Disability Inclusive Systems Strengthening in WASH:
How can we do it better?

Reflections from the Water for Women Fund’s South Asia Regional Learning Event

Kathmandu / December ‘19

Introduction

The first Water for Women (WfW) Fund Regional Learning Event was held in Nepal from 2-5 December 2019, titled ‘Systems strengthening for inclusive WASH - leaving no one behind’. The Event was jointly convened by the Australian Government’s flagship water, sanitation and hygiene (WASH) program, the Water for Women Fund, together with SNV Netherlands Development Organisation. The Event gathered nearly 50 participants from Water for Women Fund projects and partners across seven countries in South and South East Asia. They were joined by research partners, the Fund management team and Australian government representatives.

In Brief

• WASH systems are made up of individual people who reflect broader norms and attitudes in their society, which impacts on efforts to change discriminatory institutional practices. Therefore addressing these norms and attitudes is critical to inclusive WASH.

• Inclusive change is more likely to happen when people with disabilities themselves are actively involved in designing and implementing WASH systems. This requires considered approaches to working in partnership with marginalised people and strengthening rights-holder groups.

• Deliberate efforts and approaches are needed to reach specific groups of people who are most marginalised, and ensure that WASH systems do not further entrench inequality.
Disability and WASH

A human rights-based understanding of disability says that inclusion is about removing barriers that limit the equal participation of people with disability. These barriers include attitudes and social norms, the built environment, the ways that information is stored and communicated, and institutional policies and practices. Removing barriers requires bringing about systemic or societal change, while at the same time supporting individuals to access services and meet their practical needs.

The growing commitment to disability inclusive WASH within the sector has seen much progress in terms of accessible WASH infrastructure at all levels and support for people with disability to manage their WASH needs within their households and communities. The WASH sector is also increasingly focused on the broader enabling environment for WASH policy and practice, or on strengthening ‘WASH systems’. The linkage of these two streams of work, however, remains an area for further learning and innovation.

Disability inclusion in systems strengthening

One of the key questions at the event was: What does a ‘systems change’ (or ‘systems thinking’) perspective mean for how WASH programming approaches disability inclusion? The approach to disability inclusion described above suggests that a focus on systems change within WASH would present many opportunities to achieve more systemic changes for people with disability. Making this a reality in practice may involve strategies such as focusing on the attitudes and norms of individuals within WASH systems, supporting people with disability to engage with and influence these systems, and creating links between WASH and other systems or services.

Overarching learning

Closing the gap between policy and practice

Closing the gap was a recurring theme throughout the learning event. Similarly to many other countries in the region, Nepal has ratified the UN Convention on the Rights of Persons with Disabilities (CRPD) and enacted a national Disability Rights Law; however, this has not yet resulted in changes in practice in terms of WASH governance and service delivery. This situation is complicated by Nepal’s transition to decentralised governance, with the process of translating national laws and commitments into local government policy and practice yet to be determined.

This disconnect came up strongly during the field visit to education sector stakeholders. The group learned that the Ministry of Education had rolled out several programs to guide hygiene practice and WASH infrastructure in schools,
including standards relating to accessible infrastructure. However, upon visiting one local school, the group heard that the school had not received any training or funding to work towards meeting these standards. It was also clear that the central government was still working out how such a nationwide program could continue to be rolled out with each local government authority able to set its own policies.

This gap also arose in the health sector field visit, with the team finding that staff were unaware of national disability accessibility standards for healthcare facilities. The group visiting public WASH facilities found that municipal governments received a lump sum budget for infrastructure, without guidance on how that could be applied to ensure disability inclusion.

Field Trip Group B – the education subsector presents their findings after visiting The Department of Education, Ministry of Education Science & Technology, Mangal Secondary School, and the Disabled Service Association in Nepal

Strong local leadership and local action can be opportunities for disability inclusion

Although there are challenges inherent in decentralisation, there are also opportunities that might not be feasible at the national level. The group visiting educational facilities met the director of a non-government disability-inclusive education provider linked to an adjoining public school. The local mayor was engaged with this service and the public school had invested to build accessible WASH infrastructure, suggesting that local advocacy and the support of local leadership may have enabled inclusion outcomes that might not have been possible at a broader scale or at the national level. (The challenge, of course, is that this is only one of more than 700 independent municipalities in Nepal; strategies are needed to extend and replicate good practice at scale.)

Inclusive education approaches are integral to achieving universal access in WASH

The gap between disability policy and practice is often bigger and more complicated when it comes to WASH in schools, where the approach to inclusive WASH is interlinked with the approach to inclusion within education systems. Although Nepal has committed to an inclusive education model wherein...
every child has a right to attend his or her local mainstream school, it is still transitioning from an established special education model where children with disability are sent to separate impairment-specific schools in major towns. These special schools are still being supported by the government, which encourages leaders of mainstream schools to assume that there is no need to make their school inclusive. The secondary school visited during the field trip had not made any adjustments to make its WASH infrastructure more accessible, and the principal advised that any potential students with physical impairment were referred to a disability-specialist school in Kathmandu.

**Awareness and capacity of individuals to make change happen**

Another common theme throughout the learning event was that it is often the awareness and capacity of individuals within the WASH system that determine whether disability inclusion happens on the ground. Ms. Rama Dhakal, vice-president of the National Federation of the Disabled – Nepal (NFD-N), made this point clearly at the learning event, when she pointed to the lack of implementation of disability inclusion aspects of the government’s menstrual hygiene management (MHM) policy (on which she had been consulted and influenced), due to a lack of awareness among staff. She made the plea that “if you are working in this space, please raise the awareness and build capacity”. As the WASH in schools field visit group noted, inclusion requires deliberate effort and leadership; it won’t happen by accident.
The important role of individuals as enablers (or hinderers) of inclusive change came out in all four field visits. The teams noted that stakeholders responsible for implementing WASH in the health sector, education sector, in public facilities and through community mechanisms, all had minimal awareness of the government’s commitments to disability inclusion. These stakeholders would greatly benefit from training, support and guidance on how to apply these commitments in their roles.

Many WfW Civil Society Organisations (CSOs) are already aware of these challenges and are taking steps to build capacity and awareness in the WASH systems with which they are engaging. For example, SNV Nepal has already commenced a disability inclusion capacity building exercise with rural municipalities. Thrive Vietnam has engaged a Disabled Persons’ Organisation (DPO) to train local government partners. WaterAid and LSHTM are conducting research in Cambodia to understand how disability inclusive WASH policies can be translated into practice.

### Changing norms and attitudes is key to strengthening disability inclusion

Underlying the importance of working with individuals in WASH systems is the fundamental role of norms and attitudes in shaping approaches to disability inclusion. Shivnath Raut Kahar from the Disable Inclusive and Development Center Nepal – Chandranagar (DIDCN-C) summed this up when he lamented the lack of consultation with people with disability in his part of Nepal, saying that a common view is that “disability means weakness”.

All three Gender and Social Inclusion presentations at the event highlighted norms and attitudes as determinants of inclusive change. Asahel Bush of CBM shared examples from CBM and SNV’s formative research into access to water for people with disability in Nepal, which found that negative treatment and attitudes towards people with disability were pervasive. He argued that norms and attitudes were often the biggest barrier to disability inclusive WASH, and could perhaps be the first one that needs to be addressed before broader inclusive change can happen. Di Kilsby, Consultant to Water for Women, Gender and Social Inclusion Consultant similarly highlighted the role of norms and attitudes in her presentation on Do No Harm, and noted that, since all of us are part of the ‘WASH system’, our own attitudes and behaviours also need to be examined.

### Disability rights-holder groups and individuals within WASH systems are critical

One solution which stood out as a response to these challenges was to support the participation of disability rights-holder groups and individuals within WASH systems. Across the field visits, participants noted that people with disability were not represented in ward-level WASH coordinating committees; hadn’t been engaged in the design of health centre WASH facilities; and hadn’t had their needs understood or considered in relation to public WASH facilities. All four of the field group presentations included recommendations for inclusive coordination and consultation mechanisms to be established to bring people with disability and others experiencing marginalisation into WASH decision-making processes. In her reflections on these presentations, Rama Dhakal of

Shivnath Raut Kahar from the Disable Inclusive and Development Center Nepal

Asahel Bush from CBM, Disability Inclusion Advisor to several Water for Women projects
NFD-N made a specific request to participants to make sure that people with disability are there at the table in all planning and budgeting processes.

During the event, it became clear that most (if not all) participating CSOs were already collaborating with disabled people’s organisations as a strategy for ensuring participation and representation of people with disability within WASH systems. Some CSOs have gone a step further in deepening their practice of partnering with these rights-holder organisations. World Vision Bangladesh, for example, is supporting the formation of local disability ‘self-help groups’, which are informal community networks of people with disability that are often the precursor to a formalised DPO. SNV Nepal is applying partnership principles and power analysis to its engagement of grassroots district-level DPOs, by supporting them to strengthen their own governance and organisational strategies before partnering with SNV, a much larger international NGO. WaterAid and London School of Hygiene and Tropical Medicine (LSHTM) research in Cambodia plans to work with Cambodian DPOs so that they can drive the research agenda and make use of its findings.

“...make sure that people with disability are there at the table in all planning and budgeting processes.”

Ms. Rama Dhakal, NFD-N

Lack of funding, consultation with people with disability, and training and awareness of standards, were all mentioned as contributing factors.

Accessibility of WASH facilities, information and processes is paramount

Accessibility is a fundamental component of disability inclusion in WASH – including enabling participation and consultation. Given the terrain and common types of buildings in Nepal, it was of no surprise that shortcomings in terms of physical accessibility were noted in all four field visits. The groups noted that WASH facilities at the secondary school and the public toilet at a nearby bus stop failed to meet a majority of accessibility standards; the health centre visited had installed an accessible toilet, but this failed to meet national standards. Lack of funding, consultation with people with disability, and training and awareness of standards, were all mentioned as contributing factors.
Shivnath Raut Kahar of DIDCN-C noted that he is not aware of a single school, health post, government office or any public place in his local area that has accessible WASH facilities. As Rama Dhakal of NFD-N noted, accessible public WASH is fundamental – otherwise people with disability stay at home, or they travel around all day without going to the toilet. She also reminded participants that accessibility means design for all – that is, all types of people with disability and all types of people, full stop – and that ultimately all toilets should be accessible, not just some selected or separate places. ‘We want to be included, not segregated,’ she said.

There needs to be a focus on diversity and reaching the most marginalised

The above point was also a reminder that disability is diverse and that some individuals and groups experience greater levels of marginalisation. During a lunchtime discussion on MHM, Jane Wilbur of LSHTM presented on research she has led with WaterAid Nepal looking at MHM for people with intellectual disability. The research found that most approaches to MHM education, even if adapted to be accessible to many people with disability, would not be able to reach or meet the needs of people with intellectual disability. The research resulted in a specific MHM campaign being developed to engage women and girls with intellectual disability and their carers. It was a reminder that it is not enough to aim to reach the majority of people within a certain group or to target those who are easier to reach – and that doing so may further entrench or exclude those who are most marginalised.

Reflections for wider learning

The learning event brought up a wide range of issues and experiences relating to disability, social inclusion and WASH systems change. A deeper focus on practice and learning focused on disability inclusive WASH would be needed to understand where Fund partners are at in their journey towards disability inclusion. This could include a focus on workforce development, and being mindful that disability inclusion is often driven by GESI officers or other staff who have a broad remit and for whom disability might represent a new or less familiar area of practice.

Nevertheless, the learning topics above reflect broader learning from disability inclusion advocacy and capacity building work, which points to disability inclusion being an ongoing journey rather than a destination. The starting points of this journey include looking at: accessible technologies and infrastructure; using inclusive communication methods; engaging DPOs; creating space for people with disability within WASH committees or forums, and providing disability training or sensitisation to key WASH decision makers and stakeholders.

Four ideas for the next steps of this journey – where WASH agencies and practitioners could ‘push the boundaries’ of disability inclusion – were presented by CBM.

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...disability is diverse and that some individuals and groups experience greater levels of marginalisation.
Recognising the diversity of disability and the need to work with those who are most marginalised;

The role of norms, attitudes and perceptions relating to disability as foundational barriers to inclusion;

The need to take genuine partnership approaches when working with DPOs which are mindful of power imbalances; and

The need to look holistically at WASH, health and other systems and create links between them.

Recommendations for consideration by fund partners

1 / Create space for focused discussion, learning and capacity development on disability inclusion across the Fund. A greater depth of discussion and engagement on disability inclusion is needed to better understand where CSOs and individual practitioners are at in their disability inclusion work, and then set a common language and framework for action. This will form an important part of the Fund’s learning agenda.

2 / Provide examples of more transformative and rigorous disability inclusive WASH practices within the Fund, and how CSOs can deepen their practice towards these. Guidance should be mindful that disability inclusion is an ongoing journey, with different Fund partners being at quite different stages. Document and share examples of strong practice within the Fund as learning opportunities. Some relevant examples shared during the event include SNV Nepal’s partnership brokering approach with DPOs and LSHTM’s inclusive research methods proposed for Cambodia.

3 / Provide standard guidance for Fund partners on common disability inclusion issues. Examples of topics which are likely to be of relevance across the Fund are accessibility and universal design, data collection methodologies and issues, approaches to partnering with DPOs, inclusive communications, as well as the basics concepts of disability rights and disability inclusive practice.

4 / Document and share case studies on disability inclusion from across the Fund. It is particularly important to share challenges, problems or failures relating to disability inclusion and how these were dealt with over time or what was learnt from them.

5 / Document and share common practice and learning themes across gender and social inclusion components. While disability inclusion does require specific learning and practical guidance, the Fund should continue to take advantage of the cross-sectoral expertise and experience available to it, to generate learning and guidance on intersectional or integrated approaches to inclusive WASH. Possible examples include the engagement of rights-holder groups (including women’s groups, sexual and gender minority groups and DPOs), or the design of facilities with a common set of principles to meet the needs of all people.