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**LOCAL ACTION WITH INTERNATIONAL COOPERATION TO IMPROVE AND
SUSTAIN WATER, SANITATION AND HYGIENE SERVICES**

**Understanding, respecting and including people with
mental health conditions as part of the CLTS process**

S. Cavill, P. England, S. House & S. Ferron (UK)

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Mental health conditions affect large numbers of people globally, in a variety of ways and people often face extreme stigma and marginalization as a result. Appropriately implemented, Community Led Total Sanitation (CLTS) can contribute to physical, mental and social health by helping to build pride and contribute to the inclusion and empowerment of people with mental health conditions; but there are also risks that people with mental health conditions may be mistreated, or have their rights abused, if they have difficulty in changing their sanitation and hygiene behaviour. This paper calls for all those engaged in sanitation programmes to: increase their learning on this issue; increase their awareness of the specific vulnerabilities of this group in sanitation programmes; build the capacity of stakeholders on acceptable and unacceptable practices in working with people with mental health conditions; and develop a Code of Conduct.

Introduction

During the period July 2016 and March 2017, the Global Sanitation Fund (GSF) – a pooled funding mechanism for national sanitation and hygiene programmes under the auspices of the Water Supply and Sanitation Collaborative Council (WSSCC) – commissioned a scoping and diagnosis study to gain a better understanding of the challenges, opportunities, and implementation approaches used to address equality and non-discrimination (EQND) within CLTS interventions, and how programming impacts and involves marginalized and vulnerable groups. The study involved visits to 6 GSF-supported programmes (Malawi, Ethiopia, Senegal, Nigeria, Togo and Nepal), with each incorporating a workshop with programme implementers and CLTS facilitators, key informant interviews and Focus Group Discussions and household visits with community members. The study pro-actively sought to listen to the voices of those considered disadvantaged in order to understand how their needs are being addressed, how they have participated in the CLTS process, and what impact the intervention has had on them. Challenges in responding to people with mental health conditions were raised in a number of different contexts. This paper is based on the learning from this study in the GSF supported programme areas, and addresses an important gap in sector knowledge.

Scale of the issue

WHO defines mental health as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community. Mental health conditions are “characterized by a combination of abnormal thoughts, perceptions, emotions, behaviour and relationships with others” (WHO, 2016). There are many different mental health conditions including: depression, bipolar affective disorder, schizophrenia and other psychoses, dementia, intellectual disabilities, such as Downs Syndrome, and developmental conditions including those on the autistic spectrum. Mental health conditions are widely prevalent: globally, an estimated 350 million people are affected by depression; 60 million people by bipolar affective disorder; 21 million by schizophrenia; and 47.5 million by dementia. In low- and middle-income countries, between 76%

and 85% of people with mental conditions receive no treatment for their condition. Mental health conditions affect people differently at different points in their life. Adolescents may face a variety of challenges in growing up that lead to stress-related conditions, while deteriorating mental health often accompanies aging. Mental health has a gender component, with women more likely to be affected by depression, but a larger proportion of men are successful in attempts to commit suicide. Mental health is therefore a ‘jeopardy’ factor, which adds another layer on top of existing vulnerabilities, such as age, gender and poverty.

Mental health, vulnerability and sanitation

As efforts increase to ensure that the most vulnerable and marginalised have access to sanitation, we must pay special attention to people with mental health conditions in both policy and practice. According to WHO (2010), people with mental health conditions are recognised as a vulnerable group: they are subjected to stigma and discrimination; experience extremely high rates of physical and sexual victimization; face disproportionate barriers in exercising their rights as well as in participating in public life and accessing public services. Vulnerability itself is also an important risk factor for developing mental health conditions: stigma and marginalization generate poor self-esteem, low self-confidence, reduced motivation, and result in less hope for the future as well as isolation.

The stresses associated with the lack of sanitation can also negatively affect mental health. Gender specific risk factors for common mental disorders that disproportionately affect women include poor sanitation. Recent literature highlights the potential stress, fear and anxiety around using sanitation facilities (Henley, 2014; Lennon, 2011 and WSSCC/SHARE, 2015). Sahoo et al (2015) categorise these stressors as: environmental (barriers to access, discomfort at defecation site, animals and insects), sexual (peeping, revealing, sexual assault) and social (privacy, social restriction, social conflict). The impact of these mental health stressors disproportionately affects the most vulnerable, marginalized, and stigmatized women. Addressing mental health problems in vulnerable groups can facilitate development outcomes, including improved participation in economic, social, and civic activities’ (WHO, 2010).

There are two different sets of challenges for CLTS:

1. Where people have a cognitive impairment that affects how they process conscious reflective behaviours (those that require reflection - and may be influenced by rational knowledge, emotions, social norms) – which CLTS targets – as well as unconscious reflexive habits (i.e. those that are done by reflex action) (Neal et. al 2016; Sigler et al. 2014). For example, those with severe dementia will be less capable of being ‘triggered’ and then forming positive habits. Excreta related behaviours occur in several conditions, including intellectual disability, dementia and psychoses (for instance, eating, smearing, or throwing faeces or involuntary faecal incontinence). Many people with mental conditions find this extremely distressing. Intentional defecation in inappropriate places, when bowel control is normally expected, is also associated with several psychiatric conditions.
2. Where people’s reflective and reflexive cognitive faculties (which relate to processes of perception, memory, judgment and reasoning) are functional, but their participation in social life and decision-making is affected by mental health conditions (anxiety, depression, for example); these mental health conditions may be less visible to facilitators, the community, or both. People with depression are less likely to participate during CLTS activities or else may not have the motivation to build a latrine or to change their behaviour, due to low mood or a lack of interest. People with anxiety may find it difficult to attend the triggering or other community meetings due to panic attacks or wanting to avoid people. This could be the result of a combination of low self-esteem, feelings of isolation, disconnection (opting out of participation) or social stigmas. Toilet anxiety and fears of public urination are also recognized conditions.

People with physical symptoms may face external barriers to participation (e.g. due to stigma compounded by different layers of vulnerability), those with ‘invisible’ conditions that affect their self-esteem may opt out of participating in community initiatives like CLTS and resist change, which in turn can affect the ability of a community to reach Open Defecation Free (ODF) status. In addition, families with people with mental health conditions may also be poorer than their peers, because of lack of ability to earn an income due to the mental health condition or having to care for someone with a mental health condition. The key challenges and opportunities confronting CLTS facilitators include:

Challenges/risks	Opportunities
<ul style="list-style-type: none"> • Difficulties changing behaviours and building positive habits • Facilitating active participation where people with mental health conditions are stigmatized • ‘Doing no harm’ where the use of shame or community reprisals can lead to abuse • Families of a person with mental health conditions, may be poorer, face challenges leaving the person they care for, or not have someone in their family able to construct, if other family members are not able 	<ul style="list-style-type: none"> • Addresses a contributing factor to mental health stressors • Empowers, and increases self-confidence in abilities to contribute and succeed • Entry-point for community members to confront their own prejudices

During the EQND study, CLTS facilitators shared some approaches they have seen used for addressing challenges associated with mental health. Some examples include:

- A person was banished from a community because they could not stop him practicing OD. It wasn’t clear how long this was for or if it was just for each ODF validation day, but it was an abuse of his rights. On return to the community he would probably still be practicing OD, jeopardizing both ODF status and health.
- Natural leaders found shit at the house of a woman with a mental health condition. Neighbours wouldn’t let her use their toilet. A CLTS facilitator told her that if she built a toilet he would marry her and he gives her small money each time he sees her. Now she uses the latrine every time. The facilitator’s intention was to find a positive way to persuade the woman to stop OD but people with mental health problems are particularly vulnerable to sexual and other abuse, so such promises, even with good intention, should not be utilized.
- A Natural Leader persuaded a man with a mental health condition to use a latrine by claiming if he didn’t he wouldn’t be able to have a child. The Natural Leader, together with the community, found a woman (also with mental health issues) for him to marry provided he kept using a latrine. They now have a child.
- People with addictions to drugs and alcohol, whose cognitive reasoning may be impaired, can also need additional support in the CLTS process. A facilitator said a young marijuana user refused to build or use a latrine. He was eventually persuaded to build a good quality latrine by the facilitator claiming that if he didn’t his shit might be used to conduct witchcraft. The team found a way to convince the young man to build a latrine in line with common local beliefs, but there was some concern that if the man found the argument was made up, he may have become angry. To prevent this, the facilitators followed-up with the man to build a relationship with him and continue to influence him on why using a latrine is important.

While these examples highlight challenges and potential risks during CLTS, the approach has also been used to build pride and contribute to the inclusion and empowerment of people with mental health conditions: One female facilitator from a mountainous region of Nepal, said she uses the strategy to trigger family members or carer of the person with mental health conditions, who then triggers the person they care for or are close to. The facilitator knew that those closest to the person are most likely to be able to convince and support them. In the case of a divorced man with a mental health condition she said: *“We triggered the smallest child (13 year old son) and he triggered his father ... I suggested to the Village Development Committee that they should provide a pan and pipe to the family and also tried to persuade the community to support them. But the father refused the support and said he would collect stone and build it himself”*. A study of the UNICEF CATS programme in Mali (Alzua, n.d.) also found positive and statistically significant impact of the CLTS programme on behaviors such as cooperation and community empowerment and increased feelings of privacy and safety reported by women when defecating at night.

Dos and don’ts for CLTS implementation

CLTS is fundamentally about human dignity. CLTS programmes can be designed in ways that promote and protect mental health (rather than result in stigmatization and discrimination). CLTS could therefore also ‘trigger’ for equity, by triggering a collective self-understanding that not supporting vulnerable people to access appropriate sanitation that suits their needs – including those with mental health conditions – is shameful, as they’re everyone’s neighbours. This is critical if a community is to become ODF in a manner that is not only respectful of people’s capacities, needs and rights, but also increases the self-confidence in

their own abilities (agency) and voice of marginalized and vulnerable groups. Another key outcome for CLTS is for the community to confront their own prejudices and identify ways to help their neighbours. This means ensuring that people with mental health conditions are welcome, included in the process and their contributions valued, as well as supported to ensure defecation occurs in the appropriate place (or if not that their faeces are safely disposed of) and that this group is not blamed or scapegoated by the community for failure to reach ODF. High-quality facilitation is necessary to create a space where the community takes the lead to confront the special needs of vulnerable groups by building on a person's strengths and ensuring their inclusion.

While the mantra of 'community problem, community solution' is the guiding principle of CLTS, the facilitator has an ethical obligation to ensure that these solutions do not result in making vulnerable people worse off. Programme staff, Natural Leaders, community-level sanitation committees, CLTS facilitators and community health workers can play a role in building general awareness to combat stigma. In many cases, this process must begin by confronting some of the attitudes and practices of CLTS facilitators themselves. It is often said that in order to facilitate CLTS, you need to change your own behaviour and be triggered and the same principle applies to this issue. As CLTS inevitably works within community power structures, it is the ethical obligation of the facilitator to step-in when there are risks that can lead to human rights abuses, that deepen stigma and discrimination against persons with mental health conditions. Promoting the concept of 'Do No Harm' (i.e. ensuring interventions do not make vulnerable groups worse off) can be done through training on EQND (recognizing the link between vulnerability and mental conditions), use of terminology that doesn't promote stigma, M&E and targets that measure progress on this issue, and ensuring a Code of Conduct for stakeholders involved in the CLTS process. This will ensure a shared understanding of acceptable or unacceptable actions in preventing OD. The following tables provide some suggestions for Dos and Don'ts for working with people with mental health conditions. It has been developed through the experiences and ideas shared during the EQND learning process as well as from published literature.

1	In pre-triggering
Dos	Investigate the nature of marginalization/stigmatization of people with mental health conditions embedded in the community, and if there are any potential negative implications if they attend community functions
	Promote the community's role in respecting and protecting the rights and needs of people with mental health conditions - facilitate leadership and the community to see such people as equal members of the community who have rights and a contribution to make to the sanitation programme. Identify and involve organisations or individuals who are skilled/have experience in building a rapport with people with mental health issues.
	Invite organizations with skills and experience in mental health to support your programme to develop appropriate strategies to respond and how to integrate this good practice into the CLTS training.
	EQND training or workshops for all facilitators that can trigger participants to confront their own stigmas/assumptions (on mental health/others)
	Identify and assess engrained stigmas against vulnerable groups which can potentially put them at risk
	Find out how the person's condition impacts on their ability to understand and use a toilet and wash hands
Don'ts	Do not assume that all people with mental health conditions are the same but treat people as individuals

2	In triggering
Do	Work closely with family members / carers (including children) to: identify needs and gaps; include them in the programme; address specific problems and encourage the use of a toilet as a positive thing
	Use parents or children to trigger the person – they will often know how best to convince their child or parent
	Use drawing as an opportunity to explain the good practices. The use of pictures may also be particularly useful for people who find it difficult to communicate in language or to have eye contact with other people (such as people on the autistic spectrum) – for example the person or the carer pointing to, or drawing, a picture of a toilet, or a tap with soap to indicate the need to use these items
	Help communities to confront their own stigmas (e.g. via Natural Leaders, sanitation committees), and to trigger a self-realization that it is shameful to leave anyone behind
	Encourage people with mental health conditions to become Natural Leaders (could be effective to change behaviour amongst their peers) or encourage NLs to give them as much self-confidence in their own ability as possible in the design of their facilities. CLTS should be building pride and self-esteem as a key outcome
	Facilitators should trigger a supportive community response to include people with mental health conditions

Don'ts	Don't allow people with disabilities to be mocked when speaking in public
	Don't exclude people further from the process because they are not conforming
	Don't misinterpret motor/speech impairment as a mental illness

3	In follow-up
Dos	Where there is resistance, identify incentives rather than punishments that might encourage change for that specific individual e.g. recognition, awards, responsibility, training, etc. For instance, consider suggesting Natural Leaders build a toilet specifically for that person, possibly adding features such as colour, plants or mirror etc., which might also build pride in having and using the toilet
	Identify when the person may be most receptive to discussions about sanitation e.g. periods of remission or times when they are more lucid/calmer etc.
	Listen carefully to what each person has to say and their reasons for resistance. It may be they have specific beliefs about excreta disposal that prevent them from complying e.g. they may hear voices telling them not to use a latrine or they may be paranoid about washing their hands – ask them how to overcome the problem. Sometimes other people with the same condition (for example schizophrenia) understand the experience of hearing voices and can use this knowledge to persuade the person that the voices are not always correct
	Encourage family /carer to take responsibility for sanitation needs of person with mental health issues – if necessary to pick up faeces in the same way as they would a child's to dispose of it in a toilet, if there is no other way to stop the person practicing OD
	Be aware that some basic challenges may pose particular issues for people with mental health conditions – for example as a lack of water for anal cleansing in a toilet may be particularly stressful for someone with developmental difficulties such as autism or learning difficulties, such as Downs Syndrome
	Share learning on mental health and CLTS with other CLTS actors – as this may be a gap in their knowledge
	Regular programme monitoring and evaluation needs to include mental health conditions as part of their tracking of vulnerable groups. This information may be difficult to collect for facilitators, or even for community members if there is extreme stigma. However, including changes in mental health as an outcome of the process is important for the overall evaluation of programmes. Make specific efforts to follow up with people who were identified to have mental health conditions to establish the outcome of the process.
	Staff, partners and all must know their responsibilities for protection and what are appropriate behaviours
Don'ts	Do not exclude people with mental health conditions from being Natural Leaders where they have the capacity. They may have a lot to contribute and it may also help their self-esteem and confidence to grow
	Don't abuse anyone else's rights while finding incentives for a person with mental health conditions to stop OD. Don't exclude people from the community to stop them practicing OD in the community – they also have a right to feel secure in their home. Don't endorse community sanctions that include corporal punishment (beating or flogging) or, in extreme cases, exiling; instead, encourage the community to come up with a positive option. Don't exclude people further from the process because they are not conforming.
	Don't forget that people with mental health conditions need particular care and protection – some may be at particular risk of physical and sexual abuse because they may not understand when someone does something inappropriate to them
	Don't assume that there have been no problems faced by people with mental health conditions just because: a) ODF means everyone has access to and is using a latrine; b) you haven't heard about the problems. It is important to pro-actively ask, listen and learn

Conclusions

1. There are many people in the world with mental health conditions, some of whom are unable to act to stop open defecation.
2. There are risks inherent in any community-led process: people with mental health conditions who do not conform to the practice of stopping open defecation may be mistreated or have their rights abused. People engaged in CLTS processes, at all levels, must be aware of these vulnerabilities and the risks of discrimination.
3. Appropriately implemented, CLTS can contribute to physical, mental and social health. It can also help build pride and contribute to the inclusion and empowerment of people with mental health conditions.

4. Those working on sanitation programmes should: increase their own learning on this issue; build the capacity of other stakeholders so that they are aware of the issue as well as what constitutes acceptable and unacceptable practices in working with people with mental health conditions; and to develop a Code of Conduct to provide guidance to all stakeholders.

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Contact details

Dr Sue Cavill is a freelance consultant with a particular interest in women and WASH; Dr Sarah House is a Public Health Engineer with particular interest in working with vulnerable and marginalised groups; Suzanne Ferron is a freelance consultant with a background in public health; Patrick England is a Learning Analyst for the Global Sanitation Fund at the WSSCC secretariat in Geneva, Switzerland.

Dr Sue Cavill
Freelance WASH Consultant
Email: suecavill@hotmail.com

Patrick England
Learning Analyst WSSCC
Email: patrick.england@wsscc.org

Dr Sarah House
Freelance WASH Consultant
Email: sjhouse.majisafi@gmail.com

Suzanne Ferron
Freelance WASH Consultant
Email: suzanne.ferron@gmail.com