



Childhood Disability In Malaysia

A study of knowledge,
attitudes and practices



“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 [to be] 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. ...”

A Parent of a Child with 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. ...”



An Adolescent without Disabilities



Lisa Surihani
Actress

Glossary

- OKU** Orang kurang upaya (OKU), ‘less abled person’
- Cacat** Disabled or handicapped
- CBR** Community-based rehabilitation (CBR)
- CBO** Community-based organisation
- KAP** Knowledge, attitudes and practices
- NGO** Non-governmental organisation

To ensure that this booklet is accessible to a large audience, UNICEF Malaysia has used Dyslexie Font, created an accompanying audio version and designed this document to be Reader Friendly.



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Why was the Study Conducted?



Assess the knowledge, attitudes and practices of society towards children with disabilities, the children themselves, and their peers.

Analyse the root causes of stigma and discrimination faced by children with disabilities, and their drivers.



Form strategies to change behaviour and social norms.



Assess the life satisfaction and perception of children with disabilities.

WHEN?



The study was conducted between **JANUARY** and **SEPTEMBER 2016**

WHERE?

The study took place in **Selangor, Kelantan, Sabah and Sarawak**



HOW?



Survey

Group Discussions

Interviews

Adolescent Workshops

In total, 756 total respondents/participants



National-level stakeholders, such as government ministries

Community members, such as community and religious leaders, and caregivers of children without disability

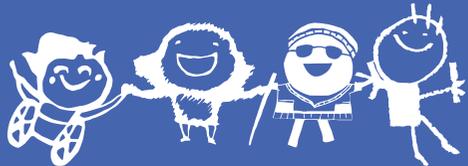


Service providers, such as health workers, community-based rehabilitation (CBR) workers, and teachers



Caregivers of children with disabilities

Children and adolescents (both with and without disabilities)



What do respondents know about children with disabilities?

58% are under informed about children with disabilities

87% want more information about disabilities



Although there are these naturally recognised categories of disabilities, not every condition is perceived to be a disability. In the study, we found that the respondents' perceptions of disabilities are as follow:

80%

On average, **8 out of 10** respondents perceive physical conditions as disabilities.

Such as loss of vision, inability to walk, total loss of hearing and impaired limb

30%

Only **3 out of 10** perceive behavioural and mental conditions to be disabilities.

Such as hyperactivity, aggression, difficulty concentrating, difficulty in learning

20%

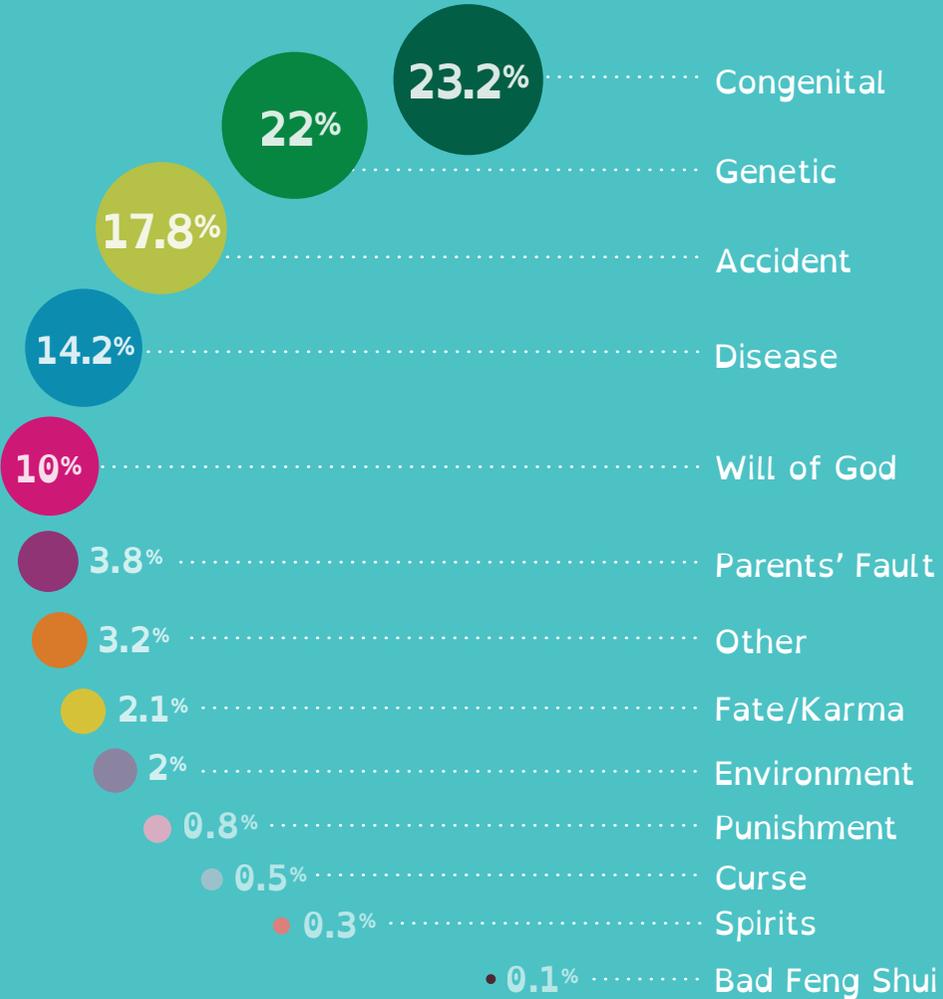
Less than **2 out of 10** perceive strange and anti-social behaviour to be a disability.

Such as defiance

Finding:

Respondents have limited knowledge about the actual causes of disability.

Many do not understand what causes disability. Here are the perceived causes identified:



Where do respondents get information on disabilities?

Here are the **Top 4 Sources** of information according to areas

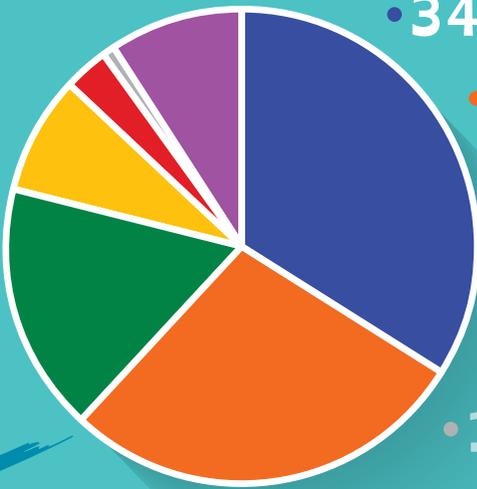
Urban

26% TV
25% Internet
20% Newspaper
11% Radio

Rural

31% TV
23% Internet
20% Newspaper
11% Radio

How do respondents feel about children with disabilities?



• **34%** Sympathy

• **28%** Like they want to help

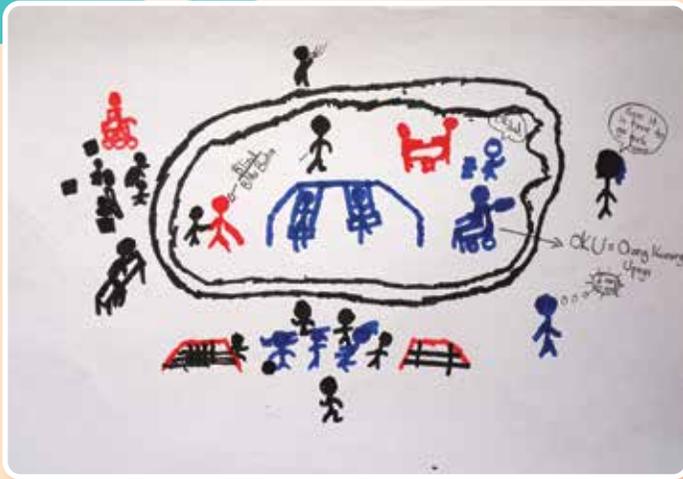
• **17%** Grateful they don't have disabilities

• **8%** Normal (no particular feelings)

• **3%** Scared

• **1%** Like they want to avoid

• **9%** Other Feelings



“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 that guy, he can’t play football. But he feels happy because he remembers that when he had legs he also played.”

– Drawing by boys without disabilities, Sarawak



A Parent of a Child with Disabilities

“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 [to be] 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. ...”

How much do respondents accept children with disabilities?

Would you encourage your children to be friends with all children, including those with disabilities?

Most parents who took part in the study allow their children to play with children with disabilities, depending on the type of disabilities. However, children with mental and learning disabilities were the least accepted.

Most accepted disabilities:
hearing, speech, physical and learning disabilities



9 out of 10 respondents do not mind living in the same neighbourhood or their child being best friend with a child with either of these disabilities.



7 out of 10 respondents accept their child having a boyfriend/girlfriend with such disabilities.



6 out of 10 respondents accept their child marrying a person with any of these disabilities.

Least accepted disabilities:
mental and learning disabilities



About half of the respondents don't accept living in the same neighbourhood as a child with mental disability.



Less than a quarter of the respondents accept their child having a boyfriend/girlfriend with mental disability.



87% of respondents don't accept their child marrying a person with mental disability.

What are the respondents' experiences with disabilities?

Children with disabilities are commonly hidden and kept out of sight.



1 in 3

believe that children with disabilities are 'kept hidden from society'



1 in 8

think that children with disabilities caused embarrassment to their families



1 in 4

think they are a **burden** for their families

"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 [*Orang Kurang Upaya*]. 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 *kampung* [*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.

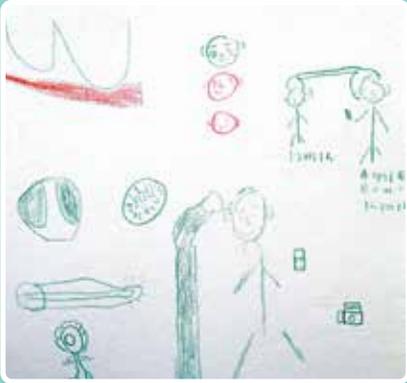
Sometimes I am embarrassed. When we are going out with my family and they will bring my brother, I will walk away from them. Sometimes it's society that makes me feel sad, but I don't know how they can be more accepting. ...I think people with disabilities can contribute to society. Like in sports, because 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."



An adolescent sibling of boy with Cerebral Palsy, Sarawak

What are the future concerns for children with disabilities?

Welfare and protection are the greatest concerns expressed by caregivers of children with disabilities.



“I was beaten, there was blood.”
– Drawing by an adolescent boy with Down Syndrome, Selangor



“We do not know what their future is like... Let's say if one day we pass away... what will happen to him?”

A mother of a child with disabilities

“... 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 [residential homes] 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’.”



A community-based rehabilitation centre representative from Sabah

Are children with disabilities more vulnerable?

Children with disabilities are perceived to be vulnerable to their surrounding environment and society, because they were **'easily influenced by others'** and **'don't know right from wrong'**. Bullying and manipulation were reported to be common for children with disabilities.

Children with disabilities were often seen to be **easy targets and scapegoats** because they had little agency or power to assert themselves.

They were taught by their non-disabled peers **how to access pornography and other inappropriate content** on their mobile phones.

Children with disabilities were coerced into **vaping, smoking, selling drugs, watching pornography** and, in some cases, **prostitution**.

Caregivers of children with disabilities

(i.e. teachers and CBR workers) shared their observations

They are seen as **vulnerable to being teased, bullied and beaten**, and also exposed to **sexual abuse such as rape**.

Stakeholders agree that children with Down Syndrome and 'slow learners' were the **most vulnerable to sexual abuse**.

67.2% agreed that they are more at **risk of sexual abuse**.

How accessible is education for children with disabilities?

Should children with disabilities have access to mainstream education? The opinion was divided.



Q ■ Is it disruptive for children to be in school with children with disabilities?

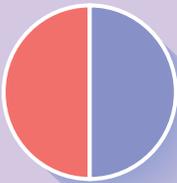
48.8% Disagree
43.1% Agree
8.1% No Answer

10% of the Respondents

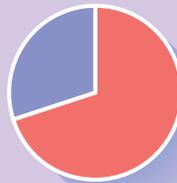
say that neither girls nor boys with disabilities need to attend school



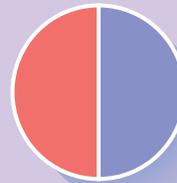
Level of acceptance of children in school, according to disability type



On average, **half of the respondents** accept children with physical disabilities in school.



However, **more than 70%** believe children with mental disabilities should not be in the same school as children without disabilities.



About half do not mind children with learning disabilities in school.

Should children with disabilities be studying in the same school as children without disabilities?



Teacher in mainstream education

“Not possible to teach children with and without disabilities in the same class.

They should be educated in special classes or at special schools.”

Teacher in special education

“If the children with disabilities had the capacity and capabilities, they should be offered an opportunity to study in mainstream education.”





A mother of boy with physical disabilities in 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. They said that the school 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. ..."

Children with Disabilities: How are they perceived?

How well informed are the respondents about children with disabilities?



5 in 10
respondents are **not informed** about children with disabilities.



However, **87%** would like more information about disabilities.



3 in 5 don't consider learning difficulties to be a disability.

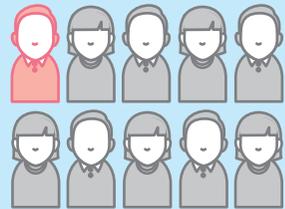
Growing up as a child with disabilities.



3 in 10 say that children with disabilities are kept hidden.



6 in 10 agree that children with disabilities are at greater risk of sexual abuse.



1 in 10 do not feel comfortable working with a person with disabilities.

Education for children with disabilities.

4 out of 10 agree that it is disruptive for children to be in school with children with disabilities.



Financial constraints prevent the child with disabilities & his/her siblings from attending school.

Only 16% accept children with mental disabilities being in school.

Children with disabilities are at greater risks of abuse.



More than half think that children with disabilities are more likely to be abused.



Some respondents suggest that it is acceptable for a child with disabilities to be tied up or restrained.



Some respondents think that they need less food than other children.

Mental disabilities are the most stigmatised.



Only 58% would live in the same neighbourhood as a child with mental disabilities.



Only 6% would accept their child to have a boyfriend or girlfriend with mental disability.

What are the obstacles faced by children with disabilities?



Discrimination and stigma are associated with having an OKU card.



Lack of infrastructure in public environments.

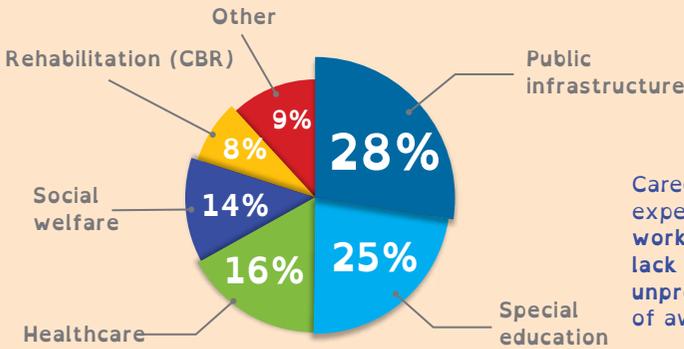


Limited and expensive transportation.

How accessible are healthcare services for children with disabilities?

Children with disabilities have particular healthcare needs. Health workers are generally their 'first point of contact' and regarded as hubs of information about health and disability.

According to the respondents of the survey, some special services are made available to children with disabilities



Caregivers shared their experiences where health workers are perceived to lack sensitivity and are unprofessional due to lack of awareness and training.

A caregiver

[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."



Perceived constraints faced in healthcare services are

✗	lack of specialised care	✗	long waiting time
✗	limited supply of assistive devices	✗	short consultation periods
✗	distribution and coverage of services offered is inequitable		

How helpful are community-based rehabilitation (CBR) services for children with disabilities?

Community-based rehabilitation (CBR) centres provide an important space for integration, stimulation and learning for children with disabilities.

Positive progress reported after attending **CBR centres** includes:



Socialisation



Skill development



Self-management

CBR workers not only provide support to the children, but also the family in the following areas:



Techniques for home care



Information about key resources



The child's progress and achievements assessment

CBR workers agree in the following areas of improvement



Training opportunities



Recognition



Technical experience



Incentives

What are the current perceived constraints?

✘	Distribution of CBRs in East Malaysia were 'still behind' compared to Peninsula	✘	Transport and financial barriers to accessing care in rural areas
✘	Specialist care provided at government CBR centres was insufficient, of poor quality, and lacked continuity of care	✘	Insufficient training & high turnover rate for CBR workers

What are the employment prospects for adolescents with disabilities in Malaysia?



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.

This is the common belief held by people with and without disabilities. However, it is perceived that there is no additional training or skill enhancement provided to guide adolescent with disabilities into adulthood and the work place.

Discrimination at workplace



Restrictive employment opportunities



Limited support in the workplace



Reduced salaries

As a result, employment in the corporate sector is seen to be unrealistic/unattainable.

11%  are not comfortable working with a person with disabilities



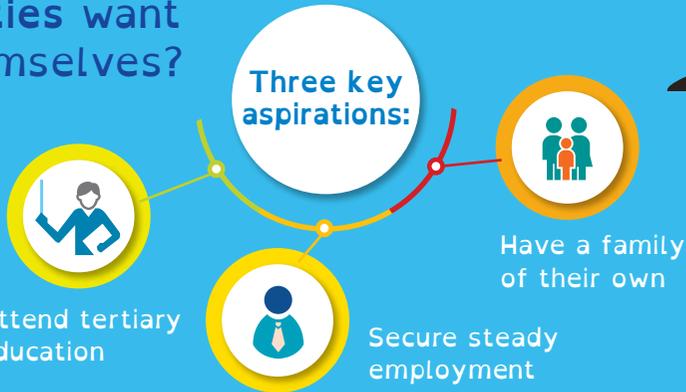
Conversely, a group of adults with Down Syndrome who participated in the study in Selangor, were not worried about employment and all appeared confident that they would be employed by 'McDonalds', at a 'Petronas Oil Pump' or in 'a big office'.

The jobs are really limited for OKU [Orang Kurang/Kelainan Upaya]. 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.



A visually impaired participant in Selangor

What do children with disabilities want for themselves?



Top 6 areas of improvement for children with disabilities, according to respondents

1	More financial assistance	19%
2	Better educational opportunities	18%
3	Community-based rehabilitation (CBR)	14%
4	Better medical services	13%
5	Support groups	12%
6	Better vocational training	11%

Top 4 barriers faced by children with disabilities according to the respondents



1) Registration of children with disabilities

- The process of applying for and obtaining an OKU card is perceived to be complicated and time-consuming.

2) Financial barriers



- Expenses of a child with disabilities include transport to services, medical bills, nutritional supplements, diapers, and assistive devices.
- Full-time carers receive limited disability allowances, hence the financial strain becomes greater.
- This may affect school or rehabilitation services attendance for the child with disabilities and his/her siblings.



3) Transport barriers

- Rural areas have greater transportation problem due to distance to services.
- Caregivers with their own vehicles face higher costs.
- The implementation and regulation of disability parking was a concern.
- Discrimination from bus and taxi drivers makes public transport a challenge.

4) Physical/infrastructural barriers



- Infrastructural barriers such as no elevators, stair ramps, or modified bathrooms etc. are the main obstacle to inclusion.
- The lack of planning makes public places inaccessible to children with disabilities.

How can we make society more inclusive?

How to address the stigma, discrimination and vulnerability faced by the children of disabilities today? By changing the attitudes towards them...

Here are the main **recommendations** made by the respondents and stakeholders:



Children and adolescents without disabilities

Child-centric activities to change social norms



A platform for youths to voice their ideas and opinions

Youth-centric materials and social media



Community engagement

Community-based organisation and NGO partnerships to implement and scale initiatives.

Create awareness on zero-tolerance for discrimination

Use acceptable and standardised language consistently

Increase visibility of people with disabilities by engaging high-profile ambassadors



Caregivers of children with disabilities

Caregivers education, through study groups and virtual platforms

Role models and the promotion of positive experiences



Support groups



Children and adolescents with disabilities

Peer-to-peer support forums to bring together children and youth with and without disabilities

Give greater visibility to children and adolescents with disabilities

Present ambassadors with disabilities as positive role models

Study the impact of online violence, abuse and manipulation of children and adolescents with disabilities in Malaysia

Constructive participation by children and adolescents with disabilities to plan, design and implement programmes



National level recommendations

Increase inter-agency collaboration across health, education, rehabilitation and protection

Strengthen national policies and keep with international standards

Provide inclusive education for children with disabilities

Consistent and standardised language and terminology in communication strategies

Improve healthcare for children with disabilities



Multi-lateral consultation with different stakeholders



Improve infrastructure in public buildings for people with disabilities

Private sector engagement through corporate social responsibility

Simplify and standardise the registration process





Service provision



Health workers

Training on prevention, early detection, diagnosis and intervention.

Improve on knowledge about disabilities, services and resources.



Practise a strong code of ethical conduct.



Training in counselling and psychosocial support.

Identify developmental issues as early as possible.

Offer guidance to caregivers.



Teachers in inclusive, integrated and special education informed about the benefits of inclusive education.

Highlight appropriate community-based organisations and NGOs.

All schools to be accessible to children with disabilities.

Training in counselling and psychosocial support.

Empowered to create personalised education plans for children with disabilities.

Regular refresher training.

Job and career guidance for children with disabilities.





Social welfare services

Equipped with the requisite knowledge

Stronger links to medical and education services

Well-resourced with the necessary equipment

Increase number of CBR workers

Offer home-based rehabilitative care

Standardised training and regular refresher trainings

Proper remuneration



Lisa Surihani, UNICEF Malaysia's National Ambassador, provides the voiceover for the audiobook available online. Just scan the QR code.





“In this picture I’m teaching a blind friend how to play a computer and walk with him. He is wearing glasses so that people won’t make fun of him. People make fun of people with disabilities a lot.”

– Drawing by boy without disabilities, Sarawak

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#ThisAbility