

# Children with Disabilities in Malaysia



The purpose of this issue brief is to outline the national context for girls and boys with disabilities in Malaysia. In recognition that children with disabilities must be supported to fully realise their rights, this analysis highlights the core attitudinal, environmental and institutional barriers that can prevent children and adults with disabilities from actively participating in society. In conclusion, this brief will outline five strategic calls to action, targeting stakeholders responsible for children with disabilities in Malaysia.

## 1. POLICY CONTEXT AROUND DISABILITY IN MALAYSIA

There are a number of national social welfare and service policies which help to define the rights of people with disabilities in Malaysia; however, as the most recent Universal Periodic Review report notes, Malaysia's Constitution (1957) does not include reference to children or adults with disabilities.<sup>1</sup>

The National Welfare Policy (1990) was an early attempt to set out the government's intention to create a society which promotes 'equalisation of opportunities' and made provision for those with disabilities. The National Social Policy (2003) specified that people with disabilities should 'enjoy equal rights and full participation in society' and focused on fifteen different areas where inclusion should be prioritised including for example around rehabilitation, education, employment, social assistance and accessibility. Women and children with disabilities were also specifically mentioned as a target group.

The most significant step forward in recognising the rights of people with disabilities came in 2008 with both the signing of the UN Convention on the Rights of Persons with Disabilities (CRPD) and the enactment of the Persons with Disabilities Act.

This was the first time that the Government of Malaysia (GOM) formally acknowledged the need to reduce barriers to participation and adopted a rights-based approach to disability.<sup>2</sup> GOM went on to ratify the CRPD in 2010 which demonstrated its serious intent to promote inclusion, albeit with reservations on article 15 (freedom of torture or cruel, inhuman or degrading treatment or punishment) and Article 18 (liberty of movement and nationality).<sup>3</sup>

A key gap within the Persons with Disabilities Act, however, is that it makes no specific provisions for children or young people with disabilities beyond ensuring their right to access education (Art. 28) and their right to access recreation, leisure and sport (Art. 32).<sup>4</sup> In addition, there is also no reference to the impact of age or gender on disability. Another significant gap within the Act is the lack of a monitoring and redress mechanism in place, should any party or the government violate the rights of persons with disabilities. Similarly, GOM has yet to sign the Optional Protocol to the CRPD concerning procedures for individual communications and inquiry, which indicates the lack of legal mechanism if the rights of persons with disabilities are violated.<sup>5</sup>

<sup>1</sup> Report of the Office of the United Nations High Commissioner for Human Rights Human Rights Council Working Group on the Universal Periodic Review Thirty-first session 5–16 November 2018. Page 2.

<sup>2</sup> Abdullah, Hanafi and Hamdi (2017), *The rights of persons with disabilities in Malaysia: the underlying reasons for ineffectiveness of Persons with Disabilities Act 2008*. International Journal for studies on children, women, elderly and disabled. Vol.1

<sup>3</sup> Tah and Mokhtar (2017), *Malaysia's ratification of the UN Convention on the Rights of Persons with Disabilities (UN CRPD)*. International Journal of Business, Economics and Law, Vol. 11, Issue 4

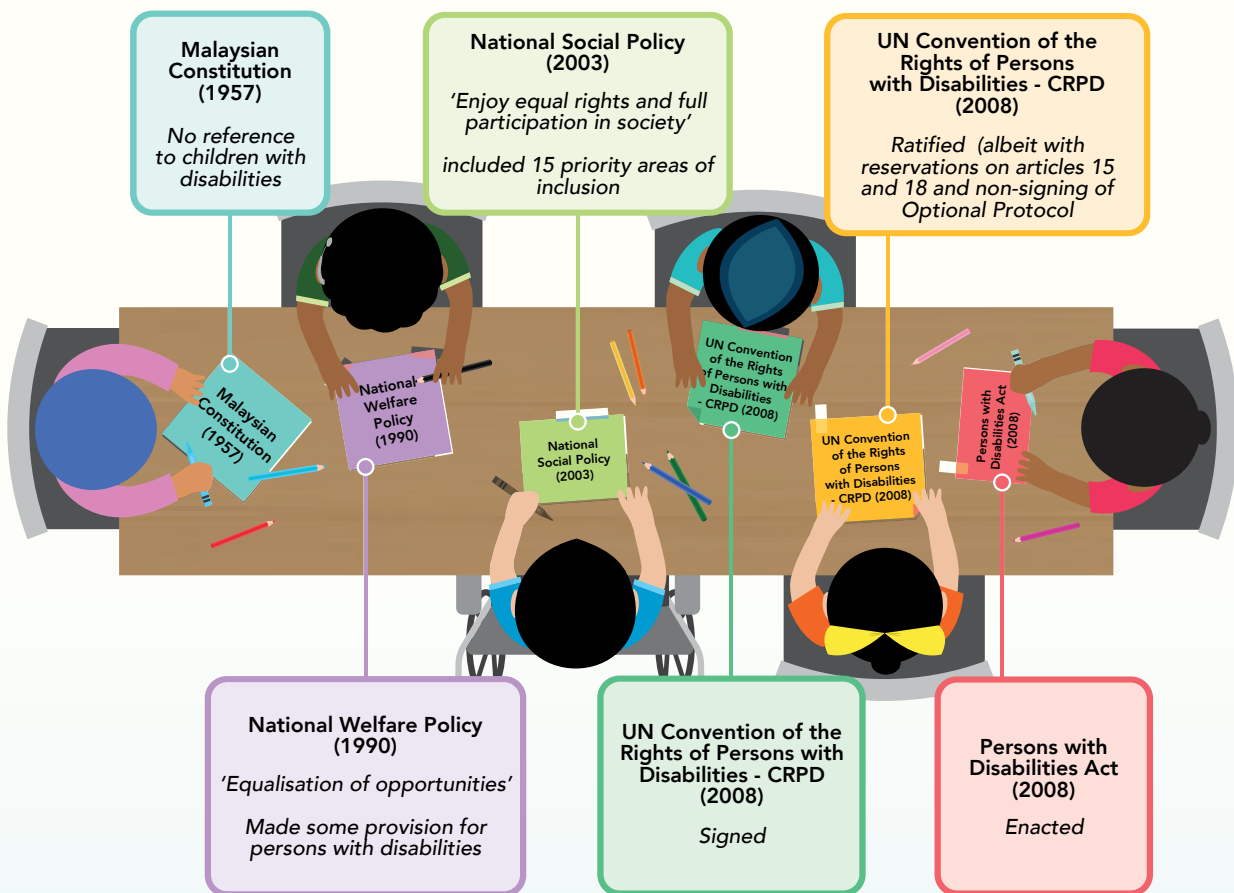
<sup>4</sup> Persons with Disabilities Act 2008, Act 685, Government of Malaysia

<sup>5</sup> Abdullah, Hanafi and Hamdi (2017), *The rights of persons with disabilities in Malaysia: the underlying reasons for ineffectiveness of Persons with Disabilities Act 2008*. International Journal for studies on children, women, elderly and disabled. Vol.1

# 1. POLICY CONTEXT AROUND DISABILITY IN MALAYSIA (CONT'D)

The National Council for Persons with Disabilities has responsibility to oversee national progress against plans and policies, but there are no penalties for non-compliance to the Persons with Disabilities Act and Malaysians with disabilities are unlikely to be able to bring a legal claim against the government or service providers for violation of rights.<sup>6</sup> A recent paper by Abdullah et al. (2017)<sup>7</sup> on the effectiveness of the Persons with Disabilities Act noted that in the years following its enactment, no case has referenced it for protecting the rights of persons with disabilities in court. As such, calls for the Persons with Disabilities Act to be abolished have been made, with proposals for the enactment of a Disability Discrimination Act as well as the establishment of a commission with enforcement powers to put in place legal measures for non-compliance.<sup>8</sup>

There is little direct protection of the rights of children with disabilities across the legislative framework. Malaysia enacted the Child Act in 2001 as part of its obligations under the UN Convention on the Rights of the Child (CRC). Although it is based on non-discrimination, the Federal Constitution and reservations in the CRC do not protect children with disabilities from discrimination.<sup>9</sup> Since the Persons with Disabilities Act also fails to specifically reference children and young people with disabilities there is a significant gap in the protection and promotion of their rights.



<sup>6</sup> Section 41 in Part V of Persons with Disabilities Act 2008.

<sup>7</sup> Abdullah, Hanafi and Hamdi (2017), *The rights of persons with disabilities in Malaysia: the underlying reasons for ineffectiveness of Persons with Disabilities Act 2008*. International Journal for studies on children, women, elderly and disabled. Vol.1

<sup>8</sup> Group: Do away with People with Disabilities Act <https://www.thestar.com.my/news/nation/2018/07/02/group-do-away-with-disabilities-act-it-merely-serves-as-an-administrative-document-with-no-enforcement/>

<sup>9</sup> Children with Disabilities in Malaysia: Mapping the Policies, Programmes, Interventions and Stakeholders [https://www.unicef.org/malaysia/UNICEF-Children\\_with\\_Disability\\_in\\_Malaysia\\_2014\\_lowres.pdf](https://www.unicef.org/malaysia/UNICEF-Children_with_Disability_in_Malaysia_2014_lowres.pdf)

## 2. OFFICIAL DATA ON CHILDREN WITH DISABILITIES IN MALAYSIA

Data on the numbers of children with disabilities in all contexts in Malaysia remains unreliable. The main estimates are still taken from the 2011 World Report on Disability which suggest that 5.1% of children (0-14 years) have a disability with around 0.7% of those children experiencing 'severe disability'.<sup>10</sup>



**1 in 2 children registered with disabilities in Sabah are out of school.**

Children with disabilities are likely to experience a range of barriers depending on factors such as degree and type of impairment, age, location, gender and ethnicity for example. For girls especially, having a disability can seriously impact on participation; globally girls with disabilities are less likely to be successful in education, to benefit from vocational training or to find employment even compared with boys / young men with disabilities or girls without disabilities.<sup>11</sup> Global estimates of primary school completion rates for example show just 42% of girls with disabilities complete primary education compared with 51% of boys with disabilities.<sup>12</sup> A recent UNICEF study on children out of school in Sabah, reports that at least half of registered children with disabilities do not attend school at all levels when compared to their peers without disabilities.<sup>13</sup>

Until 2019, Malaysia collected very little household level data on disability, so there is limited reliable measure of disability prevalence in children. Given a current 0-14 years population of around 9 million,<sup>14</sup> global prevalence rates would suggest there could be around 440,000 children with disabilities in Malaysia<sup>15</sup> although rates of 10-16% have also been reported.<sup>16</sup> It is worth noting that in 2018, UNICEF commissioned the translation of the UNICEF/Washington Group Child Functioning Module into Bahasa Malaysia with the intention of making it easier for the Department of Statistics to collect childhood disability data within their household survey (currently underway mid-2019).

The Child Functioning Module question sets have been designed specifically to enable data on disability to be sensitively collected within a rights-based framework. UNICEF advocated for the use of the Child Functioning Module in both household and institutional care surveys to ensure a more accurate recording system of childhood disability.<sup>17</sup>

Notwithstanding the above, the latest statistics released by the Department of Social Welfare report that there were 120,243 persons with disabilities under the age of 18 in 2017.<sup>18</sup> The reason the rates are so low is because this data just reflects the numbers of children who have been officially registered as having a disability as part of the OKU registration system. OKU or Orang Kurang Upaya is the official terminology used to describe people with disabilities which roughly translates to 'less abled person'.<sup>19</sup>



<sup>10</sup> WHO, World Report on Disability, accessed June 27 2018, [http://www.who.int/disabilities/world\\_report/2011/en/](http://www.who.int/disabilities/world_report/2011/en/).

<sup>11</sup> Groce, Nora Ellen, 'Adolescents and Youth with Disabilities: Issues and challenges', Asia Pacific Disability Rehabilitation Journal, vol. 15, no. 2, July 2004, pp. 13-32.

<sup>12</sup> WHO, World Report on Disability, accessed June 27 2018, [http://www.who.int/disabilities/world\\_report/2011/en/](http://www.who.int/disabilities/world_report/2011/en/), p.12

<sup>13</sup> UNICEF (2019). 'Children Out Of School – Malaysia: The Sabah Context', p 25. [online]: <https://www.unicef.org/malaysia/media/896/file/Out%20of%20School%20Children.pdf>

<sup>14</sup> [https://www.indexmundi.com/malaysia/demographics\\_profile.html](https://www.indexmundi.com/malaysia/demographics_profile.html)

<sup>15</sup> That is 5% of 9,000,000

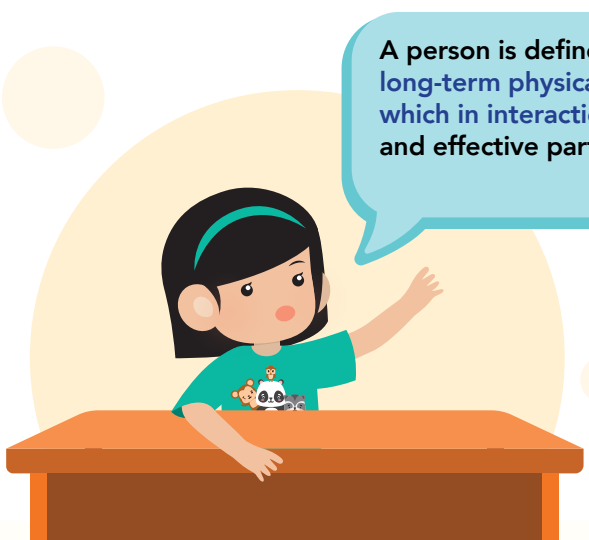
<sup>16</sup> Suiker, Bakar, Othman, Mohd (2017) *Barriers to unmet needs among mothers of children with disabilities in Kelantan, Malaysia: A qualitative study*. Journal of Taibah University Medical Sciences (2017) 12(5), 424-429

<sup>17</sup> See: <http://www.washingtongroup-disability.com/>

<sup>18</sup> Department of Social Welfare, 2017, Data extracted from SMOKU in June 2017

<sup>19</sup> UNICEF Malaysia (2016), Childhood disability in Malaysia: a study of knowledge, attitudes and practices. Malaysia. (P.3)

## 2. OFFICIAL DATA ON CHILDREN WITH DISABILITIES IN MALAYSIA (CONT'D)



**A person is defined as having a disability when they '... have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers, may hinder their full and effective participation in society.'**

- Definition from person with Disabilities Act (2008)

Under the Persons with Disabilities Act (2008) a person is defined as having a disability when they '... have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers, may hinder their full and effective participation in society.' However, for the purpose of OKU registration, the government is much more prescriptive in defining seven types of impairments that can be categorised as a disability: hearing (which it further refines by decibels of hearing loss [dBHL]); sight; speech difficulties (which in children have to be assessed at 5 years or above); physical; learning disabilities (which includes Down Syndrome, autism and other learning difficulties); psychosocial (which includes diagnosed psychiatric conditions); and multiple (where there is more than one significant impairment present).<sup>20</sup>

Since this is a voluntary process and one that can be difficult to navigate or even feels shameful, with perceived minimal incentives many parents choose not to register their children. Efforts are underway to encourage registration of children with disabilities<sup>21</sup> and to highlight the importance of registering.<sup>22</sup> These include initiatives to increase the awareness of the benefits of registering such as financial assistance, subsidies, job attachments and places at education institutions.<sup>23</sup>

However, until there is national survey data published, using internationally recognised data collection tools (such as the UNICEF/Washington Group Child Functioning Module), rates of disability in children will remain under-reported in Malaysia.

Consistent with a lack of prevalence data is a general lack of empirical research relating to the voice and lived experiences of children and young people with disabilities in Malaysia. In 2016, UNICEF Malaysia commissioned an important population-based Knowledge, Attitudes and Practices survey to try and address this knowledge gap; this provides some key observations.<sup>24</sup> It noted that the medical model is still the dominant approach in Malaysia to understanding disability and has helped maintain a situation where children and young people with disabilities remain: 'passive recipients of services'<sup>25</sup> with no sense of them having individual agency. Generally, people do not focus on environmental and social barriers to inclusion but rather viewing the impairment as being the main barrier to participation. So, whilst government policy can be said to align with a rights-based approach this is not well understood at community level. Therefore, the underlying drivers for stigma and discrimination remain essentially unchallenged.

<sup>20</sup> Department of Social Welfare web portal <http://www.jkm.gov.my/jkm/index.php?r=portal/left&id=UnN2U3dtUHhacVN4aHNPbUIPayt2QT09>. Worth noting that the government is determined to stop use of the term 'mental disability' and adopt the more rights based psycho-social impairment terminology. This has yet to be publicly visible.

<sup>21</sup> Register with welfare department to be eligible for benefits, urges deputy minister <https://www.thestar.com.my/metro/metro-news/2018/07/24/record-on-the-disabled-inaccurate-register-with-welfare-department-to-be-eligible-for-benefits-urges/>

<sup>22</sup> The importance of registering a disabled child <http://www.theborneopost.com/2013/06/08/the-importance-of-registering-a-disabled-child/>

<sup>23</sup> Parents urged to register children with disabilities <https://www.nst.com.my/news/2015/09/parents-urged-register-children-disabilities>

<sup>24</sup> UNICEF Malaysia (2016), Childhood disability in Malaysia: a study of knowledge, attitudes and practices. Malaysia.

<sup>25</sup> Op cit. p. 85

### 3. PERCEPTIONS OF CHILDREN WITH DISABILITIES IN MALAYSIA

The Knowledge, Attitudes and Practice study commissioned by UNICEF in 2016 revealed that most respondents (approximately 60%) were under-informed about disability.<sup>26</sup> The lack of awareness and understanding, as well as misconceptions of disability in Malaysia, appear to be key barriers that restrict the opportunities available to children with disabilities in comparison to their peers without disabilities.



#### 3.1 Barriers at family level

These attitudinal barriers have created anxiety amongst parents of children with disabilities, who hesitate or refuse to officially register their children. Those who do attempt to access services for their children, such as enrolling them in mainstream schools, continue to face resistance to be included among children without disabilities.<sup>27</sup> A recent study by Sukeri et al (2017) noted high levels of unmet needs especially amongst mothers of children with disabilities.<sup>28</sup> This study found that parents of children with disabilities often find themselves quite isolated as they struggle to find appropriate information, financial and social protection. They reported experiencing a wide range of challenges from lack of accessible transport, increased healthcare costs, inaccessible services, fragmentation of support, to poor coverage of specialist services, lack of experience of professionals and widespread negative attitudes.

Mothers are expected to take on the responsibility of raising children with disabilities, adding considerable levels of psychological pressure to more general financial and logistical difficulties which often change the dynamics within families. Sukeri et al. (2017) noted that it was the mothers who were most often expected to take their children to hospital or habilitation/rehabilitation appointments or to accompany them to school. The mothers themselves reported feeling very unsupported by their families, communities and service providers, partly because of the negative attitudes prevalent towards disability which they experienced as feelings of shame.

#### 3.2 Barriers at community level

At the community level, disability is still subject to deep rooted taboos. Strong religious and cultural beliefs around disability being linked to past misdemeanours can hamper people's understanding of what causes impairments.<sup>29</sup>

Whilst the majority of people recognise that disabilities have congenital and genetic causes or result from accidents or disease (77%) a significant minority believe that disability is caused by the 'will of God' (10%); the fault of parents (4%); or fate/Karma (2%). At the community level, disability is still subject to deep rooted taboos. Strong religious and cultural beliefs around disability being linked to past misdemeanours can hamper people's understanding of what causes impairments. Whilst the majority of people recognise that disabilities have congenital and genetic causes or result from accidents or disease (77%) a significant minority believe that disability is caused by the 'will of God' (10%); the fault of parents (4%); or fate/Karma (2%).<sup>30</sup>

Welfarist based thinking is also pervasive, reflected in the language used to describe disability: terms such as cacat, a derogatory word meaning handicapped for example, is still widely used and is often synonymous with the official term Orang Kurang Upaya (OKU).<sup>31</sup> There is still a strong assumption that having a disability implies a state of abnormality, dependency and a need for specialist provisioning. Services are provided within a culture which implies an act of charity, rather than being a right or entitlement, and as such can be poorer in quality, regulation, availability and under-funded.<sup>32</sup>

The level of discrimination in Malaysia, however, varies for each type of disability. UNICEF Malaysia (2016) for example, found that children with psychosocial or behavioural disabilities, such as hyperactive disorders, face greater stigma compared to those with physical disabilities. There is a lack of social acceptance for children with these impairments, even if they manage to enrol in mainstream schools.<sup>33</sup>

Nevertheless, there has been some transition in awareness and perception of children with disabilities. Usage of the term "special" which is typically used about children with disabilities, is starting to be recognised as potentially segregating and contributing to the overall experience of exclusion.<sup>34</sup>

<sup>26</sup> UNICEF Malaysia (2016), *Childhood disability in Malaysia: a study of knowledge, attitudes and practices*. Malaysia.

<sup>27</sup> Study shows that Malaysians don't understand disability <https://www.star2.com/people/2017/11/21/disability-prejudice-malaysia/>

<sup>28</sup> Sukeri, Bakar, Othman, Mohd (2017) *Barriers to unmet needs among mothers of children with disabilities in Kelantan, Malaysia: A qualitative study*. Journal of Taibah University Medical Sciences (2017) 12(5), 424-429

<sup>29</sup> Islam R., (2015) *Rights of Persons with Disabilities and social exclusion in Malaysia*, International Journal of Social Science and Humanity, Vol. 5, No. 2

<sup>30</sup> UNICEF Malaysia (2016), *Childhood disability in Malaysia: a study of knowledge, attitudes and practices*. Malaysia. P. 42

<sup>31</sup> Op cit.

<sup>32</sup> Islam R., (2015) *Rights of Persons with Disabilities and social exclusion in Malaysia*, International Journal of Social Science and Humanity, Vol. 5, No. 2

<sup>33</sup> Malaysians meaner towards children with mental disabilities, Unicef study shows <https://www.malaymail.com/news/malaysia/2017/10/16/malaysians-meaner-towards-children-with-mental-disabilities-unicef-study-sh/1487855>

<sup>34</sup> When we use the word 'special' too much <https://www.freemalaysiatoday.com/category/opinion/2018/12/03/when-we-use-the-word-special-too-much/>

## 4. INSTITUTIONAL BARRIERS TO SERVICES



Children with disabilities do not experience equitable access to services. The predominant term used in policy to determine inclusion is 'equal access' for people with disabilities. Although equal access is necessary, it is not sufficient if the service is unable to meet individual needs in an equitable manner. A competent, integrated and holistic cradle-to-grave health, education and social care system is critical to ensure children with disabilities grow up to become healthy, educated, independent and productive members of Malaysian society. Current barriers to service access include attitudinal, financial, informational, legal, and structural obstacles. The following three services are of primary importance to children with disabilities and their families:

### 4.1 Barriers to education

Primary education is compulsory in Malaysia and children with disabilities have the right to access education with 'reasonable accommodation' to meet their individual needs. However, a tiered system exists where most children with disabilities do not realise their right to a quality, inclusive education, but instead experience segregated (as in special education) or integrated education systems<sup>35</sup>. A 'zero reject' policy stipulates that no child can be turned away from education. Since its implementation, over 10,000 children with disabilities have been enrolled in education<sup>36</sup>. However, education continues to be difficult to access for many children with disabilities. The current education blueprint goal is for 75 per cent of children with disabilities to be enrolled in inclusive programmes by 2021. However positive this target may seem, without a strong underpinning implementation plan has led to a large number of children with disabilities out-of-school whilst the rest have not been guaranteed the quality inclusive education they have been promised. It also means that parents of children with disabilities will retain caregiving duties, increasing the need for state protection mechanisms if they are unable to work.

### 4.2 Barriers to health and rehabilitation

Health services play a pivotal role in the prevention and early detection of disability and provision of ongoing support. However, evidence suggests that Malaysia's vision of affordable, accessible health care

for people with disabilities<sup>37</sup> is yet to become a reality for the most vulnerable.<sup>38</sup> Lack of access to vaccination, nutrition and growth monitoring programmes in the early years can also contribute to the incidence of developmental delay (which can become disability) in young children, since disease and poor nutrition can negatively affect neurological and physical development. To the same extent, children with disabilities and their families face barriers in accessing health and nutrition services equally, due to physical and attitudinal barriers. Although an early disability detection programme is in place for 0-6-year-olds, healthcare staff feel ill-equipped to deal with the needs of children with disabilities, and their families and parents experience poor quality services and stigma. Community-based rehabilitation (CBR) centers are becoming 'one-stop centres' for registration, early detection, rehabilitation, advocacy, and referral to other services. Although a positive development, many families struggle to access the centres, particularly in rural areas where transport can be costly and inaccessible. There also remains a shortage of rehabilitation professionals to provide independence-promoting support.

### 4.3 Barriers to social protection

Disability can have an impact on an entire family. It is not uncommon for mothers of children with disabilities to be abandoned by their partner and wider family. They can experience 'disability by proxy' including stigma, isolation, loss of income, and health issues. A loss of income, and/or the additional costs associated with disability can impact upon siblings who may also suffer food insecurity, poor nutrition, or reduced access to services. An ongoing global movement advocates for child disability benefits to absorb these additional costs and 'level the playing field' for children with disabilities and their families.

An allowance for carers of the 'chronically disabled or bedridden' is currently in place in Malaysia, but the cost of collecting these benefits often outweighs the transfer value, particularly in rural areas. Strengthening the registration systems, as well as modernizing cash distribution systems, are required to ensure these entitlements benefit the children for whom they are intended.

<sup>35</sup> See Government of Malaysia (2015). *Education Blueprint 2015-2025* <https://www.um.edu.my/docs/default-source/about-um-document/media-centre/um-magazine/4-executive-summary-pppm-2015-2025.pdf?sfvrsn=4>

<sup>36</sup> Chonghui, L (2019). *Dr Mazlee: over 10,000 special needs children enrolled in schools under zero reject policy*. The Star Online. <https://www.thestar.com.my/news/nation/2019/05/07/over-10000-special-needs-children-enrolled-in-schools-under-zero-reject-policy/>

<sup>37</sup> Government of Malaysia (2008). *Disability Act* <http://www.agc.gov.my/agcportal/uploads/files/Publications/LOM/EN/Act%20611.pdf>

<sup>38</sup> UNICEF (2014). *Children with disabilities in Malaysia: mapping the policies, programmes, interventions and stakeholders*. UNICEF Malaysia

## 5. CONCLUSION

UNICEF advocates for five strategic calls to action, targeting duty bearers<sup>39</sup> responsible for children with disabilities in Malaysia:

### 5.1 Review and revise policy and legal commitments to disability-inclusion:

- Reviewing the gaps in provision/protection of children with disabilities in the Child Act and Disability Act
- Establishment of a Disability Discrimination Act and mechanism for monitoring/redress
- Highlight mechanisms/timeframes to lift the reservations and sign optional protocol attached to the Convention of the Rights of Persons with Disabilities

### 5.2 Collect and disaggregate data on childhood disability and integrate into cross-sectoral data management systems:

- Incorporating the Washington Group/UNICEF Module on Child Functioning in all future household/institutional care surveys/ census. The purpose is to identify the subpopulation of children who are at greater risk of experiencing limited participation in an unaccommodating environment, which is linked to understanding more about the levels of developmental delays and disabilities within this group.
- Reviewing the systems for assessment/registration of persons with disabilities and strengthen the systems for disability-related financial benefit disbursement

The narrative detailed in this Issue Brief has been extracted from several internal UNICEF Malaysia literature reviews of 2019. In addition, various sections have been updated to reflect recent developments in policy and practice. This paper is accurate as of December 2019.

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### 5.3 Review and revise accepted language and terminology around disability:

- Move towards full adoption of UN person first language which underpins the social/rights-based approach towards disability. This move would support duty bearers to reject outdated terminology rooted in a charity/medical approach to disability

### 5.4 Increase participation of children with disabilities and partnerships with Organizations of Persons with Disabilities (OPDs). Critical to this is:

- Review and reform the function and authority of the National Council of Persons with Disabilities with the view to establish an independent Commission for Disability-Inclusion
- Ensure that the National Children's Council is disability-inclusive
- Build the capacity of children and persons with disabilities to understand and advocate for their rights.

### 5.5 Improve discourse, attitudes and behaviours towards children and young people with disabilities at the home and community levels:

- Duty bearers such as government, civil society organisations, media and private sectors to design a social and behaviour change communication strategy aimed at promoting right-based mind-sets around disability
- Support the development of a Disability Social Movement led by children and young people with disabilities



<sup>39</sup> Duty bearers include: government agencies, Civil Society Organisations (CSOs), Organisations of Person with Disabilities (OPD), corporate/private sector agencies, academic institutes, parents, community leaders and children/persons with disabilities.