BESIK

BEE, SANEAMENTU NO IGENE IHA KOMUNIDADE

Disability

and

Rural Water, Sanitation and Hygiene (RWASH)

in Timor Leste

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February 2010

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- The Leprosy Mission Timor Leste (TLMTL);
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- The Public Sector Capacity Development Program (PSCDP) Disability Service Policy;
- Ra'es Hadomi Timor Oan (RHTO), the National Disabled People's Organisation (DPO) of Timor Leste; and
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Thanks also to Bob Reed for facilitating the first WASH and Disability Workshop in Timor Leste. Hazel Jones and Bob Reed are the authors of an essential book *Water and Sanitation for Disabled People and other Vulnerable Groups. Designing services to improve accessibility.* Water, Engineering and Development Centre, Loughborough University, 2005.
http://www.homemods.info/resource/bibliography/water_sanitation_for_disabled_people_and_other_vulnerable_groups

Data was collected by a research team consisting of Maria Gabriela do Santos Soares, Silvia Antonia D.C. Soares, Joaozito dos Santos, Angelo Venceslau, Laurentina Ximenes, Frederica Maria de Fatima, Francisco Ximenes, Vivienne Topp and Natalie Smith.

The photograph on the cover is of Senyora Ursula Maris Johannes of Becora, Dili - a woman living with the effects of polio.

All photographs, videos and case-studies are copyrighted to the agencies involved in compiling this report: RWSSP / BESIK, TLMTL, MSSDU, PSCDP, RHTO / DPO.

This report was written by Natalie Smith and prepared in English for translation to Tetun.

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Executive Summary

Introduction

The Leprosy Mission was contracted by the Rural Water and Sanitation Support Program (RWSSP) to research information available about disability in Timor Leste. This research and the resulting discussion paper has been prepared by a partnership group comprising The Leprosy Mission Timor Leste (TLMTL), the Ministry of Social Solidarity Department of Disability and the Elderly (MSSDU) and the Public Sector Capacity Development Program (PSCDP) Disability Service Policy and members of Ra'es Hadomi Timor Oan (RHTO) the National Disabled People's Organisation (DPO) of Timor Leste.

Objectives

The objectives of the research were as follows:

- To summarise existing disability data in Timor Leste.
- To emphasise that disability is a RWASH issue.
- To highlight the importance of involving people living with disability in RWASH community consultation processes.
- To document the:
  - personal stories of people living with disability
  - issues faced in rural communities as they attempt to access water and sanitation facilities
  - extent to which a range of disabilities exist in every community.
- To enable RWASH stakeholders to reflect on how:
  - people with disability can benefit from and participate in WASH activities at community level
  - the whole community can benefit in a range of ways from their involvement
  - to target people living with disability in the process of planning and implementing RWASH programs
  - to include people with disability as part of RWASH social inclusion strategies.

Findings

Disability means an inability to function in areas where others are able. The impact of a disability is individual and depends upon how the person adapts to their disability and how they function. A disability can influence access to education and employment, relationships, transport and basic activities of daily living - bathing, toileting, cooking, eating, dressing, washing clothes and cleaning. Disability has many social and cultural impacts. People with disability often experience alienation and stigma due to community misunderstanding and fear.

There is very little data existing on disability in Timor Leste, but previous surveys indicate that less than two percent of the population suffer from a disability. Globally, people with disability comprise an estimated ten percent of any population, so it seems that the current figures in Timor Leste are grossly understated. It is hoped that the 2010 population census will reveal more accurately the disability situation in Timor Leste.

Qualitative information was gathered from 15 people with disability, 2 technical experts and one disabled people's group, using semi-structured interviews. Issues raised for RWASH agencies covered a number of areas, primarily being the promotion of inclusive programs, the importance of community and agency education about disability, the necessity for consultation and partnership, the priority of access for all, and understanding about disability hygiene and the importance of water for women.

Recommendations

Inclusive Programs

- Support people with disability's right to be individuals in ways that they define
- The community should make adjustments to include people with disability, remembering that every disability is unique and there is no universal design for disability inclusion
- Agencies need to remember that an accessible environment means access for all

Community and Agency Education

- All existing and new agencies include disability awareness programs in orientation and in-service training
- All existing and new agencies conduct an access audit of their previously implemented RWASH activities and use the results to develop a strategic plan to ensure inclusion for all
- Social inclusion for all should be encouraged by government and good examples published and circulated for agencies to learn from
- People with disability should be invited to participate in planning activities and community developments which affect them or will improve their quality of life
- People with disability can become positive champions for others with disability in their communities
- Agencies need to respect the local knowledge and experience that people with disability already have and use their personal stories, challenges and successes to educate to the community and staff

Consultation and Partnership

- Documentation of the results of partnerships with vulnerable groups is essential
- Communication between agencies and promotion of the benefits of such relationships is necessary
- Promotion of positive examples of inclusive activities in key to encouraging the participation of other agencies in disability inclusion
- Agencies should be commended for good practice and creative disability initiatives

Access for All

- Water and sanitation facilities need to be accessible at all times and *accessible by all*
- Agencies need to remember that accessible infrastructure provides a safer environment for all (including older people, pregnant women, and parents with young children) and helps to reduce accidents
- Agencies must use universal standards when designing water and sanitation facilities
- Agencies must recognise the knowledge and life experience of people with disability and allow them to be the *'disability expert'*
- Inclusion of people with disability requires both input on design and input on social and cultural education, to sensitise the community about the unique needs of people with disability

Disability Hygiene

- Agencies need to remember that people with disability often have greater hygiene needs and need more water
- Agencies must be aware of the stigma and alienation experienced by people with disability and encourage the community to address barriers and take local responsibility to encourage equal access
- Safety of both people with disability and their carers needs to be a priority, and factored into design when water also requires heating
- Observe and discuss daily activities with people affected by disability and ensure that modifications are practical and easy to maintain

Women and Water

- Agencies must consider the specific hygiene needs of **all** women in sanitation and hygiene public awareness campaigns
- Special consideration needs to be given to women with disability and women who are carers for children or adults with disability
- Agencies need to make every effort to ensure safety and privacy for women, who are more vulnerable to harassment, sexual abuse and rape, when accessing water and sanitation facilities
- Agencies must consider the extra water needs of women who have to manage menstruation and sexual hygiene, when planning water and sanitation facilities for communities, as these issues are important to 50% of the community's population

Disability

According to my experience, the community has a perception that people with disability are people who need care; [they believe] it is a pity…they would like to do something to them…they want us to be dependent. They don't give opportunity [for people with disabilities] to participate in any events in community, so they are just hidden behind. They don't understand discrimination….they don't care about ability, just disability In the community the family are sometimes ashamed…

Spokesperson RHTO Interview, National Disability Policy Project

Definition of Disability

Disability is a product of an interaction between characteristics *(e.g., conditions or impairments, functional status, or personal and social qualities)* ***of the individual and characteristics of the natural, built, cultural, and social environments.***

The construct of disability is located on a continuum from enablement to disablement.

Personal characteristics, as well as environmental ones, may be enabling or disabling, and the relative degree fluctuates, depending on condition, time, and setting.

Disability is a contextual variable, dynamic over time and circumstance.

Environments may be physically accessible or inaccessible, culturally inclusive or exclusive, accommodating or unaccommodating, and supportive or unsupportive. [1]

This definition is based on the new framework for disability and health published by the World Health Organization (WHO), the United Nations' public health arm, in 2001. This framework is called the International Classification of Functioning, Disability and Health, known as the ICF. It was further developed by the National Institute for Disability Research and Rehabilitation (NIDRR), and is cited as above in its Long Range Plan (2005-2009).

Impact of Disability

Disability has many social and cultural impacts. People with disability often experience alienation and stigma due to community misunderstanding and fear.

People with disabilities may be shunned, ignored, driven from their communities, imprisoned in rooms or chained to objects to keep them out of sight. They are often forbidden to attend social and cultural functions. In Timor Leste, families seek treatment from traditional healers often in preference to Western medical treatment, which is often unavailable, expensive and treated with scepticism.

[1] National Institute for Disability Research and Rehabilitation (NIDRR), 2005. *Long Range Plan* (2005-2009). http://www.un.org/disabilities/default.asp?id=150

Disability means an inability to function in areas where others are able.

Table 1 Functions and Disabilities

Areas of Function	Resulting Disabilities
Mobility	Inability to walk, run or move like others
Vision	Reduction or loss in vision
Hearing	Reduction or loss in hearing
Communication	Inability to speak or communicate verbally
Feeling sensation	Inability to feel touch sensation or pain
Cognition	Difficulty with or loss of cognitive thinking
Emotional or psychological	Impairment to mental health

A disability can impact directly on access to education and employment, relationships, transport and basic activities of daily living - bathing, toileting, cooking, eating, dressing, washing clothes, cleaning, etc

Disability may also be:

- life-long or temporary
- the result of a natural process (eg. pregnancy)
- due to a chronic illness (eg. diabetes or leprosy)
- gradual (eg. occur with age)
- be transient (eg. mental health crisis or reactive depression) or
- dependent on the weather (eg. arthritis in winter).

Thus the number of people with disability in a community is variable

The impact of a disability is individual and depends upon how the person adapts to their disability and how they function. When assisting a person with a disability, it is important to ***ask them how their disability prevents them from functioning in any area of life***. The challenge is then to assist them to enable them to function in a way that is as independent and dignified as possible.

Global Disability

Globally, at least 10% of people live with a disability on a daily basis. [2] The UN Development Program estimates that 80% of people with disability live in the developing countries. Two thirds of this population are found in the Pacific and Asia [3] and the World Bank estimates that 20% of the poorest of the poor have a disability. [4] Children make up a third of the people with disability, and two thirds of these have preventable impairments. Women and children with disability often face the greatest barriers. [5] These percentages are likely to increase due to factors like poverty, conflict, population growth, malnutrition, HIV/AIDS, lifestyle diseases (eg. diabetes), traffic accidents, injuries, natural disasters, ageing and medical advances that preserve and prolong life. [6]

With up to one in five of the world's poorest having a disability, [7] the relationship between disability and poverty is strong and complex. Disability is both a cause and consequence of poverty. [8] The circumstances experienced by people with disability also impact on their families and communities. Disability reduces opportunities and access to education, employment and resources. There is a higher risk that poor people without disability will be affected by disability, because they lack the resources to access good nutrition, clean environments, disease prevention, and health services. [9] Untreated diseases (eg. treatable eye infections like trachoma), non-communicable and chronic diseases (eg. cardiovascular diseases, diabetes and cancer) are now affecting increasing numbers of people in developing countries, resulting in a double burden of physical and functional disability. [10]

Disability is about people and their social relationships. It is about the response by the community to people with disability in their environment. People with disability are not only the most deprived in the developing world, they are also the most neglected. The extent of mental illness is largely unknown because of the stigma and shame and lack of available accessible services. However, because of a combination of the above factors and high levels of trauma and abuse experienced particularly by woman, the conservative estimate of 1 in 5 having some form of psychological disorder that is applied in the Western world, ought to be accepted in developing countries as well. [11]

[2] United Nations (UN), 2008 Mainstreaming disability in the development agenda (E/CN.5/2008/6), www.un.org/disabilities/documents/reports/e-cn5-2008-6.doc

[3] Asian Development Bank (ADB), 2005. Disability Brief: Identifying and Addressing the needs of Disabled People www.adb.org/Documents/Reports/Disabled-People-Development/disability-brief.pdf

[4] Elwan A, 1999. Poverty and Disability; A background paper for the World Development Report. World Bank

[5] Asian Development Bank (ADB), 2005. Disability Brief: Identifying and Addressing the needs of Disabled People www.adb.org/Documents/Reports/Disabled-People-Development/disability-brief.pdf

[6] Thomas, P. 2005. Disability, Poverty and the Millennium Development Goals: Relevance, challenges and opportunities for the United Kingdom Department for International Development www.addc.org.au/disabilitypoverty.html

[7] Mont, D., 2007. Measuring Disability Prevalence *http://siteresources.worldbank.org/DISABILITY/Resources/Data/MontPrevalence.pdf*

[8] Department for International Development (DFID), 2000 *Disability, poverty and development* *www.dfid.gov.uk/pubs/files/disability.pdf*

[9] World Bank (WB), 2007. *Social Analysis and Disability: A Guidance Note. Incorporating Disability-Inclusive Development into Bank-Supported Projects.* Social Development Department in Partnership with the Human Development Network's Social Protection, Disability and Development Team.

[10] World Health Organisation (WHO), 2005. *Disability, including prevention, management and rehabilitation.* World Health Assembly Resolution 58:23, May 25. World Health Organisation, Geneva, Switzerland. http://www.who.int/disabilities/WHA5823_resolution_en.pdf

[11] Topp, V. 2010. Unpublished Draft *National Disability Policy for Timor Leste*

Disability in Timor Leste

Little is known of disability figures in Timor Leste before 2002. Since then two surveys have been conducted to provide some information more current information on disability figures. The findings are as follows:

Ministry of Social Solidarity National Disability Survey, 2002

A National Disability Survey was conducted in Timor Leste in 2002. The table below is the summary data table from the Ministry of Social Solidarity. However, neither the raw data nor the final report with details of methodology were available, making comparison and analysis of this information difficult (Plan, 2008).

Table 2: People with Disability in Timor Leste, 2002

District	Number with Disability	Sex		Type and Number with Disability					
		M	F	Physical	Blind	Mute	Mentally ill	Chronic	Multiple
Aileu	853	558	295	402	157	149	120	4	21
Ainaro	799	484	315	302	178	149	128	-	42
Baucau	1610	983	627	626	381	272	219	25	87
Bobonaro	1627	1021	606	656	382	344	148	10	87
Covalima	827	528	299	326	243	142	76	2	38
Dili	1022	628	394	475	186	152	144	8	57
Ermera	1663	1079	584	734	331	247	246	7	86
Liquica	360	217	143	187	78	36	45	-	14
Lautem	756	466	290	370	176	108	71	-	31
Manufahi	811	532	279	380	183	128	93	2	25
Manatutu	655	372	283	275	168	105	70	8	29
Oecussi	1343	799	544	385	376	311	85	131	55
Viqueque	631	419	212	259	205	98	42	4	23
Total	**12,957**	**8,086**	**4,871**	**5,377**	**3,044**	**2,241**	**1,487**	**201**	**595**

Data provided by the Ministry of Social Solidarity, 2002

In 2001, the population of Timor Leste was estimated at 787,342. Using the total of 12,957 people with disabilities found in the 2002 disability data, this means 1.65 percent of the population had a disability. The 2004 Timor Leste Census of Population and Housing reported that 29,365 or 15 percent of private households were affected by disability.

Plan Timor Leste's National Survey of Disability in Timor-Leste's Primary Schools, 2008

In 2008, the First National Survey of Disability in Timor-Leste's Primary Schools was conducted by Plan Timor-Leste, the Ministry of Education and Assert Rehabilitation Centre. The survey was conducted in 336 primary schools across Timor-Leste to determine how many students have a disability and the type and severity of that disability (Plan, 2008). Below is a summary of the key findings of the survey. However, given that the methodology was not clear and the raw data was not available, comparison and analysis of this information is difficult.

Key Findings:

1. *Nationally, there are approximately 2000 primary school students, or 1 in every 100 students with a disability in Timor Leste.*

2. *On average, each primary school can expect to have 3 students (3%) with a disability. Even small, remote schools are likely to have at least one student with a disability.*

Table 3: Summarised Results of Plan Survey, 2008

District	Total Schools 2006	Schools Surveyed 2008	Primary Population 2006	Students Surveyed 2008	Average School Size (range)	Students with a disability in 2008
Aileu	62	29	8,728	5,893	203 (45 - 664)	69
Ainaro	64	27	11,134	7,114	263 (42 - 600)	118
Baucau	135	27	18,618	7,626	282 (26 -1450)	74
Bobonaro	121	26	17,160	6,793	261 (92 - 728)	85
Covalima	79	26	9,520	5,833	224 (99 - 479)	95
Dili	73	40	20,824	20,403	503 (20 - 1305)	90 – Inaccurate data
Ermera	89	19	17,877	5,661	298 (55 - 908)	58
Liquica	50	24	11,111	7,089	295 (31 - 597)	92
Lautem	76	27	12,815	6,839	253 (31 - 597)	65
Manufahi	62	28	9,182	6,992	250 (105 - 554)	70
Manatutu	48	28	7,826	5,644	202 (46 - 464)	70
Oecussi	46	8	8,741	2,673	334 (155 - 500)	Incomplete data
Viqueque	86	27	16,121	7,163	265 (68 - 503)	85
Total	**991**	**336**	**169,657**	**95,723**	**285 (20 - 1450)**	**972**

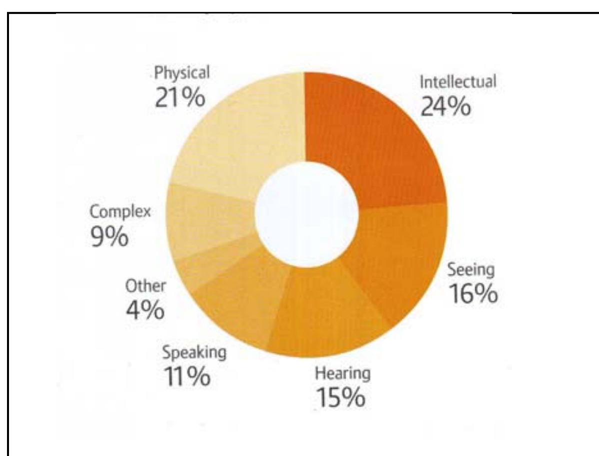
Data provided by Plan Timor-Leste's *Report on the First National Survey of Disability in Timor Leste's Primary Schools, 2008*

3. *The most common disability type is intellectual (24%), followed by physical (21%).*

4. *Almost half (41%) of all disabled students enrolled were older than they should be for their age.*

5. *One third (33%) of all disabled students had a moderate or server disability.*

Chart 1: Primary School Students with Disability (% Disability Type)



Data provided by Plan, 2008.

6. *There are more boys with a disability (64%) than girls with a disability (36%) attending primary school.*

Table 4: Gender of Disabled Students Surveyed by Plan, 2008

Disability / Sex	Boys	Girls	Total
Physical	127	73	200
Intellectual	162	74	236
Seeing	80	74	154
Hearing	95	51	146
Speaking	70	39	109
Other	26	10	36
Complex	67	24	91
Total	**627**	**345**	**972**

All data was obtained from Plan Timor-Leste's *Report on the First National Survey of Disability in Timor Leste's Primary Schools, 2008.*

7. *There is only one special school in the country (Taibesse Special School) which had 13 students enrolled in 2008.*

8. *Global estimates of disability indicate that 10% of the population have disability, but in Timor Leste only 1% of those currently in school have a disability. It is easy to conclude that many children with disabilities are not in school. Many are never enrolled in school and others drop out after only a few years due to difficulties associated with their disability.*

Given that many children without obvious disability reach the end of their primary education with few literacy and numeracy skills, there may be many more children who have developmental disabilities.

Timor Leste National Population Census, 2010

The Population Census - April 2010 will include following disability categories:

- walking
- seeing, reading
- hearing
- intellectual / mental condition

Measurement of extent of disability will be made as levels of difficulty:

1. No-no difficulty
2. Yes-some difficulty
3. Yes a lot of difficulty
4. Yes cannot do at all

The following causes for disability will be asked:

- congenital / at birth
- short term health condition (< 6 months)
- long term health condition
- conflict
- transport accident
- occupational injury
- other accident
- age
- other

It is hoped that this data will inform agencies in Timor Leste of the reality of the disability situation in Timor Leste and assist with the planning of future programs.

WASH and Disability Training in Australia
Report from the 7 Trainees from Timor Leste

In September 2008, 8 employees from water and sanitation agencies in Timor Leste applied on line to attend a CBM - Nossal Institute Partnership course on Disability Inclusion in WASH programs, funded by AusAID and organised in Melbourne, Australia. In March 2009, they met with Plan International (Australia) to discuss the details. Seven trainees attended for 7 weeks during September and October 2009. Only one trainee is a woman. The trainees completed the course with a certificate in WASH and Disability Inclusion.

The trainees attended from 7 organisations which included:

- ASSERT Physical Rehabilitation Centre
- Naroman Timor Foun (NTF)
- Fraterna
- Klibur Aleizadus Timor Loro-sa'e (KATILOSA)
- Plan
- WaterAid
- Oxfam

The course topics included:

- Disability in Developing Countries
- Advocacy for People with Disability to Agencies and the Government
- Inclusive Education
- CBR Programs
- Environment and Accessibility
- Types of Water and Sanitation Installations
- Disability Access
- Access for the Elderly
- Access for Pregnant Women
- Inclusive Program Planning
- Visits to other agencies including:
  - Engineers without Borders
  - Water Aid Australia
  - Plan Australia
  - Caritas
  - People with Disability Organisations

Since they returned to Timor Leste, only a few of the trainees has had the opportunity to implement the skills and the lessons learnt from the course. She is working with an organisation that has assisted 3 people with disabilities and has 2 more people to assist. The same trainee has given a presentation to their staff of 12 people, to inform them about the need to include people with disabilities in their water and sanitation programs. Nevertheless, all trainees are keen to disseminate their knowledge and implement many of the things they learnt, and are frustrated by the lack of opportunity to do so.

Disability and RWASH in Timor Leste

Table 5 National and International Disability and RWASH Agencies

No	National NGOs	Year Started	Any Disability Focus? Yes / No	Aust. Course Trainee	Districts for Disability Implementation	Focal Areas										Districts of Timor Leste													Funding Organisations / Donors																																								
						Agriculture	Capacity Building	CLTS	Community / Rural Development	Health Promotion / Education	Livelihood	Nutrition	Social & Psychosocial	Sanitation	Water Supply	Aileu	Ainaro	Baucau	Bobonaro	Covalima	Dili	Ermera	Liquica	Lautem	Manufahi	Manatutu	Oecussi	Viqueque	ADB-PMU	AusAID	Aust Care	British Embassy	CARE Int.	CEP-WB	CFET	CIDA	Columbia University	CVTL	CWSSP	DAP	DNSAS	ECHO	ENI	ETCAS	FAO	Finland Aid	GTZ	Health Alliance Int.	IOM	Irish Aid	ISF	JICA	NSAID	NZAID	Oxfam	Plan Int.	RWSSP	The Leprosy Mission Int.	Timor Children's Fund	UNDESA	UNICEF	UNMIT	USAID	Water Aid Aust.	WVI
1	AMAR	2004	No											√	√						√	√															√					√													√								√				
2	Amizade	2001	No											√	√				√																						√																		√								
3	ASSERT Rehabilitation		Yes	Yes - 7 weeks	Dili / All									√								√																																													
4	Bia Hula	1997	No											√	√	√			√		√	√	√																		√							√										√	√							√	
5	Central Haburas	1999	No											√	√						√																		√																												
6	CLOTIHAFU	2003	Yes		Bobonaro									√	√				√																						√					√																					
7	Corea-Erc	2001	Yes		Aileu									√	√	√							√																																													
8	ETADEP	1987	No			√								√	√				√		√	√	√			√											√			√																			√								
9	East Timor Blind Union		Yes		All		v		v	v			v			√	√	√	√	√	v	√	√	√	√	√	√	√																																					
10	FOLSETIL	1999	No											√	√						√		√												√																						√				√				
11	FRATERNA		Yes	Yes - 7 weeks										√	√									√																																										
12	FSHF	2007	No											√	√				√		√																				√																		√								
13	Fundasaun Lafaek Diak	2005	Yes		Baucau					√				√	√				√						√				√																																					
14	Fundasaun Moris Hamutuk	2002	No											√	√				√																						√																									
15	Habura Moris	2005	No			√				√		√		√	√				√													√		√											√	√		√							√									√		
16	Haksolok	2004	No											√	√				√																√			√																					√				
17	HealthNet TL	2006	Yes							√						√	√	√	√	√	√	√	√	√	√	√	√	√																						√							√	√			√		√				√
18	HIM	2004	No											√	√						√	√													√					√													√								√				
19	HTL	2000	Yes											√	√	√				√	√		√		√				√							√			√																	√								√	
20	KALISE	2002	No											√	√													√													√	√									√	√												√			
21	KATILOSA		Yes	Yes - 7 weeks	Baucau									√	√				√																																															
22	Klibur Domin		Yes		Liquica		√		√	√			√																																																				
23	Lia Lulik		No											√	√					√																																														
24	Naroman Timor Foun (NTF)	2003	Yes	Yes - 7 weeks	Liquica, Manufahi, Aileu, Ainaro, Oecussi									√	√	√	√						√		√		√						√	√			√	√													√						√				√	√			√	
25	Natiles	2003	No											√	√	√	√				√				√												√														√		√					√				√				
27	Soha Fitun		No																			√																√																	√												
28	Servbfutilos	2003	No											√	√				√		√		√		√									√					√																					√				
29	Ra'es Hadomi Timor Oan (RHTO)	2006	No		Dili / All		√			√			√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√																																					
	International NGOs																																																																
1	Timor Aid	1999	Yes		Dili, Covalima, Oecussi		√		√	√	√			√	√					√	√						√																																							
2	Water Aid	2005	Yes	Yes - 7 weeks	Liquica, Ermera			√						√	√						√	√	√																																											
4	CVTL		No											√	√																																																	
5	World Vision	1999	No											√	√	√		√	√		√	√																																													
6	Plan Timor Leste	2001	Yes	Yes - 7 weeks	Aliue, Lautem									√	√	√					√			√							√												√	√														√								
7	Triangle	20005	No						√				√	√	√											√																	√																	√				
8	Anteater	2003	No													√	√	√	√	√	√	√	√	√	√	√	√	√																						√								√				
9	Oxfam	1999	Yes	Yes - 7 weeks					√		√		√	√	√					√	√						√																																							
10	The Leprosy Mission Timor Leste	2002	Yes	Yes - 2 days	Dili, Oecussi, Baucau, Manatutu, Viqueque, Suai		√		√	√	√		√	√																√																												√						
11	CARE Int.		Yes	Yes - 2 days	Liquica, Bobonaro				√	√				√	√																																																	

Disability Issues related to RWASH

Methodology for Data Collection

Interviewees for this research were identified by the National Disability Policy Project (NDPP) and RHTO, the National Disabled People's Organisation. All interviewees participated in group discussions for people with disability, which were held by the NDPP and RHTO throughout the districts and in Dili.

The information in the following sections was then gathered, using semi-structured interviews with those who identified water, hygiene and sanitation as key policy considerations. It is a purposeful sample, utilising first person interviews, experiences and photographs. Verbal consent was given by all participants, however the interviews have been de-identified and photographs used only when the researchers were fully satisfied that the interviewee provided informed consent.

The following table provides some basic information about the people interviewed.

Table 6 People Interviewed regarding Disability and RWASH issues

No	Interviewed	District	Sex	Age	Disability	Remarks
	Technical Experts					
1	Ms E	Dili	Female	45	**No**	Teacher who works with children with disabilities in a segregated facility
2	Ms N	Dili	Female	36	**No**	Midwife who works for an NGO as a sexual health counsellor, primarily for women
	Disabled People's Group					
3	Oesilo Disabled People's Group	Oecussi	Mostly Males	Adults	**Yes** Mental illness, visual impairment, leprosy related disability	Some represented by non-disabled family members
	People with Disabilities					
4	Mr V	Balibo, Bobonaro	Male	70	**Yes** Mental illness, immobile	Lived in isolation since 1975, has not move from bed since then
5	Mr S	Maliana, Bobonaro	Male	14	**Yes** Cerebral Palsy, no mobility	Cared for by grandmother, lives with disabled sibling (below)
6	Ms R	Maliana, Bobonaro	Female	12	**Yes** Cerebral Palsy, crawls	Cared for by grandmother
7	Mr P	Maliana, Bobonaro	Male	53	**Yes** Mental illness	Lives with mother and relatives
8	Mr M	Atauro, Dili	Male	51	**Yes** Mental illness	Lived with family, 6 months in jail with no criminal charges, for long periods locked up, tied to the bed
9	Ms S	Dili	Female	26	**Yes** Polio in both legs, uses a walking stick	Lives with family
10	Mr A	Dili	Male	29	**Yes** Intellectual disability	Lives with mother and siblings

No	Interviewed	District	Sex	Age	Disability	Remarks
11	Ms U	Becora, Dili	Female	35	**Yes** Polio in both legs, walks with a stick	Married, mother of 7 living children
12	Ms J	Maubara, Liquica	Female	28	**Yes** TB of Spine paralysing both legs, uses a wheelchair	Cared for by 11 year old daughter
13	Mr A	Tibar, Liquica	Male	55	**Yes** Below knee amputation of right leg due to gunshot wound, and stroke of right side – arm and leg, walks with artificial limb	Lives with wife and children
14	Ms C	Manatutu	Female	27	Yes Polio in both legs, uses a wheelchair	Lives with family
15	Mr M	Manatutu	Male	40	**Yes** Cerebral palsy, uses a wheelchair	Almost totally dependent on others for his care
16	Ms A	Manatutu	Female	22	**Yes** Cerebral palsy, uses a wheelchair	Totally dependent on others for his care
17	Mr G	Manatutu	Male	42	**Yes** Cerebral palsy, uses a wheelchair	Almost totally dependent on others for his care
18	Mr A	Manatutu	Male	3	**Yes** Cerebral palsy, uses a wheelchair	Almost totally dependent on others for his care
19	Mr S	Oecussi	Male	45	**Yes** Spinal cord injury paralysing both legs, uses a wheelchair	Lives with wife and 3 children
20	Mr B	Oecussi	Male	40	**Yes** Polio in both legs, uses crutches and wheelchair	Lives with wife and 2 children

Included, not Mainstreamed

The 1970's embraced the theory of normalisation and mainstreaming. At the time it was believed that people with disability must behave as so called 'normal' [12] people in order to be accepted. The theory expected people with disability to adjust in order to fit in.

The contemporary human rights approach supports people with disability as a diverse group with the right to be individuals with inherent self worth and to be supported in ways that they define. It asks the non-disability community to make adjustments to include people with disability.

> *Disability is a human rights issue! I repeat: disability is a human rights issue. Those of us who have a disability are fed up being treated by the society and our fellow citizens as if we did not exist or as if we were aliens from out of space. We are human beings with equal needs, claiming equal rights ….*
>
> *Bengt Lindqvist, special Rapporteur on Disability* [13]

[12] Wolfensberger W, 1991 *A brief introduction to social role valorization as a high-order concept fro structuring human services. Syracuse, NY. Training Institute for Change Agentry (Syracuse University)*

Every disability is unique and there is no universal design for disability inclusion. However there are some excellent inclusive design principles that can assist builders, architects and engineers to ensure that the built environment is accessible to all people.[14]
We do not need data on people with disability to prove when adjustment for inclusion is required. An accessible environment means access for all, is simply good design and achieves improved and equitable outcomes for all - women, men, girls and boys, elderly people, people with disability, pregnant women, people with an injury, people with cognitive impairment, and people with mental illness.

Recommendations:

- Support people with disability's right to be individuals in ways that they define

- The community should make adjustments to include people with disability, remembering that every disability is unique and there is no universal design for disability inclusion.

- Agencies must remember that an accessible environment means access for all

Community and Agency Education

People with disability are largely invisible in Timor Leste. The NDPP in 2009 conducted district visits and observed a few people with disability participating in daily village activities. The people interviewed were often known to exist by the Suco chief or the administrator, but they knew no more than where the person lived. The project visited many of these families and found that they lived isolated lives and seldom ventured from the family home. Invisibility means that the normal legal protections to ensure that people are safe and free from abuse and harm are not applied. It means that they are not included in civil society plans and that the barriers to their participation are not considered.

Vulnerable groups such as women, children, the elderly, people with disability, people with leprosy and people with mental illness are often excluded due to their limited voice, different levels of function and reduced decision making power. Relief and development agencies are largely unaware or unwilling to address the need to include such groups in their programs.

It is not that they don't care but just that they didn't think to include people with disabilities.
Bob Reed 20 Feb 2010

Agencies are advised to have a Disability Inclusion and Access Strategy that will guide their programs in being disability inclusive. This will increase the agency's responsibility and commitment to upholding the UN Convention on the Rights of Persons with Disability. A good example is the Australian Government's *Disability for All. Towards a disability-inclusive Australian aid program 2009-2014.* Agencies should also be responsible for implementing the corresponding disability awareness education and disability inclusive training that will be required for their staff and the communities in which they work. Practical solutions can be found when people with disabilities are invited to participate in the planning of any activities in their communities. They then take on the role of educators.

Recommendations:

- All existing and new agencies include disability awareness programs in orientation and in-service training

- All existing and new agencies conduct an access audit of their previously implemented RWASH activities and use the results to develop a strategic plan to ensure inclusion for all

[13] United Nations Commission for Social Development, 2000. 19th *Congress of Rehabilitation International, Rio de Janero.*
[14] Australian Standards for Access No 1428 http://www.standards.org.au/result.asp

Recommendations cont.

- Social inclusion for all should be encouraged by government and good examples published and circulated for agencies to learn from

- People with disability should be invited to participate in planning activities and community developments which affect them or will improve their quality of life

- People with disability can become positive champions for others with disability in their communities

- Agencies need to respect the local knowledge and experience that people with disability already have and use their personal stories, challenges and successes to educate to the community and staff

Consultation and Partnership

"*Nothing about us without us*" is the mandate of Disabled People's Organisations (DPO's) around the world. This request is also supported by the UN Convention on the Rights of Persons with Disabilities which was adopted on 13 December 2006 and had the highest number of signatories in history to a UN Convention on its opening day. The Convention entered into force on 3rd May 2008. [15]

The Convention marks a major shift in attitude and approach to people with disability from recipients of charity, medical treatment and social protection towards people with rights the same as everyone else. The Convention provides an instrument which allows people with disability to claim those rights and make decisions for their lives based on their free and informed consent, as well as being active participants in their communities. [16]

Timor Leste is not a signatory to the UN Convention on the Rights of Persons with Disabilities however many of its principles, for inclusion of people with disability, are strongly imbedded in the Constitution. [17] Timor Leste has signed and ratified other significant Conventions which include consideration of the rights of people with disability. [18]

The Prime Minister, His Excellency Mr Kay Rala Xanana Gusmau and Nelson da Silva Reading the Rights of People with Disabilities.

In the absence of this commitment from the government of Timor Leste, citizens with disability - members of RHTO - prepared and submitted a Charter of Rights which reflects the Convention's key principles. This Charter was accepted and announced by the PM and Minister of Social Solidarity on 28 December 2009.

Partnerships with people with disability should be developed. Members of the Timor Leste DPO and the

[15] United Nations (UN), 2006 *Convention on the Rights of Persons with Disabilities: Article 9* www.un.org/disabilities/convention/conventionfull.shtml

[16] The Convention is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorization of persons with disability and reaffirms that all persons with all types of disability must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disability and identifies areas where adaptations have to be made for persons with disability to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced http://www.un.org/disabilities/default.asp?id=150

[17] As stated in Section 16 of the Constitution of the Democratic republic of East Timor: *All citizens are equal before the law, shall exercise the same rights and shall be subject to the same duties. No one shall be discriminated against on grounds of….physical or mental condition.* www.constitution.org/cons/east_timor/constitution-eng.htm

[18] Convention on the Rights of the Child and the Convention on the Elimination of All Forms of Discrimination against Women, both which incorporate Articles which address special protections for children and women with disability towards social inclusion and enjoyment of life on an equal basis to all other people.

Disability Working Group (DWG) is available as experts, advisors and facilitators. They can work with the communities and project staff in the districts to ensure equitable representation and participation of the most vulnerable groups (elderly, widowed, the disabled, pregnant women, children and the mentally ill) to facilitate inclusion in all aspects of planning, implementation and management of program activities. People with disability are also available to be employed as disability advisors or consultants to conduct audits or evaluations of the work that agencies are doing in the disability arena.

In this way, people with disability who may have previously been denied educational and employment opportunities, are also given the chance to learn and develop as individuals in their own right.

Recommendations:

- Documentation of the results of partnerships with vulnerable groups is essential

- Communication between agencies and promotion of the benefits of such relationships is necessary

- Promotion of positive examples of inclusive activities in key to encouraging the participation of other agencies in disability inclusion

- Agencies should be commended for good practice and creative disability initiatives

Access for All

Access is probably the most important issue for people with disability trying to reach water and sanitation facilities. However ease of access must always be considered for all people. A steep gradient, uneven surface, slimy slippery rocks, unstable steps, stiff pumps, high taps etc all need to be considered by design engineers. RWASH programs for water and sanitation facilities need to be accessible at all times and ***accessible by all*** (including people with disability).

Water engineers need to consider the "*needs of those most restricted*" (eg. someone wheelchair-bound) or those socially restricted - isolated, shunned and avoided - like people with leprosy or mental illness – in the design of **any** type of water or sanitation facility. This will generally mean that all other community needs are considered.

An accessible, barrier-free built environment which accommodates the needs of people with disability in urban and rural areas is critical for ensuring people with disability can enjoy their right to participate in all areas of community life. [19] Accessible infrastructure also provides a safer environment for all (including older people, pregnant women, and parents with young children) and it helps reduce accidents. [20] It is also much more cost effective to plan from the outset to make services inclusive for disabled people, than to provide 'special' services which only a small minority benefit from. [21]

Accessible infrastructure requires development and implementation of appropriate standards and guidelines for accessible buildings and facilities, incorporation of inclusive design at planning stages, construction that complies with standards, and training and awareness-raising for stakeholders. [22] Guidelines for inclusive, disability access standards are readily available. Universal standards for disability access (eg. the Australian Access Standards Manual) [23] and the SPHERE standards [24] are

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[19] World Bank (WB), 2008 *Accessibility* http://go.worldbank.org/MQUMJCL1W1
[20] Australian Government (Aus Govt), 2009 *Development for All. Towards a disability-inclusive Australian aid program 2009-2014 http://www.ausaid.gov.au/keyaid/pdf/draft_disability_strategy_09to14.pdf*
[21] WELL, 2005 *Why should the water and sanitation sector consider disabled people?* Briefing Note12.
[22] United Nations (UN), 2006 *Convention on the Rights of Persons with Disabilities: Article 9*
www.un.org/disabilities/convention/conventionfull.shtml
[23] Australian Access Standards
[24] SPHERE, http://www.sphereproject.org/component/option,com_docman/task,cat_view/gid,17/Itemid,203/lang,english/

widely applied. Ideas for disability equipment are found in Disabled Village Children [25] or in Water and Sanitation for Disabled People and other Vulnerable Groups. [26]

A non-wheelchair accessible tank stand used at a water and sanitation training unit in Tibar.

Non-wheelchair accessible taps

Agencies must recognise the knowledge and life experience of people with disability. The person affected by disability is the '*disability expert'*. People with disability and other vulnerable groups must be consulted in regard to accessibility of the proposed facilities they are to use. They need to be given the opportunity to advise and instruct on any specific modifications are required, for them to be able to use the facilities independently (especially if the facility is located within their house or compound and for their and their families personal use).

A warning on *Access for All* - people with no disability do not always understand the needs of people with disability and can resent the special access compensations that are given to them. A custom-built latrine for a person with disability is accessible to all and able to be used (and abused) by people with no disability. The person with a disability can be socially deprived from using what was designed for their specific purpose.

Agencies should not assume that once a facility is custom built, all access problems will be solved. Inclusion of people with disability requires not only input on design, but also input on social and cultural education to sensitise the community about the need for such modifications and the unique attention given to people with disability. The role of disability awareness and education is crucial. Furthermore, and wherever possible, aids and equipment should be incorporated into the design of the facility. Any additional structures or mechanical devices may not be maintained and will quickly become an annoyance to others. Retrospective fitting of aids and adaptions does often not work.

Recommendations:

- Water and sanitation facilities need to be accessible at all times and *accessible by all*

- Agencies need to remember that accessible infrastructure provides a safer environment for all (including older people, pregnant women, and parents with young children) and helps to reduce accidents

- Agencies must use universal standards when designing water and sanitation facilities

- Agencies must recognise the knowledge and life experience of people with disability and allow them to be the *'disability expert'*

- Inclusion of people with disability requires both input on design and input on social and cultural education, to sensitise the community about the unique needs of people with disability

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[25] Werner, D., 1987 *Disabled Village Children.* A guide for community health workers, rehabilitation workers and families. The Hesperian Foundation, California, USA.
[26] Jones & Reed, 2005 *Water and Sanitation for disabled people and other vulnerable groups. Designing services to improve accessibility.* WEDC, Loughborough University

Disability Hygiene

People with disability often have greater hygiene needs and need more water than people with no disability because they are exposed to dirt more often due to frequent falling, crawling, sweating and using hands for support during defecation. They also may need to use latrines more or less frequently than others, depending on their disability and if they are wheelchair-bound and stay seated for long hours. Open defecation is tiring, lacks privacy and can be dangerous due to falls or reduced personal safety because of sexual harassment. [27]

People who use a wheelchair for mobility can develop pressure sores from being seated for too long. They can also develop skin complaints and rashes because they are either unable to clean themselves adequately, or their carers are unable to clean them properly. Some people with disability or chronic illness are incontinent, and have to use continence aids. This means they may be reliant on others to assist them, and this may not occur straight away, leaving the person with disability sitting or lying in excrement. This can also lead to skin breakdown, infection and ulcers.

Other people with disability have altered body temperature regulating mechanisms, and often feel cold when others do not notice any change in temperature. Frail children with poor mobility feel cold, particularly in the rain. This means that bathing with cold water can be uncomfortable and even dangerous to their health. The additional effort required by this person to warm water to wash, may place them at risk if they are required to carry hot water while attempting to move with their disability (eg. if the person is blind, walks with a stick or moves with a wheelchair). If their carer has to warm water, there is the risk of the water being too hot and having the potential to burn the person being cared for, or if the carer is under-age (eg. an eleven year-old child caring for a bed-ridden sole-parent) there is also potential danger managing the risks involved in making the water hot.

All these issues must be considered by agencies, which need to take time to understand the implications of a particular person's disability. It involves astute observation and good communication. It is crucial that daily activities are observed and discussed with the person affected by disability and their family and carers. Modifications may be required to compensate for some of the complications involved in the management of the person's disability or medical condition, but they must be practical and easy to maintain.

Recommendations:

- Agencies need to remember that people with disability often have greater hygiene needs and need more water

- Agencies must be aware of the stigma and alienation experienced by people with disability and encourage the community to address barriers and take local responsibility to encourage equal access

- Safety of both people with disability and their carers needs to be a priority, and factored into design when water also requires heating

- Observe and discuss daily activities with people affected by disability and ensure that modifications are practical and easy to maintain.

Women and Water

Women with disability and women who are carers for children or adults with disability have unique needs and require special consideration. Women who are the primary carers in families who provide care for the disabled or elderly, have demanding and time consuming role, and access to sufficient water is essential.

[27] Water Aid, Ethiopia. Guidelines for WAE and Partners. 2007

Women and children with disability can be disadvantaged by the social structure of their community. If the community is restrictive (eg. follows Islam), there are only certain activities that involve women. Women who are not able to fetch their own water due to fear of reprisal or reliance on men, may often live with shortages or delays in access to adequate water. This becomes an even greater problem for women with disability.

Personal safety and privacy when fetching water or bathing in public facilities is also a significant concern for most women. When women are required to trek kilometres to collect water from a river or other isolated water source, they are vulnerable to harassment, sexual abuse and rape. This is even more of a concern for women with disability, who are devalued and more vulnerable to abuse. Woman with disability may not be able to run away quickly or have someone to run too, and are less able to defend themselves, while they look for private places to go to the toilet. They seldom report abuse because of fear of reprisal. [28]

All women (with or without disability) have the additional concerns of managing a menstrual cycle, and if sexually active – managing sexual hygiene. In Timor Leste, there is a tradition that when menstruating, a woman should not wash for 3 days, and when they do, they must use hot water. [29] Without sufficient water for cleaning during such times, women are prone to catching or developing infections. For women with disability, this management is even more complex and difficult, and may even require assistance from a carer, who also needs to be concerned about their own cleanliness whilst caring for another.

In Timor Leste, there are taboos that prevent women from speaking about menstruation, sexual activities, domestic and sexual violence and incest. Young woman are not educated and empowered to say '*No*' to unwanted sexual advances from men. It is even more difficult for women with disability to assert this right. These taboos make it difficult for agencies to address such issues, especially if they do not have any female staff or have not spent time developing rapport and gaining the trust of the women and men in the communities. Agencies need to be aware of such intricacies when planning water and sanitation facilities for communities, as these issues are important to 50% of the community's population. [30]

Recommendations:

- Agencies must consider the specific hygiene needs of **all** women in sanitation and hygiene public awareness campaigns

Special consideration needs to be given to women with disability and women who are carers for children or adults with disability

- Agencies need to make every effort to ensure safety and privacy for women, who are more vulnerable to harassment, sexual abuse and rape, when accessing water and sanitation facilities

- Agencies must consider the extra water needs of women who have to manage menstruation and sexual hygiene, when planning water and sanitation facilities for communities, as these issues are important to 50% of the community's population

A typical water cart used for carrying small jerry-cans of water in rural areas.

[28] WaterAid, UK. Wider Impacts of water, sanitation and hygiene education projects. February 2006.
[29] Interview with Ms N, Midwife and sexual health counsellor, February 2010.
[30] Interview with Ms N, Midwife and sexual health counsellor, February 2010

Case Studies of People with Disabilities Accessing Water and Sanitation

Ms U, Dili

……..Sometimes I experience discrimination. When I am visited by ASSERT and foreigners, my neighbours believe they have given me money. Then they increase the electricity cost to my house, because they believe we have been given more money. Sometimes relatives who are drunk come to my house and try to break down the door to my house, throw stones at my house and call me names.

Ms U is 35 years old, married. She has 7 living children. Both of her legs are affected by polio and she walks with a stick. Her left knee bends backwards when she walks, and it takes her about an hour to walk the kilometer from her house to the road. Ms U lives in a rented house with her family. Her husband helps her to care for the children and with tasks around the house. She said that he is more helpful than most husbands.

Ms U can carry a bucket 'hooked' in her elbow with the same hand that she uses to hold her walking stick. But she is unable to carry her child at the same time as she carries a bucket. She can carry a jerry can of water, but she has to stand still to move it. Then she takes a step forward with her stick. Each time she picks up the jerry can, she has to stop moving. It is a long and slow process. Ms U has been assisted by ASSERT with a hose / pipe that attaches to the neighbourhood tap. This helps her to fill the barrel in her bathroom and buckets with water for washing clothes and cooking. But the water only runs for 3 hours a day because the pump is run by community. They give Ms U and her family water for free, because she has a disability. Even with polio-affected legs, Ms U is able to squat independently to use the toilet.

Most of her neighbours think Ms U is blessed by God because she has been able to have so many children without too much difficulty. She has gained their admiration, even though she has a disability.

Mr G, Manatuto

Mr G is aged 42. He developed an illness when 12 years old and the family took him to hospital. He got a fever and his body became weak. His parents took him to the hospital for treatment but there was little they could do. Now he is in the wheelchair because his hands and legs are so weak.

There is a tap near Mr G's house, so his family can get water easily. He is able to bath himself sitting on a cement block if someone gets him the water in a bucket. To go to the toilet he slides on his bottom along the floor to his front door. Then two people assist him into his wheelchair. It takes two people to lift the chair over the step and push it to the toilet. He then needs two people to help him to transfer into the toilet room. He is able to use the toilet himself and clean his body afterwards.

…the way from the verandah is over very uneven ground and it is not easy to go to the toilet. .I would like a way to get access to the toilet so I don't need too many people to help move the wheelchair…

Mr S, Oecussi

…the wheelchair came from ASSERT …. but no one came to look at my house …. So it was useless….I got around by sitting and sliding… then I put mud in front of the steps to make them smooth for the wheelchair … I drew a new toilet on a piece of paper to show the Leprosy Mission and they helped me build it…. it has cement and iron roof and I would love to have this for my whole house…

Mr S is about 45 years old. He fell from a palm tree 11 years ago and sustained a spinal cord injury. Now his legs are paralysed and he cannot walk. He is married and has 3 children, aged 14, 12 and 11 years. Before his injury, he was a farmer. He now he continues to grow crops on the small piece of land where he lives with his family. Mr S usually moves around in a wheelchair, but he is also able to pull himself along the ground in the seated position. He continues to farm by working seated on the ground and dragging himself using his upper body.

Mr S is slowly renovating his house and land, which was damaged during the crisis in 1999. He is able to collect water from the well in his compound, but usually his children help with this task. Recently he made plans for a new bathroom and toilet that would be wheelchair accessible. The Leprosy Mission Timor Leste helped him to build this new room. Mr S still has plans to continue renovating his house as he is able.

Mr S' wife secured a loan from a local NGO in Oecussi, which helped them to set up a kiosk by the road outside their house. If he needs to travel to the town, a family member accompanies him. He is able to crawl into the Microlet (public mini-bus) and they put his wheelchair on top.

Ms C, Manatutu

…I happy because I have a well close by to get water for drinking, washing clothes, clean and bath ..… the road to the well and toilet is smooth for the wheelchair … it would be nice to have a pipe that comes to the house …

Ms C is 29 years old. She got polio when she was 4 years old and this affected both of her legs. Ms C lives in a group of 5 houses that share the same water source – a well. The water from the well is used for drinking, bathing and washing clothes. The well is about 6 metres from her house and she can get there in the wheelchair by herself. Ms C carries her clothes on her lap to the well and back. To get water, she transfers from the wheelchair to a stool and then from the stool to the edge of the well. She sits on the stool to wash her clothes at the well, and once she gets home. Her family hang out the clothes for her.

Ms C is not yet married and does not work but often cares for her nephew. She can carry him around on her lap using the wheelchair. She also bathes him, but needs assistance to prepare the water and soap for her. Sitting in the wheelchair she is also able to sweep the floor and clean the windows of her house. To bath Ms C needs someone to carry the water to the bathroom. She transfers from the wheelchair to a plastic stool to bath.

Ms C's toilet is about 9 metres from her house. She wheels herself along a smooth path to the toilet room, but the wheelchair cannot enter through the toilet door. Somebody else assists to bring her the plastic stool, because she has to transfer at the toilet door onto the plastic stool so that she can then wash herself.

Mr V, Bobonaro

…..inclusive water and sanitation must consider everyone. This man was a source of public amusement and some fear. It seemed from the mirth and contempt that he attracted, that if he did emerge to wash at the public well half way up the hill, he would have been chased away…

Mr V is about 70 years of age. The Suco Chief knew Mr V and suggested that the project team visit him. Mr V lives on the outskirts of Balibo at the bottom of a very steep hill, down from the house of his brother and sister in law. His house is really only a shelter, although the thatch roof was thick and would probably offer good protection from the rain. It is not much bigger than one of the many nativity scenes constructed at Christmas. He was covered with blankets when we visited and lying on a wooden platform, but he sat up to talk and was very friendly. He was lying with 2 dogs that cleaned his plate of the rice left from his lunch.

The visit attracted a large audience, with people giggling and pointing. Despite this, Mr V is a man with much dignity and straightened his hair and beard before he agreed to be photographed. He spoke mostly Portuguese although he responded to questions asked in the local dialect. Mr V's sister in law explained that she fed him and that she had been doing this since he hid away in the shelter in 1975. She explained that he had looked after the buffalo until he was 18. He became unwell and the family handcuffed him and chained him to the bed to stop him wandering around and shouting at people. They made the hut for him and when he calmed down they untied him. She was unaware that he had left the bed since then.

His sister explained that Mr V toileted in the bed. She confirmed that he did not bathe and did not use any water for washing. There was no excrement or smell and it would appear that the dogs ate his feces. Apart from being very grubby he also appears to be very frail and complained of a sore shoulder. His toe nails indicated that he did not walk and had not walked any distance for a very long period of time.

Ms S, Manatuto

Ms S is aged 24. She developed an illness when she was 10 years old and the family took her to hospital. She was given some intra venous treatment by a nurse who damaged her spine. She does not speak and is dependent on her mother for assistance to toilet and bathe. Since her illness and the related injury she needs a wheelchair to get around, though she is dependent on others to move it.

The family has a toilet and bathing area at home, but need to walk a long distance to the neighbour's tap for water. Her mother takes her from her bed and sits her on a plastic chair beside the bed to wash her. The same chair that is used for washing is also a toilet chair from ASSERT, with a hole in the seat. Ms S's mother places some cardboard, paper or a bucket under the seat.

Mr A, Liquica

Mr A is 55 years old. He was injured with a gun-shot wound to his leg in 1977, and lived with shrapnel in his right leg and constant infections. In 2005 he agreed to have his leg amputated. He learnt how to use an artificial limb and was able to move around independently. However in October 2009, Mr A had a stroke that affected his right arm and leg. He was not able to walk with the artificial limb for some months. He then found it difficult to attach using only one hand. Recently the limb was adjusted and now he can attach it himself.

He lives with his family. He has four children from his first wife and one from a second wife. His family access the nearest water source with a cart to fill up jerry cans twice a day. Mr A is able to use the toilet independently, because he can still squat on his unaffected leg, but he has to hold onto the wall and the water trough to keep his balance. His wife helps him to bath. Mr A retired from work following the stroke. He receives a veteran pension. He is sad that he can't work the way he used to before.

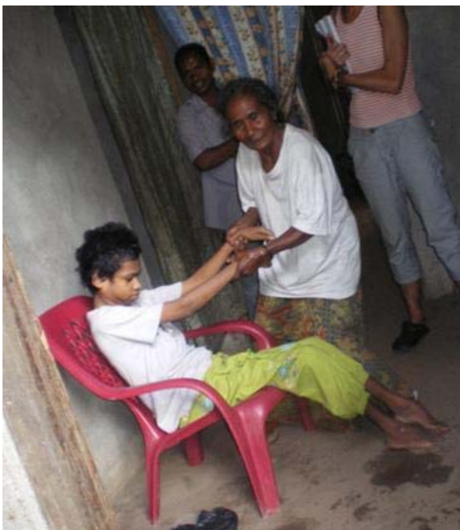
Mr S and Ms R, Bobonaro

…we took details of the family so that we can refer them to ASSERT for wheelchairs…..their grandmother is keen for this to happen although the house is inaccessible and any wheelchair could not venture beyond the front or back door unless lifted down the stairs….To be accessible it would require a home visit and appropriate modifications to the house, bathing and toileting facilities.

Mr S is aged about 14, his sister Ms R, 11 years of age. The NDPP project team noticed Ms R from the road sitting in the door way of her house. The team was actually looking for the house of a man with a mental illness who was available to be interviewed. It emerged that he was the uncle of the girl who lived with him. The household comprised of Ms R, her brother Mr S, a younger sister, parents, her uncle and her grandmother. The grandmother explained that Mr S and Ms R both became unwell with fevers and developed disabilities. Her son (the children's uncle) developed a mental illness 8 years before but continued in his employment as a police man.

Mr S is unable to toilet, feed or bath. He has no language or mobility. He sits in a plastic chair which his grandmother drags around the house with her so that he can watch her work. Or she drags him holding him under the arms. If he soils, she washes him and changes his clothes. He sleeps with her. She explained that she knows when he is about to wet the bed as his body stiffens. She then gets up and changes him so that he doesn't lie in the urine. She showed us a broken canvas pusher, designed for infant to toddler age that she had used for him when he was smaller.

Ms R sleeps with her parents and younger sister. She is also incontinent overnight, although crawls and squats in the house to ablaut during the day. She feeds herself with her hands, was covered with rice when we visited, and was cleaned up by the dogs. She spends a good deal of the day at the front door looking at the street. Her grandmother baths her on a plastic chair.



The toilet was in an open corner outside of the house. There was no privacy, the door did not close.

Mr M, Manatutu

… I want to ask the Government or NGOs to build me a bathroom and toilet, and to give me a tap and hose / pipe for water ….. I can't look after myself…..I have health problems– my skin itches … I sleep in my wheelchair.

Mr M is 40 years old. He was born with Cerebral Palsy and has limited mobility. Mr M lives with his sister and her family. They share a well with 6 other houses. Although Mr M's family uses this water for everything – drinking, cooking, cleaning, bathing and washing clothes, Mr M is not able to do any of these activities. He is almost totally dependent on assistance. When it is time to eat, people bring him food and he manages to feed himself. He said that his family don't care much about him.

If Mr M needs to go anywhere, someone must push him in the wheelchair. To bath he needs assistance to undress and for someone to bring the water. He washes himself. He explained that he doesn't bath often because he can't get help. He needs assistance to go to the toilet, and someone to wheel him. Because his wheelchair can't fit inside the toilet room, he is wheeled behind it where he ablauts. Mr M is able to move his hands and slides forward in his wheelchair putting his bottom over the edge. He cleans himself with a corn stick or leaves which are quickly eaten by nearby pigs. He is not able to clean himself. Because he is unable to wash and clean himself well, Mr M has skin rashes, body itching and smells.

When it is night, Mr M's sister wheels him into a room by himself. He sleeps in his wheelchair without blankets or pillows.

Ms J, Liquica

…..a mother and daughter who live in a very rural area…many of the key water and sanitation issues can easily be applied to their situation.

Ms J is 28 years old and lives with her 11 year-old daughter, who cares for her mother and does not attend school. They live with Ms J's brother and his wife and children. Ms J's husband died some years ago. She developed TB of the spine 9 years ago when her daughter was 2 years old. Initially she walked with a stick; now she is unable to move her legs and gets around in a wheelchair, assisted by her daughter. She said she used to be able to push herself, but now she is too sick. She has a stomach problem and pain. She has pressure sores on her buttocks. She has had them for 3 months and was initially in hospital in Dili for treatment.

In their village, the water is taken from the river. It is a long walk. Ms J's daughter carries 2 jerry cans to the river, 2-3 times a day. It takes her an hour each time. The toilet is about 50 metres from the house. Ms J is able to squat if her daughter holds her. There is 1 toilet for 2 households, in total about 10 people. For privacy there is a curtain across the doorway of the toilet. There is no water inside the toilet.

Ms J's daughter washes her with cold water when she is lying down on a raised bamboo bed. Ms J is frail feels the cold. Her daughter washes their clothes by the river. She goes alone leaving her mother in the house. Ms J cooks when she is feeling strong enough but they usually eat with the family.

Mr B, Oecussi

There are three things I'd like the government to consider for people with disability:

- *Improved living conditions*
- *Improved quality of life, especially in terms of economic opportunities*
- *training courses to improve our skills so we can work*

Mr B is 40 years old, is married and has two children aged 5 and 2 years old. His legs have been affected by polio since he was a child. For most of his life he managed on crutches Two years ago he got a wheelchair from ASSERT. Mr B is trained as a radio / watch / electrician in the 1990's. This has kept him in self-employment. He saved his earnings to build a kiosk that his wife runs. He also received a small business grant of $100 from ASSERT.

Although he uses the wheelchair for longer distances, he needs the crutches to go to the toilet or the bathroom. The bathroom does not have a toilet. His family go to the toilet in the bush or use a neighbour's toilet.

A well is 10 metres from the shop, where the family sleep. He is able to collect water himself, but cannot carry it and needs assistance to carry the bucket. He is able to wash his own clothes.

Because he rents the land where he lives, the owner does not allow him to build a toilet. His bathroom is a circular fence of bamboo type sticks with rocks at the base and a plastic sheet for the doorway. The ground is muddy and slippery underfoot, and unstable using crutches.

Mr A, Manatutu

…the wheelchair is hard to push and my son he cries a lot….. he needs special food and it is hard to get enough money to buy his milk ….

Mr A is almost 3 years old. He got a fever when he was one year old and was taken to Manatutu and then Dili hospital. The doctor told them that Mr A had an infection in his brain. This made him weak and he is unable to sit or stand. He was given a special wheelchair from ASSERT so that his mother could push him around the house and in the local area. There is a water pump close to the house.

Mr A's mother baths him in a plastic tub. She warms the water. After bathing, Mr A's mother carries him to his bed where she dries and dresses him. He wears napkins / cloths all the time. These are changed when soiled. His mother feeds him with a baby's milk bottle; he does not eat much solid food and has trouble swallowing.

Mr A's mother wheels him around with her whilst she is doing her chores, so he can see what she is doing. He has many brothers and sisters. After school they play with him and assist their mother.

Outcomes from Disability and RWASH Workshop

A Disability and RWASH Workshop was held on 24th February, 2010 in Dili, Timor Leste. The main facilitator was Bob Reed - a water, sanitation and disability expert from the UK. The aim of the workshop was to increase awareness of the two sectors about each other, and widen access to rural water supply and sanitation services to meet the needs of people with a functional disability.

Presentations at the workshop included:
- What is functional disability and why is it important to the water and sanitation sector?
- How water supply and sanitation facilities are designed and built.
- A summary of research into disability and access to water and sanitation.
- Video footage of people with disabilities accessing water and sanitation facilities.
- Technical solutions for accessible water supply and sanitation.
- Practical sessions on pregnant women using squat toilets; people with disabilities transferring to squat toilets; challenging the assumptions about water, sanitation and disability; analysis of a journey to a water supply / toilet and how access could be improved; and general discussion in relations to the different presentations.

Useful points that arose at the workshop included the following:

Engineering of water and sanitation facilities
- Consultation must be done with people with disability before the facilities are built.
- There is currently no specific type of the latrine that can easily used by people with disability in rural areas.
- There needs to be disability-sensitive engineering guidelines from the Secretary of Public Works, so that there are disability accessible standards to be used by all agencies that indicate appropriate designs that can be used for people with disability.
- There needs to be increased support and understanding from the families of people with disability

About disability issues related to access
- MSS needs to devise methods that can be used to support people with disability to access facilities that the non-disabled people already access.
- There currently seems to be no interest or funding from the Government to support people with disabilities in rural areas, including not only access to water and sanitation, but also access to education, employment and other opportunities.
- All sectors that work in RWASH related areas should be informed about the need to include people with disability in their programs.
- Lack of facilities for people with disability, especially women with disability, opens the way to sexual harassment and violence.

About working together
- There needs to be integrated inter-government ministry work to complete the access guidelines.
- Government agencies that need to be involved include SEOP (Secretary Estate of Public Works), MOE and MOH
- A Disability - RWASH working group needs to be created, with meetings at least every three months, to ensure good collaboration, sharing of information and discussion of issues.
- Families of people with disability and their communities need to be involved in the program.
- Environmental health training and sanitation issues in schools also need to be addressed.
- RWASH agencies need to invite people with disability to meetings on water and sanitation issues and other activities.

Access Tips from Bob Reed

1. Consider the **Physical Environment**
   - Getting there (to the facility – water source or latrine)
   - Getting in / on (to the facility)
   - Moving around (in the facility)
   - Ease of use (of the facility)

   Like:
   - Smooth paths
   - Cover drains and ditches
   - Use wooden or concrete ramps, instead of steps or over water source apron
   - Steps: wider, longer, more shallow; paint steps for visual discrimination; scratch steps for grip; put in rails at steps.
   - Widen doors and entrances to fit a wheelchair

2. Consider the **Internal Environment**
   - More space inside
   - Chair / bench above toilet hole with a hole in the seat
   - Rails in the toilet – in front, at the sides, above, or a rope / pole
   - Blocks on either side of the hole, which a person can sit on but go to the toilet
   - Individual / specialised equipment for person with disability
   - Hose for cleaning

3. Consider the **Social and Cultural Environment**
   - Tap stands at different heights for people with disability and children
   - Hand pumps:
     - at edge of apron instead of the middle
     - reachable handle, 90 degrees to normal position (right angle) for easier use

4. Consider **Public Facilities**
   - Many users
   - Wide range of mobility needs
   - Inclusive designs (rails)
   - May not be able to meet all needs, but as many as possible

5. Consider **Household Facilities**
   - Limited users, mostly known
   - Identifiable needs
   - Adaptions can be unique for specific family members

Appendices

Appendix 1 - Definitions of Disability Types

Physical: This includes problems with the body, especially arms or legs, problems walking and moving around, spinal problems and cerebral palsy. Included in the physical category are children with severe disabilities who might need a wheel-chair as well as others with milder problems (for example, a broken arm or leg that did not heal properly and resulted in restricted movement).

Intellectual: This includes students who have problems learning, are slow learners, are not able to concentrate in class very well, and who thus find it difficult to learn in the same way as other children. Some children in this category have severe problems; they have not learnt to read or write after many years at school and they find it difficult to follow instructions or join in games with other children. Others have milder problems and with some help and extra time from the teacher they manage to keep up with the class.

Seeing: Visual problems include blindness in one or both eyes, near- and far-sightedness, turned and crossed eyes, as well as blurred vision. Some children have very serious visual problems and need some help from their friends to walk to school safely, while others are able to manage in the classroom when they sit close to the board but have problems when book print is too small. Only children with permanent visual problems are included in the survey.

Hearing: Hearing problems include complete and partial deafness. Children with severe hearing problems often cannot hear the teacher or other students speak and rely on lip-reading and visual cues to follow the lesson. Others have a milder hearing problem and when the teacher speaks very loudly they are able to understand most of what is being said. This category does not include children with temporary hearing problems from ear infections.

Speaking: This category includes children who are mute as well as others with speech or communication problems such as a stutter, stammer or cleft palate.

Other: An 'other' category was included to capture other conditions reported by the school director such as epilepsy, 'trauma' and albinism.

Complex: This category was used for students who had problems in more than one area -for example, a child who was deaf and mute or who had a physical and intellectual impairment. Most students in the 'complex' category had a moderate or severe disability.

(These definitions were used to describe disability in Plan Timor-Leste's *Report on the First National Survey of Disability in Timor Leste's Primary Schools, 2008).*

Appendix 2 - Accessibility Assessment

The assessment purpose is to examine a water and or sanitation facility, and

a) Find out if a disabled and/or older person is able to use the facility independently.
b) Identify which features make them easy to use and difficult to use by a disabled or elderly person.
c) Make suggestions for changes that would facilitate easier use.

General Information

Date

Names of people involved in assessment (include organisation and phone numbers)

Co-ordinator / Interviewer

Note-taker

Measurer / Drawer

Photographer

Equipment used tape measure, camera (if available) paper and pencil for drawing plans

Implementing organisation

Location / District

Water Point

General description of geographic location: ☐ centre of village ☐ edge of village ☐ flat ☐ hilly ☐ distance

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General description of water point, including materials, technology used

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Ask - Who uses this water point?

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Observe different users attempting to use the water point (include people with disability, the elderly, the pregnant, children etc.)

Describe how users get to the water point

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Checklist:

Path / Route

What is access route made of (suitable for a wheelchair user)?

Is it wide enough (for a wheelchair)?

Level and firm?

Can a person trip?

Is it slippery when dry or wet?

Are there obstacles that are hard to get past?

Is the pathway clear of bushes / branches of tree?

Can a blind person follow the path? (eg. clear surface texture, landmarks, guide rail)

Are the slopes too steep (for a wheelchair)?

Steps and Rails

Are they too high (15-17cm recommended)?

Are they uneven, firm or slippery?

Are there support rails?

What is the rail made of?

What is the rail height from ground?

What is the rail diameter?

What is the rail attached to?

Ramps

Is there a ramp?

Is a ramp needed?

Is there room for a 1:8 gradient ramp?

Are there users in the community who would benefit from a ramp?

Access – how do users get onto apron / surround and into position to use the water point.……………………………………………………………………………………………………
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Checklist

Into position

Is there a difference in height between apron and ground / path?

What is the Apron height?

Is there a ramp or are steps provided?

Is there anything to lean on or a flat area to sit on whilst drawing water?

Is the Apron surface slippery?

Can the user get close enough (especially if in a wheelchair)?

Have people already adapted themselves or the water point for easier use?

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Comment on the usability of the water point
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Describe how users fetch the water and in what type of containers do they carry it?
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Checklist

Usability

Can the user reach the operating mechanism without difficulty?

Does it require stretching very high or bending very low to use?

Is a lot of strength required to use the mechanism?

Does the user need 1 or 2 hands to use the mechanism?

Is there somewhere to place the water container?

How long does it take to draw the required water?

How many trips are required to get enough water for the user's needs?

Are there users who are unable to use the water point? Why are they unable?

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Describe how users transport water

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What changes or adaptations can be made to make the facility easier to use? Consider all components of the task – approach, access, usability, water transportation etc.

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Appendix 3 - Access Problems and Solutions for RWASH

Type of Users	Type of problems experienced	Possible solutions
People who are normal and healthy	***Latrines*** • Lack of security and privacy due to lack of permanent side walls or door or lock • Space inside latrine is very small • Foot-places uncomfortable, uneven, slippery, unbalancing - when squatting • Legs can tire quickly • Danger of falling into pit if hole is big or not securely made (especially children) • Pit latrines may be smelly, dirty and full of flies and insects	• Permanent type of latrine with permanent walls, door and lock • Bigger sized latrine • Ceramic pan and levelled foot-places; education on importance of cleanliness and hygiene • Ledge in wall or rail / handles near squatting area for holding onto for support and getting up • Pit holes smaller or covered with spaced rods to prevent falls or collapse • Ventilation improved latrine; education on importance of cleanliness and hygiene
	Water Point • Long distance to walk (often more than once) • Often up / down a hill • Many small jerry cans to carry (heavy) or wheel in barrow (awkward) • Often the site for clothes washing and even bathing • Lack of privacy for bathing • Inefficient mechanisms – stiff pump handles, broken fetching containers for wells	• Installation of water point closer to the majority of the population • Use of a pump system • Devise alternative carrying methods, like backpacks, pipes / hoses • Consider alternative ways of carrying wet clothes • Permanent, safe and private bathing area near water point • More efficient and durable mechanism solutions
Women who are pregnant	***Latrines*** • All the same problems mentioned above, but with the addition of pregnancy • Stomach gets squeezed while squatting and it can be difficult to breathe • Cannot squat for a long time due to cramping, legs and hands get numb quickly, leg swelling • Foot-places uncomfortable, uneven, slippery, unbalancing - when squatting • Feeling of giving birth when urinating	• See solutions above • A back support can help ease strain on stomach • Ledge in wall or rail / handles near squatting area for holding onto for support and getting up • Distance between foot-places need to be closer than before, so that legs are not spread so wide • Construct a raised (removable) seat over hole, for sitting rather than squatting
	Water Point • All the same problems mentioned above, but with the addition of pregnancy • Heavy water loads and carrying for long distances is not good for pregnancy	• See solutions above • Alternative water carrying devices or problem solve with family to provide extra support

Type of Users	Type of problems experienced	Possible solutions
People who are elderly or sick	***Latrines*** • All the same problems mentioned above, but with the addition of being elderly or sick • Pain in knees, back, stomach and joints • Nerves get stretched if using latrine for long periods of time (numb hands and feet) • Using latrine at night, may mean a long walk in the dark, falls and latrine use in dark • May have difficulty lifting hole cover if heavy ***Water Point*** • All the same problems mentioned above, but with the addition of being elderly or sick	• See solutions above • Construct a raised (removable) seat over hole, for sitting rather than squatting • Use a pot / bucket in house at night • Ledge in wall or rail / handles near squatting area for holding onto for support and getting up • Alternative material used for hole cover • See solutions above
People with a disability	***Latrines*** • All the same problems mentioned above, but with the addition of being disabled • Pathway to latrine needs to be smooth, level, wider and obstacle free • Latrine door may be difficult to open (if in a wheelchair or using crutches). But privacy and safety are still very important. • Usually require assistance of equipment (eg. walking stick or wheelchair) or a person to help them • May have to sit on the ceramic or over the hole, because they cannot squat. This raises the issue of cleanliness and infection • May have difficulty cleaning themselves. May not be able to use water or paper. May rely on a stick to help them clean • May be more susceptible to cold water, and need warm water for washing and bathing ***Water Point*** • All the same problems mentioned above, but with the addition of being disabled • Pathway to water point needs to be smooth, level, wider and obstacle free • Access to pump / well may be impeded by surrounding apron / steps • Water fetching mechanism may be out of reach - too high or too far away or too heavy / hard for someone in a wheelchair to use	• See solutions above • Clear, grade or make path so that it is wheelchair accessible (smooth, flat) • Consider a curtain or plastic door if a solid one is too difficult to manage independently with disability (eg. when using crutches or a wheelchair) • Latrine needs to be bigger to allow for manoeuvrability (eg. of wheelchair) or another person • Construct a raised (removable) seat over hole, for sitting if unable to squat and easy transfer if in a wheelchair or being assisted. Educate family on importance of cleanliness and hygiene • Use a hose / pipe to assist with cleaning if water available. Consider some type of assistive device to assist with cleaning • Consider safety during water warming process and also process of transporting of warm water to bathroom / latrine with a disability • See solutions above • Clear, grade or make path so that it is wheelchair accessible (smooth, flat) • Construct a ramp over apron in one section, to allow wheelchair access • Adapt fetching mechanism so that it can be reached by someone in a wheelchair or even a child.

Appendix 4 - Guiding Practices for Disability Inclusion

Include the Disability Perspective

- Did the project team consult with people with disability?
- Did the project team consult (include in data collection, interview, survey etc) with a range of people with varying impairment types during the planning, implementing and evaluation phases?
- Did the project team consult with carers or parents of children with disability?
- Did the project team consult with any Disabled People's Organisations (DPO's)?
- Did the project team consult with other disability stakeholders, such as with a local community based rehabilitation (CBR) worker, disability service organisation, relevant government department?
- Has the data collected been analysed and disaggregated for disability?

Recognise, Respect and Talk about Disability Rights

- Has the project team had any education about disability rights?
- Have there been any conversations or education about disability rights in the local community?
- Have people with disability learned about their human rights?

Raise Awareness and Build Knowledge regarding Disability Issues

- Has information regarding disability been shared with the project team?
- Have the community leaders learned more about disability issues?
- Are people aware of the exclusion experienced by people with disability regarding water, sanitation and hygiene (WASH) issues?
- Has the community itself received any information regarding disability issues?
- What 'disability' advocacy activities have occurred?

Participation in Decision Making

- Have people with disability been involved in decision making processes?
- Have they participated in decision making with the project implementation team?
- Have they participated in decision making within their community, especially the community water committee?
- Have strategies to support this been identified?

Partnering with Disability Stakeholders, Identifying and Building Capacity

- Has the capacity of disability stakeholders been acknowledged?
- Have opportunities for capacity development of disability stakeholders been identified and taken place?
- Have people with disability been contracted or employed to undertake any particular project activities?

Address Barriers

- Have attitudinal barriers been addressed in any way?
  - Within the project team?
  - Within the community?
  - With other relevant groups?
- Have physical barriers been identified?
- Have strategies or solutions to overcome these been developed?
- Have various technical solutions been explored?
- Can people with disabilities utilise water and sanitation facilities?
- Is this being measured?
- Has community education, particularly hygiene promotion been conveyed in accessible formats?
- Have any institutional barriers been identified?
- Has advocacy activities occurred in order to address any institutional barriers?
- Have strategies to address access issues related to poverty been explored?
- Is there a disability budget line to address these barriers?

Women and Children

- How have women with disabilities been included?
- Have any particular strategies been identified to support the involvement of women with disabilities?
- Has any affirmative or positive action taken place?
- How are children with disabilities being supported, nurtured and included?

Have lessons learned been shared?

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