A Comparison between Official Measurement and Individual Perspectives on Disability: Investigation into Disability Statistics in Indonesia

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Introduction

Data on disability prevalence is central to monitoring and guiding progress for development agendas aimed at supporting and improving the quality of life for people with disabilities, such as the 2030 Agenda for Sustainable Development (SDGs) (UN, 2015). People with disabilities and their families often face multiple disadvantages, such as additional costs and barriers in accessing essential services such as healthcare and education (WHO, 2022). Identifying who these individuals are, where they live, and what kind of support they need is important for developing policies that effectively reach the targeted population. Therefore, accurate, comprehensive and comparable disability statistics are urgently needed to assess the extent of poverty and inequality faced by people with disabilities, to design and implement inclusive social protection systems, and to inform policy decisions that promote social inclusion. Without statistics that are representative of the lived experiences of people with disabilities, these objectives cannot be effectively achieved, and efforts to support those most in need will fall short (Kuper and Heydt, 2019; WHO, 2022).

The latest population census estimates the prevalence of people with disabilities in Indonesia is around 1.43% (BPS, 2020), which is significantly lower than the percentage of people in the world with a disability, as estimated by the World Health Organization (WHO) in 2020, of 16% (WHO, 2022). Previous studies found that disability prevalence in Indonesia is potentially underestimated due to underreporting of disability by individuals and families, including the negative stigma attached to disability (Kusumastuti, Pradanasari and Ratnawati, 2014; Cameron and Suarez, 2017). This leads to a question of whether the official disability prevalence is accurately representative of the disabled population in Indonesia.

Despite extensive discussions on the various approaches to measuring disability, there remains limited discussion on how disability is perceived across different contexts. Therefore, this study seeks to understand, from the perspective of people living with some form of disability as well as by family members closely involved in their lives, how disability is perceived and the main issues relating to disability that are faced. Further, a comparison will be made with the standard measures used to define disability for official statistics. This is important to identify barriers to reporting disabilities in Indonesia and highlight the range of disabilities that may not be visible in the current statistics.

Conceptual Framework

Disability was traditionally considered to be a result of health problems, often referred to as the medical model of disability. It sees people as disabled if they have certain impairments, such as blindness, deafness, brain damage and others that must be prevented, treated or cured (Barnes and Mercer, 2010). The medical model emphasises the individual's impairment or pathology rather than considering broader social and systemic factors contributing to disability (Oliver, 1996). In contrast, the social model defines disability as a result of societal behaviour instead of individual functional limitations (Barnes and Mercer, 2010; Mitra, 2018). This model argues that body impairment does not directly cause disability, but rather, disability is caused by the social barriers imposed on individuals who are physically impaired (Oliver, 1996). This model shifts the focus of defining disability from an individualistic problem to a societal problem. In this sense, to change the social disadvantage and discrimination experienced by disabled people, society needs to change its attitude towards individuals with impairments (McEwan and Butler, 2007).

In 2001, the WHO combined elements of both the medical and social models, and introduced the bio-psycho-social model or the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). This model acknowledges that disability results from the interaction between an individual's health condition and the surrounding social environment (WHO, 2001; Baart and Taaka, 2018). The ICF advocates flexibility in understanding disability and emphasises that it is not always clear-cut when identifying which limitations result from impairment and which from their environment. For example, for two individuals having the same impairments and/or functional limitations, their interactions with the environment around them will result in varied degrees of disablement. The ICF model creates a distinction between individual capacity (activities) and performance (participation), where the former describes an individual's individual ability in a standardised environment and the latter describes an individual's participation when situated in a social setting (see Figure 1) (WHO, 2001).

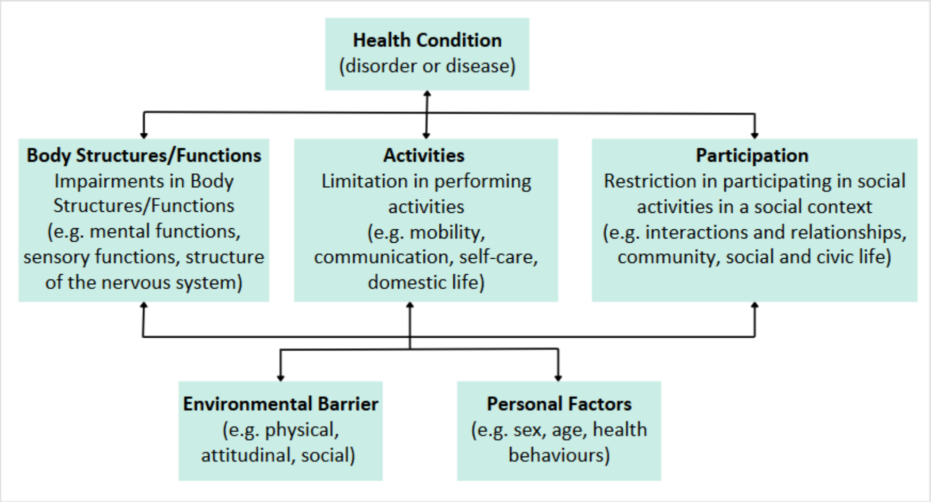

Figure 1 The bio-psycho-social model (ICF) of disability WHO (2001)

The ICF model of disability has been utilised as a conceptual framework in the development of disability measurement tools aiming to collect disability information through population censuses and surveys, such as the WHO Disability Assessment Schedule 2.0 (WHODAS-2), Washington Group (WG), and Child Functioning Module (CFM) (WHO, 2010; Madans and Loeb, 2013; UNICEF, 2021). These measurement tools consist of questions designed to assess an individual's capability to function and perform daily activities, to which the responses are used to estimate the prevalence of disability within the sample population.

In light of the discussion above, the conceptual framework will help to understand how disability is perceived both by the official measures and by people living with some form of disability, as well as by family members closely involved in their lives. This study believes that the ICF model of disability provides a definition that includes all facets of disability, highlighting the complexity of disability and acknowledging the equally important contributions of individual and environmental factors in shaping and moderating the disability experience.

Data and Methodology

This study starts by analysing two nationally representative cross-sectional surveys in Indonesia in 2018, the National Socio-Economic Survey (SUSENAS), conducted by Statistics Indonesia (BPS), and the National Basic Health Research (RISKESDAS), conducted by the Ministry of Health (KEMENKES). The 2018 wave was particularly interesting because the two surveys were linked through the same participants. As a result, the same respondents answered both surveys, with a three month gap between them, and these surveys asked different questions and took different approaches to disability measurement. A descriptive statistical analysis was conducted to estimate disability prevalence from the two surveys using the statistical software R, version 12.0.

Qualitative data were collected through semi-structured interviews during a two-month fieldwork period from April to June 2024 in order to explore the survey results further. The participants for the qualitative interviews were not the same individuals as those in the survey collected by the Indonesian government agencies. The fieldwork was conducted in two sub-districts of the Yogyakarta Special Region Province. In total, 40 interviews were conducted, 23 interviews with people with disabilities and 17 interviews with family members. The latter group include both relatives of the interviewed disabled individuals and members of families whose disabled relatives did not participate in the study. This study employed a reflective thematic analysis proposed by Braun and Clarke (2022). The qualitative data analysis was facilitated by NVivo software, version 14. Results from qualitative analysis are presented using pseudonyms to protect the identities and confidentiality of the participants.

Results and Discussion

Analysis of the Indonesian Population Surveys

Results show significantly different disability prevalence among the Indonesian population aged five and above, estimated from the two surveys, at 2.8% (95% CI: 2.8% – 2.9%) using SUSENAS and 15.2% (95% CI: 15.0% – 15.4%) using RISKESDAS. Although SUSENAS and RISKESDAS were conducted on the same participants, they used different methods for data collection. Given that both surveys serve as key data sources for various analyses conducted by wider research communities, including policymakers and other government agencies, without a substantial discussion on how disability is being measured, further analyses based on these data may lead to misleading results.

These surveys provide a unique opportunity for this analysis to combine the two datasets because the same participants were involved. A comparative analysis was conducted, and results show that across individuals with disability status, either in SUSENAS or RISKESDAS (*n = 140,435*), only a small percentage (3.9%) are identified as disabled in both surveys. This indicates a strong disagreement by the measurement tools used in SUSENAS and RISKESDAS, which resulted in some people being classified as disabled in one survey and not in the other (see Figure 2).

The prevalence estimated by the most important official data provider in Indonesia, BPS, is comparatively lower than the average across LMICs. Furthermore, analysis on both SUSENAS and RISKESDAS surveys highlights that the data collection is not consistent across the different government institutions, which indicates that there has not been any significant discussion on how best to capture the disabled population in the official statistics in Indonesia.

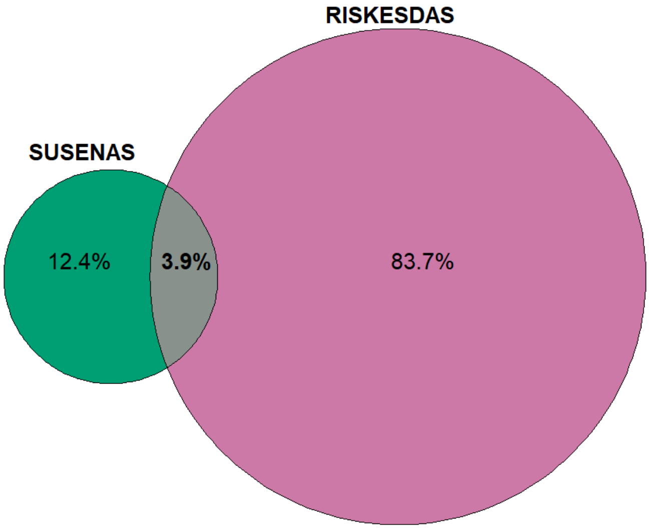

Figure 2 The overlapping group of the disabled population aged 5 and older across the two surveys[1]

Experiencing Disability: Perspectives from People with Impairments

The discussion around disability often focuses on a person's bodily functions or physical appearance as the primary criterion for classifying who is disabled and who is not. These conversations very often involve implicit comparisons, bringing up the terminology of 'perfect' and 'less/not perfect', or even 'normal' and 'not normal'. For example, Bapak Cahyo Tapa described the changes he experienced after he had the accident that resulted in a permanent impairment of one of his legs:

> *Physically, for me. For example, from birth, we are physically formed. If you were born as a normal person, then at some point in your life, something happened, and you have this (pointing to his impaired leg). It's already... like me, for example, I'm already disabled, I can't recover anymore. (Bapak Cahyo Tapa, with physical impairment)*

Bapak Cahyo Tapa described his transformation into a disabled person as no longer being a 'normal' person because of his impairment. Disability is being described in a way that explicitly refers to individuals' conditions, including their bodily functions, impairments, and physical appearances. A comparison was also being made between a disabled and a non-disabled person, regarding their bodily functioning and capability in carrying out daily activities, when describing disability.

> *Disability is when a person is in a condition where they cannot carry out activities like a normal human being. This means that they can't do... what is it... activities such as walking, and then all physical activities. So, disability can be physical, there is a lack of function of body parts, or they don't function. Or mental disability. This means it could also be that they are physically normal, but mentally, they cannot carry out normal activities like we do. Can't think, can't... what is it... something like that. (Ibu Dwi, a family member)*

Disability is often described and discussed in terms of an individual's conditions or characteristics that are seen as the source of a person's difficulties. In this view, disability is understood as a problem residing within the individual, typically due to physical or mental impairments, which

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[1] The size of the circles corresponds to the prevalence of disability in each survey.

reflects the individualistic approach to disability, and that medical intervention is needed for them to fit into the social norm. This view of disability is deeply embedded in society, where individuals with any form of impairment are classified as having a disability, regardless of their social context and the environmental factors that may influence their experiences.

In the interviews, the disability-related questions commonly used in Indonesian population surveys were discussed. This analysis found that the responses to what most people would presume to be simple survey questions gathered from the participants are very nuanced. For example, regarding the question about difficulties in walking or standing up for a certain amount of time, one might expect participants with physical impairments affecting their legs would report significant difficulty. Contrary to this expectation, quite a few participants reported experiencing only slight or no difficulty. Ibu Novi Jeja (NJ), a woman living with physical impairments, discussed having only slight difficulty in walking for 1 kilometre and no difficulty at all in standing up for half an hour:

> *INT: Do you have difficulty walking 1 kilometre?*
>
> *NJ: Walking for 1 kilometre, it's a bit difficult Sometimes this, sometimes it's a bit difficult to lift it (pointing to one of her legs), if it's a bit far.*
>
> *INT: So, those are the difficulties you are experiencing, are they slight, moderate or severe?*
>
> *NJ: A slight.*
>
> *INT: Ma'am, do you have difficulty standing up for 30 minutes?*
>
> *NJ: No.*
>
> *INT: No difficulties at all, ma'am?*
>
> *NJ: No...*

A similar account was described by Ibu Ina, a mother to a daughter with hearing and speaking difficulties.

> *INT: Does your daughter have difficulty walking for 1 kilometer?*
>
> *Ina: Walking, up to 1 kilometer, it's impossible, mbak, it's tiring. Going to the nearby health centre, she was already sweating.*
>
> *INT: What about climbing stairs?*
>
> *Ina: If going upstairs... yeah she can do it at least when at school. When going to the market, yes... my daughter rarely comes with me, mbak, when I go to the market, she wants to stay at home. So, if I shop, I shop at the market alone or with her father.*
>
> *INT: Does your daughter have any difficulty communicating with other people?*
>
> *Ina: Yes... normal... she can.*
>
> *INT: How does your daughter usually communicate with other people, ma'am?*
>
> *Ina: If she is together with her friends at school, she communicates using their own sign language. I'm usually waiting in the canteen, mbak. Sometimes I take a look at her. So, I wait in the school canteen from 07.30 to 12.30 during school day. But if on exam days, she'll be home at 10 o'clock at the latest. Well, that was it, so my child went to her friend's place, and*

> *neither of them could hear each other; they communicated with each other using sign language. If I take a look from far away, yes... sometimes they tease each other, like that. And they laugh at each other, the children.*
>
> *INT: What about communicating with other people? For example, family members?*
>
> *Ina: Yes, that's the same.*

Given the circumstances of Ibu Ina's daughter, it would be reasonable to expect that she would report on her daughter experiencing difficulties in communication. However, she stated that her daughter had no difficulty communicating with others through sign language, but instead reported that it was impossible for her to walk a distance of one kilometer. The two examples above highlight a significant gap in the understanding and interpretation of questions used to measure disability through population surveys. In many instances, individuals with impairments would not be classified as disabled based on functional difficulty questions, as they have, to some extent, managed to overcome barriers at the bodily or functional level. However, the analysis found that they continue to face substantial challenges in other dimensions of life, particularly contextual and social barriers. Participants discussed the absence of inclusivity in public places, the limited access to education, which leads to higher barriers for them to access the job market.

> *I really wanted to enter technical school. My dream was, when I was a child, or a teenager, if I was able... I would be able to go to college, majoring in civil engineering and becoming an architect. That's my dream. But, in the short term, at least I can do manual labour and become a builder. That's what I wanted. But the regulations and requirements, there was no longer any trust in me, as a disabled person, for whatever reason... the requirement was that I have to be physically and spiritually healthy. (Bapak Rudi Jeja, with a physical impairment).*

Disabled individuals continue to face discrimination and are denied equal access to basic education, which leads to a lack of educational qualifications and opportunities to secure better-paid jobs, leaving them at the bottom of the economic ladder. These barriers, created by society and systematic structures, consistently place people with disabilities at a disadvantage. The barriers and challenges faced by people with impairments do not stem solely from their physical or mental conditions but are largely imposed by their surrounding social and environmental contexts. This perspective is different from how disability is represented in official statistics, which tend to focus on individuals' physical functioning. Therefore, the current disability measures are not suitable for capturing the full extent of the disability experienced.

Through the synthesis of the analysis of the survey data and interview transcripts, the comparison between how disability is perceived both by the official measures and by people living with some form of disability, as well as by family members closely involved in their lives is discussed using the different elements under the ICF model of disability (see Figure 3). The ICF element 'Body Structures/Functions' reflects how the people with disabilities in this study define disability. Individuals with disabilities use the term 'disability' to describe people with impairments in body structures or functions, and in some cases, they discuss that only long-term impairments are classified as disabilities, which leans strongly towards the medical/individualistic view of disability (Barnes and Mercer, 2010; Palmer and Harley, 2012). Furthermore, when discussing their living experiences and how they are situated in society, their view reflects on another element of the ICF, which is 'Participation'. The emphasis is on restrictions on participation in social activities and access to essential services due to societal and environmental barriers, which have been highlighted by the social model of disability (Oliver, 1996; Mitra, 2018). Participants discussed the absence of inclusivity in public places, the limited access to education, which leads to higher barriers for them to access the job market.

On the other hand, disability measurement tools utilised by the official government to measure disability in Indonesia only measure an individual's difficulty in performing activities, which is reflected in the ICF element 'Activities'. This discussion concludes that the current disability statistics in Indonesia neither capture how disability is perceived by individuals nor the disabling barriers and challenges experienced by people with impairments that are restricting them from participating fully in society.

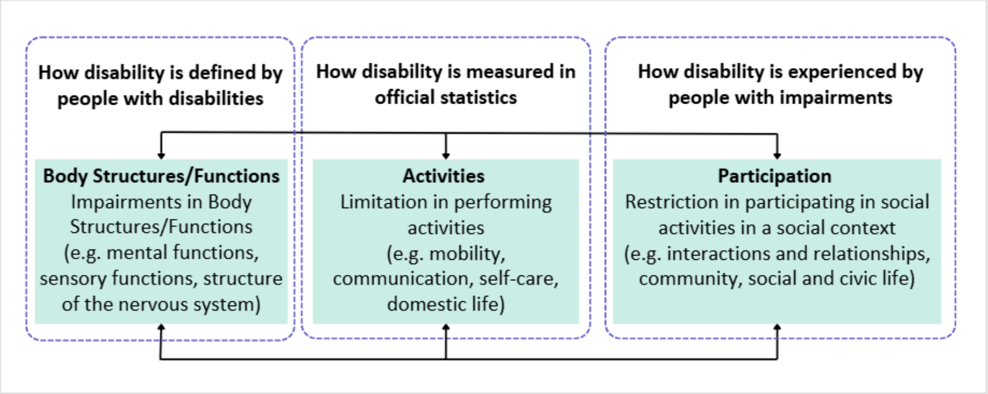

Figure 3 The different perspectives towards the definition of disability are explained using different elements from the ICF framework

In light of this study, future recommendations for the government, as the data producer for official disability statistics, are to first clarify the purpose of generating those statistics. If data collection is driven solely by the need to fulfil international reporting obligations, it may reflect limited engagement with the lived experiences of individuals with disabilities. Instead, governments should critically assess their priorities in collecting disability data, whether to inform inclusive policies, improve service access, or track progress towards SDG targets, such as reducing inequality and poverty, and, most importantly, to "leave no one behind". Based on these aims, relevant and context-sensitive measurement tools should be identified and implemented to ensure that disability statistics accurately reflect the lived experiences and needs of people with disabilities.

Reference List

Baart, J. and Taaka, F. (2018) 'Barriers to Healthcare Services for People with Disabilities in Developing Countries: A Literature Review', *Disability, CBR & Inclusive Development*, 28(4), p. 26. Available at: https://doi.org/10.5463/dcid.v28i4.656.

Barnes, C. and Mercer, G. (2010) *Exploring disability*. Polity.

BPS (2020) *Hasil Long Form Sensus Penduduk 2020*. Jakarta, Indonesia: Indonesian Central Statistical Office.

Braun, V. and Clarke, V. (2022) *Thematic Analysis : A Practical Guide*. London: SAGE Publications Ltd.

Cameron, L. and Suarez, D.C. (2017) *Disability in Indonesia: What can we learn from the data?* Jakarta, Indonesia: The Australia Indonesia Partnership for Economic Governance. Available at: https://www.monash.edu/__data/assets/pdf_file/0003/1107138/Disability-in-Indonesia.pdf.

Kuper, H. and Heydt, P. (2019) ‘The Missing Billion: Access to Healthcare Services for 1 Billion People with Disabilities’.

Kusumastuti, P., Pradanasari, R. and Ratnawati, A. (2014) ‘The Problems of People with Disability in Indonesia and What Is Being Learned from the World Report on Disability’, *American Journal of Physical Medicine & Rehabilitation*, 93(1), pp. S63–S67. Available at: https://doi.org/10.1097/PHM.0000000000000025.

Madans, J.H. and Loeb, M. (2013) ‘Methods to improve international comparability of census and survey measures of disability’, *Disability and Rehabilitation*, 35(13), pp. 1070–1073. Available at: https://doi.org/10.3109/09638288.2012.720353.

McEwan, C. and Butler, R. (2007) ‘Disability and Development: Different Models, Different Places: Disability and development: different models, different places’, *Geography Compass*, 1(3), pp. 448–466. Available at: https://doi.org/10.1111/j.1749-8198.2007.00023.x.

Mitra, S. (2018) *Disability, health and human development*. Springer Nature.

Oliver, M. (1996) *Understanding disability: from theory to practice*. London: Macmillan.

Palmer, M. and Harley, D. (2012) ‘Models and measurement in disability: an international review’, *Health Policy and Planning*, 27(5), pp. 357–364. Available at: https://doi.org/10.1093/heapol/czr047.

UN (2015) *Transforming Our World, the 2030 Agenda for Sustainable Development*. A/RES/70/1. United Nations General Assembly. Available at: https://sdgs.un.org/sites/default/files/publications/21252030%20Agenda%20for%20Sustainable%20Development%20web.pdf (Accessed: 5 March 2025).

UNICEF (2021) *Seen, Counted, Included: Using Data to Shed Light on the Well-Being of Children with Disabilities*. Available at: https://data.unicef.org/resources/children-with-disabilities-report-2021/.

WHO (2001) *International Classification of Functioning, Disability and Health (ICF)*. Geneva: World Health Organization. Available at: http://ebookcentral.proquest.com/lib/soton-ebooks/detail.action?docID=763020 (Accessed: 21 March 2023).

WHO (2010) *Measuring Health and Disability: Manual for WHO Disability Assessment Schedule WHODAS 2.0*. Malta: World Health Organization. Available at: https://www.who.int/publications/i/item/measuring-health-and-disability-manual-for-who-disability-assessment-schedule-(-whodas-2.0).

WHO (2022) *Global report on health equity for persons with disabilities*. Geneva: World Health Organization. Available at: https://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/global-report-on-health-equity-for-persons-with-disabilities (Accessed: 5 March 2025).