# **Collecting Disability Data within a Health Partnership Project**

**This guide is primarily designed to support heath partnerships, funded under the extension of the Health Partnership Scheme in 2018/19, to assess the impact their projects are having on people with disabilities. It can also be a useful guide for any health project implementer, especially if training of health workers and improvement of health services in LMICs are involved, who is looking to collect information on whether their projects are reaching people with disabilities.**

**For more tailored guidance on how to collect disability data or if you’d like to discuss this further, please contact THET’s HPS team at:** **HPS@thet.org**

## Background

As part of the extension to the Health Partnership Scheme up to February 2019, health partnerships applying for funding were asked as part of the criteria *“to pay careful attention to issues of equity within their projects, especially access of women and girls and people with disabilities to training and services”*.As such, each health partnership with funding is expected to *“evidence and report what impact their project has had on gender equality and disability”.*

This new requirement is in response to the need for more consideration for equity among health partnerships, as pointed out in an external [HPS evaluation](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/589736/Evaluation-of-Health-Partnership-Scheme.pdf) conducted by Triple Line and Health Partners International in 2016.

### Why disability?

People with disabilities make up 15% (over one billion) of the world’s population[[1]](#footnote-1), of which 80% are believed to live in low or middle income countries[[2]](#footnote-2). They encounter significant barriers to their participation in society, including accessing health care, paid employment and education.

Disability is increasingly considered in global development. Whereas the [United Nations Millennium Development Goals](http://www.un.org/millenniumgoals/) (MDGs) do not explicitly mention disability, there are 11 explicit references to persons with disabilities in the [Sustainable Development Goals](https://sustainabledevelopment.un.org/sdgs) (SDGs) including employment, reducing inequalities, human rights, vulnerable groups, and education. Additionally, there is reference in the follow-up and review section on data disaggregation by disability.

Within its mission of a world where no one is left behind and its commitment to the SGDs, DFID developed a [Disability Framework](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/554802/DFID-Disability-Framework-2015.pdf) in 2014 setting out their overall approach to disability inclusion and has been monitoring its progress ever since.

## Defining disability

The WHO’s [International Classification of Functioning Disability and Health](http://www.who.int/classifications/icf/en/) (ICF), defines a person with a disability as someone who has a health condition (e.g. clubfoot) which can lead to an impairment (e.g. difficulty walking), which in turns leads to having difficulties in participating fully in activities and society (e.g. being able to access a health service), therefore resulting in a disability.

The [United Nations Convention on the Rights of Persons with Disabilities](http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf)subsequentlyadopted the definition: *Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*

Someone can be born with a disability or become disabled at a later stage in life due to a number of factors, including infectious diseases, non-communicable diseases, accidents or deliberate harm, mental health issues or age.

## Considering disability in health partnership projects

### Some health partnerships are specifically targeting people with disabilities as project beneficiaries – e.g. an eye clinic treating patients with glaucoma, or training people with disabilities as health workers – e.g. peer support workers in a mental health hospital. Conversely, other health partnerships will not have developed projects with a specific focus on people with disabilities, hence it might be harder for them to determine whether their activities are accessible to people with disabilities and will ultimately have a positive impact on this group. **Disability inclusion can be considered at different levels of a project and should be discussed between relevant members of the partnership (in the UK and overseas) to get a better understanding of the local context.**

Different levels within a health project where disability can be considered:

* LMIC health workers supported:Is your project supporting health workers with disabilities (i.e. through training, mentoring, etc.)? Are there any health workers with disabilities within the participating institutions who could be encouraged to participate in the training? Are the training materials, formats and logistics accessible to health workers with disabilities? Are the hospital managers / other health workers supportive of health workers with disabilities?
* Patients benefitting from new or improved health services:is a health service set up or strengthened by your health partnership being used by people with disabilities? Are health workers trained through the project supporting people with disabilities? Are health services able to provide the same level of care and information to people with disabilities? Are there barriers preventing people with disabilities from accessing these services?
* Other levels that could be looked at:
* UK volunteers: Are the volunteer recruitment and management policies of your partnership inclusive of people with disabilities? Are any people with disabilities volunteering as part of the project? Is volunteering accessible to people with disabilities or can special measures be implemented to accommodate volunteers with disabilities?
* Institutions:Does a hospital, health centre, etc. have specific services for people with disabilities? Are health services provided accessible to people with disabilities? Does the institution have dedicated staff who can care and communicate with patients with disabilities? Is senior management at the LMIC institution involved in promoting access for people with disabilities?
* Guidelines/protocols/policiesat intuitional, regional or national level: are the policies, guidelines or protocols which your partnership is working on inclusive of people with disability (or explicitly mentions this group)?
* Communities: is a project reaching people with disabilities in communities? Are community health workers (CHWs) trained in providing care to people with disabilities? Are CHWs contributing to raising awareness on people with disabilities to reduce stigma and discrimination?

## HPS reporting requirements on disability

DFID and THET have devised some HPS-wide indicators that require a disaggregation of data per people with disabilities. These are detailed below.[[3]](#footnote-3)

* *Number of women and girls, and* ***people with disabilities****, using a new or improved specified health service at participating institutions.*
* *Number of developing country health workers demonstrating improved performance, at least 3 months after education or training, including number and % of female health workers and* ***number and % of health workers with disabilities***
* *Number of training course places or other educational opportunities provided to developing country health workers (directly by project or by trainers trained in project), including number and % of female health workers and* ***number and******% of health workers with disabilities***

Based on these indicators, health partnerships with current HPS funded projects are expected at a minimum to collect quantitative data and report on the following:

* Number of health workers trained or educated who have a disability
* If any health workers trained have a disability, how many demonstrate improved performance after training
* Number of people with disabilities accessing new or improved health services in the institutions supported by the project

Gathering additional qualitative information can also be useful to gain a better understanding of how a project is benefitting people with disabilities, including:

* The specific impact that the training and other support provided through the project has had on health workers with disabilities (e.g. professional practice, working relations with colleagues, confidence levels, status within their institution, etc.)
* The difference that new or improved health services has made to people with disabilities using them (e.g. access to adequate care and treatment, their status as a patient, their status in the community, quality of life, etc.)

## Integrating disability into existing data collection plans (disaggregation)

Below are some examples of how a health partnership can integrate disability measures as part of their project at different levels[[4]](#footnote-4).

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| **Relevant indicators** | **Data collection tools** | **Methods** | **Guidance for implementation**  |
| Number of health workers trained, ***including number of health workers with disabilities*** | Training registration formsOrPre-training questionnaires | Training registration forms for health workers could include a category on disability, for example:*Do you have a disability? Yes/No/Don’t know/Prefer not to say**If yes, please select the type of disability (include tick box with options or ask to specify)*Or include the **Washington Group (WG) set of short questions** ***(see section 5)****.* | Simple, easy to add to registration forms along with asking about gender. Such a question has been known to lead to under-reporting and misreporting due to stigma, different interpretation of what the term means ***(see section 6)***.A definition could be included in the forms and data collectors can explain the purpose of asking this question.Using the WG set of short questions, although less prone to bias and under-reporting, is more time consuming and might not be appropriate to include in existing training forms ***(see section 5).*** |
| Number of health workers, completing the training /showing improved skills and knowledge, immediately after training, ***including number of health workers with disabilities*** | Project database – trainee-related data, based on:* Knowledge tests
* Simulation test
* Pre and post training questionnaires
 | Relevant M&E person and/or trainers to keep track of how many health workers with disabilities ‘pass’ the training course or show ‘improved knowledge’.  | Make sure that trainers and data collectors keep track of whether any health workers with disabilities have successfully completed the training.If tests or questionnaires are completed anonymously, include the question again in the form (see above). |
| Number of health workers trained showing improved performance after training or education at least three months after training, ***including number of health workers with disabilities*** | Project database – trainee-related data, based on follow up with health workers trained after training through:* Observation of practice
* Follow up questionnaires/ surveys
* Semi structured interviews
 | Ensure health workers with disabilities trained are included in the sample of health workers followed up with after training. | As aboveFollow up questionnaires or interviews can also include specific questions on how the training has supported them in their practice as a health workers with disabilities |
| Number of patients using new or improved health services, ***including number of patients with disabilities***Number of patients with improved health outcomes after accessing a new or improved service, ***including number of patients with disabilities*** | Hospital recordsHealth worker logbooks / recordsFollow up with patients through surveys, interviews or focus group discussions | Assess whether hospital patient records specify disability.Train health workers to record if any patients they see has a disability in their logbooks if not already known to themCollect information directly from (a sample of) patients using the **Washington Group (WG) set of short questions** ***(see section 5).*** | Hospital records might be not capture this information or might be incomplete.If necessary, health workers will have to be carefully explained how to ask the question about disability to their patients to avoid biased responses, stigma and harm and explain how the information will be used so as not to violate patient confidentiality ***(see sections 6 and 7)***Using the WG set of short questions is more time consuming however it is a tried and tested method to collect robust and unbiased data on disability ***(see section 5).***Follow up questionnaires or interviews with patients can also include specific questions on how the new or improved services has benefitted them as people with disabilities |

## Using the Washington Group short set of questions on disability

The [Washington Group Short Set of questions on disability](https://www.cdc.gov/nchs/data/washington_group/wg_short_measure_on_disability.pdf) assesses whether the respondent has a disability based on responses to questions that assess how they function rather than by asking them to identify if they have a disability or not. The tool is to 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 wider assessment of access to health services. Other questions within these other measurement tools can be disaggregated by disability status.

The Washington Group recommends that the questions need to be asked directly to 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 or intellectual maturity in the case of a child)[[5]](#footnote-5).

### Set of Questions

**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

### Assessment of disability using the Washington Group Short Set of questions

As described in the DFID disability framework: *“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”.*

That said, depending on the specific needs of the health partnership project, data could be analysed in more depth either by individual question (with a particular function in mind) or based on different levels of severity i.e. from “some difficulty” to “unable to do at all” if it useful[[6]](#footnote-6).

## Issues in collecting disability data

Language used: asking the disability question using general terms such as ‘(physical or mental) disabilities, handicap, and impairments’ has been known to lead to results which underestimate the prevalence of people with a disability. The respondent might not consider themselves as being disabled, or may not wish to be ‘categorized’ or ‘labelled’ as disabled if they view it as having negative connotations. Alternatively, some people may view having a disability in politically motivated terms, as something which would allow them to access or advocate for rights. This is further amplified by the ambiguity of the term ‘disability’, and the different meanings that it can have in different contexts. The very concept of ‘disability’ is constantly evolving, and so definitions need to be identified early on in the process.

Cultural norms: different cultural perceptions of disability, including stereotypes and generalisations about people with disabilities, will also influence reporting. For instance, there might be stigma and discrimination against people with disabilities due to traditional beliefs that it is a ‘punishment’ or a ‘curse’ on the family. Alternatively, people with disabilities might be seen as incapable of participating in ‘normal’ social life. Although these views might not be expressed openly, they might still be embedded in society and communities. There might be other cultural reasons why collecting the information is difficult, for instance a female respondent might be less inclined to answer the question to a male data collector or vice-versa (in the case of an interview) or the data collector themselves might share those social perceptions on disability.

**It is important to consider and discuss potential cultural influences with local partners and to plan appropriate data collection tools and methods accordingly.**

## Ethical considerations and data protection

Due to the sensitive nature of data captured, it is vital that any data collection plans are designed in advance to ensure that these pose no risk of harm to project stakeholders and beneficiaries, including:

* Data collection forms adapted to the local context which include no use of offensive language whether verbal or written, and include options such as ‘prefer not to say’ as well as give respondents the option to skip the question
* Provide respondents with information about the purpose of the project, how the information will be collected, used and stored and their rights to withdraw at any time or to not answer questions: ***consent forms***
* Train data collectors so they fully understand the purposes of collecting data on disability. Provide them instructions on data collection including possible issues in collecting the data in practice and offer potential solutions. It is also important to discuss local myths and stereotypes associated with people with disabilities in to correct any biases or presumptions.

Prior to data collection, it is crucial to have a **data protection and confidentiality plan in place.** Data protection must be considered at each stage of the data collection and management process including how the data is collected (how the question is asked, who asks the question), how the data is stored (who has access and what protections there are), how the data is analysed and reported.

Please also refer to the sections on Data Protection and Confidentiality in HPS grant contacts and check local regulations on privacy requirements.

In any case, good practice in data collection involves:

* Informing respondents of what information will be collected, the purpose and how it will be used
* Getting consent from the respondents or if not possible get consent by proxy (e.g. child or impairment that prevents from answering) prior to collecting the data, give them the opportunity opt out of the disclosures of information about them
* Assure respondents on how their information will be handled and kept safe

### Other useful resources:

[DFID Disability Framework - One Year on, December 2015](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/554802/DFID-Disability-Framework-2015.pdf)

[Washington Group on Disability website](http://www.washingtongroup-disability.com/)

[Washington Group question sets on Disability](http://www.washingtongroup-disability.com/washington-group-question-sets/)

[ENDAN-CCM Guidelines for Disability Data Collection Tools and Measurement](http://www.cbm.org/article/downloads/82788/Guidelines_for_data_collection_tools.pdf)

1. <http://www.who.int/disabilities/world_report/2011/en/> [↑](#footnote-ref-1)
2. <http://www.un.org/disabilities/documents/resolutions/a_res_66_124.doc> [↑](#footnote-ref-2)
3. Please note that HPS indicators may be reviewed by THET and DFID at any time during the programme timeframe. Some of these indicators are still being discussed with DFID. [↑](#footnote-ref-3)
4. Please note that not all indicators in the table might be relevant to your project. [↑](#footnote-ref-4)
5. Taken from: <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/554802/DFID-Disability-Framework-2015.pdf> [↑](#footnote-ref-5)
6. <https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/554802/DFID-Disability-Framework-2015.pdf> [↑](#footnote-ref-6)