Community (i.e. public markets, water points, places where community meetings and information exchange takes place), and
- Institutions (i.e. schools, healthcare facilities and hospitals, prisons etc.).

The rights of persons with disabilities to accessible WASH facilities are documented in the Convention of the Rights of Persons with Disabilities (CRPD): in Article 9 on accessibility and Article 28 on the right to an adequate standard of living and to social protection. Depriving disabled persons access to adequate, clean water and accessible sanitation leads to health complications, loss of dignity, social isolation and exclusion from participation in school or community activity.

The international community also reflects these rights in the Sustainable Development Goals, in particular in Targets 6.1 and 6.2 under the broad goal of ensuring access to water and sanitation for all: paying special attention to the needs of women and girls and those in vulnerable situations (UNICEF, 2015). National constitutions and sector policies adopt these international principles and should promote implementation. These varied legal frameworks make clear that access to adequate, clean water supply for drinking and for hygiene needs, and access to sanitation and hand washing facilities should be viewed through a rights lens.

Approaches to including disabled people in WASH programmes

WASH practitioners often reference a seminal work: Water and Sanitation for disabled people and other vulnerable groups: designing services to improve accessibility (Jones and Reed, 2005). Based on three years international research and collaboration with WASH and disability sector organisations, it provides guidance for WASH providers and consumers.

There is a strong consensus that designing inclusive WASH facilities from the start is the most cost effective approach. Nonetheless, the cost of adapting facilities (retrofitting) costs less than might be expected since cost is often advanced as one reason for not removing barriers. Freeman et al (2011) found an additional 3% of the cost to make a school latrine block fully accessible and inclusive of facilities for menstrual hygiene management). It is clear that making WASH services inclusive for disabled people will allow several other groups (i.e. older people, pregnant women, sick people) to also benefit. There is a broad consensus that involving those who will use the facilities from the design stage is essential to understanding current barriers faced. The *process* for assessing the situation of WASH provision needs to be inclusive; as does the *technical design* of the facilities to be delivered.

People with disabilities are often able to suggest adaptations that would facilitate their access and there is a good amount of technical design material gathered from the global South available in visual formats that illustrates low cost, and low maintenance solutions; one example is the **Compendium of Accessible WASH technologies** (Jones and Wilbur, 2014). Several web based sites group 'how to' practice guides with case study experiences from across the globe - these are referenced at the end of this report.

Specifically in Ethiopia World Vision, WaterAid, and Light for the World have worked with disabled people. Their organisations have published guidance and toolkits that are helpful and relevant programming tools. These organisations also draw from a wider body of work and provide guidance from diverse programmes. These toolkits deal with:

- Identifying people with disabilities and understanding the range of needs (it is important to consider that needs of all disability groups - people with intellectual impairment and mental illness need specific responses to fully access WASH services; water and hygiene is important to the management of lymphatic filariasis, leprosy and incontinence; young women with disability need extra support with menstrual hygiene management);
- Using the Washington Short Set of Questions to quantify the prevalence of physical limitations;
- Challenging myths and stigmatising attitudes amongst staff, communities and policy makers that perpetuate the exclusion of people with disabilities from WASH services, and
- Technical adaptations and design features that will allow a far wider cross section of community members to draw and transport water safely; wash themselves and their clothes independently; access latrines frequently, and in safety.

There is good understanding shown in the literature of the additional difficulties and risks women and girls with disabilities face in accessing WASH facilities. Although men and boys are not immune to violence or attacks, testimonies from women and girls more often report anxieties about their safety and security, which act as an additional barrier to sanitation. The challenges of dealing with menstrual hygiene management are considered. The burden placed upon carers (frequently women) to assist the sick, older people, children with intellectual impairments and others, limits their time for economic activity, forcing families deeper into poverty.

The literature also covers specific issues of access to WASH that affect significant numbers of users:

- Menstrual hygiene management for all women and girls with additional barriers for disabled women and girls
- Sanitation and personal hygiene for persons affected by incontinence
- Access to clean water in the management of neglected tropical diseases such as leprosy and Lymphatic Filariasis and strategies to limit the disabling impact of these

2. Barriers to Access and Consequences

Compromised dignity and low self-esteem

Disability is a part of the human condition. The average prevalence rate in the adult population aged 18 years and over derived from the World Health Survey was 15.6% (WHO 2011:27). Almost everyone will be temporarily or permanently impaired at some point in their life, and those who live into old age will experience increasing difficulties in functioning. Most extended families have a disabled member, and many non-disabled people take responsibility for supporting and caring for their relatives and friends with disabilities (WHO, 2011). Health is also affected by environmental factors, such as safe water and sanitation, nutrition, poverty, working conditions, climate, or access to health care (WHO, 2011: 28). Ill-health, pregnancy and ageing may all

restrict or limit access to water points, latrines, public transport and healthcare facilities. Therefore, it is important to stress that inclusive approaches to water, sanitation and hygiene (WASH) are likely to bring benefit to a population that is far wider than people with disabilities. They will also contribute to preventing new cases of disability.

Since the adoption of the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2006, many national Governments recognise that disabled people have equal rights to other citizens and should be able to access all basic services. Governments have the responsibility to make adaptations or special provision to allow persons with disabilities to access the built environment; to benefit from public services such as education, healthcare, water and sanitation; and to play a full part in community decision making and influencing.

Lack of access to water and sanitation is both a denial of the basic human rights of a person with disability and an insult to their dignity and self-esteem:

- Where a person is reliant upon a carer to take them to the toilet they may soil themselves while waiting;
- Insufficient access to water for bathing or washing clothes may cause other people to avoid the person or refuse to eat with them as they smell;
- Parents and carers limit the liquid intake of their children so that they are less likely to need to use school latrines that are dirty and inaccessible. Adults self-limit their consumption so as to avoid frequent need for a toilet. This can result in dehydration and other more complex problems or infection, and
- Girls and young women with disabilities may need help to clean themselves and wash menstrual cloths; lack of private spaces where this can be done independently is invasive of their privacy.

For vulnerable people (living with disability, older persons or the chronically sick) their physical condition may limit their ability to draw water or visit a latrine but they have the right to be able to do this as easily as others. This frequently means bringing facilities closer to the home or inside the home. While this may not be culturally appropriate in all societies the use of rainwater harvesting tanks and latrines built close to living quarters makes it easier for vulnerable people to access WASH facilities more often. The situation for people with disabilities who rely on carers for basic support is frequently worse than for those who are able to manage their basic needs independently (expert communication, October 2018). It is important to consider elements of design that help vulnerable people to use facilities independently and privately.

Practice may trail behind policy intent

Freeman et al. (2011:1) found that the WASH policy in Uganda contains explicit guidelines on gender and children with disabilities; yet a majority of schools still lack gender and disability friendly WASH facilities; also hand washing facilities. The enactment of universal primary education policy (1997) dramatically increased net enrolment and pressure upon resources. Despite challenges of low funding and proper enforcement of these standards, substantial improvements have been made for water and sanitation coverage in schools. Coverage in primary schools is high at 96% for water and 83% for sanitation (Freeman et al., 2011: 71) but limitations of quality, safe water, and functional facilities are hidden by the broad definition of coverage. Case study observations of facilities concluded that there is minimal implementation of

facilities for students with disabilities and that some of those in place are poorly constructed so inappropriate (Freeman et al., 2011:80). Students with disabilities and their guardians said in interviews that teachers and parents discourage children with disabilities from attending school because of the lack of facilities. The study notes inadequate maintenance and suggests (Freeman et al., 2011:72) that until funding is allocated specifically for WASH in schools this area will always compete with other priorities as determined by the schools.

Disability or illness was given as a reason for dropout at primary level (11% boys; 9% girls) and disability was given as a reason for never attending school by 16% of boys; 18% girls aged 6-18 years (Freeman et al, 2011: 79). Children with disabilities may not attend school or dropout of school for numerous other reasons (social stigma, isolation by peers, inappropriate curriculum or learning methods etc.). The lack of WASH facilities that meet female student needs and needs of disabled students is one factor contributing to their particular low school enrolment and retention.

Positive outcome from relevant solutions

Collaborative research between WaterAid, Water Engineering and Development Centre at Loughborough University, and Leonard Cheshire Disability Inclusive Development Centre (Wilbur and Danquah, 2015) in Uganda and Zambia investigated barriers people with disabilities, chronically ill and older people face when trying to use standard WASH facilities. A key feature of this *Undoing Inequity* research was to learn what inclusive WASH looks like, how effective it is, and whether such an approach is realistic and scalable. The inclusive approach to WASH involved:

- mobilising whole communities and including everyone in activities;
- providing information in different formats (visual, audio and demonstrations);
- vulnerable people represented on water user committees;
- water supply points designed to reduce physical barriers and a barrier analysis used in a Community Led Total Sanitation (CLTS) approach to raise awareness of differing access needs;
- people with disabilities and older people taking part in accessibility audits of water points
- low-tech accessible latrine designs, including handrails for support, and raised toilet seats (static and moveable);
- subsidies for cement provided to vulnerable people in Zambia, but not in Uganda
- accessible and private school latrines installed alongside standard, gender-segregated latrines, and
- Menstrual hygiene management facilities adjoined girls' latrine blocks.

The approach produced measurable changes. Difficulties reported by vulnerable people when collecting water (distance to the water source, slippery or steep surfaces, heavy hand pump handles that are out of reach, a lack of a water container resting stand near the hand pump) were recorded less frequently. In Uganda, 75% of households using new water points included a vulnerable member and the incidence of vulnerable people reporting difficulties in collecting water dropped from 70% to 55% (Wilbur & Danquah, 2015: 3). Individual cases were resolved by installing a rainwater-harvesting jar at the home of a physically disabled person, for example. Rates of open defecation decreased (from 24% to 3% in Zambia; and from 25% to 20% in Uganda).

Improving access to WASH can increase a vulnerable person's self-esteem and social interaction. A testimony from one older woman with visual impairment records: "People never used to eat with me because I was dirty and smelling. Now everyone eats together as I am no longer dirty" (Wilbur & Danquah, 2015: 4).

After inclusive WASH facilities were installed in schools, enrolment of children with and without disabilities increased. Teachers indicated that children with disabilities face less challenges accessing school WASH post intervention and the attitudes of non-disabled children showed greater awareness and were more positive towards their disabled peers (Wilbur & Danquah, 2015: 5).

In Tanzanian schools, WASH is an entry point for inclusive programming. In each of the blocks there is a toilet for children with disabilities. The civil society organization Comprehensive Community Based Rehabilitation in Tanzania (CCBRT) makes wheelchairs, etc., and they provided the design for the toilet that is accessible to most students. (UNICEF, 2015:8)

UNICEF Uganda (2014:52) reports in *Situation of Children with Disabilities, Uganda* that the first barrier to be identified is the inaccessibility of education buildings, including latrines, toilets and classrooms. WASH for disabled people in Uganda is mostly supported at the institutional level (schools and health centres), where separate latrine stances have been designed and are constructed. The latrines stances are provided with additional space, wider door, handrails, raised latrine seats, and access ramp with a gradient 1:20. Easy accessibility to water is ensured through provision of a rainwater-harvesting tank that are nearer to classrooms than the point water sources. For CLTS, households with disabled persons are identified and supported to have useable latrines.

A review of Global Sanitation Fund work to support collective behaviour change in 13 countries (including Ethiopia) found that many people who may be considered disadvantaged had benefited and reported positive impacts in relation to safety, convenience, ease of use, self-esteem, health, dignity and improved environment (House et al., 2017). In a few cases income generation is also a positive impact. More positive incentives for disabled people were found in a Burkina Faso case study by Handicap International, (2001). Kpehounon and Serge, (2001) describe a project to provide 10 wheelchair accessible standpipes in urban municipalities. A local service provider was able to build accessible facilities using minimal resources and cement aprons around water standpipes; ramps and support rails made these accessible to wheelchair users and other persons with disabilities. Previously, women featured in this case study reported having to rely upon other family members to return from school to collect water for them as their wheelchairs became stuck in the mud. Local authorities recognised the value to the community of accessible standpipes and delegated responsibility for these to neighbourhood management committees. In some cases, disabled people have taken on management selling the water and paying the bill – thus gaining a source of income as well as independent access to water and better hygiene.

Specific and important WASH issues

Within the range of WASH topics, there are several specific issues that do not always receive the high profile they merit given the large numbers of people affected by them:

Menstrual Hygiene Management (MHM)

Menstruation is taboo in many countries. During their menstruation women and girls are often perceived to be polluting and face barriers and restrictions to their normal participation in daily life (House et al., 2012). It is likely that women and girls with disabilities face additional barriers to menstrual hygiene management but there is limited evidence. Understanding these barriers is important if women and girls with disabilities are not to be left behind by MHM interventions. Qualitative research from Nepal using photography (PhotoVoice) allowed participants to record edit and censure data, making sure that information was collected ethically with participants' full understanding and editorial control. Early findings (Wilbur et al., 2018) highlight cases such as:

- A young woman who uses crutches finds it impossible to carry water to clean herself and her menstrual cloths, and may have to keep the cloth in the house and wait for others to bring water later;
- A mother caring for her daughter with intellectual disability washes the menstrual cloths for her and cleans her. She worries for her daughter's future when she is no longer able to care for her;
- A young woman with physical disability that makes washing her body and changing her clothes difficult also needs help to latch the toilet. Being reliant on others to do this her privacy is invaded when changing a menstrual pad and at other times if others enter the toilet, and
- Physical access to toilets is difficult especially after rain, yet parents discourage use of a potty in the house. There is no water in the toilet to wash menstrual cloths.

Reliance upon others for access to WASH facilities is already a sensitive and highly personal area for people with disabilities. This is compounded for women and girls during menstruation when they need to be able to access a toilet regularly, and have access to enough water to clean themselves and menstrual cloths.

Incontinence

The International Continence Society estimates that incontinence affects one in four women over 35 years, and one in ten adult men (Hafskjold et al (2016). Data for low and middle income countries is lacking but is quite probably higher because of restricted access to health care, high numbers of young mothers, injury following sexual assaults, and unattended or complicated births that lead to obstetric fistula (a hole between vagina and rectum or bladder leaving women incontinent of urine or faeces or both). Stress from conflict and disasters can also induce bed-wetting or involuntary wetting (such as in response to loud noise resembling gunshots). For people affected by spinal injury knowledge and skills around bladder and bowel management is an important area in restoring a level of independence, and ability of that person to take part in society (author's knowledge from Motivation Tanzania, 2017)¹.

Physical effects of incontinence range from having to manage leaking, smell and sores, constant risk of urinary infection, and bladder complications. Incontinence is highly stigmatising leading to feelings of shame, embarrassment and exclusion from school, work, social life and personal

¹ Spinal injury is one cause of disability acquired in later life. The impact for a previously non-disabled person is radical and can lead to the person withdrawing from society and losing motivation to live. Regaining control over bladder and bowel functions is an important step back towards previous levels of participation. Motivation provides counselling, peer support and training from other persons with spinal injury that is highly valued by trainees.

relations. Accessing any of the range of products available to manage incontinence in high-income countries (mattress protectors, disposable nappies/pads/pants or pouches for men) is difficult in low-income countries; even where available they are likely to be out of range in terms of cost versus income (Hafskjold et al., 2016). As a minimum, it is important to give people suffering from incontinence easy access to WASH facilities.

Lymphatic Filariasis and Leprosy

Lymphatic Filariasis (LF) and leprosy are neglected tropical diseases. They are most prevalent in poor, rural and marginalised populations in low and middle income countries. Garsed and Waite (2015) describe the physical deformities and pain caused by both along with mobility impairments, loss of vision and sensation. In the long term, both diseases bring severe social and economic consequences, mental health problems in sufferers and social isolation. Improved hygiene and skin care is a key element of strategies for morbidity management and disability prevention (Garsed and Waite, 2015: 7). Access to safe water and sanitation and ability to practise hygiene should be included in guidelines to combat both diseases, though this is not always prominently featured.

High-density populations

Where there are populations living in high density, such as in urban slums or camp conditions (for refugees or following natural disasters), the pressures upon WASH facilities are considerable. Pressures upon inadequate facilities will be generally high; access for people with disabilities is often overlooked and consequently their basic needs are not addressed. In emergencies UNICEF (Disability Inclusive WASH practices, undated) advises locating households with children with disabilities close to accessible WASH facilities.

3. Practical guidance for inclusive WASH programming

Distance learning package to promote inclusive WASH

In recent years, considerable progress has been made towards achieving the global goal of universal access to WASH. The Government of Ethiopia's long term One WASH National Programme (OWNP) aims to modernise the way water and sanitation is delivered throughout the country. During 2014-2016 the Open University (OU) in the UK worked in partnership with World Vision Ethiopia (WVE) and UNICEF to develop a first set of five separate learning resources known as OpenWASH. These are available free to download from

www.open.edu/openlearncreate/course.

Although access 'for all' is an identified target, there are significant sections of society that have been left behind by developments toward this goal. Subsequently a sixth module *Count me in! Inclusive WASH* in Ethiopia has been produced in partnership between WaterAid and OU. This most recent module aims to raise awareness of the reasons why people are excluded, and how this impacts their lives. It offers guidance on what changes and provisions are needed to promote and secure all people's rights to water and sanitation. The module's five study sessions are each expected to take about two hours to study, if a person is learning alone. An OpenWASH Trainers' Handbook provides guidance on using the modules in a variety of face-to-face teaching contexts.

Inclusive Design

The main options for providing accessible WASH facilities are:

Inclusive design: this means adopting a user-friendly design from the outset. This is the most cost effective way as it incorporates accessibility into the design from the start rather than making changes with some additional expense later. However well-designed the latrine / waterpoint, other factors such as location, distance, and the approach path affect accessibility. Therefore, they need to be part of planning and design.

Retrofitting: this means making adaptations to poorly designed facilities. This is not necessarily costly, even though this may be presented as an argument for not adapting facilities designed with average users in mind. Research shows for example that the cost of making a school latrine accessible is less than 3% of the overall costs of the latrine (WEDC, 2011).

In the Abilis Guidebook (Guzman et al. 2016) argue that WASH activities are frequently designed for the 'average' person and therefore a large number of people are inadvertently excluded. Adopting an inclusive approach to design from the start of a project means that additional costs are minimal or non-existent (Guzman et al. 2016: 5). Even adapting existing facilities does not need to be a highly technical or an expensive process (Guzman et al. 2016: 7). This manual draws from practical experiences in the global South and suggests ways of making water and sanitation facilities more accessible in ways that will benefit everyone in the community. It is important to understand the **barriers** that some people currently face in accessing water and sanitation in order to design better facilities that are more inclusive. Barriers are:

Social and attitudinal: living with disability is often associated with fear or shame. People with disabilities and older people become isolated. They may be prevented from sharing family or community facilities for fear they will contaminate the water or soil the facility for other users (Guzman et al., 2016:8)

Environmental: natural barriers or those in the built environment that make it difficult for everyone to use the facility. For example, toilets and water points that are far from the home increase danger of sexual violence for women and girls; slippery paths, steps, lack of light and supportive handrails are all elements of design that contribute to limiting access.

Institutional: Legislation and policies relating to marginalised groups can lack strategies or guidelines for implementation and so remain theoretical. Many countries have now ratified the CRPD and have national disability legislation but relevant ministries responsible for water and sanitation may not be aware of this. Many policy makers are not familiar with disabilities and may not be aware of inclusive solutions (Guzman et al. 2016: 11).

Guidance is given (Guzman et al., 2016) from experience in Nepal and Tanzania about how policy makers and WASH actors can usefully consult marginalised groups to gain relevant information about the barriers they face, and so design appropriate WASH facilities. Firstly, marginalised groups must be socially included in the consultations; and then technically included by the appropriate design of WASH facilities. Checklists for each area are provided and cover aspects including:

Social inclusion: seeking knowledge from disabled peoples' organisations, ensuring that people with disabilities are encouraged to contribute their views, provide reasonable accommodation (individually tailored measures so that disabled members of a community can participate on an

equal basis with others for example signed communication). In particular, Guzman et al. (2016:14) stress the importance of positive incentives².

Technical inclusion: guidance relates to details of design around the siting of facilities, pathways and marked routes, slopes to get in to toilets, seat and rails for supportive squatting; lifting devices for gathering water, easy access to hand washing and washing points, and safe non-slip collection areas. Numerous diagrams illustrate the low cost materials that have been used with success (Guzman et al. 2016). Many more designs are to be found in

Compendium of Accessible WASH technologies

Jones and Wilbur (2014) have compiled a comprehensive, accessible set of resources that illustrates all key elements of inclusive WASH programming with photographs and diagrams of simple, low cost and low maintenance adaptations. They argue that many of these technologies are of benefit to other groups, pregnant women and older people, people who are sick. This valuable resource provides clear visual solutions from low and middle income countries to every aspect of WASH: lifting, moving, transporting and storing water; washing and self-care; the siting and approach to latrines, seating, flooring, superstructure, doors and aids for moving around.

Community Led Total Sanitation (CLTS)

CLTS aims at total sanitation and for that is has to be inclusive. If in any community disabled people, older people or people with mental health issues are forced to defecate inside their home, or in the open not only will they be exposed to health risks (often vulnerable people are forced to crawl to areas to defecate or urinate, soiling their clothes or hands in the process) but the community will suffer the impact from flies and smell. There are ethical reasons for making programmes inclusive and until and unless they are the community will not be Open Defecation Free (ODF). Action research from two wash programmes in Zambia and Uganda highlight the need to involve all those with low status who may be currently left out of CLTS processes and has found ways to address these barriers making the CLTS process more inclusive and accessible (Wilbur and Jones, 2014).

Key Actions that can be taken in a CLTS process to make it inclusive are, in summary:

- Ask people with disabilities about the problems they face with urination and defecation and how these might be overcome;
- Bring small groups of disabled people together to discuss their experiences with sanitation in a small group;
- Identify who in the community is disabled and whether they can come to triggering meetings - at these meetings the aim is to generate a collective sense of disgust as the community learns how open defecation is bad for everyone;

² Since disclosing family members with disabilities might lead to harmful consequences for the family, due to the negative image of disability in many societies, it is vital to provide them with a positive incentive or even reward. In every case, such rewards should also help in changing the family's attitude towards having a member with a disability. For example, households with family members with disabilities could pay smaller water user fees or even be exempt from fees.

- The community then decides how to address the problem and take action. Disabled people should be encouraged and supported to speak up and be heard when plans are being made - meaningful participation is vital;
- Facilitate participatory design to suit disabled peoples' needs; feed in ideas if necessary;
- Encourage links between disabled people and those willing to support them;
- Make it clear that the arrangements for disabled people are a part of ODF verification process, and
- Check that arrangements are adequate within the means of the community.

Costs of inclusion

The cost of including people with disabilities is often used as an argument against adapting development programmes so they are included. But the reality is that including people with disabilities in mainstream development is more effective and efficient than excluding them. Mobility International (an important disability specific NGO) recommends a budget allocation of 2-7%³ for including people with disabilities to cover the costs of:

- Raising awareness on disability amongst own staff and communities;
- Making buildings accessible;
- Providing sign language interpretation;
- Providing information in different communication formats (braille, audio);
- Transport for people with disabilities, and
- Assistive devices (these normally should be provided by government or disability services, but are not always available or demand exceeds supply).

How to establish levels of demand and specific issues by consultation with vulnerable groups

In order to plan for and implement inclusive WASH facilities it is essential to start from the base, in communities. Vulnerable people may not be used to being consulted, and others may be inclined to speak on their behalf. Both Light for the World and World Vision (in their disability inclusion and training manuals Count Me In and Travelling Together) counsel from their experiences to be aware of the educated, vocal disabled person who 'speaks for others'. There is a tendency to prioritise access for persons with physical disability in WASH programming; the needs of visually impaired persons and those with intellectual impairments and their carers should not be overlooked.

Some people may need to be won over: if stigma and rejection of certain community members is current (for example people with mental health issues) it will be essential to influence the attitudes of those around them before they can gain access to WASH services with others. Cavil et al. (2017) investigated community led total sanitation programmes in six countries (including Ethiopia) and found that when appropriately implemented CLTS can contribute to physical and

³ As cited in Count me In (2017: 47)

mental health by building pride and a sense of inclusion. However, there are risks that people with mental health issues may be mistreated by other community members. Current behaviours need to be considered sensitively. In some conditions such as intellectual disability, dementia and psychoses excreta related behaviours such as smearing faeces or involuntary faecal incontinence are found. While distressing to the person with a mental health condition it may be hard to trigger positive habits and so to eliminate open defecation. Natural leaders in communities can provide a positive force for change and since CLTS is fundamentally about human dignity programmes should be designed in ways that promote and protect mental health rather than stigmatising and discriminating against those whose behaviours do not correspond to social norms (Cavill et al., 2017: 3).

Local Government staff has legal responsibility to deliver access to key services. Private Sector providers are often used to build facilities, but there will be a need to monitor the quality of construction. Where a clear technical specification is provided if local contractors skimp on aspects of this they may still build a facility that is inaccessible. Many policy makers are not familiar with people with disabilities and are not aware of inclusive solutions (Guzman et al. 2016: 11). There is need to inform implementers on both disability, its prevalence and consequences as well as the technical design aspects of inclusive WASH.

The Washington Group simple set of questions provides a useable framework that can help identify the extent of different needs that are based on functional limitations not medical descriptions of disability. Several of the various inclusive WASH toolkits explain the concept behind these questions and explain how to collect data on disability prevalence. Equality, non-discrimination and inclusive WASH for example (WaterAid, 2018: 109) provides guidance on translating, administering and collecting responses to the six core questions (often called the Short Set). These are designed to be used as a short questionnaire by staff and establish the level of difficulty the person being interviewed experiences with:

1. Seeing, even if wearing glasses;
2. Hearing, even if using a hearing aid;
3. Walking or climbing steps;
4. Remembering or concentrating;
5. Self-care such as washing all over or dressing, and
6. Communicating or being understood in their usual or customary language.

These questions are reproduced in simple census format in Count me In (Bruijn et al., 2012: 46).

The process review of the *Undoing Inequity* research (Wilbur & Danquah, 2015: 4) highlighted the challenges staff faced in translating principles such as rights, inclusion, vulnerability and disability into practice. Training on disability and inclusive WASH practices and technologies is essential for both the staff of implementing agencies and local government and community level. Still, awareness of terms may be consistent in the principal organisation (WaterAid staff in this research case) but confidence to pass the knowledge to other partners less so. Sometimes concepts or terms are not defined in local language or easily accessed reference materials are not made widely available.

Coe and Wapling (World Vision manual: Travelling Together, 2010) provide a one day training module to be used by organisations wishing to take on disability in their programming. Travelling Together is a method to start unpacking entrenched attitudes including myths and superstitions

about disability (for example, that it may be catching or that disabled people can somehow contaminate water points /turn wells saline). It has been widely delivered in Ethiopia, with disabled trainers from national disability organisations, including to Members of Parliament and as a precursor to WATSAN inclusion training (World Vision: Travelling Together, 2010:63).

WaterAid (2018) has published in toolkit form the most comprehensive approach to guide staff delivering WASH programmes in *Understanding and addressing equality, non-discrimination and inclusion in WASH work (ENDI)*. This covers important concepts around equity of access, understanding marginalisation and who to work with to end it, and provides tools and checklists. These are designed for use by WASH staff in communities and cover the key stages of an inclusive WASH process:

- Raising awareness and assessing need;
- Tools for baselines and situational analyses in planning;
- Tools for promoting participation and use in programme implementation, and
- Tools for monitoring and evaluating levels of participation.

Recognising that gender, age, disability and health status are universal markers for marginalisation (WaterAid, 2018: 12) the guide challenges providers of WASH facilities to consider to what extent they engage with people of across this range. Failure to do so will lead to the type of WASH facilities described as being designed for the 'average' person and will perpetuate many others across the range of age, disability, health status being unable to adequately access facilities. Acknowledging that staff may be uncertain or fearful about how to identify and involve marginalised groups partnering with local or national organisations run by people from that marginalised group is recommended.

In addition to providing checklists and tools for assessment of current practice (i.e. how inclusive is the organisation's work on WASH) the toolkit provides checklists for design features that will help to make a facility more or less accessible. For example, there is a checklist on access to latrine at entry point, internal design features, water sources for handwashing, facilities relating to menstrual hygiene (WaterAid, 2018: 80-86).

Light for the World (LFTW) records the organisations' experience of making programmes disability inclusive in Count me In (Bruijn et al., 2012) LFTW used members of the Ethiopian Centre for Disability and Development (ECDD) as trainers and argue that disabled people are the best advocates for the rights of persons with disabilities (Bruijn et al 2012: 34) Guidance as to how to find persons with a disability in a project area includes simple steps such as (Bruijn et al 2012: 37):

- Identify persons with disabilities already enrolled in the programme;
- Use existing data from government or from disability NGOs in the area;
- Link up with local disability specific organisations or disabled people's organisations and use their contacts;
- Organise a meeting with people with disabilities and ask them for advice on how to find other disabled people, and
- Talk with community and religious leaders; explain that you want to include people with disabilities in your programme. They are likely to be willing to show you the homes of people with a disability.

People with disabilities are often able to identify the barriers they face and the reasons why they are excluded. It may be necessary to organise special focus groups where they can express their situation and ideas freely - community attitudes sometimes form a part of the barriers to

participation. Using disabled people to facilitate discussions will demonstrate that the organisation is serious about inclusion and collaboration. Disabled people are also often able to identify simple solutions: the Ethiopian Kale Heywot Church run water and sanitation programme that supported the building of a public toilet in a rural village. A blind man needed someone to bring him to the toilet but suggested that a rope be placed along the route he used to the toilet enabling him to go to the toilet by himself (Bruijn et al., 2012: 44).

UNICEF guidance note (undated) on disability inclusive WASH practices highlights five key messages:

- Encourage the participation of people with disability in all decision making processes; ensure WASH related information is accessible and in formats that people with different types of disabilities can understand;
- Address stigma and discrimination, transforming social norms related to WASH access and inclusion for persons with disabilities;
- Raise awareness and talk about the rights of people with disabilities to WASH as well as their specific needs when planning, implementing, and monitoring and evaluation of WASH activities. Promote a positive attitude towards addressing WASH needs of people with disabilities with government, sector partners and communities;
- Consider disability in the design, monitoring and evaluation of development and emergency WASH interventions. Identify specific bottlenecks faced and solutions to the bottlenecks. Disaggregate data by disability, and
- Design and build WASH facilities according to the principles of universal design so all, including people with disability, can use them. Specifically, WASH facilities should be physically accessible, and affordable for people with different types of disabilities.

This guidance encourages a twin-track approach making mainstream WASH facilities inclusive by adopting principles of universal design. Complementing this with direct interventions will address individual disability related needs.

National Wash Cluster

It is sensible to explore the experience of inclusive WASH programming within the agencies that form the National Wash Cluster in Ethiopia. This is coordinated by UNICEF. The literature scanned for this report and summarised above reveals an amount of expertise that has been developed from direct experience in Ethiopia and complemented by wider organisational experience.

4. References

Bruijn, P., Cornielje, H., Maharaj, N., Regeer, B., van Veen, S., and Wolting, R., (2012) Count me In: Include people with disabilities in development projects A practical guide for organisations in North and South www.light-for-the-world.org/sites/lfdw_org/files/download_files/count-me-in-include-people-with-disabilities-in-development-projects.pdf

Cavill, S., England, P., House, S., and Ferron, S., (2017) Understanding, respecting and including people with mental health conditions as part of the CLTS process www.wsscc.org/wp-content/uploads/2017/07/Understanding-respecting-and-including-people-with-mental-health-CLTS-Cavill.pdf

Coe, S. and Wapling, L. (2010) World Vision manual: Travelling Together www.wvi.org/disability-inclusion/publication/travelling-together

Convention on the Rights of Persons with Disabilities (2006)
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

Freeman, Erhard, Fehr and Ogden (2011) Equity of Access to WASH in Schools' presents findings from a six-country study conducted by UNICEF and the Center for Global Safe Water at Emory University
https://www.unicef.org/wash/schools/files/Equity_of_Access_to_WASH_in_Schools.pdf

Garsed, C., Waite, R., (2015) The importance of water, sanitation and hygiene for lymphatic filariasis and leprosy care and inclusion <https://www.infondt.org/resource/importance-water-sanitation-and-hygiene-lymphatic-filariasis-and-leprosy-care-and-inclusi-0>

Guzmán, N., Huuhtanen, S., Katsui, H., Kilpelä, N., Koistinen, M., Pesola, K., and Tuure, T., (2016) Inclusive WASH activities from the global South A guidebook Abilis Finland www.vammaiskumppanuus.fi/wp-content/uploads/2016/05/Inclusive_WASH_Activities_in_the_Global_South.pdf

Hafskjold, B. Pop-Stefanija, B. Giles-Hansen, C. Weerts, E. Flynn, E. Wilbur, J. Brogan, K. Ackom, K. Farrington, M. Peuschel, M. Klaesener-Metzner, N. Pla Cordero, R. Cavill, S. House, S. (2016) 'Incompetent at incontinence - why are we ignoring the needs of incontinence sufferers?' *Waterlines*, volume 35, issue 3, July 2016 -
<https://www.developmentbookshelf.com/doi/10.3362/1756-3488.2016.018>

House, S., Ferron, S., and Cavill, S. (2017) Scoping and Diagnosis of the Global Sanitation Fund's Approach to Equality and Non-discrimination Water Supply and Sanitation Collaborative Council (WSSCC) <https://www.wsscc.org/wp-content/uploads/2017/09/GSF-EQND-Study-web-EN-FINAL.pdf>

House, S., Mahon, T., Cavill, S. (2012) Menstrual Hygiene Matters www.wateraid/mhm

Inclusive and Accessible WASH in UNICEF: Good practices by country (2015)
www.unicef.org/disabilities/files/UNICEF_Accessible_Inclusive_WASH_Matrix_2_2.pdf

Jones, H. & Reed, B. (2005). Water and sanitation for disabled people and other vulnerable groups: designing services to improve accessibility. Leicestershire: Water, Engineering and

Development Centre, Loughborough University
<https://wedcknowledge.lboro.ac.uk/details.html?id=16357wsfdp>

Jones, H. and Wilbur J., (2014) Compendium of Accessible WASH technologies WEDC WaterAid Share <https://washmatters.wateraid.org/publications/compendium-of-accessible-wash-technologies>

Kpéhounon C., and Serge, D., (2001) Handicap International/Projet DECISIPH Towards Inclusive Wash Access to drinking water for people with disabilities in the town of Tenkodogo (Burkina Faso)
http://www.inclusivewash.org.au/Literature/Case%20Study%2011_Access%20to%20drinking%20water%20for%20people%20with%20disabilities.pdf

UNICEF Situation of Disabled Children in Uganda (2014)
www.unicef.org/uganda/UNICEF_CwD_situational_analysis_FINAL.pdf

UNICEF (undated) Disability Inclusive WASH Practices: Including people with disabilities in UNICEF WASH Programming
www.unicef.org/disabilities/files/WASH_Disability_Inclusion__Practices__programming_note_-_Draft_for_review.pdf

WaterAid (2018) ENDI Toolkit: Understanding and addressing equality, non-discrimination and inclusion in water, sanitation and hygiene (WASH) work

WEDC (2011) Briefing Note 1: Inclusive design of school latrines - how much does it cost and who benefits? https://wedcknowledge.lboro.ac.uk/resources/briefnotes/BN001_School_Latrines.pdf

Wilbur, J., and Danquah, L., (2015) Undoing inequity: water, sanitation and hygiene programmes that deliver for all in Uganda and Zambia - an early indication of trends <https://wedcknowledge.lboro.ac.uk/resources/conference/39/Danquah-2467.pdf>

Wilbur, J. and Jones, H. (2014) 'Disability: Making CLTS Fully Inclusive', Frontiers of CLTS: Innovations and Insights Issue 3, Brighton
<https://opendocs.ids.ac.uk/opendocs/handle/123456789/4515>

Wilbur, J., Kayastha, S., Sigdel, A., Gyawali, A., Mahon, T., Torondel, B., Kuper, H., (2018) Identifying and addressing the barriers to menstrual hygiene that adolescents and young people with disabilities face in Nepal WaterAid London School Hygiene and Tropical Medicine
<http://disabilitycentre.lshtm.ac.uk/files/2018/01/Barriers-to-Menstrual-Hygiene-Learning-Note.pdf>

WHO World Report on Disabilities (2011)
http://www.who.int/disabilities/world_report/2011/report.pdf

Acknowledgements

We thank the following experts who voluntarily provided suggestions for relevant literature or other advice to the author to support the preparation of this report. The content of the report does not necessarily reflect the opinions of any of the experts consulted.

- Dominique Porteaud; Global WASH Cluster Coordinator, UNICEF

- Priya Nath, Equality Inclusion and Rights Advisor, WaterAid
- Sarah House, Freelance Public Health / Water, Sanitation and Hygiene Engineer
- Sue Cavill, Water Sanitation and Hygiene freelance
- Jane Wilbur, London School of Hygiene and Tropical Medicine

Key websites

- AskSource – International online resource centre on disability and inclusion has links to resources on inclusive WASH and disability: <http://www.asksource.info/topics/cross-cutting-issues/inclusive-wash-and-disability>
- A large number of web resources is made available via www.inclusivewash.org.au. Among these surveys, assessments, arguments for disability inclusive wash and 'how to' guidance the most recent publications are from 2014 or before while remaining relevant.
- DID4all resources on disability and WASH (an aid donor-focused resource collection maintained by CBM www.did4all.com.au/ResourceTheme.aspx?4cc97)

Suggested citation

Enfield, S. (2018). *Mainstreaming disability and making WASH programmes inclusive*. K4D Helpdesk Report. Brighton, UK: Institute of Development Studies.

About this report

This report is based on six days of desk-based research. The K4D research helpdesk provides rapid syntheses of a selection of recent relevant literature and international expert thinking in response to specific questions relating to international development. For any enquiries, contact helpdesk@k4d.info.

K4D services are provided by a consortium of leading organisations working in international development, led by the Institute of Development Studies (IDS), with Education Development Trust, Itad, University of Leeds Nuffield Centre for International Health and Development, Liverpool School of Tropical Medicine (LSTM), University of Birmingham International Development Department (IDD) and the University of Manchester Humanitarian and Conflict Response Institute (HCRI).

This report was prepared for the UK Government's Department for International Development (DFID) and its partners in support of pro-poor programmes. It is licensed for non-commercial purposes only. K4D cannot be held responsible for errors or any consequences arising from the use of information contained in this report. Any views and opinions expressed do not necessarily reflect those of DFID, K4D or any other contributing organisation. © DFID - Crown copyright 2018.

