# Wateraid response to Special Rapporteur on the Rights to Water and Sanitation Consultation on stigmatisation and wash

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**Stigma: a mark of disgrace or infamy; a stain or reproach, as on one's reputation.**

# Introduction

WaterAid’s work on equity and inclusion has produced analysis and experience on issues of stigmatisation in relation to WASH. The use of “barrier analysis” to understand why people are excluded from WASH and what can be done about it includes analysis of attitudinal barriers experienced by different groups, as well as physical and institutional barriers. This analysis highlights issues of stigmatisation as one of the most difficult issues to address in designing WASH programmes to reach the poorest and most marginalised people.

The following response to questions raised is a compilation of some of the experiences from WaterAid’s work on equity and inclusion. However there is a growing experience in country programmes that has not yet been documented and so might not be fairly represented in this short summary.

Also attached are two appendices:

1. Specific response on caste, stigma and exclusion from WASH from WaterAid India
2. Select annotated bibliography of relevant WaterAid documents

## 1) Which groups and individuals experience stigmatization?

WaterAid has experience of working with the following groups and individuals who experience stigma in relation to water and sanitation: All, except the sex workers, are exceptionally poor.

* Disabled people – in many countries disabled people are stigmatised because of lack of knowledge about the cause of disability, different sorts of impairments are associated with different types of stigma
* Girls – especially when menstruating
* Women - who are particularly stigmatised in different cultures if they are widowed, divorced, living with HIV, or old
* Older people, especially women who are often associated with witchcraft in poor communities
* People living with HIV and AIDS
* Other chronic illness like epilepsy, TB
* Dalit or other castes (India, Nepal)
* Poor and marginalised groups that vary from culture to culture.
* In case of Bangladesh, Sex workers, tea garden workers, gypsies, ethnic minorities, child labourers etc.
* Prisoners (Burkina Faso)
* manual scavengers (India and South Asia)
* religious minorities (Pakistan)
* fishing communities (Pakistan)
* small island communities (Uganda)

## 2) How are different groups and individuals affected?

* Stigmatised people are less likely to access education, more likely to become isolated, this affects their whole household, self confidence and self esteem suffers and they become increasingly marginalised and voiceless, unable to ensure their needs are met, or their rights respected.
* As these groups of people are usually not aware about rights in general, they are unable to claim their rights.
* Power structures often take advantage and exploit them. They can’t come out of poverty, don’t get the chance to be educated and thus get trapped in the stigmatised chain.
* Lack of access to WASH due to physical barriers also reinforces stigmatising conditions – being dirty, smelly, undignified, and ashamed.
* Stigma includes concept of “unclean”, for example in relation to women menstruating, and to “unclean” work – that affects certain occupations such as manual scavenging, and it is also behind much of the caste discrimination in India. This results in systematic exclusion from water and sanitation facilities.
* Stigma can be reinforced by religious beliefs and by religious institutions that use it to consolidate their power.

The following examples show how people affected by disability, HIV and AIDS, and old age are affected by stigma in relation to access to WASH, how menstruation is associated with stigma, and how caste discrimination results in lack of access to WASH.

### Example of exclusion related to stigma and disability in Ethiopia

(Extract from: Principles and practices for the inclusion of disabled people in safe sanitation. A case study from Ethiopia, WaterAid; Jane Wilbur; 2010)

Environmental barriers force some physically disabled people to crawl on the floor to use a toilet or defecate in the open. This has implications for health and safety and negatively affects people’s self esteem. All six …. informants stated that not being able to use a safe, clean and private toilet was degrading, dangerous and extremely arduous. As entrances to the toilets are invariably too narrow for wheelchairs to enter— cubicles are dark and there is no toilet seat or handrails — all respondents who could not walk unaided, used their hands for support or to drag their bodies on the floor to reach the toilet.

AB explained that she did not go to the toilet during school time because it is inaccessible and unhygienic. As a result she experiences abdominal pain. She said, “The toilet at the school is not clean. I get out of my wheelchair outside and then I am coming on my hands. When I saw some dirt in the toilet I didn’t use the toilet—I go back to my class. If l was not disabled I could go to the toilet anywhere. It is very painful not to go to the toilet”.

Others depend on the forest or fields to provide a certain level of cover when defecating in the open. One female explained the natural barriers she faced, used to go to the forest but it was very difficult for me, especially when it is raining and there is mud and thorns.”

Forty percent of respondents (67% of the females interviewed) stated that they were ashamed to be seen crawling and how dirty they became.

One lady said, “I feel shame because I am not walking like my friends; I am walking by my hands and my feet. And I have new clothes they immediately turn dirty as I walk full time on my hands.” Without a supply of water and soap for hand-washing, the health implications are obvious.

Attitudinal barriers reduce self confidence and the ability to assert rights. The empirical findings support the literature review: all respondents disclosed that their families believed their impairment, which developed in early childhood, was caused by an evil spirit, which led to 80% of respondents being treated by traditional doctors in the first instance. Treatment included bathing in holy water and massaging the affected limbs with butter. A lack of proper medical treatment due to limited knowledge about the cause of disability could have worsened the impairment. This supports the poverty disability cycle

One female informant explained how her low status, isolation and exclusion within the household and community led to low self worth, “There was a big discrimination by the society and I was staying at home. My family sent my sisters and brothers to school but they are keeping me at home because they are ashamed of me. I am hiding myself too”.

The findings also demonstrate the importance of a strong social network and how this can combat social exclusion. One male informant’s family believed his impairment was caused by an evil spirit, but he was not isolated. He is a respected member of the household, so he is included in community life. His mother explained, “Our neighbours have good reaction to him, maybe because they are afraid of his brothers and family—we protect him.”

### Example of stigma and exclusion from people living with HIV and Aids.

A briefing paper that summarises WaterAid’s work on WASH provision for people living with HIV and AIDS concludes: Stigma and discrimination is a persistent issue, with examples of community members, healthcare workers and WASH service providers being unwilling to share water supplies and sanitation facilities with people living with HIV and AIDS for fear of infection. The level of discrimination and stigmatisation often increases with the severity of the illness and the support needed.

### Case study of person living with HIV and AIDS, from WaterAid, Zambia

Regis Sicheuunga, 48, is a widow and a mother of seven. She also has two grandchildren. Regis suffers from HIV, which she was diagnosed with after the birth of her last child, Katherine, who is now nine. Regis was married but her husband died in 1998 and she had Katherine with a new partner. Her four youngest children have been tested for HIV and are all negative.

This is Regis’ story: “I used to get the water from a well, which was a long way. I had to get up at 3am because if you were late, the water would be gone and you would have to wait for it to come up again. I was given containers and chlorine by the hospital to keep boiled water because it’s so important for my health to have clean water. Now we have a hand-pump in my village, which has been particularly beneficial for me s I don’t suffer from diarrhoea anymore. Diarrhoea used to recur about every six months and I didn’t know if I got it from the water or the toilet. I would go to the hospital to get the medicine to help me cope, but it was 18km so I would have to stay overnight.

Now that I have clean water close to my home, I keep a garden to grow vegetables and

groundnuts to help protect my body. As I’m stronger, I am very keen to build a toilet and I know people will help me, as they helped me to build my house.

Our new hand-pump has been very good for everyone, but the best thing was actually the education that came first, which we can now pass onto others. The education made me realise the error of my ways in using dirty water and, as a result, the spread of diseases has reduced. When I was diagnosed with HIV, there weren’t any support groups and a lot of people were secretive about the condition. However, the Chikuni Mission started to visit me at home once a month and would bring maize to help. They put together a list of all those willing to be known as HIV positive and we formed a support group so we could talk to others about the disease and encourage them to be safe. We started making a radio show and held a lot of seminars where we taught positive living and how to deal with the stigma of HIV. When others heard, they got in touch to ask if we’d help them. We now have 12 clubs and Kara Counseling helped us to buy some goats so the clubs can generate a small income to run. When I speak to others, I tell them to make sure they use clean water to keep disease at bay.

Things are positive for me now. I am not scared and the children don’t think about the

future when I won’t be here. I thank the people who made this possible. The knowledge

they have brought, to help me understand the importance of clean water, hand-washing

and toilets will help me live longer.”

### Example of case of older woman in Zambia

Sabrina Filumba is now a widow. She has problems with her legs making it difficult for her to be very mobile, but her 13-year-old grandson Kanama lives with her and helps look after her. Until July 2009, Sabrina did not have a toilet. She used to walk about 400 metres to use the surrounding bushes. “My toilet collapsed soon after my husband died in 1995. At that time, there was no spirit of cooperation amongst people in the village so it never crossed my mind to ask for help to rebuild it. Everyone expected to be paid cash or with chickens, but I didn‟t have either.

Even my own family never bothered to help me. People here have always suffered from diarrhoea, cholera and other related diseases but no one ever knew it was due to poor sanitation. Now people are more educated and understand the link. In 2009, the idea of helping each other was introduced to the village by the V-WASHE Committee. One day, four people came to my house to ask if they could help build me a toilet in order to avoid an outbreak of cholera in the village. I was really happy and grateful. I thanked God for finally remembering me. I am now a proud owner of a traditional latrine; I‟m just waiting for cement to arrive so that it can be improved with a sanplat.

Traditional latrines need to be re-plastered every two weeks as they become rough from sweeping, but I am an old woman who can hardly walk anymore let alone have the strength to manage such a task. I now also have a hand washing facility outside my toilet. I am very pleased with the hygiene education I received from the V-WASHE committee. I was not aware of the need to wash your hands after using the toilet. My grandson Kanema used to tell me to construct a toilet and encouraged me to wash my hands after using it as he learned about it in school. Unfortunately, I was unable to do so. I now want to spread the message to all my grandchildren so that they continue with good sanitation and hygiene practices. If it wasn‟t for the problem with my legs, I would have been accompanying the V-WASHE members on their sensitisation rounds. The V-WASHE members have now become like family and pass through once in a while to see how I am doing”.

This story was chosen to illustrate significant change because of the widespread belief that many old people in Samfya district practice witch craft. As a result they are isolated as it is believed that associating with them will lead to one inheriting their witch craft tendencies when they die. Due to this, most community members tend to marginalize old people within their communities and exclude them from benefiting and participating in activities. This change was chosen because it shows a change in the attitudes of local communities, towards a deep rooted belief.

Following the community sensitization meetings conducted by the project staff, V-WASHE committee members have realized the importance of putting aside beliefs that marginalize old people who are willing, but not able to improve their sanitation and hygiene practices.

### Stigma associated with menstruation: example from Nepal

In the Focus group discussion most of the girls expressed that first menstruation is often traumatic and very negative experience. Culturally girls of Bahun, Chhetri and Newar caste groups are put in seclusion in special place in one’s own or relatives’ house (usually kept dark) where they are confined for seven to 11 days. During this seclusion they are not allowed to see sun and male relatives (brothers and father).

### Stigma associated with caste in India

In India the Caste system is the biggest barrier in access to water, closely associated with the concept of being “unclean” . Water is often used as a weapon to perpetuate dominance by upper castes. This has been the experience of some of the programmes of WAI as well. A survey of 565 villages across 11 states shows denial of access to water facilities in 45-50% of the villages. In terms of MDGs, dalits and tribals lag behind as indicated by Census 2001. Exclusion is prevalent in schools where dalit children are not allowed to drink water from common water sources. Teachers and non-dalit students do not take water from dalit students. Discrimination gets enhanced in times of disaster and scarcity e.g. Floods and drought; when safe water is at a premium. Water tankers are directed towards upper castes hamlets because of the power they wield. There have been examples of the same during the drought in Bundelkhand and the tsunami is South India. In areas where water pollution is high, impact is much worse for excluded communities.

Infrastructure development is closer to higher caste households vis-à-vis others where repair also takes longer. Piped water schemes in panchayats often do not cover low caste habitations as the panchayat thinks they do not need piped water supply. There is poor representation of excluded groups in Pani Samitis (Village Water and Sanitation Committees, or VWSCs), hence they have little voice. They have poor access to common water points on which there are more dependent.

## 3) How is stigmatization relevant to access to water and sanitation?

The examples above show that stigmatisation is both a cause and effect of lack of access to water and sanitation

* Individuals are not allowed access to water sources
* Family members are not allowed to use latrines (eg menstrual hygiene)
* People are shunned by water and sanitation committees (eg old woman from Zambia)
* Discrimination results in poor access to sanitation, that makes people more likely to be dirty and smelly and increases stigmatisation.
* Lack of access to WASH increases risk of illness,
* This can cause disability that can make a person more likely to be stigmatised
* Health risk is high for scavengers and sanitation workers. They are prone to diseases such as TB, waterborne diseases, skin diseases etc, Their life expectancy at birth is low.
* Hygiene needs of people with HIV-AIDS are more since their immunity is low; in addition they have to battle social stigma as well.

### Decision to work with sex workers in Bangladesh

Experience in Bangladesh showed that although WA provided enough water points for the whole community. But while we went to the community for monitoring after a while we saw a certain group of people could not use those points as others were preventing them to use those. Then we came to know they were sex workers and the community leader won’t allow them to use the same points used by others. Thus we decided to start working with the sex workers.

## 4) What measures are being taken to address and overcome stigmatization?

Stigma is often a product of fear, ignorance, and lack of confidence about how to deal with something. WaterAid is taking the following measures to help address and overcome stigmatization, usually using a combination of the following:

* Voice and visibility:
  + This makes an enormous difference. After several years of documentation and discussion by WaterAid and many others menstrual hygiene, previously a largely invisible issue, is now a widely discussed subject in WASH forums. Men and women involved in WASH acknowledge it is a major issue that must be addressed. This leads to sharing of good practice, documentation and the development of a practical manual (to be launched April/May), already in demand from practitioners.
  + At the WSSCC global forum on sanitation members of excluded groups (including adolescent girls from slums, and ex manual scavengers) shared their experience of lack of access to WASH with professionals and took part in discussions at the forum. Many participants at the forum said they found insights from these discussions extremely enlightening. (We do not yet know to what extent this enlightenment has produced any change in practice).
* Awareness raising – in the organisation, with staff, with partners, with communities, with professionals in the WASH sector –.
  + By running equity and inclusion awareness raising training with all staff and with partners WaterAid has encouraged discussion of discrimination and exclusion, encouraging staff to draw on their own experience. Experiential learning exercises like ”the walk of life” show that social exclusion from WASH (and other services) is the result of a complex combination of social norms, individual prejudice, poverty, power relations, education, and physical barriers like distance. The training provides a safe space to discuss exclusion due to stigma in the different contexts.
  + In Nepal male programme staff have held awareness raising sessions with communities on menstrual hygiene management. The discussions involved men as well as women and this has been acknowledged as an important strategy.
* Promote the “social model of disability” and not the charity model, and apply this to all excluded groups.
  + WaterAid uses the social model analysis of the interconnected barriers – attitudinal, environmental and institutional. This shows that in order to tackle exclusion we need to understand and address knowledge, attitudes and beliefs that result in stigma (attitudinal barriers) , as well as making improvements in the way facilities are designed (environmental barriers) and challenging institutional barriers such as a lack of policy, legislation, representation, and accountability mechanisms.
* Use Rights concepts to promote respect and non-discrimination
  + WASH as human rights strengthens the argument that it is simply not acceptable to leave anyone out. Otherwise duty bearers excuse themselves. It is common to hear people say “we are very poor, even to get WASH to able-bodied people is difficult. We cannot make a special effort for disabled people when we have so few resources. To have any toilets in the school is difficult – we cannot make separate facilities for girls as well/
* Collaborate with excluded groups – to raise issue of WASH as rights

For example WaterAid in Ghana worked with national disabled persons organisation to hold a high level meeting and invited government ministers to hear their demands for WASH. At a community level the case study of Regis, above, shows how people living with HIV were able to challenge stigma associated with their status when they formed a group in their community. WASH was an important practical issue for them.

* Provide information to dispel myths and negative beliefs as part of WASH information and training materials
  + WaterAid uses a range of communication channels, for example using community hygiene education about how HIV is not transmitted through sharing water sources; public information for men and women about menstrual hygiene management; sharing photographs and designs on affordable and accessible household WASH options.
* Modelling inclusion – work with most marginalised
  + WaterAid staff and partners are beginning to work closely with groups who are often stigmatised, for example disabled persons organisations, and dalits (see case study below). This affects WASH professionals’ and community attitudes about disability and about caste.
  + When others in the community see the effect of good practice it can raise the profile and self esteem of excluded groups. We are also promoting more active involvement of excluded groups in programme design. When normally excluded people are able to raise their voice, and seen in a position of responsibility others view them differently.
* Provide practical solutions – demonstrate what can be done to make WASH accessible to all.
  + We are providing technical training and promoting practical guidance on inclusive design to staff and partners. Many people say “ we know we should do it but don’t know how”. This applies to disabled access, also to menstrual hygiene management and providing services to other hard to reach groups. Where practitioners see practical solutions it may be easier to take some of the power away from stigma.
* Use all available opportunities to raise issue of exclusion – present barriers along with solutions

WaterAid is using all possible forums and collaborating with other organisations and networks to highlight issues of stigma, social exclusion and attitudinal barriers, that are often not recognised or discussed in the normally technocratic WASH sector. And then share examples of more inclusive approaches to WASH that can be applied widely.

* Research, document and disseminate evidence about stigma and exclusion from WASH

As well as a number of documented projects on different aspects of inclusive WASH (listed at the end of this document) we are carrying out a major research project to document and provide evidence of costs and benefits of making WASH more inclusive. This includes gathering evidence of attitudinal barriers that people face at a baseline stage and seeing whether this changes as a result of an inclusive WASH programme.

* Designing and running specific programmes targeting stigmatised and excluded groups.

For example WaterAid in Bangladesh has a separate “inclusion programme” working with specific groups, such as sex workers and tea garden workers, as we have found that they need special focus. We are considering rights issues in these projects so that the mind set up of both the excluded and the exploiters change by long term intervention.

The following extract from the up-coming manual on menstrual hygiene management shows how this particular stigmatised issue can be addressed using a combination of all the above. There is also a detailed description of community awareness sessions in urban and rural settings in Nepal.

The second extract below shows how dalits have been able to use rights and support from external agencies to defy discrimination :

### Example of practical advice on how to address stigmatised issues from manual on Menstrual Hygiene Management

As menstrual hygiene in general is not commonly spoken about, and because the subject is taboo in many cultures and is surrounded by a number of myths and traditional practices, integrating menstrual hygiene into services, interventions or programmes requires a step-by-step approach.

Staff will need to understand and be competent the critical actions of how engage with community members from different backgrounds, whether urban, rural, richer or poorer, or from different ethnic groups or traditions, in order to ensure that menstrual hygiene interventions are appropriate to their possibly different needs.

Staff need to:

* Know the basics about menstruation, what the menstrual hygiene gaps are and why it is important to integrate it into services, interventions or programmes.
* Understand what can be done to mainstream considerations of menstrual hygiene into community programmes, including practical actions, monitoring and feedback processes.
* Have chances to openly discuss issues relating to menstrual hygiene including sensitive issues and to know how to respond if they are asked difficult questions.
* Know where to go for further information.

A range of opportunities for building the competence and confidence of staff include, incorporating menstrual hygiene in training and in sectoral or organisational guidelines, discussion in meetings, workshops and including menstrual hygiene in reviews and evaluations. Opportunities should be given to both men and women with particular encouragement and support given to male staff as they have less opportunity for learning on this issue. Integrating menstrual hygiene into organisational policies, strategies and guidelines also will aid the mainstreaming of menstrual hygiene.

There are several examples of training or learning opportunities on menstrual hygiene for staff, including at international conferences, head offices, through WEBINAR opportunities across continents, and integration into other training courses.

It is also useful to provide opportunities for discussion and looking at interventions on the ground, critiquing them from the menstrual hygiene perspective and discussing with the women and girl beneficiaries as to how the interventions or support could be improved.

Where the organisation has managed to establish good practice in menstrual hygiene in communities, it would also be positive to initiate debate and discussion with other organisations working in the same field to try and expand good practice in menstrual hygiene.

### Examples from India of overcoming stigma in relation to caste

1. In Guravareddypalem village I Prakasham district of Andhra Pradesh, dalits used to draw water from the well not for their own needs, but to carry it to dominant caste houses. They had to wait patiently for long hours for dominant caste people to fill their pitchers, sometimes, having to return empty handed. But, all this was changed by a dalit, Nadella Anjaiah. Thirsty after hours of hard work in the fields, he gave up waiting patiently after several hours and took water from the village well. Caught by the dominant caster Reddy villager, the entire dalit community was barred from accessing the well itself. Instead of taking the matter lying done, the dalit community filed an official complaint, eventually securing officials help to gain access to the well. Though the district administration sought to diffuse the caste tensions by offering a separate well to dalits, this was opposed since it would encourage the practice of untouchablilty. Eventually, four Reddy caste culprits were arrested for denying water to dalits and the latter got direct access to water, first time in the village’s history. Mangubhai & Irudayam, <http://www.dalits.de/details/dsid_hintergrund_wasser_recht.pdf>>

2. In Seetanagaram village in Andhra Pradesh, the continuous breaking down of the water pump prompted the dalit villagers to send Durga Rao on a training course on water pump repair, provided by British charity Water Aid. Rao returned and set up a water pump repair business, which soon was in high demand. Initially, the dominant caste villagers refrained from letting Rao touched the bore well. But, later they relented, when faced with the only option of a skilled dalit to set up the well. Slowly, but surely, respect for dalits in the villages grew and some caste barriers crumbled. Important among them was that the local tea shop owner stopped the practice of untouchability of two-glass system in the shop. (Mangubhai & Irudayam, <http://www.dalits.de/details/dsid_hintergrund_wasser_recht.pdf>>

**RECOMMENDATIONS**

* To carry out and scale up a combination of all the measures above
  + Voice and visibility:
  + Awareness raising training
  + Promote “social model of exclusion” – barriers and solutions
  + Use rights concept to call for non-discrimination
  + Collaborate with excluded groups to promote WASH as rights
  + Provide information to dispel myths
  + Model inclusive practice
  + Develop and promote practical solutions
  + Raise stigma as serious issue in technical forums
  + Document and disseminate evidence about exclusion
  + Design and run specific programmes targeting excluded groups
* To monitor and incentivise the use of measures to combat stigma in the WASH sector.
* Recognise that stigma and its effects are highly context specific. Flexible approaches are needed (see example below on menstrual hygiene awareness in rural and urban contexts in Nepal)
* To recognise and put in place measures to understand social exclusion and stigma of all marginalised groups, while continuing to focus on how to address the issues experienced by specific groups (women, children, people living with HIV, disabled people, older people, other groups experiencing discrimination).

### Example of specific recommendations arising from analysis of lessons on HIV/AIDS:

1. Joint programming between the HIV/AIDS and WASH sectors should include training on water, sanitation and hygiene and HIV/AIDS-related care and treatment respectively. For example, home-based care guidelines should include a component of water, sanitation and hygiene and water and sanitation programmes should **emphasise sensitising and training communities** on sharing WASH facilities with people living with HIV and AIDS.
2. Advocacy needs to be carried out with decision-makers in the sanitation sector to address the potentially increased sanitation needs of people living with HIV and AIDS due to the higher frequency of diarrhoeal illnesses.
3. Advocacy is needed for HIV/AIDS programmes and interventions to increase the provision of water treatment agents as part of medical treatment support packages.
4. The needs of people living with HIV and AIDS should be addressed throughout WASH programmes including the planning, monitoring and evaluation stages. People living with HIV and AIDS should be included at each stage of these processes.
5. Media such as radio should be used to spread hygiene messages and accurate medical information in accessible format.

### Cross-comparison of Menstrual Hygiene related training: A facilitator’s observation

Facilitator: Om Prasad Gautam, Social Development Adviser, WaterAid in Nepal

District Public Health Office, Bhaktapur (urban) and Dhading (rural) with the technical support from WaterAid in Nepal conducted one day menstrual hygiene and WASH related training during June and July 2011 targeting to Female Community Health Volunteers (FCHVs), teachers and women’s group. The similar types of presentation and methods were used in both the settings in which Mr. Om Prasad Gautam, Social Development Adviser to WaterAid in Nepal presented ‘menstrual hygiene’ and Mrs. Sharada Pandey from Ministry of Health and Population, Focal person for Environment Health and Hygiene presented overall context of ‘WASH’ paper. Few interesting observation were made based on menstrual hygiene session in both the settings which are as follows:

|  |  |
| --- | --- |
| **Urban (Bhaktapur)** | **Rural (Dhading)** |
| **Nature of Participants:**   * 60 Female Community Health Volunteers (FCHVs) * All of them were from Municipality except 9 (from VDCs) * Almost all were young and literate * Male facilitator presented menstrual hygiene and female facilitator presented general WASH context * All of them attended menstrual hygiene session for the first time | **Nature of Participants:**   * 57 participants comprised of FCHVs, women’s group and teachers * All of them were from Village Development Committee (VDC) * Almost all were old (adult) and many of them were illiterate except teachers and few FCHVs * Male facilitator presented menstrual hygiene and female facilitator presented general WASH context * All of them attended menstrual hygiene session for the first time |
| **Methodologies:**   * PowerPoint presentation on menstrual hygiene in local language * Distribution of menstrual hygiene brochures / IECs * Free distribution of pads from private company * Discussion | **Methodologies:**   * PowerPoint presentation on menstrual hygiene in local language * Distribution of menstrual hygiene brochures / IECs * Discussion |
| **A facilitator’s observations:**  At the initial phase of the menstrual hygiene presentation, participants seemed anxious and they were looking each other’s eyes. When facilitator started talking about menstrual facts, their health / physical problems, local cultural and ritual restriction and problems, use of food during menstruation, problems during period to manage bloods, use of pads and its management, and some facts related to school absenteeism, participants became more excited about the topic and seemed keen to learn more on the subject matter. It was interesting for me to see how interactive session able to create conducive environment for the participants to express their hidden and unheard voices. During discussion session, participants were so open to talk anything related to menstrual hygiene. They asked lots of questions about the abnormalities about the period, causes of excessive bleeding and pain, impact of sexual intercourse during period etc. After the discussion session, all of them were quite excited about the promotion of menstrual hygiene management practices at their working areas and they also committed to break the social silence. After the session, low cost sanitary pads were distributed to all participants by Jasmine Sanitary Pad Company as part of their CSR approach in free of cost. Participants also discussed about the use and quality of pads. Almost one third of the participants reported about the use of locally available cloth to manage the blood. All of them expressed that, if low cost pads are available, they would use them.  Finally, it was realized that, truthful facilitation of menstrual hygiene session by male facilitator and discussion about their own real life experiences make them comfortable to express their hidden agenda. To break social silence, man (male) should start discussing this topic. It was also realized that, young literate women are quite open to discuss this topic thereby to break the silence. If these types of age group front line workers mobilized, menstrual taboos will no longer be an issue for urban women as well as in the community. All the participants including district public health officer appreciated the session and acknowledge the prevailing problems. | **A facilitator’s observations:**  At the initial phase of the session, few participants became more excited and they were teasing each other. The participants from women’s group seemed quite. Facilitator shared menstrual facts, their health / physical problems, local cultural and ritual restriction and problems, use of food during menstruation, problems during period to manage bloods, use of pads and its management, and some facts related to school absenteeism etc. Rather excitement, participants became more silent. After discussion, participants raised questions which were limited to local practices on use of foods and heavy work during menstruation period. Participants didn’t raise any other questions related to malpractices during menstruation and problems they are facing. One of the women’s group participants shared her experiences, as she never discussed this topic with her daughters in past but now she realized the importance of its discussion. One of the school teacher mentioned that she was quite and nervous in the session because she had realized her mistake as she was not fulfilling her responsibility by communicating the truth and facts related to menstrual hygiene to the students. One of the women’s group participants mentioned that, though she realized the problems and wants to discuss the topic in the community, she might not be able to open her mouth because other may tease her as no one dare to discuss this topic openly in the community ever. At the end of the discussion, I have asked participants about the use of pads. Almost all used locally available cloths except two teachers. The pads were not distributed in this setting because we were not sure about the acceptance level within participants and access to pads afterwards.  Finally, it was realized that, the severity of the problems and restriction are rooted in the rural context. Adult / old women though they realized the problems, not felt comfortable to start work on breaking silence in the community as social restrictions are severely rooted and they ever discussed such topic openly in the mass in their life. It was also felt that, the session would even more silence if women facilitator discussed the topic as old women participants used to discuss only the restriction practices. As teachers realized their ignorance, menstrual hygiene related silos could be broken by mobilizing them in rural context. All the participants including district public health officer appreciated the session and acknowledge the prevailing problems. |
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**Appendix 1: Examples of exclusion and stigma from WaterAid in India**

Below is a compilation of (a) some of the findings of various studies on exclusion with respect to access, (b) stigma faced by scheduled castes or dalits and (c) two case studies on access for PwDs

1. **Some of the findings of various studies on exclusion include:**

* Caste system is the biggest barrier in access to water. Water is often used as a weapon to perpetuate dominance by upper castes. This has been the experience of some of the programmes of WAI as well.
* A survey of 565 villages across 11 states shows denial of access to water facilities in 45-50% of the villages.
* In terms of MDGs, dalits and tribals lag behind as indicated by Census 2001.
* Exclusion is prevalent in schools where dalit children are not allowed to drink water from common water sources. Teachers and non-dalit students do not take water from dalit students.
* Discrimination gets enhanced in times of disaster and scarcity e.g. Floods and drought; when safe water is at a premium. Water tankers are directed towards upper castes hamlets because of the power they wield. There have been examples of the same during the drought in Bundelkhand and the tsunami is South India. In areas where water pollution is high, impact is much worse for excluded communities.
* Infrastructure development is closer to higher caste households vis-à-vis others where repair also takes longer. Piped water schemes in panchayats often do not cover low caste habitations as the panchayat thinks they do not need piped water supply. There is poor representation of excluded groups in Pani Samitis (Village Water and Sanitation Committees, or VWSCs), hence they have little voice. They have poor access to common water points on which there are more dependent.
* Health risk is high for scavengers and sanitation workers. They are prone to diseases such as TB, waterborne diseases, skin diseases etc, Their Life Expectancy at Birth is low. Hygiene needs of people with HIV-AIDS are more since their immunity is low; in addition they have to battle social stigma as well.

**(b) Restriction in accessing resources**

Dalits are denied to draw water from public reservoirs and from public water taps. The notion of purity and pollution has been particularly strong in relation to drinking water sources. Being prohibited to purchase land in dominant caste localities, restrictions also exist in accessing common property resources like forest, water bodies, ponds and others through which livelihoods is accessed by dalits. There are also restrictions in accessing village shops and restaurants, health centers, clinics, entry to public transport and cinema halls.

In case of dalits, where segregated water supplies are not found, have to endure a combination of any of the following untouchability practices:

\* Dalits and non-dalits do not stand in the same line to fill water.

\* Dalits and non-dalits use separate pulleys to draw water from a well.

\* Dalits cannot dip their pots in a well or pond when a non-dalit is drawing water, dalits can draw water only when non-dalits have finished drawing water.

\* Non-dalits can draw water from water sources ‘allotted’ to dalits when their own water sources have dried up, but dalits cannot do the same under any circumstances, with grave penalties in case of any deviations.

\* There are separate water resources for dalits and non-dalits.

\* Dalits cannot take water from a common water source on their own, and have to request a non-dalit to pour water into their pots.

\* Imposition of differential treatment. For eg. Dalits have to wait for non-dalits to fill water first or have to move away when a non-dalit arrives to fill water.

**Exclusion at the time of disasters**

* Exclusion is all pervasive: it exists at normal times and deepens during disasters

1. The January 26, 2001 country’s worst devastating earthquake in Gujarat took lives of over 30,000 and over one million were left homeless. But what about the human-made disaster: caste and communal discrimination in the distribution of relief and rehabilitation, corruption in the handling of aid, and political squabbling that has done little to help the earthquake’s neediest victims? Government allocated equal amounts of monetary compensation and food supplies to member of all communities but dalits did not have the same access to adequate shelter, electricity, running water and other supplies available to higher caste people. There was nobody to ensure equal distribution of resources which worsened the condition of dalits in the devastated state. (Source: ‘Untouchability and segregation’ (<http://www.hrw.org/reports/2001/globalcaste/caste0801-03.htm#TopOfPage>)

2. After the 2004 Tsunami devastated the state of Tamil Nadu, dalits were not provided proper and adequate guidance on how to gain admission to relief camps, were not given a fair share of relief aid, and were sometimes abused when they demanded equal treatment. They were not only victims of natural disaster but also had to face human made discrimination by higher caste groups in terms of caste. In one case, a fishing community refused to share water provided by relief organizations, claiming that the dalits would pollute the water. They were also denied access to relief materials supplied by the government and NGOs and were also denied entry to rehabilitation camps. (Source: ‘Disaster relief and rehabilitation: Caste based discrimination’ (<http://www.bhoomikaindia.org/disaster_rehabilitation.php> )

3. In drought prone Chakwara village, near Jaipur, in Rajasthan, dominant caste Jats, Gujjars, and Brahmins imposed a fine of Rs.50,000 on two dalits, compromising the maryada (dignity) of the village by breaking its tradition where they dared to bathe in the public pond prohibited to the dalits. A Sadbhavana rally, organized by various social movements and the Centre for Dalit Human Rights, on 21 September, 2002 against this, was attacked by dominant caste mob, armed with lathis (wooden baton). Meanwhile, the state machinery has chosen to ignore the issue by closing the case, expressing its *inability* to take action against the dominant castes, despite their illegal action. Meanwhile, police orders allowing dalits to access their fundamental right to water are ignored with impunity. (Mangubhai & Irudayan, <http://www.dalits.de/details/dsid_hintergrund_wasser_recht.pdf>>

**When dalits complain about lack of basic services are these addressed?**

1. Though dalits from Chapala Dalitwada, in Pullampeta district of Andhra Pradesh have repeatedly informed government officials over the years of their lack of drinking water facilities, even going to the extent of parading in front of the officials with their empty water jars in 2000, officials have not taken any action on the matter. (Mangubhai & Irudayan, <http://www.dalits.de/details/dsid_hintergrund_wasser_recht.pdf> )

2. An Orissa panchayat has prevented at least 16 dalit families from consuming tap water on grounds of untouchablilty. Bileisarda village panchayat in Balangir has kept pending the pipe-water connection to Harijanpada, though eight other wards of the panchayat have been given pipe-water connections. Sources say the sarpanch has allegedly refused to connect Harijanpada with the same pipe that supplies water to houses of upper caste people. The panchayat, which started laying down pipes in 2005 for fetching water from the Suktel River, has completed the work only this summer. “Still, we have been denied water as the sarpanch won’t take up the issue with the high caste people,” says Sarmila Chhatria of Harijanpada. “Despite drawing the attention of the district administration, no official has turned up at our village,” says another dalit, Tulsiram Bag. The sarpanch belongs to the higher Dumbal (Kshatriya) caste. He says, “We even requested the sarpanch many times to repair the tube well, but to no avail.” While sarpanch Tapaswini Biswal refused to speak, her husband Jamidar Biswal said his wife was elected a few months ago but she did not know much about village politics. (Source: The Times of India, 13 July, 2007).

**What happens when dalits want to change the social order?**

1. On December 14, 2001, two dalits in Chakwara village decided to defy the village ‘law’, prohibiting them from using a pond and decided to bathe in it, primarily due to frustration of being denied clean water. Retaliating to such an action by the dalits, the panchayat imposed a fine of Rs. 50,000 on them and demanded a written apology. Apart from this, they also had to suffer a complete social boycott. They could not buy rations from village shops; no one would lend them money and were also barred from using the only hand-pump in the village. After much agitation, when they won the right to use the village pond, the Hindus started dumping garbage in it. Also, some men dug up the village sewer and directed it to the pond water. Every effort was made to pollute it, only because it was the dalits who were using it (Source: Dalit window).

2. Madhukar Ghadge, 48, a dalit of Buddhist faith, was brutally murdered at Kulakjai village of Satara district on 26th April, 2007. The Ghadge family in order to irrigate their agricultural lands sought permission from the government and other authorities to dig a well near the percolation tank and other wells situated there. This was sanctioned under Jawahar Vihar (well) Yojana and they were provided financial assistance of Rs. 60,000.There were four other wells in that area including a public well for the village, owned by the village panchayat which was incidentally the largest one. During the digging of the well, Madhukar was attacked by people belonging to the upper castes by weapons, and the attack was so brutal that it resulted in his death. The contention of the attackers was not only the reduced flow of water to the village well, Madhukar being a dalit, had challenged the upper caste monopoly over water, which had stinged them the most, particularly when water is such a vital resource in a drought prone area. The case exposes a clear cut issue of an atrocity over dalit. It was well planned and Madhukar was attacked when hardly anyone was near him. This was beyond any wild nightmare of the Ghadge family. (Source: ‘Kulakjai dalit murder report’, <http://vakindia.org/pdf/kulakjai.pdf> )

3. Rashmita Sethy, a SC woman, and her family have been barred from using a community tube well near her house for the last three days after she dared to lodge an FIR against two persons, who abused and assaulted her. Rashmita lives with her husband and two-year-old daughter in Khandagiri Bari on the outskirts of Bhubaneswar. (Source: ‘A Bulletin of dalit resource centre’, VAK, Mumbai, August 2007 (<http://www.vakindia.org/pdf/db-aug2007.pdf>).

4. An elderly dalit woman was burnt allegedly by the three members of the upper caste community over a dispute on fetching water from a village hand pump. Prembai, 55, suffered eighty percent burns as she was set ablaze, resulting in her death. The incident took place at Harda’s Kantada village. The reason for the atrocity was that when Prembai was when stopped from using the village hand pump. She did not budge. As a result, a quarrel erupted; following which she was set on fire, after which she succumbed to her injuries, a day later. (Source: The Times of India, June 18, 2008) .

5. Around forty dominant caste people attacked the dalit colony of Pangal village, in Mahbubnagar district of Andhra Pradesh broke into their locked houses and destroyed all they got their hands on, in retaliation of dalits having taken water from the water tap in the dominant caste people’s colony after completion of an Anti-Untouchability Conference on 16th November, 2001. The dalits were terrified and most fled from the village. (Mangubhai & Irudayan <http://www.dalits.de/details/dsid_hintergrund_wasser_recht.pdf>

**Is there hope? Yes…**

1. In Guravareddypalem village I Prakasham district of Andhra Pradesh, dalits used to draw water from the well not for their own needs, but to carry it to dominant caste houses. They had to wait patiently for long hours for dominant caste people to fill their pitchers, sometimes, having to return empty handed. But, all this was changed by a dalit, Nadella Anjaiah. Thirsty after hours of hard work in the fields, he gave up waiting patiently after several hours and took water from the village well. Caught by the dominant caster Reddy villager, the entire dalit community was barred from accessing the well itself. Instead of taking the matter lying done, the dalit community filed an official complaint, eventually securing officials help to gain access to the well. Though the district administration sought to diffuse the caste tensions by offering a separate well to dalits, this was opposed since it would encourage the practice of untouchablilty. Eventually, four Reddy caste culprits were arrested for denying water to dalits and the latter got direct access to water, first time in the village’s history. Mangubhai & Irudayam, <http://www.dalits.de/details/dsid_hintergrund_wasser_recht.pdf>>

2. In Seetanagaram village in Andhra Pradesh, the continuous breaking down of the water pump prompted the dalit villagers to send Durga Rao on a training course on water pump repair, provided by British charity Water Aid. Rao returned and set up a water pump repair business, which soon was in high demand. Initially, the dominant caste villagers refrained from letting Rao touched the bore well. But, later they relented, when faced with the only option of a skilled dalit to set up the well. Slowly, but surely, respect for dalits in the villages grew and some caste barriers crumbled. Important among them was that the local tea shop owner stopped the practice of untouchability of two-glass system in the shop. (Mangubhai & Irudayam, <http://www.dalits.de/details/dsid_hintergrund_wasser_recht.pdf>>

**(c)Case study**

**Even disabled people need toilets they can use**

Dhena Murmu, 32 has a walking disability. She belongs to the Santhal tribe and stays at

Kadrakura village in Mohanpur block of Jharkhand. Dhena uses a pair of elbow crutches to walk, or uses a wooden seat to push herself for short distances on the floor. She has lost the use of one leg fully because of being effected by poliomyelitis. The only other member in her family is her old mother, her father having died and her brother having moved away after his marriage.

One of the main challenges she faces is standing up from where she is sitting. She found it easier if the place was high like the verandah of her hut or if it was a wooden stool in her house. In the absence of this high place she needed physical assistance to get up and sit down.

According to the Indian Census 2001, women contribute 42.5 % of the total population of

persons with disabilities in India. In spite of their numbers they remain unheard. The problems that confront women with disabilities in rural India are more severe. The inadequate and total lack of access to services, information, health care and rehabilitation services is further compounded by much higher illiteracy rates, longer distances to services and facilities if they exist at all and more severe conditions of poverty than in urban areas.

Disability has a profound impact on an individual’s ability to carry out traditionally

expected gender roles. There is a misconception that because of her physical disability she is not competent in any sphere leave alone being a wife or a mother. In the absence of positive role models many consider themselves as ‘non-persons’ with no duties to perform, without any rights or privileges.

Belonging to a triply disadvantaged group(disabled, a poor tribal and a

woman), women like Dhena find themselves up against multiple discrimination as well as barriers that make accomplishing objectives essential in everyday life difficult.

“Apart from everything and other difficulties, the major challenge that I had to face was in meeting my sanitation and hygiene needs, especially the daily humiliation of trying to sit awkwardly in front of others and then looking around for help in order to stand up and

also while taking a bath in front of other ‘whole’ persons,” says Dhena. “I kept feeling that everyone was staring at my legs and that feeling persisted even after all these years.”

Dhena now has access to a toilet near her house. She feels that this has promoted self-reliance and has enhanced her self-confidence, especially reducing the physical strain and the demand of time of her old mother. This has also promoted an environment that is safe, and protects her dignity. A wooden shaft inserted into the ground besides the toilet seat helps her to sit down and stand up independently. The toilet seat is fitted in a manner so as to allow her direct access and she does not have to turn inside the toilet. Her mother keeps a bucket of water for her from the nearby community handpump.

**Simple yet significant modifications:**

Says Dhena, “The simple and low-cost adaptations have enabled me to be independent and self reliant in my house, especially in the areas of managing daily human activities.

These investments have given me the confidence to advocate similar changes outside my home – at my work place and with the community.”

Kadrakura village where Dena lives is one of the villages is a project village of Gram Hyoti, supported by WaterAid. Dhena is now a member of the Village Water and

Sanitation Committee. According to Pashupati Kumar, the chief functionary of Gram Jyoti, Dhena has been one of their early adopters and a brand ambassador for toilet usage in the village. Gram Jyoti is a member of the *Jharkhand Bikalang Punarbas Manch* (Jharkhand Handicap Rehabilitation Forum). Through this they have connected Dhena to a livelihood. She has a hand sewing machine where she uses her hand instead of the regular one’s which require both feet.

Other WaterAid partners in the region who have contributed towards this in their project

area are Lok Prerna, Deoghar , Nav Bharat Jagruti Kendra, Ranchi and RSSO Bhubaneswar.

At RSSO, Bhubaneswar a mobile toilet has been designed. It is a simple technology. A

toilet pan that is made of polypropylene plastic material is fitted to the seat of a chair. The piece equal to the size of the pan is carved out of the seat and the pan is fitted below. The water seal of the pan designed as a gooseneck is connected to a polythene pipe that can be put into a regular toilet and cane be rolled after use. The chair is connected with rollers / wheels. It is easy for the parent / caregiver of the disabled person to roll him or her into the toilet and leave her there without having to hold on to her. This reduces the burden on the care giver and ensures dignity and privacy for the person using it. This also reduces dependency.

In Nayaktoli slum of Ranchi, Nav Bharat Jagriti Kendra (NBJK) has renovated a community sanitation block with WaterAid support. This was to ensure that some of the poorest people in urban slums have access to basic sanitation facilities and a life of dignity. There were two persons in this slum living with loco motor-disability. According to Partha, Project Coordinator, NBJK, they were planning to provide a toilet facility in their homes but there was simply no space. After a lot of discussion with the community and these 2 persons they decided to convert one of the bathrooms in the community sanitation block into a disability friendly toilet. Why a bathroom? Because this had space for a wheel chair to enter and turn around. This bathroom is fitted with a commode, hand rails for support and anti-skid tiles so that one does not slip when it is wet.

**Conclusions**

Lack of proper access or denial of access to water and sanitation is a violation of

the right to human dignity. Do not discount/ exclude the needs of the vulnerable groups

Universal access is possible: all it requires is a mind set and the development and adoption of low cost simple technologies and innovations.

**Case study**

**Not toilets but dignity**

Over the last few years, implementation of the Total Sanitation Campaign (Government of India, programme for supporting people get access to sanitation facilities in rural areas) in Deoghar and Pakur districts of Jharkhand has increased toilets coverage. While this is encouraging and a reason for optimism, questions do arise: “Who is benefitted”? Is this programme really catering to ‘ALL’?”

Generally, provisions under government programmes are for BPL (below poverty line) families where set patterns of technical designs for toilets are approved by the district level authorities responsible for sanitation, the DWSMs (District Water and Sanitation Mission (, a modal body at district level for planning and implementation Total Sanitation Campaign). Based on this, toilets are constructed with government incentive for individual households. However, evidence indicates that even after such provisions and coverage, people with special needs, or the differently abled are being left out, since even if their families have toilets, these are not user friendly nor appropriate for them. This means that sometimes, the programme designed to be ‘total’ so that there is universal access and people can live with dignity may not really be so.

To enhance the inclusiveness of access and to sensitize the service providers and the community on the need for inclusive approaches in planning, design and implementation, several initiatives were undertaken by the Regional Office East for the state of Jharkhand along with Gram Jyoti, a partner of WaterAid. All this was possible because of one person, Jitendra Turi of Sisanathur village, Mohanpur block , Deoghar district Jharkhand who proved to be really special.

Jitendra suffers from multiple disabilities (locomotors, visual and mental impairments) since his childhood. He comes from a Scheduled Caste (so called ‘lower caste’ in India) family and lives with his parents. Even at the age of 25, he is still dependent on his mother for most of the activities. He, unlike other children, is unable to go to school, or participate in village activities and remains at home. Completely unaware of the importance of sanitation facilities for their son so that he could lead as normal a life as possible, with reduced dependency and with dignity, the family did not realize the need of having a toilet at home. For defecation, his mother

usually took him to the outskirts of the village. Sometimes, due to the workload when was unable to take him out, she would ask him to defecate in a corner of the village lane, which earned him the ridicule of villagers and children. “I felt such shame in telling my mother to help me for defecation. I am grown up but how can I go out? I cannot see, nor am I able to walk” recalls Jitendra while sharing his agony.

Jitendra’s family has a small land holding which is their major source of income. They were unaware about government incentives and their entitlements to these or toilet options which could help their son. Burdened with poverty and looking after the needs of Jitendra, his parents could not participate in village meetings and get information.

Gram Jyoti was working on sanitation in this village when Jitendra was spotted by the programme team. A village water and sanitation committee was already formed here to work on sanitation and hygiene related issues, government provisions for this and low cost toilet options for the same.

Gram Jyoti brought up the case of Jitendra in the committee, after which his family was approached and the benefits of having a toilet at home explained. The family contributed the mason charges and labor for constructing a toilet. His toilet is made of mud and bricks, with a raised squatting platform fitted with a rural pan, which can be used as a commode. The walls of the toilet walls wetre fixed with a shaft for support and easy movement. To help him***.***with his visual disability, a bamboo was tied from main the door to the toilet.

Gram Jyoti village motivator then taught him to locate / sense the direction and use of toilet. After few rounds of hands-on demonstration, Jitendra was ready. He now locates and uses toilet by his own. Jitendra is now self reliant and motivates others by saying, “If I can use toilet why can’t you?”

Gram Jyoti has taken up the cause of these people on different frons as well. According to Abham the project coordinator, the organization is advocating for the continuation of the presently discontinued pension for people with special needs, provisioned under the Swami Vivekananda Scheme. The organisation is also helping his family with activities/ benefits under the Mahatama Gandhi National Rural Employment Guarantee Act. Jitendra’s family has been provided with an irrigation well under this scheme, helping his father in agriculture.

**Key learning from the community process:**

* Persons like Jitendra should not just be limited to being the recipients of service provision or charity. They need to be brought into village forums, where they can also have a say in village processes.
* The environment surrounding people with disabilities is a problem, not the people who have these special needs. In case of Jitendra, his disability was a result of social shortcomings in terms of awareness, attitude, approaches and accessibility to services
* Sometimes what is required is not a new hardware technology per se, but new and sensitive ways to implement technology, with appropriate modifications. In this case, the adaptations were such that the toilet can be used by both, differently abled persons as well as the other family members.

**Linking community processes to district forums at Deoghar and Pakur**

The work with supporting Jitendra live his life independently and with dignity was an example which was used for influencing and reaching out to more such people.

A district consultation was organized in Deoghar and Pakur on ‘Influencing WASH Service delivery for person with disabilities’ in collaboration with DWSMs. Representatives of NGOs working on water, sanitation and hygiene, departments like Women and Child development, Education and Drinking water and sanitation, participated in this meeting. The forum highlighted examples such as Jitendra, to prioritize needs of differently abled in water and sanitation service delivery.

This led to the following actions at the government level:

* Restructuring of VWSC with representation of differently abled persons.
* Assurance of revision of district project implementation plans so that these include the special needs of people by the Member Secretary, DWSM, Deoghar.
* Awareness of district functionaries on specific WASH provisions (Govt programmes / schemes) for differently abled categories.
* Incorporation of technical modifications to existing Water and sanitation facilities to make them user friendly

# Appendix 2: Selection of resources from WaterAid Experience:

More available on website pages on equity and inclusion:

<http://www.wateraid.org/international/what_we_do/how_we_work/equity_and_inclusion/default.asp>

This bibliography is arranged under the following categories:

* Country analysis of who is excluded and why in relation to WASH
* People living with HIV and AIDS
* Disability
* Women
* Children
* Working with Specific Marginalised and excluded communities

## Country analysis of who is excluded and why in relation to WASH

**Reaching out to the excluded- Exclusion study on water, sanitation and hygiene delivery in Malawi**

Wateraid; 2008 *Keywords: Equity*

In its quest to ensure that the vulnerable are not excluded from their work, WaterAid Malawi has commissioned this study to investigate reasons for exclusion and how marginalised groups can be included. The study was conducted in all five districts in which WaterAid in Malawi currently supports projects – Mzimba,

Nkhotakota, Salima, Machinga and Lilongwe.

<http://www.wateraid.org/documents/plugin_documents/malawi_equity_and_inclusion_study.pdf>

**Etat de l’inclusion et de L’equite a Madagascar**

WaterAid, 2010

*Keywords: Equity, disabilities, gender, children*

Dans le cadre de la mise en oeuvre du principe de WaterAid sur l’équité, l’inclusion et le droit, le rapport suivant traite et restitue les résultats des études sur ce thème fait à Madagascar par l’équipe conjointe d’ECA et d’ERGC dans 4 communes. A Madagascar, quelques barrières notamment institutionnelles, environnementales et celles liées aux attitudes ont été identifiées par rapport aux problématiques d’équité et d’inclusion. Ces diverses barrières sont vécues par les personnes vulnérables telles les femmes, les PVVIH, les PVH, les personnes âgées, les enfants, les personnes détenues, … d’une manière assez contraignante pour leur accès aux services d’EPAH.

<http://www.wsscc.org/resources/publication/madagascar>

## People living with HIV/AIDS

[Access to water, sanitation and hygiene for people living with HIV and AIDS: A cross-sectional study in Nepal.](http://www.wateraid.org/other/startdownload.asp?DocumentID=498&mode=plugin)   
http://www.wateraid.org/images/spacer.gifWater, sanitation and hygiene (WASH) are the basic primary drivers of public health. Access to them ensures personal hygiene and, most importantly, human dignity. People living withhttp://www.wateraid.org/images/spacer.gif HIV and AIDS (PLHA) suffer particularly from the health and social impacts of inadequate water.   
**http://www.wateraid.org/images/spacer.gif** <http://www.wateraid.org/other/startdownload.asp?DocumentID=498&mode=plugin>

**Access to Water and Sanitation for People Living with HIV and AIDS: An Exploratory Study**

Water Aid, AMREF Tanzania; Diana Nkongo, Christian Chonya; 2009

*Keywords: HIV/AIDS*

This study was a collaborative effort between WaterAid Tanzania and AMREF in Tanzania. It was prompted by the observation that the water and sanitation needs of people living with HIV and AIDS (PLHIV) and the likely consequences of inadequate access to water by their households were not being explicitly identified, and not being integrated into either HIV and AIDS interventions or water and sanitation sector programmes. The study found some evidence that PLHIV have an increased need for both water and sanitation services, but lack the means to meet these needs. It confirmed that there is lack of clear arrangements on access to water and sanitation for PLHIV. It found some evidence of stigma, although this was not reported to be a major problem. And it found, in hygiene promotion, a clear area of overlapping interests between the water and sanitation sector and the HIV and AIDS sector, though this hasn’t yet resulted in much cooperation between sectors in practice or in harmonised hygiene promotion messages. Recommendations are made for increased co-operation and for further studies.

<http://www.wateraid.org/documents/plugin_documents/wateraid_and_amref_full_report.pdf>

**Different, and the same- Towards equal access, education and solidarity in WASH**

WaterAid; 2008

*Keywords: equity, HIV/AIDS, disabilities*

Over the last two years WaterAid Ethiopia (WAE) has carried out several pieces of research that suggest people with disabilities and people living with HIV/AIDS have been largely invisible to those delivering WASH. The full findings of this research are documented in longer WAE reports. Here the aim is to bring some of the key points regarding needs, coping mechanisms, access constraints etc. to a wider audience and to present policy makers and practitioners with succinct findings and possible solutions.

<http://www.wateraid.org/documents/plugin_documents/different_and_the_same.pdf>

## Disability

[**Report - What the Global Report on Disability means for the WASH sector**](http://www.wateraid.org/documents/report__what_the_global_report_on_disability_means_for_the_wash_sector.pdf)

In 2011 the WHO published the world's first report on disability which covers all forms of disability, from blindness to mental health issues. It reviews this in relation to the WASH, education and health sectors and employment. This report gives an overview of the information that is relevant to the WASH sector within the WHO report; how WaterAid is addressing the recommendations in the report, as well as where we could develop our approaches further. WaterAid, Jane Wilbur, 2011

<http://www.wateraid.org/documents/report__what_the_global_report_on_disability_means_for_the_wash_sector.pdf>

**Principles and practices for the inclusion of disabled people in safe sanitation. A case study from Ethiopia**

WaterAid; Jane Wilbur; 2010

*Keywords: disabilities, rights*

WaterAid in Ethiopia designed a pilot project to meet the needs of disabled people within their service delivery work. Learning gained through the project informed WaterAid’s equity and inclusion approach. In 2010 a formative evaluation of WaterAid Ethiopia’s pilot project in Butajira was conducted, along with an extensive review of relevant literature, including an assessment of four case studies of World Vision’s projects, semi-structured interviews and participant observation. This paper gives an overview of the evaluation of the Butajira project and draws out key principles and practices for development organisations aiming to empower disabled people.

<http://www.wateraid.org/documents/plugin_documents/briefing_note_principles_and_practices_for_inclusive_sanitation.pdf>

Briefing note 4.86MB

<http://www.wateraid.org/documents/plugin_documents/full_report_principles_and_practices_for_inclusive_sanitation_1.pdf>

full report 9MB

**Mainstreaming Disability Issues in Water, Sanitation and Hygiene Services**

WaterAid; 2010

*Keywords: Disabilities*

Report on a one-day workshop for stakeholders in the water, sanitation and hygiene (WASH) sector to share experiences around issues of disability mainstreaming in sector policies, strategies and implementation guidelines, and more importantly on how service providers are translating these polices and guidelines into practice.

<http://www.wateraid.org/documents/plugin_documents/mainstreaming_disability_issues_in_wash_ghana.pdf>

**Accès équitable à l’assainissement: Offrir des technologies d’assainissement qui répondent aux besoins des personnes vivant avec un handicap** WaterAid Burkina Faso, 2011

A report of an action research project in two villages in Burkina Faso, in which research into disability resulted in more inclusive WASH, documented costs, and the impact of inclusion on lives of disabled people in the villages

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| Women **Seen but not heard? A review of the effectiveness of gender approaches in water and sanitation service provision** | |
| *WaterAid; 2009*  *Keywords: gender* | |
| A review of the effectiveness of gender approaches in water and sanitation service provision used by WaterAid’s partner organsiation NEWAH in Nepal. This review finds that policies of affirmative action, financial support for poorest households and gender awareness training have promoted greater equality in accessing resources and services, and participation in user management committees. But training is only effective if the views of both men and women on gender are considered, focusing on women can marginalise gender as a women's issue. It is also important to understand the community-level decision-making process and local social and political context in developing an inclusive approach. | |
| http://[www.wateraid.org/documents/plugin\_documents/wa\_nep\_\_gender\_study\_report\_july\_2009.pdf](http://www.wateraid.org/documents/plugin_documents/wa_nep__gender_study_report_july_2009.pdf) | |

[Is menstrual hygiene and management an issue for adolescent school girls?](http://www.wateraid.org/other/startdownload.asp?DocumentID=351&mode=plugin)   
http://www.wateraid.org/images/spacer.gifA comparative study of four schools in different settings in Nepal.

[Is menstrual hygiene and management an issue for adolescent school girls?](http://www.wateraid.org/other/startdownload.asp?DocumentID=351&mode=plugin)

**Manual on Menstrual Hygiene Management – in draft.**

Comprehensive manual on all aspects of menstrual hygiene management drawn from a wide range of programme experience.

**To be published in 2012**

## Children

**Growing up without WASH: the impact of lack of WASH on children**

WaterAid Ethiopia has been conducting different case study researches to develop our knowledge of exclusion and forwarded recommendations for program improvement. This is one series of those studies specifically exploring the links between poor WASH provision and its impact on the general well being of **children**.

Upcoming – to be published in 2012

## Working with Specific Marginalised and excluded communities

**Promoting safe water, sanitation and hygiene in hard to reach fishing communities of Lake Victoria: Nsazi Island gets the first public toilet**

WaterAid Uganda, 2011

*Keywords: geographic*

Nsazi is one of the fishing islands on Lake Victoria in Uganda. The population is transient, multicultural, and very poor. Most people defecate in the open beside the lake, which is the only water source, and dysentery, diarrhoea, malaria and intestinal worms are the most common diseases affecting children under the age of five. WaterAid has worked closely with the community to introduce improved sanitation facilities to the island, constructing two public toilet blocks with cubicles for men, women and people with disabilities, plus a shower room.

<http://www.wateraid.org/international/about_us/newsroom/9898.asp>

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| **Burden of Inheritance – WaterAid India Report on Manual Scavenging** |
| WaterAid; 2009  *Keywords: human rights* |
| This report outlines how over one million people in the country continue to scrape an existence through manual scavenging, forced largely by social convention and caste prejudice, and calls for strong action to eradicate this practice. A violation of human rights, this discriminatory and demeaning practice was outlawed by the Indian Parliament in 1993 but still continues today. India has missed three deadlines to make the country 'manual-scavenger free'. India's booming cities help keep the practice alive, as there is often little infrastructure for sanitary sewerage and waste disposal systems. |
| <http://www.wateraid.org/documents/plugin_documents/burden_of_inheritance.pdf> |

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| **Propping up the marginalized: Equity and Inclusion. An initiative for including the excluded people of village Akli taluka Mithi District Thar** |
| Mukesh Radja;  Sukaar Foundation, WaterAid; 2011  *Keywords: equity, cast* |
| In Akli, a village 70km to south of Mithi city, 71 households of the scheduled caste Meghwar community were forcefully evicted by the feudal lord after a schedule caste girl was  abducted,  forced to marry and converted to be Muslim. The evicted community was settled in the open near Mithi city without any basic services.  With the support of WaterAid Pakistan they provided 40 toilets and 71 water tanks. Sukaar Foundation’s involvement in the community’s reintegration and rehabilitation has raised important lessons for future work with scheduled caste minorities. They identify the following priorities:  to support the organization into groups that can engage in regular development programmes;  taking special measures to empower through social mobilization, capacity building and awareness raising programs focused on their rights; helping them access alternative income generating opportunities; supporting them to  get access to their water and sanitation services, education, health and other basic necessities of life; and finally, to conduct further research into the conditions faced by schedule caste minorities when they migrate. |