



PACIFIC
WOMEN
LEAD

Guidance Note 2:

Collecting and Using Disability Data to Enable and Monitor Inclusion

PC: Women's Fund Fiji

Understanding disability

The Convention on the Rights of Persons with Disabilities (CRPD) describes people with disabilities as *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.*

Disability arises not from impairment (i.e., problems in body functions or structures) alone, but from the interaction between a person's impairment and the barriers they face to full participation in their community on an equal basis with others.



Barriers to participation can be:



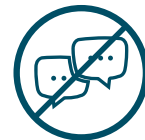
Attitudinal
Stigmatising or discriminatory attitudes towards people with disabilities.



Environmental
Barriers to accessibility in the built environment.



Institutional
Discriminatory laws, policies and practices; and



Communication
Inaccessible written or verbal information.

Objective

This guidance note aims to support Pacific Women Lead (PWL) partners to report and monitor inclusion, by collecting disability disaggregated data using the Washington Group Short Set.



Each of PWL's end of program outcomes intends to reach women and girls with disabilities. This requires mainstreaming of disability inclusion across the program outcome areas and monitoring and reporting on efforts.

As outlined in PWL's [Guidance Note 1: Reporting on Disability Inclusion](#), reporting and monitoring the journey towards disability equity and rights requires an understanding of:

- Preconditions, or the supports that were put in place to enable participation by people with disabilities.
- Inclusion, or the number of people with disabilities who have participated in activities; and
- Participation, or the experience of equitable outcomes by people with disabilities.

This guidance note will support partners in their efforts to monitor and report on disability inclusion.

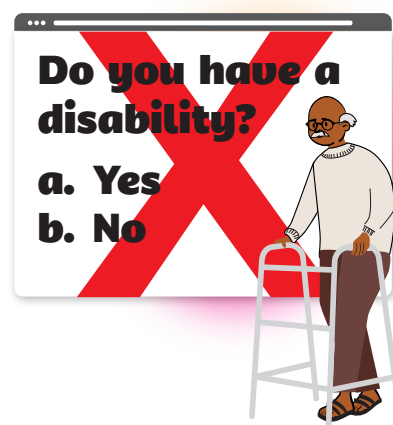
Identifying Disability Status

Planning and monitoring disability inclusive development requires intentionally collecting information from and about people with disabilities. The CRPD's understanding of disability is multi-faceted. Using it to determine an individual's experience of disability is complex and time consuming.

Should we just ask if someone has a disability?

No. Questions such as 'Do you have a disability?' or 'What type of disability do you have?' have been shown to be ineffective and result in under-reporting because:

- sometimes the word used for 'disability' in different languages is viewed negatively or is not understood by everyone.
- disability might be associated with stigma and shame in some contexts and people may not want to disclose information; and
- people may not identify as experiencing a disability, for example, some older people with disabilities may view their difficulties as a typical result of aging.



Six Questions in the Short Set



The Washington Group Short Set (Annex A) is a series of 6 questions which ask about functional abilities, or what people can do. This includes difficulty seeing, walking, hearing, understanding, self-care or communicating with others.¹

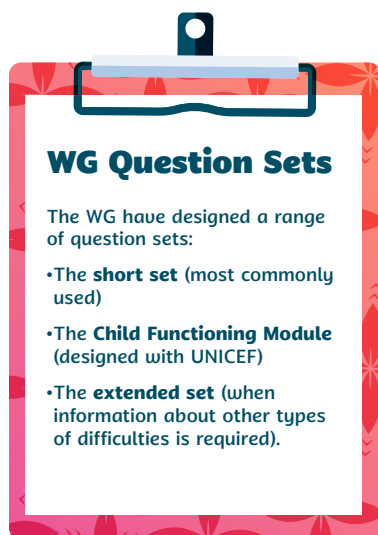
The responses to the Washington Group Short Set include “no - no difficulty” “yes – some difficulty”, “yes – a lot of difficulty” and “yes – cannot do at all”. The Washington Group advises that anyone who responds with “yes – a lot of difficulty” or “yes – cannot do at all” may be counted as a person who is likely to experience disability.

The Washington Group Short Set has been found to provide a good approximation of people who might experience disability or are at risk of having a disability. It is a proxy for disability rather than a diagnosis of disability. The Washington Group Short Set can be used to identify disability in a population without relying on specific cultural terms or conceptions of disability.

The Washington Group Short Set is recommended by the United Nations for use in censuses and population surveys for people aged 5 and above. The questions are also used to report and monitor disability inclusion in many sectors and programs. The use of a consistent tool and methodology allows progress to be tracked over time.

¹ One limitation of the Short Set is that it does not identify all people with impairments relating to mental health issues/psychosocial disability. The Extended Set of questions asks additional questions related to psychosocial wellbeing.

Using the Washington Group Short Set within Pacific Women Lead



PWL asks project partners to use the Washington Group Short Set when implementing activities that target or involve individuals. This could be through the provision of services (i.e. crisis response services or sexual and reproductive health services) or through activities such as the delivery of training or workshops.

The Washington Group Short Set can be easily incorporated into satisfaction surveys, questionnaires, registration forms or monitoring tools to allow for disaggregation of data by disability. The Washington Group Short Set can be integrated into survey forms which individuals complete themselves, or questionnaires that are administered by a staff member.

The way the tool is used depends on the context. In some places, the questions work better when verbally asked by a staff member.

The effectiveness and accuracy of these questions depend on several factors:

- the knowledge and understanding of people asking the questions.
- whether questions are asked directly to the person of interest; and
- whether the questions have been appropriately translated and are used as designed.

It is important to ensure that no initial questions about 'disability' are included and that the questions are read exactly as written/translated.

Sometimes minor adaptations are required. For example, if there are no hearing aids available in the context it may be confusing to ask if a person can hear 'even if using hearing aids', so the latter part of the question can be removed.

It is strongly advised that the wording of the questions – or response categories – is not changed without prior testing as this can result in under or over-reporting.

After identifying people with disabilities, this information can be used to:

- Have targeted discussions with people with disabilities regarding the barriers to their participation, and any inclusion support needs.
- Understand how many, or what proportion, of people participating in your activities experience disabilities.
- Compare the experiences of people with and without disabilities; and
- Compare changes or outcomes for people with and without disabilities, including the barriers and enablers experienced by both groups.

Strengthening efforts to progress disability equity and rights requires the collection of data to understand and respond to the experiences and situation of people with disabilities. After disability status has been identified, the next step is to explore barriers to participation in activities, to inform the development of strategies to overcome these. Without this understanding, there is a risk of planning and implementing activities which further isolate and marginalise people with disabilities.



Practical Tips for Using the Washington Group Short Set in the Pacific



Look for a Local Translation - Avoid Reinventing the Wheel

Instead of creating a new translation of the WGSS, which may alter the meaning of questions, consult your local National Statistics Office, Disability Desk Officer, and/or Organisations of Persons with Disabilities for an accepted translation in your local language. You can also collaborate with these entities to continually refine your approach and ensure inclusivity.



Don't Change Response Categories - Maintain Original Responses

Altering response categories to simple "yes" or "no" can lead to significant overreporting of disabilities. For instance, a program changing the responses resulted in 70% of people reporting difficulty with understanding. When the recommended response categories were used ("no difficulty", "a little difficulty", "a lot of difficulty", "cannot do at all"), only 3% reported difficulty with understanding.



Add Relevant Questions to Your Work - Tailor to Your Needs

If it would be useful for your program to address specific functional difficulties that are not covered by the WGSS, consider adding questions from the extended set. For example, a skills development program added a question about difficulty using hands and fingers from the extended set, enabling them to better support participants with difficulty using their upper limbs in vocational training.



Disaggregate by Types of Difficulty – Enable Detailed Reporting

When collecting disability data, provide an analysis of the types of difficulties experienced. This can help identify gaps in participation and improve engagement strategies. For example, a program found low participation from people with vision difficulties and subsequently developed strategies with Organisations of Persons with Disabilities to better engage these individuals.

Important Notes:

Mental Health Considerations: The WGSS does not identify psychosocial or mental health difficulties. To address these, include questions from the Washington Group's Extended Set.

Child Disability Identification: Use the UNICEF-Washington Group Child Functioning Module to identify difficulties experienced by children aged 5-17 years.

Annex A

Washington Group Short Set

Note: The text below can be inserted directly into data collection tools. The introduction can be amended to suit the 'flow' of the survey but should only refer to health problems rather than disability. The questions should not be adapted without prior consultation.

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

Questions	Responses
 Do you have difficulty seeing, even if wearing glasses?	No – no difficulty Yes – some difficulty Yes – a lot of difficulty Yes – cannot do at all
 Do you have difficulty hearing, even if using a hearing aid?	No – no difficulty Yes – some difficulty Yes – a lot of difficulty Yes – cannot do at all
 Do you have difficulty walking or climbing stairs?	No – no difficulty Yes – some difficulty Yes – a lot of difficulty Yes – cannot do at all
 Do you have difficulty remembering or concentrating?	No – no difficulty Yes – some difficulty Yes – a lot of difficulty Yes – cannot do at all
 Do you have difficulty (with self-care such as washing all over or dressing)?	No – no difficulty Yes – some difficulty Yes – a lot of difficulty Yes – cannot do at all
 Using your usual language, do you have difficulty communicating, for example understanding or being understood?	No – no difficulty Yes – some difficulty Yes – a lot of difficulty Yes – cannot do at all

People who respond with 'Yes – a lot of difficulty' or 'Yes – cannot do at all' are likely to be at risk of disability.