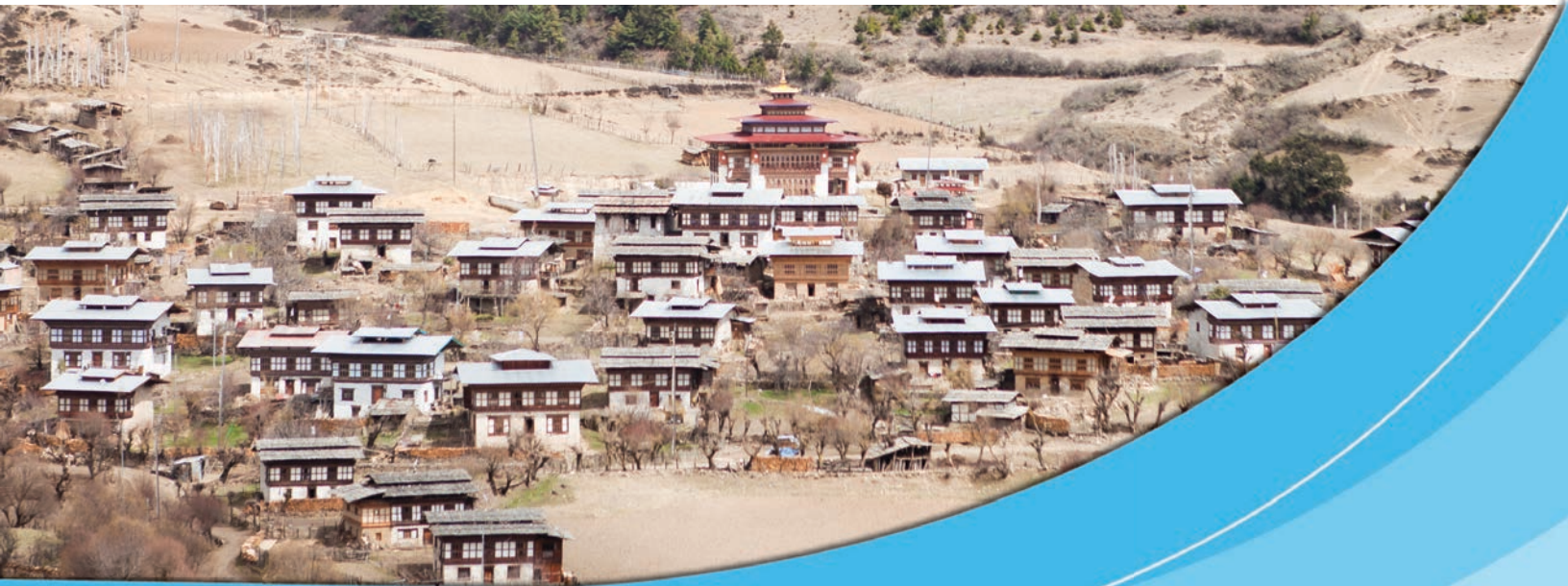




SNV

Understanding the impacts of disability on access and use of sanitation and hygiene services in rural Bhutan

Research report: March 2016



Foreword

The national Rural Sanitation and Hygiene Programme (RSAHP), implemented by the Ministry of Health (MoH), started in Bhutan in 2008 with initial pilot project interventions in four regional gewogs and was expanded during 2010-2013 to district-wide coverage in Lhuntse and Pemagatshel districts. The programme was implemented with technical support from SNV, funding from the Australian Civil Society Water, Sanitation and Hygiene (WASH) Fund and the Netherlands Directorate-General for International Cooperation (DGIS). Following the successful development and implementation of the RSAHP approach, a new Framework Agreement between the MoH, SNV and Bhutan's Gross National Happiness Commission (GNHC) was signed to scale-up RSAHP nationwide as part of the 11th Five-Year Plan 2013-2018.

Since the RSAHP's inception, Bhutan has seen encouraging progress in increasing rural access to improved sanitation and hygiene. However, without disaggregated data little was known about the impact of disability on access to sanitation and hygiene in rural households, schools, monastic institutions and nunneries. This gap was highlighted in the national strategy consultation process for the sector in 2015, and in response the national RSAHP conducted this collaborative formative research with technical support from SNV.

By directly engaging with people with disabilities and Disabled People's Organisations during the research process, the research has fulfilled its objectives of better understanding the sanitation and hygiene situation of rural people with disabilities and informing the development of guidelines for addressing disparities in the RSAHP.

The research highlights the need for systematic inclusion of disability in data collection, monitoring and evaluation to effectively target the needs of people living with disabilities and work towards eliminating the barriers.

Furthermore, the findings and recommendations of the research have been shared at the national and district levels with various stakeholders at different WASH forums. These well-informed findings and recommendations will benefit the RSAHP and the country as a whole both in fulfilling the SDGs and becoming an inclusive and a happy society.

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Acknowledgements

We would like to thank the Research Ethics Board of the Ministry of Health (MoH) for providing the ethical clearance for this study and the MoH Public Health Engineering Division (PHED) team (Ms. Yeshey Lhaden, Ms. Kuenzang, Mr. Tshering Tashi) and Ms. Khina Maya from the MoH Disability Prevention and Rehabilitation Programme (DPRB), for their assistance and for being part of this study. Thank you to our key team members Ms. Chencho and Mr. Pema Dorji and their caregivers, for their time and contribution to this study, despite the long hours of travel and accessibility challenges. We would also like to thank our CSO partners: Ms. Seema Chhetri (ABS), Ms. Sonam Yangden (DPAB), Ms. Karma Dolkar (Bhutan Nuns Foundation); and Ms. Sonam Tshokey (research assistant) for all their assistance.

We are thankful to the Australian Department of Foreign Affairs and Trade (DFAT) for the guidance provided by its *Development for All 2015-2020* strategy in the preparation and conduct of this research. We are grateful to the following researchers and practitioners working in the WASH sector, who generously shared their experiences and tools to help inform the development of research tools for this study – Jane Wilbur of WaterAid, Sian White of the London School of Hygiene and Tropical Medicine (LSHTM), and Hazel Jones, Water Engineering Development Centre (WEDC), Loughborough University, UK. Learning from their work was invaluable, especially given the lack of studies exploring disability inclusion in the WASH sector.

We would like to also express thanks to the head of PHED, Mr. Rinchen Wangdi; SNV programme coordinator, Ms. Gabrielle Halcrow; SNV advisors, SEN school coordinator, respective CSO leaders (ABS, DPAB, Draktsho), Dasho Dzungdas, Dasho Dzunggrabs, and participating district health officers and health workers for their valuable contributions, field coordination, and time.

This study would not have been possible without the support of local government leaders, girls and boys from the schools and monastic institutions, women and men of the communities, and people with disabilities. Thank you very much for your kind participation in focus group discussions, key informant interviews and in-depth interviews.

We would also like to acknowledge the support and guidance of Kathryn James, CBM and Claire Rowland, who provided a final review of the report.



This research was undertaken with support from the Australian Department of Foreign Affairs and Trade (DFAT) as part of SNV's Sustainable Sanitation & Hygiene for All programme.

This report was written by Sue Coe, Pema Cheizom and Tshering Choden with editing and design support from Nick Greenfield.

List of Abbreviations

ABS	Ability Bhutan Society
BCC	Behaviour Change Communication
BHU	Basic Health Unit
CBM	Community Based Management
CDH	Community Development for Health
CRPD	Convention on the Rights of Persons with Disabilities
CSOs	Civil Society Organisations
DEO	District Education Officer
DHO	District Health Officer
DoPH	Department of Public Health
DPAB	Disabled Persons' Association Bhutan
DPRP	Disability Prevention and Rehabilitation Programme
DPO	Disabled People's Organisations
Draktsho	Draktsho Vocational Training Center for Special Children and Youth
ECCD	Early Childhood Care and Development
FGD	Focus Group Discussion
GNHC	Gross National Happiness Commission
GSI	Gender and Social Inclusion
HA	Health Assistant
HH	Household
HHs	Households
HIV	Human Immunodeficiency Virus
IDI	In-depth Interviews
KII	Key Informant Interview
LNW	Lhawang Norbu Wangyal (Local consultant for RSAHP)
MCH	Mother and Child Health
MHM	Menstrual Hygiene Management
MoE	Ministry of Education
MoH	Ministry of Health
NCWC	National Commission for Women and Children
NGO	Non-governmental Organisation
OD	Open defecation
Paro	Paro district
PL	Pit latrine
PWDs	Persons/People with Disabilities
PHED	Public Health Engineering Division
RGoB	Royal Government of Bhutan
RSAHP	Rural Sanitation and Hygiene Programme
RSAHP MIS	Rural Sanitation and Hygiene Programme Management Information System
RWSS	Rural Water Supply and Sanitation
SACOSAN	South Asian Conference on Sanitation
SDG	Sustainable Development Goals
SEN	Special Educational Needs
SME	Small and Medium Enterprise
SNV	Netherlands Development Organisation
SSH4A	Sustainable Sanitation & Hygiene for All
Samtse	Samtse District
T/gang	Trashigang District
UTI	Urinary Tract Infection
WAB	Water Aid Bangladesh
WASH	Water, Sanitation and Hygiene

Glossary of Bhutanese terms used

Bazaar	Market
Chiwog	Group of villages
Dasho	Honorary title for heads of government agencies
Dzongdag	District administrator
Dzongrab	District administrators
Dzongkhag	District
Dzongkha	National language of Bhutan
Gewog	Administrative block consisting of several villages
Gup	Elected head of the gewog
Lhakhang	Monastery
Mangmi	Elected deputy head of a gewog
Dratshang	Monastic education institutes
Tshogpa	Head of a village

Glossary of key terms and definitions

Disability:

The UN CRPD recognizes that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

(UN CRPD definition)

Twin-track approach:

Under the “twin-track” approach to disability inclusion framework, the first “track” identifies and addresses barriers in mainstream society/approaches preventing inclusion of people with disabilities (PWDs): environmental (inaccessible physical facilities and communication systems), attitudinal (stigma, prejudice and discrimination), institutional (prohibitive or restrictive policies and laws) and communication barriers. The second “track” identifies specific actions needed to directly empower/include PWDs so they can fully participate in, and benefit from, mainstream services and activities.

Attitudinal barriers:

Negative attitudes towards PWDs, based on stigma and prejudice. These are often cited by people with disabilities as the biggest barrier they face. They are widespread attitudes – held both consciously and sub-consciously – that lead to stigma and discrimination against PWDs. PWDs are often viewed as incapable, inadequate, of low intelligence, and in need of a ‘cure’ or ‘special support’. Attitudes based on misconceptions, stereotypes and folklore linking disability to punishment for past sins, misfortune or witchcraft lead to exclusion, discrimination and bullying. These assumptions are often reinforced by media and public forum discussions about disability. Negative language reflects and can reinforce prejudices.

Institutional barriers:

These are laws, policies, strategies or practices (including formal budget allocation of resources) that discriminate against people with disabilities. For example, electoral laws that do not protect the political rights of PWDs, banks who do not allow visually or hearing impaired people to open accounts, or health centres that do not allow personal or communication support workers in appointments due to confidentiality policies. Many countries still have restrictive laws, particularly affecting people with psychosocial or intellectual disabilities.

Environmental barriers:

People with disabilities encounter these barriers in areas such as: public transport, hospitals and clinics, schools and housing, shops and marketplaces, offices and factories, places of worship, media and communications, public information systems. Most people think of the physical barriers in this category – e.g. a health clinic is inaccessible for wheelchair users if it has steps and narrow doorways. It’s relatively easy to identify these – in consultation with disabled people – once aware. But communications can also be disabling for those with sensory impairments – e.g. for Deaf people if there’s no sign language; for those with visual impairments if medication isn’t appropriately labelled. Poor communication can have devastating results where important school-based education campaigns happen (e.g. HIV and AIDS). Students with hearing, visual or intellectual impairments are unlikely to access vital information unless their access needs have been met. And since 98 per cent of disabled children in developing countries don’t attend school, they’ll miss out on important education and information. A Ugandan study found 38 per cent of women and 35 per cent of men with impairments had a sexually transmitted disease at any one time.

Equality:

Equality refers to equal outcomes for people with disabilities, enabling their full and effective participation in society on an equal basis with others. The concept of ‘equality’ is aligned with the Purpose of the Preamble of the United Nations Convention on the Rights of Persons with Disabilities, as seen in Article 1.

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Executive summary

Disability is an emerging subject of national interest in Bhutan, and one about which much is still unknown. As the first study to explore the hygiene and sanitation experiences of people with disabilities in rural Bhutan, this research was also the first inclusive study in Bhutan to include people with disabilities (PWDs) as part of the study team. Commissioned by the Ministry of Health's Rural Sanitation and Hygiene Programme (RSAHP) with technical support from SNV as part of the Sustainable Sanitation and Hygiene for All (SSH4A) programme, the study was designed to generate in-depth data that can be used to ensure the programme is accessible to and inclusive of people with disabilities. This outcome aims to contribute to achieving the programme goal of increasing the use of improved and equitable sanitation services in Bhutan.

The study's overall objective was to investigate the current sanitation (accessibility of the existing toilets) and hygiene (usage, accessibility of the handwashing facilities and menstrual hygiene management facilities) situation of people with disabilities in households, schools, nunneries and monastic institutions in three districts. An important part of the research methodology was to actively seek out and include the views of people with disabilities on their current situation in terms of sanitation and hygiene.

Research themes focused on current practices, challenges and opportunities, the gendered and poverty dimensions of disability, inclusion, and hygiene and sanitation at the community and institutional levels. This included an exploration of the accessibility of existing toilets, handwashing facilities and menstrual hygiene management facilities for people with disabilities.

Key informant interviews, in-depth interviews, focus groups discussions and accessibility and safety audits were conducted by the research team. These were 57 key informant interviews, 23 in-depth interviews with adults and children with disabilities living in communities, schools, nunneries and monastic institutions, 20 focus group discussions with adults and children without disabilities in communities, and 26 accessibility and safety audits of sanitation and hygiene facilities across 14 rural community households, six Basic Health Units and six schools and monastic institutions. Additional questions on menstrual hygiene management issues for female PWDs were asked where possible and appropriate.

Being inclusive in the research process by having two wheelchair users (a female and a male) as part of the research team guided the whole research process in terms of testing the field data collection tools during the training sessions in Thimphu and also during the actual data collection process in terms of being sensitive and inclusive in our approach. Involving expertise from people with disabilities provided invaluable information on the current practical challenges and recommendations for improved practice to achieve effective disability inclusion in the RSAHP.

Research findings were assessed using the "twin-track" approach to disability inclusion framework. Under this framework, the first "track" identifies environmental, attitudinal and institutional barriers in mainstream society/approaches preventing inclusion of PWDs. The second "track" identifies specific direct actions needed to work with PWDs so they can fully participate in, and benefit from, mainstream services and activities.

The research study's overall finding was that people with disabilities in Bhutan do not have safe, appropriate or adequate access to sanitation and handwashing facilities, including in institutions designed to directly support people with disabilities (such as SEN schools and the Draktsho Vocational Training Institute, a local DPO training institution). Barriers in accessing sanitation and hygiene facilities experienced by people with disabilities in Bhutan include several attitudinal, environmental (including some communication barriers) and institutional barriers. Some of the major barriers uncovered include deep-rooted and widespread multi-layered discrimination, stigma and karmic beliefs which has led to the neglect of people with disabilities, including of their sanitation and hygiene needs and aspirations. These attitudinal barriers have also created 'internalised oppression' and low self-esteem amongst people with disabilities, as witnessed through the research process. The negative and exclusion-oriented attitude towards people with disabilities at all levels (amongst government officials, community officials, programme implementers, community women and men) has impacted the quality of the data collected related to disability. People (both household members and community leaders) were hesitant to report disability cases due to stigma and shame; the health department's disability data at the district level was found to be incomplete, leading to a nationwide lack of reliable data collection on disability. This has contributed to policy makers and decision makers underestimating the prevalence of disability in the country and subsequent inadequate resource allocation. All of these have led to universally inaccessible sanitation and hygiene facilities, be it in the household, community, at BHUs and hospitals, in monastic institutions, training institutions (such as Draktsho vocational training institute) or at schools (including SEN schools).

Additionally, specific RSAHP related findings include that meetings to discuss RSAHP's work have not been held in accessible locations, so PWDs have not been able to attend to give inputs and in most cases were not aware of them. In instances where PWDs had managed to attend meetings, they had not been facilitated to participate according to their access needs. It was also found that training on sanitation and hygiene practices was not delivered using formats or methodologies accessible to people of different impairment groups. Although a few sanitation suppliers, SMEs and masons were aware of adaptive technologies for PWDs, they had not considered providing such technologies or received training on how to do so.

The linkages between gender, disability and poverty have also been established in Bhutan through this research. Women (particularly adult women, mothers and elderly women) were found to be the most impacted in terms of caring responsibility for disability, and women with physical impairments faced additional challenges, due to a lack of access to adequate information and facilities for menstrual hygiene management. Households with a member with a disability and people with disabilities themselves reported financial concerns, with limited access to employment, extra financial expenditure, and limited carer income potential leading to reduced household's income.

The findings were far worse than were anticipated when the study was initially commissioned and highlight the challenges ahead in addressing the multiple barriers and dimensions. A key step would be in overcoming the beliefs held by decision makers that there were no problems faced by people with disabilities in accessing sanitation and hygiene facilities. Current arrangements are leading to neglect, ill-health and do not fit the premise of the CRPD that the Government of Bhutan intends to ratify (having signed the Convention in 2010).

The need for practical measures is immediate if we are to change this dire situation where people with disabilities are being denied their human rights to basic sanitation and hygiene facilities. PHED and SNV are committed to implementing these measures, fulfilling both their obligations to DFAT and to fit their values as agencies. Thus, based on the findings from the field and discussions with stakeholders at various levels, the research team has recommended a series of urgent actions for the RSAHP to address the sanitation and hygiene related barriers faced by people with disabilities. These include disability-awareness training based on inclusive approaches for all stakeholder groups, empowerment work with people with disabilities, dissemination of accessible toilet and handwashing designs to all key stakeholders, making RSAHP consultation meetings/workshops and gatherings accessible and inclusive in terms of location and facilitation, allocation of resources for inclusive measures, and the need for commitments and practical action to collect systematic data and monitoring on disability.

Noting the urgent need to reduce and eventually remove the deep-rooted, widespread and multi-layered attitudinal barriers and to overcome the environmental and institutional barriers highlighted by this study, the research team sees that multi-stakeholder engagement and strategic partnerships, especially with DPOs and change agents identified from the PWDs community itself as part of this research process, is highly recommended.

There are multiple systemic factors that combine with deep-rooted, widespread discrimination towards people with disabilities to prevent their access to adequate sanitation and hygiene facilities in rural Bhutan. Urgent action is needed to start promoting inclusion of PWDs and to ensure their rights are realised. The goals of the RSAHP and the broader Sustainable Development Goals – specifically enabling access to these facilities for all in rural areas – will not be reached unless inclusion of people with disabilities is specifically sought and planned for. Multi-stakeholder engagement and strategic partnerships, especially with DPOs and change agents identified from the PWDs community itself as part of this research process, is highly recommended. This document recommends pathways that RSAHP and SS4HA can follow to promote the inclusion of PWDs and thus achieve improved sanitation, increased respect and equitable treatment for PWDs nationwide. Taking action on these critical issues is necessary to achieve increased use of improved and equitable sanitation services by all in Bhutan.

1. Introduction

The Royal Government of Bhutan (RGoB) has prioritised sanitation and hygiene as a key sector result area in its 11th Five Year Plan (FYP) for 2013-18. It is targeting an increase in rural access to improved sanitation and hygienic usage from 54 per cent¹ to more than 80 per cent² and nationwide scaling-up of the RSAHP, which has so far reached nine of the 20 districts. The RSAHP is based on a validated, subsidy-free, district-wide approach developed by the PHED since 2008 with support from SNV. It recognises the importance of creating demand for sanitation amongst householders (primarily through Community Development for Health workshops), increasing access to sanitation products and services, promoting safe hygiene behaviours, as well as the important role of governance and leadership in sanitation. The 11th FYP mandates the mainstreaming of sanitation and hygiene targets within the RGoB's district and Gewog five-year plans to ultimately improve the health of rural households. Supporting this scaling up, the RSAHP Strategy strives to achieve universal access to improved sanitation by 2023 within the 12th FYP. It also aims to meet the nation's regional (SACOSAN) and international commitments, including the Sustainable Development Goals for universal access and recognition of the human right to water and sanitation. Ensuring the sanitation and hygiene needs of women, girls, nuns and people living with disabilities (including the elderly and sick) are met and that they are able to meaningfully participate in WASH has been recognised as one of 10 strategic objectives to achieve this.

Whilst access for PWDs has been considered in technology options promoted by the RSAHP, this is a relatively new area for the programme which would benefit from further guidance to look beyond this. As part of SNV's current technical support to PHED, PHED and SNV have committed to:

- Undertake formative research on disability and impairment to better understand the impact disability has on access, the barriers to participation and opportunities to address sanitation and hygiene in Bhutan;
- Develop a better understanding of the existence of disability and impairment within households (for improved community member understanding of disability and improved SNV/PHED understanding of disability at the HH level);
- Gather suggestions and recommendations from communities to effectively integrate disability and impairment considerations in the programme.

These commitments led to the commissioning of the research described in this report. A qualitative research approach was selected, in recognition of the critical need for nuanced, in-depth information in this under-researched area. The findings from the study will be used to inform and adapt programme activities to promote greater inclusion and access to sanitation and hygiene for PWDs in Bhutan.

PHED/SNV understands the importance of working with partners, people with disabilities and their representative organisations to achieve disability-inclusive development. A strategic partnership with Ability Bhutan Society (ABS), a local DPO, is currently being explored to further this aim.

1.1 Disability in Bhutan

Disability is an emerging subject of national interest in Bhutan after years of being neglected. Qualitative and quantitative studies exploring the experience of disability and the needs and challenges faced by PWDs are critically needed. The Population and Housing Census and the National Health Survey are the main sources of relevant data collected to date. The 2005 Population and Housing Census revealed that 3.4% of the population (21,894 persons) live with one or more disabilities. The 2012 National Health Survey estimated that the most prevalent forms of disability are hearing impairments, followed by vision impairments. The percentage of acquired impairments was higher than that of congenital impairments. The Two-Stage Child Disability Prevalence Study conducted by the National Statistics Bureau, Ministry of Education (MoE), Ministry of Health (MoH) and UNICEF in 2010-2011 revealed that 21% of children between two and nine years of age had an impairment. The 2015 Children with Disabilities in Bhutan Study by UNICEF and the MoE reported a lack of accessible data regarding disabilities, and limited awareness around disability and the related issues and accessibility challenges faced by PWDs with all types of impairments. Further, the same study identified gaps in healthcare screening, capacity and services, education access, training and curricula, as well as limited advocacy capacity of national organisations and critical deficits in family support, social protection and child protection for PWDs. With the majority of Bhutanese people depending on the agricultural sector and living in rural communities with poor road connectivity, scattered households and in difficult topography,³ the study states that physical barriers faced by PWDs in rural areas lead to prohibitive transportation costs and

1 The baseline of 54 per cent is based on the National Statistics Bureau Bhutan Multiple Indicator Survey, 2010

2 Gross National Happiness Commission 2012, Guidelines for the 11th Five Year Plan, RGoB, <http://www.gnhc.gov.bt/?s=11th+FYP>.

3 69% of the population are living in rural areas as per the NSB 2005 Census data

consequent limitations on access and mobility. It also mentions that PWDs in both rural and urban areas face substantial discrimination due to the negative attitudes of households and community members.

A recent study conducted by Youth Development Fund in 2014 titled *A Qualitative Assessment of Child Protection Related Issues Faced by Children with Disabilities and An Action Plan to Address Those Issues*, reported that four impairment groups – those with physical, vision, hearing and learning impairments – faced protection issues. These included children with vision and physical impairments having major challenges related to accessibility, hearing impaired children being excluded from communication and learning impaired children being left undiagnosed.

In terms of legislation in support of PWDs, the Bhutan Building Rules (2002) has a section titled *Access for the Disabled*. This has provisions for accessibility in institutional buildings, such as making ground-floor entrances accessible, including ramps with handrails, including accessible toilets for wheelchair access and having sufficient toilet facilities that are accessible and usable by PWDs. However, implementation of this rule needs to be emphasised in the country.

The primary institutional and community rehabilitation services currently available to PWDs are managed by DPRP and Jigme Dorji Wangchuk National Referral Hospital under the MoH. The secondary services include the Special Educational Needs (SEN) and Early Childhood Care and Development (ECCD) programmes of the Ministry of Education. Other support to PWDs are from His Majesty's Secretariat Kidu System and Civil Society Organisations (CSOs) who include or have a main focus on disability. The CSOs are the Disabled Persons' Association Bhutan (DPAB), Draktsho, Ability Bhutan Society (ABS), Bhutan Foundation, Tarayana Foundation and Bussi-En (a Japanese NGO working in Bhutan).

The UN Convention on the Rights of Persons with Disabilities (CRPD) requires that ratifying countries pass national laws to promote and protect the rights of people with disabilities. Bhutan became a signatory to the CRPD in 2010, but has yet to extend their commitment through ratification. Bhutan does not have national policies to protect the rights of PWDs or a national definition of disability. The Disability Prevention and Rehabilitation Programme (DPRP), under the Ministry of Health, is the first programme in the country to draft a strategy for PWDs. Development support to Bhutan that is funded by bilateral and multilateral aid donors who have ratified the CRPD (including Australia and the European Union) is subject to conditions of the CRPD under Article 32 on international cooperation within the Convention.

1.2 WASH and Disability

The CRPD covers the breadth of human rights for PWDs throughout all its 50 articles.⁴ The critical importance of water and sanitation for PWDs especially applies in eight Articles: Article 6 (Women with disabilities); Article 7 (Children with disabilities); Article 9 (Accessibility of facilities); Article 11 (Situations of risk and humanitarian emergencies); Article 24 (Education); Article 25 (Health); Article 28 (Adequate standard of living and social protection – clause 2a specifically on clean water); and Article 32 (International development cooperation).

In the WASH sector, the Royal Government of Bhutan has committed to both SACOSAN and the Sustainable Development Goals, which place significant emphasis on gender equity, social inclusion and reducing inequalities to disadvantaged and marginalised peoples within countries, in order to reach all.⁵

Relatively few studies and resources have been commissioned globally to investigate and address the inclusion of PWDs in WASH, and this lack of research is itself contributing to the gap in understanding disability inclusion in WASH. This research study aims to provide important information towards this gap. Research studies and programming work that are available consistently demonstrate similar themes – in summary, that prohibitive attitudinal, physical access and institutional (resource allocation and policies) barriers exclude PWDs from adequate WASH provision and use. For example, WaterAid's *Undoing Inequity* research in Uganda and Zambia showed that key concepts of inclusive WASH (disability, rights-based approaches, social inclusion) are difficult to initially introduce to implementers and communities and require more training for implementing partners and communities than expected, as well as that early interventions are often not significantly disability-inclusive (focusing on hardware-based solutions to address physical access barriers only). A recent study by WEDC and LSHTM (UK university institutions) in northern Malawi found that people with disabilities experienced widespread barriers (differing according to specific personal circumstances and severity of impairment) in accessing WASH. When they had adequate access to WASH, which addressed the barriers they faced, their quality of life was reported to have significantly improved.⁶ It is noted that, women and girls with disabilities often experience "double discrimination" due to compounded

4 <http://www.un.org/disabilities/convention/conventionfull.shtml>

5 <http://www.un.org/sustainabledevelopment/sustainable-development-goals>; http://www.endwaterpoverty.org/sites/endwaterpoverty.org/files/SACOSAN_VI_declaration.pdf

6 Wapling L, WaterAid, 2014 <http://www.wateraid.org/what-we-do/our-approach/research-and-publications/view-publication?id=25633f29-8f85-4f0e-9a54-ffe2ca085f5e>; White S, 2016, https://www.researchgate.net/publication/303008869_A_Qualitative_Study_of_Barriers_to_Accessing_Water_Sanitation_and_Hygiene_for_Disabled_People_in_Malawi

issues of gender discrimination and the increased burden of WASH on women – fetching water and taking responsibility for WASH needs of the household.⁷ Definitions of barriers are given in section 2.3.

The three major barriers PWDs experience in accessing goods and services in society (including water and sanitation) are:⁸

- **Environmental barriers:**

Inaccessible environments (physical barriers in the natural or built environment, inaccessible communication systems).

- **Attitudinal barriers:**

Negative attitudes towards PWDs, based on stigma and prejudice. These are often cited as the biggest barriers PWDs feel they face. They are widespread attitudes – held both consciously and sub-consciously – that lead to stigma and discrimination against PWDs. PWDs are often viewed as incapable, inadequate, of low intelligence, and only in need of a ‘cure’ or ‘special support’. Attitudes based on misconceptions, stereotypes and folklore linking disability to punishment for past sins, misfortune or witchcraft lead to exclusion, discrimination and bullying. These assumptions are often reinforced by media and public forum discussions about disability. Negative language reflects and can reinforce prejudices.

- **Institutional barriers:**

Laws, policies, strategies or practices (including formal budget allocation of resources) that discriminate against people with disabilities. For example, electoral laws that do not protect the political rights of persons with disabilities, banks who do not allow visually or hearing impaired people to open accounts, or health centres that do not allow personal or communication support workers in appointments due to confidentiality policies. Many countries still have restrictive laws, particularly affecting people with psychosocial or intellectual disabilities.

⁷ As reported by the RSAHP gender study report

⁸ <http://www.gsdrc.org/topic-guides/disability-inclusion/barriers-to-disability-inclusion>; Coe and Wapling ‘Travelling together: how to include disabled people in the main road of development’ World Vision UK 2010 p. 41-43. <http://www.worldvision.org.uk/travelling-together>

2. Methodology

Summary of stages of the research process

The nine stages of the research process are listed below. Specifics are described in sections 2 and 3:

1. Recruitment of core research team: Two expert consultants were recruited (one international, Sue Coe; one national, Pema Cheizom) to form the core research team to guide study direction and tools, with full involvement from PHED, acknowledging and adhering to the RGoB's research study protocols.
2. Design of research protocol and study tools: The research team designed four participatory qualitative research tools, adapted for a range of stakeholder groups who were interviewed, drawing on best available international practice in disability-focused WASH research (see section 3.1). These tools were pre-tested during the three days training of the research team in Thimphu.
3. National/central-level interviews with key stakeholders in Thimphu: Interviews started with key informant interviews with eight stakeholders in Thimphu, using guided research questions. DPOs were important stakeholders to include, along with government and SNV staff. See section 3.2 for tools used.
4. Initial analysis from central-level interview findings and finalisation of field study research tools.
5. Final identification of field research team members: The field research team consisted of 12 people (two male, 10 female), including representatives with different skills from government and civil society (PHED, DPRB (MoH), DPAB, ABS, Bhutan Nun's Foundation and SNV). Recruitment from Disabled Peoples' Organisations (DPOs) was a central principle. Two field research study team members were PWDs with physical impairments. Their engagement strengthened the research team's ability to understand the needs of people with disabilities in the localities visited, and helped support the mobilisation of people with disabilities to participate in the research.
6. Training of field research team: Structured training was delivered over three days. This was the first study in Bhutan to include PWDs in its research team.
7. Field study visits: Visits to three geographic locations – Paro (in the west), Samtse (in the south) and Trashigang (in the east) took place between 22 October and 9 November, 2016. Guided research tools for focus group discussions, key informant interviews and accessibility audits were used, adapted for different stakeholder groups. The districts were chosen for variance in regional/cultural context, sanitation status, prevalence of disability and existence of special schools. A total of 57 key informant interviews were conducted (18 female and 39 male interviewees across central, district and community levels), along with 23 in-depth interviews with adults and children (19 people living with disabilities [eight females] and four carers [one female], 20 focus group discussions with adults without disabilities (held separately for females and males in communities, schools, nunneries and monastic institutions), and 26 accessibility and safety audits of sanitation and hygiene facilities (14 rural community households; six Basic Health Units; six schools and monastic institutions).
8. Analysis of field study according to the "twin-track" approach to disability inclusion.
9. Production of draft and final report.

2.1 Objectives of the research

The research study's overall objective was to investigate the sanitation (accessibility and use of existing toilets) and hygiene (accessibility of the handwashing facilities and menstrual hygiene management facilities) situation of people with disabilities in households, schools, nunneries and monastic institutions across three geographic areas.

2.2 Expected benefits from the research

This was the first research to explore disability, sanitation and hygiene in Bhutan and the first disability study conducted in the country to include PWDs as part of the research team. It is hoped that the findings and recommendations from this study will help achieve improved sanitation and hygiene for all in Bhutan and also inform and influence policy and strategy development in the national WASH sector. In the first instance it will be used to guide PHED and SNV Bhutan programming decisions in their current RSAHP work. After this, it is expected that the research process will lead to a nationwide discussion on the WASH needs of people with disabilities in Bhutan through active engagement with local DPOs, as well as incorporation of the WASH needs of PWDs in the strategy of the National Disability Prevention and Rehabilitation Programme, and incorporation of disability considerations in the National RSAHP Strategy, 2015.

2.3 Definitions

Definition of disability

Bhutan does not have a national definition of disability. As Bhutan is a signatory to the United Nations Convention on the Rights of Persons with Disabilities (a key stage indicating intent to ratify the CRPD in future) and the Australian Government (donor for SSH4A) has ratified the CRPD (meaning CRPD content is applicable under Article 32), the definition of disability in the CRPD has been used for this research study:

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.⁹

Models of disability

The research took an approach based on a **social model of disability** according to CRPD principles. Descriptions of the three main conceptual models of disability are given below:

Individual models

Previous views of disability models are generally described as '**individual models**' (specifically the '**medical model**' and the '**charity model**'). In summary, individual models tend to conceptualise disability as a specific problem of the individuals with impairments, often as a personal tragedy for the individual.

The **medical model of disability** focuses on a person's specific impairment, which is viewed as the reason for their exclusion from mainstream society. This view leads to attitudes that disabled people need to be 'cured' as the main/only intervention in their lives. PWDs are perceived as passive and dependent on medical specialists who make decisions on their behalf to improve their lives – if PWDs are acknowledged and recognised for diagnosis (as this can be an expensive route, many PWDs are not diagnosed or supported, so few benefit). Many other needs/rights that PWDs have (e.g., adequate living standards, education and employment, family and community life) are unrecognised and not addressed, as PWDs are viewed only as patients with medical needs. This model segregates people with disabilities from mainstream society.

The **charity model of disability** emphasises that PWDs are 'unfortunate', should be 'pitied' and need long-term welfare support based on assumptions of dependency and inability to be educated, work and self-support. This model focuses on the 'helplessness' of people with disabilities and the fact that it is 'morally right' to support them. This model takes away autonomy and decision-making freedom from people with disabilities and in many cases, their rights. Like the 'medical model' view, it also segregates PWDs from mainstream society.

Social model

In contrast, **the social model of disability** (the rights-based approach builds on the social model and is consistent with it) starts with viewing PWDs as equal members of society. PWDs are prevented from participation by the way society is organised, rather than their individual impairments. It is not a person's impairment that 'disables' them, but rather the disabling nature of society – society is organised in a way that disadvantages and discriminates against people with impairments, excluding them from involvement and participation. The main focus is on the need for society to identify and remove barriers – attitudinal, cultural, institutional, environmental, and economic – that prevent PWDs from participating fully and on an equal basis with others.¹⁰

The social model makes a distinction between 'impairment' – an individual's physical, sensory or cognitive difference (for example being blind, experiencing bipolar disorder, having multiple sclerosis or a learning difficulty) – and 'disability'. 'Disability' is the social consequence of having an impairment in a world where barriers exist. In this model barriers can be identified and removed, enabling fuller participation of PWDs as equal members of society. The social model of disability regards PWDs as part of society with the same needs as people without disabilities for love, education and employment. Disability is created when society denies the rights and opportunities of these individuals.

⁹ Article 1, United Nations Convention on the Rights of Persons with Disabilities <http://www.un.org/disabilities/convention/conventionfull.shtml>

¹⁰ Adapted from British Council and World Vision UK materials on descriptions of disability models

2.4 Research themes

The design of the research was based on the following key themes:

- **Current understanding:** The study aimed to draw out the understanding all stakeholders interviewed have about the situation of people with disabilities (women and men, girls and boys in schools, nuns and monks in religious institutions) in relation to sanitation and related hygiene practices, and their understanding of the challenges PWDs face in accessing and using sanitation and hygiene facilities
- **Current practices:** The study aimed to gain an understanding of sanitation and related hygiene (including handwashing) practices of PWDs, including women and men in communities, girls and boys in schools and nuns and monks in religious institutions.
- **Challenges and opportunities:** The study aimed to document the challenges people with disabilities (and others with physical limitations¹¹ where they presented) face and the opportunities they have with respect to:
 - Toilet construction
 - Toilet use
 - Toilet maintenance
 - Handwashing with soap
 - Participation in WASH programmes (for example, consultation processes and decision making; awareness-raising programmes; trainings provided by the programme, etc).
- **Gendered dimensions:** The study aimed to document the gendered dimensions of disability, including menstrual hygiene management issues for women and girls with disabilities and extra caring responsibilities undertaken by women and girls in HHs with members including people with disabilities.
- **Poverty and disability:** The study aimed to document links between poverty and disability using data from an aligned field study. This includes information about the percentage of PWDs who are poor and the reasons why people with disabilities may remain poor (for example higher costs for accessible facilities, barriers experienced to receiving education services, health services, economic opportunities; family caregivers with fewer opportunities/time to earn money).
- **Inclusion:** To make recommendations to improve disability inclusion in the RSAHP (both general and component specific). To lead to improved capacity of the PHED, local civil society organisations (ABS, Draktsho, DPAB, etc.) and SNV WASH advisors to integrate disability inclusion in the implementation of programme components to contribute to improved sanitation and hygiene for all.



¹¹ Including older people, pregnant women and people with chronic illnesses

2.5 Research locations

Initial, central-level interviews were conducted with eight key stakeholders (five females and three males) in Thimphu to yield initial findings for detailed investigation in field locations.

The qualitative research study was then conducted in the three districts of Paro, Samtse, and Trashigang using structured research tools. These three districts were chosen in consultation with PHED for their variance in regional/cultural practices and beliefs, sanitation status, prevalence of disability and existence of special schools as follows:



Map of Bhutan showing the three pre-selected districts for the research.

- **Samtse:** Samtse is a RSAHP programme district and represents the southern/central region. It has the second-highest rate of disability incidence in Bhutan. Samtse, Trashigang and Paro districts all have mixed populations following either Hindu- or Buddhist-based cultural practices and beliefs.
- **Trashigang:** The first school for the visually impaired, the Draktsho Vocational Training Institute for Special Needs Children and Adolescents, is located in Trashigang. Located in the eastern region, it is also a district identified for inclusion in the RSAHP expansion process.
- **Paro:** Located in the western region, Paro has special schools for the hearing impaired.

2.6 The field research team

A field research team with a total of 12 members (10 females and two males) was formed to lead the collection of data in the field. The team incorporated representatives from PHED, DPRB (MoH), DPAB, ABS, Bhutan Nuns Foundation, SNV and PWDs. The 12-member team was divided into two equal groups after the first district (Paro) to take up one subsequent district each (Samtse and Trashigang). Each group had two facilitators/moderators and three note takers. The study team met after each interview/discussion and in the evenings to refine the data collected while in the field. The final data analysis was carried out by the core team members comprising of the SNV gender and inclusion advisor and the two consultants. The analysed data was also shared with the other study members for their review and comments.

Inclusion of PWDs in the research team was critical to the study design. PWDs have been excluded from many decision-making processes in most countries. Families, communities and development organisations have tended to make decisions on their behalf – even when these decisions directly affect their lives. The phrase “Nothing about us without us” is very important to people with disabilities across the world, who often have little opportunity to participate in and decide on practical measures which impact their lives; the research aimed to embody and follow this principle.¹²

The participation of two members of Disabled People’s Organisations (DPOs) in Bhutan were proactively sought for participation in the field study teams. The selected representatives, Ms. Chencho Om and Mr. Pema Dorji, both live with physical disabilities. Their selection, involvement and engagement strengthened the research



Part of the research team taking a group photo and holding discussions after the first day of data collection

12 Coe and Wapling, ‘Travelling together – how to include disabled people on the main road of development’ 2010 p. 51-52

team's ability to understand the needs of people with disabilities in the localities visited, and helped support the mobilisation of people with disabilities to participate in the research. Their involvement was important to the research study in demonstrating that PWDs should not be only subjects of research but should also be actively involved in defining, leading and researching issues directly affecting their lives. The views of the DPOs that PHED/SNV partnered with also helped inform the research findings.

2.7 Research tools

Specific tools suitable to the context of investigating disability accessibility and inclusion in sanitation and hygiene practices in rural Bhutan were developed for this research study. This proved a significantly greater challenge than expected, as there are very few precedents to draw upon for a study of the type intended.

The international consultant sought inputs from those who have conducted similar studies elsewhere. The research study team are grateful for their generous sharing of information and time to explain the strengths/limitations of their studies. In particular, the following people shared invaluable information to help the Bhutan research study team design and develop their own research tools:

- Hazel Jones, Water Engineering Development Centre, Loughborough University, UK
- Jane Wilbur, WaterAid, UK (sharing information from WaterAid and the specific experiences of their "Undoing Inequity" project research in Zambia and Uganda, and information from WaterAid Bangladesh's equity and inclusion work)
- Sian White, London School of Hygiene and Tropical Medicine (sharing information from an innovative research study in northern Malawi)

The research tools were carefully designed to gain authentic, credible responses from all participants, especially from PWDs. It was decided to use qualitative participatory tools to explore access and participation barriers faced by the PWDs in accessing sanitation and hygiene. This was because the research team's experiences in Bhutan and of disability-inclusive research generally demonstrated that this approach can better capture the perceptions and attitudes of all stakeholders at different levels.



Images drawn by children in schools and monastic institutions of their existing vs desired inclusive and user-friendly sanitation and hygiene facilities.

These included key informant interviews (KII); in-depth interviews (IDI); focus group discussions (FGD) and guided accessibility and safety audits.

2.8 Data collection

Having finalised the research tools and gained ethical clearance for the research protocol from the MoH, a three-day training led by the core team was held in Thimphu from 22 to 24 October 2015. The purpose of the training was to prepare the study team members on the methods and tools to be used and provide awareness and sensitization on disability and the discrimination faced by PWDs.

The core team conducted eight central level key informant interviews during the first two weeks of October, using a semi-structured questionnaire template provided by the international consultant. These interviews gathered initial insights from decision-makers on their views on the research study topics, and provided a basis to test and compare insights gained from field-level research study findings. Field research study tools were finalised after these initial interviews.

The field study commenced on 25 October 2015, with all the study team members collecting data together in Paro after which the team broke into two groups, one to go to Samtse district and the other to Trashigang district. Both groups completed their field research on 9 November 2015.

Research participants and specific stakeholder groups were carefully selected to include information and perspectives on the research themes from both people with and without disabilities. In particular there was deliberate and considered design to informing approaches to maximise authentic, credible input from PWDs in the research.

The PWDs participating in the research team played a leading role in guiding the research process, both in terms of testing the field data collection tools during training sessions in Thimphu and ensuring an inclusive approach was applied to data collection in the field.

Stakeholders were selected to represent the full breadth of those deciding on, implementing and experiencing sanitation and hygiene access and inclusion for people with disabilities in rural Bhutan:

- **Decision-makers, duty-bearers and those responsible for budget allocation:**

Understanding of the issues forming from the basis of decisions made by those with responsibility for laws, policies and budgets create the **institutional enabling environment** for disability-inclusive sanitation and hygiene facilities/practices to happen.

- **Government technical staff, masons, SNV and other civil society programming implementers:**

The understanding (including technical knowledge of physical access barriers) of these stakeholders creates the **enabling environment to prevent inaccessible sanitation and hygiene facilities** being constructed, and reducing barriers to adequate PWDs use of existing facilities.

- **People without disabilities living in communities and running institutions (schools, monasteries, nunneries):**

Attitudes and understanding of the issues and challenges of PWDs' access and use of sanitation and hygiene facilities form the direct **attitudinal enabling environment** for disability inclusive sanitation and hygiene practices to happen,

- **PWDs and representative organisations of PWDs (DPOs):**

Perspectives of PWDs and their direct experiences critically **inform the actual reality of the current situation of people with disabilities** in terms of access to sanitation facilities and hygiene practices and their use.

*The attitudes and understanding of the issues and challenges of PWDs in terms of access and use of sanitation by everyone interviewed form the **direct and indirect attitudinal enabling environment**.*

Focus Group Discussions (FGDs)

FGDs were conducted separately for female and male participants (at the community, school, monastic institution and nunnery level) by female and male facilitators respectively (wherever possible). 20 FGDs were conducted at the four levels. Separate FGDs were held for people with disabilities, family members of people with disabilities, and people without disabilities in communities. Different FGD guides developed for adults and children were used when holding discussions with the different groups.

Key Informant Interviews (KIIs)

KIIs were conducted separately for female and male informants at the central level, in communities, schools and monastic institutions by female and male interviewers respectively. Even gender representation was sought in the number of KIIs held with different groups.

Central-level KIIs:

A total of eight central-level interviews were conducted prior to the field data collection. The stakeholders interviewed included:

- Government officials from the Public Health and Engineering Division (PHED) Disability Prevention and Rehabilitation Programme (DPRP) within the Ministry of Health and the Special Education Unit of the Ministry of Education
- Officials from Dratshang Lhentshog¹³ (monastic institution) and the Bhutan Nuns Foundation
- Disability Persons' Organisations: Ability Bhutan Society; Disabled Persons' Association of Bhutan; Draktsho
- SNV advisors: to assess their attitudes and documenting their practical experience of including disability in WASH at the field level (for the different components of the RSAHP)

A total of 49 KIIs (13 females and 36 males) were conducted at the district and community levels. The stakeholders interviewed included:

At the district level:

- KIIs with district leaders (Dzongdas: district administrators, district health officers, district education officers, planning officers, legal officers, SMEs only in the RSAHP project area of Samtse, 2 LCBs-local long terms consultants of SNV in the field implementing)

13 The representatives from the Dratshang Lhentshog were not available for the central-level interview but were interviewed at the district levels

At the community level:

- KIIs with gewog leaders (Gups [administrative block heads]; Mangmis [block deputy heads], Tshogpas [village representatives]; Health Assistants; masons [only in Samtse])
- KIIs with adults/children living with a disability (combined with household visit)
- KIIs with school leaders (school heads, school health coordinators, school health captains)
- KIIs with school-going children living with a disability
- KIIs with monastic institution leaders (institution heads, monastic institution coordinators, monastic institution captains)
- KIIs with nunnery leaders (nunnery heads, nunnery coordinators, nunnery captains)
- KIIs with monks/nuns living with a disability

Direct observations: household/school/monastic institutions sanitation and hygiene facilities

Observations of current facilities and practices provided invaluable information on the current practical challenges and recommendations for improved practice to achieve effective disability inclusion. The facilities observed were:

- Household sanitation and hygiene facilities (14 rural households in the three districts)
- School, monastic institution and nunnery sanitation and hygiene facilities (two in each district visited –totalling six schools and monastic institutions, including special schools)

In total fifty-seven KIIs were conducted with 18 female and 39 male stakeholders at the central, district and community levels. 23 in-depth interviews were held with adults and children living with disabilities living in communities, schools, nunneries and monastic institutions (19 people living with disabilities [(8 females] and care givers [1 female])). 20 of the focus group discussions held involved non-disabled adults and children (separately for females and males) at communities, schools, nunneries and monastic institutions. 26 accessibility and safety audits of sanitation and hygiene facilities were conducted. Of these, 14 were undertaken in rural households, six in Basic Health Units and six in schools and monastic institutions. Additional questions were asked on menstrual hygiene management issues for female PWDs where possible and appropriate.

Participant category	Number of non-disabled participants		Number of participants with disabilities	
	Male	Female	Male	Female
National-level stakeholders (MoH, SNV, DPOs, MoE, etc),	4	6	1	0
District leaders	11	4	0	0
Gewog leaders	9	4	0	0
School teachers / Student representatives	12	5	1	0
Monastic institution/ Nunnery leaders / Monk/Nun representatives	1	1	0	0
SMEs / Masons	1	1	0	0
Adults who were parents/carers of children/adults with disabilities	7	13	0	0
Adults (from the community, monastic institutions and nunneries)	15	42	1	3
Children (from the schools, monastic institutions and nunnery)	65	71	49	43
Adult participants with disabilities met during the research in addition to the above categories (who participated with assistance from their carers in cases where they couldn't participate on their own)	0	0	11	7

2.9 Analysis

A content analysis of the qualitative data collected through the study was carried out. The team discussed and organised their notes after each interview/FGD/accessibility and safety audit based on the research themes. The data collected were then organised by topic coded into theme or category. The coded data were analysed in a categorised manner, with data categorisation performed manually.

All responses were analysed according to the “twin-track” framework, which is used by the Australian Government (who fund the SSH4HA programme) as their approach to disability inclusion. ¹⁴

¹⁴ “Development for All 2015-2030 Strategy for strengthening disability-inclusive development in Australia’s aid programme”. Australian Government DFAT, May 2015

This framework also provides a structured approach to generating practical recommendations to positively improve the inclusion of people with disabilities in sanitation and hygiene work.

2.10 Ethical considerations

Ethical considerations were a key component for this study, based on the understanding that people with disabilities face very high levels of stigma and discrimination in all societies. All interviewers received disability awareness training as a pre-requisite to conducting site-study interviews.

The following principles were critically important to implementing this study, especially in guiding the personal behaviour and attitudes of all interviewers, note-takers and data analysers:

- Ensuring non-judgmental approaches and attitudes regarding the situation of people with disabilities and their families;
- Maintaining respectful attitudes towards all study participants, especially people with disabilities who may not be used to engaging in such conversations and may find the situation unusual and potentially intimidating;
- Adopting personal behaviours to acknowledge the dignity of everyone interviewed, especially people with disabilities.
- Interviewers were trained to conduct themselves to uphold the dignity and respect of people with disabilities, not make assumptions on their behalf or to anticipate their responses, not use language that disempowers or victimises people with disabilities, and not generalise or assume what the needs of persons with disabilities are;
- Considering and accommodating the personal welfare and safety of all study participants;
- Defining and respecting the privacy of study participants and the confidentiality of their responses. Interview venues were selected to allow privacy and confidentiality where necessary. Interviewers were trained to recognise the importance of ensuring interviews did not provoke responses in families, institutions and communities that further disempowered people with disabilities after the interviewing team had departed;
- Ensuring representative responses. Focus group discussions were facilitated to receive responses from all participants.
- Some FGDs were segregated by gender to enhance this, while facilitators were required to be conscious of gaining representative responses and to adapt their approach accordingly in mixed gender groups.

2.11 Informed consent

All study participants were asked for their verbal consent to participate in the study and were informed of the



Benefits of having PWDs as research team members

There were many benefits in having PWDs as research team members. Firstly, this enabled them to share their first-hand experiences with other PWDs during the research process, as well as with other stakeholders and the study team members. This helped the stakeholders and other respondents to realise the pressing need to look at disability access issues and adjust existing structures.

PWD team members also reported feeling a significant sense of personal empowerment as a result of their participation in the study:

"I would like to thank SNV and the MoH for giving me this opportunity to get out of my house and see the world beyond, meet and interact with other people in similar situations as me."

Ms. Chencho Om, wheelchair user team member

"I feel good to be part of the SNV and MoH research study team, so that I can contribute and encourage my fellow people with disabilities to speak up about their concerns"

Mr. Pema Dorji, wheelchair user team member

Challenges of having PWDs as research team members

Accessibility for PWD team members was found to be a major issue everywhere in the country. A lack of wheelchair accessible hotels, restaurants and government offices often meant the PWDs had to be carried. Visits to rural HHs and monastic institutions were tough due to inaccessible paths, requiring the PWDs to be carried in certain circumstances. PWD team members were unable to undertake some access and safety audits due to difficult terrain and the inaccessible locations of the facilities to be audited.

confidentiality of the information gathered from them. In the case of visual/hearing impairment or intellectual impairment, translators (teachers in the case of schools, carers at the household levels) were used to ensure that participants understood fully the purpose and implication of their involvement.

2.12 Limitations of the methods

Changing the ingrained and negative attitudes of some researchers towards PWDs was a particularly challenging element of the research process. Even after three days of training, some of the research team members were not clear on inclusive and disability-sensitive principles in conducting qualitative research. This was evident when they began team discussions in English, a language not understood by the two PWDs, and when they started taking pictures of PWDs without adopting the full ethical considerations outlined above. The team leaders promptly reminded the team members to speak in the local language during team discussions and reminded the members not to take pictures without first obtaining consent from the research participants. This negative behaviour was mitigated effectively and promptly to ensure the study maintained an inclusive approach.

The research started with the development of research tools specifically suited to the context of rural Bhutan. This proved a greater challenge than expected, as there were few precedents available to draw on for their design. The international consultant sought inputs from those who have conducted similar studies elsewhere and their inputs are kindly acknowledged.

3. Research findings

The research findings are presented according to available data on disabilities in Bhutan plus analysis linked to the “twin-track” approach to disability inclusion – i.e. understanding of the concept of disability, three barriers to inclusion (attitudinal, environmental, institutional) and disability-specific considerations.

3.1 Prevalence of disabilities in Bhutan

In line with the Disability Prevention and Rehabilitation Programme strategy and data from the disability survey conducted, the number of people (adults and children) living with disabilities in the districts visited was higher than the national average. Information about 321 recorded cases were gathered and 116 PWDs (53 females, 63 males) were met as part of this study.

The type of impairments reported were diverse. These included visual impairment, hearing impairment, speech impairment, physical impairments (loss of limbs, loss of limb function due to paraparesis, muscular dystrophy, cerebral palsy, paraplegia, hemiparesis etc.), intellectual/cognitive impairments (Down syndrome, autism, and others) and mental illnesses.

3.2 Perceptions of disability

Almost all people interviewed during the study clearly held an individual model perspective towards disability – i.e., they believed disability was solely a “problem” of the individual with an impairment, rather than the set of consequences people with disabilities experience in accessing services and participating in society due to environmental, attitudinal and institutional barriers placed upon them.

These strong attitudes have led to the following:

A lack of initiative from district officials in relation to including people with disabilities in society. The main justification of officials interviewed when asked why they had not addressed disability in planning decisions to date was a lack of budget and directives/guidelines from the central level

Supporting PWDs is seen as both a poor and unnecessary investment by critical decision makers. PWDs are considered a minority in the population, so are overlooked. People with disabilities were viewed as being “lesser” citizens, not having the same rights as non-disabled people to access and benefit from services that non-disabled people receive.

At all levels, no dedicated budget or human resources was available for disability inclusion in any work areas. The same three reasons were provided for this lack of engagement: “people with disability represent only a small proportion of the population [and are therefore not important]”, “there is no budget”, and “they are not included in the yearly plan from the central level”.

A common issue identified by the research team was the lack of institutional responsibility for disability inclusion in governance and service delivery. Some of the perspectives expressed by interviewees are outlined in the following quotes:

The initiative should come from the grassroots. Only then we can review and do something about it.

Central-level official

There is no budget or programmes from the central level for disability, so we cannot do much.

District-level government official

We do not have any knowledge and experience in this area so we need some guidance initially from the respective heads.

Gewog-level official

Despite broad-based general apathy towards disability inclusion, the research team encountered representatives at different levels who were enthusiastic about including disability in their programmes if they could. Opinions expressed included:

The construction process [for toilets] is happening, so we have an opportunity.

District-level programme implementer

We had talked about implementing disability in the WASH programme, but didn't include it because they thought the sanitation concept would be diverted. However, I personally believe it should be included (not just in schools).

District-level programme implementer

People from the top level should come up with programmes and then teach us on how and what to do in this area. Then within a few years' time we will be able to take the lead.

Community-level local leader

The definitions of disability expressed by the majority of participants across all levels were based on descriptions of specific impairments – physical, visual, hearing and verbal impairments. Most participants focused on impairments that are visible. There was no acknowledgement of the barriers that people with disabilities face as a consequence of having an impairment or evidence of perspectives aligned with the social model of disability. A more detailed definition was shared by those interviewed who worked in Disabled Peoples' Organisations (DPOs).

3.3 Attitudinal barriers to inclusion

The research found evidence that discrimination and stigma against persons with disabilities is both deep-rooted and widespread. The biggest barrier to inclusion discovered by the researchers was the depth of stigma and discrimination against people with disabilities across all sectors of society in Bhutan (central and district level).

Discrimination and stigma was found towards people with disabilities in the following groups:

- Central government staff and SNV programme implementing partners
- District level: government officials/decision makers
- District level: programme implementers, including a local partner, LNW
- Community level: local leaders
- Community level: school/nunnery/Dratsang leaders
- Community level: health workers
- Community level: adult women and men
- Community level: children (girls and boys)

Different attitudes leading to discrimination against PWDs included:

Disability is believed to be due to bad karma

A major attitudinal barrier identified in the study is the widespread belief of "Tshey Hey Mey Ley" – meaning past karmic deeds are the cause of impairment. These beliefs were very strong within the monasteries and amongst people who pursued religious teachings. Many respondents did not recognise these beliefs as a barrier at first. Exploring interviewees' beliefs about the causes of impairment required careful interview techniques.

Some quotes from the interviewees demonstrated this discriminatory belief system:

The cause of her disability is because of her past life doings

Because he was lavish and naughty before the accident

Bad karma and black magic

The mother is not taking care of her child

Adults living in a rural community

Disability is only caused by past karma – nothing else.

Community-level leader

(NB: This sentiment was expressed by all school, nunnery and monastic institution leaders interviewed)

Disability is caused by accident, alcohol, genes, poor care during pregnancy, at birth – and also in our beliefs it is said because of past karmic deeds.

Adult living in a rural community

Children with disabilities are seen as a 'problem' for schools

All children with disabilities considered under the scope of this research experienced discrimination within schools they attended. A SEN school principal said, "The other students say that because of Dorji (name changed)¹⁵, they cannot move up to the first floor". The same principal said "I regret taking children with disabilities in my school." Similarly, another SEN school principal said, "Since the school has mixed group of students [impaired and non-impaired students] the teachers have to slow their teaching technique." A student from a SEN school said, "We are friends with everyone, but we try to avoid the mental boy in our class." Another stated "We have a rule not to go to their [children with disabilities] school toilet and they cannot come to ours."

¹⁵ A young boy who is physically challenged

Children with disabilities can be denied vital support and training to use sanitation facilities because of attitudinal barriers they experience. For example the SEN department head from the MoE shared a story of child in the Eastern Blind School who was sent home due to lack of toilet training, which could also be an issue of lack of facilities, training or appropriate support. Similarly, another child from the Draktsho East School was also sent home due to lack of toilet training. One student stated: "We didn't inform the teachers to repair our broken toilet because we are afraid". In another school soap was not given to students as it was believed they did not use it appropriately: "There is no soap in the toilet. Students misuse it or throw it when the soaps are kept". It is not just inaccessible toilets that prevented these children's education – it was lack of access to knowledge and information, and a lack of support from teaching staff. In the examples discussed, the schools sent the children home instead of providing the training and support that their families were unable to provide.

People with disabilities are seen as sub-human

The view that people with disabilities are sub-human and therefore not worthy of care, support and services was evident across families and communities interviewed throughout the research. People with disabilities were frequently referenced using demeaning terms such as "tsagay", "yongba", and "yongmin" ('useless', 'not knowing anything'). Dismissive and derogatory practices from community members towards people with disabilities were found to be commonplace.

The following quotes highlight the realities faced by children and adults with disabilities at a community level:

A Bhutanese man in a wheelchair who had come from the United States and had visited Thimphu town felt very bad after he witnessed everyone looking at him. He asked: "Is this the attitude of Bhutan? Why aren't we allowed to go out? Are we not human?"

Story shared by one of the DPO executives

A man with physical impairments emailed about his problem where he cannot go to the chorten/temple as he cannot wear a gho [national dress for men].

Story shared by one of the DPO executives

Once the bus driver stopped the bus while I crossed the road and everyone watched me. I felt embarrassed.

A monk with disability

He is a bastard [the child with disability] so he wasn't included in the census.

Local leader

I like to make friends, but I don't have friends. I don't know why they don't want to be friends.

15-year-old boy with intellectual impairment

When we go out for community gatherings people say:

"Why are these blind people here to see the celebration when they cannot see?"

Child with disability

At a community and family level, researchers found perceptions of people with disabilities as sub-human resulted in rejection and significant neglect of people with disabilities. Stories of people with disabilities being left in their own urine/faeces, being systematically denied food and drink as a method of reducing their toilet use, and not being taken for treatment when ill (partly as facilities were not accessible and did not support them) arose multiple times during the research process.

The following quotes indicate how attitudes impact on the health and opportunities of some PWDs:

She [girl with disability] cannot go to toilet herself so she pees in the bucket and if anyone is there then we have to carry her. Her main caregiver is our grandmother [81 years old] and she cannot carry her to toilet. Because of this we control her water intake.

Community member

I heard of a child in Paro who is locked inside the toilet. The child eats, urines, defecates and sleeps in the toilet.

Community leader

Both parents have rejected their child with Down syndrome.

Community leader

*I have no exercise, eat a lot and have gained a lot of weight.
It's been four years since I was last taken to a hospital when I was ill.*

Physically impaired woman with visual impairment

I poo once every three days. I get dehydrated.

Person with disability

I poo once every 7-10 days. I feel shy to ask for help from my mother-in-law.

Women with disability

He refuses to go to hospital although he has many health problems, including piles, UTI and has been bleeding when pooing for two years. It is because he is scared of people harassing him and his family there.

Wife of man with impairment

People with disabilities experience pity that leads to exclusion not inclusion

The research study team experienced many study participants expressing pity towards PWDs, which led to a view of them as “abnormal”. Compassion as an attitude can be important in motivating inclusion of PWDs, but if the attitude evident is inappropriate pity it will not yield inclusion or the reduction of barriers experienced by PWD.

Mothers are held responsible for disability

A common response among study participants (at the household and institution levels) for cause of disability included, “when pregnant mothers drink alcohol”, “when mothers do not go to the hospital for routine check-ups”, “when mothers consume drugs” Children interviewed by the research team reported being told these ‘causes’ of disability in class at school. Male study participants held strong views that mothers were responsible for the impairments of their children with disabilities.

People with disabilities are viewed as incapable of working or being productive members of society

Perceptions of people with disabilities as lacking competence were widespread at the community level. Regardless of the specific impairment, they are often seen as having limited skills and abilities applicable to productive activities in the workplace, at home or in the community, as demonstrated in the following quotes:

They [people with disabilities] cannot fit in certain professions.

District-level programme implementer

There is no community support for people with disabilities.

Community-level local leader

Village people look down on the disabled and say they cannot do anything.

Community member

People with disabilities are viewed as a social and financial ‘burden’

Having a household member with a disability was seen as both a financial and social burden by multiple interviewees. The researchers documented cases of verbal abuse from carers when taking PWDs to the toilet. The view of PWDs as a burden was stronger in regards to women with disabilities as families incurred additional costs for sanitary pads. A mother of a child with disability said to the researchers in front of her daughter:

Nu.7000/- a month is spent on purchasing her diapers, which are also not available here. We have to order from Samdrup Jongkhar. A lot of our money goes on this and we are hoping to request this to be included in kidu [destitute allowance from His Majesty's Secretariat]

There was evidence PWDs had absorbed and internalised the belief that they burdened their families (see section 3.6).

Families not accepting disabilities and responding by seeking a ‘cure’

Families of PWDs were frustrated and expressed ‘hopelessness’ due to frustrated efforts to find a ‘cure’ for their household members with disabilities. This caused considerable strain within families and upon individuals. Many had tried a range of ‘cures’ including Western medicine and spiritual approaches. This sense of hopeless is described in the following quotes:

I have tried everything, but nothing seems to help.

Carer

We did rimdos [religious ceremonies] and took [family member] for blessing and it did help a little, but not so much.

Carer

We even try to control diet to vegetarian as informed by the rimpoche [religious teacher].

We have taken [family member] to hospital in the country and in India also.

Carer

We have done everything by seeking medical help and also going to a rimpoche [religious teacher], but nothing seems to help.

Carer

My parents divorced because of my birth. My father is as dead to me since he never comes to visit and check up on me.

Female PWD

Lack of recognition and negative attitudes by government staff

Discrimination and stigma towards persons with disabilities existed in every stakeholder group interviewed (except the Disabled Persons' Organisations), from central-level government staff to local-level community members. This included some staff working in SEN schools. Most study participants without disabilities (including many government staff) stated there was no discrimination towards people with disabilities in Bhutan, since services were provided equally to all people. People with disabilities disagreed, stating they did not have equal access to services, including sanitation facilities and hygiene practices and training.

People in duty-bearing positions often stated in interviews that they didn't "know enough about disability", suggesting a strong need for awareness-raising training and implementation of practical measures (such as enhanced data collection and discussion) in their areas of responsibility. The range of attitudes amongst government and service providers towards PWDs are illustrated in the quotes below:

First we need to reach the general population, then we can think of reaching the vulnerable groups.

Central-level government official

There is no discrimination towards people with disabilities, it is accepted by the society.

District-level government official

I don't think people with disabilities face discrimination.

Central-level government official

I don't know why our district is selected for this study because to my knowledge disability cases are low.

District-level government official

Women face double discrimination – disability and violence against disabled women is very common.

A NCWC official refused to accept this. She says, there are no disability issues among women and children and she is not willing to listen to our presentations in the meetings.

DPO member

There is no initiative or support for disability in Bhutan. Am I not human? Everyone in town stares at me in my wheelchair.

DPO member

Despite the widespread existence of discrimination and denial, there were a few hopeful examples where officials recognised the need to support disability initiatives and improve service provision to PWDs as shown in the quotes below:

I am happy to learn about this initiative from all of yours.

People with disabilities in our country are left behind and not really looked at.

District-level government official

We have seen some positive attitudes from those who have received some training or engaged in projects with people with disabilities.

District-level government official

Misuse of power towards PWDs

There were a number of cases reported to the research study team in which PWDs and their families experienced abuse of power and corruption in interactions with government officials. For example, families of PWDs not receiving their monthly kidu allowances regularly, on time or in full:

We have to approach the Kidu Officer many times. Despite that, he doesn't pay us our full allowance.

Carer

In another case a PWD said:

Once I visited the bank and asked for help from the staff to deposit my money. But later I found that the money was not deposited.

Hearing and visually impaired woman

3.4 Environmental barriers in relation to access and use of sanitation and hygiene

Inaccessible toilets and handwashing facilities

Toilets and handwashing facilities visited by the research team in rural households, schools (including SEN schools), monastic institutions, hospitals and BHUs were all found to be inaccessible and not user-friendly to PWDs. The researchers found that even sanitation and hygiene facilities at some DPOs offices (where children/adults with disabilities are present on a regular basis) were not accessible. Reasons cited by management included: "we haven't made any adjustments to our school structure because it is a rented house and the house owner will not allow it". Inaccessibility issues observed included toilets being located far from buildings, dangerous paths leading to toilets, small doors, wet and slippery floors, raised toilet doorways, high toilet door latches and light switches, toilet bowls installed on raised platforms, handwashing taps installed too high to be reached by all, etc. Some of the SEN schools visited had made their school compounds accessible to certain extents with the construction of ramps and hand-rails, but this did not include access to the sanitation and hygiene facilities.

Other service providers and government officials acknowledged this issue and explained some of the physical barriers faced by PWDs. Significantly, even some DPOs expressed that their buildings were not accessible, despite existing to support and serve people with disabilities:

People with disabilities in Bhutan face many physical barriers due to unfriendly structures everywhere.

DPO member

The importance of accessibility for people with disabilities is not considered in existing buildings.

DPO member

Not all DPOs have made disabled-friendly facilities in their own institutes.

DPO executive

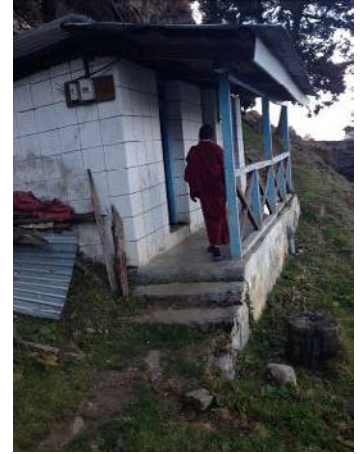
Even here in our office in the Dzong area, people with disabilities cannot access our office and the toilet is outside.

District-level government official

Our buildings are accessible on the outside, but there are no adaptations in the toilets themselves.

Local leader

Some of the challenges related to inaccessible and lack of disabled friendly sanitation and hygiene facilities (both at household and community levels) recounted by people with disabilities during the research included "having to crawl to the



Non-disabled-friendly toilets and handwashing facilities in rural households, SEN schools and monastic institutions.

toilet”, “controlling water and food intake to reduce toilet visits”, restrictions on their mobility, heavy reliance on (feeling they are overburdening) their family members; and having to control their toilet use when there was no-one at home to help them:

I don't go to ihakhangs/monasteries or any gatherings in the community because there is no toilet and someone has to carry me from my house.

Adult woman with a physical impairment

When the elder sister left the school, the younger sister who was physically disabled also left. I think because the elder sister used to help the younger one.

Focus group participant at a SEN school

The institute is not accessible for wheelchairs, but friends help. But I don't like to ask my friends for help every time. And they are also hesitant to help me each time.

Boy with a physical impairment

Samtse hospital provided a wheelchair, but the toilet isn't accessible, so the wheelchair cannot be used.

Monk with a physical impairment

One physically impaired adult man explained how he defecates due to being unable to access a toilet:

I keep a paper/cloth and lay down on the bed and keep a mirror to check. After defecation I wash my hands with water and soap which I keep below my bed. And I wrap the faeces in the paper or a cloth and ask my brother to throw it out in the forest or the nearby stream. I would prefer a baby pot that will help me to ease the way I defecate.

Physically impaired adult male

The research team came across many PWDs suffering from additional ailments such as hypertension, piles, obesity, anaemia, and dehydration due to controls on their food and liquid intake, lack of regular health check-ups, intimidation/stigma experienced in going to public places including hospitals/BHUs for treatment, difficulty in accessing hospitals/BHUs due to distance, inaccessibility, dependence on carers, etc.

Additionally, the research team observed that in addition to a lack of access to disabled-friendly menstrual hygiene management (MHM) facilities, women and girls with disabilities noted a lack of knowledge sharing on MHM for women and girls with disabilities. This was also supported by a district-level programme implementer who noted “menstrual hygiene management is a challenge for women/girls with disabilities.”

Adaptations made for disabled-friendly access are limited

Researchers observed a limited number of instances in which adaptations had been made to toilets for people with disabilities. For example, a small hole made in a small plastic chair for a teenage boy with disabilities in Paro district town, and a plastic chair adapted for a physically impaired older man in one chiwog under Drugyel, Paro district. But the majority of carers interviewed were either not knowledgeable about possible adaptations and what was appropriate/adequate, or saw adaptations as being expensive.

The research team found that the few cases of adaptations seen had been undertaken without consulting the user, (the PWD). For example, a husband who was carer for his physically disabled wife said that he didn't discuss the design of adaptations he made with his wife design as it was easier to do it on his own terms.



Non-disabled friendly locations and access issues:

(Top L) Inaccessible wooden path to a toilet for HH with an elderly physically disabled female HH member;

(Top R) Inaccessible toilet at a SEN school with wheelchair users;

(Bottom L) An outside toilet for a HH with an elderly visually-impaired woman, without any handrail or string support;

(Bottom R) Dangerous path to a HH toilet for a HH with a physically disabled elderly male member.

Many SMEs/masons are not aware of adaptive technologies for people with disabilities

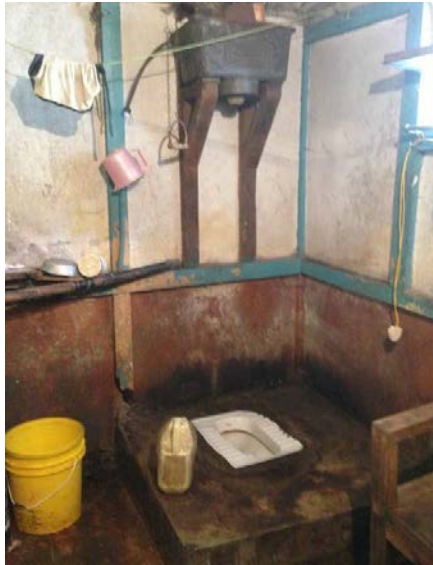
The SMEs and masons interviewed during the field work were not aware of, or knew very little about, simple adaptations that can be made to ease toilet use for impaired persons:

Right now we are not selling anything for PWDs.

SME in Samtse

We are not trained in the adaptations for PWDs.

Trained mason in Samtse



Adaptations: (L) A homemade toilet adaptation made using a broken plastic chair for a special needs teenage boy; (R) A hard-to-reach hand support for a female wheelchair user

Accessibility challenges preventing people with disabilities attending community meetings and RSAHP meetings

In all communities visited, the research study team learned PWDs never attend meetings. A number of reasons were given for this:

- Physically impaired people did not go due to inaccessible meeting locations and long distances; and /or
- Leaders' assumptions of PWDs not being able to understand and contribute to the content (due to hearing, intellectual, or speaking impairments). This is demonstrated by the following quote:

Even if people are paralyzed and understand things they don't attend meetings. The Tshogpa never informs people with disabilities about the meetings.

Trained mason in Samtse

Inaccessible meeting methodologies and non-inclusive content cause participation and communication barriers

People with disabilities of different impairments face communication and participation barriers. For example: trainings are not delivered in ways that account for different impairment needs (physical, hearing, visual) and have not been reviewed for disability sensitivity in their messaging. Additionally, informal participation policies (such as a criteria provided by local authorities on who from the household should attend meetings/workshops/discussions) have excluded PWDs. Programme implementers have encountered hearing impaired participants but found it difficult to fully engage them and enable them to participate in the discussions. This shows that existing BCC messages are not disability sensitive. For instance, there are no strategies to share messages with people with hearing impairments. Similarly, facilitators of the CDH workshops do not currently ensure that impaired persons are actively involved in the meetings. It is imperative that the RSAHP works towards ensuring that everyone who comes to trainings can understand content and messaging.

The research team found that in the limited number of cases where PWDs had attended CDH workshops in the past, they faced communication barriers and could not fully understand meeting content or could not participate due to inaccessible meeting venues.

3.5 Institutional barriers

In summary, the research study has found there are three major institutional barriers – a lack of resource allocation, a lack of reliable data collection on disability, and a lack of proactive policies amongst service providers (especially health and education service providers) and in communities on how to address the access and inclusion needs of people with disabilities. There is currently no specific resource allocation for disability inclusion related to sanitation and hygiene facilities. Disaggregated data on disability is yet to be collected, so no-one is aware of the true extent of impairment in rural Bhutan and this lack of data has contributed to the lack of resource allocation by the government

More detailed information is given below:

Inadequate understanding and acknowledgement of disability within institutions

Disability is not seen as a priority area to focus by the programme implementers at present because it is considered as a minority issue. However, few resources have been invested in establishing the full extent of disability. This study has identified a number of significant barriers from field-based investigations. Further, disability inclusion considerations are being added to the current RSAHP as one of the key outcomes required by the donor, DFAT.

People do not report disability cases, data is not appropriately collected, and cases are not monitored

A key reason for the lack of disability data is that people do not report cases to BHUs/hospitals. A physiotherapist informed the research team that they usually found new cases either through their visits to the communities or when a PWD is brought to the hospital for treatment for another illness or injury. In addition, the case records are not maintained properly, leading to a lack of follow up treatments.

Inadequate discussion about vulnerable groups by policy-makers and programme implementers

There are no serious discussions taking place amongst programme staff about vulnerable groups (including PWDs) and ways to overcome the challenges they face.

Lack of monitoring of student toilets by teachers

Teachers in the SEN schools visited by the research team reported never having visited the WASH facilities for students in their schools: "I don't know how my Tshewang [a female student with physical disability] is doing in the toilet." A student health captain informed the researcher, "Teachers have their own toilets so they don't come here." One teacher interviewed was not aware about the number of toilets in the school, the problems students faced in accessing toilets (including electrical shocks) and that the students used a pit latrine outside the school.

No community support towards people living with disabilities and their families

In all three districts visited, community leaders did not talk about how to support PWDs and their families. PWDs are not included in community meetings in any of the three districts visited. A number of reasons were given for this including: "they cannot attend because they cannot go", "they will not understand" (intellectually impaired), "it is difficult to carry and take them to the place", "we just inform each household member to join and we have never focused on disability". All the PWDs the research team met were unemployed and depended heavily on other household members for financial and social support. This indicates that PWDs have no influence or reduced influence in decision making on WASH facilities in their house or community. During a community discussion, adults said the following about inclusion of PWDs in community-level decision making and services:

There are no discussions about disability in the meetings. The leaders say there is no budget.

There is no help from the head of the community. It is useless asking for help as he only gambles.

There is no support [human resource/financial] from the communities and gewog office. There are no visits from the health assistants.

There is no discussion in either village or group meetings about disability. The head of the community said they cannot do anything because money comes from the government.

Lack of data-based decisions on resource allocation by policy makers

Government staff believe the number of people with disabilities to be low, but there is no data on which to base this perception. From the district to gewog level, no separate data on disability is collected – either generally or for programme-specific purposes. The only gender-sensitive disability data available to the research team came from BHUs, and even here the data collected reflected only the bare minimum number of disability cases. These BHU-reported figures were significantly lower than the figures collected by Draktsho, a local DPO, from Trashigang gewogs (except Merak and Sakteng). A health assistant who had missed a case of disability that the research team had found explained that, "I didn't remember that. Maybe during the household survey the household was not there".

But according to the household in question: "The BHU knows about our daughter's case since we go to them also."

Village heads also had minimal information on the number of disability cases in their villages. One of them said, "We don't do anything in relation to disability, so I don't know much. The BHU will know more." Health workers reported that disaggregated data is not collected without a central-level requirement. People with disabilities reported to researchers that they did not leave their houses or attend meetings. This lack of visibility of PWDs at the community level is likely fueling government perceptions that disability incidence rates are low in Bhutan.

There is no specific category for disability in data collection.

District-level government official

If the central level provides us with a data collection sheet, then we can collect data.

District-level government official

I am not aware of any laws on disability or any Disabled Persons' Organisations.

Legal officer

I do not collect data on disability.

Statistical officer

Lack of systems to share disability information

The district officials were not aware of the disability rate in their respective districts and the district health officials did not share the data they had with the district officials. Families were not aware of services available through the hospital for PWDs.

Reduced employment opportunities and discriminatory institutional policies towards PWDs

A principal informed the research study team that children with impairments had fewer opportunities than non-disabled children because of their impairments. Job vacancy notices circulated in the national newspapers commonly have the following key criteria: "Good in speaking English/local dialects, physically fit (required to give medical certificate as a proof)". The latter requirement is one which appears to be interpreted as disqualifying any person with impairments from applying for posts or being offered employment. No disabled people were employed in the dzongkhag/gewog offices visited by the research team. Only a few were employed as teachers in SEN schools and one in the SEN division of the Ministry of Education. A small minority of PWDs interviewed were involved in piece work.

In Samtse the district head shared an incident in which monks with impairments were not accepted by higher level dratshang after completing studies at their institute. The reason given was their impairments and that the institute had to take additional care of them – something they were not prepared to do. In this case, the head of the institute had to approach the ranking leader of the Bhutan's monastic community (Dratshang Lhentshog) and only then were the monks admitted to further training. Concerns were also expressed about the treatment these monks would receive on joining their new dratshang:

I also don't know what will happen to these three monks after they complete from here.

Head monk of Chengmari Dratshang

Lack of budget

The majority of stakeholder representatives interviewed reported that no resources were allocated for disability-inclusive measures or directions given for sanitation measures to be accessible to PWDs. This is a core problem. It is partly based on another institutional barrier – the lack of adequate data to base resource allocation on. These issues are illuminated in the following quotes:

Our budget and resources are for rural and school WASH. But nothing has been done in disability.

Government officials

Government rules and regulations restrict the disabled's chances of getting a job.

SNV programme implementers

Being a CSO, we have to always try to get budget from different donors and from that we have to implement our programmes. It is difficult.

DPO member

There is no budget or programmes from the central level for disability, so we cannot do much.

District government official

We are not looking at access problems in SEN schools – we work with pre-planned designs.

District government official

The construction process is happening, so we have an opportunity.

Programme implementer

Lack of disability sensitivity in trainings, workshops and meetings

Consultations, meetings and trainings do not currently specifically include issues or messaging about disability inclusion.

I attended the CDH workshop, but there were no discussions about special toilet designs and implementation.

Monk with a physical impairment

We don't do anything in particular for disability. We don't know how to do unless someone from the head office should come up with an initiative and guide us.

Health worker

3.6 Disability-specific issues

This section covers issues the research team identified as applicable to the second “track” of the “twin-track” approach to disability – identifying specific issues requiring direct empowerment of people with disabilities so that they can fully participate in, and benefit from mainstream services and activities.

PWDs have internalised oppression and low self-esteem

A direct consequence of the multi-layered discrimination faced by people with disabilities who were interviewed from every sector of society appears to be widespread ‘internalised oppression’¹⁶ – they have absorbed the negative belief systems of others as ‘truth’ that they are personally to blame for their impairments and deserve their suffering. People with disabilities interviewed expressed no concept of their human rights and have adopted false messages about themselves and the causes of their impairments. These are examples of many similar sentiments expressed to the research team:

She was already shy before, but now since she cannot move she is more shy to go to town or any gathering.

Carer

I am useless as I cannot do anything to help myself and the family.

Male PWD

Many families feel their family members with impairments need to be kept separate from the rest of society. This could be seen in the way carers and other family members talked about their family member with an impairment “being kept at home all the time”. Many PWDs have internalised justifications for their separation from others:

I don't go out of the house and I don't want to go either.

Female PWD

Now after this incident I prefer to stay by myself most of the time. I don't like to talk to others. Maybe because I don't have anything to talk about also. I watch television every day and update myself about the news.

Male PWD

She doesn't have any friends. Her friends from school are not in touch anymore.

We have given her a phone and she checks her Facebook page.

Carer

Depression amongst people with disabilities was observed to be widespread, often related to their frustrations, social norms, the attitudes of their carers and the community at large, and beliefs in concepts such as “tse ney ma gi lay” (‘disability is a punishment for sins in the past’).

According to one DPO representative, stigmatisation of people with disabilities leads to a sense of disempowerment and helplessness, where PWDs accept the discriminatory and stigmatising views held by non-disabled people about them. The expression “khung me, zhung ku mey” (‘they are useless and not able to do anything’), is often used to describe PWDs and is internalised by them. Perceptions of PWDs as lacking competence are widespread in communities had been internalised and accepted as fact by PWDs interviewed in the research.

The majority of respondents – including people with disabilities – had firm beliefs that impairments were caused by “karma”, “being cursed” and “sins from a past life”.

The cause of my disability is my past doings.

Adult PWD

16 <http://www.allisonj.org/non-profit-work/internalized-oppression-and-its-impact-on-social-change>

My mother blames my disability on my own bad deeds and hopes I will walk someday.

Student living with a disability

Knowledge of the costs incurred and labour necessary to support PWDs further contributed to the impaired person's sense of causing burden, compounding their low self-esteem and lack of dignity. This is especially true for those who need to get support from household members to access toilets, wash their hands and bathe themselves.

In one case, an adult man with disabilities shared that he preferred to attempt to use the toilet without support to avoid burdening his carers and avoids going to town for the same reason:

I don't like to ask my brothers or parents to help me because I will be alone one day and I will have to know how to take care of myself. And this condition of mine is my own fault.

Male PWD

I feel shy to go to town and I don't want my brothers to carry me. It is a lot of burden to them.

Female PWD

I feel shy to go to the bazaar in a wheelchair and my brothers also have to help to carry me, so I don't want to burden them. I go to Lhaxhang when my father comes because he has a car and I pray from the car.

Female PWD

My husband (man with disability) has to crawl to toilet and cannot ask for help from our daughter. Sometimes he defecates in his pants. He stinks.

Carer

Poor personal hygiene of PWDs due to lack of training, hygiene supplies and support for implementing adequate personal hygiene practices

Poor personal hygiene, including handwashing, was observed by the research team as common amongst people with disabilities and was frequently mentioned in responses from both people with disabilities and their caregivers.

Caregivers of those with intellectual impairments said they needed to remind them each day to wash themselves and keep themselves clean, "I have to tell my sister every time to wash herself and clean herself. Otherwise she will not do it and she forgets". For those with physical impairments, assistance from a caregiver was frequently seen as necessary to maintaining personal hygiene. "My husband helps to clean me", "Either me [mother] or her elder sister helps her to take bath as and when she informs us to", "I have to help clean my mother". However, as documented earlier in this section, the fear of burdening others has led to many PWDs minimising their requests for assistance. Some families minimise their assistance to PWDs, with direct implications for their personal hygiene.

Incidences of students at SENs with disabilities being sent away from school for not being toilet trained were also reported. Many children with disabilities are not being trained to use sanitation facilities by their families, and schools are not willing to support training but are excluding the children instead.

PWDs are restricting their diet (or having restrictions imposed on them) to minimise toilet use

All the people with disabilities the research study team met who were physically impaired reported that they controlled their intake of food to minimise toilet use. In addition women also controlled their intake of water. This was also observed amongst research team members with disabilities and research participants with disabilities by the non-disabled team members. Such dietary restrictions pose serious health consequences. Reports such as the following were common:

Compared to before when I was able to walk, now I don't eat a lot and I defecate once every 7-10 days.

Male PWD

He defecates once in three days.

Carer

Her appetite has decreased, unlike before, and she drinks about a litre of water a day.

Carer

I have lost a lot of weight compared to before.

Female PWD

When my wife (main caregiver) is not home then I control my food and water intake because I feel uncomfortable with other household members to go to the bathroom.

Elderly male PWD

Peer support between people with disabilities is not a given

Non-disabled people often assume people with disabilities will support each other. However, it cannot be assumed people with disabilities will automatically seek or create support and advocacy groups. There are many reasons for this, including discriminatory attitudes towards other PWDs. During the study, the research team encountered came across a person with disability in a leadership position who exhibited attitudes of discrimination towards other PWDs (particularly school children). Careful support and advocacy work is needed with people with disabilities to support and mobilise them to be able to articulate issue they are facing and generate support for the human rights they are being denied.

3.7 Poverty, disability and gender

Disability, poverty and gender are interlinked

Almost all people interviewed as part of this study regarded people with disabilities as a single, homogenous group. They were not aware of linkages between poverty, gender and disability, such the additional suffering and greater barriers faced by PWDs (and their families) living in poverty, or the additional challenges faced by females with disabilities (including menstrual hygiene management, burdensome domestic labour expectations, missed opportunities, stigma, difficulties faced by mothers with disabilities in taking care of their children, etc.).

PWDs from poor households face greater challenges

The poorest households faced disproportionately greater financial barriers to constructing toilets, especially if they had PWDs or elderly people in their HH. Explaining this, one carer of a PWD said: "For some it is technical know-how and for others it is the affordability issue. We do not have a toilet and all of us practice open defecation. We do not use our neighbour's toilet because they lock it and they do not like when we use it. But we are afraid to defecate in the open because of snakes."

Women with disabilities faced more discrimination

It was also reported that women with disabilities faced greater discrimination. For example, it was reported that when a man with a mild intellectual impairment was the head of a HH, the community did not say that he was "impaired". On the other hand, a female with a mild intellectual impairment would be referred to with demeaning names and it would be expected that she would not be able to fill a productive role in society.

Lack of affordability and accessibility of hygiene supplies

Handwashing with soap difficulties for women and the poor with disabilities particularly in terms of affordability and accessibility issues for hygiene supplies came up often as an issue: "Only those who can afford to buy soaps and pads are able to keep themselves clean." (Draktsho school).

Another major issue that came up was the lack of soap for women with disabilities and their carers who assist them in changing their sanitary napkins.

Menstrual hygiene management for girls with disabilities in schools and institutions

Although women and girls in Bhutan in general lack knowledge on proper menstrual hygiene management (e.g., not being aware of the need to change their sanitary napkins every six hours; not drying their washed menstrual pads/cloth in the sun; maintaining traditional beliefs such as that women should not drink tea, eat chilli or bathe during their menses to avoid heavy periods etc.), the researcher found that women and girls with disabilities faced additional challenges in menstrual hygiene management. Interviewees reported being dependent on their mother/parents/carers for menstrual hygiene materials, and in some cases being dependent on their carers to change their sanitary napkins. Cases of women with disabilities being scolded and seen as extra burden, both in terms of menstrual hygiene-related costs and labour, were witnessed by researchers.

Women caregivers and single mothers

During the course of this study, the majority of carers met by the research team were women (mothers and grandmothers caring for their children or elderly HH members with disabilities). This gender imbalance is also reported for persons with disabilities in low and middle income countries in the WHO Journal of Water and Health in 2011.¹⁷ The challenges faced by elderly female carers in supporting PWDs to maintain proper sanitation and hygiene struggles of elderly can be seen in the following quote:

17 http://www.ohchr.org/Documents/Issues/Water/ContributionsStigma/others/WHOjournalWaterHealth2011_Groce_9_4_617_627.pdf

Even if she [wheelchair-using granddaughter] wants to, she cannot use the toilet and I [her grandmother] cannot carry her. She needs to wait for her mother [since the father left the family after the birth of the daughter] or her aunt to go to toilet.

Grandmother of girl with disability

Reported data shows more men are disabled

Data obtained from the BHU and hospitals shows a significantly higher reported rate of men with disabilities than of women with disabilities. When questioned about possible reasons for this, one Health Assistant (HA) said: "It may be because when HA are men then they tend to collect more information on men's disabilities than women's, and the same applies if the HA is female [they will collect data on women]". In all the BHUs visited by the research team, the senior HAs (responsible for data collection and reporting decisions) were men, with female HAs at junior levels.

Abuse of women with disabilities

The study team came across incidences multiple cases of rape of girls/women with disabilities by male caregivers. One such incident was reported by a HA in Trashigang, where a young child with an intellectual impairment was alleged to have been raped by her grandfather (main caregiver). These incidents were not formally reported, and there were no consequences for the abusers.

4. Suggestions from research participants

Interviewees were asked for their views on how to address the different barriers faced by people with disabilities in order to improve their sanitation and hygiene status. These are presented below:

<p>4.1 Suggestions to overcome attitudinal barriers:</p> <ul style="list-style-type: none">• Promoting acceptance and kindness;• Prioritising PWD;• Raising awareness of disability; drawing on traditional values to promote inclusion;• Engaging media and communities in creating change.	<p>Quotes:</p> <p><i>It is important that society accepts PWDs and makes them understand that they are equal and accepted by the society.</i> District-level government official</p> <p><i>PWDs should always be dealt with with kindness and without discrimination or else they become aggressive.</i> District-level government official</p> <p><i>Prioritize PWDs first and everyone need to think in that manner.</i> DPO member</p> <p><i>We need to train people, create awareness, educate and promote Bhutanese values through good deeds. With modernisation, people's attitudes are changing, so with this change we should emphasise Bhutanese values.</i> District administrator</p> <p><i>Currently, the mainstream media is not communicating very effectively about disabled persons, so they can help change the outlook of the disabled by including activities.</i> District administrator</p> <p><i>It is very essential to have community support for the PWDs especially for those PWDs without any family members.</i> District-level government official</p>
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4.2 Suggestions to overcome institutional barriers:

- Promoting PWDs' voice in decision making;
- Reviewing and revising existing policies and rules;
- Ensuring central-level commitment to plans and appropriate budget lines;
- Incorporating disability considerations into development activities;
- Greater access to caretakers;
- Provision of capacity building of teachers; health workers and parents;
- Conducting studies specific to PWDs and schools;
- Providing technical knowledge for promoting inclusion of PWDs; and improved support from physiotherapists.

Quotes:

There is a great need to review the rules and policies considering the needs of PWDs, for instance the PWDs are not able to access education. These [issues] need to be studied during planning, design and implementation of any plans.

District-level government official

Act and policies need to be in place by government and then the plan needs to be initiated from the central level and later the grassroots level can implement it. Only then the grassroots developmental activities can take place.

District-level government official

Special budgeting is required to implement accessibility and disability issues.

District-level government official

Disabled friendly policies need to be developed from the central level, then the lower levels can implement it.

District-level government official

Ensure that new structures integrate the problems faced in the existing structures. Right now the new constructions are occurring so we have an opportunity.

District-level government official

The PWDs should be asked for suggestions on their problems and needs.

District-level government official

They should be provided with additional caretakers in schools. And the higher secondary students should take care of junior students.

District-level education official

Teachers should be professionally sound to effectively communicate with the children, getting their views and suggestions and acting according to it. Similarly, the HsA need training on the specific impairments and even the parents need to attend consultation on how to treat and understand their children with impairments.

District-level education official

There is a need to carry out surveys to improve the situation in schools.

District-level education official

Right now we do not know how to communicate with the mute people so we need to know that.

District-level education official

We need better support from the physiotherapist.

Carer

<p>4.3 Suggestions to overcome environmental barriers:</p> <ul style="list-style-type: none"> • Translating policy into action; • Tailoring toilets to disability. 	<p>Quotes:</p> <p><i>It is a must to construct toilets based on the adaptations required and for this the technical intervention should come into place to mobilise this. We have the technical option on paper, but it's not translated into action.</i> District-level government official</p> <p><i>Indian-style [a squat toilet] is comfortable for an impaired person because the English pot is difficult for him to climb, especially when there are not hand rails. However, for his impaired friend the English pot is convenience.</i> Monastic institution leader</p> <p><i>A one-handed impaired girl requested an English pot with a latch that can be accessible to her height.</i> SEN school teacher</p>
<p>4.4 Suggestions on inclusive facilitation of workshops and meetings:</p> <ul style="list-style-type: none"> • There should be active, two-way discussion; • Workshops and meetings should include processes where PWDs are valued and appreciated. 	<p>Quotes:</p> <p><i>For an interactive discussion the facilitation should ensure an active conversation with the PWDs and listen to their feedback and encourage all of them to voice out their opinions.</i> District-level government official</p> <p><i>PWDs should be appreciated in whatever input they provide. With more appreciation they will be willing to participate and be empowered and willing to learn.</i> District-level programme implementer</p>



5. Discussion

5.1 Attitudinal barriers and their implications

Deep-rooted and widespread discrimination faced by PWDs has led to exclusion, neglect and inadequate sanitation facilities and hygiene support for people with disabilities

The research team unearthed very deep and broad multi-layered discrimination faced by people with disabilities in every sector studied. The extent of this discrimination has been a sobering finding by the research team, and does not fit with the views of a number of government officials interviewed that there is no discrimination against PWDs in Bhutanese society.

One consequence of the breadth and depth of this discrimination at every level in society is that it has led to widespread 'internalised oppression' amongst the people with disabilities who were interviewed – they have absorbed the negative belief systems of others as 'truth'. Additionally, the research team found evidence of significant neglect of people with disabilities. It is vital that disability awareness training is carried out for all stakeholders, including PWDs themselves.

Deep-rooted and widespread belief that impairments are caused by one's karmic actions

Karmic action was seen as a common cause of disability by the majority of the study participants, meaning that the majority of PWDs are being socially ostracized, as was seen during the field visits. Thus, the different factual causes of disability and their links with poverty (nutrition, lack of access to proper medical care, etc.) need to be emphasised during disability awareness and sensitization sessions.

Limited awareness of different impairments and their consequences on sanitation and hygiene

Study participants (including the HAs) had difficulty identifying intellectual and mental impairments and, more importantly, assumed that the barriers to safe and improved sanitation and hygiene faced by people with different impairments were the same. Thus it is imperative that disability awareness and sensitization sessions talk about the nature of different impairments and the issues/barriers to improved sanitation and hygiene faced by people with these impairments.

5.2 Environmental barriers and their implications

Significant accessibility issues are faced by people with disabilities, preventing their use of sanitation and hygiene facilities. The research study established multiple accessibility barriers related to distance to sanitation facilities, type of toilet, inaccessible paths to sanitation facilities, a lack of disabled-friendly structures both outside and inside toilets, and a lack of adaptations/modifications to existing toilets and handwashing facilities.

It is imperative to include people with disabilities in decision-making processes at the household, community, district and national levels to ensure that their needs and concerns are taken into account and the RSAHP works towards reducing and eventually eliminating the sanitation and hygiene-related barriers PWDs experience (e.g. "Pit latrine is more difficult to use because it is outside and more difficult to go"; and "There is no place to hold on to while we are in the toilet.")

Inaccessible sanitation and hygiene facilities are everywhere

In terms of the environmental barriers faced by people with disabilities, the research uncovered that almost all toilets and handwashing facilities in rural Bhutan are currently inaccessible to people with disabilities, even in SEN schools where all pupils are children with disabilities. This finding comes despite the existence of Section 8 (8.1-8.6), titled Access for the Disabled of the Bhutan Building Rules 2002, which has clear building rules to be followed. These include, for instance, making ground-floor entrances accessible, including ramps with handrails, providing wheelchair-accessible toilets and having sufficient toilet facilities and accessible to and usable by people with disabilities.

There are additional barriers for women living with disabilities due to the design and location of toilets

The global consensus on the implications for women with disabilities if sanitation facilities are far outside their house and if designs do not take into account women's practical and menstrual hygiene management needs and safety concerns was validated by this study. Women with disabilities particularly expressed safety concerns related to using poorly located sanitation facilities ("When I am home alone I am afraid to go to the toilet because I fear to meet drunk men since the toilet is outside").

It is important that household members are made aware of the importance of having an accessible toilet near to (or preferably inside) the house, especially taking into account the heightened safety risks faced by women with disabilities, such as rape and abuse when toilets are located outside.

RSAHP meetings, workshops and consultations should be held in accessible venues and use inclusive communication methodologies

The research found that the logistics arrangements of CDH workshops and other RSAHP meetings do not currently take into account the needs of PWDs. Explaining their decisions not to include PWDs in these events, workshop implementers cited the burden attending would place on PWDs (“It’s torture to ask PWDs to attend CDH meetings/stakeholder meetings”; “it is unfair to make these people attend”). However, the research team also felt that the additional effort that would be required from implementers to ensure meetings were accessible to PWDs also played a significant role here.

It is crucial that the programme implementers shift their attitude towards an inclusive model in which they recognise the importance of choosing accessible workshop venues and implementing additional steps to enable and promote the participation of PWDs to attend CDH workshops, mason trainings, global day of action celebrations, etc. This is important because the study revealed the dire sanitation and hygiene status of PWDs (especially those PWDs who lack education in sanitation and hygiene practice).

Equally important is the need to ensure that everyone who attends training courses and workshops understands them, whether they have a disability or not. This research study uncovered the communication barriers faced by the few PWDs who have attended CDH workshops in the past. Thus, it is crucial that the RSAHP review its current stakeholder meeting/CDH process and workshop/meeting guidelines from a disability-sensitive point of view to ensure disability inclusion.

Examples of adaptations to sanitation and hygiene facilities for different impairments are needed

Since most of the study participants (including programme implementers, suppliers, masons, PWDs and carers) had very limited knowledge on the different adaptations that could be made to their existing sanitation and hygiene facilities to cater to PWDs with different impairments, it is imperative that the RSAHP’s technology options handbook has an addendum on different impairments and suitable technology options (either new or adaptations) to enable access and use by PWDs.

There is limited knowledge on sanitation and hygiene materials and adaptations for PWDs

The sanitation suppliers visited as part of the study did not offer any accessible sanitation designs for PWDs, reporting that they had not considered providing such designs or supplies. Even the masons interviewed during the study had very limited knowledge and ideas on how to make sanitation and hygiene facilities inclusive for people with disabilities. Since these suppliers and masons have not been made aware of disability considerations during mason trainings, a lack of knowledge on accessible designs was expressed almost universally. It is imperative that the RSAHP incorporate disability considerations (such as incorporating a session on the recommended addendum to the existing RSAHP’s technology options handbook on different impairments and suitable technology options; the need to consult with HH members who are living with disabilities to construct a toilet and make adaptations that suit their impairment, etc.) in its mason trainings and while consulting with suppliers.

5.3 Institutional Barriers and their implications

Duty bearers are using an inappropriate definition and conceptualisation of disability

The approach to disability adopted and accepted in the central, district and gewog levels in Bhutan falls under the medical and charity approaches (individual model perspectives), where people with disabilities are seen as separate to society, requiring long-term medical help and welfare. This approach is not in line with the definition used within the UN Convention on the Rights of Persons with Disabilities (CRPD), which the Government of Bhutan signed in 2010 and intends to ratify. Once ratified, these individual model approaches will no longer be legal. Further, any international aid grants provided by governments who have ratified the CRPD (which includes the Australian Government) will require all work funded under these grants be inclusive of people with disabilities in compliance with Article 32 of the CRPD.

To avoid PWDs being excluded from RSAHP activities and to ensure that their needs are considered, it is recommended that the RSAHP adopt a social approach to disability. This social model looks at PWDs as part of society and the emphasis is on identifying and eliminating the barriers preventing inclusion of PWDs from effective participation in mainstream RSAHP activities.

Limited knowledge on disability and WASH

The majority of the RSAHP implementers expressed very limited knowledge on integrating disability considerations in WASH programmes. However, since they all acknowledged the importance of disability inclusion in WASH, there is a clear opportunity to build on this enthusiasm and carry out disability inclusion activities.

Clearer definition of disability required

Without a clear definition of disability in Bhutan, people living with psychosocial impairments run the risk of not being reported or included in national disability data. In turn, this may result in them being excluded from disability-related interventions. Thus, when the RSAHP designs interventions for disability inclusion, care needs to be taken to ensure that

people living with mental impairments are also included and that the disability inclusion interventions are not only limited to people with physical impairments or to physical access issues.

Lack of systematic data collection and monitoring on disability leads to a lack of resource allocation

The study found there was no requirement to record (and thus no record of) disability cases except a list maintained by the district physiotherapist as part of the DPRP. The research team also found no system in place to share disability information – district officials were not aware of the disability rate in their respective districts and neither did the district health officials share the data they had with the district officials. This may be one of the main reasons why disability considerations are currently not mainstreamed in district development plans. Thus, it is important that disability awareness and sensitization sessions stress the importance of a maintaining a comprehensive disability database, based on definitions of impairments and disability in line with CRPD principles. Further, some care should be taken while implementing this considering the risk of stigma being enhanced, children being excluded from schools etc.

It was also found that the district physiotherapists did not maintain accurate files. It is imperative that RSAHP implementers also collect and maintain accurate data on disability incidence (in addition to liaising with the district physiotherapy department) so that this can be used for proper planning, budgeting and implementation to ensure disability inclusion in the programme. Additionally, the review of the current government monitoring systems used in the RSAHP MIS (RSAHP Management Information System –an Excel-based system to collect, compile and analyse PMI data) shows minimal collection and monitoring of data on disability. Basic data on the prevalence of different types of impairments per household is collected, which then feeds into the annual health bulletin report. It is important that the RSAHP strengthen the collection, analysis and use of the collected disability prevalence data in the MIS. Furthermore, it is also important to include the collection of additional disability information in the MIS, such as based on the prevalence data collected at the HH level, and monitoring of the toilets to see they are accessible (especially if there is a PWD in that HH).

The accurate collection of impairment data should be implemented alongside appropriate disability awareness training, to avoid the process increasing the stigmatisation of PWDs as a result. Further, systems need to be carefully designed with this integrated into them, and with those responsible for collecting info, the tools to do so etc properly designed before systems are implemented.

5.4 Disability-specific issues and their implications

Working with People with disabilities to support their empowerment and appropriate self-image, rejecting the negative views they have had imposed on them by all in society

The research found widespread internalised oppression amongst people with disabilities. Without empowerment work they will struggle to fully advocate for, and receive, the human rights and access to public services they are entitled to (especially after the Government of Bhutan ratifies the CRPD). It is also crucial for programme implementers to understand that empowerment is not 'done to' someone but rather can be promoted or supported amongst groups. Thus, collaboration with DPOs such as ABS and DPAB (with the support of other relevant agencies such as the GNHC and programme implementing agencies) would be highly important to support the empowerment of PWDs to overcome the widespread internalised oppression.

Access and use of sanitation and hygiene for PWDs

This research identifies how poor the sanitation and hygiene status of PWDs is in rural Bhutan and the different environmental, institutional and attitudinal barriers they face. PWDs have pit toilets that are too distant to reach, with no accessible paths or structures either inside or outside of the toilets. They lack both knowledge and practice in handwashing with soap at critical times. They lack access to accessible facilities, have limited knowledge and thus poor inclusion in the RSAHP. The prevalence of stigma is high and most HHs with PWDs are poor. It is imperative that existing RSAHP BCC materials and activities are i) reviewed from a disability lens, and ii) new BCC materials and activities are disability inclusive. Furthermore, the BCC materials need to include disability-targeted messages, such as encouraging inclusion of PWDs in advocacy campaigns and in celebrations around global days of action (whether in schools or rural communities); having specific messages targeting PWDs and their carers (advocating for hand washing with soap for PWDs and their carers especially after handling diapers and sanitary napkins in addition to at other critical times).

MHM for women and girls with disabilities

In addition to limited access to menstrual hygiene management facilities for PWD, the study established that women and girls with disabilities faced additional challenges to proper menstrual hygiene management. Thus, knowledge on accessible sanitation and hygiene designs should be made available to all stakeholders, including carers, school authorities and girls and women living with disabilities. Stakeholders need to be made aware of proper MHM and its health implications in order to avoid issues (such as perception of PWDs' MHM needs as being a cost/labour burden and thus limiting the number of

napkins/pads used during menstruation) faced by women and girls living with disabilities in the proper management of their menstruation. Institutional authorities also need to be made aware of the need to include sessions on MHM for girls and women living with disabilities in their advocacy workshops and meetings, and to look at the possibility of having at least one male and one female health coordinator (in school contexts) to mitigate the risk of girls and women not feeling comfortable discussing their MHM needs with male health coordinators/teachers. Furthermore, MHM sessions as part of the RSAHP need to take into account the specific challenges faced by girls and women with disabilities. In-depth research on MHM and disability is required to enable design of effective MHM interventions for women and girls with disabilities.

Diet control placed on PWDs to reduce toilet use

One of the major reasons cited for the control of food and water consumption by PWDs was to reduce their dependence on their carers and to limit their toilet visits, especially in the context of toilets that are not easily accessible or useable by PWDs. The dangers of other health complications resulting from reduced water and nutrition intake is overlooked by PWDs and their carers in the midst of the hardships of actually going to the toilet. Global studies in line with this local finding support that when PWDs need assistance to use toilets, they lower their intake of food and water during the day until their carer is home to help them to use the toilet.¹⁸ Restricting either water or food intake has serious health implications. As cited by Yousafzai et al. 2003, restricting food can lead to malnutrition or undernutrition, especially for PWDs.¹⁹ Thus, the RSAHP needs to recognise the consequences of inaccessible sanitation and hygiene facilities on the overall health and wellbeing of PWDs in order to minimise negative health impacts.

5.5 Implications of interlinkages between disability, gender and poverty

Disability and poverty are interlinked

Globally studies have confirmed that high poverty rates, poor nutrition and low quality of health care lead to prevalence of disability and this is expected to be higher in poor countries.²⁰

In Bhutan, the two-stage child disability study conducted in 2010 among children aged 2-9 years, states that children aged 2-9 years from poorer HHs are highly likely to have a disability, unlike the children from richer HHs. These findings have been validated by this study. Thus, emphasis is required from the RSAHP to ensure that PWDs are included in its efforts to develop pro-poor support mechanisms to achieve sustainable improved sanitation and hygiene for all. Furthermore, since all the research study participants viewed PWDs as a single, homogenous group and were unaware of the links between poverty, gender and disability, there is a clear need to raise awareness of these linkages, particularly the gendered dimensions of sanitation and hygiene.

Since people with disabilities were viewed as a social and financial 'burden' and were viewed as incapable of working or being productive members of society, it is imperative that the RSAHP, in its planning stage, allocate sufficient resources to facilitate the inclusion of PWDs in programme activities, including mason trainings, and explore the possibility of engaging PWDs as active agents of change in RSAHP – either as trained masons or as sanitation and hygiene suppliers – in order to achieve greater equity in accessibility and use of toilets by all.

Highlight the additional negative consequences for rural women with disabilities who face 'double' discrimination and double burden

This research study found that women with disabilities in rural areas faced more discrimination than men with disabilities. The prevalent perception is that they are not capable of being productive members of society. Rural women with disabilities have a higher risk of being excluded from mainstream development activities and also faced a higher risk of not receiving proper support in times of need (including if neglected, denied care, or otherwise abused). The disability awareness and sensitization sessions proposed for the RSAHP need to include this finding and its consequences.

Additionally, the findings from global reports and studies show that women with disabilities face "double discrimination" since they are more vulnerable than men with disability in all aspects²¹ have also been confirmed by this research in rural Bhutan. Cases such as women and girls with disabilities being abused by their male carers, and lower enrolment of girls in SEN schools were found. This calls for the need to emphasize the gendered dimensions of disability in the RSAHP.

Earlier formative research on the role of rural women on sanitation and hygiene found that rural women in Bhutan were overburdened with WASH related HH labour with the general belief (by both women and men in the rural areas) that HH work was women's domain while the men's tasks was outside the house. The current research saw that this belief and practice

18 http://www.un.org/disabilities/documents/review_of_disability_and_the_mdgs.pdf

19 <http://files.enonline.net/attachments/1514/feeding-difficulties-in-disabled-children-leads-to-malnutrition-experience-in-an-indian-slum.pdf>

20 Khan, NZ, Muslima H, Begum D et al. Validation of Rapid Neurodevelopmental Assessment Instrument for Under-Two-Year-Old Children in Bangladesh. PEDIATRICS Volume 125, No. 4, April 2010

21 <http://wedc.lboro.ac.uk/resources/conference/35/Ahmed-S-1132.pdf>

was no different for rural women with disabilities. Thus, rural women with disabilities faced double burden of living with a disability and being over burdened with WASH related HH labour.

Highlight the varied, factual causes of disability

Since the study discovered a widespread belief that the mothers were solely responsible for disability in their children, it is important that disability awareness and sensitization trainings explore the many factual causes of disability. Trainings should actively seek to overcome traditional beliefs that blame women for children's impairments and in doing so avoid further discrimination towards already stigmatised women/mothers in rural Bhutan.

Disability and its burden on rural women and girls

Women in rural Bhutan are already weighed down with childcare and other HH tasks (RSAHP Gender Study, 2014) and this study found that the task of caring for disabled HH members also fell largely on women. In some instances girls dropped out of school to take care of family members with disabilities. These additional time-consuming responsibilities can have adverse effects on women's health and also limit the time women and girls have for productive, economic and social activities. In addition to the care responsibilities often placed on women in HHs with a PWD, women with physical and also other impairments (e.g. psychosocial, vision) impairments faced additional challenges due to the lack of access to adequate information, materials and facilities for menstrual hygiene management.

Both households with a member with disability and PWDs themselves reported income limitations due to low access to employment for PWDs, extra expenditure (particularly for female PWDs due to menstrual hygiene expenses), and reduced carer (generally female) income potential due to the time requirements of caring for their disabled HH member. Special attention is thus required for gender and gendered-disability inclusion in the RSAHP to help mitigate these issues.



6. Opportunities for improved disability inclusion in the RSAHP

Continue to strengthen the collaboration with DPOs and PWDs

Three DPOs and two PWDs (a female and a male) were part of the research study team and are well versed on the impact disability has on institutional and toilet access, barriers to participation and opportunities to address sanitation and hygiene in Bhutan. Thus, working with them towards making sanitation and hygiene inclusive from a disability perspective makes great sense. The DPOs and PWDs could be engaged during RSAHP stakeholder meetings, in giving feedback on the RSAHP publications and BCC materials, in reviewing RSAHP reports, as a source of feedback and knowledge on how to be more inclusive in the RSAHP, or by engaging them during CDH and other meetings/trainings.

Furthermore, this research uncovered several attitudinal, environmental and institutional barriers that PWDs faced at all levels (central, district, local community). Some of these barriers can be addressed directly by the RSAHP, however, some of the barriers identified – especially the deep-rooted, widespread and multi-layered attitudinal barriers – need strategic partnerships and a response from all relevant stakeholders, including working with the DPOs and change agents from the PWD community itself. The need for multi-stakeholder engagement (from the government, CSOs, DPOs and the community) is thus stressed to ensure that the reduction and eventual removal of the challenges currently faced by PWDs in Bhutan becomes everyone's responsibility.

Build on the enthusiasm and interest created by this research

During this research, programme implementers at all levels acknowledged the importance of disability inclusion and accepted that they have limited knowledge and know-how in this area. Thus, the enthusiasm and interest created by this research is a good opportunity to design and implement disability inclusion activities for the RSAHP.



7. Recommendations for improved disability inclusion in the RSAHP

7.1 Recommendations to overcome attitudinal barriers

Since attitudinal barriers form the basis for institutional and environmental barriers, it is imperative that these barriers are overcome as a priority:

- There is a priority and urgent need to implement disability awareness training based on inclusive approaches in all stakeholder groups, and particularly to challenge the false and damaging beliefs that widely exist about people with disabilities. Duty-bearers and programme implementers should be trained as a first priority given their influence and importance. Training should be based on the principles of the United Nations Convention on the Rights of Persons with Disabilities and take a rights-based approach.²²
- The RSAHP should ensure all activities in all its areas of operation include people with disabilities. This could include developing a relationship with key DPOs and seeking their input in design/implementation, promoting recruitment of people with disabilities, etc.
- If suitable DPOs do not exist in SNV Bhutan's areas of operation, the programme should develop a strategy to work with existing DPOs and possibly other disability organisations (for example CBM or Handicap International) to establish strategies for outreach in those areas.

7.2 Recommendations to overcome environmental barriers

Since toilets and handwashing facilities are currently inaccessible to people with disabilities in rural Bhutan, it is recommended that:

- The RSAHP should source and proactively disseminate accessible toilet and handwashing designs to all key stakeholders – including government and community leaders, schools, masons, and users of facilities.
- All new construction of toilets and public buildings should be designed for disability access. The RSAHP should provide guidance (e.g., use of Accessible Design Guide, reference to some of the many existing resources on inclusive WASH construction), and other steps required to implement this (e.g., training, budgeting). It is also important to note that the additional cost at construction stage is minimal (typically 0.5–3%). Adapting existing inaccessible facilities can typically cost 25% of the original construction budget.
- Consultation meetings for the RSAHP should be held in locations accessible to people with disabilities. The participation of people with disabilities should be sought and facilitated to ensure not only the physical participation of people living with disabilities but broader inclusion in the RSAHP.

7.3 Recommendations to overcome institutional barriers

Since this research found three major institutional barriers – lack of resource allocation, lack of reliable data collection on disability and lack of proactive policies amongst service providers (especially health and education providers) and in communities on how to address access and inclusion needs of people with disabilities, it is recommended that:

Resources must be allocated in order for inclusive measures to progress as both policy and practical decisions by government departments. The RSAHP should allocate budget and time resources to accommodate disability inclusion in its rural sanitation and hygiene work.

²² <http://www.un.org/disabilities>

Commitments and practical action should be made to collect systematic data and monitoring on disability. This can be done by strengthening the collection, analysis and use of the collected disability prevalence data. For example, by including the collection of additional disability information in the existing monitoring systems, such as based on the prevalence data collected at the HH level, monitoring of toilet construction needs to explore whether they are disability accessible, especially if there is a PWDs in that HH.

Duty-bearers and service providers should develop and implement proactive policies (especially health and education) on how to address the access and inclusion needs of people with disabilities.

7.4 Recommendations to address disability-specific issues

- Empowerment work is needed with people with disabilities to inform them of their human rights and address widespread 'internalised oppression'.
- Training on basic toilet training skills and handwashing is also needed for people with disabilities.
- Disabled Peoples' Organisations (DPOs) – representing the breadth of impairment groups (physical, visual, hearing, intellectual, psychosocial) should be consulted and involved in supporting empowerment work for people with disabilities, raising their awareness of their human rights and self-esteem. This will counterbalance the overwhelming internalized oppression this research study found they currently experience. These Organisations may have very low capacity themselves and require capacity-building support from SNV and PHED.

8. Conclusion

The research methods developed for this study yielded a breadth and depth of information about the situation of people with disabilities in rural Bhutan regarding access to and use of sanitation and hygiene facilities and practices. Deep-rooted and widespread multi-layered discrimination, stigma and karmic beliefs prevalent in Bhutan have led to the neglect of people with disabilities, including of their sanitation and hygiene needs and aspirations. These attitudinal challenges have also created 'internalised oppression' and low self-esteem amongst people with disabilities, as witnessed through the research process. The negative and exclusion-oriented attitude towards people with disabilities at all levels impacts the quality of the data collected related to disability. People (both household members and community leaders) were hesitant to report disability cases due to stigma and shame; the health department's disability data at the district level was found to be incomplete, leading to a nationwide lack of reliable data collection on disability. This has contributed to policy makers and decision makers underestimating the prevalence of disability in the country and subsequent inadequate resource allocation. All of these have led to universally inaccessible sanitation and hygiene facilities, be it in the household, community, at BHUs and hospitals, in monastic institutions, or at schools (including SEN schools).

The linkages between gender, disability and poverty have also been established in Bhutan through this research. Women (particularly adult women, mothers and elderly women) were found to be the most impacted in terms of caring responsibility for disability, and women with physical impairments faced additional challenges, due to a lack of access to adequate information and facilities for menstrual hygiene management. Households with a member with a disability and people with disabilities themselves reported financial concerns, with limited access to employment, extra financial expenditure, and limited carer income potential leading to reduced household's income.

The findings were far worse than were anticipated when the study was initially commissioned and highlight the challenges ahead in addressing the multiple barriers and dimensions. A key step will be in overcoming the beliefs held by decision makers that there are no problems faced by people with disabilities in accessing sanitation and hygiene facilities in rural areas. Current arrangements are leading to neglect, ill-health and do not fit the premise of the CRPD that the Government of Bhutan intends to ratify (having signed the Convention in 2010).

The need for practical measures is immediate if we are to change this dire situation where people with disabilities are being denied their human rights to basic sanitation and hygiene facilities. PHED and SNV are committed to implementing these measures, fulfilling both their obligations to DFAT and to fit their values as agencies. Thus, based on the findings from the field and discussions with stakeholders at various levels, the research team has recommended a series of urgent actions for the RSAHP to address the sanitation and hygiene related barriers faced by people with disabilities. These include disability-awareness training based on inclusive approaches for all stakeholder groups, empowerment work with people with disabilities, dissemination of accessible toilet and handwashing designs to all key stakeholders, making RSAHP consultation meetings/workshops and gatherings accessible and inclusive in terms of location and facilitation, allocation of resources for inclusive measures, and the need for commitments and practical action to collect systematic data and monitoring on disability.

Noting the urgent need to reduce and eventually remove the deep-rooted, widespread and multi-layered attitudinal barriers and to overcome the environmental and institutional barriers highlighted by this study, the research team sees that multi-stakeholder engagement and strategic partnerships, especially with DPOs and change agents identified from the PWDs community itself as part of this research process, is highly recommended. The research study team calls on all committed to seeing positive developments in the sanitation and hygiene status of people living in rural Bhutan, to actively ensure they include people with disabilities in their considerations and their work to achieve an inclusive and happy society.

Further reading

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SNV is dedicated to a society where all people enjoy the freedom to pursue their own sustainable development. We contribute to this by strengthening the capacity of local organisations.



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