

WASH experiences of people with disabilities

Beyond The Finish Line Formative Research
SNV Nepal and CBM Australia
July 2019



ABOUT SNV NETHERLANDS DEVELOPMENT ORGANISATION

SNV Netherlands Development Organisation is a not-for-profit international development organisation. We provide practical know-how to make a lasting difference in the lives of people living in poverty by helping them raise incomes and access basic services. Our team of 1,300 is the backbone of SNV.

For further information visit: www.snv.org

ABOUT CBM Australia

CBM Australia is an international Christian development organisation, committed to improving the quality of life of people with disabilities in the poorest countries of the world. As part of an international federation, CBM Australia supports work to end the cycle of poverty and disability in Africa, Asia, South-East Asia and the Pacific.

For further information visit: www.cbm.org.au

Disclaimer

The following text is the unedited formative research of SNV Nepal and CBM Australia, 'WASH experiences of people with disabilities'. For more information, contact Gabrielle Halcrow, Multi-country programme manager of the DFAT-supported Beyond the Finish Line programme, ghalcrow@snv.org.



This research was undertaken with support from the Australian Department of Foreign Affairs and Trade (DFAT) as part of SNV's Beyond the Finish Line – Inclusive and Sustainable Rural Water Supply Services in Nepal.

This report was written by Teresa Lee (Disability Inclusion Advisor, CBM Australia) and reviewed by Asahel Bush (Disability Inclusion Advisor, CBM Australia)

Contents

Contents.....	3
Executive Summary	5
1 Background	7
1.1 Purpose and scope of the study	7
2 Methodology	8
2.1 Limitations and constraints	10
3 Findings.....	11
3.1 Perceptions of disability.....	11
3.2 Caste	12
3.3 Access to services.....	13
3.4 Participation within the community.....	14
3.5 Access to water.....	17
3.6 Handwashing with soap at critical times	21
3.7 Bathing and personal hygiene.....	23
3.8 Menstrual Hygiene Management (MHM)	26
4 Conclusions and Recommendations	28
4.1 Overarching recommendations	28
4.2 Detailed recommendations according to research themes.....	29
5 Annexes.....	32
Annex 1 - Terms of Reference	32
Annex 2 - Summary Methodology.....	32

Abbreviations

CBMA	CBM Australia
DFAT	Australian Department of Foreign Affairs and Trade
DPO	Disabled People's Organisation
FGD	Focus Group Discussion
FCHV	Female Community Health Volunteers
IDI	In-depth interviews
KII	Key informant interviews
MHM	Menstrual Hygiene Management
WASH	Water, Sanitation and Hygiene

Executive Summary

In 2019, CBM Australia jointly facilitated a formative research process, together with SNV Nepal and local disability stakeholders, on the experiences of people with disability in accessing water and hygiene within the two target districts of SNV's *Beyond the Finish Line* project in Nepal.

The purpose of the formative research was to assess barriers, enablers and strategies of people with disability in accessing water and hygiene in Dailekh District (Province No. 6) and Sarlahi District (Province No.2). The findings and recommendations developed from the formative research are intended to inform SNV Nepal's approaches to disability inclusion in efforts to strengthen inclusive, sustainable and resilient water supply services.

A qualitative approach was used to generate in-depth information and to complement existing information collected through the project baseline and other processes. The categories of the Washington Group Questions were used to guide the identification of research participants, and people with high levels of difficulty functioning were selected as the majority of research participants. Data collection took place in March-April 2019 and comprised of in-depth individual interviews and focus group discussions with people with disability, key informant interviews with disability inclusive WASH stakeholders and accessibility audits of select WASH facilities. Two teams were formed to conduct the primary data collection processes in Sarlahi and Dailekh Districts, involving CBM Australia, SNV Nepal, and Disabled People's Organisation (DPO) representatives. The Sarlahi research team was trained and guided by CBM Australia, and SNV Nepal then independently replicated the process in Dailekh. Preliminary data was jointly analysed by research team members and then transcripts were coded for further analysis. CBM Australia collated the findings and developed the report.

Findings from the research indicate that there are key contextual factors that impact upon the general inclusion and participation of people with disability within their communities. Many people with disability experience discrimination, shame and hurt due to negative community perceptions about disability. Caste-based discrimination was also mentioned by some interviewees, reflecting the intersection of perceptions about caste and disability. People with disability reported low levels of access to services such as assistive devices and existing WASH government initiatives, and also low levels of participation in community groups and decision-making processes. Participation in community groups and decision-making processes was particularly low amongst women with disability and female carers.

Findings in relation to specific aspects of water and hygiene are:

Access to water

People with difficulties in walking, seeing, and with multiple disabilities which included both physical and learning difficulties, often could not get to water sources or use water facilities. Obstructions on pathways to the water facility and around the immediate vicinity of the water facility made it difficult to get to the water facility. Challenges are exacerbated during the monsoon season when the ground becomes even muddier and slippery. Using the hand pump or water facility was difficult for some due to the height and movement needed to operate the facility. Whilst people with high levels of difficulty walking were not able to access water from sources outside the home without assistance, there were practices of some households that enabled the family member with disability to independently access drinking water within the home. On the other hand, when drinking water was not stored in an accessible place they needed to wait for assistance. Other barriers affecting the access to water of people with disability included a lack of finances to pay for closer water connections and also negative attitudes from others in the community which caused shame. Long distances to get water for those in Dailekh had an additional impact on the access to water for people with high levels of functional difficulties, their hygiene practices, and the responsibilities of their carers.

Handwashing

People who cannot walk and those who had severe multiple disabilities were most likely unable to independently wash their hands and required assistance. People who cannot walk and needed to use their hands to move, faced challenges with keeping their hands clean as well as difficulty using soap and water without the help of a family member. Older children or teenagers with multiple disabilities experienced difficulties with understanding and following social norms in handwashing as well as sanitation. Barriers affecting the handwashing practices of people with disability included being able to afford soap, the local availability of soap to purchase, and the location of the soap within the handwashing vicinity. The general lack of hygiene awareness within the community was also considered by some to be a contributing factor to poor hygiene practices.

Bathing and personal hygiene

The bathing and personal hygiene practices were poorer amongst people who had high levels of difficulty walking and seeing, and multiple disabilities which included both physical and learning difficulties. They were bathing less frequently than others with different impairments. However those who were married generally had better bathing and personal hygiene practices as they were assisted by their wife. The hygiene of some interviewees who were highly dependent on family members for assistance was impacted by the uneasiness

they felt in asking for help with getting water to bathe. People who could not walk and used their hands to move, found it difficult to keep their bodies and clothes clean, and this was also affected by their challenges in using toilets. Lack of privacy and associated feelings of shame or discomfort also influenced the bathing practices of women with disability. The monsoon season exacerbated the challenges of bathing and hygiene practices particularly for people who cannot walk, as they needed to wait for someone to carry them out of the house due to the rain and mud.

Menstrual Hygiene Management

Women and girls with difficulties in walking, seeing, or multiple disabilities which included both physical and learning difficulties, experienced additional implications on their hygiene, comfort, dignity and reliance on other female family members during the time of their menstruation. This was particularly seen in Dailekh, where staying in a separate location outside the family home during menstruation is common. Menstruation had impacts not only for some women and girls with disability, but their carers due to added responsibilities with helping to change sanitary cloths, washing and bathing, which was particularly difficult for those who lived far from water sources.

Conclusion and recommendations

Overall, it was found that people with high levels of difficulty in walking, seeing, and those with multiple disabilities which included both physical and learning difficulties, experienced the greatest barriers in accessing water and hygiene practices. They were more likely to be reliant on a family member to assist with their water and hygiene needs. Challenges in getting water and the impacts on hygiene practices were compounded for people who used their hands to move.

Some of the key recommendations that have resulted from the research include working with the local government and disability forums to:

- Develop approaches for people according to their level of assistance required for water and hygiene activities. Prioritise interventions for people who require a high level of assistance from others with their water and hygiene needs.
- Support families of people with disability and help family members to understand the importance for everyone in the household to have equal access to water and good hygiene practices.
- Facilitate specialised support for carers of people with disability who have high needs for assistance with water and hygiene activities.
- Promote DPO involvement in WASH planning and implementation activities.
- Build on existing local government initiatives that promote hygiene awareness and work with DPO representatives and local government to ensure hygiene promotion activities are accessible and inclusive.
- Prioritise awareness raising and other attitude change strategies for inclusion in social behaviour change communication.
- Facilitate referrals of people with disability to community groups and other support services.
- Ensure that people with disability who are most marginalised are included in monitoring processes so that their experiences and participation are tracked.



Photo 1: Research team conducting interviews in Dailekh

1 Background

CBM Australia has a partnership with SNV Netherlands Development Organisation to support disability inclusion within SNV's *Beyond the Finish Line* project in Nepal, funded by the Australian Department of Foreign Affairs and Trade (DFAT) from July 2018 – December 2022.

CBM Australia was requested by SNV Nepal to support formative research on the experiences of people with disability in accessing water and hygiene in the project target locations in Nepal. The support of CBM Australia was intended to contribute disability inclusion expertise to the research methodology and findings, and to strengthen the capacity of SNV Nepal in working alongside people with disability and collecting and analysing qualitative data about the experiences of people with disability.

The research took place in the first half of 2019 in the two districts where the project will be implemented: Dailekh District (Province No. 6) and Sarlahi District (Province No.2). The geographical context of the research had a significant influence on the experiences of people with disability and access to water and hygiene practices. This was particularly due to the hilly terrain and distances involved in getting water in Dailekh, which would consequently impact upon the hygiene practices of people with disability.

1.1 Purpose and scope of the study

The purpose of the formative research was to assess barriers, enablers and strategies of people with disability in accessing water and hygiene in the target areas of the project.

The findings from this study are expected to provide in-depth qualitative information on the water, sanitation and hygiene (WASH) experiences of people with disability in selected districts in Nepal. The findings and recommendations developed from the formative research are intended to inform SNV Nepal's approaches to disability inclusion within efforts to strengthen rural water supply services and hygiene promotion. As a secondary purpose, the findings from this formative research are also expected to contribute to the evidence base to support disability inclusive policy and practice in water and hygiene sectors in Nepal.

Given that SNV Nepal's *Beyond the Finish Line* project is focused on water supply services and hygiene promotion, the research was tailored towards these topics. Whilst recognising the links between water, hygiene and sanitation, the research did not specifically seek to generate information on the experiences of sanitation specifically.

This study therefore took an action-oriented approach, with research questions targeted towards the specific information needed to inform the development of disability inclusion strategies within each component of the *Beyond the Finish Line* project. An emphasis was also placed on skills transfer and individual learning through the research process, with CBM Australia leading on data collection and analysis in one location and supporting the Nepal-based team to replicate this process in the second location.

The key learning questions for the research were:

1. What are the barriers for women, men, girls and boys with disability to accessing water and practicing hygiene behaviours:
 - a. water supply from tap to mouth
 - b. handwashing with soap
 - c. bathing and keeping self clean
 - d. menstrual hygiene management
2. What are the strategies of people with disability, and where relevant their caregivers, in managing water supply and hygiene and what are the consequences of these strategies?
3. What are the enablers for people with disability in accessing water and practicing hygiene behaviours?

The research took place in the two districts where the project will be implemented, which are areas considered by SNV to be representative of the two main types of water systems in Nepal^{1 2}:

- Dailekh District (Province No. 6), situated in the hilly area of mid-western Nepal. Households in Dailekh typically have poor access to water, which has impacted on the hygiene behaviours of the population. Dailekh has gravity-fed water supply systems which are common across the hill regions and most households get access to water through shared community taps. The area is also prone to landslides. SNV has previously worked in Province 6 to strengthen rural water supply services.
- Sarlahi District (Province No.2), situated in the terai, the lowland regions of Southern Nepal close to the border of India. Safe and equitable water supply is a significant issue in Sarlahi with the high risk of ground water contamination. Water supply in Sarlahi is through groundwater-based systems, which is typical of the terai. Sarlahi is an area prone to flooding. SNV has previously worked in Province 2 to improve sanitation.

¹ SNV 2018, *Beyond the Finish Line – Inclusive and Sustainable Rural Water Services Supply in Nepal: Project Design Document*, p. 27

² SNV 2017, *WASH Context and Gender and Social Inclusion Analysis Report, Nepal*, p.3

2 Methodology

A qualitative research approach was selected for the formative study to generate some in-depth information and insights on the experiences of people with disability in accessing water and hygiene practices, to complement quantitative and broader qualitative information on WASH collected separately by SNV through its project baseline study. A Terms of Reference (attached at Annex 1) was developed to guide the scope of the study, including the key learning questions which were discussed and agreed jointly by CBM Australia and SNV Nepal.

Research was conducted in each of the target districts of the project: Dailekh District (Province No. 6) in April 2019 and Sarlahi (Province No. 2) in March 2019. In Sarlahi, the study was conducted in Kaudena Rural Municipality. In Dailekh, the study was conducted in Mahabu and Thantikadh Rural Municipalities.

Two teams were formed to conduct the research – one team for Sarlahi and one for Dailekh - which included SNV Nepal staff and representatives of district-level disabled people's organisations. Training was facilitated by CBMA with the team involved with the Sarlahi research process. Direct support to the team was also provided by CBMA during the data collection and analysis of the research process in Sarlahi. This process was then replicated independently by the team conducting the research in Dailekh, with CBMA playing a remote quality control and peer review role over data and analysis for this district.

The research teams comprised of the following members:

Table 1: Research teams

Sarlahi Team	Dailekh Team
CBM Australia <ul style="list-style-type: none"> Teresa Lee – Disability Inclusion Advisor 	SNV Nepal <ul style="list-style-type: none"> Harishova Gurung, BCC Advisor Ambika Yadav, District WASH Advisor Lek Bikram Shah, District WASH Advisor Nadira Khawaja, WASH Sector Leader
SNV Nepal <ul style="list-style-type: none"> Harishova Gurung, BCC Advisor Ambika Yadav, District WASH Advisor Lek Bikram Shah, District WASH Advisor Krishna Hari G.C., District WASH Advisor Nadira Khawaja, WASH Sector Leader 	DPO representatives <ul style="list-style-type: none"> Ratna Bahadur Shahi, Chairperson of Panchkoshi Disabilities Development Forum, Dailekh Kamal Khadka, Member of Panchkoshi Disabilities Development Forum, Dailekh
DPO representative <ul style="list-style-type: none"> Birendra Yadav, Chairperson of Nepal Apanga Sangh, Gamariya, Sarlahi 	Additional enumerator <ul style="list-style-type: none"> Kumar Thapa, Everest Club (previous SNV partner)
Sign language interpreter <ul style="list-style-type: none"> Sadare Alam Nikrani, Sign language teacher 	Local Government <ul style="list-style-type: none"> Takma B.K, Executive Member, Thantikadh Rural Municipality, Dailekh Arjun Malla, Head of Administration, Mahabu Rural Municipality, Dailekh
Local Government <ul style="list-style-type: none"> Yogendra Thakur, Executive Member, Kaudena Rural Municipality, Sarlahi 	

The categories of the Washington Group Questions were used to guide the selection of research participants. SNV Nepal worked with local DPOs to select men and women with disability and carers of children with disability of different age groups mostly with high levels of difficulty in functioning. This included people with:

- A lot of difficulty or cannot see at all
- A lot of difficulty or cannot walk or climb steps
- A lot of difficulty or unable to wash or dress
- A lot of difficulty cannot hear at all
- Some difficulty (but not a lot of difficulty) walking, climbing steps or seeing
- Intellectual disability
- Psychosocial disability

People with high levels of difficulty in functioning were selected as the main research participants in order to develop insights on the barriers faced by those who are most marginalised and generate recommendations that would support their inclusion in SNV's WASH program. This sampling frame was based on CBM Australia's experience that unless more marginalised people are deliberately selected and supported to participate, research with people with disability often only includes those who are more socially active, easier to reach or having lower levels of functional difficulties.

As a result, research findings and recommendations for action are less likely to reflect the situations and needs of those who are most marginalised or most likely to be excluded from WASH. However it is expected that through designing an intentional process of understanding and addressing the needs of the most marginalised people with disability, research and project stakeholders will be well placed to understand and include those experiencing a lesser degree of marginalisation or exclusion.

Key project stakeholders including local government and DPO representatives also participated in the research. In both districts of the research, a representative of the rural municipality participated as an observer to learn during the research process and as an active participant during data analysis.

Data collection tools included focus group discussions (FGD), in-depth interviews (IDIs), key informant interviews (KII). The research team was divided into two during data collection to be able to allow for a gender-sensitive approach, with one male sub-team and one female sub-team. Accessibility audits were also conducted on public school WASH facilities.

A combination of semi-structured interviews and focus group discussions were conducted in Sarlahi, but only semi-structured interviews were conducted in Dailekh. This was due to the geographical difficulty in organising FGDs in Dailekh and also the team's observation that data collected during the FGDs in Sarlahi was of limited depth and that prioritising in-depth interviews instead of FGDs in Dailekh would likely generate more relevant and useful findings.

The following tables show the number of people who participated in the research. On some occasions, there were more than one carer of a child with disability interviewed as they were in the household at the time. In Dailekh, carers of adults with disability were interviewed when the individual with disability had difficulties or uncomfortable with communicating with the research team.

Table 2: Sarlahi participants

Research tool	No. of Meetings	Participants						Total
		Women with disability	Men with disability	Carers of girls/women with disability	Carers of boys/men with disability	Women without disability (excluding carers)	Men without disability (excluding carers)	
In depth interviews	13	4	4	2 carers (1F; 1M) For 2 females with disability	3 carers (2F; 1M) For 3 males with disability	0	0	13
Focus Group discussions	3	5	5	3 carers For 3 females with disability	6 carers (4F; 2M) For 6 males with disability	0	1	20
Key Informant interviews	5	1	1	0	0	1	3	6
TOTAL	21	10	10	5	9	1	4	39

Table 3: Dailekh participants

Research tool	No. of Meetings	Participants						Total
		Women with disability	Men with disability	Carers of girls/ women with disability	Carers of boys/ men with disability	Women without disability (excluding carers)	Men without disability (excluding carers)	
In depth interviews	20	4	6	6 carers (4 F, 2 M) for 6 females with disability	9 carers (6 M; 3 F) for 8 males with disability	0	0	25
Key Informant interviews	4	1	1	0	0	1	6	9
TOTAL	24	5	7	6	9	1	6	34

There were a total of 33 in-depth interviews, 9 key informant interviews, and 3 focus group discussions conducted for the research across both Sarlahi and Dailekh.

Daily debriefs were conducted during the data collection processes to facilitate reflection and analysis. After the data collection process in each district, the preliminary data was then jointly analysed by research team members. Transcripts from the Sarlahi research process were then coded and analysed by CBMA, whilst transcripts from the Dailekh process were coded and analysed by SNV Nepal. CBMA provided overall quality control and peer review, and compiled the analysis and report.

2.1 Limitations and constraints

Quality and consistency of translation

- Interview tools were prepared in English and translated by the research team into Nepali. The tools were also translated into the appropriate local language of the interviewee at the time of the data collection rather than working from a translated interview guide. This means that there may have been some inconsistencies in the way the questions were asked to individual participants.
- Interpretation and translation of the data into English was reliant on SNV Nepal staff. Whilst the quality of translation was considered sufficient for the research, the degree of accuracy in interpretation and translation varied.
- A sign language interpreter was recruited to assist in the Sarlahi research process. However none of the deaf participants used formal sign language. Research teams asked family members to assist in interpretation whilst the sign interpreter also tried to continue assisting. This led to some confusion for the participant with too many interpreters and may have limited the quality of information collected from people who are deaf.

Sampling issues

- The research team was reliant on local DPO networks to identify people with disability and carers to participate in the research. In Sarlahi, there was a gap in identifying women with certain disabilities and of menstruating age. The research team attempted to respond to these gaps in the Dailekh process through deliberate sampling. In both districts there were fewer girls with disabilities (and their carers) represented in the research process compared to boys with disabilities (and their carers).

Accessibility audit

- The accessibility audit conducted in Sarlahi took place in a secondary school at the same time as another school event, which led to difficulty in ensuring that participants could hear and participate effectively in the activity.

3 Findings

The first few sub-sections provide an overview of key contextual factors that impact upon the inclusion and participation of people with disability within their communities. These include the local perceptions of disability, caste, access to services, and the participation of people with disability in community groups and decision making processes. The following sub-sections then describe the findings about access to water and hygiene practices of people with disability in the project's target areas.

3.1 Perceptions of disability

Whilst not everyone who was interviewed directly experienced negative treatment by community members related to their disabilities, many shared experiences of discrimination, shame and hurt due to stigmas about disability. It was common for people with disability in both Sarlahi and Dailekh to be called by their disabilities rather than their names. A few people with disability also experienced negative physical actions like stone throwing, alongside with verbal abuse.

"They use abusive words like Lata (deaf), Langada (disabled), Bataha (unable to speak clearly). People call me 'disable come here' (Langada yeta aija)." (Man who cannot walk, Sarlahi)

"Small kids give trouble, beat, tease, say 'disability', but not in front of parents." (Father of teenage boy who cannot walk, Dailekh)

Many interview participants described feelings of hurt, anger, and worry when discussing community perceptions of their disability.

Disability was also considered to be infectious by some community members and therefore a reason for people with disability to be kept away from others.

"Community, sister in law says not to go to her house, diseases may transmit." (Mother of girl with multiple disabilities, Dailekh)

"No one takes property or assets of the people with disability. Because there is a saying that, "if you eat visually impaired person's meal, then you become visually impaired," (Community health volunteer, Sarlahi)

Several interviewees mentioned that their disability was perceived to be associated with previous sins of the person in their past life. This belief is likely to be linked with religious beliefs associated with karma and possibly affects other people with disability.

"Some tell me when they saw me, it was the sin of my previous life. I don't know what my previous life was but I feel sad after hearing that." (Man with multiple disabilities, Dailekh)

During interviews, there were comments and also jokes made about the low likelihood of people with disability in getting married.

"The community respects people with disability. But the no one wants to marry or help the people with disability. For example, 35 year olds with disability have not got married yet. (Community health volunteer, Sarlahi)

A young man with disability reported that this low likelihood of getting married was linked with the perceptions that people with disability are reliant on others and not able to earn money, which made it less likely for them to be able to look after a family.

"People think that, we are not able to feed enough to our own stomach and how can we run family and support wife." (Young man who cannot walk, Sarlahi)

When discussing the low likelihood of marriage, a few interview participants also referred to the implications for the person with disability in getting the assistance they required around the home or with daily tasks if they were unable to get married. This was expressed particularly in the context of young men with disability. Older parents of a boy with multiple disabilities were concerned about what would happen to their child if they were no longer around or able to help.

"If the child do not have disabilities than they can get married. My child has disability and he cannot get married. If he can get married than wife can take care. But my child will not have that and we need to look out after him. (Mother of boy with multiple disabilities, Sarlahi).

There was significant shame and despair felt by parents of children with disabilities, and particularly those who had children who were highly dependent.

"I feel trouble, what misfortune God has given to me..." (Mother of girl with multiple disabilities, Dailekh)

"Discrimination by others. I am sad and worried to hear the words "what you have given birth to such people." (Father of boy with visual impairments, Dailekh)

"It would have been better to be barren rather than giving birth to such a child." (Mother of woman who cannot walk, Dailekh)

It is likely that the perceptions of disability that have been described in this section have a significant influence on the way people with disabilities and family members are treated by others in their community, the way in which they perceive their own value, and their confidence in participating in community groups or development processes.

3.2 Caste

Although the caste system still exists across Nepal, the influence of the caste system on access to water and hygiene practices was more apparent in Dailekh compared to Sarlahi. There were several interviewees in Dailekh who mentioned the influence of caste on access to water and hygiene practices. This was most likely due to norms Dailekh on accessing water from community taps, where interactions and differences in caste are more obvious compared to the situation in Sarlahi, where most are accessing water from private sources, and any community groundwater wells are generally used by a cluster of houses from a single caste/ethnic group. In Dailekh or where people are accessing water from public taps, people of lower castes have to wait for those of higher castes to get their water first. People of lower castes are also associated with impurity and can experience associated discriminations.

"Other castes will clean the tap to purify it." (Mother of woman who cannot walk, Dailekh)

The link between poverty, education and higher concentration of people from lower castes was also cited as an influence on sanitation and hygiene practices.

If the settlement would have been mixed, then sanitation condition would be better. Due to same caste people live in same area, thus sanitation is poor. (Government staff, Dailekh)

A woman with disability in Dailekh also mentioned the use of words associated with castes in addition to negative labels of disability. The following quote expresses the bullying felt by an interviewee who referred to the words used by upper classes to address her in a condescending manner.

"They used word 'Kami' to lower castes for bullying. (Woman with physical disability, Dailekh)

The caste-based discrimination reported by some interviewees is likely to be reflective of the intersection of community perceptions about caste and disability.

3.3 Access to services

Assistive devices

Most of the interviewees did not have assistive devices. In Sarlahi, the three men interviewed who could not walk currently had tricycles. Tricycles had been obtained by interviewees from different sources previously, including the rural municipality, a district coordination committee, a minister, and the NGO Prerana. Their access to tricycles was likely linked to their leadership roles of ward level DPOs and better awareness of or connections to available services. Others in Sarlahi did not have access to tricycles. One of the interviewees mentioned that he knew of at least four others in his community who needed tricycles but have not been able to get them. One teenage boy who cannot walk previously had a tricycle, but could no longer use it as his family were unable to find a new tyre of the appropriate size, indicating issues with maintenance.

For those who had tricycles, these were large and used outside of the home to travel. However around their home and to get to WASH facilities, they were unable to use their tricycles and used their hands to move. People interviewed in Dailekh who could not walk would use their hands to move, and none had tricycles. None who were interviewed in Dailekh had tricycles. This is likely due to the hilly terrain of the district, which would make it difficult to use tricycles.

The only other type of assistive device mentioned throughout the interviews was crutches. One man in Dailekh reported that he previously purchased his own crutches without receiving any support.

Although there was limited information obtained through interviews on access to assistive devices, the data suggests that there was very poor access to assistive devices, difficulties in maintaining assistive devices, and the available assistive devices also did not particularly make it easier to water and hygiene.



Photo 2: Example of tricycle used by interviewee

Disability services

Information obtained by SNV Nepal stated that according to the 2017 Disability Rights Act in Nepal, there are four categories for eligibility of disability support services by government. These are as follows:

- Category A: people who have difficulties in activities of daily functioning, even when assisted by others. Eligible for 3000 NPR per month³.
- Category B: people who always need assistance with daily activities. Eligible for 1600 NPR per month.
- Category C: People who need some assistance with daily activities, and are able to be involved in social or community work when barriers are addressed. Not eligible for financial assistance.
- Category D: people who are able to do daily activities if physical or social barriers are addressed. Not eligible for financial assistance.
- All categories are eligible for the relevant assistive devices, concessions in transport, tax exemptions, lower interest rate for bank loans, and employment opportunities under the quota system.

In Sarlahi, a number of the interviewees reported receiving 2000 NPR per month from the government, which indicated that they were receiving the allowances for Category A of the government eligibility criteria for disability support services.

In Dailekh, most people interviewed did not receive any disability support from the government. Only one carer of a woman who cannot walk mentioned receiving 2000 NPR per month. It was unclear from the data what the reasons were in not being able to access financial assistance, particularly as many of the people interviewed in Dailekh had high levels of difficulty functioning, and also multiple disabilities. The difficulties in accessing disability support was likely to be linked with a number of factors including distances to get to administrative headquarters to get an ID card, difficulties in getting a medical report to verify the disability, and administrative delays with the transition in implementing revised disability legislation.

The NGO Prerana was mentioned by several interview participants in Sarlahi who had received disability-related support from the organisation. Types of assistance from Prerana had included a modified hand pump, tricycle, and referral information.

"Prerana representatives visited the house and gave advice about the disability. Prerana suggested to take to HRDS hospital in Banepa, Kavary district." (Father of boy who cannot hear, Sarlahi)

³ Beginning from the new Nepali fiscal year 2076/77, 3rd week of July 2019. Previously the amount was 2000 NPR.

No other organisations or support services were reported by interviewees in Dailekh.

Current municipal initiatives on water supply

Government representatives mentioned several initiatives relating to water supply which have recently or are currently being implemented.

In Sarlahi, government representatives reported the distribution of water guards, piyus and water filters to help address water quality issues. There was also an initiative mentioned within a specific ward area where 200,000 NPR⁴ was allocated for disadvantaged groups in the ward budget. As a result of this allocation, hand pumps were provided to targeted households (mostly for communal wells, and also 3 private wells). However it was unlikely that people with disability specifically accessed these, as the Ward Chair had stated that no adjustments have been made to any WASH facility in the ward.

In Dailekh, there is a Rural Village Water Resources Management Project being implemented. The Rural Municipality of Thatikandha is contributing 60% of the funding of the project, with the remainder funded by the Government of Finland. There have also been awareness campaigns in Dailekh by community health volunteers who provide information to mothers on safe and clean water sources.

In Mahabu, Dailekh, government staff stated that the policy of 'one house one tap' has started with pipes already being laid and the intention of ensuring water tap stands are constructed nearby each household.

Existing initiatives on hygiene promotion

Government representatives in Sarlahi reported that training is provided to female community health volunteers (FCHVs) on sanitation and hygiene. FCHVs then conduct awareness sessions in communities on hygiene promotion and sanitation. However according to a FCHV in Sarlahi, information on hygiene and sanitation was not intentionally provided to people with disability due to lack of a clear directive, guidance and budget. This was reflected in the responses of people with disability interviewed in Sarlahi. Most interviewed had not received information on hygiene and sanitation before. One interviewee mentioned that he had received WASH related information from an NGO called Prerana, and whilst the other did not specifically state where she received hygiene and sanitation information, it is likely that they she may have also have received this information from Prerana given that the organisation installed a hand pump for her. Two men who cannot walk mentioned that they built their own toilets because of difficulties going to the field, rather than due to hygiene awareness.

In Mahabu, Dailekh, some of the municipality's activities around supporting handwashing and hygiene included: installation of accessible taps and handwashing stations with soap, construction of a washing area, community construction of dish drying racks, and accessible toilets. Whilst most interviewees from Mahabu did not specifically mention accessing hygiene information, many of their responses to questions on handwashing indicated a higher level of awareness compared to others in Thatikandh, Dailekh. One person mentioned receiving information on water and hygiene in a mother groups meeting.

There were also sanitation initiatives taking place in schools within Mahabu, supported by Save the Children in wards 3 and 4, and another sanitation, hygiene and nutrition program supported by SUAHARA. Given that most of the children with disabilities who were included within this research do not attend school, their access to sanitation and hygiene information was lower than other peers.

Mahabu government representatives also discussed an ongoing awareness raising program to reduce *chhaupadi* practices⁵, and distribution of sanitary pads as part of the program. Although women with disability and carers in Dailekh were not specifically asked about this program, none mentioned this during discussions about menstrual hygiene management.

3.4 Participation within the community

This section discusses the participation of people with disability in their communities, including in community groups and local decision-making processes.

Participation in district DPOs and self-help groups of people with disability

In both Sarlahi and Dailekh, district-level DPOs exist however neither of them were actively functioning. Although both of the DPOs have constitutions, leaders of the DPO are self-appointed chairpersons, there was a loose-knit executive group, no clear membership process, and a lack of clarity amongst the executive group and other members about the function and role of the DPO. In Sarlahi, there was a network of self-help groups of people with disability at the Ward level, which is currently inactive. In both districts, interviewees who had participated in any formal government meetings of the rural municipalities were doing so on their own individual basis and not as a nominated representative of any DPO.

⁴ 1 AUD = 77 NPR

⁵ Refer to section 4.4 on Menstrual Hygiene Management for further details.

Generally across Sarlahi and Dailekh, women with disabilities who were interviewed and carers of people with disabilities (also predominantly women) were not participating in either the local self-help group (Sarlahi) or the district DPO and were unaware of their existence. In Sarlahi, several of the men and one woman with disabilities interviewed were mostly chairpersons of the local self-help groups of people with disability (which are currently inactive).

From CBM's experience of working with people with disability and communities, the low level of participation in DPOs is likely to be linked with low levels of collective action and representation of people with disability in the community. Limited representation of people with disability in the community is also likely to result in their needs not being considered in the development of programs and services, thus impacting on their inclusion and ability to participate.

Participation in community meetings

Most people with disability and their carers in Sarlahi and Dailekh reported not participating in any community meetings or receiving any information about the meetings. There appeared to be lower levels of participation of women with disability and carers (who are generally women) in community meetings, compared with men with disability.

Of the people who mentioned participation in community meetings in Dailekh, they were mainly men with disability who were also involved in DPOs. However their participation was irregular and at the very local level of community meetings, rather than at the ward level which is the smallest unit of administration and governance in Nepal.

There was generally a lack of clarity amongst respondents about who is invited to go to community meetings and who represents the perspectives of people with disability at these meetings.

At the rural municipal level, government representatives in Mahabu, Dailekh mentioned that people with disability were invited but were not attending community meetings. None of the respondents in Dailekh mentioned participating in meetings at the rural municipal level.

Few people with disability in Sarlahi reported to be participating in community meetings. Only one father of a boy with disabilities mentioned regular participation in community meetings and the other was a male ward representative with disability who appeared to often be requested to represent people with disability.

"I have participated all kind of the meeting in community. They call me as representative of people with disability." (Man with difficulty walking and Ward Representative)

At the rural municipality level in Sarlahi, government representatives reported the formation of a committee for people with disability which was participating in municipal forums. None of those who were interviewed in Sarlahi mentioned participating in meetings at the rural municipal level.

There was also a lack of clarity cited by a respondent on how people with disability were consulted on budget allocations for disability and how funds were spent, particularly after the decentralisation process.

"Government allocates budget for people with disability, but we have no idea how it is been used. In previous structure, Village Development Committee (VDC) chairperson used to ask us how do you want to spent the budget, but after federal structure implemented I have no idea who organise the meeting and who calls for the meeting." (Woman with disability, Sarlahi)

Barriers to the participation of people with disability

Failure to inform or invite

The most common reason given by interviewees for not participating in community meetings or DPOs was that they did not receive any information about the meetings and therefore felt like they were not invited.

"People with disability are also not getting information about meeting." (Man with difficulty walking, Dailekh)

"But I am not called in other development related program. So I cannot participate. People think 'why should we let people with disability know? We will work for them.' Hence, because of not knowing we cannot participate. I am chair of the self-help group. Still they do not call me. I think they call no one." (Man who cannot walk, Sarlahi)

"Don't know about disability organisation. We don't know about the date and time of meetings." (Parents of family members with disabilities, Dailekh)

The lack of information about DPO meetings available to people with disability could also be indicative of the level of functioning of the DPO in the area, and/or also whether carers being invited to join DPOs.

Government awareness and support for participation

The levels of government understanding about disability inclusion was another factor limiting the participation of people with disability. Government representatives in both Sarlahi and Dailekh mentioned the need for laws or guidelines to ensure that people with disability are participating in community development processes.

Government representatives in Dailekh also acknowledged that more could be done to engage with people with disability beyond sending an invitation.

"Perhaps notice does not reach to people with disability. Practice of engaging people with disability in meetings is not common here. People with disability also feel that they should attend meetings. There is not any clear guideline for making sure the participation of people with disability in every meeting. RM also has not prepared such guideline yet meetings." (Government representative, Dailekh)

DPO representatives in Dailekh also felt it was important for elected representatives of government to have disability orientation to support the participation of people with disability in community and municipal development processes.

Community perceptions about people with disability

Some respondents felt that negative community perceptions about people with disability discouraged their participation in community meetings. Teasing by community members was reported to be a deterrent from public gatherings in general for people with disability. Negative perceptions that people with disability cannot contribute or make decisions were cited as barriers to their participation, and a limitation on their influence when they do participate.

"Nobody listens to my voice and no is decision made for me." (Man with difficulty walking, Dailekh)

"We don't want to go in the peoples' gathering places, meeting or outside of the home because other people use negative or neglected word to us like Anhari (blind), Bataha (unable to speak clearly) etc." (Female DPO representative, Sarlahi)

The impact of negative perceptions on the low participation of people with disability was also recognised by government representatives.

"Communities still do not perceive people with disability in positive way. They feel that the people with disability cannot do anything." (Government representative, Dailekh)

"Generally people do not pay attention to people with disability, only family members take care of them." (Government representative, Dailekh)

Travel to meetings and lack of reasonable accommodation

A lack of assistive devices combined with no reasonable accommodation measures were mentioned by respondents in Dailekh and Sarlahi as factors that made it more difficult for people with disability to participate in community meetings.

"People with disability do not participate because they have problem to move. Hence, people with disability need supports materials like wheel chair, tricycle etc to support participating in meetings." (DPO representative, Sarlahi)

"Reason of not participation are lack of invitation, absence of reasonable accommodation for travel cost. There not such good example of works done for people with disability so far. Some challenges are related to travel." (Ward Chair, Dailekh)

"People with disability cannot go to the venue of meetings. (DPO representatives, Dailekh)

"There is no supporting person available to go with me." (Man with visual impairment, Dailekh)

Due to the hilly terrain in Dailekh, distances to community meetings also affected the participation of people with disability.

"I participate in community meeting, but do not go far, only go to nearby meetings." (Man with difficulty walking, Dailekh)

"In hill areas, it takes more than 4 hours walking from one ward to another. How can the people with disability walk such a long distance to attend the meeting even if they are invited. The challenge is how to help them to access the meeting venue and who should be with them to assist (as needed)." (Government representative, Dailekh)

Structure of representation of people with disability

In Dailekh, the absence of an active district DPO network and therefore the lack of structured representation at the rural municipality level was seen as a barrier to the participation of people with disability by both government representatives and DPO representatives.

"It would be effective if the networks of people with disability are in function, they could come up with collective voices, coordinate the required process. (Government representative, Dailekh)

"The network is not functioning smoothly, thus opportunity is not available for raising or sharing our problems...It is necessary to activate the DPO networks, initiation required for participation in all sectors to realise our rights." (DPO representatives, Dailekh)

3.5 Access to water

This section explores the situation of general access to water for people with disability and also specifically their access to drinking water. Access to water also has implications for hygiene practices, which are discussed in further detail in other sections of this report.

Source of water

People who were interviewed in Sarlahi consistently said that they accessed water from hand pumps. Many of them had their own hand pump within the household premises; otherwise they accessed water from a community or neighbour's hand pump within walking distance. The longest time taken to get water mentioned by a respondent was 10 minutes to and from the hand pump. Those who relied on a neighbour's hand pump seemed to also resort to alternative sources of water to avoid overuse of the neighbour's hand pump.

"I do not have hand pump in my house so need to depend on neighbour house (private hand pump). My wife goes to pond for bathing as well as washing clothing." (Man who cannot walk, Sarlahi).

There were two respondents who had electric water pumps installed to make it easier for them to use, and one woman with physical impairment mentioned that she had a hand pump that was modified for her by an NGO so that it required less force for pumping water.

Interviewees generally stated that water was available throughout the year in Sarlahi.

In Dailekh, given the terrain of the district, people reported a greater variety of water supply points: directly from spring, pipe pieces connected to an open water source (spring or stream), or community or private tap connections from a gravity-fed water supply system. There were a number of caregivers reporting walking long distances to collect water: between 10 minutes and 1 hour to reach the water point, sometimes additional time waiting in queues to get water (e.g. up to 35 minutes), and the time required to walk back home.

Some interviewees commented on the water source being less plentiful in May and June, but still sufficient for their needs.

According to government staff interviewed in Dailekh, the water supply systems constructed are not functioning well and it is challenging to find water sources with adequate yields.

"The challenge is to find the suitable water source with adequate water yield. Currently sources are dried up. Major challenge is absence of water source. One water source is 7 KM far from village." (Government staff, Dailekh)

In most cases in both Sarlahi and Dailekh, it was women who were responsible for collecting the water. However there were some cases of male household members, particularly fathers of children with disabilities, who were responsible for collecting water for the family.

Need for family member's assistance to get water

In both Sarlahi and Dailekh, respondents who have difficulties walking or seeing required the assistance of a household member with collecting water. They were unable to move to the water source outside the home without support or able to carry water on their own. There were no reported modified assistive devices that were used to help with collecting water for people with limitations in mobility.

"I can't go to hand pump on my own so I go with my children and wash clothes there and come back with my children." (Woman with vision impairment, Sarlahi)

"My body cannot be moved without support of tricycle, hence I cannot carry water. I need to depend on family member for water." (Male who cannot walk, Sarlahi)

"Access to water is a problem. For the people who have to crawl using two hands and feet to move is problem." (Female DPO representative, Sarlahi)

"We are dependent on family members to serve us with water." (DPO representatives with difficulty walking and visual impairment, Dailekh)

The need for a family member's support with getting water from outside of the home has implications on when the person with disability is able to access water and how much they are able (or feel appropriate) to use. This is discussed further in subsequent sections of 'Access to water' and also in other findings of the report relating to hygiene practices.

Access to drinking water

Whilst getting to water sources outside of the home required assistance for people with physical or visual impairments, often they were able to independently get drinking water if it was stored in an accessible location within the home. Some families had intentionally stored water within the home such as in a nearby bucket or jug so that their family member with disability was able to get drinking water by themselves, which was of the same quality as other family members.

"When we go for work, we keep her in cow shed, water is kept in jug (Lotta) nearby, drinks water by bending." (Mother of girl with multiple disabilities, Dailekh)

"If family members are not in home, I do drink water from bucket." (Man who cannot walk, Sarlahi)

"We keep water in bucket. Sometimes he takes water from bucket and drinks." (Mother of boy with multiple disabilities, Sarlahi)

For other people with disability who were heavily reliant on carers and did not have water stored in an accessible place, they needed to wait for assistance to drink water. If there was nobody at home, they would need to wait until a family member came back home to be able to drink water and several people mentioned asking a neighbour to help them with getting drinking water. Whilst some interviewees reported having to wait to get drinking water, all stated that they received sufficient drinking water.

"I cannot drink water, if nobody is at home." (Woman who cannot see, Dailekh)

"When there is nobody at home, request neighbour for water and drink. I cannot pour water myself, hence other family member need to give me." (Man with multiple disabilities, Dailekh)

For those who had the most severe mobility limitations, assistance was always required for getting drinking water.

"He cannot take water for drinking because of his hands and legs are shivering." (Father of boy with multiple disabilities, Dailekh)

Respondents with other types of functional difficulties did not discuss any challenges with accessing drinking water independently.

Barriers to accessing water

The following section discusses some of the barriers that people with disability faced when trying to access the water source for various hygiene purposes, and also for drinking.

Getting to the water source



Photo 3: Example of public water pump in Sarlahi

For people with visual impairments, obstructed pathways and a lack of guides made it difficult for them to independently access water from public or neighbour's water facilities.

"Nothing has been done to make path smooth, sishnu and bush with nails are on the way. We cannot go due to bush with needles (kada) and hot plant (sishnu)". (Man who cannot see, Dailekh)

"There is the problem of the path uphill, downhill...it is difficult to make sure of the direction." (Man who cannot see, Dailekh)

For people who cannot walk and need to crawl to move, getting to the water source is a challenge even if it is not far from the home. It is difficult to stay clean whilst moving to the water source.

The immediate area around the water facility can also be hazardous for people with disability, particularly with limited mobility or vision impairments.

"There is no platform in hand pump. There is mud surrounding the hand pump. We need to bathe children by laying them on plastic first" (Mother of boy with physical impairment, Sarlahi).

These challenges are exacerbated during the monsoon season when the ground becomes even muddier and more slippery. This was specifically mentioned by a mother of a girl who has difficulty walking.

Furthermore, carrying or transporting water from the water source was problematic for people who have limited mobility or vision impairments. There were also added responsibilities for carers of people with severe physical or visual impairments (usually women), particularly if they had long distances to the water source.

Using the water facility

Through interviews with participants in Sarlahi and Dailekh and observations during the research, using a hand pump or water facility can be difficult for people who cannot walk or stand due to the height of the water facility. For instance with hand pumps, people who cannot walk or stand are not able to reach the pump or use it without getting themselves wet.

"It is difficult to use the hand pump because it is too high, I would get wet, and the floor is dirty." (Man who cannot walk, Sarlahi)



Photo 4: Example of tap stand in Dailekh



Photo 5: Example of hand pump in Sarlahi

The movement needed to turn on the water or use a hand pump can also prevent people who experience mobility challenges in using the facility.

"Sometimes she tries to use hand pump but falls down, sometimes succeeds by hanging in the handle"
(Mother of girl with difficulty walking, Sarlahi)

"There is water supply at home, but tap stand is not constructed. Therefore it is not so easy to access water. The existing water supply tap stands are not easy for us to use." (DPO representatives with difficulty walking and visual impairment, Dailekh)

Therefore the design of the water facility is likely to be a barrier for people with limited mobility – both in upper body or lower body mobility.

Lack of water storage and alternatives that encourage independence

"Sometimes if there is water available in the house, I crawl and get water. Some days I have to wait family member to get water for drinking." (Man who cannot walk, Sarlahi)

The responses appear to suggest that one of the barriers to people with disability being able to access drinking water is the perceived dependence of people with disability by family members or by people with disability themselves. This contributes to a lack of solutions being considered or provided by family members which could support the independence of the person with disability, even when such solutions are possible. This sentiment was articulated in the following quote which describes one participant's suggested future solution for being able to drink water independently:

"For drinking water, if a long hose is connected with bucket, then I can drink water easily by sucking the hose pipe even if nobody is at home" (Man with multiple disabilities, Dailekh)

Economic situation

Some of the people with disability and carers interviewed mentioned their access to water was affected by their financial situation. They were not able to afford options which would make it easier to get access to water, such as household connections to water.

"I had to deposit money. I did not have deposit, thus do not have tap at home." (Mother of woman who cannot walk, Dailekh)

"I bought pipe for water connection but did not get it connected because I am poor." (Woman with physical impairment, Dailekh)

Financial difficulty was also mentioned by a man who relied on his neighbour's hand pump.

"I do not have hand pump in my house because of not having enough money to make it." (Male who cannot walk, Sarlahi)

Negative attitudes from others in the community

Attitudes of the community sometimes affected the access to water by people with disability or their carers, and caused additional embarrassment or shame.

Discrimination associated with caste was mentioned in Dailekh when discussing access to water. This discrimination added to the difficulty felt by a carer of a woman with disability who cannot walk, and who also had to travel a long distance to get water.

“Even though we reach there earlier than others, those people arriving later used to say leave the tap, that is from other caste or same caste with saying “Dumbadi⁶ go go”, after we fetch water. Other castes will clean the tap to purify.” (Mother of woman who cannot walk, Dailekh)

For those who relied on the private water sources of others, they also felt that they had to put up with the emotional impacts of negative attitudes.

“We use our neighbour’s hand pump and sometimes they use abusive words but we need to bear it” (Man who cannot walk, Sarlahi)

3.6 Handwashing with soap at critical times

This next section discusses the handwashing practices of people with disability in Sarlahi and Dailekh.

What they use for handwashing

In both Sarlahi and Dailekh, most people who were interviewed reported washing their hands with soap if it was available. In Sarlahi, there were a several respondents who did not have soap and would use either water only, or mud to wash their hands.

In Dailekh, when soap was not available, ash was commonly used, otherwise water only. Only one respondent mentioned using mud when other options were not available. It was more common for respondents from Thatikandh in Dailekh to report using only ash or water in handwashing.

When they wash their hands

Generally in both Sarlahi and Dailekh, respondents mentioned washing their hands with soap after defecation.

Most people who were interviewed in Sarlahi only used water for handwashing before meals. There was little mention of handwashing with soap at other times of the day in Sarlahi.

In Dailekh, some mentioned washing their hands with soap before eating, whilst others used only water. Noticeably, many of the respondents in Mahabu, Dailekh gave more detailed answers about handwashing practices using soap, which included washing before eating, after touching dirt, cow dung or cleaning children. One of the influencing factors on higher levels of hygiene awareness could be SNV Nepal’s previous sanitation and hygiene program in Mahabu, which included behaviour change communications through local partners.

Need for assistance

Across the interview participants in Sarlahi and Dailekh, people who cannot walk and those who had severe multiple disabilities were most likely unable to independently wash their hands and required assistance. Where assistance was required by the person with disability, the carer would often bring a bucket or container of water to them to facilitate the handwashing.

People with other types of functional difficulties were generally able to wash their hands independently.

Barriers influencing handwashing practices

The following barriers to good handwashing practices were experienced by people with disability and their carers.

Physical barriers

People who cannot walk and needed to use their hands to move, faced challenges with keeping their hands clean. Due to using their hands to move along surfaces, they were more likely to have a higher need to wash their hands. However they also had difficulty using soap and water without the help of a family member because they were unable move back and forth to the handwashing area staying clean or able pour water for themselves.

⁶ Term used by higher castes towards people from lower castes, intended to be condescending.

"I have problems for walking and moving around. Because of this I cannot wash my hands with soap and water." (Man who cannot walk, Sarlahi)

"To wash hand with soap, I cannot pour water myself. I need to depend others. But my family members can wash their hands in their own." (Man who cannot walk, Sarlahi).

Communication and cognitive barriers

From the interviews with carers in Dailekh, older children or teenagers with multiple disabilities including difficulties in learning, appeared to have difficulties with understanding and following social norms in handwashing, when they would normally be expected to be old enough to independently wash their hands. They required the assistance of a family member in washing their hands.

"Different problems are there, like she does not know how to clean soap from hand, how to erase the dirt from body." (Mother of teenage girl with multiple disabilities, Dailekh)

"He cannot wash hands by himself. He needs other's support. He tries to wash hand when he likes." (Mother of boy with multiple disabilities, Dailekh)

Some children with multiple disabilities that included both physical and learning difficulties, had challenges in understanding social norms related to sanitation practices, which also impacted on their hygiene and handwashing practices and difficulties of carers in assisting them to keep clean. For instance, the issue of children or teenagers touching faeces was mentioned by carers:

"I support them for defecating based on experiences. We have small baby pot to use for defecation. I tie the hands by rope for defecation otherwise he touches the faeces by hands." (Mother of 2 boys with disabilities, Dailekh).

"It is not possible to wash his hands always, because he crawls. His body gets faeces, as he touches. It is difficult to keep him clean... At the time of cooking food in the kitchen, he throws faeces. Defecates everywhere." (Carer of teenage boy with multiple disabilities, Dailekh)

Buying soap

Being able to afford soap was cited in some instances as a barrier for some people with disability in Sarlahi in being able to wash their hands with soap.

"We are poor so we cannot buy soap. I do wash my hand from mud." (Male with difficulty walking, Sarlahi)

"There is no money always to bring the soap." (Woman with visual impairment, Sarlahi)

Whilst people who were interviewed in Dailekh were also from very low socio-economic situations, affordability of soap was not mentioned specifically as a factor in influencing handwashing practices. However there was mention of the need to travel long distances to buy soap at the market. This sometimes affected the availability of soap at home and ease in purchasing soap, particularly in the case of carers who are unable to leave a family member with disability at home for long.

"The shop is far, therefore when soap is not available, I use ash or water only to wash hands." (Mother of girl who cannot walk, Dailekh)

Location of soap

For people with visual impairment, their practice of handwashing is affected by whether or not they can find the soap within the area of handwashing. When soap is not easily located, they will use water only to wash their hands.

"Soap is not found when I search, due to not keeping in certain place. There is no practice of keeping it in the same place." (Man with visual impairment, Dailekh)

In contrast, a woman with visual impairment in Sarlahi was able to wash her hands with soap regularly because her family kept the soap in the same location which made it easy for her to use.

"As I can't see, I move from one place to other by touching things. So my hands get dirty very fast and I wash my hand quite frequently. In my house I know where water and soap kept are." (Woman who cannot see, Sarlahi)

Lack of hygiene awareness

Some see the lack of understanding in the general community about handwashing with soap to be a contributing factor to poor hygiene practices of people with disability.

No awareness about handwashing, if soap is not available. FCHV said, people of wardno. 5, 6,7 & 8 often ask question, why to wash hands with soap? (Man with visual impairment, Dailekh)

Overprotection by parents was also considered to impact on the independent hygiene and handwashing practices of their child with disability. Whilst reflecting on the handwashing practices of her child with disability,

a mother recognised that she was not encouraging her child's independence by continuing to assist his handwashing rather than helping him to understand hygiene behaviours.

"I think because we love much. So he is not being able to wash himself. I think if we properly guide him or keep his outside the home then he can learn." (Mother of boy with hearing difficulties, Sarlahi)

3.7 Bathing and personal hygiene

The following section provides an overview of the bathing and personal hygiene practices of people with disability in Sarlahi and Dailekh.

Regularity of bathing

In Sarlahi, regularity of bathing amongst respondents was around 2 to 3 times a week. In Dailekh, the regularity of bathing varied from roughly 2 to 3 times a week, to once a month. The regularity of bathing generally seemed to correlate with difficulties in getting water, as well as the level of the person's mobility, i.e. those who could not walk or had a lot of difficulty walking were bathing less frequently, most likely because they were dependent on others collecting water for them. The frequency of bathing for people in Dailekh who had high difficulties with mobility was also lower due to the distances involved with getting water. However women who had high levels of difficulty walking seemed to bathe more frequently than men, which was influenced by menstruation.

"She takes a bath in 7 day intervals. During her periods, she takes bath regularly, each day." (Mother of woman who cannot walk, Dailekh)

"He takes bath sometimes, once in 2 to 3 weeks, sometimes once in a month." (Father of teenage boy who cannot walk, Dailekh).

People with visual impairment and were unmarried also were bathing less regularly than people with other disabilities. The unmarried men and women with visual impairment bathed once a week, compared to the married man and woman.

"No problem for me, my wife helps with more bathing tasks." (Man with vision impairment, Dailekh)

"My husband brings water for me to take bath. My husband informs neighbours if he is going outside so that neighbours can help me if I need... After marriage my husband and mother in law supported me a lot and now I also have children and they also support me." (Woman who cannot see, Sarlahi)

The examples above suggest the role of a partner in supporting with water and bathing needs, and the woman's situation also refers to the broader networks of support facilitated through her husband.

This was a similar pattern in amongst adult interviewees who were unmarried and had high difficulties in moving or seeing. The man who could not walk and man who had great difficulty walking bathed less regularly compared to the two married men who could not walk. They would also bathe less frequently than other people in their household, and would limit the amount of water they used because they could not get water by themselves.

"I use less water compared to other family member. Because I could not use water regularly." (Man with multiple disabilities, Dailekh)

The two married men who could not walk were bathing at least daily and one reported bathing even more during the summer. There was only one woman interviewed who could not walk, and although she was unmarried, her mother was her primary carer. Whilst there were a small number of interviews with men with difficulties walking, these findings suggest that married men are dependent on their wives to assist with bathing and single men often do not have dedicated support which limits the regularity of their bathing.

From the interview data with carers, it was difficult to tell whether children with disabilities were bathing as frequently as other family members.

Specific hygiene requirements

Most of the carers of children with disabilities in Dailekh reported that their children required more water for bathing and washing than others in the family. This was unsurprising given that many of the carers interviewed had children with multiple disabilities including difficulties with mobility, and needed their carer to bring water for them.

"Other children goes to different place and do clean themselves. My child with disability cannot go outside. Hence we need to support to them for all activities in house and he needs more water." (Mother of teenage boy with multiple disabilities, Sarlahi)

"More water is needed for daughter with disability for bathing, toilet use, washing clothes" (Mother of woman who cannot walk, Dailekh)

The type of disability sometimes influenced the ability to keep clean and requirements for more regular washing and amount of water needed, for example those who crawled to move.

One interviewee shared that her daughter with multiple disabilities also had a severe skin condition which meant that she was unable to use soap on her skin and found it challenging to manage hygiene. This example depicts that some people may require specific medical services and/or products to help manage their hygiene.

Location of bathing

In Sarlahi, most people interviewed reported bathing within their household compound. Some mentioned designated areas for bathing and these were as simple as a small cemented area, yet important for those who crawled to be off the dirt when bathing. In one household, there was a small concrete slab for bathing in a narrow private area between two houses, which was used by the family of a man who could not walk. However the area was poorly drained and presumably would worsen during the monsoon season. This man mentioned that during the rainy season, he would crawl up to the rooftop to bathe in a sunny location.

None of the interview participants mentioned bathing at the hand pump, although other members of the family would do so. This was likely due to difficulties moving to the hand pump and operating it, as well as no adapted spaces to bathe comfortably, whereas at home there was a more private or suitable bathing area.

In Dailekh, many of the people interviewed reported bathing at the tap stand where they bathe in the open and where other family members also bathe. This was with the exception of a woman who could not walk and a woman with visual impairment, whose mothers would carry water back to the house or yard due to the long distances and difficulties involved for them to get to the tap stand.

Assistance from other household members

Similar to those who require assistance in getting water or washing their hands, people who cannot walk and those who had severe multiple disabilities including physical and learning difficulties, relied on the assistance of a family member for bathing. Some were able to bathe independently if water was brought to them, however others needed help with changing clothes as well as bathing. This also applied to other personal hygiene activities such as washing clothes.

"He takes bath himself. He does not change clothes by himself. His mother helps to change clothes, no additional management." Father of teenage boy who cannot walk, Dailekh)

"Other family members need to support child for bathing...he does not do anything, he has no idea...we need help him to take off his clothes." (Parent of teenage boy with multiple disabilities, Dailekh)

"It is difficult for us to take bath, wash clothes and maintain cleanliness. Currently we receive support from our parents." (DPO representatives with visual impairment and difficulty walking, Dailekh)

The reliance on other household members was likely to affect the level of personal hygiene of the person with disability, and often this depended on the willingness or availability of the household member to assist.

Barriers affecting bathing and personal hygiene practices

Difficulties in getting support from family members

Some interviewees who were highly dependent on family members for assistance indicated that it was difficult to expect or ask for help with their bathing needs. This particularly seemed to be the situation for the unmarried men who were interviewed, and possibly could be because they did not have an obvious primary carer. Both of the unmarried men interviewed lived with their brothers and their families.

"I cannot take bath every day. This is mainly because I cannot operate hand pump and I cannot trouble other members daily by asking water to bathe." (Man who cannot walk, Sarlahi)

"I have to depend on others for bathing. Other family members need to operate the hand pump... Sometime, I feel problems when family members do not give water to me." (Man with difficulty walking, Sarlahi)



Photo 6: Private bathing area of interviewee

Women with disability in Sarlahi expressed the emotional impact of feeling the lack of understanding and support from family members. During a discussion with a woman who cannot walk, she began to cry when talking about the lack of support she felt at times from family members with relation to her personal hygiene needs. Similarly during another interview, a woman with physical impairment started crying when sharing that family members shout at her when she takes a longer time to bathe and dress. These examples indicate the emotional burden and lack of understanding that is felt by people with disability with relation to their personal hygiene needs, which likely leads to challenges getting the appropriate support they require.

Impact of sanitation access and practices

People who could not walk and used their hands to move, inevitably found it difficult to keep their bodies and clothes clean. In both Sarlahi and Dailekh, people with disability who have difficulties with mobility mentioned that their hygiene and ability to keep clean was affected by their challenges in using toilets. Some people mentioned not having a toilet and resorted to open defecation. In other cases, distance to toilets, slopes getting to the toilet, steps to get into the toilet and a lack of assistance made it more difficult for people with difficulties moving, and especially those who crawl to move, to keep clean.

"It is difficult to climb up and come down the steps, difficult to sit down on pan, nothing to hold in wall. No thought given for what is easy and difficult for people with disability." (Woman with difficulty walking, Dailekh)

"While going to the toilet child gets wound due to rough surface. During defecation he uses toilet and urinate back of the home. Cement is more difficult to him than mud floor as he need to move crawling." (Mother of teenage boy with multiple disabilities)

The dirtiness and difficulties in keeping clean caused by crawling also resulted in feelings of embarrassment or shame felt by some interviewees.

"Mother brings water. He takes bath to remove dirt because of shame feeling." (Father of teenage boy who cannot walk, Dailekh)

Difficulties in keeping clean when moving, using toilets, combined with difficulties in bathing, has a compounded impact on the hygiene and dignity of people who cannot walk or people with multiple disabilities.

Lack of privacy

Some people in Dailekh who were interviewed mentioned issues of lack of privacy when bathing at community tap stands. Whilst men did not mention specific issues related to the lack of privacy, the interview data suggested that women experienced various challenges.

Feelings of discomfort or shame caused by the lack of privacy were indicated during interviews with women with disability. People with visual impairments are unable to tell who is around at the time of bathing, and also unable to bathe in a more discrete way as is common with women bathing in public places in Nepal.

"While bathing if other people come I feel afraid. I feel uncomfortable if they may see me." (Woman who cannot see, Dailekh)

Another woman mentioned that her inability to afford and bring toiletries to the bathing area made her feel ashamed and she would wait for others to bathe first.

"I need to take bath in last at tap stand; I do not have soap, shampoo because of weak economic condition, so feel shy to take bath first." (Woman with physical impairment, Dailekh)

Seasonal impacts

People who cannot walk in Sarlahi reported that the monsoon season had a significant impact on their bathing and hygiene practices. Their difficulties in keeping clean were exacerbated by the rain and mud. Whilst normally they could crawl to a bathing area or toilet, their reliance on a family member during rainy season would increase as they would need to be carried outside the house.

"It is even more difficult in rainy season. I have to wait for rain to stop to take a bath and need to be carried out of the house." (Young man who cannot walk, Sarlahi)

"It is more difficult in the rainy season. I once had a bad experience falling on the slippery floor. I need to be carried to go to the toilet. It is difficult to wash hands, bathe. It is difficult to go out of the house and so I sleep a lot at home and have back problems. This lasts for 2-3 months." (Man who cannot walk, Sarlahi)

There were no seasonal impacts on bathing and hygiene practices reported by interviewees in Dailekh.

3.8 Menstrual Hygiene Management (MHM)

This section discusses the situation of women and girls with disabilities in managing menstrual hygiene. The most significant difference between the menstrual hygiene management practices in Sarlahi and Dailekh was the practice of staying outside of the home during menstruation. Although generally believed to be decreasing in Dailekh district as a whole, this practice was reported to be common for all women and girls in the two rural municipalities of the study in Dailekh, including for women and girls with disabilities. This practice leads to further barriers experienced by those with disabilities in managing menstrual hygiene.

Beliefs and practices

Many of the interviewees in Dailekh mentioned that women and girls with disabilities would stay in outside in a different hut (called a *chhau hut*) or separate location during menstruation, as is the practice amongst women and girls in the area.

This was due to *chhaupadi*, a tradition practiced in some parts of Nepal which restricts Hindu women and girls from participating in certain activities while they are menstruating, due to beliefs that menstruation is impure. Women and girls who are menstruating are restricted from entering the family home, kitchen, and touching water sources, amongst other prohibitions.



Photo 7: Chhau hut of an interviewee who cannot walk

Whilst government representatives in Dailekh discussed an awareness raising program to stop *chhaupadi* and promote hygiene, most of the women with disability and carers of girls with disabilities interviewed slept outside of the home in very small huts during menstruation.

"Menstruation is called stay away. During the period I stay outside but one corner of the house, I wash all the clothes, bedding and take bath, I stay away for 5 days during the period" (Woman with disability, Dailekh)

"At menstruation time she stays in cowshed and wears old clothes." (Father of girl with disability, Dailekh)

"During periods, she sleeps in separate hut (katero), saying is that God comes becomes angry, so that sleeps in separate place (Katero)." (Mother of woman with disability, Dailekh)

In Sarlahi District, whilst there were fewer women and girls of menstruating age interviewed, none mentioned that they stayed outside the family home during menstruation. Whilst there were few interviewed in Sarlahi about MHM, based on SNV's experience of working in previous WASH programming in the area, the *chhau hut* is not practiced in Sarlahi. There were other beliefs about women being impure when menstruating in Sarlahi and limiting other activities such as cooking and worship.

"It is impure, so it is not good to cook food." (Woman who cannot walk, Sarlahi)

"It is impure, not worship to God for 4 days." (Woman with a lot of difficulty walking, Sarlahi)

However these beliefs about impurity did not appear to specifically impact on the management of menstrual hygiene of women with disability in Sarlahi.

Materials used

Generally in both Sarlahi and Dailekh, women or parents of girls mentioned the use of cotton cloths as sanitary items, which are washed regularly, dried outside and reused. When cloths are too old to be reused, they are buried or thrown into the river, pond or canal. There is the belief that sanitary cloths cannot be burnt otherwise it will result in infertility.

Only one woman mentioned the use of disposable pads, and these are thrown into the nearby stream after use.

Barriers affecting menstrual hygiene management

The beliefs about impurity and stigma associated with menstruation has additional implications on the dignity, comfort, and independence of women and girls with disability. This is particularly exacerbated for women and girls who have to stay in a separate location during menstruation.

Additional discomfort

Women and girls with physical disabilities in Dailekh reported experiencing greater levels of discomfort during menstruation when staying outside of the house compared to when they were staying at home.

"I have back pain. It feels cold and feel uncomfortable to eat outside. I feel uncomfortable to stay outside." (Woman with physical disability, Dailekh)

Women who are menstruating and staying outside of the house generally have to resort to using different toilets, bathing areas and areas for washing to those which they normally use (when not menstruating) and which their other household members normally use (at all times). Women with physical disabilities in particular reported difficulties moving to other locations, and having to adopt various alternative sanitation and hygiene practices while menstruating which impact on their safety, comfort, hygiene and dignity.

"It is difficult to go outside at night. I go to nearby open place for defecation at night." (Woman who cannot see, Dailekh)

"The washing place is far, I need to go with my children. The place is open." (Woman who cannot see, Dailekh)

"People do not wash such clothes in their own hand pumps, so how can I get access to their hand pumps to wash my clothes. Therefore, I go to farm land to wash my clothes." (Woman with difficulty walking, Sarlahi)

For women and girls with disabilities who have difficulties moving, staying in a separate hut outside of the home during menstruation may also have added implications on hygiene management due to the unclean floors.

"For people with disability, it is more difficult. Women used to stay in 'Chhau goath' where the place is dirty, blood is on the floor." (Community health volunteer, Dailekh)

Aside from the discomforts experienced by women or girls with disabilities of staying in *chhau huts*, one interviewee mentioned not being able to wear underwear during menstruation and the associated discomfort experienced. Whilst the interviewee did not elaborate further, it is likely that the discomfort experienced also impacts upon self-confidence and dignity.

Additional assistance required

Women or girls in Dailekh District with high levels of difficulties in moving, seeing, and multiple disabilities were often unable to independently manage their menstruation. They required the assistance of their mother or sister to help with changing sanitary cloths, washing the cloths, and bathing.

Similarly in Sarlahi, the mother of a young woman with intellectual disability mentioned the need to assist her daughter during her periods.

The additional hygiene needs of women and girls with disabilities during menstruation, when combined with dependency on others to help with the hygiene needs, placed additional responsibility on mothers or female carers. This was especially burdensome in situations where the water source was very far from household. The discussion of MHM and the associated difficulties triggered a very emotional response from a mother of a woman who cannot walk, and who also had long distances to travel to get water. The emotional response was likely due to the additional challenges she faced in caring for her daughter during menstruation, given the higher need for water and washing. Even fathers recognised this extra burden on carers of girls with severe disabilities as reflected in the following quote:

"Instead of a son, if he had been a daughter she would have menstruation in this age (pakha) and that would create more difficulty." (Father of boy who cannot walk, Dailekh)

Many of the girls with disabilities also did not go to school and would therefore not be able to receive any basic information on MHM through school. They were likely to be reliant on their mother or other female family members to learn about MHM.

Additional stigmatisation

When women or girls with disability are unable to follow social norms around menstrual hygiene management, they can face further stigmatisation. For example in Dailekh District, a father mentioned that when his daughter with multiple disabilities (including learning difficulties) goes against social norms and speaks openly about her periods, she faces discrimination by her brother and others in the community.

4 Conclusions and Recommendations

The research conducted in Sarlahi and Dailekh shows that there are key contextual factors that impact upon the general inclusion of people with disability within their communities. These factors include the local perceptions of disability, caste, level of access to services, and levels of participation in DPOs, self-help groups for people with disability, community groups and decision-making processes.

People with high levels of difficulty in walking, seeing, and those with multiple disabilities which included both physical and learning difficulties, experienced the greatest barriers in accessing water and hygiene practices. They were more likely to be reliant on a family member, usually a woman, to assist with their water and hygiene needs. The type of support from carers and their willingness to assist was therefore a critical factor influencing many of the experiences of people with disability who were interviewed. However there also were certain practices of some households that enabled some degree of independence of the person with disability, which was evident in their access to drinking water within the home.

People with difficulties in walking, seeing, and with multiple disabilities often could not get to water sources or use water facilities. Challenges in getting water and the impacts on hygiene practices were compounded for people who used their hands to move. It was even more difficult to maintain hygiene during the rainy season. The hygiene of some interviewees who were highly dependent on family members for assistance was also impacted by the uneasiness they felt in asking for help with hygiene needs.

Women and girls with difficulties in walking, seeing, or multiple disabilities that included both physical and learning difficulties, experienced additional implications on their hygiene, comfort, dignity and reliance on other female family members during the time of their menstruation. This was particularly seen in Dailekh, where staying in a separate location outside the family home during menstruation is common. The weight of responsibility and emotional impacts upon carers who assist people with disability were felt more acutely by those who assist female family members during menstruation.

Drawing from these findings, key lessons and recommendations for disability inclusive WASH practice are provided below. These are divided into overarching recommendations, which apply across the spectrum of WASH and related development interventions, as well as detailed recommendations, which relate to specific research sub-questions designed to inform components of SNV Nepal's WASH program model. While these recommendations draw from the specific context of the two research locations and are primarily intended to inform SNV Nepal's WASH programming approach, they are likely to also be relevant to broader WASH programming in Nepal and elsewhere.

4.1 Overarching recommendations

- **Modify approaches for people according to their level of assistance required for water and hygiene activities.** Prioritise interventions for people who require a high level of assistance from others in their household with their water and hygiene needs. When identifying people with disability in the program area, discuss with them the level of their independence in accessing water and hygiene practices and their level of reliance on others to assist with these tasks. People who require a lot of assistance are most likely to face the biggest barriers in water and hygiene and have their rights to water and hygiene unaddressed. Understanding the level of assistance that a person with disability requires with their personal water and hygiene needs is important in being able to work with them to develop appropriate options to improve access to water and hygiene. The following categories could be helpful in identifying the level of assistance the person generally requires for WASH activities:

- a. Assistance not required
- b. Some assistance required
- c. A lot of assistance required

Generally, for those who require a lot of assistance from others, a household level approach is needed from the program to help facilitate their access to water and hygiene. This would include working with the person with disability and family members to identify possible improvements for access to water and hygiene, facilitating information and social support for carers where required, and intentional follow-up of the household to check that their WASH needs are being met.

- **Work with families of people with disability** – In coordination with the local government, support the local level disability network to help family members to understand the importance for everyone in the household to have equal access to water and good hygiene practices, and manage these with as much independence and dignity as possible. Facilitate conversations with family members together with the person with disability to identify opportunities and adaptations suited to their household/local context that encourage their independence in accessing water and managing hygiene to the greatest extent possible. This should include engaging family members and carers who may be 'overprotective' of people with disability about the value of supporting independence.

- **Facilitate specialised support for carers of people with disability who have high needs for assistance with water and hygiene activities.** Carers of people with high needs for assistance with water and hygiene activities carry a heavy weight of responsibility. Develop and provide information tailored to carers and ensure they are linked to other forms of support where appropriate, such as active mothers groups in the community. Encourage conversations amongst family members about sharing responsibilities to relieve the primary carer. Facilitate connections with other carers of people with disability, through the local DPO if they are eligible to join, or potentially helping to initiate a local self-help group where needed.
- **Promote DPO involvement in WASH activities and support capacity building of DPOs.** Build capacity of DPO representatives (where existing) to engage with local government initiatives in providing WASH services to people with – for example, helping to find people with disability or ensure that WASH facilities and processes are accessible. It is important that people with disability are engaged (and seen by others to be engaged) in active, productive and valued roles of the project, rather than being seen as passive beneficiaries. This will require taking steps to address barriers such as negative attitudes, lack of transport or inaccessible meeting venues, or coming up with alternative solutions where addressing these barriers is beyond the scope of the project
- **Build on existing local government initiatives that promote hygiene awareness.** Work with DPO representatives and local government to ensure hygiene promotion activities are accessible and inclusive, for example using a variety of ways to communicate information, distributing information through DPO networks to ensure that people with disability and carers do not miss out on opportunities to receive information provided to communities.
- **Prioritise awareness raising and other attitude change strategies for inclusion within social and behaviour change communications.** While physical barriers in accessing water and hygiene were significant, negative attitudes and behaviour from community members increased the difficulties experienced by people with disability in accessing water and their hygiene practices. Identify and develop opportunities in local government's engagement with communities to change negative perceptions and stigma relating to disability. This will likely require a comprehensive and complementary set of actions, such as strengthening DPO representation in the Rural Municipality WASH Coordination Committee, supporting active participation and leadership of people with disability, adapting WASH behaviour change communication content, developing disability sensitisation and awareness raising approaches (in addition to WASH-specific content) and training key stakeholders on disability inclusion.
- **Facilitate referrals to community groups and other support services** – Ensure that when people with disability are identified in the community, they have the opportunity to be referred to the local DPO and active community groups where relevant. Ensure that people with disability are referred to information and access to assistive devices – through municipal programs and also explore with the NGO Prerana what current services may still be available. It would also be worth following up with the National Federation of the Disabled - Nepal (NFDN) if there are other services for assistive devices available, particularly any options for assistive devices that can help facilitate access to water and hygiene. Support DPOs in advocating with municipal government (and other development organisations where available) for access to health and other social support services by people with disability.
- **Analyse the information from this report within the context of other data collected by the project.** The collection of other contextual and program data, for example through the baseline study, will provide more comparative information that is outside the scope of this research report. This can help to further identify if there are particular experiences or barriers specific to people with disability compared with other community members that need to be addressed through the project.
- **Monitoring and Evaluation** – Ensure that people with disability who are most marginalised are included within monitoring processes, both in terms of participating in M&E roles (such as data collection) and also so that their experiences and participation are properly understood and tracked. This should include some qualitative data collection at appropriate intervals of the project, which could draw from the methods and areas of inquiry used in this formative research.

4.2 Detailed recommendations according to research themes

Community participation

- **Promote understanding of disability inclusion with municipal governments** - Work alongside DPOs (where existing) and individuals with disabilities to advocate for the systematic inclusion of people with disability in WASH processes and broader development processes. Identify opportunities to talk about the situation of people with disability and encourage government support and resources for services. Support municipal governments in ensuring that people with disability are intentionally and systematically invited and supported to participate in decision-making processes. For example:
 - targeting invites to people with disability, not only to households;
 - promoting understanding on reasonable accommodation and the importance of including this within government processes and budget allocations;
 - developing a reference document that compiles national inclusion policies and guidelines from different sectors to assist local governments in understanding requirements on inclusion of people with disability.

- **Support the capacity building of district DPO networks** to promote their engagement with the governance processes of rural municipalities and to support inclusive water and hygiene improvements in communities. In collaboration with the DPOs in each district, develop tailored strategies to strengthen DPO membership, functioning of the DPO networks, representation and participation within local governance. This would include encouraging the development of disability networks at the rural municipality level, to be able to engage with the governance processes of the rural municipality. Where there is interest, encourage the development of ward level disability networks to promote engagement with ward governance processes.
- **Identify ways to support the participation of women with disability and female carers** in community groups and decision-making processes. Given that women with disability and female carers appeared to be largely unaware of or not participating in various community groups or decision-making processes, develop specific strategies to encourage their awareness, confidence and participation. For example:
 - facilitate conversations with male and other family members of the carer to promote shared responsibilities of caring, to allow time for the carer to participate in a community group or meetings;
 - encourage their participation in locally active mothers' groups to promote inclusion and interaction with other community members;
 - facilitate connections of women with disability who are not mothers to other relevant community groups and programs.

Access to water

- **Work with local government to prioritise household connections for households of people with disability who require a lot of assistance from others for their water and hygiene needs.** Alternatively if household connections are not possible, work with local government to formulate and implement strategies to prioritise construction of communal water points close to their houses. For example, identify possibilities for government to support household connections to water for those who are unable to afford it. People with high levels of difficulties in functioning and their carers may have less capacity to pay for water and sanitation because of barriers to participating in livelihoods activities. Targeted support or subsidies to people with disability and their households should be coupled with clear awareness raising and communication strategies to counter the potential for targeted support to cause resentment within communities towards the recipients of support or to reinforce assumptions that people with disability are dependent or weak.
- **Work with suppliers of water facilities to understand the needs of people with high levels of difficulties in accessing water.** Help suppliers to understand universal design principles and ensure that the design of any public or community water facilities are easily operable by the broadest range of community members. Encourage suppliers to explore more tailored options where required for households with a member who requires a high level of assistance from others in water and hygiene activities. Wherever possible, help to ensure that the design of the household tap or water facility is easily operable by the specific household member with disability to support their independence (and not simply offering one or a number of predetermined solutions).
- **For people who are identified as requiring assistance in water and hygiene activities, identify support options that help to maximise their independent access to water.** This would include ensuring that the pathways to community water sources are accessible where possible, working with neighbours and community members to understand the importance of accessibility of public WASH facilities to assist with maintaining accessibility, putting mechanisms in place to ensure adequate and consistent access to water for drinking and hygiene within the household, and referrals to relevant rehabilitation services and access assistive devices where required.

Handwashing with soap

- **Encourage community members to designate a specific area for handwashing** at home and at public water facilities where relevant. Designated and accessible areas for handwashing can assist people with visual impairments, as well as those with other disabilities, to independently wash their hands.
- **Promote the awareness of household and community members about placing soap in an accessible location** near the tap stand or water source for all to be able to reach, even if they cannot stand. Also promote awareness about leaving soap in the same place to assist people with visual impairments to be able to find the soap easily.
- **Identify or develop tailored education and support for carers of people with difficulties understanding hygiene promotion**, to be able to encourage increased independence of the family member in handwashing and hygiene practices. Ensure that education on hygiene promotion links with education on sanitation behaviours. For example, it may be necessary for some people to develop an appropriate education approach to toileting behaviours of people with learning difficulties to be able to better respond to the effectiveness of education on handwashing and hygiene.
- **Encourage the local availability of soap in communities.** As part of behaviour change communication campaigns, check that there is soap available within easy access of communities. Where soap is not easily available, explore opportunities with local vendors or a relevant community network in selling soap.

Bathing and personal hygiene

- **Work with family members to discuss and prioritise the hygiene needs of people who require the highest level of assistance.** Facilitate conversations with families about the frequency of bathing and amount of water needed, so that the person with disability is able to bathe at least as regularly as other family members. Encourage solutions that share the responsibilities of assisting the individual with disability who requires assistance with bathing needs. Discuss the accessibility and maintenance of any private bathing areas so it is as easy as possible for the person with disability to use. Ensure that there are also discussions about the impact of different seasons (e.g. monsoon season) on the hygiene needs and practices of people with limitations in mobility, and help facilitate improved strategies with families.
- **Promote the privacy for bathing of people with disability, particularly women.** Work with women with disability to identify local adaptations or solutions that increase the privacy and dignity when bathing in public places.
- **Encourage accessible design and maintenance of bathing areas** – In designing public water facilities and bathing areas, ensure that they are accessible and that there is appropriate drainage to avoid stagnant water and hazardous areas particularly for people who have difficulties seeing or moving.

Menstrual Hygiene Management

- **Build on the existing local government awareness raising initiative** in Dailekh about *chhaupadi* and ensure that information about MHM is made available to women and girls with disabilities and their carers.
- **Promote awareness of menstruation especially for girls with disabilities and carers before menstruating age.** As many girls with disabilities may not attend school, identify other ways that MHM information can be distributed to girls with disabilities and help to connect them with peers to encourage interaction, social support and learning.
- For households that are continue the practice of *chhau huts*, work with families to ensure that there are appropriate support strategies in place for the girl or woman with disability. Facilitate conversations with families to ensure that there are household responses to minimise discomfort and stigma related to the woman with disability staying in the *chhau hut*, and the assistance available where required to respond to the maintaining the individual's hygiene during menstruation.
- **Explore more tailored approaches to information about MHM for girls and women with learning difficulties.** The Bisheshta Campaign⁷ by WaterAid is a useful project to learn from about addressing barriers to MHM for women and girls with intellectual disability in Nepal.
- Ensure that carers of girls and women who require high levels of assistance with MHM are connected to information and social supports. During the research process, carers expressed high levels of stress when discussing MHM. Facilitating connections to other peers, for example self-help groups of carers, can help to relieve emotional stresses and promote learning on coping strategies.

⁷ <https://washmatters.wateraid.org/blog/disability-and-menstruation-in-nepal-how-we-developed-our-behaviour-change-intervention>;
<https://washmatters.wateraid.org/blog/disability-and-menstruation-in-nepal-five-wide-reaching-effects-of-empowering-young-people>

5 Annexes

Annex 1 - Terms of Reference



SNV Nepal -
Formative research 1

Annex 2 – Summary Methodology



Formative research
methodology_final.doc