

Report of the Round Table Meeting on Children with Disabilities

3 June 2013

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Final Draft: 14 JUNE 2013

REPORT OF THE ROUND TABLE MEETING ON 3 JUNE 2013 ON CHILDREN WITH DISABILITIES

1. On 3 June 2013, UNICEF launched the State of the World's Children (SOWC) 2013 Report in Malaysia, at the Park Royal Hotel in Kuala Lumpur. The focus of SOWC 2013 is children with disabilities, and following its launch, UNICEF conducted a round table meeting on children with disabilities to discuss and exchange information on issues affecting the full realisation of the rights of children with disabilities in Malaysia.
2. The launch and the round table discussion was attended by 54 people and included representatives from the Ministry of Women, Family and Community Development (MWFC), the Ministry of Health (MOH) and the Ministry of Education (MOE), representatives from numerous national bodies, non-government organisations, corporates, UN agencies as well as individuals who work with and promote the rights and interests of children with disabilities. The **Attendance List** for the event is annexed as **Appendix 1** to this report.

THE LAUNCH OF SOWC 2013

3. The events of the day commenced with the screening of the '*SOWC 2 Lives video on Malaysia – Sports*', produced by UNICEF-Malaysia. Thereafter, Ms. Wivina Belmonte (UNICEF Representative to Malaysia) gave the welcoming address, followed by opening remarks from Datuk Harjeet Singh (Deputy Secretary-General, MWFC). The full text of Wivina Belmonte's **Welcoming Address** is annexed as **Appendix 2** to this report and the full text of Datuk Harjeet Singh's **Opening Remarks** is annexed as **Appendix 3**.
4. Mr. Azril bin Che Ibrahim, a 20 year old who is blind then spoke about his experiences with his loss of sight, the difficulties he had to overcome in obtaining an education and how he eventually represented Malaysia in international 'blind futsal' tournaments.
5. Datuk Harjeet Singh and Mr. Azril bin Che Ibrahim officiated the launch of SOWC 2013.

THE ROUND TABLE MEETING

The Objectives of the Meeting

6. The objectives of the round table meeting were:
 - To share with stakeholders the key findings, conclusions and recommendations of the mapping report conducted by UNICEF;

- For the key government ministries and departments to give an overview of government policies, laws and programmes for children with disabilities and critical challenges / gaps to fulfilment of rights for children with disabilities;
- For NGOs to share some of their programmatic responses and key issues and challenges to full realisation of rights for children with disabilities; and
- To identify concrete recommendations on what UNICEF should do to support on-going policy and programmatic initiatives related to children with disabilities in Malaysia.

Presentation by Cliff Meyers

7. The meeting commenced with Cliff Meyers, the Regional Education Advisor of UNICEF (EAPRO), providing a summary of the global and regional perspectives on the rights of children with disabilities and UNICEF's work in promoting such rights. Mr. Meyers explained the evolving concept of disability, from a medical model to a social model. He also addressed the fundamentals of moving from an exclusionary to inclusionary society, such as:

- changing attitudes;
- focusing on the ability of the child and not setting limits;
- supporting the child and his / her family;
- community based rehabilitation (CBR);
- building assistive technology; and
- incorporating universal design in all facilities.

8. Mr. Meyers also summarised the key recommendations in the SOWC 2013:

- 8.1 **Ratify and implement the CRPD**, which contains specific provisions on inclusion of children with disabilities in education;
- 8.2 **Fight discrimination and enhance awareness**, which must be implemented at a leadership level, in policies and guidelines, at the operational level and at an individual level;
- 8.3 **Dismantle barriers to inclusion**, for example in schools, health facilities and public transport;
- 8.4 **End the institutionalisation of children with disabilities**, since institutional care is often seen as a first option for children with disabilities;
- 8.5 **Support families to meet higher costs of living and lost economic opportunities**, for example by providing vouchers for hospital care and schools, transport allowance,

income subsidies, social welfare schemes and protection measures, as well as ensuring affordable assistive technology and reducing barriers and stigma for families;

- 8.6 **Move beyond minimum standards** by, for example, applying child friendly principles, conduct monitoring using rubrics rather than simple checklists and involve children and adolescents with disabilities in target-setting and monitoring;
 - 8.7 **Coordinate services across all sectors** by for example, organising community centres and pre-schools that are accessible to all children, linking early detection with referral and support, avoiding secondary disabilities, linking social protection and welfare with education and health, having resource centres that reach out to schools and communities with skills, medical support and educational support;
 - 8.8 **Involve children and adolescents with disabilities as decision makers** in target-setting and monitoring, utilising self-assessments by service providers, families and children as the basis for plans and targets and respecting children with disabilities as agents of change; and
 - 8.9 **Promote a concerted global research agenda.**
9. Mr. Meyers ended his presentation with a list of ways through which UNICEF is able to support children with disabilities:
- 9.1 Conducting research on the status of children with disabilities, situation analysis, good practices, barrier and bottleneck analysis;
 - 9.2 Policy review and reform;
 - 9.3 Assist in integrated early childhood detection centres;
 - 9.4 Facilitating capacity development by conducting training and skills development;
 - 9.5 Setting implementation guidelines;
 - 9.6 Facilitating coordination and networks to strengthen NGOs and support government agencies;
 - 9.7 Assist in providing resource centres that reach out to schools and communities;
 - 9.8 Facilitating advocacy through the media.

Should we include Cliffs presentation as annex 4 ?

Presentation of Key Findings of UNICEF-Malaysia's Mapping Study

10. Cliff Meyer's presentation was followed by the presentation of a summary of the issues, conclusions and recommendations of UNICEF-Malaysia's Mapping Study on the Policies, Programmes, Interventions and Stakeholders for children with disabilities in Malaysia. Dr. Victor Karunan, the Deputy Representative of UNICEF-Malaysia provided a background to the mapping study and its context in relation to the round table meeting.
11. Ms. Mahaletchumi Balakrishnan, the consultant for the Mapping Study, presented its key findings, beginning with a brief outline of the mapping sectors under the study, the methodology used and the constraints faced. A summary of the key findings is as follows:

Sector	Key Findings and Recommendations
Laws and Policies	<p>On the international level, Malaysia has signed on to both the CRC and CRPD, although it has placed a number of reservations in relation to each. Malaysia has yet to sign the Optional Protocol to the CRPD, which sets up two complaints and redress mechanisms for those aggrieved by a violation of the CRPD by parties to the convention.</p> <p>On the national level, there is no specific legislation or national policy for children with disabilities. The policies and strategies for children with disabilities are subsumed within two Acts, the PWD Act and the Child Act, and the national policies enacted under them are as follows:</p> <ul style="list-style-type: none"> (a) National Policy for Persons with Disabilities and National Plan of Action for Persons with Disabilities, which covers access to education, healthcare, information, public facilities, public transportation system and recreation, sports and leisure; (b) National Policy for Children and Action Plan, which covers survival, protection, development, participation and advocacy; and (c) National Child Protection Policy & Action Plan which covers protection of children who have been abused, neglected or ill-treated. <p>Malaysia has signed on to the Incheon Strategy, which was developed by the United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP). It is the first set of regionally agreed disability-inclusive development goals that aims to create an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific.</p> <p>The key findings and recommendations from the Mapping Study in respect of the legal and policy framework for children with disabilities were as follows:</p>
Sector	Key Findings and Recommendations
Laws and Policies	<ul style="list-style-type: none"> • Malaysia's reservations to the CRC and the CRPD should be lifted and it

(cont'd)	<p>should sign the Optional Protocol to the CRPD.</p> <ul style="list-style-type: none"> • There is no prohibition against the discrimination of persons with disabilities in the Malaysian Federal Constitution. This is inconsistent with the CRPD, which prohibits discrimination against persons with disabilities. This gap in the Federal Constitution could allow laws that discriminate against persons with disabilities to still be passed and enforced in the country. It is recommended that the Federal Constitution should be amended to include prohibitions against discrimination of persons / children with disabilities. • There are also no penalties or a redress mechanism in the PWD Act to address violations of the Act. It is recommended that the Act should be amended to include penalties and a redress mechanism against violations of the Act. • The recent commitment to the Incheon Strategy and the intention of the Malaysian government to draft a new Plan of Action for persons with disabilities that takes into consideration the goals and targets of the Incheon Strategy, is welcomed. Where necessary, the National Policy for Persons With Disabilities and all health and education policies relating to persons / children with disabilities should be harmonised.
Defining Children With Disabilities	<p>Malaysia does not use a single definition or classification of children with disabilities across all services sectors:</p> <p>(a) The definition of persons with disabilities under the PWD Act includes <i>“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”</i>.</p> <p>(b) Under the registration system established by the MWFCDD, those with hearing disabilities, visual disabilities, speech disabilities, physical disabilities, learning difficulties, mental disabilities and multiple disabilities may register as persons with disabilities.</p> <p>(c) However, under the Education (Special Education) Regulations 1997, only children who are able to manage themselves without help are eligible for the special needs education system. Those who are physically handicapped with the mental ability to learn like normal pupils and those with multiple disabilities, profound physical handicap or severe mental retardation are not eligible.</p> <p>It is recommended that the limitations to eligibility for special needs education in the education regulations should be removed and a standard definition of children with disabilities should be adopted for all sectors of service.</p>
Sector	Key Findings and Recommendations
Data on Children With	<p>Currently, there is no comprehensive data collection mechanism and there is insufficient disaggregation of the data that is available. Three sources of data</p>

Disabilities	<p>were considered:</p> <p>(a) The DSW collects data on persons with disabilities through the non-compulsory registration process. However, this data is insufficiently disaggregated by age and since the registration process is not compulsory, the data is non-conclusive. The total number of registered persons with disabilities as at the end of 2012 is 445,006, which is approximately 1.6% of the total population in Malaysia. This percentage is significantly lower than the estimated average percentage of persons with disabilities in a community, which is said to be approximately 10% of the total population. The number of children with disabilities from the total of 445,006 is unknown. However, since 2010, the DSW's registration system has been electronised with online registration available. This enables registration data from 2010 onwards to be disaggregated by age, gender and type disability.</p> <p>(b) The MOH collects data from the registration of children with disabilities at hospitals and health centres, and this data is disaggregated into specifics of age, gender and type of disability. However, the data is non-conclusive because the registration process is not compulsory.</p> <p>(c) The MOE has data on the number children enrolled in the special needs education system. Again, as a source of data, the statistics are not conclusive since only a portion of children with disabilities qualify for special needs education and a large portion of children with disabilities are not in the national education system.</p> <p>The lack of reliable data on children with disabilities affects the ability to develop policies and programmes targeting children with disabilities. It is recommended that the Ministries concerned should work together to establish a systemised and comprehensive data collection mechanism.</p>
Key Stakeholders	<p>Three key national stakeholders were mapped who were responsible for the majority of programmes and services concerning children with disabilities. They are the MWFCDD, the MOH and the MOE. Their functions and services overlap in certain areas.</p> <p>In addition, the National Council for Persons With Disabilities that is established under the PWD Act has overall responsibility to oversee, co-ordinate and monitor the implementation of national policies and plans of action. It is chaired by the Minister in the MWFCDD and comprises senior government officers from the DSW, the MOH, the MOE, Ministry of Transport, Ministry of Human Resources and Ministry of Finance. There are 6 committees under the National Council each with specific focus areas: transport, employment, education, universal design and building environment, quality of life care and registration of persons with disabilities.</p>
Sector	Key Findings and Recommendations
Key Stakeholders	<p>Apart from the government stakeholders, there are also national bodies and non-government organisations that represent and provide support services</p>

(cont'd)	for the disabled community and that advocate for the rights of persons with disabilities and specifically children with disabilities. Many NGOs run early detection and intervention programmes, special education and skills training programmes and rehabilitation services.
Underlying Shortcomings in Policies, Stakeholders & Programmes	<p>The Mapping Study found several underlying and interrelated shortcomings that underpin the planning and execution of programmes and services for children with disabilities.</p> <ul style="list-style-type: none"> • A number of services provided by different agencies, such as MOH's health centres and the DSW's CBR centres may be optimised by synergising some resources and facilities. • Similarly, detection and intervention of children with disabilities are carried out by the MOH and the MOE at different age groups, and the shortcomings in their reach and effectiveness could be reduced by the ministries combining infrastructure and expertise. • Some of the barriers to accessing services such as the inability of certain communities to attend rehabilitation in health centres and CBR centres may be overcome by leveraging on the services run by other government agencies that routinely access these communities. • In addition, there should be a shift to a more proactive instead of reactive approach to the delivery of services to children with disabilities. 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. However, many, especially those in the lower income group, may not have the capacity, resources or requisite knowledge to do so. Government agencies have the multidisciplinary resources and multi-agency access to implement programmes proactively. • 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 supervision of a child with disabilities may be lost. • To improve cohesion between government agencies and programmes, it is recommended that the functions and role of the National Council should be enhanced so that it is empowered to directly formulate, coordinate and enforce multidisciplinary and multi-agency policies and programmes. 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 for allocation and disbursement of funds.
Sector	Key Findings and Recommendations
Early	It has been stated that more than 95% of CWDs and their families are accessible by public health staff in the newborn period and in primary school under existing programmes. Therefore, the roles that the MOH and the MOE

Detection	<p>play in the early detection process cannot be overstated.</p> <p>(a) Currently, the MOH combines certain screening tests (such as for autism) and tracks child development in its monitoring programme that it runs for 0 – 6 year olds in government hospitals and health centres.</p> <p>(b) The MOE conducts Literacy and Numeracy Screening (LINUS) tests on all students in the first three years of primary level education. Where a child fails these tests repeatedly, his / her parents are asked to refer the child to the MOH for further medical assessment and screening.</p> <p>Observations made in respect of early detection include the following:</p> <ul style="list-style-type: none"> • Effective early detection programmes require a multidisciplinary approach and should involve the MWFC, MOH and MOE. Expertise from each should be incorporated in the process. • Early detection programmes should be proactive, not reactive. The current programmes depend largely on the diligence or ability of parents / guardians to monitor the child and actively participate in the process. • The screening tools used in early detection must be validated. • The implementation of a compulsory and multidisciplinary screening programme for 0 – 8 year olds should be considered, as recommended by the National Early Childhood Intervention Council (NECIC).
Healthcare	<p>With regard to healthcare services for children with disabilities:</p> <p>(a) The MOH has 242 health centres with rehabilitation services, which are serviced by paramedics such as public health nurses and medical assistants. Physiotherapists and occupational therapists based in government hospitals provide input and supervise the cases in these health centres. Certain health centres with heavy attendances have their own physiotherapists and occupational therapists.</p> <p>(b) The MOH also provides technical input and outreach services to most CBR centres.</p>

Sector	Key Findings and Recommendations
Healthcare (cont'd)	<p>Observations made in respect of healthcare services include the following:</p> <ul style="list-style-type: none"> • Healthcare services for children with disabilities have advanced significantly in recent years, and the MOH should be commended for their efforts. However, a number of impediments stand in the way of the optimisation of these services. • There is a deficiency in skilled health care providers at every health centre, including physiotherapists, occupational therapists, clinical psychologists and psychiatrists. • While most parents send their children to CBR centres for screening, intervention and rehabilitation, the MOH's allocation of manpower and resources to these centres is limited. Not all of the CBR centres are serviced by the MOH's healthcare providers, and the healthcare providers are only able to visit those centres once a month for screening and intervention programmes. • There also remains a severe lack 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. Health centres are generally located in cities and towns. While the health teams at these centres do carry out home visits in cases of children with severe disabilities, there remain many children with disabilities, 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.
Education	<p>There are three different schooling options for children with disabilities in national special needs education system:</p> <ul style="list-style-type: none"> (a) Special Education Schools (schools for children with disabilities); (b) Special Education Integrated Programmes (SEIP), (classes in mainstream schools dedicated to children with special needs); and (c) Inclusive Education Programmes, (children with disabilities are integrated into mainstream classes).

Sector	Key Findings and Recommendations
Education (cont'd)	<p>Observations in respect of the special needs education system are as follows:</p> <ul style="list-style-type: none"> (a) Eligibility requirements for special needs education under the education regulations exclude a number of categories of children with disabilities. (b) Within the schooling system, there are problems identifying children with disabilities through the LINUS screening test. (c) The quality of special education teachers varies enormously, and the training syllabus for special education teachers needs to be reviewed. (d) In addition, there is also an extremely limited availability of speech and language therapists and educational psychologists in national schools. (e) The principle shortcoming in the special needs education system is the failure to make inroads in the implementation of Inclusive Education in mainstream schools. In 2012, only 562 children with disabilities were enrolled in the Inclusive Education Programme in mainstream classes. This figure represents around 1% out of the 50,738 children with disabilities enrolled in special needs education in that year. <p>The following actions are recommended with regard to special education:</p> <ul style="list-style-type: none"> • Immediate efforts to implement inclusive education practices; • Basic training in special needs education for all teachers; • Upgrade facilities and infrastructure in all schools to cater for students with a range of disabilities; • Work together with NGOs with experience in early intervention and special education initiatives; • Consider the strategies for the implementation of inclusive education recommended by the NECIC, which include training of teachers and development of curricula. <p>The Preliminary Report on the New Education Blueprint by the Malaysian government (for 2013 – 2025) seeks to focus on Inclusive Education for children with disabilities and to reach a target of 75% enrolment in Inclusive Education programmes by 2025. This proposal is encouraging. However, NGOs like the NECIC have questioned some of the strategies and targets in the Blueprint. It is understood that the government is taking into account the</p>

	issues raised by these NGOs and is in the midst of revising the Blueprint.
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Sector	Key Findings and Recommendations
CBR	<p>CBR centres are established throughout the country by the DSW and community groups. A CBR centre is meant to be a one-stop centre for persons with disabilities, and is intended to provide such services as diagnosis, rehabilitation, treatment, special education and vocational training. There are currently about 486 CBR centres across the country.</p> <p>Observations with regard to the operation of CBR centres include:</p> <ul style="list-style-type: none"> (a) While CBR centres are placed within communities for accessibility, many parents still find it difficult to access them and many are unaware of the service. (b) The CBR centres have a shortage of adequately trained staff, and even trained therapists. Where there are therapists, their numbers are often insufficient to handle the case loads. (c) Children with severe disabilities are often confined to the home and are unable to access CBR centres for any intervention. Some CBR teachers / trainers 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 / trainer. <p>The following actions are recommended to be taken with regard to CBR:</p> <ul style="list-style-type: none"> • Provide a full range of CBR services in all CBR centres; • Increase the number of trained personnel in each CBR centre; • Increase and concretise tie-ups with other bodies for more expertise and resources, for example with the MOH, the MOE and NGOs with experience in rehabilitation, treatment and vocational training.
Protection	<p>SOWC 2013 states that children with disabilities are particularly susceptible to abuse, and are three to four times more likely to be victims of violence. 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.</p>

Sector	Key Findings and Recommendations
Protection (cont'd)	<p>Some of the child protection services available in Malaysia are:</p> <p>(a) Child Protection Teams (the composition of which includes a social worker, a medical officer and a senior police officer) which coordinate district-based services to families and children in need of protection. In addition, 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.</p> <p>(b) 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 and provide clinical management, counselling, temporary shelter and assists in arranging for social welfare, shelter and legal support for the victims of child abuse. 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.</p> <p>Observations in respect of protection services include the following:</p> <ul style="list-style-type: none"> • Child advocacy groups have said that the interagency collaboration between the MOH's SCAN Teams, the police and Protectors under DSW helps make the process of reporting an abuse less traumatic. • However, 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, other relevant professionals who need to work with the child must be trained to work with children with disabilities. • There are an insufficient number 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. • There is inadequate information on the abuse / exploitation of children with disabilities. There is also inadequate information on the number and situation of children with disabilities in institutional care. A study should be conducted to analyse the risks and vulnerabilities of children

	with disabilities to abuse and neglect in institutional care.
Sector	Key Findings and Recommendations
Accessibility	<p>The provision of access to premises and transportation is connected to the ability of children with disabilities to fully utilise their other 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. In the education system, the lack of disabled-friendly infrastructure or facilities in a school can determine whether or not the school will accept a child with disabilities into mainstream classes under inclusive education.</p> <p>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.</p> <p>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.</p> <p>The following actions are recommended:</p> <ul style="list-style-type: none"> • All buildings (including older ones) should be out-fitted with a full range of facilities for persons with disabilities, and a deadline for compliance must be set. • All public transport vehicles and facilities must be disabled-friendly and a timeline for compliance should be set.

Presentations by Key Government Stakeholders

12. The presentation of the summary of the Mapping Study was followed by presentations by representatives of three government ministries, the MWFC, the MOH and the MOE, who provided an overview of policies, laws and programmes for children with disabilities and the gaps and constraints they face.

Ministry of Health (MOH)

13. The first presentation was by Dr. Aminah Bee binti Mohd. Kassim (Deputy Director of the Family Health Development Division, MOH). She identified the following constraints faced by the MOH:

- Insufficient knowledge;
- Insufficient networking;
- Lack of manpower (i.e. of skilled professionals);
- Attitude of service providers, including medical professionals;
- Insufficient funding.

14. Dr. Aminah Bee summarised the MOH's programmes for children with disabilities as follows:

- Prevention and promotion of screening and treatment;
- Early detection and treatment;
- Disability limitation and rehabilitation.

15. She stated that the MOH has a format for registration for children with disabilities and a Health Care for Persons With Disabilities 2011 – 2020 Plan of Action. With the assistance of NGOs, the MOH also develops screening instruments for children and disability-specific manuals and guidelines for medical professionals and care-givers.

16. She further mentioned that there is insufficient training of medical students in the universities to identify and treat learning disabilities. She said that the MOH has begun to conduct training programmes (such as on management of the child, early detection and prevention and disability awareness training). She also pointed out that proper training is most effective in small groups and through an intensive programme, which is both time and cost consuming.

17. Dr. Aminah Bee stressed the need to increase expertise to work with the child, the family, the community and the government, to empower parents to detect the early signs of disability and to care for the child. She also pointed out the need for strengthening interagency cooperation and the public support system for children with disabilities.

18. She also referred to the new MOH record book for children between 0 – 6 years, which allows health centres and hospitals to monitor the development of children in that age group by fixing appointments for the parent / care-givers to bring the child in for follow-ups. In respect of CBR centres, Dr. Aminah Bee added that the MOH currently provides technical support to 474 CBR centres.

19. **Dr. Aminah Bee's Slide Presentation** is annexed to this report as **Appendix 5**.

Department of Social Welfare (DSW)

20. Ms. Yeoh Joo Ai who is the Senior Principal Assistant Director of the Social and Community Development Division of the DSW, presented an overview of the MWFCDD's policies, laws and programmes for children with disabilities. She stated that based on the registration data of the last three years under the new SMOKU online registration system that allows for disaggregated data, 37% of registered persons with disabilities were children.

21. She pointed out that the DSW provides financial assistance for children with disabilities and for the purchase of prosthetics and that the DSW has set up 7 institutions for rehabilitation and care of children with disabilities under the 'Taman Sinar Harapan' institutions. She further noted that CBR centres are currently still heavily funded by the DSW, and that the MWFC targets to open at least 20 new CBR centres a year.
22. Ms. Yeoh Joo Ai stated that some of the challenges the DSW faces is that its data is not comprehensive and not integrated. Further, she noted that the skill level among services providers needs to be improved to be able to cater for the multiple needs of children with disabilities. She further pointed to insufficient family support services and insufficient physical accessibility for persons with disabilities.
23. **Ms. Yeoh Joo Ai's Slide Presentation** is annexed to this report as **Appendix 6**.

Ministry of Education (MOE)

24. Ms. Lim Weng Fong, Assistant Director of Planning and Evaluation in the Special Education Division of the MOE presented an overview of the special education provisions in Malaysia. She ran through the legislative provisions for special education in the Education Act 1996 as well as Malaysia's international commitments on the subject. She set out the three options available under the special education system, namely the Inclusive Programme, the Integrated Special Education Programme and Special Education Schools.
25. She provided the following data on the number of students enrolled in the special education system:

YEAR	2006	2007	2008	2009	2010	2011	2012
TOTAL	25,106	28,591	29,935	38,453	43,162	46,005	53,024

26. Ms. Lim Weng Fong also identified the following challenges in special education:
- Early detection and identification;
 - Intervention and rehabilitation;
 - Education for all;
 - Inclusiveness (physical, social and emotional);
 - Multiple disabilities;
 - Curriculum and assessment (quality and relevancy);
 - Employability and marketability;
 - Multi-agency coordination;
 - Mind-set and self-advocacy.

27. **Ms. Lim Weng Fong's Slide Presentation** is annexed to this report as **Appendix 7**.

Plenary Discussion

28. The presentations were followed by plenary discussions, in which a number of issues were raised:

28.1 There is a need for coordination, synergy and optimal allocation and utilisation of resources by and between government agencies. There is also a need to engage and involve other ministries / departments (apart from the DSW, MOH and MOE) that have a role to play with regard to people / children with disabilities, for example the Ministry of Housing and Local Government and the Ministry of Transport, etc.

28.2 While registration of children with disabilities is important, there needs to be an understanding of the pros and cons of registrations. For example, a child with disabilities with a registration card is likely to be automatically pushed into special education classes, which reinforces stigma and exclusion, even if the child is able to cope within mainstream classes.

28.3 With regard to the extent to which CBR programmes should operate independently of the government, the general consensus was that the government must continue to invest in CBR programmes and not leave them to be run purely as an NGO initiative / venture.

28.4 On inclusive education, while the government was aiming at total inclusion, there was a need for caution. Schools need to be prepared and equipped for inclusive education. Otherwise we may run the risk of failing the children we want to help.

28.5 To implement inclusive education, schools should engage teacher aids for children with disabilities. Big classroom sizes are also an obstacle to inclusive education. Classes should be smaller in order to effectively use teacher aids. There should be pre-training for all trainee teachers in basic special education.

28.6 The policies and social programmes relating to children with disabilities need to be disseminated widely within government agencies, to parents of children with disabilities and to the public. Currently, these policies and programmes are not known to many people and this lack of knowledge significantly impacts the ability to execute or enforce these policies and programmes.

28.7 Development of plans and policies for children with disabilities should be participatory and involve all the relevant stakeholders.

28.8 Data collection needs to be strengthened. While each of the primary ministries / departments collects data, it does not give a true picture of the prevalence of disabilities amongst children. A true picture can only be obtained by conducting specific disability studies. The MOH has conducted some studies on the prevalence of specific disabilities within the community. The MOE is currently trying to ascertain the exact

number of children with disabilities / special needs in national schools, as the data it currently has is not accurate.

- 28.9 There were some concerns that money targeted for special education in schools was being diverted for other uses. It was however clarified that money given to the schools is coded and in general, the money is used well and for the purposes for which it is allocated.

Presentation by representatives of NGOs

29. The meeting broke for lunch and when it reconvened, Mr. Phillip Chong from Malaysian Care spoke about his experiences as a person with autism.
30. This was followed by a presentation by Dr. Amar-Singh HSS, Senior Consultant Paediatrician (Community) and Head of the Paediatric Department at HRP Ipoh Hospital, Perak and President of the NECIC, who gave an overview of the initiatives, programmes, key challenges and obstacles to the full realisation of rights of children with disabilities in Malaysia. **Dr. Amar-Singh HSS's Written Paper** is attached as **Appendix 8** to this report.

Group Discussions

31. After Dr. Amar-Singh HSS's presentation, the participants were divided into three groups and to discuss the following questions:
- 31.1 What are the opportunities and constraints to collaboration between Government ministries and departments and with NGOs / private / corporate sectors for better realisation of the rights of children with disabilities?
- 31.2 What are the recommendations for strengthening linkages and collaboration between government agencies, and with NGOs and other actors to address physical, cultural, economic and attitudinal barriers hindering children with disabilities from accessing their full rights?
- 31.3 In what ways can UNICEF support on-going initiatives by government and NGOs in respect of children with disabilities?

Group One

32. Group One was of the opinion that in order to answer the issues posed for discussion, one should start by determining who is responsible for the realisation of the rights of children

with disabilities. **Group One's recommendations for strengthening linkages and collaboration between government agencies, NGOs and other actors were as follows:**

- 32.1 Remove physical barriers to access by engaging grassroots commitment. There are about 152 town councils across the country, and the federal government agencies should form local working committees with them that include people from various sectors and agencies including non-government organisations and persons with disabilities, to work on improving physical access to buildings and facilities.
- 32.2 The culture of acceptance of disabilities varies, from believing it's "God's will" to non-acceptance. A lack of awareness of disabilities heightens differences, so education is important. Education and awareness must start from young.
- 32.3 The people surrounding a child with disabilities (parents, friends and teachers) must be activated as a network of support for the child. A "buddy system" should be considered to help adjust a child with disabilities into mainstream schools. Personal assistants should be engaged in class for those with physical disabilities.
- 32.4 There should be general education for the public and specific education for the child diagnosed with a disability and his / her caregivers.
- 32.5 There should also be more training for professionals in the medical profession to work with children with disabilities and to understand policies and procedures relating to programmes and services for persons with disabilities:
 - (a) All doctors must be targeted with the right information and must be taught to be parent-focused.
 - (b) Doctors must also be trained on assessment of disabilities.
- 32.6 There should be more real life stories and personal accounts of children with disabilities to create more public awareness. The media should be engaged to assist in this endeavour.
- 32.7 The granting of disabilities allowance must be based on the disability and not based on the family's earnings.

33. On the question of how UNICEF can support on-going initiatives for children with disabilities, Group One made the following suggestions:

- 33.1 UNICEF, as a non-service agency, can be a neutral platform to facilitate discussions and coordination between various NGOs and ministries on a regular basis and also play the role of evaluator to 'audit' and set standards for policies and services;

- 33.2 With its wide connection network, UNICEF can bring more partners to the table, and integrate other organisations and government agencies;
- 33.3 UNICEF, as an international agency, has a wider public reach and can help take the issues facing children with disabilities to a wider audience to help create paradigm changes in society;
- 33.4 UNICEF can also play a role in capacity building by coordinating and facilitating international training for government agencies and non-government organisations, so that international standards can start being incorporated in local policies and programmes.

Group Two

34. Group Two identified a number of constraints and opportunities to collaboration between government agencies and non-government groups:

- 34.1 Where there is a scarcity of funding for programmes within one government agency, there may be funding available in a different ministry that could collaborate on a particular project.
- 34.2 There are programmes and services by different government agencies that overlap, but it is necessary to analyse the overlaps that are positive which increase reach, and those that are negative which replicate, and are an ineffective use of, resources.
- 34.3 Collaboration between the agencies and ministries should be communicated and operationalised.

35. Group Two made a number of recommendations for improving collaboration between government agencies and with non-government organisations.

- 35.1 There should be a non-political, multi-agency, multi-disciplinary body to oversee and monitor policies, programmes and services for children with disabilities, and the body should include corporations and persons with disabilities.
- 35.2 Any gap between the transition of a child with disabilities from one stage to another (for example, from early detection to schooling or from school to employment), should be closed so that a child's transitional needs through each stage are adequately catered for.
- 35.3 Organisations such as UNICEF and WHO should meet with ministries and NGOs on a regular basis to follow up on policies and programmes.

36. Group Two agreed with Group One's suggestion that UNICEF should create a neutral platform where all issues can be discussed between all stakeholders, and that UNICEF could play an important role in capacity building.

Group Three

37. Group Three saw possible opportunities for inter-government agency and NGO cooperation in the following areas:

- 37.1 The use of standardised screening tools;
- 37.2 Reviewing and agreeing on the methods to be used for data collection;
- 37.3 Advocacy on the CRC and the CRPD;
- 37.4 Widening the number of stakeholders involved in the delivery of services to children with disabilities, including the PEMANDU unit (from the Prime Minister's Office) and NGOs;
- 37.5 Amending the PWD Act and the regulations relating to special education;
- 37.6 Placing the National Council directly under the Prime Minister's Office, and for it to manage all affairs relating to persons with disabilities; and
- 37.7 Improving the coordination and cooperation between government agencies and NGOs on the running of CBR centres.

38. As for the constraints facing inter-government agency and NGO cooperation, Group Three identified the following issues:

- 38.1 There is insufficient monitoring and communication between government agencies and their officers on the ground;
- 38.2 There is a lack of continuity in policies and programmes, as there have been occasions where the policies and programmes change when the head of a particular department is replaced;
- 38.3 There are laws and regulations that impede the ability of government agencies to collaborate more with NGOs, and these need to be amended; and
- 38.4 There is a general lack of awareness of the rights of children.

39. Group Three made the following recommendations for improving collaboration between government agencies and with non-government organisations:

- 39.1 The National Council should be empowered to carry out policy determination and programme delivery;
 - 39.2 The policies and programmes for children with disabilities should be benchmarked against UNICEF and WHO standards;
 - 39.3 The government should collaborate with NGOs and corporate bodies on disability equality training.
40. Group Three also suggested that UNICEF could play a role by providing avenues for sharing of international expertise and conducting of training, as well as to monitor and comment on government programmes.

WRAP UP AND CONCLUDING REMARKS

41. The round table discussion concluded with Dr. Victor Karunan summarising the main issues and recommendations in the advancement of the rights of children with disabilities in Malaysia, as follows:
- 41.1 On the areas of laws and policies, there is a need to promote an understanding of the commitments that have been made by the government.
 - 41.2 On data collation, there needs to be a more robust, reliable and disaggregated data collection system. For children to be counted, it is necessary to know how many children with disabilities there are. UNICEF is able to contribute some expertise in this area.
 - 41.3 On the question of collaboration and partnerships between various entities:
 - (a) There is an overlap between some programmes and services, some of which are redundancies.
 - (b) A critical question is, who is leading? There is a bifurcation of responsibility, and the leadership for a particular programme has to be clearly located.
 - (c) It is important to establish formal and effective ways by which government agencies can work with others (such as NGOs, religious bodies and so on).
 - (d) There needs to be a move away from sectoral programming to holistic programming. The obvious answer is to move the programmes and services beyond a particular ministry, in other words, to move the overall leadership out.

- 41.4 The discussions at the round table meeting also illustrate that there needs to be a continuum of care of a child with disabilities so that his or her transition into adulthood or employment is also catered for and monitored.
- 41.5 There is also an urgent need to change mind sets and attitudes through awareness-raising initiatives. UNICEF can help in this area. This would include activities such as training of care-givers, teachers and welfare officers. In relation to this, partnerships should be forged with media organisations.
- 41.6 The question of protection of children with disabilities has not been dwelled on much, but it is an area that needs to be addressed.
- 41.7 Another important suggestion that came out of the deliberations in this round table meeting was providing opportunities for children with disabilities to speak for themselves. This involves advocacy and empowerment initiatives, in which UNICEF can play a part as it focuses on starting with the children themselves on advocacy and empowerment.
42. Dr. Victor Karunan stated that throughout the year, UNICEF will be working on a number of activities with the government and NGOs. UNICEF will facilitate dialogs like this round table meeting whether on general areas or in smaller groups on specific topics. As for standard setting, both UNICEF and WHO play a monitoring role under the CRPD and can use that platform for evaluation and to promote standards. UNICEF will also continue to push for the lifting of the remaining reservations to the CRC and the CRPD. It will also play an auditory role over national policies and programmes.
43. The round table meeting ended at approximately 5.15 pm with Dr. Victor Karunan thanking the speakers and participants.

Reported by: Mahaletchumi Balakrishnan

Date: 14 June 2013

Attached:

- Appendix 1** *Attendance List for the Launch of SOWC 2013 and the Round Table Meeting*
- Appendix 2** *Welcoming Address by Wivina Belmonte (UNICEF Representative to Malaysia)*
- Appendix 3** *Opening Remarks by Datuk Harjeet Singh (Deputy Secretary-General, Ministry of Women, Family and Community Development)*
- Appendix 4** *Slide Presentation by Dr. Cliff Meyers, Regional Education Advisor of UNICEF (EAPRO)*
- Appendix 5** *Slide Presentation by Dr. Aminah Bee binti Mohd. Kassim (Deputy Director of the Family Health Development Division, Ministry of Health)*
- Appendix 6** *Slide Presentation by Ms. Yeoh Joo Ai (Senior Principal Assistant Director of the Social & Community Development Division, Department of Social Welfare)*
- Appendix 7** *Slide Presentation by Ms. Lim Weng Fong (Assistant Director of Planning and Evaluation in the Special Education Division, MOE)*
- Appendix 8** *Dr. Amar-Singh HSS. Overview of initiatives & programmes, key challenges & obstacles to the full realisation of rights of children with disabilities in Malaysia. UNICEF Round Table Discussion on Children with Disabilities, 3 June 2013, Kuala Lumpur, Malaysia*

Appendix 1 - Attendance List for the Launch of SOWC 2013 and the Round Table Meeting

	Name	Position	Organization	E-mail address
1	Dr Aminah Bee	Deputy Director	Family Health Development Division, Ministry of Health	aminahbee@moh.gov.my
2	Dr Cheoh Siew Tin	Head Matron- Health	Family Health Development Division, Ministry of Health	cstin@moh.gov.my
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7	Rosmiati Ahmad	Assistant Secretary	Ministry of Women, Family & Community Development	rosmiati@kpwkm.gov.my
8	Yeoh Joo Ai	Principal Asst. Director, Social & Community Development Division	Department of Social Welfare	yeoh@jkm.gov.my
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12	Goh Soo Leng	Sign Language Interpreter	Malaysian Federation of the Deaf	adrienne_gsl@yahoo.co.uk
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16	George Thomas	Council Manager	CBR Network Malaysia	bobangt@yahoo.com
17	Chng Cheng Hui	Executive Secretary	PERKOBP (Society of Families of Person with Learning Difficulties)	perkobp@streamyx.com
18	Pauline Wong	Director	Malaysian Care	paulinewong@malaysiancare.org
19	Philip Chong		Malaysian Care	
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24	Sumit Pillai	Strategic Planning Director	Alpha 245 Agency	sumit.pillai@alpha245.com
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26	Nadiah Hanim	Head, CSR, Group CSR	Sime Darby Sdn. Bhd	nadiah.hanim@simedarby.com
27	Norhaslinda Salleh	Head of Corporate Planning & Strategy Section, Corporate Development & Policy Division	Companies Commission of Malaysia	norhaslinda@ssm.com.my
28	Dr Toh Teck Hock	Paediatrician & Head of Clinical Research Centre	National Early Childhood Council (NECIC)	thto@yahoo.com
29	Dr Lim Boon Hock	Special Needs Consultant	BH Lim Special Needs Consultancy	bhlim97@gmail.com
30	Dr Amar Singh HSS	Head Clinical Research Center Perak, President National Early Childhood Intervention Council (NECIC)	National Early Childhood Council (NECIC)	amarhss@gmail.com
31	Peter Tan	Senior Trainer	Disability Equality Training Forum Malaysia	mail@petertan.com
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33	Sunny Shalesh	Azril's Football Coach	IMC Training Centre	
34	Azril bin Che Ibrahim	Footballer		
35	Cliff Meyers	Regional Education Advisor	UNICEF EAPRO	cmeyers@unicef.org
36	Graham Harrison	WHO Representative	WHO	harrisong@maa.wpro.who.int
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Appendix 2 – Welcoming Address by Wivina Belmonte (UNICEF Representative to Malaysia)

Speech

**Launch of SOWC 2013
Roundtable on Children with Disabilities
3 June 2013**

Good morning honourable guests, members of the media, ladies and gentlemen.

Thank you for your presence here today. And your participation at this important roundtable discussion.

Let me also thank you for allowing us to use this occasion, to launch UNICEF's annual flagship publication – the State of the World's Children – which this year focuses on Children with Disabilities.

This report is a departure for UNICEF. It is unlike previous Reports, which typically start with a statistic, highlighting a global problem that afflicts children.

The girls and boys to whom this edition of the State of the World's Children is dedicated are not problems.

A child is not disabled because they cannot walk, see or hear. They are disabled by a society that excludes them. So our report this year brings attention to our blind spot – as we remind ourselves that we need to see the child, before the disability.

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 right compromised more consistently or more cruelly, than children with disabilities. When they're not objects of pity, they're frequently targets of abuse. Discrimination on the grounds of disability is a form of oppression. It pushes children and their families to the margins, and subjects them to multiple deprivations;

- Globally, they're three to four times more likely to be subjected to violence than other children.
- Children with disabilities experience multiple challenges. Including difficulty in accessing education and an increase risk of violence, abuse and exploitation.
- Left off birth registers, hidden behind closed doors, shut away in institutions and stigmatize, they are too often over-looked and under-estimated.

They're not only excluded. They're forgotten.

The reason so many of you are here today is because you share our conviction that when we see the disability before the child, it is not only wrong for the child, it also deprives society of all that child has to offer.

So today, we are building on the leadership Malaysia has already shown. Malaysia already has important policy and legal frameworks for people with disabilities; the 2007 national policy for persons with disabilities and the national plan of action for persons with disabilities, 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.

The challenge is shifting real commitment into relevant action. And that's what brings us together today – to discuss and address the gaps in implementation; gaps in access to health, education and other essential services for children with disabilities in Malaysia. Public awareness and education on issues of disability are still required, as are strong social support systems and referral mechanisms. There is also a dire 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.

We want to acknowledge the work of the Social Welfare Department in this regard. And congratulate them on the award they received in March of this year, for their online registration programme, which makes it easier for the community of people living with disabilities to register for benefits with them, and with the Ministry of Education, Ministry of higher Education, Road and Transport Department and Inland Revenue Board. The online registration is available in all 14 states, and all 104 districts.

The data is crucial – 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.

UNICEF's annual State of the World's Children's report calls for a fundamental change in the way children with disabilities are viewed and treated, with a focus on the abilities of these children – rather than what they cannot do. The report recognizes that these barriers are often more disabling than any impairment itself.

We are convinced such a shift would benefit the child, their family and society as a whole. We are convinced, because we have the evidence that proves it is so.

UNICEF has worked with partners and communities all over the globe to support inclusive education.

The merit of such schools is not only that they are capable of providing quality education to all children, they also help change discriminatory attitudes, by creating welcoming communities and building inclusive societies.

Schools that include everybody, celebrate differences, support learning, and respond to individual needs.

The discrimination children with disabilities face, arises from social exclusion so entrenched, that it traps these children and their families in a life of poverty, social isolation, ignorance and lack of services and support. Time and again we've seen inclusive education radically change that dynamic.

On behalf of UNICEF, I thank you for your active participation in today's roundtable.

I hope that this year's State of the World's Children and our roundtable 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.

I would like to conclude with something that I hope will set the tone for the upcoming roundtable.

Children are not disabled because they cannot see, read or hear, they are disabled because society excludes them.

Every child has something to contribute, as long as they're given the chance.

Thank you.

Appendix 3 – Opening Remarks by Datuk Harjeet Singh (Deputy Secretary-General, Ministry of Women, Family and Community Development)

WELCOMING REMARKS BY
YBHG DATUK HARJEET SINGH
DEPUTY SECRETARY GENERAL OF THE MINISTRY OF WOMEN, FAMILY AND COMMUNITY
DEVELOPMENT, MALAYSIA
AT
ROUND TABLE MEETING – CHILDREN WITH DISABILITIES
PLAZA 1 (LOWER LOBBY), PARK ROYAL HOTEL, KUALA LUMPUR
3 JUNE 2013

[Salutation]

Distinguished participants,

Ladies and Gentlemen,

1. First of all let me extend my warmest greetings and welcome to all of you to the Round Table Meeting on Children with Disabilities.
2. This meeting is indeed very significant as it brings together government and non-government actors to discuss and exchange information on issues affecting full realisation of rights of children with disabilities in Malaysia.

Children in Malaysia

3. Children are the most valuable asset for our nation and future. The Malaysian Government recognises that children play an integral role in the country's survival, development and prosperity. The participation and advancement of the present generation should usher in a future generation that is confident, responsible and caring. Thus, Malaysia has undertaken efforts in ensuring the rights of the children are protected. Malaysia's multi-ethnic, multi-religious, multi-lingual and multi-cultural society is our strength. The Government will harness on the richness of diversification and provides the platform for making national unity as the overriding objective and the goal of the national development agenda.
4. In view of this, Malaysia ratified the Convention on the Rights of the Child (CRC) in 1995 to uphold its commitment to the protection and well-being of its children. There are 4 key components in the CRC which have been given great emphasis by the Government for the best interest of the child, namely:

- (i) survival;
- (ii) protection;
- (iii) development; and
- (iv) participation

Legislation and Policies related to children in Malaysia

5. The Child Act 2001 was approved by the Parliament as an important step in our effort to protect the rights of the children. This Act recognises the child as a crucial component of society, and appropriate provisions are accorded to the child in line with the general principles of the CRC regarding care, protection, maintenance, support, rehabilitation and development. It also takes into account the role and responsibility of the family as the source of care, support and development for the child. In other words, the Child Act 2001 safeguards the best interests of children.
6. Recognising that children make up to 10 million (or 34%) of the country's population, the Ministry of Women, Family and Community Development has formulated 2 important policies in 2009, namely the National Policy on Children and the National Child Protection Policy. These policies translate the legal provisions of the Child Act 2001 into proactive measures that can be implemented at all levels in the Malaysian society.
7. The National Policy on Children in particular, stresses that each child including a child with disabilities has the right to be protected from any form of neglect, abuse, violence and exploitation. It calls for providing with rehabilitation and integration into the family and society. This is to ensure that each child has the right to holistic development in terms of physical, cognitive, linguistic, socio-emotional, personality and spiritual development.
8. The National Child Protection Policy, on the other hand encourages all organisations that deal with children to develop guidelines on child protection. The policy focuses on aspects of prevention, advocacy, intervention, reporting and support services in protecting the children. Recognising that violence against children requires a holistic approach, the policy provides for greater outreach, counselling and support services not only to any child who is a victim, but also to families, offenders, and the society at large.
9. In addition, the importance of providing protection and well-being of children in Malaysia is embedded in other policies as well such as the National Policy on Women and the National Family Policy.

Government's Initiatives Towards Realising the Rights of Persons with Disabilities in Malaysia

10. For the past 2 decades, issues relating to persons with disabilities have experienced a paradigm shift, from charity-based to rights-based approach. This is in line with the United Nations' calls on the concept of "non-discrimination" where persons with disabilities have equal rights and opportunities like other members of the society.

11. As Malaysia sets its pace to become a fully developed nation by 2020, the Malaysian Government strives to promote the rights of persons with disabilities in the country especially children with disabilities. The Government also believes that in order to achieve the aspiration to become a fully developed nation by the year 2020, every citizen of the country should be given the opportunity to realise their full potential. Thus, the Government of Malaysia in its Tenth Malaysia Plan (2011-2015) introduced “inclusive development” as the national agenda.
12. The Tenth Malaysia Plan encapsulates the spirit of 1Malaysia to create a fair and socially just society with national unity as its ultimate objective. A fair and socially just society is where all people, without exception, have the rights, freedom, and capacity to access services and resources to enhance their well-being, and where the most disadvantaged are given extra support to ensure such success.
13. In ensuring persons especially children with disabilities enjoy equal opportunities, full participation in the society and to be mainstreamed into the national agenda, Malaysia has ratified the Convention on the Rights of Persons with Disabilities on 19 July 2010, thus joining the global community in affirming the human rights of persons with disabilities.
14. Prior to that, the Government has formulated the Policy and Plan of Action for the Persons with Disabilities in 2007. The National Policy of Persons with Disabilities and its Plan of Action which was drafted based on the gist of the Convention on the Rights of Persons with Disabilities, served as the foundation and basis to ensure persons with disabilities in this country enjoy their full and effective participation in the society on an equal basis with others. This Policy recognises that persons with disabilities are free from any physical, social, economic, cultural as well as attitudinal barriers.
15. Following that, the Persons with Disabilities Act was passed by the Parliament in December 2007 and came into force in July 2008. The Act is aimed to ensure that the rights, interests and welfare of persons with disabilities are protected. This Act is also intended to assist persons with disabilities towards a better life and to be able to contribute in the national development.
16. With the enforcement of the Act, the National Council for Persons with Disabilities was established in August 2008 and chaired by the Minister of Women, Family and Community Development. Among the functions of the Council as stipulated in the Act is to monitor the implementation of the national policy and national plan of action relating to persons with disabilities and also to make recommendations to the Government on all aspects of life including matters relating to support, care, protection, rehabilitation, development and well-being of persons with disabilities. The Council is assisted by the Department for the Development of Persons with Disabilities, which was set up in May 2009.
17. In November 2012, Malaysia and other members of the *Economic and Social Commission for Asia and the Pacific* (ESCAP) also endorsed the Incheon Strategy to Make the Rights Real for Persons with Disabilities in Asia and the Pacific as part of our strategy to move forward

towards building a stronger policy framework to mainstream persons with disabilities and to ensure their effective participation in the society.

Ladies and Gentlemen,

18. Therefore, this round table meeting is timely organised and I would like to take this opportunity to highlight several issues that we need to focus on:

- (i) Prevention and early detection of disabilities;
- (ii) Health and rehabilitation;
- (iii) Education;
- (iv) Potential/talent development (especially those with learning disabilities such as autism, dyslexia and down syndrome). (for example: some of the many talented and accomplished individuals who are dyslexic, or had traits associated with dyslexia or related learning styles are Tom Cruise, Orlando Bloom, Keanu Reeves, Leonardo Da Vinci and John Lennon – The Beatles).
- (v) Reliable and comparative data collection pertaining to disabilities; and
- (vi) Research/studies on disabilities;

19. In 2016, Malaysia will host the 2nd World CBR Congress. This itself is a recognition to Malaysia and we hope to showcase the best practices on disability development in Malaysia and children with disability will be one of the focus.

Ladies and Gentlemen,

The State of World's Children (SOWC) 2013: Children with Disabilities Report

20. I was made to understand that the State of World's Children (SOWC) 2013: Children with Disabilities Report had been launched on the 30th May 2013 by UNICEF's Executive Director Anthony Lake, joined by Ms. Nguyen Thi Doan, Vice-President of Viet Nam and Mr. Peter Baxter, Director General, AusAID in DA NANG, Viet Nam. I was also informed that UNICEF offices around the world will have special events to mark the release of the flagship report. I am honoured to be part of these programmes where in Malaysia, we are not just launching the report but also holding a panel discussion with disability experts and activists in this hotel. I would like to take this opportunity to acknowledge and congratulate UNICEF and the research team for their efforts and dedication in putting together this report.

21. I hope that the key findings and recommendations of this report can be shared among the stakeholders, be it the government agencies as well as the civil societies, to ensure that children with disabilities in Malaysia can enjoy their childhood in full and effective participation in all aspects of life on an equal basis with others.

Ladies and Gentlemen,

Conclusion

22. I would like to end my speech by recording my appreciation to the organisers – United Nations Children’s Fund (UNICEF) for organising this round table meeting and for choosing Kuala Lumpur as the venue. We are also truly honoured to have such an impressive line-up for this meeting and I personally thank all of you for investing your time here despite your hectic schedule, to formulate and to create a better environment for children with disabilities in Malaysia. We appreciate your presence, your ideas and your contribution to this meeting.

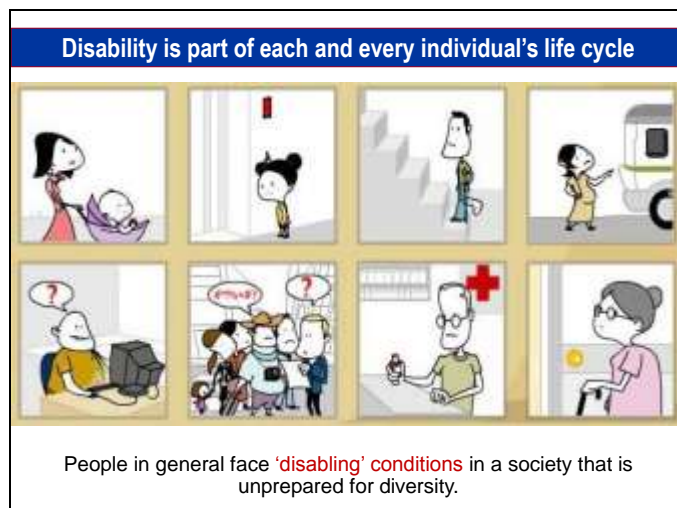
Thank you.

Appendix 4: Slide Presentation by Dr Cliff Meyers, Regional Education Advisor of UNICEF (EAPRO)

Slide 1



Slide 2

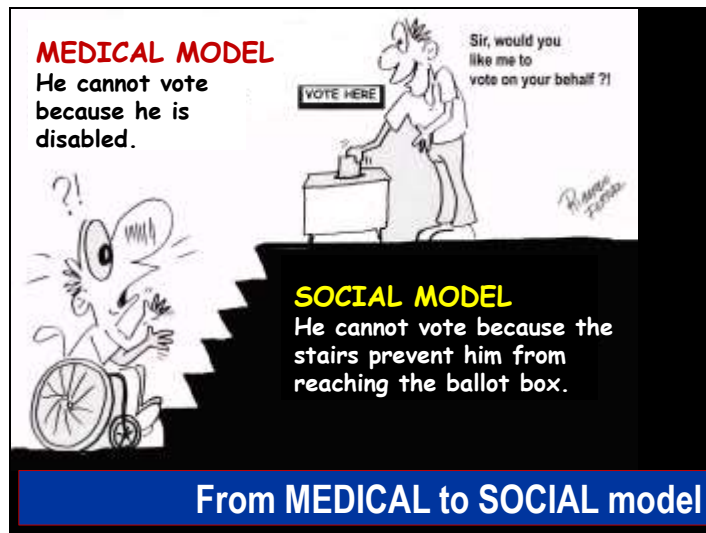


Slide 3

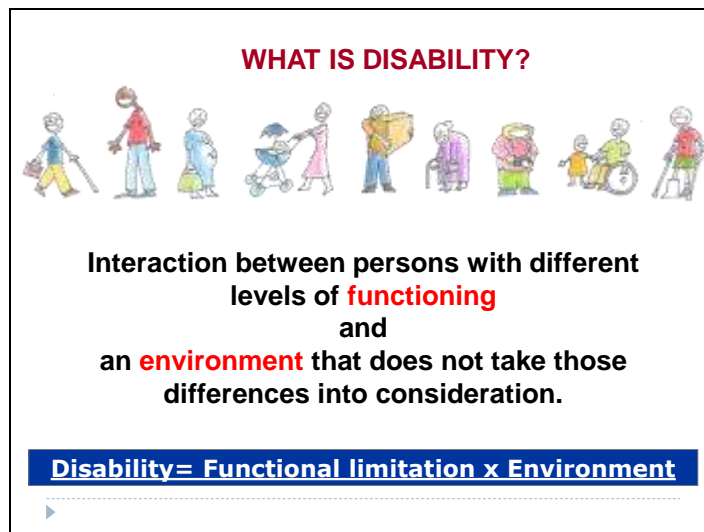
Disability as an evolving concept

- ▶ Disability was previously seen as an individual, medical problem = **medical model**
- ▶ New approach considers role of social and physical barriers in disability = **social model**
- ▶ Medical and social model should not be viewed as dichotomous

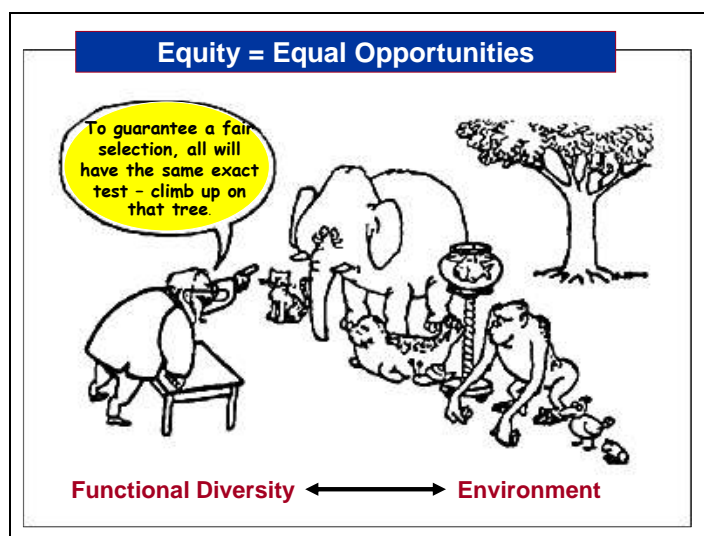
Slide 4



Slide 5



Slide 6



Slide 7

Equity is an exponential issue

$-10 \times -10 = -100$

Poverty x Disability
Remote x Disability
Gender x disability
Linguistic Minorities x disability
Race x Disability
Refugees x Disability
Orphans x Disability
and other associations, including all of the above

INVISIBILITY ↔ STIGMA ↔ EXCLUSION

$-10 \times -10 \times -10 = -1000$

Slide 8

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

- ▶ From exclusion to inclusion – fundamentals
 - ▶ Changing Attitudes
 - ▶ All about ability – not setting limits
 - ▶ Supporting children and their families
 - ▶ Community based rehabilitation
 - ▶ Assistive technology
 - ▶ Universal design

Slide 9



Slide 10

SOWC 2013 – Children With Disabilities An Agenda for Action - Key Recommendation

1. Ratify & Implement Convention on Rights of Persons with Disabilities
2. Fight Discrimination and enhance awareness
3. Dismantle barriers to inclusion – schools, health facilities, public transport
4. End the institutionalization of children with Disabilities
5. Support families to meet higher costs of living – and lost economic opportunities
6. Move beyond minimum standards
7. Coordinate Services across all sectors
8. Involve children and adolescents with disabilities as decision makers
9. Promote a concerted global research agenda

Slide 11



Slide 12

CRC	CRPD
<p>Article 28 - education must be provided to every child on the basis of equality of opportunity States must:</p> <ul style="list-style-type: none"> • make primary education compulsory and free to all • make secondary school available and accessible to every child and take measures to make it free • make higher education accessible to all on basis of capacity • make vocational information available and accessible to all children • take measures to increase attendance and reduce drop-outs. <p>Article 29 - Education must be directed to the development of children to the fullest potential...</p>	<p>Article 24 - affirms the right of people with disabilities to inclusive education, at all levels States must ensure that children with disabilities:</p> <ul style="list-style-type: none"> • are not excluded from the general education system and can access inclusive, quality and free primary and • secondary education on an equal basis with others in the communities in which they live • are provided with reasonable accommodation of their needs • receive the support they need within the general education system • are provided with individualised support measures, consistent with full inclusion.

Slide 13

Covention on the Rights of Persons with Disabilities

Article 24

- ▶ **States** must also take measures to enable **people with disabilities to participate equally in education** and their communities by supporting learning of all alternative forms of communication, and enabling deaf, blind and deaf-blind children to learn in the most appropriate languages and modes and in environments that maximise their development.
- ▶ The education system must enable people with disabilities to achieve the full development of their personality, talents, creativity and mental and physical abilities, a sense of dignity and self-worth, respect for human rights and effective participation in society.

CRPD has 153 signatories, 110 ratifications

Slide 14

2. Fight Discrimination & enhance awareness

Strategic - Leadership

- * Leadership: Culture & Values.
- * Laws & Acknowledgement

Institutional - Policy & Guidelines

- * Commission - Purposeful exclusion.
- * Omission - Ignorant discrimination

Operational - Interpretation and Implementation.

What happens in pre-schools, schools and hospitals

Individual - Tough Luck attitude & Lack of Awareness

Don't recognize the rights of disabled people

Slide 15

3. Dismantle barriers to inclusion – schools, health facilities, public transport

- ▶ **Inclusive Approach across society**
 - ▶ Address disabilities holistically – social model & response
- ▶ **Barrier & Bottleneck Analysis –**
 - ▶ including baselines and situation analysis
- ▶ **Institutional barriers –**
 - ▶ review of guidelines, policies & legislation
- ▶ **Make services accessible –**
 - ▶ Community based Rehabilitation – Home based care – Inclusive education and early childhood centers

Slide 16

4. End Institutionalization of Children with Disabilities

- ▶ **Rights-based perspective**
 - ▶ Research clearly shows that I-I Care & Attachment especially in early years – is required to ensure children reach their full potential
- ▶ **Economic Perspective**
 - ▶ Investing in communities and families, equipped with training and facilities – reduces costs over the long term with increased returns
- ▶ **Social Perspective**
 - ▶ Mainstreaming children with disabilities into existing pre-schools and schools, into social events and festivals, into media and textbooks, creates a different type of society

Slide 17

5. Support families to meet higher costs of living – and lost economic opportunities

- ▶ Vouchers for hospital care and schools. Transport allowance
- ▶ Income subsidies. Social welfare schemes and protection measures for the family – including Conditional cash Transfers
- ▶ Ensure affordable (or subsidized) assistive technology is available to all children
- ▶ Reduce barriers and stigma for families.

Slide 18

6. Move beyond minimum standards

- ▶ Apply Child Friendly Principles – identify dimensions and domains of quality as guidance for service providers.
- ▶ Conduct monitoring using Rubrics rather than simple checklists. Continuum of quality - to strive for higher goals each year
- ▶ Involve Children and adolescents with Disabilities in target setting and monitoring.

Slide 19

7. Coordinate Services across all sectors

- ▶ Integrated ECD – organize community centers and pre-schools that are accessible to all children. Link early detection with referral and support. Avoid secondary disabilities, provide family support, create basis for inclusive society
- ▶ Inclusive approach – link to social protection & welfare with education and health
- ▶ Pan-disability approach. Don't cherry pick select disabilities
- ▶ Resource Centres reach out to schools and communities with skills, medical support and educational support



Slide 20

8. Involve children and adolescents with disabilities as decision makers

- ▶ Involve Children and adolescents with Disabilities in target setting and monitoring.
- ▶ Utilize self-assessments by service providers, families and children as the basis for plans and targets
- ▶ Respect Children with Disabilities as agents of change



Slide 21

9. Promote a concerted global research agenda

- ▶ Very limited knowledge on status and scope of disabilities at national levels
- ▶ Even more limited data on the impact of disabilities on children's lives
- ▶ Investments in solutions that work – but limited knowledge of what works.

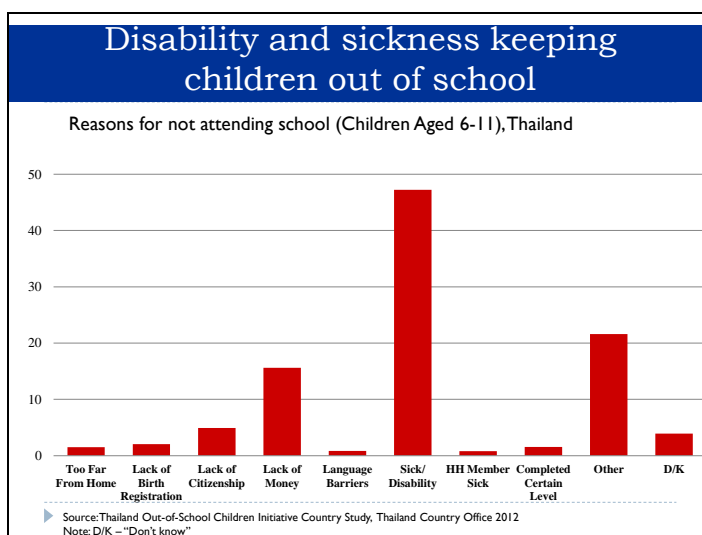


Slide 22

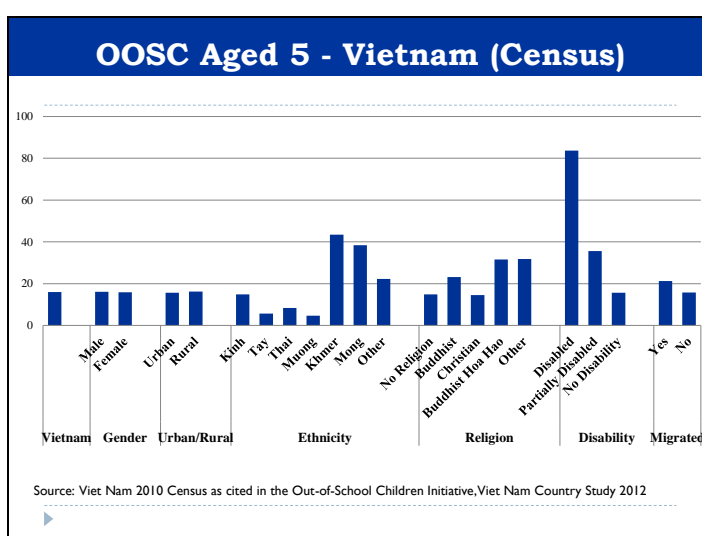
Approaches to Measuring Disabilities

- International Classification of Functioning, Disability and Health (ICF)
 - promotes a “**bio-psycho-social model**” with **human functioning** categorized into three interconnected areas: **impairments** to body function (paralysis or blindness); **activity limitations** in executing activities (walking or eating); and **participation restrictions** problems with involvement in any area of life (facing discrimination in employment or transportation)
- Washington Group on Disability Statistics
 - set up by the United Nations Statistical Commission
 - questions cover **six functional domains** or basic actions: **seeing, hearing, mobility, cognition, self-care, and communication**
- Ten Question Screening Instrument (TQSI)
 - used in Cambodia and Bhutan, where the world-first 2nd stage childhood disability assessment of 2-9 year olds in 2011
- The **Capabilities Approach**
 - places the analysis of access barriers within a framework of human development and freedom, thereby including limitations in terms of social participation and choices; (used in Afghanistan)

Slide 23



Slide 24



Slide 25

UNICEF's Support to Children with Disabilities

- ▶ Research – Status of children with Disabilities, Situation Analysis, Good Practices, Barrier & Bottleneck analysis
- ▶ Policy Review and Reform – what are existing guidelines and legislation, how do they support or contradict, what are gaps and omissions?
- ▶ Integrated ECD – Inclusive centers with early detection and referral
- ▶ Capacity Development – training, skills development, Critical mass of teachers and health workers with skills and awareness
- ▶ Implementation guidelines - setting standards and professionalization, review of practices in schools and health services
- ▶ Coordination and Networks – Strengthen NGOs and Associations, Support between Ministries and Levels within the system
- ▶ Resource Centres - reach out to schools and communities. From specialized resource centers. No longer isolated and walled centers where children are hid
- ▶ Advocacy – Media featuring disabled characters, partnerships, with news and television, events and outreach, Illustrations in textbooks

Slide 26

THANK YOU!



Appendix 5 – Slide Presentation by Dr. Aminah Bee binti Mohd Kassim (Deputy Director of the Family Health Development Division, Ministry of Health)

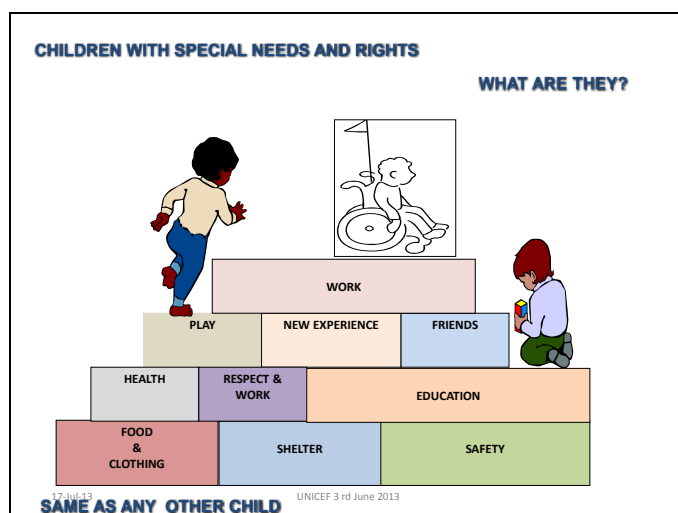
Slide 1

**Overview on Policies, Laws
and Programmes for CWSN –
gaps and constrains to full
realisation of their rights**

Aminah Bee Mohd Kassim
Public Health Physician
Ministry of Health

17-Jul-13 UNICEF 3 rd June 2013

Slide 2



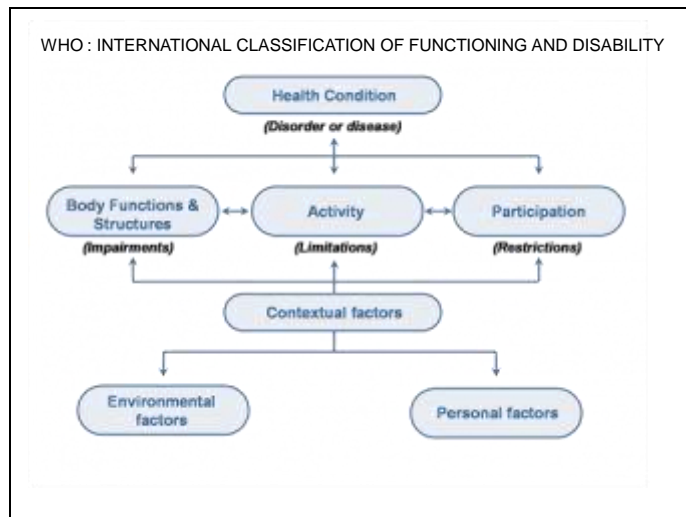
Slide 3

National Policies

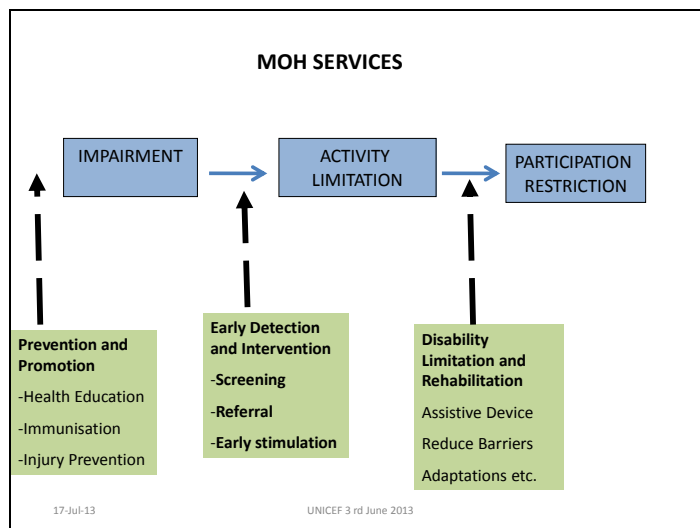
- Emphasize the need to give attention to children with disabilities.
 - Convention on rights of PWD
 - PWD Policy and Plan of Action 2007
 - PWD Act 2008
- Program for CWSN in primary care - 1996

17-Jul-13 UNICEF 3 rd June 2013

Slide 4



Slide 5



Slide 6

Early detection – health clinic

New born : physical examination

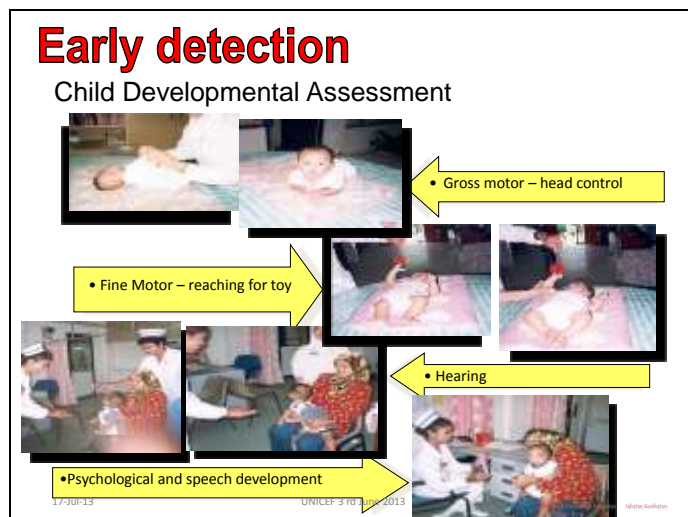
Anthropometry (Weight / Length / Head circumference)

Child Developmental Assessment

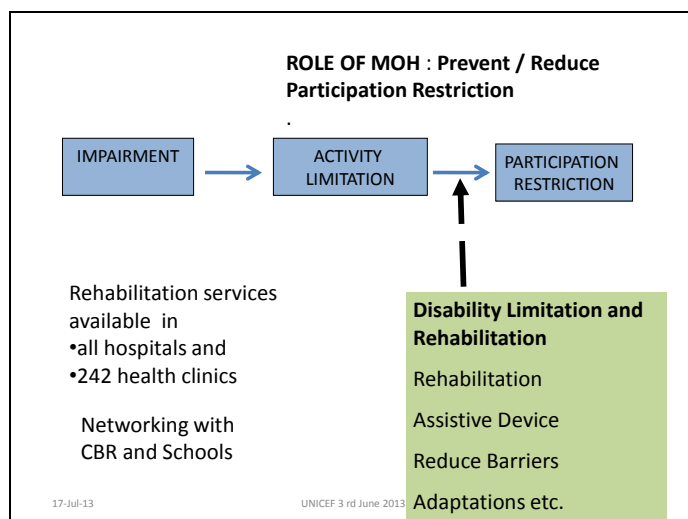
• Primitive reflexes

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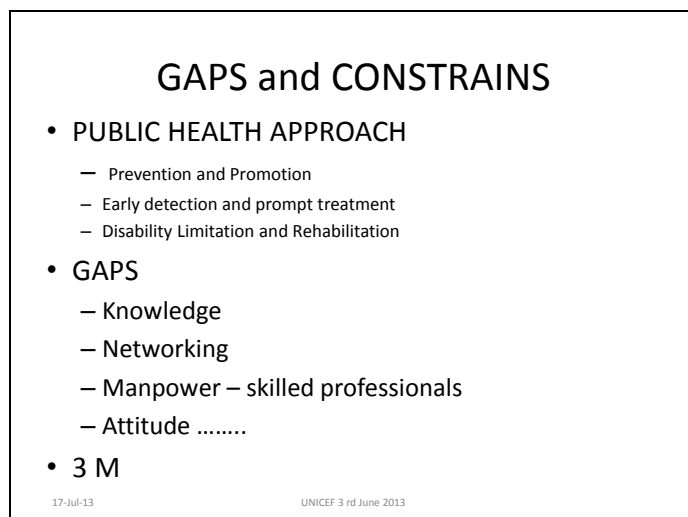
Slide 7



Slide 8



Slide 9



Slide 10

Interagency Collaboration- Achievements

1. Policy Development and Implementation

- Development of **format for registration** of child with special needs and suggested placement in school/CBR etc.
- Development of **National Health Program** for Prevention and Management of **Specific Disabilities**
- Development of **screening instruments** for children in school for early identification of learning problems

Slide 11

2. Development of Health Education Material

- NGO involvement– depth of knowledge in specific disabilities
 - Spastic center
 - Dyslexia Society
 - Autistic Society
 - Malaysian Care
 - Associations of the Deaf and for the Deaf
 - Malaysian Association for the Blind
 - Malaysian Mental Health Association
 - Etc.



Slide 12

Resources for Prevention of Blindness



Resources for Prevention of Deafness



Slide 13



Slide 14

3. Training module development

- Development of manual and training of Caregivers in Institution and at home

The image shows two book covers. The left one is 'Caregiver Training Manual' and the right one is 'Modul Latihan Bagi Penjaja'.

Slide 15

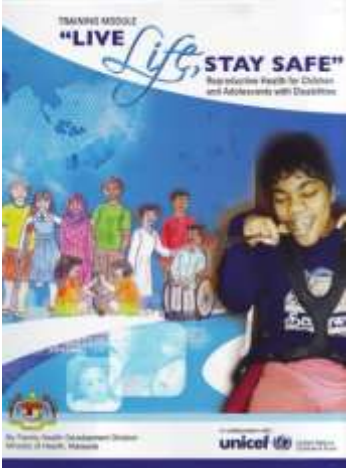
A Series of Six Manuals on the Management of Children with Disabilities

Ministry of Health, Malaysia

- Manual Development and Training of Health Staff in management of CWSN

The image shows a stack of six manuals. The top one is titled 'A Series of Six Manuals on the Management of Children with Disabilities' and features a photo of a child.


Slide 16



Module was launched in 2009

Training began in 2010

Slide 17



4. Training Awareness

Training on prevention and early detection

- Parents and Carers –
 - Buku Rekod Kesihatan Kanak
 - Modul intervensi awal – BAKTI
- Care providers in nursery and kindergarten –
 - network with UPM for training of PERMATA program

Disability Awareness Training –

- working with NGOs and PWD – just beginning....

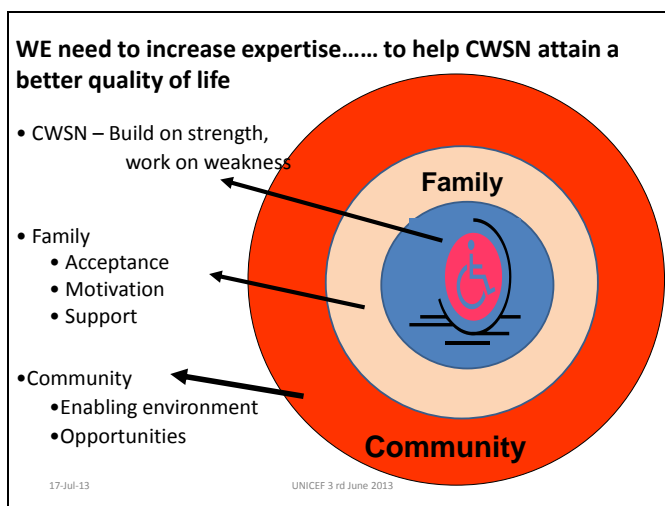
Training on management of child with delay in 'gross motor, fine motor, ADL, visual impairment, communication, personal & social

- Network in the training of health personnel, teachers and CBR workers

Training of Caregivers in Institution and at home

- Network with Cheshire Home, DSW and MAKPEM

Slide 18



Slide 19

What we need to do more

Improve Early detection

- Empower parents
 - nationwide rollout of new child health record
- Empower care providers in nursery and kindergarten
 - Training care providers PERMATA, KEMAS PERMATA
- Empower community
 - Panel of Advisors, Village Health Workers, Community Leaders
- Work with NGOs and private GPs

17-Jul-13

UNICEF 3 rd June 2013

Slide 20

New Child Health Record Book

- Section on parents concern
- Expected milestones to identify delay in development
- M-CHAT to screen for early signs of autism at 18 months
- Tips for parents on care of child – Safety and nutrition
- Examination by doctor at 1 month, 18 months and 4 years



17-Jul-13

UNICEF 3 rd June 2013

Slide 21

What more

Public campaigns

- health campaign ,
- manual for parents and care providers



- Strengthen inter-agency cooperation
 - intra, inter, international
- Sharing of resources – 3M and training

17-Jul-13

UNICEF 3 rd June 2013

Slide 22

Health Services in CBR Centers

- Launched by PM 2012
 - Health services – health appraisal, treatment, immunisation, nutrition, rehab, exercise etc
 - 474 CBR centers
 - 2013 KPI Health Minister - > 80% PWDs provided with health services



17-Jul-13 UNICEF 3 rd June 2013


Slide 23

Conclusion

- We need to work together to close the gaps
- Empower parents and educators detect early
- Parent support system
- Public education

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Slide 24



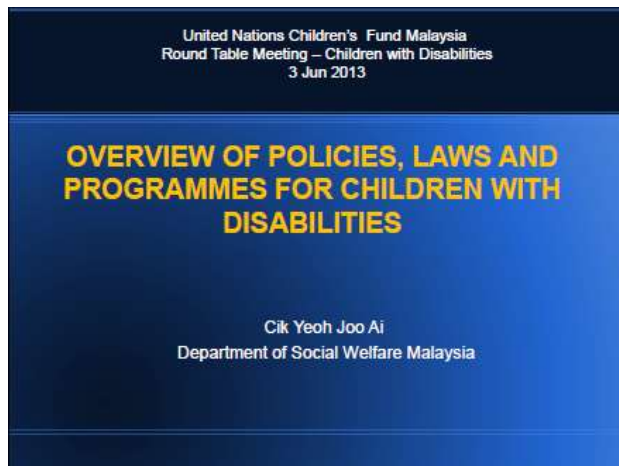
**MY DAUGHTER –
MY TEACHER**

E-mail aminahbee@moh.gov.my

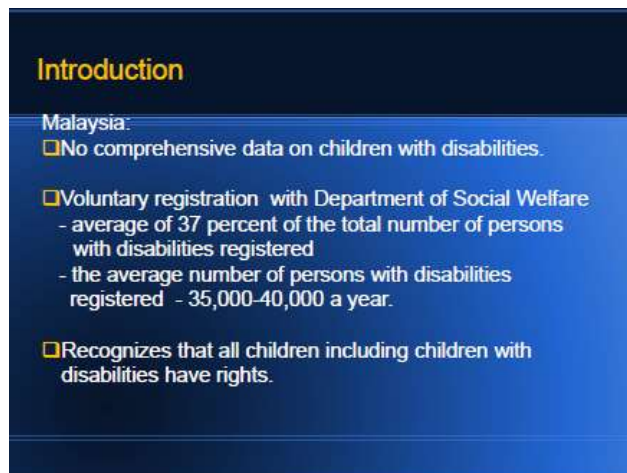
THANK YOU

The more you do..... the more you know you haven't done enough

Appendix 6: Slide Presentation by Ms. Yeoh Joo Ai (Senior Principal Assistant Director of the Social & Community Development Division, Department of Social Welfare)



Slide 1



Slide 2



Slide 3

LEGAL FRAMEWORK AND POLICIES

❑ Child Act 2001

- principles of the CRC
- recognises that every child is entitled for protection and assistance in all circumstances without regard to distinction of any kind, such as race, religion, colour, sex, language, religion, social origin or physical, mental or emotional disabilities or any other status.

❑ National Policy on Children

- ensure children's welfare including rights to survival, protection, development and participation in the best interest of the child.

Slide 4

❑ National Policy on Child Protection

- ensure children's protection from all forms of violence, abuse, neglect, and exploitation.

❑ National Policy for Persons with Disabilities

- foundation to ensure persons with disabilities enjoy their full and effective participation in the society on an equal basis with others.

❑ Persons with Disabilities Act 2008

- ensure that the rights, interests and welfare of persons with disabilities are protected and they are given the rights in every aspect of their lives.

Slide 5

PROGRAMMES AND SERVICES FOR CHILDREN

❑ Financial Assistance

- help children with disabilities and families who are poor or facing financial difficulties
- help meet their basic living needs, as well as to increase their quality of life.

❑ Financial Assistance for Children

❑ Financial Assistance for carer of persons with severe disabilities and chronically ill person

❑ Financial Assistance for Artificial Aids and Assistive Devices

- ❑ Free white cane and Braille machine to all visually impaired children

Slide 6

- Rehabilitative services
 - Institutional rehabilitation
 - 7 institution for children with learning disabilities
 - Taman Sinar Harapan
 - provide care, rehabilitation, to improve quality of life and enable them to live a more independent life
 - Programmes include ADL, basic academic, rehabilitation, vocational training and recreation
 - Community-base rehabilitation (CBR)
 - reduce impact of disability and provide support services to families through community participation
 - 486 CBR
 - Programmes - Gross and fine motor skills, language and social development, basic academic , vocational training and recreation
 - PDKNet

Slide 7

CHALLENGES

- Statistics and data
 - not integrated
 - registration voluntary
- Skills among services providers
 - multiple skills needed to cater for the different needs
- Family support Services
 - lack of support for sibling and parents on disability
- Accessibility to services
 - physical inaccessibility as well as lack of access to information resulting in problems of access to facilities and services

Slide 8

Appendix 7: Slide Presentation by Ms. Lim Weng Fong (Assistant Director of Planning and Evaluation in the Special Education Division, Ministry of Education)

Slide 1

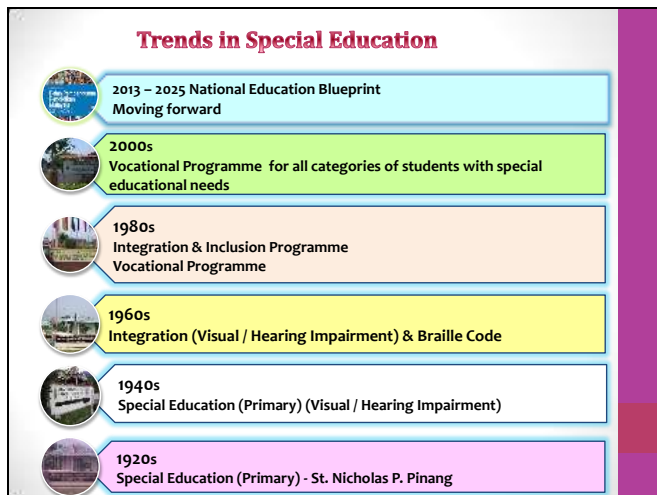


Round Table Discussions on Children
with Disabilities
03 June 2013

**An Overview of
Special Education Provisions
In Malaysia**

Lim Weng Fong
Assistant Director
Policy and Planning Section
Special Education Division
Ministry of Education

Slide 2



Trends in Special Education

- 2013 – 2025 National Education Blueprint
Moving forward
- 2000s
Vocational Programme for all categories of students with special educational needs
- 1980s
Integration & Inclusion Programme
Vocational Programme
- 1960s
Integration (Visual / Hearing Impairment) & Braille Code
- 1940s
Special Education (Primary) (Visual / Hearing Impairment)
- 1920s
Special Education (Primary) - St. Nicholas P. Pinang

Slide 3



The Roles of Special Education Division

- Students with Special Educational Needs**
 - Learning Difficulties
 - Visual Impairment
 - Hearing Impairment
 - Speech Impairment
 - Physical Disabilities
 - Multiple Disabilities
- Juvenile & Students of Correctional Facilities
- Children in Hospital
- Special Remedial Students

Slide 4

Legislation
ACT 550 – EDUCATION ACT (1996)

Chapter 8 – Special Education

Minister to provide special education

40. The Minister shall provide special education in special schools established under paragraph 34(1)(b) or in such primary or secondary schools as the Minister deems expedient.

Slide 5

Legislation
ACT 550 – EDUCATION ACT (1996)

Chapter 3 – Primary Education

Power to prescribe the duration of and curriculum on special education

41. (1) Subject to subsections (2) and (3), the Minister may by regulations prescribe—

- (a) the **duration** of primary and secondary education suitable to the needs of a pupil in receipt of special education;
- (b) the **curriculum** to be used in respect of special education;
- (c) the **categories of pupils** requiring special education and the methods appropriate for the education of pupils in each category of special schools; and
- (d) **any other matter** which the Minister deems expedient or necessary for the purposes of this Chapter.

Slide 6

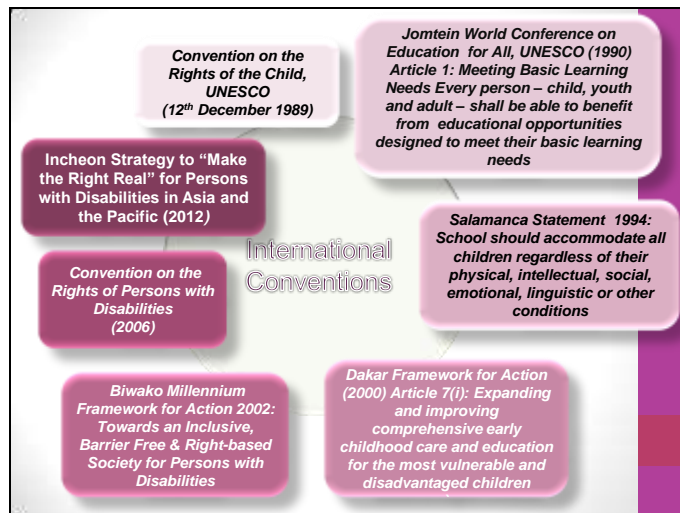
Circular
Surat Pekeliling Ikhtisas

Pekeliling Ikhtisas Bil. 16/2002

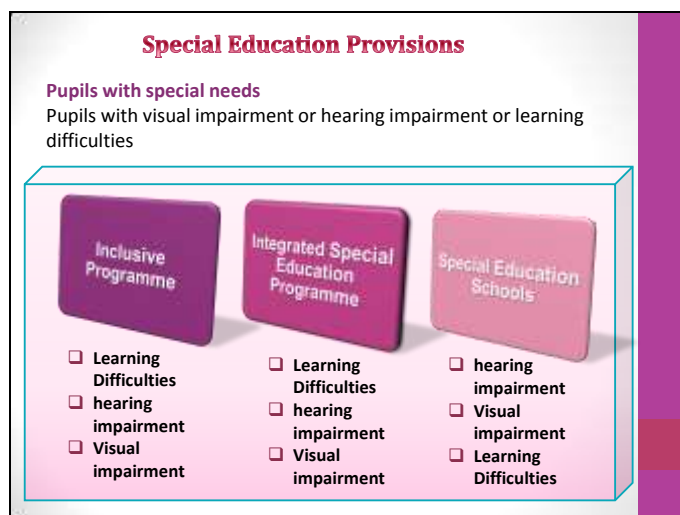
KPM telah memutuskan tempoh belajar murid berkeperluan khas boleh dilanjutkan kepada tambahan tempoh selama 2 tahun.

Boleh diambil sama ada diperingkat rendah atau menengah ataupun kedua-duanya iaitu satu (1) tahun di peringkat rendah, satu (1) tahun di peringkat menengah

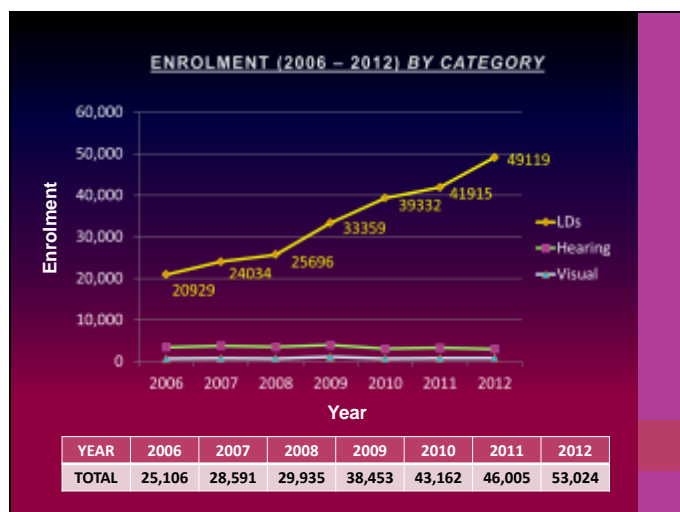
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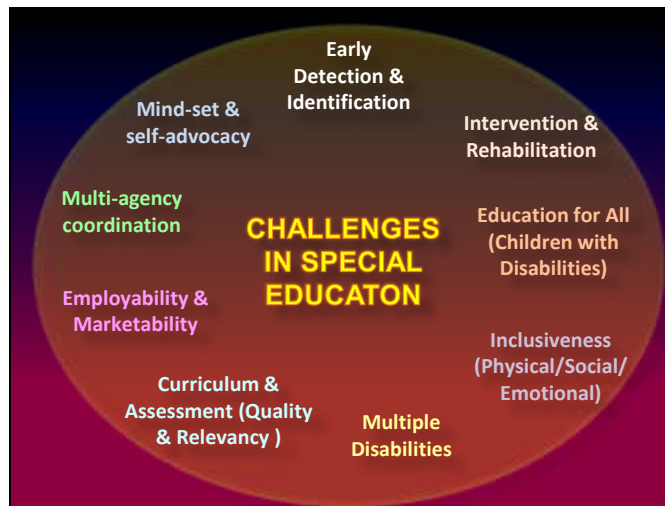
Slide 8



Slide 9



Slide 10



Slide 11



Appendix 8: Dr. Amar Singh HSS. Overview of initiatives & programmes, key challenges and obstacles to the full realisation of rights of children with disabilities in Malaysia

Overview of initiatives & programmes, key challenges & obstacles
to the full realisation of rights of children with disabilities in Malaysia

1

Amar-Singh HSS (Dato' Dr)

Cert Theology (Aust, Hong), MBBS(Mal), MRCP(UK), FRCP(Glasg), MSc Community Paeds (Lond, dist.)
President, National Early Childhood Intervention Council
Senior Consultant Paediatrician (Community)
Head Paediatric Department at HRP Ipoh Hospital, Malaysia
Head Clinical Research Centre at Perak



Introduction

Children with disability have become more important health problems in society and emerged on the national agenda. Data suggest between 15-20% of all children have some SEN. Services for children with disability or special needs (SEN) in Malaysia have had around 40 years of growth. Services began for children with cerebral palsy, severe intellectual (Down syndrome) or visual/hearing impairment handicap and were largely led by non-governmental organisations (NGO). With time governmental departments took a greater lead and currently offer a sizeable portion of services. And we have seen the growth of policies and services nationally but implementation is still an issue. The enormous burden of learning disability including attention deficit hyperactivity disorder (ADHD), autism, and dyslexia is the current challenge nationally.

This brief paper looks at the provision of services, focusing specially on the key challenges & obstacles that limit the full realisation of rights of children with disabilities in Malaysia. It is assumed the reader is familiar with:

- the United Nations Convention on the Rights of the Child (UNCRC 1989) - all children with disability have the right that "education be directed to the development of the child's personality, talents, mental and physical abilities to her or his fullest potential"
- the UNESCAP Biwako Millennium Framework for Action (2003) target - "all infants and young children (0-4 years) will have access to and receive community based early intervention services by 2012"
- the Memorandum on Early Childhood Intervention adopted by delegates to first Malaysian National Conference on Early Childhood Intervention (NECIC 2006) which states - "Parents, carers and families should be recognized, and empowered, as positive partners in all aspects of screening, diagnosis, assessment and intervention."

The approach taken here is to use the Memorandum on Early Childhood Intervention adopted by delegates to first Malaysian NECIC in 2006 as a template to assess services. This memorandum was jointly written by families, professionals, therapists, NGOs and policy makers.

Note that services provided by NGOs, Private & University are not adequately outlined but are alluded to below (NGOs being the more important service provider of the three). The focus has been largely on the National/Government Agencies (MOH, Welfare, MOE). This is because it is the responsibility of the government to meet the needs of the people. In the 1981 Mahathir Report & the Recommendations of the Cabinet Committee Pertaining to the Education of Children with Special Needs, recommendation 169 stipulates: "realising that the government should be responsible for the education of handicapped children, the government should completely assume this responsibility of providing education from the organisations that are managing it at present."

Overview of Initiatives & Programmes

	Health	Welfare	Education
Key Services & Programmes	<ul style="list-style-type: none"> Routine developmental surveillance & screening at health clinics Specialist assessments & therapy in hospitals Specialised rehabilitation services (OT, PT, ST, etc) Some community rehabilitation via health clinics 	<ul style="list-style-type: none"> Routine EIP services via CBR centres Should focus on the more severe disabilities Responsible to build communication participation to support children with disability Help to disperse government financial support for registered children with disability 	<ul style="list-style-type: none"> Routine special education services in normal schools Specialised education schools (deaf & visually impaired) Should be responsible to assess children with educational needs Help to disperse government financial support for registered children with disability in school
Early Detection & Prompt Diagnosis			
Routine developmental surveillance for all children	<ul style="list-style-type: none"> Child Health programme revamped 2006 Parent-held Child Health Surveillance Record given to all parents by 2009/10 Do not reach some segments of urban population 	Not relevant	<ul style="list-style-type: none"> All teachers should be trained to recognise and detect special needs in children (not currently available)
Routine developmental screening for specific conditions	<ul style="list-style-type: none"> High risk hearing screening at birth Autism at 18 & 36 months Vision acuity at school entry 	Not relevant	<ul style="list-style-type: none"> Dyslexia (ISD) at school entry but uncertain as to tool quality, coverage & sustainability LINUS "screening"
Multi-disciplinary assessment for every child upon identification of a disability	<ul style="list-style-type: none"> Available but most children do not get it due to limited manpower Long waiting time 	X	X
Assessments in child-friendly environment, in close partnership with parents or carers	<ul style="list-style-type: none"> Dependent on individuals providing the service, not uniform or policy Parents opinion often not adequately listened to 	<ul style="list-style-type: none"> Dependent on individuals providing the service, not uniform or policy Parents opinion often not adequately listened to 	<ul style="list-style-type: none"> Dependent on individuals providing the service, not uniform or policy Parents opinion often not adequately listened to
Immediate & Appropriate Intervention, Access to all Children			
Immediate access to early intervention programmes (EIP)	<ul style="list-style-type: none"> EIP available but limited in rural areas Children not referred routinely, dependent on service provider Often end up in hospital based "EIP" Waiting time long in good EIPs 	<ul style="list-style-type: none"> Large EIP service provider, usually meeting needs of rural communities Urban services limited, left to NGOs 	<ul style="list-style-type: none"> Not relevant in past But Education department now moving into provision of pre-school education routinely Unsure if provide routine EIP for special needs in pre-school

High quality intervention services (EIP & specialised services)	?	<ul style="list-style-type: none"> • Dependent on individuals providing the service, not uniform (poorly trained & motivated doctors not uncommon) • Lack integration • Very limited Speech & language therapy services • Almost non-existent Psychology services • Limited Social Worker services 	X	<ul style="list-style-type: none"> • Generally lack expertise and initiative • Quality generally poor • Extremely limited specialised staff (PT, OTS, trained teachers, etc) 	?	<ul style="list-style-type: none"> • Dependent on individuals providing the service, not uniform (poorly trained & motivated special education teachers are not uncommon) • Lack specialised expertise (ST, Education Psychologists, etc)
Families as Focal Point of Positive Partnerships						
Empower parents, carers, and families as positive partners at every stage of services	X	<ul style="list-style-type: none"> • Parents usually not consulted or involved, no policy 	X	<ul style="list-style-type: none"> • Parents usually not consulted or involved, no policy 	X	<ul style="list-style-type: none"> • Parents usually not consulted or involved, no policy
Special attention to disadvantaged and vulnerable families	?	<ul style="list-style-type: none"> • Policy in place but does not appear to reach the truly vulnerable 	?	<ul style="list-style-type: none"> • Policy in place but does not appear to reach the truly vulnerable 	?	<ul style="list-style-type: none"> • Policy in place but does not appear to reach the truly vulnerable
Meet parents/families need for respite care	X	<ul style="list-style-type: none"> • No policy, service almost non-existent 	?	<ul style="list-style-type: none"> • No policy, but offer the service by default 	X	<ul style="list-style-type: none"> • No policy
Financial Needs for Families & Services & Government provision						
Special provision to adequately cater for children with disabilities in the annual budgets of all relevant government departments	?	<ul style="list-style-type: none"> • No focused funding; part of general resources allocated; competing with many other health needs 	?	<ul style="list-style-type: none"> • Funding pitiful 	?	<ul style="list-style-type: none"> • Funding provided but inadequate to meet school's need for classroom or environmental modification (barrier free environments)
Provide adequate financial support through disability allowance, increased tax relief benefits, and subsidies for intervention and rehabilitation needs of children	X	<ul style="list-style-type: none"> • Funding only for very poor families via TBP fund • The majority have to purchase aids out of pocket or via NGOs 	X	<ul style="list-style-type: none"> • Funding only for registered children with disability • Those attending NGO services side-lined • Minimal funds to purchase aids 	X	<ul style="list-style-type: none"> • Funding only for registered children with disability • Those attending NGO or private services side-lined
Meet diverse educational needs of all children						
Pre-school education should be provided by the Ministry of Education to ALL children, Special Needs		Not relevant		Not relevant		<ul style="list-style-type: none"> • Some provision by Education department but coverage needs to grow • Unsure if syllabus caters for special needs in pre-school
Every SEN child should have an Individualised Education Plan (IEP) that is communicated to parents & reviewed/modified to meet the child's changing needs	?	<ul style="list-style-type: none"> • Not relevant • But there should be a clear plan for the management of each child with is lacking • And this should be communicated to parents 	X	<ul style="list-style-type: none"> • Dependent on individuals providing the service, not uniform or policy • Parents not routinely informed of child's status & progress 	X	<ul style="list-style-type: none"> • Dependent on individuals providing the service, not uniform or policy • Parents not routinely informed of child's status & progress

Key Challenges & Obstacles

Current Challenges for Services for Children with Disability

- Continued charity model by government agencies with lack of respect for children & parents opinion in service provision
- Lack of uniform professional & quality services by Health, Welfare & Education Departments
- Lack of integration between various sectors
- Growth of poorly trained professional manpower
- Unhealthy rise in financially motivated services
- Vulnerable segments of the population still have limited access to services

1. Challenges & Obstacles faced at National/Government Agencies level (MOH, MOE, Welfare)
 - a. Despite growing recognition & some concerted national plans, critical recognition of the importance of early intervention remains limited.
 - b. Continue to stigmatise and segregate children with disability.
 - c. Despite written policy, a charity, rather than an integrated social model, is still in the mind sets of service providers of the Health, Welfare & Education Departments.
 - d. Empowerment/Involvement of parents in decision making of services in these agencies (and even among some NGOs) is very limited.
 - e. Serious need to address the limited uniformity in the basic quality of services provided in the Health, Welfare & Education Departments.
 - f. There is a lack of ownership by some departments for children with SEN. Hence they are not well supported.
 - g. Despite some inter-ministry cooperation, this is not very effective both national and regionally (on the ground). The time has come for a Ministry for Children that seriously looks after the needs of children in all areas.
2. Ministry of Health
 - a. Young doctors qualifying have very limited knowledge and skills to evaluated children with disabilities (universities continue to remain out of date).
 - b. Medical student's training curriculum for learning disabilities is almost non-existent in some universities and extremely limited in most.
 - c. Most qualified doctors, whether in MOH or private, are not able to identify correctly children with learning disabilities, often dismissing parental concerns.
 - d. Growth in medical rehabilitation manpower but the delivery of services is still institutional based.
 - e. Quality of services not uniform & "concrete" (very dependent on expertise, very 'clinical', and not family focused).
3. Welfare Department
 - a. CBRs continue to struggle to grow in professional quality.
 - b. Administration is authoritarian.
 - c. Respect from other service providers lacking (esp. NGOs).
 - d. Some Welfare CBRs have "lost" the EIP focus (Many children grown up with & stayed with the CBR; Many in CBR are school aged children or young adults).
 - e. Failed to develop as independent NGOs which is the concept of CBR. Become very dependent on government assistance.
4. Ministry of Education
 - a. Enormous growth in services but not able to offer a uniform service.
 - b. Children still stigmatised by law as "uneducable". In the Education (Special Education) Regulations 1997 (regulation 3) under eligibility for special education it is stated that "pupils with special needs who are educable are eligible". It is time to eradicate the term "educable" and "non-educable" as it is against the tenets in the UNCRC.
 - c. Our current education programme and is failing children with learning disabilities. MOE services are better for children with severe disabilities in special education classes.

- Special education classes are not suitable for children with learning disabilities. These form the bulk of children with special needs whose needs are not currently met.
- d. MOE has no serious commitment to inclusive education for children with learning disabilities. As well as a reluctance to institute a teacher aid programme to support children in main stream education.
 - e. The quality of special education teachers varies enormously, even within the same school. Some teachers choose special education for monetary or transfer reasons.
 - f. Frequent complaints from parents about the lack of a focused education plan, no baseline assessment, no target skills/objectives and no review to see if objectives have been met. There is a need to implement an Individual Education Plan (IEP) for every child.
 - g. The training syllabus for special education teachers needs a review of its content & style of training (too much lecture based training).
 - h. Recent literacy KPIs (full literacy at Standard 3) linked to career advancements has resulted in teachers in the main stream education system "unloading" (getting rid of) children with mild learning problems to special education. This is inappropriate as we cannot be labelling 15% or more of our children as disabled.
 - i. Registering children as disabled currently appears to victimise than rather than support them.
 - j. MOE developing pre-school services for the disabled but NGOs still offering the larger pre-school services, especially in quality.
5. NGOs & Private Professionals
 - a. Remain "one step ahead" of government agencies.
 - b. Growth of services, changing with the needs of the children & parents.
 - c. There are unhealthy NGOs where either the focus is 'exclusive control of that area of child disability' or use the disabled to maintain organisation rather than service focus.
 - d. Significant unhealthy rise in commercial-base (financially motivated) professionals who run private practices and organisations. These individuals/organisation feed into the fear of parents for their child's future and charge exorbitant sums for assessment and therapy.
 - e. Due to the failure of MOE in providing a quality education service for children with learning disorders, NGOs & private professional services have mushroomed. Some of these private organisations ("home school services") are excellent and compassionate. Others are unhealthy and financially motivated.
 6. Implementation still an issue with vulnerable segments have limited access to services. Some remote rural communities have no services (Orang Asli, Interior of Sabah & Sarawak, urban poor).
 7. Disability services are strongly linked to social class disparity (strongly linked to poverty and disadvantaged social economic background).

Acknowledgements

I want to acknowledge and appreciate some ideas provided by Ms Khor Ai-Na, Dr Toh Teck-Hook and Dr Lim Boon-Hook in the preparation of this paper.

Citation:

Amar-Singh HSS. Overview of initiatives & programmes, key challenges & obstacles to the full realisation of rights of children with disabilities in Malaysia. UNICEF round table discussion on children with disabilities, 3 June 2013, KL, Malaysia.

References/Useful Documents

1. NECIC. Memorandum on Early Childhood Intervention. Unanimously adopted at the first national early childhood intervention conference. 18-20 November 2006, Penang. Available from: <http://www.necicmalaysia.org/newsmaster.cfm?&menuid=6&action=view&retrieveid=4>
2. Memorandum on Inclusive Education as National Policy for Children with Special Needs National Early Childhood Intervention Council, April 2012 (Full document available at: <http://www.necicmalaysia.org/newsmaster.cfm?&menuid=6&action=view&retrieveid=5>)
3. Annual Report, Department of Social Welfare, Malaysia. 2010.
4. Annual Report. Division of Family Health Development, Ministry of Health Malaysia. 2010.
5. Ministry of Education. National Report on the provision of inclusive quality primary and secondary education. UNESCO Conference Jakarta, Indonesia, 3 – 5 November 2009
6. Kenji Kuno. Community-Based Rehabilitation In South East Asia: Case Studies From Indonesia And Malaysia. Dissertation, August 1998. Available from: <http://www.arsvi.com/1990/9808kk-e.htm>
7. Aminah Bee Mohd Kassim. MOH Programme and Initiatives to Detect for Disability in Children. Family Health Development Division, Ministry of Health. First national early childhood intervention conference. 18- 20 November 2006, Penang. Available from: http://asiacommunityservice.org/NECIC/necic_speaker_st2.htm
8. Malaysian Child & Adolescent Health (0-18 years) Programme. Ministry of Health, Malaysia 2006
9. Amar-Singh HSS. Editorial: Meeting the Needs of Children with Disability in Malaysia. *Med J Malaysia* March 2008 Vol 63(1):1-3.
10. Amar-HSS. Community Based Rehabilitation Services For Children With Disability. *Medical Journal of Malaysia* 2002 57(D):9.
11. Amar-Singh HSS. Paediatricians Advocacy Role in Education. Proceedings of the 10th National Paediatricians Meeting. KL, July 2008
12. Amar-Singh HSS. Whither (Wither?) Services for Children with Disability in Malaysia. Keynote Address at NECIC June 2012, Sibu Malaysia.
13. Amar-Singh HSS. Screening & Diagnosing Learning Disabilities. SUHAKAM Forum on Children With Learning Disabilities, April 2013. KL, Malaysia.