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

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

## 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-Hock and Dr Lim Boon-Hock 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.

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