

# DFID's guide to disaggregating programme data by disability

## Why does disability data matter?

The Sustainable Development Goals (SDGs) have the potential to be truly transformative for people with disabilities. For the first time in history, people with disabilities are clearly included in a universal and ambitious plan of action that aims to end poverty and hunger by 2030 and pledges to leave no one behind. Monitoring progress is critical to the achievement of the SDGs.

By 2030 we want to live in a world where data has changed the power dynamic between citizens and governments, where policies and programmes are routinely designed around putting those who are furthest behind first, and where robust systems are in place that enable people to hold their governments to account. To achieve this objective, disaggregated data is essential.

Disaggregating data is not a new technique and has most commonly been done for characteristics such as age and sex. To make it possible to determine if a programme is reaching and successfully serving people with and without disabilities, we must disaggregate by disability status – this means information on programme objectives and other characteristics is available according to disability status<sup>1</sup>.

We ask all partners to use the [Washington Group Short Set of Questions on Disability](#) to disaggregate programme data by disability status using the approach outlined in this guide. Asking these 6 questions in existing surveys and registration processes is known to add 1 minute 15 seconds per person to the data collection process. Our policy is that partners should use the questions without any changes to the wording of questions, order of questions, response categories, and cut-off points for classification of disability. It is also critical that the questions are asked without using the word 'disability' to prevent any stigma, discrimination or bias that this can incur.

## The approach:

### History:

Asking one question to assess disability, such as 'Do you have disability?', with the response categories 'yes' or 'no' is known to lead to under-reporting of disability. There are many reasons for this. For example, many people with disabilities face daily stigma and discrimination and as a result do not like to identify or be labelled as having a disability. There is also a great deal of variability in how the term 'disability' is interpreted. Much of this is culturally determined. The lack of consistency and agreement about the meaning of the term disability and the stigma attached to it has resulted in poor quality and non-comparable disability statistics that have limited programme and policy use.

To address this, the UN formed Washington Group on Disability Statistics developed a short set of 6 questions which allows individuals to self-report functional limitation against 4 response categories. Although the questions were developed to be used in a census, they were specifically designed to be used as a disaggregation tool and to be included in other data collection tools in order

to take advantage of the information on all aspects of life that was already being collected. The questions can be incorporated into smaller-scale surveys, programmes, or administrative systems which collect data at the individual level. The Washington Group is in the process of publishing a list of frequently asked questions to support the use of the questions in the collection and disaggregation of programme data, from which much of the content of this guidance note is drawn.

### **The Washington Group Short Set of Questions on Disability:**

#### **Introductory phrase:**

The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?
  - a. No - no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
  
2. Do you have difficulty hearing, even if using a hearing aid?
  - a. No- no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
  
3. Do you have difficulty walking or climbing steps?
  - a. No- no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
  
4. Do you have difficulty remembering or concentrating?
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
  
5. Do you have difficulty (with self-care such as) washing all over or dressing?
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
  
6. Using your usual language, do you have difficulty communicating, for example understanding or being understood?
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all

## **How to use the Short Set to disaggregate data by disability status:**

The Washington Group Short Set assesses whether the respondent has a disability based on their responses to questions that assess functioning rather than by asking them to identify as having a disability. The tool is not designed to be used in isolation; rather it should be used in conjunction with other measurement tools. For example, the questions could be included as part of a larger survey or as part of a register for access to services (e.g. clinics, schools, legal access). This enables any of the other questions to be disaggregated by disability status.

Collecting data using the Washington Group Short Set will provide valuable insight into whether people with disabilities are benefitting from programme interventions. Results can either be compared with available population data to see if access is equitable or the questions can be asked at several points in time to see if progress has been made during the intervention period in order to ascertain whether people with disabilities are being included or left behind. These do not have to be large-scale surveys which may be beyond the resources of a programme. In many cases it will be possible to integrate the questions into the programme's usual management/monitoring and data collection processes. For example, the questions could be used in an existing employment survey to determine the % of people with disabilities who are unemployed in comparison to the % of people without disabilities who are unemployed.

All programmes reporting on data which have been gathered using the Washington Group Short Set need to articulate clearly how the questions were used, the age range of participants and the cut-off point used to determine disability status (see below). For example:

### **Employment disaggregated by disability status: 18-64 years**

Data from the US National Health Interview Survey (NHIS – 2013)

<b>Employment status<sup>2</sup></b>	<b>Disability status<sup>1</sup></b>	
	<b>% with disability</b>	<b>% without disability</b>
<b>Working</b>	29.1	73.4
<b>Not working</b>	70.9	26.6

<sup>1</sup> Disability status determined by use of the Washington Group Short Set of Questions. The sub-population *with disability* includes everyone that answers at least one question with *a lot of difficulty* or *cannot do it at all*.

<sup>2</sup> NHIS question: What was your employment status last week?

### **Method of data collection:**

To disaggregate data by disability status, questions need to be asked directly of individuals, or when necessary through a proxy (for example, when a person is unable to give consent or participate directly due to their level of functional difficulty).

Asking functioning or disability questions through the head of household is known to reduce identification, as persons with functional limitation tend to be missed (deliberately or inadvertently). This method may help identify households with a member who has a disability, but unless intra-household equity in participation and access can be assumed, it doesn't allow understanding of individual level access to programmes or services. This makes it difficult to evaluate whether the intervention has effectively included people with disabilities. Likewise while the key informant method may identify some people with disabilities, particularly those with more obvious types of difficulties, assessing functioning of individuals through observation or assumed knowledge of individuals is subjective and can be very inaccurate. Key informant methods will lead to an underestimate of disability.

A key challenge might be that individual level surveys cost more than obtaining information from the head of the household or some other community informant. However, there are ways to reduce the costs of the data collection. If the programme visits households and interacts with household members for other purposes, data collection can be incorporated into those visits.

### **Translating the questions:**

In order for the Short Set of Washington Group Questions to be understood in a way that is comparable within and across countries that rely on different languages and dialects, it is necessary to have a translation procedure that yields equivalent versions of the test questions across a variety of settings and cultures. The Washington Group has [detailed guidance](#) on its [website](#) and some standard translations are available. The aim is not to produce a literal translation but to capture the concepts being mindful of how words are used in the local context. Often different words have the same general meaning but how they are interpreted can vary. It is important to select the correct translation not only for the questions but also for the answer categories.

### **The cut-off:**

To allow comparison of data across DFID's programmes and with wider global disability data collections, our partners should be using the same cut-off point to identify disability in their reports to DFID:

If any individual answers 'a lot of difficulty' or 'cannot do it at all' to at least one of the questions, they should be considered a person with a disability for data disaggregation purposes.

However, programmes using the Washington Group Short Set of Questions should not feel restricted to producing data solely based on the above cut-off.

Depending on the specific programme needs, data could be analysed by individual questions (functional domain specific) or based on different levels of severity from very mild (some difficulty) to very severe (unable to do at all) where useful.

### **Adapting the questions:**

The Washington Group Short Set have been developed and tested (including cognitive testing and translation testing). DFID's policy is that partners use the questions without any changes to the wording of questions, order of questions, response categories and cut-off points for classification of disability status.

Extensive testing and experience from the Washington Group in a variety of contexts has demonstrated that making changes to the questions in an attempt to 'improve' them tends to have unforeseen consequences in terms of reducing accuracy and comparability. Using the questions as developed allows for comparability of data across communities and contexts.

Where partners do feel an adaption is needed, other than those highlighted as exceptions below, the Washington Group should be ask about the implications of any adaptations before they are made. Please ask partners to contact [DFID's Disability Team](#) in the first instance to discuss.

### **Possible exceptions:**

**One:** If pre-testing highlights that aspects of the questions are not relevant or confusing in particular contexts, small adaptations, such as removal of reference to the use of hearing aids in contexts where they are not used, can be made. So the question would be adapted from:

2. Do you have difficulty hearing, even if using a hearing aid?

to:

2. Do you have difficulty hearing?

**Two:** If resources really do not allow all 6 questions to be included, the first 4 questions (seeing, hearing, walking/climbing and remembering/concentrating) are considered essential.

**Three:** The introductory sentence 'The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM' was included as a way of transitioning from one section of the questionnaire to another for censuses and helping respondent to focus on difficulties linked to health rather than their environment (i.e. lack of pavements causing difficulties to walk). It is recommended that programmes also use this introductory sentence but should you choose not to, it is important to not replace this with an introductory sentence which uses the term 'disability'. The Washington Group Short Set has deliberately been developed to focus attention on functioning and does not use the term 'disability' given the many different ways it can be interpreted and the stigma that can be associated with the term.

### **Identifying disability in children:**

The Washington Group has acknowledged that the short set of questions are not ideally suited for the child population and that certain domains of functioning particular among children will be 'missed' when using the short set, for example difficulty learning, focusing attention, or controlling behaviour. While the Short Set has been used for children (5 years and older) in a census format, a tool developed specifically for use with children is currently being developed by the Washington Group and UNICEF to more accurately identify disability in children. The Washington Group is collaborating with UNICEF to develop and test the Washington Group/UNICEF Module on Child Functioning and Disability. UNICEF and the Washington Group have also begun a similar process to develop a module on inclusive education: identifying facilitators and barriers to school participation for children with and without disabilities. More information can be found on the Washington Group [website](#).

### **If you want to collect more information than the short set allows:**

Where information is required beyond disaggregation of data by disability, additional questions can be asked such as questions from the [Washington Group Extended Set of Questions](#). For example, if a programme wants more information on availability and use of assistive devices, they could ask a question similar to that included in the Washington Group Extended Set such as 'Do you wear glasses?' or 'Do you use any equipment or receive help for getting around?'. If additional information is required, questions should be added to the short set, rather than taking away or changing the questions in the Short Set.

### **Training enumerators:**

Local partners differ in their understanding of disability and their capacity to appropriately use the Washington Group Short Set in communities, and then to subsequently analyse and use the data to inform programmes. Training enumerators and administrative staff in how to use the Short Set is therefore crucial and should be followed up by ongoing supervision in the field. Role playing the questions with enumerators is a good way to get people comfortable with using the questions. Key points to emphasise in training include:

- The reasons why Washington Group focuses on 'functioning' as opposed to 'disability', noting that the questions are not diagnosis, disease or condition-based, but instead are looking at difficulties in functioning that anyone might experience.
- The use of screening questions (e.g. 'Do you have a disability?') or introductory statements (e.g. 'The next set of questions are about disability') will affect responses to the subsequent short set questions. Screening questions or statements should not be used under any circumstances, whether in a census or in a household survey.
- Questions need to be asked exactly as they have been worded. If questions are explained to participants using inappropriate or negative language, this may influence the way participants respond.

- Enumerators should never skip questions or fill in the answers based merely on their observations (e.g. if they observe that the respondent is using a wheelchair): they must ask all the questions to the participant.

**For more information and advice:**

For more information please refer to the Washington Group [website](#) or contact DFID's Disability Team at [disabilityframework@dfid.gov.uk](mailto:disabilityframework@dfid.gov.uk).

---

<sup>i</sup> Seeing, hearing, mobility, remembering or concentrating, self-care and communicating.