

JONES

36th WEDC International Conference, Nakuru, Kenya, 2013**DELIVERING WATER, SANITATION AND HYGIENE SERVICES
IN AN UNCERTAIN ENVIRONMENT****WASH, disability and ageing – a continuum framework
to monitor progress on mainstreaming***Hazel Jones, UK***BRIEFING PAPER 1799**

A desk study was designed by WEDC and WaterAid to map the extent to which issues of disability and ageing have been mainstreamed in the WASH sector, and what the impact of this has been. Study findings indicate that disability and ageing have received increasing attention in the WASH sector over the last decade, but there is still a long way to go to achieve genuine mainstreaming. The picture emerging from the study is of a range of disability/elderly inclusive activities and approaches that can be represented on a 'continuum' of progress towards mainstreaming. This continuum framework is presented, along with examples of the type of activities that characterise each stage on the continuum. This continuum provides a framework for WASH implementers to analyse their own equity and inclusion activities. With further refinement, it could also provide a practical tool for use by implementers in reviewing progress, and planning next steps in mainstreaming disability and ageing within their organisation and programmes.

Background

It is becoming apparent that progress on MDGs is not happening in an equitable way, that averages mask huge inequities, and that the poorest in the world have scarcely benefited from improvements in water and sanitation provision (UNICEF/WHO, 2012). One reason is that the current MDG focus on numbers and coverage 'implies neglecting, leaving out, not serving, the more difficult, more challenging, and more deprived 'last' whose need is so often greater. For achieving targets, those who are last are not cost-effective.' (Chambers, 2012). Amongst these 'last', disabled and older people are disproportionately represented. Over 1 billion people globally have some kind of impairment (WHO/World Bank, 2011), and are more likely to be poor than the general population (Jones and Reed, 2005). 600 million people aged over 60 currently lack income security, the majority of whom are women (OHCHR, 2012).

What is known

There is an increasing body of literature related to access to water, sanitation and hygiene (WASH) for disabled and older people. The problems caused by this lack of access are widely documented for disabled people (e.g. Jones et al., 2002; NEWAH, 2004) and to a lesser extent for older people (HAI, 2000; Sleaf, 2006). In terms of solutions to problems, the most widely documented are 'hardware' solutions, i.e. the technology required to improve accessibility and use, which appear to be straightforward (e.g. Jones and Reed, 2005; Norman, 2010). Less has been documented about 'software' solutions: what changes are needed in the way programmes are planned and implemented, to effect the delivery of accessible and inclusive services. A range of general programming guidance is available, mainly produced by the disability/ageing sector, about mainstreaming disability/ageing into programme approaches, (e.g. (HAI, 2000; CBM, 2012), but the devil is in the lack of detail – on consultation with disabled and older people, on appropriate information and designs, on capacity building (Jones et al., 2012).

Much of the learning to date about mainstreaming disability and ageing has necessarily been through small-scale pilot projects, usually implemented by WASH NGOs, which require high time and resource input. Added to this, pilots are often implemented in partnership with disability organisations, which tend to take a more individualised approach to service provision. Given the unsustainability of taking such an

individualised approach at scale, how do the hardware solutions that we know to be effective, get put into place in the course of a usual WASH programme? In other words, how do we mainstream disability and ageing into WASH in practice?

Original aims of the study

A desk study was designed, the original aims of which were to identify:

- a) the extent to which disability and ageing issues are being genuinely incorporated into mainstream WASH programming and practice, and
- b) the benefits and drawbacks of this, for disabled and older people, for wider communities and for programmes and implementers.

The first step in the study was to review existing literature in this area, both published and unpublished, via

- a systematic search of academic databases – this confirmed that the relevant published literature is sparse;
- a search of grey literature produced by implementers on relevant WASH websites and portals;
- a call for information circulated via global WASH networks.

Initial findings

To achieve the original aims of the study would require a focus solely on information that described genuinely mainstreamed initiatives, i.e. initiatives that constituted ‘*an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes*’ as defined in the Box below.

Mainstreaming – a definition

“Mainstreaming a [disability] perspective is the process of assessing the implications for [disabled persons] of any planned action, including legislation, policies and programmes, in all areas and at all levels. It is a strategy for making [disabled people’s] concerns and experiences *an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes* in all political, economic and societal spheres so that [disabled and non-disabled people] benefit equally and inequality is not perpetuated.”

Source: UN ECOSOC (1997) cited in: Miller and Albert (2006) with disability substituted for gender.

Very little information was received that fulfilled these criteria, making the original aims unachievable. There is plenty of anecdotal evidence of benefits for individuals of improved access to WASH, but limited examples of genuine mainstreaming, and insufficient information to be able to analysis the impact on WASH programmes more broadly.

Current WASH contextual factors

In considering a possible framework to represent the available information, several external factors were considered, including the post-2015 debate, the rights to water and sanitation, and gender mainstreaming.

Human rights to water and sanitation

The concept of the ‘progressive realisation’ of the human rights to water and sanitation recognises that ‘the full realisation of human rights is *a long-term process* that is frequently beset by technical, economic and political constraints. ... [that] is normally achieved *incrementally*, and that improved conditions are always possible.’ (Satterthwaite et al, 2012: 23).

MDGs and inequitable progress

The debate about what replaces the MDGs post-2015 is under way, with a key focus on reducing inequity. Efforts are being developed to monitor progress in WASH not just in terms of numbers and coverage, but in more nuanced ways, e.g. Index of Equality Betterment (Satterthwaite et al, 2012), whilst Luh et al (2013) propose an index to measure the ‘progressive realisation’ of the right to water.

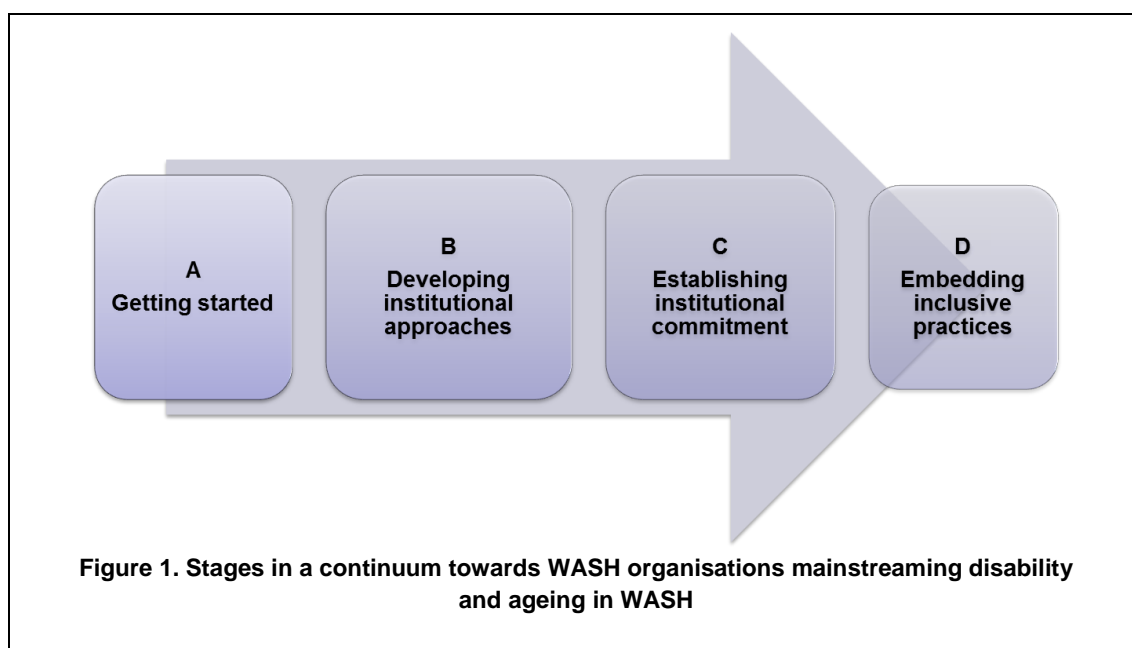
Parallels with gender mainstreaming

Parallels can be drawn with gender mainstreaming, which is “a long-term, dynamic process of change, with recognisable phases” (Derbyshire, 2012:417). Phases depend on several factors, including number of years since beginning mainstreaming, and a range of organisational activities including ‘internal influencing, reviews, policies and strategies, awareness-raising and skill development, systems and incentives for planning and monitoring, and promoting equality at work’ (*ibid*: 409).

For example, organisations at early stages of mainstreaming tend to be characterised by ‘gender advocates as volunteers ... operating from the margins’, informal gender networks, with ‘achievement individual and incremental’. Organisations that have been working in this area for 10 years or more are more likely to have ‘advocacy and network roles formally embedded in management structures’, ‘strong corporate commitment’, ‘measurable indicators and accountability mechanisms at senior management level, and systematic analysis and planning’ (*ibid*: p.409).

Mainstreaming as a continuum

Most of the information collected during the study demonstrated different aspects of inclusive practice to a greater or lesser extent. The question was, how to represent this range of practice in a way that acknowledged the progress that had been made. A continuum was therefore conceptualised with a view to categorising information according to the progress that the implementing organisation was making towards mainstreaming (Jones, 2013). For ease of representation, this continuum was broken down into stages (see Figure 1). The following sections describe examples of the kind of activities that organisations are likely to be carrying out at each of these stages.



Stage A. Getting started

This stage is characterized by learning and trying out new ideas, which in practical terms might include:

- **Studies and situation analyses** to gather information and improve understanding of the problems of disabled and older people. Examples include studies by WaterAid in different countries, e.g. an early study in Nepal to understand the problems faced by disabled and older people, pregnant women and overweight people when using latrines (NEWAH, 2004).
- **Small pilot projects** with a focus on practical learning about accessibility and inclusion, often involving collaboration between WASH and disability agencies/ elderly associations. These may or may not result in learning being documented, and recommendations or guidance produced to be applied to the wider programme. WaterAid have again been prolific. In Mali a pilot project in Thienfala in collaboration with Sightsavers, helped design and construct wells and toilets that were accessible initially for people with

visual impairments, but broadened to include other people with access problems, including frail older people (Russell, 2008).

- *Advocacy documents*, an example of which is a recent 2-pager from Timor Leste (WaterAid, 2011).

Stage B. Developing institutional approaches

Stage B exhibits a more coherent organisational approach, and is likely to include:

- *Strategic planning/roadmap*: disability and ageing specifically included in aspects of organisational policy and strategy, such as WaterAid Equity and Inclusion framework (Gosling, 2010).
- *Awareness raising/ advocacy activities* aimed at changing people's thinking and behaviour.
- *Training materials*: e.g. materials on identifying and solving exclusion from WASH, developed collaboratively by WEDC and WaterAid with staff globally (open source from WEDC, 2012);
- *Advice and guidance* on mainstreaming disability/ageing within WASH, (presented separately from usual WASH guidance), e.g. an Introductory guide to mainstreaming disability in international development, aimed at practitioners. It includes sector specific sections, including the WASH sector (CBM, 2012).
- *Piloting of inclusive WASH elements within a wider WASH programme*. In Uganda and Zambia, WaterAid and local partners are piloting inclusive WASH activities within a broader WASH programme. The purpose is to learn how to make routine project activities more inclusive, identify additional activities that may be needed, and what interventions are effective in improving provision for disabled and older people (Wilbur et al, *in press*)
- *Developing inclusively designed facilities*: e.g. WaterAid Madagascar collaborated with Handicap International to design and construct accessible public latrines and water points, using an iterative and consultative 'inclusive design' process. A key part of the process was an accessibility audit carried out by disabled people, to assess whether the facilities were accessible and usable by intended users, and identify any problems. Designs were then adjusted based on the results of the audit, and further facilities constructed (WaterAid Madagascar, 2010).

Stage C. Establishing institutional commitment

This stage is characterised by a range of inclusive practices routinely implemented as part of the norm, and /or a range of elements in place as part of a coherent strategy towards embedding equity and inclusion in the organisation and programmes. This might include staff induction procedures, capacity building, development of inclusive designs, consultation procedures, partnerships with disability/ elderly associations.

In terms of inclusive design, World Vision in Mali now use an inclusive design of handpump surround as the norm throughout their programme (Kamban and Norman, *in press*). WaterAid Bangladesh now routinely incorporates inclusive design of facilities in their wider WASH programme. For example, a communal latrine complex for a sweeper community in Tangail District incorporates features that are user-friendly for children, women and wheelchair users, including handrails, raised seat, and spacious cubicle (Ahmed, *in press*).

Stage D. Approaches to disability/ ageing embedded as the norm throughout the institution, its programmes and services

No evidence is currently available that any WASH organisation or programme has reached this stage.

What has been learnt about progress on mainstreaming

It would be easy to feel disheartened by the apparent lack of progress on mainstreaming of disability and ageing in WASH programming, until a historical 'progressive realisation' perspective is taken.

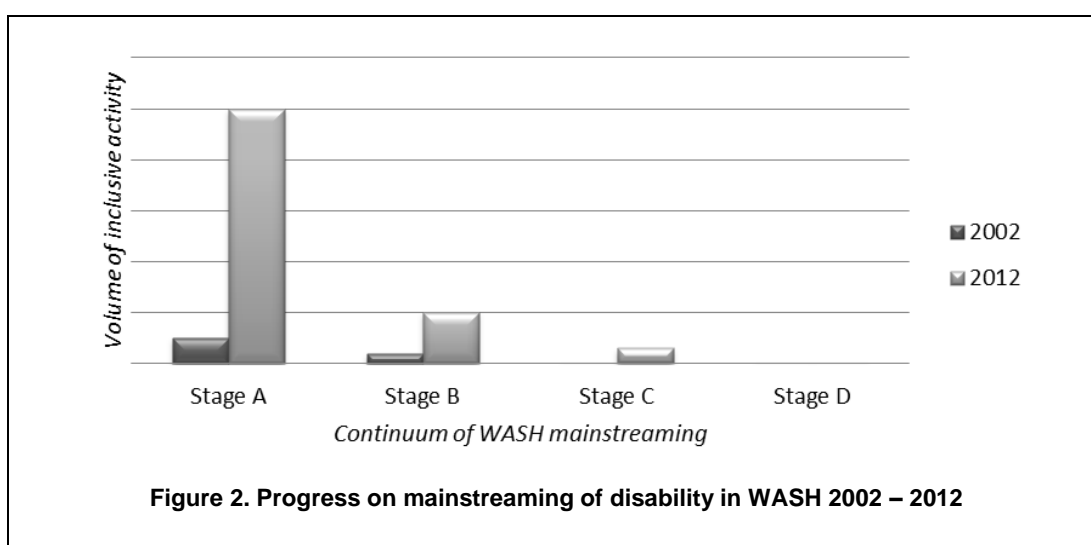
In 2002, when the author first started researching access to WASH for disabled people in low-income countries, no published literature was found on the issue. At that time, a call for information was circulated via WASH networks and disability networks globally. The overwhelming majority of responses received were from the disability sector, mostly highlighting problems. No information was received from the WASH sector (Jones et al, 2002).

In 2012, ten years later, a review of published literature found more than a dozen documents, plus a range of 'grey literature' from WASH websites, most of which there is not space to refer to here. The call for information this time was deliberately *only* circulated to the WASH sector, and referred specifically to

mainstreaming of disability within WASH. Over 60 responses were received from the WASH sector in response to the call. Some referred to specific contacts or organisations that they knew were addressing disability issues. Others had no information, but nonetheless had taken time to reply. Very little information was received that referred specifically to older people; however, many of the examples and case studies about benefits to disabled people were disabled older people.

A (subjective) interpretation of this is that, aside from web networking being more widespread and effective, the issue of disability inclusion is higher on the agenda than a decade ago. Even where nothing may be happening, it is more likely to be on the radar of WASH personnel, who are far more likely to recognise that inclusion is a legitimate concern and part of their responsibility.

There are many more WASH organisations implementing disability-inclusive activities, the majority still at a pilot project/ learning stage (A), but there are a number of organisations that are committed to equity and inclusion as an organisation, with disability and inclusion articulated in strategic plans, staff commitment at senior level and active learning and progress to apply learning throughout the organisation. (See Figure 2).



How could the continuum framework be used?

This ‘continuum’ provides a useful theoretic framework to review current practice on mainstreaming disability and ageing in WASH. It is a work in progress, but with refinement it is proposed that it could also provide a practical tool for WASH implementers to:

- Review progress on mainstreaming of equity and inclusion as a whole, not only of disability and ageing issues. It can help identify whether activities are heading in the desired direction, moving forwards or regressing, and identify gaps or unevenness in practice.
- Plan for both the short-term, by identifying what steps to take next, and for the longer-term, by identifying strategic goals, and how to achieve them.

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References

- Ahmed, S. (*in press*) Reaching the marginalised and socially isolated sex worker and sweeper communities of Tangail, Bangladesh. Paper submitted to the 36th WEDC International Conference, 2013, Kenya.
- CBM (2012) *Inclusion Made Easy: a quick program guide to disability in development*. Christoffel Blinden Mission. <http://www.cbm.org/Inclusion-Made-Easy-329091.php>
- Chambers, R. (2012) Equity and Inclusion: Pulling the scales from our eyes. In: WSSCC, ed, *Global Forum on Sanitation and Hygiene. Insights on Leadership, Action and Change*. Geneva: p. 14.

- Derbyshire, H. (2012) Gender mainstreaming: recognising and building on progress. Views from the UK Gender and Development Network. *Gender and Development*, 20(3), pp. 405-422.
- Gosling, L. (2010) *Equity and inclusion: A rights-based approach*. UK: WaterAid.
- HAI (2000) *Older People in disasters and humanitarian crises: Guidelines for best practice*. London: Helpage International.
- Jones, H.E. and Reed, R.A. (2005) *Water and Sanitation for Disabled People and other Vulnerable Groups: designing services to improve accessibility*. WEDC, Loughborough University: UK.
- Jones, H.E., Fisher, J. and Reed, R.A. (2012) Water and sanitation for all in low-income countries. *Proceedings of the ICE: Municipal Engineer*, 165(3), pp. 167-174.
- Jones, H.E., Parker, K.J. and Reed, R.A. (2002) *Water and sanitation access and use by physically disabled people: literature review*. WEDC, Loughborough University, UK.
- Jones, H.E. (2013) *WASH disability and ageing*. (Draft Report for WaterAid under review). WEDC: UK.
- Kamban, N. and Norman (in press) Inclusive WASH development: Technology adaptations for persons with disabilities. Paper submitted to the 36th WEDC International Conference, 2013, Kenya.
- Luh, J., Baum, R. and Bartram, J. (2013) Equity in water and sanitation: Developing an index to measure progressive realization of the human right. *International Journal of Hygiene and Environmental Health*. Online : <http://www.sciencedirect.com/science/article/pii/S1438463912001435#FCANote>
- Miller, C. and Albert, B. (2006) Mainstreaming disability in development cooperation: lessons from gender mainstreaming. In: B. Albert, ed, *In or out of the mainstream? Lessons from research on disability and development cooperation*. Leeds, UK: The Disability Press, pp. 40-56.
- NEWAH (2004) *Making Latrines User-Friendly for Everyone*. An exploratory research study on the discomfort faced by pregnant women, elderly, overweight, sick and disabled people when using squat latrines. Nepal Water for Health, Western Region Office: Pokhara, Nepal.
- OHCHR (2012) *Older persons among the poorest in the world*. Online: <http://www.ohchr.org/EN/NewsEvents/Pages/Olderpersonsamongthepoorestintheworld.aspx>
- Norman, R.W. (2010) *Water, Sanitation and Disability in rural West Africa: enhancing access and use of WASH facilities*. A summary report of the Mali water and disabilities study. USA: Messiah College.
- Russell, T. (2008) All people, all access: WATSAN for disabled people in Mali, 33rd WEDC International Conference, Accra, Ghana, WEDC, pp. 77-81.
- Satterthwaite, M. et al. (2012) *JMP Working Group on Equity and Non-discrimination. Final Report*. http://www.wssinfo.org/fileadmin/user_upload/resources/JMP-END-WG-Final-Report-20120821.pdf
- Sleep, B. (2006) Access for All: securing older people's access to water and sanitation, 32nd WEDC International Conference, Colombo, Sri Lanka, 2006 2006.
- UNICEF and WHO (2012) *Progress on Drinking Water and Sanitation 2012 Update*. New York, Geneva: WHO/UNICEF Joint Monitoring Programme for Water Supply and Sanitation.
- WaterAid (2011) *How the WASH sector in Timor Leste can consider disabled people. Issue Sheet*. WaterAid Timor Leste.
- WaterAid Madagascar (2010) *Technical Manual on Community Water Supply, Hygiene and Sanitation Facilities*. Madagascar: WaterAid.
- WEDC (2012) *Equity and Inclusion in Water, Sanitation and Hygiene Resources*. Webpage: <https://wedc-knowledge.lboro.ac.uk/collections/equity-inclusion/>.
- Wilbur, J., Jones, H., Gosling, L., Groce N., Challenger, E. (in press) Undoing inequity: Inclusive water, sanitation and hygiene programmes that deliver for all in Uganda and Zambia. Paper submitted to the 36th WEDC International Conference, 2013, Kenya.
- WHO and World Bank (2011) *World Report on Disability*. Geneva.

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