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Disability Data in Indonesia

7 May 2021

A Research Report prepared
by Saraswati (Consultant) for
United Nations Country Team (UNCT)
in Indonesia





REPORT

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Abbreviation

Abbreviation	Indonesia / Original Abbreviation	English
ADL	Aktivitas Sehari-hari	Activities of Daily Living
AIPJ	Kemitraan Australia Indonesia untuk Keadilan	Australia Indonesia Partnership for Justice
APBD	Anggaran Pendapatan dan Belanja Daerah	Regional Budgets and Expenditures Budget
APBN	Anggaran Pendapatan dan Belanja Negara	National Budget and Expenditures Budget
APK	Angka Partisipasi Kasar	Gross Enrollment School Participation
APM	Angka Partisipasi Murni	Net Enrollment School Participation
ASEAN	N/A	Association of Southeast Asian Nations
BAPPEDA	Badan Perencanaan Pembangunan Daerah	Regional Development Planning Agency
BAPPENAS	Badan Perencanaan Pembangunan Nasional	National Development Planning Agency
BPS	Badan Pusat Statistik	Statistics Indonesia
CBM	N/A	Christian Blind Mission
COPS	N/A	Conference of State Parties
COVID-19	Virus Korona 2019	Coronavirus disease 2019
CRPD	Konvensi Hak-Hak Penyandang Disabilitas	Convention of the Rights of Persons with Disabilities
CRVS	Pencatatan Sipil dan Statistik Hayati	Civil Registration and Vital Statistics
Dapodik	Data Pokok Pendidikan	Basic Data of Education
DFAT	N/A	Department of Foreign Affairs and Trade Australia
DFAT	Departemen Luar Negeri dan Perdagangan Australia	Department of Foreign Affairs and Trade
Dinsos	Dinas Sosial Kesejahteraan	District Welfare Office
DPOs	Organisasi Penyandang Disabilitas	Disabled People's Organizations
DPOs	Organisasi Penyandang Disabilitas	Disabled People Organisations
DTKS	Data Terpadu Kesejahteraan Sosial	Integrated Social Welfare Data
Dukcapil	Dinas Kependudukan dan	Population and Civil Registration

	Pencatatan Sipil	Agency
FGDs	Diskusi Kelompok Terarah	Focus Group Discussions
GEDSI	N/A	Gender Equality Disability and Social Inclusion
GIZ	The Deutsche Gesellschaft für Internationale Zusammenarbeit	N/A
GOI	Pemerintah Indonesia	Government of Indonesia
HH	Rumah Tangga	Household
IAEG-SDGs	N/A	The Inter-Agency and Expert Group on SDG Indicators
ICFDH	N/A	International Classification of Functioning, Disability and Health
IFLS	Survei Kehidupan Keluarga Indonesia	Indonesia Family Life Survey
ILO	Organisasi Buruh Internasional	International Labour Organization
JICA	N/A	Japan International Cooperation Agency
JPAL	N/A	Abdul Latif Jameel Poverty Action Lab
Kemendagri (MoHA)	Kementerian Dalam Negeri	Ministry of Home Affairs
Kemendikbud (MoEC)	Kementerian Pendidikan dan Kebudayaan	Ministry of Education and Culture
Kemenkes/Ke mkes (MoH)	Kementerian Kesehatan	Ministry of Health
Kemensos (MoSA)	Kementerian Sosial	Ministry of Social Affairs
Kepres	Keputusan Presiden	Presidential Decree
KIP	Kartu Indonesia Pintar	Indonesia Health Card
KPD	Kartu Penyandang Disabilitas	
KPPPA (MoWECP)	Kementerian Pemberdayaan Perempuan dan Perlindungan Anak	Ministry of Women's Empowerment and Child Protection
KTP	Kartu Tanda Penduduk	National ID Card
MAHKOTA	Menuju Masyarakat Indonesia Yang Kokoh Sejahtera	Towards a Strong and Prosperous Indonesian Society
MAMPU	N/A	Australia Indonesia Partnership for Gender Equality and Women's

		Empowerment
MISC	N/A	Multiple Indicator Cluster Survey
MSBP	Modul Sosial Budaya dan Pendidikan	Socio-cultural and Education Survey Module
NGOs	Lembaga Non Pemerintah/ Lembaga Swadaya Masyarakat	Non-Governmental Organisations
NLR	N/A	Netherlands Leprosy Relief
PATTIRO	Pusat Telaah dan Informasi Regional	N/A
PKH	Program Keluarga Harapan	Family Hope Program
PMKS	Penyandang Masalah Kesejahteraan Sosial	Persons with Social Welfare Problems
PODES	Potensi Desa	Village Potential
PP	Peraturan Pemerintah	Regulation of The Government
PPPLS	Pendataan Program Perlindungan Sosial	Data Collection for Social Protection Program Survey
PROSPERA	N/A	Australia-Indonesia Partnership for Economic Development
PUSKAPA	Pusat Kajian dan Advokasi Perlindungan dan Kualitas Hidup Anak Universitas Indonesia	Center on Child Protection and Wellbeing at Universitas Indonesia
PWD	Penyandang Disabilitas	Persons with Disabilities
Q4	N/A	4th Quarter
RAD	Rencana Aksi Daerah	Regional Action Plan
RAN	Rencana Aksi Nasional,	The National Action Plan
RINDI	Rintisan Desa Inklusi	Inclusive Village Model
RIPD	Rencana Induk Penyandang Disabilitas	the Master Plan of Persons with Disability
RISKESDAS	Riset Kesehatan Dasar	Basic Health Research
RPJMN	Rencana Pembangunan Jangka Menengah	National Medium Term Development Plan
SAKERNAS	Survei Angkatan Kerja Nasional	National Labor Force Survey
SDGs	Tujuan Pembangunan Berkelanjutan	Sustainable Development Goals
SIGAB	Sasana Inklusi dan Gerakan Advokasi Difabel	Institute for Inclusion and Advocacy Movement of Persons with Disability
SIKS-NG	Sistem Informasi Kesejahteraan	Social Welfare Information System

	Sosial-New Generation	New Generation
SIMPD-DTSK	Sistem Informasi Penyandang Disabilitas- Data Terpadu Kesejahteraan Sosial	Disability Information System-Unified Social Welfare Data
SMA	Sekolah Menengah Akhir	Senior Secondary Education
SMK	Sekolah Menengah Kejuruan	Vocational School (Senior Secondary-level)
SMP	Sekolah Menengah Pertama	Secondary Education
SNSAP-PWD	N/A	Survey on the Need for Social Assistance Programs for People with Disabilities
SP	Sensus Penduduk	Population Census
SUPAS	Survei Penduduk Antar Sensus	Inter-censal Population Survey
SUSENAS	Survei Sosial Ekonomi Nasional	Socio-Economic National Survey
TNP2K	Tim Nasional Percepatan Penanggulangan Kemiskinan	National Team to Accelerate Poverty Reduction
UNCRPD	Konvensi Hak-Hak Penyandang Disabilitas Perserikatan Bangsa-Bangsa	The United Nations Convention on the Rights of Persons with Disabilities
UNCT	N/A	The United Nations Country Team
UNESCAP	Perserikatan Bangsa-Bangsa Komisi Ekonomi dan Sosial untuk Asia dan Pasifik	United Nations Economic and Social Commission for Asia and the Pacific
UNFPA	Dana Kependudukan Perserikatan Bangsa-Bangsa	United Nations Population Fund
UNICEF	Dana Anak Perserikatan Bangsa-Bangsa.	United Nations ChildrenFund
UNSD	Divisi Statistik Perserikatan Bangsa-Bangsa	United Nations Statistics Division
UNY	Universitas Negeri Yogyakarta	Yogyakarta State University
UU	Undang-undang	Law
WGSS	Rangkaian Pertanyaan Singkat Washington Group	Washington Group Short Set Questions
WHO	Organisasi Kesehatan Dunia	World Health Organization
WHODAS	N/A	WHO Disability Assessment Schedule

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Executive Summary

Disability data is increasingly being championed on the global development agenda. In the 2030 Sustainable Development Agenda, the terms 'disability' or 'persons with disabilities' appear explicitly 11 times and the term 'persons in vulnerable situations' is mentioned six times. The latter makes the definition of people with disability and acknowledgement of their unique challenges much clearer and how making them visible is a way to strive for the realisation of their rights. This promising commitment for inclusion has again been restated in the UN SDG Report in 2017 maintaining how the absence of sound disability data limits the ability of the international community to fully understand the discrimination and exclusion faced by people with disability and worsens their vulnerabilities.

Data is needed not only to highlight where deprivation and disparities of exclusion exist, but also as it helps to develop evidence-based policies to count when and in which contexts targets are met, evaluate the progress, and record as well as work on identified challenges that remain.

In response, the UNCT in Indonesia hired Saraswati, an Indonesian company focusing on development innovation, to provide a mapping of disability data, examining the state of disability data and its data ecosystem in the country, as well as to identify the challenges and opportunities of having adequate disability data.

Key research questions included the following:

- What disability data is the Government of Indonesia (GOI) currently collecting to measure adults, children and older persons with disability? What is the state of this disability data in the country, in terms of quality and use, (especially those that are collected through national surveys, census and SDGs data? What disability data are also disaggregated by sex, age, gender, rural or urban location, migrant or refugee status, and ethnic or religious minority group?
- Who are the existing and potential data producers and data sources for measuring the status of people with disability in the country, especially the SDGs indicators that are prioritized in the UN Sustainable Development Cooperation Framework?
- What are the gaps and challenges in collecting disability data? What are the opportunities? Does the regulatory framework support the provision of disability data or mechanisms to produce disability data? Does the regulatory framework demand it?

Saraswati conducted research for this report from February–March 2021. The research involved a review of planning documents, reports, publications, and other relevant documents from both Government of Indonesia and non-state actors, particularly Disabled People's Organisations (DPOs). Interviews with experts and two Focus Group Discussions (FGDs) were also conducted to provide a more coherent picture of disability data in Indonesia, including challenges and opportunities. These FGDs were co-designed and facilitated by leading disability experts.

This report details the following key findings on the state of disability data in Indonesia:

- ***The issues of mandates among GOI agencies and data disintegration.*** Different GOI agencies and line ministries have different focuses and ways of approaching disabilities issues, which leads to difficulties in reconciling definitions and

methodologies to determine the key aspects of disabilities that the GOI has to measure.

- ***Different disability definitions and methodologies used in data collection by different institutions resulting in limited accuracy and comparability.*** Different approaches to disability issues by different government agencies lead to the fact that data collections conducted by different agencies, such as Statistics Indonesia (BPS), the Ministry of Social Affairs, and the Ministry of Health employ different data categories of disability, modified questions and measure different levels of subjects. This has resulted in inconsistencies in disability prevalence figures in Indonesia.
- ***Disability issues are yet to be fully understood--reflected in what data the GOI currently collects, how it is collected and the unavailability of crucial data.*** People with disabilities are still not viewed as a mainstream issue in the implementation of the SDGs, but rather seen as a group or community that requires 'separate' analysis instead of being incorporated in intersectional analysis of the development sector in Indonesia.
- ***The self-identification and prone-to-stigma nature of disability data collection.*** BPS and the Ministry of Health rely on self-reporting and self-identification, which can be problematic due to the following: stigma, shame and taboo surrounding disability; disability is usually only associated with visible major and severe impairments that are easily noticed; the elderly with age-related disabilities rarely consider themselves as disabled, and many people do not diagnose themselves with disability.
- ***Exclusion of people with disability from data collection.*** Reliant on self-registration or self-reporting mechanisms by the family, registering children with disabilities faces geographical and cultural challenges. Many families are reluctant or are not aware of the needs to register their children or themselves as persons with disabilities due to lack of access and/or negative stigma. People with disabilities are excluded from data collection and registration processes that leave them undocumented.
- ***Limited disaggregation.*** Disaggregation of sector data by people with disabilities is yet to be a priority for the government. As an example, apart from five indicators that specify the needs to include disaggregation by disability, the GOI does not disaggregate its national SDGs indicators data by people with disabilities.
- ***Limited evidence of data utilisation and quality assurance.*** There is a clear-cut utilisation and purpose of administrative data that is designed for social protection programs but the use of statistical disability data is unclear. Important data sources, such as SIMPD/DTKS, do not employ appropriate quality protocols for data entry.

Background

Disability data is increasingly being championed on the global development agenda. In the 2030 Sustainable Development Agenda, the terms 'disability' or 'persons with disabilities' appear explicitly 11 times and the term 'persons in vulnerable situations' is mentioned six times. The latter makes definition of people with disability and acknowledgement of their unique challenges much clearer and how making them visible¹ is a way to strive for the realisation of their rights. This promising commitment for inclusion has again been restated in the UN SDG Report in 2017² maintaining how the absence of sound disability data limits the ability of the international community to fully understand the discrimination and exclusion faced by people with disability and worsens their vulnerabilities. Data is needed not only to highlight where deprivation and disparity of exclusion exist, but also as it helps to develop evidence-based policies to count when and in which contexts targets are met, evaluate the progress, and record as well as work on identified challenges that remain. Building on this, and drawing on the Situational Analysis on the State of Data in Indonesia, this report aims to undertake a specific mapping of disability data, examining the state of disability data and its data ecosystem in the country. Furthermore, it aims to identify the challenges and opportunities of having adequate disability data.

Methodology

Given the growing awareness on the importance of disaggregated data in global and national efforts to monitor Sustainable Development Goals (SDGs) and, at the same time, enhance capacities of countries to contribute to better and internationally comparable data, there is limited understanding and information on the state of disability statistics in Indonesia and how the data and capacity gaps can be addressed.

The United Nations Country Team (UNCT) has responded to this challenge by supporting engagement with local actors and key agencies through conversations and group discussions facilitated by Saraswati to gain insights on the scope and scale of disability in Indonesia with a focus on answering the following questions:

- What disability data is the Government of Indonesia (GOI) currently collecting to measure adults, children and older persons with disability? What is the state of this disability data in the country, in terms of quality and use, (especially those that are collected through national surveys, census and SDGs data (in reference to Indonesia's SDGs Metadata and global SDGs metadata)? What disability data are also disaggregated by sex, age, gender, rural or urban location, migrant or refugee status, and ethnic or religious minority group?
- Who are the existing and potential data producers and data sources for measuring the status of people with disability in the country, especially the SDGs indicators that are prioritized on the UN Sustainable Development Cooperation Framework?
- What are the gaps and challenges in collecting disability data? What are the opportunities? Does the regulatory framework support the provision of disability data

¹ Abualghaib, Groce, Simeu, Carew, Mont, and Daniel, [2019](#).

² UNDESA, [2017](#).

or mechanisms to produce disability data? Does the regulatory framework demand it?

- What are the pathways to support the GOI in overcoming the challenges and paving the way to having adequate disability data (to inform policy making that reflects commitment to disability inclusion) and SDGs indicators that are disaggregated by disability?

Guided by these questions, Saraswati conducted a review of planning documents, reports, publications, and other relevant documents from both GOI and non-state actors, particularly Disabled People's Organisations (DPOs). Interviews with experts and two Focus Group Discussions (FGDs) were also conducted to provide a more coherent picture of disability data in Indonesia, including challenges and opportunities. These FGDs were co-designed and facilitated by leading disability experts.

Findings

Before providing a mapping of available disability data in Indonesia and the state of this data, this report first discusses the background context of disability data provision in Indonesia, including how disability is defined and the regulatory framework that regulates and promotes demand for disability data in Indonesia.

How disability is understood in Indonesia

According to Cameron and Suarez (2017)³, there are three approaches for measuring disability that imply how disability is defined differently:

- The traditional approach sees disability as a reflection of health impairment. People are considered to have a disability if they have a health condition (for example, blindness, deafness, or brain damage).
- The social model environment approach sees disability as a product of barriers in the social environment rather than an individual's characteristics.
- The bio-psycho-social framework is the most recent thinking on disability that integrates medical and social models. This framework reflects the notion that disability is a result of interaction between a person's health condition and the environment.

In understanding disability issues in Indonesia, the GOI mostly adopts the social approach: the statutory definition of people with disabilities (*Penyandang Disabilitas*) as stipulated in Law 8/2016 (UU *Penyandang Disabilitas*) refers to persons with disability in terms of physical, intellectual, mental and/or sensoric limitations for a longer period hindering their full and effective participation in society on equal basis with those without disability. Such law retains partial understanding of Law 4/1997⁴ on People with Impairment (UU *Orang Cacat*) as the emphasis is on individuals' physical inability. Limited understanding of the government eventually affects how analysis of disability is being made and further

³ Cameron and Suarez, [2017](#).

⁴ Government of Indonesia, [1997](#).

influences the ability of the government to satisfactorily fulfill the rights of people with disability, promoting inclusion and investment in the quality of data on disability and children.

The definition of Persons with Disabilities under Law No 8/2016 is aligned with that of the CRPD⁵ referring to persons with disabilities as: *those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.*⁶

Regulatory framework on disability data provision and production

Building on the above approach, there are a number of regulations and laws in Indonesia that specify what disability data is required to be collected. According to several disability researchers, it is questionable to what extent the implementation of these disability-related laws, particularly the programmatic ones, has been successful, considering that there are limited practical guidelines that ideally follow the high level law on people with disability⁷. Nevertheless, the following data-specific regulations are the basis for a number of disability data collection processes in the country.

Regulatory framework before Indonesia ratified Convention of the Rights of Persons with Disabilities (CRPD)

Long before the ratification of the Convention of the Rights of Persons with Disabilities (CRPD), the Government of Indonesia (GOI) passed Law 4/1997 on Persons with Impairments (UU *Penyandang Cacat*). Another law that followed soon after, Law 16/1997⁸ on Statistics, stipulates the obligation of the government to regularly collect and report population data, including disability data that was classified as 'Special Statistics'. However, the need for disability data had become more apparent which led to the enactment of Kepres (Presidential Decree) 103/2001⁹ to designate BPS as the responsible body to collect basic statistics for further utilisation by relevant government departments (BPS 2013).

Ratification of CRPD in 2011 and regulatory implications

The Convention of the Rights of Persons with Disabilities (CRPD)¹⁰ greatly influenced global policy making for disability inclusion. Reaching near universal ratification, the signatory countries adopt the Convention into their national policy and are politically committed to ensure all persons with all types of disability enjoy all human rights and fundamental freedoms. Statistics and data collection, as stipulated in Article 31, lays out a legal framework for collecting disability data and refers to Article 40, under which signatories shall

⁵ UN General Assembly, [2007](#).

⁶ Government of Indonesia, [2016](#).

⁷ Priebe and Howell, [2014](#).

⁸ Government of Indonesia, [1997](#).

⁹ Setneg, [2001](#).

¹⁰ UN General Assembly, [2007](#).

participate in the regular Conference of State Parties (COSP). The regular COSP has become an important forum for advocacy, including advocacy led by the Disability Data Advocacy Working Group, under the umbrella of the Stakeholder Group of Persons with Disabilities that called for the CRPD member states to adopt disability data disaggregated for global SDGs indicators¹¹. The collective advocacy led by the Stakeholder Group of Persons with Disabilities and the International Disability Alliance has resulted in a fruitful outcome with the global launch of the Disability Data Advocacy Toolkit during the recent Virtual World Data Forum¹². The toolkit¹³ aims to contribute to the growing global dialogue on the importance of data on persons with disabilities, specifically in providing some basic knowledge on data collection, analysis, and use of data for evidenced based advocacy to influence policy and decision makers. The toolkit is made available together with the other SDG Data Disaggregation guidelines prepared by the Inter-Agency and Expert Group on SDG Indicators (IAEG-SDGs) and United Nations Statistics Division (UNSD)¹⁴.

Following ratification of the UN Convention on the Rights of People with Disabilities in 2011 with the enactment of the Law No. 19/2011 on Ratification of the Convention On The Rights of Persons With Disabilities¹⁵, the GOI enacted a new Law 8/2016 on People with Disabilities to amend Law No. 4/1997 on Persons with Impairment. Article 17 of this Law specifically sets out how to collect disability data. The Ministry of Social Affairs (*Kemensos*) is mandated as the responsible ministry to collect data of persons with disability with BPS as a collaborating agency. Under the law, people with disabilities have the right to be registered and access information. Disability data, as demanded by the Law, will be an accurate reference of the main characteristics and detailed characteristics of persons with disabilities. The data will be further utilised to identify and solve problems related to the fulfilment of persons with disabilities' rights. The data will also serve to inform design and implementation of disability-related social protection programs. Nevertheless, the regulatory framework remains vague as it does not specify any details on how to use the data and who should be using the data.

The primary reference in technical implementation of Law No. 8/2016 is Government Regulation (PP) 70/2019¹⁶ on Planning, Implementation, and Evaluation of Respect, Protection, and Fulfillment of Rights of Persons with Disabilities. This PP stipulates that the fulfilment of rights of persons with disabilities is the responsibility of all parties. The regulation has become an umbrella regulation for the Master Plan of Persons with Disability (*Rencana Induk Penyandang Disabilitas* or RIPD), a set of 25-year national plans to achieve inclusive development for people with disability, which serves as a reference in mainstreaming disability issues in the policy-making process. Ministries and agencies, sub-national governments (provincial and district governments), the private sector, and the public are expected to align with the RIPD when formulating new policies as well as

¹¹ Christian Blind Mission (CBM), [2019](#).

¹² Christian Blind Mission (CBM), [2020](#).

¹³ UNSTATS, [n.d.](#)

¹⁴ IAEG-SDGs, [2021](#).

¹⁵ Government of Indonesia, [2011](#).

¹⁶ Setneg, [2019](#)

implementing programmes and activities, including when budgeting the National Budget (APBN) and Regional Budgets (APBD).

The Government Regulation mandates disability data collection as a core component of RIPD for inclusive development planning¹⁷. One of the strategic targets in the Regulation is regarding data collection and inclusive planning for persons with disabilities that needs to be implemented through four key actions, namely:

1. Increase the ownership of civil documentation (Dukcapil) for persons with disability
2. Develop ministerial regulation on the annual implementation of disability disaggregated data, classified based on types of disability that is applicable to all sectors at the national and local levels
3. Collect data of persons with disability in all sectors at the national and local levels
4. Monitor and evaluate data collection on persons with disability.

The National Action Plan (*Rencana Aksi Nasional*, RAN) for disabilities 2014-2023 is essentially the elaboration of the national RIPD that is stipulated in Government Regulation (PP) No. 70/2019¹⁸. At the sub-national level, the Regional Action Plan (RAD) that is derived from the RAN is also mandated to be developed and implemented.

Moreover, the Medium-term National Development Plan (RPJMN) 2020-2024¹⁹ includes social protection data including disability data as one of the national priorities. Data of persons with disabilities, as part of vulnerable groups, is central to social welfare programming and is targeted as part of the improvement agenda for civil administration coverage. The improvement has been aligned with the pre-existing DTKS²⁰ (Integrated Social Welfare Data) system managed by Kemensos that has been foundational for the implementation of various social protection programs, such as the Family Hope Program (PKH), Indonesia Health Card (KIP), and Energy Subsidy.

Focusing more on social protection, PP 52/2019 on the Implementation of Social Welfare for Persons with Disabilities has been followed with a technical regulation, Permensos 5/2019 concerning the DTKS. This database is especially critical to assess the needs, conditions of population, and eligibility of the recipients of the social protection programs²¹. To that end, Kemensos has established an integrated Disability Management Information System (*Sistem Informasi Manajemen Penyandang Disabilitas*, SIMPD) that is expected to provide accurate and accountable information on Persons with Disabilities (PWD) and inform and help improving targeting of many development programs targeting PWD²².

¹⁷ *ibid*, [2019](#).

¹⁸ Setneg, [2019](#).

¹⁹ Bappenas, [2020](#)

²⁰ Kemensos, [2020](#).

²¹ World Bank, [2020](#).

²² Dinas Sosial dan Pemberdayaan Masyarakat Wonosobo, [2019](#)

Data produced and existing data producers

This section examines different data producers and datasets available on people with disability from the GOI and non-state actors.

Government data

In accordance with the national disability law (Law 8/2016), Kemensos has the authority and responsibility related to disability data collection²³. For administrative data, Kemensos has the *Sistem Informasi Manajemen Penyandang Disabilitas (SIMP)*²⁴, part of the DTKS database which serves as a basis to implement disability social protection programs. Originating from TNP2K, it was first referred to as *Pendataan Program Perlindungan Sosial (PPLS)*²⁵ that included persons with disability who are within the 40% of Indonesia's poorest as social protection targets. The 2014 version covered 25 million households included in the previous PPLS in 2011, plus around 5 million additional households as recommended by the public and community, including more than 800,000 households having a person with severe disabilities as respondents. The decision on the list of items to be surveyed in PPLS 2014 was decided with inputs from local governments and communities. The PPLS 2014 prioritised additional households whose members have permanent mental or physical disabilities.

Other key administrative data which has become one of the top priorities in RIPD as per PP 70/2019 is the Civil Registration and Vital Statistics (CRVS)²⁶, in this context provided by the Dukcapil at the Ministry of Home Affairs (*Kemendagri*). Events of birth, death, the cause of death, marriage and divorce, and adoption are among the scope of vital events recorded in the CRVS. Birth certificates, National Identity Cards (with a unique identity number), and Family Cards (*Kartu Keluarga*) are some legitimate civil documentation that are very important for ensuring access to public facilities such as schools and Puskesmas, and, more importantly, to have *Kartu Penyandang Disabilitas (KPD)*, released by the Ministry of Social Affairs) that allows access to disability-specific social protection programs²⁷.

In terms of bureaucratic rank, BPS, as the national statistics agency, can conduct disability surveys as long as Kemensos requests these. In the past, before the ratification of UNCRPD in Indonesia in 2011, BPS collected data on population with disability through the Population Census across six provinces with only one screening question: *Are you disabled?* Y/N followed by one question on the type of disability: 1. *tunanetra (blind)*, 2. *tunawicara/rungu (deaf/dumb)*, 4. *cacat anggota tubuh (physically handicapped)*, 5. *cacat mental (mentally handicapped)*. However, following the global establishment of the Washington Group on Disability Statistics by the United Nations Statistical Commission in 2001, BPS adopted three questions from the International Classification of Functioning, Disability and Health

²³ Article 117 of Law 8/2016 specifies that disability issues and data is the domain of Kemensos (Setneg, [2016](#)).

²⁴ See SIMPD platform [here](#).

²⁵ Kemensos, [n.d.](#)

²⁶ Civil Registration and Vital Statistics: a two-pronged mechanism that confers a state's recognition of vital events to individuals through the provision of legal identity documents and produces data on the features of these events (Siagian et al., 2007).

²⁷ As per Permensos [21/2017](#).

(self-care, communication and movement domains) in addition to questions on types of difficulties and the needs for assistance in performing daily activities in SUSENAS 2006.

Currently, BPS, as well as Kemenkes and Kemensos, have collected various data related to health, employment and welfare status of people with disabilities, and the collected data points have evolved. From Table 1 below, the instruments have evolved to include five questions on functioning limitations with three response scales on degree of impairment (none, a little and severe) in the 2010 Population Census. The censuses became the basic source of demographic data on disability, along with information collected from the intercensal census (SUPAS 2015), National Socio-Economic Survey (SUSENAS 2000-2019), the Socio-Cultural and Education Module, Village Potential (PODES), and National Labor Force Survey (SAKERNAS 2016).

In 2013, BPS received technical support from the United Nations Population Fund (UNFPA), UNICEF (for child disability inclusion) and World Health Organisation (WHO), and in close consultation with BAPPENAS, Kemensos, Kemenkes and various DPOs, adapted the Washington Group (WG) short set questions to develop national instruments (standard questionnaires and field guidelines) for the Special Survey on Disability, for the whole population including children. The questionnaire, as well as the survey guidelines, were prepared with reference to the Washington Group on Disabilities. There are three types of questionnaires, namely for children of 2 – 17 years old, adults of 18+ years old, and for families and households not only to collect disability data but also wider information on the causes of disability and access to basic services. The survey was piloted in 2015 in three areas (Jakarta, Bekasi, Bogor).

Despite its global use in identifying disabilities, including among children, the WG SS Questionnaire does not accurately capture the degree of functional difficulty, particularly for children under five years of age, because of the following limitations²⁸:

- Potentially misses some children with developmental issues aged 5-18
- Misses those with psychosocial issues that do not affect communication, cognition of self-care
- Does not capture age of onset
- Does not directly capture environmental barriers
- Does not address functioning with and without assistive devices.

In response to these limitations, UNICEF worked with the WG to develop the Module on Child Functioning in 2016 that is suitable for child disabilities identification for children between 2 and 17 years of age. Measuring child disabilities should be differed from adults for the following reasons²⁹:

- Children are in a process of development and transition, thus not all the WGSS domains are applicable to young children nor do they cover the full range of domains of particular interest in child development;

²⁸ Washington Group Secretariat, [2021](#)

²⁹ Cialesi, R, [2012](#)

- Child development does not follow a fixed schedule – there is natural variation in the attainment of functional skills;
- Disability measurement often takes place through the filter of a parent or other adult.

The questions are designed to target a child's mother or primary caregiver³⁰ divided into two modules, for children aged 2 to 4 years old and for children aged 15 to 17 years old. The questions cover functioning domains of hearing, vision, communication/comprehension, learning, mobility and emotions. In addition to this collaboration to develop disability data collection instruments, there was no data collection using follow-up utilising the instruments due to lack of availability of funding.

Apart from the intent for improving disability data collection instruments, Kemenkes has consistently collected disability data through the national basic health research survey (Riskesdas) in collaboration with BPS in 2007, 2013 and 2018. The questionnaire, however, has modified responses from supposed to be 4 to 5. The Riskesdas resulted in fluctuating national disability prevalence at 25%, 11% and 22%³¹ for the respective years.

³⁰ GIZ and Hauschild, [2017](#).

³¹ Adioetomo, Mont and Irwanto 2014; Kemenkes Riskesdas 2018

Table 1. Disability Categories Across Censuses and Surveys³²

CENSUS AND SURVEY	POPULATION CENSUS (SP) 2010	VILLAGE POTENTIAL (PODES) 2011, 2014, 2018	BASIC HEALTH (RISKESDAS) 2013 and 2018	INTER CENSAL SURVEY (SUPAS) 2015	NATIONAL LABOUR FORCE SURVEY (SAKERNAS) 2016	NATIONAL ECONOMIC SURVEY (SUSENAS) 2012
Data Producer	BPS	BPS	MoH	BPS	BPS	BPS
Measurement of disability	Difficulty in seeing, hearing, walking/climbing, remembering, or concentrating, or communicating with others, and self-care even after using disability aids (for seeing and hearing)	Asking village officers on the number of people with disabilities in the village for 9 types of disability: blind, deaf, mute, physical, intellectual, psychotics, leprosy, and mental disabilities	Adapting 12 questions from WHODAS 2 as an operationalization of ICF. Riskesdas uses broader definition of disability	Short questionnaire from modified WGS	Difficulty/disorder in seeing, hearing, walking/climbing (mobility), using/moving fingers/hands, speaking and/or understanding/communicating with others, other disability (e.g. remembering, concentrating, emotion, self-care, etc.)	Dysfunction/limitation in disability in seeing (even after using glasses), hearing (even after using hearing aids), communicating with others (in term of speaking), remembering/concentrating, walking/climbing, and self-care
Disability Identification Questionnaires	Adopted the WG SS, modified with remembering/concentrating and the	Did not use WG Questions, used the impairment concept.	Riskesdas 2018 used 3 sets of different questions for 3 age groups (5-17, 18-59, and above	Adopted 8 WG Short Set Questions with modified responses	Used a combination of the medical definition and functioning	Adopted WG functioning domains and added two more questions but the response

³² ILO, 2017

	communicating domains as a combined question; modification of responses about the level of difficulty ³³		60) ³⁴ . Identification of children with disabilities used 10 questions and 5 options adopted from WG (similar to Unicef's MICS) but the response categories differ from WG recommendations . Identification of elderly with disabilities used assessment questions referred to Barthel Index of Activities of Daily Living (ADL) ³⁵			difficulties (WG). Modified WG responses	categories differ from that recommended by the WG
Level	HH and individuals	Village (HH & individuals)	HH	Individuals	Individuals	Individuals	HH

³³ Cameron and Suarez, 2017.

³⁴ SMERU, 2020.

³⁵ [Barthel Index for Activities of Daily Living \(ADL\)](#) is a tool to assess functional independence, generally in stroke patients.

Non-state actors' data

In addition to government data, there is also another survey made available by RAND and SurveyMeter, the Indonesian Family Life Survey (IFLS)--albeit that this survey is not specifically designed to understand disability issues. It is, nevertheless, a rich source of information about health and physical conditions of households, and it allows identification of disabled individuals using a medical definition of disability. The survey also includes a section on characteristics that follows the WG questionnaire in principle but is widely expanded: *“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)”*³⁶.

In collaboration with TNP2K, the Demographic Institute of the University of Indonesia also conducted an ad-hoc survey called the Survey on the Need for Social Assistance Programs for People with Disabilities (SNSAP-PWD 2012)³⁷. SNSAP-PWD 2012 does not only provide information on the type of disability, but also information on the causes of the disability. It also provided information on the limited opportunities experienced by persons with disability to participate in community activities. In a sense, the survey highlighted the needs and living conditions of persons with disability in Indonesia which are missing from the country database.

Apart from statistics, there are a lot of other more robust or nuanced data and assessments collected by non-state actors to complement the absence of reliable disability statistics. This data collection process is conducted either on a smaller scale (not at the national level) or ad-hoc. One example is as follows: in light of COVID-19, a network of DPOs organised an ad-hoc COVID-19 Response (Disability) Task Force that researched the impact of the COVID-19 pandemic on the daily life of persons with disabilities, the challenges those individuals face as well as inclusiveness of social assistance schemes. The research covers 261 kota/kabupaten in 32 provinces and involved disability organisations as enumerators. Only aggregated and processed data is available from this research, but this initiative also resulted in further research and collaboration with other research centers such as Economic Impacts and Access to Social Protection during the COVID-19 Crisis³⁸ by Australian DFAT-funded program MAHKOTA.

Research from non-state actors can also provide important insights on the interconnectedness between disability and other sectors, analysis that is otherwise unavailable in Indonesia. One example is the Individual Deprivation Measure (IDM), a multi-country gender-sensitive and multidimensional measure of poverty developed by Australian National University (ANU) and the International Women's Development Agency,³⁹ which was trialled in South Sulawesi in 2018. Despite having only a small sample, IDM has a lot of dimensions in its questionnaire, including disability, gender, and others, and through its cross-analysis it is able to identify the deprivation that women with disabilities face in relation to poverty--in particular, relating to work, family planning, and sanitation. Similar to IFLS, IDM is

³⁶ Cameron and Suarez, [2017](#).

³⁷ Priebe and Howell, [2014](#).

³⁸ MAHKOTA Program, [2020](#).

³⁹ Bexley and Bessell, [2020](#)

not specifically designed to assess disability, but is nevertheless useful in providing additional disability data beyond prevalence statistics.

Innovation in disability data collection models has also been piloted and recorded in the PEDULI program⁴⁰. The innovations tested out by six NGOs (including two DPOs) aimed to improve the data collection processes to be more disability friendly. The recommended practices include new approaches for modified procedures of registration (civil registration offices are not accessible in many regions in Indonesia), registration forms, data collection tools/instruments, and technical recording (especially for electronic identity), a type of identity for people with disabilities that is not disability-friendly, and community participation in the data collection process.

Aside from contributions of non-state actors for promoting availability, quality and accessibility of disability data, a number of DPOs and NGOs also work to provide evidence to advocate disability inclusion development, capacity building, and partnerships in Indonesia. GIZ, Christian Blind Mission (CBM), Netherlands Leprosy Relief (NLR), Hellen Keller, and Australian DFAT have made it mandatory for all their funded programs to mainstream Gender Equality Disability and Social Inclusion (GEDSI)--in the case of DFAT through umbrella programs such as MAMPU (Australia Indonesia Partnership for Gender Equality and Women's Empowerment), PROSPERA (Australia-Indonesia Partnership for Economic Development) and KOMPAK (Australia funded program on Governance for Growth).

SDGs indicators and disability data

In the context of SDGs, in Indonesia, PP 70/2019⁴¹ identifies six SDGs as goals that are specifically relevant in planning programs to benefit people with disabilities: goal 1 (Poverty), goal 4 (Education), goal 8 (Economic Development), goal 10 (Inequality), goal 11 (Sustainable Cities), and goal 16 (Peace). However, when one examines in more detail, there is more nuance to this inclusion of disability to SDGs indicators, as can be seen below. The table below includes analysis based on the latest national SDGs metadata⁴².

Table 2. Reference to disability data on National SDGs Metadata (RAN 2017 and 2020)

Indicator in RAN 2017	Present in RAN 2020? ⁴³	Reported in SDGs Report 2019 (published Q4 2020)	Source of data
<i>Disability as disaggregation</i>			

⁴⁰ PEDULI is a DFAT-funded program aimed to promote a social movement of CSOs and communities in realising social inclusion development in Indonesia, including targeting specific vulnerable groups such as persons with disabilities.

⁴¹ Setneg, [2019](#).

⁴² The table below includes analysis based on the latest national SDGs metadata 2017 and 2020.

⁴³ Reference from Bappenas' guidelines to develop RAN: [2017](#) (version I) and [2020](#) (version II).

<p>1.3.1 Proporsi penduduk yang menerima program perlindungan sosial, menurut jenis kelamin, untuk kategori kelompok anak berkebutuhan khusus, pengangguran, lansia, penyandang difabilitas, ibu hamil/melahirkan, korban kecelakaan kerja, kelompok miskin dan rentan.</p> <p><i>Proportion of the population who received social protection, disaggregated by sex, for groups of children with special needs, unemployed, elderly, persons with disabilities, pregnant/lactating mothers, survivors of occupational accident, poor and vulnerable groups.</i></p>	Yes	No	DTKS, Kemensos
<p>10.2.1 Proporsi penduduk yang hidup di bawah 50 persen dari median pendapatan, menurut jenis kelamin dan penyandang difabilitas.</p> <p><i>Proportion of the population who live below 50% of income median, disaggregated by sex and persons with disabilities.</i></p>	Yes	Yes	Susenas, BPS
<p>11.2.1 Proporsi populasi yang mendapatkan akses yang nyaman pada transportasi publik, terpilah menurut jenis kelamin, kelompok usia, dan penyandang disabilitas.</p> <p><i>Proportion of the population with proper access to public transportation, disaggregated by sex, age group, and persons with disabilities.</i></p>	Yes, identified as indicator that is yet to be measured (will have proxy)	No	N/A, national indicator is yet to be developed
Disability data			
<p>1.3.1.(c). Persentase penyandang disabilitas yang miskin dan rentan yang terpenuhi hak dasarnya dan inklusivitas.</p>	No, deleted	Yes	DTKS, Kemensos

<i>Percentage of poor and vulnerable persons with disabilities whose basic rights and inclusiveness have been fulfilled.</i>			
<p>4.a.1.* Proporsi sekolah dengan akses ke: (d) infrastruktur dan materi memadai bagi siswa disabilitas.</p> <p><i>Proportion of schools with access to: (d) adequate infrastructure and materials for students with disabilities.</i></p>	No, deleted	No	Dapodik and Statistik Pendidikan, Kemendikbud

Table 3. New references to disability data on National SDGs Metadata in RAN 2020

New indicator in RAN 2020	Source of data
<i>New metadata available in RAN 2020 -- disability as disaggregation</i>	
<p>4.5.1 Rasio Angka Partisipasi Murni (APM) pada tingkat SD/ sederajat, dan (ii) Rasio Angka Partisipasi Kasar (APK) pada tingkat SMP/ sederajat, SMA/ SMK/ sederajat, dan Perguruan Tinggi untuk (a) perempuan/ laki-laki, (b) pedesaan/ perkotaan, (c) kuintil terbawah/ teratas, (d) disabilitas/ tanpa disabilitas.</p> <p><i>Net Enrollment Rate (NER) Ratio at Primary Education (SD/ equivalent), and (ii) Gross Enrollment Rate (GER) at Secondary Education (SMP/ equivalent), Senior Secondary (SMA/ SMK/ equivalent), and Higher Education for (a) female/ male, (b) rural/ urban, (c) bottom/ top quintile, (d) persons with disabilities and without disabilities.</i></p>	N/A, indicator is yet to be developed (will have proxy)
<p>11.7.2 Proporsi orang yang menjadi korban kekerasan atau pelecehan seksual menurut jenis kelamin, usia, status disabilitas, dan tempat kejadian (12 bulan terakhir).</p> <p><i>Proportion of survivors/ victims of violence or sexual harassment according to gender, age, disability status and location of the incident (last 12 months).</i></p>	N/A, indicator is yet to be developed (will have proxy)

There are a number of insights that one can observe from these findings. First, on changes between disability-related indicators included in RAN 2017 and 2020: there are two new national indicators included in the new RAN, one each on goals 4 and 11. However, it is worth noting that all disability data required or referenced in RAN 2020⁴⁴ are about disaggregation: they are other sectors' datasets that are to be disaggregated by people with disability. While this in itself is of course better than nothing, the GOI decision to eliminate two national indicators that are specifically about disability data (not disaggregation by people with disability) negates the possibility of mandating relevant government agencies to collect data specific on disability (beyond disaggregation and beyond disability prevalence).

This raises the following issue: it is unclear why the two disability-specific data points which existed in RAN 2017 were eliminated from the latest RAN. RAN 2020 has more indicators than its predecessor, with the GOI continuing to adopt more global SDGs indicators to the national system, which even further contradicts the omission of the two crucial indicators in the disability sector. At the time of researching this report, conversations with an official from the Directorate of Religion, Education, and Cultural Affairs at Bappenas were not able to clarify the considerations behind it. As discussed with the source at Bappenas, one likely possibility is that the data required by these indicators is not available in Indonesia, but further probes might be required, considering that absence of data does not always lead to omission of indicators:

- Indicator 11.2.1, which is yet to be developed (thus, no measurement/no data yet) since RAN 2017, is still included in RAN 2020;
- Indicator 1.3.1.(c) has data available in Indonesia (reported in SDGs report 2019), but was still deleted from RAN 2020.

The tables above also show that not all disability-related indicators included in RAN 2017 are reported in the 2019 SDGs report (published in Q4 2020), for example, indicator 4.a.1(d) on proportion of schools with inclusive learning infrastructure for students with disability. Again, there is a possibility that the GOI does not have enough data for 4.a.1(d), which eventually led to the absence of the reporting and the deletion of the indicator; however, Dapodik *does* collect data on inclusive infrastructure, material, and support to students with disability from schools that record its *Program Inklusi* to the system and thus are registered as institutions that conduct inclusive teaching and learning.⁴⁵ The reason why it is unreported is thus unclear.

Moreover, while the issues discussed here are about availability of disability-related indicators and their data (underreported and omitted from the new RAN), that does not mean that there is no issue with the quality assurance process of the data. As discussed in the Situational Analysis on the State of Data, DTKS and Dapodik (the source of data for three indicators above) have issues that worsen their state of data in terms of availability and quality

⁴⁴ Five indicators in RAN 2020 with explicit reference to people with disability: 1.3.1, 10.2.1, 11.2.1, 4.5.1, 11.7.2 (Bappenas, 2020).

⁴⁵ Kemendikbud collected 9 data points on schools and students with disability, including types of disabilities present in respective schools, infrastructure and accessibility, health track records, academic records of students with disability, and others (Dinas Pendidikan Kab. Purwakarta, 2018; Kemendikbud, 2020; Permen Kemendikbud 70/2009).

assurance process: DTKS with its unclear updating scheme and risk of data security, and Dapodik with its underreporting during the COVID-19 pandemic. There is also limited evidence on the quality assurance mechanisms for both DTKS and the self-reported Dapodik.

Lastly, when going forward with the RAN 2020, it is crucial that the GOI develops clear proxies and ways to measure the indicators that still have to be developed, in order to avoid the GOI omitting other disability-related indicators in the future (both indicators which have disability as disaggregation or disability-specific indicators). Alignment between PP 70/2019 and the RAN also has to be strengthened: currently, goal 8 and goal 16 that are listed as specifically relevant in planning programs to benefit people with disabilities in PP 70/2019 are also yet to be included in RAN 2020.

The state of disability data and its challenges

Having identified the disability data produced in Indonesia, a larger question emerges: what is the state of those datasets? The following section presents the analysis of the state of disability data in Indonesia and, more importantly, identifies the underlying issues behind it.

The issues of mandates among GOI agencies and data disintegration

From the previous sections we can see that a number of stakeholders are involved in disability data collection, with Kemensos as the main mandate holder for the sector. That said, some of the key statistics on disability, such as SUSENAS and the Population Census are produced by BPS. According to a conversation with an official from BPS, the national government aims to provide an identity card for people with disabilities, which allows them to access designated programs. However, for this to be realised and implemented, the GOI has to be able to build the registry system based on the census data, and thus reconcile the census data from BPS with the administrative data managed by Kemensos, which currently only lists the poorest 40% of population but is to be expanded to 100% of the population in Indonesia (not only the poor)⁴⁶. With disability being the sole responsibility and mandate of Kemensos, though, there is a lack of clarity on whether BPS has the authority to drive the process and work with Kemensos to become the primary disability data producers.

There is also a need to monitor the progress of *Rencana Induk Penyandang Disabilitas* (RIPD) as per PP 70/2019. Unclear responsibilities among GOI agencies that exacerbate data issues are also shown in the RIPD planning document. As discussed in the previous section, there are several data-related targets as part of the RIPD, for example, ensuring that all people with disability are included in the Dukcapil data record. However, more importantly, the data that should exist following specific target outcomes that RIPD demands are: i) the baseline of the RIPD target outcomes, and ii) the extent to which RIPD is achieved, several years from 2019 when it was signed. At the moment, this is unlike the *Rencana Pembangunan Jangka Menengah Nasional* (RPJMN), which draws clear responsibilities and data sources from which it will be monitored⁴⁷. It is unclear which GOI agency has the mandate to conduct the RIPD baseline, which agency should provide the data (unclear source of data), and there is no

⁴⁶ Based on the interview with the team managing DTKS at Kemensos (during the previous research).

⁴⁷ Specific indicators and line ministries responsible for the implementation (and reporting) are mentioned in both the RPJMN planning document (see example for [2020-2024](#)) as well as evaluation (BAPPENAS, [2017](#)).

indication whether the data is currently available. There is also an indication that RIPD is to be broken down in detail in a *Rencana Aksi Nasional Hak Penyandang Disabilitas*, which means there could be more details in division of roles, responsibilities, and mandates on the issue among GOI agencies. But this document is also yet to be developed⁴⁸.

Dynamics between responsible agencies in the sector are further exacerbated by the fact that different GOI agencies and line ministries have different focuses and ways in approaching disabilities issues. For example, Kemensos sees disability as a social welfare problem (along with street children, sex workers, ethnic minority groups, children dealing with laws, homeless/homeless with psychosocial disorders, to name a few)⁴⁹. The end goal of the policies is for the people with disability to be assisted, rehabilitated, and protected in order to be accepted by society⁵⁰.

For Kemenkes, the perspective is more about prevention and cure of disease and disability through health interventions (for example, medications to prevent worsened conditions of the disability⁵¹) and provisions of health services for those with mental illness. Its mandate is largely in creating comprehensive health for the community so that future generations will be healthier and have minimal disabilities⁵².

This tug-of-war in approaching disabilities can have a number of implications, one of which is potential difficulties to reconcile definitions and methodology to determine the key aspects of disabilities that the GOI has to measure. In light of Satu Data, which targets an integrated approach in managing and governing data, this presents a challenge. Not to mention that this can become a root of inconsistencies across disability data in Indonesia (as explained in the next subsection), which has been acknowledged by the Vice President⁵³.

Different disability definitions & deviation from WG data collection instruments and methodologies used in data collection by different institutions resulting in limited accuracy and comparability

As previously explained, different approaches to disability issues by different government agencies lead to the fact that data collections conducted by different agencies, such as BPS, the Ministry of Social Affairs, and the Ministry of Health employ different data categories of disability, modified questions and measure different levels of subjects (individual and household levels), as seen in Table 1 above. Censuses by the BPS, for example, capture only a small proportion of people with disabilities and identify individuals with different levels of functioning domain. Surveys conducted by the Ministry of Health have collected disability data at the household level using a medical approach, which may lead to under-reporting as not all disabilities can be defined and diagnosed as medical impairment. Thus, different data

⁴⁸ Kemensos, [2020](#).

⁴⁹ Kemensos refers to people with disabilities as '*penyandang masalah kesejahteraan sosial*' or PMKS, or people with social and welfare problems (Kemensos, [n.d.](#))

⁵⁰ Law 11/2009 (Article 5, 6) includes people with disability as one of the groups with "social problems" thus becoming one of the targets to receive social welfare programs, including social rehabilitation and protection, among many others. (Kemensos, [n.d.](#); Setneg, [2009](#)).

⁵¹ Kemenkes, [2016](#).

⁵² Kemenkes, [2013](#).

⁵³ Kuswandi, [2021](#).

collection may be good for use only for specific purposes but validation and comparability are limited and consequently have resulted in significant differences in disability statistics and prevalence.

Moreover, although data collection modules in SUSENAS, RISKESDAS, SUPAS, IFLS, PODES and Population Census are modified from the Washington Group Short Set Questions (WGSS), the disability definition and instruments are further adjusted and implemented differently by various government agencies (see Annex I). This further complicates cross-regional comparison of similar indicators. For example, based on the 2010 Census, disability prevalence rates were around 4.3% (for mild and severe disabilities) while the 2007 National Basic Health Research (RISKESDAS) recorded more than 25%. Both surveys consistently applied the Washington Group's recommendations. However, RISKESDAS has more extensive questions (compared to the 2010 Census), and this might be driving the discrepant results of disability prevalence from both surveys⁵⁴. Not to mention that even one type of survey (SUSENAS or RISKESDAS) could have different disability definitions and prevalence across data collection intervals, in order to reflect the shifts in the social and national development agenda, for example from charity to more equitable, inclusive, and universal social protection. This is perceived to negatively hamper sectoral coordination and monitoring of program reach and effectiveness.

Another factor in the methodology that contributes to the different figures of disability prevalence is the fact that different surveys have used different age groups in their calculation. Kemenkes for example, used a breakdown of 'Anak' (Children) (5-17 years old), 'Dewasa' (Adult) (18-59 years old), and 'Lanjut Usia' (Elderly) (>60 years old) in calculating disability prevalence in 2019 RISKESDAS survey, but back in 2010 it measured aged 24-59 months for category of Children, and 18 years old or over for Adult in 2013. BPS and Kemensos have different age groups thresholds as well, above 2 years old and above 15 years old, respectively. More details are available in the footnote section of Table 4.

This resulted in inconsistencies in disability prevalence figures in Indonesia. For example, Kemensos states that in 2010 over 11 million people in Indonesia had disabilities: over 3 million visually impaired; 2.5 million hearing impaired, 3 million physically disabled; 1.4 mentally disabled; and 1.2 chronically disabled⁵⁵. However, Kemnaker registered only 7.1 million people with disabilities in the same year.⁵⁶ Alternatively, analysis by TNP2K states that based on its analysis on Kemenkes RISKESDAS 2007 data, 11% of the population (around 25.5 million) has a moderate to severe disability; however, if light disabilities are included in estimates, the number then soars to over 25% of the population (58 million)⁵⁷. But BPS' reports a few years afterwards (SUSENAS 2012) identified only 2.31% (approx. 5.8 million) of the population have a disability.⁵⁸ So, as we can see from this snapshot, existing statistics on disability in Indonesia reflect inconsistent definitions, as well as inaccurate and/or incomplete data. It also raises questions if compared to the internationally accepted calculations: The

⁵⁴ Adioetomo, Mont, and Irwanto, [2014](#).

⁵⁵ ILO, [n.d.](#)

⁵⁶ BPS, [2020](#).

⁵⁷ Adioetomo, Mont, and Irwanto, [2014](#). Indonesia's population in 2007 was 232.4 million (World Bank, [2007](#)).

⁵⁸ TNP2K, [2020](#). Indonesia's population in 2012 was 248.5 million (World Bank, [2012](#)).

World Health Organisation (2011) estimates that about 15% of the world population has a disability⁵⁹, which would imply that almost 38 million Indonesian citizens have some form of disability, adding yet another figure of disability prevalence that is different from the others.

The charts and table below further show how different disability prevalence could be, depending on which survey the GOI uses.

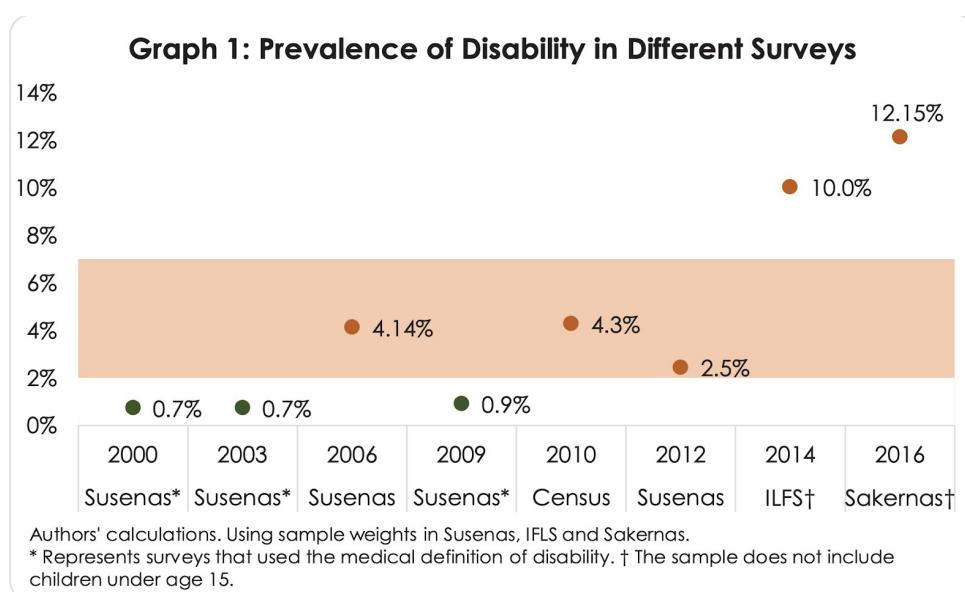


Figure 1: Prevalence of disability in different survey⁶⁰

Table 4. Disability Prevalence Across Censuses and Surveys (compiled from various sources)

CENSUS AND SURVEY	POPULATION CENSUS (SP)	VILLAGE POTENTIAL (PODES)	BASIC HEALTH (RISKESDAS)	INDONESIAN FAMILY LIFE SURVEY (IFLS)	INTER CENSAL SURVEY (SUPAS)	NATIONAL LABOUR FORCE SURVEY (SAKERNAS)	NATIONAL ECONOMIC SURVEY (SUSENAS)
Data Producer	BPS	BPS	Kemenkes	RAND & Surveymeter	BPS	BPS	BPS
Data collection Frequency	Per 10 years	Per 3 year	2007, 2010, 2013, 2018	Per wave	Per 10 year between SP	Per semester (Feb and Aug)	Per semester (Mar and Sept)
Disability prevalence (below) 2000-2005					N/A (2005) ⁵⁶		0.69% (2003) ⁶¹

⁵⁹ WHO, 2011.

⁶⁰ Cameron and Suarez, 2017.

⁶¹ BPS, 2020 with a population of 2 years and over for SP 2010 and no information of age group on SUSENAS.

2006-2010	4.45% (2010) ⁵²		21.3% (2007) ⁶²				1.38% (2006) ⁵² 0.92% (2009) ⁵²
2011-2015		0.41% (2011) ⁴⁶	Incomplete (2010) ⁶³ 11% (2013) ⁶⁴	10% (2014) ⁵¹	8.56% (2015) ⁶⁵		2.45% (2012) ⁵²
2016-2020	Not yet available (2020) ⁶⁶		22% (2018) ⁶⁷			12.15% (2016) ⁶⁸	14.2% (2018) ⁶⁹ 9% (2019) ⁷⁰

Disability issues are yet to be fully understood -- which is reflected in what data the GOI currently collects, how it is collected and the unavailability of crucial data

People with disabilities are still not viewed as a mainstream issue in the implementation of the SDGs, but rather seen as a group or community that requires 'separate' analysis instead of being incorporated in intersectional analysis of the development sector in Indonesia⁷¹. In addition to the fact that it is unclear how the GOI would provide data as the baseline for RIPD disability planning as discussed above, the ASEAN Disability Forum also mentioned that there is a lack of data for targets that are already included in the RPJMN: the GOI does not monitor and evaluate the achievement of targets for persons with disability, specifically psychosocial disabilities and leprosy, referring instead to the unavailability of such data⁷².

⁶² Kemenkes, [2007](#) with a population of 15 years and over for the category of 'bermasalah' and 'sangat bermasalah'.

⁶³ Kemenkes, [2010](#) data collection on disability was only collected for children aged 24-59 months (avg. 0.12%).

⁶⁴ Kemenkes, [2013](#) with a population of 15 years and over.

⁶⁵ BPS, [2015](#) with a population of 2 years and over.

⁶⁶ Kemensos, [2020](#). Data collection on disability has become the agenda in the 2021 Long Term population census. The Ministry of Social Affairs requested for the matching of various disabilities in the SP21 long form instrument will be followed up, including the adoption of a survey instrument for persons with disabilities in the Integrated Social Welfare Data (DTKS).

⁶⁷ Kemenkes, [2018](#) for age group 18-59 years old.

⁶⁸ ILO, [2017](#) for population above 15 years old (SAKERNAS).

⁶⁹ Liputan 6, [2020](#) with no further information on the age group or scope are provided.

⁷⁰ TNP2K, [2020](#) with a population of 2 years and over with moderate and severe disability

⁷¹ Analysis from Christian Blind Mission ([2018](#)) based on observation of how disability issues are discussed in Indonesia's SDGs Voluntary National Report 2017.

⁷² ASEAN Disability Forum, [2020](#).

Participants at the FGDs conducted in support of this research argued that lessening the priority for disability issues can be linked to the GOI's limitation in understanding disability issues: when disability is seen as impairment or limitation, the aim of statistics is only to count people with disability, rather than considering how to ensure that they are able to access education, buildings, transportation, employment, health services, legal services, and political participation. Until now, disability statistics remain insufficient as the data collected cannot provide useful information about persons with disability, their needs, capacity and well-being. Not to mention that disability has a wide spectrum. People with disabilities are a diverse group; disabilities vary and affect different people in different ways. This can lead to complexity in measuring disability accurately.

Data on eligibility and coverage of social protection programs are also not readily available and are outdated⁷³. According to a DPO activist who participated in this research, conversations with community facilitators, households with disabilities, and DPOs throughout 2012 to 2014 suggest that even persons with disability are often unaware of these programs. The DPOs also raised a concern of widespread inappropriate targeting of social assistance in the form of one-off supply of assistive devices rather than other in-kind assistance (such as reduced health care expenses or school fees, food, transportation subsidies, housing, and skills training programs) for which they are eligible.

Moreover, given current practices, the government cannot always correctly identify people with disability, does not know how many disabled people are vulnerable or living below the poverty line, and more importantly, what causes their poverty. For example, what do people with disabilities need? Access to finance, physical access, subsidised transport, water and electricity, or telecommunications? Furthermore, the existing poverty measurement could be biased towards people without disability. In targeting the poorest 40% for social protection programs, Kemensos has been using assets to predict the welfare status of a household. Motorcycles and cell phones could be interpreted as luxuries by enumerators, but could arguably be supportive devices for mobility for people with disabilities, including those among the poorest segments.⁷⁴

In order for the Indonesian government to implement a range of social protection support for people with disabilities and ensure the provision of services and rights stipulated in numerous national disability laws, several non-governmental institutions, universities, disability organizations along with their civil society allies have made concrete efforts to address economic and social inequality among populations with disability in the hope of improving data and policy. As raised by several participants in the FGDs conducted in support of this research, there is a need for transformative change and leadership within the government to seriously count its population with disability, beyond basic demographic data like age, sex, disability types, marital status, level of schooling as these data do not tell us much about how they fare in reality.

⁷³ Mont and Irwanto, 2014; JICA, 2015.

⁷⁴ Bachtiar and Sudharta, [2014](#).

Improving the data and measuring what counts requires more robust microdata or even more in-depth qualitative data related to persons with disability—such as what useful skills are needed to earn income, services to function in society, support for family/ households to invest in their child with disability, what support system for those with psychosocial disability and intellectual disability to thrive in society—that matter for the public and the SDGs. This information can be made available through appropriate data collection methodologies. While surveys and censuses require relatively lengthy processes, improvement in the current civil registration or population administration could contribute to better quality and accuracy if the methodologies, tools and instruments are disability-friendly and conducted collaboratively.

To go beyond headcounts and look at what truly matters, Kemensos also needs to address the structural barriers to policy and programming in disability-specific discussions and meetings between government agencies, disability activists and organizations. The proposed solution from disability groups and research institutes calls for effective partnership with civil society, local universities and disability groups to improve the quality of disability research and data⁷⁵. This, however, raises another question: how exactly can non-state actors help? At present, non-state actors might know better than the GOI the barriers people with disabilities face in obtaining services such as health care, education, skills training or employment placement or even access to microfinance. However, the technical and statistical capacity of the NGOs, in particular the Disabled People's Organisation (DPO), remain questionable, as also mentioned by disability issues activists themselves.

The self-identification and prone-to-stigma nature of disability data collection

Data collection processes are prohibitive in terms of cost, time and human resources. Partly due to this, BPS and Kemenkes rely on self-identification based on questions such as: do you have a disability? What kind of disability do you have? SUSENAS and RISKESDAS rely heavily on this type of self-identification questions, which, while commendable, can mean that a significant proportion of those with disabilities may not be counted. For instance, someone with severe intellectual disabilities or with mental health issues may not self-identify as disabled, inadvertently resulting in not being documented.

There are also a number of other reasons why self-identification approaches are problematic and need to be avoided or complemented with a door-to-door approach⁷⁶:

- Stigma, shame and taboo surrounding disability. People with disabilities or households with a disabled member may not want to identify themselves or a family member as having a disability. Family and friends may exhibit a reluctance to acknowledge a relative or friend's disability, also resulting in not being counted.
- Disability is associated with visible major and severe impairments that are easily noticed. This results in people with invisible or mild and moderate impairments being missed out or undercounted.

⁷⁵ J. Yulianto 2014, personal communication, 14 July; F. Nursyamsi 2020, personal communication, 24 April; A. Tsaputra 2021 personal communication, 16 February.

⁷⁶ Mont (2013), in his design document for BPS and TNP2K to include disability questions in the Labour Force Survey

- Elderly with age-related disabilities rarely consider themselves as disabled. The difficulties in activities experienced are seen as due to aging rather than disability.
- Many people do not diagnose themselves with disability, and when asked to self-diagnose, they are unaware that the diagnosis will be able to help them to access healthcare services, thus resulting in data biases.

Exclusion of people with disability from data collection

In the case of CRVS data at Dukcapil, it has been the GOI target in RIPD to include all people with disability into the database in order for them to be able to access programs and assistance whenever needed. Law 8/2016 also lists the right to be registered (*hak pendataan*) as one of the rights of people with disabilities that needs to be respected, protected, and fulfilled. This includes: i) the right to be registered as a citizen with disabilities in the civil registration, ii) the right to civil identification (ID and other related documents), and 3) the right to have a *Kartu Penyandang Disabilitas* (Article 22).⁷⁷ Often unable to have themselves registered through the conventional mechanism of the civil registration system set up by the government, people with disabilities who have no ID cards or other civil documents are denied many of their rights.

Complicating matters, birth registration in Indonesia and the general population administration data system under Kemendagri has been challenging and there is a massive backlog to ensure universal access across the country. UNICEF⁷⁸ estimates that the birth registration rate in Indonesia for under fives is slightly over 70%, meaning that more than a quarter of children under five whose births have been registered with a civil authority do not possess a birth certificate. Reliant on self-registration or self-reporting mechanisms by the family, registering children with disabilities faces geographical and cultural challenges. Many families are reluctant or are not aware of the needs to register their children or themselves as persons with disabilities due to lack of access and/or negative stigma. People with disabilities are excluded from the data collection and registration processes that leaves them undocumented. PATTIRO research⁷⁹ for the PEDULI Program found that some PWDs in Sorong district (West Papua) and West Lombok (West Nusa Tenggara) did not have national ID cards (KTP) because of challenges in self-registration and unavailability of door-to-door registry mechanism for PWD while families and relatives have poor awareness of the importance of the civil registration documents.

Limited disaggregation

Given the fact that the aggregated disability data described above (i.e. national prevalence of disability and disability data in the SDGs) already presents problems, disaggregation of other sector data by people with disabilities are yet to be a priority for the government⁸⁰. As an example, apart from five indicators that specify the needs to include disaggregation by disability, the GOI does not disaggregate its national SDGs indicators data by people with

⁷⁷ Sudarno and Utomo, [2018](#).

⁷⁸ UNICEF, [2019](#).

⁷⁹ Pattiro, [2018](#).

⁸⁰ Christian Blind Mission, [2018](#); ASEAN Disability Forum, [2020](#).

disabilities. For example, there is no data on the number of people with disabilities that have access to national health insurance (indicator 8.2).⁸¹

It is even less likely for the GOI to present robust disability data that is also disaggregated by sex, age, gender, rural or urban location, let alone by migrant or refugee status, and ethnic or religious minority group. Kemenkes provides processed statistics on disability prevalence disaggregated by age, sex, and urban-rural but aggregated only at the national level and no microdata is provided⁸². Even for SUSENAS, which makes its microdata available, the disaggregated data might not be ready. It is possible to create the disaggregation using SUSENAS microdata, for example, by creating cross-tabulations for data from disability questions in SUSENAS with the sex, age group, gender, and geographical attributes of the respondents. However, from an interview with BPS, this might not be statistically ideal: as disability data has a small prevalence⁸³, the sample size would be too small and not representative for further disaggregated analysis.

That said, while the statement in itself is correct, a bigger question should be asked: is it a problem of low prevalence, or because by sampling design the survey is not targeted to specifically represent people with disability? Moreover, the argument of low prevalence preventing more robust analysis should be avoided, in order not to be mistakenly understood as seeing low-prevalent communities as those not entitled to be represented with data. Nevertheless, the current disability data do need more robust methodology in data collection before they can be disaggregated.

Limited evidence of data utilisation and quality assurance

As also discussed in the Situational Analysis on the State of Data in Indonesia, there is a clear-cut utilisation and purpose of administrative data that is designed for social protection programs such as SIMPD (as part of DTKS). Government social protection and social assistance programs rely on this database to monitor and decide how many resources are needed to be disbursed⁸⁴. There seems to be a different matter, however, with statistical data, or in this case, disability prevalence: it is difficult to explain how exactly disability prevalence data would be used beyond descriptive use or providing better understanding of the sector.

In terms of quality assurance, apart from BPS, which employs strict quality assurance mechanisms for its statistics (as discussed in the Situational Analysis), the absence of appropriate quality protocols for SIMPD-DTKS data entry and the fact that the database relies only on the data collected by local governments without cross-verification or comparing with other data sources from other institutions may limit the quality and accuracy of the data. The quality and accuracy may be improved if the DTKS can be set up to be interoperable with SIAK (Population Registry) and potentially used to support disaster response or other rapid-onset assistance programs.

⁸¹ ASEAN Disability Forum, [2020](#).

⁸² Kemenkes, [2018](#).

⁸³ Below 10% (SUSENAS 2019).

⁸⁴ Dinas Sosial Kota Banjarmasin, [2019](#)

Potential data actors beyond the GOI and DPOs

One key important finding identified in the sections above is that non-state actors, in this case DPOs, in particular, can play an important role to support the GOI in: i) collecting nuanced data beyond headcounts, albeit on a small scale and ad-hoc basis, and ii) providing advice to the GOI in terms of how to best understand disability phenomena and what data is best to be collected. United Nations organisations and its specialised agencies have mandates and commitment to assist member states in attaining the equality of all people including PWD. The role of the UN as the custodian agencies of the global SDGs data indicators positions the UN as an important global advocate for inclusive and sustainable development. International Development Cooperation Organisations (e.g. GIZ, DFAT, JICA) have contributed to the work with the availability of funding, technical assistance, and partnerships.

As the demand for applied, policy relevant research to support evidence-based disability inclusion policy making is increasing among inclusive development actors and institutions,⁸⁵ local universities and organizations serving disabilities are also starting to accumulate requisite knowledge and evidence to contribute to district and national governments' priorities in inclusive social development programs and to serve as a nexus of applied disability research and knowledge. Think-tank organisations such as PUSKAPA, SMERU Research Institute, and PATTIRO that have interests and research experience in disability issues can be information partners (and *knowledge makers*) in policy influence on disability inclusion.

Some local universities, such as Universitas Indonesia's Research Center for Disability⁸⁶, Universitas Negeri Yogyakarta (UNY) Center of Studies for Disability Services⁸⁷ and Universitas Brawijaya's Research Center for Disability Services⁸⁸ have started to produce social research on the situations of persons with disabilities and factors perpetuating disabling conditions of persons with disability. When disability studies within tertiary institutions are allowed to grow and mature over time, a range of perspectives and multiple approaches to knowledge that is critical, intersectional, respectful and emancipatory will be readily available. Academics, the government and development actors can work better together in creating practical knowledge and data that advance equality and sustainability.

Going forward: potential pathways

Saraswati has outlined--in a separate report--potential pathways for disability data improvement based on consultations with the UNCT and disability experts. The potential pathways are presented as recommended steps for the UNCT in Indonesia to develop a use-case on disability data in Indonesia.

⁸⁵ Duran, 2017; Data4Now, 2020.

⁸⁶ Research Center Universitas Indonesia, [2012](#).

⁸⁷ Universitas Negeri Yogyakarta, [2017](#).

⁸⁸ Kompas, [2020](#)

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Annex 1. Modified Washington Group Questions in SUPAS, SUSENAS and RISKESDAS

SURVEY/ CENSUS	# of QUESTIONS ASKED	RESPONSE SCALE	AGE
SUPAS 2015	6 questions related to <ol style="list-style-type: none"> sighting hearing walking/ climbing stairs using hands/ fingers remembering/ concentrating behaviors/ emotional disorders speech/ communicating with others 	<ol style="list-style-type: none"> Always (selalu mengalami kesulitan) Often (seringkali mengalami kesulitan) Slight (sedikit mengalami kesulitan) No difficulty 	10+
SUSENAS 2019, 2020	8 questions related to <ol style="list-style-type: none"> sighting hearing walking/ climbing stairs using hands/ fingers remembering/ concentrating behaviors/ emotional disorders speech/ communicating with others caring for self 	<ol style="list-style-type: none"> cannot do at all much difficulty slight difficulty no difficulty 	2+
RISKESDAS 2018	5 core WG functioning screening questions and other questions related to self-care as well as for emotional/psychological functioning (specifically emotions, behaviour, attention and coping with change).	<ol style="list-style-type: none"> none mild (ringan) moderate (sedang) severe (berat) very severe (sangat berat) 	2-5 5-17

Reference: Form Questionnaire SUPAS, SUSENAS, and RISKESDAS

Annex 2. List of Key Informants

No	Name	Institution	Title	Roles
1	Ekawati Liu	The Asia Foundation	Disability Inclusion Specialist	Disability Experts/ Facilitators (Jan-March 2021)
2	Ishak Salim	the Indonesian Difabel Movement for Equality (PerDIK)	Chair / Independent Researcher	
3	Eva Rahmi Kasim	the Ministry of Social Affairs (Kemensos)	Head of the Social Welfare Research and Development Center	Participants of Group Discussion 1 (16 February 2021). See documentation here
4	Indra Gunawan	the Ministry of Social Affairs (Kemensos)	Head of Section for Social Rehabilitation of People with Psychiatric Problems	
5	Emma	the Ministry of Social Affairs (Kemensos)	N/A	
6	Sunarman Sukamanto	Presidential Staff Office (KSP)	Associate Expert Staff for Law and Human Rights	
7	Sinta Satriana	J-PAL/MAHKOTA	Social Protection Policy Specialist	
8	Cindy Hidayati	J-PAL/MAHKOTA	N/A	
9	Antoni Tsaputra	N/A	Disability Academics	
10	Nahar, SH, MSi,	Ministry of Women Empowerment and Child Protection (KPPPA)	Child Protection Deputy	
11	Nora Kartika Setyaningrum	Ministry of Manpower (Kemnaker)	Acting (Plt.) Director of Placement of Domestic Workers (PTKDN)	Participants of Group Discussion 2 (18 February 2021). See documentation here
12	Joni Yulianto	Australia-Indonesia Partnership Justice (AIPJ) 2/ Inclusion and the Disability Advocacy	Consultant/ Board	

		Movement (SIGAB)		
13	Colley Windya Tyas Buwana	J-PAL/MAHKOTA	Research Manager	
14	Jonna Aman Damanik	Indonesian Inclusive Institute/ FORMASI Disabilitas	N/A	
15	Endra Dwimulyanto	SurveyMETER	Research Staff	
16	Patricia Bachtiar	DFAT Australia	Senior Manager	E-mail (February-March 2021)
16	Patricia Bachtiar	DFAT Australia	Senior Manager	
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