







**Embracing Diversity and Inclusion for All: Landscape Analysis on Children with Disabilities in Indonesia** 



Hati Cinta Harapan



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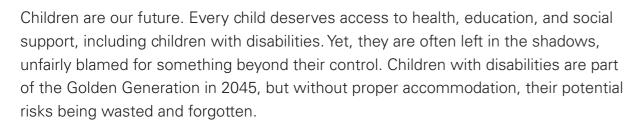
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Embracing Diversity and Inclusion for All: Landscape Analysis on Children with Disabilities in Indonesia

## **Foreword**

#### Maliki, ST, MSIE, Ph.D

Deputy Minister for Population and Manpower Ministry of National Development Planning, BAPPENAS



We are proud to collaborate with the SMERU Institute and UNICEF in conducting this research to highlight the institutional issues facing children with disabilities. Through our partnership with development partners and academics, the Government of Indonesia continues its efforts towards inclusive development. We have ratified the UN Convention on the Rights of Persons with Disabilities and developed Law Number 8 (2016) on People with Disabilities. This law is further detailed in Government Regulation Number 70 (2019) on Planning, Implementation, and Evaluation of the Respect, Protection, and Fulfillment of the Rights of Persons with Disabilities, which includes the Master Plan for Persons with Disabilities as a demonstration of our commitment to inclusivity.

Despite these efforts, the results of this study reveal that much work still needs to be done for children with disabilities. They continue to face unique challenges, such as limited access to education, social stigma, and health inequity.

This report serves as a reminder of our responsibility to ensure the inclusion of children with disabilities in national development efforts. However, achieving this goal requires the support and assistance of all stakeholders to foster an inclusive environment for all children. We anticipate that the insights provided by this research will support addressing the challenges in terms of regulations and programs, ensuring that children with disabilities have equitable access to services.

As we envision Indonesia in 2045, we hope for a future where no potential is lost, and no child is forgotten.



## **Foreword**

#### Maniza Zaman

UNICEF Representative in Indonesia



The Landscape Analysis on Children with Disabilities breaks ground as the first analytical report about children with disabilities in Indonesia. It is a significant contribution to knowledge and data in Indonesia on the situation of some of the most vulnerable children in the country and the factors that contribute to their daily challenges.

In Indonesia, children with disabilities and their caregivers face an array of obstacles to access essential services, including education, health, nutrition, water and sanitation, social and child protection services. Fifty-four per cent of girls with disabilities are stunted, only 62 per cent of children with disabilities are immunized and 36 per cent of children with disabilities are not attending school. These figures attest to significantly greater deprivations faced by children with disabilities when compared to the situation of children living without disabilities.

It is encouraging that there are several initiatives to support children with disabilities and their families. These initiatives materialize through a synergy of government efforts and strong support networks of civil society and organizations of persons with disabilities. Over the last decade, there have been positive developments in Indonesia's legislation for children with disabilities, including the shift towards a rights-based approach. However, more needs to be done to strengthen implementation of disability-inclusive policies. The government of Indonesia can make further progress through the implementation of the National Master Plan on Persons with Disabilities. This strategic action plan contributes significantly towards the realization of the UN Convention on the Rights of Persons with Disabilities in Indonesia.

The report identifies policy adjustments and interventions required at various levels, therefore serving as an invaluable reference for policymakers, researchers, professionals, child rights advocates, organizations of persons with disabilities, parents and all those committed to addressing the challenges faced by children with disabilities in Indonesia. The findings provide a lens through which we can better understand the challenges that children with disabilities face, and how we can collaboratively address them. The full and meaningful inclusion of children with disabilities is pivotal for the comprehensive achievement of the Sustainable Development Goals, ensuring that no one is left behind in the pursuit of national and global development.

Our aspiration is that the evidence in this report will inform and shape government policies, planning and budgeting to support the fulfilment of the rights of children with disabilities and their full participation and inclusion in society. With political will, multistakeholder collaboration, inter sectoral coordination, understanding and resources we can create more inclusive environments for every child.

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## **Acronyms**

**ARI** Acute Respiratory Infection

**CLTS** Community Led-Total Sanitation

**COVID** Coronavirus Disease

**UNCRPD** United Nations Convention on the Rights of

Persons with Disabilities

**DFAT** Australian Government's Department of Foreign

Affairs and Trade

**DRR** Disaster Risk Reduction

**EMIS** Education Management Information System

**GDP** Gross Domestic Product

**GEDSI** Gender Equality, Disability and Social Inclusion

**GIZ** Deutsche Gesellschaft für Internationale

Zusammenarbeit

**Gol** Government of Indonesia

**ICF** International Classification of Functioning,

Disability and Health

IDR Indonesian Rupiah

**MHH** Menstrual Health and Hygiene (to use capital for the

sword Health and Hygiene)

MoECRT Ministry of Education, Culture, Research and

Technology

**MoH** Ministry of Health

**MoHA** Ministry of Home Affairs

**MoNDP** Ministry of National Development Planning/National

Development Planning Agency

**MoPWPH** Ministry of Public Works and Housing

MoRA Ministry of Religious AffairsMoSA Ministry of Social AffairsMoT Ministry of Transportation

**MoWECP** Ministry of Women Empowerment and Child

Protection

NTT East Nusa Tenggara

**OPD** Organization of Persons with Disabilities

RAD PD Regional Action Plan on Persons with DisabilitiesRAN PD National Action Plan on Persons with Disabilities

**RIPD** Master Plan on Persons with Disabilities

**SDG** Sustainable Development Goals

**UN** United Nations

**UNICEF** United Nations Children Fund

**USD** United States Dollar

**WASH** Water, Sanitation and Hygiene

**WFP** World Food Programme

**WG** Washington Group on Disability Statistics

**WG-SS** Washington Group Short Set of Questions

**WG/** Washington Group/

**UNICEF CFM** UNICEF Child Functioning Module

**WHO** World Health Organization

# **Executive Summary**

The purpose of the Landscape Analysis on Children with Disabilities in Indonesia was to present the situation of children with disabilities with regards to the fulfilment of their rights in Indonesia. The evidence generated on the evolving legislation framework, implementation of legislation and the impact on the lives of children with disabilities, as well as the resulting recommendations can inform the work of different stakeholders, including the Government of Indonesia (GoI), UNICEF, development partners and civil society including organizations of persons with disabilities (OPDs).

## **Key findings**

Indonesia is taking a rights-based approach to disability legislation development. The analysis found that, although laws and regulations are in place to protect the rights of children with disabilities, policies are not well implemented and children with disabilities experience inequity compared to children without disabilities when accessing services and programmes in Indonesia. The lack of coordination across ministries and agencies at different levels of government hampers efforts to implement the complex legislative framework and limits the harmonization of approaches. Disability-related terminology and concepts are not consistent across ministries and stigmatizing language related to disability is still evident in legislation and policies.

Survey data suggests that there are up to two million children with disabilities in Indonesia, however this is likely an underestimate due to challenges in data collection tools and methodologies. This limits the validity and comparability of the data on children with disabilities in Indonesia.

Children with disabilities in Indonesia are more likely to be stunted, underweight, and have wasting, yet there is limited consideration

of their needs in nutrition regulations and plans such as the National Action Plan for Food and Nutrition. Children with disabilities also have poorer health outcomes with higher prevalence of illness (acute respiratory infection and diarrhoea), and lower vaccination coverage than children without disabilities. Children with disabilities require access to both basic health services and specialized health services. However, there are no disability-specific health regulations.

Children with disabilities in Indonesia are less likely to attend and complete school, across all education levels than children without disabilities. Efforts are required to review and progressively strengthen the inclusive education system to meet the learning needs and provide quality education to children with disabilities. Inaccessible water, sanitation, and hygiene (WASH) facilities in schools, including in special schools and inclusive education schools, are one of the barriers for children with disabilities to gain positive health and better educational outcomes.

Children with disabilities in Indonesia face increased child protection risks, including being less likely to be registered at birth and facing higher rates of sexual abuse (compared to other forms of violence). The absence of a deinstitutionalization strategy and lack of community-based services for children with disabilities create barriers for children with disabilities to stay with or return to their family and communities.

In Indonesia, more children with disabilities are living in poor households compared to children without disabilities. While access to social protection for households of children with disabilities has increased, there is not a comprehensive social protection system for persons with disabilities.

#### Recommendations

Based on the evidence in the Landscape Analysis, recommendations were identified to provide a path forward towards a more inclusive and accessible Indonesia for children with disabilities. A summary of

the recommendations is presented below. The full recommendations including timeframes, levels of prioritization and key stakeholders can be found in the conclusion and recommendations.

Strengthen a disability coordination mechanism in the GoI. The current coordination mechanism across ministries/agencies, OPDs, private sectors, and across national, provincial, district/city, and sub-district levels need to be strengthened to harmonize efforts. Such a mechanism could promote cross-sectoral approaches that can strength government systems, services, and programmes to be disability inclusive and accessible.

# Align terminology and definitions to be rights-based by adjusting all new and existing disability-related terminology and definitions in legislation to align with the Disability Law (No. 8/2016). This will assist in harmonizing planning, programmes, and services in terms of data collection, targeted groups and contribute to reducing

Use the UNICEF/Washington Group Child Functioning Modules for any data collection on children with disabilities.

stigma towards persons with disabilities.

The modules should be used in their entirety and without modifications to capture data that is accurate, comparable, and representative of all types of disabilities. Coordinate and share data between ministries to inform planning and budgeting.

Develop targeted and inclusive programmes for children with disabilities to address nutritional inequities. Programmes should address the absence of nutritious food in households and provide caregivers with knowledge and skills for safe food consumption and to access essential nutrition services for children and caregivers with different impairments. Strengthen disability in data collection and data management systems to monitor the responsiveness of programmes to the needs of children and caregivers with disabilities.

Create stronger linkages between nutrition, food assistance, and social protection by targeting households of children with disabilities and households of caregivers with disabilities with children under five. Monitoring the nutritional status of children, including those with disabilities, in households receiving food assistance and cash grants will determine the linkages between improved nutritional outcomes and social protection.

## Strengthen equity-based monitoring on access to WASH

by incorporating best-practice data collection tools and methodologies related to disability, gender, indigenous groups, poverty, and other factors to determine if certain groups are facing WASH barriers. The data should be used to inform WASH services and programmes.

Improve the accessibility of WASH in schools with priority to Inclusive Education Schools and Special Schools through working with the education sector to accelerate progress on accessible WASH infrastructure improvements in schools.

Establish clear and measurable standards with specific indicators for the provision of quality health services for children with disabilities. Standards should cover children with disabilities access to basic health services and specialized disability health services. The implementation of standards will require strengthening the health system for children with disabilities, including updating health sector plans and budgets at the national and subnational levels.

Developsystematicschool-baseddevelopmentalmonitoring and screening programme with referral pathways for identification of disabilities and family- and child-centred support and intervention. Referral pathways should include healthcare services for assessment and intervention, and to Disability Services Units for access to accessible learning materials and assistive technology.

Conduct an inclusive education sector analysis to inform the strengthening of the inclusive education system across all levels of education. The research will identify how the education system is meeting the needs of children with disabilities and identify supply, quality, and demand issues. A coordinated effort across all levels of government and at all levels of education is required to further transition the education system towards inclusion.

Strengthen inclusive child protection systems, including justice systems, to prevent and respond to violence, exploitation, abuse, neglect, and harmful practices. Identify barriers for children with disabilities and strengthen the social service workforce to be more inclusive and better equipped to protect children with disabilities.

Support the prevention of family-child separation, end institutionalization and strengthen family-based alternative care for children with disabilities. This requires reinforcing family-friendly policies, community-based inclusive services, strengthening the capacities of social service workers, implementing systematic deinstitutionalization strategies and promoting family-based alternative care services.

Conduct research to assess the additional cost of raising a child with a disability in Indonesia to estimate adequate benefit level for children with disabilities and use the evidence

to assess if current social protection programmes adequately meet the needs of families of children with disabilities.

**Expand access to assistive technology for children with disabilities** by assessing the availability and barriers to assistive technology. Strengthening national systems, services and workforce to deliver assistive technology that are appropriate for children, affordable, consistently available and delivered through services by trained personnel.

Develop participatory social and behaviour change programmes to eliminate stigma and empower children with disabilities to demand and exercise their rights.

Include children with disabilities and their families in future research with consideration to ethics protocols and disability inclusive safeguarding processes.

Develop disability inclusive and accessible emergency preparedness programmes including in inclusive education schools, special schools and targeting out of school children with disabilities.

siblings, grandparents, and other relatives, as well as childcare

## **Glossary**

The terminology and definitions that are used contributes to understandings of evolving concepts related to disability. Words have the potential to empower or diminish children, adolescents, and adults with disabilities. The terminology and concepts used in this report are aligned with a rights-based approach and the Convention on the Rights of Persons with Disabilities.

Access	bi	litv
, 100000	$\sim$	,

Persons with disabilities accessing, on an equal basis with others, the physical environment, transportation, information and communications, including information and communication technology and systems, and other facilities and services open o provided to the public, both in urban and rural areas.<sup>1</sup>

#### Adolescents

The United Nations defines adolescents to be persons aged 10-19 years old.<sup>2</sup>

## Assistive technology

Assistive technology is an umbrella term for assistive products, including devices, and their related systems and services. Assistive technology is of fundamental importance for persons with permanent or temporary functional difficulties as it improves their functional ability and enables and enhances their participation and inclusion. Assistive products may be physical products such as wheelchairs or hearing aids; or they may be digital in the form of software and apps.<sup>3</sup>

#### Caregiver

The term 'parent or caregiver' is not limited to biological parents, but extends to any guardian providing consistent care to the child. Those caregivers include fathers, mothers,

1 United Nations (2006), Convention on the rights of persons with disabilities and Optional Protocol. Article 9.

UNICEF (2022), Adolescent data: Investing in a safe, healthy and productive transition from childhood to adulthood is critical. https://data.unicef.org/topic/adolescents/overview/#:~:text=Defined%20by%20the%20United%20Nations,it%2C%20significant%20growth%20and%20development.

3 UNICEF and WHO (2022), Global report on assistive technology.

	providers who play a significant role in caring for infants and young children. <sup>4</sup>
Child	Person below the age of eighteen years old. <sup>5,6</sup>
Committee on the Rights of Persons with Disabilities	A body of independent experts which monitors mplementation of the Convention on the Rights of Persons i with Disabilities by the States parties.
United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)	A legally binding international agreement and human rights instrument that reaffirms that all persons with disabilities must enjoy all human rights and fundamental freedoms. <sup>7</sup>
Disability	Long-term impairments that affect the functioning of a person and that in interaction with attitudinal and environmental barriers hinder the person's full and effective participation in society on an equal basis with others.8
Disability inclusion	An approach that aims to address barriers faced by persons with disabilities, support their specific needs and ensure their

participation.9

**Impairmesnt** 

A significant deviation or loss in body functioning or

structure. 10 Impairments may be either temporary or

permanent, and people may have multiple impairments.<sup>11</sup>

<sup>4</sup> UNICEF (2017), Guidance: Including children with disabilities in humanitarian action- General.

<sup>5</sup> United Nations (1989), Convention on the Rights of the Child. Article 1.

<sup>6</sup> Indonesia Law no. 35/2014 on Child Protection

<sup>7</sup> UNICEF (n.d.), We All Matter! Situation Analysis of Children with Disabilities in Albania

<sup>8</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>9</sup> UNICEF (2017), Guidance: Including children with disabilities in humanitarian action – General.

<sup>0</sup> UNICEF (2017), Guidance: Including children with disabilities in humanitarian action – General.

<sup>11</sup> UNICEF (2017), Guidance: Including children with disabilities in humanitarian action – General.

#### Inclusive education

An education system that includes all students, and welcomes and supports them to learn, whoever they are and whatever their abilities or requirements.<sup>12</sup>

#### Special education

Special education or special needs education refers to separate schools, classes, or instruction specifically designed for students categorized as having special educational needs, often students with disabilities.<sup>13</sup> It differs from inclusive education as it relies on separation or integration, rather than inclusion.

# Organization of persons with disabilities (OPDs)

Non-governmental organizations led, directed, and governed by persons with disabilities, who should compose a clear majority of their membership.<sup>14</sup>

#### Persons with disabilities

Persons who have long-term physical, psychosocial, 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.<sup>15</sup>

# Reasonable accommodation

Necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.<sup>16</sup>



<sup>12</sup> UNICEF (2017), Inclusive Education: Including children with disabilities in quality learning: what needs to be done?

<sup>13</sup> UNESCO (2017), A guide for ensuring inclusion and equity in education.

<sup>14</sup> Committee on the Rights of Persons with Disabilities, General Comment No. 7 (2018) on the participation of persons with disabilities, including children with disabilities, through their representative organizations, in the implementation and monitoring of the Convention, CRPD/C/GC/7, para. 11.

<sup>15</sup> United Nations (2006), Convention on the rights of persons with disabilities and Optional Protocol. Article 1.

<sup>16</sup> United Nations (2006), Convention on the rights of persons with disabilities and Optional Protocol. Article 2.

## 1. Introduction

Globally there are an estimated 240 million children with disabilities, which is one in ten children.<sup>17</sup> Children with disabilities are first and foremost children. They have all the same rights as their peers without disabilities, but children with disabilities may require additional support to enjoy these rights. 18 UNICEF is mandated to protect the rights of every child, focusing particular attention on reaching the most marginalized and excluded children, realizing that this will benefit all children, everywhere.<sup>19</sup> While UNICEF has long worked around the world to support and improve outcomes for children with disabilities, in 2022 the organization introduced its first global strategy: UNICEF Disability Inclusion Policy and Strategy (2022-2030). Through the strategy UNICEF commits to redoubling current efforts and rapidly expanding its work to advance the rights of children with disabilities.<sup>20</sup> UNICEF's efforts align with the Sustainable Development Goals (SGDs) which pledge to 'leave no one behind.' The SDGs emphasize reaching those furthest left behind, which includes children with disabilities and their families.<sup>21</sup>

Having ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2011, the Government of Indonesia (GoI) has been strengthening legislation to support the implementation of the UNCRPD. Under the leadership and coordination of the Ministry of National Development Planning Indonesia (BAPPENAS), this study was commissioned by UNICEF Indonesia to inform stakeholders, both government, civil society including organizations of persons with disabilities (OPDs) and

development partners, on the situation of children with disabilities with regards to the fulfilment of their rights in Indonesia. Further it aims to build evidence on how the evolving legislative landscape is being implemented and how that in turn is impacting the lives of children with disabilities. The evidence collected and recommendations can inform the work of various stakeholders. For the GoI, the situation analysis can inform policy development and revision, as well as disability inclusive and accessible service provision. For UNICEF, development partners and civil society, the report can be used to inform programmes to both mainstream and target children and adolescents with disabilities.

## 1.1 Purpose

In 2022, UNICEF commissioned a study on the situation of children with disabilities in Indonesia. The objectives of the study were to:

- Identify the barriers children with disabilities face to realizing their rights to nutrition, clean water and sanitation, health, education, protection and to live free of poverty in Indonesia.
- Determine the bottlenecks to providing quality and inclusive services for children with disabilities in Indonesia.
- Provide recommendations for the government, UNICEF, other United Nations (UN) agencies and civil society organizations, including OPDs, to address barriers and bottlenecks to create an enabling environment and fulfil the rights of children with disabilities through inclusive approaches and services, and coordinated action.

The study compiled comprehensive data and evidence on children with disabilities in Indonesian regulatory frameworks, policies and programmes.

<sup>17</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

<sup>18</sup> UNICEF (n.d.), We All Matter! Situation Analysis of Children with Disabilities in Albania.

<sup>19</sup> UNICEF (2022), Disability Inclusion Policy and Strategy (DIPAS) 2022-2030.

<sup>20</sup> UNICEF (2022), Disability Inclusion Policy and Strategy (DIPAS) 2022-2030.

<sup>21</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities

## 1.2 Methodology

The research used a mixed-method approach, combining quantitative and qualitative research. The following research questions guided the study's design:

- 1. What is the situation of children with disabilities in Indonesia?
- 2. What are the challenges, barriers, and bottlenecks in implementing regulatory framework, policies, and programmes regarding children with disabilities in Indonesia?
- 3. What are the feasible recommendations, including areas for capacity building, for the government to improve the inclusion of children with disabilities in programmes and policies?

The research was designed and conducted in close consultation with the GoI. BAPPENAS was consulted on the design of the research, seeking feedback and input on the research questions, research scope, and engagement of OPDs. Representatives of government ministries and agencies were key informants, see Annex 1.

The research was initiated with a desk review, inception report, and quantitative analysis based on available data. Data collection methods were primarily qualitative and based on key informant interviews and focus group discussions conducted between August and December 2022. Stakeholders for key informant interviews were selected based on key actors identified via the desk review that looked at key legislation and in close consultation with UNICEF and BAPPENAS. 22 interviews were conducted with representatives from 16 government ministries, agencies, civil society organizations and OPDs. At BAPPENAS' recommendation more OPDs were engaged in the research via a focus group discussion. The focus group discussion was facilitated in August 2022 with eight representatives (five female and three male) from five OPDs. The selection of OPDs for the discussion focused on those that work with children with disabilities and the group included parents of children with disabilities. Sign language

interpretation was provided for the focus group discussion to ensure equal participation of all persons with disabilities.

Across the interviews and focus group discussion, in total 68 informants contributed to this research, 31 male (45 per cent) and 37 female (55 per cent) (see Annex 1). The key findings and recommendations from the Landscape Analysis were presented to key stakeholders in June 2023. Two validation workshops were conducted; one workshop was with Government Ministries and Agencies; and the second workshop was with OPDs. The feedback and inputs from stakeholders were integrated into the report.

The research integrated quantitative secondary administrative and survey data. Data sets from three large scale household surveys were used in the research:

- The 2015 Intercensal Population Survey (SUPAS 2015), a survey carried out in the mid-term between population censuses collecting demographic information, covering 652,000 households.
- National Socioeconomic Survey (SUSENAS) 2018-2021, an annual survey reaching up to 300,000 households collecting demographic information and information on health care, nutrition, household income and expenditure, etc.
- The Indonesia Basic Health Research (RISKESDAS) 2018, a household -based health research carried out every five years to assess public health status, risk factors and measure health development efforts.



68 Informants
Contributed



31 Male (45%)



37 Female (55%)

## 1.3 Limitations

The differing concepts and methodologies used for disability identification between the three surveys (the Intercensal Population Survey, National Socioeconomic Survey and Indonesia Basic Health Research) created challenges in the comparability of the datasets. The data collection tools used in the three surveys are likely to underestimate the number of children with disabilities. The discrepancies in the number of children with disabilities reported in administrative data are explored further in the section on quantifying children with disabilities.

The research interviewed a limited number of informants. It is a significant constraint that children with disabilities, and their parents and caregivers were not interviewed as part of the data collection. As a result, the barriers that children with disabilities in Indonesia face are based on the knowledge and perceptions of other stakeholders. This makes the barriers presented in this report mostly at the institutional level, rather than barriers at the individual or community level. Further research is required to collect evidence on the impact of disabilityrelated policies and programmes at the community and household level, and future research would benefit from the involvement of children with disabilities and their parents and caregivers. Persons with disabilities from six OPDs were engaged in the research as informants, however the data generated is not intended to be representative of the experience more generally of all persons with disabilities in Indonesia. Quotes are included in the study report to indicate the specific experience or perception of stakeholders interviewed, including persons with disabilities.

The research focused on government policy and its implementation, however not all government ministries or agencies were included in the data collection. Government ministries were selected based on their relevance and function in relation to children's rights with prioritization given to ministries working on child protection education, leisure, cultural, health, social protection, family and alternative

care, and civil rights. The focus on government policy also resulted in the findings primarily being at a national level. There was limited information captured on the variations in the implementation of policies and programmes at regional levels (provincial or district). Indonesian private sector stakeholders were not included as informants as it was determined to be outside of the scope of the research.







The Disability Law sets out a rights-based framework for the implementation of the UNCRPD.

The Disability Law sets out a rights-based framework for the implementation of the UNCRPD. The rights of children with disabilities are mandated in laws and regulations across the different ministries, however implementation at the subnational level is challenging. Given the complex legislative environment across ministries and agencies as well as the different levels of government, a strong coordination mechanism is required to ensure implementation of the CRPD, including for children with disabilities...

## 2.1 Legislative commitments

The UNCRPD is an international human rights convention which sets out the fundamental human rights of persons with disabilities. Since its adoption in 2006, the UNCRPD has been ratified by 186 States as of May 2023<sup>22</sup> and is the most swiftly ratified international treaty.<sup>23</sup> The Gol ratified the UNCRPD on the 30<sup>th</sup> of November 2011, by Law No. 19/2011, committing to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.<sup>24</sup> Indonesia is yet to sign the Optional Protocol to the UNCRPD.

In 2022, the Committee on the Rights of Persons with Disabilities in their Concluding Observations on the initial report of Indonesia welcomed the measures taken by Gol to implement the Convention since its ratification in 2011 through legislative and policy measures to promote the rights of persons with disabilities, including the adoption of the Disability Law (Law No. 8/2016).<sup>25</sup> The Disability Law (Law No.8) was enacted in 2016 and in 2019 the Government Regulation on Planning,

Implementation, and Evaluation of Respect, Protection, and Fulfilment of Rights of Persons with Disabilities (Government Regulation No. 70/2019) provided the operational guidance for the implementation of the law. The aim of this regulation is to ensure that the rights of persons with disabilities are fulfilled, with each related ministry being responsible for its implementation. The introduction of the Disability Law and accompanying regulation promulgated the rights of persons with disabilities in national legislation, aligned with the UNCRPD.

While the Disability Law is not specific to children with disabilities, there are some references to children with disabilities within the legislation, specifically in Article 5(3) (see Annex 2). The Disability Law requires the government to develop regulations to enable the enforcement of the law. To date, nine regulations have been enacted along with two presidential decrees with only one implementing regulation specific to children with disabilities.<sup>26</sup>

The Government Regulation on Planning, Implementation, and Evaluation of Respect, Protection, and Fulfilment of Rights of Persons with Disabilities (Government Regulation No. 70/2019) has also become the umbrella regulation for the Master Plan on Persons with Disabilities (RIPD). The Master Plan is a 25-year national plan that provides guidance to ministries and local government on designing inclusive development policies to fulfil the rights of persons with disabilities. Ministries, agencies, subnational governments (provincial and district/city), private sector, and the public are expected to align with the Master Plan when formulating new policies, implementing programmes and activities, and when developing state and regional budgets. Beginning in 2019, the Master Plan aims to harmonize policies at the different levels of government and ensure a humanrights based approach is taken.<sup>27</sup>

<sup>22</sup> United Nations Department of Economic and Social Affairs (2022), Convention on Rights of Persons with Disabilities Webpage https://social.desa.un.org/issues/disability/crpd/convention-on-the-rightsof-persons-with-disabilities-crpd#:~:text=There %20were %2082 %20signatories%20to,1%20ratification%20of%20the%20Convention, retrieved 11 June 2023.

<sup>23</sup> United Nations Department of Economic and Social Affairs (2022), 10th anniversary of the adoption of the CRPD webpage - https://www.un.org/ development/desa/disabilities/convention-on-the-rights-of-persons-withdisabilities/the-10th-anniversary-of-the-adoption-of-convention-on-therights-of-persons-with-disabilities-crpd-crpd-10.html. Retrieved 11 June

United Nations (2006), Convention on the rights of persons with disabilities and Optional Protocol. Article. 1.

United Nations (2022), Committee on the Rights of Persons with Disabilities - Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

The regulation specific to children with disabilities is Implementing Regulation No. 13/2020 on Reasonable Accommodation for Students with Disabilities.

Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

The Master Plan has seven strategic plans:

- Data on persons with disability and involvement in development processes.
- Disability friendly environment.
- Politics and justice.
- Empowerment.
- Inclusive economy.
- Education and skills.
- Access to health care.

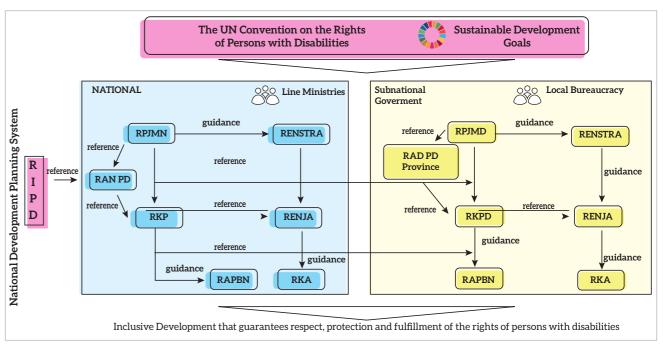
Each strategic plan in the Master Plan includes a policy plan, implementation strategy, objectives, and responsible actors. Explicit mention of children with disabilities are found in four of the seven strategic plans: disability data; empowerment (related to the rehabilitation programme); education and skills (related to inclusive education for students with disabilities); and health (related to increasing national health insurance membership).

The 25-year Master Plan on Persons with Disabilities is elaborated into a five-year National Action Plan on Persons with Disabilities (RAN PD) which consists of technical strategies and policies as well as activities, targets, and indicators for implementation by government ministries and agencies. The current National Action Plan is from 2021-2025. While not specific to children with disabilities, in the Plan there are references to children with disabilities across several activities and indicators including those related to access to justice, inclusive education including early childhood education and early detection of developmental delays and disabilities. Despite being halfway through the five-year period, informants from the national government had limited knowledge of the National Action Plan.

At the local government level, provincial and district/city governments are expected to further contextualize the strategies in the National Action Plan into a Regional Action Plan on Persons with Disabilities (RAD PD), which should inform local government workplans and budgets. Figure 1 illustrates the legislative landscape related to persons with disabilities.

Figure 1.

Legislative landscape related to persons with disabilities in Indonesia



<sup>\*</sup> Government workplans and budgets are developed annually at both national and sub-national levels.

The Child Protection Law (No. 23) of 2002, which has been amended in 2014 (Law No. 35) and further supplemented with Law No. 17 of 2016 serves as an umbrella legislation for the rights of children in Indonesia, including children with disabilities. The definition of a child with a disability in Law No. 35/2014 on the first amendment of the Child Protection Law (No. 23/2002) is aligned with the definition in the Law on Persons with Disabilities (Law No. 8/ 2016) and with the definition in UNCRPD. The amendments include changing the language around disability from a defect and medical framework to rights-based terminology (see section on definition of disability). While the Child Protection Law is intended to protect and promote the rights of all children, children with disabilities are included in a category of children that require special protection. There are several specific references to children with disabilities in the law, including in relation

to rights to education, rights to rehabilitation and social assistance, special protection, and prohibition of discrimination against children with disabilities. Annex 2 summarizes the rights of children with disabilities as mandated by the umbrella regulations, the Disability Law, and the Child Protection Law.

In 2017, The Ministry of Women Empowerment and Child Protection (MoWECP) issued a Ministerial Regulation on the Special Protection for Children with Disabilities (Regulation No. 4/2017) which acts as an umbrella regulation for other ministries regarding the protection for children with disabilities. The regulation provides a 3-year national plan (2017-2019) for ministries to use as reference for initiating programmes specifically related to children with disabilities in response to identified priority areas. Some of the identified priority issues for the protection of children with disabilities include lack of quality data, stigma and discrimination, lack of access to healthcare services, education and justice, inaccessible infrastructure, limited birth registration, and limited access to information and opportunity to have a voice (see Annex 3). While the list of priority issues in the regulation identifies programmes with timeframes and responsible government stakeholders, the plan is not budgeted. A lack of coordination amongst ministries and lack of budget has resulted in the national plan not being fully implemented or monitored. As of 2022, none of the key programme indicators have been measured.

While the umbrella laws, the Disability Law and the Child Protection Law, are not specific to children with disabilities, the Ministry of Education, Culture, Research and Technology (MoECRT) and the Ministry of Social Affairs (MoSA) have regulations and policies specifically related to children with disabilities, see Annex 4.

The legislative framework on disability in Indonesia is complex and still evolving. However, putting policy into practice is challenging. Most informants of this study felt that the current national regulations for persons with disabilities were sufficient, but the commitment and implementation at sub-national levels remains a barrier to the

fulfilment of rights for children with disabilities. At the sub-national level (provincial and district/city), only a small number of regulations exist related to children with disabilities, with local governments often relying on the central government for programme implementation. This is explored further in the sector-specific sections below.

# Coordination amongst government ministries and agencies

One of the challenges in the implementation of disability legislation is coordination between ministries and agencies, particularly MoSA and MoWECP. According to Presidential Regulation (No. 46/2015), MoSA is responsible for social rehabilitation, social security, social protection, promoting inclusion and other support to those in poverty. As many programmes in Indonesia related to persons with disabilities fall within this scope, the MoSA tends to be the lead ministry on issues related to persons with disabilities. It is stipulated in the Disability Law (Article 1) that the implementation of the law is organized by MoSA. The National Commission on Disabilities, established in 2020 under MoSA, is an institution tasked to monitor and evaluate the implementation of the rights of persons with disabilities through national complaint mechanisms and to provide recommendations to relevant stakeholders, including Gol.<sup>28</sup> Our informant also explained that the National Commission on Disabilities is responsible to leverage the coordination on disability issues between MoSA and other national ministries. Appointed by the President, most members of the Commission are persons with disabilities.

While MoWECP according to Presidential Regulation (No. 65/2020) is tasked with leading on women's empowerment and the protection of children, including those with disabilities. Legislation, services, and programmes for children with disabilities intersects the work of both MoSA and MoWECP. More broadly, the implementation of the robust, but complex legislative framework on disability requires

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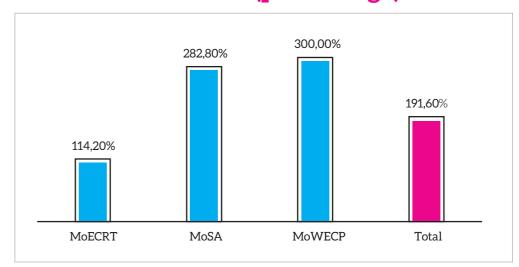
<sup>28</sup> United Nations (2022), Report of the Working Group on the Universal Periodic Review Indonesia. A/ HRC/52/8

coordination between ministries and agencies across the different levels of government. Amongst informants of this study, coordination was identified as a persistent issue both within and between ministries and agencies, at national and sub-national level. The lack of coordination results in legislation related to disability not being aligned or harmonised. In 2022, the Committee on the Rights of Persons with Disabilities recommended the creation of an effective coordination mechanism to ensure implementation of the UNCRPD and the Disability Law across national, provincial, district/city and sub-district levels to ensure that the same human rights standards are applied throughout Indonesia.<sup>29</sup>

## Expenditure on disability

Ministry expenditure on children with disabilities shows that MoECRT, MoSA and MoWECP have significantly increased expenditure on children with disabilities over time, see Figure 2. Expenditure on children with disabilities by the MoECRT doubled between 2015 and 2019, while spending by MoSA and MoWECP tripled in that time. Despite this increase, some areas remain under-funded or not budgeted for, such as the strategies in the regulation on the Special Protection for Children with Disabilities (Regulation No. 4/2017), as mentioned above. There is currently no regulation that addresses the allocation of budget specifically for persons with disabilities or children with disabilities.

Growth in expenditure on children with disabilities by key GoI ministries between 2015-2019 (percentage)



Source: Calculated from the Audited Financial Report of the Ministries (Directorate General of Budget – Ministry of Finance database, 2015 and 2019).<sup>31</sup>

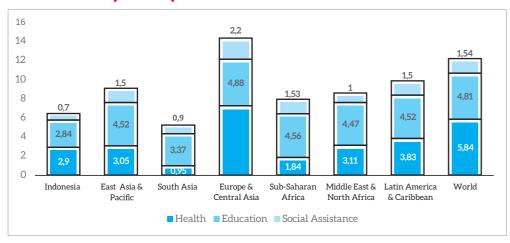
Overall government expenditure on social services, such as education, health and social protection, is relatively low compared to regional and global expenditure, see Figure 3. While the expenditure specifically on children with disabilities has increased over time in Indonesia, given the allocation of budget to social services is smaller compared to other countries, this will hamper the governments' capacity to implement legislation and delivery of inclusive and accessible social services for all children, including those with disabilities.

<sup>29</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>30</sup> UNICEF (2022) Discussion paper: Key issues for children with disabilities in Indonesia.

<sup>31</sup> UNICEF (2022) Discussion paper: Key issues for children with disabilities in Indonesia.

Indonesia expenditure on essential services compared with regions and global, as percentage of Gross Domestic Product (GDP)



Source: World Bank Open Data (2020)32

## 2.2 Definition of disability in Indonesia



The definition used in the Disability Law of 2016 is aligned to the UNCRPD social-model of disability and represents a shift in legislation from a medical approach to a human-rights based approach.

However, terminology and concepts are not consistent across ministries and stigmatizing language related to disability is still evident in legislation and policies. Differing terminology and definitions have the potential to exclude certain groups of children with disabilities and create a disconnect in planning, programmes and data collection between sectors.

Disability is a complex and evolving concept.<sup>33</sup> Understandings of disability have evolved over time. The outdated charity model viewed persons with disabilities as passive recipients of charity or welfare. The medical model conceptualizes disability as a medical condition that requires treatment. While still common, the medical model places decision making in the hands of medical specialists, rather than empowering the person with a disability. The most recent model, the social or human rights model as defined in the UNCRPD, conceptualizes disability as 'long term impairments that affect the functioning of a person and that in interaction with attitudinal and environmental barriers hinder the person's full and effective participation in society on an equal basis as others.'34 This model recognizes that disability is a part of human diversity and places emphasis on society to remove barriers in order for persons with disabilities to participate and attain equal rights. The model and terminology used for disability has an impact on attitudes towards persons with disabilities, the type of policies and programmes designed to target them and can even influence a person with a disability's self-esteem and dignity. This study adopts the social model of disability with terminology and concepts aligned with the UNCRPD.

In Indonesia, the concept of disability and terminology used are not consistent across legislation and within government ministries and agencies. Following the ratification of the UNCRPD in November 2011, the Disability Law (Law No. 8/2016) was introduced and revoked the Law on People with Defects (*penyandang cacat*) (Law No. 4/1997). The revoked law from 1997 had defined persons with disabilities as: 'people with physical and/or mental deficiencies that can disturb or is a barrier and challenge to do something normally.'35 Instead the Disability Law of 2016 uses the term 'persons with disabilities' and adopts the UNCRPD definition as described above. Similarly, the Child Protection Law (Law

32 UNICEF (2022) Discussion paper: Key issues for children with disabilities in Indonesia

<sup>33</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

<sup>34</sup> United Nations (2006), Convention on the rights of persons with disabilities and Optional Protocol.

Government of Indonesia (1997), B. Act of the Republic of Indonesia Number 4, of 1997, Concerning Disabled People. Translation from: https://www.refworld.org/docid/4da2d1b92.html. Retrieved 11 June 2023.

No.23/2002) used 'children with defects' (anak yang menyandang cacat) and was amended in 2014 (Law No. 35/2014) to use language aligned with the UNCRPD, 'children with disabilities' (anak penyandang disabilitas). The change of terminology and concepts from a defect-approach to one aligned with the UNCRPD demonstrates a shift from a medical approach to a social or human rights-based approach to disability. However, in 2022 the Committee on the Rights of Persons with Disabilities highlighted that the term people with defects (penyandang cacat) was still being used in legislation and policies, including Law No. 11/2009 on social welfare, and Law No.11/2020 on job creation.<sup>36</sup> The Committee was concerned that this terminology would 'devalue and pathologize persons with disabilities and promote inequality and discrimination,'<sup>37</sup> recommending the Gol to repeal or amend legislation to remove these terms and concepts.

Across Indonesia's education laws and policies there is not a consistent term used in relation to disability. Both 'children/students with disabilities' and 'children with special needs' are used. MoECRT regulations use the terms 'students with disabilities' (peserta didik berkelainan) and 'disabled' (ketunaan). Note that the UNCRPD represented a shift away from the term 'disabled,' instead promoting person first language, such as 'persons with disabilities.' Within education regulations the definitions of disability vary with different terminology and scope used for impairment types. See Table 1.

MoWECP defines 'children with special needs' as 'children who have limitations or extraordinariness, be they physical, mental-intellectual, social, or emotional, that significantly affect growth or development compared to other children of the same age.'38 See Table 1. While 'special needs' is still widely used particularly within education contexts, the United Nations disability-inclusive language guideline describes 'special

needs' as offensive and condescending because it euphemistically stigmatizes that which is different.<sup>39</sup>

Terminology and definitions used for children with disabilities in Indonesia legislation

Terms in English	Terms in Bahasa	Definition	Reference
Children/students with disability	Anak/Peserta Didik dengan disabilitas; Peserta Didik Berkelainan	Physical, mental, intellectual, sensory, and social disability	Minister of Education Regulation No. 157/ 2014 on Special Schools Curriculum
Disabled	Ketunaan	Physical, hearing, vision, intellectual and mental disability	Minister of Education Regulation No. 33/ 2008 on Infrastructure Standards for Special Schools
Children/students with special needs	Anak/ Peserta Didik Berkebutuhan Khusus	Children who have limitations or extraordinariness, be they physical, mental-intellectual, social, or e motional	MoWECP Guidelines for Handling Special Needs Children for Caregivers (Parents, Family, and Community).

Note: While the UNCRPD uses the term 'mental impairment,' the recommended terminology is now psychosocial impairment. The terms used in the table above are also overlapping. The preferred term of 'psychosocial' would likely cover mental, social and emotional impairments.

The terminology and types of impairments that are covered by the different definitions used in education regulations (see Table 1) have the potential to both create confusion in the development of policies and programmes and result in exclusion of children with different types of impairments. Particularly with terms such as 'limitations' and 'extraordinariness' being open to interpretation.

<sup>36</sup> Government of Indonesia (1997), *B. Act of the Republic of Indonesia Number 4, of 1997, Concerning Disabled People.* Translation from: https://www.refworld.org/docid/4da2d1b92.html. Retrieved 11

<sup>37</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>38</sup> Ministry of Women Empowerment and Child Protection (2013), *Panduan Penanganan Anak Berkebutuhan Khusus Bagi Pendamping (Orang Tua, Keluarga, dan Masyarakat)*. English translation: Guidelines for Handling Special Needs Children for Caregivers (Parents, Family, and Community).

United Nations (n.d.), *Disability-inclusive language guidelines*. https://www.ungeneva.org/sites/default/files/2021-01/Disability-Inclusive-Language-Guidelines.pdf. Retrieved 11 June 2023.

Using the terminology of 'special needs' also has the potential to create confusion. As it does not specifically refer to disability, what is considered 'special' may be interpreted differently. The Ministry of Religious Affairs (MoRA) uses 'special needs' to refer to both children with disabilities and children who are intellectually gifted (note that these groups may not be mutually exclusive). It was also highlighted by an education sector representative that a 'student with special needs may extend beyond disability and include students that face barriers accessing education on the basis of other factors, such as religion and ethnicity. All children have the right to education on an equal basis and free from discrimination. However, a broad interpretation of 'special needs' that covers barriers and accommodations related to all aspects of a child's identity creates challenges in ensuring that the disability-related needs of children with disabilities are catered to within education settings.

Differences in definitions and understandings of disability between different government ministries also creates challenges in collecting comparable data on children and adults with disabilities that can be shared amongst ministries and used to inform planning and budgeting. It also has the potential to exclude certain groups of persons with disabilities in the data collection due to definitions covering different impairment types (see section below on quantifying children with disabilities).

## 2.3 Determination and assessment

Early identification of developmental delays and disabilities enables the timely implementation of targeted interventions that can support the unique needs of children with disabilities and ensure they grow and reach their full potential.41 Measuring and capturing key developmental milestones for children aged 2-4 years old can be achieved via the Early Childhood Index 2030, which is being piloted in national household surveys by the Statistics Indonesia with support from UNICEF. In Indonesia, the Ministry of Health (MoH) is responsible for the determination of disability based on assessments. Under Minister of Health Regulation No. 4/2019, one of the minimum services standards for children includes routine monitoring of child growth and development. This is done through the stimulation, detection and early intervention for child growth and development programme. The programme targets infants and small children between 0-5 years old, and pre-school children aged 5-6 years old. In addition, every pregnant woman should receive a 'Maternal and Child Health Book', which is used to monitor their pregnancy and child until they reach 6 years old. Screening is conducted by health workers in primary health care facilities, both community-based centres (posyandu and Early Childhood and Development (ECD) centres) and health facilities (puskesmas). The study identified that the tools used screened for development disorders, hearing loss, loss of vision, behavioural and emotional



Two screening programmes are implemented in Indonesia to detect and assess developmental delays and disabilities amongst infants, young children and pre-school children.

The main programme has reached 78 per cent of children under 5 and includes a focus on stimulation and early intervention, and a referral system for any delays or disabilities detected.<sup>40</sup> The screening programmes are conducted in community-based health centres and health facilities.

<sup>40</sup> Kementerian Kesehatan (2023), *Laporan Akuntabilitas Kinerja Instansi Pemerintah (LAKIP) Tahun* 2022. https://kesmas.kemkes.go.id/assets/uploads/contents/others/LAKIP\_DITJEN\_KESMAS\_rev1.

<sup>41</sup> UNICEF (2022), Disability Inclusion Policy and Strategy (DIPAS) 2022-2030.

difficulties, autism spectrum disorders, attention deficit disorder and hyperactivity disorder. However, further investigation is required to see if screening tools are aligned with globally recognised approaches;<sup>42</sup> determine if the tools cover all developmental delays and disabilities; and if they are sensitive to detect mild and moderate disabilities. Following screening, any developmental delays and indications of disabilities are referred to a paediatrician, psychologist, or therapist for further examination and early intervention.

As the stimulation, detection and early intervention programme is part of the five-year National Long-Term Plan it has clear targets and is routinely evaluated. The target is for 85 per cent of all children under the age of six years old in Indonesia to be monitored for growth by 2024. As of 2022, 77.65 per cent of children under five had been monitored (more than 21 million children), <sup>43</sup> indicating the programme is on track to meet the target.

Gol has also set a target that by 2024, all 514 districts/cities will be capable of delivering healthcare services to children under 6 years old, including the implementation of the stimulation, detection, and early intervention programme. As of 2021, 59 per cent of districts and cities were meeting this target, 44 suggesting that efforts need to be accelerated to have universal access to child health services in all districts and cities in Indonesia.

In Indonesia, the other means of assessing and determining developmental delays and disabilities is screening programme for Congenital Hypothyroidism, which is a disorder affecting the function of the thyroid gland that can cause intellectual and physical disability. The screening is done via monitoring the growth of the infant from birth in health care facilities (puskesmas and hospitals). While the aim

The monitoring of both screening programmes measures the number of healthcare facilities that conduct the screening and/or the number of children screened. Data is not systemically collected on the number of children that are referred for further assessment and early intervention, nor the types of developmental delays and disabilities detected. Further research and improved data collection systems are required to assess the effectiveness of Indonesia's screening and referral systems to detect developmental delays and disabilities.

## 2.4 Quantifying children with disabilities



Estimates suggest, based on the Indonesia Basic Health Research 2018, there are up to two million children with disabilities in Indonesia.

However, available data underestimates the number of children with disabilities. While national surveys used globally recommended data collection tools, the methodologies resulted in much lower prevalence of children with disabilities (between 0.6 per cent and 3 per cent) compared with the global estimate of ten per cent. This limits the validity and comparability of the data on children with disabilities in Indonesia.

Worldwide, there is an estimated 240 million children with disabilities, which is one in ten of all children.<sup>45</sup> The East Asia and Pacific region is home to 43.1 million children with disabilities, the second largest regional population after South Asia with 64.4 million.<sup>46</sup>

of the MoH is to have screening conducted in all health facilities, the programme is yet to be widespread.

<sup>42</sup> The WHO International Classification of Functioning, Disability and Health (ICF) is used to measure health and disability at an individual and population level, and is commonly used as basis to assess disability.

<sup>43</sup> Kementerian Kesehatan (2023), Laporan Akuntabilitas Kinerja Instansi Pemerintah (LAKIP) Tahun 2022. https://kesmas.kemkes.go.id/konten/142/0/laporan-akuntabilitas-kinerja-instansi-pemerintahditien-kesmas-tahun-2022

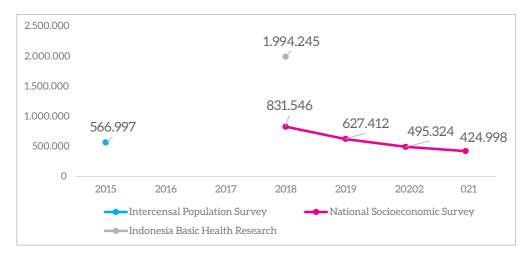
<sup>44</sup> Kementrian Kesehatan (2022), *Laporan Akuntabilitas Kinerja Direktorat Kesehatan keluarga Tahun 2021.* https://gizikia.kemkes.go.id/assets/file/pedoman/LAKIP%20KESGA%202021.pdf.

UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

<sup>46</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

In Indonesia, the estimated number of children with disabilities ranges widely from almost 2 million, down to only 425,000. Figure 4 shows the variation in estimates on the number of children with disabilities from different data sources over a seven-year period.

Number of children with disabilities in Indonesia\*



\* Note that the Indonesia Basic Health Research measured disability in children aged 5-17 years old, while the other two surveys measured disability in children between 2-17 years old.

In the data from National Socioeconomic Survey 2018-2021, an annual household survey reaching 300,000 households, the number of children with disabilities has decreased by almost half over recent years, see Figure 4. While the challenges in data collection, including in this specific survey, are highlighted below, further investigation is required to understand this decrease. As the questions to measure disability have not changed over this period, it is likely due to a change in survey methodology and data collection protocols over the years.

The numbers in Figure 4 as a percentage are between 3.3 per cent<sup>47</sup> and 0.6 per cent of children in Indonesia having disabilities.<sup>48</sup> See Table 3. The Indonesia estimates of children with disabilities are well below (by seven percentage points) the global estimate of ten per cent, see Figure 5. These figures should be used with caution. Like many countries, variations in estimates on the number of children with disabilities are a result of a lack of standardized data collection methodology. Gol has yet to fully adopt a standardized data collection tool to collect data on children with disabilities. In their report to the Committee on the Rights of Persons with Disabilities in 2013, Gol recognized the challenge of availability of comprehensive and disaggregate data on disability. 49 The Committee has expressed concern on the shortcomings regarding data and statistics on persons with disabilities at all levels, including lack of disaggregated data and uniform methodology and interpretation.<sup>50</sup> Specifically the Committee noted the lack of disaggregated data related to the situation of women and girls with disabilities, children with disabilities and indigenous persons with disabilities. 51 The Committee on the Rights of the Child also recommended the collection of specific and disaggregated data on children with disabilities in order to adapt policies and programmes to their needs.<sup>52</sup>

Looking further into the shortcomings related to data, one of the clear issues is the use of different data collection tools to measure the number of children with disabilities limiting the validity and the comparability of the data. The specific challenges in estimating the number of children with disabilities in Indonesia are described below.

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<sup>47</sup> Badan Penelitian dan Pengembangan Kesehatan Kementerian RI tahun (2018), *Riset Kesehatan Dasar (Riskesdas)* 2018.

<sup>48</sup> Badan Pusat Statistik (2021), Survei Sosial Ekonomi Nasional (SUSENAS) 2021. Jakarta.

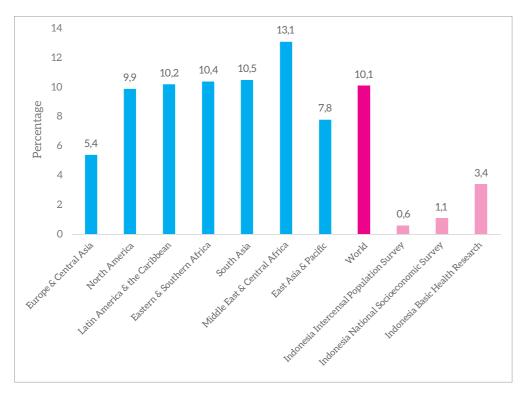
<sup>49</sup> United Nations (2019), Committee on the Rights of Persons with Disabilities – Initial report submitted by Indonesia under Article 35 of the Convention, due in 2013. CRPD/C/IDN/1.

<sup>50</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>51</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>52</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

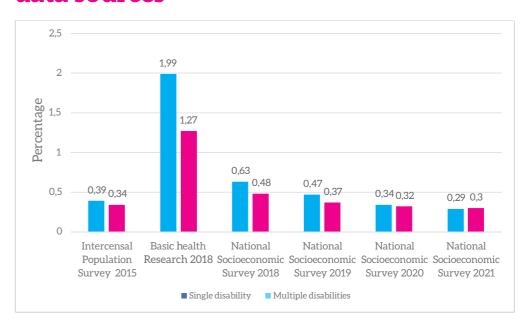
Percentage of children with disabilities in Indonesia, based on different data sources, compared with global and regional estimates



Source: Global and regional estimates from UNICEF (2021), Seen, Counted Included 53

Aligned with global data that shows most children with disabilities have functional difficulties in only one domain,<sup>54</sup> most of the data sets in Indonesia show that more children have a single disability, rather than multiple disabilities. See Figure 6. The latest round of data collection (2021) for the annual National Socioeconomic Survey shows a very slight increase in children with multiple disabilities compared to single disabilities.

Percentage of children in Indonesia with a single disability compared with multiple disabilities, based on different data sources



In Indonesia, there are more boys than girls with disabilities across the three data sets – see Table 2. The global data shows that in most countries, there are no statistically significant differences in the proportion of boys and girls with disabilities. However, in those places where a significant difference is found, a greater proportion of boys have disabilities, 55 as seen in Indonesia. The Indonesia Basic Health Research 2018 found that more children with disabilities lived in rural areas, while the annual National Socioeconomic Survey data did not find a major difference in the proportion of children with disabilities living in rural versus urban settings in Indonesia (see Table 2).

<sup>53</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with

<sup>54</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

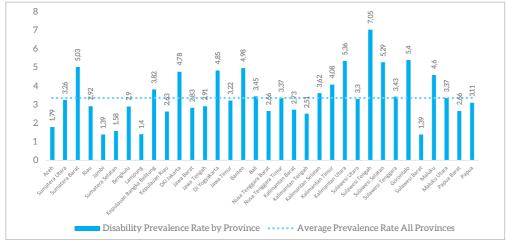
Table 2.

Children with disabilities in Indonesia based on demographic characteristics

	Intercensal	Indonesia Basic	Nationa	l Socioe	conomic	Survey
Demographic factors	Population Survey 2015	Health Research 2018	2018	2019	2020	2021
Sex						
Boys	0.79	3.42	1.24	0.90	0.71	0.68
Girls	0.72	3.09	0.97	0.77	0.61	0.5
Living area						
Urban	-	2.90	1.11	0.82	0.69	0.6
Rural	-	3.58	1.1	0.86	0.62	0.59

The prevalence of children with disabilities varies by province ranging from as low as 1.4 per cent in Jambi, Lampung and Sulawesi Barat Provinces to 7.1 per cent in Sulawesi Tengah (Central Sulawesi). See Figure 7. More research is required to understand the variation in prevalence of children with disabilities across provinces.

Percentage of children with disabilities (5-17 years old) in Indonesia by province<sup>56</sup>



Source: Indonesia Basic Health Research 2018

#### 6 UNICEF (2022) Discussion paper: Key issues for children with disabilities in Indonesia.

## 2.5 Challenges in disability data collection in Indonesia

### Disability data collection tools

The Washington Group on Disability Statistics (Washington Group, WG) has developed data collection modules that provide a standard approach to producing disability data. These data collection tools take a functional approach to disability – asking questions about difficulties in functioning across different domains. For example, 'Do you have difficulty seeing, even if wearing glasses?' Asking questions about functioning (rather than disabilities) overcomes issues of bias, stigma and misunderstanding that historically have resulted in the under-estimation of populations of persons with disabilities. The Washington Group has a series of data collection tools to collect data on adults and has worked with UNICEF to produce sets of questions to specifically collect disability data on children (aged 2-17 years old).

The three data sources used in this study all used modified versions of the Washington Group questions. See Table 3.

Table 3.

Data sources for quantifying children with disabilities in Indonesia<sup>57</sup>

Data set	Produced by	Sample	Disability data collection tool	Estimate of children with disabilities
Intercensal Population Survey 2015	Statistics Indonesia	652,000 households	Modified version of WG Short Set of Questions (designed for adults over 18 years old). Children are identified as having functional difficulty if they answer "a lot of difficulty" or "cannot do at all" in at least one domain.	0.76% of children aged 2-17 years old
National Socioeconomic Survey 2018- 2021	Statistics Indonesia	300,000 households	Modified version of WG Short Set of Questions (designed for adults over 18 years old). Children are identified as having functional difficulty if they answer "a lot of difficulty" or "cannot do at all" in at least one domain	1.11% (2018) 0.84% (2019) 0.66% (2020) 0.59% (2021) of children aged 2-17 years old
Indonesia Basic Health Research 2018	Ministry of Health	300,000 households	Combined and modified versions of WG Short Set of Questions (designed for adults over 18 years old) and WG/UNICEF Child Functioning Module (CFM) (designed for children aged 5-17 years old). The response options were also modified. Children will be identified as having functional difficulty if they answer "severe" or "very severe" in at least one domain.	3.26% of children aged 5-17 years old

Currently the Government of Indonesia is collecting data related to functioning and disability through two big surveys namely 'Socioeconomic Registration (REGSOSEK) 2022' and 'Indonesia Health Survey (SKI) 2023'. Socioeconomic Registration is implemented by Bappenas and Statistics Indonesia, meanwhile Indonesia Health Survey is under the MoH. The Socioeconomic Registration uses ten questions (combination of WG-SS, WG-SS Enhanced, and WG-UNICEF CFM). Meanwhile Indonesia Health Survey has adopted WG-UNICEF CFM to capture child's disability. However, both survey results are not yet available during our study.

While the three data sources referenced all used the globally accepted functional approach to data collection developed by the Washington Group, there are multiple reasons why the specific data collection tools and methodologies used resulted in an underestimate in the prevalence of children with disabilities.

## Data collection tools designed for adults

For any household member over 2 years old, both the Intercensal Population Survey 2015 and the National Socioeconomic Survey 2018-2021 used modified versions of the Washington Group Short Set of Questions (WG-SS). The Indonesia Basic Health Research 2018 used a combination of questions from both WG-SS and the WG/UNICEF Child Functioning Module (CFM). The WG-SS is designed to collect disability data on adults over 18 years. Identifying children with disability is more complex than for adults as children develop at different rates, particularly young children. Measuring disability in children needs to account for the typical variation in development compared to variation due to a development delay or impairment.58 The WG/UNICEF CFM has been designed to take this complexity into account. The CFM has two question sets: 16 questions for children aged 2-4 years old; and 24 questions for children aged 5-17 years old. This is compared to the 6 questions in the WG-SS for adults. More guestions are required to capture childhood disability in all its complexity. Using questions designed for adults would have contributed to the data on children with disabilities being underestimated given the questions are not sensitive to child development. While Statistics Indonesia has tested the use of the WG/UNICEF CFM, it is not yet used at scale.

Functional domains covered

The WG approach to disability data collection assesses difficulties in functioning across different functional domains. A child or adult that has difficulties<sup>59</sup> across one or more functional domains is considered a person with a disability. Each data collection tool covers different functional domains. For example, the WG-SS for adults over 18 years old covers 6 functional domains (seeing, hearing, mobility, cognition, selfcare, and communication). By taking into account the age of the child and the complexity of child development, the CFM for children aged 2-4 years old covers eight functional areas, while the are 13 functional areas covered by the CFM for children aged 5-17 years old. Additional domains covered by the CFM include fine motor, communication/ comprehension, controlling behaviour, learning, relationships, coping with change, and for older children anxiety and depression. 60 Annex 5 maps the functional domains covered in the different data collection tools used in Indonesia. By not including questions on some functional domains, some children with disabilities will not have been counted. As the Intercensal Population Survey 2015 and the National Socioeconomic Survey 2018-2021 used modified versions of the WG-SS, the guestions only covered six of the twelve functional domains. By covering only half of the functional difficulties that are seen in children with disabilities, many children with disabilities will not have been counted. This is evident by the prevalence figures by functional domain being well below the global estimates as show above in Figure 5.

Comparing the functional domains covered in Indonesia Basic Health Research 2018 to the CFM for the same age range (5-17 years old), three functional domains are not covered in the Indonesia data: selfcare, affect (anxiety and depression), and relationships. See Table 4. In the Indonesia Basic Health Research data estimates of children aged 5-17 years old are lower than global estimates across all difficulties functioning. While just under half of the functioning domains were within

UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

The response categories that are considered as having difficulty are: a lot of difficulty and cannot do

UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with

a percentage point of the global estimates, the functional domains that make up the largest share of children with disabilities in global data were either not measured (anxiety and depression) or were 3 percentage points lower in Indonesia (controlling behaviour). This is significant as global data shows that psychosocial difficulties consistently affect the largest share of children with seven per cent of children aged five to 17 globally showing signs of anxiety or depression. Not measuring psychosocial difficulties amongst this age group across the surveys in Indonesia will result in underestimating the prevalence of children with disabilities.

Percentage of children with disabilities (aged 5-17 years old) by functional domain in Indonesia compared to global estimates

Functional domain	Percentage children in Indonesia <sup>62</sup>	Percentage children worldwide <sup>63</sup>
Seeing	0.4	0.5
Hearing	0.2	0.3
Mobility	0.2	2
Self-care	-	0.8
Communication / comprehension	0.5	0.8
Learning	1.2	2
Remembering	1	2
Attention and concentrating	0.9	1
Relationships	0.5	1
Coping with change	0.8	2
Signs of anxiety	-	7
Signs of depression	-	4
Controlling behaviour	0.9	4

<sup>61</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

### Modifications to questions and response options

The CFM underwent extensive review and was tested in several countries to determine the quality of the questions and how well the questions and response options are understood by people in diverse cultures. 64 Modifications in the way questions and response options are framed can impact the validity of the data. As described above the WG and CFM questions ask about difficulties in functioning. Asking if a child has difficulty with particular function makes it easier for caregivers to respond without needing a medical diagnosis and avoids the stigma often associated with disability-related terminology. In both the Intercensal Population Survey 2015 and the National Socioeconomic Survey 2018-2021 the question related to controlling behaviour, anxiety and depression was framed as, '[Do/does] [you/he/she] have any behaviour/emotional disorder?' (see Annex 6). To respond accurately to this question, the caregiver would need to understand what a behaviour/ emotional disorder is and would need their child to have been diagnosed with a psychosocial impairment. Caregivers may also be reluctant to identify their child as having a 'behaviour or emotion disorder' due to stigma. The prevalence figures illustrate this with between 0.3265 and 0.1966 per cent of children in Indonesia having a 'behaviour or emotional disorder', compared to the global prevalence figures of 7 per cent showing signs of anxiety, 4 per cent showing signs of depression and 4 per cent having difficulties controlling behaviour.<sup>67</sup>

There were also issues with the response options in Indonesia Basic Health Research. While the Indonesia Basic Health Research framed questions in terms of difficulties in functioning (see Annex 6), the response options given did not ask about difficulty, but followed a medical approach asking the level of severity from: 'no'; 'mild'; 'moderate'; 'severe;' and 'very severe.' The difference between severity

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<sup>62</sup> Badan Penelitian dan Pengembangan Kesehatan Kementerian RI tahun (2018), *Riset Kesehatan Dasar (Riskesdas) 2018.* 

UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities

UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities

<sup>65</sup> Badan Pusat Statistik (2021), Survei Sosial Ekonomi Nasional (SUSENAS) 2021. Jakarta.

<sup>66</sup> Badan Pusat Statistik (2015), Survei Penduduk Antar Sensus (SUPAS) 2015. Jakarta.

<sup>67</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities

levels is not clear and to respond caregivers were required to make their own assessment. Asking about severity would have made it harder for caregivers to accurately respond and contributed to inaccurate data on children with disabilities.

For the most valid and comparable data, the questions and responses of the WG-SS for adults and the CFM for children should be used in their entirety without modification. See Annex 6 for the full list of disability-related questions included in the three surveys.

In addition to these challenges, there may also be issues related to the lack of training and knowledge of enumerators. OPD informants thought that the stigma of enumerators may contribute to parent's being reluctant to respond accurately to the questions related to disability. While in theory the use of the WG questions should avoid this stigma as a functional approach avoids using the term "disability", it was suggested that due to a lack of training enumerators may be using the term "disability" when collecting data. This would negate the design of the questions to avoid any bias or stigma related to disability.





Realizing the rights of children with disabilities requires that communities, infrastructure, programmes and services be inclusive and accessible for all, and where necessary adapted to the specific needs of children with disabilities. In Indonesia, children with disabilities' access to basic services such as education, nutrition and health is less than their peers without disabilities. Compounded with higher rates of poverty and stigma, children with disabilities face exclusion and marginalization in all aspects of their lives.

All children have the right to meaningful participation and leadership, and to have their voice heard, especially in decisions-making about the issues that affect their lives. However, children with disabilities face barriers to participation and the study found little evidence of meaningful participation of children with disabilities in services and programmes. More research is required to understand the opportunities and barriers for the participation of children with disabilities in Indonesia.

## 3.1 Nutrition



Children with disabilities in Indonesia are more likely to be stunted, underweight and wasted; with children with disabilities are 62 per cent more likely to be stunted than children without disabilities.<sup>68</sup>

Gender and education level of parents have an impact on the nutritional status of children with disabilities. Despite interlinkages between nutrition and disability, there is only one specific reference to children with disabilities in the activities of the National Action Plan for Food and Nutrition.

SDG 2 calls for an end to hunger and for all people to have access to safe, nutritious and sufficient food all year round. <sup>69</sup> The interlinkages between nutrition and disability are strong and complex. The interrelationship tends to be addressed in relation to the role of adequate nutrition to prevent certain types of impairments. <sup>70</sup> Children who are malnourished may develop developmental delays and are at greater risk of illness, which can both lead to disability. <sup>71</sup> At the same time, children with disabilities globally have disproportionately higher rates of malnutrition. <sup>72</sup> It can be described as a cycle: malnutrition can cause disability, and disability can lead to malnutrition. <sup>73</sup>

In Indonesia, when infants and young children have disabilities, they are less likely to be breastfed, including early initiation of breastfeeding (50 per cent of children with disabilities), and have less diversity in their food consumption (34 per cent of children with disabilities). See Figure 8. The biggest gap between infant and young children with disabilities and those without disabilities is seen in the diversity of their consumption, with infants and young children with disabilities have 11.89 percentage points lower access to a variety of foods. More research is needed to understand this gap in lack of food diversity, but it may be due to higher poverty rates in households of children with disabilities (see section on social protection) to access diverse foods or a lack of caregivers' skill to prepare various foods to feed children with disabilities responsively.

<sup>69</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

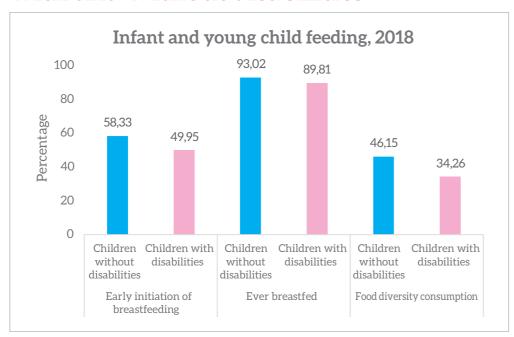
UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities

<sup>71</sup> UNICEF (2018), Guidance: Including children with disabilities in humanitarian action– Nutrition.

<sup>72</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

<sup>73</sup> UNICEF (2018), Guidance: Including children with disabilities in humanitarian action – Nutrition.

Percentage infant and young child feeding in Indonesia, comparing children with and without disabilities<sup>74</sup>



Source: Based on Indonesia Basic Health Research 2018.

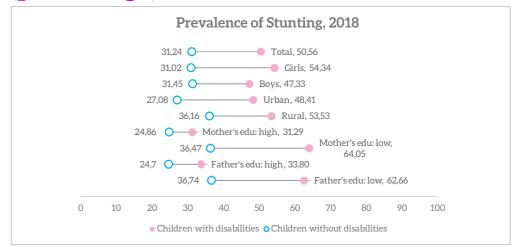
Note: children with disabilities are measured by children born with birth defect as Basic Health Research 2018 did not collect difficulty in functioning data for children less than five years old

Globally, children with disabilities are three times more likely to be underweight, two times more likely to be stunted or wasted and twice as likely to die during childhood from malnutrition.<sup>75</sup> Iln Indonesia, greater prevalence of malnutrition is also seen in children with disabilities with higher rates of stunting and being underweight compared to children without disabilities. See Figures 9, 10 and 11.

Examining the nutritional gaps between children with and without disabilities, having a disability has a bigger impact on stunting than on being underweight and having wasting. According to the data, 51 per cent of children with disabilities are stunted, compared with 31 per cent of children without disabilities. See Figure 9. As stunting is measured

Gender has a significant impact on stunting with 54 per cent of girls with disabilities are stunted. Girls with disabilities are 75 per cent more likely to be stunted than girls without disabilities, and 15 per cent more likely than boys with disabilities. Education levels of parents also has a large impact on stunting among children with disabilities. In households where parents have low education, children with disabilities are over 70 per cent more likely to be stunted than children without disabilities. In comparison, for children whose parents have higher levels of education, children with disabilities are only 30 per cent more likely to be stunted compared to children without disabilities. Further, children with disabilities whose parents have low levels of education are nearly twice as likely to have stunting than children with disabilities whose parents have high levels of education.

Prevalence of stunting in Indonesia amongst children with and without disabilities aged 0-59 months



(percentage)

Source: Based on Indonesia Basic Health Research 2018. Note: children with disabilities are measured by children born with birth defect as Basic Health Research 2018 did not collect difficulty in functioning data for children less than five years old.

by impaired growth and development, which can result in limitations to physical and cognitive functioning.<sup>76</sup> the link between disability and stunting is concerning, but not surprising.

<sup>74</sup> UNICEF (2022) Discussion paper: Key issues for children with disabilities in Indonesia.

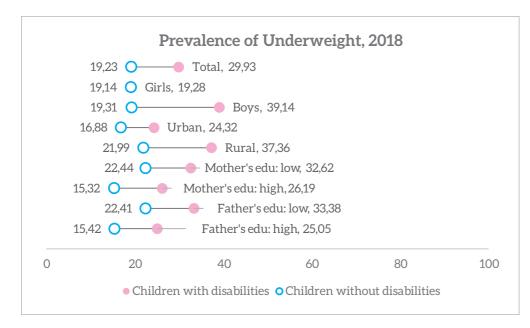
<sup>75</sup> UNICEF (n.d.) Virtual convening on Improving Nutrition among Children with Feeding Difficulties and Children with Disabilities; Key Takeaways and Resources - https://www.advancingnutrition.org/sites/default/files/2023-05/Key\_takeaways\_and\_resources-5-16-23.pdf. Retrieved on 11 June 2023.

WHO (2015), Stunting in a nutshell - https://www.who.int/news/item/19-11-2015-stunting-in-a-nutshell#:~:text=Stunting%20is%20largely%20irreversible%3A%20a,to%20suffer%20from%20chronic%20diseases. Retrieved on 11 June 2023.

Compared to stunting, the prevalence of being underweight was lower for both children with and without disabilities, however children with disabilities still had higher prevalence of being underweight (30 per cent) compared to children without disabilities (19 per cent). See Figure 10. In a reverse of what was observed in stunting, more boys with disabilities were underweight than both boys without disabilities and girls with disabilities.

Prevalence of being underweight in Indonesia among children with and without disabilities aged 0-59 months

(percentage)

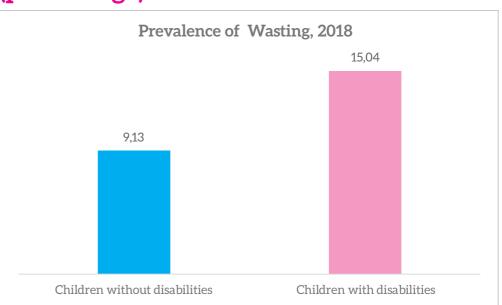


Source: Based on Indonesia Basic Health Research 2018. Note: children with disabilities are measured by children born with birth defect as Basic Health Research 2018 did not collect difficulty in functioning data for children less than five years old.

Compared to both stunting and being underweight, the prevalence of wasting was lower again amongst both children with and without disabilities. In Indonesia, 15 per cent of children with disabilities had wasting in 2018, compared to nine per cent of children without disabilities. See Figure 11. Further disaggregation by socio-economic

factors was not possible for the data on wasting due to the small sample sizes causing higher relative sample errors.

Prevalence of wasting in Indonesia among children with and without disabilities aged 0-59 months (percentage)



Source: Based on Indonesia Basic Health Research 2018. Note: this data should be used with caution as the relative sample error was above 20 per cent, but less than 25 per cent (which was the limit for use in the research)

Malnutrition in infants and children, including those with disabilities can lead to poor health outcomes, missing or delays in developmental milestones, secondary conditions and in extreme cases, death.<sup>77</sup> While further research is required to identify the causes of malnutrition in children with disabilities in Indonesia, based on global research there are some likely causes, including:

- Physical problems feeding due to the child's impairment, such as difficulties chewing and swallowing.<sup>78</sup>
- Suboptimal feeding practices due to caregivers' lack of knowledge

<sup>77</sup> UNICEF (2018), Guidance: Including children with disabilities in humanitarian action - Nutrition.

<sup>78</sup> UNICEF (2018), Guidance: Including children with disabilities in humanitarian action - Nutrition.

- or skills,<sup>79</sup> such as modifying food to meet the needs of their child with a disability.
- Stigma and discrimination with children with disabilities being fed less, denied food or provided with less nutritious food than household members without disabilities.<sup>80</sup>
- Availability of food in the home with children with disabilities more likely to be living in poverty (see section on social policy).

The correlation between low education levels of parents and children with disabilities being stunted and underweight can potentially be linked to their lack of knowledge and skills on the feeding needs of their child with a disability, household income and subsequent availability of food within the household, and time available to support the feeding of their child with a disability. The vast differences between girls and boys with disabilities in their nutritional status requires further investigation but may be based on discriminatory food allocation as described above.

A further challenge is that some nutrition programmes are delivered in schools. For example, UNICEF and Gol's Aksi Bergizi, a comprehensive gender-responsive multisectoral adolescent nutrition programme, which targets adolescents in schools. After being piloted in select districts, the Gol has committed to include this package of interventions in schools nationally. As children with disabilities are more often out of school compared with their peers without disabilities, they are less likely to benefit from these programmes. However a food assistance programme that provides low-income households with staple food packages increased the proportion of households receiving food assistance over the last three years, for both households with and without disabilities. In 2021, the programme reached 35 per cent of poor households with disabilities (See Social Policy Section below). Further research is required to

determine if staple food packages for households with and without disabilities provide sufficient variety and quality of food to meet minimum acceptable diet of children and caregivers with disabilities.

While malnutrition and disability are closely interrelated, they have been rarely linked in policy, practice and research.<sup>82</sup> The National Action Plan for Food and Nutrition 2017-2019 is Gol's guide for the implementation of food and nutrition policies with the aim to increase food security and improve nutrition outcomes, especially among women and children,83 A review by SNV Netherlands Development Organisation found that while the importance of disability along with gender and poverty, was mentioned throughout the Action Plan, there was limited evidence that the programmes implemented are specifically designed to address these issues.84 The activities of the National Action Plan are grouped<sup>85</sup> under five pillars. Across the five pillars, disability was only considered under the first pillar (community nutrition improvement). There was only one specific reference in relation to social rehabilitation programmes and provision of basic needs of people in institutions, targeting persons with disabilities, among other vulnerable groups.86 While this was the only inclusion of persons with disabilities under the five pillars, it is a worthy inclusion and of critical importance, as worldwide children with disabilities are disproportionately living in institutions, where nutrition programmes are often overlooked and where malnutrition is prevalent.87

<sup>79</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

<sup>30</sup> UNICEF (2018), Guidance: Including children with disabilities in humanitarian action – Nutrition.

<sup>81</sup> UNICEF (n.d.), Adolescent Nutrition Programme Aksi Bergizi: From District Pilot to National Scale-Up.

<sup>82</sup> Ramani, G., Go A., and Olney, D., (n.d.), Gender, Poverty and Disability in the National Action Plan for Food and Nutrition 2017-2019 of Indonesia and Ways Forward.

<sup>83</sup> Ramani, G., Go A., and Olney, D., (2020), Gender, Poverty and Disability in the National Action Plan for Food and Nutrition 2017-2019 of Indonesia and Ways Forward – Program Brief.

<sup>84</sup> Ramani, G., Go A., and Olney, D., (2020), Gender, Poverty and Disability in the National Action Plan for Food and Nutrition 2017-2019 of Indonesia and Ways Forward – Program Brief

The five pillars of the National Action Plan for Food and Nutrition 2017-2019 are: 1. Community nutrition improvement; 2. Increased accessibility of diverse foods; 3. Food quality and safety; 4. Clean and healthy living pattern; and 5. Food and nutrition development coordination.

<sup>86</sup> Ramani, G., Go A., and Olney, D., (n.d.), Gender, Poverty and Disability in the National Action Plan for Food and Nutrition 2017-2019 of Indonesia and Ways Forward

<sup>87</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities

## **3.2 WASH**



While regulations on accessible WASH are in place, there are challenges in the implementation of the legislation.

Population-based data does not indicate whether children with disabilities can access WASH on an equal basis as other household members. Inaccessible WASH facilities in schools, including in special schools and inclusive education schools, are creating barriers for children with disabilities to gain an education, with only 9 per cent of special schools having access to advanced WASH services, which includes accessible toilets.<sup>88</sup>

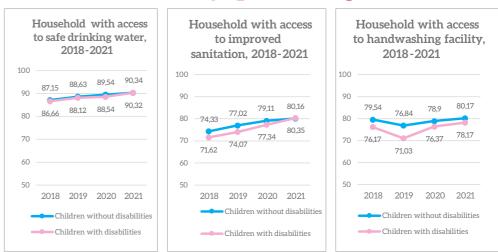
SDG 6 aims for everyone to have access to water, sanitation and hygiene (WASH). The right for children with disabilities to access appropriate, affordable and clean WASH is protected in Article 28 of the UNCRPD.<sup>89</sup> Disability accessible latrines and hand washing in public and private places, such as schools, community centres, workplaces and healthcare facilities are critical to support the participation of children and adults with disabilities in society and are fundamental to the attainment of other rights, such as rights to healthcare, education, and employment. While inaccessible WASH facilities can lead to children and women with disabilities defecating in poorly lit and secluded areas, leading to increased risk of injuries, abuse and exploitation.<sup>90</sup>

In Indonesia, access to safe drinking water and improved sanitation has increased over time for both children with and without disability. While access to handwashing facilities in households remains almost unchanged in 2021 compared to 2018. In 2021, in their households: 90 per cent of children with disabilities had access to drinking water; 80 per cent had access to improved sanitation; and 78 per cent had access to handwashing facilities. See Figure 12. As of 2021, children with disabilities access to safe drinking water and sanitation in their household was essentially equal to that of children without disabilities. This contrasts with global data that has found that worldwide, children with disabilities

are 26 per cent less likely to have improved sanitation facilities and 12 per cent less likely to have improved drinking water sources in

# Figure 12. **IMΔ SH** 2

# WASH access for households with children with disabilities and children without disability (percentage)



Source: National Socioeconomic Survey.

Figure 13 shows access to WASH facilities for households with and without disabilities disaggregated by the sociodemographic factors of poverty and location (rural and urban). 94 per cent of households of children with disabilities have access to safe drinking water in urban

their households.<sup>91</sup> Children with disabilities access to handwashing facilities in households was only 2 percentage points lower than children without disabilities in Indonesia. It is critical to note that these data are measuring access to WASH at the household level. While households with and without children with disabilities have similar access to sanitation and safe drinking water, it does not indicate whether the WASH facilities are accessible and designed to meet the needs of children with disabilities. While 80 per cent of households have improved toilets, children with disabilities may still face barriers to using their toilet hygienically and with dignity.

<sup>88</sup> Kementerian Pendidikan, Kebudayaan, Riset Dan Teknologi (2022), Profil Sanitasi Sekolah 2022.

<sup>89</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

UNICEF (2017), Guidance: Including children with disabilities in humanitarian action – WASH.

<sup>91</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

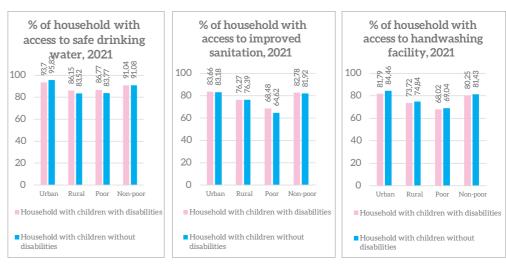
areas compared with 86 per cent in rural areas. The data shows that location and poverty have a bigger impact on households' access to safe drinking water than having a child with a disability. Households in rural areas were much less likely to have access to safe drinking water than those in urban areas, with location having a bigger impact on households without children with disabilities. Households without disabilities were 13 per cent less likely to have safe drinking water in rural areas, compared to eight per cent less likely for households with children with disabilities.

68 per cent of poor households with children with disabilities had improved sanitation, compared with 83 per cent of non-poor household with children with disabilities. See Figure 13. A similar impact is seen in access to sanitation and handwashing, where poverty has a much bigger impact on a households' access to improved sanitation than having a child with a disability. For sanitation the impact of poverty was again more pronounced for households without children with disabilities being 21 per cent less likely to have improved sanitation in poor households compared to non-poor households. Households with children with disabilities were 17 per cent less likely to have improved sanitation due to poverty. See Figure 13.

Access to handwashing facilities was very similar for households with and without children with disabilities across the different demographic factors. 73 per cent of households of children with disabilities had handwashing facilities in rural areas; and 68 per cent of poor households with children with disabilities had access to handwashing. Households were less likely to have access to handwashing in rural areas and in poor households. Families with and without children with disabilities were both 15 per cent less likely to have handwashing facilities in poor households. See Figure 13. As described above, these figures are not assessing whether the WASH facilities in households are accessible for children with disabilities.

92 Throughout the report, poor households are those with monthly per capita expenditure that is below the province's poverty line. Non-poor households have monthly per capita expenditure that is above the province's poverty line.

WASH access for households with children with disabilities and without disability by sociodemographic characteristics



Source: National Socioeconomic Survey

Noting the challenges described above on measuring and monitoring children with disabilities access to WASH, in May 2022 at the high-level Sanitation and Water For All Sector Minister's meeting in Jakarta, Gol made a commitment to strengthen equity-based monitoring.<sup>93</sup> This will be critical to determine if WASH services and facilities are leaving anyone behind.

The Disability Law (No. 8/2016) requires national and regional government to guarantee persons with disabilities access to WASH facilities. The 2005-2025 National Long-Term Development Plan (RPJPN) and the 2015-2019 National Medium-Term Development Plan (RPJMN) include the national programme, "Universal Access to Drinking Water and Sanitation in 2019," which aims to provide safe drinking water and proper sanitation for all Indonesians, including persons.

UNICEF (2022), Discussion paper: Key issues for children with disabilities in Indonesia.

Ministry of Public Works and Housing (MoPWPH) regulations and instruments stipulate that infrastructure, including WASH facilities, should be inclusive of children and persons with disabilities. Specifically, Regulation No. 14/2017 on Building Accessibility Requirements mandates the design and provision of handwashing facilities to be placed in the toilet, to be at a height that can be reached by everyone and be accessible for wheelchair users. This regulation applies to residential and public buildings, including schools and healthcare facilities. MoPWPH also has a standard operating procedure for developing disability inclusive WASH facilities.

MoPWPH has taken a participatory approach to the development of regulations by engaging with OPDs, including collaboration with the National General Accessibility Movement, (*Gerakan Aksesibilitas Umum Nasional*) which advocates for equal rights in accessibility to public infrastructure, services and public transportation. The collaboration included inputs into the drafting of regulations and promoting the regulations through media and booklets. MoPWPH engaged with persons with different types of disabilities, including representatives of the deaf and blind communities, and conducted trials of WASH designs with wheelchair users to ensure their needs were met.

Input from colleagues with disabilities is important to ensure this isn't just a gimmick, but really meets their needs. (Government Official, male, Jakarta)

The provincial government of East Nusa Tenggara have taken steps to ensure the rights of persons with disabilities to WASH. In a Governor's Circular Letter on sustainable, safe, and proper sanitation development, districts/cities in East Nusa Tenggara should accelerate safe access to WASH for persons with disabilities. The letter also specifies the involvement of women and OPDs in sanitation development. Further, a guidance by the provincial government of East Nusa Tenggara on the Use of Village Funds for Health and WASH integrates gender and disability, promoting the 'involvement of persons with disabilities in all

aspects of life and development.'94

To ensure compliance with infrastructure regulations, controls are put in place including mandatory licensing processes and the issuance of building approvals for public buildings. Meeting accessibility standards are part of the requirements in these processes. However, MoPWPH regulations not being well implemented at the sub-national level and the Ministry's capacity to monitor the accessibility of construction at the local level is limited. Other challenges include the lack of awareness and capacity on the WASH needs of persons with disabilities and disability accessibility in local government, particularly due to the high turnover of civil servants. MoPWPH does not currently have data on the compliance to disability accessibility standards of buildings.

During the construction work, if the owner is KemenPUPR [MoPWPH] and then it is handed over to the local government, you can be sure that it has met the standards for disability because there is a review process from us to make sure. Indeed, what is rather difficult is the one built by the local government itself, so we cannot control it.

(Government Official, male, Jakarta)

The MoH has a national programme that prioritizes sanitation following a Community Led-Total Sanitation (CLTS) approach (*Sanitasi Total Berbasis Masyarakat/STBM*). However, they are yet to prioritize the involvement of persons with disabilities and acknowledged that they lack a specific programme or approach for sanitation promotion with persons with disabilities. However, MoH is trialling innovative approaches to disability inclusion through partnerships. In 2020, MoH and Plan Indonesia, with funding from the Australian Government's Department of Foreign Affairs and Trade (DFAT), began trialling Gender Equality, Disability and Social Inclusion (GEDSI) CLTS. This approach increases the involvement of women and persons with disabilities in CLTS, including through engagement with OPDs.

67

Ministry of Health Indonesia and UNICEF (2022), Gender and Disability Inclusion Assessment of Institutional WASH Facilities and Services in Indonesia.

#### **WASH** in Healthcare Facilities

While the MoPWPH regulations covers all buildings, the MoH has developed regulations specifically for healthcare infrastructure. The Minister for Health Regulation No. 43/2019 requires that community health centres (*puskesmas*) have disability accessible WASH facilities. A new regulation on environmental health (No. 2/2023) stipulates that buildings including schools and healthcare facilities, should provide accessible facilities including toilets and handwashing stations as part of environmental quality standards.

A UNICEF Indonesia study found that WASH in healthcare facilities is considered as increasingly important with progress being made to improve their accessibility. Though challenges remain with the design of WASH facilities in healthcare facilities not meeting accessibility requirements such as narrow doors, lack of circulation space in the cubicle, and inappropriate placement of handrails in the toilet. Differing priorities in budget allocation were cited as the main reason some areas had not invested in accessible WASH in healthcare facilities. The Committee on the Rights of Persons with Disabilities has also recommended the government ensure that healthcare services include access to sanitation and clean drinking water. The committee of the committee of the results of the committee of the com

#### **WASH** in Schools

Within the education sector, Minister of Education Regulation No. 24/2007 stipulates the WASH requirements for schools and, while not specific to WASH, that school buildings be accessible to persons with disabilities. The MoECRT has established a programme with dedicated funding to improve WASH access for children with disabilities in special schools and schools that provide inclusive education. Within this programme, there are regulations (Regulation No. 3/2022) that require toilet construction projects be accessible for persons with disabilities.

One of the challenges for Islamic schools is they have less operational budgets and health funds than other schools, resulting in gaps in their WASH facilities.<sup>97</sup>

Despite having regulations in place, limited progress has been made on disability accessible WASH facilities in schools. According to a UNICEF study in 2022, compared with other services and buildings, 98 schools have the lowest percentage of accessible toilets. The accessibility audits undertaken in the study (in East Java, East Nusa Tenggara (NTT) and Central Sulawesi provinces) found that 82 per cent of schools did not have an accessible toilet. Further, even in special schools and inclusive education schools, WASH facilities were often not fully accessible. 99 The WASH in Schools Profile 2022 shows that only 9 per cent of special schools have access to advanced WASH services, which includes accessible toilets. 100

Inaccessible WASH facilities in schools create barriers for children with disabilities to gain an education. This is particularly an issue for girls with disabilities, who must manage menstrual hygiene in inaccessible facilities, something that can potentially undermine dignity, health and school attendance. <sup>101</sup> Inaccessible facilities in schools can also result in children with disabilities reducing their consumption of food and drink to minimize the need to go to the toilet, with potentially harmful implications. <sup>102</sup>

If I want to pee, I have to hold it until I get home. That's why I don't drink much at school to avoid that. The school toilet has a squat latrine so I can't use it at that time because I can't squat. I think I only had leaking once.

(Female with physical disability, East Java, informant in study by the Burnet Institute, et al.). 103

Institutional WASH Facilities and Services in Indonesia.

Ministry of Health Indonesia and UNICEF (2022), Gender and Disability Inclusion Assessment of

<sup>96</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>97</sup> Ministry of Health Indonesia and UNICEF (2022), Gender and disability inclusion assessment of institutional WASH facilities and services in Indonesia.

The other services and buildings include: primary healthcare facilities, public places, government offices and other workplaces, humanitarian institutions, and communities.

<sup>99</sup> Ministry of Health Indonesia and UNICEF (2022), Gender and disability inclusion assessment of institutional WASH facilities and services in Indonesia.

<sup>100</sup> Kementerian Pendidikan, Kebudayaan, Riset Dan Teknologi (2022), Profil Sanitasi Sekolah 2022.

<sup>101</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

<sup>102</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

<sup>103</sup> Burnet Institute, Survey Meter, WaterAid and Aliansi Rem aja Independen (Feb 2015) Menstrual hygiene management in Indonesia, Final Report: Understanding practices, determinants and impacts among adolescent school girls.

# Menstrual health and hygiene (MHH) for girls with disabilities

Around the world, girls and women with disabilities face challenges to managing their menstruation hygienically and with dignity. Of Girls and women with disabilities face double stigma due to social norms around gender and menstruation, as well as disability. Girls with disabilities also lack information on menstruation in formats that they can easily understand. To improve access to information, MoWECP have produced a video with girls with disabilities on MHH. As highlighted above, the lack of accessible WASH facilities in schools in Indonesia is a barrier for girls with disabilities to attend school, particularly after they start menstruation. A 2023 review of progress on MHH identified Indonesia as one of only three countries in East Asia and Pacific with menstrual health-related policies or programming that addressed disability inclusion; MoECRT, National School Health Strategy and Programme, 2014. However, there may be gaps in the implementation with a respondent in the review reporting that many regular schools are not yet following the guidelines for people with disabilities including related to WASH facilities and menstrual materials.



In Indonesia, children with disabilities have poorer health outcomes with higher prevalence of illness (ARI and diarrhoea), and lower vaccination coverage than children without disabilities.In addition to accessing basic health services, children with disabilities may also require specialized health services. However, while disability is considered in health legislation, there are no disability-specific health regulations. With limited monitoring and data available, it is challenging to determine the availability and quality of health services for children with disabilities.

# 3.3 Health

SDG 3 is a commitment to ensure healthy lives and promote well-being for all at all ages, including children and young persons with disabilities. Children with disabilities have the same rights to health as other children. Children with disabilities require access to basic health care and they also may require specialized services related to their disability, such as rehabilitation or access to assistive technology, inclusive assistive devices. Yet evidence suggests that in Indonesia,

children with disabilities have poorer health outcomes and face barriers accessing health services.

#### Severe illness

Around the world, children with disabilities face poorer health outcomes, are at higher risk of communicable diseases, have lower chances to benefit from life-saving measures and are more likely to report serious illnesses than children without disabilities. 109 Despite being mostly preventable, diarrhoea and Acute Respiratory Infection (ARI) are the leading causes of death and disease among children in low- and middleincome countries, responsible for around one third of deaths in children under five. 110 Children with disabilities that develop an illness, such as ARI, are more susceptible to severe illness, poorer health outcomes and hospitalization than children without disabilities.<sup>111</sup> In Indonesia, based on data from 2018, children with disabilities have higher prevalence of both ARI and diarrhoea than children without disabilities. Figure 14 and 15 show that 15 per cent of children with disabilities had ARI and 11 per cent of children with disabilities had diarrhoea in 2018. Age also had an impact on prevalence with children with disabilities as aged 5-14 years old more likely to have diarrhoea than children with disabilities aged 15-17 years old.

<sup>104</sup> UNICEF (2021) Guidance Note: Menstrual Health & Hygiene for Girls and Women with Disabilities.

<sup>105</sup> UNICEF (2021) Guidance Note: Menstrual Health & Hygiene for Girls and Women with Disabilities.

<sup>106</sup> Burnet Institute, WaterAid and UNICEF (2023), Regional Progress Review: Menstrual Health in East Asia and Pacific.

<sup>107</sup> Burnet Institute, WaterAid and UNICEF (2023), Regional Progress Review: Menstrual Health in East Asia and Pacific.

<sup>108</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

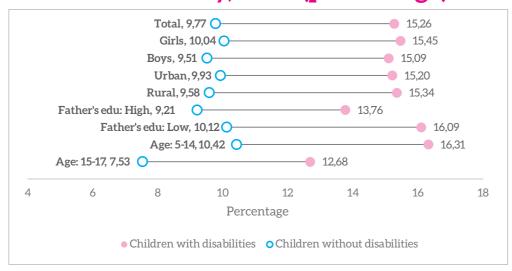
<sup>109</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

<sup>110</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

<sup>111</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

Figure 14.

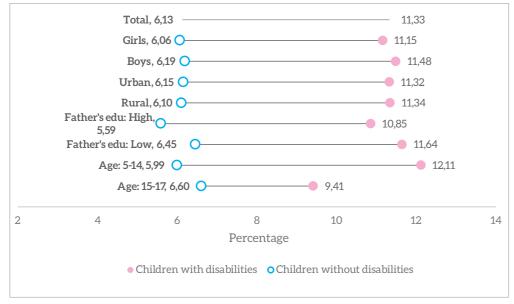
# Prevalence of Acute Respiratory Infection (ARI) among children with and without disability, 2018 (percentage)



Source: Based on Indonesia Basic Health Research 2018

#### Figure 15.

# Prevalence of diarrhoea among children with and without disability, 2018 (percentage)



Source: Based on Indonesia Basic Health Research 2018

The causes of higher incidence of ARI and diarrhoea in Indonesia are not specifically known, but based on global evidence it is likely due to both biological and social factors.<sup>112</sup>

- Certain types of impairments increase susceptibility. For example, children with neurological impairments are more likely to have comprised immune systems making them more susceptible to ARIs.<sup>113</sup>
- Social factors including poverty, limited access to clean water, inaccessible toilets and handwashing leading to unhygienic practices can increase risks of severe illnesse.
- Children with disabilities and their families face barriers to accessing quality healthcare due to stigma, lack of financial resources, inaccessible healthcare facilities, lack of transport, and lack of trained healthcare workers.<sup>114</sup> These barriers can cause delays in healthcare-seeking behaviour, denial of health services and can lead to more severe illness or even death.

## Health legislation and systems

To promote positive health outcomes and encourage health-seeking behavior among persons with disabilities, national health policies address individuals with disabilities, including children. However, there is a lack of specific regulations dedicated solely to children with disabilities. The Health Law (No. 36/2009) requires that efforts be made so as persons with disabilities can "live healthy lives and remain productive, socially, economically and with dignity." <sup>115</sup> It further mandates that the government ensure the availability of health services and facilities to persons with disabilities.

At the community level, Minister of Health Regulation No. 43/2019 on community health centres (*puskesmas*) outlines minimum standards for the provision of health services in disability-inclusive health facilities.

<sup>112</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

<sup>113</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

<sup>114</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

<sup>115</sup> Government of Indonesia (2009), Law No. 36 of 2009 about Health. Article 139, Paragraph 1.

These include the provision of:

- Priority lanes for pregnant women, persons with disabilities, and the elderly.
- Prioritized waiting rooms for pregnant women, persons with disabilities, and the elderly.
- Accessible toilet for persons with disabilities, equipped with signs and handrail.

Puskesmas funded by the National Physical Special Allocation Fund (Dana Alokasi Khusus/DAK) must also adhere to this regulation. These facilities could use the funding to provide accessible and high-quality healthcare services to all members of the community, including people with disability. To support community health centres in the implementation of the regulation, MoH has developed Guidelines for Integrated Development of Community Health Centres (Puskesmas). The guidelines require the centres to have accessible pathways and accessible toilets with these components serving as the basis for accreditation. If health facilities fail to meet requirements, including those related to disability accessibility, a low accreditation score can impact continued funding. While most community health centres are accredited (89.5 per cent), only 2.6 per cent have the highest level of accreditation. 116 As this high level of accreditation includes disability accessibility, it suggests that most (97 per cent) of accredited community health centres may not be meeting disability accessibility standards. There is an urgent need to improve the accessibility of healthcare facilities for persons with disabilities in Indonesia.

Other research also found that health facilities were inadequate to accommodate the specific needs of persons with disabilities, including the absence of handrails, accessible toilets, priority counters or lanes for persons with disabilities and a lack of assistive devices, such as wheelchairs.<sup>117</sup>

- Strengthen coordination on the implementation of disability-inclusive health service policies and regulations.
- Strengthen community participation including with persons with disabilities.
- Ensure available inclusive health services are accessible for persons with disabilities.
- Strengthen monitoring and evaluation, and use results and findings to inform government plans, and implementation and reporting of global commitments, such as UNCRPD.
- Increase the number of health staff trained on disability inclusive health services.

Specifically on children with disabilities, MoH Regulation No. 25/2014 on Child Health Efforts covers the provision of health services for children with disabilities. It includes children with disabilities receiving health services inside or outside health care facilities, including in special schools, inclusive education schools, households and other institutions. Health services provided under this regulation include counselling, support groups for families of children with disabilities, basic health facilities through to specialized hospitals for psychosocial and vision impairments, and rehabilitation services in healthcare centres and in the community. The regulation also requires community health centres located near special schools to provide immunization and other health services to children with disabilities in the school. In 2014 a guideline for the provision of child health services in special schools for children with disabilities was published by MoH. Further guidelines were developed in 2018 by MoH, MoECRT and MoRA for

As part of the implementation of regulations, MoH has undertaken initiatives related to persons with disabilities. A roadmap on inclusive health services, developed by MoH in 2019, aims to improve the health status of persons with disabilities and accommodate their needs. The inclusive health roadmap was a result of collaboration between government ministries and with development partners, WHO, civil society organisations and OPDs. The roadmap is not specific to children with disabilities, and covers strategies such as:

<sup>116</sup> Kementrian Kesehatan (2021), Pedoman Pembinaan Terpadu Puskesmas oleh Dinas Kesehatan. https://mutufasyankes.kemkes.go.id/assets/docs/PEDOMAN%20PEMBINAAN%20TERPADU%20 PKM%20OLEH%20DINKES.pdf.

<sup>117</sup> Sjafrina, A., Anggraeni, D. (2021), Penguatan Jaminan Mutu Pelayanan Kesehatan dan Pendidikan untuk Penyandang Disabilitas dalam PP No. 2 Tahun 2018 tentang Standar Pelayanan Minimum dan Peraturan Perundang-Undangan Turunannya (Permendikbud dan Permenkes). Indonesia Corruption Watch. Available at: https://antikorupsi.org/id/article/penguatan-jaminan-mutu-pelayanan-kesehatan-dan-pendidikan-untuk-penyandang-disabilitas [Accessed 17 October 2022].

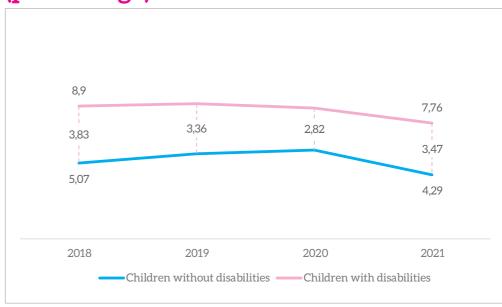
teachers on reproductive health for children with disabilities as part of a teacher programme targeting teachers in rural areas. However, access to rehabilitation services, such as physiotherapy, for children with disabilities areas is very limited, particularly in rural areas. OPD informants reported physiotherapy services being in distant locations and inaccessible buildings. In addition, the MoH has highlighted that the lack of data and evidence on children with disabilities is a barrier to disability inclusive and targeted health services. The MoH stated they lack data on areas with greatest need and prevalence of different types of disabilities to target services.

The minimum service standards for children, as outlined in MoH Regulation No. 4/2019 on Quality Basic Health Services, include routine child monitoring with stimulation, detection and early intervention for growth and development, along with Vitamin A supplementation and immunization. While the regulation aims to provide equal healthcare to all, there are no targeted health programmes for children with disabilities. Some children with disabilities required specialized healthcare services, requiring a tailored and targeted approach to meet their rights and needs. These needs are less likely to be met in a one-size-fits all approach as is currently taken by MoH. The minimum service standards for children also do not have any specific indicators for children with disabilities, which could lead to the specific needs of children with disabilities to be overlooked. Further the Committee on the Rights of Persons with Disabilities noted the physical barriers faced by persons with disabilities accessing health services, recommending strengthening action plans to ensure accessibility and availability of health services, particularly in rural and remote areas. 118

Data shows that in Indonesia more children with disabilities have unmet needs to healthcare services compared to children without disabilities with 7.8 per cent of children with disabilities having unmet needs in 2021 compared to 4.3 per cent of children without disabilities. See Figure 16. The unmet health needs of both children with and without disabilities

has slightly decreased between 2018 and 2021. While research is lacking as to the cause in Indonesia, a study in Malaysia in 2015 found that unmet healthcare service needs of children with disabilities were a result of lack of availability and inaccessibility of health services.<sup>119</sup>

Unmet need to healthcare services of children with and without disability (percentage)



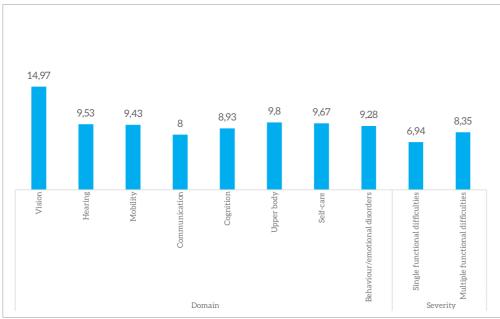
Source: Based on National Socioeconomic Survey 2018-2021.

Analysis by impairment type, using functional domains, shows that in Indonesia more children with vision impairments have unmet needs to healthcare services than other types of impairments with 15 per cent of children with vision impairments having unmet health needs. See Figure 17. More children with multiple impairments (8.3 per cent) had unmet needs to healthcare services compared to children with single impairments (6.9 per cent).

<sup>118</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>119</sup> Tan, S. H., (2015) 'Unmet health care service needs of children with disabilities in Penang, Malaysia' Asia-Pacific Journal of Public Health 27 (85).

Percentage of children with disabilities with unmet needs to healthcare services by impairment type, 2021



Source: Based on National Socioeconomic Survey 2021

Beyond regulations and their implementation, stigma can also create barriers to accessing healthcare as reported in many countries globally. <sup>120</sup> In Indonesia, there are some examples of this also being the case with families' feelings of shame preventing children with disabilities' access to health care in South Tangerang, Java. <sup>121</sup> In West Timor, a study found that children with disabilities' rights to access healthcare were hindered by stigma, cultural beliefs, including those related to karma and a preference for traditional healing practices. <sup>122</sup> See the section on stigma below. Reliance and greater trust in traditional healers over healthcare services was noted by respondents of the study. Collaborative efforts are needed to combat stigma and increase awareness amongst families on the importance of healthcare services.

Families don't understand how to respond to the disability...; they don't believe in medicine, they believe in traditional healers, until their child died [due to lack of medical treatment]. So, we still need support from other ministries/institutions partners on how to understand health [of children with disabilities]. (Government Official, male, Jakarta)

#### COVID-19

Around the world, persons with disabilities have been disproportionally impacted by the COVID-19 pandemic. They are at greater risk of contracting COVID-19, are more likely to develop severe health conditions and die from COVID-19, and are at greater risk of discrimination when accessing health services. In addition, inaccessible information and communications result in persons with hearing, vision, intellectual or physical impairments not receiving COVID-19 prevention information and health services. This was true for Indonesia, with the Committee on the Rights of Persons with Disabilities expressing concern that persons with disabilities have been disproportionately affected by the pandemic, in particular those in institutions and women and girls with disabilities. Noting the lack of accessible emergency information targeting persons with disabilities. 124

In Indonesia, a study by the Ministry of National Development Planning/ National Development Planning Agency (MoNDP) found that aside from the direct effect that COVID-19 has had on people's health, there have been significant secondary health impacts because of disruption to essential health services and heightened levels of stress. Persons with disabilities were particularly susceptible to negative health outcomes as many have underlying health conditions and higher needs for health care. In Indonesia, the study found that all rehabilitation services closed or significantly reduced on-site services due to the pandemic. This impacted children with disabilities, with one quarter of children with

<sup>120</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

<sup>121</sup> Fuaida Dyawati, Lisma and Ellies Sukmawati (2018) 'Family-based care for children with disabilities in South Tangerang City.' 153 (Icddims 2017): 154–157.

<sup>122</sup> Kiling, Indra, Clemence Due, Dominggus Li and Deborah Turnbull (2019) 'Perceptions of disability, environmental risk factors and available services among local leaders and parents of young children with disabilities in West Timor, Indonesia' Disability and Rehabilitation Taylor & Francis 41 (20): 2421–2432.

<sup>123</sup> United Nations (2020), Policy Brief: A Disability-Inclusive Response to COVID-19.

<sup>124</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

disabilities facing difficulties accessing rehabilitation or medical care during the pandemic. 125 With reduced access to rehabilitation, persons with disabilities faced deteriorating health. This could in turn require more serious medical attention in a context where medical services were less available due to being overburdened by COVID-19 cases. 126 Fear and stigma also prevented people from going to healthcare services:

If they are exposed to the virus, they will be stigmatised. They are already stigmatised for being disabled, then they get more stigma for getting COVID-19 disease. That will be more difficult for them. (Director of rehabilitation centre, Nusa Tenggara Barat, from MoNPD study)<sup>127</sup>

Gol introduced legislation to mitigate this impact on persons with disabilities. MoH developed guidelines on the protection of children with disabilities from COVID-19 virus transmission. Another MoH guideline<sup>128</sup> for health workers in community health centres stated that health services should be provided to children with disabilities without prejudice, stigma, and discrimination. The guideline further mandated the use of simple, easy-to-understand language and the use of visual aids for health promotion on COVID-19.

To mitigate the secondary health impacts on children with disabilities due to the disruption of health services, the MoSA and Ministry of Village, Development of Disadvantaged Regions, and Transmigration collaborated to advocate for the use of Village Funds to support home visits and home care to provide continuity of care of essential healthcare services for children with disabilities.

A circular was issued by MoH that compelled all regional heads, health agency heads, and heads of health service facilities to prioritize, facilitate, and ease access to COVID-19 vaccination services for the elderly and persons with disabilities.<sup>129</sup> In Jakarta, the Provincial Health Office partnered with taxi operator Blue Bird to provide transport for persons with disabilities including children to get the COVID-19 vaccine. 130 However, few children with disabilities (aged 6-17 years old) were vaccinated compared to children without disabilities. Out of an estimated 2 million children with disabilities, only 9,000 are fully vaccinated (three doses of vaccine) against COVID.<sup>131</sup> Barriers faced by persons with disabilities to access COVID-19 vaccinations include limited support and assistance, lack of understanding of persons with disabilities and their needs, and the absence of a sign language interpreters. Misinformation on vaccines causing disabilities and misunderstanding on co-morbidity have further hampered efforts to vaccinate persons with disabilities. 132

There was limited engagement of OPDs in the initial COVID-19 response with the regulations mandating OPD engagement not being adhered to. For example, OPDs were not given an opportunity to participate when COVID-19 task forces were established, either at the national or local level. However after the early response, the government engaged with OPDs. Including collecting input and feedback on disability inclusion, and mapping and addressing the needs of persons with disabilities. MoWECP and the COVID-19 task force asked OPDs and groups of parents of children with disabilities for input on COVID-19 protocols related to children with disabilities.

<sup>125</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look

<sup>126</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

<sup>127</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

<sup>128</sup> Guideline on providing health services for school age children and teenagers during the COVID-19 pandemic

<sup>129</sup> Minister for Health Circular No. HK.02.01Menkes5982021 on the Acceleration of the Implementation of COVID-19 Vaccination for Elderly, People with disabilities, as well as Educators and Education Personnel.

<sup>130</sup> Ministry of Health (2020), Pedoman Pelayanan Kesehatan Anak Usia Sekolah dan Remaja di Masa Pandemi COVID-19.

<sup>131</sup> UNICEF (2022) Discussion paper: Key issues for children with disabilities in Indonesia.

<sup>132</sup> Violleta, Prisca Triferna (2021) Vaksinasi penyandang disabilitas butuh penerapan lebih inklusif ANTARA News [online] https://www.antaranews.com/berita/2514657/vaksinasi-penyandangdisabilitas-butuh-penerapan-lebih-inklusif [12 May 2022].

<sup>133</sup> UNICEF (2021), Learning about meaningful engagement with Organizations of Persons with Disabilities in public health emergencies, including COVID-19.

<sup>134</sup> UNICEF (2021), Learning about meaningful engagement with Organizations of Persons with Disabilities in public health emergencies, including COVID-19.

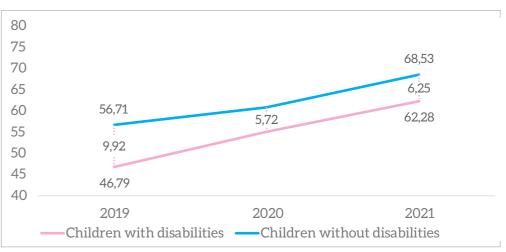
<sup>135</sup> UNICEF (2021), Learning about meaningful engagement with Organizations of Persons with Disabilities in public health emergencies, including COVID-19.

capacity of OPDs to engage in emergencies, combined with national-level policies and regulations to engage OPDs, resulted in mutual understanding and agreement between OPDs and the Government to work together during the COVID-19 pandemic.<sup>136</sup>

#### **Immunization**

Immunization is included in Presidential Regulation No. 72/2021 and is part of the minimum health service standards that children should receive. In 2024, the target is that 90 percent of children under five years old will receive immunizations. However, health inequities between children with disabilities and children without disabilities extend to routine childhood vaccination. While immunization coverage is still low, it has increased with 1.3 times as many children with disabilities immunized in 2021 compared to 2019, from 47 per cent (in 2019) to 62 per cent (in 2021). There is still a persistent gap in coverage between children with and without disabilities. Although the gap has reduced over the three-year period; there was still 6.25 percentage points gap of immunization between children with and without disability in 2021. See Figure 18.

Percentage of immunization coverage among children with and without disabilities

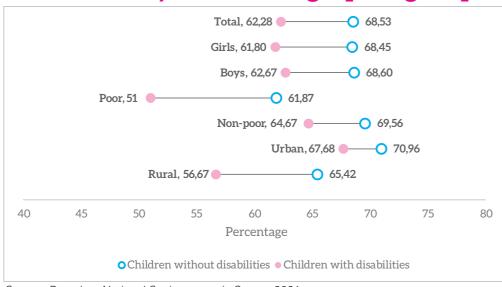


Source: Based on National Socioeconomic Survey 2019-2021.

Further analysis based on sociodemographic factors shows that disability has nearly as much of an impact on immunization coverage as poverty and location. The lowest coverage was amongst children with disabilities in poor households (51 per cent) and rural areas (57 percent). See Figure 19. Children with disabilities living in poverty were 27 per cent less likely to be immunized than children without disabilities.

<sup>136</sup> UNICEF (2021), Learning about meaningful engagement with Organizations of Persons with Disabilities in public health emergencies, including COVID-19.

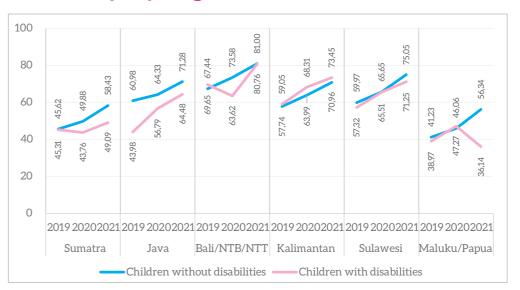
Percentage of immunization coverage among children with and without disabilities by sociodemographic groups



Source: Based on National Socioeconomic Survey 2021

Immunization coverage by region shows that while all other regions increased coverage of children with disabilities between 2019 and 2021, Maluku/Papua decreased from 47 per cent of children with disabilities vaccinated in 2020 to 36 per cent in 2021. This regionalspecific reduction in coverage was not seen amongst children without disabilities. See Figure 20. There were negligible gaps in vaccination coverage between children with and without disabilities in Sulawesi and Kalimantan. In Sumatra while there was an improvement for children without disabilities in immunization coverage, children with disabilities did not see the same improvement with 45 per cent coverage in 2019 and only 49 per cent in 2021. While there was effectively no gap between children with and without disabilities in 2019, by 2021 children with disabilities in Sumatra were 16 per cent less likely to be immunized than children without disabilities. Further investigation is required to understand the variations in vaccination coverage amongst children with disabilities in different regions.

Percentage of immunization coverage among children with and without disability by region



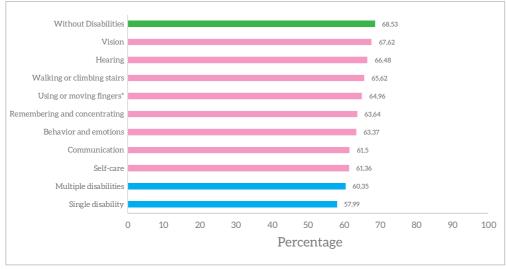
Source: Based on National Socioeconomic Survey 2019-2021. Note the 2019 data from Maluku/Papua should be used with caution as the relative sample error was above 20 per cent, but less than 25 per cent (which was the limit for use in the research).

While global data shows that immunization coverage of children with multiple disabilities is lower than children with single disabilities, <sup>137</sup> in Indonesia the data shows the opposite. 60 per cent of children with multiple disabilities are vaccinated, compared with 58 per cent of children with single disabilities. See Figure 21. Analyzing vaccination by type of disability, measured using functional domains, children with difficulties with self-care and communication had the lowest coverage of vaccination, while the highest coverage was among children with difficulties with vision and hearing. See Figure 21.

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<sup>137</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

Percentage of immunization coverage among children with and without disability by functional difficulty



Source: Based on National Socioeconomic Survey 2021

# 3.4 Education



Children with disabilities in Indonesia are less likely to attend and complete school, across all educational levels than children without disabilities.

In 2021, there were nearly 32,000 inclusive education schools, <sup>138</sup> compared with 2,250 special schools. <sup>139</sup> While there are 14 times as many inclusive education schools than special schools, efforts are required to review and progressively strengthen the inclusive education system to meet the learning needs and provide quality education to children with disabilities

According to the UNCRPD, children with disabilities have the right to education without discrimination, and to access inclusive, quality, and free primary and secondary education on an equal basis as others in the communities where they live. 140 SDG 4 on education cannot be achieved without improving children with disabilities access to education. SDG targets 4.5 141 and 4a 142 explicitly focus on ensuring equal access to all levels of education and vocational training for children with disabilities. 143

However, in Indonesia 36 per cent of children with disabilities are not attending school. Across all levels of education, children with disabilities were less likely to attend school and had lower completion rates (see Figures 27 and 29 below). 144

# Approaches to education of children with disabilities in Indonesia

A report by the World Bank described Indonesia's inclusive education to be at the early stages of development. The current approach to the education of children with disabilities operational in Indonesia is considered a two-track approach, which accommodates children with disabilities in inclusive education schools and provides learning opportunities through special schools. The Gol's Inclusive Education model aims to move from a two-track approach towards a multitrack approach, where a variety of services are provided between mainstream and special schools. As a global trend, countries that follow this sequence then transition from a multi-track approach to a

<sup>138</sup> Maharani, Herastia and Nerissa Rosalia (2021), 'Pengembangan Prototipe Sistem Informasi Sekolah Inklusi Anak Berkebutuhan Khusus.' *Jurnal Telematika* 16(1).

<sup>139</sup> Ministry of Education and Cultural (2021), Statistik Sekolah Luar Biasa (SLB) 2020/2021. https://re-positori.kemdikbud.go.id/22120/1/isi\_3E73984D-07CD-40C7-9E81-3809CBC4081F\_.pdf

<sup>140</sup> United Nations (2006), Convention on the rights of persons with disabilities and Optional Protocol. Article 24.

<sup>141</sup> SDG target 4.5: By 2030, eliminate gender disparities in education and ensure equal access to all levels of education and vocational training for the vulnerable, including persons with disabilities, indigenous peoples, and children in vulnerable situations.

<sup>142</sup> SDG target 4a: Build and upgrade education facilities that are child, disability and gender sensitive and provide safe, non-violent, inclusive and effective learning environments for all.

<sup>143</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

<sup>144</sup> Statistics Indonesia, National Socioeconomic Survey 2018-2021.

<sup>145</sup> Hata, A., Yuwono, J., Purwana, R., and Nomura, S., (2021), Embracing Diversity and Inclusion in Indonesian Schools – Challenges and Policy Options for the Future of Inclusive Education. World Bank

<sup>146</sup> Hata, A., Yuwono, J., Purwana, R., and Nomura, S., (2021), Embracing Diversity and Inclusion in Indonesian Schools – Challenges and Policy Options for the Future of Inclusive Education. World Bank

one-track approach where most children with disabilities are included in mainstream education.<sup>147</sup>

Inclusive education is where children with disabilities attend regular schools with children without disabilities. It is not only the placement of children with disabilities in mainstream schools, but also ensuring the full participation of children with disabilities academically and socially. Research has shown that when teachers are trained, quality inclusive education fosters relationships and empathy among students with and without disability. 149

In Indonesia the number of inclusive education schools increased by 29 per cent over the course of a year, from 31,724 schools in 2021<sup>150</sup> to 40,828 in 2022.<sup>151</sup> In Indonesia, there are also regular schools that are not considered inclusive education schools as they do not provide services for children with disabilities. At the primary school level, only 17,000 (11 per cent) of the 149,000 primary schools in Indonesia are inclusive education schools.<sup>152</sup> The inclusive education primary schools are found in most (95 per cent) of districts; 511 of the 534 districts in Indonesia.

It was observed by an OPD informant that while there are inclusive education schools, there is a lack of teachers or assistants to support children. More specifically, children with autism spectrum disorder find it more difficult to get support in the higher levels of education. The MoECRT is developing a system to provide teacher assistants to support children with disabilities in inclusive education schools. At an inclusive

education school in Tangerang, Banten Province, teaching assistants conduct classes for students with a range of disabilities, including students with intellectual, communication, vision, and developmental disabilities. The assistants tailor the teaching methods to the student and their learning needs. In addition to the tailored specialised learning sessions, students with disabilities also attend regular classes, following the same curriculum as students without disabilities. <sup>153</sup> In Yogyakarta where there is a shortage of teachers' assistants for children with disabilities, the education department is collaborating with Universitas Negeri Yogyakarta to enhance the capacity of teachers. <sup>154</sup>

The other approach taken in Indonesia is special schools (or SLB), where schools are established specifically and exclusively for children with disabilities. In Indonesia, special schools are categorised by the students that they cater to. The different categories are for:

- Students with vision disabilities (SLB-A).
- Students with hearing disabilities (SLB-B).
- Students with intellectual disabilities (SLB-C).
- Students with physical disabilities (SLB-D).
- Students with emotional or behavioural disorders (SLB-E).
- Students with multiple disabilities (SLB-F).

A school may specialise in one type of category or may accommodate students from more than one category. Figure 22 depicts the three different types of schools in Indonesia.

<sup>147</sup> Hata, A., Yuwono, J., Purwana, R., and Nomura, S., (2021), Embracing Diversity and Inclusion in Indonesian Schools – Challenges and Policy Options for the Future of Inclusive Education. World Bank

<sup>148</sup> Hata, A., Yuwono, J., Purwana, R., and Nomura, S., (2021), Embracing Diversity and Inclusion in Indonesian Schools – Challenges and Policy Options for the Future of Inclusive Education. World Bank

<sup>149</sup> Wibowo, S B and J A Muin (2018) 'Inclusive Education in Indonesia: Equality Education Access for Disabilities' KnE Social Sciences 3 (5): 484.

<sup>150</sup> Maharani, Herastia and Nerissa Rosalia (2021), 'Pengembangan Prototipe Sistem Informasi Sekolah Inklusi Anak Berkebutuhan Khusus.' *Jurnal Telematika* 16(1).

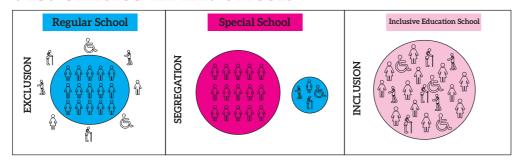
<sup>151</sup> Alim, Mutiul (2023), Kemdikbudristek Dorong Pertumbuhan Jumlah Sekolah Inklusi.

<sup>152</sup> Sekretariat Jenderal, Pusat Data dan Teknologi Informasi (2020), Statistik Sekolah Luar Biasa (SLB) 2020/2021. Data dan Teknologi Informasi, Sekretariat Jenderal, Kementerian Pendidikan dan Kebudayaan, Jakarta.

Napitupulu, Ester Lince, Hidayat Salam, dan Willy Medi Christian Nababan (2022) 'Sekolah Inklusi, Menyemai Kesetaraan bagi Penyandang Disabilitas'. Kompas.id 5 Desember https://www.kompas.id/baca/humaniora/2022/12/04/sekolah-inklusi-jadi-harapan-menyemai-kesetaraan-bagi-penyandang-disabilitas [Accessed: 16 August 2023].

<sup>154</sup> Kemendikbudristek (2022) Diskusi Pengarusutamaan Pendidikan Inklusi di Kabupaten Sleman https://pskp.kemdikbud.go.id/berita/detail/313334/diskusi-pengarusutamaan-pendidikan-inklusi-di-kabupaten-sleman [Accessed: 16 August 2023].

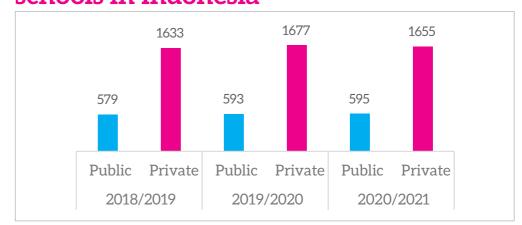
Type of schools for children with disabilities in Indonesia



Source: Based on World Economic Forum<sup>155</sup>

In Indonesia, the number of special schools is much smaller than inclusive education schools. As highlighted above in 2021 there were 31,724 inclusive education schools, compared with 2,250 special schools in 2020/2021. Most (73 per cent) of special schools were private schools in 2020/2021. See Figure 23. In 2021, East Java has the highest concentration of public and private special schools (367 private schools and 71 public schools), followed by West Java (343 private and 42 public special schools). While there are only five special schools in each North Kalimantan (all public schools) and West Papua (four public and one private school). 157

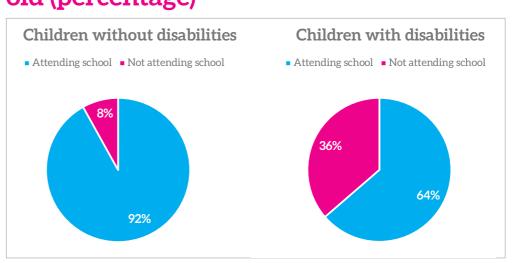
Number of public and private special schools in Indonesia



Source: MoECRT, Special Schools Statistics (Statistik Sekolah Luar Biasa SLB) 2018, 2019, 2021

In Indonesia, 64 per cent of children with disabilities are attending school, compared to 92 per cent of children without disabilities. See Figure 24.

School attendance rate for children with and without disabilities, aged 7-18 years old (percentage)



Source: Based on National Socioeconomic Survey 2021.

<sup>155</sup> World Economic Forum (2018), Vulnerable children are too often excluded from the classroom. Here's how we can change that. https://www.weforum.org/agenda/2018/07/the-promise-of-inclusive-education/ Retrieved 11 June 2023.

Ministry of Education and Cultural (2021), Statistik Sekolah Luar Biasa (SLB) 2020/2021. https://repositori.kemdikbud.go.id/22120/1/isi\_3E73984D-07CD-40C7-9E81-3809CBC4081F\_.pdf

<sup>157</sup> Ministry of Education and Cultural (2021), Statistik Sekolah Luar Biasa (SLB) 2020/2021. https://repositori.kemdikbud.go.id/22120/1/isi\_3E73984D-07CD-40C7-9E81-3809CBC4081F\_.pdf

Having signed the UNCRPD in 2011, Gol committed to "ensure an inclusive education system at all levels..." 158 Indonesia's current approach to inclusive education focuses on the placement and inclusion of students with disabilities in inclusive education schools, and introducing regulations to ensure that students with disabilities can learn with their peers without disabilities. 159 In the legislation, Gol is strengthening regulations related to inclusive education. Indonesia's laws guarantee everyone the right to education, including for children with disabilities (see Annex 8). Regulation No. 13/2020 on Reasonable Accommodation for Students covers inclusive education and reasonable accommodation, such as accessible facilities, teachers, and curriculum, based on each type of disability. Initiatives to scale up inclusive education in Indonesia are needed as the Committee on the Rights of Persons with Disabilities expressed concern in 2022 about the limited efforts towards achieving inclusive education and the prevalence of special schools. The Committee had recommended that an inclusive education strategy with targets, timelines, budget, and responsibilities be developed, covering all levels of education. 160

Making the development and implementation of an inclusive education strategy more challenging is that multiple government ministries have responsibilities for education in Indonesia. MoECRT and MoRA are the key ministries in providing education for children, including children with disabilities in Indonesia. Both MoECRT and MoRA have their own regulations on inclusive education. For example, MoRA Regulation No. 90/2013 mandates access for 'children with special needs' in Islamic schools with further decrees to guide the implementation of inclusive Islamic schools. While MoECRT is drafting a technical guideline for teachers in inclusive education schools. Both MoECRT and MoRA have their own inclusive education roadmap that are being implemented. According to an OPD informant, stronger coordination on inclusive

education between the ministries and harmonization of legislation is required.

Within MoECRT, the Community Education and Special Education Directorate leads efforts in both special education and inclusive education. This includes building special schools, developing inclusive education in regular schools and adjusting curricula to accommodate the needs of children with disabilities. The MoECRT has partnered with the Indonesian Architects Association to design accessible schools, including ramps, digital systems for students with visual impairments, and sliding doors to make it easier for wheelchair users. However, there is limited information on the implementation of these designs.

In Indonesia there are Islamic schools (*madrasah and Pesantren*) and MoRA has the responsibility for including children with disabilities in Islamic schools. MoRA has established the Inclusive Islamic Education Working Group to coordinate all programmes related to inclusive education in Islamic education. They are implementing the Inclusive Islamic Education Roadmap, including the establishment of Disability Services Units, teacher training, establishing information sharing forums for educators in inclusive Islamic schools and engaging inclusive education experts, and requiring Islamic schools to provide at least 10 per cent of its places for children with disabilities.

MoRA received support from UNICEF's inclusive education programme between 2017 and 2020, focused on generating evidence around the barriers to education for children with disabilities. MoRA has a scholarship fund for students with disabilities, which is awarded based on academic merit. Further in 2015, MoRA piloted inclusive Islamic schools in the five provinces of East Java, Central Java, Banten, West Nusa Tenggara, and South Sulawesi with IDR 2.5 billion (about USD 168,000) funding from the Australian government. These efforts led to the designation of 22 inclusive Islamic schools, which in turn triggered

<sup>158</sup> United Nations (2006), Convention on the rights of persons with disabilities and Optional Protocol. Article 24.

Hata, A., Yuwono, J., Purwana, R., and Nomura, S., (2021), Embracing Diversity and Inclusion in Indonesian Schools – Challenges and Policy Options for the Future of Inclusive Education. World Bank

<sup>160</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>161</sup> Sofiana, Sulvi (2015) Australia Sumbang Rp 2,5 Miliar untuk Pilot Project Madrasah Inklusi Artikel ini telah tayang di Surya.co.id dengan judul Australia Sumbang Rp 2,5 Miliar untuk Pilot Project Madrasah Inklusi, [online] https://surabaya.tribunnews.com/2015/08/10/australia-sumbang-rp-25-miliar-untuk-pilot-project-madrasah-inklusi [8 May 2022].

the establishment of more inclusive schools in the following years.

Assistance from AusAID [Australian Agency for International Development] has become a stepping stone for the inclusive education movement at Kemenag [MoRA] until now. And thank God, the movement is very massive. (Government Official, male, Jakarta)

However, there are challenges in the implementation of inclusive education in Islamic schools. Other research showed that 8 out of 10 Islamic schools that piloted inclusive education in 2015 did not adhere to the implementation standards or guidelines. Further, case studies in Yogyakarta found that inclusive Islamic schools lack infrastructure, financing and an inclusive curriculum for children with disabilities. 163

Another challenge faced by both MoECRT and MoRA is the limited number of teachers in regular schools trained in inclusive education and disability. Previous research had reported a limited number of teachers with inclusive education qualifications. 164 Training programmes were also reported as not effective at increasing teachers' skills in inclusive classroom. Even after training, many teachers in inclusive schools are not confident about teaching children with disabilities. 165 MoECRT is currently training about 5,000 teachers on inclusive education, which is only a small proportion of the 3,190,093 teachers in Indonesia 166. However, MoRA, in partnership with the World Bank, has established an Inclusive Teacher Working Group to increase the capacity of teachers

For children with disabilities to be included in regular schools and classrooms, and participate on an equal basis as other children, they require access to assistive technology and learning materials to support their learning. The Committee on the Rights of Persons with Disabilities recommended that Disability Service Units be established in all regions and at all educational levels to facilitate the provisions of accessible learning materials, alternative communication and information methods. including inclusive digital access, Easy Read, Braille, sign language, communication aids, and assistive technology. 167 Disability Service Units are mandated in the Regulation on Reasonable Accommodation for Students (No. 13/2020) to be established at the regional level. However only 26 out of 514 districts and cities (5 per cent) have established Disability Service Units. The lack of implementation of this regulation at the regional level is resulting in students with disabilities unable to access the assistive devices, services and support that they need to participate and learn. A report by the World Bank had similar findings noting that inclusive education schools do not have adequate equipment and materials to accommodate children with disabilities. 168

#### Early childhood education

Early childhood education for children with disabilities is important for their development, to socialize with their peers and to set them on a pathway of learning, making the transition into primary school easier and more likely. In Indonesia, there are challenges with low enrolments in early childhood education. In 2022, the enrolment rate nationally for early childhood education was only 35 per cent (for children with and without disabilities). Preschool attendance was lower amongst children with disabilities compared to children without disability. See Figure 25. While the proportion of children without disabilities did not

in inclusive Islamic schools.

<sup>162</sup> Ministry of Religious Affairs (2018), Evaluasi Program Penyelenggaraan Pendidikan Inklusif Di Madrasah

<sup>163</sup> Suryati, Ana Eka and Samsi Haryanto (2016) 'Evaluasi pelakasanaan program pendidikan inklusif di Madrasah Aliyah Negeri Maguwoharjo Yogyakarta'; and Sumarni (2019) 'Pengelolaan Pendidikan Inklusif di Madrasah' Jurnal Penelitian Pendidikan Agama dan Keagamaan.

Poernomo, Baby (2016) 'The Implementation of Inclusive Education in Indonesia: Current Problems and Challenges' American International Journal of Social Science 5 (3): 144–150.; Amka (2017) 'Problems and Challenges in the Implementation of Inclusive Education in Indonesia' International Journal of Humanities and Social Science 7 (10).; and Waldes Hasugian, Johanes, Suardin Gaurifa, Sipora Blandina Warella, Jusuf Haries Kelelufna and Josefien Waas (2019) 'Education for children with special needs in Indonesia' in Journal of Physics: Conference Series IOP Publishing.

<sup>165</sup> Hata, A., Yuwono, J., Purwana, R., and Nomura, S., (2021), Embracing Diversity and Inclusion in Indonesian Schools – Challenges and Policy Options for the Future of Inclusive Education. World Bank.

<sup>166</sup> Kementerian Pendidikan, Kebudayaan, Riset dan Teknologi. Data Pokok Pendidikan. [online] https://dapo.kemdikbud.go.id/guru [19 September 2023].

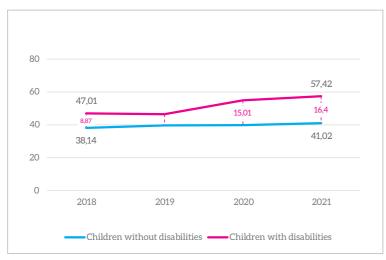
<sup>167</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>168</sup> Hata, A., Yuwono, J., Purwana, R., and Nomura, S., (2021), Embracing Diversity and Inclusion in Indonesian Schools – Challenges and Policy Options for the Future of Inclusive Education. World Bank

<sup>169</sup> Statistics Indonesia (2023), Statistik Pendidikan Indonesia (SUSENAS 2022).

change substantially between 2018 and 2021 (from 38 per cent in 2018 to 41 per cent in 2021); the proportion of children with disabilities not attending preschool increased from 47 per cent in 2018 to 57 per cent in 2021. In other terms, compared to children without disabilities, children with disabilities were 23 per cent more likely to not attend preschool in 2018, which increased to 40 per cent more likely to not attend preschool in 2021.

Percentage of children not attending preschool education

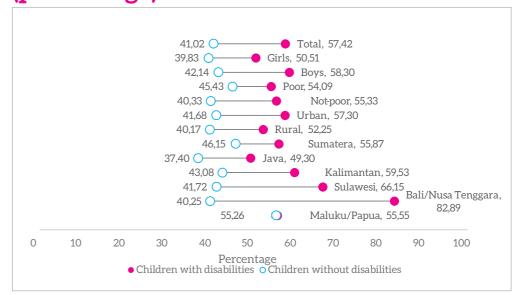


Source: Based on National Socioeconomic Survey 2018-2021.

Figure 26 shows the difference in attendance in preschool based on different factors, including gender, poverty and location. Gender had an impact of attendance in preschool with lower attendance amongst boys with disabilities (58 per cent not attending) compared to girls with disabilities (50 per cent not attending). Girls with disabilities were 27 per cent more likely to not attend preschool compared to girls without disabilities. While boys with disabilities were 38 per cent more likely to not attend preschools compared to boys without disabilities. The region where children live also had a significant impact on preschool attendance. In Bali/Nusa Tenggara double the proportion of children with disabilities were not attending preschool compared to children

without disabilities. According to the data, 83 per cent of children with disabilities in this region do not attend preschool. While in Maluku/Papua, there was no difference in attendance between children with and without disabilities with 55 per cent of both groups of children not attending preschool.<sup>171</sup>

Children not attending preschool by sociodemographic characteristics, 2021 (percentage)



Based on National Socioeconomic Survey 2021.

There was not a major variation of attendance in pre-school based on impairment type. 67 per cent of children with vision impairments, 68 per cent with upper body, and 65 per cent with mobility impairments were not attending preschool in 2021. Children with multiple impairments were less likely to attend preschool than children with single impairments. See Figure 30 below.

In 2021, MoECRT introduced a guideline on the management of inclusive early childhood education environment. The guideline emphasizes equal opportunity, accessibility, and diverse facilities to accommodate

<sup>170</sup> Statistics Indonesia, National Socioeconomic Survey, 2021.

various type of disabilities. As the guideline is newly implemented, the effectiveness and challenges are unknown at this stage.

As mentioned above, having ratified the CRPD the GoI has committed to ensuring an inclusive education system. <sup>172</sup> The transition of the current two-track approach to an inclusive education system in Indonesia will take time and requires a systems-approach. While it is acknowledged that the number of inclusive schools is insufficient overall and is highly unequal across different local governments, simply appointing schools to provide inclusive education services without adequate training and resources have proven to be ineffective. An analysis of the inclusive education sector in Indonesia would provide further information on how the education system is meeting the needs of children with disabilities and support the development or strengthen of plans for the transition towards more disability inclusive approaches.

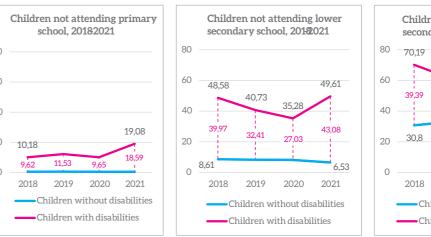
#### Primary and secondary education

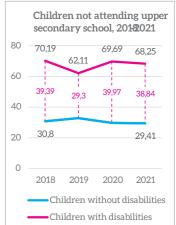
Compared to early childhood education, more children participated in primary school. While Primary school is mandatory for all children, the same cannot be said for preschool education as only 41 per cent of districts and cities have implemented compulsory preschool education.<sup>173</sup>

Close to one in five children with disabilities (19 per cent) were not attending primary school in 2021, compared to less than one per cent (0.5 per cent) of children without disabilities. See Figure 27. There has essentially been universal primary school attendance for children without disabilities between 2018 and 2021. While the proportion of children with disabilities not attending primary school was stable until 2020, non-attendance increased by 88 per cent between 2020 and 2021. This suggests that the COVID-19 pandemic and changes to schooling as a result caused attendance for children with disabilities to drop significantly. The same trend is seen in primary school completion

rates (below). The impact of COVID-19 on the education of children with disabilities is explored further below.

Percentage of children not attending school across different education levels





Source: Based on National Socioeconomic Survey 2018-2021.

As the education level increases, the proportion of children with disabilities not attending also increases. In 2021, while 19 per cent of children with disabilities did not attend primary school, this increased to 50 per cent in lower secondary school and 68 per cent in upper secondary school. In other words, half of children with disabilities were not attending lower secondary school and over two thirds of children with disabilities were not attending upper secondary school in 2021. See Figure 27.

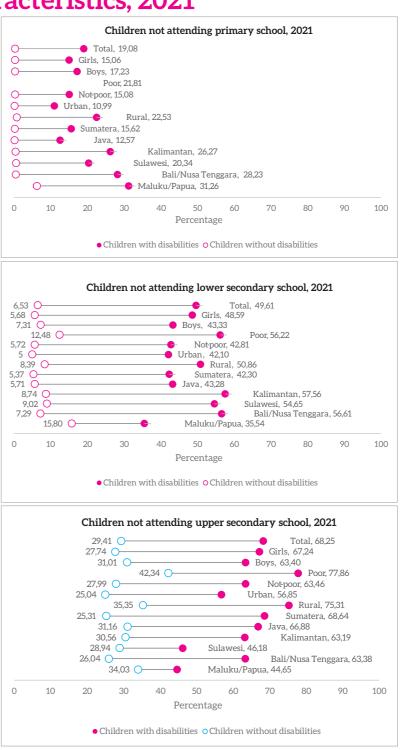
In lower secondary school, attendance was improving for children with disabilities between 2018 and 2020 with non-attendance decreasing by 27 per cent during that time. However, like seen in primary school attendance, the proportion of children with disabilities not attending lower secondary school increased by 41 per cent between 2020 and 2021. While attendance also dropped for lower secondary school students without disabilities, it was to a lesser degree with a 27 per cent increase in non- attendance. See Figure 27.

<sup>172</sup> United Nations (2006), Convention on the rights of persons with disabilities and Optional Protocol. Article 24.

<sup>173</sup> Kompas.com (2021) 'Kemendikbud Harap Pemda Buat Aturan Wajib PAUD Sebelum SD' September.

Children with disabilities living in poverty were much less likely to attend school compared to children with disabilities from non-poor households, with poverty having the biggest impact on primary school attendance. In primary school, children with disabilities living in poverty were 45 per cent more likely to not attend school, in lower secondary 31 per cent and in upper secondary 23 per cent, compared to children with disabilities that were not poor. See Figure 28. A similar trend was seen amongst children with disabilities in rural areas compared to urban. In rural areas, double the proportion of children with disabilities did not attend primary school, compared to children with disabilities in urban areas. This correlates with the finding that inclusive education schools tend to be in urban areas. 174 While proportionately more girls with disabilities attended primary school, more boys with disabilities attended both lower secondary and upper secondary school. Attendance varied between regions and education levels. For example, the proportion of children with disabilities not attending primary school was highest in Maluku Papua (31 per cent); for lower secondary school it was Kalimantan (58 per cent); and for upper secondary it was Sumatera (67 per cent).

Comparison of children not attending school based on sociodemographic characteristics, 2021



Source: Based on National Socioeconomic Survey 2021.

<sup>174</sup> Filani Olyvia (n.d.) Satu Juta Anak Berkebutuhan Khusus Tak Bisa Sekolah CNN Indonesia [online] https://www.cnnindonesia.com/nasional/20170829083026-20-237997/satu-juta-anak-berkebutuhan-khusus-tak-bisa-sekolah [27 April 2022].

In addition to lower attendance, evidence shows that for children with disabilities who do attend school, are at higher risk of dropping out and not completing their education. Dropping out of school limits the future educational opportunities and employment opportunities of these children.<sup>175</sup>

In Indonesia, across all levels of education, children with disabilities were less likely to complete their education than children without disabilities. In 2021, the completion rates for children with disabilities were: 56 per cent completed primary school compared to 96 per cent of children without disabilities. In lower secondary school, 64 per cent of children with disabilities completed this level of education, compared with 89 per cent of children without disabilities. Only 30 per cent of children with disabilities completed upper secondary education, while completion rates for children without disabilities were 63 per cent. Completion rates are lower for children with disabilities in upper secondary school, suggesting that children with disabilities face increasing barriers, as they progress through the school system, to complete their education. See Figure 29.

In 2021, while the vast majority of children without disabilities complete their primary school education (96 per cent), children with disabilities were 41 per cent less likely to complete primary school. See Figure 29. While the proportion of children with disabilities completing primary school increased between 2018 and 2020, the COVID-19 pandemic and disruptions to education caused this progress to be reversed. In 2021, primary school completion amongst children with disabilities dropped by 18 per cent from the previous year, back to rates similar to 2018. Children without disabilities did not see the same decrease, demonstrating that children with disabilities faced greater barriers to continuity of education during the pandemic – see further information below.

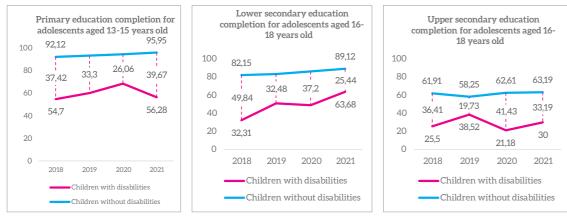
The same impact of the COVID-19 pandemic was not seen at the lower and upper secondary school levels. Lower secondary school completion rates for adolescents with disabilities have increased over the last four years, from 32 per cent in 2018 to 64 per cent in 2021. See Figure 29. While less adolescents with disabilities are dropping out of lower secondary school, there remains a gap in completion rates between adolescents with and without disabilities at this education level. In 2021, 89 per cent of adolescents without disabilities completed lower secondary compared with 64 per cent of adolescents with disabilities. However, this gap has almost halved over the four-year period. As of 2021, adolescents with disabilities were 29 per cent less likely to complete lower secondary school, compared with those without disabilities.

Fewer adolescents with and without disabilities complete upper secondary school in Indonesia compared to lower levels of education. In 2021, only 30 per cent of adolescents with disabilities completed upper secondary school. Unlike lower secondary education which saw a substantial overall increase in completion over the four-year period, the completion rate at upper secondary school for adolescents with disabilities decreased between 2019 and 2020 (from 39 per cent to 21 per cent), then increased in 2021 (to 30 per cent). There remains a gap based on disability. While 63 per cent of adolescents without disabilities completed upper secondary education, only 30 per cent of adolescents with disabilities completed this level of education. In other terms, adolescents with disabilities 53 per cent less likely to complete upper secondary education in 2021 compared to adolescents without disabilities.

<sup>175</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

<sup>176</sup> Statistics Indonesia, National Socioeconomic Survey, 2018-2021.

Percentages of completion rate across education level



Source: Based on National Socioeconomic Survey 2018-2021.

Poverty has an impact on children and adolescents with disabilities school completion. Children with disabilities living in poverty are 32 per cent less likely and 29 per cent less likely to complete primary and secondary school respectively, compared with children with disabilities from non-poor households (see Annex 9). Gender did not have a significant impact on school completion rates of children with disabilities. However, children with disabilities in rural areas in Indonesia were less likely to complete school than those in urban areas. At the primary and lower secondary level, they were 17 per cent less likely; while for upper secondary adolescents with disabilities in rural areas were 35 per cent less likely to complete school than adolescents with disabilities in urban areas.

# Access to education during COVID-19 pandemic

The COVID-19 pandemic and subsequent school closures exacerbated the already widespread educational inequalities for children with disabilities.<sup>178</sup> When schools closed due to the pandemic, to have

continuity of learning many Indonesian schools turned to other methods. These included online learning, phone and radio communication, home visits and/or sending learning materials to parents. The Students with disabilities faced multiple barriers to participating in online learning. In a survey by MoNDP, it was found that in April 2020, most students with disabilities (68 per cent) reported difficulties to learn online, with only 20 per cent were reportedly able to access and participate easily. This resulted in children and adolescents with disabilities being three times more at risk of dropping out compared to children without disabilities.

One of the barriers to online learning was access to the internet. In April 2020, 72 per cent of students studying remotely were doing so via the internet. However, fewer children with disabilities in Indonesia had access to the internet compared with children without disabilities. In 2020, only 24 per cent of children with disabilities had access to the internet, less than half the coverage of children without disabilities (50 per cent of children without disabilities) (see Annex 10). Other barriers to online learning for children with disabilities included difficulties focusing on learning in the home environment, limited access to technical support, lack of access to assistive technologies and teacher perceptions that students with disabilities cannot participate in online learning. Students with multiple disabilities face the most challenges during distance learning. 183

To improve access to remote learning for children with disabilities, Gol drafted a learning guide for students with disabilities to provide technical guidance on their specific needs. Support was also provided by the government, such as assistance to access internet data to support distance learning to students, including those with disability. Special Schools also conducted remote learning via online learning, giving

<sup>177</sup> Statistics Indonesia, National Socioeconomic Survey, 2021

<sup>178</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

<sup>179</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

<sup>180</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

<sup>181</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

<sup>182</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), s

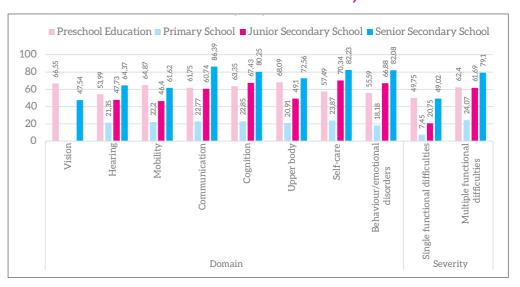
<sup>183</sup> Rohman, Yani Fathur and Vitriani Sumarlis (2020) *Study of Support for Students with Disabilities during the COVID-19 Pandemic.* 

assignments via message apps and door-to-door lessons for those that could not access the internet.

## Exclusion from education on the basis of disability type

Figure 30 shows attendance at school based on type of disability, as measured by functional domains. Across primary and lower secondary school, the proportion of children not attending school was highest amongst children with difficulties in self-care (24 per cent and 70 per cent respectively). For upper secondary school, these children had the second highest non-attendance, after children with difficulties in communication (86 per cent). Children with difficulties in cognition were also less likely to attend school, compared with other types of difficulties. In secondary school, a high proportion of children with emotional and behavioural disorders also were not attending school in 2021 (67 per cent in lower secondary and 82 per cent in upper secondary). Across all education levels, children with multiple impairments were less likely to attend school compared with children with single impairments. In primary and lower secondary school, children with multiple impairments were 3 times more likely to not attend school, while in upper secondary they were 1.6 times more likely to not attend school, compared with children with single impairments..

Percentage of children with disabilities not attending school based on education level and functional domain, 2021



Source: Based on National Socioeconomic Survey 2021.

Similar results are found with completion rates. At the primary school level, the children with the lowest completion rates were those with functional difficulties in communication (36 per cent), self-care (24 per cent), and cognition (24 per cent) (see Annex 9).

These findings align with global research which found that children with intellectual, psychosocial and multiple disabilities fare worse than children with physical disabilities when accessing education.<sup>184</sup> Research conducted by SMERU in 2020 reported that special schools in Indonesia specialize in particular types of disabilities, for example only serving students with hearing, vision and physical disabilities. This results in children with intellectual and psychosocial disabilities been excluded from these schools.

A study of inclusive education in Indonesia in 2018 found that special schools can discriminate against children with disabilities via entrance

<sup>184</sup> Male, Chata and Quentin T. Wodon (2017) Disability Gaps in Educational Attainment and Literacy (English).

test requirements. Entrance tests further marginalize children with intellectual disabilities. While current provision states that children with intellectual disabilities can access both inclusive and special schools, in reality entrance tests in special schools and some inclusive education schools asking for IQ test results, results in rejection of these children. For example, students with Down Syndrome end up in low-quality specials schools, if they go to school at all.<sup>185</sup>

#### Socioeconomic barriers to school

Financial constraints create barriers for families of children with disabilities to send their children to school. Households of children with disabilities are already more likely to be living in poverty (see section on social protection). In addition, Indonesia Corruption Watch found that many parents of students with disabilities have to spend more money to make sure their children can access education, especially in inclusive education schools. Additional expenses include paying for a special assistant teacher (between IDR 300,000-500,000, or USD 20-34) and transportation costs. <sup>186</sup>

To support school enrolment for vulnerable groups of children, the government implements the Smart Indonesia Programme, which provides cash assistance for students. Eligible students include orphans, children living in poverty, children that have dropped out of school, and children with disabilities. Only about 6 per cent of children with disabilities are benefiting from this education-related cash grant (see Annex 11). Challenges related to the Smart Indonesia Programme were that fund disbursement was often late and beneficiaries used the funds for noneducational purposes.<sup>187</sup>

Lack of awareness and stigma also limit access to education for children with disabilities. Parents may be reluctant to send their children to school due to feelings of shame or fear that their child will be ridiculed and mocked. Lack of awareness and stigma is also present within the education sector leading to limitations in the implementation of regulations related to students with disabilities at the local level.

A study in 2014 found that sub-national governments tended to give weak political support towards inclusive education as they do not perceive it as a local necessity. Furthermore, some ministerial staff believed children with disabilities to be "uneducable." 188 This results in local governments prioritizing spending elsewhere and were there were budgets for inclusive education, budgets being cut. Further in some regions, a lack of understanding leads local authorities to equate inclusive education with special education.

Some children with disabilities are denied enrolment at their closest public schools. 189 Other reasons include school buildings and facilities not being accessible. 190

#### Challenges in identification and data collection

There are challenges with the data collection of both children with disabilities in school and out of school. There is a lack of specific data to identify children with disabilities that are not enrolled in school, making it difficult for MoECRT and other organizations to monitor and target out-of-school children with disabilities with programmes and support. The data on children with disabilities in schools may not be accurate and is likely to be underestimated.

<sup>185</sup> Yayasan Peduli Sindroma Down Indonesia (2021) 'Educational Opportunities For People With Intellectual Disabilities'.

<sup>186</sup> Indonesia Corruption Watch (2021), Policy Brief: Penguatan Jaminan Mutu Pelayanan Kesehatan dan Pendidikan untuk Penyandang Disabilitas dalam PP No. 2 Tahun 2018 tentang Standar Pelayanan Minimum dan Peraturan Perundang-Undangan Turunannya (Permendikbud dan Permenkes).

<sup>187</sup> Alifia, Ulfah, Adinda Angelica, Akhmadi, Dyan Widyaningsih, Fauzan Kemal Musthofa, Nina Kusumawardhani, Niken Toyamah and Rika Kumala Dewi (2022) *The Effectiveness of PIP Implementation in Ensuring the Fulfilment of Right to Education Service for Children from Disadvantaged Families and Out-of-School Children Jakarta, Indonesia.* 

<sup>188</sup> Adioetomo, Sri Moertiningsih, Daniel Mont and Irwanto (2014a) People with disabilities in Indonesia: Empirical Facts and Implications for Social Protection Policies Jakarta, Indonesia.

<sup>189</sup> Rudiyati, Sari (2011), Potret Sekolah Inklusif Di Indonesia. Universitas Negeri Yogyakarta. http://staff-new.uny.ac.id/upload/130543600/penelitian/Potret+Sekolah+Inklusif+di+Indonesia.pdf [Accessed 8 May 2022].

<sup>190</sup> Poernomo, Baby (2016) 'The Implementation of Inclusive Education in Indonesia: Current Problems and Challenges' American International Journal of Social Science 5 (3): 144–150.; and Wibowo, S. B. (2016) 'Inclusive education, right for children with special needs (studies in Metro City Lampung)' in The First International Conference on Child - Friendly Education 2016 Surakarta.

The varying terminology and definitions used for disability by the different ministries can cause variations in who is considered a student with a disability (see section on definition). In addition, it was found that Islamic schools are reluctant to enter data on students with disabilities, which according to informants is due to concerns they will not be unable to accommodate their needs. As such, children with difficulties learning are not referred for assessment and subsequently not considered as children with disabilities. As of 2021, education data shows that there are 47,561 students with disabilities across all levels of Islamic schools out of 10.6 million students; that is less than half a per cent.<sup>191</sup>

There are also issues in the education sector to identify and assess the needs of children with disabilities. Not all schools have access or linkages to healthcare professionals who can detect and assess children with delays and disabilities. MoECRT has developed a tool to identify the needs of children with disabilities in schools. However, the tool's validity requires further assessment to ensure children with disabilities are receiving the support and services they require. A universal school-based screening and assessment programme is needed that can be used in all schools, including Islamic schools. In addition, a referral system to healthcare service is needed for further assessment and interventions.

# 3.5 Child protection



# **KEY FINDING**

More children with disabilities were victims of sexual abuse than any other form of violence.

While Indonesian laws and guidelines emphasize the role of family and community in the care of children with disabilities, institutions do exist and it is not known the number of children with disabilities living in institutions. The absence of a deinstitutionalization strategy and lack of community-based services for children with disabilities create barriers for children with disabilities to stay with or return to their family and communities. Children with disabilities are less likely to be registered at birth.

The Convention on the Rights of the Child provides the right to protection against all forms of violence, abuse, neglect, and exploitation to all children, including children with disabilities. The UNCRPD reinforces these rights for children with disabilities, including rights to liberty, freedom from torture or cruel, inhuman or degrading treatment or punishment, and the right to be included in the community. <sup>192</sup> The SDGs cover the protection of children including SDG Target 16.2 to end abuse, exploitation, trafficking and all forms of violence and torture of children, and Target 16.3 to ensure access to justice for all.

Laws regulating the protection of children with disabilities are consistent between the Child Protection Law and the Disability Law (see Annex 2 and Annex 12). In the Child Protection Law (Law No. 23/2002 and amendment Law 35/2014), child protection is defined as all activities to ensure and protect children and their rights so they can live, grow, and participate optimally in accordance with human dignity, and receive protection from violence and discrimination. Under this law, children with disabilities are included as one of the groups of children in need of special protection. The special protections are outlined in Article 70 of the law and include humane and equal treatment, fulfilment of their

192 UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

<sup>191</sup> Kemenag (2022) Lebih 40 ribu siswa disabilitas belajar di lembaga pendidikan Islam https:// kemenag.go.id/nasional/lebih-40-ribu-siswa-disabilitas-belajar-di-lembaga-pendidikan-islam-ohem74 [Accessed: 9 August 2023]

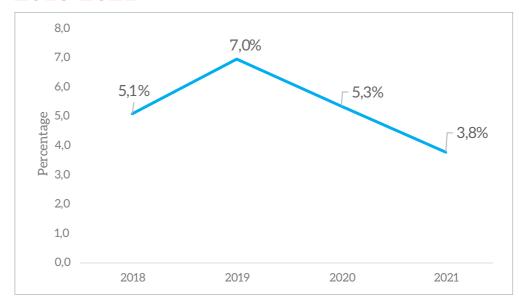
specific-needs and freedom from discrimination. The Disability Law (No. 8/2016) stipulates that children with disabilities have additional rights in addition to the general rights of persons with disabilities. Among others, these include: special protection from discrimination, neglect, harassment, exploitation, sexual violence and crime; humane treatment; and care from a family or substitute family. The protection of children with disabilities is also stipulated in Regulation No. 78/2021 on Special Protection for Children and The Ministerial Decree for Women's Empowerment and Child Protection No. 4/2017 on Special Protection for Children with Disabilities.

# Protection from violence, abuse and neglect, including online

In 2022, global estimates found that children with disabilities are more than twice as likely as their peers without disabilities to experience violence, and they had a higher likelihood of all forms of violence. <sup>193</sup> In Indonesia, data on violence against children with disabilities is limited and not coordinated between ministries. While some government ministries and institutions provide data on violence against children, there is limited data disaggregated by disability.

MoWECP has a system for the public to report abuse and violence against children, including those with disabilities. The reported number of children with disabilities that were victims of violence decreased by a third; from 1,536 in 2019 to 1,025 in 2021. Unlike global trends, the MoWECP data suggests that children with disabilities are not disproportionately represented in the reported victims. In 2019, seven per cent of reported child victims were children with disabilities, with the proportion reducing to four per cent in 2021. See Figure 31.

Proportion of child victims of violence that were children with disabilities, 2018-2021



Source: Simfoni PPA (MoWECP)

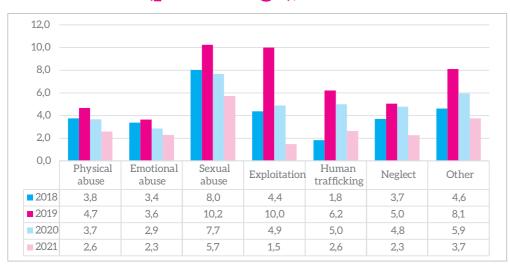
Figure 32 shows that sexual abuse had the highest proportion of victims that were children with disabilities compared to other forms of violence. In 2020 and 2021, there were twice as many children with disabilities that were reported as victims of sexual abuse compared to victims of physical violence and three times as many compared to emotional abuse. In their report to the Committee on the Rights of Persons with Disabilities in 2017, the Indonesian government recognized the need to improve efforts to combat sexual violence against persons with disabilities. <sup>194</sup> The Law on Sexual Violence Crime (No. 12/2022) has provisions on prevention of and response to sexual violence against persons with disabilities, including accessibility and provision of reasonable accommodation for victims with disabilities, and monitoring of the implementation of the law by the Commission on Persons with Disabilities. Service Centres for the Protection of Women and Children, established for the response, protection and rehabilitation of victims,

<sup>193</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

<sup>194</sup> United Nations (2019), Committee on the Rights of Persons with Disabilities – Initial report submitted by Indonesia under Article 35 of the Convention, due in 2013. CRPD/C/IDN/1.

should also respond to the needs of victims of disabilities. Figure 32 shows a decrease in the reporting of all types of violence between 2019 and 2021. While more research is needed to determine the cause, it may be a result of barriers to reporting due to COVID-19 lock downs and other public health protocols implemented over that period.

Proportion of child victims that were children with disabilities based on type of violence (percentage), 2018-2021



Source: Simfoni PPA (MoWECP)

A study by UNICEF found that while the internet has increased children with disabilities ability to communicate with friends, it also increased their exposure to online abuse. 24 per cent of the children with disabilities surveyed in the study had received sexual images via social media and three of the 52 children with disabilities had been threatened or blackmailed to engage in engage in sexual activities. <sup>195</sup> Most of these children with disabilities had experienced cyber-bullying, predominately related to their disability. Increasing their vulnerability, 70 per cent of children with disabilities had not received any online safety education. <sup>196</sup>

Online safety programmes should be made accessible to all children, in addition to programmes developed targeting children with disabilities and their caregivers.

## Shackling of persons with psychosocial disabilities

In Indonesia the practice of shackling is known as 'pasung.' Pasung refers to the physical restraint, shackling or confinement of persons with psychosocial disabilities.<sup>197</sup> Despite shackling being banned by the government in 1977, the practice has persisted in families, in the community and in government and privately run institutions.<sup>198</sup> An estimated 57,000 people in Indonesia have been shackled at least once in their life and 15,000 were still living in chains as of November 2019.<sup>199</sup> While there are reported cases, it is not known the number of children with disabilities that have been shackled.

One mother in Bali, Indonesia described why she chained her son with a psychosocial disability for over 10 years:

We took Ngurah to more than 40 traditional healers where they poked him with a stick and put herbs in his eyes, but it didn't work. We didn't know what to do. When Ngurah kept getting lost, the local police and community blamed and put pressure on us. We felt ashamed so we decided to chain him. (Informant in Human Rights Watch study)<sup>200</sup>

Since 2010, the Indonesia government has taken important steps to end the shackling of persons with disabilities. Programmes have focused on awareness raising, the provision of mental health support and treatment, and combating stigma against persons with psychosocial disabilities. Community mental health teams

<sup>195</sup> UNICEF (n.d.), An Overview of Key Findings from the Baseline Study on Children's Online Behaviour in Indonesia.

<sup>196</sup> UNICEF (n.d.), An Overview of Key Findings from the Baseline Study on Children's Online Behaviour in Indonesia.

<sup>197</sup> Human Rights Watch (2016), Living in Hell: Abuses Against People with Psychosocial Disabilities in Indonesia

<sup>198</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>199</sup> Human Rights Watch (2022), Human Rights Watch Submission on Indonesia to the Committee on the Rights of Persons with Disabilities. 27th Session.

<sup>200</sup> Human Rights Watch (2020), Living in Chains: Shackling of People with Psychosocial Disability Worldwide

at provincial and district levels have monitored and facilitated the release of people with shackles. In the first phase of the programme (2010-2017), a lack of resources, coordination and training hampered efforts to rescue people from shackles. Some that were rescued returned to shackles in their community due to a lack of follow up, access to community-based support and mental health services and persistent stigma.<sup>201</sup> Since 2017, a family-based approach by MoH that involves outreach, going house to house, and home visits has included efforts to end shackling. Integrating mental health services into a national programme that included the training of 25,000 master trainers to train staff in every community health centre has overcome some of the challenges in the previous programme.<sup>202</sup> With the aim to reach 100 per cent of households, as of September 2020 70 per cent of Indonesian households have been reached.<sup>203</sup>

#### Access to justice

In Indonesia, children are entitled to legal assistance (Law No. 23/2002, Article 18). There are provisions for children with disabilities' access to justice in legislation, including Law No. 19/2011 on the Ratification of the UNCRPD, Law No. 18/2014 on Mental Health and the Disability Law No. 8/ 2016. <sup>204</sup> The accessibility of the justice system is stipulated in Law No. 11/2012 on the Juvenile Criminal Justice System. In addition, Regulation No. 39/2020 on Reasonable Accommodation requires accommodations and appropriate services be provided for legal cases involving persons with disabilities, including those related to access to information and accessible communication.

In many countries, protection, justice systems, and reporting mechanisms often do not take into account the needs of children with disabilities, leading to difficulties in reporting and effective justice or redress. While there are examples in Indonesia of both children with disabilities effectively navigating the justice system and facing barriers to reporting, there is a lack of evidence on the implementation of the above legislation and whether the justice system is inclusive and accessible for children with different types of disabilities.

While the Disability Law (No. 8/2016) affirms the rights of persons with disabilities to be subject to legal procedures as witness, suspect or victim. One of the challenges is that in the Criminal Law Procedure Code a witness was defined as a person who has 'seen' and/or 'heard' the event. This definition discriminated against and precluded persons with visual and hearing impairments from being witnesses. Through decisions from the constitutional court, the definition of a witness has been expanded to include someone who 'experiences' the event. However, some law officials are not aware of this change and there are examples of persons who are blind being discriminated against and denied the right to report a crime due to this out-dated definition.

The Committee on the Rights of Persons with Disabilities has also expressed concerns about the limited access to justice for persons with disabilities, including the lack of age- and gender-sensitive accommodations, such as the provision of trained personnel to guide persons with disabilities through judicial processes, and sign language interpreters.<sup>206</sup> The Committee has recommended the development of an action plan on access to justice for persons with disabilities and measures to ensure that age-sensitive adjustments are available so children with disabilities can participate effectively in legal proceedings.<sup>207</sup>

<sup>201</sup> Human Rights Watch (2020), Living in Chains: Shackling of People with Psychosocial Disability Worldwide

<sup>202</sup> Human Rights Watch (2020), Living in Chains: Shackling of People with Psychosocial Disability Worldwide.

<sup>203</sup> Human Rights Watch (2020), Living in Chains: Shackling of People with Psychosocial Disability Worldwide.

<sup>204</sup> Komariah, S. and Lewoleba, KK., (2021) Penerapan Konsep Diversi bagi Anak Penyandang Disabilitas Pelaku Tindak Pidana Kekerasan. Jurnal USM Law Review Vol. No. 2 Tahun 2021.

<sup>205</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

<sup>206</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>207</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

#### Birth registration

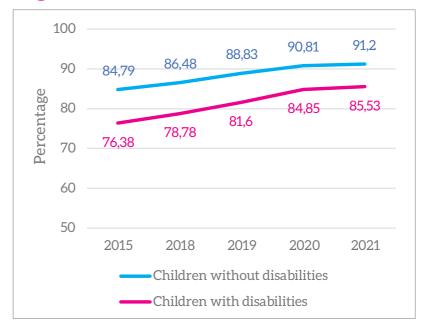
Birth registration is the first step in recognizing a child before the law and is fundamental to protecting the rights of all children. Children with disabilities in Indonesia are less likely to be registered at birth by the Civil Registry and Demography Agency. In 2021, 85.5 per cent of children with disabilities were registered at birth, compared to 91.2 per cent of children without disabilities. See Figure 33. While between 2015 and 2021 the proportion of children in Indonesia that were registered at birth increased, there remains a gap between those with disabilities and those without. The gap has reduced over time from 8.4 percentage points in 2015 to 5.6 percentage points in 2021. Global data also shows that children with disabilities are less likely to be registered at birth, however in Indonesia the level of registration for both children with and without disabilities is higher than global averages. Despite birth registration being relatively high in Indonesia, there does remain a gap between children with and without disabilities.

There are existing regulations related to the registration of vulnerable populations, outlined in Domestic Regulation No. 11 of 2010. However, the Ministry of Home Affairs acknowledges that the implementation of this regulation has been ineffective. Several factors contribute to this issue, including a lack of understanding among officials regarding disability conditions, despite the availability of forms for reporting disabilities within communities. Additionally, reluctance among the public to report disability-related conditions hampers the process (see section below on stigma). Moreover, the challenging circumstances faced by individuals in these communities make it difficult for them to travel to the Civil Registration and Population Office. Furthermore, there are government-established civil registry offices in 399 regencies across Indonesia, however only 42 regencies providing free birth

certificates.<sup>211</sup> Efforts have been made to reach out through the "*Jemput Bola* (Jebol)" program, but these initiatives are limited due to minimal budget allocations. Addressing these challenges is crucial to ensuring the effective implementation of policies aimed at registering vulnerable populations and fostering inclusivity within society.

Disparities in birth registration rates compound inequalities in access to basic services, heightening discrimination and vulnerability.<sup>212</sup> While there is a lack of evidence on the direct impact on children with disabilities of being unregistered in Indonesia or even globally, it is likely that it places children with disabilities at higher risk of human rights violations, including violence, abuse, neglect and exploitation.<sup>213</sup>

Proportion of birth certificate ownership among children, 2015-2021



Source: National Socioeconomic Survey 2018-2021.

<sup>208</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

<sup>209</sup> The weighted global average of birth registration amongst children with disabilities is 61 per cent, compared with 71 per cent for children without disabilities.

<sup>210</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with

<sup>211</sup> United Nations (2019), Committee on the Rights of Persons with Disabilities – Initial report submitted by Indonesia under Article 35 of the Convention, due in 2013. CRPD/C/IDN/1.

<sup>212</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

<sup>213</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities and UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

# Rights to family, alternative care and deinstitutionalisation

Children with disabilities are more likely to experience separation from their families, to remain separated for longer and to be placed in residential care.<sup>214</sup> Globally children with disabilities are disproportionately represented in institutional care facilities with estimates in some countries as high as one in three children in institutions having disabilities.<sup>215</sup> The number of adults or children with disabilities in institutions in Indonesia was not able to be determined by the study.

The Disability Law in Indonesia stipulates that children with disabilities have the right to receive care from their immediate family. Where living with their family is not possible, they have the right to receive care from an alternative family or an institution. In addition, the core principle of Indonesia's Child Care regulations (Regulation No. 44/2017) is that a child is not separated from the family, and that the family plays its role as the guardian. Programmes to support the regulation are designed to first and foremost support parents' capacity to fulfil their child's need for care, parenting, safety and wellbeing. There are several regulations and guidelines to implement these rights.<sup>216</sup> These regulations were created to ensure that children, including those with disabilities, receive optimal care in families, with alternative caregivers and in institutions. The Operational Guideline on Social Rehabilitation Assistance (ATENSI) stipulates that parents of children with disabilities are entitled to services, including financial support, mental health and psychosocial support, and parenting training and counselling. The guideline also mandates that campaigns be conducted to reduce stigma and promote communitybased support systems for parents and the child. The Ministry of Social

Affairs Regulation No. 16/2020 on Social Rehabilitation also prioritizes family roles and responsibilities in rehabilitation centres, compared to orphanages (see Annex 13).

The main principle underpinning the National Standard for Childcare in Social Welfare Institutions is to ensure that children are kept with their families or with alternative care, rather than in institutions. The standards are not specific to children with disabilities. Inclusivity is a principle, but the concept of disability is not mainstreamed throughout the standards. The enactment of these national standards in 2011 has been shown to reduce the institutionalization of children.<sup>217</sup> Despite the decrease in institutionalization, the implementation of the standards has been challenging.

At the family level, socioeconomic status, stigma against children with disabilities and exclusion for social assistance programmes have created barriers in preventing institutionalisation and keeping children with disabilities with their families. In addition, community-based support services are required to ensure children with disabilities can access the necessary services while staying with their families and communities. According to the ATENSI Guidelines funding for services at the community level are expected to be primarily financed by the community and private institutions. With funding expected from within the community and private sector, stigma towards persons with disabilities plays a role in the lack of prioritization of funding for disability-related community-based services. The Committee on the Rights of Persons with Disabilities commented on the lack of genderand age-sensitive community-based services. It recommended that the government "establish a community-based support system for independent living with an allocated budget that includes social protection, employment, housing, health care, education and any other support required for persons with disabilities to choose where and with whom they live and to live independently and participate in the

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<sup>214</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

<sup>215</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

<sup>216</sup> Regulations include: Regulation No. 44/2017 on The Implementation of Child Care; Social Affair Minister Regulation No. 1 /2020 on the Implementation Regulation of the Child Care Regulation; Social Affair Minister Regulation No. 13/2015 on Social Services for Children with disabilities; Operational Guidelines on Social Rehabilitation Assistance for People with disabilities (ATENSI); and Social Affair Minister Regulation No. 30/2011 on the National Standard for Child Care in Social Welfare Institutions.

<sup>217</sup> Fuaida Dyawati, Lisma and Ellies Sukmawati (2018) 'Family-based care for children with disabilities in South Tangerang City.' 153 (Icddims 2017): 154–157.

community."<sup>218</sup> The lack of age-sensitive community-based services was also confirmed in the study with no specific support programmes identified that targeted children with disabilities. A government official confirmed that services are the same for both children and adults, and are not tailored to meet the specific needs of children with disabilities. <sup>219</sup> In the Ministry of Social Affairs Regulation No. 16/2020 on Social Rehabilitation it also does not differentiate between services for children and adults with disabilities.

Interventions for children with disabilities are different to other people with disabilities. [However] this issue has not been yet understood. So far, the services have been equated. (Government Official, female, Jakarta 22 September 2022).

In Indonesia, social workers play a key role as the main contact point to assess the needs of children and families, and determine guardianship. However, social workers in Indonesia are not only limited in number but also in terms of capacity to assess the needs of children with disabilities. This is compounded by private residential centres financially incentivizing social workers to actively recruit children for their institutions in order to increase funding from the government, as found in a 2020 report. The incentive scheme led to more children in private centres with provision of low-quality services. These unethical incentive schemes are in opposition to the best interest of the child and Article 19 of the UNCRPD that recognises the equal right of all persons with disabilities to live in the community.

Regulation related to family and alternative care categorize children with disabilities as children with special protection, placing them in the same category as children in emergencies, victim of criminal activities and children in the legal system. While the initial intent was to acknowledge

that children with disabilities require additional protection given their vulnerabilities, in practice it has resulted in a reactive approach akin to that in an emergency. Such an approach does not recognize that children with disabilities require inclusive, sustainable and, in many cases, life-long services.

Despite legislation that prioritizes care within families and alternative care over institutional facilities, in practice there are a number of different residential institutions, including government social care institutions, private centres and those run by faith-based organisations in Indonesia (known as faith-healing centres). MoSA has established social care institutions to provide services and residence for persons with disabilities that are not able to be cared for by family.<sup>222</sup> The institutions provide medical services, including rehabilitation as well as training, legal assistance and livelihoods support through vocational training and support for entrepreneurism.

Despite the government's minimum standards for institutions, there are reports of neglect, abuse and forced seclusion in both publicly and privately owned institutions. Human Rights Watch in their submission to the Committee on the Rights of Persons with Disabilities in 2022 reported cases of children with psychosocial disabilities facing prolonged seclusion and involuntary electroshock therapy in institutions. It was found that forced seclusion was practiced on a routine basis in psychiatric hospitals, government and private institutions with durations lasting from a few hours to over a month. Instances were found were there was no separation between adults and children in government and faith-healing centres. Human Rights Watch also documented cases of sexual abuse of women and girls with disabilities in institutions.

<sup>218</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>219</sup> Key informant: Government Official, female, Jakarta, 22 September 2022

<sup>220</sup> O'Leary, Patrick John, Amy Young, Donna McAuliffe and Yanuar Wismayanti (2019) 'Developing the social work role in the Indonesian child protection system' *International Social Work* 62 (2): 814–828.

<sup>221</sup> McLaren, Helen and Nismah Qonita (2020) 'Good Intentions, Some Not So Good Outcomes' *Mdpi* 0 (12): 1–11.

<sup>222</sup> United Nations (2019), Committee on the Rights of Persons with Disabilities – Initial report submitted by Indonesia under Article 35 of the Convention, due in 2013. CRPD/C/IDN/1.

<sup>223</sup> Human Rights Watch (2022), Human Rights Watch Submission on Indonesia to the Committee on the Rights of Persons with Disabilities. 27th Session.

<sup>224</sup> Human Rights Watch (2022), Human Rights Watch Submission on Indonesia to the Committee on the Rights of Persons with Disabilities. 27th Session.

<sup>225</sup> Human Rights Watch (2022), Human Rights Watch Submission on Indonesia to the Committee on the Rights of Persons with Disabilities. 27th Session.

sexual violence, neglect, cruel and degrading treatment in social care institutions and faith-healing centres, including the removal of children from mothers with psychosocial disabilities.'226 The Committee has recommended that human rights violations in social care institutions be made a priority area in the National Action Plan for Persons with Disabilities and that an independent monitoring, safeguard and complaints mechanism be established that is accessible to all persons with disabilities in all settings.<sup>227</sup>

The MoSA's own monitoring of their rehabilitation centres in 2013 confirmed the poor quality of services. The report cited the causes of low-quality services ranged from low competency of staff (i.e. social workers and disability care workers), inadequate physical infrastructure, lack of assistive devices and limited support within the community in the implementation of services.<sup>228</sup>

For children with disabilities already in institutions, the Committee on the Rights of Persons with Disabilities has noted with concern in 2022 that Indonesia does not have a 'deinstitutionalization strategy for persons with disabilities, including children with disabilities, placed in residential institutions, social care institutions, hospitals, halfway homes and rehabilitation centres,' and has recommended the government adopt such a strategy.<sup>229</sup>

# 3.6 Social Policy



# **KEY FINDING**

In Indonesia, 17 per cent of children with disabilities are living in monetary poverty and they are 1.4 times more likely to be impoverished than children without disabilities.

The poverty drives discrimination and stigma, and limits their access to other basic social services, assets and visibility. Access to social assistance for households of children with disabilities has increased in recent years from 14 per cent of poor households with persons with disabilities accessing social assistance in 2018 to 20 per cent in 2021.230 However the Committee on the Rights of Persons with Disabilities has noted the lack of a comprehensive social protection system for persons with disabilities. Poverty and limitations in health insurance are likely to create barriers for children with disabilities to access the assistive technology they require.

# Disability and poverty

SDG 1 aims to eradicate extreme poverty for all people everywhere by 2030. Children with disabilities and their families are often caught in a cycle of poverty and exclusion as poverty and disability are inextricably linked.<sup>231</sup> Children who live in the poorest communities are more susceptible to acquiring disability, due to factors such as poor housing conditions, malnutrition, hazardous child labour and lack of access to health care.<sup>232</sup> At the same time households of persons with disabilities are disproportionately more likely to fall below the poverty line as a result of the additional cost of healthcare services and assistive technology, and lack of livelihood opportunities due to stigma or increased care responsibilities of a child with a disabilities.<sup>233</sup> A study found that households with persons with disabilities in Indonesia had 30 per cent higher expenses compared to other households increasing

<sup>226</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>227</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>228</sup> Astuti, Mulia, Ruaida Murni, Ahmad Suhendi, Bambang Pudjianto and Habibullah (2015) *Efektivitas Pelayanan Panti Sosial Penyandang Disabilitas Tubuh*.

<sup>229</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>230</sup> Statistics Indonesia, National Socioeconomic Survey 2018-2021.

<sup>231</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

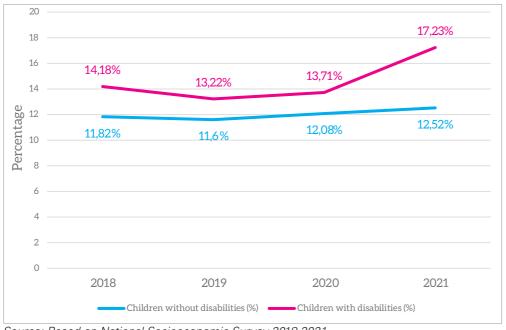
<sup>232</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

<sup>233</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

the likelihood of poverty.<sup>234</sup>

In Indonesia, children with disabilities are more likely to be living in poverty than children without disabilities. In 2021, 17 per cent of children with disabilities were living in poverty, compared to 13 per cent of children without disabilities. See Figure 34. While the gap in proportion of children living in poverty between children with and without disabilities was constant in 2019 and 2020, it nearly tripled in 2021 from 1.6 percentage points in 2020 to 4.7 percentage points in 2021. The COVID pandemic had a much more pronounced impact on the poverty of children with disabilities compared to children without disabilities. There was a 26 per cent increase in the number of children with disabilities living in poverty between 2020 and 2021, compared to only three per cent increase amongst children without disabilities (see Figure 34).

Percentage of children living in poverty in Indonesia



Source: Based on National Socioeconomic Survey 2018-2021

These findings correlate with a study by the Ministry of National Development Planning/National Development Planning Agency on the impact of COVID-19 on persons with disabilities. While not focused specifically on children with disabilities, the study found that by April 2020, 81 per cent of persons with disabilities reported reduced income with many reporting a loss of income between 50 and 80 per cent.<sup>235</sup> Given many households of persons with disabilities were already living in poverty, the loss of income led to 81 per cent of persons with disabilities respondents having difficulties affording food.<sup>236</sup>

The problem persons with disability face includes the availability of services and the affordability of services. When they are far from these two things, they will be far from living in prosperity.

(Government Official, female, Jakarta)

The Committee on the Rights of Persons with Disabilities also noted with concern the high number of persons with disabilities, including indigenous people with disabilities, living in poverty and without a regular source of income in Indonesia.<sup>237</sup>

# Access to social protection

In Indonesia, given that children with disabilities are more likely to be living in poverty, social protection, such as social health insurance and social assistance are critical to ease the financial burdens on households with children with disabilities and alleviate poverty.

<sup>234</sup> Larasati, Dyah, Karishma Huda, Alexandre Cote, Sri Kusumastuti Rahayu and Martin Siyaranamual (2019) *Policy Brief: Inclusive Social Protection for Persons with Disability in Indonesia* [online] http://www.tnp2k.go.id/download/65217190113-PB DisabilitiesEng-web.pdf [7 December 2021].

<sup>235</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

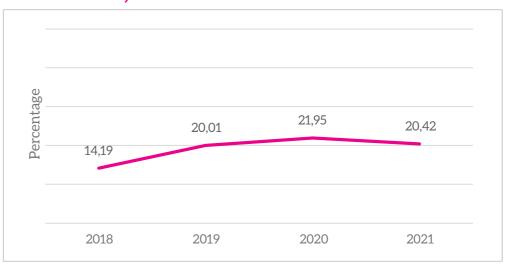
<sup>236</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

<sup>237</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

The Disability Law (No. 8/2016) stipulates that social protection<sup>238, 239</sup> for persons with disabilities includes the right to social rehabilitation, social security, social empowerment, and social protection. This is further regulated by Government Regulation No. 52/2019 on Implementation of Social Welfare for Persons with Disability, although the regulations do not specifically mention social protection for children with disabilities (see Annex 14).

A study by BAPPENAS found that historically persons with disabilities in Indonesia have received little social protection from the national government.<sup>240</sup> In 2021, only 20 per cent of households with persons with disabilities were social protection recipients. This is a small proportion given the link between poverty and disability as described above. Access to social protection for households with persons with disabilities has increased over the last four years from 14.19 per cent in 2018 to 20.42 per cent in 2021. See Figure 35. While the overall trend over this period has been increased access to social protection for persons with disabilities, there was a slight (6 per cent) decrease between 2020 and 2021. Meanwhile the MoNDP study found that the COVID-19 pandemic significantly increased coverage of social protection for persons with disabilities, mostly through COVID-19 response programmes. By July 2020, most survey respondents with disabilities had received some form of social assistance.<sup>241</sup> The results in Figure 35 may not include financial assistance provided by the Gol COVID-19 response.

Percentage of poor households with persons with disabilities receiving social assistance, 2018-2021



Source: National Socioeconomic Survey 2018-2021.

To be registered for these social protection programmes requires families of children with disabilities to recognize and disclose that their child has a disability. A lack of awareness and understanding of disabilities as well as stigma in communities, may cause parents to be reluctant to register their child as having a disability. This further deprives the child from the services that they require and creates barriers for the household to access financial assistance. See Section below on stigma.

One of the national social protection programmes is the Family Hope Programme, a cash transfer programme. Eligible families are those who have children or a pregnant woman and are ranked in the 'very poor' category of the national poverty-targeted social registry with the programme adding disability and elderly to the eligibility criteria in 2016.<sup>242</sup> Soon after disability was added as a category of eligibility in the Family Hope Programme the number of persons with disabilities enrolled increased from 45,635 beneficiaries in 2017 to 108,863 in

<sup>238</sup> The National Team for the Acceleration of Poverty Reduction's definition of social protection is: system of regular and predictable transfers to protect poor and vulnerable citizens through social safety net schemes across the life cycle, as well as to prevent health and employment related risks through accessible social insurance schemes.

<sup>239</sup> TNP2K (2018), The Future of The Social Protection System in Indonesia.

<sup>240</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

<sup>241</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

<sup>242</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

2019.<sup>243</sup> Under this programme, persons with disabilities get between IDR 2.4 million (about USD 160) and IDR three million (about USD 200), with transfers made every three months. During the COVID-19 pandemic, the transfers increased to monthly payments to mitigate the financial impact of the pandemic on poor households.

The Family Hope Programme provides the cash transfers conditional on children attending schools (including special schools), not dropping out and receiving regular healthcare services or medication. Cash transfers are reduced or withheld if families do not meet the education and health requirements. The conditional requirements were relaxed during the COVID-19 pandemic with financial assistance continuing despite children not able to attend school or dropping out of school due to increased household poverty. The Family Hope Programme also supports families of children with disabilities through family development sessions, teaching families about childcare, education, health, and financial management. The programme provides a module on services and protection specifically for persons with disabilities. The aim is to promote independence and empowerment, as opposed to a charity model that would hinder the efforts of persons with disabilities to escape poverty. One of the limitations of the Family Hope Programme is the introduction of a cap of one person with a disability per household to receive benefits, which resulted in a six per cent decrease in the number of persons with disabilities benefiting.<sup>244</sup> Other challenges include the cash transfers being conditional on access to education. In some areas, inclusive education and special schools may not be available. As highlighted above, children with disabilities are less likely to attend and complete school resulting in them not qualifying for the benefits. Families may also not be aware of the importance of education and healthcare services for children with disabilities, which creates barriers when financial assistance is conditional on the utilisation of these services.

The Social Rehabilitation Assistance (ATENSI) programme, established in 2020, provides comprehensive care and social services based on assessment by individual case managers, targeting various groups including persons with disabilities. 245 Unlike the Family Hope Programme's family-based approach, which limited cash transfers to one person with a disability per household, ATENSI uses an individual-based approach. Each family member with a disability receives separate assistance with amounts dependent on the type of disability and based on calculations of the cost of living for persons with disabilities. In addition to providing financial aid, the programme also conducts vocational training, provides temporary housing, and provides other services and activities in multiservice centres. The MoSA conducts ongoing assessments of ATENSI to ensure that persons with disabilities receive appropriate assistance. One of the limitations of the ATENSI programme is the availability and location of government institutions that provide the services. There are currently 532 institutions with half located in Java Island and 121 located in West Java alone.

The two social protection programmes (Family Hope Programme and ATENSI) are complemented with facilitators from the Family Hope Programme, who help families of children with disabilities obtain

In 2019, there were 30 percent more poor households with children with disabilities receiving cash transfers from the Family Hope Programme than households without children with disabilities. See Figure 36. Between 2019 and 2020, there was a decrease of 23 per cent in the poor households with children with disabilities receiving social protection in this programme, effectively removing the difference between the households with and without disabilities. While these statistics are measuring households not individuals, this decrease may relate to the change in policy capping transfers to one person with a disabilities per household, as it occurred at the same time. As of 2021, 29 per cent of households with children with disabilities received the cash transfers from the Family Hope Programme.

<sup>243</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

<sup>244</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), *COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.* 

<sup>245</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

information and referrals to the provision of assistive devices, food and housing provided under the ATENSI programme. However, it was reported during our interviews that the procedures for the referral system are unclear. This combined with facilitators lacking understanding on the needs of children with disabilities creates challenges for children with disabilities to access the services that they require.

Other than the Family Hope Programme and ATENSI, the other regular social protection programme is Social Assistance for People with Disabilities, formally known as Social Assistance for People with Severe Disabilities. This programme currently offers 2 million IDR (about 130 USD) per year to 22,500 persons with severe disabilities. This amount was reduced by almost half in 2020 as it was previously 3.6 million IDR (about USD 240) per year. While the impact of this reduction on persons with severe disabilities, including children, has not been assessed, it is likely to have had a negative impact compounding the increase in poverty seen at the same time in Figure 34.

Other government programmes, although not targeting children with disabilities, provide assistance to children with disabilities. A food assistance programme provides low-income households, including those with children with disabilities with staple food packages to meet nutritional needs. This is critical given the higher rates of malnutrition amongst children with disabilities in Indonesia (see Nutrition section above). The proportion of households receiving food assistance has increased over the last three years for both households with and without disabilities. See Figure 36. In 2021, 35 per cent of poor households with disabilities received this food assistance. Households of children with disabilities are more likely to receive the food assistance than households without children with disabilities. See Figure 36. However, the gap has reduced over time. In 2019, households with children with disabilities were 30 per cent more likely to receive food assistance, compared to only four and five per cent in 2020 and 2021 respectively.

As recommended in the Nutrition section, further research is required to determine if staple food packages for households with and without disabilities provide sufficient variety and quality of food to meet minimum acceptable diet of children and caregivers with disabilities.

The Child Social Welfare Programme has been helping children, including those with disabilities, access education, healthcare services, and social protection since 2009. Each eligible child is provided with 1.5 million IDR (about USD 100) each year. Data is not currently available on the number of children with disabilities benefiting from the Child Social Welfare Programme. The National Team for the Acceleration of Poverty Reduction reported in 2018 that they expected to reach just over 100,000 children through the Child Social Welfare Programme. However, this is only 2.5 per cent of the four million children who are estimated to be in poverty and are eligible for the programme. As children with disabilities are only one of the groups of children that the programme aims to benefit, the small number of beneficiaries versus the need may hinder children with disabilities ability to access assistance via this programme.

The proportion of social security cards has decreased over the last four years for both households with and without children with disabilities. See Figure 36. Between 2018 and 2021, there were 12 per cent less households with children with disabilities with social security cards. The decrease was more pronounced among households without children with disabilities with a 26 per cent decrease in social security card ownership between 2018 and 2021.

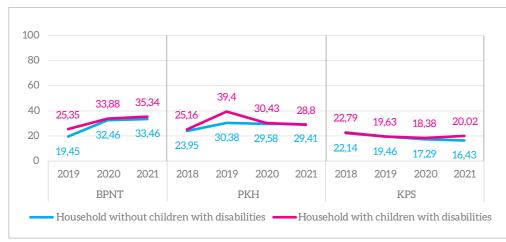
All of the mentioned social protection programmes are implemented in all provinces and districts of Indonesia.

<sup>246</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), *COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.* 

<sup>247</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

<sup>248</sup> TNP2K (2018), The Future of The Social Protection System in Indonesia.

Percentage of poor households in social protection programmes, 2018-2021



Source: National Socioeconomic Survey 2018-2021.

Beneficiaries for most social protection programmes (like Family Hope Programme) are identified via the Integrated Data for Social Welfare database, a registry that captures household poverty levels. Persons with disabilities, including children, are tagged within the registry based on their national identity numbers and address. There are some challenges in using this system to identify persons with disabilities for social protection programmes. The data is inputted at a single point in time and lacks any mechanism for real-time updating. The Integrated Data for Social Welfare database is also focused on capturing information related to poverty, rather than disability. The MoSA collects data on persons with disabilities that are not captured in the database, via outreach as part of the ATENSI programme. The data collected at the village-level is passed to the District/City-level Social Service before being entered by MoSA into the registry.

I forgot which area it was, but the Director said there were initially data on 700 people with disabilities in one district, but when the outreach involved all parties, it turned out there were more than 3,000 people with disabilities in that area [in reference to beneficiaries of the Family Hope Programme]. (Government Official, female, Jakarta)

An unconditional cash transfer programme was introduced during the COVID-19 pandemic to support people who were not recipients of other social protection programmes and had a special allocation for persons with disabilities. Given the limitations described above of the Integrated Data for Social Welfare database, this cash transfer programme identified beneficiaries with disabilities via the disability registry, Information Management System for People with Disabilities.<sup>249</sup> The disability registry was mandated in Law No. 8/2016 and set up in 2018 by MoSA. Data on adults and children with disabilities is collected by social workers, village officials, midwives, and community-based rehabilitation staff. OPDs and rehabilitation centres that have been verified and received training are also able to submit data directly. Some of the advantages of the disability registry are that the data is captured at an individual, rather than household level, persons with disabilities are registered regardless of poverty status, type of disability is captured and it allows for real-time updating.<sup>250</sup> By using the disability registry for the cash transfers, MoSA was able to include a significant number of persons with disabilities in a relatively short timeframe during the pandemic.<sup>251</sup>

These data collection and administrative issues, including the database used to identify recipients, are likely to contribute to the relatively small percentage of households of children with disabilities who access social protection (only 20 per cent in 2021, see Figure 35). Other challenges include limited budget related to children with disabilities, according to officials.

While described above are several different social protection programmes that include persons with disabilities, the Committee on the Rights of Persons with Disabilities has drawn attention to the absence of a comprehensive social protection system, guaranteeing

<sup>249</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

<sup>250</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

<sup>251</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

access to an adequate standard of living for persons with disabilities.<sup>252</sup> The Committee recommended:

- The development of social protection and poverty reduction strategies targeting persons with disabilities.
- Establishment of a universal social protection scheme for persons with disabilities.
- Include a disability perspective in programmes to promote an adequate standard of living, in particular programmes to increase access to public housing for persons with disabilities, including for those who want to leave institutions.<sup>253</sup>

A study in 2020 also found that parents of children with disabilities are generally unaware of the social services available for their children.<sup>254</sup> For parents that are aware of programmes and services, the accessibility of programme locations can create barriers. This has been reported to leave some parents feeling isolated, alone and overwhelmed with the parental responsibilities and care needs of their child, in turn making their child with a disability more vulnerable to neglect and exclusion.<sup>255</sup>

# Access to health insurance and assistive technology

The right to health and social security seeks to address and mitigate existing inequalities, including those that affect households of children with disabilities. Children with disabilities often have disproportionately higher health-care costs due to their need for extra health care, specialized services and assistive technology and transportation.<sup>256</sup> As mentioned previously, a study found that households with persons

with disabilities in Indonesia had 30 per cent higher expenses, including assistive devices and health services, compared to other households.<sup>257</sup>

The Social Security Implementing Agency (BPJS Kesehatan) implements the National Health Insurance (Jaminan Kesehatan Nasional/JKN) programme to provide health care and protection to meet the basic health needs of its participants. The health insurance covers basic immunization, outpatient care and assistive devices (as outlined in Minister for Health No. 28/2014 on National Health Insurance Operational Guidelines).

The figures below on health insurance provision cover government national and local health insurance programmes and do not include private and company provided insurance. In 2021, 62 per cent of children with disabilities had any kind of health insurance. Between 2018 and 2020, the coverage of the health insurance programmes had increased for both children with and without disabilities, see Figure 37. The proportion of children with health insurance was the same amongst children with and without disabilities in 2019 and 2021. There was an increase in both groups of children in 2020, however the increase was larger amongst children with disabilities. In 2020, 14 per cent more children with disabilities had health insurance compared to 2019, compared to a 5 per cent increase amongst children without disabilities. The COVID-19 pandemic and families' concerns about the health of children with disabilities in that context likely caused this increase.

<sup>252</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>253</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>254</sup> Widyawati, Yapina, Roy Otten, Tijs Kleemans and R. H.J. Scholte (2020) 'Parental Resilience and the Quality of Life of Children with Developmental Disabilities in Indonesia' *International Journal of Disability, Development and Education* Routledge 00 (00): 1–17.

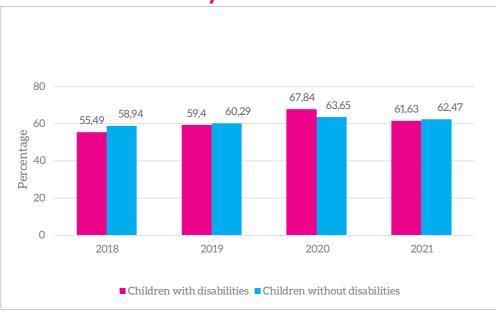
<sup>255</sup> Retnaningsih, Dwi and Indri Khizba Dini (2016) 'Analisa dukungan keluarga dengan beban orangtua dalam merawat anak penyandang cacat tingkat SD di SLB Negeri Semarang' *Electronic Journal Politeknik Harapan Bersama Tegal* 1 (1): 98–105.

<sup>256</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

<sup>257</sup> Larasati, Dyah, Karishma Huda, Alexandre Cote, Sri Kusumastuti Rahayu and Martin Siyaranamual (2019) Policy Brief: Inclusive Social Protection for Persons with Disability in Indonesia [online] http://www.tnp2k.go.id/download/65217190113-PB DisabilitiesEng-web.pdf [7 December 2021].

<sup>258</sup> Government of Indonesia (2011), Law No. 24 of 2011 on the Social Security Implementing Agency.

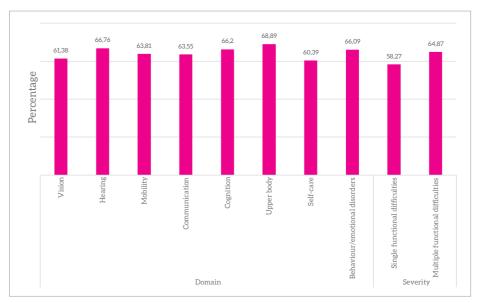
Percentage of health insurance ownership among children with and without disability



Source: Based on National Socioeconomic Survey 2018-2021.

Further analysis of children with disabilities under national and local health insurance programmes shows that there is no difference in health insurance ownership based on type of disability (see Figure 38). Children with upper body (69 per cent) and hearing (67 per cent) impairments were slightly more likely to have health insurance. See Figure 38. Comparing single to multiple disabilities, children with single disabilities were less likely to have health insurance. In 2021, children with multiple disabilities were 11% more likely to have health insurance than children with single disabilities, this is likely due to the additional complexity of their impairments.

Percentage of health insurance ownership among children with disabilities by type of impairment (measured by functional domains), 2021



Source: Based on National Socioeconomic Survey 2021.

Figure 38 shows that the national and local health insurance programmes seem to have similar coverage of children with intellectual and psychosocial disabilities, compared to other types of disabilities with 66 per cent of children with difficulties in cognition and behavioural or emotional disorders and 60 per cent of children with difficulties with self-care having health insurance. However, the Committee on the Rights of Persons with Disabilities in their Concluding Observations have expressed concern that some persons with disabilities may not qualify as beneficiaries of the health insurance programme. Government-provided health insurance was recommended to guarantee full coverage to all persons with disabilities, including those with intellectual or psychosocial disabilities.<sup>259</sup>

<sup>259</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

Around the world most of the people that need assistive technology do not have access to them; it is estimated that over 1 billion people globally need some form of assistive technology, yet 90 per cent do not have access to the products that they need.<sup>260</sup>

In Indonesia, the number of assistive devices provided through the health insurance programme (BPJS Kesehatan) to persons with disabilities has consistently increased each year from 4,028 assistive devices in 2015, 6,196 in 2016 to 10,180 in 2017.261 However, the national health insurance programme only covers a small portion of the cost of assistive devices. For example, in Indonesia a hearing aid usually costs between IDR five to seven million (between about USD 330-470) with health insurance only covering IDR one million (about USD 67). The gap in cost is a barrier for households with children with disabilities. Informant from MoSA mentioned that the ministry has tried to provide aid to buy more assistive devices for children with disabilities. The budget for each device is larger than the aforementioned-IDR one million. However, the coverage of this program seems limited where many children with disabilities have not yet been reached out to. This finding is in line with a study in 2014 which found that governmentprovided assistive devices were relatively limited and most persons with disabilities had to purchase assistive devices and repair them at their own personal expense.<sup>262</sup>The Committee on the Rights of Persons with Disabilities also noted the lack of access to quality assistive devices and technologies at an affordable cost and the lack of locally made devices with importation leading to higher prices.<sup>263</sup>

MoH had tried to discuss this issue with BPJS Kesehatan; however, this issue has not been resolved. It is recommended that government stakeholders review regulations to see if the national health insurance programme is adequately meeting the needs of all children, including

those with disabilities, particularly regarding the provision of assistive technology and devices. Efforts should aim to increase health insurance ownership for households of children with disabilities, which may be achieved via raising awareness of the importance and benefits of health insurance and improving the accessibility and affordability of health insurance programmes.



<sup>260</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

<sup>261</sup> BPJS Kesehatan (2018), *JKN-KIS Ramah Bagi Penyandang Disabilitas*. https://www.bpjs-kesehatan.go.id/bpjs/index.php/post/read/2018/827/JKN-KIS-Friendly-For-Persons-with-Disabilities.

<sup>262</sup> Adioetomo, Sri Moertiningsih, Daniel Mont and Irwanto (2014) People with disabilities in Indonesia: Empirical Facts and Implications for Social Protection Policies Jakarta, Indonesia.

<sup>263</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.



## 4.1 Stigma

This research has highlighted that stigma impacts children with disabilities fulfilment of rights and limits their access to services and facilities across all sectors. Stigma against children with disabilities, particularly those with psychosocial disabilities is prevalent in Indonesia.

Many people with psychosocial disability are hidden, not being recorded, and have no ID card. Even if they are not hidden, I am not sure that they want people to know that they are having psychosocial disability because there are so many stigma. (OPD representative, female, Jakarta).

Stigma in Indonesia stems from harmful social and cultural norms related to disability, where disability is seen as caused a curse from God or as a result of karma due to the parents' wrongdoing.<sup>264</sup>

It is difficult to give an understanding about children with disabilities. Children with disabilities in certain areas are still considered disgraceful, sometimes considered the result of a curse, considered to be hidden so that no one can see them, and their voices cannot be heard. Even in certain areas, there are still children who are shackled.

(Representative from OPD, female, Jakarta)

These incorrect beliefs that disability is a result of the parents' behaviour, particularly of the mother during pregnancy<sup>265</sup> create feelings of shame amongst parents and result in children with disabilities being hidden in their homes, shunned and isolated from their community.<sup>266</sup>

This is exacerbated by stigma and a lack of understanding outside the family, with health workers, teachers and other community members harbouring stigmatizing attitudes which leads to discriminatory practices and barriers accessing services.

Barriers related to stigma can be some of the most difficult to identify and more research is needed to further understand the stigma children with disabilities face in Indonesia and how this impacts their self-esteem, rights and participation in society. However, in general attitudinal barriers faced by children with disabilities stem from ableism, <sup>267</sup> which is discrimination and social prejudice against children and adults with disabilities based on the belief that they have less inherent value than other people. Eliminating stigma and discrimination is a human rights imperative and is one of the strategic priorities in UNICEF's global Disability and Inclusion Policy and Strategy 2022-2030. <sup>268</sup>

A recent global study by UNICEF revealed that achieving systemic social and behaviour change requires time, investment, and integrated communication, programme and advocacy interventions. Understanding the beliefs and attitudes, characteristics, contexts and challenges of target populations is key to properly targeting and planning complex programmes to respond to the drivers of exclusion and stigma.<sup>269</sup>

## **4.2 Participation**

Around the world children with disabilities, like all children, are often not consulted for their views on the matters that impact their lives. Children with disabilities are also often under-represented in initiatives to promote children's participation.<sup>270</sup> The Committee on the Rights of Persons with Disabilities observed the absence of policies, mechanisms and processes for consulting with children with disabilities

<sup>264</sup> Riany, Y. E., Cuskelly, M., and Meredith, P., (2016) *Cultural Beliefs about Autism in Indonesia*. International Journal of Disability, Development and Education 63(6): 623–640. DOI: 10.1080/1034912X.2016.1142069.

Kiling, Indra, Clemence Due, Dominggus Li and Deborah Turnbull (2019) 'Perceptions of disability, environmental risk factors and available services among local leaders and parents of young children with disabilities in West Timor, Indonesia' *Disability and Rehabilitation* Taylor & Francis 41 (20): 2421–2432.

<sup>265</sup> Riany, Y. E., Cuskelly, M., and Meredith, P., (2016) Cultural Beliefs about Autism in Indonesia. International Journal of Disability, Development and Education 63(6): 623–640. DOI: 10.1080/1034912X.2016.1142069.

<sup>266</sup> Kartika, Rani (2018) 'Pola Pengasuhan Anak Pada Orang Tua Tuna Netra (Studi Kasus Klinik Pijat Tuna Netra Barokah)' *Jurnal Pendidikan Ilmu Sosial* 27 (2): 156.

<sup>267</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

<sup>268</sup> UNICEF (2022), Disability Inclusion Policy and Strategy (DIPAS) 2022-2030.

<sup>269</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

<sup>270</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

in Indonesia, including in relation to children's forum conducted under the Child Protection Law (No. 35/2014).<sup>271</sup> Iln a joint statement from the UNCRPD and CRC Committees, it urges that 'States parties must develop strategies for consultation and participation processes for the implementation of the Conventions that are inclusive, child-friendly, transparent and respectful of their rights to freedom of expression and thought of children with disabilities." The Committee on the Rights of Persons with Disabilities has recommended that GoI establish the necessary policies, mechanism and process for participation of children with disabilities in forums and decision-making processes to ensure that they can express their views freely on all matters affecting them on an equal basis with other children.<sup>273</sup> The same year as the Committee provided these recommendations, MoWECP passed a regulation (No. 1/2022) on Children's Forums mandating local governments to ensure that at least 10 per cent of participants are children with disabilities.

Persons with disabilities rights to participation in cultural life, recreation, leisure and sport are protected in Article 30 of the UNCRPD. Of note is a gap between laws and regulations in relation to sport. The Disability Law (No. 8/2016) requires government to develop a sports system that includes a variety of sports based on different types of disabilities. However, the ministerial regulation on recreational sports<sup>274</sup> does not mention children or persons with disabilities. In practice children with disabilities face barriers participating alongside their peers in their communities. Research has shown that adolescents with disabilities (aged 10-19 years old) have low participation rates in recreational, sporting and cultural activities, with those with severe disabilities having the lowest participation rate.<sup>275</sup> In Indonesia's recreational programmes, children with disabilities tend to be separated from their peers without

disabilities. Children and adolescents face barriers participating due to a lack of accessibility in public buildings and facilities. Even in Jakarta, research shows that public facilities are not disabilities accessible.<sup>276</sup>

#### 4.3 Gender

As highlighted above, in Indonesia there are more boys than girls with disabilities. This is aligned with global data that shows that in countries where there is a significant difference in the number of children with disabilities based on gender, a greater proportion of boys have disabilities.<sup>277</sup>

Girls and women with disabilities around the world experience double discrimination on the basis of gender and disability. This makes them less likely than both boys with disabilities and girls without disabilities to access services, like healthcare. 278. While the data on violence in this research was not disaggregated by gender, globally girls with disabilities are at higher risk of violence, exploitation and abuse.<sup>279</sup> In this research it was found that girls with disabilities were 75 per cent more likely to be stunted then girls without disabilities and 15 per cent more likely than boys with disabilities (see nutrition section). Suggesting that girls with disabilities have poor nutrition and less access to diverse food. Gender also impacted school attendance for children with disabilities. While boys with disabilities were more likely to not attend school in preschool and primary levels, in lower and upper secondary school, girls with disabilities had higher levels of not attending than boys with disabilities. See Figure 39. Suggesting that as they get older, girls with disabilities face more barriers to attending school than boys with disabilities. Amongst parents and caregivers of children with disabilities, women are more likely to take on the role of caregiving, lowering her

<sup>271</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>272</sup> United Nations (n.d.), Joint statement on the rights of children with disabilities: Committee on the Rights of the Child and Committee on the Rights of Persons with Disabilities.

<sup>273</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>274</sup> Minister for Youth and Sports No. 4/2021 on Guidelines For The Development Of Recreational Sports/

<sup>275</sup> Priebe, Jan and Fiona Howell (2014) The Life Of People With Disabilities An Introduction To The Survey On The Need For Social Assistance Programmes For People With Disabilities (SNSAP-PERSONS WITH DISABILITIES 2012) Jakarta, Indonesia.

<sup>276</sup> Propiona, Jane Kartika (2021) 'Implementasi Aksesibilitas Fasilitas Publik Bagi Penyandang Disabilitas' *Jurnal Analisa Sosiologi* 10.

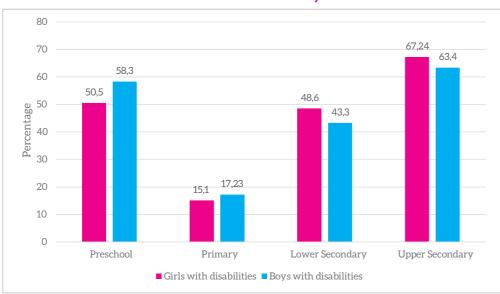
<sup>277</sup> UNICEF (2021), Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

<sup>278</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

<sup>279</sup> UNICEF (2022), UNICEF Factsheet: Children with Disabilities.

economic opportunities.<sup>280</sup>

Percentage of girls and boys with disabilities not attending school across different education levels, 2021



Source: Based on National Socioeconomic Survey 2021

The Committee on the Rights of Persons with Disabilities has noted that in Indonesia disability-related legislation and policies lack a gender perspective and vice versa with gender legislation and policies lacking a disability perspective. This leads to further exclusion of and discrimination against women and girls with disabilities. The Committee recommends that this be remedied in close consultation with and active involvement of women and girls with disabilities. Further the Committee recommends GoI include an intersectional analysis for women and girls with disabilities, including those from indigenous groups, ethnic and religious minorities, and rural areas and remote islands, across all policy areas. 282

## **4.4 Emergencies**

Climate-related extreme weather events in the East Asia and Pacific region have increased by 6 times over the past five decades.<sup>283</sup> Indonesia, located in the Pacific region's 'ring of fire' is one of the most disaster-prone countries in the world with 343 disasters recorded between 2000 and 2022.<sup>284</sup>

Emergencies have a significant impact on children with disabilities. Not only do they increase the number of children and adolescents with disabilities, due to acquiring a disability as a direct result of the disaster or conflict, but children with disabilities have higher injury and mortality rates in humanitarian contexts. In addition to being a direct threat to their lives, children with disabilities are more likely to be left behind, abandoned or neglected.<sup>285</sup> Ilf separated from caregivers in the aftermath of an emergency, children with disabilities are vulnerable to violence, exploitation and abuse.<sup>286</sup>This is exacerbated when emergency responses are not disability inclusive or accessible, creating barriers for children with disabilities to access humanitarian assistance.

In Indonesia, to mitigate the impact of disasters on persons with disabilities, laws and regulations related to disasters have included persons with disabilities. The Disability Law (No. 8/2014) and implementing regulations promote the participation of persons with disabilities in decision-making including in disaster management.<sup>287</sup> In addition regulation No. 4/2020<sup>288</sup> mandates that in disasters, central and local government ensure accessibility of persons with disabilities to settlements, WASH, education and protection. The MoSA also

<sup>280</sup> Satriana, S., Huda, K., Saadah, N., Hidayati, D., Zulkarnaen, A., (2021), COVID-19 impacts on people with disabilities in Indonesia: An in-depth look.

<sup>281</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>282</sup> United Nations (2022), Committee on the Rights of Persons with Disabilities – Concluding Observations on the initial report of Indonesia. CRPD/C/IDN/CO/1.

<sup>283</sup> UNICEF (2023), Over the Tipping Point: How multiple, overlapping climate and environmental shocks and hazards on children in the East Asia and Pacific region are eroding their coping strategies, exacerbating inequality, and forever changing their futures.

<sup>284</sup> Sheehy, K., Vackova, P., van Manen, S., et al, (2022) 'Inclusive disaster risk reduction education for Indonesian Children,' *International Journal of Inclusive Education*. https://www.tandfonline.com/doi/full/10.1080/13603116.2022.2115156.

<sup>285</sup> UNICEF (2017), Guidance: Including children with disabilities in humanitarian action- General

<sup>286</sup> UNICEF (2017), Guidance: Including children with disabilities in humanitarian action– General

<sup>287</sup> UNICEF (2021), Learning about meaningful engagement with Organizations of Persons with Disabilities in public health emergencies, including COVID-19.

<sup>288</sup> Government Regulation No. 42 of 2020 on Accessibility to Settlements, Public Services, and Disaster Protection

provides training for children and young people with disabilities, including on preparedness for disasters under the Disaster-Prepared Village Programme.

The Indonesian National Disaster Management Authority (BNPB) regulation No. 14/2014 requires the meeting of basic needs during emergencies and consideration of the specific needs of persons with disabilities. The same regulation also stipulates the community-based disaster reduction forums must invite representations of OPDs to be part of the forum.<sup>289</sup> The agency has responsibility for emergency command posts that provide data, aids and services which are differentiated and prioritized for persons with disabilities. They also provide capacity building during emergencies for persons with disabilities, their assistants, families and the community. BNPB is in the process of creating an information management system for data on refugees that will disaggregate by disability, providing evidence for more targeted disability emergency interventions in the future.

UNICEF has documented examples of Indonesian OPDs engagement in emergency preparedness and response. For example, GoI engaged with OPDs to map and address the needs of persons with disabilities within a resilient village programme.<sup>290</sup> FFurther during the earthquake eruption in Central Java in 2021, the Indonesian National Board for Disaster Management engaged OPDs to plan accessible shelters. The shelters used were in special school buildings that were already accessible.<sup>291</sup> In 2018, OPDs also worked with International Non-Government Organization (NGO), Oxfam, on an earthquake and tsunami response with persons with disabilities included in the response team. As a result of this engagement, the OPD has a response team of trained persons with disabilities that can be immediately deployed in an emergency.<sup>292</sup>

While UNICEF has collaborated with MoECRT on emergency preparedness in special schools, a study looking at inclusive disaster risk reduction (DRR) education in Indonesia determined that children with disabilities were largely absent from DRR education research and programmes.<sup>293</sup> A survey of 769 teachers found that none of the DRR education programmes being used were accessible for children with disabilities.<sup>294</sup> Given the heightened vulnerability and risk faced by children with disabilities in disasters, it is critical that they access and participate in DRR education. Further the Committee on the Rights of Persons with Disabilities noted the absence of a comprehensive and disability inclusive DRR framework, recommending that Gol work with OPDs to develop a comprehensive DRR framework, including prevention and response plans, and specific protection and assistance for persons with disabilities.

<sup>289</sup> UNICEF (2021), Learning about meaningful engagement with Organizations of Persons with Disabilities in public health emergencies, including COVID-19.

<sup>290</sup> UNICEF (2021), Learning about meaningful engagement with Organizations of Persons with Disabilities in public health emergencies, including COVID-19.

<sup>291</sup> UNICEF (2021), Learning about meaningful engagement with Organizations of Persons with Disabilities in public health emergencies, including COVID-19.

<sup>292</sup> UNICEF (2021), Learning about meaningful engagement with Organizations of Persons with Disabilities in public health emergencies, including COVID-19.

<sup>293</sup> Sheehy, K., Vackova, P., van Manen, S., et al, (2022) 'Inclusive disaster risk reduction education for Indonesian Children,' *International Journal of Inclusive Education*. https://www.tandfonline.com/doi/full/10.1080/13603116.2022.2115156.

<sup>294</sup> Sheehy, K., Vackova, P., van Manen, S., et al, (2022) 'Inclusive disaster risk reduction education for Indonesian Children,' *International Journal of Inclusive Education*. https://www.tandfonline.com/doi/full/10.1080/13603116.2022.2115156.



The key findings on children with disabilities in Indonesia have been highlighted throughout the report. Overall, Indonesia is taking a rights-based approach to disability legislation development. The analysis found that, although laws and regulations are in place to protect the rights of children with disabilities, policies are not well implemented and children with disabilities experience inequity compared to children without disabilities when accessing services and programmes in Indonesia.

Based on the evidence and data available, the recommendations outlined below provide crucial opportunities and a path forward towards a more inclusive and accessible Indonesia for children with disabilities. The recommendations are developed with the assumption that all stakeholders are committed to the implementation of the UNCRPD and more specifically to fulfil the rights of children with disabilities.

It is critical to reflect and build on these recommendations through consultations with persons with disabilities, including in consultation with children with disabilities and their families. This is important to ensure follow up actions are tailored to the needs of children with disabilities and identify opportunities for meaningful and active engagement and partnerships with OPDs in policy development, planning, programmes and services.

The recommendations can inform disability inclusive policy and practices for any stakeholder – national and sub-national government, UN agencies, development partners, civil society and OPDs. However, for each specific recommendation the key responsible actors have been identified. All actions on disability inclusion should following the principle of 'Nothing about us, without us,' which is the slogan of disability rights advocates. This means engaging and partnering with OPDs at every opportunity and consulting with children, adolescents and adults with disabilities in a meaningful way, so their lived experience and expertise informs evidence-based programmes that identify and overcome barriers.

For UNICEF, the following recommendations are aligned with UNICEF's

Disability Inclusion Policy and Strategy 2022–2030 and will contribute towards realizing UNICEF's vision that all children, especially those with disabilities, live in barrier-free and inclusive communities where they are embraced and supported, across the life cycle, to realize and defend their rights and to achieve full and effective participation.<sup>295</sup>

While the actions outlined in the recommendations are all considered necessary, levels of priority (low, medium, high priority) and timeframes (short-, medium-, long-term) have been provided to assist in prioritizing for planning and budgeting.

## **Legislative commitments**

## Recommendation 1. Strengthen a disability coordination mechanism in GoI.

High priority; short-term.

As recommended by the Committee on the Rights of Persons with Disabilities, Gol should strengthen the current coordination mechanism emanated in the National Plan of Action to make it work effectively across ministries/agencies and across national, provincial, district/city and subdistrict levels on the rights of persons with disabilities, with attention to the rights of children with disabilities. Through this mechanism, awareness can be raised and capacity built on existing legislation and its requirements for implementation at sub-national levels. Coordination is needed to harmonize efforts across ministries and to promote cross-sectoral approaches that can strength government systems, services and programmes to be disability inclusive and accessible. It is essential that government coordination create space and opportunity for the input of persons with disabilities including through their representative organisation. Coordination on disability should have a clear role for the National Commission on Disabilities. Responsible:

 MoSA, MoWECP, MoECRT, MoNP, MoH and local government in consultation with the National Commission on Disabilities, OPDs, UN agencies and development partners.

## Recommendation 2. Align terminology and definitions to be rights-based.

Medium priority; medium-term.

All ministries and agencies should adjust legislation to use the disability-related terminology and definitions outlined in the Disability Law (No. 8/2016), which are aligned to the UNCRPD. 'Children with disabilities' (anak penyandang disabilitas) should be the accepted standard terminology used. Any new laws, regulations and guidelines should use this terminology as well as making amendments to existing legislation to align language. This will assist in aligning planning, programmes and services in terms of data collection, targeted groups and contribute to reducing stigma towards persons with disabilities. Responsible:

• MoSA, MoWECP, MoECRT, MoNPD, MoH and others.

## **Data collection**

# Recommendation 3. Use the UNICEF/WG Child Functioning Modules for any data collection on children with disabilities.

High priority; short-term.

In all national surveys, censuses and any administrative data system, including the Intercensal Population Survey, (SUPAS), National Socioeconomic Survey (SUSENAS) and Indonesia Health Survey (SKI), and Socio-economic Registration (REGSOSEK) to use the UNICEF/WG Child Functioning Modules in their entirety and without any modifications to capture data on children with disabilities that is accurate, comparable and representative of all types of disabilities. In addition, strengthen data collection protocols and training to reduce any potential bias or stigma. Coordinate and share data between ministries to inform planning and budgeting and to link it with related public social protection programmes and public services. Responsible:

 Statistics Indonesia, MoH, MoHA and other ministries with technical support from UNICEF.

#### **Nutrition**

## Recommendation 4. Develop targeted and inclusive programmes for children with disabilities to address nutritional inequities.

High priority; medium-term.

Develop targeted nutrition programmes to close the gap in nutritional outcomes for infants, children and adolescents with disabilities, taking an intersectional approach that addresses disability, gender and other forms of marginalization. Programmes should address not just the absence of nutritious food in households, but also provide caregivers with knowledge and skills to ensure children with different impairments can consume food safely and easily, and to access essential nutrition services. Outreach mechanisms, such as through community centres should be mobilized to reach out of school children with disabilities. Programmes should also target caregivers with disabilities providing information on infant and child nutrition in accessible formats to support the nutrition of their children (regardless of if they have a disability). Include disability-related indicators, strengthen the collection of disability data and improve nutrition data management systems to monitor the responsiveness of programmes to the needs of children and caregivers with disabilities.

#### Responsible:

 MoNPD, UNICEF, World Food Programme (WFP), civil society, development partners in partnership with OPDs and groups/ associations of parents of children with disabilities.

## Recommendation 5. Create stronger linkages between nutrition, food assistance and social protection.

Medium priority; medium-term.

Review and strengthen food assistance and social protection policies and programmes to ensure they are targeting: 1) households of children with disabilities given their lower nutritional status; and 2) households of caregivers with disabilities with children under five. Monitor the nutritional status of children, including those with disabilities, in households receiving food assistance and cash grants to ensure all children have improved nutritional outcomes as a result of social

protection. Review staple food packages to ensure variety and quality of food provided meets the minimum acceptable diet for children and caregivers with disabilities. Provide education to families on the importance of nutrition for all children, including those with disabilities. Responsible:

 MoNPD, MoSA, in consultation with UN and civil society partners, including OPDs.

#### **WASH**

Recommendation 7: Strengthen Equity-Based WASH Access and Improve Accessibility in Schools Recommendation 6. Strengthen equity-based monitoring on access to WASH.

Medium priority; medium term.

The Government of Indonesia (GoI), following its commitments during the Sanitation and Water For All Meeting in 2022, should strengthen equity-based monitoring on access to WASH. This involves using best-practice data collection tools and methodologies related to disability, gender, indigenous groups, poverty, and other factors to identify barriers in accessing WASH.

Simultaneously, there should be an emphasis on improving the accessibility of WASH in schools, prioritizing Inclusive Education Schools and Special Schools, where the lack of accessible WASH facilities creates significant barriers for children with mobility impairments. This integrated approach requires working closely with the education sector to review and address gaps in legislation and implementation of accessible WASH in schools. The collected data should inform WASH services and programs, such as CLTS and Citywide Inclusive Sanitation, to adapt approaches to meet the specific WASH needs of all populations, particularly those being left behind, including in educational settings. Responsible:

BAPPENAS and Statistics Indonesia, in collaboration with other ministries, and with technical support from UNICEF, other UN agencies, and civil society, including Organizations of Persons with Disabilities (OPDs). The Ministry of Public Works and Housing (MoPWPH), Ministry

of Education, Culture, Research, and Technology (MoECRT), and Ministry of Religious Affairs (MoRA), along with civil society, OPDs, and private sector education actors, are tasked with accelerating progress on infrastructure improvements in schools.

#### Health

Recommendation 8. Establish clear and measurable standards with specific indicators for the provision of quality health services for children with disabilities.

Medium priority; short to medium term

Establishing standards and measuring their implementation will strengthen children with disabilities access to adequate and equitable healthcare services that meet their needs. Standards should cover children with disabilities access to basic health services, including immunization, and access to specialized disability health services. Measurement could include patient satisfaction rates using accessible feedback mechanisms, accessibility of healthcare facilities, availability of health-related information in accessible formats and the availability of assistive technology and devices for children. The implementation of standards will require strengthening the health system for children with disabilities, including consideration of children with disabilities in health sector plans and budgets at the national and sub-national levels. Responsible:

• MoH, MoSA, Ministry of Home Affairs (MoHA) with UN, development partners and civil society, including OPDs.

## **Education**

Recommendation 9. Develop systematic school-based developmental monitoring and screening programme with referral pathways.

High priority; short term

Develop a universal school-based developmental monitoring and screening programme and referral pathways for identification of

disabilities and family- and child-centred support and intervention. This will require cross-sectoral collaboration with MoH. Referral pathways should include healthcare services for assessment and intervention, and to Disability Services Units for access to accessible learning materials and assistive technology required for children with disabilities to participate and learn. Responsible:

 MoECRT, MoRA, MoH with UN, development partners and civil society, including OPDs and associations/groups of parents of children with disabilities.

# Recommendation 10. Conduct an inclusive education sector analysis to inform the strengthening of the inclusive education system across all levels of education.

High priority; medium term

An inclusive education sector analysis<sup>296</sup> led by MoECRT and MoRA will review policies, roadmaps, resources, data and practices to understand how the education system in Indonesia is meeting the needs of children with disabilities. The research will review the regulatory and policy framework, system capacity and management, cost and financing aspects of inclusive education. It will identify supply, quality and demand issues, and disparities in access and learning for children with disabilities. Through conducting this research, a coordinated effort can be established between MoECRT and MoRA, with entry points identified to further transition to more disability inclusive education approaches. Key to the transition of the system towards inclusion is ensuring that Disability Services Units are in all districts and cities to support schools and students with disabilities. Responsible:

• MoECRT, MoRA with technical support from UNICEF, development partners and civil society, including OPDs and associations/groups of parents of children with disabilities.

## **Child protection**

Recommendation 11. Strengthen inclusive child protection systems, including justice systems, to prevent and respond to violence, exploitation, abuse, neglect and harmful practices.

High priority; medium term

Review child protection systems, including birth registration, to identify barriers for children with disabilities. Strengthen the social service workforce to be more inclusive and better equipped to protect children with disabilities from violence, abuse and exploitation. Provide training to professionals that work with children (such as teachers, social workers and health workers) to recognize signs of abuse in children with disabilities and have the knowledge and skills to support the child and their family. Training is also required for police, investigators and legal actors on the accessibility and inclusion needs of children with disabilities to improve access to justice. Responsible:

 MoWECP with technical support from UNICEF, development partners and civil society, including OPDs and associations/ groups of parents of children with disabilities.

## Recommendation 12. Support the prevention of familychild separation, end institutionalization and strengthen family-based alternative care for children with disabilities.

High priority; medium term

Efforts to reform and transform care systems must be inclusive of children with disabilities and consider their specific challenges and vulnerabilities. This includes reinforcing family-friendly policies, social and child protection and community-based inclusive services, strengthening the capacities of social service workers, implementing systematic deinstitutionalization strategies and promoting family-based alternative care services. Combating stigma is also key to preventing the separation of children with disabilities from their families. Responsible:

 MoSA with technical support from UNICEF, development partners and civil society, including OPDs and associations/ groups of parents of children with disabilities.

<sup>296</sup> Methodological guidelines for an inclusive education sector analysis are available and have been used in more than 70 countries, with about 130 country-specific reports produced.

## **Social Policy**

Recommendation 13. Conduct research to assess the additional cost of raising a child with a disability in Indonesia to estimate adequate benefit level for children with disabilities.

Medium priority; short term

Through research determine the additional cost of having a child with a disability in Indonesia and examine further poverty rates between households.<sup>297</sup> Based on the evidence assess whether current social protection programmes adequately meet the needs of families of children with disabilities. It is recommended that social protection coverage should be universal for children with disabilities and conditionalities for social assistance be removed. In the context of social protection funds for households with children with disabilities dwindling significantly, understanding the additional cost of having a child with a disability can inform the targeting of households that are most in need. Responsible:

 UNICEF, MoSA, development partners and civil society, including OPDs and associations/groups of parents of children with disabilities.

Recommendation 14: Making the social protection system disability-responsive for the children with disability by taking into account different vulnerabilities, risks, inequalities and bottlenecks they face in different phases of their lives.

The Government is committed to strengthening adaptive social protection system to strengthen the resilience – to prepare for, cope with, and adapt to - of poor and vulnerable households or individuals to covariate shocks by integrating the social protection, disaster risk management (DRM), and climate change adaptation sectors. This reform initiative should include the needs of children with disability in different components of adaptive social protection system. A disability-responsive social protection system also focuses on continuum of care in different stages of the lifecycle of a child with disability by addressing

different dimensions of exclusion of exclusions and active participation of children and their caregivers.

## **Cross-cutting**

Recommendation 15. Improve the accessibility of WASH in schools with priority to Inclusive Education Schools and Special Schools.

Medium priority; medium to long term

Gol should expand its initiative to compile a comprehensive database for both government buildings and public places in need of disability-friendly renovations. Systematic identification of these structures and locations is essential for developing a strategic plan prioritizing inclusivity and accessibility for individuals with disabilities. Effective utilization of gathered data is crucial for prompt and comprehensive renovations. This approach fosters an inclusive society where everyone can participate fully, promoting equal opportunities and social integration for all citizens. Responsible:

 MoPWPH, MoH, Ministry of Transportation (MoT), MoHA, UNICEF, civil society including OPDs and private sector..

## Recommendation 16. Expand access to assistive technology for children with disabilities.

High priority; medium term

Assess the current availability and barriers to assistive technology, including local markets, procurement systems and affordability. Based on the assessment, strengthen national systems (including referral systems), services and workforce to deliver assistive technology that are appropriate for children, affordable, consistently available and delivered through services by trained personnel. Responsible:

 MoH, MoSA, UNICEF, WHO, development partners and civil society, including OPDs and associations/groups of parents of children with disabilities.

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<sup>297</sup> A similar study was conducted by UNICEF Philippines, https://www.unicef.org/philippines/reports/ cost-raising-children-disabilities-philippines

## Recommendation 17: Develop social and behaviour change programmes to eliminate stigma.

High priority; long term

Changing negative attitudes towards children with disabilities can be achieved through social and behaviour change communication to address negative attitudes, beliefs and norms that lead to stigma and discrimination. At the same time children with disabilities should be empowered to demand and exercise their rights, including them in decisions that affect their life. Programmes should be participatory, engaging children, families, communities, service providers and decision-makers, with parents and families playing a critical role. Responsible:

 MoSA, MoH, MoWECP, MoECRT, MoRA, UNICEF, development partners and civil society, including OPDs and associations/ groups of parents of children with disabilities.

## Recommendation 18: Include children with disabilities in future research.

Medium priority; long term

It was a missed opportunity that children with disabilities did not participate in this study. Any future research related to children with disabilities should include children with disabilities and their families. To ensure this participation, ethical considerations are critical and disability inclusive safeguarding processes should be developed and followed. Responsible:

 UNICEF and MoWECP, development partners and civil society, including OPDs and associations/groups of parents of children with disabilities.

## Recommendation 19: Develop disability inclusive and accessible emergency preparedness programmes.

High priority; medium term

Given the impact that emergencies have on children with disabilities, emergency preparedness programmes are needed that are adapted to their communication needs and delivered in formats and venues accessible to them. This should include in inclusive education schools

and special schools. As many children with disabilities are out of school, inclusive preparedness programmes should also be delivered in the community. Responsible:

 Indonesian National Board for Disaster Management, MoECRT, MoRA, UNICEF, development partners and civil society, including OPDs and associations/groups of parents of children with disabilities.

## **Annexes**

Annex 1.

# Study informants from key informant interviews and focus group discussions

Name of organization	Type of organization	Female informants	Male informants	Total number of informants
National Board for Disaster Management	Government	1	3	4
Statistics Indonesia	Government	1	1	2
Ministry of Religious Affairs	Government	2	2	4
Ministry of Home Affairs	Government	-	4	4
Ministry of Education, Culture, Research, and Technology	Government	-	1	1
Ministry of Health	Government	12	3	15
Ministry of National Development Planning / National Development Planning Agency	Government	3	3	6
Ministry of Woman's Empowerment and Child Protection	Government	1	1	2
Ministry of Public Works and Public Housing	Government	3	3	6
Ministry of Social Affairs	Government	3	2	5
National Disabilities Commision	Government	3	1	4
National Child Protection Commission	Government	1	1	2
Indonesian Association of Women with Disabilities	OPD	4	-	4
Wahana Inklusif Indonesia	OPD	-	1	1
Indonesian Red Cross	Civil Society	-	1	1
Indonesian Center for Law and Policy Studies	Academic institution	-	1	1
Indonesian Association of Persons with Physical Disabilities	OPD	-	1	1
Indonesian Association for the Welfare of the Deaf	OPD	-	1	1
Indonesian Mental Health Association	OPD	1	1	2
Parents Association of Indonesian Disabled Children	OPD	2	-	2
Total number of informants		37	31	68

#### Annex 2.

# Summary of the rights of children with disabilities in the Disability Law (No. 8/2016) and the Child Protection Law (No. 1/2017)

Rights of	children with	n disabilities in Indonesia
Disability Law	Sector	Child Protection law
		Note: The Child Protection law does not target children with disabilities specifically, but children with disabilities are included among those who receive special protection. As such some of the rights below apply to all children.
<ol> <li>Rights to receive special protection from discrimination, neglect, assault, exploitation, violence and sexual violence.</li> </ol>	Protection	<ol> <li>Rights to protection for their physical, mental, spiritual, and social needs.</li> <li>Rights to be protected from being misused in politics, conflict, armed dispute, social conflict, violence, sexual crime and war.</li> </ol>
<ol> <li>Protected from exploitative decision and specific interest.</li> <li>To be treated</li> </ol>		<ul><li>3. Rights to be protected from torture or inhumane verdict.</li><li>4. Rights to be facing arrest, detention or imprisonment as a last resort.</li></ul>
humanely and in accordance to the		<ul><li>5. Rights to be protected when dealing with the legal system.</li></ul>
child's right.		<ol> <li>Rights of anonymity when they are a victim of sexual assault or when the legal proceeding allows anonymity.</li> </ol>
		7. Rights to obtain legal support when dealing with the legal system.
Included in the rights for persons with disabilities.	Education	<ol> <li>Rights to obtain and receive education.</li> <li>Rights to obtain special education for children with disabilities.</li> </ol>
		3. Rights to be protected within their school environment from violence and sexual crime.

Rights of o	children with	n disabilities in Indonesia
Disability Law	Sector	Child Protection law
<ol> <li>Fulfilment of specialized needs.</li> <li>To be treated equally as other child to achieve full social integration and individual development.</li> <li>To receive social care.</li> </ol>	Health and social protection	<ol> <li>Rights to health care.</li> <li>Rights to social protection for their physical, mental, spiritual and social needs.</li> <li>Rights for children with disabilities to obtain rehabilitation, social assistance and social protection assistance.</li> </ol>
To receive care and guardianship from parents or alternative family for optimum care.	Family and alternative care	<ol> <li>Rights to know their parents.</li> <li>Rights to be raised by their own parents.</li> <li>Rights to be adopted or raised by alternative family.</li> <li>Rights to be supported financial by parents, after separation.</li> </ol>
Included in the rights for persons with disabilities.	Civil rights and freedom	<ol> <li>Rights for legal identity and citizenship.</li> <li>Rights for practicing religion as they see fit.</li> <li>Rights to express and think in accordance to their capabilities – under the supervision of their parents.</li> <li>Rights to be heard, to express their opinion, to search information in accordance to their capabilities.</li> <li>Rights of freedom and independence.</li> </ol>

#### Annex 3.

## Summary matrix of the Ministerial Regulation on the Special Protection for Children with Disabilities (Regulation No. 4/2017)

No	Priority Issue	Programme	Actor(s)
1	Lack of data availability	Population data	MoSA, Statistics Indonesia, Ministry of Internal Affair
2	Lack of dissemination on Disability Law	Communication, Information and Education	Coordinating Ministry of Human Empowerment and Culture, MoSA, MoWECP, Ministry of Information
3	Many children with disabilities are still subjected to stigma	Creating a stigma-free environment	MoRA, Ministry of Information, MoWECP, Ministry of Law and Human Rights
4	Lack of privacy protection for children with disabilities	Improving children with disabilities privation	The National Population and Family Planning Board, MoWECP
5	Not all children with disabilities have sufficient protection from the legal system	Provision of services in legal system protection	MoWECP, MoSA, Ministry of Law and Human Rights, The Indonesian Police
6	Lack of inheritance for children with disabilities	Protection for their inheritance	MoRA, Supreme Court of Indonesia, Ministry of Law and Human Rights
7	Lack of adequate effort in children with disabilities restitution	Restitution	The Indonesian Police
8	Lack of adequate mediation effort for children with disabilities in dealing with the legal system	Mediation	MoWECP, Indonesian Commission for Child Protection, MoSA, The National Population and Family Planning Board
9	Lack of differentiated approach in handling children with disabilities within the legal system	Developing the differentiated approach	The Indonesian Police, The Judicial System, The Court, MoSA, Ministry of Law and Human Rights
10	Lack of optimal education services for children with disabilities	Provision of education services	MoECRT
11	Not all children have been participating in sports events	Inclusive sport events	MoECRT, Ministry of Youth and Sports
12	Not all children have been participating in art and cultural events	Inclusive arts and cultural events	MoECRT, MoWECP
13	Not all children have been participating in a specific skilled competition event	Competitive skills events	MoECRT
14	Not all children with autism have access to information and consultation services	Provision of consultation and information services	МоН, MoWECP
15	Lack of information and comprehension on the behaviour of children with disabilities	Dissemination of information on children with disabilities	MoWECP, MOECRT, The National Population and Family Planning Board

16	Lack of adequate health services for children with disabilities	Provision of health services	МоН
17	Lack of religious services and training for children with disabilities	Provision of religious services and training	MoRA
18	Not all children with disabilities are involved in sport sector	Inclusive sport sector	Ministry of Youth and Sports
19	Not all children with disabilities are involved in tourism sector	Inclusive tourism sector	Ministry of Tourism
20	Not all children with disabilities are involved in the cultural sector	Inclusive cultural sector	Ministry of Tourism
21	Lack of adequate social welfare among children with disabilities	Provision of adequate social welfare	MoSA
22	Limited infrastructures accessible for children with disabilities	Provision of an inclusive infrastructures	MoPWH
23	Limited public services accessible for children with disabilities	Provision of an inclusive public services	MoWECP, Ministry of Information
24	Lack of rights realization in the context of disaster relief	Protection from disaster	The National Population and Family Planning Board, MoWECP, MoSA
25	Not all children with disabilities have documentation (birth certificate) and children identity card	Provision of children with disabilities identity card and birth certificate	Ministry of Home Affairs
26	Not all children with disabilities have received education and training for independent living	Support for independent living and meaningful society involvement	Ministry of Labour, MoECRT, MoSA
27	Not all children with disabilities can express their opinion and access the necessary information	Platform for free speech and access to information	The National Library
28	Many children with disabilities are still facing discrimination, neglect, abuse and exploitation	Free from discrimination, neglect, abuse and exploitation	MoSA, MoWECP
29	Lack of available human resource to provide necessary services to children with disabilities	Training for human resources	MoH, MoSA
30	Lack of adequate coordination for special protection for children with disabilities		MoWECP
31	Lack of voices of children with disabilities	Children with disabilities participation	MoWECP
32	Lack of children with disabilities involvement in entrepreneurship	Involvement in entrepreneurship	Indonesian Association of Child Friendly Corporation

Source: Ministry of Women Empowerment and Child Protection Regulation No. 4/2017 on Special Protection for Children with disabilities.

Annex 4.

Legislation and policies specifically on children with disabilities

Policies and legisl	ation on children with disabilities in Indonesia
Ministry of Education, Culture, Research and Technology (MoECRT)	Regulation No. 70/2009 – Inclusive Education for Students with Disabilities and Exceptional Intelligence and/or Talents
	Regulation No. 13/2020 – Reasonable Accommodation for Students with Disabilities
	Minister of Education and Culture Decree No. 394/P/2019 – Criteria and Accreditation Tools for Special Elementary Schools, Special Junior High Schools and Special High Schools
	Learning Guide for Students with Disabilities during the COVID-19 Pandemic
	Social Security for Persons with Disabilities – Smart Indonesia Card
	2019-2024 Master Plan on National Development of Inclusive Education
Ministry of Social Affairs (MoSA)	Regulation No. 13/2015 – Social Services for Children with Disabilities
	Child Social Welfare Programmes
Ministry of Women's Empowerment and Child Protection (MoWECP)	Ministerial Regulation No.4/2017 - Special Protection for Children with Disabilities
Ministry of Health (MoH)	Roadmap for inclusive health services*
	Guidelines for health services for children with disabilities
	Regulations on disability-friendly health service providers, including accreditation
	National Health Insurance (covers financial assistance for assistive devices for children with disabilities)

<sup>\*</sup> Not exclusive to children with disabilities.

Functional domains covered by disability data collection tools

Questionnaire	Seeing	Seeing Hearing	Mobil- ity	Cognition (remember- ing and concentrate- ing)	Self-	Communi- cation	Affect*	Fine	Learn- ing	Play-ing	Play-ing Controlling behaviours	Coping with change	Relation- ships	Upper body
WG-SS (over 18 years)														
WG/UNICEF CFM (2-4 years)														
WG/UNICEF CFM (5-17 years)														
Intercensal Population Survey (over 2 years)														
National Socioeconomic Survey (over 2 years)														
Indonesia Basic Health Research (5-17 years)														

## Annex 6.

# Questions on disability used in Indonesian surveys

## Questions used in the Intercensal Population Survey 2015 and the National Socioeconomic Survey 2018-2021

No.	Domains	Questions
1.	Vision	Does [Name] have difficulty seeing?
2.	Hearing	[Does [Name] have difficulty hearing?
3.	Mobility	Does [Name] have difficulty walking or climbing steps?
4.	Upper body	Does [Name] have difficulty using [your/his/her] hands and fingers?
5.	Cognition (Remembering)	Does [Name] have difficulty remembering or concentrating
6.	Behaviour/ emotional disorders	Does [Name] have any behaviour/emotional disorder?
7.	Communication	Using [Name] usual language, does [Name] have difficulty communicating, for example understanding or being understood?
8.	Self-care	Does [Name] have difficulty with self-care, such as washing all over or dressing?

#### **Questions used in the Indonesia Basic Health Research 2018**

No.	Domains	Questions
1.	Vision	Does [Name] have difficulty seeing?
2.	Hearing	Does [Name] have difficulty hearing?
3.	Mobility	Does [Name] have difficulty walking?
4.	Communication	Compared with children of the same age, does [Name] have difficulty being understood when [Name] speak and [Name] has difficulty to understand people in his/her family or other people?
5.	Learning	Compared with children of the same age, does [Name] have difficulty learning things?
6.	Remembering	Compared with children of the same age, does [Name] have difficulty remembering?
7.	Concentration	Compared with children of the same age, does [Name] have difficulty concentrating?
8.	Playing	Compared with children of the same age, does [Name] have difficulty playing?
9.	Coping with change	Does [Name] have difficulty accepting changes in his/her routine?
10.	Controlling behaviour	Compared with children of the same age, does (name) have difficulty controlling his/her behaviour?

Annex 7.

Regulations related to health for children with disabilities

No.	Title of regulation	Article	Specific article on children with disabilities	Using the term 'children with disabilities,'*	Catering to all types of disabilities**	Article about persons with disabilities
1	Disability Law, Law No. 8/2016	12, 21	✓	✓	√	√
2	Law No. 24/2011 on the Social Security Implementing Agency	Whole law				
3	Law No. 23/2002 on Child Protection	8, 12	✓	✓	✓	✓
4	Government Regulation No. 2/2018 on Minimum Service Standard	10				✓
5	Minister for Social Affairs Regulation No. 18/2018 on Organization and Working Procedures of Technical Implementing Units Social Rehabilitation For Persons with Disabilities In The Directorate General Of Social Rehabilitation	Whole regulat- ion			√	✓
6	Minister for Health Circular No. HK.02.01/Menkes/598/2021 on the Acceleration of the Implementation of COVID-19 Vaccination for the Elderly, Persons with Disabilities, as well as Educators and Education Personnel				✓	√
7	Minister for Health Regulation No. 43/2019 on Community Health Centres					<b>√</b>
8	Minister for Health Regulations No. 25/2014 on Children's Health Efforts		√	√	√	✓

<sup>\*</sup> Anak Penyandang Disabilitas

Annex 8.

Regulations related to education for

children with disabilities

No.	Title of regulation	Article	Specific article on children with disabilities	Using the term 'children with disabilities,'*	Catering to all types of disabilities**	Article about People with disabilities
1	Disability Law, Law No. 8/2016	26, 41 – 44	<b>√</b>	✓	<b>√</b>	✓
2	Law No. 20/2003 on the National Education System	5, 32	√			√
3	Government Regulation No. 13/2020 on Reasonable Accommodation For Students with Disabilities	Whole regulat- ion	✓	✓	✓	✓
4	Government Regulation No. 19/2005 on National Education Standard	29, 38	✓		√	√
5	Law No. 12/ 2012 on Higher Education	32				√
6	Minister of Education Regulation No. 70/2009 on Inclusive Education	Whole regula- tion	✓	✓	✓	√
7	Minister of Education Regulation No. 33/2008 on Infrastructure Standards for Special Schools	Whole regula- tion	✓	✓	√	√
8	Minister of Education Regulation No. 157/2014 on Special Schools Curriculum	Whole regula- tion	√	✓	√	√
9	Minister of Religious Affairs Regulation No. 66/ 2016 amending Minister of Religious Affairs Regulation No. 90/2013 on Implementing Education on Islamic Schools	14, 16, 18, 35	√	<b>√</b>		<b>√</b>
10	Minister for Research, Technology, And Higher Education Regulation No. 46/2017 on University-Level Special Education and Special Services Education	Whole regula- tion	√	<b>√</b>	√	<b>√</b>
11	Decree of the Director General of Islamic Education No. 631/2019 on Technical Instructions for Admission of New Students	Annex 1, Chapter 1, Section D	√	✓		<b>√</b>
12	Learning guide for students with disability during the COVID-19 pandemic	Whole guide	√	√	√	√

<sup>\*</sup> Anak Penyandang Disabilitas

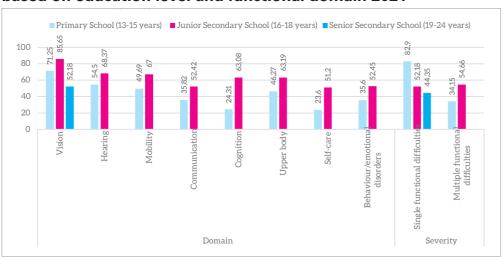
<sup>\*\*</sup> In accordance with the Disability Law

<sup>\*\*</sup> In accordance with the Disability Law

Annex 9.

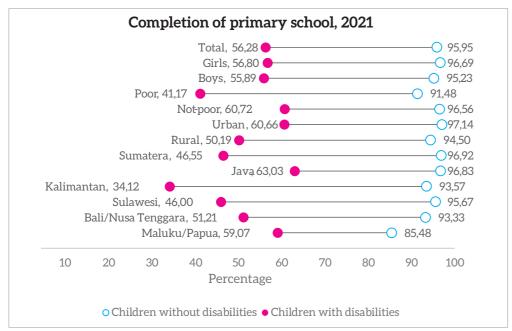
Graphs on completion rates for children with disabilities

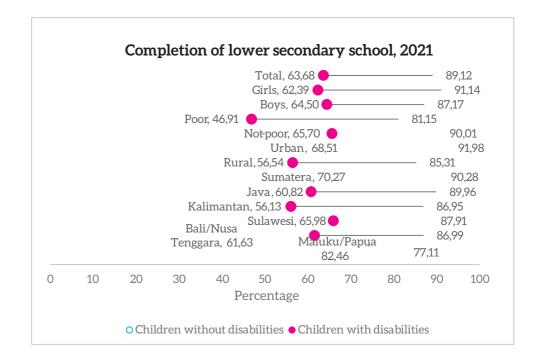
Percentage of children with disabilities completing education based on education level and functional domain 2021

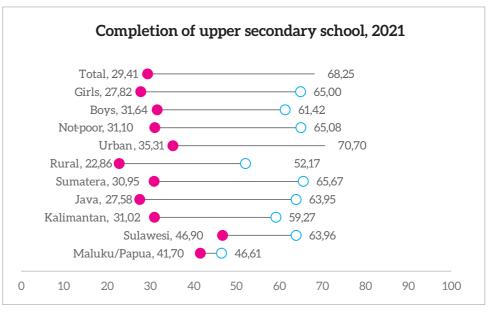


Source: Based on National Socioeconomic Survey 2021.

Comparison of school completion rate between children with and without disability based on sociodemographic characteristics, 2021





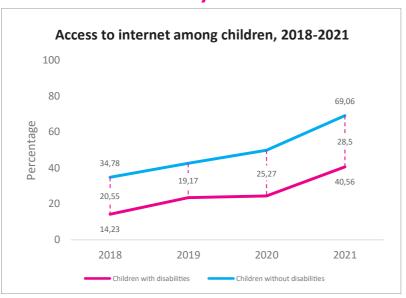


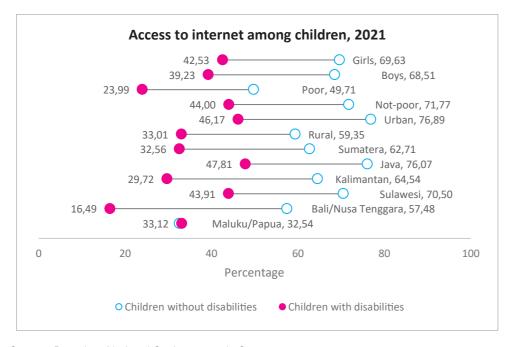
Source: Based on National Socioeconomic Survey 2021.

Source: Based on National Socioeconomic Survey 2021.

Annex 10.

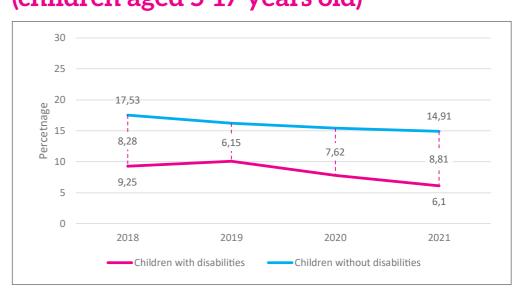
Access to internet for children with disabilities compared to children without disability





Source: Based on National Socioeconomic Survey 2018-2021.

Percentage of children who are beneficiaries of Smart Indonesia Programme - education cash grant (children aged 5-17 years old)



Source: Based on National Soc ioeconomic Survey 2018-2021.

#### Annex 12.

# Regulations related to child protection for children with disabilities

No.	Title of regulation	Specific article on children with disabilities	Using the term 'children with disabilities,'*	Catering to all types of disabilities**	Article about People with disabilities
1	Disability Law, Law No. 8/2016		✓		✓
2	Law No. 35/2014 on Amendments to Law Number 23/2002 on Child Protection	<b>√</b>	✓		
3	Law No. 23/ 2002 on Child Protection	√			
4	Law No. 11/2012 on the Juvenile Criminal Justice System	✓			
5	Law No. 19/2011 on Ratification of the Convention on the Rights of Persons with disabilities				✓
6	Regulation of the Minister of National Development Planning/ Head of National Development Planning Agency s No. 3/2021 on the Implementation of Government Regulation No. 70/2019 on Planning, Implementation and Evaluation of the Respect, Protection, and Fulfillment of the Rights of Persons with disabilities	<b>√</b>			
7	Minister of Women's Empowerment and Child Protection Regulation No. 4/2017 on Special Protection for Children with disabilities	√			
8	Presidential Decree No. 36/1990 on Ratification of the Convention on the Rights of the Child	✓			

<sup>\*</sup> Anak Penyandang Disabilitas

#### Annex 13.

# Regulations related to alternative care for children with disabilities

No.	Title of regulation	Article	Specific article on children with disabilities	Using the term 'children with disabilities,'*	Catering to all types of disabilities**	Article about People with disabilities
1	Government Regulation No.44/2017 on the Implementation of childcare	3, 33	✓	✓	<b>√</b>	
2	Social Affair Minister Regulation No.13/2015 on Social Services for Persons with disabilities	8, 16	✓	✓	✓	
3	Directorate General of Social Rehabilitation for Persons with disabilities Regulation No.5/2021 on Operational Guideline of Social Rehabilitation Assistances for Persons with disabilities	10		√	√	<b>√</b>
4	Ministerial Regulation No.1/2020 on Implementing Regulation of PP no.44/2017	Whole regulation			√	
5	Social Affair Minister Regulation No.30/2011 on National Standard for Child Care on Social Welfare Institutions		√			

<sup>\*</sup> Anak Penyandang Disabilitas

<sup>\*\*</sup> In accordance with the Disability Law

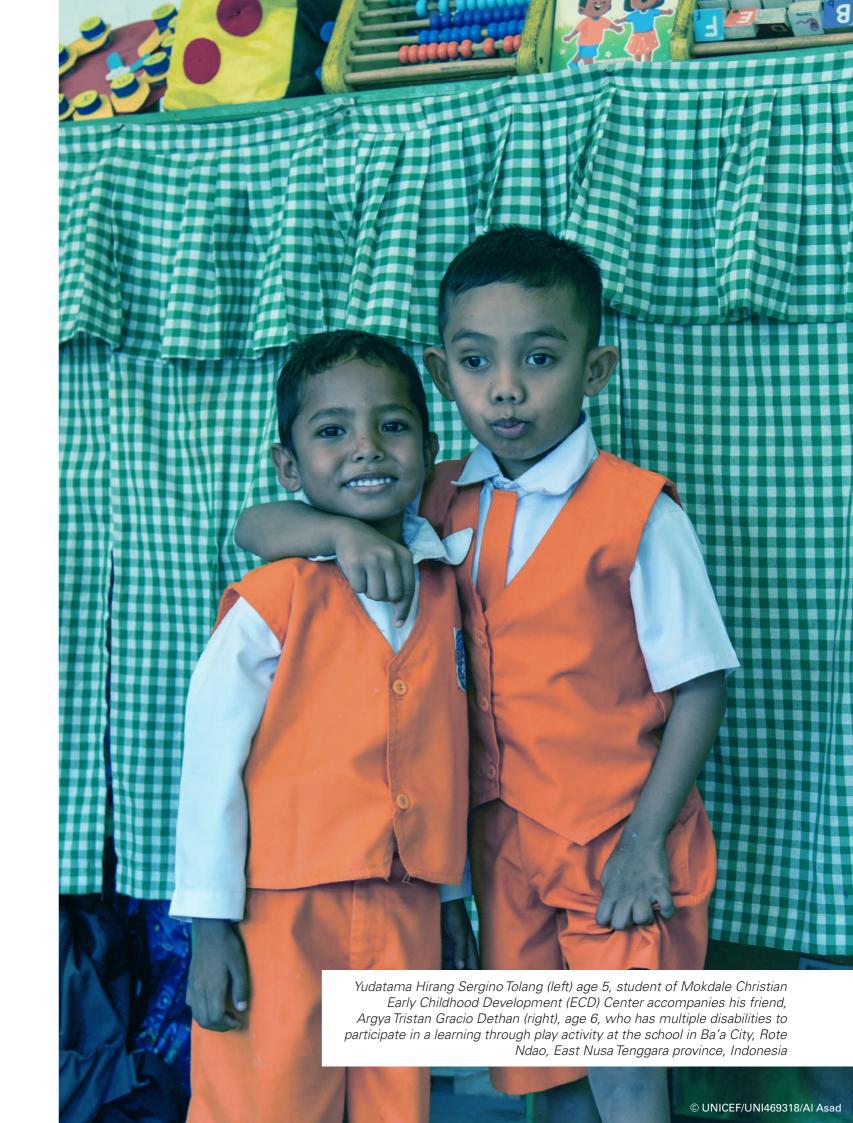
<sup>\*\*</sup> In accordance with the Disability Law

Annex 14.

Regulations related to social protection of children with disabilities

No.	Title of regulation	Article	Specific article on children with disabilities	Using the term 'children with disabilities,'*	Catering to all types of disabilities**	Article about People with disabilities
1	Disability Law, Law No. 8/2016	12, 21	✓	✓	√	√
2	Law No. 11/2009 on Social Welfare	5, 7		√		√
3	Government Regulation No. 52/2019 on Social Welfare Implementation for Persons with disabilities	Whole	✓	✓	✓	√
4	Government Regulation No. 2/2018 on Minimum Service Standard	10				√
5	Minister for Social Affairs Regulation No. 2/2021 on Disability Cards	Whole regulation			√	√

<sup>\*</sup> Anak Penyandang Disabilitas



<sup>\*\*</sup> In accordance with the Disability Law



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