

DISCUSSION PAPER

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# KEY ISSUES FOR CHILDREN WITH DISABILITIES IN INDONESIA





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## DISCUSSION PAPER

# KEY ISSUES FOR CHILDREN WITH DISABILITIES IN INDONESIA

FEBRUARY 2023

The purpose of this discussion paper is to highlight the key data, challenges, and opportunities to support children with disabilities in Indonesia. This paper presents data compiled and synthesized by UNICEF Indonesia, Altamont Group, and the SMERU Research Institute in Jakarta,<sup>1</sup> and aligns itself with the Sustainable Development Goals and UNICEF's 2021 report *Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities*.<sup>2</sup>

## BACKGROUND

Worldwide, there are an estimated 240 million children, aged 0–17 years, with disabilities. East Asia and the Pacific is home to 43.1 million children with disabilities, second only to South Asia with 64.4 million.<sup>3</sup>

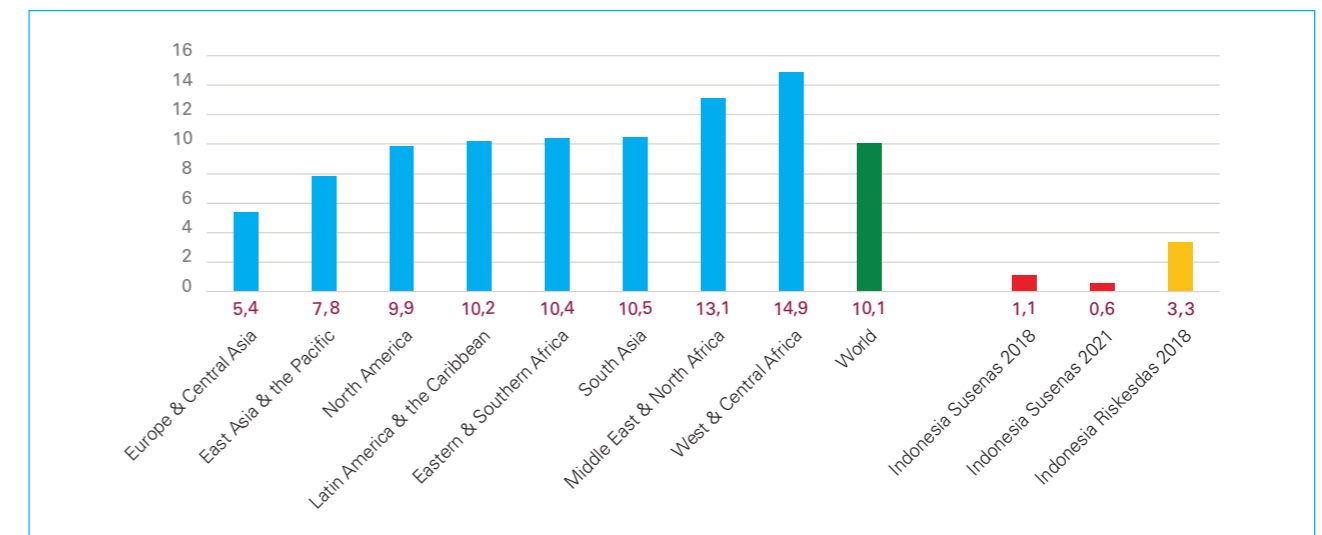
In Indonesia, according to the 2018 RISKESDAS, 3.3 per cent of children (aged 5–17 years) have disabilities.<sup>4</sup> There is a similar proportion of children with disabilities amongst females and males, as well as in urban and rural areas. The SUSENAS surveys in 2018 and 2021 found that the percentage of children (aged 2–17 years) with disabilities in Indonesia was even lower at 1.1 and 0.6 per cent, respectively.<sup>5</sup> These estimates are much lower than the average in the region at 8 per cent and 10 per cent at the global level (Figure 1).

The challenges in accurately estimating the population of children with disabilities are not confined to Indonesia, as similar hurdles are also encountered across the Asia-Pacific region.<sup>6</sup>



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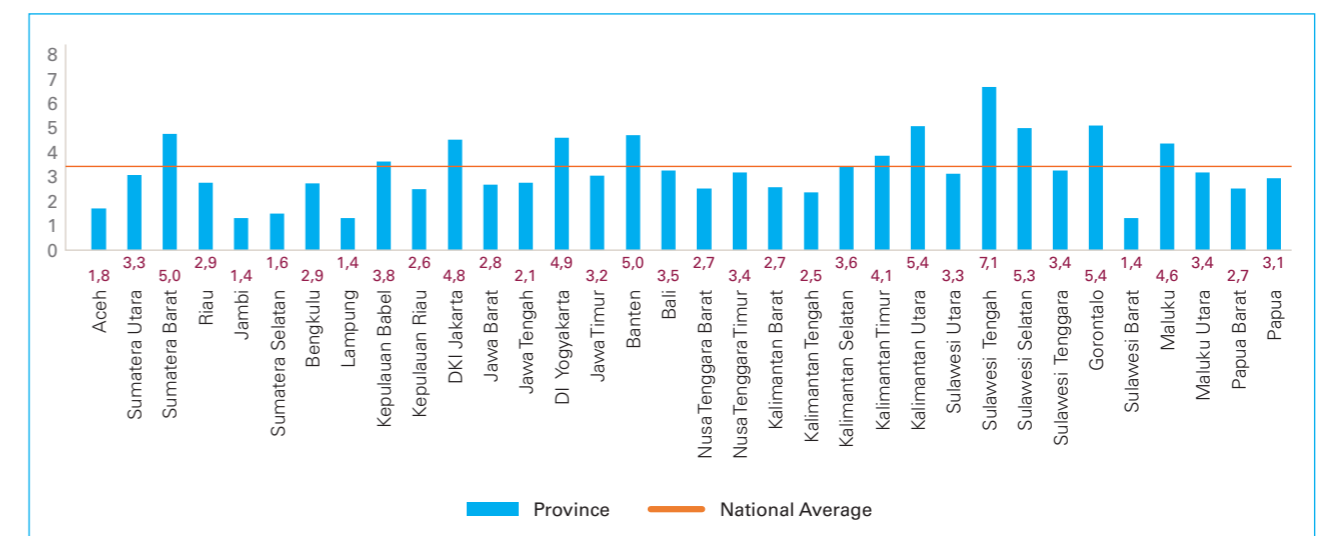
Figure 1. Percentage of children with disabilities by region and Indonesia



Source: UNICEF, 2021<sup>7</sup> and SUSENAS 2018 and 2021, and RISKESDAS 2018

When disaggregated by province, the differences in prevalence rates of children with disabilities becomes quite stark. This is seen in Figure 2, and Illustration 1 with the highest prevalence rate recorded in Sulawesi Tengah at more than 7 per cent and the lowest in Jambi (1.4 per cent).

Figure 2. Percentage of children with disabilities (5–17 Years) in Indonesia by province



Source: RISKESDAS 2018

<sup>1</sup> Primary sources of data include SUSENAS (National Socio-Economic Household Survey) from 2018–2021 and RISKESDAS (Basic Health Research) in 2018, as well as key informant interviews across government and non-governmental organizations including disabled persons organizations.

<sup>2</sup> United Nations Children's Fund, *Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities*, UNICEF, New York, 2021.

<sup>3</sup> United Nations Children's Fund, *Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities*, UNICEF, New York, 2021.

<sup>4</sup> A note of caution must be sounded with these statistics, as RISKESDAS has not fully applied the UNICEF/Washington Group child functioning module endorsed by all United Nations agencies and bilateral aid agencies. Instead, the survey used the Washington Group child functioning model, but only for those aged 5–17. A functional understanding of disability must be in line with the Convention on the Rights of Persons with Disabilities (CRPD) in defining disability through a biopsychosocial lens of an impairment in functional interaction with the social and physical environment. An age-specific module should be applied for each of the age groups, 2–4 and 5–17 years old.

<sup>5</sup> SUSENAS 2018 survey in Indonesia adopted the Washington Group short set of questions and applied it for all the population aged 2 and above.

<sup>6</sup> UNFPA (2021). *Are persons with disabilities included in the effort to leave no-one behind? Mapping disability data in development in Asia and the Pacific*. UNFPA Asia-Pacific Regional Office. <https://asiapacific.unfpa.org/en/publications/are-persons-disabilities-included-effort-leave-no-one-behind>.

<sup>7</sup> United Nations Children's Fund, *Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities*, UNICEF, New York, 2021.

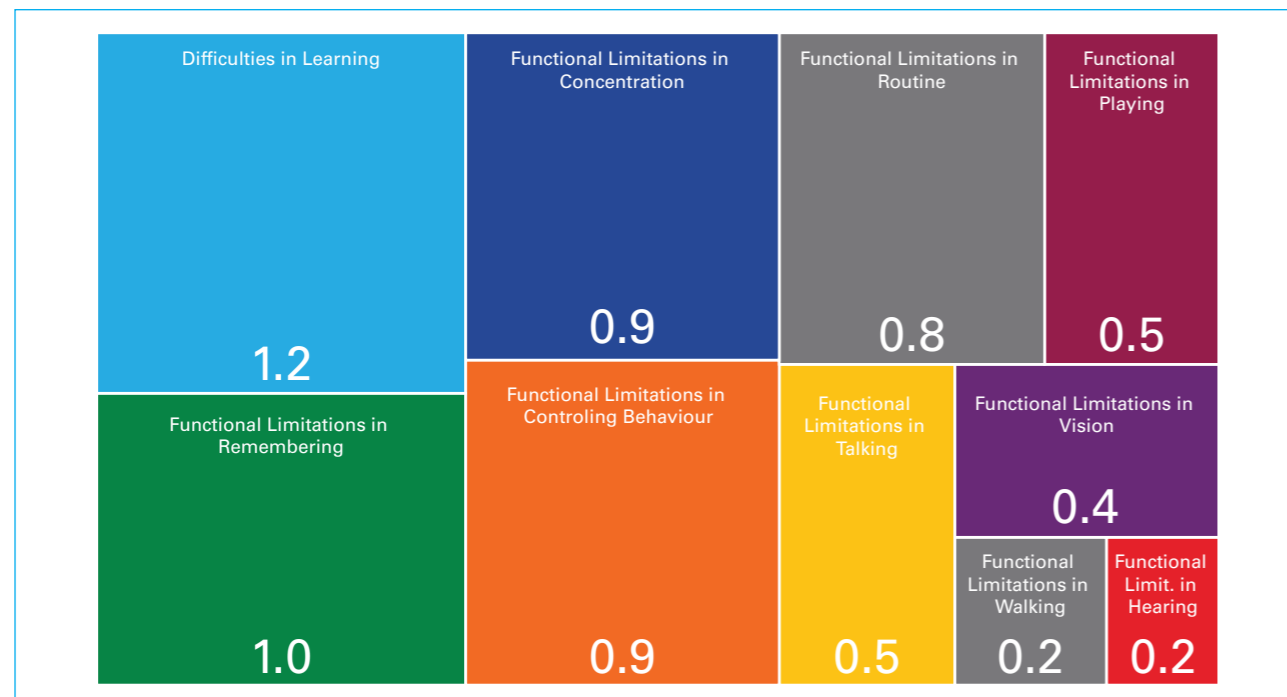
Illustration 1. Distribution of percentage of children with disabilities (5-17 Years) in Indonesia.



Source: RISKESDAS 2018

Noting the challenges in disability data in Indonesia, in Figure 3 the functional disability categorization is further delineated by RISKESDAS on approximate equivalent functional limitation categories based on the child module of the UNICEF/Washington Group questionnaire.

Figure 3. Percentage of children (aged 5-17 years) with disabilities in Indonesia, by province <sup>8</sup>



Source: RISKESDAS 2018

The Disability Law was enacted by the Government of Indonesia in 2016. With the further issuance of the government Regulation on Planning, Implementation, and Evaluation of Respect, Protection, and Fulfilment of Rights of Persons with Disabilities in 2019, the general rights of people with disabilities in Indonesia are protected with a legal framework in line with international norms.

<sup>8</sup> Source: RISKESDAS, 2018.

While this law is not specific to children with disabilities, the Ministry of Education, Culture, Research, and Technology (MoECRT) and Ministry of Social Affairs (MoSA) have specific regulations and policies tailored to this vulnerable group (Table 1).

Table 1. List of specific policies and regulations for children with disabilities in Indonesia

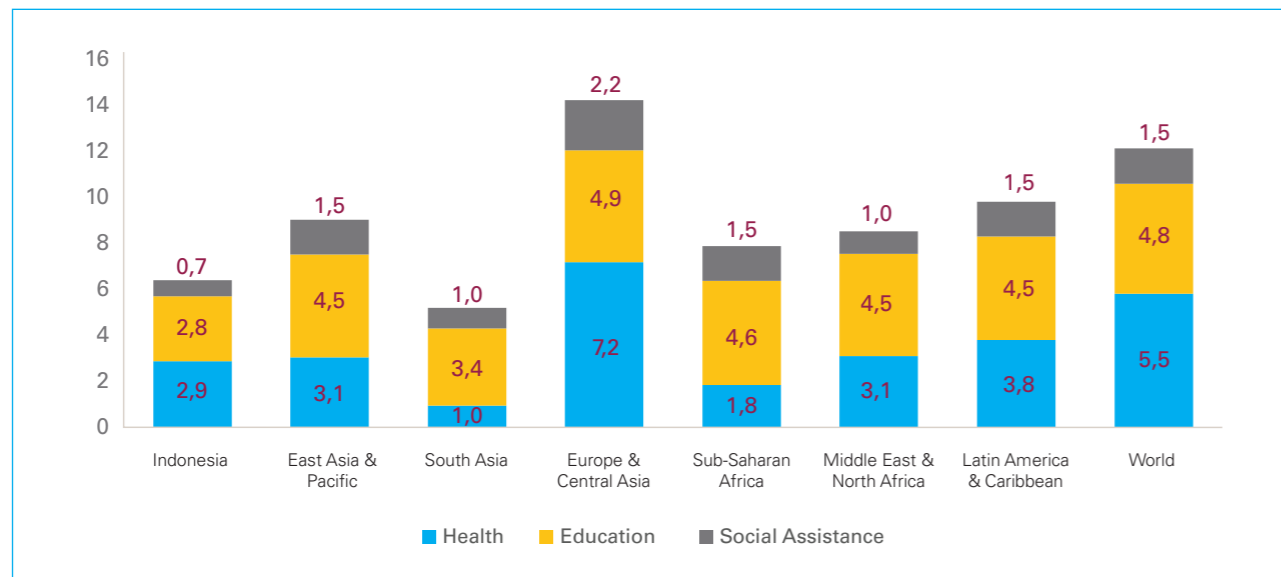
SPECIFIC POLICIES AND REGULATIONS FOR CHILDREN WITH DISABILITIES IN INDONESIA	
<b>Ministry of Education, Culture, Research, and Technology</b>	<ul style="list-style-type: none"> <li>Ministry of Education Regulation No.70/2009 – Inclusive Education for Students with Potential</li> <li>Government Regulation No.13/2020 – Adequate Accommodation for Students with Disabilities</li> <li>Minister of Education and Culture Decree No.394/P/2019 – Criteria and Accreditation Tools for Special Elementary Schools, Extraordinary Junior High Schools, and Extraordinary High Schools</li> <li>Learning Guide for Students with Disabilities During the COVID-19 Pandemic</li> <li>Social Security for Persons with Disabilities – Smart Indonesia Card</li> <li>2019–2024 Master Plan on National Development of Inclusive Education</li> </ul>
<b>Ministry of Social Affairs</b>	<ul style="list-style-type: none"> <li>Minister of Social Affairs Regulation No.13/2015 – Social Services for Children with Disabilities</li> <li>Child Social Welfare Programme</li> </ul>
<b>Ministry of Women's Empowerment and Child Protection</b>	<ul style="list-style-type: none"> <li>Law on Child Protection (Law No. 35/2014) – not disability specific, but gives rights of protection, health, welfare, citizenship, and other rights for all children</li> </ul>
<b>Ministry of Health</b>	<ul style="list-style-type: none"> <li>Roadmap for inclusive health services (not exclusive to children with disabilities)</li> <li>Guidelines for health services for children with disabilities</li> <li>Regulations on disability-friendly health service providers, including accreditation</li> <li>National Health Insurance that covers assistive devices for children with disabilities (at least partially)</li> </ul>

The Ministry of Women's Empowerment and Child Protection (MoWECP) leads on the Law on Children Protection (Law No. 35/2014), which is not disability-specific, but the rights of protection, health, welfare and citizenship, amongst others, can be assumed for all children.

Despite having adequate policies and legislation in place to ensure access and equity to essential services, such as education and health, there are still many challenges related to policy implementation and oversight for children with disabilities. The gap between policy language and policy implementation/effect needs to be studied further.

In terms of government social expenditure (health, education, and social assistance) as a percentage of GDP in 2020, Indonesia was below the regional and world averages (Figure 4).

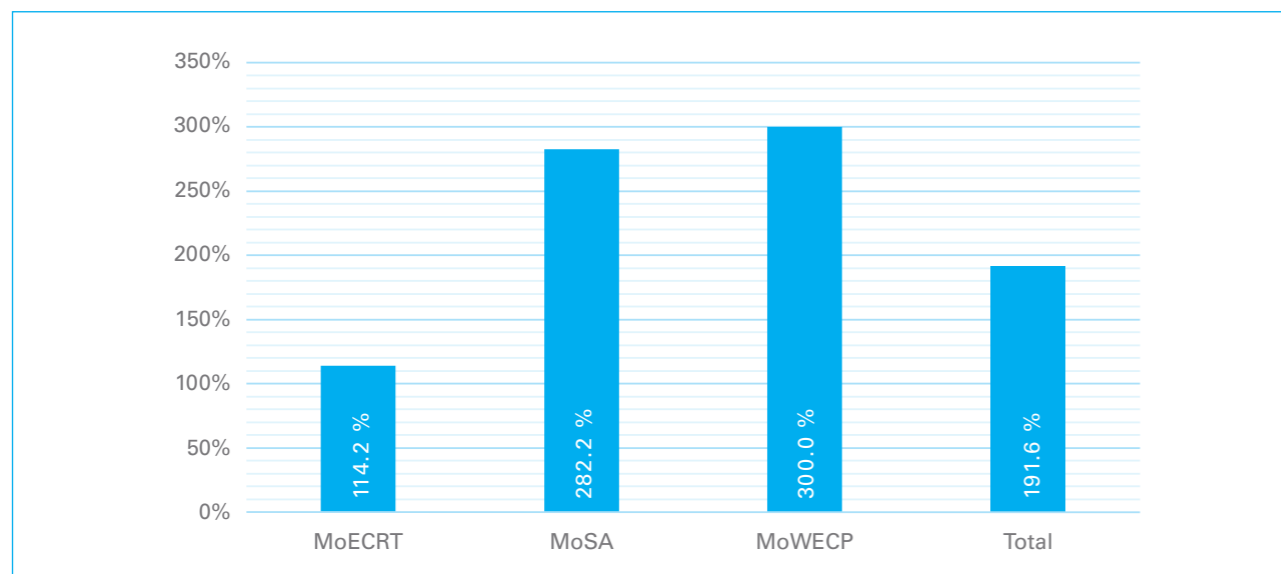
Figure 4. Comparison of government essential services expenditure as a percentage of GDP by region and Indonesia (2020)<sup>9</sup>



Source: The World Bank Open Data (2020)

Despite Indonesia’s relatively low expenditure on essential services that impact the lives of children with disabilities, in comparison to its regional neighbours and globally, the Government of Indonesia’s spend on directly supporting children with disabilities has increased since 2015. As seen in Figure 5, relevant ministries such as the MoECRT, MoSA and MoWECP have increased expenditure significantly. The Ministry of Health (MoH) does not appear to have increased its expenditure. This can be explained by the fact it does not disaggregate expenditure for children with disabilities spending.

Figure 5. Growth of spending on children with disabilities by the Government of Indonesia 2015–2019<sup>10</sup>



Source: UNICEF (2022)

<sup>9</sup> Sources: World Bank Open Data (<https://data.worldbank.org>); Bloch, C. 2020. Social spending in South Asia: an overview of government expenditure on health, education and social assistance. Research Report No. 44. Brasília and Katmandu: International Policy Centre for Inclusive Growth and UNICEF Regional Office for South Asia.

<sup>10</sup> UNICEF (2022), calculated from the Audited Financial Report of the Ministries (Directorate General of Budget – Ministry of Finance database, 2015 and 2019).

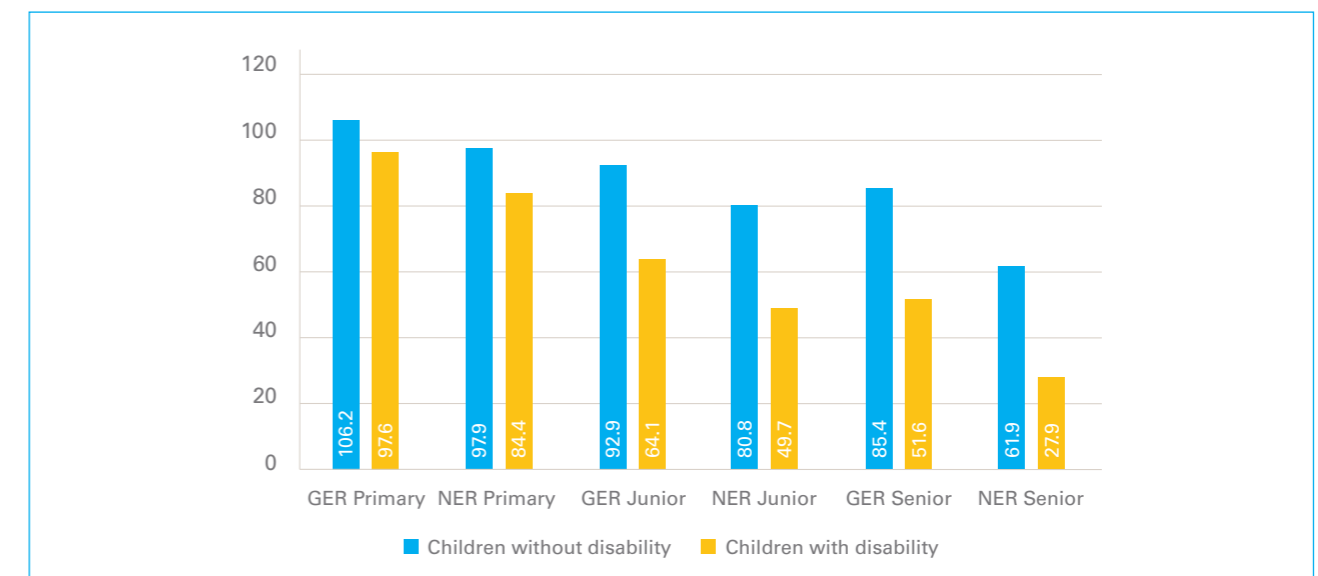
As with most countries, the COVID-19 pandemic was particularly challenging for children with disabilities in Indonesia. Not only were children with disabilities at higher risk of increased health complications due to contracting the virus, but access to education and health services was curtailed for all children and this disproportionately affected those with disabilities. Most schools in Indonesia were completely closed for 18 months, moreover, distance-based online education was also a challenge. Following the initial, staggered reopening of schools from September 2021, children with disabilities disproportionately left school or, in fact, never returned. During the period when schools were closed and distance learning was the norm, children with disabilities had extreme difficulty navigating online learning, which was often inaccessible with limited inclusive support, tailored to social and well-being needs for children with disabilities.<sup>11</sup>

## EDUCATION

The MoECRT has several policies and guidelines in place to support inclusive education, as noted previously. Furthermore, there are some upcoming initiatives, such as the drafting of a technical guideline for teachers in inclusive schools and a 2019–2024 Master Plan on National Development of Inclusive Education, that further push for inclusive mainstream education, not special schools, for all children with disabilities in Indonesia.

Children with disabilities in Indonesia participate in mainstream educational settings at lower rates than non-disabled children, and their participation decreases at each level of education. Figure 6 shows the differences in gross enrolment rates between children with and without disabilities by education level.

Figure 6. Gross enrolment rates (GER) and net enrolment rates (NER) in Indonesia in 2021 by school level comparing children with and without disabilities



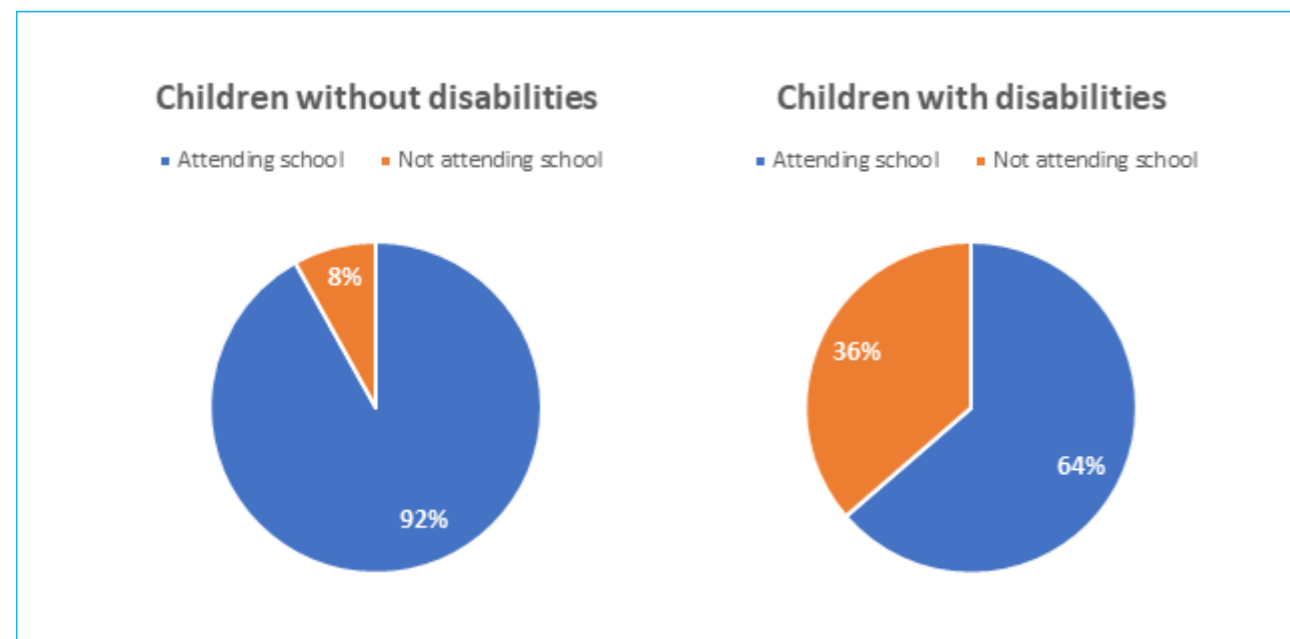
Source: UNICEF estimation (2022), based on SUSENAS 2021

It is important to note that as levels of education advance, there is an increase in the level of enrolment disparity between children with and without disabilities. Children with disabilities who have more severe functional limitations are much more likely to be out of school altogether: 19 per

<sup>11</sup> UNICEF (2021). The Impact of the Covid-19 Pandemic on Children’s Learning in Indonesia. <https://www.unicef.org/indonesia/media/15231/file/Issue%20Brief%20-%20The%20Impact%20of%20the%20COVID-19%20Pandemic%20on%20Children%27s%20Learning%20in%20Indonesia.pdf>

cent were not attending any kind of primary school and 68 per cent were not attending secondary school. In Indonesia, special schools are still considered the preferred placement for children with more severe functional limitations, although new policies, such as the Master Plan on National Development of Inclusive Education, aim to promote inclusive mainstream education. In 2020–2021, there were 595 public special schools and 1,655 private special schools. In terms of distribution, most special schools were located on East Java (438) and West Sumatra (152), with the least number in North Kalimantan (5) and West Papua (5).<sup>12</sup> Attempting to find data related to the total number of children with disabilities in mainstream and special schools proved to be challenging. On an aggregate level, according to data from Statistics Indonesia (BPS), 64 per cent of children with disabilities are attending school, compared to 92 per cent of children without disabilities.

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



Source: UNICEF estimation (2022), based on SUSENAS 2021

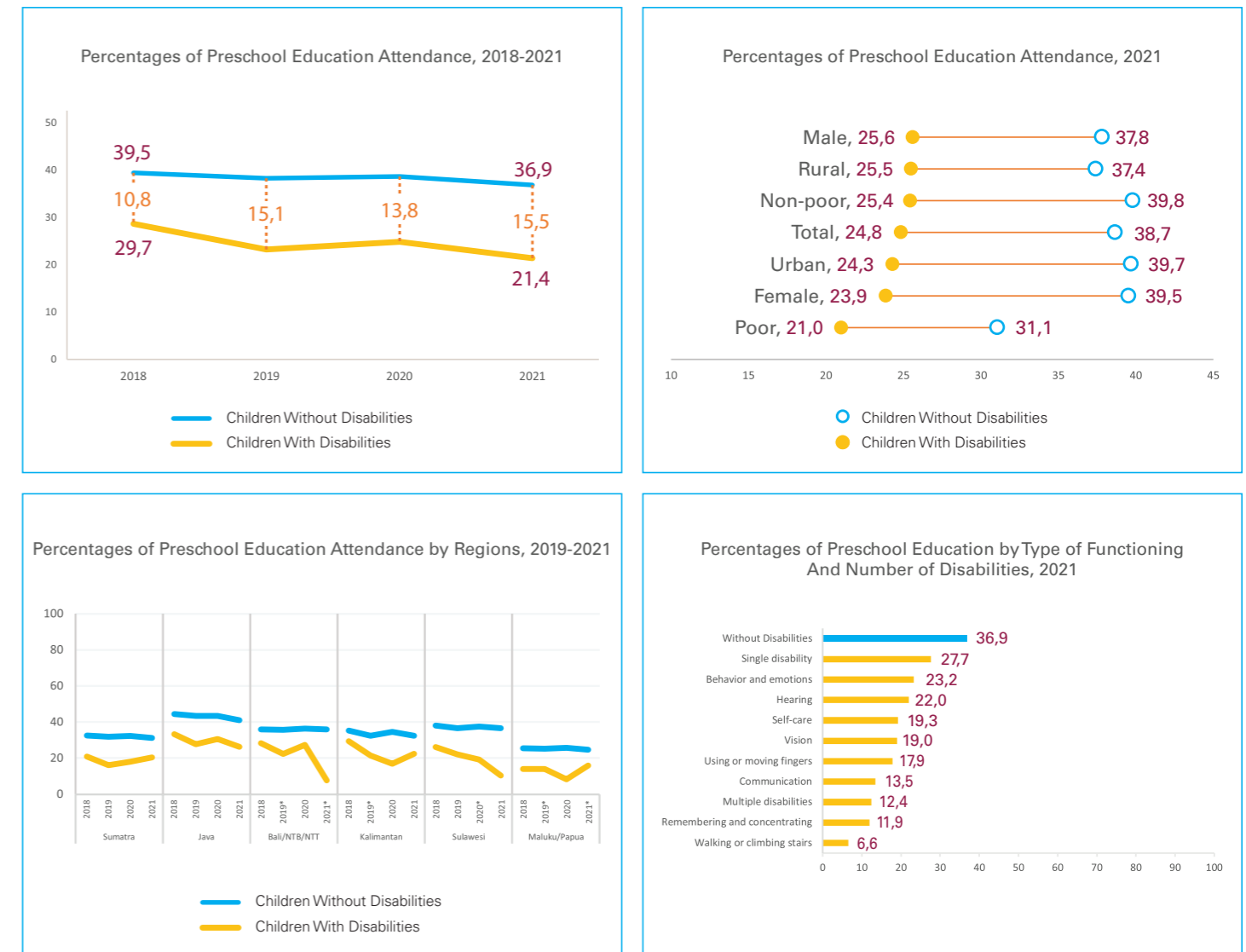
The transition in the early years and at preschool level is vital to ensure that the entire education system is seen as having utility and functionality across the life cycle. For pre-primary children with disabilities in Indonesia, the gap between children with disabilities and without in preschool has increased over time, with disparities in multiple indicators related to education (Figure 8).

As noted previously, children with disabilities who should be in senior levels of education are more likely to be out of school and not participating in any other form of education, employment, or training (NEET). This is a missed opportunity for Indonesia to not only cultivate economically contributing citizens of all abilities that would increase the country's productivity,<sup>14</sup> but also to illustrate to parents and society in general, that the education system has importance, utility, and function for children with disabilities that can lead to positive adult life outcomes. Transition from education to employment needs greater attention, as participation in the labour force is still significantly low for persons with disabilities.<sup>15</sup>

<sup>12</sup> SUSENAS, 2021.

<sup>13</sup> Happy Hearts Indonesia. (2019). Education Access for Children with Disabilities: The Forgotten Rights. <https://happyheartsindonesia.org/education-for-children-with-disabilities/>

**Figure 8. Preschool indicators in Indonesia comparing children with disabilities and without disabilities**



Source: UNICEF estimation based on SUSENAS 2018–2021

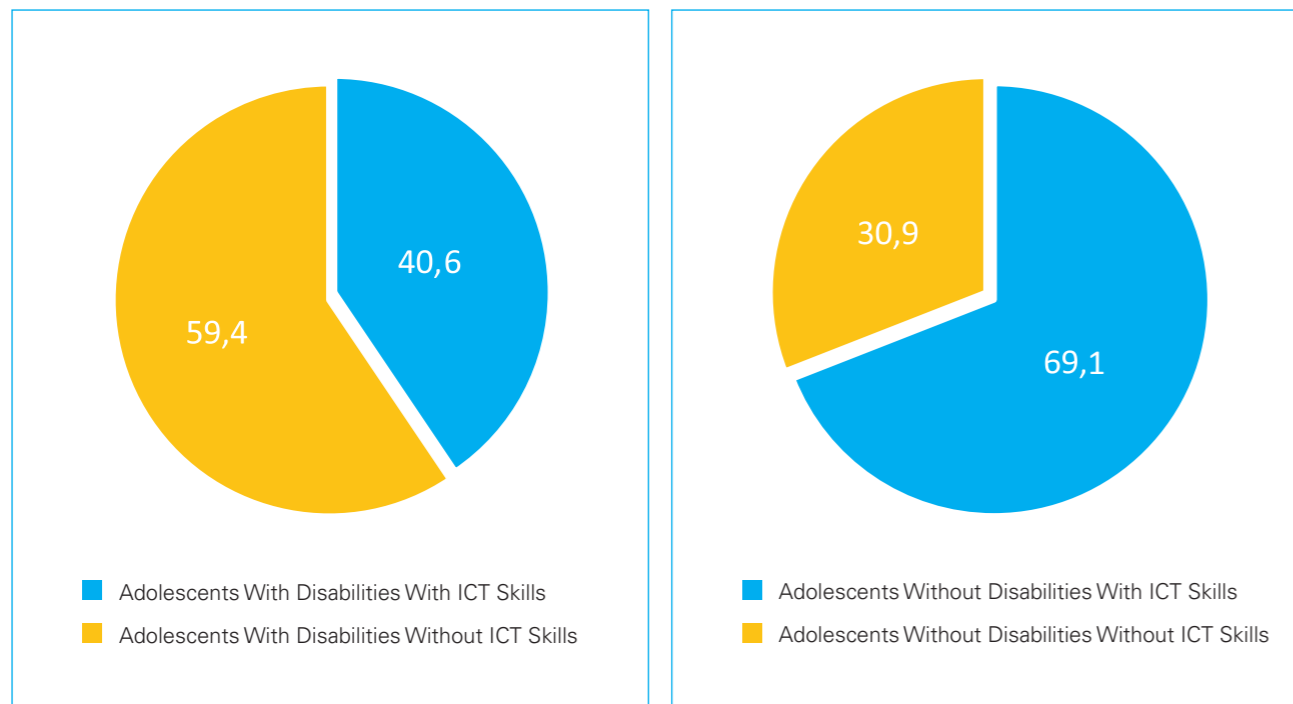
An important SDG indicator under SDG 4 on quality education related to the COVID-19 pandemic and its negative outcomes for children with disabilities is namely 4.4.1(a), Percentage of Adolescents (aged 5–17 years) with Information and Communication Technology (ICT) skills. As can be seen in Figure 9, children with disabilities have far fewer ICT skills (40.6 per cent) compared to non-disabled peers (69.1 per cent), which helps explain why children with disabilities were negatively impacted when online learning became the norm during the height of the pandemic.

<sup>14</sup> Banks, L.M. & Polack, S. (2015). The Economic Costs of Exclusion and Gains of Inclusion of People with Disabilities. CBM. [https://www.cbm.org/fileadmin/user\\_upload/Publications/Costs-of-Exclusion-and-Gains-of-Inclusion-Report.pdf](https://www.cbm.org/fileadmin/user_upload/Publications/Costs-of-Exclusion-and-Gains-of-Inclusion-Report.pdf)

<sup>15</sup> Gunawan, T. & Rezki, J.F. (2022). Mapping Workers with Disabilities in Indonesia: Policy Suggestions and Recommendations. International Labour Organization. [https://www.ilo.org/wcmsp5/groups/public/-asia/-ro-bangkok/-ilo-jakarta/documents/publication/wcms\\_836028.pdf](https://www.ilo.org/wcmsp5/groups/public/-asia/-ro-bangkok/-ilo-jakarta/documents/publication/wcms_836028.pdf)



Figure 9. Percentage of adolescents in Indonesia (5–17 Years) with ICT skills by children with and without disabilities



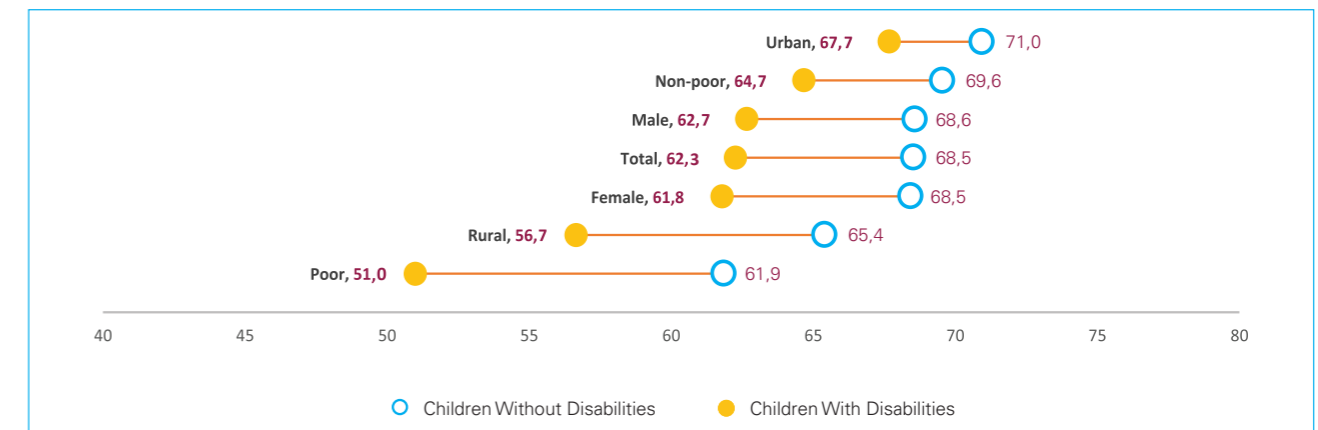
Source: UNICEF estimation (2022), based on SUSENAS 2021

This finding is not surprising given the larger, more general inequalities in the Indonesian education system in terms of access and outcomes for children with disabilities.

## HEALTH

The MoH has enacted various initiatives related to children with disabilities, including regulations related to disability-friendly and inclusive health service providers (not exclusive to children with disabilities). As part of the national pandemic response, guidelines to protect children with disabilities from virus transmission were released and an innovative vaccination campaign for children with disabilities was rolled out. Overall immunization numbers, however, show a statistically significant gap between children with and without disabilities across various disaggregation (Figure 10).

Figure 10. Immunization coverage indicators for children with and without disabilities in Indonesia (per cent)



Source: UNICEF estimation (2022), based on RISKESDAS 2018

Based on SUSENAS data, gaps in routine immunization coverage of children with disabilities are narrowing, but there are still significant gaps across various disaggregated groups, especially for those living in rural areas and for the poor. For COVID-19 vaccinations specifically, few children with disabilities (aged 6–17) were vaccinated compared to non-disabled peers. Only 9,000 children with disabilities are fully vaccinated with three doses of the COVID-19 vaccine.<sup>16</sup> During the height of the pandemic, persons with disabilities of all ages were at higher risk to contract COVID-19.<sup>17</sup>

When comparing access to healthcare and knowledge of the nearest healthcare facility, there was no statistically significant difference when comparing households with and without a child with a disability. However, when comparing unmet needs for healthcare services, children with disabilities were more likely not to utilize healthcare facilities when needed. It was also extrapolated from UNICEF estimation based on SUSENAS 2021 data that nearly 7.8 per cent of children with disabilities have unmet healthcare needs, compared to 4.3 per cent of children without disabilities. Further research is needed to understand the reasons behind this disparity.

This research is particularly important to determine which health services should be provided in school for children with disabilities who have chronic and/or complex healthcare needs, and also to screen and identify at any early age to ensure children with disabilities receive additional educational resources and services appropriate to identified needs.

## NUTRITION<sup>18</sup>

Every child has the right to survive and thrive, which makes nutrition for children a key issue. While not always statistically significant, children with disabilities early in life receive less breastfeeding and food diversity consumption overall (Figure 11). More significantly, children with disabilities in Indonesia are more malnourished than children without disabilities, with stunting, wasting and underweight rates all characterized by statistically significant differences (Figure 12). These conditions may lead to a chronic disability, or also be an indication of a congenital disability. Children with disabilities whose mothers and fathers had lower levels of education had a higher prevalence

<sup>16</sup> MoH, *Vaksin Dashboard: Vaksinasi COVID-19 Provinsi*, 2022. <https://vaksin.kemkes.go.id/#/provinces>

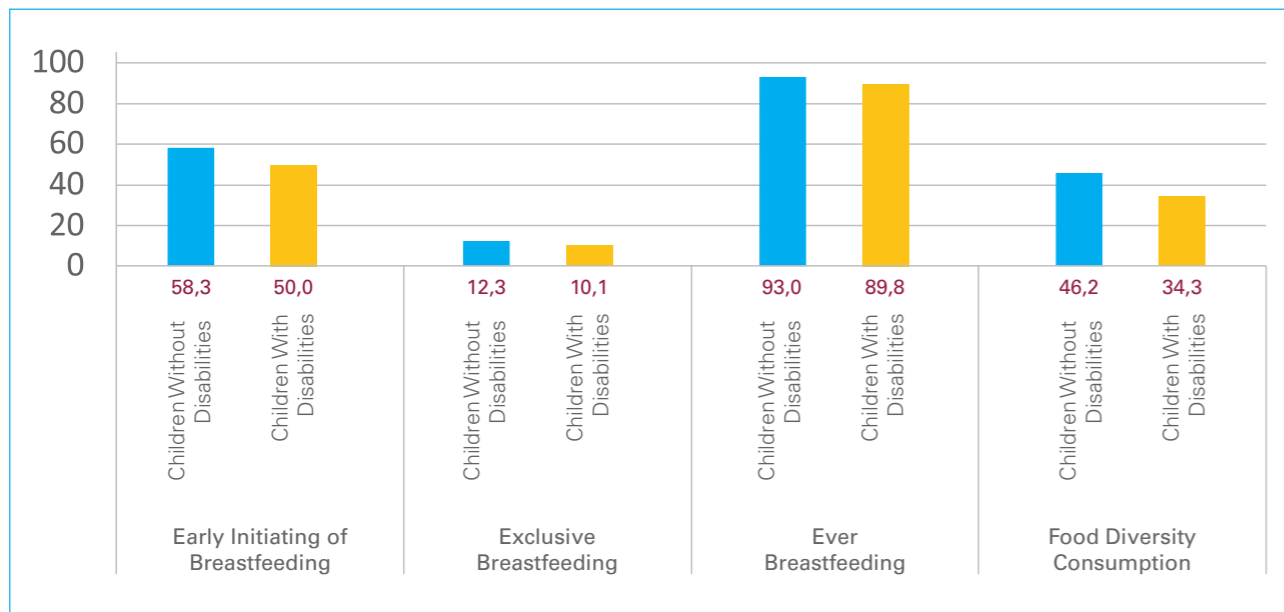
<sup>17</sup> Luthfi Azizatunnisa (2022). *Impact of COVID-19 pandemic to people with disabilities in Indonesia*. Sixth International Conference on Disability and Development. <https://www.lshmt.ac.uk/sites/default/files/2022-06/Day%201%20Plenary%20-%20Introduction%20to%20the%20conference%20slides.pdf>

<sup>18</sup> The disability data in this section is based on RISKESDAS (2018) and uses the birth defect variable, as the child functioning module in the survey only focused on children aged 5-17.



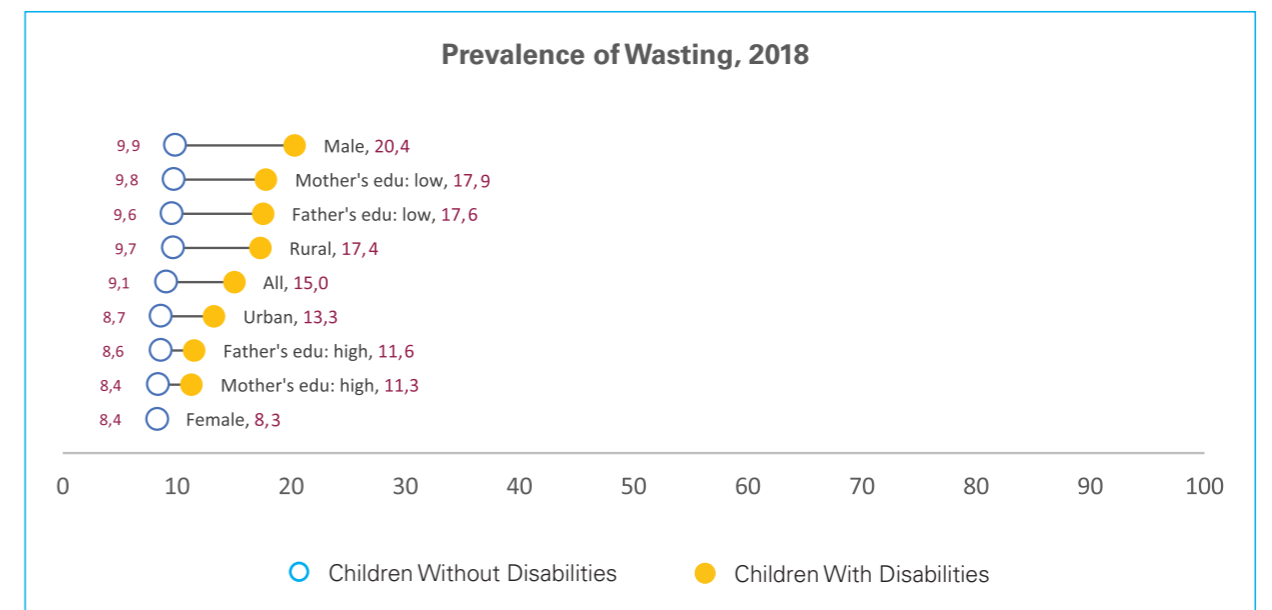
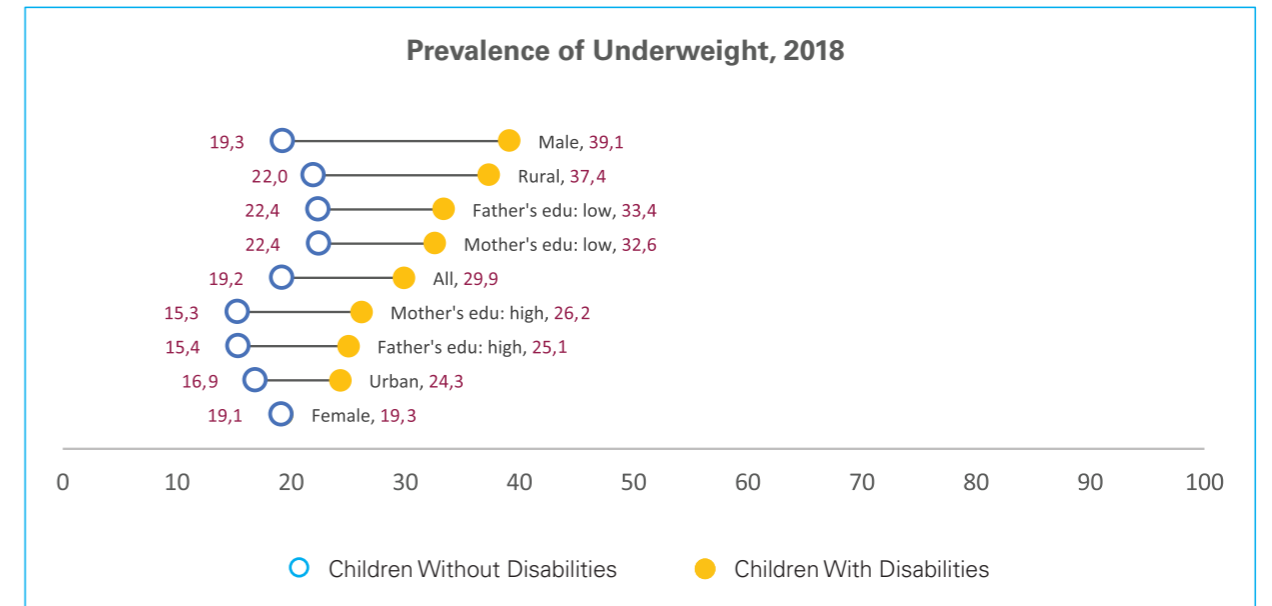
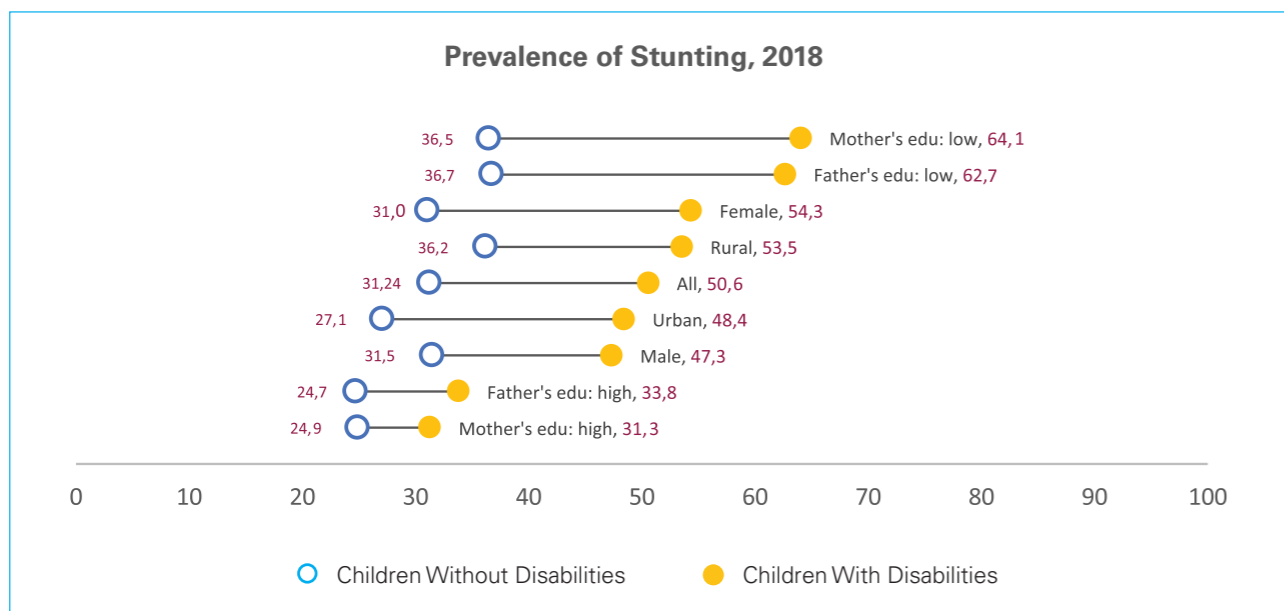
of stunting and wasting. Male children with disabilities had the highest percentage of being underweight compared to peers (Figure 12).

Figure 11. Infant and young child feeding in Indonesia comparing children with and without disabilities (per cent)



Source: UNICEF estimation (2022), based on RISKESDAS 2018

Figure 12. Prevalence of stunting, wasting and underweight in Indonesia comparing children with and without disabilities



Source: UNICEF estimation (2022), based on RISKESDAS 2018

### WATER, SANITATION, AND HYGIENE (WASH)

Every child has the right to a safe and clean environment. Many organizations have highlighted the disparities in WASH between children with disabilities and those without of all ages. A study by UNICEF and the World Health Organization, for example, found that access to adequate WASH facilities was significantly less for persons with disabilities.<sup>19</sup> Collaboration between multiple local and international organizations, including UNICEF has initiated projects to attempt to close these gaps.<sup>20</sup> The establishment of the WASH in Schools (WinS) Working Group in the Ministry of Education has increased the visibility of this issue at a policy level. However, there are multiple challenges when

<sup>19</sup> UNICEF & WHO. (2022). Learning Note: Improving water, sanitation, and hygiene in primary care health facilities during the COVID-19 pandemic in Indonesia. <https://www.unicef.org/indonesia/media/13811/file/Learning%20Note%20WASH%20FIT.pdf>

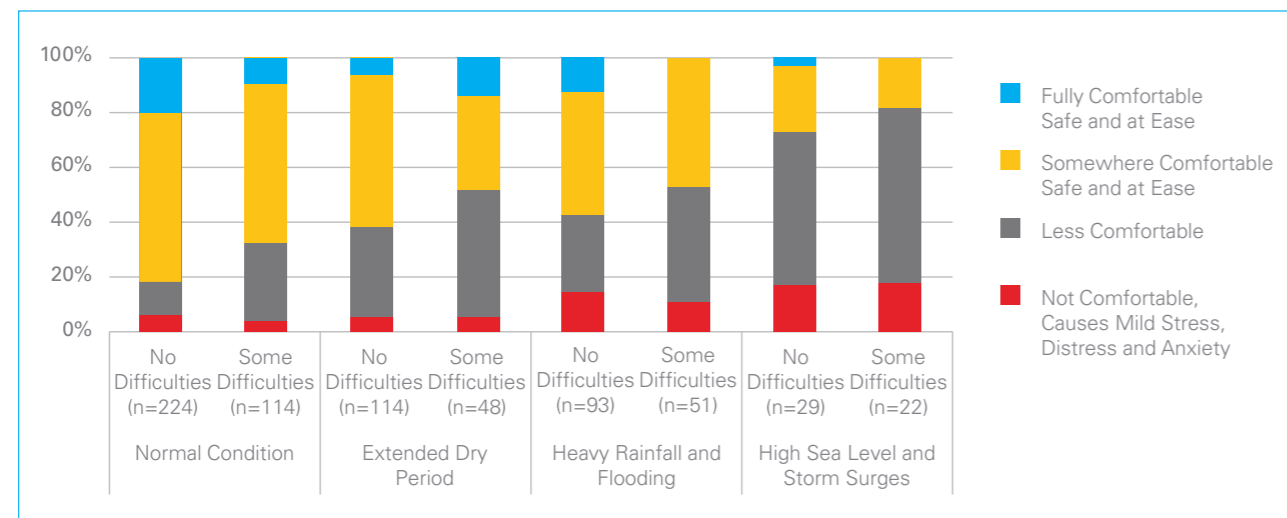
<sup>20</sup> BAPPENAS & UNICEF (2022). Collaboration for Recovery and Resilience Through Better WASH Access for All: A Compendium of WASH Best Practices in Indonesia. <https://www.unicef.org/indonesia/media/14501/file/Compendium%20of%20Wash%20Best%20Practices%20in%20Indonesia.pdf>

it comes to securing clean water for schools. The School Health Programme, Usaha Kesehatan Sekolah (UKS), has provided an opportunity to integrate more learning on WASH and Menstrual Hygiene Management (MHM) into schools.

Despite some of the steps forward, limited progress has been made on ensuring WASH facilities are suitable for girls with disabilities to manage menstruation. According to House, S and Dirgantara (2022), even in Inclusive and Special Learning Schools (SLB), WASH is still not always fully accessible, with 73 per cent of SLBs in rural areas and 56 per cent in urban areas, still offering limited sanitation services for students with disabilities. The coverage of basic SLB services in rural areas is still lagging behind those in urban areas with the highest coverage at SLB level in urban areas at 86 per cent, and a no-service rate of 10 per cent in rural areas. This is the equivalent of 28 out of 275 SLBs in rural areas having no sanitation facilities at all.<sup>21</sup>

Furthermore, schools have the lowest percentage of accessible toilets in a national survey of all WASH facilities when compared to other institutions.<sup>22</sup> Girls and boys attend Madrasahs, including day and boarding students, yet these institutions receive less operational and health funds than other schools, leading to continuous gaps in the provision of WASH facilities.<sup>23</sup> Beyond access to WASH facilities, the ease of use, comfort and safety of facilities is often affected by climate conditions. Households where a family member has a disability are less comfortable with their sanitation provisions than other households, especially during droughts and floods<sup>24</sup> (Figure 13).

Figure 13. Change in comfort with hazards and family members with some or no physical difficulties<sup>25</sup>



Source: UTS-ISF, UI and UNICEF (2021)

<sup>21</sup> House, S. & Dirgantara, E. (in print) Gender and disability inclusion assessment of institutional WASH facilities and services in Indonesia, Summary Report, Ministry of Health, Republic of Indonesia and UNICEF.

<sup>22</sup> The other institutions are: primary healthcare facilities, public places, government offices and other workplaces, humanitarian institutions, and communities and people who have particular vulnerabilities. House, S. & Dirgantara, E. (in print) Gender and disability inclusion assessment of institutional WASH facilities and services in Indonesia, Summary Report, Ministry of Health, Republic of Indonesia and UNICEF.

<sup>23</sup> House, S. & Dirgantara, E. (in print) Gender and disability inclusion assessment of institutional WASH facilities and services in Indonesia, Summary Report, Ministry of Health, Republic of Indonesia and UNICEF.

<sup>24</sup> UTS-ISF, UI and UNICEF (2021) Climate resilient urban sanitation in Indonesia: Hazards, impacts and responses in four cities.

<sup>25</sup> UTS-ISF, UI and UNICEF (2021) Climate resilient urban sanitation in Indonesia: Hazards, impacts and responses in four cities.

## CHILD PROTECTION

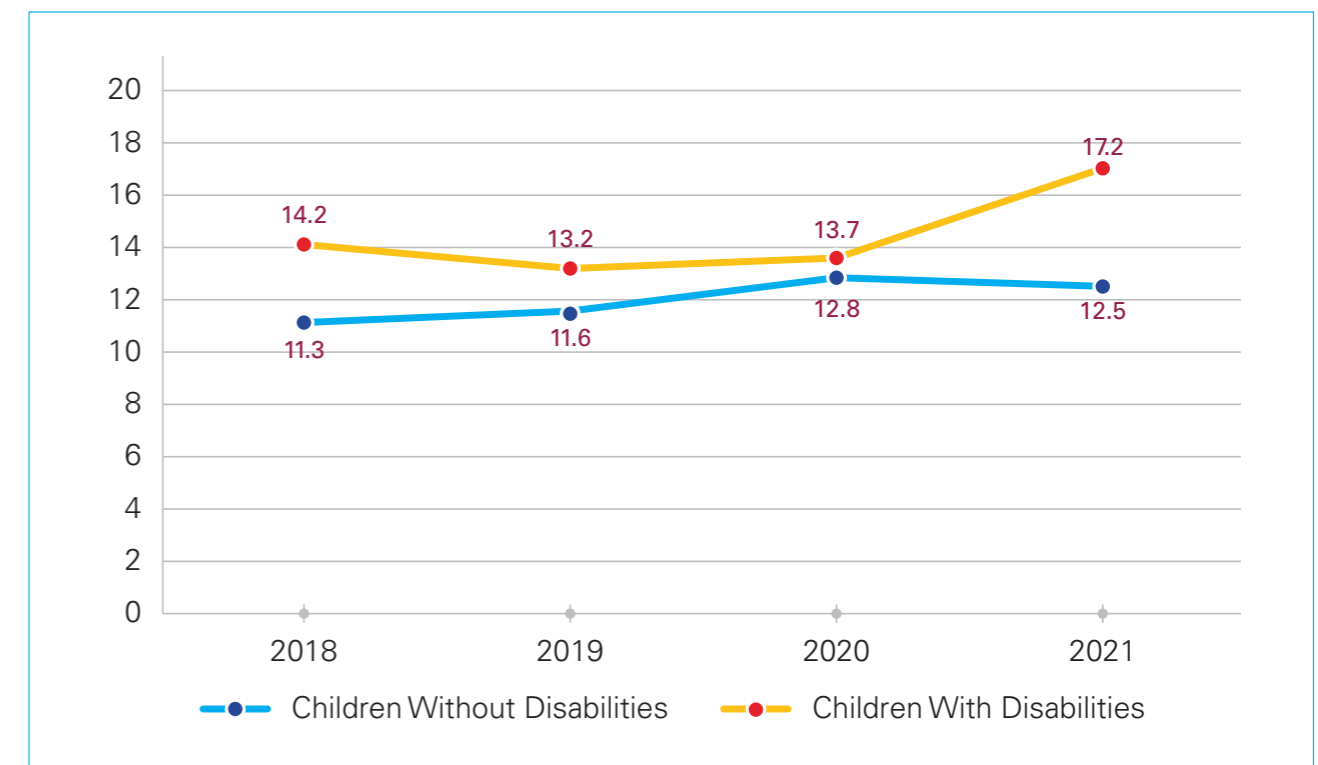
All children in Indonesia are given rights under the Law on Child Protection (Law No. 35/2014).<sup>26</sup> However, children with disabilities are less likely to be registered at birth by the Civil Registry and Demography Agency (Disdukcapil).<sup>27</sup> Among children under-5, only 78.7 per cent of those with disabilities are registered at birth, compared to 84.5 per cent of others.

Data collected was inconclusive in shedding light on the issues of violence, abuse, exploitation, and neglect with respect to children with disabilities. Despite the dearth of accurate data<sup>28</sup>, national media report on numerous cases of abuse, maltreatment, and violence towards children with disabilities. This situation further highlights that additional research is needed to fully understand and provide an accurate representation of the lived experience of children with disabilities in Indonesia.

## SOCIAL PROTECTION

Children with disabilities are more likely to be living in poverty, compared to non-disabled peers (Figure 14).

Figure 14. Percentage of children with disabilities and without disabilities living in poverty in Indonesia



Source: UNICEF estimation (2022), based on SUSENAS 2018-2021

<sup>26</sup> The National Commission on Disability (KND) has a programme called "Children's Voice" and "Parents' Voice" to ensure that children with disabilities realize their civil rights and freedom to achieve their aspirations.

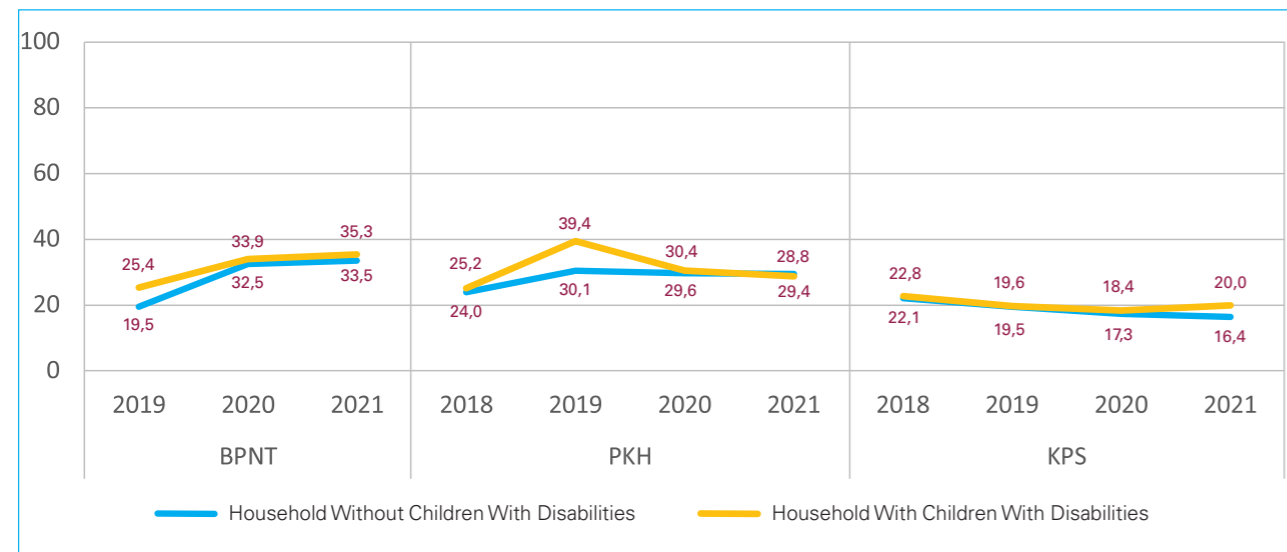
<sup>27</sup> If requested, the Civil Registry and Demography Agency directly engages with persons with disabilities to help them obtain an ID card (KTP) if they are above 17 years old and Child Identity Card (KIA) if they are below 17 years old.

<sup>28</sup> Specifically, data for child marriage and child labour is not accurate.

This situation became acute during the pandemic, with more children with disabilities living below the poverty line during 2020–2021. While this indicates that the health crisis-affected families with children with disabilities more severely, there is insufficient data to make this correlation. According to SUSENAS data, the number of households receiving social assistance – such a non-cash food assistance (BPNT), conditional cash transfer scheme (PKH), and social protection cards (KPS) – was higher if the household had a child with a disability<sup>29</sup> (Figure 15). However, the direction of causation cannot be determined with available data. Indeed, the disability-poverty nexus is significant around the world, and often the cause-and-effect cannot be neatly determined.<sup>30</sup>

According to SUSENAS, in 2021 only 20 per cent of households with children with disabilities received disability social assistance, which in real terms amounted to 82,185 households. The percentage of households receiving disability social assistance is increasing, by 14 per cent compared to 2018. However, the absolute number of households receiving it has fallen from 109,246 in 2018.

**Figure 15. Low-income households receiving social assistance in Indonesia comparing children with and without disabilities (per cent)**



Source: UNICEF estimation (2022), based on SUSENAS 2018-2021

## CONCLUSIONS AND RECOMMENDATIONS: PATHS FORWARD TOWARDS MORE INCLUSIVE POLICIES AND PROGRAMMES FOR CHILDREN WITH DISABILITIES IN INDONESIA

This Discussion Paper has highlighted key data, challenges, and opportunities to support children with disabilities in Indonesia across six primary pillars: education, health, nutrition, child protection, social protection and water, sanitation and hygiene (WASH). The analysis found that, although policies and regulations are in place to protect the rights of children with disabilities to benefit from social services, current policies are not well implemented and children with disabilities experience inequity compared to non-disabled children in terms of both access to and use of social services in Indonesia. It is important to encourage national and sub-national governments to recognize the

<sup>29</sup> According to SMERU, the percentages of households with children with disabilities that receive social assistance are relatively small (lower than 40 per cent), meaning there remains many poor children with disabilities are yet to receive social assistance. Data collection is also not accurate as some questionnaires use the term ‘handicapped’, which excludes various functional difficulties.

<sup>30</sup> Dalal, A. K. (2010). Disability–Poverty Nexus: Psycho-Social Impediments to Participatory Development. *Psychology and Developing Societies*, 22(2), 409–437. <https://doi.org/10.1177/097133361002200208>

rights of children with disabilities to the highest attainable standard of essential services, including protection of children with disabilities and their families from discrimination in provision of such services.

Based on the data available, the recommendations outlined below provide crucial opportunities and a path forward towards a more inclusive Indonesia for children with disabilities. The following recommendations are aligned with the draft of UNICEF’s Disability Inclusion Policy and Strategy 2022–2030<sup>31</sup> and focus on several key areas in the context of Indonesia. It is also critical to build on these recommendations through consultations with stakeholders to ensure they are comprehensive and tailored to local needs.

## HORIZONTAL AND VERTICAL POLICY AND PROGRAMME COORDINATION

UNICEF’s vision – actively promoted to governmental stakeholders – is 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>32</sup> The most significant opportunity for the inclusion of children with disabilities in essential services sits with the enhancement of policy coordination at all levels of governmental institutions to promote a cross-sectional system approach. Furthermore, it is important to strengthen capacity among government ministries, such as the Ministry of Health, Ministry of Education, Ministry of Women’s Empowerment and Child Protection, and Ministry of National Planning (Bappenas) and local governments to coordinate policies and programme interventions so that children with disabilities are well protected and supported to thrive on an equal basis with their peers without disabilities.

Aligned with the principles of the Convention on the Rights of Persons with Disabilities, engagement of organizations of persons with disabilities will be critical, for the design of national budgets and strategies for disability inclusion. The creation of new partnerships, including with disability researchers, private sector representatives, civil society organizations and other actors, will be essential for successful policy development and programme implementation.

## EDUCATION

The research and discussion in this paper highlighted that poor access, disjointed policies, and inadequate intervention services for children with disabilities result in a high proportion of them left in at-risk situations and under-served. Living with a disability is often life-long, but a disabling condition could occur at different stages of the life course. There is a need for essential services for children with disabilities to provide a continuum of care. This is especially important during transition points, from birth to early childhood, primary and secondary education, post-secondary education, training and employment. It is critical to promote cross-sectoral coordination with relevant ministries, including Ministry of Health and the Ministry of Social Affairs, to develop universal school-based developmental monitoring and screening programmes and referral pathways for identification and family- and child-centred support and intervention.

<sup>31</sup> In reference to draft version of 27/07/2022 of UNICEF’s Disability Inclusion Policy and Strategy 2022-2030, pending availability of the final version

<sup>32</sup> In reference to draft version of 27/07/2022 of UNICEF’s Disability Inclusion Policy and Strategy 2022-2030, pending availability of the final version.



To help support inclusive efforts at the local level, essential and comprehensive services for children with disabilities should be available at the local government level with the support of local stakeholders.

In Indonesia, there is also a specific need to focus on disability inclusion at school level. This means increasing levels of inclusion in schools through flexibility, accommodation, accessibility, alternative entry-exit points, universal design for learning (UDL)<sup>33</sup>, child-friendly spaces, multi-tiered systems of support and transition services.<sup>34</sup> Teachers in Indonesia indicated that they seek to be more inclusive, but lack the training and resources to achieve this.<sup>35</sup> These findings should encourage the government to develop teacher education (in-service and pre-service) changes that allow teachers to strengthen capacity in inclusive pedagogy, including working in multidisciplinary teams on individual education plans, identify and remove barriers, assess learning, and adapt teaching and learning in line with UDL. It is recommended that further teacher training and curriculum resources be devoted to UDL. An often-overlooked resource for disability inclusion, but one of the most important, is parents and children with disabilities themselves being provided with opportunities for input and feedback into such reform processes.

While it may be counter-intuitive to recommend employment in a paper on children, policies that support and incentivize inclusive employment and transition from school-to-work for children with disabilities play a significant role in improving the quality of inclusive education at all levels. As such, it is recommended that multiple and flexible pathways to education for learners with

disabilities are realized, especially for children out of school, to enable them to (re)matriculate and transition to further education, training or employment. In this context, a comprehensive, multi-sector community model for supporting children with disabilities in Indonesia is recommended.<sup>36</sup> It is vital that post-school outcomes be part of the conversation about children with disabilities at all ages.

In order to incentivize school participation and skills development, parents and their children with disabilities need to feel that attending school will make a positive difference in their lives. Parents should be given the opportunity for skills development in relation to caring for children with disabilities as well as be empowered to collaborate with schools on their children's behalf. This is particularly timely to strengthen tailored quality services to address pandemic-triggered development and learning losses for children with disabilities.

## HEALTH AND NUTRITION

Children with disabilities often require specialized medical care directly related to specific impairments and underlying health conditions, in addition to general health care services. It is important to ensure they can take equal advantage of the same health services as other children, especially at the initial contact with the health care system through primary health care services. An essential part to the right to health is timely, accessible, and affordable quality health care services and these should be provided to every child across the full range of support services required.

To ensure the health care system is more responsive to children with disabilities, the government needs to improve health sector plans and budgets to incorporate a disability inclusion approach. This means providing practical assistance to make health facilities accessible to children with disabilities, including providing sanitary facilities, assistive technology devices and build the skills and knowledge on disability inclusion among health professionals.

### The government needs to improve health sector plans and budgets to incorporate a disability inclusion approach

Although no appropriate data could be obtained to characterize the situation of children with disabilities in emergency settings in Indonesia (other than in relation to COVID-19 vaccination status and COVID-related health risks), it is important to ensure the continuation of disability-inclusive health and nutrition services across the humanitarian and development nexus by supporting disability-inclusive emergency preparedness, disaster risk reduction, and humanitarian actions. Further research and assessments are required to better understand the challenges faced by children with disabilities in emergency situations in Indonesia.

## CHILD PROTECTION

Lack of quality data and noted documentation gaps highlight the need to strengthen programme monitoring, data disaggregation and production of disability-inclusive child protection evidence. This includes integrating the use of the Child Functioning Module into programme monitoring and evaluation. Robust data collection and monitoring systems are essential elements and key outcomes of strong child protection systems.

<sup>33</sup> UDL is an approach to teaching that aims to meet the needs of every student in a classroom by offering different ways of learning through diverse actions, multiple means of representation and various methods of engagement (technological and pedagogical) with students. See also International Disability Alliance, 'Universal Design for Learning (UDL) and its Role in Ensuring Access to Inclusive Education for All: A Technical Paper by IDA', IDA, 2021, <[www.internationaldisabilityalliance.org/content/universal-design-learning-udl-and-its-role-ensuring-access-inclusive-education-all-technical](http://www.internationaldisabilityalliance.org/content/universal-design-learning-udl-and-its-role-ensuring-access-inclusive-education-all-technical)>, accessed 27 June 2022.

<sup>34</sup> Schuelka, M.J. (2018). Implementing inclusive education. K4D Helpdesk Report. Institute of Development Studies & Department for International Development. [https://assets.publishing.service.gov.uk/media/5c6eb77340f0b647b214c599/374\\_Implementing\\_Inclusive\\_Education.pdf](https://assets.publishing.service.gov.uk/media/5c6eb77340f0b647b214c599/374_Implementing_Inclusive_Education.pdf)

<sup>35</sup> Azizah, N., Andriana, E. & Evans, D. (2022). Conceptualising Inclusion within Indonesian Contexts. In M.J. Schuelka & S. Carrington (Eds.), *Global Directions in Inclusive Education* (pp. 81–98). Routledge.

<sup>36</sup> Indra Yohanes Kiling, Clemence Due, Dominggus Elcid Li & Deborah Turnbull (2022) A community model for supporting children with disabilities in Indonesia, *Disability & Society*, 37:9, 1523-1534, DOI: 10.1080/09687599.2021.1889979.

It is important to strengthen the inclusiveness of child protection systems, including civil registration and justice ones, to prevent and respond to violence, exploitation, abuse, neglect, and other harmful practices. Efforts are already underway to continue strengthening the child welfare and protections services including, social services, such as health, education, and social protection as already elaborated upon when discussing recommendations for comprehensive services, including support for parents, and cross-sectoral coordination.

## WATER, SANITATION AND HYGIENE (WASH)

Systematic evidence generation to assess the barriers that children with disabilities face in accessing water and sanitation services is rather limited both at the level of services and programming. As such, the impact of WASH programmes on persons with disabilities does not appear to be measured, as sectoral monitoring processes are not normally designed to collect disability-related data. Such programme data should focus on identifying relationships between disabilities or disability-specific WASH needs that will result in better designed and disability-inclusive WASH programming. At the high-level Sanitation & Water for All Sector Minister's meeting in Jakarta held in May 2022, the Government of Indonesia made a commitment to strengthen equity-based monitoring, which presents an opportunity to better inform WASH sector investments that benefit all.

Although a relatively new area, the challenges faced by households with people with disabilities in accessing WASH facilities during natural disasters are documented. People with disabilities tend to be under-represented at all levels of WASH and climate change programming and service provision. Therefore, it is important to strengthen intersectional and multisectoral programming on climate change and disability-inclusive climate action accounting for the needs of children with disabilities as well as allowing them to engage in decisions that affect their lives.

### Local governments in urban areas should be supported to undertake inclusive planning and budgeting through policy dialogues and technical assistance

Citywide Inclusive Sanitation is an approach to boost safe, equitable and sustainable access to inclusive and safely managed sanitation services in urban areas. Despite the importance of this approach upholding the human right of all to sanitation in urban areas, the multiple barriers to access this right, experiences by children with disabilities, are insufficiently addressed in this context. To further strengthen the equity and inclusion principles, local governments in urban areas should be supported to undertake inclusive planning and budgeting through policy dialogues and technical assistance.

## SOCIAL PROTECTION

To truly integrate children with disabilities and their families into the fabric of Indonesian society, social protection support throughout all life stages is essential. Intersectoral collaboration between social protection and the health, nutrition, education, WASH and child protection sectors is critical to develop disability-related social protection and care services for families of children with disabilities.

The potential of progressive disability-inclusive cash transfers, including child benefits, family benefits, disability allowances and caregiver benefits for children and adults with disabilities and their families should be evaluated. This requires generating evidence on the existing approaches to disability-related cash transfer design, coverage and adequacy to allow for further policy suggestions. It is also important for governments to develop capacity in assessing the financing implications of disability-related social protection, including cash-transfer schemes and the investment case linked to inclusion, towards securing adequate and sustainable resourcing for inclusive social protection, also in an emergency context.

## DATA AND RESEARCH

The paper identified the issue of limited data quality and information gaps on children with disability and the resulting constraints to obtaining a clear picture of the status of these children and underlying issues related to their access to essential services in Indonesia. Without sound evidence, data-driven policy development and programme implementation is lacking. Disability data collection design should be coordinated centrally, so that different ministries, institutions, organizations, and sectors are neither overlapping in their efforts nor working against each other through differing methods, definitions, and disability conceptualizations. It is recommended that the full child functioning module set of Washington Group/ UNICEF questions be adopted for Indonesia.

This initiative to improving data on children with disabilities should also be mindful of the need for stronger linkages across relevant essential services sectors – such as health, education, and other social service systems – in terms of assessments, identification and referrals of children with disabilities to relevant support services.

The full range of children with disabilities module metrics should be implemented across sectoral information systems, such as an educational management information system (EMIS), child protection monitoring systems, and cross-national health and social assistance data. Alongside statistical data, it is also important to gather data related to the lived experience of children with disabilities themselves, and efforts should be made to speak to representative samples to understand their experiences.

A parallel analysis of national and sub-national budget allocations and spending as well as public financial management systems from a disability-inclusive perspective may be appropriate to improve the efficiency, effectiveness, and equity of public resources utilization for inclusion. Likewise, it is important to develop a monitoring and evaluation framework with specific sectoral indicators measuring access to assistive technologies, access to quality services, and the inclusion and well-being of children with disabilities across the education, health, and other relevant essential services sectors.

Finally, it is hoped that multi-stakeholder discussions will take place around this important agenda for children with disabilities and ways of developing an inclusive society in Indonesia. Supporting advocacy, community engagement and social behaviour change is a way of promoting demand among children with disabilities, their caregivers, and communities to amplify their 'voice', to gain support from governments and service providers to make essential services more inclusive through breaking down barriers that impede equitable access.

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