

1 Introduction

1.1 Why is disability assessment important?

Knowing what disease a patient has requires application of the fine art and science of diagnosis. This knowledge helps to guide treatment interventions and management strategies; it can also help to predict outcome and prognosis to a certain extent. However, although diagnosis is valuable, on its own, it is not sufficient for understanding the full picture and the lived experience of a patient; the adage "there are no diseases, but patients" applies.

Just as important as the disease label itself is whether a person can work and carry out the routine activities necessary to fulfil his or her roles at home, work, school or in other social areas. Summed up by the phrase "what people cannot do when they are ill", this aspect differs greatly, independently of the disease concerned. Information on functioning (i.e. an objective performance in a given life domain) and disability is taken into account by professionals in clinical and social services; however, proper measurement of functioning and disability has long suffered from a lack of consistent definitions and tools. Defining death and disease is easy, but defining disability is difficult, as is measuring it.

Disability is a major health issue. When global assessments are made for burden of disease, more than half of the burden of premature mortality is due to overall disability (1). People generally seek health services because a disease makes it difficult for them to do what they used to do beforehand (i.e. because they are disabled) rather than because they have a disease. Health-care providers consider a case to be clinically significant when it limits a person's daily activities, and they use disability information as the basis of their evaluation and planning.

For public health purposes, disability has become as important as mortality. Although health-care advances have reduced mortality, the associated increase in longevity has led to a corresponding increase in chronic diseases that need to be managed lifelong, and special needs are emerging for the care of aged populations. Public health has to move beyond mortality and take into account disability, to set priorities, measure outcomes and evaluate the effectiveness and performance of health systems. Box 1.1 summarizes the importance of disability assessment.

1.2 Why develop a method to assess disability?

It is difficult to define and measure disability, because disability is related to many life areas, and involves interactions between the person and his or her environment. The World Health Organization (WHO) Project on Assessment and Classification of Human Functioning, Disability and Health brought together representatives of more than 100 countries, researchers and consumers in an international collaboration, to produce the International Classification of Functioning, Disability and Health (ICF) as a consensus framework (2).

The ICF takes each function of an individual – at body, person or society level – and provides a definition for its operational assessment, and defines disability as "a decrement in each functioning domain" (2). However, the ICF is impractical for assessing and measuring disability in daily practice; therefore, WHO developed the WHO Disability Assessment Schedule (WHODAS 2.0) to address this need, and provide a standardized way to measure health and disability across cultures.

Box 1.1 summarizes the reasons for learning and using a disability measure.

Box 1.1 Why learn and use a disability measure?

Diagnosis and assessment of disability is valuable because it can predict the factors that medical diagnosis (assigning a disease label) alone fails to predict; these include:

- service needs – What are the patient's needs?
- level of care – Should the patient be in primary care, specialty care, rehabilitation or another setting?
- outcome of the condition – What will the prognosis be?
- length of hospitalization – How long will the patient stay as an inpatient?
- receipt of disability benefits – Will the patient receive any pension?
- work performance – Will the patient return to work and perform as before?
- social integration – Will the patient return to the community and perform as before?

Disability assessment is thus useful for health care and policy decisions, in terms of:

- identifying needs
- matching treatments and interventions
- measuring outcomes and effectiveness
- setting priorities

As explained above, WHODAS 2.0 is grounded in the conceptual framework of the ICF. All domains were developed from a comprehensive set of ICF items and map directly onto ICF's "Activity and participation" component (2). As in the ICF, WHODAS 2.0 places health and disability on a continuum, with disability defined as "a decrement in each functioning domain". In addition, WHODAS 2.0, like the ICF, is etiologically neutral; that is, it is independent of the background disease or previous health conditions. This feature makes it possible to focus directly on functioning and disability, and allows the assessment of functioning separately from the disease conditions.

There are several different versions of WHODAS 2.0, which differ in length and intended mode of administration (see Section 2.4 for details). The full version has 36 questions and the short version 12 questions; these questions relate to functioning difficulties experienced by the respondent in the six domains of life during the previous 30 days. The different versions – which are given in Part 3 – can be administered by a lay interviewer, by the person themselves or by a proxy (i.e. family, friend or carer). The 12-item version explains 81% of the variance of the more detailed 36-item version. For both versions, general population norms are available.

1.4 Why use WHODAS 2.0?

There are numerous published measures of disability; these are also known as health status measures or functioning measures. Some of the most widely used measures are summarized in Table 1.1, (pp.6,7). Aspects that make WHODAS 2.0 particularly useful are its sound theoretical underpinnings, good psychometric properties, numerous applications in different groups and settings, and ease of use. This section summarizes the main benefits of WHODAS 2.0.

Direct link to the International Classification of Functioning, Disability and Health

A unique feature of WHODAS 2.0, which distinguishes it from other disability measures, is its direct link to the ICF (2). Although other generic instruments for assessing health status can also be mapped to ICF, they do not clearly distinguish between measurement of symptoms, disability and subjective appraisal. WHODAS 2.0 is unique in that it covers ICF domains fully and applies to all diseases, including physical, mental and substance-use disorders. It also assesses disability in a culturally sensitive way across a standard rating scale. This is discussed in detail in Chapter 2.

Health concepts (domains) measured	No. of items	Administered by	Time to complete (minutes)
<ul style="list-style-type: none"> Adaptation Autonomy Body image Decision-making Emotional well-being Health status Information seeking Life satisfaction Quality of life Self-efficacy Stress management Supportive relationships Understanding of illness Use of health services Willingness to participate in research 	36	Self or interview	5-10 20
<ul style="list-style-type: none"> Adaptation Autonomy Body image Decision-making Emotional well-being Health status Information seeking Life satisfaction Quality of life Self-efficacy Stress management Supportive relationships Understanding of illness Use of health services Willingness to participate in research 	6	Self	5
<ul style="list-style-type: none"> Adaptation Autonomy Body image Decision-making Emotional well-being Health status Information seeking Life satisfaction Quality of life Self-efficacy Stress management Supportive relationships Understanding of illness Use of health services Willingness to participate in research 	36	Self or interview	10 10
<ul style="list-style-type: none"> Adaptation Autonomy Body image Decision-making Emotional well-being Health status Information seeking Life satisfaction Quality of life Self-efficacy Stress management Supportive relationships Understanding of illness Use of health services Willingness to participate in research 	Part 1: Health problems (38 items) Part 2: Life areas affected (7 items)	Self	5-10

Measure and key references	Background	For use with	Health concepts (domains) measured	No. of items	Administered by	Time to complete (minutes)
FIM (12)	Developed by a task force sponsored by the AAPM&R and the ACRM. Designed to assess the amount of assistance required by a person with a disability to perform basic life activities.	Clinical population only	Self-care Sphincter control Transfers Locomotion Communication Social cognition	18	Interview (by physician, nurse or therapist)	30
BAI (13,14)	Developed in 1955 to assess and monitor mobility and self-care activities of daily living.	Clinical population only	Bowel status Bladder status Grooming Toilet use ^a Feeding Transfers ^a Mobility ^a Dressing Stairs ^a Bathing ^a	5-10	Interview (by therapist or other observer)	2-5

AAPM&R, American Academy of Physical Medicine and Rehabilitation; ACRM, American Congress of Rehabilitation Medicine; BAI, Barthel's Index of Activities of Daily Living; FIM, Functional Independence Measure; ICF, International Classification of Functioning, Disability and Health; ICIDH, International Classification of Impairments, Disabilities, and Handicaps; LHS, London Handicap Scale; NHP, Nottingham Health Profile; SF-36, Medical Outcomes Study 36-Item Short-Form Health Survey; WHODAS 2.0, WHO Disability Assessment Schedule 2.0

^a Items included in 5-item version.

Cross-cultural comparability

Unlike other disability measures, WHODAS 2.0 was developed on the basis of an extensive cross-cultural study, spanning 19 countries across the world. The items included in WHODAS 2.0 were selected only after exploring the nature and practice of health status assessment in different cultures. This was achieved using a linguistic analysis of health-related terminology, key informant interviews and focus groups, as well as qualitative methods (e.g. pile sorting and concept mapping¹) (3). Once developed, WHODAS 2.0 was tested in a variety of different cultural settings and health populations, and was found to be sensitive to change, regardless of the sociodemographic profile of the study group.

Psychometric properties

WHODAS 2.0 has excellent psychometric properties. Test-retest studies of the 36-item scale in countries across the world found it to be highly reliable. All items were selected on the basis of item-response theory (i.e. the application of mathematical models to data gathered from questionnaires and tests). The instrument as a whole showed a robust factor structure (see Section 3.2) that remained constant across cultures and different types of patient populations. The validation studies also showed that WHODAS 2.0 compared well with other measures of disability or health status, and with clinician and proxy ratings (15, 16).

Ease of use and availability

WHODAS 2.0 can be self-administered in around 5 minutes, and administered through an interview in 20 minutes. The instrument is easy to score and interpret, is in the public domain, and is available in more than 30 languages.

1.5 Purpose and structure of the manual

1.5.1 Purpose

This manual is aimed at health professionals (e.g. in the areas of public health, rehabilitation, physical therapy and occupational therapy), health-policy planners, social scientists and other individuals involved in studies on disability and health. It will provide users with:

- a new appreciation of health status and disability assessment in the light of the framework and classification provided by the ICF;
- a detailed overview of the development, key features and application of WHODAS 2.0; and
- a comprehensive guide to administering the system.

1.5.2 Structure

This manual is organized into three parts, covering background information (Part 1), administration and scoring of the instrument (Part 2) and the different versions of WHODAS 2.0 (Part 3).

The contents of Chapters 2–4, which make up the remainder of Part 1, are as follows:

- *Chapter 2* discusses the development of WHODAS 2.0 – the rationale and conceptual background for its development, and the method and stages of the development process. This chapter also introduces the different versions of WHODAS 2.0, and the schedule's methods, sources and major findings. It covers the technical basis and implications of incorporating disability into health assessments, and provides more detail on the links between the ICF and WHODAS 2.0.
- *Chapter 3* focuses on the psychometric properties of WHODAS 2.0. It discusses the instrument's reliability and consistency, the factor structure, sensitivity to change, item–response characteristics, validity and general population properties.
- *Chapter 4* outlines the uses of WHODAS 2.0 at population and clinical levels. It looks at how the instrument can be used in population surveys and registers, and for monitoring outcomes for individual patients in clinical practice and clinical trials of treatment effects.

Part 2 has a practical focus. It contains six chapters:

- *Chapter 5* presents generic information and instructions for the different modes of administering WHODAS 2.0, general guidelines for the application of the instrument and guidance on developing versions in different languages.
- *Chapter 6* covers the scoring of WHODAS 2.0. It includes information on sample characteristics, computing items, domain and summary scores, population norms and handling of missing data.
- *Chapters 7–10* provide question-by-question specifications for all six domains, detailed guidelines for using the various WHODAS 2.0 versions, material for self-testing and a sample training curriculum.

At the end of Part 2, there is a glossary and a list of references.

As mentioned above, Part 3 of this manual provides the seven different versions of WHODAS 2.0.

