Mitigating the impact of COVID-19 on children with disabilities in Malaysia: Immediate, medium and longer-term policy actions.

Key messages

- The barriers to accessing services (education, health and social) and rights deprivations have been exacerbated by the COVID-19 crisis for children with disabilities;
- Malaysia’s legislative frameworks must adopt a rights-based approach to disability-inclusion in order to provide greater protections for children with disabilities;
- The Government of Malaysia should begin to adapt their budgeting, policies and service provision to reflect the childhood disability prevalence rate of 4.7% reported in the National Health and Morbidity Household Survey (2019);
- Policy measures and quality service provision must become disability-inclusive to prevent further poverty, social exclusion and isolation of children with disabilities;
- A robust social and behaviour communication change strategy must be adopted to end persistent negative attitudes and discrimination against children with disabilities;
- Significant improvements in the collection and analysis of sex, age and disability disaggregated data are needed across all sectors;
- People and children with disabilities must be engaged and included in all decisions that affect their lives. This will mean specific targeted interventions developed to support and empower their participation.

Introduction

A global body of experience and evidence, including from previous pandemics and economic crises, suggests that children with disabilities and their families are being particularly adversely affected during the COVID-19 crisis. This paper draws on UNICEF’s global experience as well as recent research conducted in Malaysia to set out the key risks facing children with disabilities in Malaysia. It identifies a range of immediate, medium and longer-term measures that should be considered during key national policy and planning processes to ensure the nation recovers, rebounds and reimagines the realization of the rights of children with disabilities in Malaysia.
Reconceptualising disability in Malaysia

In Malaysia disability is commonly understood to be the presence of a permanent health condition or impairment. This approach, known as the medical model of disability, positions a person’s impairment as the cause of social exclusion and is often associated with a (typically minimalistic) charitable response. In contrast, the UN Convention on the Rights of People with Disabilities (CRPD) conceptualizes disability as the absence of full, equal and effective participation in society that arises as a result of the interaction between two factors: (i) long-term physical, psychosocial, learning or sensory impairments; and (ii) attitudinal, environmental, communication and institutional barriers. In this ‘social model’, disability can be mitigated through interventions that address impairment, psychosocial status, social or physical environment and through the provision of an enabling legal and service delivery framework. A rights-based approach goes further by conceptualizing failure to address barriers to participation in terms of denial of human rights and thereby obligates duty bearers to undertake ‘reasonable accommodations’ to ensure attainment of full and equal social participation for all.

The situation for children with disabilities in Malaysia

A large proportion of children with disabilities appear not to have been registered on the Disability Registration System (SMOKU) and are therefore at risk of not being adequately considered during policymaking and planning of public services. In 2019 the Institute for Public Health Malaysia adopted the UNICEF/Washington Group Child Functioning Module as part of the National Health and Morbidity Household Survey (NHMS, 2019). The subsequent NHMS report (2019) highlighted a childhood disability prevalence rate of 4.7%.1, a figure which is broadly in line with the global prevalence rate reported in the 2011 World Report on Disability.2 However, the Government of Malaysia’s persons with disabilities registration system reported only 133,583 children registered with disabilities aged 18 and under (1.4% of the child population).4 There is a real risk that not only are individual children with disabilities going unregistered - and therefore being deprived of access to a wide range of services and interventions - but they are also not being adequately considered in national policies, programmes, budgets, service delivery and planning processes. Now that the government of Malaysia has access to more accurate figures for children with disabilities, they should begin to adapt their budgeting, policies and service provision to reflect these more accurate numbers.

Challenges with Malaysia’s legal framework on disability

Malaysia signed the UN Convention on the Rights of Persons with Disabilities (CRPD) in 2008 and enacted the Persons with Disabilities Act in the same year. These two legal instruments provide the key legal protections for people with disabilities including guaranteeing their right to access education (Art. 28) and their right to access recreation, leisure and sport (Art. 32). However, unlike comparable legislation in other countries, Malaysia’s Person with Disabilities Act makes no specific provision for children (despite having ratified the Convention of the Rights of the Child in 1995) and makes no reference to the impact of age or gender on disability. The Act also lacks a monitoring and redress mechanism, should any party violate the rights of persons with disabilities. Malaysia has yet to sign the Optional Protocol to the CRPD, concerning procedures for individual communications and inquiry. Finally, there is little direct protection of the rights of children with disabilities across the wider legislative framework. For example, neither the Federal Constitution or the Malaysia Child Act (2001) protect children with disabilities from discrimination.5 In summary, these deficiencies in the legal framework may identify a rather ineffective commitment to a rights-based approach on disability that reflects the persistence of stigmatising social norms grounded in a charity-based model of disability.

Despite the presence of a broadly rights-based legislative framework on disability in Malaysia, negative social norms and attitudes on disability remain widespread and are often reinforced by charitable action. A Knowledge, Attitudes and Practices study conducted by UNICEF Malaysia in 2016 confirmed that, the practice of the medical model of understanding disability continues to strongly influence policymaking, planning and service delivery. This has helped maintain a situation where children, and young people with disabilities remain: ‘passive recipients of services’ with no sense of them having ‘individual agency’.6 Generally, people do not focus on the four core barriers to inclusion (attitudes, environment, communication and institutions) but rather view impairment as the primary barrier to participation and realization of rights.

As a result of both negative social norms and weak legislation, children with disabilities in Malaysia experienced considerable discrimination, social exclusion and a range of inequities even prior to the COVID-19 crisis. One of the key issues is unequal access to services (education, health and social participation). A recent UNICEF study on children out of school in Sabah, reported that at least half of registered children with disabilities do not attend school in comparison to their peers without disabilities.7 In addition, Ministry of Education enrollment records the show that children with disabilities account for only 1% of all children enrolled at school.8 This highlights that children

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1. NHMS, 2019
2. 2011 World Report on Disability
3. UNICEF/Washington Group Child Functioning Module
4. Government of Malaysia’s persons with disabilities registration system
5. Federal Constitution
6. Knowledge, Attitudes and Practices study conducted by UNICEF Malaysia
7. UNICEF study on children out of school in Sabah
8. Ministry of Education enrollment records
with disabilities are experiencing severe education access barriers which are preventing them from getting into, staying and receiving necessary support/reasonable accommodations whilst in school.

Children with disabilities are also experiencing barriers to accessing quality and appropriate health services and consequently reduced health outcomes. The impact of this reduced access to health services is evident when analyzing the health disparities uncovered during health screenings conducted by Special Olympics Malaysia (2016-2019). It showed that of all children with intellectual disabilities screened 47% had untreated tooth decay; 26% had an active skin or nail condition; 54% had never had an eye exam before, 51% had flexibility problems and 35% had blocked ear canal impacting their hearing.

Another recent study on the impact of the COVID-19 pandemic on low income families also found that 39% of participant households contained at least one member with disabilities (many of whom are children). In these low-income households, not only are people with disabilities themselves adversely affected by the COVID-19 crisis but entire families are struggling to deal with job losses and underemployment at the same time as caring for family members with disabilities.

Finally, children with disabilities are also more likely to be affected by the triple burden of malnutrition: overnutrition, undernutrition and micronutrient deficiency. Special Olympics Malaysia’s health screening data (2016-2019) highlighted that 22% are obese (18% boys: 26.4% girls) and 9% are underweight (8.1 % boys: 9.7 % girls), all of which equally increase their risk of serious health issues during child and into adulthood. Research indicates that children with intellectual disabilities are often the most impacted by lack of access to health services, and as a result are twice as likely to die before the age of 50 years old.

Girls and women with disabilities are particularly at risk of discrimination, stigmatization, violence and social exclusion. Girls and women with and without disabilities face increased levels of gender-based violence (such as sexual exploitation and abuse, intimate partner violence and forced sterilization) and are often doubly stigmatised due to the social perception that they are incapable of raising their family. Mothers and girls with disabilities will face additional barriers associated with increase burden of unpaid care duties placed upon them during the COVID-19 movement restriction order. Often these are difficult to relinquish once the crisis is over and they then face the risk of not returning to their education or employment. The specific menstrual needs of girls and women with disabilities in workplaces, home and schools are also often not considered when educating about puberty and in designing sanitation infrastructure. Sex-disaggregated data on disability in Malaysia is also rare. This creates an additional level of ‘invisibility’ around the issue’s girls and women with disability face.
Impact of COVID-19 on children with disabilities and their families

In May 2020 at the heart of the COVID-19 pandemic the United Nations Secretary General launched the Disability-Inclusive Response to COVID-19. This briefing paper highlighted that the global crisis was deepening pre-existing inequalities for people with disabilities, exposing the extent of exclusion and highlighting that work on disability-inclusion was never more imperative. It also drew attention to five key impacts of COVID-19 on persons with disabilities:

1. Persons with disabilities were at greater risk of contracting COVID-19;
2. Persons with disabilities were at greater risk of developing more severe health conditions and dying from COVID-19;
3. Persons with disabilities living in institutions are more likely to contract the virus and have higher rates of mortality;
4. Persons with disabilities were at greater risk of discrimination in accessing healthcare and life-saving procedures during the COVID-19 outbreak;
5. Persons with disabilities were particularly disadvantaged by the socio-economic consequences of COVID-19 and measures to control the pandemic.


Key Findings:
- 44% could not access the services they needed;
- 24% felt lonely and isolated;
- 24% experienced loss of earnings meaning they can’t afford necessities;
- 17% did not initially understand the risks of COVID-19;
- 14% felt their physical and mental health was regressing and getting worse;
- 34% wanted more child-friendly and disability accessible information.
COVID-19 Early Intervention Teletherapy Services

In response to the COVID-19 Movement Control Order, UNICEF Malaysia partnered with National Early Childhood Intervention Council (NECIC) to support 15 Early Intervention Centres to bring their services online for children with disabilities and their families.

NECIC implemented a programme to build the capacity of Early Intervention Centers and their practitioners’ in the follow:

• Safe use of online/remote technology to provide therapy and education;
• Psychological first aid;
• Gender-based violence risk mitigation and referral pathways;
• Supporting parents to continue with therapy and education at home;
• Development of a practitioner learning and support group to share experiences, lessons learnt and good practice.

“Children with disabilities living in remote areas have traditionally been the hardest to reach… they would now be able to access therapy services that they need. Teletherapy has the potential to equalise access to services for families [that have children with disabilities] living in remote areas.”

Dr Wong Woan Yiing, NECIC President.

After 3-months of services provision this programme has provided over 3,000 therapy sessions nationwide, reaching over 400 parents/caregivers (80% female/20% male) and close to 500 children with disabilities (26% girls / 74% boys).

“The Teletherapy sessions were really helpful especially during this trying time; can’t imagine going without therapy for a few months… especially now. She’s still a baby and there are so many fundamental /critical skills that she has to master before going to the next stage. I know that it’s quite tough to show and explain exercises online, but she is resourceful by supplementing it with videos that I could refer to and sharing her experiences to make it more practical. My “assistants” (her sibling) are also eager to join our Monday sessions.”

Mother attending the Teletherapy session with her daughter.

When analysing the situation in Malaysia during the start of the COVID-19 pandemic and the Movement Control Order (MCO), children with disabilities faced unique challenges that closely reflected the global situation outlined by the UN Briefing Paper. In Malaysia, COVID-19 exacerbated the pre-existing inequities children with disabilities faced on a day-to-day basis. In response to increasing concerns that their needs were not being met, UNICEF, Harapan OKU and National Early Childhood Intervention Council conducted a rapid assessment survey to understand the impact that COVID-19 was having on children with disabilities and their families in Malaysia. The findings highlighted that children with disabilities were unable to access the essential services they needed to thrive; they felt more lonely and isolated than normal; their parents experiencing a loss in earnings meaning they were unable to afford essential early intervention and rehabilitation therapies, many children with disabilities and also parents with disabilities did not understand the risks of COVID-19 as public information was not produced in disability-accessible formats (which can integrate with assistive technology); and children with disabilities’ physical and psychological health was regressing. In addition, quickly implemented education programmes (including online/remote learning) are often not produced in accessible formats, did not include sign language interpreter support and/or the content was not differentiated so that children with learning disabilities could equally engage and understand the content.

Recommendations for immediate actions

1. Disaggregate data related to COVID-19 by sex, age, and disability at a minimum. UNICEF recommends that data related to outbreaks and the implementation of the emergency response be disaggregated by sex, age, and disability (SAD) and analysed accordingly in order to understand the gender and disability related differences in exposure, testing, treatment, recovery and to support the design of differentiated response/preventive measures. Disaggregated data should be complemented with targeted research, including rapid assessments, on the impact of COVID-19 on children with disabilities;

2. Ensure that COVID-19 prevention protocols address barriers to accessing essential services for children with disabilities such as: environmental barriers affecting accessible health and WASH facilities; lack of accessible public transit systems; limited capacity of health workers to communicate and work with children and persons with disabilities; high costs of health care, exacerbated in some contexts by more limited access to insurance; and also include children and adults with disabilities living in institutions, care homes, residential schools and other places which are not classed as family-based care. This must also include, provision of PPE and hygiene materials (i.e. mask, soap and hand sanitizer) along with accessible information, to support the prevention of spreading the infection in these settings;
3 Ensure children with disabilities and their carers get information on how to prevent and respond to the epidemic in ways they can understand. Since children with disabilities and their carers are often marginalized from mainstream systems, UNICEF recommends that information be disseminated through relevant disability social networks and organisations of persons with disabilities, and produced in accessible formats (i.e. sign language interpretation of all announcements, audio description of press release statements, closed captioning of announcements, braille materials, and accessible web content). Accessibility features of COVID-19 helplines must be foreseen and communicated about in promotional material about these services;

4 Support essential therapeutic and rehabilitative services for children with disabilities to be delivered via disability-accessible online platforms as well as PPE, training for health workers in preventing disease transmission for those still conducting in-person services for people with disabilities. UNICEF recommends that services provided by community-based rehabilitation centres and early intervention centres are supported to build their capacity in providing services online. In addition, for services that cannot be conducted online (i.e. certain forms of physical therapy and rehabilitation), the classification of these services as “essential” and necessary support mechanisms put in place to allow providers to continue to operate during the pandemic or other such crisis. This would protect children with disabilities from the secondary COVID-19 risks such as: degradation of mobility; loss of previously acquired functions such as speech or sign language communication; and, anxiety and depression as a result of isolation;

5 Increase financial assistance (social protection) for children with disabilities in poor and low-income households. UNICEF recommends that all families eligible for the BSH (Household Living Allowance – Bantuan Sara Hidup) containing a child with disabilities are provided with monthly income support until such time as a more comprehensive disability-focused social protection instrument can be designed and established.

6 Actively promote rights-based discourse, attitudes and behaviours towards children and young people with disabilities. This should include implementation of a high quality, nationwide social and behavior change strategy aimed at promoting mind-set changes on disability from medical/charitable to rights and social models, developed in consultation with organisations of persons with disabilities;

7 Strengthen the leadership and meaningful participation of children and persons with disabilities in all decision-making processes in addressing the COVID-19 outbreak and beyond. They know what is best for them and efforts need to be made to partner with them - and organisations that represent their concerns - in the design and development of responses. In order to do this meaningfully, adolescents and youth with disabilities need to be invested to increase their capacities to understand and advocate for their rights. Supporting the establishment of a disability social movement and mobilise adolescents and young people with disabilities will increase their active participation in decisions that affect their lives.

Recommendations for medium-to-longer-term actions

1 Develop inclusive education protocols that consider the additional educational barriers that girls and boys with disabilities face. For example, risks of exclusion from early childhood development and education programmes if remote learning programmes are not disability accessible. These all need to include provision of: remote learning infrastructure to support accessible online learning; differentiated education curriculum so children with learning disabilities can engage with online content; training for teachers so they are able to provide online support to students with disabilities at home; accessible online content which integrates with assistive technologies and multiple devices; and sign language interpreters so that students who are Deaf can participate in interactive education online content;

2 Review and revise policy and legal commitments to disability-inclusion. This should take the form of addressing the gaps in provision/ protection of children with disabilities in the Child Act and Persons with Disabilities Act; establishment of a Disability Discrimination Act and mechanism for monitoring/ redress; and implement public consultations on lifting the reservations to the Convention of the Rights of Persons with Disabilities and signing the optional protocol. A revised Disability Act should adopt language (including the UN person first language) that fully reflects the social/rights-based approach to disability;

3 Strengthen systems for disaggregated disability data collection and integrate them into cross-sectoral data management systems. UNICEF recommends incorporating the Washington Group/UNICEF Module on Child Functioning in all future household/institutional care surveys/census. In addition, reviewing and redesigning the registration systems for assessment/registration of persons with disabilities i.e. SMOKU;

4 Ensure that future strategic plans for pandemic preparedness and response are disability-inclusive and grounded in stronger gender analysis. This includes ensuring that risk response and mitigation measures also address disability-equality, accessibility, the burden of unpaid care work and heightened Gender-Based Violence (GBV) risks, as well as intersectionality between gender and disability.
Conclusion

The COVID-19 pandemic is resulting in children with disabilities, and their families, becoming increasingly marginalised, isolated and vulnerable. Existing legislation, policies, protocols, services and systems do not adequately address their needs and rights. In the understandable urgency to respond to the pandemic, these children and their families are often being left behind and are at risk of becoming one of COVID-19’s invisible victims. **Having successfully suppressed COVID-19 transmission through a rapid and robust response, Malaysia should use this next phase to address the long-standing inequities faced by children with disabilities.**

In doing so Malaysia could: **RECOVER** from this pandemic better off than before; **REBOUND** by incorporating disability inclusive and gender transformative principles into future visions; and **REIMAGINE** itself as a more developed, prosperous and equitable nation.23

#NotGoingBack
Endnotes


4. That is 133,583 of 9.4 million.


18. COVID-19 Impact on Children with Disabilities Survey (UNICEF Malaysia RapidPro, 2020) Sample details: n.214. 62% Female, 34% Male, 4% Other Gender. 22% children and persons with disabilities or this figure 11.5% adolescents with disabilities aged 10-18 years old (69% girls, 41% boys). 29 % parents of children with disabilities (66% mothers, 34% fathers). 21% respondents aged 19-28 years old (11% female, 5% male).

19. Harapan OKU is a prominent coalition of persons with disabilities and activist and National Early Childhood Intervention Council is a key Disability civil society organisation.

20. NECIC is a registered coalition of parents, therapists and professionals from civil society organisations working with and advocating for children with disabilities rights.


22. Preferably, signing children who are deaf should be taught by a fluently signing teacher (preferably Deaf), and not via an interpreter. Relying on an interpreter for access to education is not bilingual education, but education in a majority spoken language mediated by an interpreter – and does not replace direct instruction in sign language or a fully accessible sign language environment. Useful WFD position Paper that articulates this well: https://wfdeaf.org/wp-content/uploads/2018/07/WFD-Position-Paper-on-Inclusive-Education-S-June-2018-FINALwithout-IS.pdf.