CHILDHOOD DISABILITY IN MALAYSIA

A Study of Knowledge, Attitudes and Practices

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This study was commissioned by UNICEF Malaysia in 2016. It was authored by Katie Moore and Juliet Bedford (Anthrologica).

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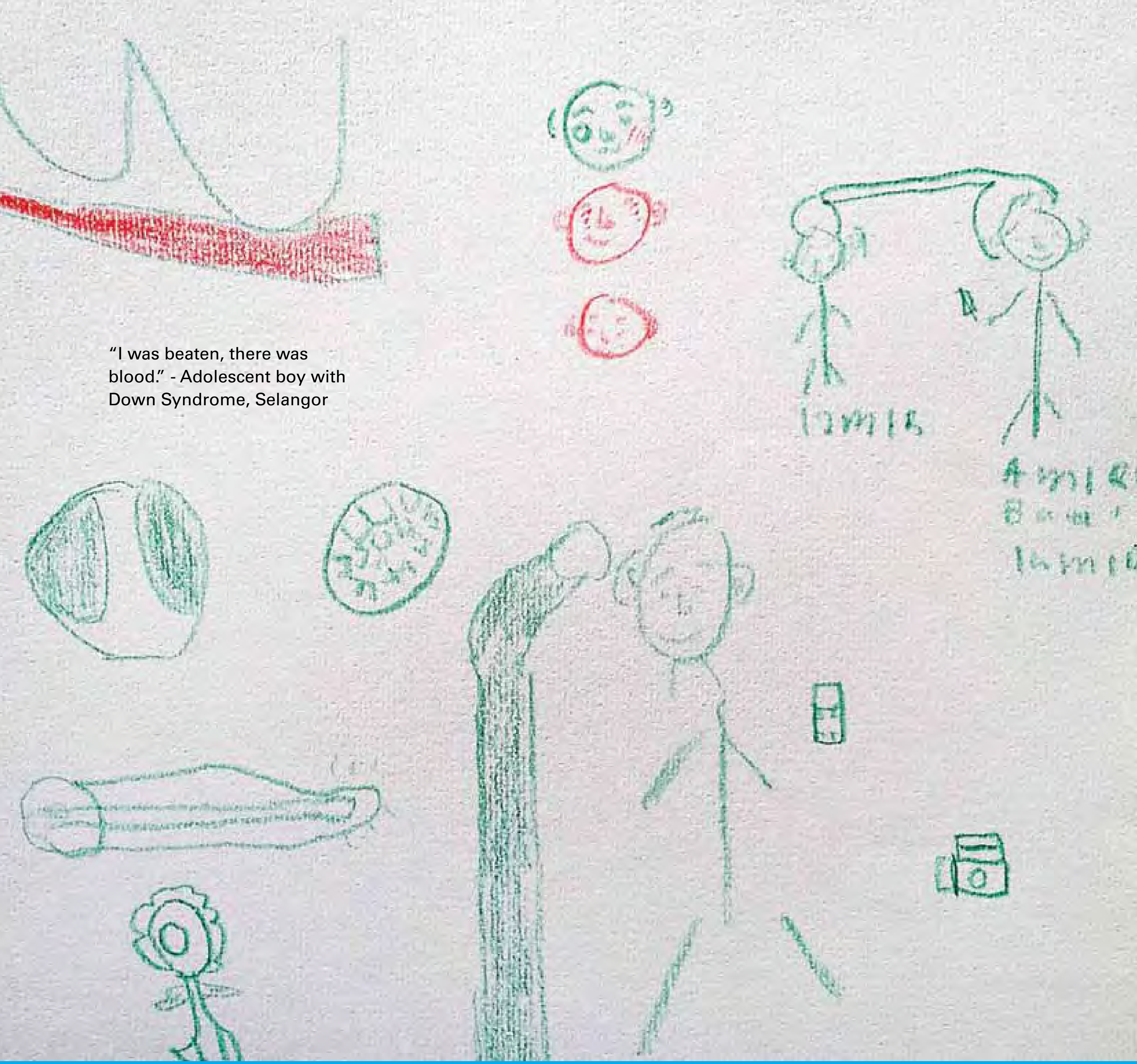

"I was beaten, there was blood." - Adolescent boy with Down Syndrome, Selangor

"Sometimes the environment won't adjust to us because the public attitude...is difficult to change. I think society has to change, only then the environment can change. Start with the Attitude."

Community-Based Organisation (CBO) Representative

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Phenny Kakama
Sr. Child Protection Specialist
UNICEF-Malaysia

This report is dedicated to the memory of Fiona Christy Anthony Oswin. A social worker by training and a committed special education teacher at SK Tanjung Aru II, Fiona was instrumental in facilitating the research with children, adolescents and teachers in urban Sabah.

FOREWORD

Malaysia has acceded to the Convention on the Rights of the Child (CRC) in 1995 and the Convention on the Rights of Persons with Disabilities (CRPD) in 2010. These commitments have been followed by policy and legal frameworks to ensure that children with disabilities have equal opportunity to survive, thrive and fulfil their full potential. These are important developments because often children with disabilities are valued less than their peers, are not registered at birth and have unequal access to basic services. These patterns of exclusion arise not because of the child's disability, but rather as a consequence of a lack of understanding in society about the causes of their disability resulting in negative attitudes and stigma placed on them. In other words they are disabled by a society that excludes and discriminates them.

Failure to fulfil, respect and protect the rights of children with disabilities represents a failure to invest in their potential. It necessarily results in a population of children growing up as dependents of their families and the state, rather than active contributors to economic, cultural, social and scientific growth of Malaysian society. As the World Bank notes, "disability is associated with long-term poverty in the sense that children with disabilities are less likely to acquire the human capital that will allow them to earn higher incomes".

Over the past few years, our disability work has gained momentum. Through partnerships with organisations and individuals, UNICEF Malaysia created resources, connected networks, publicised the issue and used social media to engage in dialogue on the rights of children with disabilities. However there was insufficient information on community perceptions about children with disabilities and the key drivers of stigma and discrimination.

To fill this information gap, a study on knowledge, attitudes and practices (KAP) was commissioned in early 2016. The inclusion of children and adolescents with and without disabilities in the study provides invaluable insights into their experiences. The study has shown that there is still limited knowledge about the actual causes of disability and that their inclusion and capacity to fully participate in society is hindered by a prevailing medical model and charitable sentiments towards persons with disability rather than the current social model adopted in many other nations around the world. Stigma and discrimination is real at different levels for these children as well as their parents and families. There is still inequitable access to education, health and social welfare services particularly in the rural areas.

The findings reinforce the fact that there is still a lot to do to create an inclusive environment for persons with disabilities in Malaysia. They highlight the need to remove attitudinal and physical barriers to inclusion and to challenge misperceptions about the abilities, capacity and potential of children with disabilities to become productive members of their society. The findings of this study must be used to guide our individual and collective efforts to ensure that children with disabilities are fully included in all development efforts and in all matters affecting them and that no child is left behind.

Marianne Clark- Hattingh
UNICEF Representative to Malaysia

EXECUTIVE SUMMARY

UNICEF in Malaysia commissioned a knowledge, attitude and practices study to expand national understanding of community perceptions of disability, and provide an evidence base to inform communication for behaviour and social change that addresses the root causes of stigma and discrimination as experienced by children with disabilities and their families. The study had four core objectives: i) to assess the knowledge, attitudes and practices of society towards children with disabilities, children with disabilities themselves, and their peers without disabilities; ii) to assess the life satisfaction and perception of children with disabilities towards their own impairment and that of their peers with disabilities; iii) to analyse the root causes of stigma and discrimination faced by children with disabilities, and the drivers of the current attitudes; iv) to establish a baseline to inform future interventions and strategies in communication for behaviour and social change.

The research comprised two related components: a quantitative KAP survey; and qualitative data collection using open, inductive and participatory methods. Adopting a mixed methods approach allowed for triangulation of material and increased validity of findings. The study was able to provide insight at community, institutional and policy levels and develop an evidence base that could be transformed into practical actions to promote behaviour and social change on the ground.

Following the introduction, the study's methods are outlined in detail. A short contextual analysis of disability in Malaysia is then followed by the demographic details of the study participants. The core findings of the research are presented in four substantive chapters: knowledge about disability; attitudes towards children with disabilities; practices, the provision of and access to services; and perceptions and experiences of children and adolescents with disabilities. The final chapter presents the study's conclusions and key recommendations.

Methodology

Ethical permission to undertake the study was granted by the Medical Research and Ethic Committee at the Ministry of Health, Malaysia. The research was supported by the UNICEF Malaysia Country Office, the Ministry of Health and the Ministry for Women, Family and Community Development. Representatives from these ministries and the Ministry of Education formed the study's Advisory Committee.

The study ran from January 2016 to September 2016, including a period of intensive data collection in Malaysia in May-June 2016. Data collection was conducted in four states in Malaysia: Selangor and Kelantan in Peninsular Malaysia and Sabah and Sarawak in East Malaysia. The four states were selected by UNICEF Malaysia in line with their programmatic work and to ensure that ethnic, social and religious diversity was captured across the study as these determinants influence both policy making and service delivery.

Five primary participant groups were defined for inclusion in the study: national-level stakeholders; community members (community leaders, religious leaders, caregivers of children without disability); caregivers of children with disabilities (including parents, grandparents, guardians and non-related primary caregivers); service providers (health workers, community-based rehabilitation (CBR) workers, mainstream and special education teachers, community-based organisations); and children and adolescents (both with and without disabilities).

Data was gathered through a combination of the following methods: desk review of data and literature, both qualitative and quantitative; in-depth interviews with key informants and stakeholders; focus group discussions with key informants and stakeholders; participatory workshops with children and adolescents with and without disabilities; KAP survey with general public and those with and without experience of children with disabilities; feedback workshops with UNICEF, government stakeholders and representatives from non-governmental organisations and civil society organisations.

Across the four states, the study comprised 473 data collection activities involving a total of 756 participants. Thirty-eight focus group discussion (FGDs) were conducted with 229 participants; 102 individual in-depth interviews (IDIs) were conducted; 320 individual knowledge attitude and practices (KAP) surveys were administered; and 16 child and adolescent workshops were conducted with 105 participants. Respondents engaged in the qualitative methodologies represented 57.7% of participants (436) whilst 42.3% of respondents answered the KAP survey (320).

The analysis process was systematic and transparent. The full analysis of all qualitative data was conducted using thematic analysis and the emerging trends were critically analysed according to the research objectives. Particular sections of *ad verbatim* narrative were used to build case studies and included in the report to ensure the participants' voice was captured and maintained. The quantitative data of the KAP survey was primarily analysed using Stata software and was largely descriptive, using cross-tabulation to provide a general overview of characteristics and trends. Wherever possible, quantitative results were used to confirm or corroborate qualitative findings in order to provide a high level of validity to the analysis and evidence-based conclusions.

Knowledge about disability

This chapter focuses on knowledge about children with disabilities in Malaysia and analyses how disability is defined and understood. It discusses the terminology used and its associated connotations, and outlines local theories of causation. The chapter concludes with an overview of information sources and trusted or preferred channels of communication.

In the KAP survey, respondents were asked to free-list three thoughts prompted by the term 'disability'. Three key themes emerged: a sense of pity, expressions of sympathy; and reference to emotions or attitudes associated with the notion of 'help', both in terms of children with disabilities needing help, support and assistance, and in relation to their own sentiment of wanting to help. Respondents were also asked how well informed they thought they were about children with disabilities. The least informed answer options accounted for 58.4% (173) of all respondents.

Language around disability was complex and subjective. Terminology and perceptions about appropriate language varied greatly and were influenced by the geographic location of participants and their level of engagement with disability. Both community members and services providers tended to define a person with a disability as being 'not normal', 'limited' or 'less' than 'normal' people. The concept of a 'normal' (*biasa*) child, those in good health and without a disability, perpetuated the notion that those with disabilities were somehow 'abnormal'. The majority of study participants were likely to identify children and people with disabilities in terms of their limitations, with reference to their functionality and ability to complete routine tasks. The tasks discussed correlated to those the age group deemed important.

Qualitative data suggested that the most widely understood term used to refer to people with disabilities was the BM word *'cacat'*. It was widely acknowledged that *cacat* was imbued with negative connotations. Despite this, the term was commonly used instead of the official BM term for people with disabilities, *orang kurang upaya* (OKU), meaning 'less abled person'. Children and adolescent participants without disabilities suggested that OKU was synonymous with *cacat*, although most could not define what OKU stood for.

Participants from different age groups forwarded various definitions about what constituted a disability. Adult respondents stressed that because some disabilities were visible and others not, it was difficult to classify and understand disability. If a disability was not clearly apparent in a physical sense, some participants described it as being 'invisible'. In the participatory workshops, the drawings children and adolescents without disabilities produced tended to differentiate between people with disabilities who used aides such wheelchairs or walking sticks, and people with other disabilities. In their drawings, participants often explained the 'invisible' disability they had depicted through accompanying. It was notable that in the workshops with children and adolescents with disabilities, only two participants illustrated their own disability. The others (47) drew themselves with a similar likeness to their friends and peers who did not have disabilities.

Participants expressed limited knowledge about the actual causes of disability. Across the four states, three dominant themes of causation emerged: medical, environmental and socio-cultural beliefs. Participants frequently cited several different contributing factors, suggesting a complex and pluralistic understanding of the causation of disability, and in some cases, this added to the confusion caregivers of children with disabilities faced in trying to understand the root cause of their child's condition. Respondents articulated three components of medical causes: congenital or genetic factors; birth complications; and acute illness and disease. The environmental causes of disability forwarded by participants included pollution and issues with air quality; exposure to chemicals or toxins in pregnancy; and accidents. Accidents were believed to be the primary cause of disability after childhood, leading mainly to physical disabilities. Socio-cultural beliefs associated with disability were more varied across states and participant groups and included references to black magic, curses and spirits; close kin marriage; punishment and taboo. In the qualitative data, punishment for breaking taboo and the behaviour of parents more generally, were highlighted as factors causing disability. Risky behaviour included: smoking; drug taking; drinking; and *'sex outside the marriage'*. Participants also discussed religious beliefs as influencing their perceptions of the causes and presentation of disability.

In the KAP survey, the three most commonly reported sources of news and information in both urban and rural locations were television, internet and newspapers. Widespread connectivity and use of mobile technology resulted in the internet being increasingly used to search for and share information, particularly in urban areas. In the KAP survey, of those who reported using the internet, 97% (254) confirmed they used social media sites, and reported Facebook, WhatsApp and Instagram most regularly used. Interview and FGD participants suggested multiple sources of information about disabilities including community and religious leaders, health workers, CBR workers and teachers. Participants from all stakeholder groups asserted that information about disabilities disseminated by the Department of Social Welfare (DSW) was inadequate. One of the most trusted sources of information was other caregivers. Support groups facilitated by CBR centres, virtual support groups on WhatsApp and networks on social media platforms such as Facebook, were critical to the flow of information between caregivers in urban areas. It was agreed by teachers, CBR workers and CBO representatives that health facilities and health workers were often the first point of information for caregivers, particularly in more rural areas, and as such they should be better equipped to deliver accurate information regarding welfare, education and healthcare services.

In the KAP survey, when asked if they would like more information about children with disabilities, 86.5% of those respondents (249) who provided an answer confirmed that they would. Participants requested further information about the daily life of children with disabilities; how to help or assist them; and information about the rights of children with disabilities. In terms of their preferred channel to receive such information, 58.4% of respondents (245) suggested the internet or social media as the most appropriate.

Attitudes towards children with disabilities

This chapter focuses on attitudes towards children with disabilities in Malaysia from the perspective of the different stakeholder groups engaged in the study. It analyses societal attitudes towards children with disabilities and discusses stigma by association. It addresses perceptions of increased vulnerability, and concludes by addressing the concerns caregivers have for their child's future.

On the surface, social attitudes towards children with disabilities and their families tended to appear sympathetic, supportive and understanding. Participants almost unanimously agreed that children with disabilities should not be discriminated against, although many participants maintained that Malaysian society was still not inclusive or equitable. Many participants reported feelings of helplessness and a lack of understanding about what one should do or say when approaching children with disabilities. Community and religious leaders agreed that pity could lead to discriminatory behaviour and negative attitudes, and emphasised that children with disabilities should be encouraged to find independence by being treated 'like normal'. In their participatory workshops children and adolescents without disabilities frequently presented a caring and supportive attitude towards children with disabilities. They acknowledged that being kind and supportive of other people was or should be the social norm and upon first questioning suggested that those with and without disabilities should be treated equally. Workshop activities elicited a broad dialogue about charity and from this perspective, participants tended to look at children with disabilities as those in need of help, who are unable to do things for themselves and who relied on others to look after them.

Both the qualitative and quantitative data suggested a correlation between people's attitudes and a) the type of disability; and b) the social proximity of a person with disability. When a person could clearly identify that a child had a disability, they were more likely to be accepting and responsive than towards a child with a 'non-observable' disability, largely because 'non-observable' disabilities were perceived to be more challenging to understand. Participants projected greater negativity and stigma towards children with behavioural, mental and intellectual disabilities than towards children with physical or sensory disabilities.

Children and adolescents without disabilities reported witnessing cruel and unkind behaviour towards those with disabilities, primarily directed to those with learning or behavioural disabilities by siblings, peers at school, and in the community more broadly. Incidences of mistreatment ranged from teasing and mocking to more severe emotional bullying and physical beating. Stigma and discrimination operated on many levels for parents and families of children with disabilities, and both caregivers and siblings described in detail the stigma, discrimination, isolation and marginalisation they experienced on account of their relative's disability.

Across ethnicities and religions many participants associated a child's disability with the conduct of their families. Parents of children with disabilities suggested that the root of much of the stigma they faced was embedded in cultural beliefs surrounding a mother's behaviour and taboo in pregnancy. Caregivers of children with disabilities routinely spoke of being blamed for their child's disability, and feelings of self-blame only served to intensify the shame that parents felt and impacted their ability to accept their child. Feelings of shame were not limited to parents, but were also reflected across the wider family unit. Even though children with learning, mental and behavioural disabilities were generally less accepted by society, parents of children with these disabilities found the day-to-day stigma they faced to be significantly less than children with physical disabilities, simply because people would not immediately ‘notice’ their children. Such issues appeared to prevent families with children with disabilities from integrating into mainstream societal activities. This limited interactions between the general public and children with disabilities, and further isolated the children and their families. Several mothers described how their own social interactions had been curtailed because of their child, even amongst once close friends and peers.

Participants from all stakeholder groups acknowledged that children with disabilities were vulnerable to their surrounding environment and society. Access to the internet was considered to increase the vulnerability of children and adolescents with disabilities. With access to social media platforms such as WhatsApp caregivers and service providers expressed concern that they had little control over the relationships adolescents developed using these technologies, although adolescents with disabilities emphasised the importance of online platforms to facilitate contact and communication with their peers.

Participants also discussed the fact that children with disabilites were vulnerable to physical and sexual abuse. During the research, cases of sexual abuse and rape of children with disabilities that were known locally and / or had received attention at the national level were frequently recounted.

One of the greatest worries expressed by caregivers of children with disabilities was concern for their future in terms of limited opportunities for employment and financial independence, and the pervasive stigma and discrimination that would continue to restrict their integration and participation in society. Many caregivers worried about who would care for and protect their child in later life. Several parents asserted that the child’s sibling(s) would assume responsibility. In several cases, caregivers discussed the possibility of institutionalisation as a way to ensure their child gained a level of independence, although there was concern about the quality of care provided in government homes.

Practices, the provision of and access to services

This chapter focuses on practices in terms of the provision of services to children with disabilities, and the uptake of services by children with disabilities and their families. It addresses four key sectors: health services; education; rehabilitation services; and employment opportunities. In conclusion, cross-cutting barriers that prevent equitable access and participation are analysed.

Health services: Across all participant groups and all states, children with disabilities were recognised as having particular healthcare needs. Following their child’s diagnosis, caregivers confirmed that health workers were generally their ‘first point of contact’ and were regarded as hubs of information about health and disability more broadly. Failure to obtain pertinent information from health workers about prevention, early detection, diagnosis, management, treatment and rehabilitation, left many caregivers dissatisfied and frustrated from an early stage of their child’s condition. Clinics and general hospitals provided free care for children with disabilities, but negative experiences at these facilities appeared to increase the demand for and utilisation of private clinics, despite their elevated costs. Caregivers discussed the lack of sensitivity they perceived in health workers, particularly during diagnosis. They were reported to use inappropriate language (such as ‘abnormal’ and ‘retarded’) and have a lack of empathy. The majority of stakeholders, including health workers themselves, identified the need for improved and specialist training. Several health workers confirmed that they had not received any training about ‘how to deal with’ children with disabilities, and demonstrated limited knowledge about causation, management and treatment for a range of disabilities. Stakeholders across the study highlighted that limitations of both human and material resources within the health system were problematic. Services appeared overburdened, and caregivers discussed the lack of specialised care, limited supply of assistive devices via physiotherapy or occupational therapy departments, long waiting time and short consultation periods. Caregivers perceived there to be a small cadre of trained specialist therapists, mainly located in urban centres, which meant the distribution and coverage of services offered was inequitable, even within the public sector. Several participants emphasised the lack of coordination between services and welfare allowances or entitlements, and suggested this complicated the procurement and allocation of medical equipment and assistive devices. Participants also reported that the physical environment of clinics and hospitals was difficult to navigate around.

Education: Opinions on how and where children with disabilities should be educated was divided. In the interviews and focus groups discussions, some participants were confident that children with disabilities should not be educated alongside other students in mainstream education, whilst others believed that integration and 'exposure' to children with disabilities was essential, not just for the learning experiences of all children, but for the benefit of society more broadly, breaking down barriers, alleviating stigma and generating greater acceptance and awareness. The KAP data indicated that perceptions about whether a child with disabilities should attend school with other children was partly determined by the type of disability. Teachers in mainstream education who took part in interviews and focus group discussions suggested it was not possible to teach children with and without disabilities in the same class, and confirmed that children with disabilities should be educated in special classes or at special schools. In contrast, special education teachers emphasised that if they had the capacity and capabilities, children with disabilities should be offered an opportunity to study in mainstream education. They concluded that the lack of classification about disability presented a major challenge in correctly placing children in schools. Caregivers of children with disabilities and representatives from community -based organisations emphasised that children with visual or hearing impairments had greater educational opportunities due to the existence of special schools for their disability. It was evident that the structure of the school system was discriminatory and set children with disabilities at a disadvantage. Although not widely discussed by teachers, caregivers and CBO representatives in Sabah, Kelantan and Selangor suggested that the Key Performance Indicator (KPI) evaluation system prevented children with disabilities being accepted by schools. The majority of teachers engaged in the study asserted that the greatest challenge they faced in teaching children with disabilities was their lack of training and many reported feeling 'vulnerable' and 'ill-equipped'.

Community-based rehabilitation services: Across the study, participants confirmed that community-based rehabilitation (CBR) centres provided an important space for integration, stimulation and learning. This was particularly true for children who found it difficult or impossible to access mainstream services, either due to their disability, geographic location and / or socio-economic status. In Sarawak and Sabah participants reported that the distribution of centres and the services they offered were 'still behind' those provided on the Peninsula. Caregivers highlighted transport and finances as being considerable barriers to accessing care in rural areas, even at the community level, as no supportive help was provided. Caregivers of children with disabilities in Kelantan, Sabah and Sarawak asserted that their children had positively benefitted from attending CBR centres and reported progress in their socialisation, skill development and self-management. Caregivers confirmed that the CBR workers were supportive not only to the children, but also encouraged their families by sharing techniques for home care, information about key resources, and providing assessments on the child's progress and achievements. Caregivers in urban Selangor indicated their preference for attending private CBR centres where specialist support services (occupational therapy, speech therapy and physiotherapy) were more routinely available. Across all the study sites, CBR workers unanimously agreed that training opportunities were lacking and recognised the need for enhanced continual professional development. Many suggested that the training they had received was 'definitely not enough' and left them feeling that they had 'a lot to learn'. High turnover of CBR workers led to an almost continuous stream of new trainees being deployed, and this strained both human resources and the quality of care provided. Many participants, both CBR workers and other stakeholders, highlighted the voluntary nature of the work and concluded that the lack of incentives and limited recognition of their service by the government to be demotivating.

Employment: In their participatory workshops, adolescents with disabilities placed great value on employment as a means to contribute to society, to be financial secure and gain independence. 'Transition', the period between completing formal education and starting a job, was a time when adolescents with disabilities frequently became 'stuck'. CBR staff explained that when adolescents finished their education at special schools or CBR centres, there was no established pathway that helped guide them into adulthood and the work place by providing additional training or skill enhancement. Numerous interventions and programmes for children with disabilities existed, but it was suggested that young adults in transition were largely overlooked. From the qualitative narratives, it was clear that discrimination against people with disabilities was systemic, from restrictive employment opportunities, to limited support in the workplace and reduced salaries. The majority of participants emphasised that mechanisms should be in place to prevent employers from taking advantage of adolescents with disabilities.

Cross-cutting barriers preventing access and participation included: registration of children with disabilities; financial barriers; transport barriers: and physical / infrastructural barriers.

Registration of children with disabilities:
The majority of participants confirmed that registration was beneficial, but its value was expressed differently across stakeholder groups. Service providers (government officials, CBOs and health workers) described the value of registration in terms of accurate statistical data to assist with planning, procurement, service provision and evidence in policy making. In contrast, community members, caregivers and CBR workers expressed the value of registration for the individual child with disabilities. Caregivers found the process of applying for and obtaining a card to be convoluted and protracted, partly due to the centralisation of the service and the perceived inefficiency of registration workers.

Financial barriers:
Both direct and indirect financial constraints were dominant themes in many of the caregivers' narratives and the issues were often magnified in households from the poorest quintiles. Out-of-pocket expenses including transport to services, medical bills, nutritional supplements, diapers, and assistive devices could be substantial. The strain on household resources is compounded if caregivers had to cease work to become full time carers and received only limited disability allowances. For many families, financial constraints prevented the child with disabilities from attending school or rehabilitation services regularly, and frequently curtailed the education and social activities of siblings and the wider family unit.

Transport barriers:
Not only was the cost of transport prohibitively expensive for some caregivers, but transport options were often limited, particularly in rural areas where the need for transport was likely to be greater given the longer distances from home to the site of service provision. In addition, physically accessing public transport was often challenging, and caregivers frequently reported facing discrimination from bus and taxi drivers.

Physical / infrastructural barriers:
The lack of physical access to public environments was a major concern expressed by all stakeholder groups. In relation to education, for example, infrastructural barriers (such as no elevators, stair ramps, or modified bathrooms etc.) were seen to be a fundamental obstacle to inclusion. Many respondents commented on the lack of planning that went into public spaces (including hospitals and clinics) to ensure they were accessible for children living with disabilities.

Perceptions and experiences of children and adolescents with disabilities

Prior to this study, there had been little research directly undertaken with children with disabilities in Malaysia. Their voices were not well captured or represented in published literature, and were largely absent from the public discourse about disabilities in Malaysia. The inclusion of children and adolescents in this study through their engagement in the participatory workshops provides new insights into the experiences of children with disabilities. Whilst the report documents their views and perceptions throughout, this chapter specifically highlights the main themes and key considerations that emerged during the workshops.

Through the workshops' main activities (story boards, role plays, illustrations, graffiti walls), participants with disabilities rarely depicted themselves as having a disability. Rather they projected themselves to be like their non-disabled friends or peers, often able bodied and without aids. For participants who had hearing disabilities, however, 'being deaf' was an important part of their cultural identity.

Workshop participants frequently described their family as a source of comfort, and their key support network. In discussions, children did not limit this to their family unit and included experiences and relationships they had with cousins, neighbours and friends who lived close by. Both children and adolescents with disabilities recognised the support given by families in accomplishing daily activities. Many participants also spoke about their desire to have a relationship and get married. Friendship was highly valued by workshop participants. Like family, friends were a critical network of support and motivation. Workshop participants recounted that they faced less discrimination when accompanied by friends. Conversely, children and adolescents discussed feelings of sadness, loneliness, embarrassment and anger when they were excluded from participating on account of their disability.

In workshops, children and adolescents with disabilities emphasised how important it was for them to attend school, receive a good education and access the same opportunities as their non-disabled peers. The majority of workshop participants attended integrated or special schools and reported that teachers were 'kind' and 'patient'. In comparison to teachers who had been trained to provide mainstream education but had been placed in special schools, participants recognised that teachers who had received specialist training were more competent and had greater skills to teach children and adolescents with disabilities. A small number of participants suggested that teachers in mainstream schools did not do enough to stop discriminatory behaviour. Workshop participants held varied opinions about what type of education was preferable: special school; integrated school; or inclusive programmes in mainstream schools. Both inclusive and exclusive education were acknowledged to have challenges. The key factor for adolescents tended to be the right to education, regardless of the disability or the school.

In the 'safe environment' created by the workshop, children and adolescents with disabilities spoke openly about their experiences of ill treatment and bullying. Many participants had experienced name calling and stressed that the use of the word *cacat* could be particularly hurtful. Some children and adolescent participants reported being scolded and beaten. It seems that scolding usually came from family members, but that physical beatings were also carried out by community members outside the family unit.

Workshop participants emphasised that they found adults with disabilities, both in real life and those who were well known through the media, to be a sources of motivation. International 'celebrities' such as Stephen Hawking were often cited as inspirations, and adolescent participants discussed examples of people with disabilities becoming lecturers and Islamic scholars.

The young adults who participated in the workshops listed attending tertiary education, securing steady employment and having a family of their own to be their key aspirations. In thinking about the future, obtaining a job with a reasonable wage, was a pertinent worry for adolescents. Difficulties in finding employment were seen to be indicative of the lack of government commitment to ensuring that people with disabilities had equal opportunities and could live independently.

Children and adolescents across all four states referred to their use of social media in finding girlfriends or boyfriends, and many found platforms such as Facebook and WhatsApp to be easier ways of meeting people than having to 'go outside'.

Conclusion and recommendations

In focusing on knowledge, attitudes and practices, this study has provided new empirical evidence about children with disabilities in contemporary Malaysian society. Findings should be used by UNICEF and other partners to inform programme design and communication strategies to support the Malaysian government to systematically address issues of inclusion, and to promote the rights of children with disabilities as part of Vision 2020.

Recommendations are based on the evidence generated through the study, and include suggestions made by different stakeholder groups engaged and through the analysis of the research team. They include a range of broad, more structural recommendations and specific areas for intervention. It is clear that UNICEF alone does not have the remit to address all the areas highlighted, and the entry points to tackling some of the issues raised will depend on the specificities of the country programme and related interventions. It is important to adopt a systems-based approach, however, so that any recommendation that shapes or is incorporated into a programmatic intervention takes account of and responds to the developing ecology of disability in Malaysia.

Recommendations for community engagement:
UNICEF has an important role to play in supporting national and local authorities and other partners to create an enabling environment for children with disabilities in Malaysia, an environment in which they are included in society, are regarded as active and equal citizens, and have the right and ability to participate without fear of discrimination or marginalisation. Recommendations appertain to general community engagement strategies, and engagement with specific target groups (caregivers of children with disabilities; children and adolescents without disabilities; and children and adolescents with disabilities). Recommendations focus on:

- Promotion of a social and rights-based approach to disability
- Zero-tolerance for discrimination
- Dissemination of more information
- Increase visibility of people with disabilities
- CBO and NGO partnerships

Recommendations for engaging with caregivers of children with disabilities:
The social inclusion of a child with disabilities and their level of participation are heavily dependent on their family and immediate social environment. Families require multiple forms of support and information including how to care for their child; how, when and where to access services (medical, educational, rehabilitative and welfare services etc.); and how to negotiate discrimination and vulnerability. There are numerous different entry points for engaging with caregivers of children with disabilities, not only in terms of service provision and uptake, but also related to the type and severity of the disability and the age of the child.

How, when and where to most effectively engage with a caregiver is likely to change over time depending on their own lived experience. Recommendations focus on:

- Support groups
- Caregiver education
- Role models and the promotion of positive experiences

Recommendations for engaging with children and adolescents without disabilities:
Meaningful engagement with children and adolescents requires targeted strategies. Evidence from this study compliments findings from the broader literature which suggests that in their discussions about disability and interactions with peers with disabilities, children and adolescents are more tolerant and accepting than the general adult population. This key group can be effective agents of change and have an important role to play in taking a stand against discrimination, promoting diversity and equal opportunities, and helping to ensure the social inclusion and participation of children and adolescents with disabilities. The development of forums that bring together children and youth with and without disabilities is critical. Positive attitudes should be encouraged as part of the social norm in this generation. Recommendations focus on:

- Child-centric activities
- Youth-centric materials and social media
- U-report

Recommendations for engaging with children and adolescents with disabilities:
In addressing disability in Malaysia, UNICEF has a specific remit and duty to work with children and adolescents who themselves have disabilities. This study has made a major contribution in this regard as it purposively engaged children and adolescents with disabilities and through participatory workshops facilitated their involvement in discussions and created a safe space in which they could share their concerns, priorities and experiences, both positive and negative. The recommendations are based on the suggestions children and adolescents made during the workshops, and on the analysis of the research team. Recommendations focus on:

- Peer-to-peer support and the value of friendship
- Youth-centric materials and social media
- Positive role models
- Constructive participation
- The strongest advocates

National level recommendations:
National level recommendations are orientated around advocacy at the policy level and building greater political leadership and commitment to disability issues, areas that UNICEF is well placed to support. Creating an enabling environment is critical to improving the lives of children with disabilities and their families in Malaysia. Recommendations focus on:

- Strengthen national policies and promote ratification of the Optional Protocol
- Increase inter-agency collaboration
- Simplify and standardise the registration process
- Strengthen the health system to improve care for children with disabilities
- Strengthen the education system to provide inclusive education for children with disabilities
- Enshrine consistent language and terminology
- Improve the physical environment and remove barriers to accessing public and private spaces
- Private sector engagement
- Multi-lateral consultation

Recommendations for service provision:
Children with disabilities are understood to be especially vulnerable and may require enhanced protection. All personnel who provide services to children with disabilities, or who interact with children with disabilities through their professional work should receive regular training and up- to-date information on child protection measures. Specific recommendations were highlighted by service providers reflecting on their own practice and needs; other stakeholders engaged in the study; and through the analysis of the research team. Recommendations focus on:

- **Health workers** – Children with disabilities have specific medical needs and the care they require may change over time. Health workers should be sensitive to these changes and promote social inclusion through the child's right to health. Health service providers of different cadres and working at different levels of the health system would all benefit from increased and / or refresher training to improve their skills and competencies in caring for children with disabilities and providing treatment.
- **Teachers in inclusive, integrated and special education** – The educational system provides an essential platform for the participation of children with disabilities, yet the inclusion of children with disabilities into the Malaysian education system continues to be challenging. Recommendations focus on improving access to education and the quality of education delivered.
- **Social welfare services** – The DSW is the primary agency responsible for the provision of social

welfare services including supportive assistance, registration of children with disabilities, and links with CBR structures. Whilst there has been an increase in the number of CBR centres across Malaysia with an associated expansion in the coverage of services, stakeholder acknowledged that there remained a shortage of trained personnel and specialist therapists to provide on-going rehabilitative care at the local level, and that CBR centres were often under-equipped. Caregivers reported that CBR centres were often difficult to access due to their location, a lack of transport, and the indirect costs associated with attendance. To provide effective care, key components in their services need to be strengthened.

"Stigma and discrimination are the primary drivers of negative attitudes in society towards children with disabilities. These attitudes create barriers, denying dignity and challenging social integration and equality, and perpetuate a 'disabling environment'."

UNICEF, World Health Organisation & World Bank.

CONTENTS

TABLES

GRAPHS

Abbreviations

BM	Bahasa Malaysia
CSO	Civil society organisation
CBO	Community-based organisation
C4D	Communication for Development
CBR	Community-based rehabilitation
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of Persons with Disabilities
DSW	Department of Social Welfare
IEP	Individualised education plan
KAP	Knowledge, attitudes and practices
MOE	Ministry of Education
MOH	Ministry of Health
MWFCD	Ministry of Women, Family and Community Development
NECIC	National Early Childhood Intervention Council
NGO	Non-governmental organisation
PWD Act	Persons with Disabilities Act
SEN	Special education needs

Glossary

Anak syurga	Children of paradise
Biasa	Normal
Bobou	Deaf [Dusun Lebu]
Bokok	Blind [Bidayuh]
Bomoh	Traditional healer
Bongom	Deaf [Bidayuh]
Cacat	Handicapped
Istimewa	Special
Kelainan	Different
Kenan	Process of cause and consequence
Komokok	Handicapped [Dusun Lebu]
Kudung	Lost one limb
Kurang sempurna	Less than perfect
Manang	Traditional healer [Iban]
Orang kurang upaya	Less abled person
Orang kelainan upaya	Differently abled person
Pimpuri	Traditional healer [Bidayuh]
Qadha	Fate
Qadar	Destiny
Redha	Willingly accept
Santau	Black magic
Sempurna	Perfect
Sekolah Tunas Bakti	Rehabilitation Centre for Young Offenders
Tak padan tak taso	Lacking body parts [Kelantanese dialect]
Warganegara	Citizens

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Girl with physical disabilities at the graffiti wall during a participatory workshop for children with disabilities, Kelantan.

INTRODUCTION

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Children with disabilities are at greater risk of being marginalised than peers without disabilities and confront a variety of challenges in their daily lives including stigma, discrimination and societal barriers.

In 2010, Malaysia ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD), with reservations on Article 15 (prohibition of torture and ill treatment) and Article 18 (the right to liberty of movement and nationality). In doing so, the government of Malaysia committed to designing and implementing policies to combat stereotypes, prejudices and harmful practices relating to people with disabilities. The convention was acceded with a view to promoting and protecting the full enjoyment of human rights and freedoms of persons with disabilities, and outlined fundamental components that need to be created, improved or reinforced in order to ensure that people with disabilities in Malaysia could fully participate in life, on an equal basis with others.

People with disabilities can be considered as one of the most vulnerable minority groups in Malaysia (Kamaruddin 2007). Children with disabilities are at greater risk of being marginalised than peers without disabilities and confront a variety of challenges in their daily lives including stigma, discrimination and societal barriers. Poverty exacerbates these vulnerabilities. Children from poorer households are less likely to access education and healthcare, but children who live in poverty and have a disability have significantly reduced opportunities and face complex attitudinal, environmental and institutional barriers (UNICEF 2013).

UNICEF's work in middle-income countries such as Malaysia has transitioned in recent decades to focus on upstream policy and advocacy interventions, capacity development and evidence generation. Malaysia acceded to the Convention on the Rights of the Child (CRC) in 1995 and the CRPD in 2010. Whilst progress has been made in improving the lives of children with disabilities, critical issues remain including inequitable access to services and participation, and negative perceptions towards persons with disabilities that have been hard to overcome.

Such discriminatory views have a profound effect at all levels, from the development and life-course of children with disabilities, to the shaping of laws and policies at the national level. In their concluding observations to Malaysia's first periodic report, the Committee on the Rights of the Child made three key recommendations: that the country combats stigma and discrimination of children with disabilities; collects adequate statistical data on children with disabilities; and ensures that such data is used in the development of policies and programmes for children with disabilities.

A key component of UNICEF's new country programme (2016-2020) is to support the national government in realising the rights of all children, reducing disparities and fostering social inclusion. This is in line with the United Nations General Assembly's High Level Meeting on Disability and Development (2013) which urged increased understanding, knowledge and greater social awareness about persons with disabilities to eliminate discriminatory social and attitudinal barriers so that they participate fully in society.

Aims and objectives of research

UNICEF Malaysia commissioned a knowledge, attitude and practices study to expand national understanding of community perceptions of disability and provide an evidence base to inform communication for behaviour and social change that addresses the root causes of stigma and discrimination as experienced by children with disabilities and their families. The study had four core objectives:

- To assess the knowledge, attitudes and practices of society towards children with disabilities, children with disabilities themselves, and their peers without disabilities.
- To assess the life satisfaction and perception of children with disabilities towards their own impairment and that of their peers with disabilities.
- To analyse the root causes of stigma and discrimination faced by children with disabilities, and the drivers of the current attitudes.
- To establish a baseline to inform future interventions and strategies in communication for behaviour and social change.

The research comprised two related components: a quantitative KAP survey; and qualitative data collection using open, inductive and participatory methods. Adopting a mixed methods approach allowed for triangulation of material and increased validity of findings. The study was able to provide insight at community, institutional and policy levels and develop an evidence base that could be transformed into practical actions to promote behaviour and social change on the ground.

Report structure and outputs

Following the introduction, the study's methods are outlined in detail. A short contextual analysis of disability in Malaysia is then followed by the demographic details of the study participants. The core findings of the research are presented in four substantive chapters: knowledge about disability; attitudes towards children with disabilities; practices, the provision of and access to services; and perceptions and experiences of children and adolescents with disabilities. The final chapter presents the study's conclusions and key recommendations.

Prior to its finalisation, UNICEF and stakeholders were given the opportunity to provide written and verbal feedback that was incorporated into the final report as appropriate. The report is structured to be of operational use to UNICEF and its partners at local, national and international levels and presents valuable new data that contributes to the evidence base about children with disabilities in Malaysia.

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> **“There are two disabled people [in this drawing]. One cannot walk because he lost his leg in an accident and the other one was born blind. They are visiting the park, asking other people for help. They [children without disabilities] feel sad when they see the boy in the wheelchair because they pity him, he can’t play football.”**

Group of boys without disabilities share their story whilst one of them draw the experience, Sarawak.

Graffiti wall, participatory workshop with children with physical disabilities, Kelantan.

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STUDY METHODOLOGY

The research was conducted in line with prevailing ethical standards that seek to protect the rights and welfare of all research participants. Ethical permission to undertake the study was granted by the Medical Research and Ethics Committee (MREC) at the Ministry of Health, Malaysia. The research was supported by the UNICEF Malaysia Country Office, the Ministry of Health (MOH) and the Ministry for Women, Family and Community Development (MWFCD). Representatives from these ministries and the Ministry of Education (MOE) formed the study's Advisory Committee. The study ran from January 2016 to September 2016, including a period of intensive data collection in Malaysia in May-June 2016 (see timeframe in Annex 1).

Research team

The study was led by Anthrologica, in collaboration with the Centre for Disability Studies (CoDS) at Universiti Malaysia Sarawak. The overall project was managed by Juliet Bedford, Director of Anthrologica, who contributed to each stage of the research and provided technical oversight. The research was led and coordinated by Katie Moore, Research Associate with Anthrologica. In-country fieldwork was conducted by four teams led by How Kee Ling, Director of CoDS, and senior staff members Dolly bin Paul Carlo, Faizah bt Hj Mas'ud and Kamsiah bt Ali with support from Katie Moore. Each team consisted of the team lead and three local research assistants who were involved in data collection, data entry, transcription, translation, and conducting preliminary analysis. The quantitative analysis was undertaken by Michael Thiede, Director, and Nina Baltes, Research & Evaluation Associate, from Scenarium Group, one of Anthrologica's collaborative partners.

Study sites

Data collection was conducted in four states in Malaysia: Selangor and Kelantan in Peninsular Malaysia, Sabah and Sarawak in East Malaysia. The four states were selected by UNICEF Malaysia in line with their programmatic work and to ensure that ethnic, social and religious diversity was captured across the study as these determinants influence both policy making and service delivery.

Selangor is largely urbanised, heavily industrialised and has an ethnically and socio-economically diverse population. It encompasses the capital city, Kuala Lumpur. Kelantan, the large northern most state in the Peninsula, is more rural and the majority of the population are Malay, who by definition are Muslim. Sabah and Sarawak in East Malaysia (the northern area of the island of Borneo) are the two geographically largest states in Malaysia. In Sabah, most of the population are from different indigenous groups including Kadazan-Dusun, Bajau and Murut. There are also large Chinese and other non-Malay populations. Similarly, in Sarawak, the majority are from non-Muslim indigenous groups collectively known as Dayaks. Iban and Bidayuh are the most populous ethnic groups within the Dayak community which also includes Kenyah, Kayan, Kedayan, Punan, Bisayah, Kelabit, Berawan and Penan. Specific field sites in each state were selected by the research team in collaboration with UNICEF and in discussion with the MOH. In each state, the study was conducted in at least one urban centre and one rural area. In Selangor, the field sites were Lembah Klang and Kuala Langat; in Kelantan, Kota Bharu, Pasir Mas and Kuala Krai; in Sabah, Kota Kinabalu and Keningau; and in Sarawak, Kuching, Samarahan and Serian.

Participants and sampling

A comprehensive mapping of stakeholders was conducted and five primary participant groups were defined for inclusion in the study: national-level stakeholders; community members (community leaders, religious leaders, caregivers of children without disability); caregivers of children with disabilities (including parents, grandparents, guardians and non-related primary caregivers); service providers (health workers, community-based rehabilitation (CBR) workers, mainstream and special education teachers, community-based organisations); and children and adolescents (both with and without disabilities).

Central stakeholders were identified in consultation with UNICEF and key government representatives were contacted at the MOH, MOE and MWFCD. Representatives from a number of non-governmental organisations (NGOs) and civil society organisations (CSOs) were also engaged, and colleagues at the UNICEF Country Office.

Service providers, caregivers of children without disabilities and community members, were identified in each field site. The sampling of participants was purposive. Families with children with a range of disabilities (physical, learning, hearing, visual) were identified through collaboration with community-based organisations (CBOs) such as the Malaysia Partnership on Children with Disabilities (a consortium of NGOs and CSOs working at national and sub-national levels on disabilities, rights and services) and through rehabilitation services. These families were the core research participants. Children and adolescents were invited to participate in age appropriate workshops (10-15 years / 16-21 years), whilst their caregivers participated in either a focus group discussion or interview. The sampling was sensitive to impairment type, gender, age and ethnicity, and included Malay, Indian, Chinese, Kadazan-Dusun, Iban and Bidayuh respondents. Additional interlocutors were identified through interviewee referral sampling and snowball techniques. Table 1 below outlines the disability of the children and adolescents in each workshop.

Table 1. Workshop disability group per state

State	Group 1	Group 2
Selangor	Children with behavioural and learning disabilities	Adolescents with learning disabilities
Kelantan	Children with physical disabilities	Adolescents with physical disabilities
Sabah	Children with physical and learning disabilities	Adolescents with hearing impairments
Sarawak	Adolescents with learning disabilities	Children with learning, and behavioural disabilities

The KAP survey was administered to a cross section of the public including people who had no interaction with or personal knowledge of children with disabilities.

Members of the public were randomly recruited within the community: at market places, eateries, shopping areas, places of worships, hospitals and universities.

Caregivers of children with disabilities and professionals providing services and care for children with disabilities were also recruited for the survey.

Participants received no remuneration or other material benefits for taking part in this study. Children and adolescent who participated in the workshops were provided with light refreshments.

Across the four states, the study comprised 473 data collection activities involving a total of 756 participants. Thirty-eight focus group discussion (FGDs) were conducted with 229 participants; 102 individual in-depth interviews (IDIs) were conducted; 320 individual knowledge, attitude and practices (KAP) surveys were administered; and 16 child and adolescent workshops were conducted with 105 participants. Both FDGs and child and adolescent workshops had an average of 6 participants per group. Respondents engaged in the qualitative methodologies represented 57.7% of participants (436) whilst 42.3% of respondents answered the KAP survey (320). Table 2 below provides an overview of the study participants per data collection method used.

Consent

Prior to commencing each data collection activity, informed consent was obtained. Researchers provided a full explanation of the study and emphasised the voluntary, confidential and anonymous nature of participation. All participants were given the opportunity to ask questions and for further explanation. Participants willing to take part signed the study's consent form (see English language version in

Table 2. Overview of study participants

Activity	Participant Group	Selangor	Kelantan	Sarawak	Sabah	Total
IDI	Caregivers of children with disabilities	8	9	8	8	33
	CBR workers	4	4	4	5	17
	CBO representatives	4	4	4	3	15
	Health workers	4	4	4	3	15
	State and local government representatives	2	2	2	2	8
	Teachers	2	2	2	2	8
	Central stakeholders	6	-	-	-	6
	Total number of participants	30	25	24	23	102
FGD	Caregivers of children with disabilities	12	17	11	18	58
	Caregivers of children without disabilities	7	14	7	9	37
	Community and religious leaders	10	14	7	11	42
	CBO representatives	7	12	11	4	34
	CBR workers	5	10	9	10	34
	Teachers	3	5	8	8	24
	Total number of participants	44	72	53	60	229
	Children with disabilities	8	10	6	5	29
	Children without disabilities	8	8	7	9	32
	Adolescents with disabilities	6	4	1	6	17
	Adolescents without disabilities	8	6	10	3	27
	Total number of participants	30	28	24	23	105
KAP	Urban participants	40	40	40	40	160
	Rural participants	40	40	40	40	160
	Total number of participants	80	80	80	80	320
Total	**Number of participants**	**184**	**205**	**181**	**186**	**756**

Annex 2). After the pilot study, the national research team suggested that if a participant did not want to provide a written signature, the option of verbal consent should be offered. In the few cases where this was necessary, the participant's verbal consent was recorded.

Particular attention was given to the consent procedure at the start of each child and adolescent workshop. The study and workshop objectives and the individual's participation were explained in detail to their parent or caregiver who was asked to complete the study's consent form. Similarly, the study and their participation were explained to the children and adolescents in an appropriate and accessible manner and they were asked for their assent. Child and adolescent participants were given the opportunity to also complete the written consent form if they wished.

At the conclusion of the fieldwork, all completed consent forms were retained in hard copy by Anthrologica.

Data collection

Data was gathered through a combination of the following methods:

- Desk review of data and literature, both qualitative and quantitative
- IDIs with key informants and stakeholders
- FGDs with key informants and stakeholders
- Participatory workshops with children and adolescents with and without disabilities
- KAP survey with general public and those with and without experience of children with disabilities
- Feedback workshops with UNICEF, MWFCD, the Department of Social Welfare, and representatives from NGOs and CSOs.

Tool development: Following the in-depth review of literature and programme documentation at the beginning of the research, a topic guide was developed by Katie Moore and Juliet Bedford to highlight key themes from the literature. This formed the basis for the design of a series of research tools including: semi-structured in-depth interview and focus group frameworks per stakeholder group; participatory workshop frameworks; and the KAP questionnaire. The KAP tool was developed in collaboration with the Scenarium Group. The tools included a broad spectrum of research questions linked to knowledge, attitudes and practices about children with disabilities in Malaysia and to the perceptions and experiences of children with disabilities and their families. Prior to pilot testing, colleagues from UNICEF, CoDS and the Advisory Group were invited to provide feedback on the tools. The national research team then translated them into Malaysia's three most widely used languages, Bahasa Malaysia (BM), Chinese and Tamil. The portfolio of final tools in English is presented in Annex 3.

Training and pilot testing: Katie Moore and Juliet Bedford conducted a three-day training in Kuala Lumpur with the 16 person national research team that included detailed briefings about the project and its core objectives. The training aimed to build skills and capacity about the qualitative and quantitative research methodologies adopted (particularly the participatory workshops with children and adolescents), and provided guidance for the production of English transcripts of all data (stressing the need for word-for-word translation that avoided personal interpretation or inclusion of opinions). Aspects of ethics, consent and confidentiality were emphasised. The training also introduced UNICEF's approach to Communication for Development (C4D) to the national research team, and gave an overview of the agency's programmatic work. On the final day, the tools were piloted in an area of Kuala Lumpur that was not going to be used for data collection. This provided a valuable opportunity for the research teams to familiarise themselves with the tools and test them in action. Following the pilot, the tools were refined and methodological concerns addressed to ensure high quality and consistent data collection by all team members. Substantial time was spent ensuring the language, particularly in the KAP survey, was clear and accurate and modifications were made across the different language versions as appropriate.

Interviews and focus group discussions: Efforts were made to ensure the space used for the interview and FGD was as private and neutral as possible. The actual location of each activity depended on what was available and appropriate in each study site. For community members, caregivers of children with disabilities and children and adolescents themselves, interviews and focus group discussions were held in community spaces, rehabilitation centres and schools. For service providers, the sessions predominantly took place in their place of work. The majority of interviews and FGDs were conducted in BM and Chinese, with consecutive translation between dialects when necessary. Tamil was only used for a small number of activities in Selangor. The national research team included assistants familiar with the local contexts and languages of each field site, and participants were encouraged to use the language they were most confident communicating in (in Kelantanese for example). In Sabah and Sarawak, the research team used local indigenous languages (Bidayuh and Kadazan-Dusun) when appropriate. The direction of each interview and FGD was directed by participants and allowed for the co-production of knowledge, but the facilitators ensured all the key themes were covered. Follow-up prompts and probes were used to obtain greater detail and clarity when necessary. Each interview lasted for approximately 60 minutes and each FGD for 90 minutes, and all were audio recorded.

Child and Adolescent Workshops: Specific participatory methods were employed for the child and adolescent workshops to ensure meaningful engagement and integration, and the workshops were facilitated by the lead researcher, Katie Moore. Each session opened with a clear introduction to the study and overview of the workshop, during which participants were encouraged to ask questions. Attention was given to each participant to confirm they understood the purpose of the workshop and were happy to participate. In a number of cases this was done on a one-to-one basis. Ground rules including the need to respect one another, listening to others and maintaining confidentially were established. Participants introduced themselves through energising icebreaker exercises. The workshops were structured around three key activities designed to encourage participants to convey their ideas, experiences and perceptions of disability in appropriate ways. Activities were adapted based on the needs and abilities of each specific group and included story circles and drawing (to express the participants' own experiences); graffiti walls (to depict perceptions of the lives of people with disabilities); language and world mapping games (to explore positive and negative terminologies related to disabilities); and drama and role plays, in which participants acted out challenges linked to disability and how they could be resolved or overcome. After each activity, a discussion about the content and emerging ideas was facilitated, and follow-up questions and probes were used to delve deeper or to clarify certain points.

Specific efforts were made to create an open, dynamic and safe space and to remove any potential preconceptions linked to mobilisation through CBR centres or schools. Most of the children and adolescents without disabilities who participated in the workshops, had some level of exposure to peers with disabilities, both directly (e.g. having family members with a disability) and indirectly (e.g. seeing people with disabilities in their community, at the market or in public places). Consequently, some of the material the participants generated during the workshops was based on their own lived experiences, whilst others developed created or imagined scenarios that were rooted in their knowledge and perception of disability (for example, imagining some of the challenges a person with disability faces on a daily basis). Workshops lasted for approximately 90 minutes and were conducted in English, BM and local dialects as most appropriate, with the national research team providing additional translation for Katie Moore where necessary. Each workshop was audio recorded, and photographs taken of the material created by participants.

KAP survey: Researchers were trained to strictly follow the questionnaire, asking the question as written in the survey. If it was an open question, the respondent would be asked for their answer(s), but if the question had prescribed answer options, all options would be provided to the respondent before answering. The survey used check boxes to record most answers. Certain questions allowed for more detailed qualitative responses, and the researcher would then note the key points in the text box provided. Every question included a 'No answer option' and an 'Other' answer option, for which the answer given was recorded. The survey took approximately 40 minutes to administer.

Mid-term review: Tools and methodological issues were reviewed and refined throughout the research, and amendments made if appropriate. The four team leads and Katie Moore were in regular contact throughout, and issues arising were shared across the research teams whilst they were in the field. A mid-term review was held following the first week of data collection in each state. Team leads, with input from all the research assistants, prepared a summary document that included: an update on participants, recruitment and sampling; an outline of initial practical and methodological challenges; emerging themes and key considerations; and other reflections. The four summaries were circulated to the whole research team for review. This provided a valuable opportunity to share lessons and experiences, to assess data quality and discuss how to best overcome or mitigate limitations faced in the first phase of the research. The midterm review was an effective way of ensuring that all researchers adopted consistent methods and a standardised approach throughout the study.

Feedback workshop with central stakeholders: At the conclusion of the in-country data collection, key findings were presented to a variety of stakeholders during three roundtable workshops. The first workshop was conducted with representatives from the Department of Social Welfare (DSW) and MWFCD. It had been intended that representatives from the Ministries of Health and Education would also attend, but due to a session in Parliament this was not possible. Feedback was therefore provided informally to representatives from these two Ministries. The second feedback workshop was held at the UNICEF Country Office with 20 members of the Malaysian Partnership for Children with Disabilities and other

CSOs. The third workshop was held with colleagues from different sections of the UNICEF country office in Malaysia. All three roundtables were conducted by Katie Moore and How Kee Ling with input from Phenny Kakama. During the workshops preliminary findings were presented and discussion facilitated around emerging themes. The timeframe, deliverables, and plan to disseminate the study's findings were outlined, and the workshop finished with a valuable question and answer session. Each workshop lasted for between one and a half and two hours. Notes were taken by the research team and Phenny Kakama to ensure key comments, feedback and questions were captured.

Data management, transcription and translation

Each data collection session was given a unique code for identification to ensure that participant anonymity was maintained.

In each state, the research team entered the KAP survey data into Excel spreadsheets on a daily basis and the database was backed-up on external USB drives and subsequently uploaded to Dropbox. At the conclusion of data collection, all hard copies of the completed KAP questionnaires were submitted to Anthrologica. Data entries were checked for inconsistencies and translations were reviewed against the original questionnaires before the datasets were collated and cleaned by Katie Moore.

During fieldwork, the recordings of all qualitative data collection sessions were uploaded onto the research assistants' computers and backed-up on a daily basis. One team member in every state was responsible for backing up all files each day and ensuring that files were stored securely and confidentially. Throughout the data collection period, the recordings were copied and securely transferred to Dropbox from where they were downloaded and stored by Katie Moore.
The four research teams were responsible for the transcription and translation into English of the data they collected. The team leads double-checked a selection of transcripts with their original audio files for quality assurance and any inconsistencies were reviewed and resolved. They also reviewed each completed transcript for coherence and accuracy and amended it in accordance to the audio file as necessary. All transcripts were submitted to Anthrologica by the national research team.

Data analysis

Preliminary analysis of qualitative and quantitative data was conducted throughout the data collection process. All the research team had access to the growing body of data and preliminary analysis of qualitative and quantitative material was conducted throughout as part of the data collection process.
At the end of data collection, the national assistants drafted a summary analysis of the research conducted, based on their field notes, and the team leads used these to draft an overview of findings and key considerations for each state. This was shared with Katie Moore as part of the preliminary analysis.

The full analysis of all qualitative data was conducted by Katie Moore using thematic analysis. Dominant themes were identified through the systematic review of interviews, focus group discussions and child and adolescent workshops and field notes. Salient concepts were coded and their occurrence and reoccurrence labelled by hand. The emerging trends were critically analysed according to the research objectives. Particular sections of *ad verbatim* narrative were used to build case studies and included in the report to ensure the participants' voice was captured and maintained. The analysis process was systematic and transparent.

The quantitative data of the KAP survey was primarily analysed by Scenarium Group using Stata software. The data was cleaned and checked, and new coding was only introduced for the survey's open-ended survey questions, including questions related to occupation, special services and barriers. For these questions, responses were grouped into meaningful categories and coded accordingly. The analysis plan was based on the survey's key areas (demographics, knowledge, attitudes, practices and communication). The quantitative analysis was largely descriptive, using cross-tabulation to provide a general overview of characteristics and trends. The scope of the analysis was then extended to provide key insights on research questions of specific interest. The analysis of the KAP survey data formed part of a mixed-methods approach that aimed to integrate the qualitative and quantitative results. Particular findings arising in one data set were purposively explored in the other. This triangulation approach followed the convergence model, and finally, the qualitative and quantitative findings were merged into one overall interpretation (Creswell & Plano Clark, 2011). Wherever possible, quantitative results were used to confirm or corroborate qualitative findings in order to provide a high level of validity to the analysis and evidence-based conclusions.

Methodological limitations

The study had a wide geographical scope, which combined with a limited timeframe, budget and human resources, posed a certain set of challenges. Throughout the research, the team sought to mitigate the impact of these issues by employing a carefully developed pragmatic methodology and by efficiently utilising resources available.

Given Malaysia's diverse composition, it is unlikely that the study's results are fully generalisable. However, saturation of findings was achieved per location, per participant group and across the study as a whole and the results are therefore broadly representative and can be largely corroborated by the findings of other published research. Where differences or contradictions occur, they are highlighted in the report.

Recruiting the majority of participants through NGOs, CBOs and CBR centres may have led to bias as the majority of children and adolescents receiving services were likely to be registered with the DSW as having disabilities. Those who were not registered or who were not engaged with services were less likely to have been recruited into the research. Efforts were made to overcome this by identifying participants via gatekeepers and key informants (including community and religious leaders) to ensure that the most vulnerable, isolated and under-served families and individuals were included.

In order to capture the voices and experiences of children and adolescents with different disabilities, it was agreed that each workshop would recruit participants with a particular type of disability (see Table 1 above). Children and adolescents with hearing or visual impairments attended special schools, and recruiting participants with these disabilities proved more difficult than recruiting through CBR centres or CBOs. Although they were, in principle, supportive of the participatory workshops, the schools required a letter of authorisation from the Ministry of Education in order to facilitate access to their students. Despite on-going communication with the Ministry at both national and state levels, letters were not issued. In addition, fieldwork was undertaken at a time when many special schools were on holiday and children were at home with their families. As a result, the workshop that had been planned for adolescents with visual impairment in Selangor not possible. In order to ensure that voices of this group were captured the research team identified several individuals via the Malaysia Association for the Blind, and one was recruited for interview.

It was possible that participants may have expressed answers that they perceived to be appropriate or socially desirable. This was most noted by the research teams in relation to value judgments participants associated with disability. On direct questioning, respondents were likely to suggest that children with disabilities should be treated equally. When the research team probed deeper, however, it became clear that many respondents felt children with disabilities should not attend mainstream schools; should not have friends or marital partners; and should take part in activities with non-disabled. Similarly, many respondents recognised the need for children with disabilities to be treated without discrimination and with respect but continued to refer to these children as *cacat* (handicapped). The issue of socially desirable answers was raised during the introduction to each activity. Participants were encouraged to speak openly and honestly about their opinions and beliefs without concern. The frank and sincere dialogue elicited from participant discussions suggests that such socially desirable bias was minimised.

Due to the composition of the research team, activities were conducted in a variety of languages. Researchers in each setting asked participants their preferred language of communication and were able to adapt accordingly, in some cases using a mix of languages. In focus groups and workshops, communication was primarily conducted in English, BM (in Peninsular Malaysia) or in the most common dialect of the group (in Sabah and Sarawak). All members of the research team spoke English and BM, and most spoke a third language (Chinese, Tamil, Kadazan-Dusun, Iban, Melanau and / or Bidayuh). Risks associated with miscommunication or mistranslation were minimised by thoroughly briefing the research teams during training, agreeing to use short phrases of speech, and by repeating and cross-checking specific sections of narrative with participants.

One of the participatory workshops in Sabah was conducted with adolescents with hearing impairments. A local interpreter (with whom the participants were familiar) was asked to sign for the respondents and translate their responses to Katie Moore in English. The interpreter was fully briefed prior to the workshop and the research team frequently asked for clarification to ensure full and nuanced answers were being accurately communicated.

The KAP survey generated rich and comprehensive information, however, due to the breadth of the information captured, the resulting data set did not lend itself to inferential analysis. Thus, the quantitative analysis was largely descriptive, using cross-tabulations to provide key insights. The survey provided a valuable overview of particularly characteristics and tendencies, and its strength lies in the mixed-method approach whereby the data can be triangulated with and used to further verify the more nuanced qualitative data.

Girl with Cerebral Palsy at a participatory workshop for children with disabilities, Sabah.

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BACKGROUND CONTEXT

3

International conventions

Movement towards inclusion of children with disabilities in society is enshrined by the UN's promotion of, and commitment to, the human rights of all people with disabilities. The CRC upholds the rights of children with disabilities to reach their fullest potential through social integration and cultural and spiritual development. In order to support children with disabilities to achieve this, the CRC outlines children's right to education, training, health and rehabilitation services, recreation and preparation for employment. In 1995, Malaysia ratified the CRC, but at the time held reservations on 12 of the Articles. Over the past 20 years the government has lifted all but five reservations, two of which are directly applicable to children with disabilities: Article 2, concerning non-discrimination; and Article 28 (1)(a) regarding compulsory education.

In 2010, the government ratified the CRPD, again with reservations to specific Articles and refused to accept the Optional Protocol to the CRPD. The Option Protocol for the CRPD is a legal instrument to help strengthen the implementation of the convention. It provides a redress mechanism for individual communication procedures and an individual inquiry procedure (UN SCRPD, 2013) that safeguards the complaints process for people who believe a party to the convention may be in violation. The government asserts that its justification for rejecting the Optional Protocol and not accepting the full convention were made 'taking into account relevant constitutional provisions and the Islamic law which together form an integral part of the country's legal framework' (UN General Assembly, 2014). Failure to accept the Optional Protocols means that not only does the government have no clear procedure for redressing issues, but legal action against the government for violations of the rights of people with disabilities is explicitly prohibited.

National policies for children and people with disabilities

At the national level, policies and strategies for children with disabilities are subsumed under two Acts; the Child Act (2001); and the Persons with Disabilities Act (2008). The Child Act (2001) has facilitated significant progress on the rights of the child in Malaysia and is based on four pillars of the CRC: non-discrimination; best interest of the child; the right to life, survival and development; and respect for the views of the child. Since its introduction, many initiatives to realise and uphold the rights of children have been advanced by both government and CSOs. Challenges remain however, particularly concerning marginalised and disadvantaged groups of children (including children with disabilities) (CRCM, 2012). Following the submission of Malaysia's first report to the Committee on the Rights of the Child in 2006 it was recommended that the Child Act (2001) be amended to ensure that the provision of liberty conforms with the CRC (UNICEF, 2008).

Enacted in 2008, the Persons with Disabilities (PWD) Act defines persons with disabilities and seeks to protect their rights by outlining obligations to ensure access to education, employment, healthcare, recreation and rehabilitation services (Laws of Malaysia, Act 685, 2008). The Act legislates for the establishment of a national body, the National Council for Persons with Disabilities, to help oversee and monitor national policies and action plans for people with disabilities (Laws of Malaysia, Persons with Disabilities Act, 2008). Despite the progress made for the provisions of rights through the introduction of the PWD Act, there are no penalties for non-compliance. The lack of a provision for redressing those who violate or discriminate against people with disabilities has been problematic, and the prohibition within the Act for persons to take a legal claim against the Malaysian government for violations of rights of people with disabilities, has led many critics to call the PWD's Act a 'toothless tiger' (US Dept. of State, 2010). Given these shortcomings, critics have challenged the Act and called for amendments to be made to ensure that provisions are pursuant to the CRPD and that the rights of all people with disabilities are comprehensively reflected.

Within both the Child Act (2001) and the PWD Act (2008) no specific legislation for children with disability exists. The policies under which children with disabilities are protected are subsumed within these acts and include:

a) National Policy for Persons with Disabilities and National Plan of Action for Persons with Disabilities, which covers access to education, healthcare, information, public facilities, public transportation system and recreation, sports and leisure.

b) National Policy for Children and Action Plan, which covers survival, protection, development, participation and advocacy.

c) National Child Protection Policy and Action Plan, which covers protection of children who have been abused, neglected or ill-treated.

Definition and registration of disabilities

The government of Malaysia recognises people with disabilities to 'include those who have a long term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society' (Laws of Malaysia, Persons with Disabilities Act, 2008). Although there is no single nor definitive legal or policy framework for classifying people with disabilities across all sectors, the Ministry of Women, Family and Community Development (MWFCD) developed a disability categorisation system to enable them to effectively register adults and children with disabilities. In order to be registered, the disability must be eligible under one of the seven categories: hearing disability; visual disability; speech disability; physical disability; learning disability; mental disability; or 'other' disabilities, which includes children with multiple disabilities, or those for whom the other categories are not 'appropriate' (UNICEF, 2014).

The State of the Worlds Children's Report (2013) found that statistics that capture data on all children, are essential for an equitable society. In order to be included, however, a child must be visible and counted. Sound data collection and analysis is therefore essential for ensuring that children with disabilities have equal rights in society, and analysis should include enhanced statistical research and disaggregation of data (UNICEF, 2013). Obtaining reliable data and information on children with disabilities in Malaysia continues to be challenging – the lack of a comprehensive and structured system of data collection is compounded by the weak relationship between registration and service provision (Amar-Singh, 2008). The initial detection of disabilities in children is coordinated by various agencies: the Department of Social Welfare (DSW); the Ministry of Health (MOH); and the Ministry of Education (MOE). Each collect and maintain distinct streams of data on children with disabilities, but the respective datasets are not collated. In 2008 when the Disability Act was passed, a review of the classification of disabilities was conducted by the three ministries. The system was modified to ensure that psychiatric cases and persons with chronic diseases with functional disabilities were adequately classified and included. However, this fuelled complications and errors in reporting accurate figures, and led to international and national pressure to integrate data collection systems.

Registration of disability is not compulsory. People register details on a voluntary basis without obligation and this contributes to the incomplete and misrepresentation of statistics on disability (Islam, 2015). According to the DSW, the number of people registered as disabled in Malaysia was 359,203 in 2011 and 445,006 in 2012, marking an increase of 85,803 registrations over the course of the year. Based on these figures, it can be estimated that 1.5% of the total Malaysian population are people living with disabilities, however this is likely to be a conservative estimation (UNICEF, 2014) and in the National Health and Morbidity Study (2015), prevalence of disability amongst adults was reported to be 3.3%. Amar-Singh (2008) suggested that reported figures are a 'gross underestimate'. Although the National Health and Morbidity Survey (2006) reported that 90% of children with physical disabilities were registered with the DSW, Amar-Singh (2008) asserted that a significant number of children who were referred to the DSW were not added to the national register (Amar- Singh, 2008). Low uptake of registration of children with disabilities has been attributed to several factors including parental fear that registration of a child with disabilities could lead to stigmatisation and discrimination, and could pre-determine choices in a child's life such as enrolment to school, access to healthcare and participation in society (UNICEF, 2014).

In order to overcome the lack of data and estimate the rate of disability amongst children in Malaysia, Amar-Singh suggested a better representation may be extrapolated using UN guidelines (UN SCRPD,

2013) and from international studies (Bhasin et al., 2006; Wing & Potter, 2002; Rydz et al., 2005; Boyle et al., 1994) which suggest that 10% of all children in a population will suffer developmental issues or disability. Applying a rate of 10% to the population of 9.5million children under 18 years of age as recorded in the 2010 census (UNICEF & EPU, 2013) would therefore indicate that approximately 950,000 children in Malaysia are living with a disability.

The lack of comprehensive and reliable statistics on the prevalence of disability amongst the population, and specifically amongst children, poses a great challenge and has a direct impact on the provision of effective policies targeted at children with disabilities.

Stigma and discrimination

Stigma and discrimination are the primary drivers of negative attitudes in society towards children with disabilities. These attitudes create barriers, denying dignity and challenging social integration and equality (UNICEF, 2013) and perpetuate a 'disabling environment' (WHO & World Bank 2011). The stigmatisation of children with disabilities can lead to systemic isolation from mainstream social, cultural and political opportunities and is a fundamental barrier to the participation of children with disabilities in society, increasing their invisibility and vulnerability to exploitation (UNICEF, 2013).

Stigma describes a set of prejudicial attitudes, stereotypes, discriminatory behaviours and biased social structures endorsed by a sizeable group about a discredited subgroup of people deemed dangerous, undesirable or unworthy (Corrigan, 2000; Major and O'Brien 2005; Thornicroft et al., 2007). When an individual's identity, or the social group of which they are part, experiences stigma they are negatively categorised by broader society (Read et al., 2015). Their failure to conform to 'mainstream' ways of communicating, behaving and participating results in the generation of a marginalised, stigmatised status through which they are defined as 'other' (Aston et al., 2014).

Normative culture moulds the way in which stigma is understood. Yang (2007) suggested that the cultural setting can facilitate a more nuanced understanding of how stigma affects people and their families within that setting (Yang, 2007). Ng (1997) supported this perspective and asserted that socio-cultural context, specifically in Asia, must be considered to better understand the origins, meaning and consequences of stigma in relation to disability in a given location (Ng, 1997).

Evidence suggests that the quality of life of persons with disabilities, and that of the broader community, improves when people with disabilities actively voice their concerns and participate in decision-making (ESCAP, 2000). Contrary to this, stigma and discrimination propagate internalised barriers for inclusion of children with disabilities in society. Internalised barriers are obstacles, perceived or otherwise, that an individual may face in how they function and participate in society (Bruijn et al., 2012). Lowering expectations about a child's capacity as a result of him / her having a disability can reinforce beliefs that individuals with disabilities are less able, and can consequently lead to low confidence and aspirations, contributing to self-stigma amongst children with disabilities themselves (DFID, 2000; WHO & World Bank, 2011; Mont, 2014). By assimilating and self-identifying social stereotypes, a child's self-esteem and self-efficacy may be diminished and this can result in social isolation and a hesitancy to participate in society (Lauber & Rössler, 2007).

In their systematic analysis of studies, Macmillan et al. (2014) identified that contact with people with disabilities was associated with more positive societal attitudes towards disability (Macmillan et al., 2014). Stigma and discrimination can lead to people with disabilities being isolated and withdrawing from active participation in society, but that isolation further reduces societies' exposure to children with disabilities thereby perpetuating the negative attitudes. The conclusions of a study involving teachers in Penang resonate with this. The teachers discussed contact between children with disabilities and non-disabled students. Findings suggested that pupils' early exposure to children with disabilities resulted in reduced stigma from other students who were more likely to develop generosity and tolerance (Lee & Low, 2013). One teacher concluded, *'Because they mix with the regular children, I feel that it's also good for the regular children. They also can help. Regardless of whether it's a normal, or special child, then they all help each other.'* Little research has been conducted with children with disabilities in Malaysia themselves to reinforce these findings or to understand personal identity, perceptions of their own impairment or their own attitudes towards disability.

Stigmatisation and negative attitudes towards children with disability, does not stop at the individual, they can also affect family members. A substantial body of literature exists which highlights that raising a child with a disability significantly impacts family caregivers and parents (Werner & Shulman, 2013) particularly mothers (Shobana & Saravanan, 2014). Asian societies tend to be family orientated. In Malaysia specifically, 'family care' is a heavily weighted tradition, and great social value is assigned to ensuring the wellbeing of family members (Bakar et al., 2014). Investigations into different forms of stigmatisation across Asia have found that family plays a crucial role in the stigmatising process and the stigma of disability has an influence on the entire familial unit (Lauber and Rössler, 2007).

Stigma significantly impacts the quality of life of family members. Family members themselves can be subjected to stigma and negative attitudes through association, particularly mothers of children with disabilities, who are often blamed for having borne a child with a disability (Mamba, 2010). A study in Sarawak assessing perceived quality of life in mothers with a child with Down Syndrome found associations between specific background characteristics (Chan et al., 2013). Characteristics which were found to be significantly associated with a decreased quality of life included: rural locality; lower attained maternal education; lower household income; single status; and older maternal age (Chan et al., 2013). Another quality of life study conducted with families with a child with a disability across five districts in Kelantan reported that among families assessed, characteristics associated with a lower level quality of life and family functioning were: female parents and caregivers; non-Malay parents and caregivers; parents and caregivers with a male child with a disability; and children with multiple disabilities (Isa, 2013).

Parental attitudes towards disability can also be correlated to disability type. In Kuala Lumpur, Shobana and Saravanan (2014) observed that mothers of children with autism and mothers of children with an intellectual disability held negative attitudes about and towards disability, whilst mothers of children with Down Syndrome perceived disability more positively (Shobana and Saravanan, 2014). A further study in Peninsular Malaysia suggested that negative parental attitudes could hinder a child's likelihood to be a productive member of society creating barriers to vocational training and formal employment (Lee et al., 2011).

> **"…but I'm the only one in the whole kampong [village] who plays basketball. It's lonely lah. I wish I had a normal brother like other people do… I wish to have the chance to teach basketball to my 'normal' brother."**
>
> The sibling of a boy with Cerebral Palsy talks about how he feels having a brother with disabilities and his drawing illustrates the difficulty he feels.

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A student with visual impairment uses a computer at a school in Setapak for students with visual impairment where he listens and responds to a learning session via special text-to-speech listening software.

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PARTICIPANT DEMOGRAPHIC DETAILS

4

The demographic details of the respondents are presented in Table 3 below.

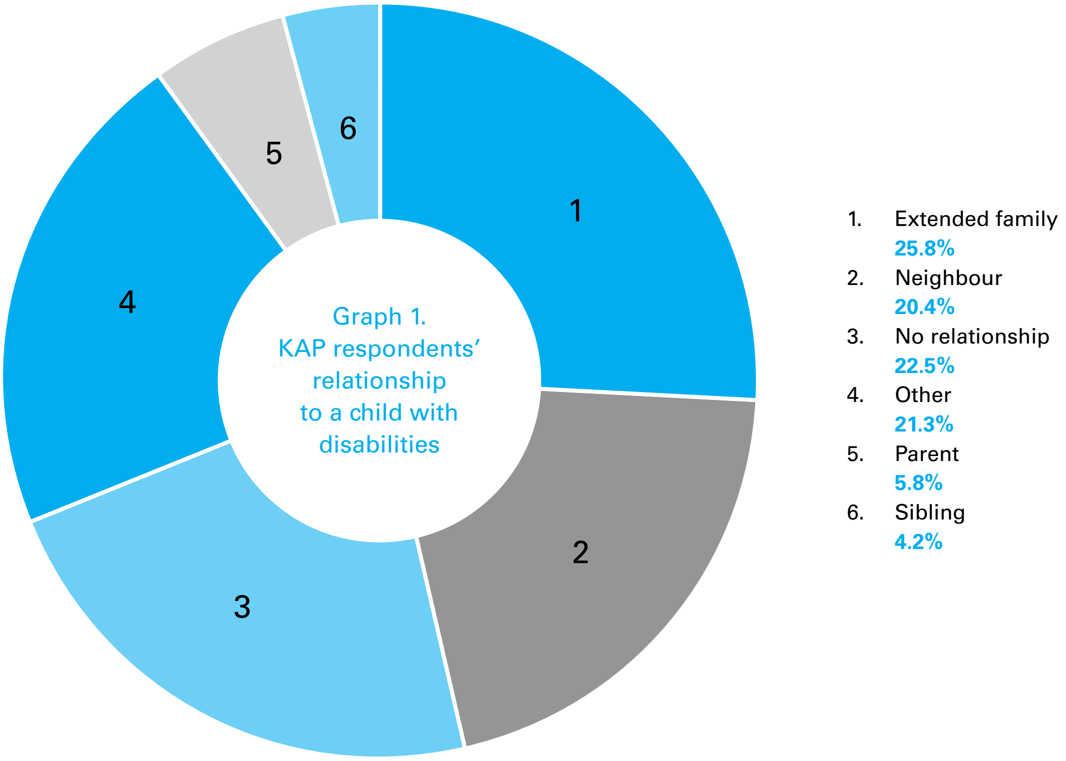
Table 3. Demographic details of respondents

Activity	Quantity / Quality	Quant	Qual	Quant	Qual	Quant	Qual	Quant	Qual
Participants	No. of participants	80	74	80	97	80	77	80	84
Location	Urban	40	44	40	61	40	48	40	52
	Rural	40	30	40	36	40	25	40	31
	No response	0	0	0	0	0	4	0	0
Gender	Male	40	22	39	36	43	18	30	25
	Female	40	52	41	61	37	59	50	58
Age	Average	35	40	36	41	36	42	35	41
	Range	19-74	19-68	19-64	21-75	20-68	22-63	18-74	22-68
	Married	30	50	51	78	40	64	38	69
	Single	46	17	28	18	36	11	36	14
	Other	3	0	1	0	4	0	5	0
	No response	1	7	0	1	0	2	1	0
Religion	Islam	39	50	74	93	24	32	23	24
	Hindu	17	11	0	0	0	0	0	0
	Christian	8	6	0	0	47	38	42	56
	Buddhist	16	1	6	1	8	2	11	1
	Other	0	6	0	3	1	5	4	2
Ethnicity	Malay	38	51	72	93	22	31	6	3
	Chinese	22	8	6	2	15	14	16	5
	Indian	17	11	0	0	2	0	0	0
	Iban	0	1	0	0	17	2	1	0
	Bidayuh	0	0	0	0	17	19	0	0
	Kadazan-Dusun	2	0	0	0	0	0	40	56
	Other	1	3	2	2	7	11	17	19

Education	No education	0	0	2	2	1	2	1	0
	Primary school	4	1	6	10	12	8	6	4
	Secondary school	28	28	30	46	38	35	48	32
	Tertiary level	46	38	32	35	29	27	22	35
	Other	0	0	7	0	0	0	3	4
	No response	2	7	3	4	0	5	0	8
Occupation	Public sector	8	34	26	31	13	43	9	41
	Private sector	56	11	45	21	19	5	44	11
	Farmer / fisherman	0	0	0	0	9	4	0	4
	Self-employed	2	0	1	2	3	0	1	4
	Housewife	4	8	5	20	12	12	7	11
	Student	8	0	0	0	12	0	15	0
	Other	2	21	3	23	12	13	4	12

Eighty KAP surveys were administered in each of the four states, with a total of 320 respondents, representing 42.3% of the study's overall sample. Of the KAP respondents, 47.5% (152) were male and 52.5% (168) were female. The age of respondents ranged from 17 to 74 years, and the average age was 35.5 years. In Kelantan and Selangor the majority of the participants were Malay (90% (72) and 47.5% (38) respectively). In Sabah, 50% of respondents (40) were Kadazan-Dusun, and 42.6% of respondents (34) in Sarawak were Iban and Bidayuh. Across the survey, 49.7% (159) of respondents were married, 45.6% (146) were single, 4.1% (13) provided the answer 'Other', and 0.6% (2) gave no response.

In terms of the highest level of education achieved, 40.3% of KAP respondents (129) had attained tertiary level education, 45% (144) secondary level and 8.8% (28) had attended primary level education. In terms of income 47.7% of respondents (153) earned under MYR 2,999 per month, 28% (90) earned between MYR 3,000-5,999 per month, and 25% (80) confirmed they earned over MYR 6000 a month. Almost half of all the respondents (46.3%, 148) worked in the private sector. Further demographic details of the KAP respondents are presented in Annex 4.

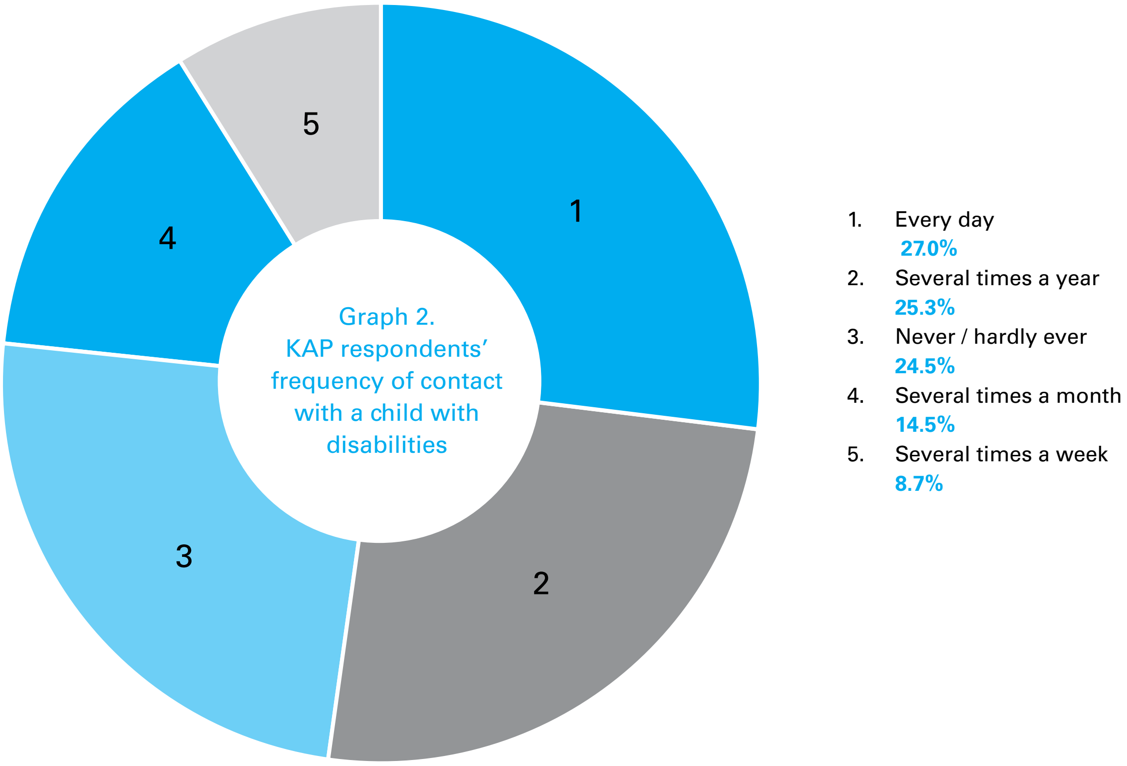


Graph 1. KAP respondents' relationship to a child with disabilities

In the KAP survey, 77% of respondents (238) confirmed that they knew a child with disabilities: 25.8% (62) had a child with disabilities in their extended family; 20.4% (49) were neighbours with a child with disabilities; and 22.5% (54) reported that they had no direct relationship, although they did know of a child with disabilities (see Graph 1 below). Of those who did have a direct relationship, 27.0% (65) had interaction with the child every day; 14.5% (35) saw them several times per month; and 25.3% (61) saw them several times a year (see Graph 2 below).

There were 331 participants in IDIs and FGDs across the study, representing 43.7% of the overall sample. Of these, 30.5 % (101) were male and 69.5% (230) were female. The age range of participants ranged from 18 to 74 years, and the average was 41 years. Across the study, 53.8% (178) participants were Malay, 8.8% (29) were Chinese, 3.3% (11) were Indian, and 34.1% (113) were from another ethnic group. The diversity of ethnicity varied across the study states. In Selangor and Kelantan, the majority of participants were Malay (68.9 % and 95.9% respectively), where as in Sabah and Sarawak, the majority were from indigenous groups (90.4% in Sabah, and 41.6% in Sarawak). Across the IDIs and FGDs, 78.9% (261) of participants were married, 18.1% (60) were single and 3% (10) gave no response. In reporting their highest level of education achieved, 40.8% (135) participants reported tertiary education, 42.6% (141) secondary education, and 6.95% (23) primary education. Income ranges were not gathered, but in contrast to the KAP survey respondents nearly half of the qualitative participants (45%, 149) were employed in the public sector.

In the workshops for children and adolescents, there were 105 participants, representing 13.9% of the overall sample. There were 51.4% (54) male and 48.6% (51) female participants. Of the participants, 58.1% (61) were involved in workshops for children aged 10 to 15 years, and 41.9% (44) in workshops for adolescents aged 16 to 21. Across the study, 52.5% (32) children and 47.5% (29) adolescents had disabilities.



Graph 2.
KAP respondents' frequency of contact with a child with disabilities

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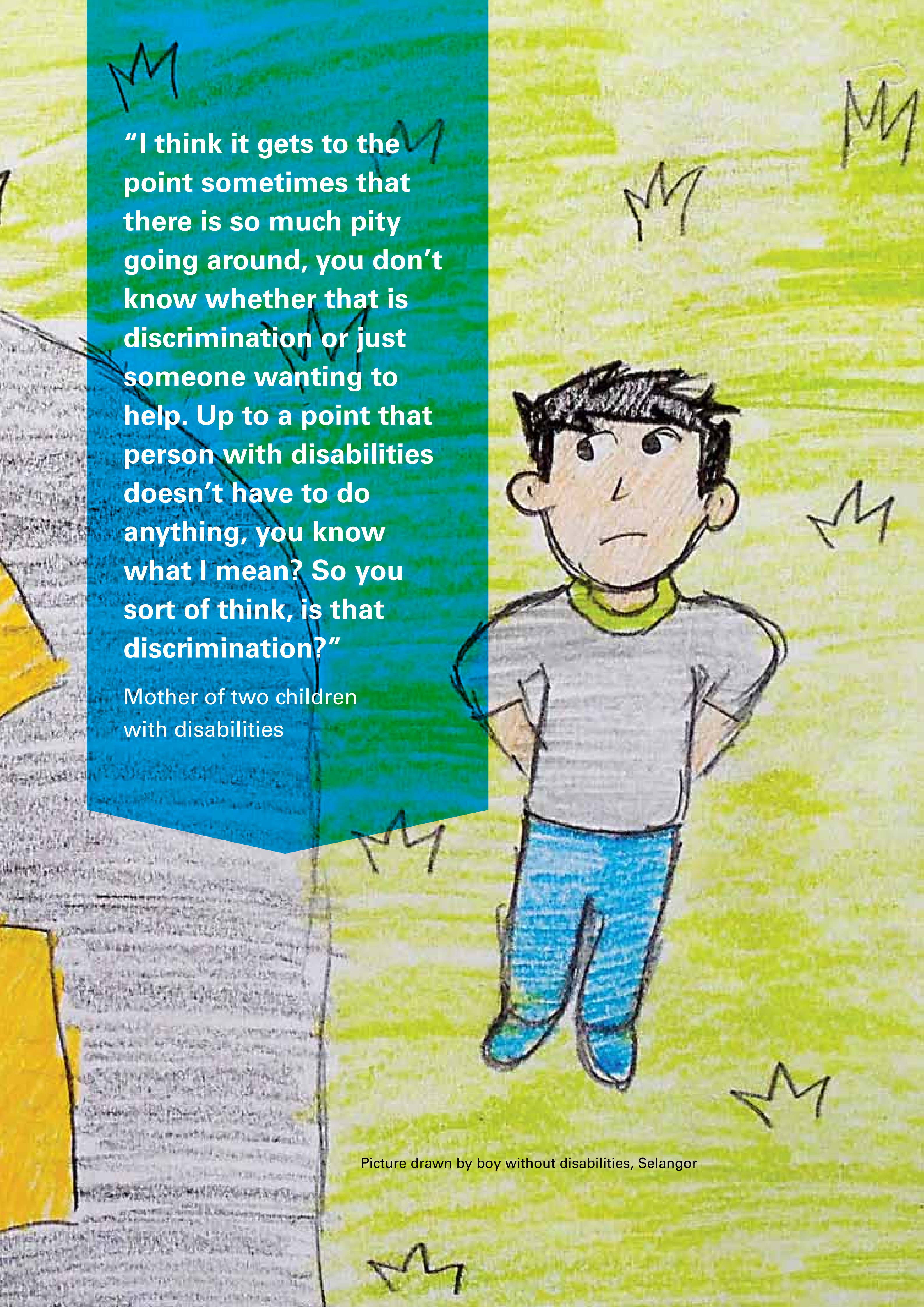

> **“I think it gets to the point sometimes that there is so much pity going around, you don’t know whether that is discrimination or just someone wanting to help. Up to a point that person with disabilities doesn’t have to do anything, you know what I mean? So you sort of think, is that discrimination?”**
>
> Mother of two children
> with disabilities

Picture drawn by boy without disabilities, Selangor

A child with disabilities participates in the special chapter of the Borneo International Marathon in Sabah, May 2017, for children with disabilities.

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5

KNOWLEDGE ABOUT DISABILITY

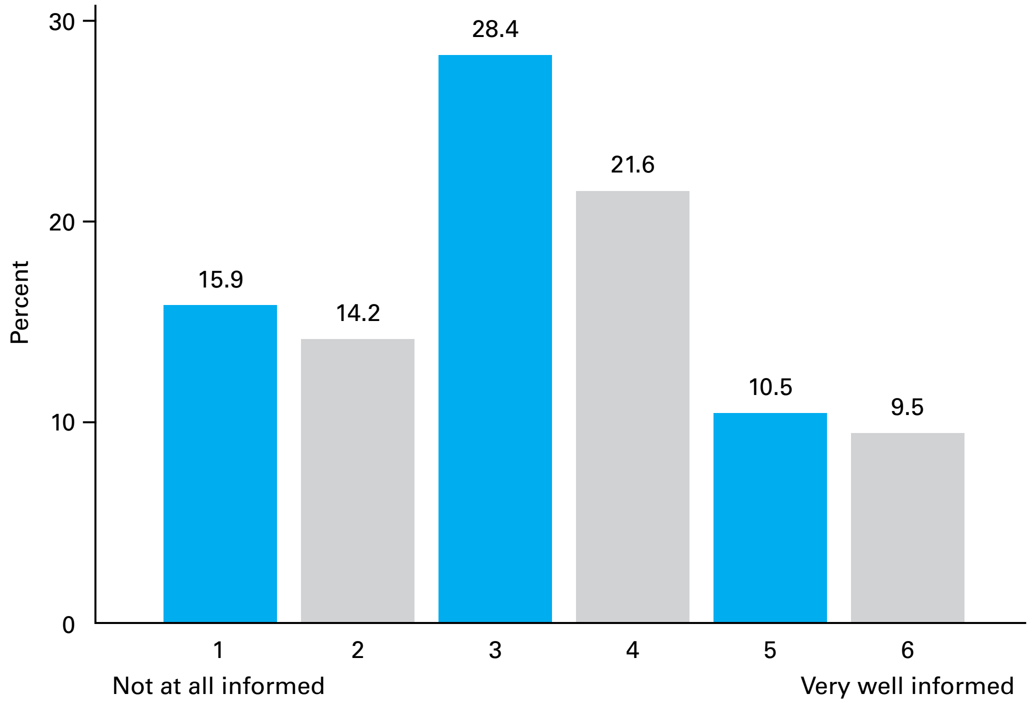
This chapter focuses on knowledge about children with disabilities in Malaysia and analyses how disability is defined and understood. It discusses the terminology used and its associated connotations, and outlines local theories of causation. The chapter concludes with an overview of information sources and trusted or preferred channels of communication. Where possible, every effort has been made to distinguish between participant groups and to highlight disparities in knowledge and information levels.

Defining disability

In the KAP survey, respondents were asked to free-list three thoughts prompted by the term 'disability'. The majority of respondents suggested that they first thought of an impairment (physical disability, visual impairment), or about the activities that people with disabilities could not do (lack of functionality). Grouping and coding the answers into coherent and conclusive categories was difficult due the variety of responses elicited from respondents. Three key themes emerged however: a sense of pity, expressions of sympathy; and reference to emotions or attitudes associated with the notion of 'help', both in terms of children with disabilities needing help, support and assistance, and in relation to their own sentiment of wanting to help.

Respondents were also asked how well informed they thought they were about children with disabilities, answering using a scale from one to six, where one was 'Not at all informed' and six was *'Very well informed'* (see Graph 3 below). As may be expected, the two largest answer groups are clustered at the middle of the scale (with more participants reporting to be less informed). Taken together, however, answer options one, two and three (i.e. the least informed answer options) account for 58.4% (173) of all respondents, whilst option six, very well informed, was least given answer reported by only 9.5% (28) or respondents. Despite this, the majority of respondents (71.3 %, 206) asserted that they had heard about the Persons with Disabilities Act (see Graph 4, next page). When asked to estimate the percentage of children up to 18 years old who had disabilities, of the

Graph 3. KAP respondents' level of self-reported knowledge about children with disabilities



participants who gave an answer, 34% suggested up to 20% of children had disabilities (see Graph 5, next page).

Language around disability was complex and subjective. Terminology and perceptions about appropriate language varied greatly and were influenced by the geographic location of participants and their level of engagement with disability. Qualitative data suggested that the most widely understood term used to refer to people with disabilities was the BM word *'cacat'.* Participants used *cacat* to mean 'blemish', 'defect' or 'flaw', but the term was also a direct translation for 'handicapped'. In interviews and focus group discussions the term *cacat* was used alongside the term *kurang sempurna*, 'less than perfect' or 'lacking'. Both community members and services providers tended to define a person with a disability as being 'not normal', 'limited' or 'less' than 'normal' people. As one community member suggested, people with disabilities are *'Lacking, it means that there are some things which are not perfect compared to normal.'* A government official concluded *'Society consists of two parts: one is normal one is abnormal. That's why the people that have perfect bodies are called normal.'*

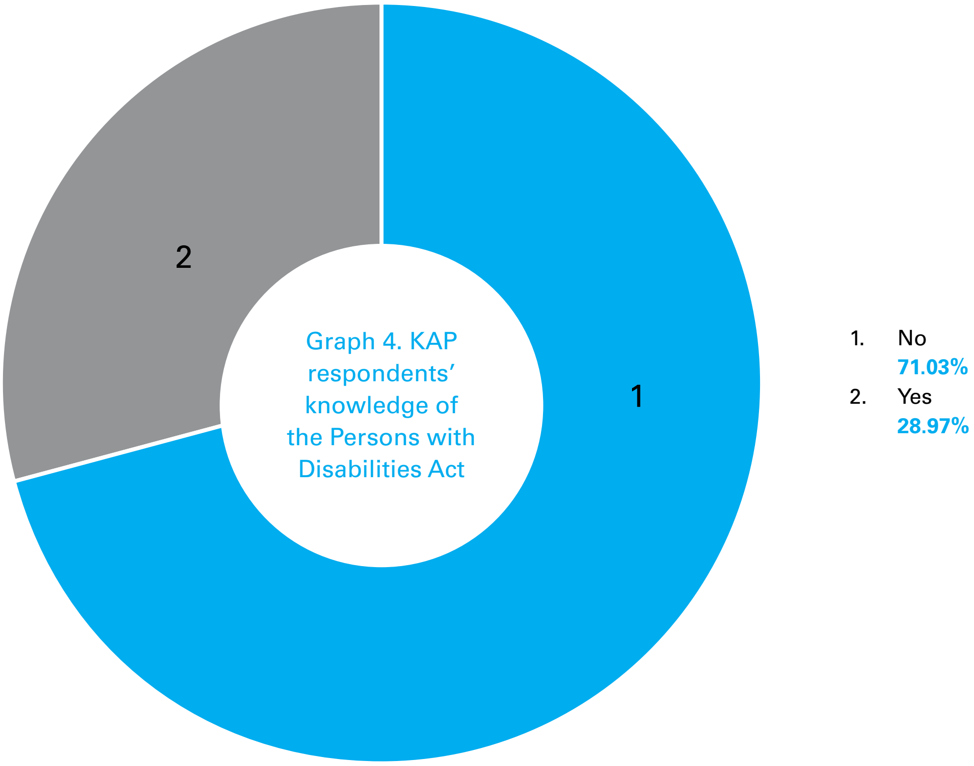
The concept of a 'normal' (*biasa*) child, those in good health and without a disability, perpetuated the notion that those with disabilities were somehow 'abnormal'. Several caregivers who participated in the study referred to children without disabilities as being 'perfect' (*sempurna*) in comparison to children with disabilities. The notion of 'imperfection' was used primarily in relation to physical disabilities (e.g. to suggest an 'imperfect body'). Parents of children with disabilities found the term *cacat* to be hurtful and insensitive regardless of their child's disability.

Participant: **We should not call them *cacat*. For me, as a parent I don't like my child to be called like that. It is not that we want them born like that. They themselves also don't want to be like that. However, we need to accept it, but at least do not call them cacat, pity them, I don't want.**

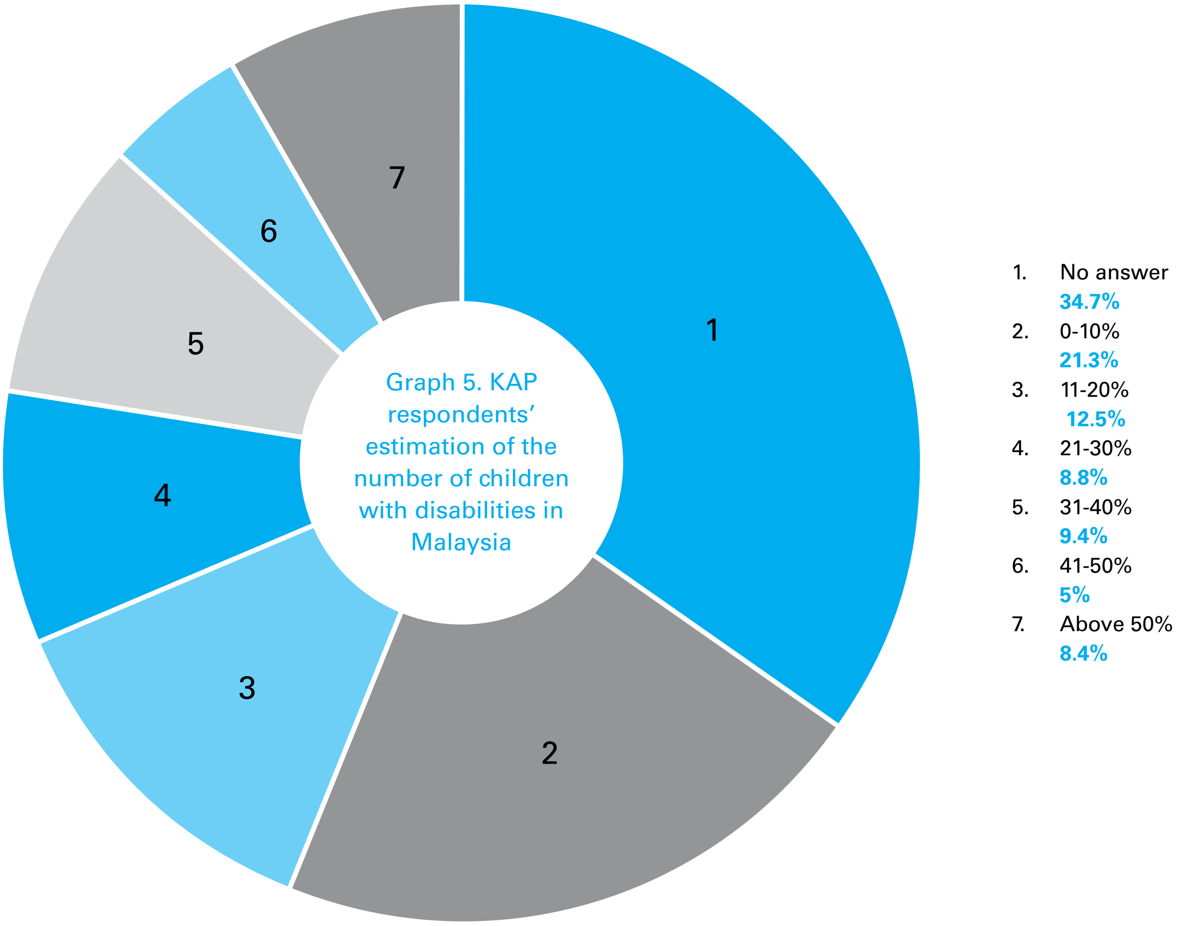
Facilitator: **Do you think that there are still people who use that term?**

Participant: **I think yes, the stupid people. Just call them special, it is nice to hear that. So we don't feel that we devalue them. They also don't want, who wants to be born like that, nobody wants. For me, as a parent, I also don't want my child to be like that. We want a normal, perfect child. Who wants their child to be born like that? It's not like we asked for that.**

It was widely acknowledged that *cacat* was imbued with negative connotations. One participant suggested, it may be acceptable to refer to a deaf person as *cacat*, but *'For someone that is able to hear, maybe*



Graph 4. KAP respondents' knowledge of the Persons with Disabilities Act



Graph 5. KAP respondents' estimation of the number of children with disabilities in Malaysia

they think that the word is rude.' Despite this, the term was commonly used instead of the official BM term for people with disabilities, *orang kurang upaya* (OKU), meaning 'less abled person'. Children and adolescent participants without disabilities suggested that OKU was synonymous with *cacat*, although most could not define what OKU stood for. CBR workers highlighted that OKU was inappropriate in some contexts as its most common symbol, a person in a wheelchair, was suggestive of physical disability and therefore unsuitable for all disabilities. During the study, it became clear that not all participants were familiar with term OKU and the research team had to sometimes use the term *cacat* to ensure respondents understood the questions posed.

Whilst many participants thought the introduction of other terms would complicate the language of disability even further, others suggested the more neutral term, *'orang kelainan upaya'* meaning 'differently abled person' should be adopted.

This generated substantial debate. As one national stakeholder with disabilities in Selangor explained,

Participant: **I also don't like the term OKU because the term *orang kurang upaya* also means that we are the people who have lesser ability, which is not true. It is actually society that disables us by putting up barriers and having negative attitudes towards disabled people.**

Facilitator: **There is also another term *'orang kelainan upaya',* what do you think of that?**

Participant: **That is also wrong… That is also not an appropriate word to use because everybody has different abilities. Even among the non-disabled people, everyone has different abilities so why are you picking on disabled people and saying that we have different abilities? You know, when you use that term *orang kelainan upaya,* you are actually discriminating against disabled people by singling us out when everybody else also has different abilities.**

Many respondents reported that language used to define and describe disability had changed over time, but suggested that this had caused confusion about the most appropriate and acceptable terminology.

As a health worker in Sabah concluded,

"Usually the term *cacat* is still used even though there is a term OKU. Now OKU is not *orang kurang upaya* anymore, it is *orang kelainan upaya*. But they still use *cacat*. And it actually depends on the area. There are certain areas that maybe people will think that is not a nice term but for other areas that is the usual language."

Respondents were aware of the sensitivity of language and articulated the *'Need to be careful with our words'.* Many expressed concern about saying the 'wrong thing', including the term 'special' (*istimewa*) which was routinely used by teachers in both mainstream and 'special needs' schools. A community member in Selangor explained, the 'correct' term is *'Supposed to be special, but I'm afraid that people might look at 'special' in a negative way, then there's a problem.'* A number of children and adolescents who participated in the workshops, highlighted a more positive interpretation of the term special. A child in Kuala Selangor noted that children with disabilities *'Are different from the others, they are very special'*, whilst another concluded, *'They are different but sometimes they are talented at things which we are not able to do. They have their own specialties.* [They are] *people whom we should respect because they are different from us.'* In Sarawak, a young boy emphasised, *'They are same with us, we are human. He is human. Everyone is special.'* Indigenous groups in Sabah and Sarawak reported a variety of local terms used to describe and define people with disabilities. Amongst the Dusun Lebu, for example, *'komokok'* was used in the place of *cacat* and *'bobou'* described people with hearing impairments. In the Bidayuh language, visually impaired were referred to as *'bokop'* and people with hearing impairments as *bongom*. The Kelantanese dialect also included specific terms associated with disability including *'tak padan tak taso'* meaning 'lacking body parts'; *'kudong'* meaning 'lost one limb'; and *anak syurga* meaning 'children of paradise'.

The lack of clarity around terminology was evident not only at the community level, but also in terms of policy, particularly regarding the definitions outlined in the PWD Act (discussed further below). One national-level stakeholder summarised their frustration,

"I do not understand actually. Under the PWD Act, we have already put the label of *kurang upaya,* but at the Department of Welfare they are starting to introduce the term *'kelainan'.* So it's quite strange that [there is a difference between] the label and what you say… So for us, we try to follow the PWD Act as much as possible. From using the word *cacat,* now we use OKU, but the OKU themselves are asking us 'why are you calling us less-abled? I am able, I have my family, I can work just I have something lacking: I can't hear or I can't talk. You can say I am deaf, but you do not say I am OKU'."

Although many participants suggested that less discriminatory terminology was being adopted, and that this was linked to and reinforced by positive changes in societal attitudes towards people with disabilities, there remained no specific term to denote disability that was universally used or accepted. As one Hindu religious leader confirmed, there is a need to codify terms *‘That are not vulgar, but are trying get a place in the heart. I think the reason why society cannot be close with them* [PWDs] *is because of the terms themselves. We have already isolated them by saying that they belong to a different category, not the same as us.’* Caregivers of children with disabilities echoed this sentiment and spoke emphatically about their frustration with disability terminology in Malaysia.

Participants from different age groups forwarded various definitions about what constituted a disability. Adult respondents stressed that because some disabilities were visible and others not, it was difficult to classify and understand disability. Most suggested that the term ‘disability’ was commonly linked to a recognisable condition, such as Down Syndrome (*‘from the face we already know’*) or a visible sign of impairment, such as ‘a missing leg’ or by observing the use of sign language. If a disability was not clearly apparent in a physical sense, some participants described it as being ‘invisible’, emphasising that if a child had learning difficulties, for example, *‘They would look normal and we cannot identify that they are disabled’.* In this context, it was suggested that disability may be misunderstood as ‘bad behaviour’. One CBO representative from Sarawak explained, *‘Some, like children with autism, you don’t know the child has this disability because they look so regular until they start to misbehave. And a lot of people are not very aware about autism so they will just blame the parents’.* In the KAP survey, respondents were asked whether different conditions would be considered a disability and the data broadly supported the qualitative findings. Data from the KAP survey supported these findings (see Table 4, below). Of respondents surveyed, 84.7% (271) considered someone with a physical impairment to be ‘disabled’, whilst respondents were less likely to consider people to be ‘disabled’ if they had ‘strange behaviour’ (21.3%, 68) or anti-social behaviour (15.9%, 51), or a non-apparent such as blurred vision (19.4%, 62).

Table 4. KAP respondents’ perceptions of conditions considered to be disabilities

Question	**Yes %**	**No %**
Has total loss of vision / is blind	90.6	9.4
Can not walk	88.1	11.9
Has total loss of hearing / is deaf	86.9	13.1
Can not speak at all	85.6	14.4
Has a physical problem (impaired limb)	84.7	15.3
Has mild loss of hearing / wears hearing aid	57.5	42.5
Neurological conditions	53.7	46.3
Has a cleft palate	37.5	62.5
Is hyperactive	35.0	65.0
Is aggressive and hurts themselves / other people	33.4	66.6
Finds it difficult to concentrate	32.2	67.8
Finds it difficult to learn	32.2	67.8
Has a stammer / speech impediment	28.7	71.3
Has strange behaviour	21.3	78.7
Has blurred vision / wears glasses	19.4	80.6
Has anti-social behaviour	15.9	84.1
Has infectious disease	6.3	93.7
Has HIV / AIDS	5.3	94.7
Non-contagious disease	4.7	95.3

In the participatory workshops, the drawings children and adolescents without disabilities produced tended to differentiate between people with disabilities who used aides such wheelchairs or walking sticks, and people with other disabilities. In their drawings, participants often explained the 'invisible' disability they had depicted through accompanying text (see Illustration 5 and 7). It was notable that in the workshops with children and adolescents with disabilities, however, only two participants illustrated their own disability. The others (47) drew themselves with a similar likeness to their friends and peers who did not have disabilities (discussed further below).

The majority of study participants were also likely to identify children and people with disabilities in terms of their limitations, with reference to their functionality and ability to complete routine tasks. The tasks discussed correlated to those the age group deemed important. In the participatory workshops, for example, children reported that children with disabilities, *'don't know how to eat using a spoon'*, *'cannot play'* and *'can't understand the alphabet'*.

Local theories of causation

Participants expressed limited knowledge about the actual causes of disability. Perhaps unsurprisingly, caregivers of children without disabilities had the least knowledge and many were unsure how to answer questions about causation. In the qualitative data from Sabah and Sarawak it was reported that disability may be contagious, and that this belief contributed to people wanting to avoid children with disabilities for fear of 'infection'. In Selangor, however, participants suggested this was a perception that was prevalent in the past, but no longer.

Table 5. KAP respondents' perceptions about the causes of disability

Causes of disability	Number of responses	Percentage of responses (%)
Congenital	206	23.2
Genetic	195	22.0
Accident	158	17.8
Disease	126	14.2
Will of God	89	10.0
Spirits	3	0.3
Curse	4	0.5
Parents' fault	34	3.8
Punishment	7	0.8
Environment	18	2.0
Bad Feng Shui	1	0.1
Fate / Karma	19	2.1
Other	28	3.2
Total	**888**	**100**

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[1] Lotus birth (or umbilical non-severance) is the practice of leaving the umbilical cord uncut after childbirth so that the baby is left attached to the placenta until the cord naturally separates at the umbilicus, usually a few days after birth.

Table 6. KAP respondents' perceptions about the causes of disability by ethnic group

Causes of disability	Ethnicity						
	Malay (394)	Chinese (157)	Indian (54)	Iban (54)	Bidayuh (51)	Kadazan-Dusun (110)	Other (68)
Congenital	22.8	24.2	14.8	29.6	31.4	20.9	22.1
Genetic	23.4	21.0	22.2	20.4	23.5	19.1	20.6
Disease	12.2	12.1	3.7	11.1	21.6	24.5	19.1
Accident	17.0	21.0	18.5	16.7	21.6	15.5	16.2
Will of God	14.2	4.5	0	13.0	2.0	10.9	8.8
Spirits	0.5	0.6	0	0	0	0	0
Curse	1.0	0	0	0	0	0	0
Parents' fault	3.0	2.5	16.7	1.9	0	4.5	4.4
Punishment	0	2.5	0	1.9	0	0.9	1.5
Environment	1.5	4.5	7.4	0	0	0	1.5
Bad Feng Shui	0	0	0	0	0	0	0
Fate / Karma	1.3	3.8	7.4	1.9	0	1.8	1.5
Other	3.0	3.2	9.3	3.7	0	0.9	4.4
Total	**100**	**100**	**100**	**100**	**100**	**100**	**100**

Across the four states, three dominant themes of causation emerged: medical, environmental and socio-cultural beliefs. Participants frequently cited several different contributing factors, suggesting a complex and pluralistic understanding of the causation of disability, and in some cases, this added to the confusion caregivers of children with disabilities faced in trying to understand the root cause of their child's condition.

Respondents articulated three components of medical causes: congenital or genetic factors; birth complications; and acute illness and disease. In the KAP survey, three of the four most frequently articulated causes of disability, across participants of all ethnicities, were 'congenital'(23.2%, 206 respondents), 'genetic' (22%, 195 respondents), accidents (17.8%, 158 respondents) and disease (14.2%, 126 respondents) (see Table 5, previous page). Congenital and genetic factors were further defined as being hereditary; associated with the mother's nutrition in pregnancy; caused by use of medicines and antibiotics; and influenced by the age of a mother at conception. One CBR worker explained, *'For me, the causes can come from marriage between the husband and wife's gene. They should check it... Apart from that, it* [disability] *can also be caused by ancestry. It can also happen when both the parents are normal but, during the pregnancy period, something happens.'*

Disability in new born children was also believed to be caused by birth complications including premature birth; medical interventions during labour such as forceps and vacuum; alternative birth methods that limit or prohibit medical interventions; and particular birthing positions (such as lotus birth).[1] Participants also highlighted that episodes of acute illness and disease in children, such as fever, epilepsy and jaundice were widely acknowledged to cause disability, especially if they were left untreated.

Lack of knowledge about how to treat fevers and difficulty in accessing services, particularly in rural areas, were seen to be key factors in disability resulting from acute illness. Stress was also suggested as a cause of mental disability. Teachers explained that stress on children and pressure from parents may lead to depression and health problems, but noted that stress could not be attributed to physical disabilities.

The environmental causes of disability forwarded by participants included pollution and issues with air quality; exposure to chemicals or toxins in pregnancy; and accidents. Accidents were believed to be the primary cause of disability after childhood, leading mainly to physical disabilities. In the participatory workshops, however, children frequently described the cause of disability to be accidents, particularly in terms of lost or damaged limbs. As one child concluded, *'My* *friend told me the stories about when he got hit by a motorcycle and his legs were operated. He has a leg but his foot is cacat. Just the toes'.*

Socio-cultural beliefs associated with disability were more varied across states and participant groups and included references to black magic, curses and spirits; close kin marriage; punishment and taboo (see Table 6, previous page).

Black magic was specifically discussed by communities in rural Sabah and Kelantan as causing disability. The parent of a child with Cerebral Palsy explained, *'There is one neighbour who said my child became disabled because he was exposed to black magic. He was cursed or even jinxed by someone, that is why my son still cannot walk until today.'* Similarly, adolescents in rural Kelantan discussed the cause of a man's mental illness in their community. They used the Kelantanese phrase *'santau'* to mean black magic.

Participant 1: Crazy…that man outside. He is depressed, stressed.
Facilitator: And how is his behaviour?
Participant 1: This is like black magic, it is something like a curse, something to do with witches or locals say *santau*. This means when someone does something to other people…he or she just needs to say words, bad words. Sometimes *santau* can be sent through the air, something which is not nice but it is evil. And then that person dies…
Interviewer: When did he get the curse?
Participant 1: He used to be a policeman.
Participant 2: Before this he was a traffic policeman, and he got the disability 10 years ago. It is related to black magic.

Consanguineous marriage (marriage to a relative) was highlighted as a cause of disability. Respondents in Sabah and Sarawak suggested that conception with a family member carried a high risk of the child having a disability. They claimed, however, that it was 'unavoidable' and there was little that could be done to minimise the risk.

Participants discussed religious beliefs as influencing their perceptions of the causes and presentation of disability. KAP data indicated that Hindu and Buddhist respondents more frequently quoted fate and karma in disease causation. Christian participants were likely to perceive disability as a 'gift from God' and believed that the condition should be accepted. Similarly, Muslim respondents suggested that disability was *'qadha'* (fate) or *'qadar'* (destiny) and a 'test' from Allah which they should willingly accept *'redha'*. Muslim caregivers found the practice of *redha* to be central to their acceptance of their child, *'When we have a gifted child, we are chosen by Allah because he wants to test us so that he can see how much we believe in him. Not everyone has a gifted child. Allah promises Jannah* [heaven] *to them. In my view, if we 'redha' when Allah test us, we should be patient.'* The Malay belief in *kenan* (process of cause and consequence) was also significant for some parents who considered the disability of a newborn baby to be a consequence of violating one of the religious taboos outlined by Malay Islamic elders.

Table 7. KAP respondents' commonly reported sources of news and information by location

	Location	
	Urban % (458)	Rural % (463)
TV	26.4	30.9
Radio	10.9	11.2
Newspapers	20.1	20.1
Internet	25.3	22.9
Magazines	2.6	1.1
Billboards / posters	0.7	1.3
Family	3.7	3.9
Friends and neighbours	5.7	6.7
Religious groups	3.1	1.1
Other	1.5	0.9
Total	**100**	**100**

In the qualitative data, punishment for breaking taboo and the behaviour of parents more generally, were highlighted as factors causing disability. Risky behaviour included: smoking; drug taking; drinking; and *'sex outside the marriage'*. In rural Sarawak, the behaviour of the father was believed to have great significance on the outcome of the unborn foetus. One local belief, for example, suggested that a child may be born with a cleft lip if their father had broken a taboo by cutting a basket with a knife. A common belief, expressed by participants in all states, held that if a pregnant woman crossed the path of a child with disabilities and made eye contact, she would be cursed and *'her own child would become like that as well.'* In the KAP survey, attributing disability to the fault of parents was more frequent amongst Indian Malaysian than respondents of other ethnicities (see Table 6, page 49).

Sources of information

In the KAP survey, the three most commonly reported sources of news and information in both urban and rural locations were television, internet and newspapers (see Table 7). The newspaper or magazine reported to be most regularly read was Harian Metro (read by 15% or 48 respondents), the TV station most regularly watched was TV3 (mentioned by 37.2% or 119 respondents) and the radio station most regularly listen to was ERA FM (reported by 10.6%, or 34 respondents). Widespread connectivity and use of mobile technology resulted in the internet being increasingly used to search for and share information, particularly in urban areas. Of those surveyed, 58.8% (188) had a computer, 29.7% (95) had an iPad or tablet and 84.4% (270) had a smartphone (although all respondents had some kind of mobile phone). In the survey, 81.9% (262) reported that they used internet and listed Google, Facebook and YouTube as the three most commonly visited sites. Of those who reported using the internet, 97% (254) confirmed they used social media sites, and reported Facebook, WhatsApp and Instagram as most regularly used.

Interview and FGD participants suggested multiple sources of information about disabilities including community and religious leaders, health workers, CBR workers and teachers. In rural areas, qualitative data suggested that community and religious leaders played a particularly important role in information sharing. Leaders acknowledged their role as trusted sources of information, but recognised the limitations in their own knowledge. As one community leader in Kelantan, explained, *'We have never been exposed to any training on disabled children'.*

Participants from all stakeholder groups asserted that information about disabilities disseminated by the Department of Social Welfare (DSW) was inadequate. At both state and district levels, respondents agreed that DSW officers did not have the correct information or mechanisms to share key information with caregivers of children with disabilities. Caregivers emphasised their frustration at the lack of accurate and timely information they were able to source from the DSW, particularly in terms of welfare assistance and training, and the support they were offered was often fragmented (discussed further below). It was evident that many caregivers lacked knowledge about CBR services, had limited information about schooling options and little awareness of their children's rights. Whilst the majority of caregivers had tried to obtain this information from other sources, some participants still struggled to gain access to the information required and several parents discussed the need *'to travel to many different places'* in order to source relevant information.

In urban areas of Peninsular Malaysia however, a number of caregivers highlighted that they had received relevant information from the DSW and had the opportunity to attend specific courses or trainings. These caregivers confirmed that they had good access to the internet, and it was suggested by a CBO representative in Selangor that educated, affluent and 'modern' parents, particularly those residing in Kuala Lumpur, were better equipped with relevant information than those in rural areas. Access to the internet enabled this group of parents to access the most up to date information and progressive techniques for supporting their children. One caregiver from urban Selangor explained how she conducted her own research on the internet about cranio-sacral therapy prior to identifying a practitioner in KL to treat her son who had Cerebral Palsy, *'The internet is a very vital source of information. There are other sources* [of information] *such as attending workshops, and there was a parent support group that I attended, but because different kids have very different needs, certain things I had to sieve out'.*

One of the most trusted sources of information was other caregivers. Support groups facilitated by CBR centres, virtual support groups on WhatsApp and networks on social media platforms such as Facebook, were critical to the flow of information between caregivers in urban areas. One mother in Selangor explained, *'For me, one of the best forms of communication is my special mothers group where they share a lot of amazing things. It started at my child's school where there is a parent support group. They will say I tried this therapy and that* [therapy].

They are on WhatsApp.' A CBR worker in Kelantan reported a similar WhatsApp support group for caregivers in the centre where she worked, stressing that such platforms facilitated *'good communication and much support'.* Health workers in rural Sarawak identified WhatsApp as a valuable channel for sharing information between professionals, *'Medical social workers of Sarawak have a WhatsApp group, so if we face a difficult case, we will discuss it in this group to ask views and opinions from other medical social workers'.* In urban Sabah, health workers identified WhatsApp and Facebook as potentially useful tools for communicating vital knowledge to parents.

The use of social media in urban centres was in marked contrast to the level and sources of information that caregivers in rural areas were able to access. The following dialogue with a father in Sarawak was representative,

Facilitator: **So before he joined CBR you didn't know that there is assistance provided for him?**
Participant: **No. I don't know about it, I didn't apply for any assistance.**
Facilitator: **Before you sent him to CBR, did you register him with the Welfare Department?**
Participant: **No, I don't.**
Facilitator: **You didn't register him because you didn't want to?**
Participant: **I just don't know. I'm illiterate too. Moreover, there's no one informed me about it… no one told me anything.**

It was agreed by teachers, CBR workers and CBO representatives that health facilities and health workers were often the first point of information for caregivers, particularly in more rural areas, and as such they should be better equipped to deliver accurate information regarding welfare, education and healthcare services. Most participants across all four states agreed that focused training on children with disabilities was needed for all health professionals, both in terms of knowledge management and their capacity and skill to deliver key information (discussed further below). Health workers did note, however, that parents, particularly those in rural locations did not always disclose the full extent of their children's needs, and stressed that the flow of information was lacking on both sides.

In the KAP survey, when asked if they would like more information about children with disabilities, 86.5% of those respondents (249) who provided an answer confirmed that they would. Participants requested further information about the daily life of children with disabilities (15.6%, 37 respondents); how to help or assist them (14.8%, 35 respondents); and information about the rights of children with disabilities (6.3%, 15 respondents). In terms of their preferred channel to receive such information, 58.4% of respondents (245) suggested the internet or social media as the most appropriate; 20.4% (50) suggested the television; and 5.3% (13) suggested the newspaper. Although mass media was acknowledged to be an effective means of information sharing, it was agreed that more sustained campaigns were needed to better promote and advocate for the rights of children with disabilities.

As one CBO representative concluded, *'It has to be, continuous, not just when it is Autism Day… or when it is Disability Day.'* The need for further information was also reflected across participant groups in IDIs, FGDs and participatory workshops (see Case Study 1).

43.1% of respondents to the KAP survey believed that it was disruptive to have children with disabilities attend the same school as children without disabilities.

Voice – Adolescent without disabilities

“I think that the way that Malaysians look at people with disabilities, the people with special needs in society, it is a bit negative. I'm not saying that all Malaysians have a negative opinion of them, there are few people who look at them as normal human beings… but I think [there are] those who are very negative minded. I think these people should have more information. They need knowledge and education to change their opinion and see these people with disabilities as human beings as well.

You know, actually, we have a BM novel in Malaysia, we called it KOMSAS, *Di Sebalik Wajah.* It's about a boy who has a disability. We study this novel about disability at school in literature. The boy, he's an albino. The way that I see it, the way people discriminate, they have the discrimination in their communication towards him. I see that happening even now. Even though the story is a very old story, I still see the discrimination towards people with special needs now in our society. So I think that this opinion should change and I think we can do it if we alert the public, maybe through education, information or campaign.”

75.3% of respondents believed children with disabilities should be placed in an institution.

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A boy with learning and behavioural disabilities drawing his favourite things and how he feels at a participatory workshop for children with disabilities, Sarawak.

6

ATTITUDES TOWARDS CHILDREN WITH DISABILITIES

This chapter focuses on attitudes towards children with disabilities in Malaysia from the perspective of the different stakeholder groups engaged in the study. It analyses societal attitudes towards children with disabilities and discusses stigma by association. It addresses perceptions of increased vulnerability, and concludes by addressing the concerns caregivers have for their child's future.

Societal attitudes towards children with disability

When asked to select three terms to describe a child without disabilities in Malaysia, KAP survey respondents most commonly selected 'happy', 'independent' and 'confident' (see Graph 6, next page). When asked to select three terms to describe a child with disabilities in Malaysia, respondents most commonly selected 'insecure / shy', 'sad' and 'stressed' (see Graph 7, next page).

On the surface, social attitudes towards children with disabilities and their families tended to appear sympathetic, supportive and understanding. Participants almost unanimously agreed that children with disabilities should not be discriminated against. Although in the KAP survey, 45% of respondents (144) agreed that a child with disabilities is equal to a child without disabilities, many participants maintained that Malaysian society was still not inclusive or equitable.

When asked about the rights of children with disability, 27.8% of respondents (88) asserted they were more respected than other children; 42.5% (134) that they were respected the same; 27.2% (86) that they were respected less; and 1.3% (4) that they were not respected at all.

Many participants reported feelings of helplessness and a lack of understanding about what one should do or say when approaching children with disabilities. In interviews and focus group discussions, community members and caregivers of children without disabilities frequently reported that they did not have the know-how to help 'in the appropriate way', and were concerned that they may 'say the wrong thing' to parents of children with disabilities risking hurting their feelings unintentionally.

As one community member in Sabah explained,

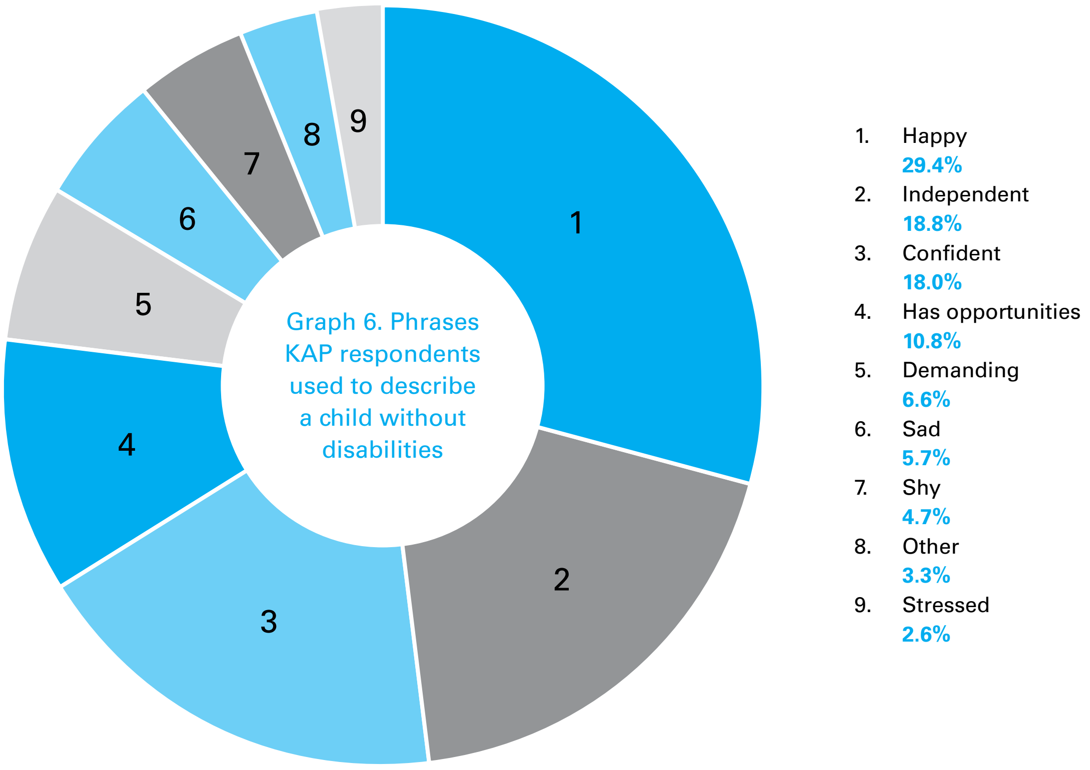
> **"For me, when I am in that situation, I feel helpless because I do not really know how to help them. So, because we do not know how to help them, it is easier for us to avoid than to approach them. And sometimes there are people who feel very pitiful towards them who go in another direction because they feel sensitive and easily cry."**

In the KAP survey, when asked how they felt when they saw a child with disabilities, respondents suggested they felt 'sympathy' (33.9%, 215), and they had 'the desire to help' (28.4%, 180) (see Table 8, next page). Feeling pity was an emotion frequently highlighted by participants in the qualitative data. In many contexts, children with disabilities were seen as objects of charity or welfare in need of 'help'. Such attitudes could be problematic as the line between sympathy and discrimination became blurred. A mother of two children with disabilities confirmed,

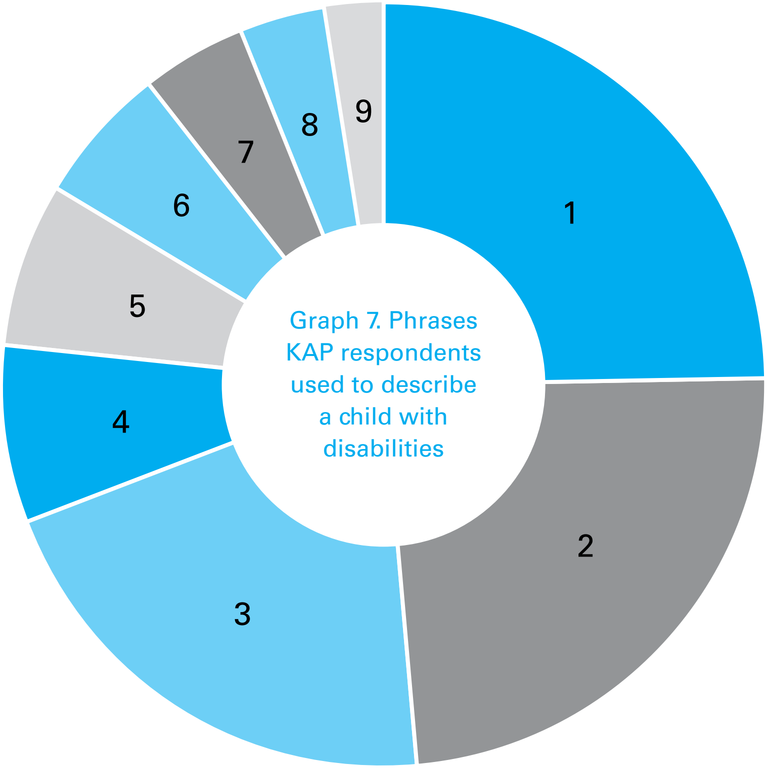
> **"I think it gets to the point sometimes that there is so much pity going around, you don't know whether that is discrimination or just someone wanting to help. Up to a point that person with disabilities doesn't have to do anything, you know what I mean? So you sort of think, is that discrimination?"**

Community and religious leaders agreed that pity could lead to discriminatory behaviour and negative attitudes, and emphasised that children with disabilities should be encouraged to find independence by being treated 'like normal'.

In their participatory workshops children and adolescents without disabilities frequently presented a caring and supportive attitude towards children with disabilities. They acknowledged that being kind and supportive of other people was or should be the social norm and upon first questioning suggested that those with and without disabilities should be treated equally. Further probing, however, revealed more discriminatory attitudes and, in line with the sentiments of adult participants, feelings that were driven by pity. This was reflected in statements such as *'They can't do what we do'* and *'When I see them I feel sad'.*



Graph 6. Phrases KAP respondents used to describe a child without disabilities



Graph 7. Phrases KAP respondents used to describe a child with disabilities

1. Insecure / shy 25.0%
2. Sad 23.8%
3. Stressed 20.6%
4. Other 7.5%
5. Happy 6.9%
6. Demanding 5.7%
7. Independent 4.5%
8. Has opportunities 3.6%
9. Confident 2.4%

Table 8. Feelings KAP participants reported when they saw a child with disabilities

	% respondents
Sympathy	33.9
Makes me feel I want to help	28.4
Makes me feel grateful I don't have disabilities	16.9
Normal (no particular feelings)	8.4
Other	8.5
Scared	3.0
Feel I want to avoid	0.9
Total	**100**

One child elaborated, *'If I had a disability I would probably commit suicide.'*

Workshop activities elicited a broad dialogue about charity and from this perspective, participants tended to look at children with disabilities as those in need of help, who are unable to do things for themselves and who relied on others to look after them.

Lack of understanding and knowledge about disability compounded by widespread misconceptions tended to perpetuate negative attitudes and was understood to be the primary cause discrimination.

A Christian Pastor in Sabah confirmed,

> **"One of the challenges they [children with disabilities] have is the lack of attention and care from the general public. The public does not care and give attention to them. Maybe there are people who care but from what I see, there aren't many who are like that. Maybe there are people who want to ease the burden on their parents but there are some who don't know what they should do. The most important thing is, there are people who want to help but they do not know how to help."**

Participants suggested that in public, children with disabilities were routinely stared at, *'People look at them like they have never seen a human'.* It was suggested that people stare because they did not feel equipped to communicate or help, but also 'out of interest'. One community member in Selangor suggested, *'If people see something different from the norm, it will be an attraction. So, they* [children with disabilities] *are different from normal. From the negative side, we see negative stigma. But if we take it from a positive side, then it is ok, because they are special. That's why people are looking like that.'* Several caregivers reported that their child was treated kindly in the community because they were 'very gentle' or 'caring'. One mother from Selangor suggested that she felt 'lucky' that her son who had Cerebral Palsy was 'cute' and did not have behavioural issues, so people were more accepting of him. Similarly, a mother of a child with Down Syndrome in rural Selangor expressed gratitude that her child's disability was 'not the hyperactive ones'.

Both the qualitative and quantitative data suggested a correlation between people's attitudes and a) the type of disability; and b) the social proximity of a person with disability. When a person could clearly identify that a child had a disability, they were more likely to be accepting and responsive than towards a child with a 'non- observable' disability, largely because 'non-observable' disabilities were perceived to be more challenging to understand (as discussed above). Participants projected greater negativity and stigma towards children with behavioural, mental and intellectual disabilities than towards children with physical or sensory disabilities. Caregivers and service providers reported that children with behavioural disabilities were frequently perceived to be 'badly behaved' and children with mental disabilities were called 'crazy', 'stupid' or 'clowns' and were often mocked.

Children and adolescents without disabilities reported witnessing cruel and unkind behaviour towards those with disabilities, primarily directed to those with learning or behavioural disabilities by siblings, peers at school, and in the community more broadly. Incidences of mistreatment ranged from teasing and mocking to more severe emotional bullying and physical beating. Children with disabilities were seen to be an easy target for ill- treatment as *'they cannot escape the problem'* and were often *'cast aside'* without friends. Participants claimed that people who believed disability to be 'disgusting' or 'insulting' considered teasing or beating a child with disabilities to be justified. In the KAP survey, 59.7% of respondents (191) thought that children with disabilities were more likely to be abused; 5.6% (18) suggested that it was acceptable for a child with disabilities to be tied up or restrained; and 13.1% (42) thought that they needed less food than other children.

Parents often reported that they would allow their children to play with children with disabilities (47.8% of respondents in the KAP survey (153) confirmed that children in their household had socialised with a child or person with disabilities in the past), but when questioned further it emerged that the nature of the socialisation was complex, and again correlated to the type of disability. Several parents clarified that whether they would allow their child to play with a child with disabilities would depend on what disability the child had. In the KAP survey, respondents reported high levels of acceptability for their child to be best friends with a child with a physical disability (96.5%, 276); hearing disability (96.2%, 276); speech disability (95.8%, 274); or visual disability (95.5%, 273). The levels of acceptability decreased significantly, however, when the nature of the relationship became more intimate: only 66.5% (157) reported that it would be acceptable for their child to have a boyfriend or girlfriend with a physical disability, and for hearing, speech and visual disabilities the numbers who reported it would be acceptable fell to 73.4% (174), 75.0% (177) and 69.8% (162) respectively. Children with mental and behavioural disabilities were the least accepted. Whilst 97.4% of respondents (300) confirmed that it was acceptable to live in the same neighbourhood as a child with physical disabilities, only 57.8% (167) reported it would be acceptable to live in the same neighbourhood as a child with mental disabilities, and only 15.7% of those surveyed (39) thought that it was acceptable for their child to have a boyfriend or girlfriend with a mental disability (see Graphs 8 to 11 on following pages). In the qualitative data, 'hyperactive' children were similarly singled out as the least acceptable friends or playmates. An Islamic leader in Selangor explained, *'To socialise there are no problems, but still it depends on the disabilities. Some of them* [children with disabilities] *are uncontrollable so in order to let them freely socialise, maybe in a controlled situation then yes. For the mentally retarded... even the hospital is separating them, so why would we do any different?'*

A health worker in Sarawak concluded that 'mentally disabled' children were the most stigmatised by society. Children with physical disabilities tended to be more accepted at public occasions and events, whereas children with mental disabilities would likely be avoided. Similarly, children with physical disabilities who were 'mentally okay' were more likely to be accepted by both their family and community. Because of their greater ability to interact and communicate without language or behavioural barriers, it appeared that children with physical disabilities were more likely to have friends, enjoy better social integration and develop more positive relationships than children with other types of disability.

Levels of inclusiveness across impairment groups appeared to be marginally better amongst children and adolescents who had disabilities themselves. Although not all self-identified as having a disability, when they did, they generally spoke of themselves as a homogenous group, 'the disabled'. The workshop with adolescents with hearing impairments in Sabah revealed that whilst general levels of acceptance for different disabilities was greater within the disability community, challenges remained in accepting people with particular disabilities.

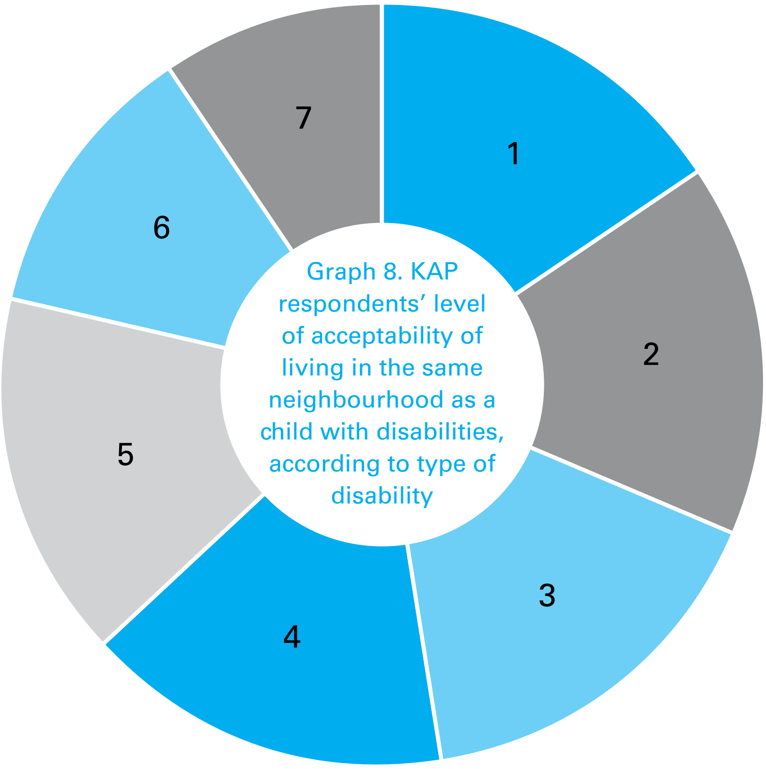
As one participant explained,

"I think people with disabilities are more accepting than the hearing society. Maybe. Except for those who are, you know, autistic or mentally retarded. Probably they don't understand you because of their own disabilities."

Almost all child and adolescent participants involved in the workshops had had some interaction with children with disabilities in the past, and many reported that they had friends and / or relatives living with disabilities. In several cases, however, participants only revealed the closeness of their relationship after the session had concluded when they could speak privately to the facilitator(s), and on several occasions, approached the research team to ask specific questions about their friend's or relative's condition.

Adolescents without disabilities appeared the most willing to explore close relationships with their peers with disabilities. Adolescents who participated in the workshop in Kelantan, for example, spoke in detail about their openness to being friends, having a partner or marrying someone with a disability, but stressed that their parents would be less likely to accept the closeness of these relationships, particularly if the disability was severe or the impairment was anything other than physical. As part of a storyboard activity, one participant drew a scenario exploring what it would be like to introduce a girlfriend with disabilities to his parents (see Illustration 6). He explained his illustration,

"That is me and my girlfriend…and she is mute. I brought my girlfriend to see my parents. When my parents saw us, my parents got really angry, my father even had a pistol with him. My mother was also very angry; she was carrying a spatula. They cannot accept her because she has a disability. But my girlfriend is very cute and has two dimples, so I can accept."



Graph 8. KAP respondents' level of acceptability of living in the same neighbourhood as a child with disabilities, according to type of disability

1. Physical **97.4%**
2. Learning **96.8%**
3. Visual **96.8%**
4. Speech **96.4%**
5. Hearing **95.4%**
6. Behavioural **72.0%**
7. Mental **57.8%**

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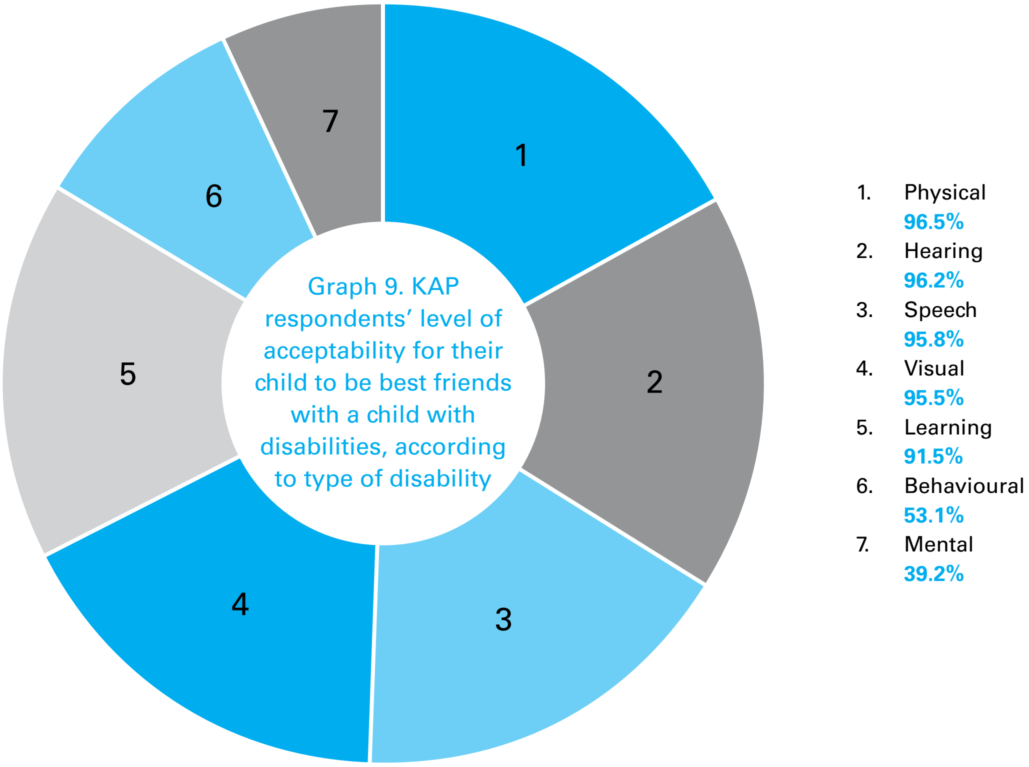
“That is me and my girlfriend…and she is mute. I brought my girlfriend to see my parents. When my parents saw us, my parents got really angry, my father even had a pistol with him. My mother was also very angry; she was carrying a spatula. They cannot accept her because she has a disability. But my girlfriend is very cute and has two dimples, so I can accept.”

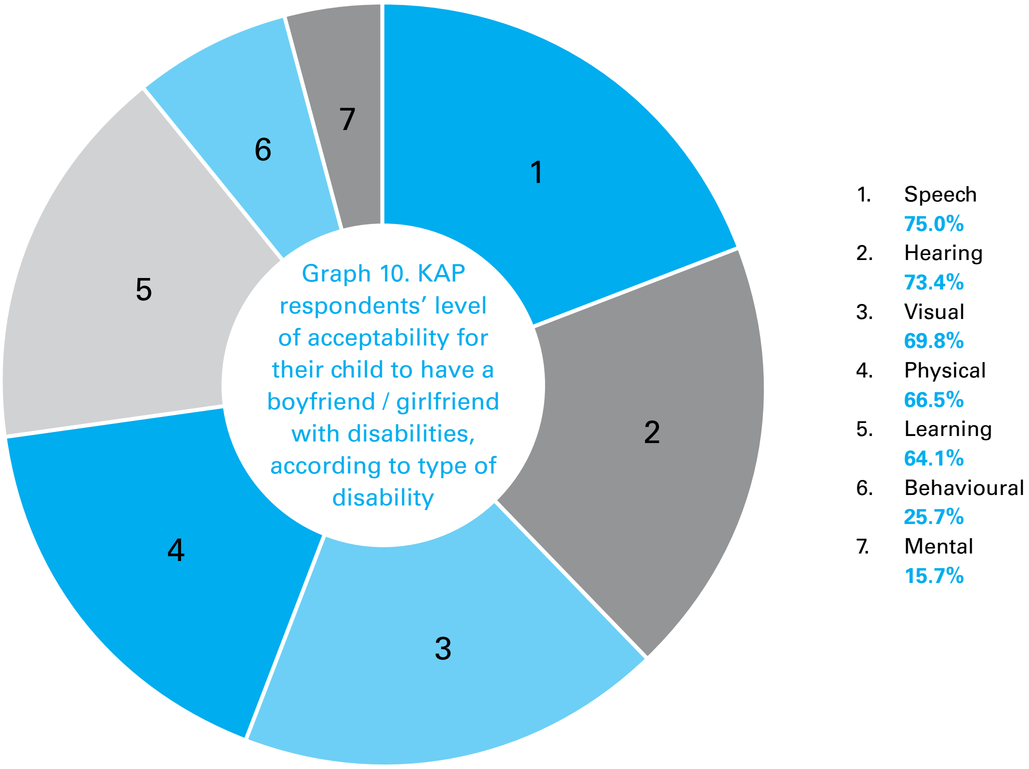
An adolescent without disabilities in Kelantan illustrates and explains how his parents reacted to meeting his girlfriend with disabilities.



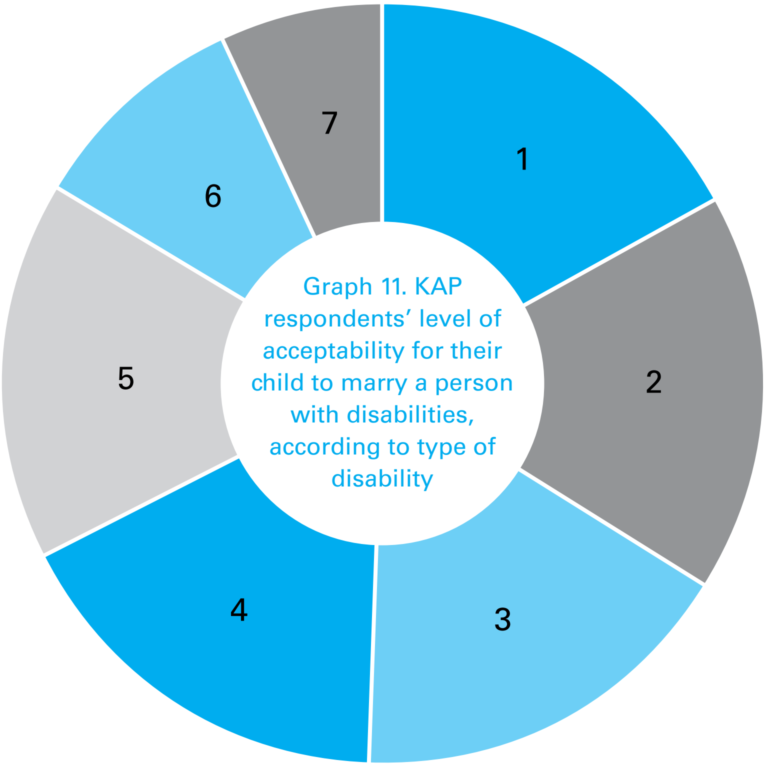
Graph 9. KAP respondents' level of acceptability for their child to be best friends with a child with disabilities, according to type of disability

Reflecting on such behaviour, one adolescent in a workshop in Sarawak highlighted that other types of discrimination and stigma also continued to be prevalent in Malaysia. She suggested that she could empathise with children with disabilities because of how she was treated at school due to her Indian ethnicity (*'Because I am Indian, my skin is dark, and the popular girls all have pale skin'*), and stressed that all discrimination was 'unfair' and unacceptable.

In their workshops, children presented more straightforward interpretations of the challenges a person may face in having a relationship with somebody with a disability. Workshop participants in



Graph 10. KAP respondents' level of acceptability for their child to have a boyfriend / girlfriend with disabilities, according to type of disability



Graph 11. KAP respondents' level of acceptability for their child to marry a person with disabilities, according to type of disability

1. Speech **72.1%**
2. Hearing **69.6%**
3. Visual **63.7%**
4. Physical **60.7%**
5. Learning **57.7%**
6. Behavioural **24.0%**
7. Mental **13.1%**

Kelantan suggested that people with disabilities could not get married because of their 'poor health'. When asked if they would consider having a girlfriend or boyfriend with disabilities, children without disabilities in Sabah concluded that *'No one wants them because people think they look ugly'* and claimed their friends would think they were 'silly'. Others foresaw no challenges, suggesting that they would accept the disability *'because of love'*, and several concluded that whilst people with disabilities may find it difficult or even impossible to marry 'normal people', they would be able to marry somebody with the 'same type' of disability as their own.

Stigma by association

Stigma and discrimination operated on many levels for parents and families of children with disabilities, and both caregivers and siblings described in detail the stigma, discrimination, isolation and marginalisation they experienced on account of their relative's disability. (See Case study 2 below and front cover illustration).

Across ethnicities and religions many participants associated a child's disability with the conduct of their families. Parents of children with disabilities suggested that the root of much of the stigma they faced was embedded in cultural beliefs surrounding a mother's behaviour and taboo in pregnancy (as discussed above in terms of causation). Caregivers of children with disabilities routinely spoke of being blamed for their child's disability. This type of discrimination called the self-respect and moral conduct of parents into question. As one mother in Selangor recounted,

"People told me that during the time of pregnancy, we need to refrain ourselves, cannot do this, cannot do that. Maybe I broke the rules, that's why [my child was born with a disability]. A lot of people frequently blame me… they say that I didn't take care. It's not like I knew it would become like this."

In many cases, feelings of self-blame only served to intensify the shame that parents felt and impacted their ability to accept their child. Caregivers reported that feelings of shame subsided over time, but recalled with sadness how they felt when they realised their child had a disability, *'I was, really frankly speaking, I was afraid. When I brought him out, everyone looked at us, I was so ashamed… How come I have this kind of child?'* Another mother emotionally recalled, *'At first, honestly, I couldn't accept him. Even at times I hate him still.'* Feelings of shame were not limited to parents, but were also reflected across the wider family unit. CBR workers in Sabah explained that as a result, it was not uncommon for children to be hidden in rooms and kept out of sight because families *'Don't want other people to know that they have an OKU.'* In the KAP survey, 34.1% of respondents (109) confirmed that children with disabilities were 'kept hidden from society'; 12.3% (39) thought that children with disabilities caused embarrassment to their families; and 27.5% (88) thought they were a burden

Voice – Adolescent sibling of boy with Cerebral Palsy, Sarawak

> “I haven’t come across disability at school, just my little brother. My little brother is about nine or ten years old. He is OKU. You know, generally he can’t speak properly and he doesn’t know how to add, doesn’t know how to do anything lah... He goes to CBR. I feel that he is OKU. I think having a disability is sad and lonely. It is difficult having a brother who is OKU, sometime I am lonely too. Behind my house there is a basketball court. I play basketball there every day but I’m the only one in the whole kampong [village] who plays basketball. Its lonely lah. I wish to have a normal brother like other people do… I wish to have the chance to teach basketball to my ‘normal’ brother… I wish again that I am not the only one to play basketball behind my house. You know, this is grief. Sometimes I am embarrassed. When we are going out with my family and they will bring my brother, I will walk away from them. Sometimes it’s society that makes me feel sad, but I don’t know how they can be more accepting. I think people with disabilities can contribute to society. Like in sports, because I see a lot of videos about people with no legs in the Paralympics. And they can contribute a lot in the wheelchair basketball at the US.”

for their families. The qualitative data indicated that the burden of caring for, or being associated with, a child with disabilities was perceived to be greater in relation to children with mental disabilities. As a CBO representative in Sarawak concluded, *‘Of course we discriminate against them because we feel that they are burden on us… We do not discriminate against another fellow because they just have one leg or because you got one arm.’*

Even though children with learning, mental and behavioural disabilities were generally less accepted by society, parents of children with these disabilities found the day-to-day stigma they faced to be significantly less than children with physical disabilities, simply because people would not immediately ‘notice’ their children. When their behaviour was recognised however, this group of parents was likely to experience a heightened sense of shame as their children were often perceived to be ‘naughty’ or ‘badly behaved’ (as discussed above). Without a clearly visible sign of their disability that may have offered justification for their behaviour, people often blamed caregivers for their lack of parenting skills and for not teaching their children properly. As a result, caregivers frequently reported their reluctance to *‘bring the child out’* into the community.

Such issues appeared to prevent families with children with disabilities from integrating into mainstream societal activities. This limited interactions between the general public and children with disabilities, and further isolated the children and their families. Several mothers described how their own social interactions had been curtailed because of their child, even amongst once close friends and their peers. Others reported stopping full time work to enable them to care for their children, thereby reducing their opportunities for social interactions even further. In addition, cultural beliefs such as pregnant women avoiding eye contact with a child with disabilities, reinforced the isolation caregivers felt, *‘My experience was when other mothers see my disabled child they run away from us. They seem to avoid me. They feel scared that they will have disabled child too.’*

Two mothers engaged in the study described how they had accepted their children from birth, but for all other caregivers (91), acceptance was a process. Caregivers described experiencing a range of emotions including ‘sadness’, ‘anger’ and ‘denial’ and one mother recalled feeling like she was ‘dying’ upon hearing the news than her newborn baby had a disability. Caregivers confided in their own mothers, spouses, family and friends, and found great comfort in the ‘moral support’ they received to help them accept their child. For practicing Christians and Muslims, religion was found to be a great source of support, one Christian mother explained, *‘God is number one. Only you see God and feel Him. Every day I went to church because I wanted to overcome my denying.’* Several Muslim parents attributed the process of *redha* (discussed above) as central to their personal acceptance.

“As Muslims, we should accept our child. We say this is *redha*. I think there is reason for why this is happening to me. I let people outside talk about my child. Sometimes, I couldn’t handle myself when I hear people saying bad things about my child, but I have been able to accept his disability. Allah has granted me a child with disability. I accepted my fate.”

Although the majority of caregivers with children with disabilities who participated in this study had reached a point of acceptance, many acknowledged that other family members had not. Female participants suggested that it took men longer than women to come to terms with having a child with disabilities, and several mothers interviewed confirmed that their husbands still felt shame, were in denial or refused to accept their child. For some, this increased their own isolation and marginalisation within the family. As a mother from Sarawak recounted,

> **"My husband never brings me and my disabled child to the supermarket. He feels ashamed. Even when the CBR organised some party, my husband refused to come. Sometimes it makes me feel angry toward him… When I ask him to take my child to CBR then he will be angry at me, saying 'do you want me to be ashamed?' My husband is always angry at me when I bring my child for appointments. But we have to accept him. Sometimes I bring my child to the hospital by foot. I feel tired you know, bringing all the stuff. I've got headache. I don't have enough sleep. Nobody cares about me. My husband doesn't want to send my child to hospital. Stop smoking and drinking, I said to him. My husband always scolds my children."**

CBO and CBR stakeholders, teachers and religious and community leaders all confirmed that a lack of acceptance from parents was one of the primary challenges they faced in their interactions with children with disabilities. Several of these participants confirmed that parents who do not accept their children or the burden of looking after them just *'tie them up and leave.'*

Stigma by association not only affected family members of children with disabilities (predominantly parents and siblings), but also peers and service providers. It was clear that in mainstream schools, many students did not associate with their disabled peers or include them in activities because they were fearful *'that they will be taunted for playing with the cacat'.* Several CBR workers reported incidents of personal discrimination on account of their work. One CBO worker explained that his family and friends were critical of his work with children with autism, and asked *'They* [children with autism] *are crazy, why are you still with them, why do you still sit with them and face them?'* Another reported that members of her community thought she was 'contagious' because of her work with children with disabilities.

Across all participant groups, the social distance between community members and children with disabilities, and the level of familiarity with or exposure to children with disabilities was found to be a primary factor influencing levels of acceptance. Perhaps unsurprisingly, people with closer relationships and with more familiarity (caregivers, services providers) acknowledged higher levels of stigma and discrimination than those with limited interactions or no direct relationships with children with disabilities. Whilst many community members were aware that discrimination did occur to some degree, many believed that it did not happen in their community. In the KAP survey, 70.9% of respondents (227) suggested that children with disabilities were 'treated well' in their community, and 80% (256) thought they were protected. In interviews and focus group discussions, caregivers and service providers suggested that the general public's persistent lack of awareness about how children with disabilities were actually treated, was as a result of people's limited direct interaction with children with disabilities. A CBO representative explained, *'That is why they are not being accepted in the society, the exposure of OKU in society is still not that much.'* Changing attitudes to facilitate understanding and awareness was highlighted as an essential prerequisite for environmental and social change. As a CBO representative concluded,

> **"Sometimes the environment won't adjust to us because public attitude is very difficult to change… I think society has a lot to change in terms of social attitudes, only then the environment can change and the practices are going to change. Start with attitude."**

Increased vulnerability

Participants from all stakeholder groups acknowledged that children with disabilities were vulnerable to their surrounding environment and society, particuarly because they were 'easily influenced by others and 'don't know right from wrong'. Several caregivers of children with disabilities suggested that such vulnerabilities were common to all children, but most acknowledged, as discussed above, that situations of bullying and manipulation were common. Teachers explained how children with disabilities were often seen to be easy targets and scapegoats because they had little agency or power to assert themeslves, and CBR workers described situations in which their students had been coerced into vaping, smoking, selling drugs, watching pornography and, in some cases, prostitution. Access to the internet was considered to increase the vulnerability of children and adolescents with disabilities. Participants recalled instances when children with disabilities had been taught by their non-disabled peers how to access pornography and other inappropriate content on their mobile phones. With access to social media platforms such as WhatsApp caregivers and service providers expressed concern that they had little control over the relationships adolescents developed using these technologies.

Two service providers ‘blamed’ the parents of children with disabilties for exposing them to elevated threats and held them accountable for not being fully aware of their ‘responsibilities’. Other participants concluded that it was society in general that was failing children with disabilities for two main reasons; firstly because the general public remained unaware of their vulnerable position; and second because *‘The safety nets that are needed to protect them are lacking’.* For example, the Child Act 2001 does not account for children and adolescents with disabilties and left them particuarly exposed in the justice system, particuarly in terms of trial and sentencing. As one community leader from Sabah concluded,

> The magistrate finds it difficult to make a decision… When the OKU children are brought to the court, and after the case hearing, if they are sent to the *Tunas Bakti Sekolah* [Rehabilitation Centre for Young Offenders] they will be mixed with the other young offenders, and they will most probably be bullied and discriminated.

Participants also discussed the fact that children with disabilites were vulnerable to physical and sexual abuse. In the KAP survey, whilst only 55.9% of respondents (176) agreed that sexual abuse happened in their community, 67.2% of respondents (215) agreed that children with disabilities were at more risk of sexual abuse. During the research, cases of sexual abuse and rape of children with disabilities that were known locally and / or had received attention at the national level were frequently recounted (discussed further below). In general, stakeholders participating in interviews and focus group discussions agreed that children with Down Syndrome and ‘slow learners’ were the most vulnerable to sexual abuse.

Concerns about the future

One of the greatest worries expressed by caregivers of children with disabilities was concern for their future in terms of limited opportunities for employment and financial independence, and the pervasive stigma and discrimination that would continue to restrict their integration and participation in society. As one mother concluded, *‘We do not know what their future is like… Let’s say if one day we pass away… what will happen to him? He can be independent, he can do self-management, it’s just the outside world that makes me anxious’.* Many caregivers worried about who would care for and protect their child in later life. Several parents asserted that the child’s sibling(s) would assume responsibility. Some were constructive about this shift in responsibility, *‘I have explained to her brother and he understands. I just pray that it doesn’t come to his sister being abandoned, that is all’,* whereas others were more prescriptive, *‘Like it or not, that is your flesh and blood, and when I’m not around tomorrow, this is all your responsibility’.* In several cases, caregivers discussed the possibility of institutionalisation as a way to ensure their child gained a level of independence, although there was concern about the quality of care provided in government homes. One parent explained, *‘If you go and visit a residential home here* [in Malaysia] *you say, ‘Oh boy I don’t want to put my child in there’’*. As CBO representative from Sabah recounted,

> **“With the state of our current residential homes, you think ‘no way’. You know, I used to have a parent who said ‘If I can out-live my child, I will be very happy, because that will save me having to think about who is going to look after him’. I had another parent who said, ‘When the time comes, I will take him with me’, and I know what she meant because he’s got a severe form of autism. She said, ‘I’ve seen what they do, you know… the kind of services they have, and that’s not the kind of life. Although he has severe autism, that’s not the kind of life I want my child to go through’.”**

"Singing makes me happy, I like singing a song name *'Tinggal Kenangan'.* I also like my mother, sister, a friend, brother and father. I go to an ordinary school but mix with special need students, but I am at ordinary class; there is no difference. My class is downstairs; if I want to go up, I just use my legs and hold something."

A girl with physical disabilities in Kelantan draws her favourite things and people.

Girl without disabilities, participatory workshop with children with disabilities, Selangor.

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PRACTICES: THE PROVISION OF AND ACCESS TO SERVICES

7

This chapter focuses on practices in terms of the provision of services to children with disabilities, and the uptake of services by children with disabilities and their families.

In the KAP survey, respondents were asked to free list three special services that were available for children with disabilities. The most often articulated was public infrastructure (e.g. access to buildings and transport), followed by special education and healthcare (see Graph 12, next page). They were also asked what three main areas (sectors or service provision) that should be improved to better help children with disabilities in Malaysia. Respondents suggested more financial assistance, better educational opportunities and more community based rehabilitation (see Table 9, next page). Of those surveyed, 96.4% (298) agreed that the government should provide services for families with children with disabilities.

Triangulating these findings with the qualitative data, this chapter addresses four key sectors: health services; education; rehabilitation services; and employment opportunities. In conclusion, cross-cutting barriers that prevent equitable access and participation are analysed.

Health services

Across all participant groups and all states, children with disabilities were recognised as having particular healthcare needs. The majority of caregivers engaged in the study discussed attending clinics and hospitals on a frequent basis for their child's observation, medicine, specialist treatment, and therapeutic or assistive equipment, and sought additional care between routine appointments as necessary.

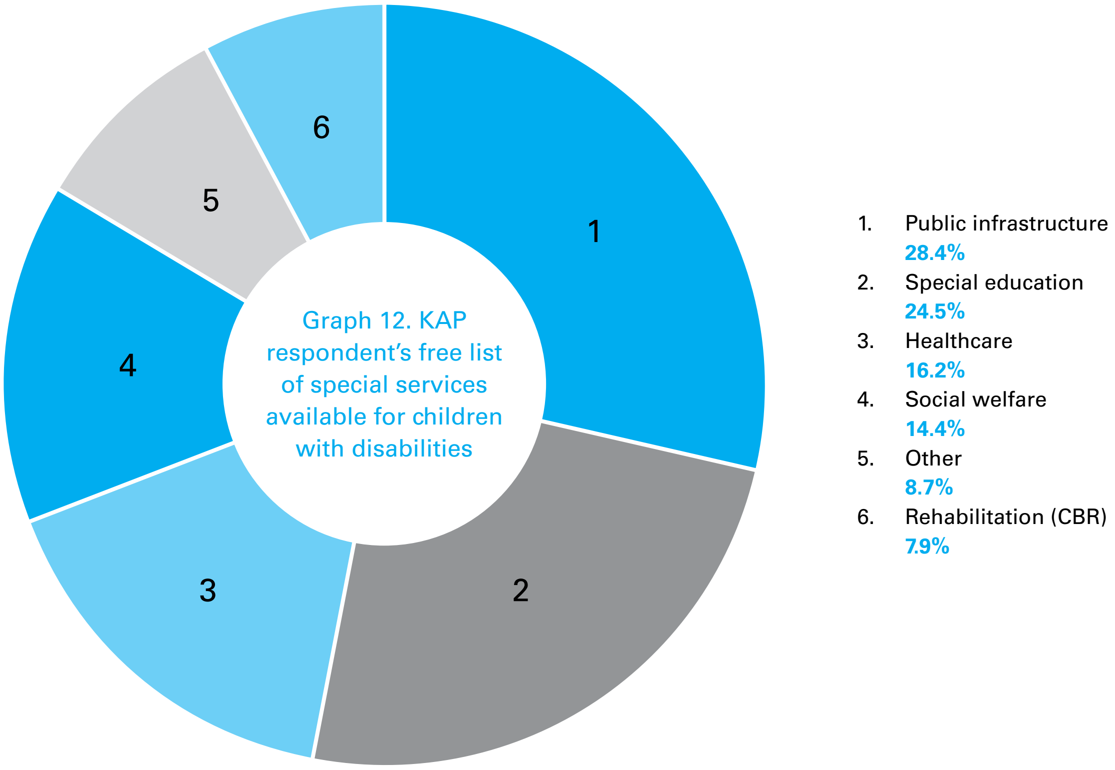
Following their child's diagnosis, caregivers confirmed that health workers were generally their 'first point of contact' and were regarded as hubs of information about health and disability more broadly. Failure to obtain pertinent information from health workers about prevention, early detection, diagnosis, management, treatment and rehabilitation, left many caregivers dissatisfied and frustrated from an early stage of their child's condition.

Clinics and general hospitals provided free care for children with disabilities, but negative experiences at these facilities (discussed further below) appeared to increase the demand for and utilisation of private clinics, despite their elevated costs. The quality of care was reported to be of a higher standard in private hospitals. Several caregivers described 'saving all our money' to enable them to seek care at a private clinic, although the associated costs remained prohibitive for many. As one middle-income caregiver explained,

"But not all parents have access to this kind of plentiful information… They can go to a government hospital but, if they don't have information, what can they do? For us, we can afford to send our child for private healthcare. We can afford it and yes, there are a lot of benefits, good information and we meet a lot of people. But for those parents who only sell vegetables, they can't go anywhere."

Caregivers discussed the lack of sensitivity they perceived in health workers, particularly during diagnosis. They were reported to use inappropriate language (such as 'abnormal' and 'retarded') and have a lack of empathy. When health workers displayed feelings of pity, caregivers often saw it as an 'unprofessional' response, driven by a lack of awareness and lack of training. In contrast, several participants highlighted more positive experiences concluding that some health workers were able to put children at ease, *'so the kids will not feel afraid to go to hospital.'*

The majority of stakeholders, including health workers themselves, identified the need for improved and specialist training. Several health workers confirmed that they had no received any training about 'how to deal with' children with disabilities, and demonstrated limited knowledge about causation, management and treatment for a range of disabilities. The following dialogue between the facilitator and a doctor in rural Selangor was illustrative.



Graph 12. KAP respondent's free list of special services available for children with disabilities

1. Public infrastructure **28.4%**
2. Special education **24.5%**
3. Healthcare **16.2%**
4. Social welfare **14.4%**
5. Other **8.7%**
6. Rehabilitation (CBR) **7.9%**

Table 9. KAP respondent's free list of areas that should be improved for children with disabilities, by location

	Location		
	Urban % (459)	**Rural % (463)**	**Total %**
More financial assistance	17.9	19.7	18.8
Better educational opportunities	17.2	19.2	18.2
Support groups	15.3	9.3	12.3
Community based rehabilitation	13.5	13.2	13.3
Better medical services	12.0	14.0	13.0
Better vocational training	11.1	10.8	11.0
Better social services	6.8	4.5	5.6
Better access to public transport	5.0	6.7	5.9
Other	1.3	2.6	2.0
Total	100	100	100

Facilitator: **Aside from some medical services, what other services do you know are available for children with disabilities?**
Doctor: **No, I don't know any.**
Facilitator: **Have you ever heard of community-based rehabilitation?**
Doctor: **Yes I have, but I never know the details. I heard about it before. I don't know where it is, what its function is. Maybe it's like a support group, but other than that I don't know.**
Facilitator: **Do they have community-based rehabilitation in your area?**
Doctor: **I don't know [laughs]. Maybe they have but I don't know.**

Stakeholders across the study highlighted that limitations of both human and material resources within the health system were problematic. Services appeared overburdened, and caregivers discussed the lack of specialised care, limited supply of assistive devices via physiotherapy or occupational therapy departments, long waiting time and short consultation periods. As one caregiver reported, health workers *'cannot give the amount of time and attention that every patient would want, of course they work along with a lot of constraints.'* Some participants suggested that children with disabilities should be given priority when attending clinics to alleviate the stress of waiting. In addition, several suggested that children should be allocated a separate waiting area, *'Because these OKU children, not all of them are ok and can sit quietly. Sometimes I can see how difficult it is for the mothers and fathers to take care of them. Some children like to disturb other kids and the mother can't accept that. Sometimes the children can fight'.*

Caregivers perceived there to be a small cadre of trained specialist therapists, mainly located in urban centres, which meant the distribution and coverage of services offered was inequitable, even within the public sector. This impacted both therapeutic care and access to assistive devices. A father in Kelantan explained, *'my child needs wheelchair. At the moment he cannot move by himself... It is a problem for me since his body is bigger than mine. He is very heavy to lift.'* Several participants emphasised the lack of coordination between services and welfare allowances or entitlements, and this complicated the procurement and allocation of medical equipment and assistive devices. As one caregiver from Kelantan recounted,

"I asked the hospital for a wheelchair but it is very difficult to get one. The staff at the hospital said that the hospital will not buy it for us. The cost to buy is only RM250.00. [They asked] me why can I not buy it because it is cheap. I was embarrassed so I never request it again. However, the doctor keeps on saying there is provision to buy a wheelchair that I can apply, and in fact I am entitled to apply for my son."

Participants also reported that the physical environment of clinics and hospitals was difficult to navigate around. They discussed the frequent lack of access ramps and elevators, which was particularly problematic for children with mobility issues. One caregiver in Sabah reported that in comparison to the public parking, the designated 'OKU parking' was far away from the hospital entrance and explained how the patients needed to cross over drainage systems to enter the facility, making access to the building unsafe for children with disabilities.

Malaysia has a complex pluralistic medical system that offers multiple paths of care, including for disabilities. Local healers (*bomoh* [Malay], *manang* [Iban], *pimpuri* [Bidayuh]) were most frequently sought in Sabah and Sarawak (by Kadazan-Dusun and Bidayuh respectively). Depending on the condition, its presentation and severity, participants recounted attending a local healer before seeking biomedical care, in parallel with biomedical care, or as a last resort if biomedical care did not seem to be having a positive impact on their child's condition. For some conditions, local medicine was seen to be effective and potentially curative, and the short-term benefits of 'taking herbs' were discussed by several caregivers, although many acknowledged that *'There are illnesses that cannot be cannot be healed by traditional healer'.* In Selangor, participants more frequently referred to 'alternative medicine' and discussed using acupuncture, cranio-sacral therapy and homeopathy to treat their child's disabilities.

Education

Opinions on how and where children with disabilities should be educated was divided. In the KAP survey, 10% of respondents (32) asserted that neither girls nor boys with disabilities needed to attend school. In relation to the education system, 43.1% (138) of respondents agreed that it was disruptive for children to be in school with children with disabilities; 48.8% (156) disagreed; and 8.1% (26) provided no answer. In the interviews and focus groups discussions, some participants were confident that children with disabilities should not be educated alongside other students in mainstream education, whilst others believed that integration and 'exposure' to children with disabilities was essential, not just for the learning experiences of all children, but for the benefit of society more broadly, breaking down barriers, alleviating stigma and generating greater acceptance and awareness.

The KAP data indicated that perceptions about whether a child with disabilities should attend school with other children was partly determined by the type of disability. Children with physical disabilities were the most accepted into school with other children (as reported by 67.8% or 217 respondents); children with behavioural disability were accepted by 40.3% of respondents (129); whilst only 16.3% of respondents (52) were accepting of children with mental disabilities being in school (see Table 10). Teachers in mainstream education who took part in interviews and focus group discussions suggested it was not possible to teach children with and without disabilities in the same class, and confirmed that children with disabilities should be educated in special classes or at special schools. In contrast, special education teachers emphasised that if they had the capacity and capabilities, children with disabilities should be offered an opportunity to study in mainstream education. They concluded that the lack of classification about disability presented a major challenge in correctly placing children in schools. It was widely understood by service providers that inclusive education was a key component of the Ministry of Education's programme to integrate children with disabilities into mainstream classes where children with disabilities learn, *'side by side with other regularly developing children'.* As teachers at a special school in Selangor concluded, however, *'inclusive education is just a term that works on paper'*, but without adequate monitoring systems and supportive supervision, *'inclusive education is not working'.*

Table 10. KAP respondents' acceptance of children in school, according to disability type

Type of disability	Yes (%)	No (%)	No answer (%)
Physical disability	67.8	28.4	3.8
Speech disability	56.9	39.7	3.4
Learning disability	55.6	40.3	4.1
Hearing disability	46.3	50.6	3.1
Visual disability	43.1	53.1	3.8
Behavioural disability	40.3	54.4	5.3
Mental disability	16.3	77.8	5.9

Caregivers of children with disabilities and CBO representatives emphasised that children with visual or hearing impairments had greater educational opportunities due to the existence of special schools for their disability. In Sabah and Sarawak, however, access to special schools was very limited. In Sabah, for example, children with hearing impairments could attend a special school until Form 3 (age 15), but in order to attend senior secondary school (Forms 4 and 5), students had to apply to special schools in Penang and Johor that had limited places.

It was evident that the structure of the school system was discriminatory and set children with disabilities at a disadvantage. Although not widely discussed by teachers, caregivers and CBO representatives in Sabah, Kelantan and Selangor suggested that the Key Performance Indicator (KPI) evaluation system prevented children with disabilities being accepted by schools. The system evaluates on the basis of grades achieved by their students, and participants reported that teachers and headmasters denied students with disabilities the opportunity to sit public exams in order for schools to achieve the best performance indicators possible (as described below in Case Study 3). A CBO representative in Selangor confirmed,

"The KPIs for schools by the Ministry of Education make it such that they [teachers] will want to segregate the children with disability because they will bring down their averages. It is so they will look good and that's wrong. They are measured the wrong way. They are not measured to be inclusive, they are measured on KPIs which discourage disability. So that's going to be a challenge to change."

The majority of teachers engaged in the study asserted that the greatest challenged they faced in teaching children with disabilities was their lack of training. Many reported feeling 'vulnerable' and 'ill -equipped'. One teacher described her daily 'struggle' with coming to work after having been posted to a special school. She claimed that despite her teacher training, she did not have the necessary skills.

"As soon as I got the offer, about special education, I straight away cried because I myself have not been exposed to this. For the first three months I really cried. Only when I entered the field did I know what their problems were, their categories [of disability]. Like autism, I had never heard about it before."

Teachers in mainstream education acknowledged that only teachers with the specific skills would be capable of teaching children with disabilities, but asserted that the MOE training for special education teachers was sufficient and 'complete'. In terms of undertaking additional or on-going trainings, teachers described having to find and fund opportunities themselves. This was also reflected by the parents of children who attended special school who reported that some teachers paid for their own training, and saw this as a display of their commitment and dedication.

Voice – Mother of boy with physical disabilities, Sabah

"I took him [my son] to a school. I went to this particular school because it is near to my house, and for sure I wanted to send him to that school. I know that my son wants to study, so I took him there. But the headmaster there said, 'We do not accept this kind of kid'. I talked back to him directly asking, 'What do you mean THIS KIND of kid?

The headmaster said 'All of my students are okay but your kid is like that, and we do not accept this kind of kid.' I talked to the headmaster frankly because I wanted to know what he meant by 'this kind of kid'. The headmaster did not want to talk with me, he opened the door and left. Then I went to another school and asked for a place for my son and they also said that they did not want to accept this kind of kid. So you have to look for a school that will accept them, then you go there. There was one more headmaster who asked me to go to the welfare department to ask what schools my son could attend.

Honestly speaking, my son only has a problem with his legs, his brain is still okay. I tried to look for a solution for him. But I also got angry. I just talk about it, and do not care who you are. It is not that we ask for it, just like you say, it is God that has given that. My son does not want to be like that. He is already in Form 3 and he told me 'Mommy I don't want to trouble you'. He is able to know by himself."

Community-based rehabilitation services

In the KAP survey, 75.3% of respondents (241) thought that children with disabilities should be sent to an institution, whilst 8.8 % (28) agreed that children with disabilities should be separated from other children. However, when asked to choose which statement they agreed with, 16.3% of respondents (52) selected 'it is better for children with disabilities to be sent to residential care'; 73.8% (236) selected 'it is better for children with disabilities to live with their families'; and 10% (32) provided no answer.

Across the study, participants confirmed that community-based rehabilitation (CBR) centres provided an important space for integration, stimulation and learning. This was particularly true for children who found it difficult or impossible to access mainstream services, either due to their disability, geographic location and / or socio-economic status. In Sarawak and Sabah participants reported that the distribution of centres and the services they offered were 'still behind' those provided on the Peninsula. Caregivers highlighted transport and finances as being considerable barriers to accessing care in rural areas, even at the community level, as no supportive help was provided. One family in rural Sabah described the situation in accessing community-based rehabilitative care for their teenage son who had Cerebral Palsy.

"When he was younger, it was easier [to access CBR] but the situation is quite different now he's grown up and gaining weight. There was the wheelchair given by the Welfare Department, but it has been damaged already. Since our son's physical condition is getting bigger, that is why it has been more complicated for us to take him to the CBR centre. We were not able to bring him because my back is painful when I lift him. So when I could not lift him anymore and carry him to the CBR, we decided to stop taking him there."

Caregivers of children with disabilities in Kelantan, Sabah and Sarawak asserted that their children had positively benefitted from attending CBR centres and reported progress in their socialisation, skill development and self-management. Caregivers confirmed that the CBR workers were supportive not only to the children, but also encouraged their families by sharing techniques for home care, information about key resources, and providing assessments on the child's progress and achievements.

Caregivers in urban Selangor indicated their preference for attending private CBR centres where specialist support services (occupational therapy, speech therapy and physiotherapy) were more routinely available. They were also more likely to access alternative therapies provided by private practitioners (as discussed above). This group of caregivers suggested that specialist care provided at government CBR centres was insufficient, of poor quality, and lacked continuity of care. It was notable that caregivers in rural Selangor appeared more satisfied with the level of care provided, but attributed this in part to the lack of alternative sources of services and care available outside the urban centre.

CBR workers engaged in the study confirmed, *'we want to work for the progress of the child'*, and described how a key aspect of their role was to the careful management of caregiver expectations. They explained how some caregivers tended to 'overprotect' their children, whilst others were dissatisfied or became disillusioned if children attending CBR did not show immediate improvement or 'become healthy'. As one CBR worker in Sarawak recounted,

"Sometimes it becomes a challenge when the parents don't want to cooperate with us. We want their child to improve but when we ask for cooperation from them, some of them will just ignore it. We do our best at CBR but when the child goes back home, it's back to zero again. We always tell the parents, we give them the schedule, for example for the toilet training, we already informed them but they didn't do it. And then they want us to keep training their child here but at the same time they don't do it at home. It's one of the challenges, the cooperation from the parents."

Across all the study sites, CBR workers unanimously agreed that training opportunities were lacking and recognised the need for enhanced continual professional development. Many suggested that the training they had received was 'definitely not enough' and left them feeling that they had 'a lot to learn'. CBR workers emphasised their frustration at not being able to communicate with sign language and their desire to have improved technical experience to meaningfully engage children with specific disabilities. A CBR worker in Sarawak concluded,

"I would like to attend more trainings, like an autism course. Other than that we also want to attend a course on how to handle a child with Down Syndrome. If possible, we hope to have more courses on how to handle a child with these disabilities, or a course for physiotherapy so that we can improve our skills."

High turnover of CBR workers led to an almost continuous stream of new trainees being deployed, and this strained both human resources and the quality of care provided. Many participants, both CBR workers and other stakeholders, highlighted the voluntary nature of the work and concluded that the lack of incentives and limited recognition of their service by the government to be demotivating. A CBO representative in Sarawak explained, for some people, *'CBR work is just temporary while they wait to get for another job. Because the payment for CBR staff is only RM800 [USD200] they will say 'While I'm waiting for the another job, I will work at CBR first.' When we've already given them training, they quit.'*

Employment opportunities

In their participatory workshops, adolescents with disabilities placed great value on employment as a means to contribute to society, to be financial secure and gain independence. Participants with and without disabilities commonly suggested, *'People look down at you when you have no job, you do not earn for yourself, you cannot fulfil your role in the society, you cannot contribute to the community or society'.* Finding employment was a critical concern articulated by adolescents with disabilities.

'Transition', the period between completing formal education and starting a job, was a time when adolescents with disabilities frequently got 'stuck'. CBR staff explained that when adolescents finished their education at special school or CBR centres, there was no established pathway that helped guide them into adulthood and the work place by providing additional training or skill enhancement. Numerous interventions and programmes for children with disabilities existed, but it was suggested that young adults in transition were largely overlooked. Some training was reported to be provided by a range of CBOs, CBR centres and NGOs, but their representatives who participated in the study emphasised that vocational skill development required further advocacy.

From the qualitative narratives, it was clear that discrimination against people with disabilities was systemic, from restrictive employment opportunities, to limited support in the workplace and reduced salaries. In their participatory workshops, adolescents claimed that many employers did not *'believe that a disabled person could do a job'*. Other stakeholders perceived that adolescents with disabilities could work, but considered them capable of only performing certain menial jobs. As a result, employment in the corporate sector was seen by many to be unrealistic or unattainable, and in Sarawak and Sabah there were fewer opportunities outside hospitality or handicrafts than in the Peninsula. In the KAP survey, 10.9% of respondents (34) concluded that they would not be comfortable working with a person with disabilities. Several CBR workers suggested that some caregivers also limited the opportunities their child could access as they wanted to 'hold them back', often to protect them.

A number of adolescents with disabilities who participated in the workshops aspired to tertiary education (discussed further below), but acknowledged that opportunities for further education were limited after high school. As a CBO representative in Sabah noted,

> **"Even after they've left high school, and they're going on into further education, even then they are discriminated against. Even people with hearing loss, its assumed that "oh… just let them work at KFC" or "let them work as a cleaner somewhere", which means that they don't even get opportunities at the higher education level. That is challenging in itself, because like with job, they won't probably get the best job, because people might think that "oh… they can't do this"."**

The majority of participants emphasised that mechanisms should be in place to prevent employers from taking advantage of adolescents with disabilities. Indeed, the MWFCD confirmed that although provisions were in place to protect people with disabilities in employment, the policy itself actually enabled discrimination as it made provision for employers to pay people with disabilities a lower wage for the same job than they would be required to pay people without disabilities. Participants across all stakeholder groups suggested that the government should invest more in helping adolescents with disabilities to secure gainful employment and assume active roles in society. As caregiver in Selangor concluded,

> **"I understand that the government has so many other needs to take care of, but as I said, they should invest early on and really support this group of kids, then later on they can give back, they can contribute back to society."**

Concerns about education and employment were particularly emphasised in the participatory workshops with youth, both with and without disabilities (see Case Study 4, next page).

Cross-cutting barriers preventing access and participation

In the KAP survey, respondents were asked to suggest three dominant barriers preventing children with disabilities having a better life. Although the scope of answers articulated by participants were too diverse to be conclusively coded, the majority of respondents recognised societal barriers such as stigma, lack of opportunity and lack of acceptance as key challenges. Infrastructural and transport barriers were also highlighted, and the absence of adequate

Voice – Adolescent girl without disabilities, Sarawak

> “We should raise awareness before we do anything. We should raise awareness among the youth, among the students because…here there are still some people with the mind-set that people who have disabilities don’t belong in the world. They don’t deserve to live. So we should change that mind-set. Those people with disabilities are also human and maybe he doesn’t have a leg, he doesn’t have an arm, but he is a human and he has the same right as you do to study normally, to live a normal life to grow, and have a job. I think people with disability, they shouldn’t keep distance themselves from society because sometimes there are things that people without disability, they can’t do but people with disability they can do it. Like there’s a case where, there’s a girl, I think she was blind, but she got a lot of A’s for her SPM [state examination]. So they’re quite smart, and there’s some people without disability they still fail their SPM. I think that the big company, they should have…employed these people with disability. They can actually help them with their income so they can participate instead of making them just stay at their home like they are useless. But they are actually useful.”

financial support and welfare particularly noted. In the survey, the need for greater financial assistance was identified as the single most important area requiring improvement by 18.8% of responses (see Table 9, page 69).

Registration of children with disabilities: The majority of participants confirmed that registration was beneficial, but its value was expressed differently across stakeholder groups. Service providers (government officials, CBOs and health workers) described the value of registration in terms of accurate statistical data to assist with planning, procurement, service provision and evidence in policy making. In contrast, community members, caregivers and CBR workers expressed the value of registration for the individual child with disabilities. Registration allowed them to receive a disability card (OKU card) and access services, allowances and discounts, although many remained unclear as to what entitlements they were due. Some participants suggested that registration should be compulsory to ensure the rights of children are observed, and considered registration a matter of child protection. Despite the perceived advantages, caregivers highlighted that significant discrimination and stigma were associated with having an OKU card and being labelled ‘disabled’, and that children were therefore at risk of further marginalisation. In addition, caregivers found the process of applying for and obtaining a card to be convoluted and protracted, partly due to the centralisation of the service and the perceived inefficiency of registration workers. Registration was seen to be even more problematic for vulnerable children including orphans or displaced children who lacked sufficient documentation. One CBO representative working with children with disabilities in a children’s home in Selangor explained, *‘Actually we can’t* [register them] *because many of them are not warganegara* [not citizens]. *So getting them registered with all of the procedures is rather a complicated procedure.’* Consequently these children are not liable to receive any support from the State, and are not enumerated in any official data.

Financial barriers: Both direct and indirect (or hidden) financial constraints were dominant themes in many of the caregivers’ narratives and the issues were often magnified in households from the poorest quintiles. Out-of-pocket expenses including transport to services, medical bills, nutritional supplements, diapers, and assistive devices could be substantial. The strain on household resources as compounded if caregivers had to cease work to become full time carers and received only limited disability allowances. For many families, financial constraints prevented the child with disabilities from attending school or rehabilitation services regularly, and frequently curtailed the education and social activities of siblings and the wider family unit.

Transport barriers: Not only was the cost of transport prohibitively expensive for some caregivers, but transport options were often limited, particularly in rural areas where the need for transport was likely to be greater given the longer distances from home to the site of service provision. In addition, physically accessing public transport was often challenging, and caregivers frequently reported facing discrimination from bus and taxi drivers. CBR workers confirmed that transport was a major factor for most families caring for a child with disabilities, and that without it, children (and sometimes their immediate family members) were likely to become further isolated and marginalised. In contrast, it was more common for participants in urban Selangor to own their own vehicle. Although this reduced transport barriers it could increase associated costs.

The implementation and regulation of disability parking was a concern raised by many participants. They suggested that registration staff and tranport officials provided insufficient advice about parking permits and several caregivers claimed that they had been denied a permit on the basis that they did not have a disability themselves. Both caregivers and service providers concluded that there insufficient designated spaces for disability car parking, and the failure of the transport agency to pursue those who parked illegitimately was an added frustration for many.

Physical / infrastructural barriers: The lack of physical access to public environments was a major concern expressed by all stakeholder groups. In relation to education, for example, infrastructural barriers (such as no elevators, stair ramps, or modified bathrooms etc.) were seen to be a fundamental obstacle to inclusion. As one father concluded, *'My daughter's classroom was on the third floor. I could attend the school to carry her myself, and her teachers were not willing. So, I decided I don't want her to go the school anymore. Now she just stays in the house and does nothing'.* Many respondents commented on the lack of planning that went into public spaces (including hospitals and clinics) to ensure they were accessible for children living with disabilities.

77% of respondents in the KAP Survey confirmed that they knew a child with disabilities.

However, 87% believed that 'disability' referred to physical impairment and were less likely to find behaviour to be considered a disability.

Girls drawing a story board at a participatory workshop for children without disabilities, Kelantan.

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8

PERCEPTIONS AND EXPERIENCES OF CHILDREN AND ADOLESCENTS WITH DISABILITIES

Prior to this study, there had been little research directly undertaken with children with disabilities in Malaysia. Their voices were not well captured or represented in published literature, and were largely absent from the public discourse about disabilities in Malaysia. The inclusion of children and adolescents in this study through their engagement in the participatory workshops provides new insights into the experiences of children with disabilities. Whilst the report has documented their views and perceptions throughout, this chapter specifically highlights the main themes and key considerations that emerged during the workshops.

Self-identification

Through the workshops' main activities (storyboards, role plays, illustrations, graffiti walls), participants with disabilities rarely depicted themselves as having a disability. Rather they projected themselves to be like their non-disabled friends or peers, often able bodied and without aids. For example, adolescents (18 to 21 years old) with moderate Down Syndrome in Selangor suggested that OKU were *'people who had no legs'*, *'were like children'* or *'were sick a lot '*. It was clear that they did not associate themselves as OKU, but in this context, it could not be determined whether they did not perceive themselves to have a disability or wanted to avoid being labelled as disabled. Similarly, children with learning and behavioural disabilities in special primary school articulated that they were 'different' but did not consider themselves to be OKU. Their descriptions of people with disabilities revolved around an impression of *'people who cannot walk, cannot talk, cannot speak.'*

For participants who had hearing disabilities, however, 'being deaf' was an important part of their cultural identity. Some had difficulty relating to and interacting with their hearing peers, but found comfort and understanding within the deaf community, a community with a strong sense of unity. As one male adolescent (19 years old) in Sabah concluded, *'I find they* [non-disabled people] *don't really accept us whereas, for our own community, because all of us can sign, we can understand each other well.'* Published research suggests that notions of deaf identity and culture can be seen to conflict with the broader discourse on disability, resulting in tensions between people with hearing disabilities and other disabled people. In contrast, however, participants with hearing disabilities engaged in this study confirmed that they valued shared experiences with children and adolescents with other disabilities. One female adolescent (21 years old) in the same group concluded, *'For me, I feel it's not a problem for us to come together with other disabilities. Because we are all the same, I mean we are the disability group. So, as the disability group, yeah, we can be united.'*

Opinions about family

Workshop participants frequently described their family as a source of comfort, and their key support network. In discussions, children did not limit this to their family unit and included experiences and relationships they had with cousins, neighbours and friends who lived close by. In the drawing activity, when asked to illustrate something that made them happy, many drew scenarios based around the home or playing with siblings and cousins. Some children drew their house as a place of happiness and comfort, others drew all their family members. Children with more severe intellectual disabilities or who had limited communication skills drew similar scenes of family, and though some of their drawings were unidentifiable to the facilitators, when asked to describe their pictures, the children identified the images as 'mother', 'sister', 'house' or other words related to their happiness (see Illustrations 4 and 8).

Both children and adolescents with disabilities recognised the support given by families in accomplishing daily activities. One girl with physical disabilities in Kelantan emphasised her reliance on family, explaining that when they were around she could do anything, *'I have no problem; if my mother is not around, my cousin will come to help. My father is a soccer player; during lunch he comes back home to help.'* Although high levels of support from family were appreciated by older participants with physical disabilities, this age group acknowledged the 'burden' a child with disabilities could be on their parents. A male adolescent (17 years old) with Cerebral Palsy explained, *'I have difficulty to move. Ninety percent of the time my parents have to help me to move. There are many things I can't do myself.'* For some participants the family situation was more complex. Another adolescent with behavioural disabilities in Sarawak explained,

> **"When I was a baby, my [biological] mother didn't care… When I grew up, I don't want to leave my foster mother. She already takes care of me, and has fed me since I was a baby. I don't want to leave her. Because in my heart I love her. But I feel confused about my biological mother. I also love my biological mother."**

Opinions about friends

Friendship was highly valued by workshop participants. Like family, friends were a critical network of support and motivation. When asked if she had friends, a young adult with Down Syndrome in Selangor asserted *'I have, of course I have'*, before listing the names of her closest friends. Similarly, during graffiti walls or storyboard activities, it was common for workshop participants to draw all their friends and list their names. When asked what made them happy, most participants concluded that their friends and participating in activities with their friends (playing football, flying kites, meeting and chatting) were their main sources of real happiness. Workshop participants recounted that they faced less discrimination when accompanied by friends. Conversely, children and adolescents discussed feelings of sadness, loneliness, embarrassment and anger when they were excluded from participating on account of their disability.

As with their self-identification, children with disabilities tended not to identify whether their friends did or did not have disabilities. Again, the exception was adolescents with hearing impairments who clearly differentiated between their hearing and deaf friends. *'For me, my experience is that I feel more comfortable with my own group rather than being with hearing counterparts, hearing friends. Sometimes it's difficult for us to understand each other, especially in communication.'*

Physically disabled participants reported that friends carried books at school, helped them to access classrooms and undertook intimate tasks such as taking them to the bathroom. As one girl (11 years old) with physical disabilities explained, *'I have many friends. My friends are always with me. All my friends are willing to help me if I need it.'* For many, school friends were a critical support network, who facilitated participation and learning. It was notable that many preferred to ask for assistance from their friends rather than teachers.

Experiences of education services

In workshops, children and adolescents with disabilities emphasised how important it was for them to attend school, receive a good education and access the same opportunities as their non-disabled peers. The majority of workshop participants attended integrated or special schools and reported that teachers were 'kind' and 'patient'. Students acknowledged that teachers must be patient because many children with disabilities had *'their own type of behaviour'*. For children and adolescents accessing CBR, the service providers, to whom they referred to as teachers, were also seen to be supportive.

Participants from a specialist school in Selangor who had dyslexia, autism and behavioural disabilities, spoke positively about their school experience. The school accepted children on a short-term basis with the intention of them (re-)entering mainstream or integrated school once they had achieved adequate scores on the Linus Test (for literacy and numeracy). As two boys with behavioural disabilities discussed,

Participant 1: This school is fun.
Participant 2: It is all about learning.
Participant 1: There are good teachers.
Participant 1: I went to another school. It was noisy in class at the other school.
Participant 2: We learn here. New techniques to learn.

In comparison to teachers who had been trained to provide mainstream education but had been placed in special schools, participants recognised that teachers who had received specialist training were more competent and had greater skills to teach children and adolescents with disabilities. A small number of participants suggested that teachers in mainstream schools did not do enough to stop discriminatory behaviour. An adolescent with a visual impairment concluded, *'My teachers advised me that it is ok if people talk harshly, we must be accepting. Even though my heart finds it to be offensive, but what can we do.'* In some schools, teachers were supported by student aids and teaching assistants, however students often found that the support they could offer was insufficient. Adolescents with hearing disabilities highlighted that the students' aids allocated to support them were not encouraging and did not know how to sign competently. Some participants concluded that they would *'rather not bother'* having such assistance.

A number of participants confirmed that they required extra support to supplement the level of engagement teachers provided. In addition to the help their friends gave (as discussed above), several relied on parents coming to the school. One participant with physical disabilities explained that she still wore nappies and that her mother waited at the school to assist her in the bathroom. Others needed their parents to feed them at lunch break. In some schools, however, teachers were willing to help children more intimately.

Older workshop participants reported similar challenges at college to those they had faced during school, but asserted that support services were even more lacking. For example, colleges lacked interpreters for students with hearing impairments and lessons that were projected in class were not always clear, exacerbating difficulties students with visual impairments had to overcome to learn.

Workshop participants held varied opinions about what type of education was preferable: special school; integrated school; or inclusive programmes in mainstream schools. Both inclusive and exclusive education were acknowledged to have challenges.

The key factor for adolescents tended to be the right to education, regardless of the disability or the school. As one female adolescent in Selangor affirmed, *'In my opinion, if possible, it is better to send them* [children with disabilities] *to school. They also want to study. Even though they are OKU, they still want their future to be bright. Right? If we didn't send them to school, then pity the OKU child.'*

Experience of stigma and discrimination

In the 'safe environment' created by the workshop, children and adolescents with disabilities spoke openly about their experiences of ill treatment and bullying. Many participants had experienced name-calling and stressed that the use of the word *cacat* could be particularly hurtful. One physically disabled participant concluded, *'Sometimes I cry because people tease me'*, whilst another asserted, *'I am angry – I do not like people calling me cacat like that.'* One girl in Kelantan recounted how she was called names because *'Because one leg is longer than other one. Some people call even call me pig'*. 'Pig' was used as a highly derogatory term as pigs are believed to be dirty and spiritually unclean and the term was associated with disgrace and shame, particularly for Muslims.

Some children and adolescent participants reported being scolded and beaten. It seems that scolding usually came from family members, but that physical beatings were also carried out by community members beyond the family unit. One young male adult (21 years old) with Down Syndrome explained that he had been beaten on the face and chest until 'there was blood' (see Illustration 9). An adolescent in Sarawak with learning disabilities spoke of the frequent bullying he faced from peers.

"My normal friend always bullies me. He always asks money from me and I don't want to give it to him. He is from a normal class and he doesn't like special school… I'm in special school. If he asked for money every day, it's called *'toyol',* it's stealing. Sometimes he asks for RM5.00 sometimes, RM50.00, [then] I can't buy ice cream. If I don't want to give it to him, he will punch me, and I will have to run."

Although some participants pointed out that teasing and name-calling was a part of growing up – *'My friends tease me, they call me fat, but no one has said anything about my disability'* – it was clear from the frequency with which children and adolescents with disabilities reported they were teased, bullied and beaten, that they were more vulnerable than their peers without disabilities. One young female adult with a visual impairment who lived in Selangor stressed, "I am usually accompanied when I go out… I don't dare to walk out alone because I am scared. My friend [also visually impaired] told me she can feel it, she said she feels like a bad person is following her. Even though our eyes can't see, the eyes of the heart can see. The eyes of our heart will let us know if you feel something is not right. So I avoid going out based on that."

Over the course of the qualitative fieldwork a number of cases involving sexual abuse and rape were (self-) reported to the research team. In line with the study's ethical guidelines, and general principles of duty of care and prevention of harm, the team leads discussed specifics on a case-by-case basis and signposted referral mechanisms and support services as appropriate.

Motivation for the future

Workshop participants emphasised that they found adults with disabilities, both in real life and those who were well known through the media, to be a sources of motivation. Interestingly, international 'celebrities' such as Stephen Hawking were often cited as inspirations, and adolescent participants discussed examples of people with disabilities becoming lecturers and Islamic scholars. The young adults who participated in the workshops listed attending tertiary education, securing steady employment and having a family of their own to be their key aspirations.

In thinking about the future, obtaining a job with a reasonable wage, was a pertinent worry for adolescents. The following excerpt, from a workshop in Sabah with adolescents with hearing disabilities, is illustrative.

Participant 1: I am worried that if I finish schooling and if I try to look for job, they won't accept me and I won't find a job. That would be a problem.
Participant 2: I am worried about my future life. I don't not know how long I will be here, how long I might live.
Facilitator: Do you think that the worries you have are the same as people your age who can hear? Or do you think you have additional worries?
Participant 2: Well I can see from my sister, my sister easily got a job.
Participant 1: It may be the same for us…
Participant 3: But because of our disabilities
Participant 2: I guess now you know discrimination.

Difficulties in finding employment were seen to be indicative of the lack of government commitment to ensuring that people with disabilities had equal opportunities and could live independently. As a visually impaired participant in Selangor concluded,

"The jobs are really limited for OKU. Like me, I have been through many interviews. And their reason [for not giving me the job] is that they want normal people. I have also thought, if they only want normal people who can see, then what work should an OKU do? We can't just be selling tissues or doing massage. We also want to experience how it feels working in an office, or any other work that normal people do… It is sad that the government doesn't really bother about the occupation aspects of OKU."

In contrast, a group of adults with Down Syndrome who participated in the study in Selangor, had few worries about finding work and all appeared confident

"I understand that the government has so many other needs to take care of, but as I said, they should invest early on and really support this group of kids, then later on they can give back, they can contribute back to society."

Caregiver in Selangor

that they would be employed by ‘McDonalds’, at a ‘Petronas Oil Pump’ or in ‘a big office’.

Many participants also spoke about their desire to have a relationship and get married. As discussed above, some of the younger participants were prescriptive about who people with disabilities should marry (i.e. a person with the same disability as their own), whereas several older participants with and without disabilities highlighted that they could have meaningful relationships regardless of their disability. For example, one participant who had a hearing impairment had a non-disabled fiancée, and whilst both emphasised the challenges they faced on a day-to-day basis, stressed that the ‘acceptability’ of their relationship was not an issue. Children and adolescents across all four states referred to their use of social media in finding girlfriends or boyfriends, and many found platforms such as Facebook and WhatsApp to be easier ways of meeting people than having to ‘go outside’. One male participant in Sabah with physical and learning disabilities had met his girlfriend via WhatsApp, but theirs was a virtual relationship due to geographical distance. Asked how he would feel if he was to meet her, the boy asserted that he would not be ‘shy’ because he felt ‘normal’ despite his ‘visible’ disability. In contrast, a male young adult with learning disabilities had met his girlfriend on Facebook but felt nervous about their first in-person meeting. By using voice recording technology and spell checks on his smartphone and laptop, he had purposively hidden the fact he had a disability.

Boy with physical disabilities at a participatory workshop for children with disabilities, Sabah.

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CONCLUSIONS AND RECOMMENDATIONS

In focusing on knowledge, attitudes and practices, this study has provided new empirical evidence about children with disabilities in contemporary Malaysian society. Findings should be used by UNICEF and other partners to inform programme design and communication strategies to support the Malaysian government to address systematically issues of inclusion, and to promote the rights of children with disabilities as part of Vision 2020.

Prior to this study, there had been little research directly undertaken with children with disabilities in Malaysia. Their voices were not well captured or represented in published literature, and were largely absent from the public discourse about disabilities. The inclusion of children and adolescents in this study, through their engagement in the participatory workshops, provides new insights into the experiences and perceptions of children with disabilities.

In Malaysia, the predominant approach to disability is derived from the medical model. It focuses on the disability or impairment itself, is driven by a sense of charity and affords little attention to social and environmental factors. The implication of this model is that children with disabilities are passive recipients of services and are often pitied, rather than being active individuals who are agents of change. In recent years, there has been a gradual shift towards a more ‘social approach’ to disability. Whilst this is now reflected in policy, this study has shown that it has not cascaded down to the community level and has not impacted many of the drivers of stigma, discrimination and vulnerability that continue to affect people with disabilities disproportionately. As a respondent from UNICEF Malaysia concluded,

“This is where the challenge is. While the government is making the shift [towards the social model], it’s not really happening on the ground, people are not seeing it that way. Those attitudes have not changed. That is where we need to do the work.”

With regards to knowledge, the study analysed how disability was defined and understood, and discussed the terminology and language of disability and its associated connotations. It outlined local theories of causation, and provided an overview of information sources and trusted or preferred channels for communication. Attitudes towards children with disabilities were addressed from the perspectives of different stakeholder groups engaged in the study. The analysis focused on societal attitudes towards children with disabilities and discussed stigma by association. It explored perceptions of increased vulnerability and documented the concerns caregivers had for their child’s future. In relation to practices, the focus of the analysis was on the provision of services to children with disabilities, and the uptake of services by children with disabilities and their families. Four key sectors were addressed – health services, education, rehabilitation services, and employment opportunities – and cross-cutting barriers that prevented equitable access and participation were summarised.

Table 11, on page 86, summarises the key findings reported per participant group and triangulated across both the qualitative and quantitative data.

Table 11: Key findings as reported per participant group

		Caregivers of Children with disabilities	Caregivers of children without disabilities	Community and religious leaders	Service providers	Children with disabilities	Children without disabilities	Adolescents with disabilities	Adolescents without disabilities	National / government stakeholders
Knowledge about disability	Perception that definitions of disability were rooted in an individual's limitations	x	x	x	x	x	x	x	x	x
	Frequent use of negative terms such as *'cacat'*		x	x	x		x		x	
	Perception that disability could be understood as both as 'visible' and 'invisible' condition		x	x	x		x		x	
	Limited knowledge about the actual causes of disability reported	x	x	x	x	x	x	x	x	x
	Suggestion that religious beliefs influenced how disabilities (both cause and presentation) are perceived and understood	x	x	x	x	x	x	x	x	x
Sources of information	Community and religious leaders, and services providers identified as vital source of information		x	x	x					x
	Support groups identified as trusted sources of reliable information	x	x		x					
	Online networks identified as valuable platforms for sharing information	x			x	x		x		
	Identification that more information about children with disabilities was needed	x	x	x	x	x	x	x	x	x
	Perception that information provided by the DSW was insufficient	x	x	x	x					x
	Acknowledgment that access to information was best in urban areas of Peninsular Malaysia compared to the rest of the country	x			x					
Societal attitudes	Perception that on the surface, attitudes towards children with disabilities appeared sympathetic, supportive and understanding	x	x	x	x	x	x	x	x	x
	Perception that attitudes towards children with disabilities were driven by pity, sympathy and a desire to 'help'	x	x	x	x	x	x	x	x	x
	Perception that attitudes towards children with disabilities were related to social proximity and type of disability	x	x	x	x		x		x	
	Perception that children with disabilities are a burden		x	x	x			x	x	x
	Behavioural, mental and intellectual disabilities were perceived to be the least accepted and most stigmatised	x	x	x	x		x		x	x

Stigma by association	Perception that a child's disability was related to the conduct of parents in pregnancy	x	x	x	x		x		x	
	Perception that families of children with disabilities experienced shame	x	x	x	x		x		x	x
	Perception that lack of parental acceptance of disability presented challenges to their child's development and positive inclusion		x	x	x					
	Perception that people working with children with disabilities faced stigma				x					
	Perception that increased exposure to children with disabilities increased levels of acceptance	x	x	x	x					x
Vulnerability of children with disabilities	Perception that children with disabilities were frequently mistreated and bullied	x		x	x	x	x	x	x	
	Perception that access to the internet and social media increased the vulnerability of children with disabilities	x			x					
	Perception that children with disabilities were at greater risk of abuse	x	x	x	x					
	Perception that society did not protect children with disabilities	x	x	x	x				x	
Concern for the future	Perception that parents and caregivers worried about care and protection of their child in later life	x	x	x	x	x		x		
	Perception that siblings were expected to assume care duties	x								
	Perception that government institutional care for people with disabilities was insufficient	x			x					
Health services	Perception that access and availability of specialised care was greater in urban areas	x			x			x		
	Perception that there was a lack of specialised therapies and assistive devices at government facilities	x	x	x	x					
	Perception that the physical environment of health facilities were not user-friendly or appropriately modified for children with disabilities	x	x	x	x					
	Perception that there were gaps in the information provided by healthcare workers	x			x					x
	Perception that health workers lacked training in appropriate behaviour and language	x	x	x	x					x
	Perception that negative experiences in government hospitals increased demand for private care	x								
	Perception that in Sabah and Sarawak traditional healers and traditional medicines were frequently used alongside biomedical care	x	x	x	x					

Education	Perception that the lack of disability classification limited opportunities for education				x		x		x	
	Perception that KPI structure of evaluation was discriminatory	x			x	x				
	Perception that bullying and discrimination occurred at both individual and institutional levels	x		x	x		x	x	x	x
	Perception that teachers in mainstream education had limited training in special education needs	x	x	x	x	x		x		
	Perception that transition programmes did not adequately prepare adolescents for tertiary education	x			x			x		
Rehabilitation	Perception that CBR centres were positive learning spaces for children with disabilities who did not access mainstream services	x			x	x		x	x	
	Perception that centres were not equally distributed and that coverage of services was inconsistent particularly in rural areas	x		x	x					
	Perception that specialist therapies at government CBR centres were limited	x			x					
	Perception that CBR workers had limited career development opportunities and low salaries	x			x					x
	Perception that CBR workers needed enhanced and / or refresher training	x		x	x					
Employment	Perception that employment was highly valued as a means to contribute to society					x		x		x
	Perception that transition interventions and programmes were insufficient				x			x		
	Perception that workplace and employment discrimination was widespread	x	x	x	x	x	x	x	x	x
	Perception that employment opportunities and salaries were limited for people with disabilities	x	x	x	x	x	x	x	x	
	Perception that opportunities beyond hospitality and handicraft production were limited (particularly in Sabah and Sarawak)				x				x	
Barriers to participation	Limited understanding about entitlements reported	x	x	x	x					
	Stigma and discrimination associated with OKU card reported	x			x			x		x
	Perception that the process of registration was convoluted and protracted	x			x					
	Perception that registration was problematic for particularly vulnerable children (e.g. not having identify papers or being an orphan)	x			x					
	Perception that families experienced direct and indirect financial constraints	x	x	x						

	Perception that school and CBR attendance were limited by financial issues	x	x		x		x		x	
	Perception that transport options were limited particularly in rural areas	x	x	x	x	x				
	Perception that access to public transport challenging and expensive	x	x	x	x					x
	Perception that the implementation and regulation of disability parking was limited	x								
	Perception that transport officials had insufficient knowledge about children and people with disabilities	x	x							
	Perception that the lack of infrastructural planning and accessible environments obstructed inclusion	x			x					x
Support for children with disabilities	Recognition of the value of registration	x	x	x	x	x				
	Perception that family support was crucial in children with disabilities achieving day to day activities	x			x	x		x		
	Reports that friends are highly valued and a critical component of the support network for a child with disabilities					x	x	x	x	
	Perception that special education teachers and CBR workers provided positive support	x			x	x		x		
	Perception that people with disabilities who were successful provided motivation for children with disabilities					x	x			

All stakeholders in the study defined disability in terms of an individual's limitations. All reported having limited knowledge about the actual causes of disability, and all groups suggested that religious beliefs influenced how disabilities (both their cause and presentation) were perceived and understood. Language used to define and refer to disability was complex, and negative terms such as *'cacat'* were widely used by caregivers of children without disabilities, community and religious leaders, children and adolescents without disabilities, and perhaps most concerning, by service providers. The same groups also reported that disabilities could be understood as both 'visible' and 'invisible' conditions, and this further complicated ideas about what constituted disability. *Cacat* was not a term used by national stakeholders, caregivers of children with disabilities, or by children and adolescents who themselves had disabilities, and neither did they class disability as 'visible' or 'invisible'.

All stakeholder groups perceived that, on the surface, attitudes towards children with disabilities appeared to be sympathetic supportive and understanding, but also reported that these attitudes were often driven by sentiments of pity and a desire to 'help'. All groups except children and adolescents without disabilities and national stakeholders demonstrated that attitudes towards children with disabilities were related to social proximity and the type of disability. Whilst it was acceptable for a child without disabilities to be friends with a child with disabilities, levels of acceptability decreased significantly as the nature of the relationship became more intimate. 'Visible' or recognisable disabilities were generally more accepted than other types of disability, and mental and behavioural disabilities were the least accepted by all stakeholder groups, except children and adolescents with disabilities.

The perception that children with disabilities were a burden on their families, was expressed by all adult participant groups, except caregivers of children with disabilities. The perception of burden was also discussed by the adolescent participants, both with and without disabilities. With the exception of children and adolescents who had disabilities, all stakeholder groups perceived that families of children with disabilities experienced shame. Whilst caregivers of children without disabilities, religious and community leaders and service providers suggested that a lack of parental acceptance of disability presented challenges to their child's development and positive inclusion, this was not an issue identified by caregivers of children with disabilities themselves. Service providers also highlighted that people working with children with disabilities faced stigma, but only this group reported facing discrimination through association due to their profession. The idea that increased exposure to children with disabilities increased levels of acceptance (both at an individual and societal level) was confirmed by all adult participant groups.

The perception that children with disabilities were frequently mistreated and bullied was widespread, and caregivers, service providers and community and religious leaders all suggested that children with disabilities were at greater risk of abuse. Caregivers of children with disabilities and service providers both highlighted that access to the internet and social media increased the vulnerability of children with disabilities, and all adult participants (except national stakeholders) and adolescents with disabilities suggested that society did not sufficiently protect child with disabilities. It was clear that bullying and discrimination occurred at both individual and institutional levels.

In terms of health services, caregivers and service providers confirmed that government institutional care for people with disabilities was insufficient, and caregivers emphasised that negative experiences in government hospitals increased the demand for private care. The perception that parents and caregivers worried about the care and protection of their children in later life was widespread and also acknowledged by children and adolescents with disabilities. It was also reported by caregivers and service providers that there was a lack of specialised therapies and assistive devices at government facilities, that the physical environment of health facilities were not 'user-friendly' or appropriately modified for children with disabilities and that health workers lacked training in appropriate behaviour and communication skills. This was also acknowledged by national stakeholders who also supported the view of caregivers and service providers that there were critical gaps in the level and quality of information conveyed by healthcare providers.

Participants who directly engaged with CBR centres (caregivers of children with disabilities, children and adolescents with disabilities and service providers) described them as positive learning spaces for children with disabilities who did not access mainstream services, but caregivers and service providers suggested that specialist therapies at government CBR centres were limited. These participant groups and community and religious leaders confirmed that centres were not equally distributed and that the coverage of services was inconsistent particularly in rural areas. They suggested that CBR workers needed enhanced and / or refresher training, and national stakeholders also agreed with these participants that CBR workers had limited career development opportunities.

In terms of education, it was notable that children and adolescents without disabilities stressed that there were limited educational opportunities for their peers who had disabilities. All adult participant groups (except national stakeholders) and children and adolescents with disabilities suggested that teachers in mainstream education had limited training in special education needs, and caregivers of children with disabilities, services providers and adolescents with disabilities confirmed that transition programmes did not adequately prepare adolescents for tertiary education.

All participant groups suggested that employment opportunities and salaries were limited for people with disabilities, and perceived that workplace and employment discrimination was widespread. The value of employment as a means to contribute to society was only emphasised by children and adolescents with disabilities and national stakeholders.

In discussing barriers to participation, many of the same issues were identified by caregivers of children with disabilities and service providers. They reported a limited understanding about entitlements, stressed that although registration was important, the process was convoluted and protracted, and highlighted issues of stigma and discrimination associated with the OKU card. The latter issue was also acknowledged by national stakeholders and adolescents with disabilities. Other barriers discussed included direct and indirect financial constraints, limited access to public transport, and the lack of infrastructural planning resulting in inaccessible public spaces which obstructed inclusion.

All stakeholder groups identified the need for more information about children with disabilities, both in terms of general knowledge and specialised knowledge, and across all the adult participant groups, it was agreed that the information provided by the DSW was insufficient. Service providers and caregivers of children with disabilities recognised that access to information was best in urban areas of Peninsular Malaysia compared to the rest of the country. Community and religious leaders and services providers were identified as important sources of information by caregivers of children without disabilities, national stakeholders and community and religious leaders and service providers themselves, but not by caregivers of children with disabilities. They identified support groups as a trusted source of reliable information and confirmed that online networks were valuable platforms for sharing information. Children and adolescents with disabilities also discussed the importance of online platforms and social media. They emphasised that connecting and communicating with friends (both with and without disabilities) was a critical component of their support network, and confirmed that having role models of successful people with disabilities provided valuable motivation.

Suggested programme indicators

As part of their 2016 -2020 Country Programme, UNICEF intends to monitor the percentage of the population surveyed who demonstrate positive perceptions and attitudes towards children with disabilities. This study has produced rich data that can be used as a baseline for future work, and UNICEF can select a number of indicators (based on questions from the KAP survey) that can act as proxy measures. It is recommended that three questions from the KAP survey (questions 26, 34 and 44) be considered and their results triangulated to illustrate changing patterns over time.

Question 26 asks *'How well informed are you about children with disabilities?'* and requires the respondent to provide their answer using a Likert scale from one to six, where one is *'Not at all informed'*, and six is *'Very well informed'*. Taken together, answer options one, two and three (i.e. the least informed answer options) account for 58.4% (173) of all respondents (see Graph 3 above).

Question 34 asks *'Is a child with disabilities equal to a child without disabilities?'* with answer options Yes, No and No Answer. Participants may interpret the term 'equal' in different ways, but for an indicator this is actually beneficial as it can encompass broad understandings of the term, but however it is understood, being equal (or equality in general) is inherently more positive that not being equal. In the KAP survey, 45% (144) of respondents stated Yes (a child with disabilities is equal to a child without disabilities); 49.7% (159) stated No (a child with disabilities is not equal to a child without disabilities); and only 5.3% (17) stated No Answer.

Question 44 asks *'Are children with disabilities more likely to be abused?'* and answer options Yes, No and No Answer are provided. Again, participants can interpret the concept of 'abuse' in different ways, but all interpretations are inherently negative and link to issues of increased vulnerability and risk. In the KAP survey, 59.7 (191) of respondents stated Yes (children with disabilities are more likely to be abused), 34.1% (109) stated No (children with disabilities are not more likely to be abused), and only 6.3% (20) replied No Answer.

As a triumvirate, the results of these three questions provide a strong baseline from which to monitor the impact of interventions, acting as a proxy measure for different components of change (knowledge, attitudes and practices) over time, particularly if the demographics of the respondent can also be captured and cross tabulated to provide more detailed results. Question 26 focuses on self-reported knowledge. Through the interventions of UNICEF and partners, respondents should acquire increased knowledge and become better informed about children with disabilities, so from the baseline results presented above, there should be a shift in future reporting to answer options four, five and six (analysed both individually and collectively). Question 34 focuses on the population's attitude towards children with disabilities, focusing on whether they are equal to children without disabilities. Due to interventions that seek to raise awareness about children with disabilities and ensure their rights are the same as their non-disabled peers, there should be a shift from the nearly 50% of negative answers in the baseline to an increased percentage of positive answers that children with and without disabilities are equal, regardless of how 'being equal' or equality is understood by individual respondents. In future work, the language of this question could be adapted to reflect a rights based approach, for example, *'Does a child with disabilities have the same rights as a child without disabilities?'* Question 44 focuses on the population's perception about the likelihood of abuse and brings associations of vulnerability and risk. Due to interventions that seek to reduce risk and vulnerability and enhance social protection mechanisms that decrease the chance of abuse, there should be a shift from the nearly 60% of positive answers to an increased percentage of negative answers that abuse is not more likely. In addition to reporting on people's perception of abuse, this question could also be a proxy indicator for how successful social protection mechanisms are at preventing the risk of abuse.

In the KAP study, participants were asked to articulate three key actions to improve the life of children with disabilities in Malaysia. The range of answers provided was too diverse to be conclusively coded, but it was evident that the majority of respondents prioritised some kind of improvement in educational opportunities for children with disabilities. Improved financial assistance for people with disabilities and their families was also regularly suggested. In addition to tracking changes in general attitudes and perceptions, UNICEF could also monitor changes associated with specific services by selecting, for

BASELINE INDICATORS

Q.26: 'How well informed are you about children with disabilities?'

15.9% of the population surveyed reported that they were 'Not at all informed' about children with disabilities. The least informed answer options (i.e. answer options one, two and three on the Likert scale) account for **58.4%** of the population surveyed.

Q34: 'Is a child with disabilities equal to a child without disabilities?'

49.7% of the population surveyed reported that a child with disabilities is not equal to a child without disabilities.

Q44: 'Are children with disabilities more likely to be abused?'

59.7% of the population surveyed reported that children with disabilities are more likely to be abused.

example, indicators that specifically focused on education. If such tracking would be useful to UNICEF programmatically, it is recommended that Question 45 of the KAP survey be utilised. This question asks *'Is it disruptive for other children to be in school with children with disabilities?'* and provides Yes, No, and No Answer options. This could be used as a compound indicator as it is a proxy measure for a) societal attitudes towards inclusion and inclusive education; and b) the quality of education services provided (i.e. if teaching and classroom management is poor, children are more likely to be disruptive). In the KAP survey conducted as part of this study, 43.1% of participants (138) responded Yes (it is disruptive for other children to be in school with children with disabilities) and 48.8% (156) responded No (it is not disruptive for other children to be in school with children with disabilities). The results of the KAP show that, at the time of writing, the general population was fairly evenly divided in opinion. As with the questions recommended above, only a small percentage of respondents (8.1%, 26) did not provide an answer to Question 45 suggesting it was a clear and easily understood question that could be well replicated to provide a measurement over time.

This study has demonstrated that attitudes are complex phenomena, with multi-faceted drivers and determinants. It is therefore recommended that in monitoring changes in perceptions and attitudes, UNICEF adopts a mixed-methods approach that can triangulate the quantitative indicators with granular qualitative data over time. A series of focus group discussions with different stakeholder groups, key informant interviews, and importantly, participatory workshops with children and adolescents with and without disabilities could be repeated at intervals throughout the programme. This would also enable UNICEF to focus on user -centred programme design that could be agile and respond to changing needs and priorities, and maximise interventions that result in positive change.

Recommendations

In conclusion, a number of key recommendations are made. In line with UNICEF's requirements, these have been arranged according to stakeholder group that programmatic work and communication strategies may directly engage with. Recommendations for community engagement are followed by recommendations appertaining to engaging caregivers of children with disabilities, children and adolescents without disabilities; and children and adolescents with disabilities. Recommendations for national level advocacy are then presented, followed by recommendations related to service provision (health workers, teachers and CBR workers).

Recommendations are based on the evidence generated through the study, and include suggestions made by different stakeholder groups engaged and through the analysis of the research team. They include a range of broad, more structural recommendations and specific areas for intervention. It is clear that UNICEF alone does not have the remit to address all the areas highlighted, and the entry points to tackling some of the issues raised will depend on the specificities of the country programme and related interventions. It is important to adopt a systems based approach, however, so that any recommendation that shapes or is incorporated into a programmatic intervention takes account of and responds to the developing ecology of disability in Malaysia.

Recommendations for community engagement

UNICEF has an important role to play in supporting national and local authorities and other partners to create an enabling environment for children with disabilities in Malaysia, an environment in which they are included in society, are regarded as active and equal citizens, and have the right and ability to participate without fear of discrimination or marginalisation. The following recommendations appertain to general community engagement strategies, and engagement with specific target groups (caregivers of children with disabilities; children and adolescents without disabilities; and children and adolescents with disabilities) is discussed further below.

Promotion of a social and rights-based approach to disability

In on-going routine programmatic work and through specific campaigns and C4D strategies, UNICEF should actively promote a social and rights-based approach to disability. Language should be standardised and, as highlighted above, acceptable (non-derogatory) terms should be used consistently in communication strategies to encourage their adoption at the community level.

Zero-tolerance for discrimination

Zero-tolerance for discrimination and social protection runs through all of UNICEF's programmatic work, but could also be the basis for a powerful campaign, raising awareness of the challenges and marginalisation faced by children with disabilities, providing tools and resources to overcome discrimination and establishing mechanisms through which discrimination can be safely discussed, reported and meaningfully addressed at the most local and immediate levels.

More information

Across all participant groups, the need for more information was clearly identified. The KAP survey illustrated that the majority of respondents felt under-informed about children with disabilities. The most frequently requested information focused on the causes and consequences of disability; the availability of services; the rights of children with disabilities; and they ways in which community members could better support children with disabilities to participate in society. It was notable that the level and perhaps quality of information in rural areas was lacking compared to that in urban centres. In fully mobilising its C4D architecture, UNICEF can make a significant contribution to overcoming this information gap.

Increase visibility of people with disabilities

UNICEF has successfully deployed high-profile ambassadors to champion the rights of children and call attention to specific campaigns. In Malaysia, ambassadors have already been used to raise awareness around disability issues. It is recommended that this continues (for example, developing the relationship with a royal patron) and that people with disabilities who are in the public sphere are invited to become ambassadors. The focus should be to highlight the abilities of children and people with disabilities and the positive contributions they make to society. Given the recent success of the Malaysian team at the Paralympics in Brazil (September 2016), collaborating with the team or a particular sports person is recommended, particularly if they can be approached quickly to capture the momentum of the Games.

CBO and NGO partnerships

CBOs and NGOs play an important role in representing people with disabilities, advocating for improvements in service provision and supporting community-level interventions. CBOs and NGOs provide excellent partnership opportunities for an agency like UNICEF. They are well placed to implement and scale initiatives, are usually trusted and well respected by their target communities, are often highly participatory, have good coverage and reach at the local level, can foster cooperation and knowledge exchange at the local level, and can cascade support through their networks to the most vulnerable children. UNICEF has already established partnerships with a number of CBOs and NGOs across Malaysia, (largely through the Malaysian Partnership on Children with Disabilities) and it is recommended that these be strengthened, new partnerships formed and the role of such organisations effectively leveraged. In parallel, mechanisms for greater accountability and reporting should be further developed.

Recommendations for engaging with caregivers of children with disabilities

The social inclusion of a child with disabilities and their level of participation is heavily dependent on their family and immediate social environment. Families require multiple forms of support and information including how to care for their child; how, when and where to access services (medical, educational, rehabilitative and welfare services etc.); and how to negotiate discrimination and vulnerability. There are numerous different entry points for engaging with caregivers of children with disabilities, not only in terms of service provision and uptake, but also related to the type and severity of the disability and the age of the child. How, when and where to most effectively engage with a caregiver is likely to change over time depending on their own lived experience.

Support groups

It was interesting that whilst community leaders, religious leaders and services providers were identified as important sources of information by national stakeholders, caregivers of children without disabilities and community leaders, religious leaders and services providers themselves, they were not prioritised as a good or trusted source of information by caregivers of children with disabilities. Rather, this key stakeholder group identified support groups as trusted sources of information. Such peer-to-peer networks are known to be important in terms of providing information, practical advice, sharing experiences and fostering relationships and a sense of collective togetherness. Members may meet in person and / or the group may function virtually, and can incorporate aspects of mentorship. In addition to providing support to members of the group, they can also act as a strong platform for advocacy. It is recommended that UNICEF works with its CBO and NGO partners to identify and further support groups that are particularly effective, continue to show initiative and drive, and have good reach, particularly with families considered to be the most vulnerable.

Caregiver education

Caregivers are often strong advocates for children with disabilities, promoting their rights, particularly their right to participation, and striving for equitable access to services. It is recommended that UNICEF explores ways to support and enhance caregiver education, through their participation in study groups and virtual platforms (potentially linked to the support groups discussed above). Training may increase the caregiver's own knowledge about disability; provide additional skills and competencies for care at the household level; build confidence in overcoming discrimination; give tools for cascading information to others in their family or community; and develop their capacity for positive advocacy.

Role models and the promotion of positive experiences

One component of creating an enabling environment, is the promotion of positive experiences. This has already been touched on above, in terms of using ambassadors to champion the rights and achievements of people with disabilities, but building the value of peer -to-peer support networks, it is also evident that caregivers need role models that they can easily identify with and with whom they have similar shared experiences. It is therefore recommended that UNICEF collaborates with caregivers of children with disabilities to document their voices and promote positive engagement. Their collective narratives would be empowering for caregivers facing similar challenges, but could also be a powerful advocacy package that address issues of inclusion and promotes the rights of children with disabilities and their families.

Recommendations for engaging with children and adolescents without disabilities

Meaningful engagement with children and adolescents requires targeted strategies. Evidence from this study compliments findings from the broader literature which suggests that in their discussions about disability and interactions with peers with disabilities, children and adolescents are more tolerant and accepting than the general adult population. This key group can be effective agents of change and have an important role to play in taking a stand against discrimination, promoting diversity and equal opportunities, and helping to ensure the social inclusion and participation of children and adolescents with disabilities. The development of forums that bring together children and youth with and without disabilities is critical. Positive attitudes should be encouraged as part of the social norm in this generation.

Child-centric activities

It is important to focus on early intervention to effect change and influence social norms. It is recommended that UNICEF supports the development of participatory methods appropriate for younger children (e.g. constructive play to foster positive attitudes), and builds the capacity of local actors to routinely implement such activities.

Youth-centric materials and social media

Again, there are many entry points for engaging with children and adolescents, through both formal structures such as schools, youth organisations, community centres and online groups, and using informal or more ad hoc channels of influence, such as 'edutainment' music, videos and social media. The importance of the incredible reach of social media in Malaysia should not be underestimated. UNICEF already has avenues into the formal structures, but it is recommended that investments should be made in social media engagement. This does not necessarily mean setting up new platforms, but maximising the networks that already exist to push out youth-centric content (e.g. by engaging national or regional You-Tubers that have large followings).

U-report

Drawing on UNICEF's innovation capacity would also be beneficial in engaging children and adolescents on issues of disability. U-report is a UNICEF developed platform for young people to voice their ideas and opinions on issues they care about and help create positive change in their communities. It has been set up in thirty countries worldwide, including Malaysia. At the time of writing there were only 706 U-reporters in Malaysia, a very small number compared to other countries, and most were active in Kuala Lumpur, Selangor and Johor. Strengthening U-report, increasing the number of reporters and promoting it in other areas of the country (particularly Sabah and Sarawak) may be a constructive and participatory way of engaging youth on key issues of disability including discrimination, access to education and child rights.

Recommendations for engaging with children and adolescents with disabilities

In addressing disability in Malaysia, UNICEF has a specific remit and duty to work with children and adolescents who themselves have disabilities. This study has made a major contribution in this regard as it purposively engaged children and adolescents with disabilities and through participatory workshops facilitated their involvement in discussions and created a safe space in which they could share their concerns, priorities and experiences, both positive and negative. The following recommendations are based on the suggestions children and adolescents made during the workshops, and on the analysis of the research team.

Peer-to-peer support and the value of friendship

In the workshops, both child and adolescent participants repeatedly emphasised that friendship was a critical component of a young person's support network growing up, and this was often magnified for a child or adolescent with disabilities. For example, some needed physical support to help them access classrooms, whereas others felt their friends without disabilities gave them courage and reduced their vulnerability. Many discussed having non-disabled friends, although some preferred to invest more in friendships with youth who had the same disability as they did (most notably adolescents with hearing impairments). Working through CBOs, NGOs and existing youth groups, it is recommended that UNICEF collaborate with peer-to-peer networks of children and adolescents with disabilities, and also support forums that bring together children and youth with and without disabilities.

Youth-centric materials and social media

As highlighted above, social media is a key component of every day communication across Malaysia, and many adolescents with disabilities emphasised its value as a way of overcoming certain social challenges associated with their disability. As well as the many positive experiences shared, participants were also cautionary about the use and role of social media. Whilst these concerns are valid for youth both with and without disabilities, those with disabilities may be at greater risk. As part of their child protection and adolescent engagement work, and to provide a strong evidence-based for online communication strategies that use social media platforms and other technology across programmes, it is recommended that UNICEF considers a follow-up study that analyses the nature or magnitude of online violence, abuse and manipulation of children and adolescents with disabilities in Malaysia.

Positive role models

In their participatory workshops, children and adolescents with disabilities highlighted how people with disabilities who were successful were a source of great motivation. Positive role models, such as UNICEF ambassadors who have disabilities, should not be presented in a way that builds false expectations or leads to an enhanced sense of underachievement, but rather creates a sense of encouragement and solidarity. It is recommended that in selecting an ambassador, children and adolescents with disabilities are consulted about who they would most appreciate in that role and why.

Constructive participation

Children and adolescents with disabilities should be invited to participate in the planning, design and implementation of programmes appertaining to disability in Malaysia. In the workshops conducted as part of this study, rich and valuable insights were provided by participants. Many commented that this was the first time their inputs had been directly sought and how they valued the opportunity to contribute to discussions. As well as conducting formative and operational research, UNICEF should be committed to developing programmes that incorporate user-centred design. Children and adolescents with disabilities should be given opportunities to make decisions and recommendations about their lives. As concluded above, in the constructive and active participation of key stakeholder groups over time, UNICEF can enable programmes to be agile and respond to changing needs and priorities, thereby maximising interventions that result in positive change.

The strongest advocates

It is well documented that children and adolescents with disabilities can be the most powerful advocates for disability related issues that affect youth. As the UN agency for children, UNICEF is uniquely placed to provide a platform that gives greater visibility to children and adolescents with disabilities and ensure that their voices, opinions and experiences are truly heard and acted on.

National level recommendations

National level recommendations are orientated around advocacy at the policy level and building greater political leadership and commitment to disability issues, areas that UNICEF is well placed to support. Creating an enabling environment is critical to improving the lives of children with disabilities and their families in Malaysia.

Strengthen national policies and promote ratification of the Optional Protocol

The lack of redress mechanisms for violations of the People with Disabilities Act 2008 compromises its effectiveness. In collaboration with disability rights organisations and advocates, UNICEF should support the government to amend the Act to include an accessible redress process and appropriate penalties for violations of the act outlined. The government should also be encouraged to lift their reservations on the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities, and in keeping with international standards, sign the Optional Protocol to enshrine the protection of children with disabilities.

Increase inter-agency collaboration

Lack of effective inter-agency collaboration and coordination is detrimental for children with disabilities and their families. In conducting this study, the research team encountered several instances of poor coordination, and national level stakeholders also emphasised the lack of collaboration between agencies in terms of planning and implementing disability related services and support. In order to break down barriers that children with disabilities face in accessing reliable and good quality services (in line with the position that the government takes care of the population 'from the cradle to the grave'), policies, strategies and services must be designed to be inter-sectoral with coordination across health, education, rehabilitation and protection sectors and commitment from the responsible Ministries. In addition to commitment for inter- sectoral policies, multi-agency collaboration for implementation must be facilitated. This would enable the government to implement stronger early detection and intervention programmes; introduce improved safeguards for children with disabilities; standardise surveillance methods; and streamline monitoring and reporting processes across sectors. Only then will gaps in the fragmented delivery of services be closed. Access to services would be improved and there would likely be a corresponding increase in the utilisation of essential services by children with disabilities and their families. It was noted by several key stakeholder groups (including national-level representatives), that the information provided by the Department of Social Welfare was lacking. Stakeholders acknowledged the need for stronger and integrated national data collection mechanisms.

Simplify and standardise the registration process

There is a need to simplify and standardise the registration process for children with disabilities. Caregivers confirmed they found the process to be difficult and convoluted and that government officers were often unable to provide adequate information about entitlements and services. The establishment of a centralised registration service would better support the collection of reliable and accurate data on diagnosis and development. A streamlined process with well-trained officers would encourage caregivers to see the value in voluntary registration. This would result in more accurate data that could then be used for evidenced-based planning, allocation of resources and service provision.

Strengthen the health system to improve care for children with disabilities

Stakeholders from the MOH and within the health sector more broadly noted that there was a national shortage of healthcare workers with specialised training to provide care for children with disabilities, including physiotherapists, occupational therapists, speech therapists and psychologists at different levels of the health system. It was acknowledged that services offered by medical and rehabilitation facilities are not equitable and coverage should be improved so that children with disabilities can have reliable access to essential services. While mobile and peripatetic services exist, they work only in localised settings and services need to be scaled up, particularly in rural areas. Greater links between the formal public health system and community-based organisations and local NGOs may also facilitate improved access, particularly for the most vulnerable children at greatest risk of being left behind. Outreach services should also incorporate health promotion and communication strategies that inform community members on issues of disability (prevention, early detection and intervention etc.) and seek to raise awareness and minimise stigma and discrimination. Levels of knowledge around disability should be increased, not just among those who provide specialised care but amongst health care practitioners in general, particularly those operating at the primary care level.

Strengthen the education system to provide inclusive education for children with disabilities

Stakeholders from the education sector identified a national shortage of teachers with specialised training to provide education for children with different disabilities, in different types of school (inclusive, integrated and special education), and at different levels of schooling (primary, secondary, tertiary levels and with regards to vocational training). Training for all teachers, including those at pre-school level, should be adapted to include enhanced theoretical and practical training on techniques and methods for engaging children with disabilities and different special educational needs. This should be promoted as part of the Government's commitment to inclusive education, whereby all teachers would have the basic skills necessary to effectively teach children with different abilities and capacities. Teachers should also receive enhanced supportive supervision.

Enshrine consistent language and terminology

The study highlighted that there were significant disparities in the language and terminology of disability used and experienced by different participants. A standard definition of disability should be adopted in policy and across all sectors. In addition, standardised and acceptable terms should be used consistently in communication strategies to ensure they are recognised and adopted at the community level.

Improve the physical environment and remove barriers to accessing public and private spaces

Negotiating both urban and rural environments can be challenging for people with disabilities and levels of supported access are not consistent in Malaysia. All public buildings and spaces should be accessible for people with disabilities, and access throughout institutions providing services specifically for children with disabilities (e.g. schools, health facilities) should be optimised. Working with the Department for Land and Transport, guidelines for access should be reviewed and consistently implemented. Public spaces should be made to comply with agreed guidelines and access should be monitored and kept at the highest possible standard. Similarly, public transport vehicles should be made accessible for people with disabilities and transport staff trained in appropriate safety measures. Private buildings and spaces should be encouraged to modify access to ensure it is suitable for people with disabilities.

Private sector engagement

As a middle-income country with a vibrant private sector, there are abundant opportunities for public-private partnership in Malaysia. UNICEF already has effective relationships with the private sector and these should be leverage so that corporate social responsibility mechanisms can meaningfully benefit young people with disabilities (e.g. developing innovation solutions, creating a positive environment, raising awareness, providing sponsorship, and more directly in terms of offering supported work placements).

Multi-lateral consultation

UNICEF should consider supporting a comprehensive consultation with public and private stakeholders to build consensus around cross-sectoral coordination and agree critical next steps in improving the environment for children and adolescents with disabilities and their families.

Recommendations for service provision

Children with disabilities are understood to be especially vulnerable and may require enhanced protection. All personnel who provide services to children with disabilities, or who interact with children with disabilities through their professional work should receive regular training and up-to-date information on child protection measures. The specific recommendations made below were highlighted by service providers reflecting on their own practice and needs; other stakeholders engaged in the study; and through the analysis of the research team.

Health workers

Children with disabilities have specific medical needs and the care they require may change over time. Health workers should be sensitive to these changes and promote social inclusion through the child's right to health. Health service providers of different cadres and working at different levels of the health system would all benefit from increased and / or refresher training to improve their skills and competencies in caring for children with disabilities and providing treatment. Several key areas need to be addressed.

- Additional training should be provided on prevention of disabilities during pregnancy, and on early detection, diagnosis and intervention.
- Crucially, health practitioners need enhanced training in counselling and psychosocial support for children with disabilities, their primary caregivers and wider family unit. Currently, this is one of the weakest areas of service provision and many health workers lack basic training in counselling.
- Health workers should be better equipped with the necessary knowledge and job aids to confidently communicate information about disabilities, available services (medical, rehabilitative and assistive, and the need to register) and resources (such as social welfare benefits) using a sensitive rights-based approach that promotes equality.
- Health workers should be supported to practice a strong code of ethical conduct, particularly in providing care for vulnerable children.
- In addition to regular clinical care, health workers should be able to offer guidance to caregivers about how to best attend to their child's daily needs. Health workers should work with caregivers to identify developmental issues as early as possible, and to make referrals to specialised and therapeutic service providers when necessary.
- In promoting a cross-sectoral approach for the holistic care of children with disabilities, health workers should also be able to highlight appropriate community-based organisations, NGOs and other key actors that could offer a child and their family valuable support (both medical and non-medical) in the local area.

Teachers in inclusive, integrated and special education

The educational system provides an essential platform for the participation of children with disabilities, yet the inclusion of children with disabilities into the Malaysian education system continues to be challenging. The following recommendations focus on improving access to education and the quality of education delivered.

- Schools that have inclusive education should ensure that all students, parents and teachers are well informed about the benefits of inclusive education to children both with and without disabilities.
- If schools are introducing inclusive education, they should inform all stakeholders about the changes that may result from the process of shifting from an exclusive approach. Special measures should be taken to ensure the idea of inclusive education and the drivers behind it are well understood and accepted. These should include the facilitation of open dialogues about disability and associated concerns; activities to raise awareness and sensitise students, parents and teachers about disabilities and the needs and rights of children with disabilities; training teachers about new classroom-management strategies and providing supportive supervision. Schools with inclusive classes may need to employ specialist personnel (resource teachers or teaching assistants), and they should be fully incorporated into the school environment so that collaboration with other

teachers is routine.

- Children with different disabilities should be able to fully access all school through the appropriate modification of infrastructure and the physical environment.
- Teachers and educational coordinators in all types of school should be empowered to create personalised education plans for children with disabilities. The personalised plan should be developed through collaboration with the child and their caregivers to ensure that the curriculum is responsive to their abilities and is delivered in a manner appropriate for their disability.
- Teachers should routinely receive refresher training (both theoretical and practical) to enable them to teach children with different disabilities, in different types of school (inclusive, integrated and special education), and at different levels of schooling (primary, secondary, tertiary levels and with regards to vocational training). Training should be incorporated into on-going professional development with short-term and periodic courses on new methods and techniques.
- Teachers should also receive enhanced training in counselling and psychosocial support for children with disabilities, their primary caregivers and wider family unit, including siblings who may also attend school.
- Schools should offer job and career guidance for children with disabilities, and when necessary support them to find appropriate courses (e.g. university entrance) or vocational training after they graduate.

Social welfare services

The DSW is the primary agency responsible for the provision of social welfare services including supportive assistance, registration of children with disabilities, and links with CBR structures. Whilst there has been an increase in the number of CBR centres across Malaysia with an associated expansion in the coverage of services, stakeholder acknowledged that there remained a shortage of trained personnel and specialist therapists to provide on-going rehabilitative care at the local level, and that CBR centres were often under-equipped. Caregivers reported that CBR centres were often difficult to access due to their location, a lack of transport, and the indirect costs associated with attendance. To provide effective care, several key components in their services need to be strengthened.

- CBR centres and CBR and social workers could provide a critical platform for the care and case management of children with disabilities. They have an important role in mediating between caregivers and services and following up on referrals. They can also foster social inclusion at the local level and provide support to the child, their family and wider community. The value of these roles should be emphasised and resources provided to scale their work.
- All DSW officers, including registration staff and social workers must have the requisite knowledge to deal with the needs of children with disabilities and their families. Training should be comprehensive and should be tailored to ensure that DSW staff understand policies, services and entitlements for children.
- As part of an inter-sectoral package of care for children with disabilities, social welfare services including CBR centres should have stronger links to medical and education services in their local area and mechanisms should be in place for cross-referral and increased supportive supervision.
- All CBR centres should be well resourced with basic equipment, and specialised equipment should be in place if specialist services are being provided.
- As a cadre, the number of CBR workers should be expanded and their skill set and competency level increased. CBR workers should receive standardised training (both theoretical and practical) on the comprehensive care and management of children with different disabilities, and regular refresher trainings should be compulsory.
- CBR workers are well placed to provide critical support for the care of children at the community level. In their training, they should be taught how to transfer skills to primary caregivers to provide routine daily care at home and equipped with job aids to support this transfer of knowledge.
- CBR workers should be supported to offer home-based rehabilitative care to children and adolescents who cannot access CBR centres, specifically those who have severe disabilities and or mobility issues. This should be based on the WHO home-based care model.
- CBR workers need enhanced training in counselling and psychosocial support for children with disabilities, their primary caregivers and wider family unit.
- CBR workers should be properly remunerated for their work, and the cadre should be imbued with a sense of professionalism. To ensure that CBR work is not regarded as a temporary position or stepping stone to another career, the DSW should establish a clear career pathway for CBR workers and value continual professional development.

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“Disability is sad and lonely”

Adolescent girl without disabilities in Sabah illustrates the isolation she feels is experienced by children with disabilities.

ANNEX 1
STUDY TIMEFRAME

Project phase	Dates	Activity
Preparation	Feb	Literature review and desk analysis
	March	Submission of ethics clearance
	March	Select partner organisations
	March	Design of research tools
	March	Drafting of inception report
	April	Submission of inception report, study protocol, timeframe
	April	Contracting of local research partner
	April	Logistical arrangements for fieldwork
	May	Finalisation of protocols and tools
Fieldwork	24-25 May	Anthrologica team travel to Malaysia
	26-30 May	Training of national team, testing and finalisation of tools
	30-31 May	Deployment of national research team to four states
	31 May-30 June	Data collection
	11 June	National research team return to home states
	12 June	Preliminary data entry and analysis
	14-15 June	National level interviews
	16 June	Stakeholder workshops
	17 June	Debrief with UNICEF
	19 June	Anthrologica team returns to UK
Analysis and reporting	By 15 July	Completion of transcription and data entry
	18-31 July	Full analysis of data
	August	Drafting of report
	24 August	Submission of draft report to UNICEF
	10 September	UNICEF reverts with comments and feedback on draft report
	14 September	Feedback presentation to UNICEF
	By 5 October	UNICEF reverts with final comments and feedback
	By 7 October	Finalisation of report based on comments received
	8 October	Submission of all final deliverables

ANNEX 2
CONSENT FORMS

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Disability Knowledge, Attitude and Practices (KAP) Study, Malaysia – interviews and group discussions

Background

This study seeks to improve our understanding of community perceptions of disability in Malaysia. Although progress has been made in improving the lives of children with disabilities, they still face many challenges including accessing services, participating in community life, and overcoming negative perceptions towards their disability. Discriminatory views can impact the lives of children with disabilities and can influence laws and policies at the national level. This study will use information gathered from community members to better understand their knowledge, attitudes and practices towards children with disabilities.

Interviews and Focus Group Discussions

For this purpose, we would like to talk to you about matters relating to disability. Specifically:

- Your perceptions and experiences of disability
- Your understanding of how disability affects the lives of children with disabilities and their families
- What you know about disabilities and how they occur
- Your ideas about how services can be improved for children with disabilities.

The interview / focus group discussion will last for approximately 60 minutes. Participation is voluntary. You have the right to withdraw from the discussion at any time without reason and without penalty. There is no cost associated with your participation. We believe there is no risk to you in participating.

We will ensure that your information, opinions and experiences are kept confidential and will only be used for the purpose of the study outlined. We will not use your name. You may ask any questions related to the study and we will answer these questions to your satisfaction. With your permission, we may make an audio recording of our discussions for our records. This will be destroyed at the end of the study. With your permission, we may also take photographs during the interview / focus group discussion. These may be used for the purpose of the current study and may be included in academic publications and other material for UNICEF or Anthrologica. If your photograph is published, you will not be identified by name and confidential processes shall be followed.

In regard to collecting information for this study, we would greatly appreciate your help and therefore seek your consent and cooperation. If you have any questions about this study, you may contact Phenny Kakama, Senior Child Protection Specialist at UNICEF Malaysia on 03-20959154.

INFORMED CONSENT

I have been informed in detail about the purpose and nature of this study.
I have received satisfactory answers to all my questions relating to this study.
I will participate willingly and understand that I can withdraw at any time for any reason.
I agree to this workshop being recorded.
I give my informed consent to participating in this study and having my photograph taken as part of the study.

______________________	______________________	__________
Name of participant	**Signature**	**Date**
______________________	______________________	__________
Name of witness	**Signature**	**Date**

As a witness of this letter, I ensure that I have the above information has been accurately conveyed to the participant. I also ensure that they have decided to participate in this study freely and willingly.

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Anthrologica

Disability Knowledge, Attitude and Practices (KAP) Study, Malaysia – child and adolescent workshop

Background

This study seeks to improve our understanding of community perceptions of disability in Malaysia. Although progress has been made in improving the lives of children with disabilities, they still face many challenges including accessing services, participating in community life, and overcoming negative perceptions towards their disability. Discriminatory views can impact the lives of children with disabilities and can influence laws and policies at the national level. This study will use information gathered from community members to better understand their knowledge, attitudes and practices towards children with disabilities.

Child and Adolescent Workshops

For this purpose, we would like to talk to your child about matters relating to disability. Specifically:

- Their perceptions of disability
- Their understanding of how disability affects their life and the lives of children with disabilities
- What they know about disabilities and how they occur
- Their ideas about how services can be improved for children with disabilities.

The workshop will last for approximately 90 minutes. Participation is voluntary. Your child has the right to withdraw from the discussion at any time without reason and without penalty. There is no cost associated with him / her participation. We believe there is no risk to him / her in participating.

We will ensure that your child's information, opinions and experiences are kept confidential and will only be used for the purpose of the study outlined. We will not use their name. You and / or your child may ask any questions related to the study and we will answer these questions to your satisfaction. With your / their permission, we may make an audio recording of our discussions for our records. This will be destroyed at the end of the study. With your / their permission, we may also take photographs during the workshop. These may be used for the purpose of the current study and may be included in academic publications and other material for UNICEF or Anthrologica. If your child's photograph is published, they will not be identified by name and confidential processes shall be followed.

In regard to collecting information for this study, we would greatly appreciate your help and therefore seek your consent and cooperation. If you have any questions about this study, you may contact Phenny Kakama, Senior Child Protection Specialist at UNICEF Malaysia on 03-20959154.

INFORMED CONSENT

I have been informed in detail about the purpose and nature of this study.
I have received satisfactory answers to all my questions relating to this study.
I have decided that my child can participate willingly and can withdraw at any time for any reason.
I agree to his / her workshop being recorded.
I give my informed consent to my child participating in this study and having his / her photograph taken as part of the study.

Name of parent / caregiver	**Signature**	**Date**
Name of youth participant		
Name of witness	**Signature**	**Date**

As a witness of this letter, I ensure that I have the above information has been accurately conveyed to the participant. I also ensure that they have decided to participate in this study freely and willingly.

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Anthrologica

Disability Knowledge, Attitude and Practices (KAP) Study, Malaysia – Knowledge, Attitudes and Practices Survey

Background

This study seeks to improve our understanding of community perceptions of disability in Malaysia. Although progress has been made in improving the lives of children with disabilities, they still face many challenges including accessing services, participating in community life, and overcoming negative perceptions towards their disability. Discriminatory views can impact the lives of children with disabilities and can influence laws and policies at the national level. This study will use information gathered from community members to better understand their knowledge, attitudes and practices towards children with disabilities.

Knowledge, Attitudes and Practices Survey

For this purpose, we would like to talk to you to understand your knowledge, attitudes and practices of matters relating to children with disability in Malaysia. Specifically:

- Your knowledge about disability issues
- Your understanding of how disability affects the lives of children with disabilities and their families
- Your attitudes towards children with disabilities and their families
- Your ideas about practices and services for children with disabilities.

Participation is voluntary. You have the right to withdraw from the discussion at any time without reason and without penalty. There is no cost associated with your participation. We believe there is no risk to you in participating.

We will ensure that your information, opinions and experiences are kept confidential and will only be used for the purpose of the study outlined. We will not use your name. You may ask any questions related to the study and we will answer these questions to your satisfaction. With your permission, we may also take photographs during the survey. These may be used for the purpose of the current study and may be included in academic publications and other material for UNICEF or Anthrologica. If your photograph is published, you will not be identified by name and confidential processes shall be followed.

In regard to collecting information for this study, we would greatly appreciate your help and therefore seek your consent and cooperation. If you have any questions about this study, you may contact Phenny Kakama, Senior Child Protection Specialist at UNICEF Malaysia on 03-20959154.

INFORMED CONSENT

I have been informed in detail about the purpose and nature of this study.
I have received satisfactory answers to all my questions relating to this study.
I give my informed consent to participating in this study and having my photograph taken as part of the study.

______________________	______________________	___________
Name of participant	**Signature**	**Date**
______________________	______________________	___________
Name of witness	**Signature**	**Date**

As a witness of this letter, I ensure that I have the above information has been accurately conveyed to the participant. I also ensure that they have decided to participate in this study freely and willingly.

ANNEX 3
RESEARCH TOOLS

TOPIC GUIDE

Attitudes and Perceptions
- Meaning of disability
- Impairment and what it constitutes
- Scope of disability
- Stigma and discrimination towards children with disabilities
- Perception of life satisfaction for children with disabilities

Family and Society
- Family perspective of disability (pregnancy / birth / later in life)
- Awareness of services and benefits
- Gender and discrimination
- Poverty and disability
- Independence and social / community participation

Environmental barriers to inclusion / participation
- Physical barriers
- Communication systems
- Accessibility of services

Institutional barriers to inclusion / participation
- Laws and policies towards children with disabilities
- Political rights
- Political support
- Data and statistics

Internalised feelings (for children with disabilities themselves)
- Perception of own impairment
- Personal barriers to participation (self-discrimination)
- Life satisfaction

Education
- Inclusive education vs special education schools
- Screening children with disabilities
- Teachers' perceptions of disability
- Training and implementation
- Transition programmes from education
- Employment / vocational training and income

Health
- Identification and intervention for children with disabilities
- Accessibility / availability of healthcare
- Commitment to rehabilitation

Financial issues
- Costs (both direct and indirect) e.g. poverty

QUALITATIVE RESEARCH TOOLS

Community members / caregivers of children without disabilities (IDI / FGD)

Demographic Information
- Gender: (male / female)
- How old are you?
- Are you married?
- What language / s do you speak?
- What religion do you practice?
- What level of schooling do you have?
- What is your occupation?
- What is your ethnicity?
- How many children do you have?

Q1 – Definition of disability
- What is disability?
- Please tell me about different types of disability you know.
- How do you know if a child has a disability?
- When you see a child / person with a disability what do you think?
- Are children with disabilities and children without disabilities the same? How are they different?

Q2 – Cause and treatment / cure of disability
- What causes disability?
- Can you prevent disability? If so, how?
- Can you treat or cure disability? If so, how?
- If a child is born with a disability, what will their parents do? What influences this?

Q3 - Language
- What terms or expressions are used to describe / talk about disability in Malaysia?
- Are these terms kind? Why / why not?

Q4 – Challenges
- What are the biggest challenges / barriers for children / people with disabilities?
- Do you think they face financial barriers – give examples

- Do you think they face barriers to accessing services – give examples
- Do you think they face barriers in taking transport / entering public buildings and space – give examples

Q5 – Stigma / discrimination

- How are children / people with disabilities treated by the community?
- If a person has a disability, are they discriminated against? In what ways? Why? By whom?
- Are their families discriminated against?
- Does this depend on the type of disability they have?
- Would you allow your child to have friends / play with children who have disabilities? Why / why not?
- Are children with disabilities more vulnerable? Why / why not?

Q6 - Education

- Do you think children with disabilities should be educated? Primary / secondary / university levels?
- What kind of school should a child with disabilities go to? (mainstream / special needs) Why?
- How do you feel about a child with disabilities learning in the same classroom / getting the same education as children without disabilities?
- Why do you think that some children with disabilities do not go to school / get an education?
- Do you think teachers who teach children with disabilities should receive special training? If yes, what kind of training? If no, why not?

Q7 - Other activities

- Are children / people with disabilities able to participate in other activities? Why / why not?
- Do you think people with disabilities can work? What kind of work? What are the challenges / opportunities?

Q8 – Health care

- Do you think people with disabilities have special health needs?
- Can people with disabilities access health services? Why / why not?
- Do you think health workers should have special training to deal with children / people with disabilities? Why / Why not?

Q9 – Supportive services

- What kind of supportive services are available for children / people with disabilities?
- Have you heard of community based rehabilitation centres?
- Who attends these facilities?
- What services are provided at community based rehabilitation centres? Are these services sufficient?
- Are these services of good quality? Why / why not?
- Is there a community based rehabilitation centre in your community?
- In your view what are the advantages / disadvantages of institutional care?

Q10 – Self-experience

- Are there children / people in your community with disabilities? Please explain what kind of disability and how you know them.
- What do you think life is like for that person? For their family?
- What would you do if you saw a child or person with disabilities being teased, stigmatised, discriminated against?

Q11 - Suggestions

- How can we give more support to children with disabilities to attend school?
- How can we give more support to young people with disabilities at work?
- What can we do to stop people in Malaysia from stigmatising and discriminating children / people with disabilities?
- Do you have any other suggestions about how we can improve the life of children / people with disabilities?

12 – Government

- Do you know about any laws in Malaysia that protect children with disabilities?
- Do you think the government of Malaysia adequately protects and provides for children with disabilities?
- Should children with disabilities be registered with the Dept. Social Welfare? Why / why not?
- What are the benefits / disadvantage of having a child registered?
- How could the government and service providers do more to help and support children with disabilities and their families?

13 - Conclusion

- What do you feel have been the most important things that we have spoken about? (recap key points)
- Is there anything else that you would like to discuss?
- Do you have any questions for us?
- Thank you and close

PRIMARY CAREGIVERS OF CHILDREN WITH DISABILITIES (IDI / FGD)

Demographic Information

- Gender: (male / female)
- How old are you?
- Are you married?
- What language / s do you speak?
- What religion do you practice?
- What level of schooling do you have?
- What is your occupation?
- What is your ethnicity?
- Which community / village do you live in?
- Location: (urban / rural)
- How many children do you have?
- How many of your children have disabilities?

Q1 – Definition of disability

- What is disability?
- What causes disability?
- Are children with disabilities and children without disabilities the same? How are they different?

Q2 – Narrative of own experience

- What kind of disability does your child have?
- When did you realise that your child had a disability? Please explain what happened.
- How did you feel when you realised your child had a disability?
- Did you discuss the problem with anybody? Who? Why / why not?
- Did you get any professional support?
- Where did you get information about the disability? Trusted sources.
- Are you / your child a member of any local community based group? How did you hear about them? How are you involved? What are the advantages to being involved with this group?

Q3 – Challenges

- What are the biggest challenges / barriers you / your child has faced because of their disability?
- Are there things that you / your child can't do because of their disability?
- Do you face financial barriers – give examples
- Do you face barriers to accessing services – give examples
- Do you face barriers in taking transport / entering public buildings and space – give examples

Q4 – Stigma / discrimination

- How are children / people with disabilities treated by the community?
- If a person has a disability, are they discriminated against? In what ways? Why? By whom?
- Are their families discriminated against?
- Does this depend on the type of disability they have?
- Have you and your child faced discrimination. Please explain.
- Does your child have friends / play with children who do not have disabilities? Why / why not?
- Is your child more vulnerable because of their disability? In what ways?

Q5 - Language

- What terms or expressions are used to describe / talk about disability in Malaysia?
- Are these terms kind? Why / why not?

Q6 - Education

- Does your child go to school? What kind of school? (mainstream / special needs) (primary / secondary / university level)
- What challenges have you faced in sending your child to school / to receive education?
- What challenges has your child faced at school / in education?
- How do you feel about a child with disabilities learning in the same classroom / getting the same education as children without disabilities?
- Why do you think that some children with disabilities do not go to school / get an education?
- Do you think teachers who teach children with disabilities should receive special training? If yes, what kind of training? If no, why not?
- Are there things you would change / improve about your child's education? If yes, what?

Q7 - Other activities

- Is your child able to participate in other activities? Why / why not?
- Will your child work when they are older? What kind of work? What are the challenges / opportunities?

Q8 – Health care

- Does your child have special health needs because of their disability?
- Does your child have treatment for their disability? If so, what?
- Do you and your child face difficulties in accessing the health services you need? If so, what / why?
- Do you think health workers should have special training to deal with children / people with disabilities? Why / Why not?
- Are there things you would change / improve about your child's healthcare? If so, what?

Q9 – Supportive services

- What kind of supportive services are available for your child / other people with disabilities? Are these services sufficient?
- Are these services of good quality? Why / why not?

- Have you heard of community based rehabilitation centres?
- Have you attended a CBR centre?
- If yes, please describe where, what happened, was it useful?
- If you have not attended, why not?
- Has your child ever been in institutional care? Why / why not?
- In your view what are the advantages / disadvantages of institutional care?

Q10 – Self-experience

- What is life like for your child and your family?
- Does your child have friends? Do they play with their siblings / other children?
- Do you have sufficient information about the disability and how to manage it? Would you like more information? If so, what kind of information? From who / where?
- What are your main worries / concerns? Now and for the future.

Q11 - Suggestions

- How can we give more support to children with disabilities to attend school?
- How can we give more support to young people with disabilities at work?
- What can we do to stop people in Malaysia from stigmatising and discriminating children / people with disabilities?
- Do you have any other suggestions about how we can improve the life of children / people with disabilities?

12 – Government

- Do you know about any laws in Malaysia that protect children with disabilities?
- Do you think the government of Malaysia adequately protects and provides for children with disabilities?
- Is your child registered with the Dept. Social Welfare? Why / why not?
- What are the benefits / disadvantage of having your child registered?
- How could the government and service providers do more to help and support children with disabilities and their families?

13 - Conclusion

- What do you feel have been the most important things that we have spoken about? (recap key points)
- Is there anything else that you would like to discuss?
- Do you have any questions for us?
- Thank you and close

SERVICE PROVIDERS – TEACHERS, HEALTHCARE & REHABILITATION WORKERS (IDI / FGD)

Demographic Information

- Gender: (male / female)
- How old are you?
- Are you married?
- What language / s do you speak?
- What religion do you practice?
- What level of schooling do you have?
- What is your occupation?
- What is your ethnicity?
- Which community / village do you live in?
- Location: (urban / rural)
- How many children do you have?
- How many of your children have disabilities?

Q1 – Disability

- What is disability?
- Please tell me about different types of disability you know.
- What causes disability?
- Can you prevent disability? If so, how?
- Can you treat or cure disability? If so, how?
- If a child is born with a disability, what will their parents do? What influences this?
- Are children with disabilities and children without disabilities the same? How are they different?

Q2 – Narrative of own experience

- In your work, what engagement do you have with children with disabilities?
- What are the challenges you face in working with children with disabilities?
- Do you feel that you have enough training to work with children with disabilities?
- Would you like more training or support? If so, what kind?
- Are there positive reasons to work with children with disabilities?
- What aspect of your job gives you the most professional satisfaction?

Q3 – Challenges

- What are the biggest challenges child with disabilities face?
- Do they / their families face financial barriers – give examples
- Do they / their families face barriers to accessing services – give examples
- Do they / their families face barriers in taking transport / entering public buildings and space – give examples

Q4 – Stigma / discrimination

- How are children / people with disabilities treated by the community?
- If a person has a disability, are they discriminated

against? In what ways? Why? By whom?

- Are their families discriminated against?
- Does this depend on the type of disability they have?
- Have you faced any discrimination in your work? Please explain.
- In your view, do parents / caregivers allow their child to have friends / play with children who have disabilities? Why / why not?
- Are children with disabilities more vulnerable? Why / why not?

Q5 - Language

- What terms or expressions are used to describe / talk about disability in Malaysia?
- Are these terms kind? Why / why not?

Q6 - Education

- What challenges do parents face in sending a child with disability to school / into education?
- What challenges does a child with disability face at school / in education?
- How do you feel about a child with disabilities learning in the same classroom / getting the same education as children without disabilities?
- Why do you think that some children with disabilities do not go to school / get an education?
- Do you think teachers should have special training to deal with children / people with disabilities? Why / Why not?
- Are there things you would change / improve about education system for children with disabilities? (Primary / secondary / university level) (mainstream / special school)

Q7 - Other activities

- Are children with disabilities able to participate in other activities? Why / why not?
- Are people with disabilities able to work? What kind of work? What are the challenges / opportunities?

Q8 – Health care

- Do children with disabilities have special health needs because of their disability?
- What difficulties do children / their carers face in accessing health services?
- Do you think health workers should have special training to deal with children / people with disabilities? Why / Why not?
- Are there things you would change / improve about the health system for children with disabilities?

Q9 – Supportive services

- What kind of supportive services are available for children with disabilities?
- How do you obtain these services? What are the challenges / opportunities?
- Have you heard of community based rehabilitation centres?
- If yes, what services are provided, who can attend?
- Is there a CBR centre in your community?
- In your view what are the advantages / disadvantages of institutional care?
- Do the families of children with disabilities have sufficient information about the disability and how to manage it?
- What is the best way to give people information about disabilities? Trusted sources?

Q10 - Suggestions

- How can we give more support to children with disabilities to attend school?
- How can we give more support to young people with disabilities at work?
- What can we do to stop people in Malaysia from stigmatising and discriminating children / people with disabilities?
- Do you have any other suggestions about how we can improve the life of children / people with disabilities?

Q11 – Government

- Do you know about any laws in Malaysia that protect children with disabilities?
- Do you think the government of Malaysia adequately protects and provides for children with disabilities?
- Should children with disabilities be registered with the Dept. Social Welfare? Why / why not?
- What are the benefits / disadvantage of having a child registered?
- How could the government and service providers do more to help and support children with disabilities and their families?

Q12 - Conclusion

- What do you feel have been the most important things that we have spoken about? (recap key points)
- Is there anything else that you would like to discuss?
- Do you have any questions for us?
- Thank you and close

HIGH-LEVEL STAKEHOLDERS – REPRESENTATIVES FROM DISTRICT / GOVERNMENT / MINISTRIES (IDI / FGD)

Q1 – Disability

- What is disability?
- Please tell me about different types of disability you know.

- What causes disability?
- Can you prevent disability? If so, how?
- Can you treat or cure disability? If so, how?
- If a child is born with a disability, what will their parents do? What influences this?
- Are children with disabilities and children without disabilities the same? How are they different?

Q2 – Narrative of own experience

- What role do you play in supporting the lives of children with disabilities and their families?
- In your department / ministry / work what engagement do you have with children with disabilities?
- What are the challenges you face in working with children with disabilities?
- Do you feel that you have enough training to work with children with disabilities?
- Would you like more training or support? If so, what kind?
- Are there positive reasons to work with children with disabilities?
- Over the course of your work have services / attitudes towards children with disabilities improved? How? What has led to these improvements being made?

Q3 – Challenges

- What are the biggest challenges child with disabilities in Malaysia face?
- Do they / their families face financial barriers – give examples
- Do they / their families face barriers to accessing services – give examples
- Do they / their families face barriers in taking transport / entering public buildings and space – give examples

Q4 – Stigma / discrimination

- How are children / people with disabilities treated by the community?
- If a person has a disability, are they discriminated against? In what ways? Why? By whom?
- Are their families discriminated against?
- Does this depend on the type of disability they have?
- Have you faced any discrimination in your work? Please explain.
- In your view, do parents / caregivers allow their child to have friends / play with children who have disabilities? Why / why not?
- Are children with disabilities more vulnerable? Why / why not?

Q5 - Language

- What terms or expressions are used to describe / talk about disability in Malaysia?
- Are these terms kind? Why / why not?

Q6 - Education

- What challenges do parents face in sending a child with disability to school / into education?
- What challenges does a child with disability face at school / in education?
- How do you feel about a child with disabilities learning in the same classroom / getting the same education as children without disabilities?
- Why do you think that some children with disabilities do not go to school / get an education?
- Do you think teachers should have special training to deal with children / people with disabilities? Why / Why not?
- Are there things you would change / improve about education system for children with disabilities? (Primary / secondary / university level) (mainstream / special school)
- What barriers do you face in trying to implement these / other changes within your job role / department / ministry?

Q7 – Health care

- Do children with disabilities have special health needs because of their disability?
- What difficulties do children / their carers face in accessing health services?
- Do you think health workers should have special training to deal with children / people with disabilities? Why / Why not?
- Are there things you would change / improve about the health system for children with disabilities?
- What challenges do you face in implementing these / other changes within your job role / department / ministry?

Q8 – Supportive services

- What kind of supportive services are available for children with disabilities?
- How do you obtain these services? What are the challenges / opportunities?
- In your view what are the advantages / disadvantages of institutional care?
- Do the families of children with disabilities have sufficient information about the disability and how to manage it?
- What is the best way to give people information about disabilities? Trusted sources?

Q9 - Suggestions

- How can we give more support to children with disabilities to attend school?
- How can we give more support to young people with disabilities at work?
- What can we do to stop people in Malaysia from

stigmatising and discriminating children / people with disabilities?
- Do you have any other suggestions about how we can improve the life of children / people with disabilities?

Q10 – Government

- Do you know about any laws in Malaysia that protect children with disabilities?
- Do you think the government of Malaysia adequately protects and provides for children with disabilities?
- Should children with disabilities be registered with the Dept. Social Welfare? Why / why not?
- What are the benefits / disadvantage of having a child registered?
- What are the challenges for the government in recognising and promoting the rights of children with disabilities?
- How could the government and service providers do more to help and support children with disabilities and their families?

Q11 – Policies

- Do you think the current legislation to protect children with disabilities in Malaysia is sufficient? Why / why not?
- What are the strengths of the current policies to protect children with disabilities?
- What are the gaps and issues in the current policies?
- Do you think that the current political environment prioritises the needs of children with disabilities and their families? Why / why not?

Q12 - Conclusion

- What do you feel have been the most important things that we have spoken about? (recap key points)
- Is there anything else that you would like to discuss?
- Do you have any questions for us?
- Thank you and close

Child and adolescent workshop – children with and without disabilities (Age groups 10-15 and 16-21)

Activities will be modified based on the type and severity of the disabilities in the group

Introduction (10mins)

- Thank participants for taking part
- Explanation of study: specific, visual, simplified and contextually relevant
- Clearly present information about the purpose of the session and how information generated will be used
- Introduce confidentiality, anonymity, no right or wrong answer, free to stop interview / withdraw participation at any time with no negative consequences.
- Setting ground rules / group contract to discuss the importance of confidentiality and ensure participants keep each other's opinions and experiences confidential

Energiser to introduce group (5mins)

For example: the group forms a circle; in turn, each person shouts out their name and an action or symbol that represents something about them or how they are feeling right now e.g. Shout out 'Mary' and hold thumbs up, then everyone else in the circle has to copy the name and action.

Story circles / timelines and drawing about experiences of children with disabilities (30mins)

- Children / adolescents are separated in pairs (larger groups with facilitator for younger age bracket)
- Each tells and draws a story / timeline of their experience of their disability: what experiences they have had in society; how they feel about their disabilities, how they think other people see / behave towards them; drawing a timeline to illustrate their own experience and feelings
- Group comes back together and presents their drawings / timelines back to whole group through story circle
- Discussion

Drama / role play based on a story circle: barriers, enablers and solutions (40mins)

- In groups of 3 / 4 discuss
  - thoughts about life as a disabled child / adolescent
  - barriers to inclusion in society
  - experiences / sources of support
  - suggestions on how to improve existing services
- Groups prepare a short role play and perform to rest of group
- Questions and discussion

Discussion and conclusion (10mins)

- Any other points to add
- Suggestions
- Thank you and close

KAP Survey

Code: __________ – __________ – ______ – _________ – __________ – ___/___ /___ – _____ – __
State District U / R Type of Act. Participant Date RA #

SECTION A Background

Q1	Date	1.1	
Q2	State *Provide 1 answer*	2.1	Selangor
		2.2	Kelantan
		2.3	Sarawak
		2.4	Sabah
Q3	District *Provide 1 answer*	3.1	Kuala Langat
		3.2	Kuala Selangor
		3.3	Lembah Klang
		3.4	Kota Bharu
		3.5	Pasir Mas
		3.6	Kuala Krai
		3.7	Kuching
		3.8	Samarahan
		3.9	Serian
		3.10	Kota Kinabalu
		3.11	Keningau
Q4	Location *Provide 1 answer*	4.1	Urban
		4.2	Rural
Q5	Language of interview *Provide 1 answer*	5.1	Bahasa Melayu
		5.2	English
		5.3	Chinese
		5.4	Tamil
		5.5	Other *(please specify)*
Q6	Gender of respondent *Provide 1 answer*	6.1	Male
		6.2	Female

SECTION B Demographics

Q7	What is your age? *Provide 1 answer*	7.1	
Q8	What is your ethnicity? *Provide 1 answer*	8.1	Malay
		8.2	Chinese
		8.3	Indian
		8.4	Iban
		8.5	Bidayuh
		8.6	Kadazan-Dusun
		8.7	Other *(specify)*
		X	No answer
Q9	What is your religion? *Provide 1 answer*	9.1	Islam
		9.2	Buddhism
		9.3	Christianity
		9.4	Hinduism
		9.5	Taoism
		9.6	Animist / local traditional religion
		9.7	No religion
		9.8	Other *(specify)*
		X	No answer
Q10	What is your marital status? *Provide 1 answer*	10.1	Single
		10.2	Cohabiting
		10.3	Married
		10.4	Separated
		10.5	Divorced
		10.6	Widowed
		X	No answer
Q11	Are you still in education? *Provide 1 answer*	11.1	Yes
		11.2	No
		11.3	No answer
Q12	What is the highest level of education you completed? *Provide 1 answer*	12.1	No education
		12.2	Primary school
		12.3	Secondary school
		12.4	University
		12.5	Other *(specify)*
		X	No answer

Q13	What is your occupation? *Provide 1 answer*	13.1	
		X	No answer
Q14	How many people live in your household including yourself? *Provide 1 answer*	14.1	
		X	No answer
Q15	How many children under 18 years live in your household? *Provide 1 answer*	15.1	
		X	No answer
Q16	What is your total household income per month? *Provide 1 answer*	16.1	
		X	No answer

SECTION C Knowledge

Q17	There are different ideas about disability. What three things can you think of when you hear the word ‘disability? *Provide 3 answers*	17.1	
		17.2	
		17.3	
		X	No answer
Q18	What are the three most common terms used with it comes to children with disabilities? *Provide 3 answers*	18.1	
		18.2	
		18.3	
		X	No answer
Q19	Would you consider a child who xxxx to be disabled? *Read each option in turn* *Circle as many answers as appropriate*	19.1	Has blurred vision / wears glasses
		19.2	Has total loss of vision / is blind
		19.3	Has mild loss of hearing / wears hearing aid
		19.4	Has total loss of hearing / is deaf
		19.5	Can not walk
		19.6	Has a cleft palate
		19.7	Has a physical problem (impaired limb)
		19.8	Has a stammer / speech impediment
		19.9	Can not speak at all
		19.10	Finds it difficult to concentrate
		19.11	Finds it difficult to learn
		19.12	Is hyperactive
		19.13	Neurological conditions
		19.14	Is aggressive and hurts themselves / other people
		19.15	Has HIV / AIDS
		19.16	Non-contagious disease

		19.17	Has infectious disease
		19.18	Has anti-social behaviour
		19.19	Has strange behaviour
		X	No answer
Q20	Do you know of any other types of disability? *Provide up answers to 3*	20.1	
		20.2	
		20.3	
		X	No answer
Q21	What are the three main causes of disability? *Provide 3 answers*	21.1	Congenital (born like that)
		21.2	Genetic
		21.3	Disease
		21.4	Will of God
		21.5	Spirits
		21.6	Curse
		21.7	Parents' fault
		21.8	Punishment
		21.9	Environment
		21.10	Bad Feng Shui
		21.11	Fate / Kharma
		21.12	Accident
		21.13	Other (specify)
		X	No answer
Q22	Do you know any children with disability? *Provide 1 answer*	22.1	Yes *[Go to Q23]*
		22.2	No *[Go to Q26]*
		X	No answer *Go to Q26]*
Q23	What type of disability does the child have? *Provide 1 answer*	23.1	
		X	No answer
Q24	What relationship do you have to that child? *Provide 1 answer*	24.1	Parent
		24.2	Sibling
		24.3	Aunt / Uncle
		24.4	Grandparent
		24.5	Neighbour
		24.6	No relationship
		24.7	Other *(specify)*
		X	No answer

Q25	How often are you in contact with them? *Provide 1 answer*	25.1	Every day
		25.2	Once a week
		25.3	Several times a week
		25.4	Once a month
		25.5	Several times a month
		25.6	Once a year
		25.7	Several times a year
		25.8	Never
		25.9	Other (specify)
		X	No answer
Q26	How well informed are you about children with disabilities? Please use scale from 1 to 6, where 1 is not at all informed and 6 is very well informed. *Provide 1 answer*	26.1	
		X	No answer
Q27	What percentage of children up to 18 years old are disabled in Malaysia? *Provide 1 answer*	27.1	
		X	No answer
Q28	Have you heard of the Persons with Disabilities Act (2008)? *Provide 1 answer*	28.1	Yes
		28.2	No
		X	No answer

SECTION D Attitudes

Q29	Which three of the following phrases would you use to describe a child without disabilities in Malaysia? *Read answer options and participant should select 3 answers*	29.1	Happy
		29.2	Sad
		29.3	Stressed
		29.4	Shy
		29.5	Independent
		29.6	Has opportunities
		29.7	Confident
		29.8	Demanding
		29.9	Other (specify)
		X	No answer
Q30	Which three of the following phrases would you use to describe a child with disabilities living in Malaysia? *Read answer options and participant should select 3 answers*	30.1	Happy
		30.2	Sad
		30.3	Stressed
		30.4	Insecure / shy
		30.5	Independent
		30.6	Has opportunities
		30.7	Confident
		30.8	Demanding
		30.9	Other (specify)
		X	No answer
Q31	How do you feel when you see a child with disabilities? *Read answer options and participant should select 3 answers*	31.1	Scared
		31.2	Sympathy
		31.3	Feel I want to avoid
		31.4	Normal (no particular feelings)
		31.5	Makes me feel grateful I don’t have disabilities
		31.6	Makes me feel I want to help
		31.7	Other (specify)
		X	No answer

Q32 – Q47: Yes / No answers

Q32	Have you ever socialised with a child or a person with disabilities? *Provide 1 answer*	32.1	Yes
		32.2	No
		X	No answer
Q33	Have your children or any children in your household ever socialised with a child or a person with disabilities? *Provide 1 answer*	33.1	Yes
		33.2	No
		X	No answer
Q34	Is a child with disabilities equal to a child without disabilities? *Provide 1 answer*	34.1	Yes
		34.2	No
		X	No answer
Q35	Are CWDs kept hidden from society? *Provide 1 answer*	35.1	Yes
		35.2	No
		X	No answer
Q36	Are CWDs treated well in your community? *Provide 1 answer*	36.1	Yes
		36.2	No
		X	No answer
Q37	Are CWDs protected in your community? *Provide 1 answer*	37.1	Yes
		37.2	No
		X	No answer
Q38	Should CWDs be sent to an institution? *Provide 1 answer*	38.1	Yes
		38.2	No
		X	No answer
Q39	Can CWDs live a normal life? *Provide 1 answer*	39.1	Yes
		39.2	No
		X	No answer
Q40	Can CWDs take part in social / religious events? *Provide 1 answer*	40.1	Yes
		40.2	No
		X	No answer
Q41	Are CWDs a burden for their family? *Provide 1 answer*	41.1	Yes
		41.2	No
		X	No answer
Q42	Do CWDs cause embarrassment to their family? *Provide 1 answer*	42.1	Yes
		42.2	No
		X	No answer
Q43	Are CWDs more likely to come from poor families? *Provide 1 answer*	43.1	Yes
		43.2	No
		X	No answer

Q44	Are CWDs more likely to be abused? *Provide 1 answer*	44.1	Yes
		44.2	No
		X	No answer
Q45	Is it disruptive for other children to be in school with children with disabilities *Provide 1 answer*	45.1	Yes
		45.2	No
		X	No answer
Q46	Should children with disabilities be friends with children without disabilities? *Provide 1 answer*	46.1	Yes
		46.2	No
		X	No answer
Q47	Are you comfortable working with people with disabilities? *Provide 1 answer*	47.1	Yes
		47.2	No
		X	No answer

Q48 – Q58: Agree / Disagree answers

Q48	Children with disabilities bring bad luck *Provide 1 answer*	48.1	Agree
		48.2	Disagree
		X	No answer
Q49	Children with disabilities can not contribute anything to the family *Provide 1 answer*	49.1	Agree
		49.2	Disagree
		X	No answer
Q50	Children with disabilities can not contribute anything to society when they grow up *Provide 1 answer*	50.1	Agree
		50.2	Disagree
		X	No answer
Q51	Girls with disabilities no need to go to school *Provide 1 answer*	51.1	Agree
		51.2	Disagree
		51.3	No answer
Q52	Boys with disabilities no need to go to school *Provide 1 answer*	52.1	Agree
		52.2	Disagree
		52.3	No answer
Q53	Sexual abuse happens in our community *Provide 1 answer*	53.1	Agree
		53.2	Disagree
		X	No answer
Q54	Children with disabilities are at more risk of sexual abuse *Provide 1 answer*	54.1	Agree
		54.2	Disagree
		X	No answer

Q55	It is acceptable for a child with disabilities to be tied up or restrained *Provide 1 answer*	55.1	Agree
		55.2	Disagree
		X	No answer
Q56	Children with disabilities need less food than other children *Provide 1 answer*	56.1	Agree
		56.2	Disagree
		X	No answer
Q57	Children with disabilities should be separated from other children *Provide 1 answer*	57.1	Agree
		57.2	Disagree
		X	No answer
Q58	Which of the following statements do you agree with? *Provide 1 answer*	58.1	It is better for children with disabilities to be sent to residential care
		58.2	It is better for children with disabilities to live with their families
		51.3	No answer

Is it acceptable or not acceptable for…. *Provide 1 answer for each scenario*

		A Visual disability			B Hearing disability		
Q67	You to live in the same neighbourhood as a child with xxxx	67.1	67.2	x	67.3	67.4	x
Q68	Your child tobe best friends with a child with xxxx	68.1	68.2	x	68.3	68.4	x
Q69	Your child to have a boyfriend / girlfriend with xxxx	69.1	69.2	x	69.3	69.4	x
Q70	A person with xxxx to marry your child	70.1	70.2	x	70.3	70.4	x

Should a child who has a XXXX attend school with other children?

		Yes	No	No answer
Q59	Visual disability	59.1	59.2	X
Q60	Hearing disability	60.1	60.2	X
Q61	Speech disability	61.1	61.2	X
Q62	Physical disability	62.1	62.2	X
Q63	Learning disability	63.1	63.2	X
Q64	Mental disability	64.1	64.2	X
Q65	Behavioural disability	65.1	65.2	X

Q66	The rights of children with disabilities are respected more, the same, less or not at all compared with the rights of other children. *Provide 1 answer*	66.1	More respected
		66.2	Respected the same
		66.3	Less respected
		66.4	Not respected at all
		X	No answer

C Speech disability			D Physical disability			E Learning disability (e.g. dyslexia / slow)			F Mental disability			G Behavioural disability (eg. hyper / obsessive)		
67.5	67.6	x	67.7	67.8	x	67.9	67.10	x	67.11	67.12	x	67.13	67.14	x
68.5	68.6	x	68.7	68.8	x	68.9	68.10	x	68.11	68.12	x	68.13	68.14	x
69.5	69.6	x	69.7	69.8	x	69.9	69.10	x	69.11	69.12	x	69.13	69.14	x
70.5	70.6	x	70.7	70.8	x	70.9	70.10	x	70.11	70.12	x	70.13	70.14	x

SECTION E Practices

Q71	Can you name three special services that are available for children with disabilities? *Provide 3 answers*	71.1	
		71.2	
		71.3	
		X	No answer
Q72	What are the three main barriers that prevent children with disabilities having a better life? *Provide 3 answers*	72.1	
		72.2	
		72.3	
		X	No answer
Q73	What three main areas should be improved to better help CWD in Malaysia? *Provide 3 answers*	73.1	Support groups
		73.2	Community based rehabilitation (CBR)
		73.3	More financial assistance
		73.4	Better medical services
		73.5	Better access to public transport
		73.6	Better educational opportunities
		73.7	Better vocational training
		73.8	Better social services
		73.9	Other *[specify]*
		X	No answer
Q74	Should the government provide services for families with children with disabilities? *Provide 1 answer*	74.1	Yes *[Go to Q75]*
		74.2	No *[Go to Q76]*
		X	No answer *[Go to Q76]*
Q75	If Yes [to Q74] what three services should the government prioritise? *Provide 3 answers*	75.1	
		75.2	
		75.3	
		X	No answer

Section F Communication and information

Q76	What are your three main sources of news and information? *Provide 3 answers*	76.1	TV
		76.2	Radio
		76.3	Newspapers
		76.4	Internet
		76.5	Magazines
		76.6	Billboards / posters
		76.7	Family
		76.8	Friends and neighbours

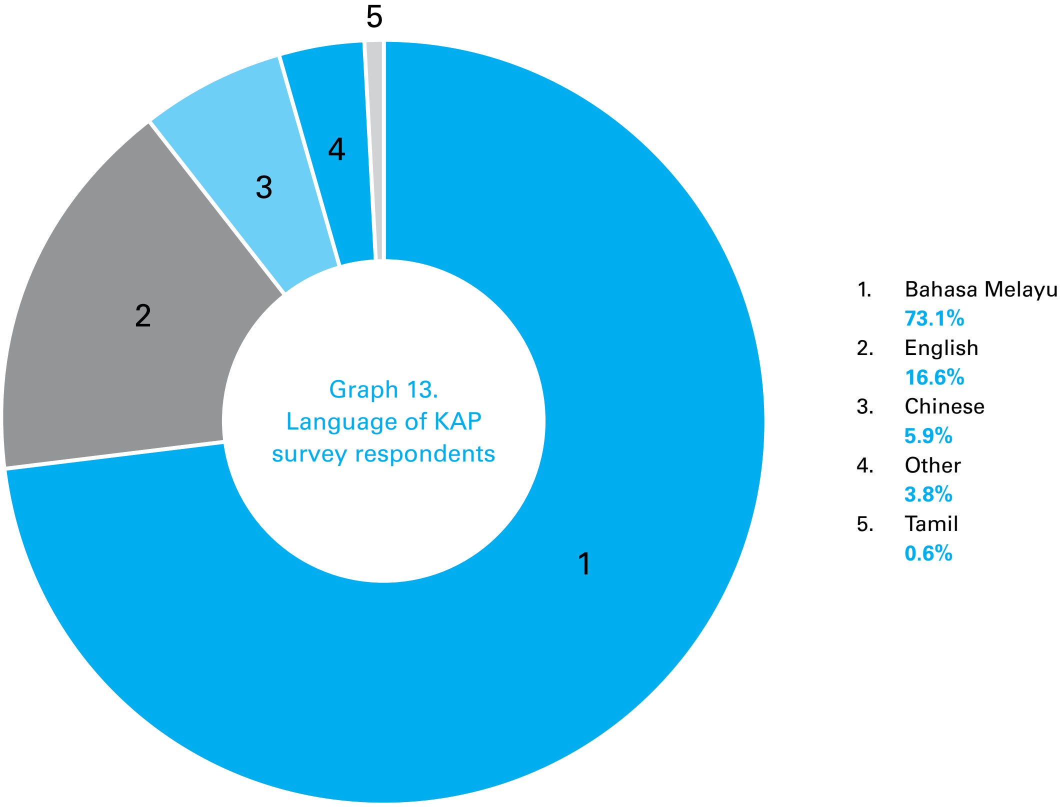
		76.9	Religious groups
		76.10	Other *(specify)*
		X	No answer
Q77	Which newspaper / magazine do you read most regularly? *Provide 1 answer*	77.1	
		X	No answer
Q78	Which TV station do you watch most regularly? *Provide 1 answer*	78.1	
		X	No answer
Q79	Which radio station do you listen to the most? *Provide 1 answer*	79.1	
		X	No answer
Q80	Do you use the internet? *Provide 1 answer*	80.1	Yes *[Go to Q81]*
		80.2	No *[Go to Q82]*
		X	No answer *[Go to Q82]*
Q81	If yes [to Q80] what three websites do you visit the most? *Provide 1 answer*	81.1	
		81.2	
		81.3	
Q82	Do you use social network sites? *Provide 1 answer*	82.1	Yes *[Go to Q83]*
		82.2	No *[Go to Q84]*
		X	No answer *[Go to Q84]*
Q83	If yes [to Q82] what three social network sites do use most often? *Provide 3 answers*	83.1	
		83.2	
		83.3	
		83.4	No answer
Q84	Which of the following do you have? *Circle all that apply*	84.1	Computer
		84.2	iPad / tablet
		84.3	Smart phone
		84.4	Other cell phone
		X	No answer
Q85	Would you like more information about children with disabilities? *Provide 1 answer*	85.1	Yes *[Go to Q86]*
		85.2	No *[Go to Q88]*
		X	No answer *[Go to Q88]*
Q86	If yes [to Q85] what information? *Provide 1 answer*	86.1	
		X	No answer
Q87	Through what channel would you prefer to receive this information? *Provide 1 answer*	87.1	
		X	No answer
Q88	Overall, what are the three main things that should be done to improve the life of children with disabilities in Malaysia? *Provide 3 answers*	88.1	
		88.2	
		88.3	
		X	No answer

ANNEX 4
QUANTITATIVE DATA

This annex presents a selection of graphs based on the analysis of the demographic details of respondents involved in the KAP survey with community members. Each graph can be further contextualised alongside data presented in the narrative section on 'Participant Demographic Details'.

Table 12. KAP survey sample distribution including location

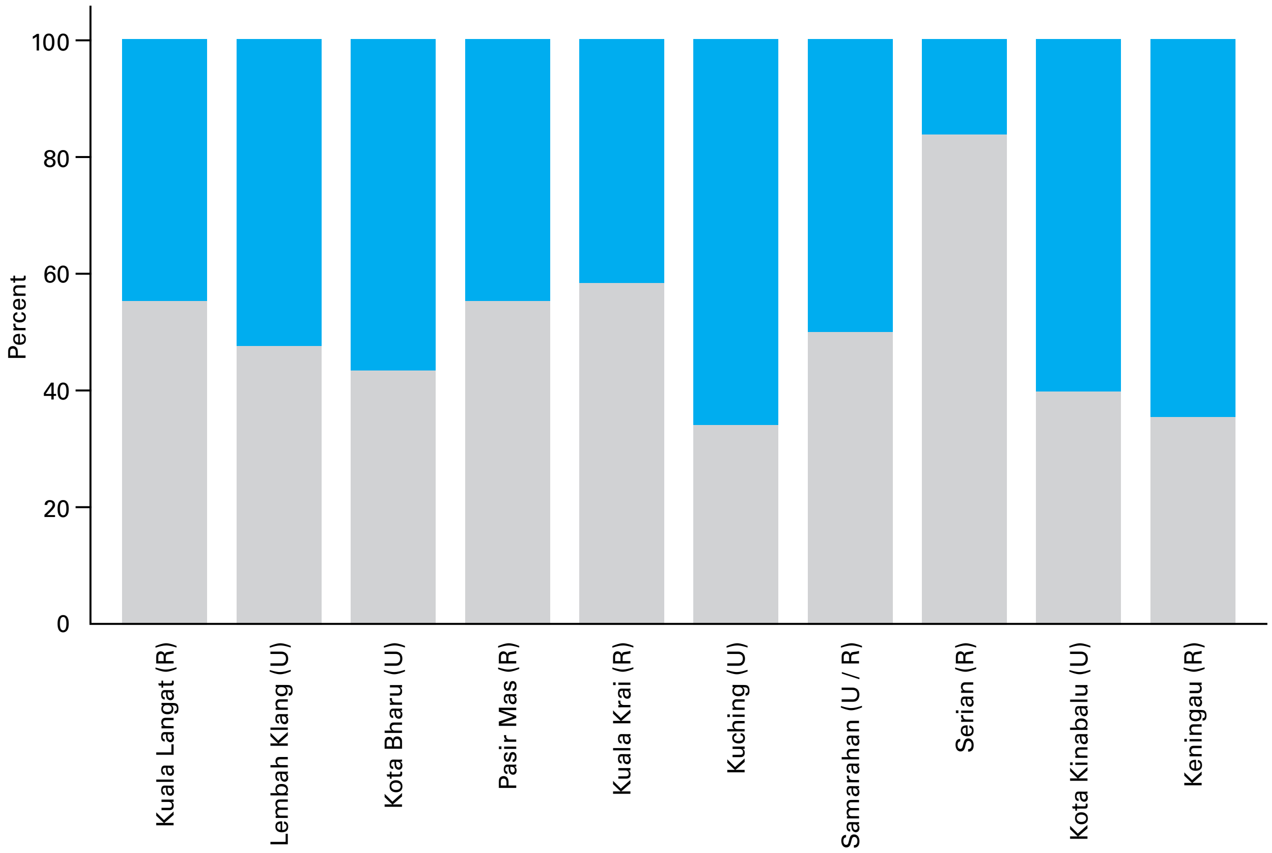
State	District	Urban	Rural	No. respondents
Selangor	Kuala Langat	0	40	40
	Lembah Klang	40	0	40
Kelantan	Kota Bharu	40	0	40
	Pasir Mas	0	20	20
	Kuala Krai	0	20	20
Sarawak	Kuching	26	0	26
	Samarahan	14	18	32
	Serian	0	22	22
Sabah	Kota Kinabalu	40	0	40
	Keningau	0	40	40
	Total	**160**	**160**	**320**



Graph 13. Language of KAP survey respondents

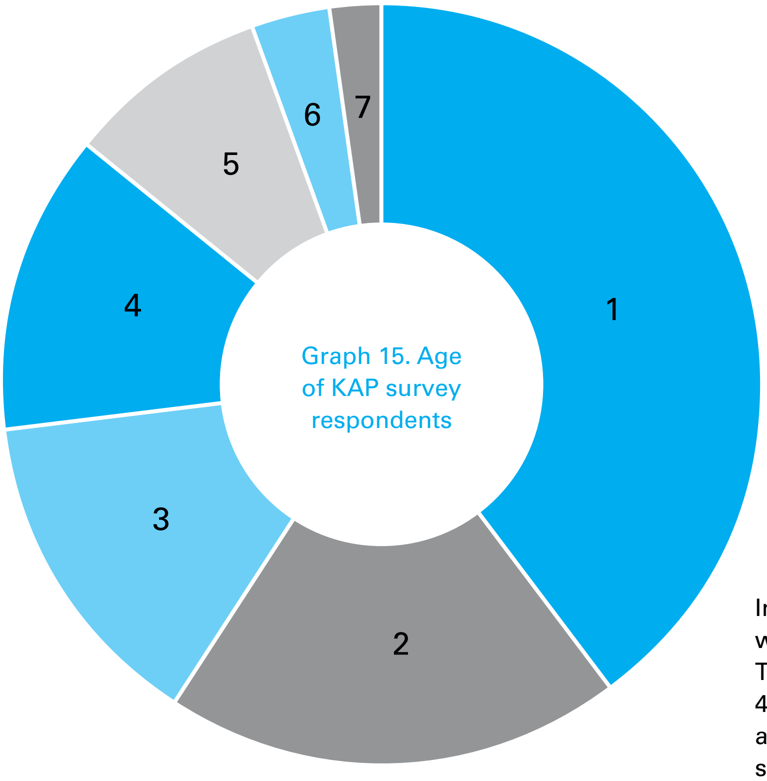
Most KAP surveys were administered in BM (73.1%), followed by English (16.6%).

Graph 14. Gender of KAP survey respondents per district and location type



▨ Male ■ Female

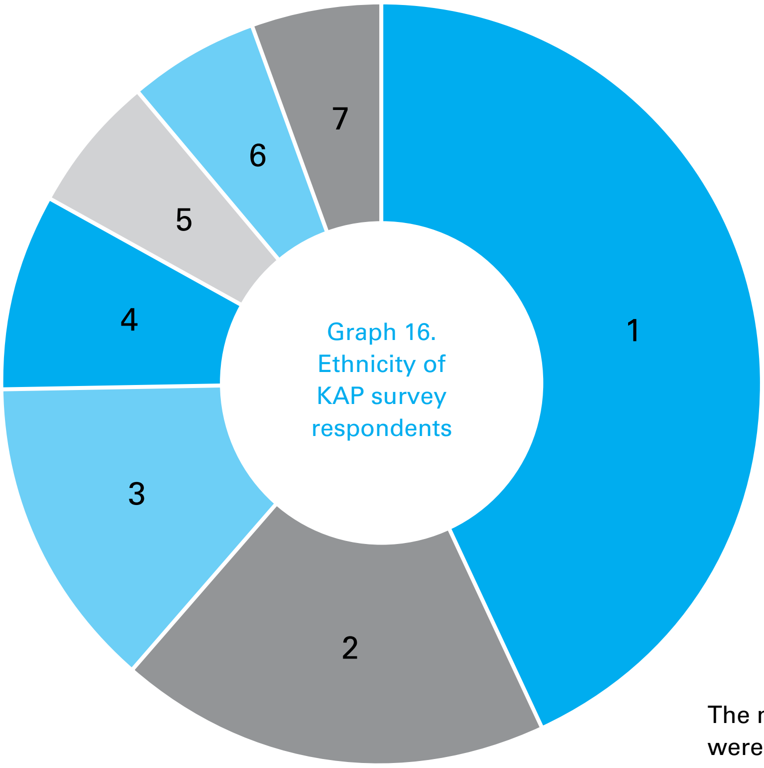
In the KAP survey, 47.% of respondents (152) were male, and 52.5% (168) were female. The gender distribution different across districts and urban and rural locations as depicted in Graph 14.



Graph 15. Age of KAP survey respondents

1. 21 to 30 **40.0%**
2. 31 to 40 **19.4%**
3. 51 to 60 **13.8%**
4. 41 to 50 **12.8%**
5. Under 21 **8.8%**
6. 61 to 70 **3.1%**
7. Above 70 **2.2%**

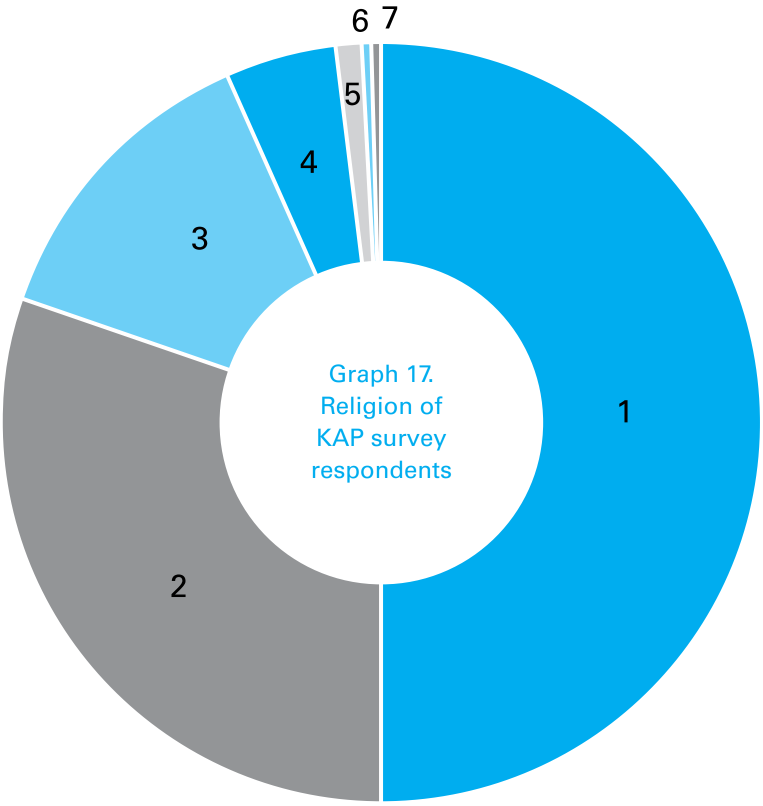
In the KAP survey, 40% of the respondents were aged between 21 and 30 years. The second largest age group was 31 to 40 years (19.4%). Taken together, these age groups represent nearly 60% of the sample size.



Graph 16. Ethnicity of KAP survey respondents

1. Malay
   43.1%
2. Chinese
   18.4%
3. Kadazan-Dusun
   13.1%
4. Other
   8.4%
5. Indian
   5.9%
6. Iban
   5.6%
7. Bidayuh
   5.3%

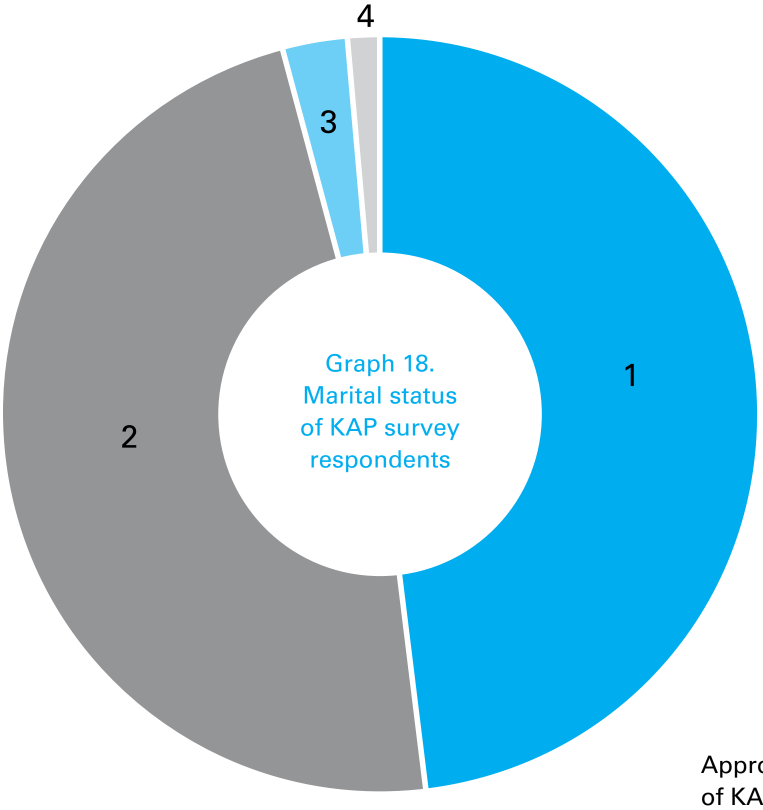
The majority of KAP survey respondents were ethnically Malay (43%). The second largest group of respondents were Chinese Malaysian (18.4%).



Graph 17. Religion of KAP survey respondents

1. Islam
   50.2%
2. Christianity
   30.4%
3. Buddhism
   12.9%
4. Hinduism
   4.7%
5. No religion
   1.3%
6. Animist / local trad. religion
   0.3%
7. Other
   0.3%

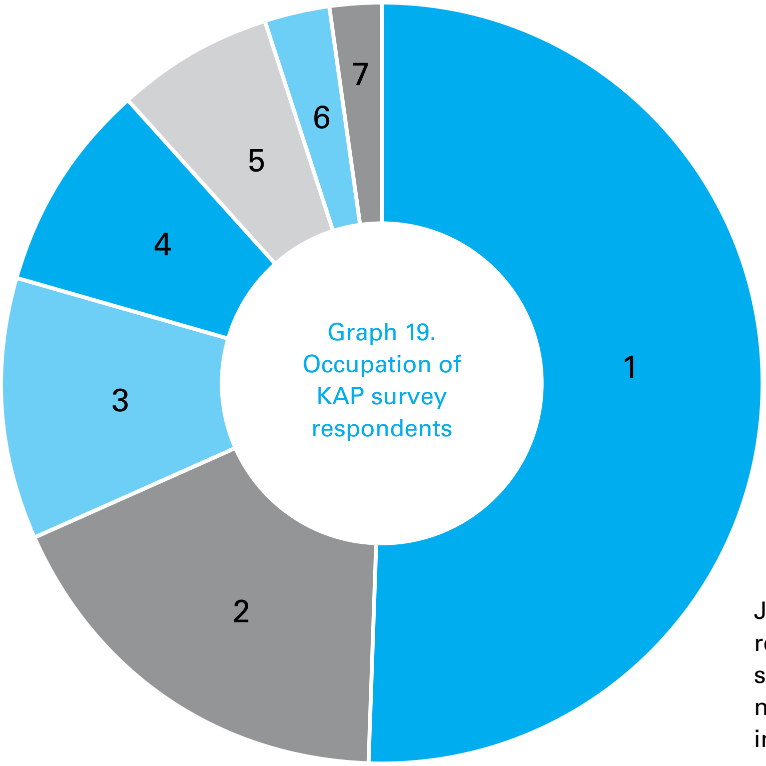
Just over half of the KAP respondents were Muslim (50.2%). Christians accounted for 30.4% of the sample.



Graph 18. Marital status of KAP survey respondents

1. Married **48.1%**
2. Single **47.8%**
3. Widowed **2.8%**
4. Divorced **1.3%**

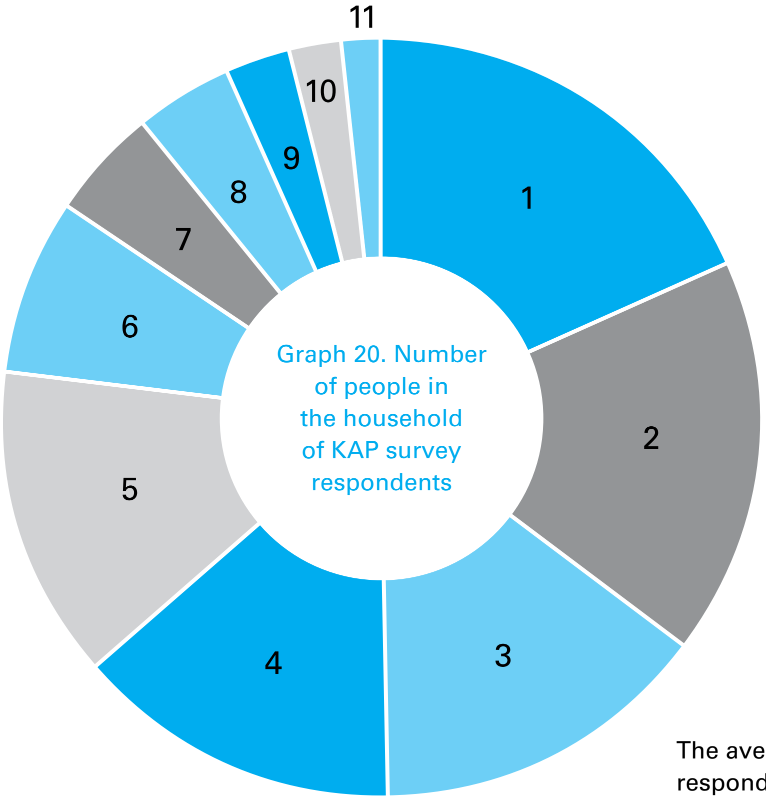
Approximately the same number of KAP survey respondents were married (47.8%) and single (48.1%).



Graph 19. Occupation of KAP survey respondents

1. Private sector **50.7%**
2. Public sector **17.8%**
3. Student **11.0%**
4. Housewife **8.9%**
5. Other **6.8%**
6. Farmer / fishermen **2.7%**
7. Self-employed **2.1%**

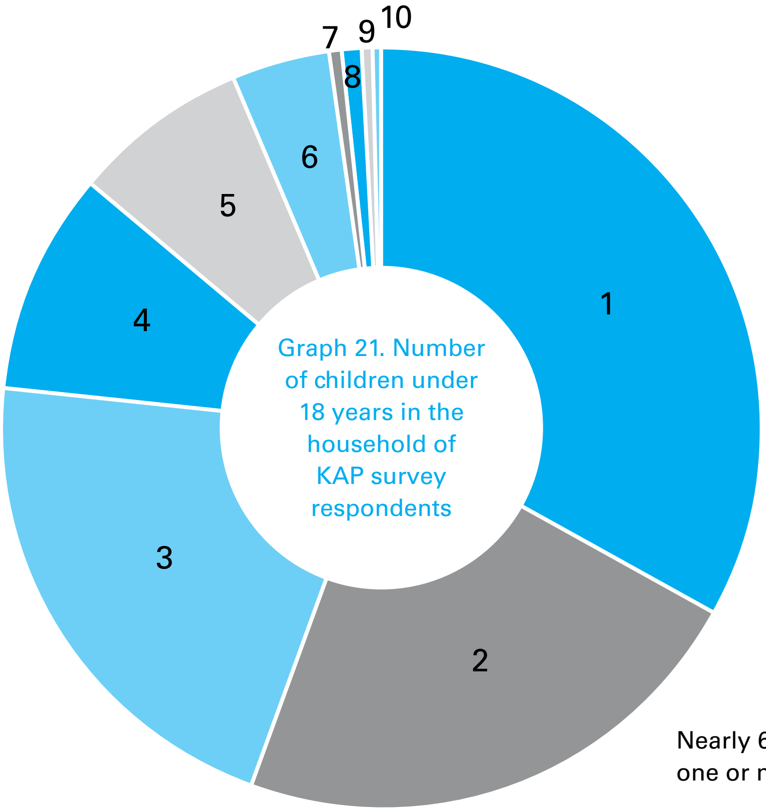
Just over half of the KAP survey respondents worked in the private sector (50.7%), although the data did not distinguish between formal and informal employment sectors.



Graph 20. Number of people in the household of KAP survey respondents

1.	4	18.3%
2.	5	17.0%
3.	6	14.4%
4.	3	13.8%
5.	7	13.5%
6.	2	7.4%
7.	8	4.8%
8.	1	4.2%
9.	10	2.6%
10.	9	2.2%
11.	>10	1.9%

The average size of a KAP respondent's household was five people.

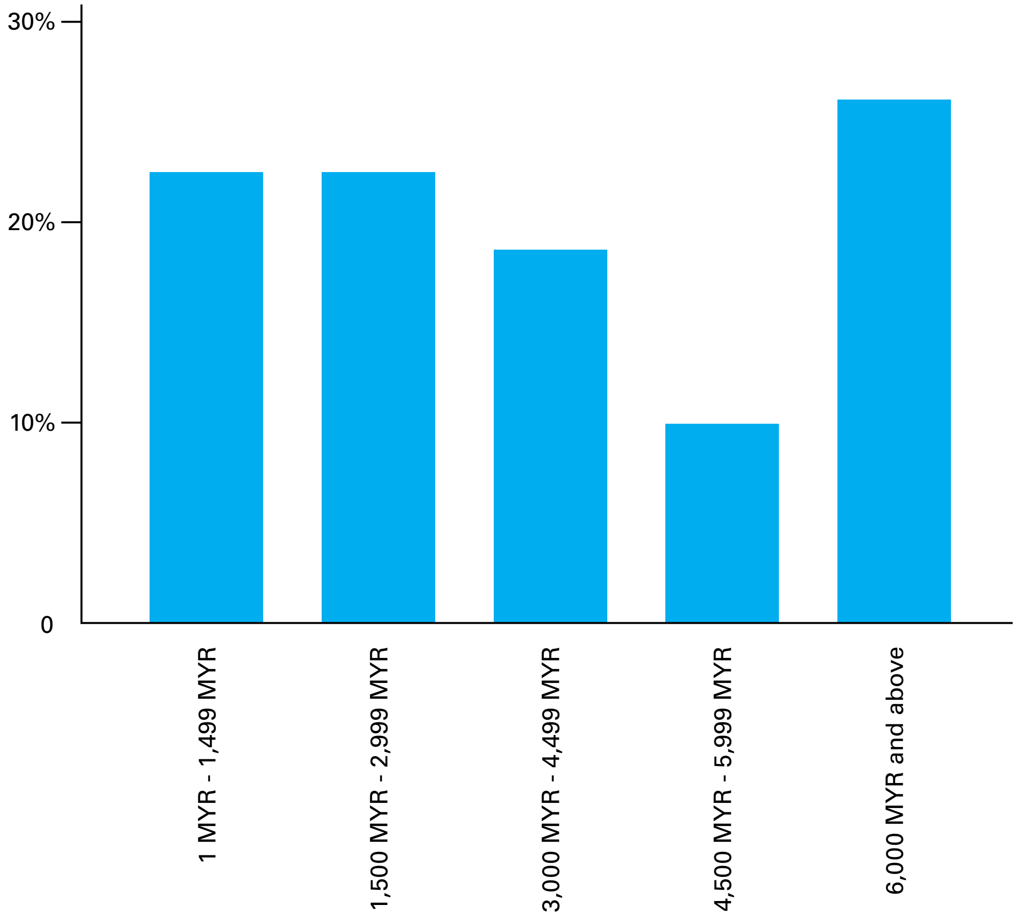


Graph 21. Number of children under 18 years in the household of KAP survey respondents

1.	0	33.1%
2.	2	22.6%
3.	1	21.1%
4.	3	9.5%
5.	4	7.6%
6.	5	4.0%
7.	6	0.7%
8.	7	0.7%
9.	8	0.4%
10.	11	0.4%

Nearly 66.9% of KAP respondents had one or more child in their household.

Graph 22. Total household income per month in ringgit



47.7% of respondents (153) earned under MYR 2,999 per month, 28% (90) earned between MYR 3,000-5,999 per month, and 25% (80) confirmed they earned over MYR 6,000 a month.


BUS

“Me, my friends and things I like,”

drawn by non-verbal boy with learning and physical disabilities, during a workshop in Kelantan.

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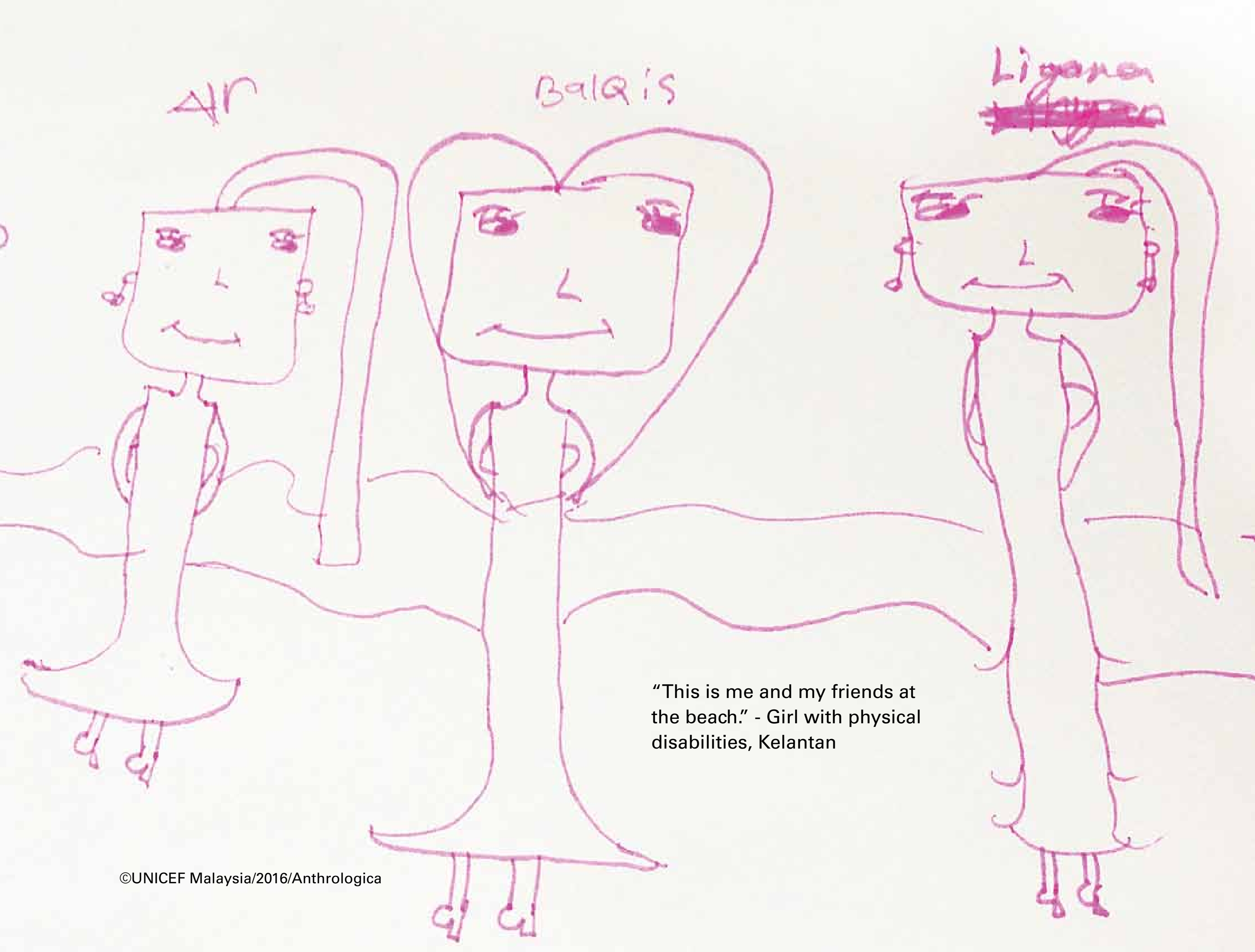

“This is me and my friends at the beach.” - Girl with physical disabilities, Kelantan

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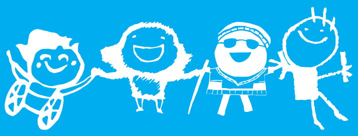
“We want to work for the progress of the child.”

Community-based rehabilitation (CBR) workers

> “When you see the disability before the child, it is not only wrong for the child, but it deprives society of all that child has to offer. Their loss is society’s loss; their gain is society’s gain.”
>
> **UNICEF Executive Director,**
> **Anthony Lake**

> “They are different but sometimes they are talented at things which we are not able to do. They have their own specialties. [They are] people whom we should respect even if they are different from us.”
>
> **Child from Kuala Selangor,**
> **under 15 years**



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