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# Who is disabled? On whether the functional definition of disability targets the same individuals as the subjective definition

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With the increased attention to disability as a vulnerability criterion in the Sustainable Development Goals, international organizations and NGOs within the international development sector have started to pay explicit attention to persons with disabilities, including the collection of data on persons with disabilities. The Washington Group Short Set of Questions, which focuses on functional limitations, has been gaining popularity as an assessment tool for disability. This set of questions reflects a categorization of disability that does not necessarily correspond with subjective disability assessments, such as the yes/no question (“do you have a disability?”) which many development actors have used in their assessment tools when they collect disability data. This study compares the subjective and the functional limitations assessment tools for disability to answer the question: do they identify the same individuals as persons with disabilities? Based on a survey carried out amongst persons with disabilities in Cambodia, we included both the Washington Group Short Set and a subjective question asking respondents to self-identify their disability type. We find that, although all respondents self-identified as disabled, not all respondents would be considered disabled according to the Washington Group Short Set of questions. In addition, there is little overlap between specific disability types according to a subjective classification method and the domains of functioning measured through the Washington Group methodology. Our findings affirm that categorization as able or disabled depends on the tool used. This is important, as the assessment approach chosen by those collecting disability data can shape the design choices of policies and programs, and determine who benefits.

## KEYWORDS

functional limitations, categorization, international development, disability measurement, Washington group question sets, disability assessment

## 1. Introduction

Over the past decades, persons with disabilities are increasingly playing a role in international development cooperation, especially since the 2015 Sustainable Development Goals have focused on “leaving no one behind.” With the Sustainable Development Goals, the international community globally agreed that persons with disabilities should participate in society on an equal level to persons without disabilities, and the development sector is well-placed to play a key role in this paradigm shift. Development agencies and institutions, when they collect data on disability, often use either subjective or functional models in identifying persons with disabilities when developing programs, identifying beneficiaries,

and measuring impact. Even though categorizations – who is and who isn't considered “disabled” – directly shape how policy choices are made, who benefits, and whose views are silenced, disability categorizations in international development have hardly been examined in the literature. In this study, we look at whether, and to what extent, subjective and functional assessment tools of disability identify the same individuals as persons with disabilities.

This study makes two important contributions to the literature. First, we demonstrate that the categorization of individuals as abled or disabled is dependent on the tool used to make the categorization. Second, we show that the Washington Group domains of functioning are not directly related to the seemingly similar impairment types as used in the subjective model of categorization. This means that those using and analyzing data on disability need to be well-informed with regards to the intent and impact of each assessment tool for disability.

The remainder of this paper is as follows. Section 2 considers the rise of the disability agenda in the context of international development. Section 3 examines why categorizations of disability matter, and zooms in on two often-used assessment tools for categorization in the development sector. Section 4 states the methodology; Section 5 presents the results of our analysis. Our discussion (Section 6) examines why it matters that assessment tools categorize (dis)ability differently. Section 7 provides a conclusion and discusses the practical consequences of our findings.

## 2. Disability and international development

Globally, but particularly in low- and middle-income countries, persons with disabilities are not accessing the same services and opportunities compared to their able-bodied peers. Disability has been linked to exclusion from education, less access to healthcare, reduced employment, lower earnings, and food insecurity (Meekosha and Soldatic, 2011; Banks and Polack, 2014; Trani et al., 2018; United Nations, 2018; Mitra and Yap, 2022). Disability has also been linked to poverty: impairment causes poverty, while poverty increases the risk of impairment (Grech, 2016; Trani et al., 2018).

Within the international development field, the United Nations Convention for the Rights of Persons with Disabilities (UNCRPD) has been a landmark. This convention was adopted by the UN in 2006, and as of June 2022 has 164 states as signatories. As a human rights instrument, it affirms that persons with disabilities are “subjects” with rights, who are capable of claiming those rights and making decisions for their lives (United Nations, 2022). The Convention specifically recognizes the importance of international cooperation and international development, stating in Article 32(a) that measures should ensure “that international cooperation, including international development programs, is inclusive of and accessible to persons with disabilities” (UN General Assembly, 2007). The Sustainable Development Goals (SDGs) have put disability even higher on the development agenda. The SDGs were adopted in 2015, and consist of 17 goals that act as a compass for national and global policies to achieve a better and more sustainable future for all. The SDGs aim to “leave

no one behind,” specifically addressing the inclusion of persons with disabilities in five of those goals, namely access to education and vocational training (Goal 4), productive employment for all (Goal 8), the reduction of inequality (Goal 10), access to public transport and public spaces (Goal 11) and the increased availability of high-quality disability-disaggregated data (Goal 17) (UN General Assembly, 2015). Many countries, including low- and middle-income countries, are increasingly collecting data on persons with disabilities in order to understand and address the equality gap between those considered to have disabilities and those that do not (See, for example Berlinski et al., 2021; Lewis et al., 2022; Mitra and Yap, 2022).

The call for inclusion in the development sector is thus increasingly being heard, driven in part by the lobby of disability-specific development organizations (Grech, 2016) such as Light for the World, Sightsavers, and CBM International. Large funders, such as the British Department for International Development (DFID) and Australia's Department of Foreign Affairs and Trade (DFAT), have started making funding available for the inclusion of persons with disabilities. In doing so, they act as a driver for development organizations without a specific disability focus to make changes to address the needs of persons with disabilities in their programs.

Organizations working in the development sector are thus increasingly looking for a way to include persons with disabilities in their programs, their monitoring and evaluation, and their beneficiary groups (Altman, 2016), motivated by the increased requests of funding agencies to monitor disability inclusion in their projects (Leonard Cheshire Humanity Inclusion, 2018; Robinson et al., 2021). Good data is important for development agencies to measure progress toward their goals and the goals of the SDGs, make evidence-informed decisions, and ensure they are targeting the right people (Abualghaib et al., 2019). Many agencies, however, currently lack reliable and relevant data on disability (Chataika and McKenzie, 2016; Madans, 2016; Mitra, 2017; Trani et al., 2018; Chibaya et al., 2022). A particular challenge relates to defining and categorizing persons with disabilities, which is the focus of this paper.

## 3. Disability and categorization

The concept, definition, and subsequent measuring of disability has been struggled with over decades, with “different studies using different operationalizations of disabilities” (Mitra, 2006; Grönvik, 2009, p. 1). How disability is defined and assessed – whether individuals are categorized as abled or disabled – is dependent on the theoretical model underlying the concept (Eide and Loeb, 2016; Toro et al., 2020). One such model is the medical model, whereby disability is considered an individual problem caused by a (clinically observable) disease, injury or health condition. People are considered not able to function as they should; rehabilitation is needed to bring them as close to “normal” as possible (Mitra, 2006; Toro et al., 2020). The social model – initiated by disability movements in the United Kingdom and North America – sees disability as a creation of the social environment: persons with impairments or diseases are excluded from society through sensory, attitudinal, cognitive, physical, and economic barriers; social change is needed to include persons with

disabilities in society (Mitra, 2006; Eide and Loeb, 2016; Toro et al., 2020). The International Classification of Functioning, Health and Disability (ICF), which considers disability to be an intersection between health conditions, environmental factors and personal factors (World Health Organization, 2002), is used often in the development sector. This is also the model used by the UNCRPD, which states that “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” (UN General Assembly, 2007, p. 4).

To assess whether persons with disabilities are participating on an equal basis to persons without disabilities, development agencies need to make comparisons between that part of the population that is considered as having a disability and that part of the population that isn't (Madans et al., 2017). This requires the grouping of individuals into “disabled” and “not-disabled.” The very act of defining disability is challenging (Altman, 2016; Mitra, 2017), and depends on how one views disability. Even more challenging is defining it in such a way that individuals can be grouped into one category or the other. Seeing disability as a dichotomy – one either has it, or one doesn't – “does not sit well with the continuous, multidimensional, and [...] heterogeneous notion of wellbeing and deprivation” (Mitra, 2017, p. 16). Categories – such as those of disabled and not-disabled – are useful, as they “are used to identify discriminated minority groups, to strengthen their position in organizations and society, and to combat the discrimination they face” (Risberg and Pilhofer, 2018, p. 135). But how the categorization is done can have far-reaching consequences for individual lives and society at large (Beaudry, 2020). Bennani and Müller (2018), for example, give an interesting overview of the changing categorization of disability within the UN context, necessary for the political mobilization of persons with disabilities, and the debate that exists as states and (disability) NGOs contest or advocate for certain definitions of disability. Choosing to use a certain definition of disability can be empowering, supporting persons to make claims for equality, but can also contribute to the (further) marginalization of people (Beaudry, 2020; Thorjussen and Wilhelmsen, 2020). Over time, “(classifications) often come to be considered as natural, and no one is able completely to disregard or escape them” (Bowker and Leigh Star, 1999, p. 53). They can lead to stigmatization and discrimination; the label of “disability” is often associated with marginalization (Anastasiou and Kauffman, 2013; Grue, 2016; Thorjussen and Wilhelmsen, 2020); the prefix ‘dis’ already implies something negative (Schippers, 2021).

Categories, however, are not universal, but a process of “negotiation or force” (Bowker and Leigh Star, 1999, p. 46), based on social agreements and not dictated by the materiality of things (Bennani and Müller, 2018). How the categories are created and defined results from power play: “those determining the categories have the power to define the norm” (Risberg and Pilhofer, 2018, p. 136). Even a (clinical) diagnosis or impairment, seen by some as “objective,” is the result of politics (Grue, 2011; Haslanger, 2019). Those doing the categorization thus have the power to prescribe a label and, consequently control access to assistance and attach a stigma to the person labeled (Ghosh, 2016). In addition, those doing the categorization are, most often, the socially dominant group

(Meekosha and Soldatic, 2011; Beaudry, 2020). In the development sector, categorizations that are used in surveys, monitoring tools and inclusion criteria for services are typically established by those organizations in the global North that control the funding (Meekosha and Soldatic, 2011). This seemingly goes against the grain of the disability sector's adage “Nothing about us, without us.” Certain models, and thus categorizations, of disability do not necessarily take into account the lived experience of those that have impairments (Grönvik, 2007); members of the general public may not use the same conceptual framework when categorizing themselves, and may not consider themselves as having a disability (Bogart et al., 2017; Mitra, 2017). The assessment tools used to categorize disability have the power to label, and thus “the use of categories in empirical research calls for ethical consideration” (Thorjussen and Wilhelmsen, 2020, 2), and, in our opinion, inquiry into how categories (of disability) are being used, who they are, in fact, labeling, and who is doing the labeling.

The little research that has been done on disability categorizations is often not from the global South in general, nor more specifically from the development field. One study from Norway compared a functional measure of disability (i.e. the Washington Group) to a more subjective measure of disability (“do you have a disability”) and found that only 46.6% of respondents were considered disabled on both measures, thus concluding that the two tools identify different groups of individuals to be disabled (Molden and Tøssebro, 2010). This is similar to results from South Africa census data, reporting a 46.8% overlap between those reporting “a lot of difficulty” using the Washington Group questions, and those considered disabled using the more subjective question “Does the person have any serious disability that prevents his/her full participation in life activities?” (Schneider et al., 2009). Some research has been done on how the Washington Group Set of questions compares to clinical measures of impairment (Mactaggart et al., 2016; Sprunt et al., 2017; Boggs et al., 2022). The different studies demonstrate that the population identified through a clinical measure is not the same population as identified through the functional measure of disability. Hardly any studies are known to the authors which look at the extent to which the subjective measure and the functional measure of disability identify the same population, and breaking it even down further, no studies are known that look at whether the “type” of disability a respondent identifies themselves as having, correlates to the type of functional limitation they report having.

Within the development sector, the most often used assessment tools for categorizing individuals into disabled or abled are direct questioning (based on a subjective definition of disability) and the Washington Group Short Set of questions (based on a functional limitations definition of disability). For this study, we thus zoom in on these two assessment tools.

Although many development agencies and institutions do not yet monitor the inclusion of persons with disabilities, those that do often use a subjective measure of disability to find and define persons with disabilities, namely direct questioning: “do you have a disability?” (Leonard Cheshire Humanity Inclusion, 2018). For a further breakdown within the category of disability, respondents are then typically asked “what type of disability do you have?,” often

presented with a list of categories such as visual, hearing, physical, epilepsy, multiple, etc.

Direct questioning is still ubiquitous in the development sector, as well as the most commonly asked disability question in nationwide censuses and surveys in low- and middle-income countries (Mitra et al., 2022). It is short, requires little prior training, and can even – as experienced by the first author – be more preferred by fundraising and communication staff who find numbers of “deaf” and “blind” people reached easier to use in fundraising with a lay public than more vague terminologies such as numbers of “people who have difficulties seeing.” The population it captures is those that self-identify – those that answer “yes” consider themselves to have a disability – and is in that sense subjective.

Direct questioning, however, leads to underreporting due to stigma and cultural understandings of disability: people may have a negative connotation with the word “disability,” be unwilling to disclose information on disability due to the shame associated with it, or may not consider their impairments as being typical of having a disability (Schneider et al., 2009; Plan International Australia CBM, 2015; Mactaggart et al., 2016). In addition, direct questioning requires respondents to understand the terminology used for certain types of impairments and to identify with those terms. This is particularly problematic in low-income countries, where many may not have a formal diagnosis as they are not able to access health care (Mitra, 2017). Presented lists of “types of disabilities” or “types of impairments” are also not mutually exclusive, non-exhaustive, may not pick up milder impairment types such as low vision, and are ignorant of the multi-dimensionality of disability, nor is there a standard, comprehensive tool to measure disability this way. This makes further disaggregation to be inadequate as well (Eide and Loeb, 2016).

In recent years, the Washington Group set of questions, developed for use in censuses and national surveys, has become an increasingly common approach in the field of disability measurement (Eide and Loeb, 2016; Weeks, 2016; Abualghaib et al., 2019). The tool focuses on activity limitations in various core domains of functioning. The questions are explicitly presented as a health question, with the word “disability” not being mentioned during questioning to avoid the stigma associated with labeling the self or the other as disabled (Groce and Mont, 2017). The series of questions are introduced with the statement: “The next questions

ask about difficulties you may have doing certain activities because of a health problem” and continue by asking six questions on various functional limitations, as seen in Figure 1 (Eide and Loeb, 2016, p. 58).

Four possible responses follow each of the questions, namely: No, no difficulty; Yes, some difficulty; Yes, a lot of difficulty; Cannot do at all. For disability statistics and data disaggregation, the recommendation by the Washington Group is to categorize people reporting “a lot of difficulty” or “cannot do at all” in at least one domain as having a disability (Eide and Loeb, 2016; Washington Group on Disability Statistics, 2020). In addition to the short set, consisting of these six questions, the Washington Group has also developed an Extended set, in case a more detailed analysis of disability is needed, and a Child Functioning Module intended to identify children with disabilities (Washington Group, 2022; Washington Group and UNICEF, 2022).

The Washington Group Short Set of questions is gaining popularity as an assessment tool for disability, with an increasing uptake of their use development organizations (Leonard Cheshire Humanity Inclusion, 2018; Robinson et al., 2021). The tool is standardized, extensively tested, and validated in all the regions of the world, and quick to administer (Groce and Mont, 2017). They have been developed with the intent to enable disaggregation and are not intended for use in isolation (Abualghaib et al., 2019). However, practice-based evidence suggests that staff in development organizations have difficulty interpreting the data. NGO staff have interpreted the different Washington Group questions as disability types, suggesting that persons who indicate “having difficulty hearing” must then be Deaf, and those who “have difficulty remembering” are intellectually disabled (Leonard Cheshire Humanity Inclusion, 2018). This is also the experience of the first author during her work with disability-focused development organizations. The question is whether they are correct to do so: is the self-reported measure of functional limitation directly related to a subjective measure of disability? In other words: do both tools consider the same individual to be a person with a disability?

Based on original research conducted in Cambodia, this study aims to investigate the relationship between a subjective assessment tool for disability, and a functional assessment tool for disability. Put simply, does an individual categorized as a disabled

Because of a health problem:	
1.	Do you have difficulty seeing, even if wearing glasses?
2.	Do you have difficulty hearing, even if using a hearing aid?
3.	Do you have difficulty walking or climbing steps?
4.	Do you have difficulty remembering or concentrating?
5.	Do you have difficulty (with self-care such as) washing all over or dressing?
6.	Using your usual (customary) language, do you have difficulty communicating (for example understanding or being understood by others)?

FIGURE 1

Washington city group on disability statistics: short set of disability questions (Eide and Loeb, 2016, p. 58).

person through direct questioning also report having a functional limitation, and is there a direct relationship between the type of disability they report having and the types of functional limitations they have?

## 4. Methodology

Data was collected as part of a study on access to public information for persons with disabilities in Cambodia, initiated by Light for the World Cambodia and local disability development organization DDSP (Disability Development Services Program) within their Communicating for Advocacy program. The study, which consisted of a survey with quantitative and qualitative questions, took place in the province of Pursat in late 2018 and early 2019. Pursat is a province in the northwestern part of Cambodia. The survey took place in 121 villages in the districts of Kandieng, Krakor, and Pursat Municipality, and was carried out amongst 422 persons with disabilities, to understand how persons with disabilities are getting information about public services, and what works and does not work for them. As this was a large study taking place amongst persons with disabilities, we chose to include both assessment tools of disability in the study to answer our research question regarding the categorization of individuals in the subjective vs. functional assessment of disability.

Respondents with disabilities were recruited by asking the village chief, commune chief, and other villagers about where persons with disabilities lived in the community, to identify as many respondents with disabilities as possible, using purposive sampling (Palinkas et al., 2015). This also made sense in light of the secondary purpose of the study, which was to identify individuals with disabilities who were not yet reached by rehabilitation services. All included respondents self-identified as persons with disabilities, or were identified as persons with disabilities by community members. All respondents agreed to and signed a consent form before inclusion in the study, which included a statement that withdrawal from the study was possible at any time. Where it was difficult to communicate, a family member was asked to answer questions for the respondent. People were interviewed at home by data collectors, staff members of DDSP, who administered the questionnaire orally and recorded answers digitally using a tablet and Kobo Toolbox software. Questions were developed in English and translated into Khmer. The DDSP staff members who did the data collection were all community-based rehabilitation workers who were experienced in working with persons with disabilities, and able to address any needs that came up during the interviews or refer respondents to relevant organizations and services for follow-up. Anonymity of responses was maintained, and data is stored securely to prevent the disclosure of sensitive information. The results of the study on access to public information for persons with disabilities were published in an easy-to-read report in English and Khmer in 2020 (Light for the World and DDSP, 2020).

In the survey, all respondents were first asked to answer the Washington Short Set of questions, and were then asked “what type of disability do you have?” followed by a multiple choice list of “disability types” to choose from. To identify those that are considered disabled according to a functional measure of disability, we used the Washington Group Short Set of questions, as translated

into Khmer for the Cambodia Demographic and Health Survey 2014. Following the Washington Group’s recommendations, the cut-off for being “disabled” or having “significant functional limitations” for each domain included “A lot of difficulty” or “Cannot do at all.”

To identify those that are considered disabled according to a subjective definition of disability, respondents were asked “What type of disability would you say you have?” after having responded to the six Washington Group Questions. Respondents were given their choice of responses, consisting of the options: Auditory, Intellectual, Physical, Visual, Speaking, or Multiple. Response options provided were based on the most common answers given in an earlier survey which had an open question asking individuals to describe their disability (Light for the World and DDSP, 2018). Respondents were asked to further elaborate on certain responses through follow-up questions. These consisted of the options Deaf and Hard of Hearing after Auditory; Upper Body, Lower Body or Upper and Lower Body after Physical; and Blind, Low Vision and Partially Sighted after Visual.

We analyzed the data using IBM SPSS Statistics 29. With descriptive analysis, we established the frequencies for each of the types of responses. In addition, we developed cross-tabulations, or contingency tables, to describe the co-occurrence amongst the different domains of functional limitations, as well as to describe the relationship between the various domains and the types of disability as provided by the subjective disability line of questioning.

### 4.1. Limitations

There are several limitations to this study. Due to the nature of the original study on access to public information for persons with disabilities, all respondents in this study were persons who identified as having a disability by community members, and who considered themselves to be persons with disabilities. This means that the study does not include any respondents who would be categorized as disabled based on the Washington Group questions but would not consider themselves to be disabled when asked directly if they have a disability. If these had been included, the observed differences would most likely be even bigger. In addition, a relatively large number of respondents (105 out of 422

TABLE 1 Sample age and sex characteristics.

Age group	Female <i>n</i> (%)	Male <i>n</i> (%)	Total <i>n</i> (%)
<21	6 (1%)	7 (2%)	13 (3%)
21–30	27 (6%)	29 (7%)	56 (13%)
31–40	25 (6%)	24 (6%)	49 (12%)
41–50	20 (5%)	28 (7%)	48 (11%)
51–60	17 (4%)	90 (21%)	107 (25%)
61–70	36 (9%)	52 (12%)	88 (21%)
>70	35 (8%)	26 (6%)	61 (14%)
	166 (39%)	256 (61%)	(100%)

respondents) had support from a family member when answering the survey questions. This was mostly the case for respondents who identified as having a speaking, auditory, intellectual or multiple disability, indicating a lack of sign language (translation) or other communication methods between the data collectors and the respondents. Official sign language or other easy communication methods are not used widespread in Cambodia, which means that family members often develop their own modes of communication. Although the intention is that the family member would adequately support the respondent in answering the data collector's questions, there is room for error in any case where a proxy responds for an individual. Lastly, some types of impairments, particularly physical impairments such as upper and lower body impairments, were represented in larger numbers in this study than other impairments. This is because such impairments are more easily recognized and found when identifying respondents, and are more common in the study area. For example, due to the high occurrence of land mines in the province of Pursat, there is a relatively high population of persons with mobility impairments due to missing limbs. As a result, the power of the comparisons for these impairments is not as strong. Similarly, a large proportion of the respondents (39%) represented older (50+ years) males. This could lead to a less-than-ideal comparison of the data as responses could be age or gender biased.

## 5. Results

### 5.1. Sample characteristics

422 individuals aged 4–91 were included in our study. There were more males (256; 61%) than females (166; 39%) represented in the sample. In addition, older males were overrepresented

in comparison to other categories, with males 51–60 years old representing 21% of the sample and males 61–70% representing 12% of the sample (Table 1).

As respondents were selected to participate in the survey on the basis of being identified as having a disability, there were no respondents who did *not* identify as being disabled using the subjective disability assessment tool, as can be seen in Table 2. 61% of respondents categorized themselves as having a physical disability, of which Lower Body was the most common sub-category selected (40.5% of all respondents, Table 2). Further categories included Visual (14%,  $n = 58$ ), Multiple (12%,  $n = 49$ ), Intellectual (8%,  $n = 33$ ), Speaking (3%,  $n = 14$ ), and Auditory (3%,  $n = 11$ ).

91% of all respondents reported having significant functional limitations (i.e. reporting A Lot of Difficulty or Cannot Do At All on one or more of the domains of functioning of the Washington Group Short Set), and would therefore be categorized as Disabled using this assessment tool (Table 3). The most commonly reported functional limitations include difficulty walking/climbing (284;

TABLE 3 Distribution of reported functional limitations.

	N	%
Any significant functional limitation	384	91%
Walking/Climbing	284	67%
Self-Care	156	37%
Communicating	92	22%
Seeing	74	18%
Remembering/Concentrating	63	15%
Hearing	42	10%

TABLE 2 Distribution of subjective types of disability.

Type of disability	N	%	Further specification	N	%
Auditory	11	3%	Deaf	6	1.4%
			Hard of Hearing	5	1.2%
Multiple	49	12%	Intellectual impairment with sensory or physical impairment	34	8.0%
			Physical and visual	11	2.6%
			Physical and auditory	2	0.5%
			Visual and auditory	2	0.5%
Intellectual	33	8%		33	7.8%
Physical	257	61%	Lower body	171	40.5%
			Both upper and lower body	54	12.8%
			Upper body	28	6.6%
			I have a chronic disease	3	0.7%
Speaking	14	3%		14	3.3%
Visual	58	14%	Low vision	25	5.9%
			Blind	18	4.3%
			Partially sighted	15	3.6%
Total	422	100%		422	100%

67%) and difficulty with self-care (156; 37%). Further results were that 22% reported difficulty communicating, 18% difficulty seeing, 15% difficulty remembering/concentrating, and 10% difficulty hearing. As the questions on the Washington Group Short Set are not mutually exclusive, respondents can score as having significant limitations in more than one domain (co-morbidity).

Table 4 shows the co-occurrence of the different functional limitations. Only in the domains of seeing and mobility did respondents report high levels of *only* experiencing functional limitations in that domain. This demonstrates that for most other domains, although respondents may have a “main” limitation, they will most likely experience functional limitations in multiple areas. The highest co-occurrences were found between hearing and communication, cognitive and communication, and self-care and walking/climbing.

### 5.2. Relationship between functional limitations and subjective disability type

Table 5 presents a cross-tabulation of the domains of the Washington Group (no limitation, seeing, hearing, walking/climbing, remembering/concentrating, self-care, and communicating) with the subjective disability types as selected

by the respondents. The majority of respondents (54; 73%) that reported having functional limitations in the domain of seeing, also identified as being visually disabled. 19% (n = 14) identified as multiply disabled. Of those that indicated significant functional limitations in the hearing domain (n = 42), only 24% (n = 10) identified as having an auditory disability. A larger number (13; 31%) identified as having a speaking disability, and 21% (n = 9) considers themselves to have multiple disabilities.

The majority of respondents (222; 78%) that indicate having a lot of difficulty walking also identified as having a physical disability and 7% (n = 19) identified as having a visual disability. Only 13% (n = 37) identified as being multiply impaired. Inability to remember or concentrate is often correlated with an intellectual disability. However, only half (30; 48%) of those with significant functional limitations in the domain of remembering/concentrating consider themselves to be intellectually disabled. Just under a third (29%, n = 18) self-identify as multiply disabled; 11% (n = 7) consider themselves to have a speaking disability.

65% (n = 102) of respondents who have significant functional limitations in the domain of self-care would identify as being physically disabled. Other disabilities related to limitations in self-care include intellectual disability (15; 10%), multiple disability (27; 17%), and visually disabled (11; 7%). Persons with functional limitations in communicating identify as having an auditory

TABLE 4 Co-occurrence of functional limitations.

> A lot of difficulty	n	No other difficulty	Seeing	Hearing	Walking/ Climbing	Remembering/ Concentrating	Self-Care	Communicating
Seeing	74	36 (49%)		4 (5%)	36 (49%)	6 (8%)	25 (34%)	9 (12%)
Hearing	42	2 (5%)	4 (10%)		9 (21%)	25 (60%)	12 (29%)	37 (88%)
Walking/ Climbing	284	130 (46%)	36 (13%)	9 (3%)		24 (8%)	140 (49%)	41 (14%)
Remembering/ Concentrating	63	5 (8%)	6 (10%)	25 (40%)	24 (38%)		34 (54%)	53 (84%)
Self-Care	156	5 (3%)	25 (16%)	12 (8%)	140 (90%)	38 (24%)		49 (31%)
Communicating	92	5 (5%)	9 (10%)	37 (40%)	41 (45%)	53 (58%)	49 (53%)	

Percentage >80  
 Percentage 60-79  
 Percentage 40-59  
 Percentage <40

TABLE 5 Crosstabs of domains of significant functional limitations and subjective disability types.

Subjective disability type	Visual n (%)	Auditory n (%)	Physical n (%)	Intellectual n (%)	Speaking n (%)	Multiple n (%)	Total n (%)
<b>Functional limitations</b>							
No significant functional limitations	4 (11%)	1 (3%)	30 (79%)	1 (3%)	0 (0%)	2 (5%)	38 (100%)
Seeing	54 (73%)	0 (0%)	4 (5%)	2 (3%)	0 (0%)	14 (19%)	74 (100%)
Hearing	0 (0%)	10 (24%)	2 (5%)	8 (19%)	13 (31%)	9 (21%)	42 (100%)
Walking/Climbing	19 (7%)	0 (0%)	222 (78%)	6 (2%)	0 (0%)	37 (13%)	284 (100%)
Remembering/Concentrating	1 (2%)	3 (5%)	4 (6%)	30 (48%)	7 (11%)	18 (29%)	63 (100%)
Self-Care	11 (7%)	0 (0%)	102 (65%)	15 (10%)	1 (1%)	27 (17%)	156 (100%)
Communicating	1 (1%)	9 (10%)	17 (19%)	28 (30%)	14 (15%)	23 (25%)	92 (100%)

Percentage >80  
 Percentage 60-79  
 Percentage 40-59  
 Percentage <40

disability (9; 10%), intellectual disability (28; 30%), multiple disabilities (23; 25%), physical disability (17; 18%) or speaking disability (14; 15%). Of those ( $n = 38$ ) that reported not having any significant functional limitations, the majority (30; 79%) described themselves as a person with a physical disability.

### 5.3. Commonly assumed relationships between functional limitations and disability types

To further assess the relationship between the functional limitations reported and the subjective type of disability chosen, we have compared the most logical relationships, i.e. between difficulty seeing and visually disabled; difficulty hearing and auditory disabled; difficulty walking/climbing and physically disabled and difficulty remembering/concentrating and intellectually disabled.

#### 5.3.1. Difficulty seeing and visual disability

As seen in Figure 2, there is a relatively high overlap (69%) among individuals that define themselves as having a visual disability and those reporting significant functional limitations in the domain of sight. 5% define themselves as being visually impaired without reporting significant functional limitations in

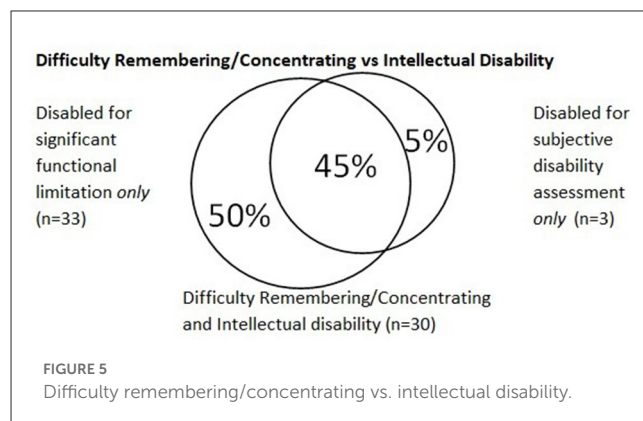
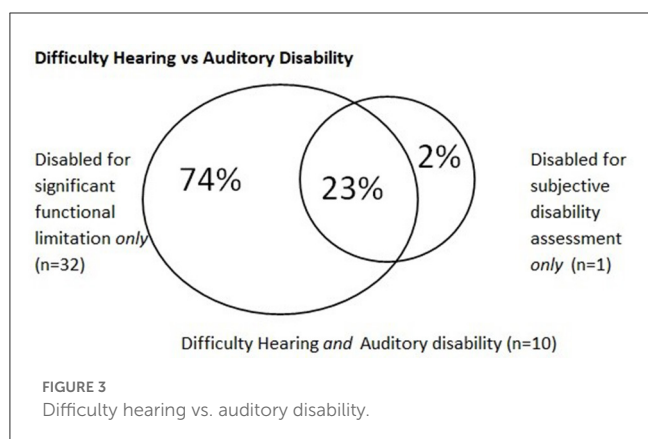
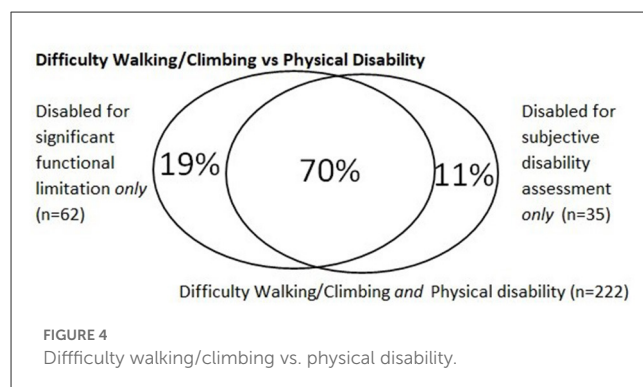
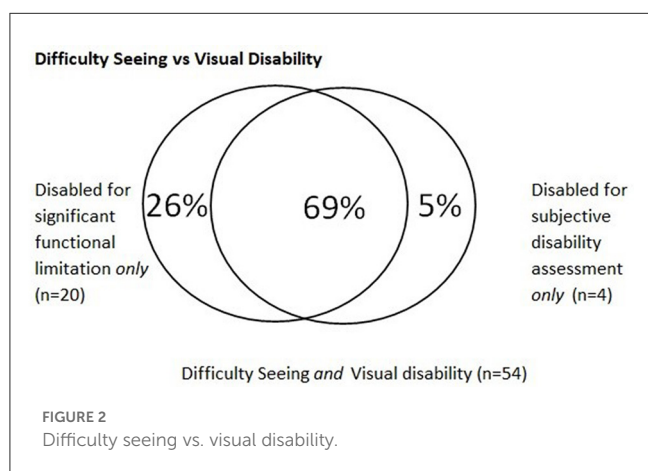
seeing; 26% report having at least a lot of difficulty seeing, but do not identify as a visually disabled person.

#### 5.3.2. Difficulty hearing and auditory disability

In general, very few respondents identified with having an auditory disability when given the option to choose how they would define themselves. This shows in the results in Figure 3. Nearly three-quarters of respondents who had indicated having significant functional limitations in hearing did not choose Auditory disability as their type of disability. 1 respondent reported being auditory disabled but did not report having significant functional limitations in the domain of hearing; 23% overlapped and reported having an auditory disability as well as having significant functional limitations in hearing.

#### 5.3.3. Difficulty walking/climbing and physical disability

When comparing difficulty walking/climbing and having a self-classified physical disability, we see a high correlation with a 70% overlap, as illustrated in Figure 4. 19% report having significant functional limitations in walking/climbing, but do not identify as physically disabled; 11% identify as being physically disabled but do not report significant functional limitations in the domain of walking/climbing.





### 5.3.4. Difficulty remembering/concentrating and intellectual disability

Another often assumed relationship is between the domain of remembering/concentrating, and having an intellectual disability. However, less than half (45%) of overlap is reported between the two, as seen in [Figure 5](#). Half of the respondents that reported having significant functional limitations in the domain of remembering/concentrating, did not choose intellectual disability when asked to define their disability.

## 6. Discussion

The Washington Group Short Set – a good methodology for assessing disability for purposes of data disaggregation – is currently used and promoted by development agencies and funders as the measure of disability. Funders and experts promote a functional limitations models of disability<sup>1</sup> but fail to adequately communicate the limitations of the tools, leading to misuse as development practitioners are using the tool for identification and diagnostic purposes. With this paper, we aim to address the current norm of using the Washington Group Short Set without an adequate understanding of its purpose and limitations.

Results showed that many – but certainly not all – of the persons identified as being disabled through a subjective disability question, would also be considered disabled using the Washington Group Short Set of questions. Crosstabulation of the two disability assessment tools, as well as the comparison between the most commonly assumed relationships between the tools, show that there is not usually a direct relationship between certain domains of functioning and specific disability types as selected through direct questioning. This shows that, although there is overlap, the tool used to label individuals as being disabled influences who is categorized as disabled, and who is not. Even more specifically, certain ‘types’ of disabilities will vary even more depending on which assessment tool has been used.

Being categorized as disabled according to one assessment tool does not necessarily mean that an individual will be categorized as disabled when using another assessment tool. Two studies found that there was only about 47% overlap between individuals that score as disabled using a subjective measure and those that are disabled according to the Washington Group question set ([Schneider et al., 2009](#); [Molden and Tøssebro, 2010](#)). A study by [Baart et al. \(2019\)](#) found that 2% of persons who were categorized as disabled through a subjective disability question had no functional limitations in any domain. This matches our findings in this study: although all our respondents were considered disabled using a subjective assessment of disability, 9% of those would not be considered disabled using the Washington Group cut-off. Considering that the population studied in this research were all individuals who were seen by the community as disabled,

it is also very likely that the research population consists of individuals who have more extreme and visual disabilities. A comparison that also includes persons without disabilities (as measured using a subjective disability question) may yield an even bigger difference between the two assessment tools. This means that those collecting and using the data need to be aware of the fact that there are multiple models of disability and that the various tools used are each based on a different definition of disability, and will thus target a different group of people as those having disabilities.

In addition, this study specifically included the recommended Washington Group cut-off point of including only those reporting “a lot of difficulty” or “cannot do at all” in at least one domain as having a disability. Yet researchers and data collectors have been using a variety of cut-off points to determine those categorized as able-bodied or disabled (see e.g., [Mitra and Yap, 2022](#)). Changing the cut-off point, for example to also include those reporting “some difficulty” in any domain, would also change the group categorized as disabled in a certain domain. Further research could compare the various cut-off points in a functional disability assessment to the categorization based on the subjective model of disability.

In this study, we specifically aimed to understand whether there is a direct relationship between the type of disability individuals report having and the types of functional limitations they have. NGO staff have in some cases interpreted the different Washington Group questions as disability types, suggesting that persons who indicate “having difficulty hearing” must then be Deaf, and those who “have difficulty remembering” are intellectually disabled ([Leonard Cheshire Humanity Inclusion, 2018](#)). Our study demonstrates that the functional limitations as measured by the Washington Group questions should not be directly translated into disability types as measured using a subjective disability question. Although there is overlap, such as between difficulty seeing and visual impairment, and difficulty walking and physical impairment, this is not guaranteed and is certainly not the case in all domains, such as difficulty hearing and auditory impairment. In fact, when looking at difficulty hearing, surprisingly only a small amount of people who have difficulty hearing identify *themselves* as being auditory disabled (such as Deaf or Hard of Hearing). Many people who have difficulty hearing identify as having a Speaking Disability, Intellectual Disability, or Multiple Disability. This could indicate that despite having trouble with hearing, many consider their inability to speak or communicate as the problem and/or the type of disability they identify with. In this situation, we also see the objectification of the individual with hearing difficulties: defining them as Deaf or Hard of Hearing on the basis of the Washington Group Questions means imposing *your* view of disability upon the individual rather than asking them how they would like to be defined. An interesting subject for further research would be to analyse how respondents choose an impairment type when confronted with a list; whether we can understand how those who indicate that they are not able to perform a certain function identify themselves in relation to that function (e.g., when would someone who indicates not being able to hear, identify as Deaf or Hard of Hearing).

The subjective disability question allowed respondents to only choose one “main” disability type to identify themselves.

<sup>1</sup> See for example: IFAD. (2020). Disaggregating Data on Persons with Disabilities in IFAD Projects; DFID. (n.d.). DFID’s guide to disaggregating programme data by disability; Australian Aid. (2021). Disability Inclusion in the DFAT Development Program: Good Practice Note.

However, looking at the co-occurrence of the Washington Group domains of functioning demonstrated that many persons had difficulties functioning in multiple domains: 49% of respondents reported having significant functional limitations in multiple domains. The findings in Table 4 match those of Sprunt (2019), whose research compared co-occurrence in the Washington Group Child Functioning Module, a variation of the Washington Group questions designed specifically for use in children. As with Sprunt, scoring Disabled on only one functional limitation generally only occurs among individuals with functional limitations in the Visual and Walking/Climbing domains. And as with Sprunt, large co-occurrence exists between Self-Care and Walking/Climbing, between Cognitive (Learning in the Child Functioning Module) and Communication (Speaking), and between Hearing and Communication. Yet only 12% of respondents in the present study identified themselves as having multiple disabilities when asked to define themselves according to the subjective assessment tool. Asking persons with disabilities to categorize themselves based on a list of disability types, as often used in a subjective disability assessment tool, automatically forces the individual to “choose” a single type of disability to associate themselves with. The only option often provided in disability lists that can support a range of disabilities is the “multiple” category, making it a catch-all category of anyone that cannot place themselves or does not want to place themselves into a single category. The fact that one of the disability assessment tools requires making a “choice” in which difficulty a person associates themselves with most, whereas the other doesn’t, may explain some of the lack of agreement between the two tools.

Why does all this detail matter? It matters because having a functional limitation, and considering oneself to be a disabled person, are thus two different experiences that may overlap for some, but certainly not all of the population. How disability is measured will have implications on the group of persons that will be in or excluded from the measurement (Grönvik, 2009; Madans et al., 2017), and will have “concrete repercussions on people’s lives” (Beaudry, 2020, 4). Development organizations – often the ones defining and deciding which model of disability to use – thus have a part to play in critically deciding which concept they are wanting to assess when studying disability, and choosing the tools to assess disability accordingly and carefully. As Grönvik states, “The researcher<sup>2</sup> has to decide how disability is best represented in the study. Functionally? Administratively? Subjectively? Environmentally? [...] this decision will affect the research outcome” (Grönvik, 2007, p. 37). Misunderstanding what a certain tool to assess disability is actually measuring, can lead to misidentification and failure to address the individual’s own perception of the category they belong to, as well as inadvertently stigmatize. Misuse and misinterpretation of the disability data that is being collected can undermine the goal of understanding whether

or not persons with disabilities are, indeed, being included or left behind.

## 7. Conclusions

Overall, we conclude that although both the Washington Group Short Set and a direct question are assessment tools of disability, there is a core group of people who would be categorized as disabled using both tools, but also people whose categorization would depend on the tool used. We thus affirm earlier studies (Schneider et al., 2009; Molden and Tøssebro, 2010) which also find that the categorization of individuals as able or disabled is dependent on the tool used. Going into further detail, we conclude that it would not be justified to “translate” the data at impairment level from one methodology to another, such as saying that individuals experiencing difficulty hearing are Hearing Impaired and individuals that experience difficulty seeing are Visually Impaired. Yet practice demonstrates that this has confused practitioners working with persons with disabilities in the development sector: the complexity and nuance of measuring disability is rarely understood. As summarized by Grech: “Disability is mentioned with ease, including in the SDGs, giving the impression of a coherent group of people, feeding into the illusion that we know who or what we are talking about” (Grech, 2016, p. 16).

We echo the point made by Abualghaib et al. (2019, p. 5) that “the measurement and interpretation of disability statistics should not be employed uncritically.” The assessment tool chosen to categorize (dis)ability has major real-world consequences by shaping design choices of policies and programs and determining who benefits. The categorization, and those doing the categorizing, has significant impact on individual lives. See, for example, Crooks et al. (2008) examination of institutions’ power as they classify those requesting state income support as disabled or not disabled. Categorization is not neutral, but “can lead to stigmatization and hierarchization among people if left unexamined” (Thorjussen and Wilhelmsen, 2020, 1). NGOs and Organizations for Persons with Disabilities are often the organizations closest to persons with disabilities: they are well placed to monitor the lived experience of persons with disabilities and play a crucial role in collecting and sharing data used to understand whether persons with disabilities are being left behind by the Sustainable Development Goals. Ensuring that they understand that there is no one model of disability, nor one true way to measure disability, but that each disability assessment tool has its place and purpose, would ensure that the data we have on persons with disabilities and their progress toward the Sustainable Development Goals would significantly improve.

## Data availability statement

The data analyzed in this study is subject to the following licenses/restrictions: Dataset will be made available *via* DANS: <https://dans.knaw.nl/nl/>. However, the data is in principle owned

<sup>2</sup> Or replace researcher with any role representing individuals making decisions on the categorizing of disability within the development sector: the monitoring and evaluation specialist, the inclusion expert, the program manager.

by the organizations who requested the original research to be carried out. Any further requests to use the data should be approved by them. Requests to access these datasets should be directed to [judith.baart@uvh.nl](mailto:judith.baart@uvh.nl).

## Ethics statement

The studies involving human participants were reviewed and approved by the Ethische Toetsingscommissie Universiteit voor Humanistiek. Written informed consent to participate in this study was provided by the participants or an individual representing them.

## Author contributions

JB designed and was principal investigator for the study, carried out the statistical analysis, and wrote the first draft of the manuscript. All authors contributed to manuscript revision, read, and approved the version submitted.

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## Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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