

CHILDREN WITH DISABILITIES IN MALAYSIA

Mapping the Policies, Programmes, Interventions and Stakeholders





COVER PHOTO:

Art by Nurafidah Mohamed (16), Visual disability

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We are Malaysians and nothing can differentiate us as long as we have the heart and hands to listen and express ourselves.

I live in a harmonious world in which I have many friends from different cultures. Love the ones who are called OKU.

Do not put them in a separate place, but hold their hands and guide them every step of the way.

God made us different in many ways and we are all special.

Lovira Jospely (14)
Hearing disability

* OKU—Orang Kurang Upaya (Person with Disabilities)



FOREWORD

A child is not disabled because they cannot walk, see or hear. They are disabled by a society that excludes them. It is a tragic irony that children who so often stand out *because* of their disability – who are so often *targeted* because of their disability – subject to teasing, to stigma, to humiliation, to violence – are too often INVISIBLE when it comes to policies, services and compassion.

No one group has its rights compromised more consistently or more cruelly than children with disabilities. When they're not objects of pity, they're frequently targets of abuse. Globally, they are up to three to four times more likely to be subjected to violence than other children. Children with disabilities often experience multiple challenges, including difficulty in accessing education and other basic services and an increased risk of abuse and exploitation. Left off birth registers and hidden behind closed doors, shut away in institutions and stigmatised, millions of children with disabilities are, too often, over-looked and under-estimated. They're not only excluded, they're forgotten.

This report provides vital information to enable all stakeholders to further build on the leadership Malaysia has already shown to fulfil the rights of children with disabilities. Malaysia already has important policy and legal frameworks for people with disabilities; the 2007 National Policy For Persons With Disabilities, the National Plan of Action for Persons With Disabilities and the 2008 Persons with Disabilities Act. And in 2010, Malaysia was among the first to sign and ratify the Convention on the Rights of Persons with Disabilities.

What is required now is shifting this commitment into relevant action and to address the challenges and gaps pointed out in this report. Together, we need to discuss and address the gaps in implementation of policies and legislation; gaps in access to health, education and other essential services for children with disabilities; public awareness and education on issues of disability are still required; and so is a strong social support system and referral mechanisms. There is also a need for the collection of adequate statistical data on children with disabilities. And we need to make sure that data is used in the development of policies and programmes for these children; and as a guide for allocating resources and support to children and their families.

All of us have a role to play in removing barriers to inclusion and participation as well as providing a loving and nurturing environment to better support children with disabilities and their families.

By identifying the stakeholders, available services, gaps and challenges and providing recommendations, I hope this report will help push the agenda of children with disabilities forward in Malaysia, and serve to recognise the potential they have to live their lives to the fullest.

Nivina Belmonte

UNICEF Representative to Malaysia

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ACRONYMS

ADHD Attention Deficit Hyperactivity Disorder

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, Malaysia

LINUS Literacy and Numeracy Screening

MOE Ministry of Education, Malaysia

MOH Ministry of Health, Malaysia

MWFCD Ministry of Women, Family and Community Development, Malaysia

NECIC National Early Childhood Intervention Council

OKU Orang Kurang Upaya

(Person with Disabilities)

PEMANDU Performance Management and Delivery Unit, Prime Minister's Office Malaysia

PWD Person with Disabilities

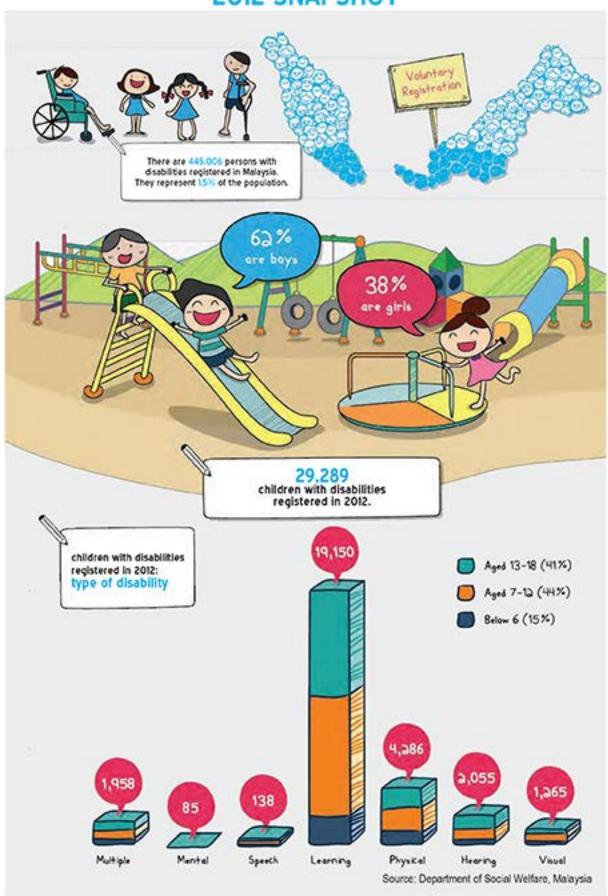
SCAN Suspected Child Abuse and Neglect

SEIP Special Education Integration Programme

SMOKU Sistem Maklumat Orang Kurang Upaya

(National Information Registration System for Persons with Disabilities)

CHILDREN WITH DISABILITIES IN MALAYSIA 2012 SNAPSHOT



Friends having fun under the sun without feeling shy about being different.

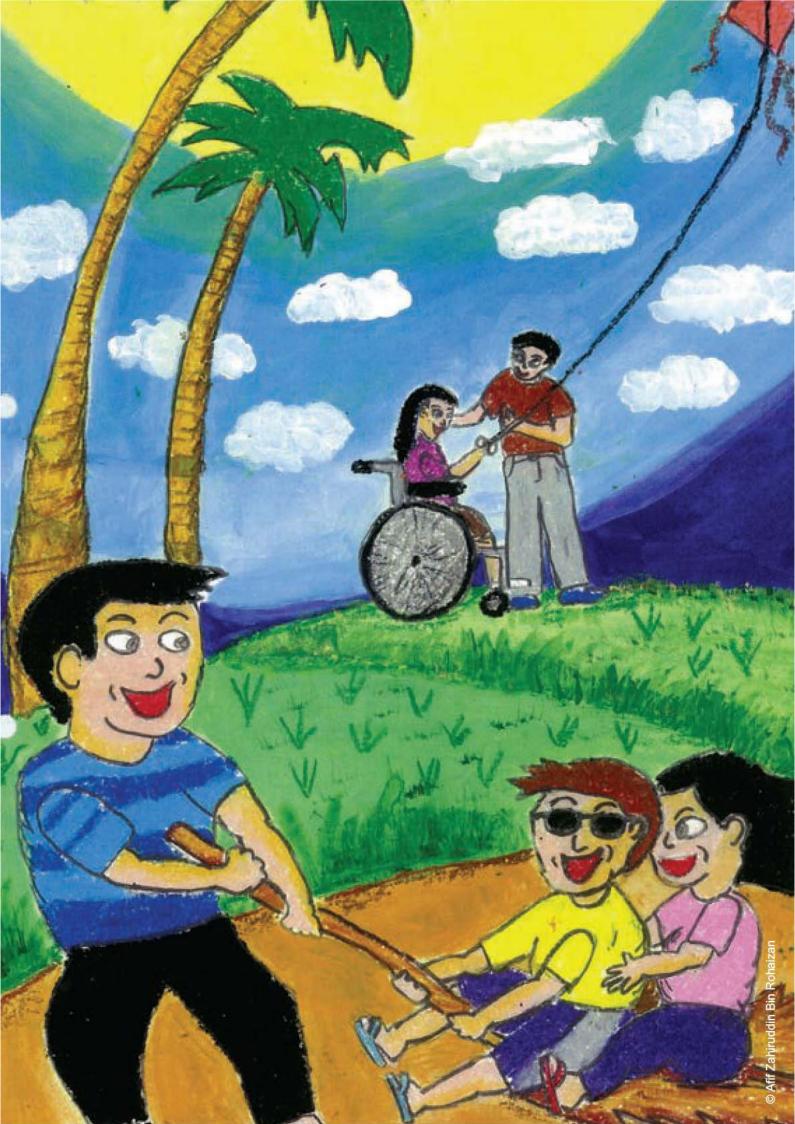
Friends experience new things with a happy face and heart because others support them, and encourage them.

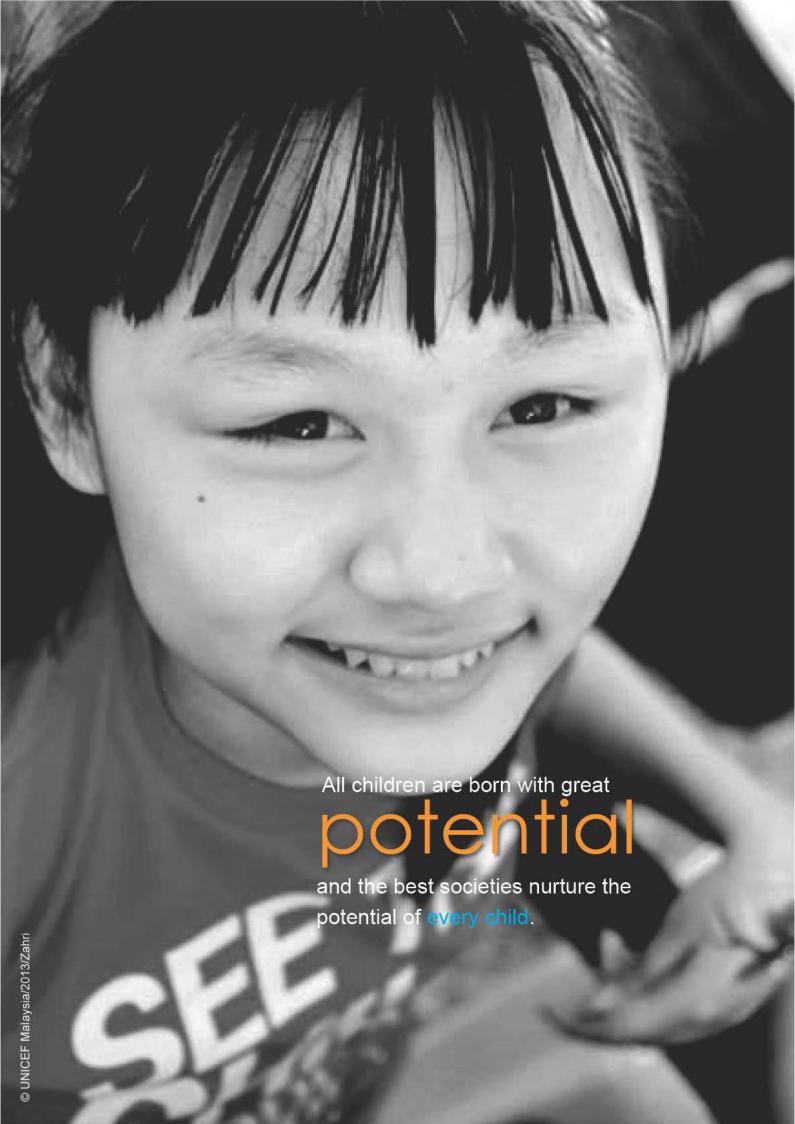
Even when we are different,
friends still treat us as a friend.
With friends, we can run as fast as we can
without being told we can't see.

Friends help each other, friends understand one another.
That's fun under the sun.

Afif Zahiruddin Bin Rohaizan (14)

Development disability





INTRODUCTION

alaysia ratified the Convention on the Rights of the Child (CRC) in 1995 with several reservations, of which five remain. To uphold its obligations under the CRC, Malaysia enacted the Child Act 2001 (Child Act).

In 2008, Malaysia enacted the Persons with Disabilities (PWD) Act; and in 2010, the government ratified the Convention on the Rights of Persons with Disabilities (CRPD) with two reservations. However, Malaysia has yet to ratify the Optional Protocol to the CRPD.

There is no national Act specific to children with disabilities. The rights of children with disabilities to care, protection and development are subsumed primarily within the Child Act and the PWD Act and fall under the Constitutional umbrella of protection of fundamental liberties under the Malaysian Federal Constitution.

The key national stakeholders that provide programmes and services for the care, protection and development of children with disabilities are the Department of Social Welfare (DSW) under the Ministry of Women, Family and Community Development (MWFCD), the Ministry of Health (MOH) and the Ministry of Education (MOE).

Policies at a ministerial level are framed for persons with disabilities, including children, as a general class. Goals and strategies for the care, protection and development of children with disabilities filter down from policies for these general classes.

In preparing this report, a number of gaps in legislation, policies, participation and service delivery were identified. The interconnection, but lack of effective synergy, in the provision of healthcare, education, rehabilitation, protection and welfare services to children with disabilities was apparent.

The absence of an integrated national policy or statement of direction that cuts across service

One of the key principles and policy direction of the Incheon Strategy is "respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities".

sectors likely contributes to the barriers faced in healthcare, education, rehabilitation and protection services for children with disabilities. One of the recommendations of this report is that the formulation of policies, strategies and services in these areas should be holistic, multidisciplinary and coordinated.

In November 2012, Malaysia together with other members of the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP), adopted the Incheon Strategy to "Make the Right Real" for persons with disabilities in Asia and the Pacific. The Incheon Strategy comprises 10 goals, 27 targets and 62 indicators for improvements on the quality of life and the fulfilment of the rights of persons with disabilities, which include strategies for expanding early intervention of children with disabilities, strengthening social protection and enhancing accessibility to the physical environment, public transportation, knowledge, information and communication. One of the key principles and policy direction of the Incheon Strategy is "respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities".

Malaysia will be adapting its national policies for persons with disabilities in light of its commitments under the Incheon Strategy. It is hoped that the gaps in existing policies, programmes and service delivery that have been identified in this report will assist in the revision and improvement of policies and strategies for children with disabilities.



Methodology

Preparing this report commenced with an analysis of the international commitments and national laws and policies of Malaysia, to understand the international and national commitments and obligations of the government in relation to children with disabilities.

The government stakeholders involved and services provided were identified next. An outline of specific stakeholder roles, functions, obligations and services was developed.

This was followed by the identification of the issues and practical problems that have arisen in the delivery of services by these stakeholders.

Once the issues and possible gaps were identi-fied, government stakeholders were approached to verify the scope of their functions and services, for clarification on issues and gaps; and to obtain further data and information.

Various non-government organisations and groups concerned with children with disabilities were contacted to obtain the perspectives of advocates for the rights of children with disabilities. These included organisations involved in the teaching, training and rehabilitation of children with disabilities.

Interviews were conducted with the officers in the DSW, MOH, MOE, the National Human Rights Commission (SUHAKAM), four children's disability rights NGOs, one concerned individual, one private practitioner and one public hospital-based service.

Documents, reports and data gathered from the interviewees, the websites of the MWFCD, MOH, MOE, various national bodies, international bodies and non-government organisations were also analysed.

Activities

The following activities were undertaken to meet the objectives of this report:

- Identify and analyse existing data on children with disabilities from a spectrum of sources including from the DSW, MOH, MOE, population census, SUHAKAM and NGOs;
- Review existing policies and laws to determine the extent to which they address the needs and rights of children with disabilities and conduct a qualitative assessment of key obstacles for effective delivery of services for children with disabilities;
- Identify existing coordination and networking and constraints to effective coordination between different government ministries and departments and between government and NGOs in respect of children with disabilities;
- Examine strengths and weaknesses of existing systems for the care and support of children with disabilities;
- Map the stakeholders working on the issue of children with disabilities;
- Provide recommendations on the way forward.

Constraints

The first stage of the preparation of this report occurred from 12 November 2012 to 11 January 2013.

The second stage which was to review and revise the report taking into consideration the original terms of reference and comments provided on the first draft, occurred from 8 May to 31 May 2013.

INTRODUCTION

There were a number of limitations and constraints faced in conducting the mapping study:

- It was not possible to carry out field visits to centres where the stakeholders provide their services, such as the MOH health centres, MOE special education schools and classes or the DSW's community based rehabilitation centres.
- While ministry officers were largely cooperative in providing data and documents, in some instances, relevant documents were not readily available.
- Some difficulties were also encountered in setting up interviews with a key ministerial department, despite written requests.
- 4. While the principal and secondary govern-ment bodies involved in formulating policies and delivering services to children with disabilities have been identified in this report, an exhaustive mapping of all government agencies involved could not be done within the parameters of the assignment.

I have a dream.
My dream is as high as a mountain.
There is no dream that we cannot achieve as long as we have the passion for it.
Be a dreamer and get success out of your dreams.

Renaldy Raphael (16) Hearing disability Life is like a picture.

I need to paint it colourful.

There are flowers, butterflies, bubbles and birds in my world.

They represent the peacefulness
I receive as I live in this world.

The angel in the middle represents the people around me who are friendly and full of love.

I also love music because it brings peace and happiness.

What a wonderful and colourful world.

Stephanie Tam Zhu Shin (14)

Development disability





2

DEFINING CHILDREN WITH DISABILITIES

he national legal and policy framework in Malaysia does not have one definitive classification of disabilities.

Malaysia's Persons with Disabilities (PWD) Act states that persons with disabilities "include those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society".

The broad terms and the word "include" in the definition suggest that the categorisation of persons with disabilities is open to interpretations.

The Ministry of Women, Family and Community Development (MWFCD)² however has specific categories of disabilities for the purpose of registering persons with disabilities.³

CATEGORIES OF DISABILITIES ELIGIBLE FOR REGISTRATION AS PERSONS WITH DISABILITIES 4

HEARING

Hearing Disabled means unable to hear clearly in both ears without the use of a hearing aid or unable to hear at all even with the use of a hearing aid. Hearing disabilities can be divided into four levels, namely:-

- Minimum 15 <30 decibels (a child)
- 20 <30 decibels (adults)
- Moderate 30 <60 decibels
- Severe 60 <90decibels
- Profound ≥ 90decibels

VISUAL

Visually Disabled means blind in both eyes OR blind in one eye OR limited vision in both eyes OR any other permanent visual impairment. Visual disabilities can be divided into:-

- Low vision means vision that is worse than 6/18 but equal to or better than 3/60 even with the use of visual aids or a visual field that is less than 20 degrees from fixation.
- · Blindness means vision of less than 3/60 or a visual field of less than 10 degrees from fixation.
- ** Less than 3/60 means counting Fingers (CF), Hand Movement (HM), Perception of Light (PL) and No-Light Perception (NPL).

Other permanent visual disturbances (must be confirmed by an Ophthalmologist)

SPEECH

Speech Disability means an inability to speak that impairs proper communication and cannot be understood by those who interact with the person. The condition is permanent or incurable.

With regard to children, it must be based on an assessment at age five years and above.

In case of doubt, an Otorhinolaryngology Expert is to be consulted.



PHYSICAL

Physical Disability means the permanent inability of parts of the body whether caused by loss OR absence OR the inability of any part of the body that can affect their functions in fully carrying out basic activities. Basic activities refer to self-care, movement and changing the position of the body.

The condition can occur as a result of injury (trauma) or disease in either the nervous, cardiovascular, respiratory, haematology, immunology, urology, hepatobiliary, musculoskeletal, gynaecology and others systems that cause malfunctions. Examples of causes of malfunctions:

- · Limb defects (congenital / acquired), including loss of thumb
- Spinal Cord Injury
- Stroke
- Traumatic Brain Injury
- Dwarfism (achondroplasia) namely ≤ 142cm for men and ≤ 138cm for women
- Cerebral Palsy

Note:

Individuals who suffer from impairment without jeopardising their functionality, for example the loss of a finger, additional fingers (polydactyly) and without a earlobe or without a fully-formed earlobe cannot be considered for registration purposes.

LEARNING

Learning Difficulties mean intellectual capabilities that do not conform with biological age. Those that fall within this category are Late Global Development, Down Syndrome and intellectual disabilities.

This category also includes conditions that affect the learning ability of an individual such as autism (autistic spectrum disorder), Attention Deficit Hyperactivity Disorder (ADHD) and specific learning difficulties such as (dyslexia, dyscalculia and dysgraphia).

MENTA

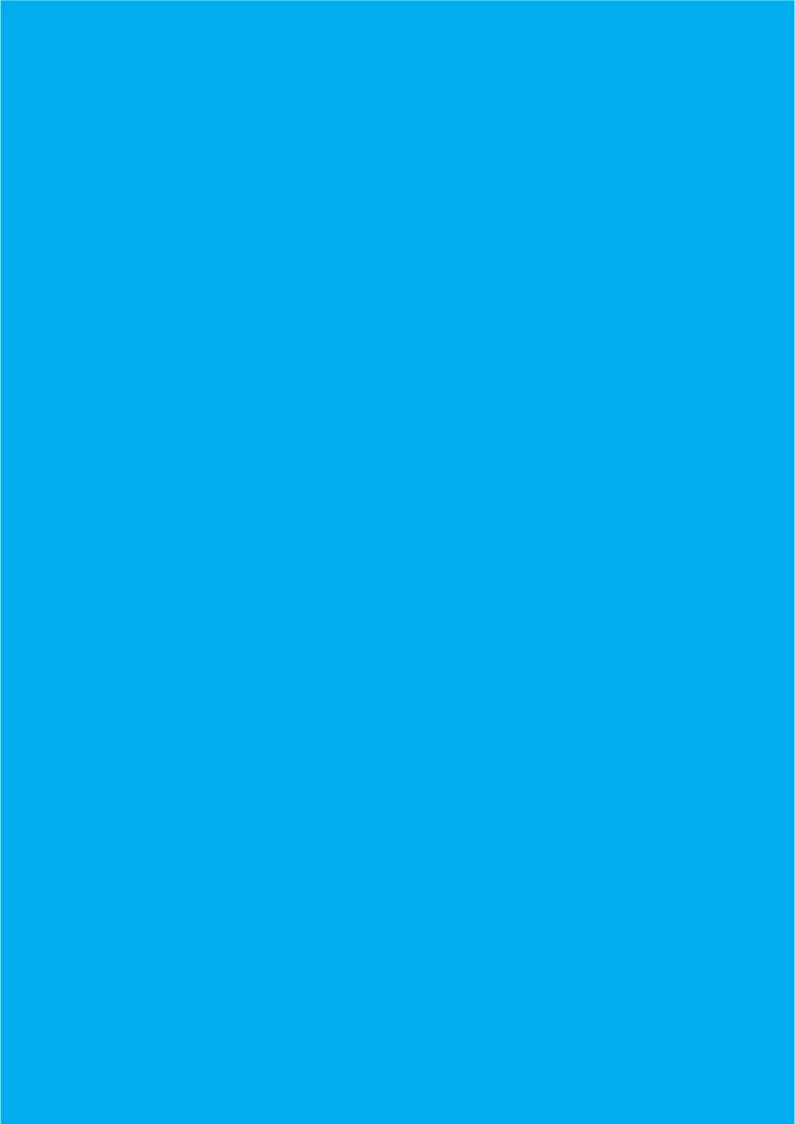
Mental Disability refers to a state of severe mental illness that causes an inability to function in person whether partly or fully in matters related to him/ herself or his / her relationships within the community. Among the types of mental illness are serious and chronic Organic Mental Disorder, Schizophrenia, Paranoia, Mood Disorder (depression, bipolar) and other Psychotic Disorders such as Schizoaffective Disorder and Persistent Delusional Disorders.

Note:

- · Clients must have undergone psychiatric treatment for at least two years.
- A psychiatrist will determine if the levels of social, cognitive and behavioural control functions of the patient are significantly or severely affected before (s)he is considered for the purpose of registration as a person with disabilities

VARIOUS

Multiple Disabilities means having more than one type of disability and in general is not appropriate to be classified in category 1 to 6.



We are all born with equal rights.

Regardless of our disabilities,

we still have the right
to be loved, to start our own family,

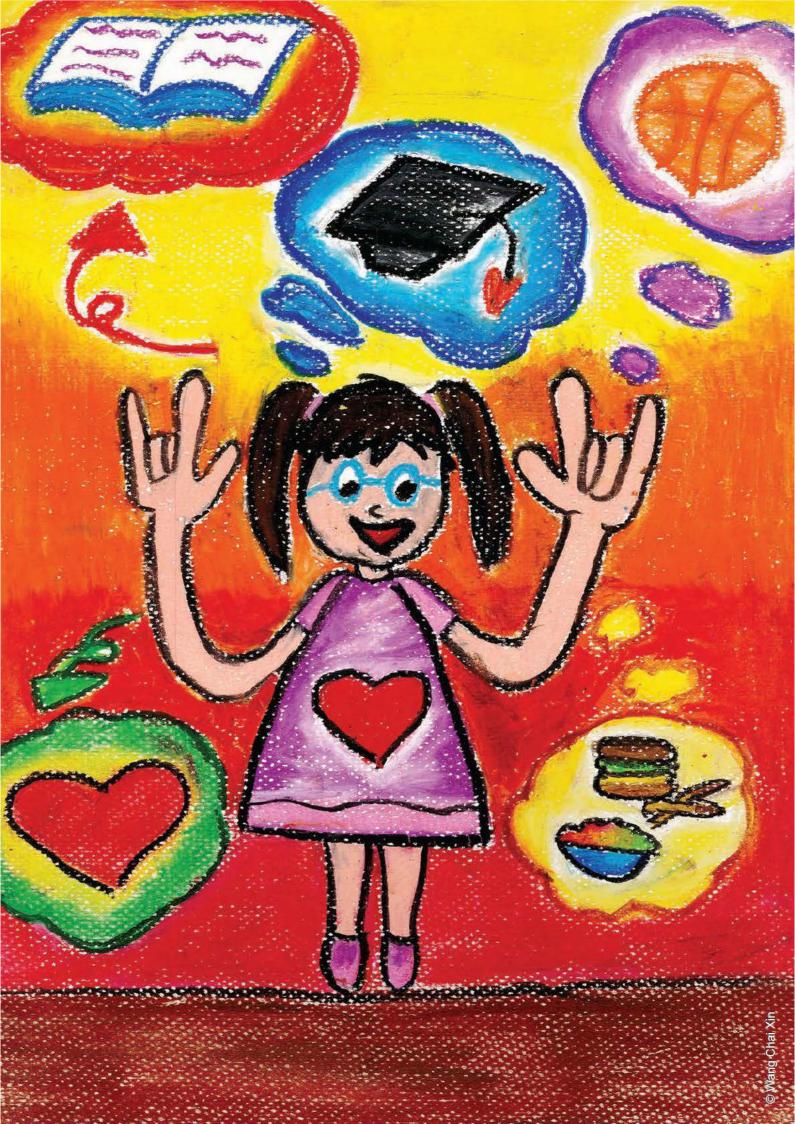
to have access to good education and live a normal healthy lifestyle.

I am proud to be a deaf Malaysian because I enjoy all the privileges above.

I am thankful and hope that someday
I can represent Malaysia in an
international basketball tournament
to show my gratitude
and make my country proud.

Wang Chai Xin (15)

Hearing disability





LAWS AND POLICIES

uman rights have provided both the inspiration and the foundation for the movement towards inclusion for children with disabilities.⁵

Inclusion requires the recognition of all children as full members of society and the respect of all of their rights, regardless of age, gender, ethnicity, language, poverty or impairment. Inclusion involves the removal of barriers that might prevent the enjoyment of these rights, and requires the creation of appropriate supportive and protective environments.

Over four decades, the United Nations (UN) has made a strong commitment to the human rights of persons with disabilities.

Convention on the Rights of the Child

Adopted by the UN General Assembly in November 1989, the CRC recognises the human rights of all children; and identifies four general principles that provide the foundation for the realisation of all other rights:

- non-discrimination
- the best interests of the child
- survival and development
- · respect for the views of the child

The CRC provides a binding implementation framework with implications for law, policy and practice with respect to children with disabilities. Article 23 of the CRC is specifically dedicated to children with disabilities. It requires States Parties to recognise the rights of the child with disability to special care; and to render assistance free of charge to the child whenever possible.

The CRC also upholds the rights of a child with disability to receive education, training, health care and rehabilitation services, recreation opportunities and preparation for employment in a manner conducive to the child achieving the fullest possible social integration and individual development, including her or his cultural and spiritual development.

In 2006, the Committee on the Rights of the Child issued a General Comment on children with disabilities "to provide guidance and assistance to States Parties in their efforts to implement the rights of children with disabilities, in a comprehensive manner which covers all the provisions of the CRC".

Convention on the Rights of Persons with Disabilities

Along with the CRC, the Convention on the Rights of Persons with Disabilities (CRPD), adopted by the UN General Assembly in December 2006, provides a new impetus to promote the human rights of all children with disabilities.

The CRPD is a human rights instrument with an explicit social development dimension. It adopts a broad categorisation of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms.

In recognition of children's specific situation, several articles in the CRPD make explicit reference to their right:

- The preamble recognises that children with disabilities have full enjoyment of all human rights on an equal basis with others.
- The general principles include respect for the evolving capacities of the child and children's right to preserve their identity.
- The general obligation requires that children with disabilities must be consulted when States Parties are developing and implementing legislation and policies that relate to them.
- Other articles address the rights of children with disabilities, including their right to participation, information, education, family life and freedom from violence.



A. INTERNATIONAL COMMITMENTS

A.1 Convention on the Rights of the Child

Malaysia ratified the CRC in 1995, originally with 12 reservations. The government has progressively lifted most of these reservations. Five reservations however have been maintained:

Article 2

A child has a right to non-discrimination regardless of race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status.

Article 7

A child has a right to a name and nationality.

Article 14

A child has a right to freedom of thought, conscience and religion.

Article 28 (1) (a)

A child has a right to free and compulsory primary level education.

Article 37

A child has a right to freedom from torture or cruel, inhuman or degrading treatment.

The reason provided for Malaysia's reservations to these CRC Articles is that they do "not conform with the country's Constitution, national laws and national policies of the Government of Malaysia, including the Syariah law".

Two of Malaysia's reservations to the CRC touch directly on the situation of children with disabilities:

- Article 2 of the CRC protects (amongst others) non-discrimination of the child by reason of any disability. The issue of discrimination against children with disabilities remains a core concern.
- With regard to Article 28(1)(a) of the CRC, it is noted that primary education has been compulsory in Malaysia since 2003.⁸

TIMELINE
MALAYSIA'S
COMMITMENTS
FOR CHILDREN
WITH DISABILITIES,
AGAINST AN
INTERNATIONAL
BACKDROP

1978 1980 1990

CRC

1979 1981 1989

Declaration International UN General Assembly Rights Disabled adopts the

Persons

of Disabled

Persons

1983-1992 UN International Decade of

Disabled Persons

UN Standard Studes on the Equalisation of Opportunities for Persons with Students St

1994 Salamanca Statement and the Framework for Action on Special Needs

Malaysia

to the CRC

accedes Education

National Eye Survey 1996

Act

Education

(Special

Education)

Regulations

1993-2002

Asian and Pacific Decade of Disabled Persons

LAWS AND POLICIES

A.2 Convention on the Rights of Persons with Disabilities

Malaysia ratified the CRPD in 2010. However the ratification was with reservations to:⁹

Article 15

Freedom from torture or cruel, inhuman or degrading treatment or punishment

Article 18

The right to liberty of movement and nationality. This Article also upholds a child with disability's right to be registered immediately after birth and the right to know and be cared for their parents.

Malaysia has yet to sign the Optional Protocol to the CRPD. ¹⁰ The Optional Protocol introduces two procedures to strengthen the implementation of the CRPD: an individual communications procedure and an inquiry procedure. ¹¹

In short, it sets up a complaints and redress mechanism for those aggrieved by a violation of the CRPD by parties to the Convention.

The non-acceptance of the Optional Protocol by the Malaysian government is connected to the larger concern that Malaysia at present provides no legal mechanism for redress, and in fact expressly prohibits legal action against the government, for violating the rights of persons with disabilities. 12

The reason provided for Malaysia's reservations to these CRC Articles is that they do "not conform with the country's Constitution, national laws and national policies of the Government of Malaysia, including the Syariah law".

National Plan of Action for Persons with Disabilities 2008-2012 National National Policy for Persons National Malaysia Ear & SMOKU M-CHAT Education Persons with Child accedes Hearing Child Act (Special Education) with Disabilities Protection to the Online (early Disorder Survey Disabilities Policy CRPD System detection) Regulations Act 2010 2000 2005 2015 2002 2003 2006 2012 2013 World **UN General** Biwako Incheon **UNICEF State** Education Millennium Assembly Strategy of the World's Forum — Framework adopts adopted Children Statement the CRPD of Action 2002 2003-2012 2013-2022 2nd Asian and Pacific Decade 3rd Asian and Pacific Decade A World Fit for Children' of Disabled Persons of Disabled Persons



B. NATIONAL LEGAL AND POLICY FRAMEWORK

B.1 Federal Constitution of Malaysia (Federal Constitution)

Malaysia is a federation with a constitutional monarchy. The Federal Constitution is the supreme law of the Federation.¹³

Article 4 of the Federal Constitution stipulates that any law passed by Parliament that is inconsistent with the Federal Constitution will be void to the extent of that inconsistency.¹⁴

Articles 8 and 12 of the Federal Constitution are particularly relevant to persons with disabilities in Malaysia.

- Article 8(2) of the Federal Constitution, which prohibits discrimination on various grounds, does not prohibit discrimination against those with disabilities.¹⁵
- Article 12(1) that deals with the right to access to education, does not specifically prevent discrimination against children with disabilities with regard to admission into educational institutions and the provision of government financial aid.¹⁶

Because of these lacunae in Articles 8(2) and 12 (1), laws that discriminate against persons with disabilities can still be passed and enforced in Malaysia.

The failure to amend Articles 8(2) and 12(1) of the Federal Constitution to extend the prohibition against discrimination to persons with disabilities is of concern for non-government organisations; and there have been calls for an amendment of those constitutional provisions to protect discrimination based on disabilities.¹⁷

Non-discrimination is one of the defining principles of both the CRC and the CRPD.

In light of this, the failure to enshrine the prohibition against non-discrimination of persons with disabilities in the Federal Constitution facilitates the perpetuation of discrimination against them.

An amendment to Articles 8(2) and 12(1) of the Federal Constitution to include such a prohibition would likely allow Malaysia to lift its reservations to Article 2 of the CRC and could act as a further tool of empowerment to advocate, protect and enforce the rights of children with disabilities in Malaysia.

B.2 Child Act 2001 (Child Act)

In 2001, Malaysia enacted the Child Act. In its initial report to the Committee on the Rights of the Child in 2006, ¹⁸ Malaysia cites the four core principles of the CRC as the basis for the provisions of the Child Act, namely:

- 1. non-discrimination
- 2. best interest of the child
- 3. the right to life, survival and development,
- 4. respect for the views of the child.

Despite basing the Child Act on the four core principles of the CRC which includes non-discrimination against the child, Malaysia's reservation regarding Article 2 of the CRC that concerns non-discrimination ¹⁹ remains in place and the provisions in the Federal Constitution that protect against discrimination have not been extended to cover persons with disabilities.

The definition of "child" in the Child Act²⁰ is a "person under the age of 18 years"

Consequently, all the rights and protections available to children under the Child Act extend to children with disabilities.

3

LAWS AND POLICIES

B.3 Persons with Disabilities (PWD) Act 2008

The PWD Act was passed in 2008.

The Act defines "persons with disabilities" as including "those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society".

The PWD Act also establishes a national body called the National Council for Persons with Disabilities (National Council) with obligations under the Act to oversee, co-ordinate and monitor the implementation of national policies and plans of action relating to persons with disabilities.²¹ The functions and roles of the National Council are addressed in Chapter 5.

Advocates for the rights of persons with disabilities in Malaysia have pointed to a number of significant omissions in the PWD Act, including: ²²

- The lack of any or any comprehensive monitoring,²³ penalties or remedies mechanism against parties who violate the PWD Act or the rights of persons with disabilities;
- The lack of a redress mechanism against the government for violating the PWD Act or the rights of persons with disabilities;
- The lack of specific anti-discrimination and anti-harassment provisions.

The significant omissions in the PWD Act have led it to be labelled a "toothless tiger". ²⁴

There have been calls for the PWD Act to be amended to address its shortcomings, ²⁵ including from the Human Rights Commission of Malaysia (SUHAKAM) which opined that a more comprehensive Act is required to reflect the CRPD and cover all the rights of persons with disabilities. ²⁶

The Persons with Disabilities Act protects the rights of persons with disabilities and imposes obligations on the government, the private sector and non-government organisations in relation to:²⁹

- access to public facilities, amenities, services and buildings
- · access to public transport facilities
- access to education
- access to employment
- access to information, communication and technology
- · access to cultural life
- access to recreation, leisure and sport
- · habilitation and rehabilitation services
- access to healthcare, health personnel and protection against further occurrence of disabilities
- lifelong protection for persons with severe disabilities
- access to assistance in situations of risk and humanitarian emergencies.

Rights advocates have repeatedly asserted that a paradigm shift is needed so that laws relating to persons with disabilities are rights-based and not drafted from a charity or social welfare perspective. ²⁷

It is understood that the government is presently considering including enforcement mechanisms within the PWD Act, although no information could be obtained on the exact nature and scope of the proposed mechanisms.²⁸



B.4 Education Act and Regulations

The legal framework for education insofar as children with disabilities are concerned is the Education Act 1996 (Education Act) and the Education (Special Education) Regulations 2013:

- Section 40 of the Education Act requires the Minister for Education to provide special education in special schools or designated primary and secondary schools.³⁰
- The Special Education Regulations which is applicable to a government school or a government aided school which implements Special Education.³¹

B.5 National Policy Framework for Children with Disabilities

There is no national policy specifically for children with disabilities.

The policies, strategies and programmes for children with disabilities are subsumed within:

- national policies and action plans for persons with disabilities; and
- national policies and action plans for children.

As such, the policies behind the services and programmes for the health, rehabilitation, education, protection and advancement of children with disabilities are developed from two distinct focal points: the child with disabilities as a "person with disabilities" and the child with disabilities as a "child".

B.6 National Policy for Persons with Disabilities 2007

The National Policy for Persons with Disabilities sets out the national strategies for the implementation of the PWD Act; and includes strategies for persons with disabilities relating to:

- Advocacy;
- Accessibility to facilities, transport services and information and communications technology;
- Health services;
- Rehabilitation programmes;
- Access to education;
- Employment opportunities;
- Personal safety and social protection;
- Capacity Development;
- Participation of society in programmes for persons with disabilities;
- Housing; and
- Development, advancement and empowerment of children with disabilities.

However, critics say that it lacks full commitment from the main stakeholders. In meetings to discuss the implementation of the policy, no timelines were set.

Also, the outcomes of the policy were stated in large sweeping statements and objectives were not operationalised. There was no clear idea of who, or which departments, would be responsible for each of the outcomes.³²

B.7 National Plans of Action for Persons With Disabilities

The strategies in the National Policy for Persons With Disabilities are to be executed through National Plans of Action.

The first National Plan of Action for persons with disabilities was in force from 2008 to 2012. There has not been a review or evaluation of progress of the first National Plan but the Department of Social Welfare (DSW) is presently conducting a study on the policies, implementation and outcome of the past and current strategies and programmes for persons with disabilities.³³

LAWS AND POLICIES

With the expiry of the National Plan of Action (2008 – 2012), a new 10-year action plan is being created.

The government intends to seek input from local and foreign experts and organisations and to take into consideration the terms of the Incheon Strategy in the formulation of the new action plan.³⁴

The Incheon Strategy, developed by the United Nations Economic and Social Commission of Asia and the Pacific (UNESCAP), is the first set of regionally agreed disability-inclusive development goals and was developed after consultations with governments of State parties in the region and civil society stakeholders.

The Incheon Strategy builds on the CRPD, the Biwako Millennium Framework for Action and the Biwako Plus Five to create an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific.³⁵ It comprises 10 goals, 27 targets and 62 indicators.³⁶

The Malaysian government, as one of the State parties within UNESCAP, has agreed to adopt and commit to the implementation of the Incheon Strategy by promoting action to reach the Incheon Strategy goals and targets by 2020.³⁷

B.8 National Policy for Children and Action Plan

The National Policy for Children and Action Plan set out strategies, programmes and targets for (amongst others) survival, protection, development, participation and advocacy with regard to children.³⁸

In the policy and plan of action, there is explicit reference to children with disabilities in relation to policies for development (education, early detection and intervention and rehabilitation programmes) and advocacy (raising awareness on equality and discrimination issues).

B.9 National Child Protection Policy and Action Plan

The National Child Protection Policy and Action Plan 2009 contain strategies for child protection and these include advocacy, prevention, support services and research and development.

This policy is discussed further in Section F of Chapter 6.

Deaf people
like me can
also live in
the community,
serving the
country like
any other
individual.

Jyvalleysca Jolling (15) Hearing disability The dark colours in the background are the angry faces, the harsh tones, the rolling eyes, the pointing fingers, mocking and the prejudice that I face.

However, the time to come when into the kaleidoscope of beautiful bright colours that would eventually overcome the dark colours.

My mother's love, my daddy's gentle teasing,
my friends who come to my house
to play with me, playing computer games,
eating chocolate cake and ice (yummy!)
are parts of the bright beautiful colours of my life.

Chan Kin Kok (15)
Autism





4

STATISTICAL DATA

Society cannot be equitable unless all children are included. To be included, a child must first be visible; sound data collection and analysis are therefore essential. This should include enhanced statistical research, disaggregation of facts and improved methodology.

The State of the World's Children 2013: Children with Disabilities

A. SOURCES AND MECHANISMS FOR DATA COLLATION ON CHILDREN WITH DISABILITIES IN MALAYSIA

alaysia lacks a comprehensive and structured system of data collection and compilation for children with disabilities. As a result, reliable statistics on the actual number of children with disabilities in the country is not available.³⁹

A lack of reliable and comprehensive data results in a gross underestimate of the total population with disabilities, 40 and affects the ability of State entities to develop policies targeting children with disabilities. 41 It also contributes to the large number of children with disabilities who remain undetected. 42

Over the years, there have been calls from both international and local groups for the government to establish an integrated data collection system. 43

There are a number of reasons for the difficulties in collecting comprehensive statistical data.

The primary database, which is maintained by the Department of Social Welfare (DSW), is compiled from the data obtained from the registration system for persons with disabilities established under the Persons with Disabilities (PWD) Act. 44

The registration system in Malaysia is voluntary, Low registration numbers have been attributed to a fear that registration as a 'person with disabilities' might cause a child to be stigmatised, ⁴⁵ or might pre-determine the child's enrolment into special needs education in the national school system; instead of being assessed as to whether he / she is able to cope under the mainstream schooling system. ⁴⁶

Further, the initial detection of disabilities is not confined to or coordinated by a single government agency but by several. Therefore, there is no system in place to ensure that a child with disabilities will come into contact with the principal record-keeping entity, which is the DSW, let alone that he or she will submit to the voluntary registration process.

Presently, the DSW, Ministry of Health (MOH) and Ministry of Education (MOE) maintain separate databases on children with disabilities.

Their respective data however has not been collated into a single source.



B. STATISTICAL DATA — DEPARTMENT OF SOCIAL WELFARE

By the end of 2012, the DSW national registration system had 445,006 registered persons with disabilities, 85,803 of which were new registrations in 2012.

The total number of registered persons with disabilities as at 2012 is not disaggregated by age since statistics prior to 2011 did not capture this information. As such, it is not possible to tell how many of the 445,006 persons with disabilities are children.

The 445,006 registered persons with disabilities as of end 2012 represent 1.5 per cent of the country's population of approximately 29.3 million in that year. 47

This is lower than the average percentage of persons with disabilities in general (estimated to be around 10 per cent of the total population).48



29,336,800 (2012)

It is also lower than the estimated average percentage of children with disabilities in a community (estimated to be around three per cent of the population).49

TABLE 1: REGISTRATIONS OF PERSONS WITH DISABILITIES, 2011-2012 50

	REGISTRATIONS		
DISABILITY	2011—TOTAL	2012—TOTAL	2012—NEW
Visual	31,924	40,510	8,586
Hearing	43,788	53,357	9,569
Physical	123,346	148,461	25,115
Learning	134,659	165,281	30,622
Cerebral Palsy	0	0	0
Speech	725	1,734	1,009
Mental	8,927	14,990	6,063
Others*	15,834	20,673	4,839
TOTAL	359,203	445,006	85,803

^{* &}quot;Others" means those with multiple disabilities or severe disabilities

4

STATISTICAL DATA

Prevalence data on specific disabilities in Malaysia also suggests that the DSW's registration data is lower than the actual number of persons with disabilities within the overall population. For example:

a. The National Eye Survey carried out in 1996 on the prevalence of blindness and low vision in the Malaysian population estimated the prevalence of blindness to be 0.29 per cent of the total population; and the prevalence of low vision to be 2.44 per cent of the total population.⁵¹

However, the number of persons registered with visual disabilities (comprising blindness and low vision) ⁵² as at 2012 is 40,510 (Table 1); approximately only 0.14 per cent of the total population of about 29.3 million.

- b. The National Ear and Hearing Disorder Survey carried out in 2006 ⁵³ showed a prevalence of hearing loss in 21.57 per cent of the total population where:
 - 63 per cent comprise persons above 56 years of age;
 - 16.1 per cent comprise persons aged 18 to 55; and
 - 16.7 per cent comprise children aged 3 to 17.

The survey also found the prevalence of deafness (moderate and severe) to be 3.83 per cent of the total population. In contrast, the number of persons registered with hearing disabilities as at 2012 is 53,357, which is approximately only 0.19 per cent of the estimated total population of 29.3 million.

The prevalence rates from the National Eye Survey (1996) and the National Ear and Hearing Disorder Survey (2006) indicates that the statistics compiled from the national registration database on persons with disabilities is unlikely to be representative of the true population of persons with disabilities in Malaysia.

In 2010, the DSW embarked on a pilot project to develop an online registration service for persons with disabilities and to manage the data collected through an electronic information management system (which is known by the acronym 'SMOKU').

The service was initially available only at social welfare departments. In 2011, the project was officially launched; and in 2012, the information management system was modified to allow registration of persons with disabilities online from anywhere.

However, direct verification by a medical officer of the person's disabilities must still be provided before the registration is accepted and a registration card issued.

With the introduction of the electronic information management system, data on persons with disabilities who have registered from 2010 onwards may be disaggregated by age, gender and disability.⁵⁴

- In 2011, 15,263 out of 44,956 new registrations were children with disabilities.
- In 2012, 29,289 out of 85,803 new registrations were children with disabilities.
- The percentage of child registrants in 2011 and 2012 remained constant at approximately 34 per cent.



TABLE 2: NUMBER OF NEW REGISTRATIONS IN THE YEAR 2011 50

DISABILITY	VISUAL		HEARING		PHYSICAL		LEARNING	
SEX	M	F	M	F	M	F	M	F
0 - 6 months	62	47	113	102	514	356	1,380	666
Age 7 - 12	113	72	141	141	412	278	3,908	1,792
Age 13 – 18	139	95	171	115	550	279	1,715	903
TOTAL	314	214	425	358	1,476	913	7,003	3,361
ADULTS	3,556		3,181		11,869		4,186	

TABLE 3: NUMBER OF NEW REGISTRATIONS IN THE YEAR 2012 50

DISABILITY	VISUAL		HEARING		PHYSICAL		LEARNING	
	М	F	М	F	M	F	M	F
0 - 6 months	114	70	169	153	630	467	1,390	879
Age 7 - 12	306	214	411	356	884	729	5,799	3,057
Age 13 – 18	317	244	513	453	925	651	5,101	2,924
Total (a)	737	528	1,093	962	2,439	1,847	12,290	6,860
Age 19 – 21	184	133	247	228	655	320	1,343	979
Age 22 – 35	971	574	1,478	1,282	3,356	1,617	3,010	2,456
Age 36 – 45	854	492	772	685	2,864	1,305	967	878
Age 46 – 59	1,448	810	964	829	4,319	2,210	622	586
Age 60 above	1,150	705	638	391	2,716	1,467	352	279
Total (b)	4,607	2,714	4,099	3,415	13,910	6,919	6,294	5,178
Total (a + b)	5,344	3,242	5,192	4,377	16,349	8,766	18,584	12,038

4

STATISTICAL DATA

SPEECH		MEN	TAL	OTHERS		
М	F	M F		М	F	
30	14	1	0	224	163	
64	22	7	12	160	111	
26	23	44	47	178	73	
120	59	52 59		562	347	
212		5,1	53	1,536		

SUB-TOTAL								
M F								
2,324	1,348							
4,805	2,428							
2,823	1,535							
9,952	5,311							

TOTAL
3,672
7,233
4,358
15,263
29,693

TOTAL CHILDREN AND ADULTS

44,956

SPEECH		MEN	TAL	OTHERS		
M	F	М	F	М	F	
56	39	-	-	306	281	
163	94	10	6	443	315	
79	59	39	30	382	231	
298	192	49	36	1,131	827	
40	31	90	65	130	100	
102	81	1,238	654	591	414	
52	49	1,093	671	330	235	
61	51	912	724	401	277	
29	23	257	274	237	166	
284	235	3,590	2,388	1,689	1,192	
582	427	3,639	2,424	2,820	2,019	

SUB-TOTAL							
М	F						
2,665	1,889						
8,016	4,771						
7,356	4,592						
18,037	11,252						
2,689	1,856						
10,746	7,078						
6,932	4,315						
8,727	5,487						
5,379	3,305						
34,473	22,041						
52,510	33,293						

TOTAL
4,554
12,787
11,948
29,289
4,545
17,824
11,247
14,214
8,684
56,514
85,803



C. STATISTICAL DATA - MINISTRY OF HEALTH

The MOH collates some statistics on the number of children with disabilities, through registration data compiled from hospitals and health clinics.

However, the data is not conclusive as it is dependent on the child's disability being apparent or manifesting during a medical examination.

Children with mild or non-apparent disabilities are unlikely to be identified and registered as such.⁵⁵

Table 4 below is a tabulation of the number of children with special needs detected and registered in the MOH registration database from 2004 to 2012.⁵⁶

'Special needs' include hearing impairment, visual impairment, physical disabilities, cerebral palsy, late development, down syndrome, autism, ADHD, mental disabilities and other specific learning disabilities.⁵⁷

TABLE 4: REGISTRATION OF CHILDREN WITH SPECIAL NEEDS, 2004-2012

YEAR	CHILDREN REGISTERED
2004	5,710
2005	2,644
2006	2,349
2007	1,542
2008	1,446
2009	1,468
2010	1,925
2011	2,239
2012	2,766
Total	22,089

TABLE 5: 2011			IMPAIRMENT	IMPAIRMENT	VISUAL			
	Age Group (years)	MINIMAL	MODERATE	PROFOUND SEVERE		BLIND	LIMITED VISION	
	0 - < 1	1	1	(*)	(#X	6	4	
	1 – 2	1	3	10	1	1	4	
	3 – 4	1	2	7	2	1	4	
	5-6	1	8	5	2	2		
	7 – 12	1	5	5	3	1	6	
	13 – 18	1	7	4	2	1	1	
	TOTAL	6	26	31	10	12	19	

TABLE 6: 2012		IMPAIRMENT	IMPAIRMENT	VISUAL		
Age Group (years)	MINIMAL	MODERATE	SEVERE	PROFOUND	BLIND	LIMITED VISION
0-<1	=	2	1	1	4	8
1-2		6	7	129	4	10
3-4	1	4	14	2	3	1
5-6	1	2	6	(4)	5	5
7 – 12	5	6	6	(+)	3	4
13 – 18	2	3	2	(+)	7	1
TOTAL	7	23	36	3	26	29

DETECTED AND REGISTERED SPECIAL NEEDS CHILDREN *58

PHYSICAL DISABILITY	HEMIPLEGIA	CEREBRAL DIPLEGIA	QUADRIPLEGIA	LATE DEVELOPMENT	DOWN SYNDROME	AUTISM	АДНД	MENTAL DISABILITY	SPECIFIC LEARNING DIFFICULTIES	SLOW LEARNER	OTHERS**	TOTAL
44	9		16	58	220	100	5	6 6	=	16	75	434
47	22	10	29	155	78	9	4	2	5	4	79	464
13	7	9	15	44	34	37	11	7	11	5	60	270
11	8	10	6	20	18	43	24	19	32	30	36	275
20	9	5	4	16	19	26	45	71	168	213	54	671
8	1	2	8	5	6	2	3	19	19	29	7	125
143	56	36	78	298	375	117	87	118	235	281	311	2,239

PHYSICAL DISABILITY	HEMIPLEGIA	CEREBRAL DIPLEGIA	QUADRIPLEGIA	LATE DEVELOPMENT	DOWN SYNDROME	AUTISM	ADHD	MENTAL DISABILITY	SPECIFIC LEARNING DIFFICULTIES	SLOW LEARNER	OTHERS**	TOTAL
57	18	7	19	96	274			>	, ;	192	135	622
37	25	10	24	169	102	14	7	2	12	8	62	497
20	24	5	14	93	26	54	14	2	14	13	49	353
11	11	7	2	21	24	58	28	6	59	38	37	321
31	9	13	14	16	26	33	43	5 9	251	205	47	771
10	5	2	6	5	18	11	4	20	50	44	14	202
166	92	44	79	400	470	170	96	87	386	308	344	2,766

^{*}This record of detected and registered special needs cases in 2011 is stated to be of 'major cases only'.59

****Others*** means those with multiple disabilities or severe disabilities.



C. STATISTICAL DATA - MINISTRY OF EDUCATION

The MOE collects statistics on the number of enrolments in the special needs education system for children with disabilities in government-run schools.

Table 7 is a comparison of the number of children enrolled in the special education system against the total number of children enrolled for pre-school, primary and secondary level education in government-run schools. The data is extracted and tabulated from 'Quick Facts 2012 – Malaysia Educational Statistics' published by the Ministry of Education in July 2012.⁶⁰

The MOE statistics on the total number of children with disabilities who are enrolled in the government's special needs education system remains consistent at around 1 per cent of the total number of children enrolled between 2010 to 2012.

The number of children with disabilities in the special needs education system for the 2013 enrolment is estimated at approximately 54,000 which remains at 1 per cent of the total number

of students enrolled.⁶¹ These statistics do not take into account the number of children with disabilities who are registered in private education institutions.

Given that eligibility for special needs education does not extend to all children with disabilities (as defined in the PWD Act and classified by the MWFCD, it is possible that these statistics do not account for children with disabilities who do not qualify for the special needs education system but are nevertheless in the mainstream education system.

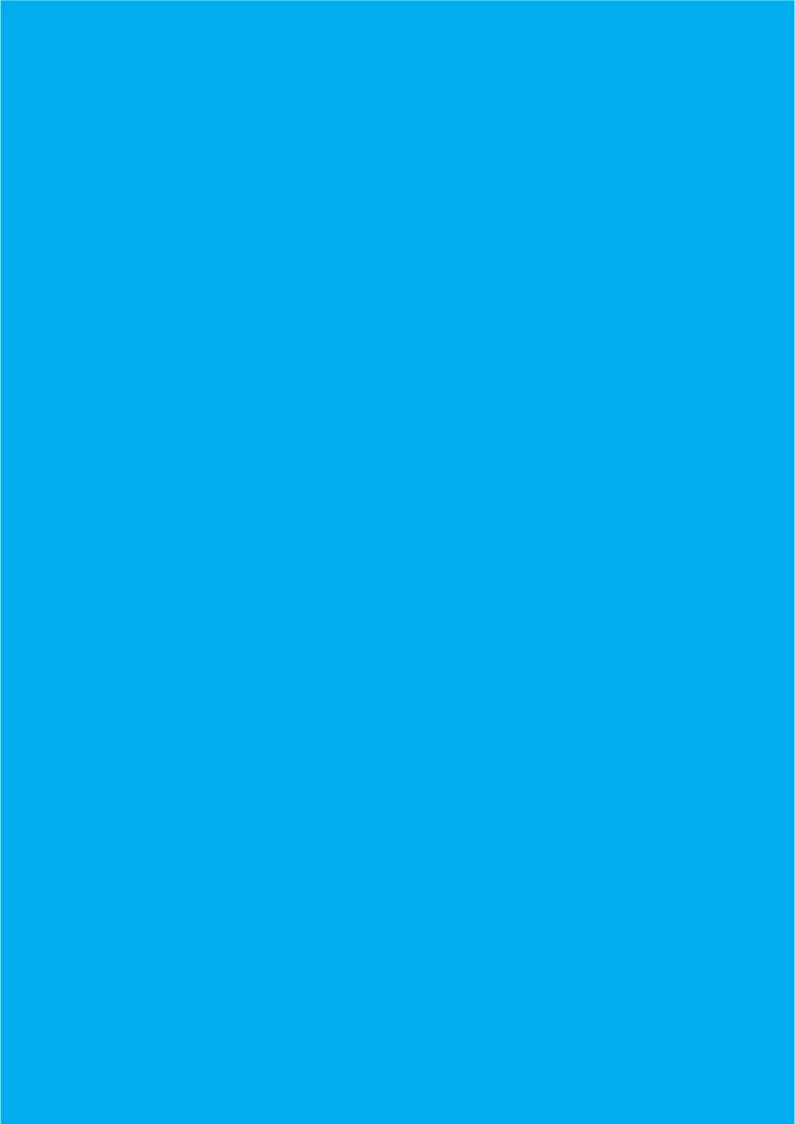
It was estimated that there were likely to be around 200,000 students with disabilities in the primary school population that have gone unidentified and another 23,000 children with disabilities or so out of school in 2010.⁶²

As such, the MOE statistics based on the enrolment of children in its special education system is not conclusive as to the number of children with disabilities in Malaysia.

TABLE 7: PERCENTAGE OF CHILDREN ENROLLED IN THE SPECIAL NEEDS EDUCATION SYSTEM, 2010-2012

	2010	2011	2012
Total enrolment in pre-school, primary and secondary level ⁶³	5,386,824	5,332,777	5,272,478
Enrolment in Special Needs Education*	48,140	49,661	50,738
Percentage of enrolment in Special Education Programmes	0.9%	0.9%	1.0%

^{*} Enrolment in the special needs education system means the total enrolment in government-run special education schools, special education integrated programme (SEIP) and inclusive education programme.



I come from a small family.

They are my father, my mother and my elder brother.

My mother works very hard to support my family.

My father is too old to do heavy work so
he helps my mum to do simple house chores.

I remembered the day when
I was admitted to the hospital for surgery.
My mother looked after me for days and nights.
Even now when I flash back to those days,
tears flow down my cheeks.

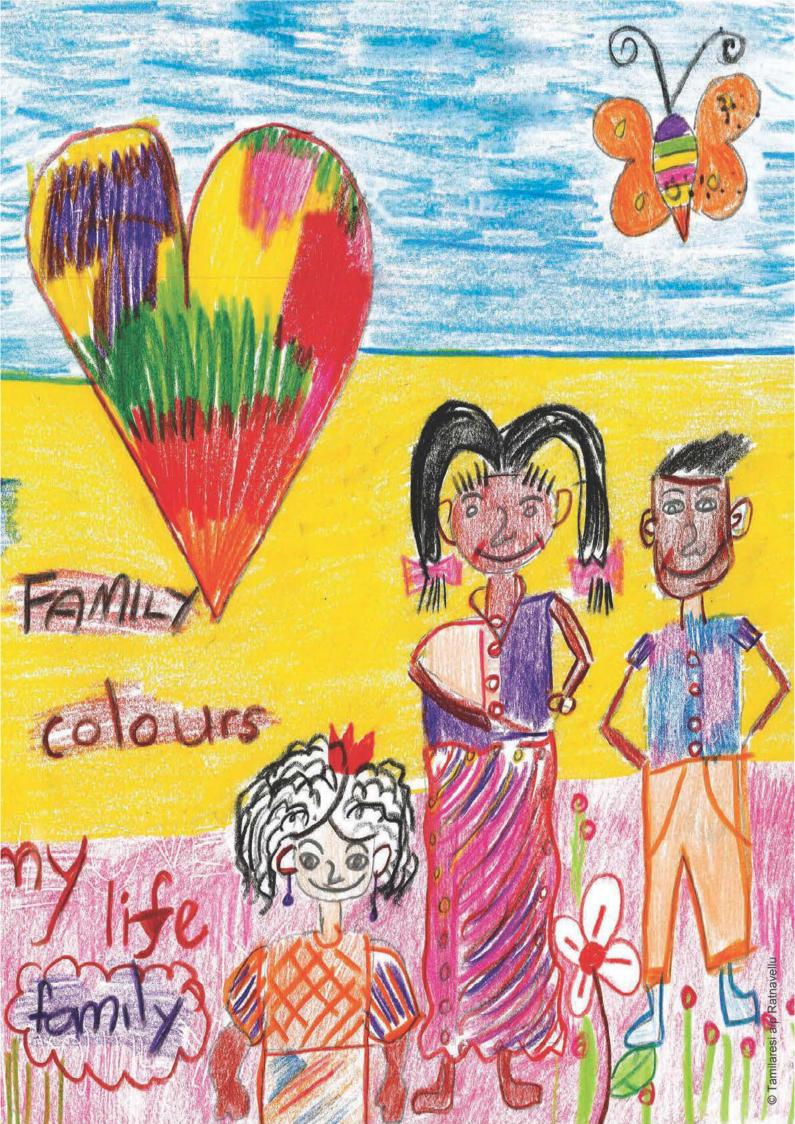
Only God knows how much I love my family.

I do not know how to express my love in words but deep in my heart, my family comes first.

And I wish every child in the world deserves a good, lovely and a colourful family.

Tamilaresi a/p Ratnavellu (14)

Physical disability





STAKEHOLDERS

A. NATIONAL COUNCIL FOR PERSONS WITH DISABILITIES (NATIONAL COUNCIL)

he National Council was established under the Persons with Disabilities (PWD) Act to have overall responsibility to oversee, co-ordinate and monitor the implementation of national policies and plans of action relating to persons with disabilities.

To achieve its objectives, the National Council uses a multisectoral and collaborative approach with the various government agencies that provide services to persons with disabilities.⁶⁴
The National Council comprises:⁶⁵

- senior officers of the core government ministries involved in the healthcare and development of persons with disabilities:
 - Minister of the Ministry of Women,
 Family and Community Development (MWFCD);
 - Secretary-Generals of the MWFCD, Ministry of Finance, Ministry of Transport and Ministry of Human Resources;
 - Director-Generals of the Department of Social Welfare (DSW), Ministry of Education (MOE) and Ministry of Health (MOH);
 - Attorney General of Malaysia;
 - Chairman of the Commercial Vehicle Licensing Board; and
- no more than ten other persons with appropriate experience, knowledge and expertise in problems and issues relating to persons with disabilities.

The National Council is required by law to meet at least three times a year. ⁶⁶ In 2011, it held three meetings ⁶⁷ as well as a dialogue with welfare organisations for persons with disabilities and a seminar on accessibility for persons with disabilities. ⁶⁸

Six committees are presently set up under the National Council to assist in the performance of its functions with regard to specific services, namely:⁶⁹

- Committee for Universal Design and Building Environment, chaired by the Secretary-General of the MWFCD, which focuses on accessibility for persons with disabilities in buildings and public spaces;
- Transport Committee, chaired by the Secretary-General of the Ministry of Transport, which focuses on accessibility for persons with disabilities in public transportation systems;
- Employment Committee, chaired by the Secretary-General of Human Resources, which focuses on the creation of employment and career opportunities for persons with disabilities;
- Education Committee, chaired by the Director-General of the MOE, which focuses on the access to education for persons with disabilities;
- Committee for Quality Life Care, chaired by the Director-General of the MOH which focuses on early detection and prevention of disabilities, residential care and community based rehabilitation services and access to healthcare for persons with disabilities; and
- Committee for the Registration of Persons With Disabilities, chaired by the Secretary-General of the MWFCD, which focuses on improving the persons with disabilities' registration system and improving the number of registrations.



B. GOVERNMENT AND NATIONAL BODIES

The key government bodies that formulate and deliver programmes and services relating to the protection, rehabilitation, development and well-being of children with disabilities in Malaysia are the MWFCD's Department of Social Welfare, the MOH, the MOE, the Economic Planning Unit in the Prime Minister's Department and the Performance Management and Delivery Unit (PEMANDU) in the Prime Minister's Department.

An analysis of the key services provided by these ministries and bodies; and any constraints are presented in Chapter 6. Other ministries and agencies that also play a role in the provision and delivery of programmes and services for children with disabilities include the Ministry of Transport, the Ministry of Information, Communication and Culture, the Ministry of Science, Technology & Innovation and the Ministry of Youth and Sports.

A number of national bodies also exist to represent and provide services and support for people with disabilities. A non-exhaustive list of such agencies and organisations; and their primary functions and services are set out in Annex 1 to this report.

KEY GOVERNMENT BODIES IN THE FORMULATION AND DELIVERY OF SERVICES FOR CHILDREN WITH DISABILITIES

ORGANISATION

Department of Social Welfare, MWFCD 70

SERVICES / PROGRAMMES

- · Register and issue the identification card for children with disabilities
- Manage institutional care and rehabilitation services for children with disabilities who are abandoned, orphaned or without a caregiver
- Provide pre-vocational training and rehabilitation programmes
- · Operate 11 institutions for persons with disabilities
- Provide and manage facilities and privileges for children with disabilities including financial assistance for prosthetics, reimbursement of white canes and Braille machines
- · Monitor and adapt the running of the Community Based Rehabilitation (CBR) programme
- Conduct Disability Equality Training (DET) to enhance understanding of the cause of disabilities and train advocates of the rights of persons with disabilities
- Support and facilitate training of persons with disabilities in Independent Living programmes
- Coordinate the delivery of services from other government agencies such as the Ministry of Transport and the MOH to children with disabilities
- Develop and periodically review policies, services and programmes for persons with disabilities

ORGANISATION SERVICES / PROGRAMMES 2. Ministry of Provide and promote early detection of disabilities Health 71 Provide initial assessment of children with disabilities Provide follow-up treatment of children with disabilities · Provide primary health care, management and rehabilitation services including speech therapy, hearing therapy / audiology, physiotherapy and activities of daily living in hospitals and health clinics Provide immunisation and nutritional guidance Formulate healthcare policies and plans for the detection, treatment and rehabilitation of children with disabilities Develop health education materials focused on specific disabilities · Conduct national campaigns to increase public awareness on disability detection and prevention Provide essential medical examination for students entering the first year of primary education including physical and eye examinations and hearing assessment Conduct post basic training for health care providers Provide technical input and outreach services to some CBR centres Advocate on issues and policies on persons with disabilities Develop and periodically review health policies, services and programmes for persons with disabilities 3. Ministry of Provide and manage special needs education to certain categories of children with Education 72 disabilities through special education schools, Special Education Integration Programme (SEIP) and inclusive education programmes Formulate curricula and educational modules for special needs education Manage training of teachers and teaching resources for special needs education Provide support services and augmentative and assistive devices for students in special needs education Facilitate sports and co-curriculum activities and art programmes for children in special needs education Manage early intervention for children with disabilities at pre-school level and from 0 – 6 years at Special Education Service Centres Register and monitor private special education institutions at pre-school, primary and

secondary level including teaching curricula and infrastructure

with disabilities

Develop and periodically review education policies, services and programmes for persons



ORGANISATION

SERVICES / PROGRAMMES

- 4. Economic
 Planning Unit,
 Prime Minister's
 Department 73
- Formulate the country's policies and strategies for socioeconomic development including in health, family and community development and youth and sports development sectors
- Provide a sectoral planning work structure for the medium and long-term periods for these sectors
- Evaluate and coordinate the financial allocation for projects and programmes under these sectors
- PEMANDU,
 Prime Minister's
 Department ⁷⁴
- Oversee the implementation and assess progress of (amongst others) the government transformation programme in relation to education
- Coordinate the multi-sectoral effort to develop the new National Education Blueprint (which includes policies on the education of children with disabilities)

C. NON-GOVERNMENT ORGANISATIONS (NGOS)

NGOs that work with or advocate for the rights of children with disabilities are instrumental in the care and development of these children.

There are non-profit learning and care centres that provide early intervention, learning, rehabilitation and training programmes for children with disabilities. This fills an important gap in the public system.

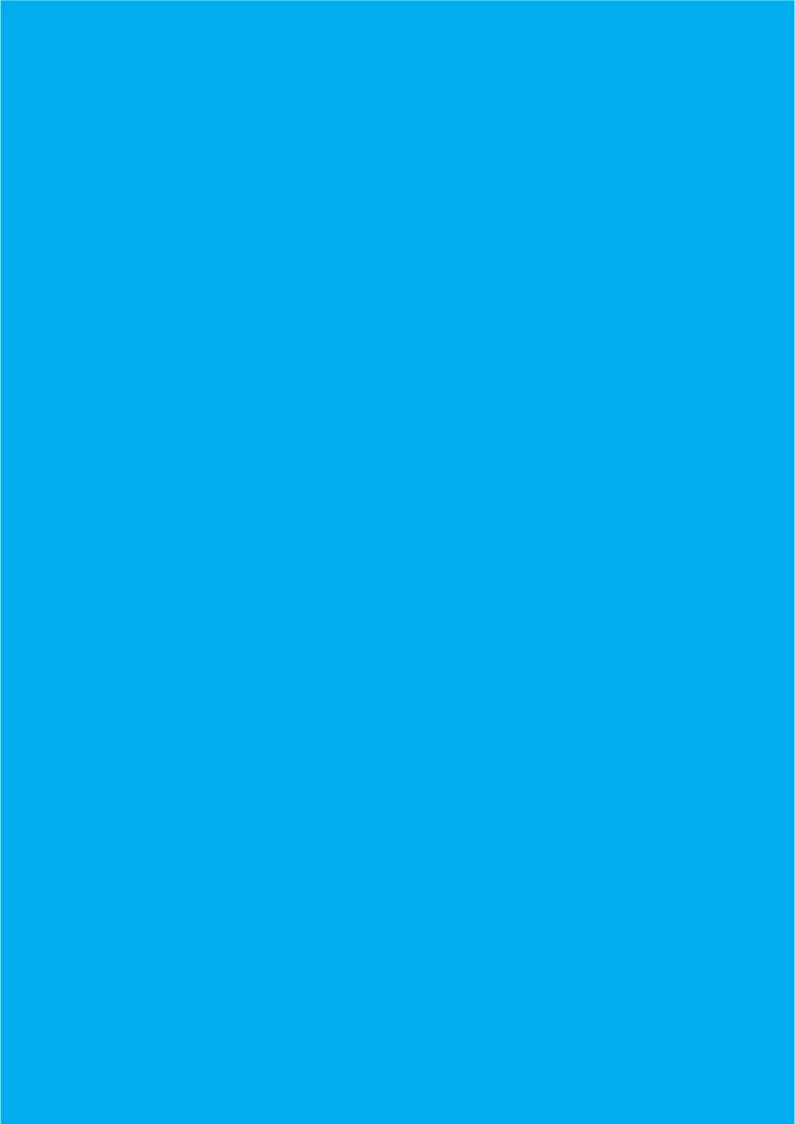
For example, Malaysian Care, Asia Community Services, Kiwanis Centre for Learning Disabilities are some of the NGOs that provide early intervention education for the child and the parents. They also provide training for the children to help them fit in better in mainstream schools. They also advocate for the admission of children with special needs into mainstream schools.⁷⁵

There are also NGOs that play a crucial role in advocating with the government for improvements in early detection mechanisms, health and education services and accessibility for children with disabilities. For example, the National Early Childhood Intervention Council (NECIC) actively campaigns for effective early childhood intervention methods and improving the special needs education system for children with disabilities.⁷⁶

The exact number of NGOs and other service providers working with children with disabilities are unavailable to MWFCD since many of these NGOs are not registered with the Ministry. The types of services provided by the different NGOs are also not available to the government.

However, Malaysian Care maintains a directory of organisations and agencies that work on issues relating to persons with disabilities in Malaysia.⁷⁷

Annex 2 contains a non-exhaustive list of NGOs who work with children with disabilities, and a summary of their services.



My world is too small.

Nobody desires to be near me and in my world probably because of my weakness.

But I do appreciate encouragements and guidance from some of them to motivate myself.

They would usually find my talent and mould it.

That's what I really need to improve myself, to get away from the feelings of disappointment and frustrations.

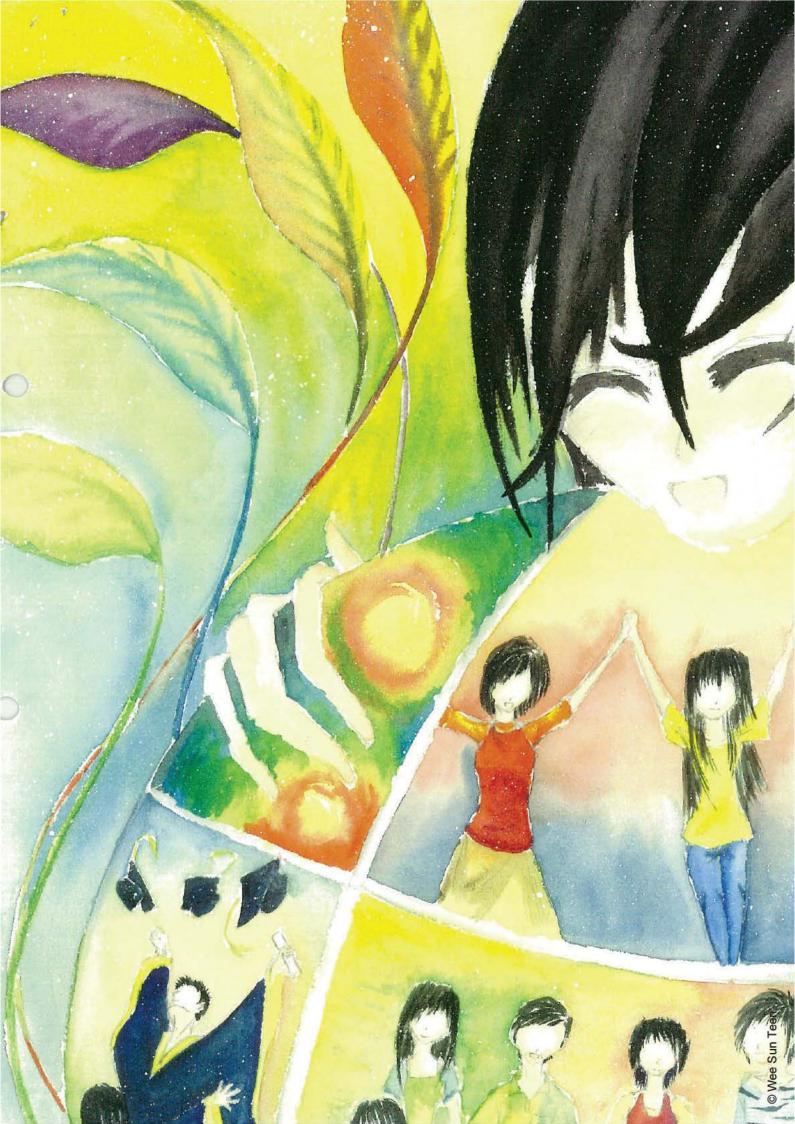
People with a perfect mind and without disability are very much needed to make my world shine bright.

I got the confidence in myself to succeed, and I've got the initiative too. The only thing I expect from you is support and do not avoid me.

This is what my heart says "don't hate me for who I am".

Wee Sun Teen (17)

Hearing disability





A. EARLY DETECTION AND INTERVENTION OF CHILDREN WITH DISABILITIES

arly childhood intervention is key to optimise the learning and development of children with disabilities. The early childhood years of 0 – 8 are critical for all children in establishing learning patterns and in acquiring foundational skills.⁷⁸

The UNESCAP *Biwako Millennium Framework* for Action (2003), endorsed by Malaysia, identified three main aims for early intervention and education:

- a. By 2010, at least 75 per cent of children and youth with disabilities will be able to complete a full course of primary schooling;
- By 2012, all infants and young children (0-4 years) will have access to and receive community based early intervention services;
- By 2015, children everywhere will be able to complete a full course of primary education.

Malaysia has not fulfilled the first two targets by their projected dates.

- In 2010, the number of children with disabilities enrolled in primary school under special needs education was 25,674. This was approximately 9 per cent of 297,053 (total estimated population of children with disabilities of primary school going age in that year).⁷⁹
- The goal to provide all infants and young children aged 0 – 4 years access to community based early intervention services has not been met.⁸⁰

A.1 Current detection methods

Early detection of children with disabilities falls within the purview of both the Ministry of Health (MOH) and the Ministry of Education (MOE).

It is stated that more than 95 per cent of children and their families are accessible by public health

staff in the new born period and in primary school under existing programmes. ⁸¹ It is therefore ideal and crucial that these ministries have in place effective, holistic and proactive mechanisms for early detection of disabilities in children.

Specific development screening tests are conducted at various stages of the child's growth and development. This programme engages both parents and healthcare providers to look out for and act on the early signs of potential disabilities.

In recent years, the MOH Family Health
Development Division has begun to put in place
early detection initiatives to improve and accelerate
the detection of children with disabilities.

With UNICEF support in 2008, the MOH piloted a programme in five areas that included specific development health screening at 5 months, 12 months, 18 months and 4 years.

The programme strongly encouraged health professionals to take note of parental concerns of developmental delay; and incorporated a child developmental checklist to assess parental concerns, M-CHAT (Modified Checklist for Autism in Toddlers) at 18 months and ADHD / Learning Disorders screening at four years.⁸²

In 2012, the programme was launched and implemented at national level as a health monitoring programme for 0 – 6 year olds that commences at the pre-natal stage and which is targeted at identifying the earliest signs of potential disabilities.⁸³



Parents in both public and private medical institutions are issued a 'Health Record for Baby and Child (0 – 6 years)' that contains checklists to chart a child's developmental stages, information on childcare, immunisation and certain disabilities, and a schedule of healthcare appointments.

Specific development screening tests are conducted at various stages of the child's growth and development. These engage both parents and healthcare providers to look out for and act on the early signs of potential disabilities.⁸⁵

While the health monitoring programme is disseminated to both public and private medical institutions and is available to all parents, it may not be easily accessible by the urban poor and those in rural areas. Adherence to the monitoring programme is not compulsory, ⁸⁶ and the effectiveness of the programme depends on the vigilance, proper implementation and follow-up by parents, caregivers, private medical institutions, state health departments and individual health centres.

In the national schooling system, children with disabilities who remain undetected are expected to be filtered out when they take the Literacy and Numeracy Screening (LINUS) Programme, which are tests conducted over the first three years of primary level education that all students in mainstream schools are required to pass. Where a child fails the LINUS screening tests repeatedly over the three year period, his / her parents will be asked to refer the child to the MOH for medical assessment and screening.⁸⁷

However, the LINUS screening test is not specifically catered to detect all forms of learning disabilities. The threshold of the screening test is also low, so that it is also possible for some children with learning disabilities to pass the tests.⁸⁸

Even in when the test identifies a child with potential learning disabilities, it will be up to the parents of the child to follow through with the process of assessment at the MOH.

A.2 Shortcomings in the current system of early detection

Both the MOH and the MOE recognise that early detection and intervention is critical and that problems exists in the implementation of their programmes, which they attribute to:

- The lack of screening tools and expertise to carry out assessments;⁸⁹
- b. The lack of a more comprehensive identification procedure for children with disabilities; 90
- The lack of prevalence rates and the normality of disabilities; ⁹¹
- d. The absence of a well-concerted multidisciplinary team approach in the identification and intervention process and in addressing the needs of the child and his / her family.⁹²

Early detection and intervention advocacy groups have identified other contributing problems to the poor early detection and intervention process:⁹³

- The training curriculum for learning disabilities for medical students is almost nonexistent in some universities and extremely limited in most;
- Most doctors, whether in government-run or private medical institutions, are not able to identify correctly children with learning disabilities and often dismiss parental concern;
- Many specialists lack skills to adequately assess milder learning disabilities such as dyslexia, high functioning autism and dyspraxia;
- d. There is a serious lack of educational psychologists, developmental paediatricians, community paediatricians and other trained professionals both in the MOH and the MOE to aid in the assessment.

The screening tools for early detection of disabilities is also of concern. For example, while schools have incorporated a screening tool developed by psychologists, the screening tool has not been validated. Additionally, reports from

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persons interviewed suggest that the tool does not consist of internationally recognised screenings for learning disabilities.⁹⁴

A.3 The way forward

There is some consensus that a multi-disciplinary approach must be adopted in the early assessment process, involving the three government agencies that provide primary services, namely the MOH, MOE and the DSW. Expertise from each of these sectors should be incorporated as core elements in early detection processes.

While the MOH has taken great strides in recent years to improve the process of early detection by including early detection checklists into the routine check-ups for children aged 0 – 6 at government-run medical facilities, 95 these efforts are reactive and not proactive in tackling the problem as they depend on the diligence and ability of parents to monitor the child and to follow through with medical appointments.

Rights advocates for children with disabilities have recommended: 96

- Compulsory and multi-disciplinary routine developmental surveillance and screening for all children from 0 – 8 years.
- Early childhood intervention units established and run together by the MOH, MOE and DSW that operate or carry out assessments in all hospitals, health clinics, local pre-schools, early childhood education and community service centres.
- The needs of parents of children with disabilities, especially the poor and disadvantaged, should be identified and provided for.
- A comprehensive and integrated national database of children with disabilities should be established as a collaborative effort between the MOH, MOE and DSW to better analyse the needs of the target population and enable for effective policy formulation and programme implementation.

B. HEALTH

B.1 Healthcare system for children with disabilities

Apart from early detection, the MOH provides healthcare programmes for children with disabilities at the following facilities:⁹⁷

As at 2011, 242 (30 per cent) health centres
As at 2011, 242 (30 per cent) health centres have rehabilitation services for children with special needs, provided by paramedics including public health nurses and medical assistants who undergo six-month training in acute hospital-based care and follow-up management for chronic conditions in primary care

Physiotherapists and occupational therapists based in government hospitals provide input on case management plans and supervise the rehabilitation cases in health centres. Certain health centres with heavy attendances have their own physiotherapists and occupational therapists.

As of 2011, there were 55 occupational therapists, 56 physiotherapists and 8 medical social workers operating at the various health centres.

b. Community Based Rehabilitation (CBR) centres

The MOH provides technical input and outreach services to some CBR centres across the country including, for example, training of both CBR staff and social welfare officers to provide awareness training to children with disabilities on personal safety and sexual reproductive health.

The MOH also operates school health teams in every district. These teams conduct annual health screening for students in Years 1 and 6 in primary schools and Form 3 in secondary schools⁹⁸; including physical examination, eye examination and hearing assessment.⁹⁹



There are inadequate skilled health care providers who are trained to work with children with disabilities at every health centre, including physiotherapists, occupational therapists, clinical psychologists and psychiatrists.

The MOH Health Care for Persons With Disabilities Years 2011 – 2020 Plan of Action (PWD Healthcare Plan of Action) is said to meet the obligations and strategies under the CRPD, PWD Act and National Policy. Its strategies are: 100

- Advocating issues and policies relating to persons with disabilities;
- Increasing accessibility to facilities and services;
- Empowering individuals, families and communities;
- d. Strengthening inter-sectoral collaboration with both government agencies and NGOs;
- Ensuring an adequate and competent workforce in the medical facilities that offer rehabilitative care;
- f. Intensifying research and development; and
- g. Developing programme planning and implementation for specific disabilities.

In 2012, the MOH rolled out a health monitoring programme for 0 – 6 year olds that commences at the pre-natal stage and which is targeted at identifying the earliest signs of potential disabilities. ¹⁰¹

Parents in both public and private medical institutions are issued a 'Health Record for Baby and Child (0 – 6 years)' record book that contains checklists to chart a child's development at various stages, information on childcare, immunisation and certain disabilities, and a schedule of healthcare appointments.

During these healthcare appointments, the health nurses will go through the checklists with the parents and conduct specific development screening tests to assess the child's development and identify if there are any signs of atypical development or possible symptoms of disability that should be escalated to a doctor.¹⁰²

Some home visits are conducted by public health nurses if the mothers-to-be who have registered with the health clinics default in attending follow-up appointments. However, this health monitoring programme faces a number of constraints as indicated previously, including difficulties in accessibility by the urban poor and those in rural areas and the reliance it places on parents, care-givers, private medical institutions, state health departments and individual health centres to ensure proper implementation and follow-up. 103

B.2 Problems in the delivery of health care services to children with disabilities

Healthcare services for children with disabilities have advanced significantly in recent years. However, a number of fundamental problems stand in the way of the optimisation of the MOH's healthcare programme for persons with disabilities, in particular for children with disabilities.

There are inadequate skilled health care providers placed at every health centre who are trained to work with children with disabilities.

They include physiotherapists, occupational therapists, clinical psychologists and psychiatrists.

While most parents send their children to CBR centres for screening, intervention and rehabilitation, the MOH allocation of manpower and resources to these centres is severely limited.

However, not all CBR centres are serviced by MOH healthcare providers, and even those that are serviced are only visited by healthcare providers once a month for screening and intervention programmes. 104

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The health centres are generally located in cities and towns. Consequently, there remains a shortage of infrastructure and resources that prevents healthcare and rehabilitation services at health centres and CBR centres from reaching those in rural areas and the urban poor.

While the health teams at these centres do carry out home visits in cases of children with severe disabilities, ¹⁰⁶ there remain many children, especially those from rural communities (including the interior areas of Sabah and Sarawak) and lower income groups, who face difficulties in accessing healthcare due to lack of transport and the costs associated with it.¹⁰⁷

One solution to bridge the physical distance between health clinics, hospitals and CBR centres and the child, is for the service providers concerned to leverage on other government agencies such as the Ministry of Transport, the Ministry of Rural and Regional Development or the respective State governments that would have developed access routes to these areas.

Another potential and related solution is to work together with these other government and state agencies to run mobile health clinic services to these areas.

For example, in remote regions of Sabah, the authorities have successfully implemented 'Mobile Courtrooms' where buses, modified and out-fitted with the necessary facilities and equipment carry magistrates and legal officers to rural areas to conduct hearings. ¹⁰⁸

C. EDUCATION

C.1 Early childhood care and education

Early childhood care and education for children aged 0 – 4 years is regulated by the DSW under the Ministry of Women, Family and Community Development (MWFCD). The DSW regulates affordable childcare centres or nurseries under the Childcare Centres Act 1984.

Colloquially known as "TASKA", these childcare centres are licensed by the DSW; and childcare providers must undergo a course in childcare services that is accredited by the DSW. 109

In 2012, it was announced that the MWFCD would include within all TASKA childcare centres, programmes for early detection of disabilities.¹¹⁰

In the 2013 Budget, provision was made for six TASKA childcare centres to be set up specifically for children with disabilities for six separate categories of disabilities:

- Down syndrome
- Autism
- Blind or partially sighted
- · Hearing and speaking disabilities,
- Physical disabilities
- Other learning difficulties

It is unknown if these two programmes have been implemented. For children aged 4 – 6 years, early intervention programmes are provided by the MOE in Special Education Schools under the special needs education system.¹¹¹

The Salamanca Statement

The 1994 World Conference on Special Needs Education (UNESCO) produced a statement and framework for action which argues that regular schools with an inclusive orientation are "the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost effectiveness of the entire education system."



C.2 Options in the national school system

There are three schooling options provided by the MOE for children with disabilities under the national special needs education system: 112

- Special Education Schools, which are specific schools for children with disabilities. There are currently 28 primary and five secondary Special Education Schools.¹¹³
 Of the 28 primary schools, 22 are for children who are hearing impaired, five for children who are visually impaired and one for children with learning disabilities.
 - Of the five secondary schools; three are vocational schools, while two are academic schools for the hearing and the visually impaired respectively.
- Special Education Integrated Programmes (SEIP), which are specific classes in mainstream schools dedicated to children with special needs. There are currently just under 2,000 mainstream schools with SEIP of which around 1,300 are primary schools and around 670 are secondary schools.
- Inclusive Education Programmes, where children with disabilities are integrated into mainstream classes. Information on the number of mainstream schools currently running inclusive education programmes was not established during this mapping. 115

C.3 Education options in the private sector

The private sector and NGOs also provide some options for education for children with disabilities. There are home schools and private special needs schools that cater for children with learning disabilities such as MAJoseph Special Needs 116 and Sri Rafelsia. 117

NGOs and faith-based organisations (FBOs), mostly church-based, provide services which include assessment and treatment of learning disabilities; which fill a gap in the public system. Malaysian Care, for example, provides early intervention education for the child and training for the parents; training for children to fit in better in

mainstream schools; and advocates the admission of these children into mainstream schools.

The NGO also encourages parents to involve themselves in the child's education and they are given guidance to continue the child's education and training at home. ¹¹⁸

C.4 Identifying children for special needs education

The Education (Special Education) Regulations 2013 enacted on 18 July 2013, provides for special needs education for children with disabilities in Malaysia.

The Regulation stipulates that a "pupil with special education needs" means a pupil who is certified by a medical practitioner, an optometrist, an audiologist or a psychologist to have:

- i. Visual disability
- ii. Hearing disability
- iii. Speech disability
- iv. Physical disability
- v. Learning difficulties (or)
- Any combination of the disabilities or difficulties listed above.

The 2013 Regulations revokes the earlier 1997 Special Education Regulations which restricted eligibility to the national Special Needs Education system only to children with special needs who were 'educable'. Educable was defined as pupils with visual and auditory disabilities and specific learning difficulties namely: (i) Down Syndrome; (ii) Mild Autism; (iii) Attention Deficit Hyperactivity Disorder (ADHD); (iv) minimal mental retardation; and (v) specific learning difficulties (such as dyslexia). 119

'Physically handicapped children' who were excluded in the earlier 1997 Regulations¹²⁰ are now included in Special Needs Education in the 2013 Regulations.¹²¹

Under Regulations 2013, children who intend to enroll in special needs education will be required to attend a probation period of no more than three months at a government or government-aided

school to determine suitability. After completion of the probation, the school the child attended will submit a Probation Period Report to a panel for consideration. The Panel will comprise the 1) School Principal, Head Teacher or Senior Assistant for Special Education; 2) the State Education Department or District Education Officer; and 3) the Social Welfare Department Officer or Persons with Disabilities Development Department Officer. 122

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conducted over the first three years of primary
education that all students in mainstream schools
are required to pass.

Where a child fails the LINUS tests repeatedly over three years; his/her parents will be asked to refer the child to the MOH for medical assessment and screening. 123

There are a number of shortcomings with the LINUS screening test as a tool for detecting disabilities, and these shortcomings have been mentioned earlier in this chapter. They include the fact that the test is not specifically catered to detect all forms of learning disabilities and that the threshold of the test is low, such that it is possible for some children with learning disabilities to pass the tests. 124

Where a child is assessed as having learning disabilities, the choice of placing the child in inclusive education programmes (integration into mainstream classes) or in SEIP lies in the hands of the special education coordinator or the school principal within the school concerned.¹²⁵

The lack of a streamlined process of identification of children with disabilities and placement into the different special needs education options allows for its misuse.

There are reports that schools may tend to place students with learning disabilities into the special needs education system to avoid impact on the schools overall academic performance in public examinations. ¹²⁶

The decision whether to place a child with disabilities in mainstream classes is influenced not simply by the child or the nature of his/her disability, but by the school's capacity to cope child with disabilities in mainstream classes, such as the availability of trained teachers or the necessary teaching facilities / infrastructure.¹²⁷

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TABLE 8: ENROLMENT IN SPECIAL EDUCATION SCHOOLS BY LEVEL AND GENDER, 2010-2012 134

	2010			2011			2012		
LEVEL	Male	Female	Total	Male	Female	Total	Male	Female	Total
Pre-school	63	38	101	55	54	109	55	36	91
Primary	896	719	1,615	888	718	1,606	835	700	1,535
Secondary (Forms 1 – 5)	313	256	569	373	301	674	355	287	642
Secondary Form 6	1	2	3	0	0	0	0	2	2
TOTAL:	1,273	1,015	2,288	1,316	1,073	2,389	1,245	1,025	2,270

TABLE 9: ENROLMENT IN SPECIAL EDUCATION INTEGRATION PROGRAMME BY LEVEL, 2010-2012 135

LEVEL	2010	2011	2012
Pre-school	536	573	490
Primary	23,104	25,181	27,096
Secondary (Forms 1 – 5)	15,844	18,252	20,296
Secondary (Form 6)	8	5	24
Total	39,492	44,011	47,906

TABLE 10: ENROLMENT IN THE INCLUSIVE EDUCATION PROGRAMME, 2010-2012 136

LEVEL	2010	2011	2012
Inclusive Education	6,360	3,261	562

TABLE 11: EXPENDITURE BY LEVEL, 2004-2006

7	PRE-SCHOOL	PRIMARY Education	SECONDARY EDUCATION	SPECIAL EDUCATION	TOTAL
2004 Expenditure (RM)	176,477,000	5,601,625,600	4,991,467,300	59,369,200	112,490,000,000
%	1.31	41.63	37.10	5.38	100
2005 Expenditure (RM)	178,061,100	5,674,836,800	5,057,590,900	54,760,000	117,444,984,600
%	1.31	41.60	37.07	7.07	100
2006 Expenditure (RM)	173,528,500	6,060,289,900	5,421,272,800	56,875,800	136,748,522,510
%	1.22	42.66	38.16	7.21	100

disability, but by the school's capacity to cope child with disabilities in mainstream classes, such as the availability of trained teachers or the necessary teaching facilities / infrastructure. 132

C.5 Children with disabilities enrolled in the special needs education system

The number of children with disabilities in Special Education Schools has remained consistent between 2010 and 2012, with approximately 2,300 students enrolled each year (Table 8).

The enrolment of children with disabilities in the SEIP however has seen an increase from 39,492 in 2010 to 47,906 in 2012 (Table 9).

In contrast, the number of children with disabilities enrolled in inclusive education programmes (Inclusive - Students with physical disability in a normal classroom (e.g. hearing or visually impaired) has shown a significant decline from 6,360 in 2010 to 562 in 2012 (Table 10).

The overall percentage of children with disabilities within the total student population in the national school system is inordinately low, at around one per cent. ¹³³

C.6 Problems in the delivery of education services to children with disabilities

There are various reasons for the low enrolment rate of children with disabilities in the special needs education system.

The shortcomings recognised by the government include: 137

- shortage of qualified teachers
- shortage of professional support such as audiologists and occupational therapists
- lack of a tailored curriculum for certain learning disabilities
- general lack of facilities in mainstream schools such as disabled-friendly facilities
- lack of assistive technological devices like hearing aids and Braille typing machines.

However, rights advocates for children with disabilities point to wider and more systemic reasons for the shortcomings in the education options available to children with disabilities, including:

- a. The quality of special education teachers varies enormously. The training syllabus for special education teachers needs to be reviewed. There appears to be a reluctance to institute a teacher aid programme to support children in the mainstream education system. Without adequate training, teachers in mainstream classes are unable to deal with children with learning disabilities.¹³⁸
- b. There is an extremely limited availability of speech and language therapists and educational psychologists in national schools. There is also a lack of uniformity of access to education services, specifically in smaller towns in Sabah, Sarawak and the interior of Peninsular Malaysia.¹³⁹
- c. Although children with disabilities are estimated to comprise around 10 per cent of all children, only some 5 to 7 per cent of education expenditure appears to be channelled to special needs education. Table 11 sets out data on education expenditure from 2004 to 2006 provided by the Malaysian government to the Committee on the Rights of the Child during consideration of Malaysia's Initial Report.¹⁴⁰

C.7 Inclusive Education

The principal shortcoming in the special needs education system in Malaysia is the failure of the government to make inroads in the implementation of the Inclusive Education Programmes in mainstream schools.¹⁴¹

The principle of Inclusive Education for children with disabilities starts from the core concepts that all children are educable although they may learn at different rates and levels and that all children will benefit from an inclusive programme regardless of their differences.¹⁴²

Research has shown that children with special needs improve in their communication and social skills when placed in mainstream school settings, in addition to improving in other academic skills,



and that children who have classmates with special needs in their classroom grow up to be more accepting of people with different needs.¹⁴³

The 1994 UNESCO Salamanca Statement, ratified by Malaysia, states that those with special needs must have access to mainstream schools and that mainstream schools with an inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities and building an inclusive society.¹⁴⁴

The principle of Inclusive Education is also enshrined in the CRPD (Article 24) and in Malaysia's own PWD Act (Section 28).

Yet Malaysia's international and national commitments to implement Inclusive Education do not appear to have been translated into action, and this has called into question Malaysia's commitment to implementing Inclusive Education as the core policy of special needs education. 145

The data on the enrolment of children with disabilities in Inclusive Education Programmes demonstrates that these criticisms have basis.

In 2012, only 562 children with disabilities were enrolled in the Inclusive Education Programme in mainstream classes. This figure represents:

- around 1 per cent out of the 50,738 children with disabilities enrolled in special needs education in that year;¹⁴⁶ and
- around 0.01 per cent out of the 5,086,180 students (both with and without disabilities) who were enrolled in the national education system in that year.¹⁴⁷

It is worth noting that the government has recognised that the inclusion of children with disabilities within mainstream schools through Inclusive Education Programmes is the most effective means of overcoming discriminatory attitudes and building an inclusive society, and is in line with the government's commitment under the PWD Act to facilitate their "full and equal participation in education." 148

In the Malaysia Education Blueprint 2013 – 2025 Preliminary Report (September 2012), the government proposed to improve the special needs education system in three stages ('waves'):

 The first wave seeks to link schooling options for students with special needs to competency levels, so that only "high-functioning" special needs students

Biwako Millennium Framework

In May 2002, ESCAP adopted the resolution "Promoting an inclusive, barrier-free and rights-based society for people with disabilities in the Asian and Pacific region in the twenty-first century". The resolution also proclaimed the extension of the Asian and Pacific Decade of Disabled Persons, 1993-2002, for another decade, 2003-2012.

In October 2002, Governments at the High-level Intergovernmental Meeting to Conclude the Asian and Pacific Decade of Disabled Persons 1993-2002, adopted the "Biwako Millennium Framework for Action towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific" as the regional policy guideline for the new decade. The "Biwako Millennium Framework" outlines issues, action plans and strategies towards an inclusive, barrier-free and rights-based society for persons with disabilities. To achieve the goal, the framework identifies seven priority areas for action, in each of which critical issues and targets with specific time frames and actions follow. In all, 18 targets and 15 strategies supporting the achievement of all the targets are identified.

The next decade will ensure the paradigm shift from a charity-based approach to a rights-based approach to protect the civil, cultural, economic, political, and social rights of persons with disabilities.

who can cope with the mainstream curriculum and assessment will be encouraged to attend inclusive education programmes, while moderate functioning special needs students will attend the SEIP.

- b. The basic training of all teachers in special needs education and the exploration of partnerships with other government agencies and non-government and international organisations to provide support for special needs education are to occur during the second wave of the proposal.
- c. The target at the end of the third wave is to have 75 per cent of students with special needs enrolled in Inclusive Education Programmes and every teacher equipped with a basic knowledge of special education.

The segregated approach proposed in the first wave of the Education Blueprint that bases access to education on potential, competency or "high-functioning" has been rejected as going against the principles of Inclusive Education, which seeks to bring children with special needs, except for the severely disabled, into mainstream education. 149

The Education Blueprint was also criticised for paying only superficial attention to special needs education, without the meticulous analysis and documentation presented in other areas covered by the Education Blueprint.

For example, while measures to improve the training of teachers and building partnerships with relevant local organisations in respect of other areas addressed in the Education Blueprint are to start in the first wave, in respect of special needs education, the improvement in training of teachers and exploring partnerships with local organisations will only be undertaken in the second wave. ¹⁵⁰

A Memorandum on Inclusive Education as National Policy for Children With Special Needs, prepared by the National Early Childhood Intervention Council (NECIC) and supported by over 60 non-government organisations was submitted to the MOE in 2012 for consideration in the drafting of the proposals for special needs education in the Education Blueprint.¹⁵¹

The Memorandum contains detailed and comprehensive recommendations of policies and strategies to integrate children with disabilities into mainstream classes. 152

However, much, if not all, of the recommendations in the Memorandum were not adopted into the Education Blueprint.

A response to the various criticisms raised against the Education Blueprint was sought from an official in the Special Education Division of the MOE.

However, the official declined to comment citing confidentiality as the finalisation of the Blueprint is ongoing. 153

The Incheon Strategy

The Incheon strategy to "make the right real" for persons with disabilities in Asia and the Pacific. The Incheon strategy provides the Asian and Pacific region, and the world, with the first set of regionally agreed disability-inclusive development goals. It comprises 10 goals, 27 targets and 62 indicators, including ensuring disability-inclusive disaster risk reduction and management.

The Incheon strategy builds on the Convention on the Rights of Rersons with Disabilities and the Biwako Millennium Framework for action and Biwako plus five towards an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific.

It is intended to enable the Asian and Pacific region to track progress towards improving the quality of life, and the fulfilment of the rights, of the region's persons with disabilities.



D. COMMUNITY-BASED REHABILITATION

Community Based Rehabilitation (CBR) centres are available throughout the country. Established by the DSW, a CBR centre is meant to be a onestop centre for persons with disabilities, and is intended to provide such services as diagnosis, rehabilitation, treatment, special education and vocational training.¹⁵⁴

There are currently 486 CBR centres in Malaysia, with approximately 20,000 trainees. The government's initial report to the Committee of the Rights of the Child in 2007 states that at least 10 new CBR centres will be opened by the MWFCD every year. The report adds that the MWFCD provides annual monetary grants to these centres for their operational expenses, programmes and activities.

People with disabilities who participate in CBR received a monthly allowance of RM 25 from the MWFCD. This allowance was reported to have been increased to RM 50 per month from January 2007. 157

According to the same report, CBR centres organise several activities for the benefit children with disabilities, including: 158

- Therapy: Three kinds of therapy are offered, and training is done under the close supervision of selected specialists.
 - Physiology therapy focuses on the rehabilitation of the human body which involves activities concerning basic motion skills such as crawling, walking, running, jumping and kicking.
 - Occupational therapy teaches persons with disabilities various occupational skills.
 - Speech therapy focuses on verbal communications skills that help persons with speech impediments learn to speak better

- b. Language and Social Development: Persons with disabilities are taught to express themselves verbally, through writing and inscriptions. This allows them to communicate properly and for other people to understand them better. Under this activity, persons with disabilities are also taught interaction skills, such as sign language.
- c. Basic Daily Life Skills: This activity provides basic skills training on how to take care of oneself. It includes regular food and water intake, bathing, toilet training, grooming, wheelchair handling as well as getting in and out of bed and vehicles.
- d. Reading, Writing and Arithmetic (3R): Persons with disabilities are taught basic skills in reading, writing and arithmetic. In addition, they are trained to handle writing tools and materials.
- Recreational Therapy: Persons with disabilities are encouraged to explore their talents through games, making handicrafts and playing musical instruments. Often, outdoor excursions to various places are conducted.
- f. Independent Living Training: This is training that focuses on helping persons with disabilities achieve independence in all aspects of their lives. It can provide children with various needs with positive as well as fun activities to improve their cognitive, physical and motor skills. Several 'hostels' are set up where four to five people with disabilities learn to live together on their own under the supervision of a coordinator.

The CBR programme is a preferred alternative to institutional care since: (i) it provides decentralised rehabilitation services and early intervention for children with disabilities within their own communities; and (ii) it helps to ensure the acceptance and social integration of children with disabilities. 159

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Children with disabilities are particularly susceptible to abuse, and are three to four times more likely to be victims of violence. Child protection policies should therefore prepare strategies, services and resources that specifically cater to these children.

However, the services offered at CBR centres are not specialised for children. The space is open for adults and children alike. While CBR centres are placed in communities for accessibility, many parents still find it difficult to access it.

Many parents are also unaware of the service. 160

The CBR centres also lack adequately trained staff, and even trained therapists. ¹⁶¹ Where there are therapists, their numbers are often insufficient to handle the case loads. These shortcomings have led some to term CBR centres as little more than childcare centres. ¹⁶² The centres are also frequented by "educable" children who can, and should, attend school. Some organisations insist that these centres should be prioritised for those who are found to be ineligible to be admitted to mainstream schools. ¹⁶³

Children with severe disabilities are often confined to the home and are unable to access CBR centres. Some CBR teachers do visit these children at their homes for therapy but this is not done on a regular basis and is dependent on the commitment of the teacher. ¹⁶⁴ As such, there is inadequate intervention for children with severe disabilities. In some rural communities, CBR centres are only available to children below the age of eight. ¹⁶⁵

Many private organisations also run rehabilitation programmes along with their assessment services. These, again, are an expensive option. These services are hospital or centre based and can result in similar problems of access as noted in the paragraphs above.

E. SOCIAL PROTECTION

While most social protection programmes for persons with disabilities target adults, some are directed to children with disabilities, including:

- a. MOE provides a monthly allowance of RM 150 for children in special needs education in the national primary and secondary schools.¹⁶⁶
- Taman Sinar Harapan homes under the DSW provide residence, care and rehabilitation for children with disabilities. There are seven such homes across the country.¹⁶⁷

F. PROTECTION

Information on the extent and risks to abuse for children with disabilities in Malaysia is not readily available. International studies however illustrate that children with disability are more vulnerable to violence and abuse.

Studies from the United States have shown that children with disabilities who are in pre-school or younger are more likely to be abused than peers without disabilities. ¹⁶⁸ A national survey of deaf adults in Norway found that girls were twice as likely to experience sexual abuse, and boys three times as likely, as peers who had no disability. ¹⁶⁹

Factors which place children with disabilities at a higher risk of violence include stigma, discrimination and ignorance about disability, as well as a lack of social support for those who care for them. ¹⁷⁰ State parties to the CRPD are obligated under Article 16 to provide effective legal protec-tion for children with disabilities and to take all appropriate measures to prevent all forms of exploitation, violence and abuse. ¹⁷¹

For resulting legislation to be meaningful, it is essential not only to ensure that the laws are enforced but also that children with disabilities are educated about their right to protection from discrimination and abuse and how to exercise the right. 172



F.1 National legal and policy framework

The Child Act, which extends to children with disabilities, covers 12 categories of children in need of protection and these include cases of physical, sexual, mental and emotional abuse, and ill-treatment, neglect and abandonment. 173 It allows authorities to:

- a. take over temporary custody or remove to a place of safety a child deemed to be in need of care and protection and the conduct of medical examinations and treatment by the appropriate authorities;¹⁷⁴
- remove a child to a place of refuge and rehabilitation for a child deemed to be in need of pro-tection and rehabilitation.

The Child Act makes it mandatory for family members, child care providers and medical officers or practitioners to report any suspected cases of child abuse to the relevant authorities. ¹⁷⁶ The Child Act also establishes a special Court for Children which decides on issues relating to the custody, removal, care and rehabilitation of a child in need of protection. In making decisions, the Court for Children is obliged to take into consideration the best interests of the child. ¹⁷⁷

The National Child Protection Policy and Action Plan 2009 formulated strategies for child protection including advocacy, prevention, support services and research and development strategies. These strategies are:

- a. To ensure children are provided with an understanding of their rights to protection under the CRC and with basic knowledge of how to protect themselves from neglect, abuse, violence and exploitation and to recognise situations of risk; and
- To develop a standardised training module on child protection and screening system for persons who work directly with children.

F.2 Programmes and primary agencies

The DSW and MOH are the main service providers involved in coordinating child protection

services. The Royal Malaysia Police also plays a crucial role in the enforcement of child protection programmes. Child Protection Teams (the composition of which includes a medical officer and a senior police officer) are set up to coordinate district-based services to families and children in need of protection. ¹⁷⁸ Some social welfare officers are designated as Protectors under the Child Act and are empowered to take a child into temporary custody if they are satisfied, on reasonable grounds, that the child is in need of care and protection, and if deemed necessary, to have the child examined or treated by a medical officer. ¹⁷⁹

The MOH coordinates One-Stop Crisis Centres and Suspected Child Abuse and Neglect (SCAN) teams. The One-Stop Crisis Centres are located in most government hospitals; in the emergency departments. The centres provide clinical management, counselling, temporary shelter and assist in arranging for social welfare, shelter and legal support for the victims of child abuse, domestic violence, rape and sodomy. SCAN Teams are placed in specialist government hospitals and are multidisciplinary, multiagency hospital-based teams with welfare officers and police officers that provide medical care, treatment and support to maltreated children. 181

The Child Rights Coalition Malaysia has noted that the interagency collaboration between the MOH SCAN Teams, the police and Protectors under the DSW helps make the process of reporting an abuse less traumatic. 182

However, it has also identified a number of constraints with the current child protection system: 183

- a. There are insufficient numbers of Protectors and their caseloads are too high to allow for effective case management and proper review of a child's placement. This has led to some children being returned to their families, with the risk that the abuse may continue.
- b. The implementation of child protection policies and services is not evenly applied and vulnerable groups such as children with disabilities continue to face difficulties in accessing the full reporting and investigative processes.

When the child in need of protection has a disability, specific mechanisms must be set in place to ensure that the child can fully access and utilise the child protection services that are in place.

Social workers, medical officers, law enforcement officers, lawyers, judges and other relevant professionals who aid or work with the child must be trained to work with children who have disabilities.

Children with disabilities are particularly susceptible to abuse, and are three to four times more likely to be victims of violence.¹⁸⁴ Child protection policies should therefore prepare strategies, services and resources that specifically cater to this group.

For example, certain nurse home-visiting programmes for children at risk of violence and trainings to improve parenting skills have been shown to work to prevent violence against non-disabled children. The authorities should therefore consider implementing these forms of interventions as a routine programme both in private homes and in institutions that have children with disabilities.

G. ACCESSIBILITY

The PWD Act guarantees the rights of access for all persons with disabilities to among others, public facilities and transport.

The provision of access to premises and transportation is intertwined with the ability of children with disabilities to fully utilise their other basic rights, such as to healthcare and education.

In the healthcare system, a lack of an adequate means of transport for children with disabilities in rural or interior areas impedes their ability to utilise rehabilitation services in health clinics and CBR centres. ¹⁸⁶

In the education system, the lack of disabledfriendly infrastructure or facilities in a school can determine whether or not the school will accept a child with disabilities into mainstream classes under the Inclusive Education programme.¹⁸⁷

G.1 Access to public premises

Local authorities require architects and builders to adhere to Malaysian Standard Codes of Practice for building plans to be approved.

After a building is constructed, an "access audit" is done to gauge the usability and functionality of the premises for people with disabilities. The purpose of the audit is to: 189

- Increase awareness among planners and architects about barrier-free environments for people with disabilities;
- Ensure in both new buildings and in retro-fitting, the use of universal design concepts and adherence to the standard codes relating to people with disabilities.

As a result of the government's efforts, new buildings and renovated buildings are generally built and equipped with a full range of facilities for persons with disabilities. However, many older public facilities and public walkways and spaces have not been adapted to be disabled friendly. 190

G.2 Access to public transport facilities

While persons with disabilities receive a number of rebates and discounts for road tax and fares for public transport, the question of physical access to such transport has still not been adequately addressed and much of public transportation is still not disabled friendly. ¹⁹¹

Easing the financial burden of public transport in itself does not achieve the objectives of the CRPD; access to transport facilities and buildings must be read together with the other rights under the CRPD, such as to healthcare and education services, as the former facilitates the latter.

In other words, when providing education, healthcare and rehabilitation programmes to children with disabilities, the government agencies concerned should also put in place services that provide access to those facilities, for those children who would not otherwise be able to utilise them.

I was born deaf in a modest family but I have been very much loved by my parents and siblings.

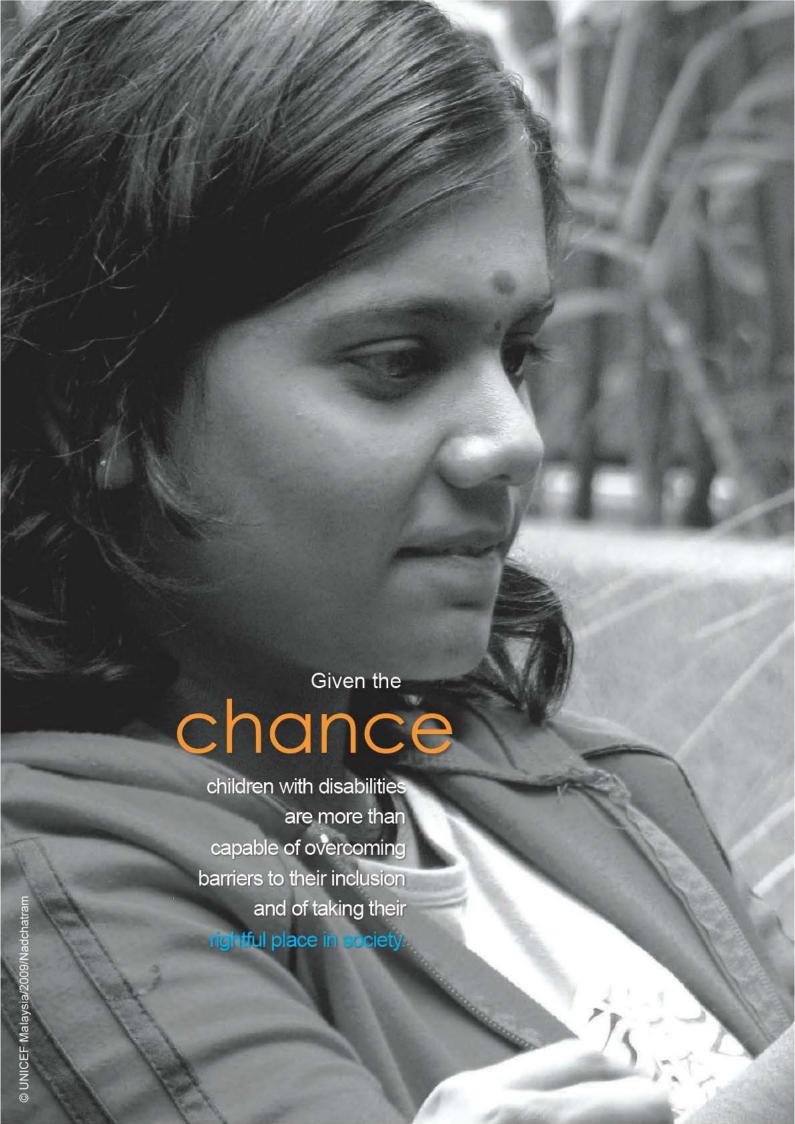
This painting reflects my soul like a butterfly flying in the vast and beautiful land; full of lively colours.

Living in a country with
different customs and beliefs,
we sincerely hope that you
can listen to the whispers of
our heart that we are able to
pass only through sign language,
with support of family and teachers.

Jack Schell Petrus (17)

Visual and hearing disability





CONCLUSIONS & RECOMMENDATIONS





1. LAWS AND POLICIES

- There is a lack of consistency between the Convention on the Rights of Persons with Disabilities (CRPD), which prevents discrimination against persons with disabilities, and Articles 8(2) and 12(1) of the Federal Constitution. This gap could allow laws that discriminate persons with disabilities to be passed and enforced.
- Non-discrimination is one of the defining principles of both the Convention on the Rights of the Child (CRC) and the CRPD. A failure to include a prohibition against discrimination of per-sons with disabilities in the Federal Constitution and to remove the reservation to Article 2 of the CRC could perpetuate discrimination.
- The lack of penalties or a mechanism to redress violations of the PWD Act and the government not signing the Optional Protocol to the CRPD, The apparent protection of the rights of persons with disabilities under the PWD Act would be illusory without an effective redress mechanism that is accessible by those the Act seeks to protect.
- The fact that the government is considering including enforcement mechanisms within the PWD Act is encouraging and to be lauded.
- Malaysia's recent commitment to the Incheon Strategy (developed by UNESCAP), and the intention of the government to draft a new national action plan for persons with disabilities that takes into consideration the goals and targets of the Incheon Strategy, are welcomed.

- Malaysia's reservations to the CRC and the CRPD should be lifted and it should sign the Optional Protocol to the CRPD.
- Articles 8(2) and 12(1) of the Federal Constitution should be amended to include prohibitions against discrimination of persons with disabilities.
- The PWD Act should be amended, in consultation with rights advocates and NGOs who work with persons with disabilities, to include penalties and a redress mechanism for violations of the Act.
- The goals and targets of the Incheon Strategy should be used as a basis for the strategies and plans of the new national action plan for persons with disabilities.
- Where necessary, the National Policy for Persons With Disabilities and the health and education policies relating to persons / children with disabilities should be harmonised accordingly.





2. DATA

- There is currently no comprehensive and structured data collection mechanism on children with disabilities. Data available does not present the actual number of children with disabilities, and is not sufficiently disaggregated by age, gender and disability type.
- The underestimate of the total population with disabilities, affects the ability of State entities to develop policies for children with disabilities, and results in a large number of children with disabilities who remain undetected.
- However, the recent institution of the SMOKU information management system by the Department of Social Welfare that allows for disaggregation of data is to be lauded.
- Similarly, the maintenance of databases on children with disabilities by the Ministry of Health (MOH) and the Ministry of Education (MOE) are to be lauded.

- The collection of data on children with disabilities must be systematised and comprehensive.
- Data on children with disabilities should be shared between and collated from the primary agencies that provide services to children with disabilities (Department of Social Welfare, Ministry of Health and the Ministry of Education).

7



3. PRIMARY STAKEHOLDERS INVOLVED IN PROVIDING SERVICES FOR CHILDREN WITH DISABILITIES

- There are several underlying and interrelated shortcomings that underpin the planning and execution of programmes and services for children with disabilities.
- There is no synergy and optimal utilisation of resources in the provision of services by different agencies, such as the MOH health centres and the Department of Social Welfare (DSW) Community-Based Rehabilitation (CBR) centres. Similarly, disability detection programmes are carried out by MOH and MOE at different age groups which affects the reach and effectiveness of these programmes.
- Early detection, intervention and rehabilitation services still rely on the child's parents or guardian to make the approach to service providers or to take the lead in accessing such services, when many, do not have the capacity, resources or requisite knowledge to do so. On the other hand, government agencies have the multidisciplinary resources and multiagency access to implement proactive early detection and intervention programmes as recommended by certain rights advocates.
- The fragmented delivery of services to children with disabilities and the lack of cohesion between the primary government agencies suggest that the current organisation structure under the National Council for Persons With Disabilities may be less than ideal. Any body that coordinates the formulation and delivery of services to children with disabilities should have sufficient and direct authority over the various ministerial departments concerned.

- The functions and role of the National Council should be enhanced so that it is empowered to directly formulate, coordinate and enforce multidisciplinary and multiagency policies, strategies and programmes for children with disabilities.
- The National Council should also be empowered to facilitate and oversee funding for programmes and services, by liaising directly with the Ministry of Finance and the ministries that execute these programmes and services, to request the allocation and disbursement of funds.
- Some of the barriers to accessing services such as the inability of certain communities to attend rehabilitation services in health care centres and CBR centres may be overcome by leveraging on the services run by other government agencies that routinely access these communities.
- There should be a shift to a more proactive approach in the delivery of services to children with disabilities. The core objective should be that the various services for children with disabilities must be seamless, so that there is no gap through which the agencies could lose supervision of a child with disabilities.





4. EARLY DETECTION OF CHILDREN WITH DISABILITIES

- Effective early detection programmes require a multi-disciplinary approach, involving the three government agencies that provide key services – the MOH, MOE and DSW. Expertise from each of these sectors should be incorporated as core elements in early detection process.
- The current early detection programmes are reactive and not proactive, as they depend largely on the diligence or ability of parents / guardians to monitor the child and actively participate in the process.

Recommendations

- The Recommendations in the Memorandum on Early Childhood Intervention (2006) proposed by the National Early Childhood Intervention Council should be adopted.
- Any early detection programme must be a multi-disciplinary and multiagency effort. Expertise from each of these sectors should be incorporated as core elements in early detection processes. This core strategy must be proactive. and screening tools used must be validated.



5. HEALTH

- Healthcare services for children with disabilities have advanced significantly in recent years. The MOH health monitoring programme for 0 – 6 year olds is to be commended.
- However, there remains a shortage of skilled health care providers to work with children with disabilities while access to the centres is difficult for certain segments of society particularly those in rural areas and the urban poor.
- The fee schedule for citizens vs.
 non-citizens should be reviewed to
 ensure all children with disabilities
 can access the public health care
 system.

- Health care providers in hospitals and health centres should be sufficiently trained in the health needs of children with disabilities.
- Sufficient numbers of specialised health care providers such as physiotherapists, occupational therapists, clinical psychologists and psychiatrists, should be available at all medical facilities that offer services for children with disabilities.
- The Public Works Department's criteria for clinical psychologist should be tightened to ensure adequately trained psychologists are employed.
- The MOH should mobilise healthcare services and leverage on other government agencies such as the Ministry of Transport, the Ministry of Rural and Regional Development and state governments to access rural and interior areas.

7



6. EDUCATION

- Within the schooling system, there are problems identifying children with disabilities through the LINUS screening test.
- Teachers in special needs
 education are not sufficiently trained
 and there is a limited availability of
 speech and language therapists and
 educational psychologists in
 national schools.
- The implementation of the Inclusive Education Programme in mainstream schools is poor.

Recommendations

- Only adequately validated screening tools should be used to identify children with special needs in schools.
- All teachers should undergo basic training in special needs education.
- The facilities and infrastructure in all schools should be upgraded to be disability friendly.
- The government should work with NGOs in early intervention, special education and skills training programmes for children with disabilities.
- There should be immediate efforts to implement inclusive education in schools and the recommendations of the National Early Childhood Intervention Council in its Memorandum on Inclusive Education should be considered for adoption in the new national education blueprint.



7. COMMUNITY-BASED REHABILITATION

- The number of CBR centres nationwide and the continued yearly increase is encouraging, as is the number of participants.
- However, there remains a shortage
 of sufficiently trained personnel
 and equipment to conduct
 adequate rehabilitation activities,
 while access to the centres is difficult
 for certain segments of society.

- A full range of community-based rehabilitation services should be available in all CBR centres.
- Sufficient numbers of trained personnel and more resources such as rehabilitation equipment should be made available to provide proper rehabilitation services at CBR centres.
- The DSW should work together with communities to mobilise the services provided at CBR centres and leverage on other government and state agencies to access rural and interior areas.





8. PROTECTION

- Children with disabilities are particularly susceptible to abuse, and are three to four times more likely to be victims of violence.
- Child protection policies should include strategies, services and resources that specifically cater to this group.
- There is inadequate information on violence / abuse and exploitation of children with disabilities.
- There is inadequate information on the number and situation of children with disabilities in institutional care.

Recommendations

- Child Protection Teams, Protectors, social workers, medical workers, police officers and others involved in the child protection services should undergo specialised training on how to work with children with disabilities.
- Where the child in need of protection has a disability, an officer specially trained in that particular disability should be on hand to assist the child.
- A routine programme of home-visits in both private homes and institutions that have children with disabilities should be implemented.
- Research should be conducted to establish the nature and magnitude of violence, abuse, ill-treatment and neglect for children with disabilities in residential care.



9. ACCESS

- The provision of access to premises and transportation is intertwined with the ability of children with disabilities to fully utilise their other basic rights, such as to healthcare and education.
- There are insufficient means of access to public transport facilities for children with disabilities.

- All buildings and public spaces (including older ones) should be out-fitted with a full range of facilities for persons with disabilities, and a timeline for compliance should be set.
- All public transport vehicles must be disabled-friendly and a timeline for compliance should be set.
- When providing education, healthcare and rehabilitation programmes to children with disabilities, the government agencies concerned should ensure that the services and facilities are easily accessible.



Art by Nur Aishah Abd Aziz



ANNEX 1: NATIONAL BODIES THAT PROVIDE FUNCTIONS AND SERVICES FOR CHILDREN WITH DISABILITIES

<u></u>	
ORGANISATION	FUNCTIONS AND SERVICES
Malaysian Council for Rehabilitation	 Coordinates the work of voluntary disability organisations in the country Promotes the concept of Full Participation and Equal Opportunities for persons with disabilities Collaborates with state, national and international bodies to develop and promote meaningful habilitation and rehabilitation services for persons with disabilities Promotes early intervention programmes to equip persons with disabilities with basic living techniques and compensatory skills, provide parents with knowledge and skills in counselling and foster the development of self-reliance among persons with disabilities
	 Teaches and promotes Abilympics 192 and Very Special Arts 193 Conducts workshops and training in traditional dance, drumming, music and handicrafts Organises biennial national rehabilitation conferences to share knowledge and expertise and update information on developments in rehabilitation programmes for persons with disabilities
Malaysian Council for Child Welfare ¹⁹⁴	 Promotes the well-being of children Complements government efforts in the welfare and development of children Promotes the general principles embodied in the Convention on the Rights of the Child
Malaysian Association for the Blind (MAB) ¹⁹⁵	 Advocates for the rights and welfare of persons with visual disabilities Conducts early intervention programmes to assess and train children who are blind or have low-vision Conducts educational programmes, rehabilitations courses, vocational training and placement services
National Council of Welfare and Social Development ¹⁹⁶	 Advocates the development and wellbeing of (amongst others) persons with disabilities Acts as the primary body for all welfare and social development organisations
Malaysian Paralympic Council ¹⁹⁷	 Implements and maintains a "Sports For All" policy to benefit the quality of life of persons with disabilities Coordinates participation of persons with disabilities in international paralympic events

ANNEX 2: NON-GOVERNMENT ORGANISATIONS THAT WORK FOR CHILDREN WITH DISABILITIES

	NGO	DISABILITY	SERVICES	ACTIVITIES / PROGRAMMES
1.	Asia Community Service ¹⁹⁸	Learning disabilities	Early intervention Skills training Educational therapy Awareness	 Provides early childhood special education to toddlers and pre-school children Conducts transition programmes for entry into regular pre-schools and mainstreaming schooling which focuses on the areas of social competence, communication, self-help skills and pre-academic skills Conducts inclusion support programmes for pre-schools by providing training, resources and consultation support to enable screening of students
2.	Association of Learning Disabilities, Petaling District ¹⁹⁹	Learning disabilities	Education therapy Skills training Vocational training Advocacy	 Provides learning and training programmes Advocates integrated education programmes Promotes independent living
3.	Association of Resources & Education for Autistic Children (REACH) ²⁰⁰	Autism	Early intervention Skills training Educational therapy Advocacy & Awareness	 Provides early intervention and skills training including computer classes, sensory integration, music and movement and pre-vocational training Provides resources and information on autism Advocates and supports integration and inclusion of children with autism into mainstream education and society.
4.	Bethany Home ²⁰¹	Learning disabilities	Early intervention Skills training Rehabilitation	 Conducts early intervention programmes Conducts skills training programmes Conducts rehabilitation programmes



ANNEX 2: CONTINUED

170	NGO	DISABILITY	SERVICES	ACTIVITIES / PROGRAMMES
5.	Bureau of Learning Difficulties (BOLD) ²⁰²	Learning disabilities	Early intervention Skill training Educational therapy Advocacy & Awareness	 Provides early intervention and skills training Conducts inclusive pre-school programmes in pre-schools and schools by providing training and technical support to teachers and parents Provides resources on special needs Promotes effective early childhood intervention methods Promotes inclusive education in mainstream education
6.	CADS Enhancement Centre ²⁰³	Learning disabilities	Early intervention Skills training Rehabilitation Advocacy & Awareness	 Conducts vocational and technical training Conducts early intervention programmes Conducts rehabilitation programmes
7.	Cheshire Home ²⁰⁴	Learning disabilities	Early intervention Rehabilitation Advocacy & Awareness	 Conducts early intervention programmes Conducts rehabilitation services Advocates and campaigns for the rights of the disabled Provides skills training and residential care Provides skill and vocational training
8.	Down Syndrome Association of Malaysia ²⁰⁵	Down Syndrome	Early intervention Advocacy & Awareness	 Promotes integration and collaboration with the government to generate awareness towards persons with Down Syndrome Conducts weekday day care centre for children with down syndrome and hosts support group meetings for families Conducts early intervention programmes for children with developmental disabilities or delays

	NGO	DISABILITY	SERVICES	ACTIVITIES / PROGRAMMES
9.	Handicapped Children's Centre (HCC) ²⁰⁶	Learning and physical disabilities	Skills training	Provides training for the mentally retarded, physically disabled, multiple handicapped, hyperactive and those with Down syndrome and autism
10.	Kiwanis Centre for Learning Disabilities ²⁰⁷	Learning disabilities	Early intervention Skills training Educational therapy	 Conducts education and training programmes to provide self-help skills and behaviour modification therapy to enable continued education in normal mainstream schools
11.	Kiwanis Down Syndrome Foundation ²⁰⁸	Down Syndrome	Education Educational therapy Awareness	 Conducts special education programmes Conducts training of teachers in special needs education Maintains a comprehensive resource centre Promotes public awareness.
12.	Malaysian Association for the Protection of Children (MAPC) ²⁰⁹	Children (non-specific)	Protection Advocacy & Awareness	 Advocates for child rights Raises awareness on child abuse and neglect Protects children from abuse and neglect Supports abused children through the legal system to prevent further trauma
13.	Malaysian Federation of the Deaf ²¹⁰	Deaf / Hearing impaired	Skills training Advocacy & Awareness	 Advocates for the rights and needs of persons with hearing disabilities at all levels Conducts Independent Living Skills Programmes to train basic living skills to equip persons with hearing disabilities for entering the employment Operates a communication centre for the deaf (PUSKOM) which is a one-stop centre that provides sign language translators, sign language classes and various activities for persons with hearing disabilities



ANNEX 2: CONTINUED

	NGO	DISABILITY	SERVICES	ACTIVITIES / PROGRAMMES
14.	Malaysian Care ²¹¹	Learning disabilities	Early intervention Skills training Educational therapy Awareness raising	 Conducts early intervention programmes that provide educational and practical training for pre-school children Collaborates and provides training, resources and guidance with other organisations for the setting up and management of early intervention programmes throughout the country Conducts inclusive pre-school programmes in pre-schools by providing training and technical support to teachers and parents Collaborates with government departments and main-stream schools to provide teacher training and resources Conducts outreach programmes in urban poor and rural areas to identify and carry out intervention programmes
15.	National Council for the Blind (NCBM) ²¹²	Blind / Visually impaired	Advocacy & Awareness	 Coordinates the activities of member organisations for the blind Promotes progress in the fields of education, Braille literacy, rehabilitation and vocational training Runs the Malaysian Braille Press (MBP)
16.	National Early Childhood Intervention Council ²¹³	Disabilities (non-specific)	Advocacy	 Acts as a forum to discuss, advocate, monitor and review all policies and actions related to early child-hood intervention Promotes effective early childhood intervention methods Promotes inclusive education in mainstream schools Conducts biennial national conferences on early childhood intervention issues

	NGO	DISABILITY	SERVICES	ACTIVITIES / PROGRAMMES
17.	National Early Intervention Service (PPIA) ²¹⁴	Blind / Visually impaired	Training Advocacy & Awareness	 Provides resources Assists in education and rehabilitation through training and support services Coordinates employment opportunities Provides facilities, visual aids, reading materials in Braille, audio, digital and other forms easily accessible by the blind Encourages social integration and assistance in overcoming discrimination in education, employment and access
18.	New Horizons Society ²¹⁵	Learning disabilities	Early intervention Skills training	 Conducts early intervention programmes Conducts skills training programmes
19.	Society of Families of Persons with Learning Difficulties ²¹⁶	Learning disabilities	Advocacy Support of caregivers	 Acts as support network for families of persons with learning difficulties Develops appropriate care services and activities for persons with learning difficulties Advocates for the needs and rights of persons with learning difficulties.
20.	Society of the Orthopedically Handicapped ²¹⁷	Physically handicapped	Advocacy	 Promotes ways and means of improving the physical, special and economic conditions of the orthopedically handicapped Assists in the education and training of the orthopedically handicapped Organises sports, social and other events for the benefit of the orthopedically handicapped



ANNEX 2: CONTINUED

	NGO	DISABILITY	SERVICES	ACTIVITIES / PROGRAMMES
21.	Spastic Children's Association of Selangor and Federal Territory (SCASFT) ²¹⁸	Cerebral palsy	Educational therapy Rehabilitation	Provides educational therapy programmes Provides rehabilitation services
22.	Special Children Society of Ampang ²¹⁹	Learning disabilities	Education Skills training	Provides individual education programmes
23.	The National Autism Society of Malaysia (NASOM) ²²⁰	Autism	Assessment and Diagnosis Early intervention Skills training Educational therapy Vocational training Advocacy & Awareness Support for caregivers	 Conducts autism intervention programmes; Conducts programmes to integrate children into main-stream schools Conducts pre-vocational training programmes and vocational programmes Promotes treatment, education, welfare and acceptance of people with autism Provides advice for families of people with autism
24.	United Voice	Learning disabilities	Advocacy	 Provides assistance and training in developing self- advocacy for those with learning disabilities
25.	Y-Self Reliance Centre for the Deaf (YMCA)	Deaf / Hearing impaired	Intervention Education Skills training Awareness	 Promotes early education, bilingual education and training opportunities Promotes public awareness of deafness and participation of the deaf community in society



Art by Niresh



CHAPTER 2

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- 15. Laws of Malaysia, Federal Constitution, Article 8 (2).
- 16. Laws of Malaysia, Federal Constitution, Article 12(1).
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- UN Committee on the Rights of the Child (CRC), UN Committee on the Rights of the Child: Initial Report of States Parties Due in 1997, Malaysia, 22 December 2006, CRC/C/MYS/1, p. 21.
- 19. Article 2 of the CRC reads:
 - "State Parties shall respect and ensure the rights set forth in the present Convention to each child within their jurisdiction without discrimination of any kind, irrespective of the child's or his or her parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national, ethnic or social origin, property, disability, birth or other status."
- The complete definition of "child" under Section 2 of the Child Act is as follows: "achild" – Means a person under the age of eighteen years; and
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Andrea Painter 13 years old Cerebral Palsy

Children with disabilities have abilities too.

Like all children, they should be defined by their talents, not their limitations. It's time to see the child before the disability.

Disable our misconceptions. Enable their lives.

Show your support. Visit disable2enable.unicef.my













Despite my limited eyesight,

I love the beautiful colours

of the hibiscus flowers;

which symbolise both my
happiness and my sadness.

The dusky orange hibiscus
represents my deep sadness
because there are
some people who insult and
make fun of my disability.

But there are also flowers
which are pink. These are the
colours of love and compassion which
I hope to receive from
the people around me.

Nurafidah Mohamed (16)

Visual disability

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