

Meeting the Needs of Children with Disability in Malaysia

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INTRODUCTION

With improvements in health care, disability and developmental problems in childhood have become more important health problems¹. Global developmental delay, cerebral palsy, intellectual impairment, hearing impairment, vision impairment, Autism, ADHD, mental health problems, etc have become more important concerns in recent years. It is important to detect these early as data suggest that, early detection and intervention, offers better long term outcomes and better family well being.

Size of the Problem

The actual number of children with disability locally is not available. The Department of Social Welfare figure of 170,455 registered children and adults with disability is a gross underestimate². Local experience has shown that a significant majority of children referred to the Welfare Department do not get on the national register and an even larger number go undetected. Ministry of Health (MOH) data reported only 2,881 new children aged 0-12 years with disability in 2005 that were registered³. Possibly the best indication of the true rate of children with significant disability is from international studies which suggest that more than 10% of all children have developmental problems and that the rate detected increases with age^{4,8}. Applying a rate of 10% to the population of children under 15 years for 2005 population figures suggests that more than 850,000 children have a disability, with at least one third of these being severe and requiring rehabilitation. Table I shows the frequency of various childhood disabilities with a special focus on developmental disabilities presenting in the pre-school period. Note that the rates vary according to the data source, definition used and community surveyed.

Detection of Children with Disability

An important question to ask is whether developmental delay and disability in childhood is missed by health professionals. The Centers for Disease Control and Prevention suggests that less than 50% of children with developmental delay or problems are identified before starting school in the USA⁹. A retrospective review in the United Kingdom (UK) showed that routine child health surveillance contributed to the early detection of children with pervasive developmental disorders (Autism)¹⁰. Routine child health surveillance remains an integral part of the child health programme in the UK.

An American Academy of Pediatrics (AAP) survey showed that 96% of pediatricians who provide health supervision to pre-school children assessed for developmental risk¹¹. An average of 9% of their patients had been identified with a possible developmental problem but the majority used a clinical

assessment without a screening instrument/checklist. The AAP has recently extensively revised its 2001 policy¹² on the area and clearly states "We recommend that developmental surveillance.... be incorporated at every well-child visit. Any concerns raised during surveillance should be promptly addressed. In addition, standardized developmental screening tests should be administered regularly at the 9, 18, and 30 month visits"¹³.

Many screening developmental instruments have been designed and validated. However, most suffer from limited sensitivity and specificity, often only reaching 70-80% in both areas. It is beyond the scope of this editorial to discuss them but a good reviews are available^{7,13,14}. Two of these screening tools are utilised in a research article published in this issue of the journal – the Denver-II Developmental Screening Test and the Schedule of Growing Scale II (SGS)¹⁵. The authors have used the SGS tool here not for screening but to monitor the progress of children with disability undergoing rehabilitation.

The data above supports routine developmental surveillance and encourages the use of specific screening tools to supplement this. In addition there is good data that parental concern about developmental delay is of importance. Parents often have concerns and these must not be dismissed lightly. Health professionals must adequately address these concerns and not falsely reassure parents. Of course there are also parents who may not recognise that their child has developmental problems, and some who may not attend routine health surveillance.

The Family Health Development Division of the MOH has taken initiatives to improve the detection of children with disability. From 2005 to 2006, MOH instituted a revision of the 0-18 Child Health Programme, to be introduced as a pilot in 2008, with a view to improve screening of medical and developmental problems in children^{14,16}. The revised child health programme includes specific developmental screening at 5 months, 12 months, 18 months and 4 years. The programme also introduces a formal anticipatory guidance component and strongly encourages health professionals to take note of parental concerns of developmental delay. Among the screening tools used will be the child developmental check list to assess parental concerns, M-CHAT (Modified Checklist for Autism in Toddlers) at 18 months and ADHD/Learning Disorders screen at 4 years. This will allow for early identification of developmental/learning problems and early placement in specialised preschool/school services.

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Table I: Frequency of various childhood disabilities detected in the pre-school age groups^{4,8}

Type of Disability	Rate
Intellectual/Learning disability	
Intellectual Handicap (includes Mild, Moderate, Severe, Profound)	10-30 per 1000
Attention Deficit Hyperactivity Disorder (School going children)	50-100 per 1000 US estimates 20-50 per 1000 UK estimates
Pervasive Developmental Disorders (Autism, ASD, Asperger)	6-9 per 1000
Learning Disability (eg. Dyslexia)	50-100 per 1000
Physical disability	
Cerebral palsy	3-4 per 1000
Sensory disability	
Hearing Impairment	1-2 per 1000
Visual Impairment	1-2 per 1000
Visual disorders (squint, amblyopia, refractive error)	20-50 per 1000
Overall Rate of Disability	10-16% of all children

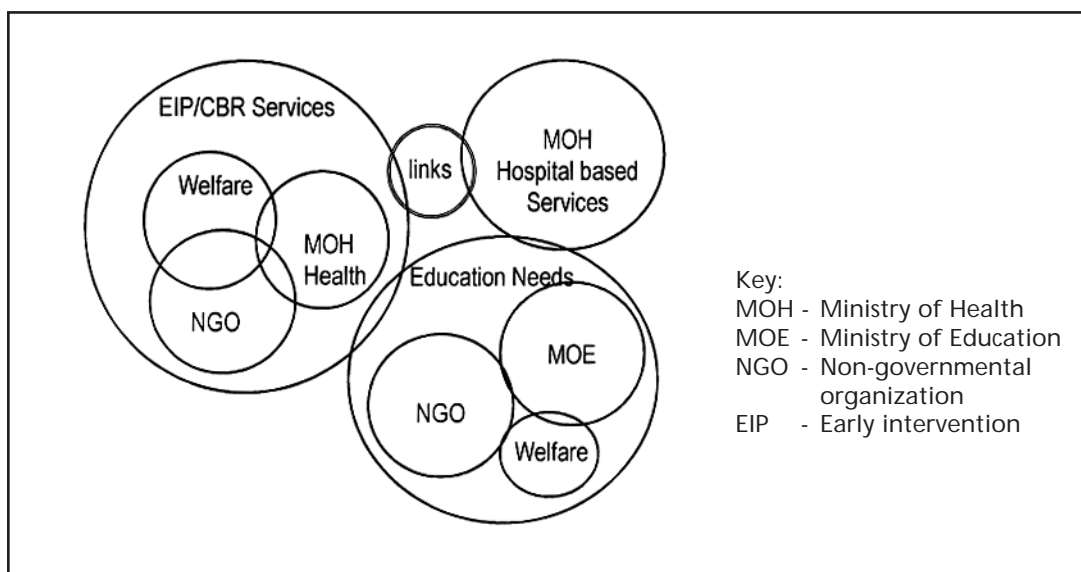


Fig : Overview of Current Disability Services

Assessment of Needs for Children with Disability

Developmental screening does not result in a diagnosis but identifies a child who has development problem when compared with her/his peers. There are no medical tests for diagnosing many of the childhood disabilities. Ideally a child requires a multidisciplinary assessment that involves evaluation by a paediatrician, physio and occupational therapist, speech/language therapist, child psychologist, etc. Assessment many involve the use of diagnostic tools or rating scales. There has been improvement in availability of professionals in this area but not uniformly across the country. A single evaluation is often not sufficient and, as shown by the article published in this issue of the journal¹⁶, re-evaluation is also important.

Provision of Services for Children with Disability

Early intervention is vital for any children identified to have a disability. It is beyond the scope of this editorial to discuss all therapeutic options but key principles are outlined below. A comprehensive account of the needs of children locally can be found in the “Memorandum on Early Childhood Intervention”¹⁷. All children with a disability should be

placed in an early intervention programme (EIP). Most children respond well to a highly structured, specialised programme, tailored to the individual needs of the person. A well designed intervention approach will include some level of communication therapy, physical therapy, social skill development, and behaviour modification, at a minimum delivered by trained professionals in a consistent, comprehensive and coordinated manner. The ideal programme is one which offers a 1:1 therapist/trainer to student ratio with a small group environment. Meeting with other parents of children with similar disabilities is very helpful (family support groups). Parents must appreciate the importance of their role not just as advocates of the child but also as “co-therapists” in extending the training to the home environment. Medication and dietary interventions have limited roles.

The majority of services in this country have adopted models of from industrialised countries. While aspects of these models may be applicable locally, they are by and large not suitable to meet the vast needs of the disabled. The figure shows the provision of services by various service providers in

the country. Services for the disabled are currently fragmented, hospital based, inadequate and do not appear to be a priority in medical development locally. Parents face many hindrances from service providers. Children with disability are often managed by a number of different departments with little integration. Services are better at assessment than rehabilitation. The chronic care for these children fatigues service providers and parents. There is a prevailing sense of hopelessness. Most services do not adequately address the emotional burden of the family. Hence there is a high "dropout" rate in the utilisation of rehabilitative services by parents.

We need workable, "feet on the ground" models that are developed from the ground up. Different models will be required for different regions. There is an urgent need to combine services provided by various professionals, not merely in one multi-disciplinary or inter-disciplinary team but in a trans-disciplinary concept. Services and support necessary to meet the needs of children with disabilities should be part of a local, integrated and co-ordinated service system. Rather than start new services or centres it is vital that we combine efforts with existing services and centres as it is extremely difficult to sustain such services.

The development of services for children with disability and their family is largely in the hands of professionals or therapists working in government agencies and non government organisations (NGOs). This has often resulted in services that are developed to meet the needs of the professional, therapist or organisation rather than those of the child or family. Children with disability and their parents should be consulted and involved in the decision making process of proposed and existing services which cater for their needs¹⁸.

Finally, to meet the needs of children with disability in Malaysia we need to have a paradigm shift¹⁹. Professionals and therapists need to change their perspective from service provision to training. There is a need to train the disabled and parents to look after their own rehabilitation (empowering them), to train CBR staff to run day to day service needs and to train (advise) government agencies and NGOs on the way forward in developing services. We require the will to relinquish "control" and distance ourselves from the "politics" of disability. We need instead to see children with disability and their family as partners and offer them care in a way which dignifies, best meets the needs of the person with disability and takes into account his or her cultural and spiritual needs.

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