



Disability in Indonesia: What can we learn from the data?

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Executive Summary

Disability is an issue that touches many lives in Indonesia. There are at least 10 million people with some form of disability. This represents 4.3% of the population, based on the latest census which almost certainly understates its prevalence. More than 8 million households, or 13.3 percent of the total, include at least one person with a disability.

Disability affects not only people with a disability themselves but also their families. Households with a person with a disability have a lower monthly expenditure per capita, with female headed households being particularly vulnerable.

Most common disabilities arise from difficulties with vision, hearing and walking. Forty percent of those who have a disability have multiple disabilities.

Diseases and accidents cause the vast majority of disabilities (76%), compared with 17% caused by congenital factors. This means that many disabilities are preventable and there is scope for policy to improve outcomes.

People with disabilities in Indonesia have lower educational attainment, worse health, fewer economic opportunities and lesser access to public services than people without disabilities.

The average years of education of a person without a disability is 6.5 years. However, for someone with a moderate disability it is 4.4 years, and for someone with a severe disability it is on average only 2.8 years.

The majority of people with disabilities in Indonesia do not use assistive devices (e.g. hearing aids, walking aids, etc). For people with limited vision, 80% of those who report that they need glasses also say that they do not have them, and 28% of those who say they need a white cane do not have one.

For those with hearing impairments who say that they need a hearing aid, 91% do not have one. Given that hearing is one of the most prevalent conditions (12% of people with a disability), improving access to and use of hearing aids has the potential to considerably improve the daily functioning of many people living with a disability.

Access to prosthetics is also very low in Indonesia. For people with a difficulty using their arms, fingers, legs or with a physical deformity who need prosthetics, on average across these categories of disability less than 25% of people who could benefit from having a prosthetic are able to access one.

Policy has been hampered by a paucity of information about the specific barriers facing people with disabilities and how best to address them. There is, therefore, an urgent need for improved data and analysis.

This report covers the prevalence of disability; disability and education, health, labour market activity and access to services; future directions and policy options. It is intended as a resource for Indonesian policy-makers in developing measures specifically tailored to meet the needs of people with disabilities in the environments in which they live to improve access to education and employment.

Recommendations include:

- **Promote inclusion of people with disabilities in the civil service**, where they are currently under-represented, partly owing to regulations that make it difficult to hire them.
- **Improve access to assistive devices** and support their use with training. Efforts aimed at those with vision, hearing and walking difficulties will have the largest impact given that these disabilities are the most prevalent.
- **Improve economic opportunities for people with disabilities** by making transport and other infrastructure more accessible, in particular for those whose mobility is hindered, and adopting new technologies that can assist people with disabilities to work.
- **Social protection that targets households with a disabled member** to reduce the risk of families caring for dependents with a disability from falling into poverty.
- **Improved health services and working conditions** to prevent many disabilities occurring in the first place. Most of the disabilities reported in Indonesia are non-congenital and instead acquired or developed as a result of diseases and accidents.

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Introduction

Indonesia recently passed Law No 8 /2016. This law follows the ratification of the UN Convention on the Rights of People with Disabilities in 2011 and commits the Indonesian government to the eradication of discrimination against people with disabilities and to actively work to support and provide services to this segment of the population. It also espouses the principle that public programs be inclusive and accessible to people with disabilities.¹ This document seeks to use Indonesia's statistical resources to establish a baseline from which progress in disability-inclusiveness can be measured and also to highlight areas for immediate policy attention.

It has been estimated that between 4% and 11% of the Indonesian population is affected by a disability that limits their ability to participate in society. This wide range in the prevalence rate arises from different surveys defining and measuring disability differently.² Although there are differences in the number of people who are classified as disabled by the various surveys, there are patterns that are consistent across the various surveys. For example, people with a hearing difficulty participate more in the labour market than any other disabled group, and households with a person with a disability have lower expenditure per capita. We will use information from the 2010 Indonesian Census as the main source of data for our analysis and complement it with data from other surveys. The main reason to place the census data at the centre of the analysis is that it covers the entire nation's population and allows representative sub-group analysis (e.g. rural\urban). It also most closely follows the Washington Group guidelines on how to define disability and provides a similar estimate of the prevalence rate to most other surveys.

The document is organised as follows: It starts with a description of the data sources and methodology used in the report. This is followed by a discussion of the prevalence of disability in Indonesia and how this varies with geographic location and socio-demographic characteristics. The causes of disability and the use of assistive devices are then discussed. The document goes on to examine the differences between people with and without a disability in terms of educational attainment, labour market opportunities and ability to access services. The socio-economic status of people with disabilities and their families are then examined. The paper concludes with a discussion of areas in particular need of policy attention. At the end of the document we include an annexure with a literature review of disability and its impact on education, employment and household welfare in Indonesia and in relation to other countries.

¹ DFAT (2015) *Development for All*, lays out the guiding principles for the Australian aid program in addressing the key challenges of disability-inclusive development in the Asia-Pacific.

² 4% is the estimate from the 2010 Census and 11% is the estimate from 2007 National Basic Health Research Survey (Riskesdas), Adieoetomo et al. (2014). These are estimates of moderate and severe disability. More detail on the various surveys is provided below.

Data sources and Methodology

This report uses a number of different datasets that provide information on disability in Indonesia. Here we describe their general features and explain how they measure disability. Measuring disability is complex. In 2001 the United Nations Statistical Commission established the Washington Group on Disability Statistics (WG) to promote international cooperation in disability measurement to allow comparability across countries (Mitra et al., 2011; ILO, 2007). The WG developed a short questionnaire which is designed for use in censuses and other large data collection efforts. Due to the complexity of disability measurement, the WG short set questions are not designed to measure all aspects of difficulty in functioning that people may experience, but rather those domains of functioning that are likely to identify the majority of people at risk of participation restrictions. The functioning difficulties included are:

- Difficulty seeing, even if wearing glasses
- Difficulty hearing, even if using a hearing aid
- Difficulty walking or climbing steps
- Difficulty remembering or concentrating
- Difficulty (with self-care such as) washing all over or dressing
- Difficulty communicating (using your usual language), for example understanding or being understood.

Respondents are asked to indicate whether in each domain they have “no difficulty”; “some difficulty”; “a lot of difficulty” or “cannot do at all”. These domains are then qualified as generating no limitation, moderate or severe limitation.

As the WG was established to homogenize the measurement of disability in 2001, different surveys in Indonesia have gradually adjusted the way they collect information in this area. However, the surveys all differ in terms of the questions they include which are designed to measure disability. This is true even across years within the same survey. Some surveys take a more medical approach by attempting to identify sufferers of particular medical conditions associated with disability (e.g. blindness, deafness, brain damage). Some surveys use both the WG approach and the medical model. Table A1 in the appendix provides details on the specific questions from each of the surveys used in this report. The differences in methodology mean that the prevalence estimates from each of the datasets are not directly comparable to each other, and also not comparable across time.

Population Census 2010

The Population Census 2010 aims to provide information on all households in Indonesia in 2010. This survey follows the WG short set methodology, except that it combines the remembering/concentrating and the communicating domains (which are separate in the WG short set questions). The allowed responses about the level of difficulty also differ slightly from the WG recommendation. Respondents indicate for each functioning domain whether they have no difficulty; a little (sedikit) difficulty; or severe (parah) difficulty.

Susenas

The Indonesian National Social and Economic Survey (Susenas) is a nationally representative household survey which collects information on household

characteristics and composition, education, health, main activities and fertility for ever married women. The questionnaire consists of core questions which are asked every year and a module. The modules ask specialised questions on particular topics and rotate in and out of the survey every three years. Questions on disability are included in the "Social, culture and education" module that was implemented in 2000, 2003, 2006, 2009 and 2012.

The 2000, 2003 and 2009 survey rounds measure disability using the medical model definition. They ask whether the person is blind, deaf, dumb, etc. with the response being "yes" or "no". It has been recognized that this measure excludes people with mild health impairments that might find it difficult to function in the community, and so produces a lower bound of the incidence of disability. Susenas 2006 also uses the medical model of disability but includes a different array of descriptions of medical conditions. For example, it asks whether the respondent has vision difficulties, rather than whether s/he is blind, (see Table A1 in the appendix for details). It also collects an additional set of questions on functioning but which differ from the WG questions. Allowed responses to the question of whether such difficulties are experienced are "Yes" or "No". Finally, Susenas 2012 follows the WG more closely. It asks questions about the WG functioning domains but the response categories differ from that recommended by the WG. Allowed responses are "No", "Modest" and "Severe", compared to the WG categories of No/Some/A lot/Cannot do at all.

Although the Susenas collects information on disability in five survey rounds. The changes in the questionnaire make it unsuitable for examining trends across time. Although the survey questions on disability are the same in 2000, 2003 and 2009, the medical definition used in these years generates very low estimates of disability prevalence (less than 1% of the population) and so is also unsuitable.

Sakernas

The National Labour Force Survey (Sakernas) is a nationwide survey that collects information on the labour market characteristics of all working age individuals (aged 15 and over). This survey is conducted annually and is predominantly used to construct labour market statistics. The 2016 Sakernas included some questions designed to identify disability. It uses a combination of the medical definition and functioning difficulties. Allowed responses were: No difficulty, some difficulty or severe difficulty.

IFLS

The Indonesia Family Life Survey (IFLS) is a multi-topic longitudinal survey that started in 1993 and has been following the same people for more than 20 years. The sample is representative of 83% of the Indonesian population living in 13 of the 27 provinces in the country (mostly in western Indonesia). For this analysis we use the latest round which was conducted in 2014. This is a rich source of information and asks individuals aged 15 and older about their health and physical conditions. It allows identification of disabled individuals using a medical definition of disability. Unlike the other surveys, it asks if a health practitioner (doctor, nurse, midwife, etc.) has diagnosed each condition with the allowed responses being “yes” or “no”.³

The survey also includes a section on difficulties with physical functioning (walking, squatting, carrying, standing, reaching), daily living (dressing, bathing, getting up, eating, toileting) and activities of daily living (shopping, cooking, chores, managing money, medicines). We do not include these in this analysis as although they follow the spirit of the WG they are very different from the other surveys and so difficult to compare.

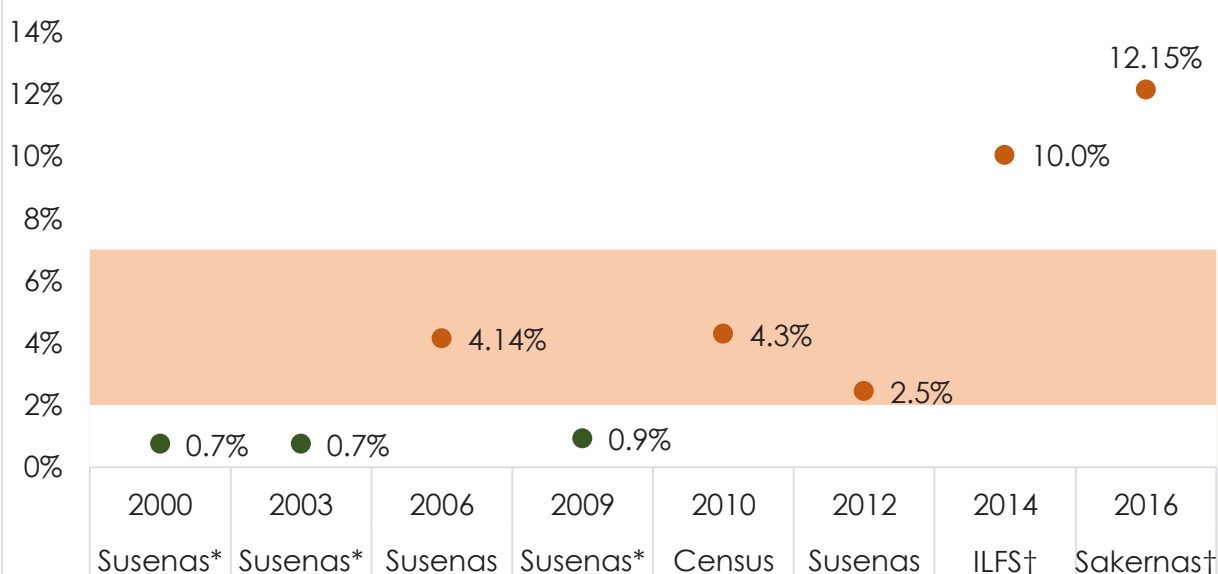
In addition to analysing the data sets mentioned above, this report also draws on the results of a literature review of disability and its impact on education, employment and the household, putting Indonesia in an international perspective (see Annexure); and discussion with civil society organisations and various other stakeholders in the area of disability.

Disability Prevalence

We start with an examination of the differences in prevalence rates across different data sources. Graph 1 presents the proportion of people that each survey identifies as disabled. In 2000, 2003 and 2009 Susenas used a medical model definition where they asked people if they were blind, deaf, dumb, or had a learning or physical disability. Using this approach to disability we calculate that around 0.8% of the population has one of those conditions. This measure, however, does not include people who have other difficulties and does not exclude people who have a difficulty but with an assistive device can function within the community (as suggested by the Washington Group). Susenas 2006 and 2012, the Census 2010, the Indonesian Family Life Survey (IFLS) 2014 and Sakernas 2016 use a definition more in line with the WG.⁴ From these surveys we calculate that the proportion of the population with a functional disability is between 2.5% and 5%. If we look at the Census, the prevalence rate is 4.3%, or 10,150,719 people with a disability, where disability is defined as having a little or severe difficulty in one or more of the functioning domains.

³ The medical diagnostic generates a lower bound of the disability prevalence as it does not include people who have not been diagnosed for example if they do not have medical access.

⁴ The high prevalence of disability found in the IFLS and the Sakernas data may reflect that these data only cover individuals aged 15 and over.

Graph 1: Prevalence of Disability in Different Surveys

Authors' calculations. Using sample weights in Susenas, IFLS and Sakernas.

* Represents surveys that used the medical definition of disability. † The sample does not include children under age 15.

Map 1 and 2 present how people living with a disability are distributed across Indonesia. Gorontalo and North Sulawesi have the highest prevalence in the country at above 6%, and the next highest-prevalence provinces are Central Sulawesi, South Sulawesi and East Nusa Tenggara, with rates of 5-6%. Surprisingly, Papua, West Papua and Riau have low prevalence (below 3%) while other provinces such as Jakarta and Yogyakarta, where a more supportive environment would be expected, do not have particularly low rates.⁵ In the appendix we present the percentage for urban and rural Indonesia. Disability is concentrated slightly more in rural areas (4.6% compared with 3.9%).⁶ This is consistent with the findings in Adioetomo et al (2014) for Indonesia and Mitra et al (2011) which finds that disability is higher in rural areas in most of the fifteen developing countries they study.

⁵ We calculate a correlation of 0.56 between the prevalence rate generated by the Census 2010 and the Susenas 2012, indicating a similar pattern.

⁶ The provinces that have the highest proportion of people with disabilities in its rural areas are North and South Sulawesi, Gorontalo, West Sumatra and Riau Island.

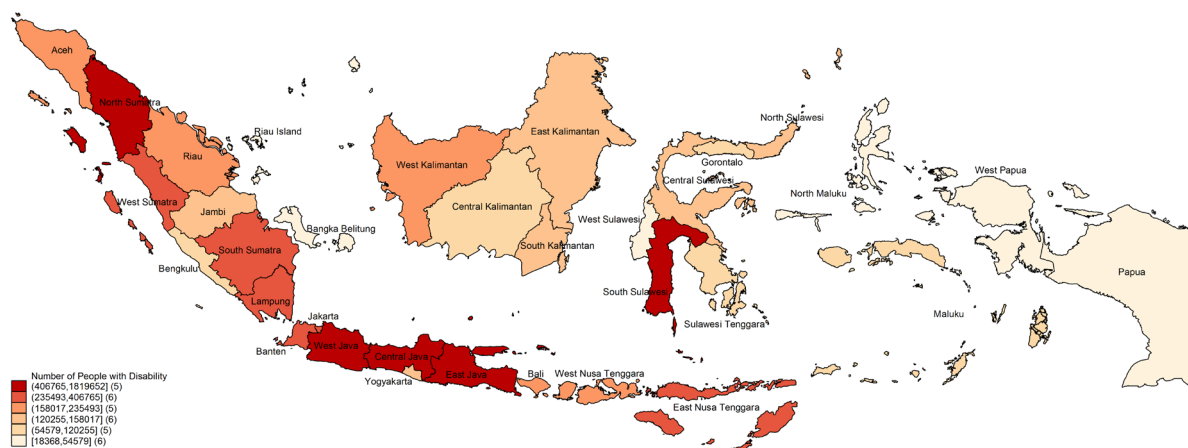
Map 1: Prevalence of people with a disability by province



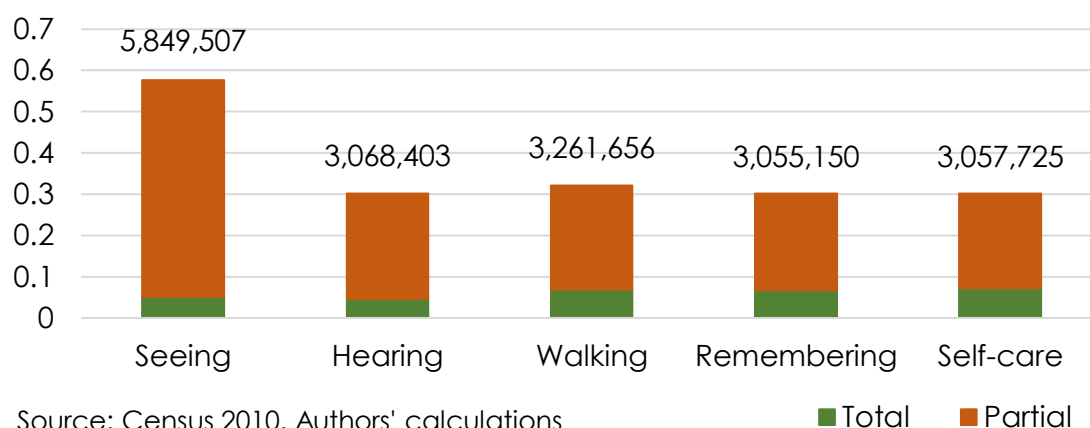
Source: Census 2010, authors' calculations

Map 1 shows the provinces that have higher percentages of the population living with a disability. Map 2 presents the distribution of the number of people affected which provides some indication of the provinces where more resources (in absolute terms) may be required to support people with disabilities. The map shows that the greatest number of people living with a disability are concentrated in Java, North Sumatra and South Sulawesi. The eastern part of the country has the lowest number of people with a disability. We find that, in relative and absolute terms, Papua and West Papua have the lowest incidence of disability. Adioetomo et al (2014) similarly find that disability prevalence is relatively low in these two provinces, based on analysis of the Riskesdas 2007 data.

Map 2: Number of people with disability by province



Source: Census 2010, authors' calculations

Graph 2: Types of Disability as a Share of Total Disabilities

Graph 2 shows how the number of people with a disability are distributed across the different functioning domains.⁷ Vision difficulties are consistently the most prevalent limiting aspect across different surveys. However, severe difficulties are relatively evenly distributed across the types of difficulties. It is common that people experience more than one type of disability. Forty percent of people with a disability have more than one type of limitation. While the WG short set of questions by themselves explicitly address only limitations in undertaking basic activities, they are designed for analysis with other information in a way that incorporates the full bio-psychosocial model of disability.⁸ By bringing together the medical model definition of disability and the domains of limiting function one can examine interaction between the physical medical condition the person has and the limitation he or she faces. Susenas 2006 provides information on both medical conditions and limitations in functioning. Table 1 presents the percentage that each health condition contributes to each domain of limitation. The health conditions that limit the daily functioning of people the most are vision difficulties, hearing difficulties and impairments in the use of legs. Fifty-one percent of people who have limitations in their ability to care for themselves have an impairment in using their legs, arms or fingers or a vision problem. Sixty-four percent of people who have difficulties communicating and interacting with others have vision, hearing and speaking problems. People who have an impairment using their legs, a vision or a hearing problem constitute 61% of the people who have a physical mobility difficulty. Hence, in the absence of information on functioning, policies that target people with these physical difficulties are likely to provide the greatest benefits in terms of improved functioning and participation in society.

⁷ In the Census 2010 the categories remembering/concentrating and communicating were combined.

⁸ See <http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/>.

Table 1: Interaction between health and limiting conditions

	Limiting condition				
	Self-care	Comm. and SA	Physical mobility	Sight	Total
Vision	13%	17%	17%	58%	42%
Hearing	10%	31%	12%	16%	17%
Speaking	9%	15%	5%	3%	6%
Using arms and finger	15%	5%	7%	3%	4%
Using legs (walking)	24%	10%	33%	10%	14%
Physical deformity	4%	2%	5%	1%	3%
Paralysis	12%	4%	8%	2%	3%
Chronic diseases	7%	5%	11%	6%	7%
Epilepsy	1%	1%	0%	0%	0%
Learning and understanding	1%	2%	0%	0%	1%
Mental impairment	2%	5%	1%	0%	2%
Mental Disorder	3%	3%	0%	0%	1%
Total	100%	100%	100%	100%	100%

Health impairment

Source: Susenas 2006. Authors' calculations. Using sample weights.

Self-Care: Self-care such as eating, bathing, and going to the toilet.

Comm. and SA: Communication and social activities such as speaking, understanding conversation, etc.

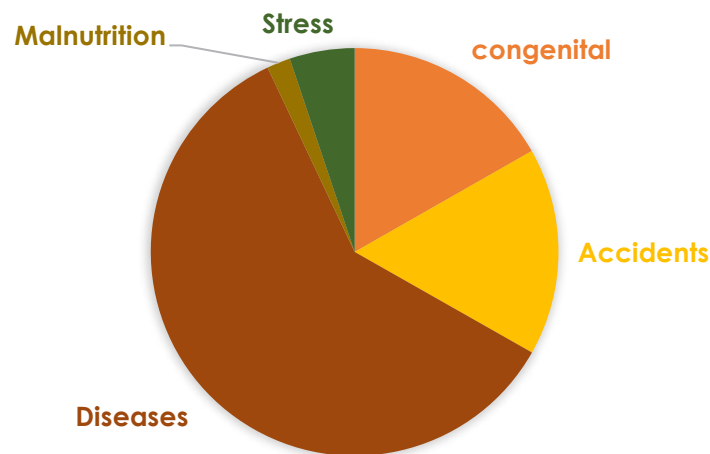
Physical Mobility: Physical mobility such as waking up from sleep, moving around, long distance walk

Sight: Seeing such as observation or looking at an object within 30 cm

Causes of Disability

The Susenas surveys in their various versions enquire about the cause of disability. Knowing the cause of disability helps to determine what disabilities it may be possible to prevent. For example, a congenital condition is less likely to be prevented while a disability that is a results of an accident or disease could be diminished or avoided. Graph 3 shows that 60% of disabilities are caused by diseases and 16% are caused by an accident.⁹ Malnutrition is only reported as being the cause of disability 1.8% of the time. This may reflect that malnourishment often leads to other diseases which may be reported as the cause of the disability. Congenital disorders account for 17% of disabilities.

Graph 3: Cause of the disability



Source: Susenas 2012. Authors' calculations. Using sample weights

⁹ The 2012 Susenas asks about accidents and natural disasters. The 2003 Susenas asked about natural disasters and accidents separately and shows that the contribution of natural disasters to disability is small (2%).

Table 2: Type of disability by cause

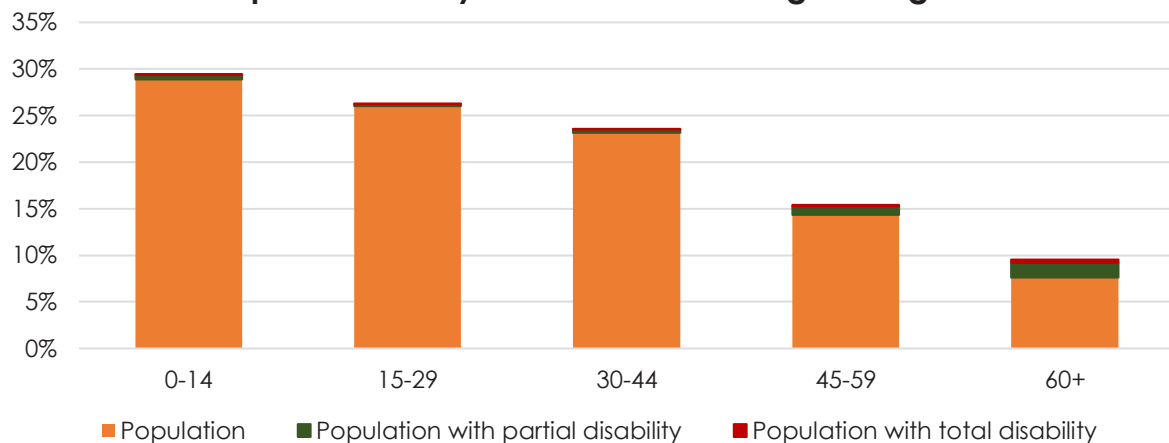
	Congenital	Accidents	Diseases	Mal-nutrition	Stress	Total	N
Difficulty seeing, even if wearing glasses	10%	12%	76%	3%	0%	100%	3058371
Difficulty hearing, even if using a hearing aid	18%	16%	65%	1%	0%	100%	1740788
Difficulty communicating (speech impaired)	40%	22%	37%	1%	0%	100%	1061278
Difficulty remembering or concentrating	14%	39%	20%	0%	26%	100%	1109543
Difficulty walking or climbing steps	15%	24%	60%	1%	0%	100%	2008966
Difficulty with self-care (eating, bathing, dressing, toilet)	16%	23%	55%	1%	5%	100%	1335875

Source: Susenas 2012. Authors' calculations. Using sample weights

Table 2 shows the reported causes by disability type. Vision difficulties are often caused by diseases and accidents (in 88% of cases). Important points to highlight are that communication difficulties are often related to congenital causes (40%) while difficulties remembering or concentrating are often the result of an accident (39%) or stress (26%). Diseases and accidents also often cause walking difficulties (60% and 24% respectively) compared with 15% of walking difficulties which are a result of congenital conditions.

Graph 4 presents the age distribution of the total population in Indonesia and the proportion that has a disability. Indonesia is a young country, with 29% of the population aged between 0 and 14, and 26% between 15 and 29. In these age groups only 1.9% and 1% are affected by a disability. In contrast, while people older than 60 are only 8% of the population, 26% of them are affected by a disability, indicating that most disability is concentrated among the elderly.

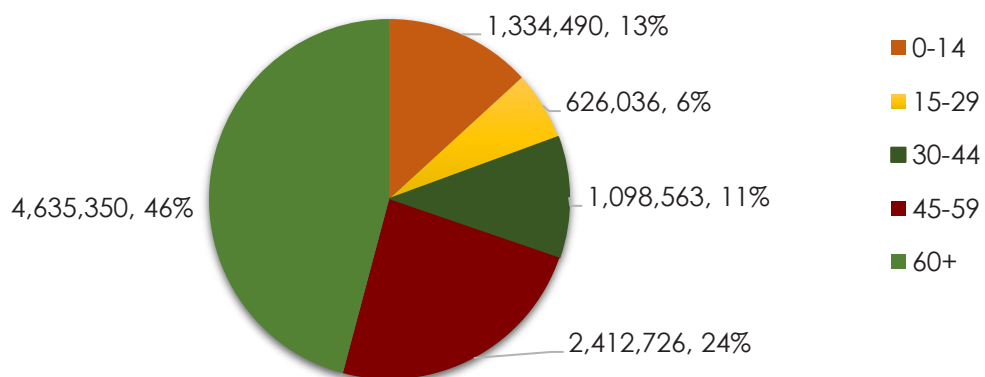
Graph 4: Disability Prevalence within age categories



Source: Census 2010. Authors' Calculations.

Graph 5 presents the age distribution of people with a disability (PwD). As mentioned above the majority of people with a disability are elderly. They are around half of the PwD population. When we examine the types of difficulties they face, we find that the most common limitation is having a vision problem - 68% of the elderly report vision difficulties even when using glasses. A further 49% report hearing problems and 48% have difficulties walking and climbing stairs.

Graph 5: Age distribution of people with a disability



Source: Census 2010. Authors' Calculations.

Finally, across the different surveys we find that disability prevalence does not vary markedly by gender. Census data shows that the incidence of disability is similar for males and females - 4.6% of women have a disability compared with 3.9% of men; 54% of people with disabilities are women. Figures from the Susenas differ slightly, indicating that 47% of the disabled are women in 2009 and 50% in 2006.

Assistive Devices

Table 3 shows the proportion of people who indicate that they do not have an assistive device which they report needing. This is reported by type of health impairment and type of device that the individual reports that they need. For people with limited vision, 80% of those who report that they need glasses also report that they do not have them, and 28% of those who report they need a white cane do not have one. This could be related to limited access to the cane itself but also to lack of access to appropriate training on how to use it. For those with hearing impairments who report that they need a hearing aid, 91% do not have one. Given that hearing is one of the most prevalent conditions (12% of PwD), improving access to and use of hearing aids has the potential to considerably improve the daily functioning of many people living with a disability. Access to prosthetics is also very low in Indonesia. For people with a difficulty using their arms, fingers, legs, or with a physical deformity who need prosthetics, on average across these categories of disability less than 25% of people who could benefit from having a prosthetic are able to access one.

Table 3: Unmet demand for assistive devices

Health Impairment	Assistive device needed	% unmet need
Vision	Glasses	80%
	Blind stick	28%
Hearing	Hearing Aid	91%
Speaking	Sign language	54%
Using arms and finger	Prosthetic	60%
Using legs (walking)	Prosthetic	75%
	Wheelchair	24%
	Walking aid	28%
Physical deformity	Prosthetic	90%
	Wheelchair	25%
	Walking aid	33%
Paralysis	Wheelchair	11%
	Walking aid	63%
Chronic diseases	Breathing aid	31%

Source: Susenas 2006. Authors' calculations. Using sample weights.

Disability and Education, Health, Labour Market Activity and Access to Services

Table 4: People with disability - access to education, health and the labour market

	PwD severe (1)	PwD moderate (2)	Pw/oD (3)	Diff (1-3)	Diff (2-3)
Years of education ¹	2.8	4.4	6.5	-4	-2
Attending school of age 5 to 17	32%	62%	79%	-47	-17
Attending school of age 5 to 12 ²	29%	65%	84%	-56	-19
Attending school of age 13 to 17 ²	28%	54%	83%	-54	-29
Attending school of age 18 to 25 ²	3%	14%	16%	-13	-2
Any health problem last month ²	53%	46%	20%	33	26
Participating in the labour force	28%	61%	66%	-38	-5
Participating in the labour force by difficulty					
Difficulty seeing, even if wearing glasses	35%	65%	66%	-31	-1
Difficulty hearing, even if using a hearing aid	42%	54%	66%	-24	-12
Difficulty walking or climbing steps	18%	45%	66%	-48	-21
Difficulty remembering or concentrating or have difficulty communicating with others because of a physical or mental condition	18%	41%	66%	-48	-25
Difficulty with self-care (eating, bathing, dressing, toilet)	10%	31%	66%	-56	-35

Source: Census 2010. Authors' calculations.

Notes: ¹ After controlling for age. ² Source Susenas 2012 using individual weights.

Experiencing a disability is likely to restrict access to public services. In this section we look at some areas where people with a disability are likely to be disadvantaged. Table 4 shows the difference between people with (PwD) and without (Pw/oD) a disability in educational attendance and attainment, health status, and participation in the labour market. Educational attainment is lower among people with a disability. The average education of a person without a disability is 6.5 years, however for a person with a moderate disability it is 4.4 years, and for someone with a severe disability it is only 2.8 years on average.¹⁰ These differences could be because families decide not to send children with a disability to school as they are viewed as being unlikely to ever work or earn a reasonable living, and/or a lack of access to education for children with a disability from families who do want to send their children to school.¹¹ With the available data it is not possible to identify the main causes.

If we look at school attendance, there is a 17 percentage point (ppt) difference in school attendance between school-aged children with a moderate disability and those without a disability (62% versus 79%). There is an additional 30 ppt difference between children with a moderate disability and children with a severe disability, with only 32% of school-aged children with a severe disability attending school. It is thus likely that access to the labour market in the future will be severely limited.

If we look at school participation by school level, we find that the gap in school attendance between children with a disability is larger for children of secondary school age than for primary-school-aged children. This is particularly true for those with a moderate disability. Only 65% of children aged 5 to 12 with a moderate disability are attending school (versus 84% of those without a disability) whereas for children aged 13 to 17 attendance decreased to only 54% for those with a moderate disability. Attendance is more or less maintained at 83% for children without a disability. Progression through school grades is also affected by disability. In separate calculations we find that 22% of children with a moderate or severe disability who are aged between 13 and 17 are still in primary school, compared with only 3% of children without a disability in this age range. The cause of this lack of progression is unclear given the existing data.

Schooling can be also hindered by the presence of multiple difficulties. Table A2 in the appendix shows a similar analysis of school attendance and compares children with multiple and single disabilities. Having multiple disabilities is as restrictive as having a severe disability, with only 37% of children with multiple disabilities attending school. Schools are often not equipped, nor prepared, to enrol children with a disability. This is even more so when children have multiple disabilities.

¹⁰ Susenas 2012 asks respondents to indicate whether they have difficulties in the various functioning domains. The available responses are Yes, moderate (ringan); Yes, severe (berat); or No. In the 2010 Census respondents when asked whether they have a particular difficulty are able to respond No; A little (sedikit) or severe (parah).

¹¹ These are widely acknowledged as common occurrences by disability advocates in Indonesia. Source: conversations with disability CSOs and other practitioners.

Having a birth certificate is an official requirement for school enrolment and for accessing other services (although 22% of children attending school are reported to not have a birth certificate). Only 60% of children with a disability have a birth certificate compared to 75% of children without disabilities at the same age, Susenas 2012. Difficulty obtaining birth certificates may be a barrier to education for children with disabilities. And their ability to access other public services.¹²

Health is also poorer among people with a disability. Around 50% of PwD report health problems, which is 30 ppts more than people without a disability.¹³ A higher prevalence of health problems indicates that PwD are likely to face higher health risks and/or lesser access to health services appropriate for their needs.

Participation in the labour market is also significantly lower for people with disabilities.¹⁴ The overall small difference between people with moderate disabilities and people with no disabilities (61% versus 66%) is mainly driven by those with moderate vision difficulties. If we exclude this group, we find that only 38% of PwD are participating in the labour market (compared with 66% of people without a disability). Difficulties with self-care impose the greatest restrictions, while hearing difficulties are the least restrictive. There are more work opportunities and work environments that are friendly towards people who have a hearing impairment. Even people who have a severe hearing disability participate in the labour market more than other groups with a severe difficulty. This indicates that it is possible to create economic opportunities for PwD through the use of appropriate technology and the willingness of employers to adapt and accommodate the needs of people with disabilities.

The restrictions associated with having a disability may differ by gender. Table A3 in the appendix presents educational attainment and labour force participation by gender for people with and without disabilities. Women with a disability obtain on average 2.3 years of education versus 1.5 years for men. The difference in educational attainment between people with and without a disability is however similar across the genders (approximately 3 years less education). The difference in school attendance rates between men aged over 12 with and without a disability is greater than that for women, suggesting that disability may be associated with greater educational disadvantage in terms of proceeding beyond primary school for men. Disability is also associated with a greater decrease in the probability of working for men than for women (an 11 percentage point decrease for men and an 8 percentage point decrease for women), although 72% of men with a disability work relative to 41% of women.

¹² Further exploration of the data show that “being too expensive” is the main reason for not having a birth certificate (43% for both children with and without a disability). However, the second most common reason for children with disabilities is that they “do not see the need for it” (18%, compared to 9% for children without a disability). It may be that parents of children with a disability do not know about the services that are provided by the national government and that they are entitled to access.

¹³ The health problems included are: fever, cough, cold, asthma\breathlessness, diarrhoea, migraine, toothache, or other.

¹⁴ For this analysis we restrict the sample to those of working age (15 to 64 years).

Table 5: People with disability – Labour Market Conditions

A: Industry of employment			
	PWD severe	PWD moderate	Pw/oD
Agriculture	48%	47%	30%
Mining, quarrying	1%	1%	1%
Manufacturing	8%	9%	14%
Electricity, gas, water	0%	0%	0%
Construction	3%	4%	7%
Wholesale, retail, hotel	20%	21%	24%
Transport, communication	3%	3%	4%
Finance/insur., real estate	1%	2%	3%
Community, psnl. services	16%	13%	17%
Total	100%	100%	100%
B: Occupation of employment			
	PWD severe	PWD moderate	Pw/oD
Military	0%	0%	1%
Manager	1%	1%	1%
Professional	2%	4%	6%
Technical and assoc. prof.	0%	2%	3%
Office Clerks	0%	3%	6%
Service and Sales	22%	22%	24%
Skilled Agriculture	45%	40%	25%
Craft and trades work	10%	10%	12%
Operators and assemblers	1%	4%	7%
Elementary occupation	18%	15%	16%
Total	100%	100%	100%
C: Employment Institution			
	PWD severe	PWD moderate	Pw/oD
Government	3%	5%	8%
International institution	0%	0%	0%
Non-profit Institution	1%	1%	1%
Profit Institutions	3%	7%	17%
Cooperatives	0%	0%	0%
Indiv./household business	75%	71%	62%
Household	16%	13%	10%
Other	2%	2%	2%
Do not know	0%	0%	0%
Total	100%	100%	100%
D: Status of employment			
	PWD severe	PWD moderate	Pw/oD
Own account	30%	23%	16%
Employer, assisted by unpaid w.	29%	29%	16%
Employer, assisted by paid w.	2%	4%	3%
Paid worker/employee	12%	22%	40%
Casual in agriculture	3%	6%	4%
Casual not in agriculture	7%	4%	6%
Unpaid/family workers	17%	13%	14%
Total	100%	100%	100%

Source: Sakernas 2016. Authors' calculations. Using sample weights.

We also explore the types of work done by PwD. The results are presented in Table 5. PwD are over-represented in agriculture. While only 30% of people without disabilities work in agriculture, 48% of people with a severe disability work in this industry. Agriculture is the dominant industry of employment for PwD, in part because there is a higher prevalence of PwD in rural areas. The second most common industry of employment is the trade (wholesale and retail) and hotel sector, where 20% of people with a severe disability work, followed by community and personal services, with 16%. This distribution is also reflected in the occupation of employment (presented in panel B). Forty-five percent of people with a severe disability work in agricultural activities, 22% are in services and sales, and 18% in elementary occupations (such as street food vendors, shoe cleaners, etc.). Only a very small proportion are in managerial, professional, technical and clerical positions.

In panel C we show that the majority of PwD work in individual or household business (75% of people with a severe disability, compared with 62% of people without a disability) or are household workers (16% c.f. 10% for people without a disability). Only 3% of PwD work in for-profit institutions (17% for people without a disability) and 3% in the government (compared to 8%). PwD thus have fewer opportunities and are more likely to be in more vulnerable jobs, with less security and worse conditions. There is considerable scope for the government to play a leadership role in promoting inclusion and economic opportunities for PwD. Finally, panel D shows the status of employment. Seventy-five percent of PwD work in the informal sector (own account employer assisted by unpaid workers, casual workers and unpaid/family workers), and most of them are either self-employed, have a business assisted by non-paid casual employees, or are unpaid family workers.¹⁵

Limited options for employment can reflect mobility restrictions. For example a blind person who does not have a physical mobility problem can find his mobility restricted by the limited access to transportation options or footpaths. In Table 6 we look at the location of the job or business and in Table 7 we look at access to infrastructure services. While only 18% of people without a disability work at home, 29% of PwD do. In urban areas the proportion of people with disabilities working at their homes is double the proportion of people without a disability. This likely reflects limited formal work opportunities and the need to create work opportunities for themselves in a place that is easily physically accessible.

¹⁵ We disaggregate the analysis by status of employment (formal/informal) and geography (rural/urban), the results are in Tables A4 to A7 in the appendix.

Table 6: People with disability – Location of the workplace/business

	PWD severe	PWD moderate	PWnoD	N
Yes, at own home	29%	23%	18%	22,238,218
Yes at friend/relative's home	1%	1%	1%	836,759
Yes at employer's home	6%	8%	11%	12,931,506
Other	64%	69%	70%	84,641,214
Total	100%	100%	100%	120,647,697
Yes, at own home				
Rural	22%	20%	16%	9,663,069
Urban	39%	27%	19%	12,575,149

Source: Sakernas 2016. Authors' calculations. Using sample weights

Table 7: People with a disability - access to services

Access to services	No Access	Use it	Don't use it
Access to public transport	38%	14%	48%
Access to information	44%	13%	43%
Access to shopping centres	56%	7%	37%
Access to sidewalks	55%	6%	39%
Access to pedestrian bridge	67%	6%	27%
Access to crossing the roads	49%	10%	40%

PwD has participated in rehabilitation services last year

	Total
Medical	4%
Education	1%
Training	0%
social	0%
None	94%

Source: Susenas 2012. Authors' calculations. Using sample weights.
N=6,008,661

Table 7 presents some information on obstacles to accessing infrastructure and rehabilitation services by people with a disability. A disaggregation by urban/rural is presented in Table A7 in the appendix. The majority of PwD do not access services. For example, 38% of PwD do not have access to public transport and 48% do not use it. So only 14% use public transport. Barriers in access to services are likely to be the result of the facilities not being disabled-user friendly. This is likely a factor restricting PwD to work at home.

Similarly, it seems that there is very low availability of rehabilitation services for PwD. Only 4% access medical rehabilitation and only 1% have access to special education services. This is an area with significant potential for improvement at the local level. Table 3 shows that many people who would benefit from learning and using sign language and speech therapy do not have access to it. Providing education and training for people with vision, hearing and speaking difficulties will increase their ability to function in their communities.

Families of People with Disability

Having a disability affects the general wellbeing of the person who has the condition but its impact also extends to his or her family. Census data show that while 4.3% of the population face a disability, 13.3% of households have a household member with a disability. This is more than 8 million households that have at least one person with a disability. The disability of a household member likely imposes a cost on the household. For example, a higher share of expenditure on health and a reduction in the time the household is able to devote to economically productive activities, as household members may need to devote time to the care of the person with a disability.¹⁶ In this section, we describe some of the effects disability has on other household members.

Table 8 presents some differences in terms of the effects on children, the caregivers and the household expenditures between households with a PwD and households without a PwD.¹⁷ For the smallest children in the house we find that breastfeeding is almost a universal practice with 95% and 96% of the children aged 0 to 5 having been ever breastfeed in PwD and Pw/oD households, respectively. In households where there is a PwD, 2% of children aged 5 to 9 are working. This represents approximately 450,000 children and double the proportion of children in households where there is not a person with a disability.¹⁸

Children may be working to help supplement household income to meet the increased costs associated with the presence of a member with a disability and to compensate for adults' reduced ability to work because of caring responsibilities. Another possible explanation is that poverty is related to disability. That is, poor households are more likely to have a member with a disability and child labour is another expression of their poverty. To date, it is not clear whether poverty is a cause or a consequence of disability (or both) and more research is required in this area. However, it is likely that poverty is a risk factor for non-congenital disability. Chronically

¹⁶ Susenas 2006 shows that 38% of PwD need help in their daily activities at least occasionally.

¹⁷ Tables A9 and A10 present the break up by urban/rural.

¹⁸ This difference is statistically significant at the 1% level.

poor people are at risk of ill health and injuries which can lead to disability through a variety of routes. They often live in unsanitary and substandard housing conditions, are unable to afford nutritious foods, lack the ability to access clean water and basic sanitation, are more likely to have dangerous jobs, and live in areas where there is a higher probability that they will be victims of violence (Groce et al., 2011).

Table 8: Differences with Disability Status

	PwD (1)	Pw/oD (2)	Diff (1-2)
Children			
Children 0 to 5 ever breastfed ¹	95%	96%	1 ppt
Child labour (age 5 to 9) ¹	2%	1%	1 ppt
Proportion of children 5 to 17 attending school	76%	79%	3 ppt
Proportion of siblings 5 to 17 who are attending school	81%	80%	1 ppt
Main caregiver			
Female spouse participating in the labour force	49%	50%	1 ppt
Female head participating in the labour force	45%	65%	20 ppt
Household			
Monthly total Expenditure per capita ²	303,204	346,999	-43,794
Monthly total Expenditure per capita ³	383,722	485,307	-101,584

Source: Census 2010 (unless stated). Authors' calculations.

Notes: ¹ Using Susenas 2003. ² Using Susenas 2006 and a functional disability definition. ³ Using susenas 2009 and a medical disability condition. Monthly expenditure in current prices. All Susenas calculations include sample weights.

In households with a PwD, 76% of school aged children attend school compared with 79% when there is none. We also examine the effect on school attendance of children without a disability who have a sibling with a disability. We do not find a significant difference between siblings' attendance and that of children in a household without a child with a disability.

In households with a married couple, we look at the economic participation of the female spouse as she is most often the caregiver. We find a lower rate of participation in households with a disabled member but the difference between women's participation in households with and without a person with disabilities is small. In contrast, in households where the household head is a woman (divorced or widowed) the difference in participation rates is large, 20 ppt. These households thus appear to be particularly vulnerable and disproportionately affected by the presence of a PwD.

Finally, we examine total expenditure per capita. We find that using a definition of functional disability, expenditure per capita is 13% lower in households with a PwD compared with those without.¹⁹ However, if we use the health impairment definition of disability, as incorporated in the 2009 Susenas, the difference is about 21% (result not shown in the table). The health impairments definition captures the most severe cases of disability where more care is required and a heavier burden is borne by families. In light of this large difference in expenditure per capita, social assistance payments to compensate these households for at least some of the extra costs they face is likely to significantly improve the wellbeing of these households.

Summary

In Indonesia disabilities impose considerable burdens on both people with a disability and their families. Overall, PwD have lower educational attainment than others. Children with a disability are less likely to be attending school, particularly at their age-appropriate school level. Very few children with a disability are studying beyond age 18. PwD also seem to be more at risk of common health problems. Lower education and training, lower health status and limited access to services and infrastructure hampers their economic opportunities.

Most PwD work in the informal sector – in either household businesses or as household workers and predominantly in agriculture, retail and personal services. This reflects their limited economic opportunities.

Families of PwD are also at a disadvantage. Caregivers, usually women, participate less in the labour market if there is a member with a disability. This is particularly true in households where the woman is the household head (as a result of divorce or the death of a spouse). Finally, households with a member with a severe disability have lower household expenditure per capita, and so are at greater risk of poverty.

Future Directions and Policy Options

We highlight several ways in which the livelihoods of PwD and their families can be improved. These are consistent with our findings and arise out of discussions with disability stakeholders.

- **Adequate access to education.** Access to appropriate education requires removing barriers to the education system for people with disabilities. This includes making it easier for PwD to obtain birth certificates and also removing physical and

¹⁹ This difference is statistically significant at the 1% level.

other barriers to PwD being able to obtain education at all levels – primary, junior and senior secondary and tertiary. For example, relatively simple actions to facilitate access to buildings, appropriate assistive devices and facilities could play a significant role. Appropriate training for teachers is likely to also be important.

- **Access to assistive devices and supporting use with training.** Prioritizing efforts aimed at those with vision, hearing and walking difficulties will have the largest impact given that these disabilities are the most prevalent. Increased access to assistive devices is one way to improve welfare. Training on how to use the devices is just as important, in particular for those who become disabled as adults. Increased access to prosthetics also has the potential to considerably increase welfare as many people with mobility difficulties lack access.
- **A social protection program that helps families with members with disabilities.** PwD and their families are more at risk of poverty. A social protection program targeted at households with a disabled member could help reduce this risk - in particular one targeted at the families of children with disabilities, elderly with disabilities, working-age people with severe disabilities that limit their economic opportunities, and carers of people with disabilities.
- **Improving the economic opportunities for people with disabilities.** Economic opportunities for PwD can be improved by improving transport and other infrastructure and adopting new technologies that can assist PwD to work in some industries. For example, visually-impaired people can be employed as telemarketers or in call centres if they are trained and have access to software that allows them to use a computer. Increasing economic opportunities for PwD decreases the burden on the state by allowing any system of transfer payments to focus on those with severe disabilities who cannot work to support themselves, with those with lesser disabilities being able to be better integrated into the formal economy.
- **The Government as a leader in work inclusiveness for PwD.** There is great scope for the government to champion inclusion of PwD in their own labour force. PwD are currently under-represented in government employment, due in part to regulations that inhibit government's ability to employ PwD. Incentivising the private sector to employ PwD through tax exemptions is a further role that government could play.
- **Infrastructure and access to services.** Physical access to services can be significantly improved by investment in appropriate infrastructure, in particular for those whose mobility is hindered, such as the blind and those with walking impairments who use a wheelchair or walking aids. Improving access to affordable and disability-friendly transport options - for example appropriately designed pedestrian paths, bridges and public transport stops and interchanges - will improve access to education, health, other services, and also to economic opportunities. Before PwD can access services they need to know about the existence of such services. The provision of information about entitlement to and availability of services, possibly through a centralised information hub, is needed to ensure equality of access.

- **Injury and disease prevention that leads to disabilities.** Most of the disabilities reported are non-congenital and instead are acquired or developed as a result of diseases or accidents. Some disabilities can thus be prevented by improved health service access and working conditions standards. For example, health service protocols could be put in place to identify children and adults at risk of acquiring a disability. Also early diagnosis of low-level disabilities and early intervention can diminish the probability of increasing severity. Implementing regulations that establish minimum workplace standards will reduce the risk of workers acquiring permanent disabilities. Finally, in the event of accidents, all companies should be made to comply with the BPJS employment accident insurance.

Our final recommendation relates to the need for high quality data on disability which reflects the WG recommendations in their entirety and so is consistent across time.

- **Data on disability which is consistent over time and measures disability in accordance with international standards.** Consistency in data collection across time is essential to the study of progress with regard to disability inclusiveness, as laid out in the UN CRPD principles. The National Socio-economic Survey (Susenas) is a natural place in which to collect these data as it allows an analysis of disability alongside other social and economic outcomes. Disability data was last collected in the Susenas in 2012.

The need for high-quality data on disability is especially pressing given the passing of Law No. 8/2016. Through this law, the Indonesian government has committed to improving the welfare of Indonesians with disabilities and their ability to participate in society. Data will allow progress against goals in key areas to be measured - such as educational attainment and labour force participation by industry and sector. A system for monitoring implementation of the law and associated regulations, and evaluating progress over time is vital to ensuring that the intent of the law becomes a reality.

Further research could fruitfully focus on evaluating the likely impacts of the approaches suggested above on the welfare of people with a disability and their families.

Reference

Groce, N., Bailey, N., Lang, R., Trani, J. F., & Kett, M. (2011). Water and sanitation issues for persons with disabilities in low-and middle-income countries: a literature review and discussion of implications for global health and international development. *Journal of Water and Health*, 9(4), 617-627.

Appendix 1: Additional Tables and Figures

Table A1. Survey details.

	Susenas					Census	IFLS	Sakernas
	2000	2003	2006	2009	2012	2010	2014	2016
Medical model definition								
Types of disability:								
Blind	x	x		x				
Deaf	x	x		x				
Dumb	x	x		x				
Deaf and Dumb	x	x		x				
Physical disability	x	x		x			x	
Learning disability	x	x		x				
Insane	x	x						
Physical and mental disability/ multipl.				x				
Other				x				
Brain damage							x	
Vision problem							x	
Hearing problem							x	
Speech Impairment							x	
Autism							x	

Disability in Indonesia: What can we learn from the data?

	Susenas					Census	IFLS	Sakernas
	2000	2003	2006	2009	2012	2010	2014	2016
Type of Difficulty:								
Seeing			x					x
Hearing			x					x
Speaking			x					
Using arms and finger			x					x
Using legs (walking, climbing stairs)			x					x
Physical deformity			x					
Paralysis			x					
Chronic diseases			x					
Epilepsy			x					
Learning and understanding			x					
Mental retardation			x				x	
Mental Disorder			x					
Talking and understanding/communicating with others								x
Other (ex. Remembering/concentrating, behavioural/emotional, self-care, etc.								x

Disability in Indonesia: What can we learn from the data?

	Susenas					Census	IFLS	Sakernas
	2000	2003	2006	2009	2012	2010	2014	2016
Extent of disability (Allowed responses)	Yes; No (Allowing only for 2 medical conditions)	Yes; No (Allowing only for 2 medical conditions)	Yes; No	Yes; No (Allowing only for 2 medical conditions)				No; Some (Sedikit/S edang); Total (Parah)
Functioning Definition:								
Difficulty in:								
Seeing an object at a distance of 30 cm			x					
Physical activity such as waking up from sleep, moving around, long distance walk			x					
Self-care such as eating, bathing, and going to the toilet			x					
Communication and social activities such as speaking, understanding conversation, etc.			x					
Difficulty seeing, even if wearing glasses					x	x		
Difficulty hearing, even if using a hearing aid					x	x		
Difficulty walking or climbing steps					x	x		

Disability in Indonesia: What can we learn from the data?

	Susenas					Census	IFLS	Sakernas
	2000	2003	2006	2009	2012	2010	2014	2016
Difficulty remembering or concentrating					x	x and communicating		
Difficulty with self-care (eating, bathing, dressing, toilet)					x	x		
Difficulty communicating (speech impaired)					x			
Extent of disability (Allowed Responses)			Yes; No		No; Yes, modest (ringan) ; Yes, severe (berat)	No; A little (sedikit); Severe (parah)		
Other related questions								
Require help for daily activities			x					
Disability limits your interaction with the community				x				
Population	all	all	all	all	all	all	15+	15+
Sample Size	241,189	259,231	275,086	1,155,566	277,854	236,785,424	36,379	131,339

Table A2: People with multiple disabilities – access to education

	PWD multiple (1)	PWD single (2)	Pw/oD (3)	Diff (1-3)	Diff (2-3)
Attending school of age 5 to 17	37%	63%	79%	-42%	-16%
Attending school of age 5 to 12	42%	64%	81%	-39%	-17%
Attending school of age 13 to 17	23%	60%	75%	-52%	-15%
Attending school of age 18 to 25	4%	17%	16%	-12%	1%

Source: Census 2010. Authors' calculations.

Table A3: People with disabilities – by gender

	Male			Female			PwD by gender
	PWD (m1)	Pw/out D (m2)	Diff (m1-m2)	PWD (f1)	Pw/out D (f2)	Diff (f1-f2)	Diff-Diff ((m1-m2)-(f1-f2))
Years of education ¹	1.5	4.7	-3.2	2.3	5.6	-3	0.10
Attending school of age 5 to 17	55%	79%	-23	57%	80%	-23	0.8
Attending school of age 5 to 12	58%	81%	-23	59%	82%	-23	0.0
Attending school of age 13 to 17	45%	75%	-30	50%	76%	-26	5.0
Attending school of age 18 to 25	12%	17%	-5	14%	16%	-1	4.0
Participating in the labour force	72%	83%	-11	41%	49%	-8	3.0

Source: Census 2010. Authors' calculations.

Notes: ¹ After controlling for age.

Table A4: People with disability – Labour Market Conditions: Urban

A: Industry of employment				C: Employment Institution			
	PWD high	PWD low	Pw/oD		PWD high	PWD low	Pw/oD
Agriculture	20%	22%	11%	Government	3%	8%	10%
Mining, quarrying	0%	1%	1%	International institution	0%	0%	0%
Manufacturing	14%	12%	17%	Non-profit Institution	0%	1%	1%
Electricity, gas, water	0%	0%	1%	Profit Institutions	5%	12%	25%
Construction	4%	5%	7%	Cooperatives	0%	0%	0%
Wholesale, retail, hotel	37%	31%	31%	Indiv./household business	76%	67%	54%
Transport, communication	5%	6%	6%	Household	14%	10%	6%
Finance/insur., real estate	3%	3%	5%	Other	2%	2%	2%
Community, psnl. services	18%	20%	22%	Do not know	0%	0%	0%
Total	100%	100%	100%	Total	100%	100%	100%
B: Occupation of employment				D: Status of employment			
	PWD high	PWD low	Pw/oD		PWD high	PWD low	Pw/oD
Military	0%	0%	1%	Own account	39%	25%	16%
Manager	2%	2%	2%	Employer, assisted by unpaid w.	23%	20%	11%
Professional	1%	5%	7%	Employer, assisted by paid w.	2%	5%	4%
Technical and assoc. prof.	0%	3%	5%	Paid worker/employee	17%	33%	53%
Office Clerks	0%	5%	8%	Casual in agriculture	2%	4%	2%
Service and Sales	39%	32%	31%	Casual not in agriculture	7%	5%	6%
Skilled Agriculture	18%	17%	8%	Unpaid/family workers	8%	8%	8%
Craft and trades work	14%	12%	14%	Total	100%	100%	100%
Operators and assemblers	3%	6%	9%				
Elementary occupation	23%	17%	16%				
Total	100%	100%	99%				

Source: Sakernas 2016. Authors' calculations. Using sample weights.

Table A5: People with disability – Labour Market Conditions: Rural

A: Industry of employment			
	PWD high	PWD low	Pw/oD
Agriculture	68%	67%	52%
Mining, quarrying	2%	1%	1%
Manufacturing	3%	7%	9%
Electricity, gas, water	0%	0%	0%
Construction	3%	3%	6%
Wholesale, retail, hotel	9%	14%	16%
Transport, communication	1%	2%	3%
Finance/insur., real estate	0%	0%	1%
Community, psnl. services	14%	7%	11%
Total	100%	100%	100%
B: Occupation of employment			
	PWD high	PWD low	Pw/oD
Military	0%	0%	0%
Manager	0%	1%	1%
Professional	3%	2%	4%
Technical and assoc. prof.	0%	1%	1%
Office Clerks	0%	1%	2%
Service and Sales	11%	14%	16%
Skilled Agriculture	63%	58%	44%
Craft and trades work	8%	8%	10%
Operators and assemblers	1%	3%	5%
Elementary occupation	15%	12%	16%
Total	100%	100%	100%
C: Employment Institution			
	PWD high	PWD low	Pw/oD
Government	3%	3%	7%
International institution	0%	0%	0%
Non-profit Institution	1%	0%	1%
Profit Institutions	2%	3%	8%
Cooperatives	0%	0%	0%
Indiv./household business	75%	74%	70%
Household	17%	16%	13%
Other	2%	2%	1%
Do not know	0%	0%	0%
Total	100%	100%	100%
D: Status of employment			
	PWD high	PWD low	Pw/oD
Own account	24%	21%	16%
Employer, assisted by unpaid w.	33%	36%	23%
Employer, assisted by paid w.	1%	3%	3%
Paid worker/employee	9%	13%	25%
Casual in agriculture	4%	7%	6%
Casual not in agriculture	7%	3%	6%
Unpaid/family workers	23%	17%	21%
Total	100%	100%	100%

Source: Sakernas 2016. Authors' calculations. Using sample weights.

Table A6: People with disability – Labour Market Conditions: Formal

A: Industry of employment			
	PWD high	PWD low	Pw/oD
Agriculture	13%	15%	8%
Mining, quarrying	1%	3%	1%
Manufacturing	23%	18%	22%
Electricity, gas, water	0%	0%	1%
Construction	9%	8%	7%
Wholesale, retail, hotel	6%	14%	18%
Transport, communication	8%	4%	5%
Finance/insur., real estate	6%	4%	6%
Community, psnl. services	33%	34%	32%
Total	100%	100%	100%
B: Occupation of employment			
	PWD high	PWD low	Pw/oD
Military	1%	1%	1%
Manager	4%	4%	3%
Professional	10%	12%	12%
Technical and assoc. prof.	1%	5%	6%
Office Clerks	2%	10%	12%
Service and Sales	17%	16%	19%
Skilled Agriculture	11%	10%	5%
Craft and trades work	19%	13%	13%
Operators and assemblers	3%	8%	11%
Elementary occupation	31%	20%	18%
Total	99%	99%	99%
C: Employment Institution			
	PWD high	PWD low	Pw/oD
Government	25%	20%	19%
International institution	0%	0%	0%
Non-profit Institution	4%	2%	2%
Profit Institutions	19%	27%	38%
Cooperatives	0%	0%	1%
Indiv./household business	43%	39%	33%
Household	7%	8%	5%
Other	2%	3%	2%
Do not know	0%	1%	0%
Total	100%	100%	100%
D: Status of employment			
	PWD high	PWD low	Pw/oD
Own account	0%	0%	0%
Employer, assisted by unpaid w.	0%	0%	0%
Employer, assisted by paid w.	12%	14%	8%
Paid worker/employee	88%	86%	92%
Casual in agriculture	0%	0%	0%
Casual not in agriculture	0%	0%	0%
Unpaid/family workers	0%	0%	0%
Total	100%	100%	100%

Source: Sakernas 2016. Authors' calculations. Using sample weights.

Table A7: People with disability – Labour Market Conditions: Informal

A: Industry of employment			
	PWD high	PWD low	Pw/oD
Agriculture	54%	58%	47%
Mining, quarrying	1%	1%	1%
Manufacturing	5%	6%	7%
Electricity, gas, water	0%	0%	0%
Construction	2%	3%	7%
Wholesale, retail, hotel	22%	24%	28%
Transport, communication	2%	3%	4%
Finance/insur., real estate	0%	1%	1%
Community, psnl. services	13%	5%	5%
Total	100%	100%	100%
B: Occupation of employment			
	PWD high	PWD low	Pw/oD
Military	0%	0%	0%
Manager	0%	0%	0%
Professional	0%	1%	0%
Technical and assoc. prof.	0%	0%	0%
Office Clerks	0%	0%	0%
Service and Sales	23%	24%	28%
Skilled Agriculture	50%	50%	40%
Craft and trades work	9%	8%	11%
Operators and assemblers	1%	3%	4%
Elementary occupation	16%	13%	15%
Total	100%	100%	100%
C: Employment Institution			
	PWD high	PWD low	Pw/oD
Government	0%	0%	0%
International institution	0%	0%	0%
Non-profit Institution	0%	0%	0%
Profit Institutions	0%	1%	1%
Cooperatives	0%	0%	0%
Indiv./household business	81%	82%	83%
Household	17%	15%	13%
Other	2%	2%	1%
Do not know	0%	0%	0%
Total	100%	100%	100%
D: Status of employment			
	PWD high	PWD low	Pw/oD
Own account	35%	31%	29%
Employer, assisted by unpaid w.	34%	39%	29%
Employer, assisted by paid w.	0%	0%	0%
Paid worker/employee	0%	0%	0%
Casual in agriculture	4%	8%	7%
Casual not in agriculture	8%	5%	11%
Unpaid/family workers	19%	18%	25%
Total	100%	100%	100%

Source: Sakernas 2016. Authors' calculations. Using sample weights.

Table A8: People with disability – access to services Urban/Rural

Access to services	No Access	Yes	No
RURAL			
Access to public transport	39%	14%	47%
Access to information	47%	14%	40%
Access to shopping centres	59%	7%	34%
Access to sidewalks	63%	5%	31%
Access to pedestrian bridge	71%	5%	24%
Access to crossing the roads	54%	9%	37%
URBAN			
Access to public transport	36%	14%	50%
Access to information	40%	13%	46%
Access to shopping centres	53%	7%	40%
Access to sidewalks	44%	8%	48%
Access to pedestrian bridge	61%	7%	32%
Access to crossing the roads	44%	12%	45%

PwD has participated in rehabilitation services last year

	Urban	Rural
Medical	4%	4%
Education	2%	1%
Training	1%	0%
social	1%	0%
None	92%	95%

Source: Susenas 2012. Authors' calculations. Using sample weights.

N Urban = 2,676,077, N rural= 3,332,584.

Table A9: Effect of disability on the household - Urban

	PwD (1)	Pw/oD (2)	Diff (1-2)
Children			
Children 0 to 5 ever breastfed ¹	93%	95%	-1.3 pp
Child labour (age 5 to 9) ¹	1%	1%	-0.1 pp
Proportion of children 5 to 17 attending school	79%	81%	-2 pp
Proportion of siblings 5 to 17 who are attending school	84%	83%	1 pp
Main caregiver			
Female spouse participating in the labour force	38%	40%	-2 pp
Female head participating in the labour force	36%	56%	-20 pp
Household			
Monthly total Expenditure per capita ²	408,114	461,589	-53,475
Monthly total Expenditure per capita ³	470,883	616,533	-145,650

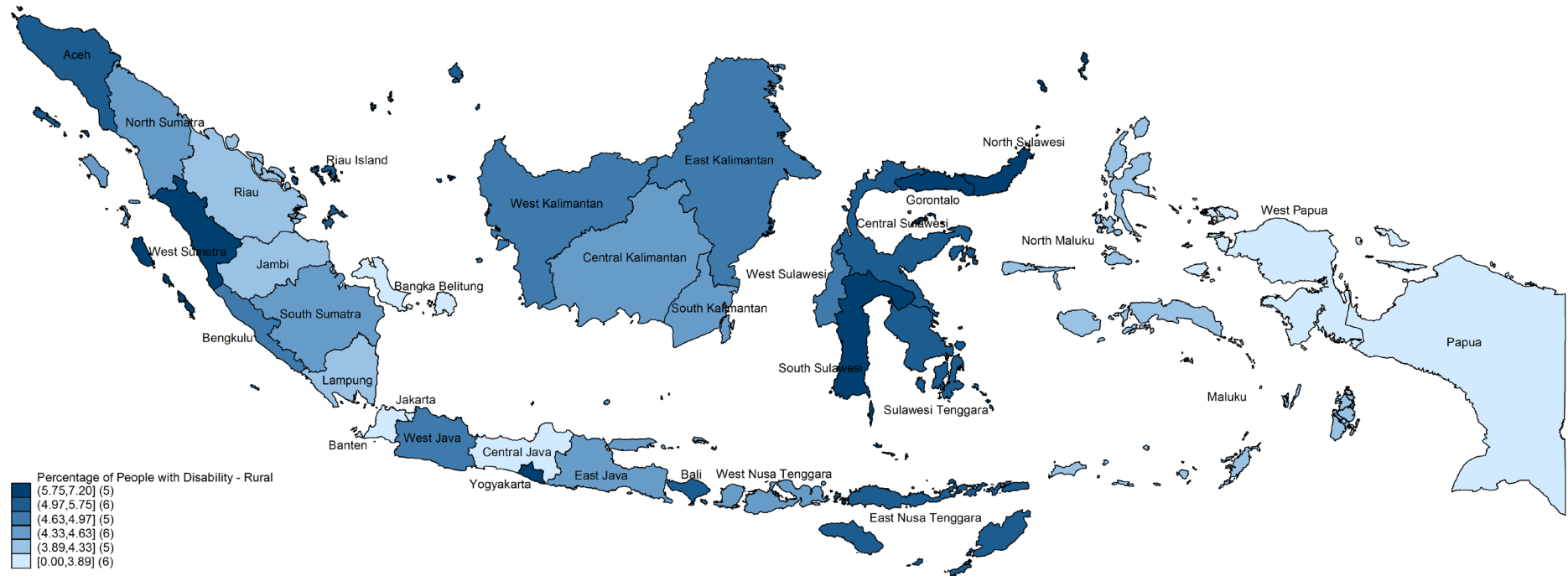
Source: Census 2010 (unless stated). Authors' calculations. Notes: ¹ Using Susenas 2003. ² Using Susenas 2006 and a functional disability definition. ³ Using susenas 2009 and a medical disability condition. Monthly expenditure in current prices. All Susenas calculations include sample weights.

Table A10: Effect of disability on the household - Rural

	PwD (1)	Pw/oD (2)	Diff (1-2)
Children			
Children 0 to 5 ever breastfed ¹	96%	97%	-0.8 pp
Child labour (age 5 to 9) ¹	3%	1%	1.8 pp
Proportion of children 5 to 17 attending school	74%	77%	-3 pp
Proportion of siblings 5 to 17 who are attending school	78%	78%	0 pp
Main caregiver			
Female spouse participating in the labour force	58%	60%	-2 pp
Female head participating in the labour force	51%	74%	-23 pp
Household			
Monthly total Expenditure per capita ²	226,137	241,350	-15,213
Monthly total Expenditure per capita ³	314,040	360,929	-46,888

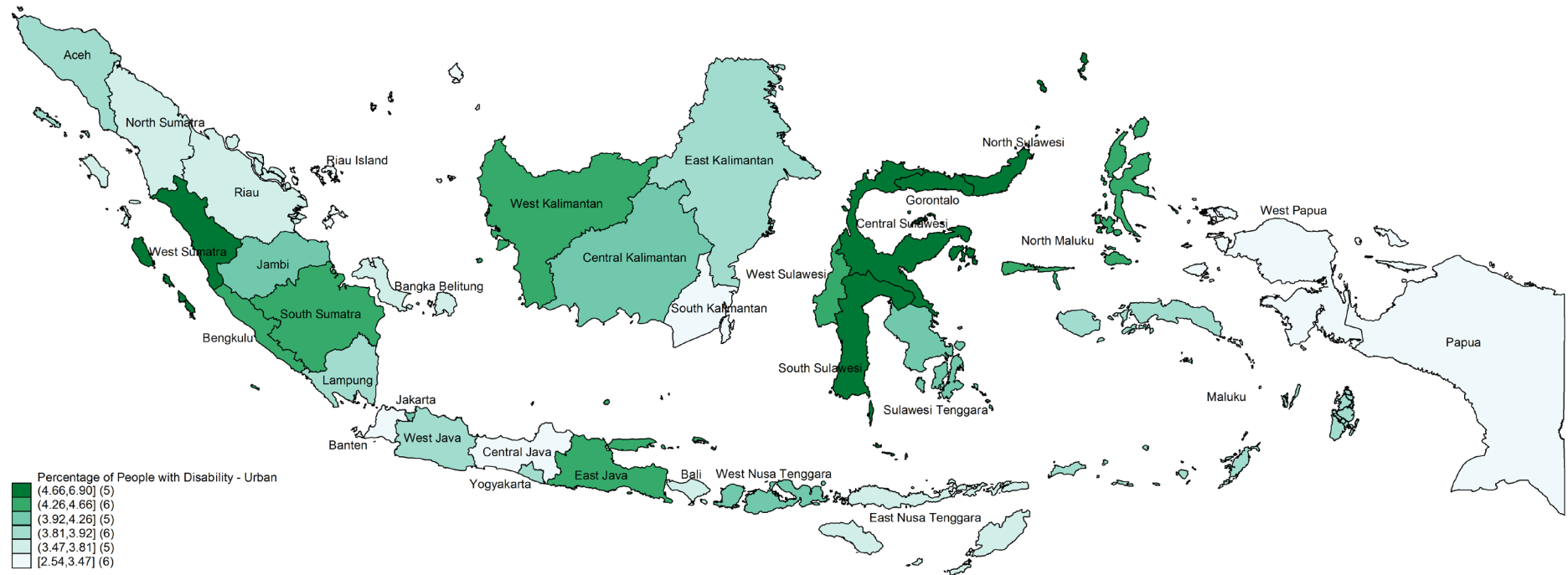
Source: Census 2010 (unless stated). Authors' calculations. Notes: ¹ Using Susenas 2003. ² Using Susenas 2006 and a functional disability definition. ³ Using susenas 2009 and a medical disability condition. Monthly expenditure in current prices. All Susenas calculations include sample weights.

Map 3: Percentage of people with disability by province - Rural



Source: Census 2010, authors' calculations

Map 4: Percentage of people with disability by province - Urban



Source: Census 2010, authors' calculations

Annexure: Disability - Indonesia in International Perspective

Disability and Impacts on Education, Employment & the Household

1. Introduction

“Largely overlooked in data collection and policy formulation, people with disabilities are often rendered socially invisible.” (International Labour Organization (ILO), 2015, p. 1)

For many of us, the concept of disability is at once familiar and unknown. While it is common when considering disability to think of a woman in a wheelchair or a man who is blind, it is less usual to recall that “[d]isability [also] encompasses the child born with a congenital condition such as cerebral palsy[,] ... the young soldier who loses his leg to a land-mine, ... the middle-aged woman with severe arthritis, [and] the older person with dementia, among many others” (World Health Organization (WHO) & World Bank, 2011, p. 7). In addition, the diversity of disability extends well beyond the type of health impairment to factors including severity, duration, age, age of onset, gender and income. For disabilities can be mild or severe, temporary or permanent, and can affect all people, whether they are young or old, men or women, rich or poor. Significantly, some factors do appear to be more common than others (for example, disability tends to be more prevalent among women, the elderly and the poor) but each set of circumstances gives rise to different needs and experiences, which are further influenced by the physical and cultural environment in which a person lives. Notably, around the world, and in developing countries in particular, this wide variation in the experiences and challenges faced by people with disabilities and their families, and the policies and programs that could best support them, are still poorly understood, largely as a consequence of a lack of reliable, comparable data.

In this review, we consider the data that is available and what it reveals about: (i) the nature of disability statistics, including their limitations and comparability; (ii) the prevalence of disability globally, and in developing countries in particular; (iii) the relationship between disability and education, employment, old age, poverty and the broader family; and (iv) the state of disability policy. In doing so, we predominantly draw on the findings of four key studies, the scopes of which are summarised in Table AA1, and wherever possible we assess and compare the Indonesian experience with that in similar countries in the region. Significantly, we identify wide variations and inconsistencies in the data. Nevertheless, there are sound reasons for expecting that environmental factors play an important role in explaining why people with disabilities tend to have lower rates of school attendance and employment than their non-disabled peers. There also seems to be a credible basis for expecting that a two-way relationship exists between disability and poverty, and that the impact of disability extends beyond disabled people to affect their broader households. The fact older people are more likely to experience disability can also be expected to pose an increasing challenge in places with rapidly aging populations, including Indonesia

(Faizal, 2016; Adioetomo, Mont & Irwanto, 2014). Lastly, it appears that little is known about what works in the area of disability policy. Together, these findings indicate there is much scope for further research, especially into the drivers of disabled people's lack of access to education and employment, and the effectiveness of disability policies and programs.

2. Defining and Measuring Disability

“Disability can occur at any time during life—from birth to old age. It can be caused by a multitude of factors from poor nutrition to violence to poor health care. It can be mild or severe, and it could potentially affect a wide range of functional areas: mobility, vision, hearing, communication, psychosocial function limitations, etc.” (Adioetomo et al., 2014, p. 2)

Around the world there are estimated to be one billion people with disabilities, 80% of whom are thought to live in developing countries (ILO, 2015). But what does this mean? What is it to be a person with a disability? The answer is more complex than it seems. For example, does someone who is unable to walk have a disability? What if their inability to walk is only temporary? Or if they are unable to walk long distances, but short distances are okay? Or, even if they cannot use their legs, they have a wheelchair so they are still able to get around? Does that make a difference? How about if, although they are very mobile in their wheelchair, they are unable to go down rough and pot-holed streets, or enter offices where the doorways are narrow or there are steps at the entrance?

The traditional approach to thinking about disability reflected the medical model, which focussed on the health impairment (Mitra, Posarac & Vick, 2011). Under this approach, people were considered to have a disability if they had a health condition, such as being unable to see or hear or communicate, regardless of whether they were restricted in their life activities (Mitra et al., 2011). This means that a person who did not have the use of their legs would be considered disabled. However, over time it increasingly came to be recognised that a person's environment has a significant influence on the extent to which their impairment affects their capacity to participate in community life. The idea that disability was a product of barriers in the social environment (rather than an individual's characteristics) was captured in the social model of disability (Mitra et al., 2011), which reflected the view that although a person may be unable to walk, if their environment was accommodating (e.g. if they had a wheelchair or prosthetic limb, an accessible school or workplace, and a supportive community) their ability to carry out day-to-day activities may not be severely restricted.

The most current thinking on disability integrates the medical and social models into a “bio-psycho-social framework” called the International Classification of Functioning, Disability and Health (ICF) (see Figure 1), which was developed by the WHO in 2001 (Mitra et al., 2011). This model reflects the notion that people are disabled by “the interaction between their health condition and the environment” (p. ii). In other words, it is a health impairment in conjunction with an environment that poses barriers for a person with that health impairment that creates a disability; the health impairment or the environment alone does not. In this approach, a person who must use a

wheelchair in a town in which many streets and buildings are not wheelchair-friendly and there is little public transport may have severe difficulty moving around and thus be considered to have a disability. However, if that person lived in an area where the streets were smooth, buildings had wide doorways, ramps and elevators, and buses were wheelchair-accessible, they may only have mild difficulty moving around and no longer be classed as disabled. This means that two people with the same health impairment in different locations may have different disability statuses (Mitra et al., 2011).

“Because disability is not a readily identifiable attribute such as gender or age, but a complex, dynamic interaction between a person’s health condition and physical and social environment, it has proven very difficult to measure.” (Mitra et al., 2011, p. 4)

The substantial scope for variation in approaches to defining and measuring disability poses considerable challenges. This is because even relatively small differences in the way disability is assessed (including how disability questions are phrased, whether they are asked by a trained interviewer, and which disability thresholds are used) can have a very large impact on the final statistics (ILO, 2007), with the effect that the results of different studies may appear to be conflicting and cannot be easily compared.²⁰ By way of example, consider the global prevalence of moderate and severe disability in children aged 0-14 years. The WHO and the World Bank (2011) report a prevalence rate of 5.1%,²¹ while Mizunoya, Mitra and Yamasaki (2016) estimate a rate of 1.4%. How can this discrepancy be explained? Is one study right and the other wrong? Has substantial progress been made in recent years? Or did the studies measure different things? In this case it appears there were important definitional and methodological differences between the studies, including that the WHO and the World Bank analysis drew on a much broader dataset that took into account pain and discomfort, anxiety and depression, and cognition and social participation (Mizunoya et al., 2016). Therefore, the results of these studies are not comparable.

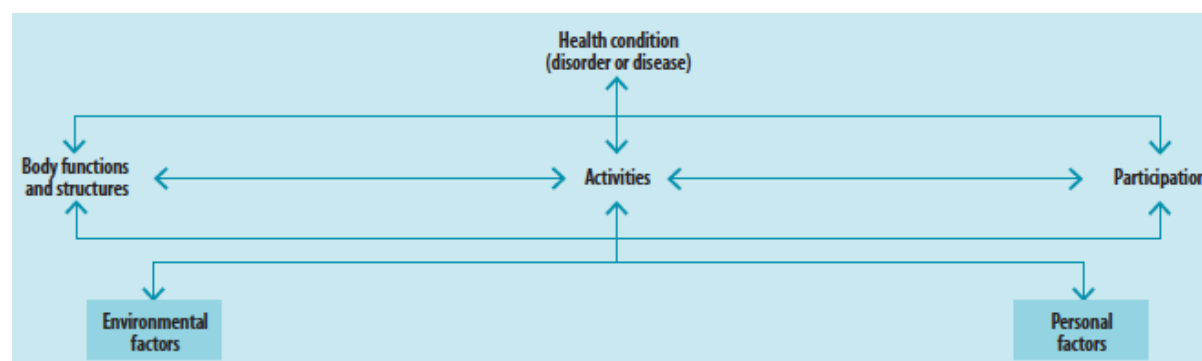
In recognition of the challenges caused by inconsistent methods and approaches, the United Nations Statistical Commission established the Washington Group on Disability Statistics (Washington Group) in 2001 to promote international cooperation in disability measurement and to develop measures for use in censuses and surveys (Mitra et al., 2011; ILO, 2007). The Washington Group’s recommendations are based on the International Classification of Functioning, Disability and Health (ICF), with disability defined as having severe or extreme difficulty in at least one functioning domain (seeing, hearing, walking, remembering and concentrating, self-care or communicating) (Mizunoya et al., 2016). However, despite the fact that the Washington Group’s recommendations have become “one of the most widely accepted and internationally tested tools” (Mizunoya et al., 2016, p. 10), they are still far from universally utilised. Reflecting this, a recent screening of approximately 2,500 household surveys and censuses from countries around the world found that less than

²⁰ It is even necessary to be cautious when comparing the results for different countries based on a single standard, since interpretations of disability vary across countries and surveys (Mizunoya et al., 2016).

²¹ Based on the WHO Global Burden of Disease study of 2004 (2004 GBD).

2% complied with the Washington Group's recommendations, although, positively, Indonesia has incorporated the standards into its census (Mizunoya et al., 2016). A further complication is that, even where the approach of the Washington Group is followed, there is still room for inconsistency (see section 3 for examples). Such wide variations in the measurement of disability, and the incomparability of much of the available data, mean it is essential to approach disability statistics with caution.

Figure 1. Representation of the ICF. Source: WHO & World Bank, 2011



3. The Prevalence of Disability

“There is no agreed international standard to measure disability.” (Mitra et al., 2011, p. ii)

When assessing performance, we are accustomed to comparing countries across many indicators, from gross domestic product and poverty rates to ease of doing business, as a means of gaining insight into where things are going well and where there is a need for improvement. However, as noted above, in the area of disability such comparisons are tricky given the wide variation in the definition, measurement and interpretation of disability, both between countries and across studies. Nonetheless, provided comparisons are approached with circumspection they do offer a basis for developing a sense of how a country is tracking vis-à-vis other nations around the world. It is for this reason that we outline key inter-country prevalence rates below. When reviewing these rates, it is useful to bear in mind the differences between the studies (see Table AA1 for a comparison of the principal studies referred to in this review), and that disability reflects the interaction between health impairments and the physical and cultural environment. Therefore, a low disability prevalence rate could indicate a low level of health impairments within a country (e.g. due to better nutrition, safer working conditions and greater access to medical services) or the existence of very accommodating environments and the widespread use of assistive devices (such that health impairments do not pose barriers to participation in community life) or both. Learning more about the drivers of disability prevalence can provide valuable insight for policymakers, who have substantial scope to influence the impairment-related and environmental aspects of disability through well-targeted policies and programs. We return to policies in section 5.

“Country specific estimates of disability prevalence vary tremendously.” (Mitra et al., 2011, p. iii)

Based on data from the World Health Survey of 2002-2004 (2002-2004 WHS), the WHO and the World Bank (2011) estimated the average rate of disability prevalence among adults in 59 developed and developing countries (representing 64% of the world's population) to be 15.6%,²² with rates ranging from 11.8% in higher-income countries to 18.0% in lower-income ones.²³ Mitra et al. (2011) also drew on the 2002-2004 WHS data in their study into the prevalence of severe disabilities among people aged 18 to 65 in 15 developing countries in Asia (not including Indonesia), Africa and Latin America, and found substantial variation in the inter-country estimates. Their analysis revealed prevalence rates ranging from a low of 3.08% in Lao PDR to a high of 16.21% in Bangladesh, with rates of 5.30% in Kenya and Mexico, 8.49% in the Philippines, 12.97% in Malawi and 13.45% in Brazil.²⁴ Significantly, they found disability prevalence was higher among women than men in every country, and higher in rural areas than urban areas in most countries (Mitra et al., 2011).

More recently, Mizunoya et al. (2016) drew on nationally representative data from 18 censuses and surveys in 15 low- and middle-income countries, including Indonesia's 2010 Population Census (2010 Census), and found much lower rates of disability prevalence. Based on their estimates, the prevalence of severe disabilities in the general population aged five and above ranged from 0.8% in Indonesia to 9.7% in the Maldives, and was just 1.1% in Malawi and 1.6% in Bangladesh, which is substantially lower than the rates reported by Mitra et al. (2011) (see column 4 in Table 1 and the right-hand side of Table 2 for a breakdown by functioning domain) (Mizunoya et al., 2016). Highlighting the substantial scope for variation that exists even where consistent methodologies are applied, both Mizunoya et al. (2016) and Mitra et al. (2011) followed the recommendations of the Washington Group in their analyses.

Lastly, in a study on Indonesia, Adioetomo et al. (2014) report disability prevalence rates for mild and severe disabilities of around 4.3% based on the 2010 Census,²⁵ compared with over 25% based on the 2007 National Basic Health Research (2007 Rikesdas).²⁶ The authors attribute this discrepancy to the more extensive questions in the 2007 Rikesdas and differences in the way the surveys were implemented, even though both applied approaches consistent with the Washington Group's recommendations. Overall, Adioetomo et al. (2014) estimate the prevalence of disability in Indonesia to be between 10% and 15%, which they suggest may be a conservative estimate. Like Mitra et al. (2011), they find that disability is more prevalent among women and people living in rural areas.

²² This estimate relates to significant functioning difficulties. The average adult prevalence rate of very significant difficulties was estimated to be 2.2% (WHO & World Bank, 2011).

²³ The WHO and the World Bank (2011) obtained similar estimates based on data from the 2004 GBD, finding that an average of 15.3% (2.9%) of the world population, and 19.4% (3.8%) of the world's population aged 15+, experienced a moderate (severe) disability.

²⁴ These estimates are drawn from the study's base measure of disability. When the expanded measure of disability is used, the prevalence rates range from a low of 7.44% in Mexico to a high of 21.48% in Brazil. For more on the study's base and expanded measures, see Table A1.

²⁵ Similar to Mizunoya et al. (2016), Adioetomo et al. (2014) report a prevalence rate of 0.76% for severe disabilities based on the 2010 Census.

²⁶ If only moderate and severe disabilities are included, the 2007 Rikesdas suggests a disability prevalence rate of around 11% (Adioetomo et al., 2014).

Together, these findings illustrate the wide variation that exists in estimated disability prevalence rates, and how factors including the data source, data collection method, definition of disability, and population specifications (such as age range, gender, severity and location (including rural / urban)) studies employ can significantly influence the estimates they obtain, even within a single country.

Table 1. Disability prevalence by age group. Source: Mizunoya et al., 2016

Country	Primary-Age Children (1)	Secondary-Age Children (2)	Primary- and Secondary-Age Children Combined (3)	Overall Population Aged 5+ (4)	Ratio of Disability Prevalence in Overall Population to that in School Age Children (5) = (4) / (3)
Indonesia	0.3% (0.00%)	0.3% (0.00%)	0.3% (0.00%)	0.8% (0.00%)	2.7
Papua New Guinea	0.8% (0.15%)	1.5% (0.27%)	1.0% (0.14%)	6.3% (0.17%)	6.3
Vietnam	0.8% (0.16%)	1.0% (0.12%)	0.9% (0.10%)	3.6% (0.10%)	4.0
Albania	0.8% (0.14%)	0.8% (0.23%)	0.8% (0.12%)	1.8% (0.09%)	2.3
Saint Lucia ^a	1.0%	data unavailable for analysis		3.9%	/
West Bank and Gaza	1.5% (0.08%)	2.0% (0.21%)	1.6% (0.08%)	2.7% (0.06%)	1.7
Bangladesh	0.6% (0.09%)	0.6% (0.09%)	0.6% (0.06%)	1.6% (0.06%)	2.7
India ^b	0.4% b (0.03%)	0.4% (0.05%)	0.4%b (0.03%)	0.9%b (0.02%)	2.3
Maldives	5.0% (0.29%)	5.5% (0.32%)	5.2% (0.22%)	9.7% (0.15%)	1.9
Ethiopia, rural	0.9% (0.14%)	0.8% (0.22%)	0.9% (0.12%)	2.5% (0.12%)	2.8
Malawi	0.6% (0.06%)	0.4% (0.09%)	0.5% (0.05%)	1.1% (0.05%)	2.2
Nigeria	0.4% (0.09%)	0.4% (0.10%)	0.4% (0.07%)	1.2% (0.07%)	3.0
South Africa (2013)	3.3% (0.16%)	1.1% (0.11%)	2.4% (0.10%)	3.5% (0.06%)	1.5
South Africa (2011)	4.5% (0.03%)	1.8% (0.02%)	3.3% (0.02%)	4.4% (0.01%)	1.3
Tanzania (2010-11)	0.8% (0.14%)	1.0% (0.18%)	0.9% (0.11%)	2.6% (0.12%)	2.9
Tanzania (2008)	1.1% (0.13%)	1.2% (0.16%)	1.1% (0.10%)	2.2% (0.09%)	2.0
Uganda (2011)	2.9% (0.16%)	2.4% (0.19%)	2.7% (0.12%)	4.9% (0.11%)	1.8
Uganda (2010-11)	1.3% (0.19%)	1.3% (0.23%)	1.3% (0.15%)	2.6% (0.14%)	2.0
Mean	1.4%	1.3%	1.4%	3.1%	2.6

Notes: Estimated standard errors of proportions in parentheses. ^aStandard errors were not estimated for disability prevalence in Saint Lucia as microdata is unavailable and results were obtained through the online REDATAM analysis portal. ^bIn the India Human Development Survey 2005, disability data was collected for individuals aged 7 and above only; the lower bound of the overall, primary-age, and combined school-age populations are constrained accordingly.

Source: authors' analysis based on data described in the text.

Table 2. Disability prevalence by functioning domain. Source: Mizunoya et al., 2016

Country	Primary- and Secondary-Age Children							Overall Population Aged 5+						
	Seeing	Hear.	Walk.	Rem.	Self.	Com.	Range	Seeing	Hear.	Walk.	Rem.	Self.	Com.	Range
East Asia and the Pacific														
Indonesia	0.0%	0.1%	0.1%	0.2%	0.2%	/	0.2%	0.2%	0.2%	0.3%	0.3%	0.3%	/	0.1%
Papua New Guinea	0.2%	0.4%	0.3%	0.3%	0.2%	/	0.2%	2.2%	1.3%	3.5%	1.2%	0.5%	/	3.0%
Viet Nam	0.1%	0.2%	0.5%	0.3%	0.3%	0.4%	0.4%	1.4%	0.7%	1.8%	1.2%	0.9%	1.0%	1.1%
Europe and Central Asia														
Albania	0.3%	0.1%	0.4%	0.2%	/	0.3%	0.3%	0.5%	0.4%	1.0%	0.6%	/	0.4%	0.6%
Latin America and the Caribbean														
Saint Lucia	/	/	/	/	/	/	/	1.6%	0.5%	2.1%	1.0%	0.9%	0.7%	1.6%
Middle East and North Africa														
West Bank and Gaza	0.3%	0.3%	0.5%	0.6%	0.4%	0.6%	0.3%	0.7%	0.4%	1.3%	0.7%	0.6%	0.6%	0.7%
South Asia														
Bangladesh	0.1%	0.2%	0.3%	0.2%	0.2%	0.3%	0.2%	0.7%	0.4%	0.6%	0.3%	0.4%	0.3%	0.4%
India	0.2% (far)	0.2%	0.2%	/	0.2% (dress)	0.2%	0.0%	0.4% (far)	0.3%	0.4%	/	0.3% (dress)	0.3%	0.1%
	0.2% (near)				0.2% (toilet)			0.3% (near)				0.3% (toilet)		
Maldives	2.1%	0.7%	0.8%	2.0%	0.7%	1.1%	1.4%	2.6%	0.8%	0.5%	1.9%	0.4%	1.1%	2.2%
Sub-Saharan Africa														
Ethiopia, rural	0.3%	0.2%	0.3%	0.2%	0.2%	0.2%	0.1%	1.3%	0.6%	0.8%	0.5%	0.4%	0.2%	3.7%
Malawi	0.1%	0.2%	0.2%	0.1%	0.2%	0.1%	0.1%	0.4%	0.3%	0.5%	0.1%	0.1%	0.1%	0.4%
Nigeria	0.1%	0.0%	0.1%	0.2%	0.1%	0.1%	0.2%	0.3%	0.1%	0.6%	0.2%	0.3%	0.2%	0.5%
South Africa (2013)	0.3%	0.2%	0.4%	0.7%	1.5%	0.4%	1.3%	1.0%	0.4%	1.0%	0.8%	1.3%	0.3%	1.0%
South Africa (2011)	0.6%	0.4%	0.3%	0.7%	2.0%	0.5%	1.7%	1.7%	0.7%	1.0%	1.0%	1.4%	0.4%	1.0%
Tanzania (2010-11)	0.1%	0.3%	0.1%	0.2%	0.1%	0.1%	0.2%	1.1%	0.5%	1.0%	0.5%	0.5%	0.2%	0.9%
Tanzania (2008)	0.1%	0.2%	0.4%	0.5%	0.3%	0.4%	0.4%	0.5%	0.4%	1.0%	0.6%	0.4%	0.4%	0.6%
Uganda (2011)	0.5%	0.7%	0.5%	1.0%	0.4%	0.6%	0.6%	1.7%	1.0%	1.8%	1.4%	0.8%	0.5%	1.3%
Uganda (2010-11)	0.1%	0.4%	0.4%	0.5%	0.3%	0.5%	0.4%	0.8%	0.5%	1.2%	0.5%	0.4%	0.4%	0.8%

Notes: Range is the range of prevalence rates across domains. Bold prevalence rates indicate the most commonly-impaired domains respectively in each country and age group. The WGSS terms are Seeing, Hearing, Walking or climbing steps, Remembering and concentrating, Self-care, Communicating. Disability prevalence was not computed for school-age children in Saint Lucia due to data unavailability.

Source: authors' analysis based on data described in the text.

4. The Impact of Disability on Children, Working-Age Adults and Other Groups

“The disability experience resulting from the interaction of health conditions, personal factors, and environmental factors varies greatly.” (WHO & The World Bank, 2011, p. 7)

As we have noted, people with disabilities are a heterogeneous group whose experiences vary widely based on a multitude of individual and environmental factors such as age, gender, location, type, severity and duration of disability, age of onset, socioeconomic status, access to services, and family and community attitudes. Given the diverse experiences of people with disabilities (WHO & The World Bank, 2011), together with the fact that disability research in the developing country context remains limited (Mitra et al., 2011), it is not easy to capture the full extent of the ways in which disability impacts people's lives. However, across broad social groups, general patterns are evident. Above all, “people with disabilities are more likely to be poor and less likely to receive an education, be employed, and be full participants in the life of their families and communities” (Adioetomo et al., 2014, p. xiv).

Here, we review the principal links between disability and lower welfare outcomes for children, working-age adults, the elderly, the poor and the broader family.

Children

“Children with disabilities are less likely to attend school, thus ... facing reduced employment opportunities and decreased productivity in adulthood.” (WHO & The World Bank, 2011, p. 10)

Empirical evidence suggests that children with disabilities face many more barriers to attending and completing school than children without disabilities (Mizunoya et al., 2016). While some of these barriers may arise from the health impairment itself (especially in the case of very severe disabilities) (Mitra et al., 2011), many are likely to reflect family-, school- and community-based factors, which can be expected to interact with, influence and reinforce one another. Consequently, there are likely to be a wide range of reasons for disabled children not attending school that extend well beyond their health condition. In some cases, the decision not to educate a disabled child may reflect personal attitudes. For example, parents may not perceive there to be any benefit in sending a disabled child to school (Mizunoya et al., 2016) or may be “ashamed or overly protective of their children” (Adioetomo et al., 2014, p. 66). In others, it may reflect financial considerations. That is, given the financial position of a family and their disabled child's future prospects, it may not be considered worthwhile to invest in that child's education (Mitra et al., 2011), or it may not even be possible, especially if it would require higher-than-normal education costs (e.g. to send the child to a special school) (Adioetomo et al., 2014). In further instances, it may be that the school and its broader environment are ill-equipped to support the child. Curricula and teaching methods may be too rigid, teachers may lack the necessary training, the school may not have the resources or physical environment to accommodate the child's needs, negative attitudes and bullying may be pervasive

(WHO & The World Bank, 2011; Adioetomo et al., 2014), or, due to limited transport options or other constraints, there may be no safe way for the child to travel to school. Additionally, in places where disabled children are not usually sent to school, the decision not to educate a disabled child might reflect community norms or cultural attitudes.

The limited available data consistently shows that disabled children are less likely to attend school than non-disabled children (Mizunoya et al., 2016; Sæbønes et al., 2015; Mitra et al., 2011). In addition, while there is considerable variation in the estimated rates of school attendance both between countries and studies, Indonesia regularly performs poorly. For example, in an analysis of 14 nationally representative household surveys from 13 developing countries between 1992 and 2004,²⁷ Filmer (2008) found the difference between the rates of school attendance of disabled and non-disabled children (i.e. the attendance gap) ranged from a low of 10% in India to a high of almost 60% in Indonesia among children aged 6 to 11, and from 15% in Cambodia to 58% in Indonesia among children aged 12 to 17. Most significantly, this suggests that Indonesia had the highest attendance gap at both the primary and secondary school levels (see Figure 2). Mizunoya et al. (2016) also report a wide non-attendance gap in Indonesia. They find the average difference between the proportion of disabled and non-disabled children not attending school at the primary and secondary levels to be 30.2% across 15 low- to middle-income countries, and 49.2% in Indonesia. This was the second-highest gap (after Albania (55.1%)), and higher than those in other countries in Asia and the Pacific, including Vietnam (44.1%), India (30.4%), Papua New Guinea (31.5%), and the Maldives (8.9%). In other words, even though Indonesia has achieved close to universal primary education among non-disabled children, school attendance among disabled children remains very low (Mizunoya et al., 2016).

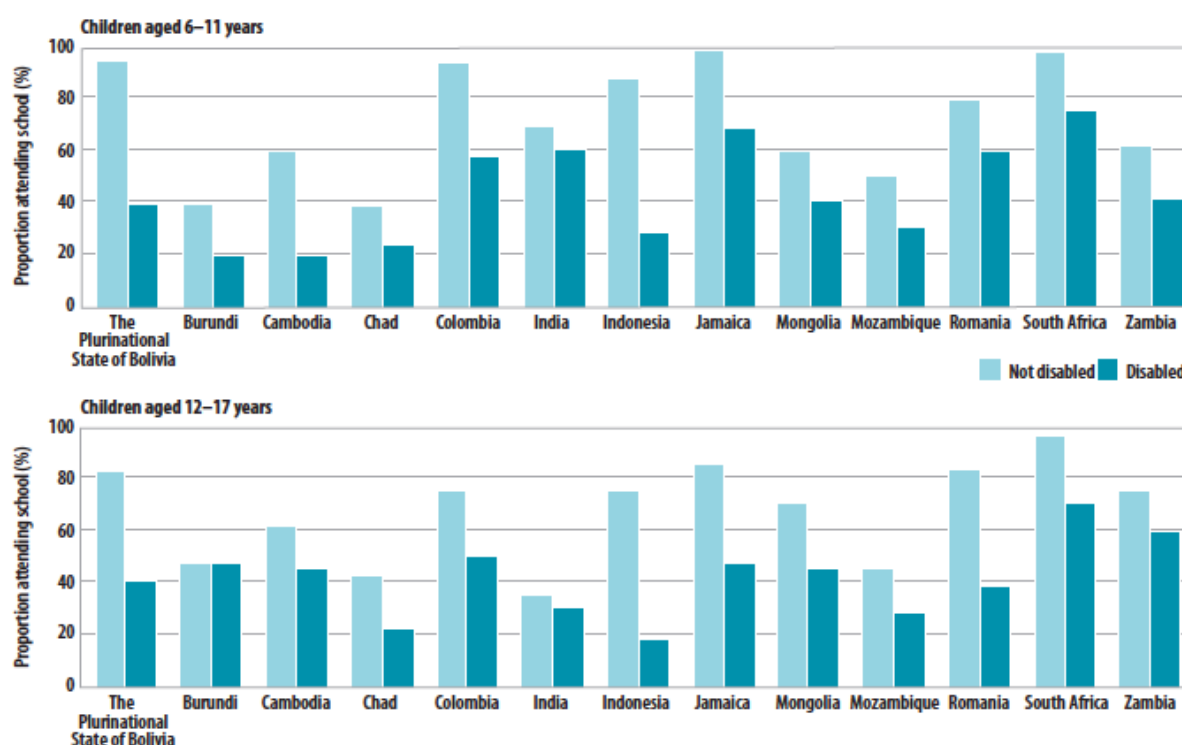
The low rates of school attendance among children with disabilities in Indonesia may largely be driven by barriers that prevent many of these children from ever attending school. In their study, Mizunoya et al. (2016) find that 54.1% of children with severe disabilities in Indonesia do not attend primary school (compared with 5.0% of non-disabled children), and 80.9% of severely disabled children do not attend secondary school (compared with 30.8% of non-disabled children). By disaggregating this data, they further find that 90% of out-of-school disabled primary-age children have never attended school (compared with 68% of out-of-school disabled children at the secondary level), suggesting that special efforts must be made to “resolve the access bottleneck which currently prevents disabled children from going to school at all” (p. 36). Adioetomo et al. (2014) form a similar conclusion,²⁸ noting that “[a]ccording to the Ministry of Education and Culture (MoEC), close to 70 percent of children with

²⁷ The countries in the study were: Bolivia, Burundi, Cambodia, Chad, Colombia, India, Indonesia, Jamaica, Mongolia, Mozambique, Romania, South Africa and Zambia. The Indonesian data was based on the 2000 National Socioeconomic Survey. Although all of the surveys in the study included an impairment-based definition of disability, there were substantial variations in the definitions across the datasets (Filmer, 2008).

²⁸ As does Filmer (2008), whose findings suggest “that efforts are needed to boost enrollments of children with disabilities at the earliest grades in order to increase education attainment for this population” (p. 159).

disabilities have no access to education" (p. 58) and that the barriers to entering and completing primary school are larger than those for secondary school. Reflecting this, they find that, based on the 2007 Rikesdas data, Indonesians with a mild or severe disability during childhood are only 66.8% as likely to complete primary school as their non-disabled peers,²⁹ while children with a mild disability are 88.2% as likely to complete secondary school.³⁰

Figure 2. Proportion of children with and without a disability who are in school (based on Filmer (2008)). Source: WHO & The World Bank, 2011



Source (8).

These data highlight the magnitude of the challenges that children with disabilities face in obtaining an education. Further reiterating this, Mizunoya et al. (2016) find that disability is a "powerful predictor of a child's school attendance" (p. 26), with disability reducing the probability that a child will attend school by an average of 32.8% (and a much higher 61% in Indonesia). The authors also show that the challenges to obtaining an education confront all disabled children "regardless of their individual and socio-economic characteristics such as sex, age, household income and location of residence" (p. 6),³¹ that this reveals the existence of "specific hurdles ... for children with disabilities which cannot be solved even for households with higher [socioeconomic status]" and that "the current inequality between educational

²⁹ The 2010 Census data suggests that children with a mild (severe) disability are 63.4% (24.2%) as likely to complete primary school as non-disabled children (Adioetomo et al., 2014).

³⁰ The odds ratio for children with severe disabilities is a far lower 35.6%, but Adioetomo et al. (2014) note that this "is still significantly higher than for primary school" (p. 62).

³¹ This is in line with the finding of Filmer (2008) that the gap in school participation associated with disability is larger than the participation gaps associated with other characteristics, such as gender, rural residence and economic status, in many countries including Indonesia.

outcomes of non-disabled and disabled children fundamentally arises due to the structural failure of education systems to provide sufficient support for disabled children to attend school" (p. 37).

Lastly, it should be noted that school attendance is a minimal measure of education (since it does not capture the extent to which disabled children who attend school are catered for and enabled to learn) (Mizunoya et al., 2016), and that enrolment rates also vary based on the type of disability a child has (with children with intellectual and sensory impairments generally having lower rates of attendance) (WHO & The World Bank, 2011).³²

Working-Age Adults

"People with disabilities are more likely to be unemployed and generally earn less even when employed." (WHO & The World Bank, 2011, p. 10)

Around the world, approximately 800 million people with disabilities are of working age (ILO, 2015). Yet despite the fact that "[a]lmost all jobs can be performed by someone with a disability" (WHO & The World Bank, 2011, p. 235), many of these people are absent from the labour force. In part, this may be because people with disabilities may be less able to work, more limited in the work they can do, and less productive as a consequence of their health impairment, particularly where they have very severe disabilities, or lack education and training, access to accommodating workplaces and assistive devices,³³ and the support of social initiatives such as vocational rehabilitation programs (Mitra et al., 2011; WHO & The World Bank, 2011). However, as with education, there are also likely to be structural, cultural and environmental drivers at play.

Above all, workplace-related exclusionary factors are likely to be a significant contributor to both the unemployment and under-employment of people with disabilities. In many places people with disabilities face considerable obstacles to obtaining decent work. These include negative attitudes and discrimination (such as stigma, stereotypes and misconceptions), inaccessible work environments (workplaces with limited physical access, signage and communication options), unaccommodating workplaces (that are unwilling to make adjustments in working hours, tasks etc. to allow for employees' needs), social environments that lack accessible transport options and support services, and a lack of access to capital (Mitra et al., 2011; WHO & The World Bank, 2011; Adioetomo et al., 2014). In addition, in cases where they receive income through disability-benefit schemes, people with disabilities may choose not to work (WHO & The World Bank, 2011), although the

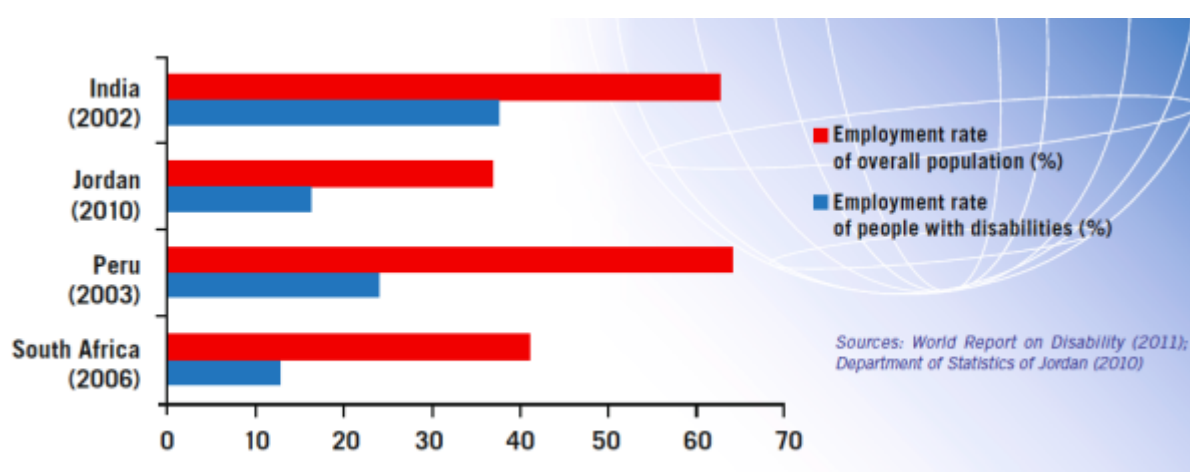
³² In addition, when reviewing education-related disability statistics more generally, it is important to bear in mind that comparing the educational attainment of disabled and non-disabled adults can be misleading to the extent that some of the respondents became disabled after their school years (and thus their disability would not have impacted their schooling) (Adioetomo et al., 2014).

³³ In a study of 261 people with disabilities in Ethiopia, Grider and Wydick (2016) found that those who were given access to a wheelchair devoted 1.75 more hours per day to work and realised a 77.5% increase in income.

extent to which this decision is driven by the lower wages and unaccommodating working conditions that disabled people often encounter is unclear.³⁴

The difficulty in determining the nature and extent of such labour market and other barriers is exacerbated by the fact that reliable, detailed and up-to-date data on the employment of people with disabilities remains limited in many countries, and in developing countries in particular (WHO & The World Bank, 2011; ILO, 2007). Nevertheless, the available evidence overwhelmingly suggests that people with disabilities have lower rates of employment than people without disabilities. According to the 2002-2004 WHS data from 59 developed and developing countries, the employment rate for disabled men was 52.8% (compared with 64.9% for non-disabled men), and just 19.6% for disabled women (compared with 29.9% for non-disabled women) (WHO & The World Bank, 2011). In addition, Mitra et al. (2011) report that a large majority of studies conducted in countries in Asia, Africa, South America and Eastern Europe, including their own, have found that people with disabilities are less likely to be employed than people without disabilities (see Figure 3 for an example of the differences in employment rates in India, Jordan, Peru and South Africa).

Figure 3. Employment rates of people with and without disabilities. Source: ILO, 2015



In Indonesia, the 2010 Census revealed a similar pattern, with the employment rate of people with mild disabilities being lower (56.4%), and with severe disabilities being substantially lower (26.4%), than the employment rate of the non-disabled (64.1%) (Adioetomo et al., 2014). Notably, the 2007 Riskesdas data painted a different picture, suggesting that people with mild disabilities had a slightly higher rate of working

³⁴ The availability of social protection for people with disabilities is an important policy area. While a detailed analysis of disability-related social assistance is beyond the scope of this review, we note that the Asian Development Bank (2013) found disability payments to comprise an extremely small component of social assistance in Asia and the Pacific, “accounting for only 3% of total social assistance expenditures and 2% of beneficiaries. With rare exceptions [such as in Japan, Nauru, Singapore, Tajikistan and Uzbekistan], these programs are small, and in about one-third of countries hardly exist” (p. 87). In Indonesia, while a Social Assistance for Severely Disabled Persons Scheme (ASODKB) is in place, its coverage is so low that Adioetomo et al. (2014) describe the program as “almost insignificant” (p. 105). However, people with disabilities may also receive other forms of social protection payments, such as health, food or old age benefits, where available.

(59.72%), and people with severe disabilities only a moderately lower rate of working (47.3%), than people without disabilities (57.93%). However, Adioetomo et al. (2014) attribute this anomalous result to possible problems with the survey's data on labour activity and the nature of its definition of mild disability.

Lastly, it is significant that, even where general employment figures are available, there is much that they do not disclose. Above all, they hide the fact that the employment rate of the disabled varies substantially based on age, age of onset, gender, and type and severity of disability, and does not convey anything about wages, the type of employment nor the quality of employment (Adioetomo et al., 2014; WHO & The World Bank, 2011). This is important given that people with disabilities frequently work in low-paid jobs with poor working conditions and jobs for which they are over-qualified, that people with certain disabilities (such as intellectual and mental health impairments) face greater challenges in obtaining employment, that disabled women are less likely to have a decent job than non-disabled women or disabled men (ILO, 2013), and that people with disabilities are more likely to be self-employed (Adioetomo et al., 2014).

The Elderly

"Older people are disproportionately represented in disability populations."
(WHO & The World Bank, 2011, p. 35)

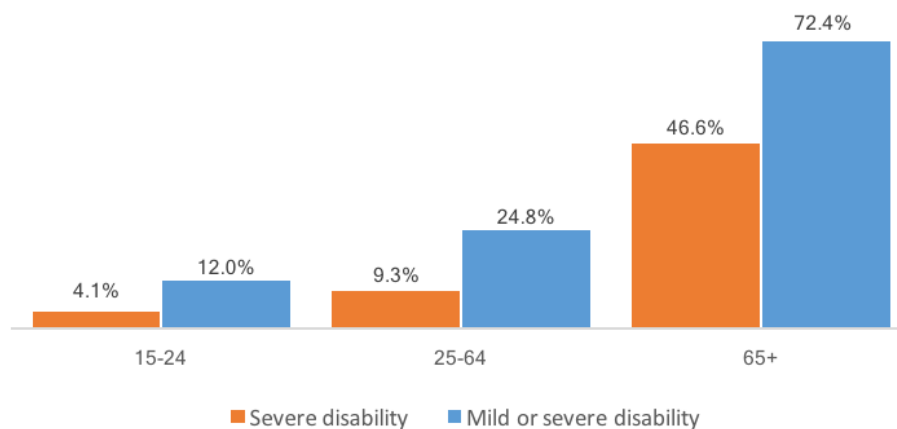
The elderly are at higher risk of having a disability than younger people. This is because, as a consequence of a lifetime's accumulation of health risks and increasing frailty, they are more likely to experience injury, chronic illness and other health impairments (WHO & World Bank, 2011). Reflecting this, it has been estimated that 43.4% of people over 60 have a disability in lower-income countries (29.5% in higher-income countries), and that the elderly comprise a substantial proportion of the disabled population around the world (WHO & World Bank, 2011). For example, in Sri Lanka, while only 6.6% of the general population were 65 or older in 2001, the 65+ cohort represented 22.5% of the people with disabilities (WHO & World Bank, 2011).

Consistent with this, disability prevalence in Indonesia appears to be highest among the elderly. According to the 2007 Riskesdas, 46.6% of Indonesians aged 65 or older had a severe disability, compared with 4.1% of youths and 9.3% of people aged 25 to 64 (Adioetomo et al., 2014). If mild disabilities are included, this proportion jumps to 72.4% of people aged 65 or over (compared with 12% of youths and 24.8% of people between 25 and 64) (see Figure 4) (Adioetomo et al., 2014). Interestingly, however, Adioetomo et al. (2014) find that having a disability has less of an effect on the consumption of the elderly than the non-elderly, possibly because they have more resources (such as assets and children) to draw on for support.

The higher prevalence of disability among older people is likely to become increasingly important as populations age in many countries, including Indonesia, over the coming decades (Faizal, 2016; Adioetomo, Mont & Irwanto, 2014). Reflecting this, studies such as those by Payne, Mkandawire and Kohler (2013), which investigated physical limitations and ageing in Malawi, and Flores, Ingenhaag and Maurerb (2015), which analysed the well-being of older people with disabilities in five

low- and middle-income countries including China and India, have highlighted the importance of interventions to support elderly people with disabilities in developing countries.

Figure 4. Proportion of people with a disability in Indonesia by age (2007 Riskesdas)
Source: Adioetomo et al., 2014.



The Poor

“[D]isability may increase the risk of poverty, and poverty may increase the risk of disability.” (WHO & The World Bank, 2011, p. 10)

Disability and poverty are closely linked. Although there is little systematic empirical evidence demonstrating the relationship between the two (Mitra et al., 2011), it appears probable that having a disability increases a person's likelihood of being poor, while being poor increases a person's likelihood of having a disability. It is for this reason that disability is considered a development issue (WHO & The World Bank, 2011). The principal way in which disability may lead to poverty is by reducing a person's earnings and increasing their expenditures (Mitra et al., 2011).³⁵ As noted above, people with disabilities are less likely to attend school and gain employment, and when they do work, they typically earn lower wages. In addition, disabled people are likely to spend more on health care, transportation, assistive devices, personal assistance and other support services (Mitra et al., 2011; WHO & The World Bank, 2011).³⁶ In the reverse case, poverty may also lead to disability. This is because being

³⁵ One factor that may weaken this link is the availability of disability benefits that replace earnings and cover disability-related expenditures (Mitra et al., 2011). For a brief note on social protection programs for people with disabilities, see footnote 34.

³⁶ The fact that people with disabilities are likely to face higher living costs means traditional poverty lines, which represent a minimum standard of living for non-disabled people, may not

poor may both increase a person's risk of having a health condition associated with disability (e.g. due to malnutrition, lack of clean water, and unsafe work and living conditions),³⁷ and the risk of an existing health impairment becoming more severe (such as through a lack of access to health services, assistive devices or an accessible physical environment) (WHO & World Bank, 2011; Mitra et al., 2011; Adioetomo et al., 2014).³⁸

Highlighting the association between disability and poverty, in all 15 of the developing countries studied by Mitra et al. (2011), people with disabilities were found to be “significantly worse off in several dimensions of economic well-being” (p. iv). The study also found that people with disabilities were significantly more likely to experience multidimensional poverty than people without disabilities, and that households with a disabled household member were likely to have substantially fewer assets and considerably higher healthcare expenditures (we return to these results in connection with the impact of disability on the family below).

Evidence from Indonesia similarly suggests that the disabled are more likely to be among the poorest of the poor. Drawing on data from the 2007 Riskesdas, Adioetomo et al. (2014) find that people with disabilities are 30% to 50% more likely to be poor than non-disabled people (particularly in urban areas) and that, even when compared with other low-income people, those with disabilities are concentrated towards the bottom of the income distribution. Lastly, it is worth noting that, where data is collected at the household level, that data may understate the incidence of poverty among the disabled to the extent that people with disabilities in non-poor households do not receive an adequate share of income and resources (Mitra et al., 2011).

The Family

“[M]any non-disabled people take responsibility for supporting and caring for their relatives and friends with disabilities.” (WHO & The World Bank, 2011, p. 3)

Studies on disability often focus on the impact of having a disability on the disabled. However, in many cases the impact of disability extends far beyond those with disabilities to the lives of their families, friends, schools, workplaces and communities. Of these broader groups, it is a disabled person's family that is likely to be most affected by the responsibilities of caring for them. The extent and nature of this impact can also be expected to vary substantially depending on factors including the type and severity of the family member's disability, the family's socioeconomic position,

fully capture poverty amongst the disabled and households with disabled household members. As Mont and Cuong (2011) note, “ignoring the extra costs of disability means that poverty statistics can miss these households [with people with disabilities] whose standard of living, if the higher costs were taken into account, would be equal to that of poor households without people with disabilities” (p. 340).

³⁷ For example, Subbaraman et al. (2014) find that slum-related stressors are associated with a risk of mental illness and disability in an Indian slum.

³⁸ It should be noted that in some cases wealth may also lead to disability, such as by increasing the incidence of motorcycle ownership and thus the risk of road traffic injuries (Mitra et al., 2011).

who the disabled family member is, whether the disabled person lives with the family, and whether care services or social assistance programs are in place (Mitra et al., 2011). For example, a family with a child who has a disability and access to support services is likely to be in a very different position to a family whose principal income earner becomes disabled and for whom no assistance is available, or a family whose elderly grandparent becomes disabled in later life.

This diversity means there are many ways in which a family can be affected by having a disabled family member. However, the principal impacts appear to relate to family finances and quality of life. Families with a disabled household member may have lower household incomes (particularly where the disabled family member used to earn income or a family member is unable to work due to caring responsibilities), higher household expenses (e.g. to pay for healthcare or support services) and lower standards of living (e.g. greater food insecurity and poorer housing) (Mitra et al., 2011; WHO & The World Bank, 2011). In addition, family members may bear caring responsibilities (such as providing assistance with self-care, shopping, cooking or managing money), experience a lower quality of family life (Adioetomo et al., 2014), and receive less assistance and support within the family. Reflecting this, studies based on data from the United States have shown that having a disabled child negatively affects a mother's labour market activity (Powers, 2003), particularly where her children have physical disabilities or self-care limitations (as compared with mental, emotional, cognitive or sensory conditions) (Wasi, van den Berg & Buchmueller, 2012). In addition, a study in Vietnam found that the disability of a parent may negatively affect their non-disabled children's school attendance rates (Mont & Nguyen, 2013), while a Canadian study showed that higher disability benefit payments can help reduce the gap in developmental outcomes between the children of poor disabled and non-disabled parents (Chen, Osberg & Phipps, 2015).

To date, the results of the limited but growing body of empirical evidence on the economic well-being of households with a disabled household member in developing countries have been mixed. For example, while studies in Africa and Asia have found households with a disabled household member to have fewer assets than other households, the findings in respect of household income, expenditure and living conditions have been less conclusive. Mitra et al. (2011) found that households in which a person had a disability tended to be worse off across a range of poverty measures, although results varied depending on the measure used. In particular, households with a disabled household member had a significantly lower level of average asset ownership in most countries (11 out of 15), were over-represented among those with the lowest asset ownership in around half the countries (6 out of 15), and spent a significantly higher proportion of their expenditure on health care in two thirds of the countries (10 out of 14).³⁹

³⁹ These estimates are drawn from the study's base measure of disability (see Table A1 for more on the study's base and expanded measures).

Table 3. Percentage of extra living costs for households with members who have a severe disability in the ten most populous provinces in Indonesia. Source: Adioetomo et al., 2014

Province	Urban (%)	Rural (%)
Banten	13	13
Central Java	11	7
DKI Jakarta	6	4
East Java	5	1
Lampung	10	15
North Sumatra	2	7
Riau	16	13
South Sulawesi	3	6
South Sumatra	19	5
West Java	7	7
Unweighted average	9.2	7.8

In Indonesia, the 2007 Riskesdas data suggests that households with a disabled household member are likely to have lower consumption than households in which no one has a disability, except where they are very rich (Adioetomo et al., 2014). It has also been estimated that the costs associated with living in a household in which someone has a disability are on average 4% higher than living in a household in which no one has a disability, and as much as 30% higher in some provinces (irrespective of whether a low or high threshold measure is used), but that in the ten most populous provinces the average costs are around 8-9% higher (see Table 3).⁴⁰ This is of a similar magnitude to the finding of Mont and Cuong (2011) in Vietnam, where the extra costs of disability were estimated to be 11.5%, based on data from the 2006 Vietnam Household Living Standards Survey.

In relation to quality of life, the Indonesian 2012 Survey on the Need for Social Assistance Programmes for People with Disability (SNSAP-PWD) revealed that, of those respondents with more significant disabilities, nearly two-thirds said their disability caused financial problems, more than half said it affected family life, and up to a quarter said that their disability made their family unhappy (Adioetomo et al., 2014). The impacts were less pronounced, but still notable, among those with mild disabilities – about half said their disability caused financial problems, over a third said family life was affected, and up to one fifth said their disability to make their family unhappy. Given that up to 44.2% of households in Indonesia are estimated to include a mildly

⁴⁰ These estimates represent the extra expenses incurred by households in which a person has a disability, and not necessarily the extra costs associated with maintaining a good quality of life for a disabled person. This is because the cost of items and services that households chose to forego (e.g. where a prosthetic limb was not purchased despite a need for one), or received for free, are not included.

or severely disabled household member,⁴¹ and “nearly one-half to three-fourths of all households with a person aged 60 years or older contain a person with a disability” (Adioetomo et al., 2014, p. 88), these results suggest that a substantial proportion of Indonesians are directly or indirectly impacted by disability.

5. Policies to Support People with Disabilities

“In the current context, perhaps the most important omission from the literature is a clear picture of what works in terms of policy.” (Jones, 2016, p. 8)

The evolution of the concept of disability from the traditional medical model to the current International Classification of Functioning, Disability and Health (ICF) has had significant implications for the role of disability policy, and the way it has been approached and implemented. This is principally because each model has emphasised a different underlying cause of disability, and this has influenced the focus of the policy response. For example, under the medical model disability was considered to be caused by a health impairment, and thus disability policy concentrated on treatment, rehabilitation and care. The subsequent adoption of the social model, which identified the social environment as the cause of disability, shifted attention to reducing and removing the physical and cultural barriers that exist within society (Mitra et al., 2011). The recent transition to the ICF has developed this understanding further, highlighting that disability is the product of both personal and environmental factors. It therefore focuses on the extent to which people are able to function within their environment, and directs policymakers to consider the barriers that prevent people from participating in society given their health condition. In places such as Indonesia, it appears that the move away from the medical conception of disability is yet to be fully reflected in law and policy, and thus changing people’s attitudes and mindsets is of particular relevance (Adioetomo et al., 2014).

While disability policy has many important aspects, one area that appears to deserve special attention is improving access to education and employment.⁴² In the context of education, it is now widely acknowledged that the formulation of appropriate, inclusive policy has been hampered by a lack of reliable, comparable data (Mizunoya et al., 2016; Sæbønes et al., 2015; Filmer, 2008).⁴³ The impact of this is reflected in the finding of Mizunoya et al. (2016) that even “countries which are able to allocate more resources towards the restructuring of their educational system to reduce the overall [out-of-school children] rate see no progressive improvement in the situation of disabled children” (p. 19), which suggests that the effect of current

⁴¹ This is based on the 2007 Riskesdas data using the low threshold measure. If the high threshold measure is used, 22.5% of households in Indonesia are estimated to include a household member with a severe disability (see Table A1 for more on these measures). To give a rough comparison, Mont and Cuong (2011) estimated that 23.4% (12.4%) of households in Vietnam included a person with a disability using their low (high) threshold measure.

⁴² Mitra et al. (2011)’s results “suggest that policies that promote access to education, health care and employment may be particularly important for the well-being of persons and households with disabilities” (p. 63).

⁴³ Sæbønes et al. (2015) note that “[w]ithout reliable data, children with disabilities are frequently invisible in policy discussions, and when they are addressed, this is usually through mainstreaming efforts that lack resources, funding and political will” (p. 4).

education policies on disabled children is, at most, likely to be limited and that substantial structural inequities remain. It is therefore unsurprising that many priority issues have been identified in this area.

However, ensuring that children with disabilities have access to school from the earliest years seems to be particularly important (Mizunoya et al., 2016; Sæbønes et al., 2015; Filmer, 2008).⁴⁴ Pre-requisites for this include fostering enabling home and community environments and accessible, inclusive schools, supporting the development of well-trained teachers and appropriate teaching and learning materials, and broadening the availability of assistive devices (Mizunoya et al., 2016; Sæbønes et al., 2015). Consistent with this, the World Bank has been involved in a range of programs that promote inclusive education for children with disabilities, including the Intergenerational Deaf Education Outreach pilot program, which taught sign language to 260 very young deaf children in Vietnam to help prepare them for school, the Togo Education and Institutional Strengthening Project, which built almost 1,000 accessible classrooms that now serve over 42,000 children in Togo, and India's Sarva Shiksha Abhiyan program, which is seeking to deliver primary education to all children, including disabled children, across India (World Bank, 2015).⁴⁵

The development of employment policy suffers from many of the impediments that apply in the area of education. In particular, there appears to be a lack of consensus on what constitutes effective policy for people with disabilities, which is at least partly due to the fragmented nature of much of the evidence and the complexity of the policy area (Jones, 2016). Notwithstanding this, there is a general recognition of the need for policies "addressing the physical, social, economic and cultural barriers that prevent people with disabilities from accessing decent work... [including] lack of access to education, lack of skills required in the labour market, ... as well as inaccessible built environments, information and public transport and lack of affirmative action and reasonable accommodation provisions in laws and policies" (ILO, 2013, p. 2). In connection with this, the ILO is supporting a number of policies and programs that appear promising, although we are not aware of rigorous evaluations of them. These include assisting the Government of Zambia to provide equal employment and vocational training opportunities for people with disabilities and to improve the accessibility of public vocational training programs, and delivering training to around 500 people with disabilities as part of the Bangladesh Skills for Employment and Productivity Project. In Indonesia, the ILO is supporting the piloting of a program to train and place people with disabilities, and provide advice about employing people with disabilities, within the garment sector as part of the Better Work Programme (ILO, 2015). Adioetomo et al. (2014) also note the work of employer organisations such as the Business Disability Forum in the United Kingdom and the

⁴⁴ This is especially so given that "[a] child's education lays the cornerstone for his or her future life, not only in terms of income but their overall wellbeing" (Mont & Nguyen, 2013, p. 88).

⁴⁵ The World Bank (2015) reported that, through the Sarva Shiksha Abhiyan program, "[t]he share of children with special needs enrolled at [the primary and upper primary levels] has risen from 84% in 2012-13 to nearly 90% today. ... In addition, over 116,000 children with special needs receive home-based education, taking the total coverage of identified children to 96% or nearly 2.7 million under Sarva Shiksha Abhiyan".

Employers Federation of Ceylon in Sri Lanka, which have partnered with the private sector as a means of encouraging the establishment of accessible work practices in their countries.

“[P]olicy and programmatic approaches adopted to improve the lives of people with disabilities must be designed with sufficient flexibility to adapt to local conditions and concerns.” (Adioetomo et al., 2014, p. xviii)

Above all, there is a need for education and employment policy that is expressly designed for people with disabilities. Reflecting this, Mizunoya et al. (2016) find that “traditional education policies that increase general attendance do little to benefit disabled children” (p. 36). Adioetomo et al. (2014) point to a lack of “systematic effort [in Indonesia] to make governmental training programmes accessible to people with disabilities or to establish a government programme that focuses on them” (p. 82). More generally, Jones (2016) notes that the government can play an important role by providing incentives for employers to employ disabled workers. This calls attention to two critical aspects of disability policy formulation in the future. First, policies must be tailored, not only for people with disabilities generally, but also to the needs of people with particular types of functional limitations in the specific environments in which they live and the barriers they face. This means that policy requirements are likely to vary from country to country, province to province, and by disability type. Second, further research is needed to trial programs and evaluate interventions so as to determine which are most effective and in what circumstances. This is particularly critical given that, as Mitra et al. (2011) state, “[s]ome interventions, such as community-based rehabilitation, have long been in the field, but little is known on what works” (p. 64).

6. Conclusion

“Robust evidence helps to make well informed decisions about disability policies and programmes.” (WHO & The World Bank, 2011, p. 21)

Disability is a complex, heterogeneous phenomenon that significantly reduces participation in education and employment, disproportionately impacts the lives of the elderly and the poor, and has far-reaching consequences for affected families, but about which much remains unknown. Above all, a lack of consistent, reliable and up-to-date data has substantially constrained the current understanding of who is affected by disability, in what ways and why, especially in developing countries. This is evident in Indonesia, where estimates of disability prevalence range from 0.8% based on a narrower examination of severe disability, through to over 25% using a more extensive measure where mild disability is included.⁴⁶ Nevertheless, while specific estimates vary, general trends are apparent. In particular, the available data suggests that, as in many other countries, a significant proportion of the Indonesian population is directly or indirectly affected by disability, prevalence is higher among the poor and the elderly, and substantial barriers to employment and education persist.

⁴⁶ These estimates are discussed in section 3 on this annex.

Most striking of all is the extent to which Indonesia lags behind other countries in respect of the gap between disabled and non-disabled children's school attendance. This is an area in which a paucity of data poses a considerable hindrance for policy development since, as Mizunoya et al. (2016) note, "in the absence of internationally comparable data, ... governments rarely possess the necessary evidence required to design appropriate policy adaptations and enhancements to improve the situation of disabled children" (p. 8). Their comment equally applies to the development of policy to assist people with disabilities more broadly.

It follows that there is a pressing need for high-quality, dependable data, and especially longitudinal data (Mitra et al., 2011), that will allow detailed analyses of the key barriers that prevent people with disabilities from participating fully in education and employment, and the most effective ways to address them. Importantly, while the increasing focus of disability data on functioning is welcome, the collection of functioning-related data in conjunction with data on the type and extent of physical or mental disability remains essential. Without the latter, it is not possible to analyse the impact a health impairment has on functioning, nor to assess the extent to which policies alleviate functioning difficulties (as high functioning responses could merely reflect a low prevalence of health impairments).

Further rigorous analysis would develop a deeper understanding of the impact of disability in the developing world and provide a sound basis for policy aimed at increasing the ability of the disabled to participate fully in society. Given that disability is fundamentally a human rights issue, over two-fifths of Indonesian households are thought to be affected by it (Adioetomo et al., 2014),⁴⁷ and developing countries are estimated to lose up to 7% of their gross domestic product due to the exclusion of persons with disabilities from the labour market (ILO, 2015), progress in this area would be highly valuable.

⁴⁷ See footnote 41.

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Table AA1. Overview of the key studies referred to in this review

Authors and year of publication	World Health Organization & The World Bank (2011)		Mitra, Posarac & Vick (2011)
Report title	World Report on Disability		Disability and poverty in developing countries: A snapshot from the World Health Survey
Commissioning, implementing institution(s)	World Health Organization (WHO) and the World Bank		The World Bank Social Protection and Labor Unit
Geographical scope	Developed and developing countries around the world		15 developing countries: Bangladesh, Brazil, Burkina Faso, Dominican Republic, Ghana, Kenya, Lao PDR, Malawi, Mauritius, Mexico, Pakistan, Paraguay, Philippines, Zambia and Zimbabwe.
Data source(s)	The WHO World Health Survey of 2002-2004 (2002-2004 WHS), which includes data from 59 countries, and the WHO Global Burden of Disease study of 2004 (2004 GBD). The authors also consider country surveys and censuses.		The 2002-2004 WHS
Disability questions	2002-2004 WHS Eight (short survey) or 16 (long survey) questions on difficulties over the last 30 days in eight life domains (mobility, self-care, pain, cognition, interpersonal relationships, vision, sleep and energy, and affect (but not hearing or communicating)), with five response categories (no difficulty, mild difficulty, moderate difficulty, severe difficulty, extreme difficulty).	2004 GBD Data was collected on a set of core health domains that included mobility, dexterity, affect, pain, cognition, vision and hearing. The data was used to calculate disability adjusted life years (DALYs), which are a key metric used by the 2004 GBD. They measure the lost years of healthy life from mortality and disability. Years lived in states of less than full health are converted to the equivalent number of lost years of full health using disability weights, which range from 0 (for full health) to 1 (for a health state equivalent to death).	The authors drew on two sets of questions from the 2002-2004 WHS that matched, to the extent possible, the short and long lists of questions recommended by the Washington Group on Disability Statistics (Washington Group) (see left for further information regarding the 2002-2004 WHS, and section 2 of this review for more on the Washington Group). The first set of questions (four questions in the areas of vision, mobility, cognition and self-care) was used to construct a base measure of disability, while the second set of questions (eight questions in the areas of vision, mobility, cognition, interpersonal relationships and self-care) was used to construct an extended measure of disability.

Authors and year of publication	World Health Organization & The World Bank (2011)		Mitra, Posarac & Vick (2011)
Disability threshold(s)	A disability score (from 0 to 100) was calculated based on the responses. A score of 40 (50) was set as the threshold for experiencing significant (very significant) difficulty in everyday life.	The disability weights were grouped into seven classes, with Classes III and above constituting moderate and severe disability (e.g. arthritis or low vision), and Classes VI and VII equating to severe disability (e.g. Down syndrome, quadriplegia or severe depression).	A person was identified as having a disability if they reported having severe or extreme difficulty (or inability) in response to any of the questions. Therefore, the study did not cover people experiencing mild or moderate disabilities.

Table AA1: Overview of the key studies referred to in this review

Authors and year of publication	Adioetomo, Mont & Irwanto (2014)		Mizunoya, Mitra & Yamasaki (2016)
Report title	Persons with disabilities in Indonesia: Empirical facts and implications for social protection policies		Towards inclusive education: The impact of disability on school attendance in developing countries
Commissioning / implementing institution(s)	Commissioned by the National Team for the Acceleration of Poverty Reduction (TNP2K), and conducted by the University of Indonesia		The United Nations Children's Fund (UNICEF) Office of Research
Geographical scope	Indonesia		15 low- to middle-income countries: Albania, Bangladesh, Ethiopia, India, Indonesia, Malawi, Maldives, Nigeria, Papua New Guinea, Saint Lucia, South Africa, Tanzania, Uganda, Vietnam, and West Bank and Gaza.
Data source(s)	The Indonesian Population Census 2010 (2010 Census) and the 2007 National Basic Health Research data (2007 Riskesdas). The authors also rely on the 2012 Survey on the Need for Social Assistance Programmes for People with Disability (SNSAP-PWD), and focus group discussions and interviews.		18 nationally representative household surveys and censuses dating from 2005 to 2013 (two sources were considered for each of South Africa, Tanzania and Uganda).
Disability questions	2010 Census	2007 Riskesdas	All of the surveys and censuses asked questions in at least five of the six physical and mental domains (seeing, hearing, walking, remembering and concentrating, self-care and communication) covered in the Washington Group's short set of disability-screening questions, and offered respondents three or more response categories (see section 2 of this review for more on the Washington Group).
	Five functional questions, such as "Do you have difficulty seeing, even when wearing glasses?" and "Do you have difficulty in self-care?", and three response categories (none, a little, a lot).	20 more extensive functional-based questions, such as "In the past month, how difficult is it to see and to recognise people across the street (approximately within 20 meters), although you have used glasses / contact lenses?" and "In the past month, how difficult is it to maintain friendships?", and five response categories (none, a little, mild, severe, very severe).	

Authors and year of publication	Adioetomo, Mont & Irwanto (2014)		Mizunoya, Mitra & Yamasaki (2016)
Disability threshold(s)	People were classified as having a mild disability if they had a little difficulty in one or more functional domains but did not have a lot of difficulty in any functional domain. People were classified as having a severe disability if they had a lot of difficulty in at least one functional domain.	People were classified as having a disability that was mild if they had a little or mild difficulty in at least one domain but never severe or very severe difficulty, and severe if they had severe or very severe difficulty in at least one domain. In addition, a low disability threshold captured those experiencing mild and severe disabilities, while a high disability threshold covered those only experiencing severe disabilities.	A person was identified as having a disability if they gave a positive response to the top response category (if there were three severity levels) or one of the upper two response categories (if there were more than three severity levels) in at least one domain. Therefore, this study focused on people with severe disabilities.

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