

Whither (Wither?) Services for Children with Disability in Malaysia

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Introduction

- o Brief history of disability services for children (Malaysia)
- o Based on 30 years of experience:
 - Listening to & learning from parents/children with disabilities (primary source)
 - Health services
 - Working with NGOs & various government departments
 - Establishing and sustaining services
 - The title is intentionally proactive
- o Hope:
 - Key issues identified
 - Suggest ways we can meet the needs of children with disability in Malaysia

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The Early Days (Pre 1970s)

- o Services began as charity models in 1960s/70s
 - Extension of compassion of religious groups (mainly Christian)
 - Many were residential homes for physically disabled
 - Often expatriate initiated & run by voluntary groups
 - Most were managed based on public donations
 - Visits to them by society were viewed as “social concern” for the less fortunate


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The Early Days (Pre 1970s)


- o The earliest service St. Nicholas' Home for the blind in 1926
- o Other examples (not comprehensive)
 - Cheshire Homes for the disabled (Johore 1960, Selangor, 1963, Sarawak 1969)
 - Selangor Spastic Children's Association (1960)
 - Bethany Home for children with epilepsy and disability (1966)

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The Early Days (Pre 1970s)




St. Nicholas' Home
FOR THE BLIND



Selangor Spastic Children's Association



Cheshire Homes



Bethany Home

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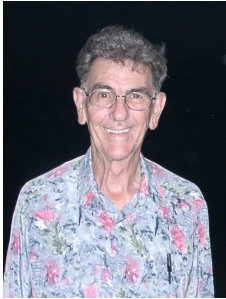
Some Light Emerging & Early Government Involvement (1970-1990)

- o Growth was slow
- o Services primary focused on cerebral palsy, severe intellectual handicap or visual/hearing impairment
- o Largely led by NGOs
 - NGOs emerged to meet felt needs
 - Many were focused on EIP service provision
 - Majority were provider, rather than parent led

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Some Light Emerging & Early Government Involvement (1970-1990)

- One notable expectation was Peter Young
 - Helped to start Malaysian Care
 - Models he develop were empowering & advocacy based
 - One of the earliest voices of advocacy for the disabled in the country
 - Pioneered a “model” special needs people home in 1981 (Rumah Rahmat)
 - Malaysian Care involved in setting up EIPs since 1988



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Some Light Emerging & Early Government Involvement (1970-1990)

- Improvements in health care
- Disability become more important & on the national agenda
- Beginning of services led by government agencies
 - Cabinet Committee Report (1979) recommended that government should be main provider of education for children with special educational needs

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Some Light Emerging & Early Government Involvement (1970-1990)

- Ministry of Health
 - 1986 (Family Health Development Division) moved from detecting children & hospital rehabilitation to training Nurses in rehabilitation
 - Provision of rehabilitation services at health centres for children began in 1996
- Ministry of Education
 - Established a Special Education Unit in 1964
 - Deaf/blind catered since 1970s
 - Inter-Ministerial Committee on Special Education (Welfare, Health, Education) formed 1981
 - Education for learning disabled only considered in the late 1980s (parents met Minister of Education)
 - Growth of school special education services was slow until the 1990s
- Welfare Department
 - Long been involved in offering residential care for the severely disabled
 - Community Based Resources (CBR) model adopted 1983
 - Growth of EIPs in many rural settings by 1995

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Advocacy & Organisation (1990-2000)

- 1990s saw advocacy to recognise enormous burden of learning disability especially ADHD, Autism, Dyslexia
- Some moved from a charity model to a social model
- NGOs
 - National & collaborated
 - Advocacy being firmly on the agenda
 - Grew in the scope of services
 - Moved from residential care/EIPs to transition to school, employment training, job placement, group homes for young adults, respite care, etc.
- Government
 - Formal organisation by MOH, Welfare, MOE
 - Expansion of routine services of children with disabilities

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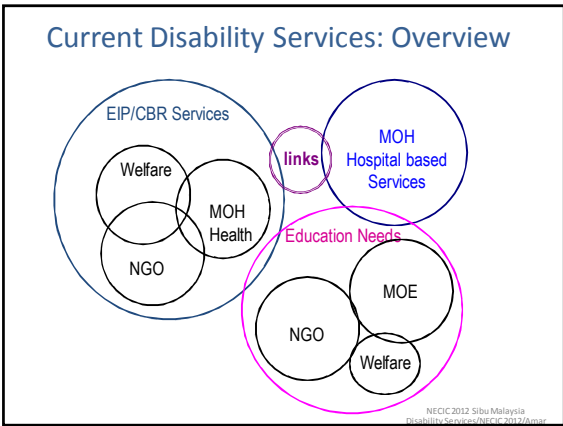
Example: Education Department

| Year | All Areas (Total Primary School) | | |
|------|----------------------------------|----------|---------|
| | Students | Teachers | Classes |
| 1998 | 5321 | 847 | 1249 |
| 2008 | 18429 | 4199 | 3103 |

Special Education classes in Perak:

- 5 in 1988
- 496 in 2008
- Primary growth in children with learning problems
- Recent training of new teachers

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Explosion, Policy, Greed (2000-Current)

- Enormous growth of policies/services nationally
- But implementation still an issue
 - Vulnerable segments have limited access to services
 - Rural communities no services (Orang Asli, Interior of Sabah & Sarawak, the Poor)
- National agencies
 - Despite growing recognition & some concerted national plans, critical importance of early intervention remains limited
 - Continue to stigmatise and segregate children with disability
 - 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
 - Empowerment/Involvement of parents in decision making of services in these agencies (and even among some NGOs) is very limited

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Explosion, Policy, Greed (2000-Current)

- MOE developed pre-school services for the disabled but NGOs still offering the larger pre-school services, especially in **quality**
- Serious need to address the limited uniformity in the **basic quality of services** provided in the Health, Welfare & Education Departments

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Explosion, Policy, Greed (2000-Current)

- Ministry of Health
 - Young doctors qualifying have very limited knowledge and skills to evaluated children with disabilities (universities continue to remain out of date)
 - Growth in medical rehabilitation manpower but the delivery of services is still institutional based
 - Quality of services not uniform & “concrete”

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Explosion, Policy, Greed (2000-Current)

- Welfare Department
 - CBRs continue to struggle to grow in professional quality
 - Staff remain poorly paid
 - Administration is authoritarian
 - Respect from other service providers lacking (esp. NGOs)
 - Some Welfare CBRs have “lost” the EPI focus
 - Many children grown up with & stayed with the CBR
 - Currently 428 CBRs catering for 18,932 children (Oct 2010 data) but many are school aged children or young adults

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Explosion, Policy, Greed (2000-Current)

- Ministry of Education
 - Enormous growth in services
 - But not able to offer a uniform service
 - Quality of teachers/services varies enormously
 - Some teachers choose special education for monetary reasons
 - Children still stigmatised by law as “uneducable”
 - Recent literacy KPIs 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
 - Registering children as disabled currently appears to victimise than rather than support them

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Explosion, Policy, Greed (2000-Current)

- NGOs & Professionals
 - Remain “one step ahead” of government agencies
 - Growth of services, changing with the needs of the children & parents
 - But 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

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Key Challenges for Services for Children with Disability

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

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The Way Forward

- In this new millennium we must address these challenges vigorously in a strong partnership of parents, practitioners and policy makers
- We must embody the 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”
- We must fulfil 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”
- We need to keep our focus on Memorandum on Early Childhood Intervention adopted by delegates to first NECIC 2006 :
 - “Parents, carers and families should be recognized, and empowered, as positive partners in all aspects of screening, diagnosis, assessment and intervention.”

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The Way Forward

- Detailed Suggestions are embodied in the “Memorandum on Early Childhood Intervention” (NECIC 2006) and will not be repeated here

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The Way Forward

- As services grow we are at **many crossroads, choices that will define us as a nation**
- Government agencies, professionals and therapists need to have a paradigm shift
- 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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