Disability: Making CLTS Fully Inclusive

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CLTS Knowledge Hub at www.communityledtotalsanitation.org
IDS has been working in support of Community-Led Total Sanitation (CLTS) since its beginnings. CLTS has now become an international movement for which IDS is the recognised knowledge hub.

The Knowledge Hub is dedicated to understanding the on-the-ground realities of CLTS practice and to learn about, share and promote good practices, ideas and innovations that lead to sustainability and scale. We seek to keep the CLTS community well connected and informed and to provide space for reflection, continuous learning and knowledge exchange. We work in collaboration with practitioners, policy-makers, researchers and others working in the development, sanitation and related communities.

Ultimately, the Hub’s overarching aim is to contribute to the dignity, health and wellbeing of children, women and men in the developing world who currently suffer the consequences of inadequate or no sanitation and poor hygiene.

Front cover
Raised pathway to toilet in North Timor Tengah District, NTT Province, Indonesia. The pathway gives easy, safe (non-slippery) access to the toilet, even during the rainy season. The toilet is now completed and a secure wooden door has been installed in place of the sackcloth.
CREDIT: TETHY VESTHU/ PLAN INDONESIA
Disability: Making CLTS Fully Inclusive

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CLTS aims at total sanitation. For that it has to be inclusive. The CLTS Handbook stresses facilitating people to do their own appraisal and sanitation profile, community self-help and cooperation, and social solidarity between the rich and poor. There are ethical reasons for being inclusive. There is also the bottom line that while any open defecation continues, all are affected. The Handbook message to facilitators and those who follow up on triggering is:

Be alert for and promote emerging donors in the community. Facilitate the identification of those who are weaker, poorer, landless or otherwise unable to construct their own toilets. These may be old people, widows, single mothers, the disabled, those who are chronically sick or others. Ask the gathered community how they will solve their problems. Do not make suggestions. Proposals for action can be expected in communities where total sanitation has been fully understood. Your role is to facilitate the linkages between the weaker and poorer and those who are better off and willing to help them, whether through labour for digging and construction, materials, money or loans (Kar with Chambers 2008).

This issue of *Frontiers of CLTS* takes this further, focusing on people with disabilities and particular needs for access. There are many forms of disability, including mobility impairments, sensory impairments (affecting sight or hearing), chronic illness, impairments caused by older age or mental health issues. People affected tend not to be present at triggering, to lack voice in the community, to have their needs overlooked, and may even be hidden by their families. This issue outlines the reality of the experiences of people with disabilities, the varied nature of their needs and how they can be met, and concludes with practical recommendations for facilitators and all those engaged in CLTS to make the different phases and processes of CLTS more inclusive.

The related and vital topic of menstrual hygiene management will be the subject of another issue of *Frontiers* and will only be touched on lightly here.
To address inclusiveness and accessibility for people with disabilities, we draw on current (2014) research in Uganda and Zambia and on other water, sanitation and hygiene (WASH) programmes that aim to be fully inclusive (Wapling 2010; Wilbur 2010; Jones 2013). We outline barriers to access, and propose practical actions to ensure that CLTS and related programmes are inclusive and accessible for disabled people.

The research

The research experience in Uganda and Zambia has focused on people who are likely to have difficulty accessing and using WASH facilities because of age, disability or chronic illness; on the barriers they face, and on how these can be overcome. The practical findings from this action research in two on-going WASH programmes should be widely applicable. Both programmes aim for 100 per cent open defecation free (ODF) status. Each country team followed the CLTS stages, applied the same triggering tools and promoted local leadership.

Box 1: What does ‘making CLTS fully inclusive’ mean?

What applies to people with disabilities also applies to others who may be left out of CLTS processes – those who have low status, minorities, those who are very poor, women, girls, children and others. The voices, views and needs of all these people can be relevant in deciding technical options for toilets, their location and accessibility. Their empowerment throughout CLTS and WASH processes can be enhanced by awareness and efforts by facilitators and local-level workers, who can:

- Convene community members to appraise, analyse and discuss the issues.
- Encourage and support disabled people and others whose views may be dismissed to speak up and be heard when plans are being made.
- Facilitate awareness of the access barriers faced by different groups.
- Encourage local innovation while being prepared to supply information about low cost, low-tech, accessible sanitation and hygiene options.
- Communicate in ways accessible to people with sensory impairments.

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1 WaterAid, the Water, Engineering and Development Centre (WEDC) and Leonard Cheshire Disability (LCD) are collaborating on this research, with funding from SHARE. The Institute of Economic and Social Research (University of Zambia) and the Appropriate Technology Centre are research partners in Zambia and Uganda respectively. The implementing partners are Development Aid from People to People (DAPP) in the Mwanza West ward in Zambia, and WEDA and CoU-TEDDO in Amuria and Katakwi districts in Uganda.
The scale of the problem

One billion people globally are estimated to have disabilities (WHO and World Bank 2011; Satterthwaite and Winkler 2012). A rising total of 740 million people are aged 60 and over. The 2.5 billion people in the world who lack access to adequate sanitation (WHO/UNICEF 2014) includes a high number of people with disabilities, probably hundreds of millions, since access for them is often so difficult (Satterthwaite and Winkler 2012). In community participatory mapping exercises the proportion of the population defined by participants as disabled often surprises outsider facilitators by being in the range of 10 to 15 per cent (Trevett and Luyendijk 2012), underlining that they and other marginal groups can easily be overlooked. Disabled people who cannot access the sanitation and hygiene facilities constructed will either continue open defecation, or need support, increasing the workload of the family. The ideal is that all can access facilities independently. The bottom line is that unless sanitation facilities are accessible to all, communities will never be truly ODF.

Barriers to access

The need for convenient access to sanitation and hygiene is stark and acute for many disabled, older and chronically ill people who have to defecate in their dwellings or in the open. In their homes there are problems of smell and disposal. In the open, people with visual impairments have to rely on a guide or make their own way with dangers of trampling shit (see quotes on next page). Problems faced by people with a mobility impairment are similar, and if they move on all fours, risk getting filthy crawling among the shit (Wilbur 2010). If the toilets are dirty it is harder for disabled people to keep themselves clean, especially if they are blind. The dangers of getting dirty affect their health, degrade their self-esteem and can affect how others see and treat them. This can undermine their confidence and make them unwilling to express their needs (WaterAid 2013a).

Physical barriers

These may be in the natural environment or in the built infrastructure, and include:

- Long distances to facilities.
- Paths that are rough or steep or no paths at all.
- Toilets with high steps or narrow doors.
- Inside, a lack of space.
- Nothing to hold onto, or to raise oneself up from squatting.
- Nothing to sit on for those who cannot squat.
‘I used to go to the bush with a child who leads me, but they would lead me to the thorns and I would get cut on my ankles and legs. Sometimes the child would not see a ditch and I would fall in. I used to be scared that people would see me as I didn’t know if I was near the road or covered, but with time I got used to it; it became normal’ (Esther Cheelo, who is older and has a visual impairment, Zambia).

There are many things that could go into my hands – sharp stones and thorns; there is no alternative. If there is a toilet beside my house it would be better for me’ (Young man, Ethiopia, see image below).

‘There are times you ask somebody to help you and the person refuses, so you have nothing to do but just have to endure’ (Older woman, Uganda).

A young man demonstrating his route to OD area. Credit: WaterAid/Jane Wilbur.
‘Before we had the toilet we had so many flies that would be sitting on our food. Look at her she cannot walk, she would defecate in the nearby bushes and flies would come and sit on our food’ (Robert, 56 years (no surname recorded), speaking on behalf of his daughter, Pricilla, 16 years who is physically disabled and cannot speak, Zambia).

‘Before, I used to dig a hole in the ground and covered it after. Sometimes I would get tired digging a hole. My back would get sore. Sometimes I have to kneel’ (Joyce Mary Apiny, 13 years old, Uganda. Physically disabled).

‘Before she had to dig on the ground. Sometimes her clothes got littered with faeces. Her hands used to be covered in faeces as she used to cover it with her hands’ (Edisa Lucy Igali - Joyce’s mother).

‘I tie[d] shoes on my hands and I went to the toilet but it was very difficult. I went early in the morning when no one was getting up... I was using my hands to go to the toilet and I become very dirty’ (Alyaka Gebrim, 18 year old physically disabled woman, Ethiopia).
Attitudinal barriers

Ignorance of the causes of disability or illness can lead to stigma and discrimination. Some families hide disabled family members. Disabled people then lack opportunity or confidence to participate in society. They may even be denied access to WASH facilities.

‘They refused me to enter a toilet. I have started being embarrassed of my disability’ (Young disabled man, Zambia).

‘Sometimes they [community members] tell me to stop talking. I don’t feel good when I am told to stop talking. I explain the problems, they tell me to stop. They think what I am saying is not benefiting them’ (Loingnios Hachalambwela, 55 years, physically disabled man, with a condition that causes him to shake).

Organisational and institutional barriers

Disabled, older or chronically ill people may:

• Be excluded by the way a programme or service is delivered.
• Not hear about a meeting.
• Not be able to reach it.
• Not be invited or feel able to speak.
• Have their opinions dismissed.

Lack of consultation and participation can then lead to inappropriate design or location of facilities, overlooking their needs, and limiting or denying their access to sanitation. Addressing these barriers is crucial throughout the processes of CLTS.

Implementing staff often lack information about low-cost ways of making toilets accessible for disabled and older people. People themselves are often unaware of the options available, so they do not know to ask for improvements (Jones and Reed 2005).

Making CLTS inclusive and accessible

The Uganda and Zambia research has found ways in which a CLTS approach can address many of these barriers and make each stage of CLTS more inclusive and accessible.
Preliminaries: Learning and orientation

Useful learning and orientation can precede the launch of a WASH or CLTS programme. However, the following should be remembered:

- Too much knowledge can lead to too much awareness of social constraints and inhibit CLTS triggering.
- Too many preliminaries can delay a programme.
- Timing, scale, length and depth of these preliminaries should be optimised, not maximised.

With these things taken into account, five actions to improve awareness of disabilities and learn about local issues are:

1. Knowledge and awareness on disability. Care is needed to avoid a didactic mode which is totally contrary to the spirit of CLTS. Be alert to ignorance of the origins or nature of disabilities, and be prepared to correct these. For example, note that a person may be born disabled, or they may become disabled due to an illness, such as polio or skeletal tuberculosis, or as a result of an accident, and that blame should not be attached to disability. Ensure that disabled people are represented in publications, speeches by leaders, and in CLTS campaigns. For useful awareness-raising activities see WaterAid (nd).

2. Capacity development. Improve understanding/skills by training staff, including local government, in barrier analysis (see point 5). Facilitate their analysis of what this means for their own work, including finding solutions to address barriers through programming and technical designs (WEDC and WaterAid 2012, 2013, WaterAid and WEDC nd).

3. Accessibility and safety audit. Conduct an accessibility and safety audit of existing WASH facilities with a group of women and men, girls and boys, including disabled people with different impairments. This is an excellent way to increase practitioners’ understanding of the barriers related to technical design and their impact on some users (WEDC and WaterAid 2014).

4. Scoping study. Conduct a scoping study on barriers to access to existing facilities which disaggregates data by sex, age and disability, asks about menstrual hygiene management and explores traditional attitudes about gender, disability and age in relation to WASH. Collect views from women and adolescent girls, children, older people, disabled people and their households, people living with chronic illness, and

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2 Disability is often considered a curse, for example in Ethiopia, where some believe that disabled people have been attacked by a ‘devil spirit’ (Wilbur 2010). Misunderstanding of the causes of disability leads to stigma, discrimination and exclusion.
any groups living in the area whose needs are liable to be neglected. This may include different caste groups, pastoralists, migrant workers, displaced people and sex workers.

Where possible ask affected people directly, rather than relying on their carers or family members, whose responses have been found less accurate. Also, questions about a person’s impairment have been found unhelpful. For people with disabilities, examples of exploratory learning questions are:

- What do you do about defecation and urination?
- Where do you go?
- When do you go?
- Do you have any problems? Responses might be:
  - It is too far away
  - The path is difficult
  - I must crawl and get filthy
  - I cannot squat and there is nothing to hold onto
  - There is no privacy
  - I feel unsafe
  - I am not allowed to use the same toilet as others
  - People tease and bully me
  - Or others
- Could you take me with you to see what it is like?
- How do you deal with these problems?
- What would make a difference for you? For instance:
  - Install a toilet near the house
  - Provide a rail for support/ guidance
  - Add a seat so I don’t need to squat or get my clothes dirty
- How could that be done? And by whom?

The scoping study can be designed as a baseline if one is needed.

5. Participatory barrier analysis. The scoping study should highlight groups of people who face barriers to accessing sanitation in a community. In participatory barrier analysis, people with and without impairments in the community are invited to carry out their own appraisal and analyses (WEDC and WaterAid 2013).³ Their findings and those of the scoping study can be presented to stakeholders, followed by a facilitated discussion. Participants categorise the issues by the kind of barrier: physical, social and cultural (negative attitudes) or organisational

³ See the ‘Equity and Inclusion in WASH’ - learning materials (WEDC and WaterAid 2013). These include a powerpoint with script, facilitator notes for group activities, and accessibility audits. All resources are available in English and French from: https://wedc-knowledge.lboro.ac.uk/collections/equity-inclusion/ (accessed 7 July 2014).
and institutional. They then discuss and suggest solutions to these barriers, and develop action plans to realise these. The action plans contribute to the programme of work.

Analysis by community members raises awareness of the barriers that people face and how the community can address those challenges. Where disgust is a primary trigger for behaviour change this makes it clear that older or disabled people may not be defecating in the open out of choice but because they lack facilities that meet their needs. The process also increases levels of ownership and responsibility to take action. Participatory barrier analysis can be applied with all actors at any of the stages of CLTS.

Table 1 is based on a worked example from the research project in Uganda and Zambia (Wilbur et al 2013).

Table 1: Highlights from the barrier analyses

<table>
<thead>
<tr>
<th>Barrier</th>
<th>Barriers to access and inclusion identified in baseline survey</th>
<th>Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical</td>
<td>• Long distance to toilets. • Lack of privacy. • Nothing to hold onto. • High steps. • Narrow doors. • Unsafe toilets. • Dark inside.</td>
<td>• Nearer toilets. • Private toilets (e.g. doors that lock). • Toilets with seats. • Handrails. • Wider doors with level entrances. • Ramps instead of steps • Increased space inside toilets. • Designed to allow light inside toilets.</td>
</tr>
<tr>
<td>Barrier</td>
<td>Barriers to access and inclusion identified in baseline survey</td>
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</tbody>
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| Social and cultural (negative attitudes) | • Discouraged from using shared toilets.  
• Family doesn’t allow to fetch water.  
• Teasing/bullying.  
• Limited social support.  
• Isolation in the family/community. | • Run awareness raising campaigns to highlight issues at the community level.  
• Target different stakeholders in the community to drive attitudinal change (e.g. religious leaders). |
| Organisational and institutional     | • Lack of law, policies, strategies and guidelines on WASH for disabled people.  
• Lack of information on accessibility options.  
• Lack of accessible information (visual, oral).  
• Lack of consultation with disabled people.  
• Limited awareness of disabled people’s rights within the organisation and externally (community, NGOs, private sector, governments). | • Develop accessible designs and guidelines, and train local masons on the construction.  
• Provide demonstrations of accessible toilets.  
• Information, education and communication materials to include disability in accessible formats (posters, pictures, radio) to raise awareness.  
• Ensure effective participation of older and disabled people, and those living with chronic illness. |

After data collection and analysis, setting targets is an option to:

• Increase accessibility of facilities.
• Reduce numbers of people who are not able to access and use facilities.
• Increase participation and active roles of older or disabled people.

Targets can be monitored throughout all stages in a CLTS programme.
Disability-related actions through the stages of CLTS

1. **Pre-triggering**
   Informed by the scoping study findings, besides building rapport and identifying potential leaders, facilitators should:
   
   - Gain a sense of the barriers that different groups face in accessing sanitation.
   - Find meeting places for the triggering that are accessible to as many as possible.

2. **Triggering**
   Triggering stimulates a collective sense of disgust as the community learns how open defecation is bad for everyone. The community then decides how to address the problem and take action. Meaningful participation is vital to CLTS. Box 2 provides a checklist of ways to facilitate meaningful participation at this stage by those who are disabled and who have less power.

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**Box 2: Ensure full and meaningful participation**

During all stages of CLTS, using participatory approaches during triggering and soon after triggering should enable different groups to actively take part, including those with less power.

**When arranging meetings:**
- Ensure meeting times are convenient for both women and men (e.g. not during meal preparation).
- Agree locations of meetings to be close to homes of the least mobile, and in buildings without steps.
- Take care that disabled and older people are not pushed to the back of meetings and arrangements are made for those with difficulty hearing or seeing to be near the front.
- If visual media are used, ensure they are described verbally to those with difficulty seeing, and verbal presentations supplemented with visuals for those with difficulty hearing.

**When arranging additional meetings:**
- Consider separate group discussions with people who may feel unable to speak in community meetings.
- Visit disabled or older people who cannot attend meetings in their homes to ensure their concerns are not ignored.
- Share issues raised in these additional meetings with the wider community or their selected representatives.
3. Post-triggering
The post-triggering stage includes community action planning, follow up visits, meetings and actions by local government staff and/or NGOs and natural leaders, and monitoring.

For monitoring, those with additional/particular needs, and those who need help, can be marked on participatory maps where these are used. Tools and techniques to ensure that outcomes from this stage are accessible and inclusive are covered under Box 2 and below.

Local solutions and participatory design and problem solving can be encouraged, for example using accessibility and safety audits (p14), see also Frontiers of CLTS No 1 on Participatory Technology Development.

On providing ideas and information:
For the household level, consider providing information about low cost, low tech options to make household latrines easier, more comfortable and safer for use by everyone in the family, especially disabled people. Features of accessible designs could include:

- Level, marked paths. A firm, even path clear of hazards benefits everyone, not only wheelchair and crutch users.
- Ramps or low steps with handrail to the latrine entrance.
- Wide entrances to toilets, and enough space inside for a person and her/his carer to turn inside.
- Simple handrails and movable toilet seats that can be placed over pit latrines.
- Hand lever to replace a foot lever on ‘tippy taps’ for people with weak legs.
- Toilets that are safe (location appropriate) and secure (e.g. lockable doors).
- Door handles and locks that can be easily reached by all.
- Facilities for menstrual hygiene management, both at the household level and for institutional and public facilities (see Menstrual Hygiene Matters Toolkit (WaterAid 2013b) and forthcoming issue of Frontiers of CLTS).

- Ensure tactfully that people who are usually excluded are included in the committee created in the community and encourage and actively support them to take leadership roles if it does not overburden them.

For more practical ideas on making participatory processes accessible and inclusive, see Lewis (2000).
Joyce (who is physically disabled and uses crutches) on level path. *Credit: WaterAid/CoU-TEDDO.*


Marked pathway to toilet for visually impaired older couple in South Timor, Tengah District, NTT Province. *Credit: Agus Haru/ Plan Indonesia.*

Fixed toilet seat with handrails. Rails could be made from wood to reduce cost. *Credit: WaterAid/Jane Wilbur.*

Low steps, cross hatched to make them less slippery when wet, Nepal. *Credit: Jones et al 2009.*

Lower cost wooden toilet seat, moveable so others can remove it and squat. *Credit: WaterAid/WEDA.*
Much can be done through local innovation with local materials. Entrepreneurs can also be made aware of the market for appropriate materials and encouraged to make them available. For example, as part of their efforts to make WASH disability inclusive, Plan Indonesia has carried out disability inclusion training for sanitation marketing entrepreneurs. The training included the introduction of different latrine options to support people with disabilities (see Triwahyudi and Setiawan (2014) and photographs below).

Monitoring accessibility and usability of facilities

‘Accessible facilities’ are often constructed without returning to check whether or not they are usable and used by the people they were designed for. Accessibility and safety audits (WEDC and WaterAid 2014) are the perfect tool to evaluate sanitation and hygiene facilities. For household latrines, the audit team should involve family members with and without disabilities. For institutional facilities, as with sanitation and hygiene in schools, the audit team should involve disabled and non-disabled students and adolescent girls.

Audit teams:
• Identify which features make the facility easy to use, and which make it difficult.
• Find out if there are any safety concerns, particularly for adolescent girls, women and children.
• Make suggestions for changes and improvements.

Involving disabled people is pivotal for improving designs and monitoring
An effective monitoring measure to assess whether CLTS has improved access for those previously excluded is identifying the most significant change story. Stories of significant changes are told by disabled people in the community. Once the stories have been captured, selected groups read out the stories and have an in depth discussion about the value of these changes. They then agree which story is the most significant. Facilitated discussions can be held in the community with the story tellers present (if consent is given), within the project team or with key stakeholders involved in the programme. This process encourages an analysis of the outcomes and impacts on users rather than merely on outputs. The process can reignite interest of stakeholders as changes can be surprising and unexpected. If consent is given, stories can also be used in publications to raise the profile of different voices in the community and when recorded and communicated, can be powerful and inspiring.

Box 3 shows an example of this, and also highlights the fact that complementarities between water and sanitation are especially important for people with disabilities.

**Box 3: Esther Cheelo – the most significant change story**

In Zambia, change stories were collected. The group agreed that Esther Cheelo’s story was the most significant. Esther Cheelo is a blind, older, unmarried lady who now has an accessible toilet and wash room next to her home.

She said: ‘The biggest change is personal hygiene as well as a change in the village surroundings in terms of hygiene... Before they brought water, I could bathe once a month. I was smelling. That is the truth. I am even getting tired of bathing now. I can bathe two to three times a day if I want. The smelling has now stopped. People never used to eat with me because I was dirty and smelling. Now everyone can eat together as I am no longer dirty.’

The biggest change for her was that her interactions with others had increased, which gave her a renewed sense of pride and dignity. This shows that attitudes can change simply by providing accessible WASH facilities.

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4 See for example, www.mande.co.uk/docs/MSCGuide.pdf (accessed 8 July 2014).
Influencing the district level and national levels

Local level actions can be a powerful influence on district and national level decision and opinion makers, raising awareness of the problems of those who are disabled, old or chronically sick. To this end:

• Invite key stakeholders at the national and district level to take part in a participatory barrier analysis (see above).
• Invite key stakeholders to meet representatives from disabled people’s organisations, and from the health, education, aging and WASH sectors.
• Involve key stakeholders from the district and national level to take part in accessibility and safety audits within the community, or at any venue where meetings are being held.
• Lobby relevant stakeholders to include targets on improving access and use for everyone in national planning, monitoring and evaluation systems and procedures.
• Include access and use by disabled people as a criteria of ODF in national ODF verification protocols.
• Engage with organisations or networks promoting the rights of women, children, disabled and older people to jointly raise awareness of the issues different people face in relation to accessing sanitation.
• Bring the issues into the public realm through publications, mass media, meetings and events. Use available data on the topic from interviews with different people, insights from change stories, accessibility audits and the participatory barrier analysis.
• Include accessible sanitation designs in national standards and protocols.

A summary of key actions that can be taken in CLTS

• *At any time:*
  • Ask people with disabilities what problems they face and how these might be overcome.
  • Bring small groups of disabled people together to discuss their experiences with sanitation in a supportive group.
  • Convene community meetings and encourage everyone to listen to what disabled people have to say.
• *Pre-triggering:*
  • Ask who in the community is disabled and whether they can come to the triggering.
If audits are carried out during the planning, implementation, monitoring and evaluation of the facilities, people with a range of different needs and perspectives can actively contribute to each stage. This results in facilities that can be accessed and used by everyone.

References


Jones, H., Jones, O., Kumar, K. and Evans, B. (2009) Sustainability and equity aspects of total sanitation programmes: A study of recent WaterAid-supported programmes in Nepal, WaterAid and WEDC: UK


About the series

This is a series of short notes offering practical guidance on new methods and approaches, and thinking on broader issues. We welcome comments, ideas and suggestions, please contact us at clts@ids.ac.uk

Other key resources on CLTS

These and many other resources are available at www.communityledtotalsanitation.org/resources


Other titles in this series


Ben Cole, who helped UNICEF to adapt and trial participatory latrine design in Malawi, describes the different stages of participatory latrine design and gives practical guidance based on the experiences in Malawi.

Issue 2: Maulit, J.A. (2014) ‘How to Trigger for Handwashing with Soap’

This guide, developed in Malawi by UNICEF, addresses the need for specific tools that help to incorporate handwashing into CLTS.
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About the authors

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Illustration by Regina Faul-Doyle