Disability-inclusive WASH:

Practice within Water for Women











In brief

This brief consolidates learning from Water for Women around what it takes to engage meaningfully with people with disabilities in their full range of diversity and highlights how more marginalised people with disabilities can be successfully reached, even when disability inclusion is relatively new to an organisation or team.

To enable all people with disabilities to participate and benefit from WASH processes and services on an equal basis with others requires:

- a combination of mainstream actions and disability-specific actions in and outside the WASH sector
- a transformative framework that engages with power dynamics and supports the social empowerment and inclusion of people with disability well beyond the sector's traditional approaches
- staff capacity building to understand the needs and interests of people with disabilities.

About Water for Women

Water for Women supports improved health, gender equality and wellbeing in Asian and Pacific communities through socially inclusive, sustainable and climate-resilient water, sanitation and hygiene (WASH) projects and research. It is the Australian Government's flagship WASH program, investing AUD \$154.9 million over seven years. Water for Women is partnering with civil society organisations, research organisations and local partners to deliver 33 projects in 15 countries from 2018 to 2024. Knowledge and learning are central to Water for Women, positioning the Fund as an important contributor to global knowledge development and sharing in inclusive and climate-resilient WASH. Water for Women's Learning Agenda promotes collaborative learning, knowledge development and sharing to support long-term transformative change to WASH policy and practice globally.

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Front cover: A man who has vision impairment accesses clean water as a result of a decade long partnership between WaterAid and local disabled person's organisation, Ra'es Hadomi Timor Oan (RHTO) in Timor-Leste. Credit: WaterAid / Jafet Potenzo Lopes

Abbreviations

IAG CBM Global's Inclusion Advisory Group
CFAR Centre for Advocacy and Research, India

CRPD Convention on the Rights of Persons with Disabilities

ESDPA East Sepik Disabled Persons Association

GEDSI Gender Equality, Disability and Social Inclusion

IRC International Rescue Committee
Lao PDR Lao People's Democratic Republic

LSHTM London School of Hygiene and Tropical Medicine

M&E Monitoring and Evaluation

MEL Monitoring, Evaluation and Learning

MHH Menstrual Health and Hygiene
MHM Menstrual Hygiene Management

OPD Organisation of Persons with Disabilities

PNG Papua New Guinea

RHO Rights Holder Organisation

SNV Netherlands Development Organisation

Thrive/EMW Thrive Networks/East Meets West WASH Water, Sanitation and Hygiene

WGQ Washington Group Short Set of Questions



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Introduction

This learning brief explores **key lessons learnt from implementing disability-inclusive** WASH projects and research across Water for Women – in particular, strategies that contribute to meaningful participation and equality of outcomes. It is based on the collective experience and learning of Water for Women and partners as part of a dedicated initiative under Water for Women's collaborative Learning Agenda. It builds on commitments to consolidate learning and drive improved practice regarding the inclusion of people with disabilities.

This brief answers the following key learning questions:

- What have we learnt about engaging meaningfully with people with disabilities in their full range of diversity, and enabling people with disabilities to participate in water, sanitation and hygiene (WASH) processes on an equal basis with others?
- What have we learnt about reducing inequalities between people with disabilities and people without disabilities in WASH access?

This brief aims to document **emerging areas of learning and good practice** within Water for Women, including those that have not yet been widely documented in the sector. It is envisaged that this approach can generate ideas for how others working in inclusive WASH programming and research can progress efforts towards meaningful participation and equality of outcomes for all people with disabilities.



Disability inclusion within Water for Women

Transformative framework

The Water for Women Fund seeks to lead and inspire a transformative framework for disability inclusion. This is in line with evidence-based development practice that recognises that, like all members of a population, people with disabilities are both **beneficiaries** and **agents** of development. The implementation of the framework seeks to go beyond improving living conditions of people with disabilities to improving their social positions and realising their rights, while recognising that both are inextricably linked. The improvement of living conditions and wellbeing for people with disabilities depends on the realisation of their voice and agency in decision-making processes and structures. It actively promotes redistribution and sharing of power and control over decision-making, resources and benefits. This is both a process – something that can be done – and an outcome that can be achieved (Water for Women 2018).

Holding ourselves accountable

Water for Women recognises that **transformation starts with us**. Social transformation is not something we can 'do to' others – it must be lived. Positive societal change can only happen if we are prepared to challenge and change ourselves, individually and collectively. We must recognise and address our individual biases, be honest about our own power and privilege, and listen deeply and respectfully to the lived experience and perceptions of others. We must challenge the attitudes, cultures and behaviours within our organisations. This can only happen if transformative capacity, expertise, work and partnerships are resourced.

Inclusive systems-based approach

Water for Women pursues a **systems-based approach**, which looks beyond WASH infrastructure and services and includes the people, organisations, governance and environment that are critical to longterm and resilient

WASH services. Creating disability-inclusive WASH systems requires (among other things) inclusive policies that are committed to and resourced, inclusive governance, and opportunities for people with disabilities to claim their rights and monitor and influence how systems and services are managed. It also requires linking and coordinating WASH sector policies and systems with those of other sectors, such as disability support, health or education. This work is essential to creating sustainable local WASH services and systems that truly work for people with disabilities, as well as ensuring that WASH systems strengthening efforts do not ignore or perpetuate existing systemic inequalities.

Do No Harm

'Do no harm' is a key principle of Water for Women's Towards Transformation Strategy in WASH and recognises that any WASH program can have negative consequences for marginalised groups, including people with disabilities. This means that WASH programs and projects **strive to support empowerment, inclusion and equality measures** for people with disabilities in safe, respectful and culturally appropriate ways. People with disabilities are best placed to advise on strategies to do no harm, identify and mitigate risks, and provide feedback to WASH organisations on the impact of their approaches.

Placing the right people at the centre

It is essential that **marginalised people are at the centre of, and lead the way in, their own development**. This requires WASH projects to resource and work closely with organisations of persons with disabilities (OPDs) and recognise them as an integral part of the WASH system. It also means using both 'mainstream' and 'disability-targeted' approaches, and recognising the different capacities, situations, interests and needs of people at different stages of their lives.

Methodology

This learning brief draws on semi-structured interviews with Water for Women partners¹ and a desk review of disability project data and knowledge products generated between 2018 and 2022, many of which included input from OPD field partners. These summarise key strengths and challenges in Water for Women partners' work on disability-inclusive WASH. A thematic analysis of key learning topics was conducted. Additional information was drawn from key informants, CBM Global's Inclusion Advisory Group (IAG), and review and discussion from Water for Women's Disability Community of Practice.

Understanding the contexts and experiences of people with disabilities

This section presents key learning from the design and start-up phase of Water for Women projects and makes recommendations on actions needed to understand the context for people with disabilities.

Invest in research

Investing in formative research, context analysis and evidence collection relating to disability and WASH in program start-up phase is necessary in WASH programming contexts. In almost all Water for Women project locations, there was a lack of existing, reliable, local and national information about disability to inform project designs and serve as a reliable baseline. The main exception was where projects were building on previous disability-inclusive WASH programs or research.

¹ Yayasan Plan International Indonesia (Plan Indonesia), International Development Enterprises (iDE), International Rescue Committee (IRC), Plan International Papua New Guinea (Plan PNG), Thrive Networks / East Meets West Cambodia (Thrive/EMW), WaterAid Australia, World Vision Vanuatu, Centre for Advocacy and Research (CFAR) India, London School of Hygiene and Tropical Medicine (LSHTM).

Fill key evidence gaps early on

WASH projects need to fill key evidence gaps in data and policy momentum prior to designing projects, and/or seek to evolve project designs and strategies as disability information is gathered. A significant focus of Water for Women – and one of its key strengths – has been in context analysis in the design phase. For example, all partners undertook a gender and power analysis; most included a disability lens and collected disability evidence that informed project designs.



Key areas of enquiry to inform WASH activities

Across Water for Women, partners identified key areas of enquiry to inform WASH activities.

The general context of people with disabilities

For example, understanding the prevalence of disability, availability of support services, availability and functions of OPDs or other disability networks, and the disability and WASH policy context.

Existing WASH experiences and barriers to access

For example, existing adapted/accessible WASH infrastructure; household strategies to manage people's WASH activities; accessibility of facilities or information; attitudes, stigma and discrimination in accessing WASH services; and participation within WASH decision-making.

Intra-household inequalities

Most existing information or baseline surveys focused on households as the unit of analysis. Water for Women projects have sought to compare the experiences of individual people with disabilities to those of other household members, and determine whether household WASH solutions are fully inclusive.

Experiences of women and girls with disabilities or more marginalised groups of people with disabilitiesFor example, access to menstrual health and hygiene (MHH) information for women and girls with disabilities, access to WASH information for people with communication difficulties, and home-based WASH management strategies for people with complex disabilities.



Participatory research action group members with vision impairment participate in a stakeholder mapping exercise Credit: Yayasan Plan International Indonesia

Adapt WASH surveys and undertake additional sampling

Adaptions to traditional WASH surveys and/or additional sampling are required to inform disability inclusion. In line with international best practice, Water for Women partners and research organisations added the Washington Group Short Set of Questions (WGQ) on disability to the demographic section of survey questionnaires to enable disaggregation of data by disability. A major challenge with this is that WASH surveys traditionally collect information only at the household level, whereas the WGQ are used for individual data collection (see also Measuring disability and transformative WASH below). Partners have worked around this by:

- using the questions to identify which households may have a person with disability and then comparing their household situation with that of other households
- following up with those individual people to collect further information
- using this information to inform targeting and selection of project participants.

This is a pragmatic approach to using the WGQ given limited time and resources. Some **partners have added or adapted survey questions about access to WASH** to better capture the situations of people with disabilities. For example, in Bhutan, Lao People's Democratic Republic (Lao PDR) and Nepal, SNV Netherlands Development Organisation (SNV) added questions to its standard household WASH survey tool relating to:

- existing adaptations to household infrastructure
- the extent to which all household members could manage their WASH tasks independently
- any challenges in accessing WASH for individual household members
- whether any household members required personal support or used any assistive devices while bathing or using the toilet.

Box 1. Disability survey in Vanuatu

World Vision and the London School of Hygiene and Tropical Medicine (LSHTM) conducted a detailed population-based disability survey in Vanuatu to overcome major data gaps on inclusive WASH. It included a case-control study that compared the situations of people with and without disabilities. The study found that **people with disabilities were statistically less likely to meet seven of eight intra-household indicators,** including the ability to:

- · access water at home when they need it
- collect water themselves (all)
- · feel safe when collecting water
- use the same facility as other members of the household
- use the toilet without assistance
- use the toilet without coming into contact with faeces or urine
- use the toilet as frequently as desired.

World Vision and LSHTM also conducted qualitative research into the experiences of people who menstruate and those experiencing incontinence. They found that **WASH-related stigma**, **reliance on informal caregivers**, **and under-resourcing of WASH personnel** were critical issues for these groups.

Go further than simple disaggregation of data

Simply disaggregating general WASH baseline information by disability, particularly if only collected at household level, often provides insufficient detail to inform inclusive WASH strategies. In order to overcome these challenges, several project teams commissioned more comprehensive research on the specific experiences of people with disabilities (see example in Box 1). This work has contributed substantially to the evidence base for disability inclusion and WASH in the projects' contexts.

Invest in qualitative research

Other projects have found value in **smaller-scale, more targeted formative research or participatory action research**. These have supported project teams to complement existing or general WASH information (such as that from baseline studies) with in-depth qualitative information. Such research often focuses on particular topics or population sub-groups in which evidence or knowledge gaps exist. For example, SNV undertook formative research on the WASH experiences and barriers of people with disabilities in Lao PDR and Nepal (see Box 2), and Plan International in Indonesia has conducted annual participatory research with groups of people with disabilities.

Box 2. SNV Nepal formative research

During the Water for Women design phase, SNV identified that its baseline survey and situation analysis provided information on household-level access to water and hygiene and where people with disabilities were living. However, it did not identify specific experiences of people with disabilities (for example, the extent to which community-level water delivery translated into practical access to water for all household members).

SNV, with technical support from CBM Global's IAG, designed a formative research process that involved district OPDs. Research team members were trained on disability awareness, inclusive communication skills and inclusive research methods.

Data collection tools included in-depth interviews, focus group discussions, key informant interviews and accessibility audits in public school WASH facilities. Research findings revealed:

- barriers to accessing community water points and/or household water facilities for people with difficulty walking and/or seeing
- · challenges to understanding and following social norms on handwashing for children with multiple disabilities
- lack of privacy and dignity and feelings of shame or discomfort relating to bathing and maintaining personal hygiene (including MHH), particularly for women with disabilities.

A key learning for SNV was on the crucial role of family members — almost always women — in supporting WASH access for people with multiple or complex disability, and the physical and emotional impacts of providing care.

Hearing directly from people with disabilities and carers had a big impact on project staff and OPD representatives involved in the interviews.

The **research findings prompted SNV to include several new approaches** within its established WASH programming approach, including:

- an assessment tool and prioritised project initiatives for people who require a high level of assistance with their water and hygiene needs
- · working with family members of people with high support needs
- involving OPDs to build the team's skills and confidence to start working with people with disabilities and establish effective partnerships with OPDs as the project progressed.

Use the qualitative information collected to inform programming

The information available at project design and start-up stages, and the processes used to collect it, have a significant impact on programming responses. Qualitative information has influenced the design of Water for Women project disability-inclusion strategies strongly. This is in part due to the in-depth, personal insights that come from understanding and relating to the unique experiences and perspectives of people with disabilities.

In Cambodia, Thrive Networks/East Meets West's (Thrive/EMW) community mapping process identified significant numbers of people with disabilities who were not included within the existing government household poverty classification scheme, and began targeted outreach to those households.

In Vanuatu, World Vision's Water, Women and Disability study had approximately 20% of people with disabilities as enumerators, including in team lead positions. Having people with disabilities as part of the enumeration/research team is very important, and as people with disabilities are unlikely to have attended or completed schooling, reasonable adjustments should be considered, such as removing educational requirements from recruitment, and extra time and opportunities for remedial training. Now, 40–50% of World Vision Vanuatu's <u>Laetem Dak Kona</u> project team are people with disabilities and/or their family members.

Placing the right people at the centre

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) requires full and effective participation by individuals with disabilities or OPDs in all work related to disability inclusion. Participation is understood as both a process and an outcome. OPDs are organisations led, directed and governed by people with disabilities, and are mandated to represent the needs and interests of their constituents.

Fund-level commitments to rights-based, transformative WASH enables projects to engage meaningfully with people with disabilities. For WASH programming, participation means that people with disabilities and/or OPDs have opportunities to design inclusive services, contribute to decision-making and governance, and influence individual WASH projects and the WASH system as key stakeholders.



"Water for Women has allowed the resourcing to focus on rights, and gender and disability, that has given the space to support that work and focus on participation. Plus the broader shift in WASH practice towards systems strengthening that enables that."

Water for Women partner

Members of the Participatory Action Research group with Yayasan Plan International Indonesia who live with vision impairment Credit: Yayasan Plan International Indonesia



Supporting effective participation of individuals with disabilities

Supporting effective participation of individuals with disabilities often requires a combination of mainstreaming actions and targeted strategies.

Mainstreaming strategies from Water for Women projects that have promoted participation include:

- raising awareness and building WASH staff capacity on disability inclusion from the start of the project
- **challenging negative attitudes or beliefs about disability** of local WASH stakeholders, to create an enabling environment for mutual respect and meaningful dialogue with people with disabilities
- ensuring WASH processes are accessible and reasonable accommodations are supported, including
 decision-making forums, government meetings, community activities and project management; accessible
 information and communication, meeting places; provision of support persons and meeting assistants; and
 funding to cover disability-related costs of attendance
- **ensuring people with disabilities have access to hygiene as a precondition** to their broader participation in WASH and in society; participation is often seen as a step towards achieving inclusive WASH, however, findings from LSHTM's <u>Water for Women research project</u> suggest that access to hygiene is fundamental for many people to feel a sense of personal wellbeing, dignity and confidence to participate widely within society
- · recruiting people with disabilities in the WASH workforce.

Targeted strategies include **building the confidence of people with disabilities to join national and subnational WASH processes**.

- In Pakistan, the International Rescue Committee (IRC) found that few organisations had engaged people with
 disabilities previously. As a result, people with disabilities lacked the experience or confidence to participate
 in local WASH governance committees. It took a year of involving people with disabilities in community
 awareness sessions before they were ready to join the committees.
- In Indonesia, Plan International found that **pairing people with disabilities with existing champions of inclusion** among local WASH leadership strengthened people with disabilities' influence in community processes, and made them more likely to have a positive and effective experience of engaging in local WASH mechanisms.

Engagement with OPDs is at the centre of system-strengthening and do no harm approaches

A key achievement of Water for Women has been the broad extent of engagement with OPDs across the projects. This is reflective of its mandate to engage rights holder organisations (RHOs) as key stakeholders. Working alongside OPDs elucidates barriers to influencing decision-making processes and points to strategies for improved inclusion.

In Bangladesh, World Vision is supporting informal disability self-help groups to collaborate and claim their rights from local authorities and government agencies. Such efforts strengthen local civil society and establish ongoing mechanisms for representation of people with disabilities within WASH systems and wider development.

In Timor-Leste, WaterAid has collaborated with OPDs for advocacy at multiple levels. At community level, they raise community awareness of the rights of people with disabilities and promote their participation in community WASH committees. At national level, they have collaborated with OPDs to advocate for the ratification of the CRPD and for accessibility to be part of public building codes.

Water for Women has consolidated and presented lessons learnt on partnering with OPDs in a published guidance for WASH and RHOs (Water for Women 2022). The key lessons from this guidance are outlined below.

Intentional partnerships with OPDs are vital

Partners report that both WASH organisations and OPDs benefit from an intentional approach to building trust and taking time to identify priorities of both OPDs and WASH projects. Engaging with OPDs is a two-way exchange. As the inclusive development agenda gathers momentum, OPDs may be called upon to participate in programming that can pull them away from their existing priorities and strain already stretched resources.

Water for Women has sought to **engage OPDs in ways that progress OPDs' own agendas**. Examples include:

- strengthening their operational or technical capacities
- financially resourcing their core organisational functions
- collaborating on OPDs' existing advocacy or policy change priorities
- strengthening their role (recognised by the CRPD) as intermediaries between community rights holders and government duty bearers.

Working in these ways, Water for Women partners have taken the time to help OPDs understand the scope of a particular WASH project or governance process and how it might relate to their own priorities **so that OPDs can shape the scope of collaboration**.

Several Water for Women partners have invested significantly in organisational capacity support for emerging local OPDs. This is intended to ensure the basic resourcing and functioning of these groups, prior to any involvement in WASH activities (see Box 3).

"Collaboration with people with disabilities and facilitating their direct involvement ... highlighted how the OPD had challenges in advocating to government. They've said government don't like them as they criticise, government won't meet with them. [The OPD] wanted to advocate on WASH and raise this at national level."

Water for Women partner



People with disabilities participate in a dissemination workshop of the 'translating disability policy into practice' research project with WaterAid and LSHTM in Cambodia Credit: WaterAid / Sokmeng You

Box 3. WaterAid Papua New Guinea and the East Sepik Disabled Persons Association

In Papua New Guinea (PNG), WaterAid's <u>Water for Women project</u> aims to strengthen WASH governance and service delivery systems and ensure the effective participation of women and people with disabilities within them. The project baseline study revealed that **existing services and governance mechanisms did not include the voices of people with disabilities**. To fill these gaps, WaterAid identified a strategic local partnership with the provincial OPD, the East Sepik Disabled Persons Association (ESDPA), which was small, had few resources and was not very active at the time.

WaterAid supported the capacity of ESDPA to effectively engage in and influence WASH governance mechanisms. It focused on providing core organisational development support to ESDPA as a key component of strengthening the overall WASH system. Support has included strengthening ESDPA's board functioning and election process, improving their operational systems and gaining access to other funding through grant applications. WaterAid also had a disability technical advisor supporting its team, allowing ESDPA to focus on strategic representation work in the district (without having to become technical WASH specialists).

The collaboration has seen significant growth in ESDPA's governance and operational systems, and its capacity to represent people with disabilities in the district and to engage WASH stakeholders. ESDPA now has a permanent role on the District WASH Committee, raising awareness and informing the District WASH Plan's specific provisions on inclusive WASH. Its members lead awareness-raising workshops and join WaterAid staff on community visits to collect data on people with disabilities and provide links to disability services. ESDPA is continuing to work and seek funding with CSOs and other partners.

Engaging with marginalised people with disabilities

A remaining challenge and potential next step for WASH programming and systems strengthening efforts is ensuring the meaningful participation of more marginalised people with disabilities. This includes women and girls with disabilities, who may not be active in community roles or within OPDs. Doing so may require:

- engaging diverse OPDs representing specific groups of people with disabilities
- facilitating links to RHOs representing women or people from sexual and gender minority communities
- engaging OPDs in ways that support them to broaden their membership or representation to include more marginalised groups.

Changing social norms that prevent the voice and agency of people with disabilities in and through WASH programs is a growing field with a small evidence base. Water for Women has contributed to this process by producing guidance for WASH actors on how to shift harmful social norms for transformative WASH (Water for Women 2022).



East Sepik Disabled Persons Association Executive Officer, who is vision impaired, and a WaterAid team member meet with carers of a person with disability in Wom Village, Papua New Guinea Credit: WaterAid Wewak team

Holding ourselves accountable

Progressing disability inclusion requires incremental change building towards more extensive and transformative outcomes. It requires a range of strategies at organisational, project and individual/professional levels. Water for Women partners have found that a combination of up-front capacity building, technical support, practical guidance and tools, budget allocation and dedicated staffing are important enablers for inclusive WASH. A key learning for the Fund has been that transformation starts with us, in line with the Fund principles of 'holding ourselves accountable' and 'do no harm'. Water for Women projects and partners began their relationships with different levels of disability inclusion experience and capacity. They soon discovered that going beyond inclusive WASH 'protocols' to engage effectively with and understand the needs and interests of people with disabilities is paramount for achieving disability-inclusive WASH.

The Water for Women GEDSI Towards Transformation in WASH self-assessment tool was designed to support Fund partners and other WASH practitioners to reflect on and strengthen their gender equality, disability and social inclusion (GEDSI) practice as individuals and as teams. Water for Women partners who have used the tool report that they think more intentionally about engaging with OPDs, and strengthen their 'do no harm' strategies to better support people with disabilities.

World Vision Vanuatu and the LSHTM conducted research exploring incontinence and disability in Vanuatu (Wilbur et al. 2021). They found that a key barrier to engaging WASH actors in thinking about inclusion beyond physical infrastructure was a lack of a more comprehensive definition of 'disability-inclusive WASH'. So, in collaboration with people with disabilities, they developed one.

In the design phase, World Vision in Bangladesh developed partnerships with disability service providers. Together, they prioritised project areas that overlapped so they could create mutual benefit for people with disabilities. The disability partners supported the project through providing disability inclusion advice and assistive devices and sharing their networks of disability self-help groups.

"Disability inclusion was a new dimension of the WASH program for us that WfW brought – and we have had lessons every few weeks!"

Water for Women partner

"We talk about inclusion, but [staff] capacity has to match that. Staff need training and support to [to be able to] ask questions, how to understand barriers ... [how to use] personfirst language was really important ... Taking the time to actually understand a person's needs, how to really listen ... [beyond what's] listed on the assessment form. All of that was taught to staff before they went out [to the field]."





Internal factors that have enabled stronger disability-inclusive practice

Several factors that are internal to how projects are delivered have enabled stronger disability-inclusive practice across Water for Women, as outlined below.

Working with people with lived experience of disability

Involving people with disabilities in planning/research processes and recruiting them as trainers or advisors improves the awareness and confidence of WASH team members to take action on disability inclusion. Several partners have employed people with disabilities on their project teams and learnt significantly from this process.

A dedicated staff member for disability inclusion

Projects with a team member who has a clear responsibility for coordinating disability inclusion are often more successful. This can be a dedicated disability officer/advisor, a GEDSI officer, or another team member appointed as a focal point alongside their primary role. These staff help manage relationships with OPDs, coordinate disability approaches across team functions, and bring disability and inclusion expertise.

Staff capacity development

Training on rights-based disability inclusion facilitates inclusive practice. It has been most successful when staged over time to allow staff to apply their learning, or when coupled with coaching or mentoring.

Access to disability technical expertise

Technical expertise is crucial to supporting innovative inclusive WASH strategies. Project teams have drawn on technical expertise to train staff, support research, and for ongoing mentoring. Advice has been sourced from OPDs, academic institutions, disability consultants (including allied health professionals), and disability specialist organisations.

A stated organisational commitment and approach to disability

Clear organisational commitment to inclusion has a positive flow-on effect to projects. Organisational commitments in the form of disability strategies are reported to be the most instructive.

Do No Harm

Across Water for Women, projects employed a range of mainstream and disability-specific measures to facilitate access to WASH services for people with disabilities. The most common strategies to remove barriers for people with disabilities across the Fund are set out in Table 1.

A 'do no harm' lens illuminates the risks of standalone inclusive WASH actions (such as the adaptation of infrastructure or setting requirements around participation) that may result in backlash and/or harm. To pre-empt potential backlash, partners developed specific approaches to reduce the risks to persons with disabilities.

"... other partners were talking about inclusion and accessible toilets – but then we saw that no one was using them, as they weren't designed to meet the needs of people who lived there. So many examples of this."

Table 1. Common strategies for removing WASH barriers for people with disabilities

Disability-specific strategies
Designing/adapting individualised approaches to household facilities for individuals with disabilities.
Developing and providing content that meets the specific needs of people with disabilities (e.g., approaches to hygiene for women with different types of disabilities).
Arranging or providing referrals to disability support services (e.g., assistive device fitting and training, rehabilitation, or communication services).
Finding, engaging and supporting people with disabilities and their family members (including those providing caregiving support) through outreach to households or other community networks and mechanisms.
Providing or advocating for subsidies or concessional rates for people with disabilities to access WASH services or improve household WASH facilities.
Supporting individual people with disabilities to participate in WASH decision-making and advocacy activities (e.g., leadership training, counselling, peer-to-peer support).
Targeting efforts to reduce stigma and negative attitudes, including: challenging individuals' and families' views of the capacity of people with disabilities engaging with WASH governance mechanisms or community decision-making processes and actors to promote safe spaces for people with disabilities.
Managing expectations of people with disabilities and their family members regarding available supports (e.g., in low-resource contexts where essential disability services are unavailable or unaffordable).

In India, the Centre for Advocacy and Research (CFAR) convened a resource group of 29 men and women with different types of disabilities and transgender persons from 13 wards in Jaipur. The group included members of the Community Management Committee, Single Window Forum, disability self-help groups, Slum Development Committee, and male and adolescent forums. The group took part in a multi-stakeholder consultation on the design of handwashing stations in institutional facilities, including Anganwadi (childcare centres), schools and health centres. Representatives of the Social

Justice and Empowerment Department and Integrated Child and Development Services, OPDs and the fabricator-vendor designing the unit were invited to the consultation. An audit of the existing handwashing station design was conducted. Based on the audit, the resource group recommended changes in design to make it accessible and disability-inclusive, and for the duty bearers to be sensitised to the needs of people with disabilities.

The design recommendations were incorporated into 30 handwashing units as part of Water for Women's supported intervention in Jaipur and Bhubaneswar. This process was the first to establish the practice and norm that WASH design is best done in a participatory manner.

In Indonesia, Plan International found that its guidance for **community-led total sanitation needed to be adapted to include a pre-triggering step** - engaging with local government to mobilise support and encouragement for disability inclusion activities. Preliminary engagement ensures that people with disabilities have positive and respectful experiences of participating in triggering activities and helps prevent rejection from their community.

"[The] team was surprised that they hadn't focused on [health behaviour change communication] or COVID prevention with support persons – hadn't realised the extent of barriers for support persons. There was a possible gap in knowledge around [the] gendered nature of disability support."



A member of a resource group of persons with disabilities in Swami Basti, Jaipur, demonstrates use of accessible handwashing stations

Credit: CFAR archives

Reaching those experiencing additional discrimination and marginalisation

Many people with disabilities experience multiple disadvantages resulting from the interplay between disability and poverty and discrimination related to gender, age, ethnicity and other characteristics. This can sometimes result in project implementers prioritising 'easier to reach' groups of people with disabilities. However, several projects showed that more marginalised people with disabilities can be successfully reached with specific strategies, even when disability inclusion is relatively new to an organisation or team (see Box 4).



Strategies that have supported inclusion of marginalised people with disabilities

Strategic approaches that have supported WASH projects to include more marginalised people with disabilities are:

- providing outreach support to people who are unable to independently manage WASH tasks or participate in WASH processes (e.g., due to having multiple/complex disabilities) and their caregivers
- addressing 'preconditions' to disability inclusion that fall outside the WASH sector, such as access to psychosocial support services or social protection payments
- engaging targeted OPDs representing more marginalised groups of people with disabilities, such as people with psychosocial and cognitive disabilities
- using specific strategies focused on the WASH rights of women and girls with disabilities (see Box 4).

Women and girls with disabilities are often expected to undertake household WASH and disability support roles despite the additional barriers they face. Nonetheless, they are often under-represented in OPDs and women's organisations or overlooked within WASH activities targeted to women and girls.

Specific strategies to realise the WASH rights of women and girls with disabilities, which show signs of being effective, include:

- focusing on strengthening the participation of women with disabilities within community WASH mechanisms and WASH sector governance
- asking OPDs about the situation of women and girls in their constituency and/or **requesting women representatives** alongside male representatives in project activities
- adapting MHH approaches to respond to the specific requirements of women and girls with disabilities
- **including people with additional caregiving responsibilities** (who are predominantly women and girls) for hygiene behaviour change support
- · considering disability in interventions to reduce gender equality in households and communities
- **instilling leadership skills in emerging women leaders with disabilities** to support their engagement in WASH governance and wider health and local governance
- **supporting engagement between OPDs and women's organisation** partners to address compounding forms of disadvantage arising from the intersection of gender and disability.

A key area of learning within Water for Women relates to **identifying approaches to working with people with multiple or complex disabilities** requiring a high level of support in WASH tasks like toileting (including continence management), bathing or managing personal hygiene (including MHH), or understanding WASH messages.

Box 4. Menstrual Hygiene Management in Pakistan

In Pakistan, IRC explored aspects of menstrual hygiene management (MHM) for women and girls with disabilities. IRC staff made **door-to-door visits and spoke to women and girls with disabilities and caregivers** about challenges they face. Through this process, they found that:

- women and girls **needed more tailored information** and improved accessibility; as it is often caregivers that translate information for women and girls with disabilities, they must also be engaged by the project
- **people with multiple disabilities and cognitive disabilities were least prioritised**, most stigmatised, often considered a burden in households, and were subject to high risk of sexual assault
- families of girls with intellectual disabilities would often organise surgery to have their uterus removed before or upon puberty an **abuse of their sexual and reproductive rights**.

In response, IRC **undertook desk reviews** of available literature and **brought in experts** to support the development of a specific module for women and girls with disabilities. Following its implementation, IRC **observed changes and improvements in the lives of women and girls with disabilities**. For example, some families are no longer pursuing sterilising surgery for girls with intellectual disabilities, and the provision of assistive devices has improved independence. IRC **learnt** that there is a **great need to talk about women and girls with disabilities** and bring that knowledge to MHM working groups and other organisations. The MHM working group is now using the module.



In Peshawar, Pakistan, IRC transformation facilitators provide personalised menstrual hygiene management training for a woman with disability and her carer Credit: IRC Pakistan



Strategies that have supported people with multiple or complex disabilities' independent living

Strategies that have been found useful in removing barriers and supporting independent living are outlined below.

Targeted household outreach

- In Vanuatu, World Vision collected comprehensive household data and used this to target households for outreach (see <u>Box 5</u>). World Vision is procuring locally produced assistive products, co-designing solutions with individual households with disability.
- In Nepal, SNV worked with rural municipalities to develop an assessment tool that helped the municipal
 disability focal person categorise households based on members' level of independence in undertaking WASH
 activities and their existing WASH access strategies. Those with high support requirements and less accessible
 household WASH arrangements were prioritised for support.
- In Pakistan, IRC gathered information through the first few years of their project by engaging and seeking
 feedback from community members. IRC developed an independent living support toolkit to train people with
 disabilities and caregivers on basic household WASH access and use of assistive devices, as well as supporting
 life skills such as problem solving, self-awareness and self-esteem.
- In Timor-Leste, WaterAid developed monitoring tools to capture change at the household and community level. The monitoring team consists of OPD representatives and WaterAid staff and partners, who conduct monitoring visits to households with disability. The OPD then provides follow-up assistance to households that need it, including referral to rehabilitation services.

Carer support

- In Nepal, SNV found that family members providing WASH support were stressed and overwhelmed, and is now providing them with support such as hygiene strategies.
- In Lao PDR, SNV is convening peer support networks of caregivers to share WASH information and provide mutual support.
- In Vanuatu, World Vision is training caregivers on the basics of WASH access and hygiene management (see Box 5).

Advocacy support

In India, CFAR is supporting people with disabilities to organise together, advocate and claim their social
protection entitlements to help meet the higher health and WASH management costs facing people with
complex support requirements.

Box 5. World Vision Vanuatu household outreach

In Vanuatu, World Vision found that there were no services available to people with disabilities in its <u>Water for Women</u> <u>project</u> areas (Mactaggart et al. 2021). Moreover, people with more complex disabilities were often kept at home in bed, without adequate sanitation and hygiene strategies.

World Vision **developed an assessment tool that was used to discuss how** the person manages activities of daily living and personal tasks, such as washing/bathing, toileting, managing continence and MHH. The tool focuses on the activities the person is trying to do, the barriers they are experiencing in doing them, and what could be modified in the household to overcome those barriers.

World Vision was cautious about managing expectations of people with disabilities. It first mapped out potential solutions that could be feasibly arranged within the local context, then **revised the assessment tool to only cover those aspects where there was capacity to respond**. In some cases, this required working with local businesses to manufacture products such as commodes, mattress protectors and continence wear that were not previously available in the country.

Staff conducted outreach visits to households of people with disabilities (identified from survey data) and used the assessment tool as part of a conversation with the person with disability and, if relevant, their support person. They then came up with an **individualised plan** for how that person could access WASH independently (if possible) or with the support of others in their household (if required). These included:

- **small adaptations to household facilities or supplies of products** such as mattress protectors or continence diapers
- training and supporting household caregivers on topics relating to daily personal care activities (toileting and bathing); these included use of assistive devices, and simple health and hygiene strategies (such as safe manual handling techniques, prevention and treatment of bed sores, simple wound care and treatment of common skin conditions)
- **building empathy among household members** who might not have imagined how their family member with a disability could or could not access something, or the challenges involved
- **building the capacity of field staff key to the effectiveness of this work to work** with the person with disability themselves to really understand their situation and priorities; this required upfront training of field staff and then an ongoing process of visiting households and discussing and troubleshooting issues with disability specialists.

"[People with disabilities] are not a homogenous group ... the economic status of their families, the geography they belong to, education level of their families have a huge impact on their lives, marginalisation and opportunities."

An inclusive systems strengthening approach

In the sector, WASH practice has evolved to take systems strengthening approaches – including through frameworks such as the Sanitation and Water for All <u>building blocks</u>. **Integrating disability inclusion within WASH systems strengthening approaches is an emerging area of practice**. Engaging in this space has been a major focus of Water for Women. Although the CRPD has been widely ratified and many countries have national disability rights laws, government WASH policies are rarely aligned to them or implemented in practice. A key first step has been developing approaches to identify outcomes for disability in systems strengthening work.



Strategies for planning disability-inclusive systems

Disability-inclusive systems frameworks

In Timor-Leste, the WaterAid project team worked with disability advisors to map a **transformative approach to disability against its existing WASH systems strengthening framework**. The framework guides complex analysis and programming approaches in diverse areas, including attitude change, OPD participation, policy and planning change, budget allocation, monitoring and accountability.

Water for Women has built on work by the University of Technology Sydney's Institute for Sustainable Futures to develop a <u>framework for inclusive climate resilient WASH</u>, using the WASH systems building blocks (five Sanitation and Water for All blocks, plus infrastructure, environment/water resources and user engagement).

Policy analysis tools for inclusion

LSHTM and WaterAid adapted the human rights policy analysis tool (Equiframe) and developed a <u>tool</u> that **assists in analysing WASH policy for inclusion**. They found that some national WASH policies included commitments to persons with disabilities, but these are not translated into practice consistently (Scherer et al. 2021). This analysis has enabled project partners to influence the Bangladesh National Institute of Local Government to include materials on disability inclusion in its training package for local government officials.

CBM Global has developed a briefing paper that identifies '4 Ps' for Inclusion of People with Disabilities in Climate Change Plans: Personal, Programmes, Policy and Political (CBM Global Disability Inclusion 2020). Water for Women's community of practice on disability inclusion is using this briefing paper as a reference document in addressing climate change for people with disabilities.

Two key areas of practice have emerged in Water for Women.

1. Public policy change

Project teams have worked to influence a range of government policies, standards, plans and practices relating to disability and WASH. Examples of this include:

- integrating disability inclusion into Bhutan's National Strategy for WASH in healthcare facilities
- working with OPDs to ensure the new draft law for civil construction, office code and housing standards in Timor-Leste includes accessibility
- influencing a district health agency in Indonesia to adopt an accessibility check as one of its standard monitoring tools for health centre appraisals.

2. Strengthening local government functions and the implementation of existing policies

For several projects, strengthening local government functions and the implementation of existing policies has included a focus on strengthening disability service provision and policy implementation roles outside of the WASH sector that enable better access to WASH.



Strategies that have influenced public policy changes and strengthened local government functions

Strategies used to influence public policy changes include:

- using research evidence to support advocacy
- working with OPDs to strengthen their advocacy and monitoring functions
- ensuring people with disabilities are active within governance and coordination bodies
- training and **awareness focused on shifting the perspectives of decision-makers** towards seeing WASH as a fundamental human right (rather than a need or a technical challenge).

Strategies that have strengthened local government functions include:

Prioritising efforts in locations where there is a clear policy mandate

In Nepal, SNV encouraged and provided technical support to rural municipalities to establish and staff disability helpdesks, which were legislated but not yet established in project areas. The helpdesks link people with disabilities to services and social protection entitlements, conduct outreach to communities, receive feedback on local governance, collect disability data and provide information.

SNV has provided WASH training and developed WASH resources to be used through the helpdesks. As a result, helpdesks can identify households requiring additional support for WASH and distribute MHH information to women and girls with disabilities and caregivers.

· Training and awareness raising

In Vanuatu, World Vision and an OPD and disability service agency have begun training local area councillors on 'community-based inclusive development'. The project also influenced the creation of a disability desk officer (in Torba Province), who is a person with disability and was an enumerator in the project's research. This has seen greater provincial-level buy-in on disability inclusion (for example, greater accessibility of latrines in the provincial airport and early childhood education centres).

Integrating WASH functions within existing government mechanisms

In India, CFAR has developed a community-led Single Window mechanism that local urban authorities can use to coordinate a range of essential services, bridging between WASH authorities and other government departments. The model aims to enable more holistic responses from public authorities, including linking people with disabilities to essential support or services that might be required to access WASH services.

Measuring disability and transformative WASH

Disability is diverse and multi-dimensional, and many ways to collect disability data exist. These and other complexities present challenges for project monitoring, evaluation and learning (MEL), with which the WASH sector is still grappling. For instance, the degree to which projects contribute to changes in access and participation is often influenced by factors outside their control. Water for Women has found that context-appropriate mixed methods should be used to reflect this diversity and complexity. Partners are using a range of quantitative methods and tools (example e.g., WGQs) and qualitative ones (e.g., interviews, most significant change stories) to measure disability. Some of these approaches and considerations are discussed below.

Measuring WASH outcomes

The WGQs are the recommended tool for disaggregating data within population censuses and surveys. They are commonly used in Water for Women projects, including in baseline surveys, research tools and activity monitoring tools. They are designed to identify most people with disabilities in a surveyed population. The purpose of the WGQs is to enable projects to see if data collected from people with disabilities is different to people without disabilities and ultimately whether there are equal outcomes – that is, to identify disability gaps.

In order to use the WGQs effectively, Fund partners have found they need to invest in building capacity of enumerators to use the tool (including combating attitudinal barriers that can prevent the tool being used as intended), as well as accurate contextual translations. Some Water for Women projects have **used this learning on data collection to influence national and subnational government agencies** to encourage and strengthen their use of the WGQs. For example, one partner supported the Vanuatu National Statistics Office to strengthen disability data collection approaches in the 2021 national census.

"... when we used WGQs
we found that there was
a large number of people
who are struggling to access
WASH. So now ... we will
redefine using the WGQs.
We will make it part of the
government response.
But there is some resistance
as government doesn't
want to accept such large
numbers ..."

Water for Women partner

The WGQs were originally designed to be used in censuses, and for that purpose it may not be statistically necessary to identify all people with disabilities, just the majority. However, many WASH projects use surveys to develop client registers that can be used for follow-up support. Such projects may benefit from using the Enhanced Short Set, the Extended Short Set, and/or the Child Functioning Modules, which include questions on the psychosocial and upper body function and include ages 0 to 4 years. However, the cost and time associated with adding questions to surveys are substantial and need to be balanced against project goals and the purpose of data collection.

As discussed in the section on understanding the contexts and experiences of people with disabilities, a key challenge for WASH projects is that monitoring data (both from project and government data collection systems) is often collected at the household level and may preclude differences in access between members of a household. Water for Women partners have learnt that qualitative tools, such as interviews, are required to understand household members' specific situations. Sometimes this can be done at scale – for example, through research, or when projects conduct regular outreach visits and document the situations of people within their households. In most cases, however, sampling for qualitative data collection needs to be prioritised in ways that capture a diversity of disability and other characteristics associated with risk of exclusion from WASH outcomes.

In Cambodia, iDE administers a survey to a sample of householders after they have purchased and installed a latrine. It covers intra-household use of and access to latrines, WASH dynamics and WASH behaviours. In Bhutan, Lao PDR and Nepal, SNV's survey tool asks questions about challenges for individual household members in using waterpoints and latrines independently, and whether any personal support is required. **Partners are still exploring the complexities of interpreting and responding to data collected from these tools**, including whether the survey respondent is a person with disability or another household member answering questions about disability on their behalf.

Measuring participation

The WASH sector should strengthen the monitoring of outcomes and systemic changes relating to disability inclusion. Water for Women has met this need using WASH systems thinking. For example, participation is often measured at the output level – such as the numbers of partnerships with OPDs and number of people with disabilities participating in WASH governance mechanisms. However, measuring the quality and effects of participation (outcome) is harder. Capturing this information requires mixed methods, as well as iterative approaches. This includes identifying and monitoring social norms change, which is important for empowering people with disabilities. Measuring norms change is complex and a key area for learning that is critical for GEDSI transformation.

"We've come a long way in the sector in creating legitimacy of OPDs as WASH stakeholders, in supporting their involvement. But we don't have ways to systematically measure meaningful change in this space."

Water for Women partner



Collecting information about disability-inclusive WASH access and participation

Various methods, tools and approaches are needed to collect information about disability-inclusive WASH access and participation.

- Physical, social and environmental barriers to the access and participation of people with disabilities are interlinked. Projects need to be able to identify these barriers (including outside of program reporting cycles) to find contextually appropriate strategies to remove them.
- Water for Women's focus on 'do no harm' has necessitated the development of tools that can capture the unintended impacts of project activities on people with disabilities and their families.
- Meaningful participation of people with disabilities also means ensuring they have a stake in monitoring and
 evaluation (M&E) and research processes 'Nothing about us without us!' Therefore, indicators for participation
 in project processes need to be included in M&E.
- Information must be collected from highly marginalised groups, including information that often touches on sensitive topics or experiences of stigma and discrimination.



This young woman is happy with her new portable toilet chair built locally and provided through World Vision Vanuatu's Water for Women project.

Credit: World Vision Vanuatu

Recommendations for practice

The following 10 recommendations are offered as ways to build upon the lessons outlined in this brief and respond to the challenges of designing, implementing or evaluating disability-inclusive WASH interventions.

Invest in research, analysis and data collection

Invest in research, analysis and data collection that represents the WASH experiences of diverse people with disabilities

Qualitative information that captures diverse, in-depth, personal insights into people's lived experience of disability and WASH, including how they obtain and benefit from caregiving support, is particularly valuable.

Create participation opportunities

Create opportunities for diverse people with disabilities to participate meaningfully within internal project processes and in WASH sector mechanisms

This in turn can have a big impact on the attitudes and behaviours of WASH staff and stakeholders. It requires accessible and inclusive processes and supporting individual people with disabilities to have the skills and confidence to contribute effectively.

Engage OPDs and disability service providers

Engage OPDs in the WASH sector in ways that progress their own agendas

This may involve:

- strengthening OPDs' operational capacities, providing financial resourcing, and/or collaborating on their existing organisational priorities
- strengthening their role as intermediaries between community members with disabilities (rights holders) and government agencies (duty bearers)
- strengthening OPDs' understanding of WASH issues so that they are more confident to strategically engage in WASH systems, structures and decision-making
- adopting specific measures to enable meaningful participation of more marginalised people with disabilities, including
 women and girls with disabilities, as a core component of disability-inclusive WASH practice; this may involve engaging
 diverse OPDs, and addressing more complex issues around accessibility, power dynamics, gender, stigma and 'do no
 harm' approaches.

Partner with the experts

Work with experts across OPDs, disability service providers and government to develop social and health support referral pathways for people with disabilities who need further support.

Apply a norms change approach with Do No Harm

Be intentional about changing norms through WASH activities

In working with households, communities, organisations and institutions, take a norms change approach to reduce stigma and harm relating to people with disabilities.

Guard against unintended consequences by applying a strong 'do no harm' lens

Ensure do no harm principles are applied to mainstreamed and targeted activities that seek to support and empower people with disabilities.

Account for intersectionality

Consider the intersectionality of gender and disability

For example, the needs of women/girls with disabilities, as well as people from sexual and gender minority communities, which may include:

- · consideration of individuals who are invisible/neglected in the household
- addressing their particular needs within MHH
- attention to their strategic interests in regard to representation in OPD leadership and in women's organisations, where they are often under-represented.

Foster independence

Support people with complex disabilities, or those requiring high levels of support in WASH tasks, in their right to live as independently as possible

This support may involve:

- community mapping or outreach to locate households
- engaging caregivers/family members
- · recognising that people with disabilities are the experts in their own lives
- ensuring that they are central to sharing their ideas, opinions and making decision about any proposed strategies.

Arranging individualised WASH access strategies and engaging caregivers in other WASH interventions, such as hygiene behaviour change or policy engagement processes, are also important to enable opportunities for higher levels of independent living.

Strengthen systems

Integrate disability inclusion strategies and change objectives within WASH systems strengthening efforts

This may include supporting systematic analysis of policy frameworks to help target efforts more efficiently. Ensure that:

- inclusive policies are in place
- resources are allocated
- stakeholders are aware of and committed to inclusion
- · governance mechanisms are accessible and inclusive
- people with disabilities have been supported with WASH technical knowledge so they can claim their rights, and monitor and influence how systems and services are managed.

Look for linkages

Strengthen local government functions and policy implementation mechanisms relating to disability and disability-inclusive WASH

Create links to policy and service provision outside the WASH sector to ensure people with disabilities have access to supports that enable access to WASH.

Capture disability-inclusive data

Ensure that project MEL systems capture relevant information about disability-inclusive WASH, including on participation, barriers to inclusion and equality of access and outcomes

This requires efforts to define, measure and understand transformative outcomes and complex changes in WASH systems that relate to disability inclusion, including participation, barriers to inclusion and equality of access and outcomes. This may involve individual-level data collection to capture intra-household inequalities, as well as developing effective tools for capturing systems-level change.

Support knowledge and learning

Fill learning and research gaps in disability and WASH

This can be achieved by:

- studying groups experiencing multiple and compounding disadvantage
- measuring norms change for transformation
- · measuring the sustainability of disability-inclusive WASH systems change
- · evaluating programming and transformative approaches to disability-inclusive WASH.



Participants of <u>leadership training</u> for women with disabilities facilitated by SNV in Bhutan in partnership with Ability Society Bhutan, CBM Australia and research partners at UTS-ISF

Credit: Ability Bhutan Society / Chey Chey

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