Conducting disability inclusive baseline assessments for Community-level WASH Projects

Summary Report – August 2016

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Introduction

It is estimated that 15 per cent of the world's population have a disability, with higher prevalence in low income countries.[1] Although all people have the right to access water, sanitation and hygiene (WASH), people with disabilities may face significant barriers to accessing WASH, compared to people without disabilities, and have often been unintentionally excluded from WASH efforts. With the Sustainable Development Goals (SDGs) aiming to achieve universal and sustained access to WASH, programs must overcome these barriers. Collecting baseline data in WASH programs can provide critical information about the demographics of a community, existing WASH facilities and practices, and a baseline from which to measure change. Ensuring this data collection process is inclusive of people with disabilities is critical in setting the foundations for a disability inclusive WASH program. The focus of the SDGs on reaching all people also has implications for data collection. It increases the need for greater disaggregation of data (e.g. by sex, age and disability) to measure intra-community and intra-household level inequalities and has also resulted in increased pressure on WASH actors to capture information that helps monitor elimination of inequalities in access to WASH.

Since 2014, CBM Australia has been partnering with World Vision and with WaterAid to support disability inclusion within their five rural and peri-urban Civil Society WASH Fund[2] projects in Papua New Guinea (2 projects), Timor-Leste, Sri Lanka and Zimbabwe in partnership with local Disabled People's Organisations (DPOs). To learn from these experiences, and particularly given a focus on disability data in these settings is relatively new, CBM has led the process of documenting the experiences of collecting disability data in these five project settings. This summary report shares the main findings, with the aim of learning from the approaches and therefore strengthening disability inclusive data collection processes in future programming.

Baseline data collection in WASH projects

Collecting baseline data is an activity undertaken by many WASH programs to inform program planning, implementation and for monitoring and evaluation purposes. Some WASH organisations use a household survey to collect quantitative information, which is then supplemented by

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[1] WHO and World Bank (2011) World Report on Disability, http://www.who.int/disabilities/world_report/2011/en/.

[2] The Civil Society WASH Fund ($103m over five years (2013-18)) is an initiative of the Australian Aid Program and aims to increase access to safe water, sanitation and hygiene in developing countries. It funds 13 Civil Society Organisations involved in implementing 29 projects.

qualitative information collected through community meetings, focus groups and key informant interviews. While collecting other demographic information about household members such as age and sex is relatively straightforward, collecting information about disability is complex and disability cannot reliably be identified through asking 'do you have a disability?'[3]

The UN Washington City Group on Disability Statistics has developed and tested a set of six questions (called the Washington Group Short Set of Questions on Disability (WGSS)) originally designed for national censuses. These ask whether a person has difficulty performing basic functions, rather than about disability directly (e.g. do you have difficulty seeing, even if wearing glasses). Whilst the WGSS Questions were originally designed for use in national censuses, in the absence of alternative methods, they are also increasingly being integrated into other data collection processes. Thus far however, there is limited documented evidence as to the usefulness of the questions in these contexts, or the most appropriate ways to use them.

In the baseline processes for the five WASH projects, all organisations included the WGSS questions in their household surveys to some extent. They also added disability-specific questions in other tools and processes, such as infrastructure accessibility audits, community meetings, interviews and focus groups. In some cases, a disability-specific situational analysis was done.

Key Lessons on Disability Inclusive Data Collection

The following is a summary of the key lessons learnt about conducting disability inclusive data collection. Further information and project examples are provided in the full report[4].

1. **Including people with disabilities in data collection processes resulted in positive outcomes for people with disabilities, their communities and other stakeholders, but needs to be resourced appropriately.**

WASH projects all included people with disabilities as active participants in data collection teams to some degree, generally by establishing partnerships with DPOs. This was found to:

- increase the confidence of people with disabilities and have immediate outcomes in relation to challenging negative attitudes in communities
- result in new forms of collaboration between DPOs, NGOs and governments which helped to change their attitudes and approaches towards people with disability and acknowledge their capacities
- increase the quality of data collected by encouraging community members with disabilities to speak up during focus groups and community meetings, and improve interpretation of the findings.

People with disabilities recruited as data collectors in Sri Lanka reported that prior to being involved in the project they had lost their confidence and thought they had nothing to offer. Being involved as data collectors gave them back their dignity.

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[3] Cultural understanding of the term 'disability' and stigma associated with identifying as having a disability tend to lead to under-reporting if this question is used.

[4] The full report will be available at /http://www.addc.org.au/content/resources

While including people with disabilities clearly had significant benefits, it also presented logistical challenges and required additional time and resources. In particular, logistics associated with transporting a team with diverse impairments over rough terrain was reported as a challenge. Sufficient time and resources also needed to be dedicated to brokering relationships, building trust among organisations, strengthening the capacity and confidence of data collectors and training DPO representatives in data collection methodologies.

2. Collecting data on people with disabilities in communities needs to be done sensitively

The term ‘disability’ can be understood differently across cultures and communities. In many communities, people with disabilities are not “classified” as a separate group and the word ‘disability’ is not widely used or understood. Instead, people may have difficulty doing certain tasks because they are ‘elderly’ or for another reason. In the WaterAid projects in PNG and Timor-Leste, project staff found it more useful to talk about difficulties with aspects of functioning (as recommended by the Washington Group) when working with the community as opposed to talking about ‘disability’, which would potentially create a whole new group in the communities which previously did not exist.

Increasing the visibility of people with disabilities by including them in community consultations for the first time also needs to be closely monitored to ensure that any backlash from communities for challenging social norms is addressed. For example, in Zimbabwe, community members wrongly scape-goated people with disability as a reason for a project changing direction and 'punished' them by excluding them from community funeral contributions. Such issues can be addressed through adequate awareness raising, but it is important to identify these issues through strong monitoring. This will help to ensure that people with disabilities will not be further marginalised within their communities as a result of the inclusive WASH project.

3. Household surveys need to collect individual level data about access to WASH in order for that data to be disaggregated by disability. However, inclusion of the WGSS questions is also useful for identifying <u>households</u> which include people with disabilities who can then be followed up throughout the project.

The SDGs and some donors require data to be disaggregated by disability, sex and age to assist in determining who does and does not benefit from development programs and encourage a focus on universal access. This was one of the common objectives of including the WGSS in the baseline surveys of the WASH projects. In most countries, this was the first time the NGOs and implementing partners had used the WGSS questions in a household survey.

The fact that surveys collected information at a household level only (generally from the head of household) rather than individual level data, meant that individual differences in access to WASH within households were not identified and data could not be disaggregated by disability, age and sex. The surveys could generally only identify whether a household included a person with a disability and whether a household had access to WASH, rather than identifying whether the person with a disability within the household had access to WASH. In some cases, surveys also did not identify how many people within a household had a particular functional difficulty or the age/sex of those people which prevented data disaggregation.

In Sri Lanka this issue was largely overcome by asking the WGSS questions (to the head of household) about each individual within the household once an initial question was asked ‘does anyone in this household have any difficulties in seeing, hearing, walking, remembering, self-care, communicating, or in using hands?'. Questions about the person's age and sex were also included, along with whether and how people with difficulties accessed water and sanitation facilities, providing a solid baseline on which to monitor inclusion.

Finding people with disabilities within communities is often a key challenge reported by NGOs undertaking development projects. It is therefore noteworthy that while in most cases including the WGSS questions did not enable disaggregation of data because of the structure of the survey, they were generally effective in identifying households which included people with disabilities. This was very useful for identifying people with disabilities who could then be invited to participate in qualitative processes.

4. There were challenges with but also unexpected findings of using the WGSS questions

While the WGSS are often promoted as being easy to use and proved useful, all NGOs faced some challenges in using the questions as they were intended and analysing the results appropriately. Pressure to complete the baseline quickly and with limited resources meant that in some cases insufficient time was spent explaining to NGOs and data collectors why the WGSS questions were recommended to identify people with disabilities and how to use them appropriately. As a result in some cases the questions were not translated appropriately or were changed without sufficient testing. Deciding on an appropriate 'cut-off'[5] to use to classify people 'with' and 'without' disability and using this consistently was also challenging. This meant that in some projects, different cut-offs were used in different project locations, while in others data collectors were unsure when to ask to ask follow up questions which were designed to be asked when household members with disabilities were identified.

While the Washington Group generally recommends that people are classified as having a disability if they answer 'yes – a lot of difficulty' or 'cannot do at all' to at least one question, for WASH projects, there may be advantages in using a more sensitive 'cut-off' (e.g. also including people who answer 'some difficulty' to at least one question). This is because people with minor difficulties performing tasks in fact reported significant difficulties accessing WASH and were often still expected to undertake WASH work for the household. This is further illustrated in the example below.

In PNG, WaterAid unintentionally classified people who reported 'some difficulty' to one of the WGSS questions as people with disabilities, meaning that people with relatively minor disabilities were included in their disability analysis. While this was unplanned, it lead to revealing findings as people who would not traditionally have been thought of as having a disability reported a range of substantial difficulties accessing WASH. This was particularly the case for women who were still culturally expected to undertake WASH work and have caring and other household duties despite the difficulties they faced. These women reported spending significantly longer undertaking WASH tasks (particularly collecting water) because they were not able to carry the same quantity of water as others, took longer to travel to the water source and had to make more return trips.

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[5] The WGSS questions require projects to select an appropriate 'cut-off' to enable classification of people as 'with' or 'without' disability. This is generally recommended to be anyone who answers 'yes – a lot of difficulty' or 'cannot do at all' to at least one question. Alternative cut-offs can be used provided these are clearly defined by projects.

5. **A combination of quantitative and qualitative data collection processes produces the most useful baseline data on people with disabilities**

Even in Sri Lanka where extensive quantitative data was collected on people with disabilities during household surveys, this only resulted in an understanding of who did/did not have access to WASH rather than why or how to address barriers faced. Collection of qualitative data on the experiences of people with disabilities accessing WASH facilities was critical to enable an understanding of the type of difficulties people with disabilities were experiencing in accessing WASH (and therefore strategies to address these). When conducting qualitative data collection (e.g. interviews, focus groups or community meetings) the following was observed:

- In many cases, household surveys were an important mechanism to identify people with disabilities for inclusion in qualitative data collection processes.
- Projects which completed qualitative data collection specifically with people with disabilities ended up with richer baseline information about barriers to WASH, than those who tried to include people with disabilities in general WASH community planning processes.
- Standard community consultation and planning tools (such as community mapping or WASH audit tools) can be used with people with disabilities with minor adaptations.

6. **Collecting baseline data on people with disabilities led to more inclusive WASH programming and had a range of positive outcomes**

Collecting baseline data on people with disabilities has prompted a range of changes to project planning and inclusive programming. These include:

- the construction of accessible WASH infrastructure
- successful use of the baseline findings for advocacy and training purposes with stakeholders including government
- involvement of people with disability in local government decision-making processes about WASH and in some cases even on issues beyond the project.

While all projects have seen some benefits from conducting disability inclusive baselines, a range of factors have influenced the extent to which baseline information has informed project planning and programming. It was found to be most effective when:

- it was completed and shared with stakeholders early in project implementation
- collection and analysis of data was recognised as a tool to inform project implementation rather than as a stand-alone activity for monitoring and evaluation
- data analysis was resourced appropriately.

In Zimbabwe, data from the baseline has prompted the construction of accessible public toilets, and two schools have refurbished latrines with accessibility features. Information from the baseline assessment is also being used in training workshops with council workers and WASH sector staff to influence policy and planning. Furthermore, Gender and Social Inclusion (GESI) Champions have been established in each community to strengthen representation at community meetings and identify households who have a person with a disability to facilitate access to disability services and government support. GESI Champions are now being consulted by the Local Authority on disability and gender issues beyond the WASH project. The Local Authority is even planning to replicate the GESI model to other communities beyond the project area, as they have found it an excellent way to consult with people with disabilities.

Discussion

The above key findings demonstrate that in many ways, inclusive baseline data collection processes laid the foundations for inclusive practice and produced a broad range of benefits and outcomes to projects on multiple levels. They empowered people with disabilities, established relationships and enabled learning between DPOs and other program partners, raised awareness of access challenges, challenged negative attitudes and identified people with disabilities for direct follow up. They were however not without their challenges and required substantial resourcing in terms of time and budget.

While there are a broad range of lessons discussed above, there are two major areas where further analysis is recommended. The first relates to the current design of household surveys used by WASH programs to gather baseline information which were found to be inadequate to allow full disaggregation of data by disability and therefore understanding the extent to which people with disabilities differed in their access to WASH in comparison to people without disabilities. Further analysis is required to determine the best tools for exploring differences in access to WASH within the household within quantitative surveys. Tools such as the Rapid Assessment of Disability[6] and the Individual Deprivation Measure (IDM) [7] could be explored.

Secondly, given the time and budget constraints which come with any community development project, program implementers need to carefully consider the balance of qualitative and quantitative data that should be collected, based on an analysis of what information is required to inform disability inclusion within that context. Quantitative data can be used to powerfully highlight inequalities in access and measure progress of some indicators towards inclusion. However, there is a danger that analysis stops at identifying people with disabilities and that not enough attention is given to understanding the situation of people with disabilities more broadly and developing strategies and solutions to address this, which can impact on the effectiveness of planned WASH interventions.

Further information

This report has been produced in partnership with WaterAid and World Vision. The detailed report will soon be available on the ADDC website. For further information please contact:

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[6] The RAD survey consists of household and individual questionnaires. Each head of household is invited to complete the household questionnaire, while individuals residing in the household are then invited to complete the individual questionnaire with the interviewer that explores the situation of people with disabilities that can be included in household surveys when a person with disability is identified.

[7] See https://www.iwda.org.au/assets/files/IDM-Poster_digital.pdf

Recommendations

Including people with disabilities in data collection teams	1. Involve people with disabilities/DPO representatives in the data collection process as much as possible, not just as 'subjects' of data collection.
	2. Allow sufficient time to discuss and sensitise the methodologies used and provide training for data collectors to undertake their role.
	3. Think through how data collectors with disabilities will travel to project sites, taking account of time needed to collect and drop-off people, and additional space required in vehicles for support people and assistive devices.
	4. Develop a realistic and clear understanding of the DPO's involvement, role and responsibilities and where needed strengthen/formalise this through a clear Memorandum of Understanding.
Conducting data collection sensitively	5. Be aware of the language you are using when talking about disability within communities. Referring to 'difficulties' with doing certain tasks rather than using the word 'disability' when engaging with communities may help.
	6. Aim to consult both people with disabilities as well as the wider community and be clear about the purposes of consultations. In doing so, it is important to provide "safe spaces" for people with and without disabilities to bring up and discuss issues and community dynamics or beliefs around WASH use which may impact on the project. Close monitoring of consultation processes are vital to identifying issues as they arise.
Use of the WGSS Questions in baseline data collection	7. Using the WGSS questions in surveys that primarily collect household level information was insufficient to enable disaggregation of data by disability. With the Sustainable Development Goals' renewed focus on universal access to water and sanitation, WASH implementing organisations should reconsider their approach to collecting baseline information to better identify and monitor inequalities to accessing WASH within households.
	8. Even where disaggregation of data will not be possible, the WGSS questions should be included in household surveys for the purposes of identifying households with people with disabilities for future follow-up. In doing so, ensure processes are used during surveys to enable identification of households where people with disabilities have been identified so they can be contacted later. Undertaking follow-up analysis at the same /similar time as when the survey is being undertaken will help to avoid difficulties in finding households.
	9. If relying primarily on DPO contacts to find people with disabilities within communities, consider what impairment types are/are not represented and aim for a broad representation. This may require contacting a range of DPOs or using additional key informants.
	10. Ensure adequate time is spent discussing and explaining why the WGSS questions are recommended for use in baseline surveys to increase buy-in of local DPOs, implementing partners and data collectors. This should highlight the importance of not changing the questions unnecessarily and of appropriate translation and testing.
	11. Prior to use, provide face to face training for data collectors on how to ask the WGSS questions, why they are being asked and how they are expected to

	interpret the questions (if relevant).
	12. If data collectors are required to interpret the WGSS questions during the survey, in order to “trigger” additional questions, ensure the more sensitive cut-off is used (e.g. answering “some difficulty” to at least one question) so that people with minor functional difficulties are also asked about their access to WASH. Where possible also state this cut-off on survey templates to remind data collectors.
Influencing project planning and inclusive programming	13. Conduct baseline data collection and share findings as early in the project as possible and support implementing partners to think through what the findings mean for project implementation.
	14. Plan for how baseline data will be analysed before it is collected and ensure adequate training and support is provided to implementing partners and DPOs to facilitate this.