



Childhood Disability in Malaysia: An insight into the UNICEF Study findings on knowledge, attitudes and practices

7th National Early Childhood Intervention Conference:

Child, Family, Community

Batu Pahat, Johor, Malaysia

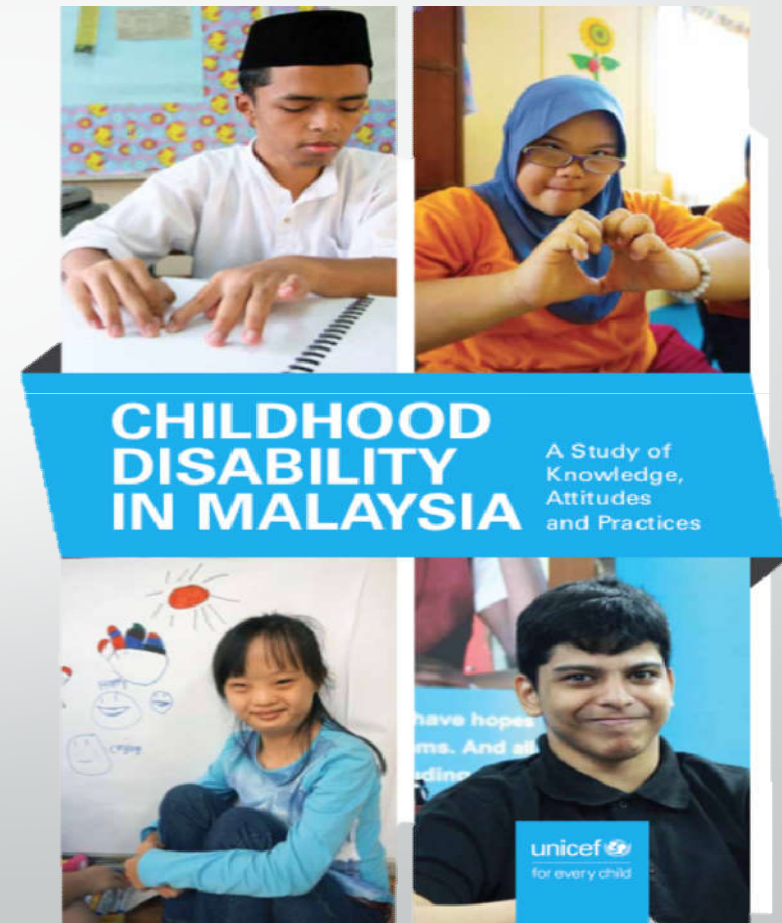
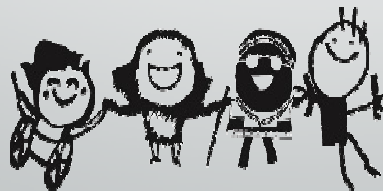
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Acknowledgement

UNICEF Malaysia for their permission to share the findings of the study *Childhood Disability in Malaysia* (UNICEF 2017)



Voices from the parents in the study

*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 the CBR then he will be angry at me, saying '**DO YOU WANT ME TO FEEL 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 on 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.

- A mother from Sarawak -






*"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 asked.. 'What do you mean by **THIS KIND** of kids?'*

The headmaster said 'All of my students are okay but your kid is like that, and we do not accept this kind of kid.'...

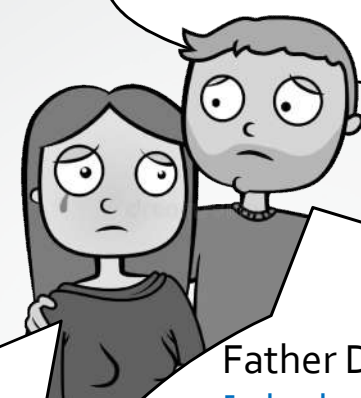
- A mother of a boy with physical disabilities, Sabah




Mother A: Sometimes, if we bring this child to any place, the people will look from far and from top to down. They look at this child like he is something weird.. We do have feelings, you know.

Mother A: It's not that we ask for it. God has given us a child like this. .. This is because we are given a child like this, so we have to accept him.

Mother C: In terms of taking care of him, .. people don't understand. The community in our village do not understand. So, when there is events such as wedding, or funeral and we couldn't help them, I feel so devastated because they said to me that (sad voice) oh, you why didn't you come and help with activities in the village? But they do not understand that my son is in this condition. They even said things like when I die later, nobody will come and help with my funeral. How dare they say things like when but they do not understand about the condition of my son



Father B: They look at our kid like there is a free show.



Father D: ...if we enter the church, my child [who has autism] like to disturb the light socket and will disrupt the congregation. So, people will automatically scold us. They will say something like why do we bring a child like this to the church where other people want to focus praying and he will disturb their concentration. So it means, this type of children should not be brought to the church. So, it is already a type of discrimination..

Focus group discussion with parents of children with various learning disabilities, Rural Sabah

The study: 4 core objectives

1. to assess the Knowledge, attitudes and practices of society towards children with disabilities

2. to assess the life satisfaction of and perception of children with disabilities towards their own impairment and that of their peers with disabilities

3. to analyse the root causes of stigma and discrimination faced by children with disabilities

4. to establish a baseline to inform future interventions and strategies in communication for behavioural and social change

Study Method

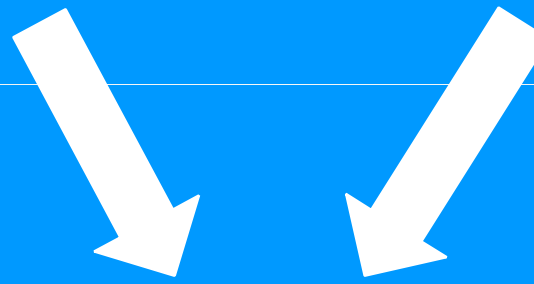
Mixed Method

Qualitative

- In-depth Interview
- Focus group discussion
- Child & adolescent workshops

Quantitative

- KAP Survey



Triangulation

Research sites: Selangor/ Kuala Lumpur, Kelantan, Sabah & Sarawak (one urban and rural region for each state).

Ethnic, social and religious diversity was included; both gender represented

Participatory and Inclusive

- A range of disabilities were represented

Child and Adolescent workshops

with disabled and non-disabled children (14- 18 yrs old)

- ❖ Story circles and drawing
- ❖ Graffiti walls
- ❖ Drama and role plays
- ❖ Providing a open and safe space for sharing of experiences



Total 756 participants

KAP survey - 320 persons

38 FGDs = 229 participants

102 IDIs

18 child and adolescents
workshop = 105
participants



Knowledge (what do respondents know about children with disabilities?)

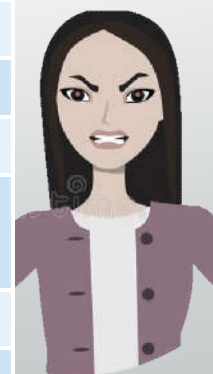
- 58.4% reported being not well informed about CWD
- Disability understood in terms of a person's limitations and functionality (ability/inability to complete routine tasks)
- 'Visible disabilities' (physical, and visual impairment) better understood, learning and mental disabilities less understood/ accepted
- Language on disability is complex and subjective. Informal terms e.g 'imperfect child', 'abnormal child' can be stigmatising
- Formal terms not always used and either confusing or contentious e.g disabled? less abled? differently abled?

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 them, but at least do not call them cacat, pity them, I don't want."

- A father of a girl with cerebral palsy

Knowledge (perception on causes of disabilities)

		Number of responses	Percentage of responses (%)
Causes of disability	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



People told me that during the time of pregnancy, we need to refrain ourselves, cannot do this, cannot do that. May be I broke the rules, that's why [my child was born with a disability]. Lot of people blame me ..they said that I didnt take care.

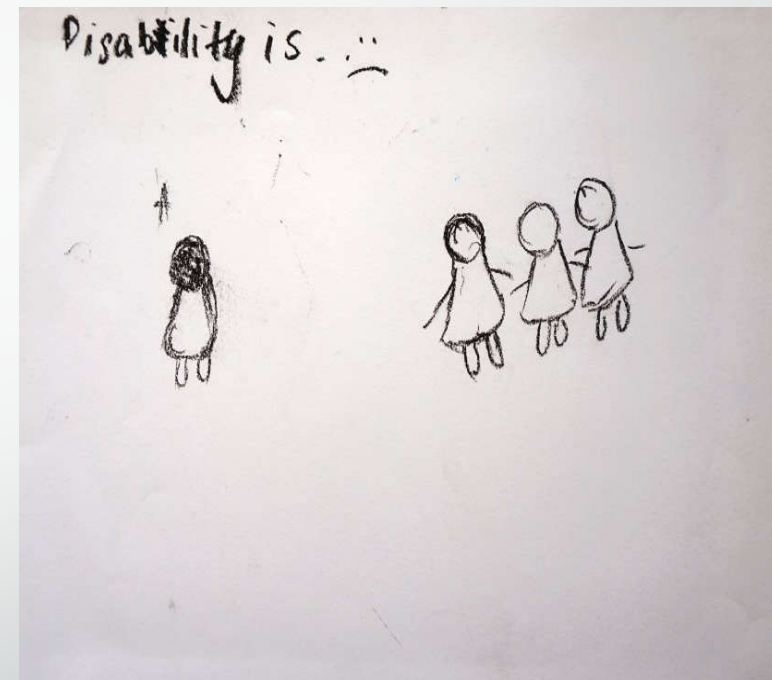
Knowledge (where do you get information on disabilities?)

	Location	
	Urban % (458)	Rural % (463)
TV	26.4	30.9
Internet	25.3	22.9
Newspapers	20.1	20.1
Radio	10.9	11.2
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



Attitudes (how much do you accept children with disabilities?)

- Societal attitudes towards CWD and their families appeared **sympathetic**
- A perception that CWD **should not be discriminated against**
- Community and religious leaders agreed that **pity could lead to discriminatory behaviour and negative attitudes**
- **But many reported they do not know what to do or how to help**



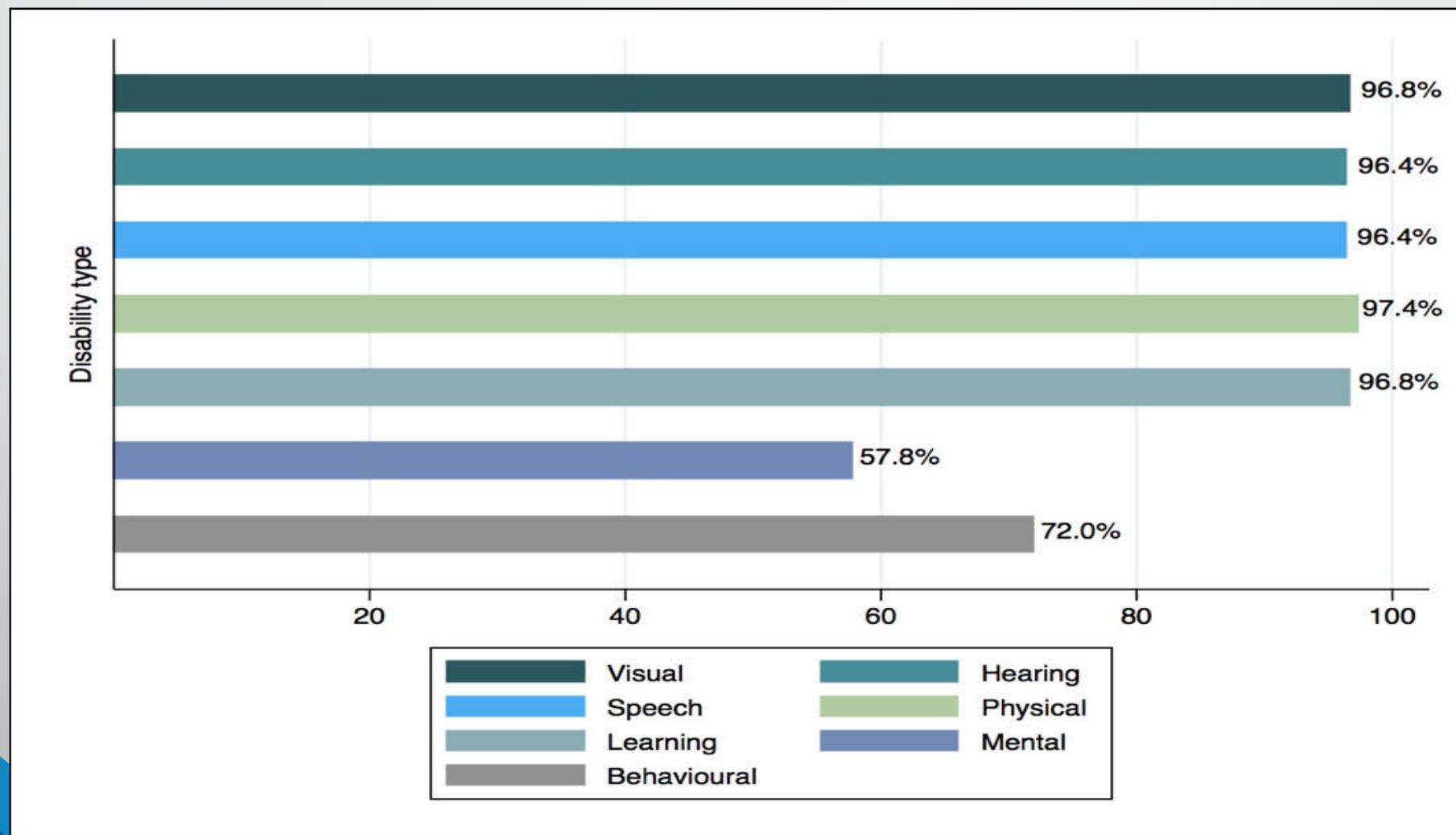
Drawing from participatory workshop, Sabah

Attitudes (feelings when they saw a child with disabilities?)

Feeling when seeing a CWD	% 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

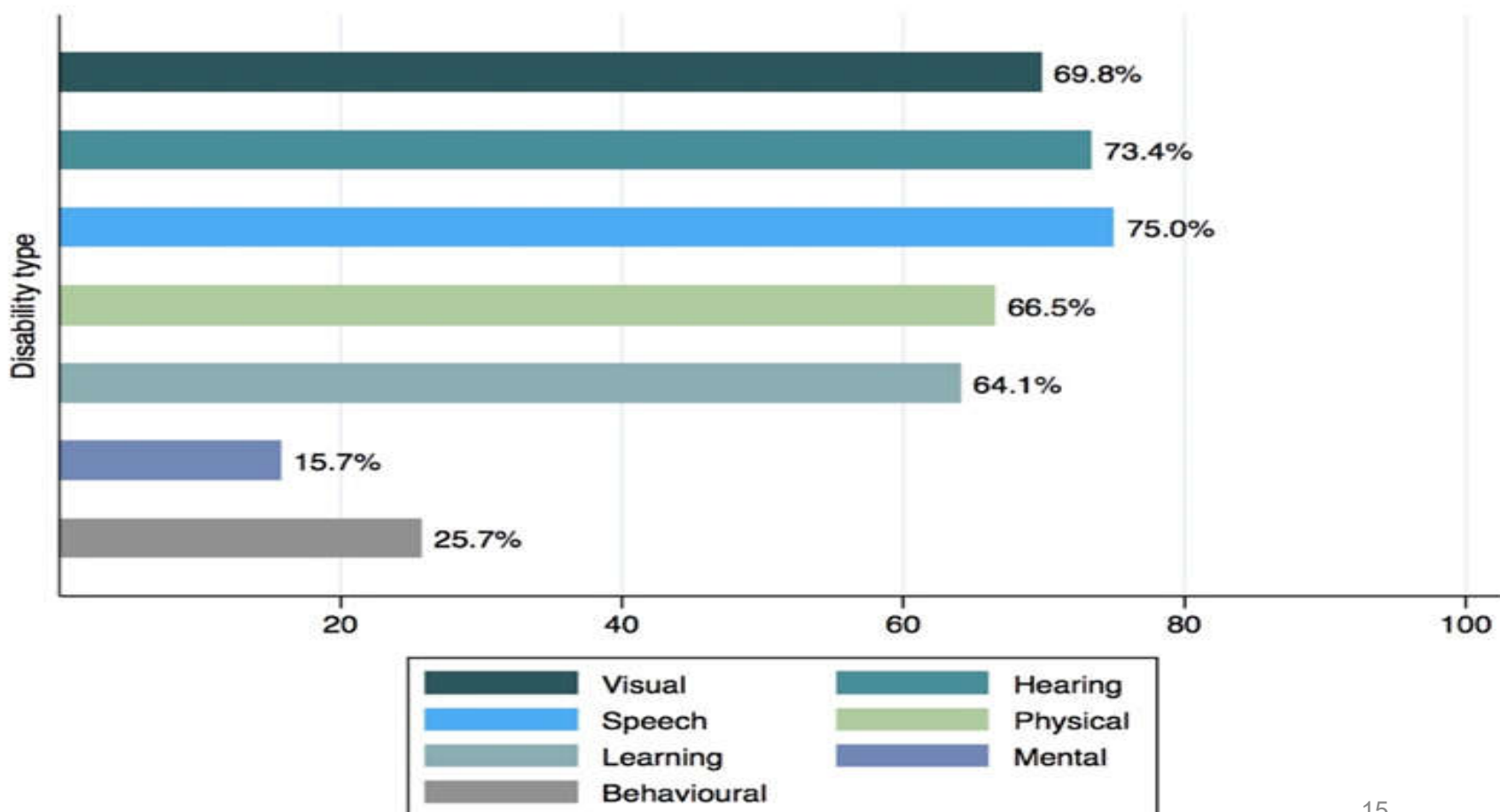
Attitudes

Level of acceptance of a child with disabilities living in the same neighbourhood, according to type of disability



Attitudes

Level of acceptance for their child to have a boyfriend/girlfriend with disabilities, according to type of disability



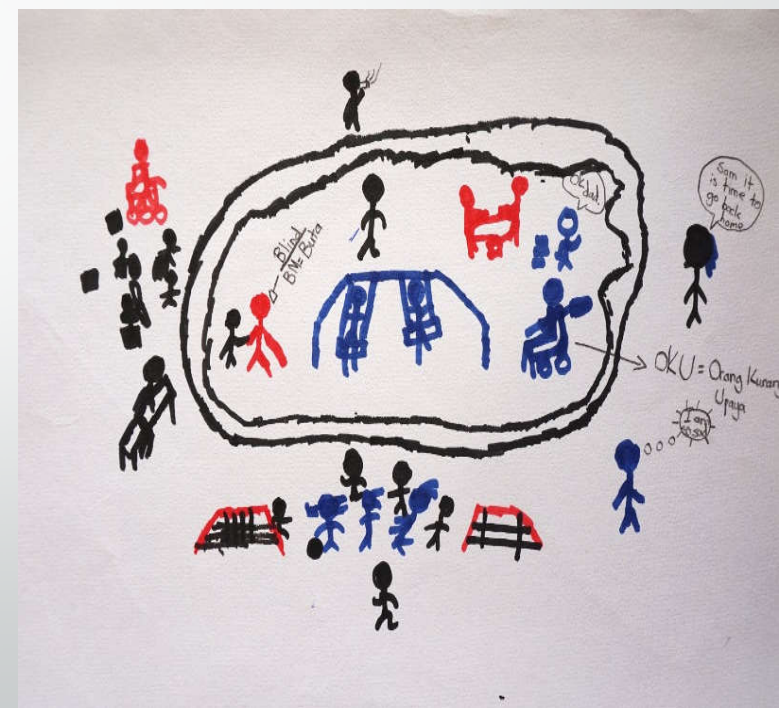
Attitudes

Acceptance of children in school, according to disability types

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

Attitudes ➡ Practices

- Children and adolescents reported frequent experiences of bullying and mistreatment
- Respondents acknowledged that CWD were vulnerable; increased by Internet and social media
- 67.2% believed CWD were at greater risk to sexual abuse
- Caregivers expressed great concern for their children's future in terms of welfare, and protection
- Lack of societal acknowledgement for role in protecting CWD



Practices (how well do we meet the needs of children with disabilities? What are the barriers?)

Registration of children with disabilities

- Value of registration recognised
- Process of registering slow and complicated especially for those in rural areas

Financial constraint

- Transport to services, medical bills, assistive devices = additional expenses
- Caregiver ceasing work to provide full time care
- Limited disability allowance

Transport barriers

- Distance to services
- Access to public transport challenging, private transport expensive

Physical/Infrastructural barriers

- Infrastructure barriers in public places posed obstacle to inclusion
- Disabled car parks and toilets were misused
- Lack of barrier-free facilities in schools to facilitate needs of physically disabled children



Practices Health Services

- Health workers seen as first point of contact
- Caregivers: dissatisfied and frustrated in terms of obtaining information about early detection, diagnosis, management and rehabilitation.

Health workers not trained in sensitive and appropriate behaviour and language

- Some hospitals not disabled-friendly in terms of physical accessibility and no priority given
- Access and availability greater in urban areas and for middle income families who can afford private health services

- 'Traditional' methods used by those in Sarawak, Sabah and Kelantan and 'alternative medicine' in Selangor

A Hospital Assistant in a district clinic in rural Sabah admitted not having much knowledge about disabilities

A doctor in rural Selangor revealed that he is not aware of any CBR centre in that region, and neither what CBR is intended to be

Practices

Education

10 % survey respondents asserted that neither boys and girls with disabilities need to attend schools

- 43.1% survey respondents thought it was disruptive for children to be in school with children with disabilities
- Mainstream teachers believed children with disabilities could not be educated in the same classes, even if can, 'our KPIs will be affected'.
- Teachers sent to special schools with very little training
- Bullying and discrimination experienced by children in 'integrated' schools



Drawing from participatory workshop, Sarawak
2 children, 1 visually impaired and the other non-disabled learning side by side

Practices **Community based rehabilitation services**

- Provided an important space for integration, stimulation and learning, particularly for children not accessing mainstream services
- Provision of centres inadequate particularly in rural areas
- Special therapies at government CBR services limited and lacked continuity
- Lack of career development opportunities and and low salary for CBR workers; improved training needed



Practices

Employment Opportunities

- Employment valued by adolescents with disabilities as a means to contribute to society
- Workplace and employment discrimination was systemic
- Employment opportunities and salaries were limited for people with disabilities
- Opportunities for tertiary education limited
- Disabled workers allowance provided by Social Welfare Department : protecting rights or perpetuating discrimination?

"The jobs are really limited for OKU. Like me, I have been through many interviews, the reason [for not giving me job] is that they want normal people...We cant 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..

A visually impaired participant in Selangor



Social barriers

'Sometimes the environment won't adjust to us because the public attitude is difficult to change.

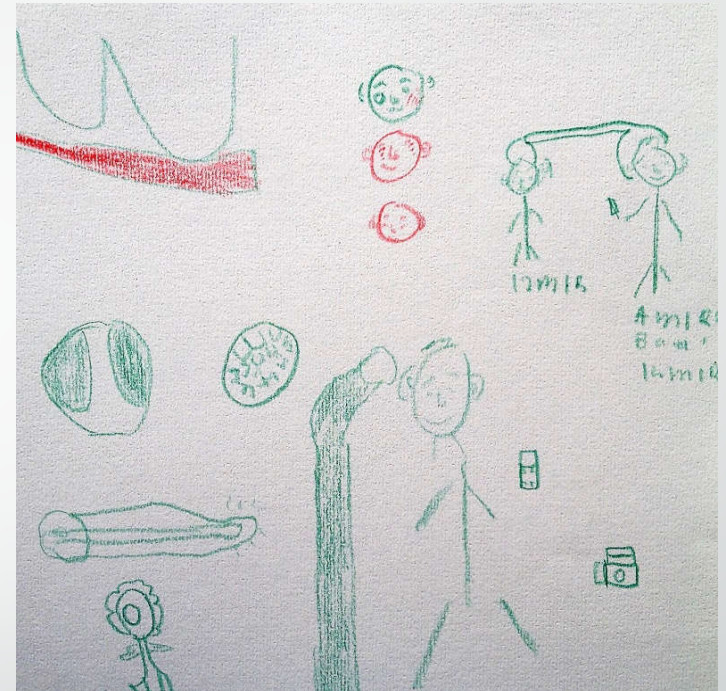
I think society has to change, only then the environment can change.

Start with the attitude'

A CBO representative

Social model of disability:

It is society which disables disabled people



Drawing from participatory workshop, Selangor

Tell the story of an adolescent boy being beaten, "I was beaten, there was blood"

Insights from the study

- ❖ What we know (**knowledge**) and feel about disabilities (**attitudes**) and what we do with people with disabilities (**practices**) are interrelated
- ❖ Evidence based strategies for behavioural and social change grounded in the data
- ❖ Promote inclusive and participatory research (Including with CWD)
- ❖ Early intervention programmes to take into consideration the complexity of socioeconomic, cultural and regional differences
- ❖ Rural disparity needs to be addressed

Making our society more inclusive

Community Engagement

- ❖ Create awareness and educational programmes to address the root causes of stigma and discrimination as experienced by CWD and their families
- ❖ Use of media accessible to all age groups, all languages, all regions
- ❖ Increase visibility of people with disabilities
- ❖ Organise more activities for children and adolescents of all abilities to interact and learn from one another

Empowering children with disabilities and their families

- ❖ Empowerment Counselling for mothers and fathers
- ❖ Support groups at grassroot level
- ❖ Peer-to-peer support forum for children and youth with disabilities
- ❖ Opportunities for participation by children and youth with disabilities in all educational, arts, sports and recreational programmes - as early age as possible
- ❖ Intervention programmes to address/prevent bully, abuse and manipulation of children and youth with disabilities



Towards an inclusive Malaysia



- ❖ As with *The Convention on the Rights of Persons with disabilities* mainstream disability issues as an integral part of sustainable development
- ❖ **Legislative changes must begin to ensure disability rights are upheld**
- ❖ **A Disability Discrimination ACT is called for !!**

YES, WE CAN !!



References

- https://www.unicef.org/malaysia/Final_File_Childhood_Disability_in_Malaysia_Book
- https://www.unicef.org/malaysia/resources_publications_children-with-disabilities.html

