A STUDY OF DEVELOPMENTAL ASSESSMENT AMONG CHILDREN WITH SPECIAL NEEDS IN EARLY INTERVENTION PROGRAMME IN KUCHING, SARAWAK

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A STUDY OF DEVELOPMENTAL ASSESSMENT AMONG CHILDREN WITH SPECIAL NEEDS IN EARLY INTERVENTION PROGRAMME IN KUCHING, SARAWAK.

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A thesis submitted in fulfilment of the requirements for the degree of Masters of Public Health (Health Promotion).

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2008
DECLARATION

No portion of the work referred to in this thesis has been submitted in support of an application for another degree of qualification of this or any other university or institution of higher learning.

Signature: [Signature]

Name: HAIRONI YUSOFF

Date: 21st January 2008
DEDICATIONS

To my husband, thank you for your unconditional love and support.

To my children, especially Humaira for the nine months that she spent with me throughout this course.

And, to my friend, Norrihah Takuan, with whom I shared most of the journey.
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### ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
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<tbody>
<tr>
<td>AAP</td>
<td>American Academy of Pediatrics</td>
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<tr>
<td>ANOVA</td>
<td>Analysis of Variance</td>
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<tr>
<td>CBR</td>
<td>Community-based Rehabilitation</td>
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<tr>
<td>EIP</td>
<td>Early Intervention Programme</td>
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<tr>
<td>ICD</td>
<td>International Classification of Disease</td>
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<tr>
<td>MSGS</td>
<td>Modified Schedule of Growing Skills</td>
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<tr>
<td>NHMS2</td>
<td>Second National Health and Morbidity Survey</td>
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<tr>
<td>PIBAKAT</td>
<td>Parental Association for Children with Special Needs</td>
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<td>SGS</td>
<td>Schedule of Growing Skills</td>
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ABSTRACT

There is an estimate of around 12 to 26 percent of children with special needs attending early intervention programmes throughout Malaysia. However, very little research has been done on evaluation and monitoring of children with special needs attending these programmes. In order to determine a new method of developmental assessment of children with special needs attending early intervention programmes and to compare their development between clinic (n=27) and community-based (n= 29) centres, a cross-sectional study was conducted. A modified Schedule of Growing Skills (MSGS) assessment was used for this purpose. Concurrent validity was established when MSGS was compared with Denver Developmental Assessment (DDA) which showed an excellent correlation between the two measurements (Spearman’s rho = 0.87, p<0.001). Reliability statistical analysis (Cronbach’s Alpha = 0.856-0.984) verified MSGS as an appropriate tool to be used for the developmental assessment. The inter-item factor analysis showed consistency between the nine items assessed. The sensitivity and specificity of MSGS in this study was observed to be 83.33% and 33.33% respectively. When the mean scores for children from both centres were compared, it was noted that the children attending the community-based programme (mean = 111.69, CI 95%, 102.18 to 121.20) were more delayed than the clinic-based programme (mean = 80.04, CI 95%, 69.16 to 91.02) and the results were significant (p<0.05). However, there was no difference for gender, diagnosis and severity of developmental delay. This study provides a preliminary data that implicates the usefulness of MSGS as a tool for assessment of developmental milestone for children with special needs. It also has the potential to be used as a tool for monitoring developmental milestone of those attending the intervention programme. Moreover, more studies are recommended to assess the early intervention programmes so that its approach, methods and facilities can be further improved.
ABSTRAK

Setakat ini, dianggarkan seramai 12 hingga 26 peratus kanak-kanak khas mengikuti program intervensi awal di seluruh Malaysia. Namun, tidak banyak kajian yang dilakukan untuk meneliti keberkesanan dan perkembangan kanak-kanak khas yang mengikuti program tersebut. Bagi menentukan cara terbaik untuk menilai perkembangan kanak-kanak khas di dalam program awal intervensi, satu kajian menggunakan kaedah keratin rentas dijalankan di antara 27 orang kanak-kanak khas dari program di klinik dengan 29 orang kanak-kanak khas dari program di pusat masyarakat. Penilaian perkembangan kanak-kanak tersebut dibuat dengan menggunakan ‘Schedule of Growing Skills’ (MSGS) yang telah dimodifikasi. Kajian statistik untuk kesahan serentak terbukti apabila perbandingan MSGS dan Denver Developmental Assessment (DDA) menunjukkan hubungkait yang amat tinggi (Spearman’s rho = 0.87, p<0.001). Analisa kebolehpercayaan juga membuktikan keberkesanan kaedah MSGS (Cronbach’s Alpha = 0.856-0.984). Analisa faktor untuk kesembilan item dalam MSGS juga menunjukkan statistik yang konsisten. Sensitiviti MSGS dalam kajian ini adalah 83.33% dan spesifisitinya adalah 33.33%. Perbandingan purata markah bagi kanak-kanak dari kedua pusat dibandingkan dan didapati kanak-kanak dari pusat masyarakat (purata = 111.69, CI 95%, 102.18 to 121.20) lebih ketinggalan dalam perkembangan dari kanak-kanak di klinik (purata = 80.04, CI 95%, 69.16 to 91.02) dan perbandingan tersebut adalah signifikan (p< 0.05). Walaubagaimanapun perbandingan untuk jantina, diagnosa dan tahap perkembangan adalah tidak signifikan. Kajian ini jelas menunjukkan bukti awal keberkesanan MSGS untuk digunakan sebagai kaedah pemeriksaan saringan bagi kanak-kanak khas dan juga mempunyai potensi untuk digunakan sebagai kaedah mengawasi perkembangan mereka yang mengikuti program intervensi. Namun begitu, lebih banyak kajian perlu dijalankan untuk menilai keberkesanan program intervensi supaya strategi dapat di atur untuk memperbaiki kaedah dan kemudahan yang sedia ada.
Chapter 1

Introduction and Literature Review

1.1 Introduction

1.1.1 Preamble

The study on early intervention programme in Malaysia is very scarce. Attendance of children with special needs to rehabilitation programme is sadly deficient in Malaysia, as reported in the Second National Health and Morbidity Survey (NHMS2, 1996) by the Ministry of Health. Efforts to help improve the facilities for the disadvantaged group are being encouraged.

Children with special needs are defined as those who have or are at risk of a chronic physical, developmental, behavioural or emotional condition and who also requires health and related services of type or amount beyond that required by children generally (McPherson, 1998). Early intervention programme are services that focus on development of infants and toddlers (0-3 years old) to meet the requirements in the following areas; namely physical, cognitive, communication, social, emotional and adaptive functions (Bailey, 2002). It includes therapy and support services that minimizes the potential of developmental delay, enhances development of children with special needs, addresses their needs and helps educate families or their caregivers.
1.1.2 Background

In Kuching, children with special needs are currently being encouraged to attend the Early Intervention Programme, either at the clinic-based centres in Maternal & Child Health Clinics or in community-based rehabilitation centres (CBR), which are usually conducted by welfare services or non-governmental organisations. Most Maternal & Child Health Clinics are now providing early intervention programmes as part of their extended programmes. These programmes are managed by the medical officer of the clinic, if available, or more often, by the trained community nurses, with assistance from visiting physiotherapist and occupational therapist from the general hospital or from the Maternal & Child Health Clinic in Jawa Road, Kuching, which has a full time physiotherapist and occupational therapist. In addition, the Maternal & Child Health Clinic Early Intervention Programme is fully supported by a visiting Public Health Specialist and Paediatrician who sees the patients once a week. This clinic also provides home visits for patients who are unable to attend the clinic sessions.

The community-based rehabilitation centres are usually conducted by volunteers from the Association of Parents with Children of Special Needs (PIBAKAT), or workers employed under the Welfare Department. These centres usually obtain assistance from non-governmental organisations, which are able to employ physiotherapist, occupational therapist, speech therapist or social workers from other agencies or international resources. The Early Intervention Programme in Ong Tiang Swee Road is run by the parental association, PIBAKAT. There are eight workers, called physiotherapist aides, who are trained in physiotherapy and basic
occupational therapy. Occasionally they obtained assistance from visiting specialists from overseas, mainly from Japan.

Both centres work closely with the Child Psychiatrist or Clinical Psychologist. Whenever available, a speech therapist will be invited to provide services to both centres. Both centres accept children whose developmental age is below seven years, regardless of chronological age.

To date, there are 16 existing facilities for children with special needs throughout Sarawak, which includes clinic-based rehabilitation centres, community-based rehabilitation centres, special schools and special classes in mainstream schools. Out of the 16 facilities, 3 are community-based centres and 4 are clinic-based rehabilitation centres located in Kuching, Sarawak. Jawa Clinic is the referral centre for the government service and the PHBAKAT programme has been very well established in Kuching.

The types of diagnoses of children with special needs attending these facilities in Kuching include Down’s syndrome (26.2 percent), cerebral palsy (20.9 percent), mental retardation (38 percent) and others (14.9 percent). 38.5 percent are newly diagnosed cases, with the majority identified between 6 to 10 years of age (Wan Asma et al, 2000).
1.1.3 Research Questions

Current developmental assessment of these children is fairly subjective, and totally based on observations of health workers or volunteers, using the Denver Developmental Assessment. Although Denver Developmental Assessment is sufficient as a screening test for the general population, a more specific developmental assessment method may be necessary for monitoring the development and progress of children with special needs. Denver Developmental Assessment helps to identify those children that require special attention and a more detailed assessment. For monitoring of children with special needs, a more standardized and structured format may be necessary to identify the developmental impairment and how these impairment may improve over time and with early intervention. Various methods have been used by various centres. To date, there is a vast selection of screening and pre-screening measures and there are no specific guidelines in choosing the accurate and appropriate tests. Studies looking at the shortfalls of developmental surveillance to screen developmental disabilities have recommended the need for a more psychometrically sound and standardized method of assessment. (Sices et al, 2004; Rydz et al, 2005; Allen, 2007).

Currently, there are no known studies that examine the method of assessing developmental milestones and the progress of children with special needs in early intervention programme in a more objective manner. This could be due to the wide diversity in the types of cases attending early intervention programmes, its services, the approach to therapy and the facilities available. However, there is encouraging evidence for early intervention effectiveness with autism (Bruce & Kristin, 2003).
In the current setting in Malaysia, early intervention programme can be conducted either in the community or as part of the extended programme in the Maternal & Child Health clinics. In view of the different facilities available, it would be of interest to see if differences in the two groups of children with special needs attending these facilities exist, in terms of socio-demographic background, types of diagnosis and severity of their developmental delays.

1.2 Literature Review

1.2.1 Identification of developmental delay

Under-identification of developmental delay among young children is a common problem (Berkoff, Leslie & Staltmer, 2006). In the United Kingdom, for example, only 45-55% of children with developmental disabilities are detected before school entrance (Glascoe & Dworkin, 1993). This figure is even lower when developmental disabilities are detected only by clinical examination or in children with behavioural or emotional problems. A study that compared paediatrician’s intuition against a complete standardized developmental assessment for behavioural problems showed a low sensitivity level of only 20% (Lavigne, Binns & Christoffel, 1993).

A periodic survey conducted by the American Academy of Paediatrics (2001) reported that an estimate average of 9% of their patients have been identified with a possible developmental problem. Only 35% of the paediatricians used clinical
assessment guided by the Denver Developmental chart, while the others used clinical
assessment without any screening instrument, or checklist filled out by them, their
staff or the parents. Furthermore, only 39% of their current patients with
developmental delay were referred to the early intervention programme (AAP, 2001).
If this is the statistics noted from a developed country, it is estimated that the figures
for Malaysia will be worse due to insufficient number of paediatricians, medical
officers and lack of facilities available and lack of awareness on the early intervention
programme.

In the United States, it was reported that the average age of children attending
the Early Intervention Programme was 17 months, with about 70% having
developmental delays and almost all cases were classified as potential or established
high risk of having developmental delay (US Department of Education Report, 2002).

Hence, the developmental screening and surveillance programme to identify
children with developmental disability is pertinent. Developmental screening is the
process of systematically identifying children with suspected delay who needs further
assessment (Rydz et al, 2005). A good screening test can improve the rate of
identification and those identified can be referred to intervention programmes earlier,
which has been proven to be beneficial (Shônkoff & Hausser-Cram, 1987). The
screening process also helps to identify children who are noted to have delays in
various aspects of development. It is pertinent to identify these developmental delays
early so that appropriate intervention can be performed earlier. Bruce & Kristin
(2003) have proven the benefits of early identification and early intervention.
Once the developmental delay has been identified, the child can then be referred for early intervention programme. To date, there are no specific guidelines for monitoring the progress of children with special needs undergoing early intervention programme.

1.2.2 The Malaysian Setting

In Malaysia, there is very little studies done on developmental assessment or monitoring the progress of children with special needs. Most studies are conducted on school children to examine the facilities in integrated or special schools and their intervention programmes. Evaluation of the early intervention programmes conducted throughout the country is inadequate. The need to review methods used for developmental assessment and monitoring the progress of children with special needs is crucial as the prevalence of children with developmental delay is on the rise. The number of children with special needs registered to the Ministry of Health in 2004 was 2,563 as compared to 1,864 in 2003. Of the total number in 2004, 25% (640) had Down syndrome, 14% (347) had global developmental delay and 12% (317) had cerebral palsy. The other cases comprised of autism, learning disabilities, mental retardation, blindness, deafness and physical disability (Aminah Bee, 2006).

The prevalence of self-reported impairment in Malaysia was 6.9 % (Wan Asma et al, 2000). The prevalence of self-reported disability was 1.5% (1.4-1.7%) as reported in the National Health & Morbidity Survey (1996). The survey also showed a prevalence of impairment of 94.9 per 1000 persons (9.49%) which is comparable with World Health Organisation estimates of 10%. The prevalence of impairment and
disability was reported to be higher in rural areas (8.3% and 1.8% respectively) as compared to urban areas (5.7% and 1.3% respectively). It was also noted that the prevalence was also higher in low socio-economic and low educational groups (NHMS2, 1996).

Studies on developmental assessment and facilities for children with special needs in Malaysia are also deficient. Wan Asma and colleagues (2000) reported that there are 425 facilities for children with special needs in Malaysia, of which, 33% (194) were community-based centres, 10.5% (62) were clinic-based centres and 54.8% (332) were integrated into main stream schools or converted into special schools. A total of 9,080 children with special needs attended these facilities, whereby, 26% attended the community-based centres, and only 12.2% attended the clinic-based facilities. The types of cases attending the community-based centres were mainly Down syndrome and mental retardation, whereas, the majority of cases attending the clinic-based centres were mainly Down syndrome and cerebral palsy.

1.2.3 Developmental assessment methods

Developmental assessment provides comparison of the child’s level of functioning in relation to his/her peers. The Denver Developmental Assessment is the most widely used test for screening and is considered as a well accepted method (Frankenburg et al, 1992; Abubakar et al 2007; Chang et al 2007; Nelson et al 2006, and Arnould et al 2004). Its accuracy in terms of sensitivity and specificity has been extensively studied (Glascoe, 1992; Frankenburg, et al 1992). Glascoe (1992) has shown that its sensitivity is 80% and specificity as 56% if “questionable scores” are
considered as 'abnormal' and sensitivity of 50% and specificity of 80% if "questionable scores" are considered as 'normal'.

There are other developmental screening tests that have been used including the Bayley Infant Neurodevelopmental Screener, Battelle Developmental Inventory Screening Test and Brigance Screens. The Bayley Scales have been shown to have a sensitivity and specificity of between 75 to 86% (Franzen & Berg, 1998). Its test-retest reliability ranges from 0.71 to 0.84 and its inter-rater reliability ranges from 0.79 to 0.96 (Franzen & Berg, 1998). The Battelle Developmental Inventory Screening Test is designed to suit both healthy and developmentally delayed children and has a sensitivity of 80% and specificity of 74% (Newborg et al, 1984). The test has been shown to be beneficial in identifying children that are eligible for intervention and educational services (Wodrich, 1997). However, it requires extensive training, which can be time consuming if it were to be used in a therapy session. The Brigance Screens has an accuracy of identifying 72 to 77% of developmentally delayed children and 73 to 100% of healthy children (Palfrey, 1992). Its accuracy has been shown to be 70-80% with reliability ranging from 0.98 to 0.99 (Brigance & Glascoe, 2002).

The Schedule of Growing Skills II is adapted from the United Kingdom (Bellman et al, 1997) and is widely used for screening and assessment of developmental milestones. It examines nine skills including postural skills, locomotor skills, manipulative skills, visual skills, hearing, speech and language skills, social and cognitive skills. A scoring system is given for each item assessed so that the higher the level of achievement, the higher the score. This score is then converted into developmental age and enables the assessor to ascertain if the child is generally
delayed or has isolated or mixed deficiency in any of the nine items. This is one of the few developmental assessment methods that use the scoring system, which is valuable when monitoring the positive improvement of early intervention in children with developmental delay. In addition, its simplicity enables medical personnel from various backgrounds to use it without problems, including health visitors, community nurses, occupational therapists, speech therapists, physiotherapists, general practitioners and paediatricians. It is also quick and easy to conduct, requiring a duration of only 20 minutes per session, which minimises interruption of the child’s intervention programme.

Studies on validity and reliability of Schedule of Growing Skills (SGS) (Bellman et al, 1997) are scanty. The schedule had been used to assess progress of children who had paediatric cochlear implantation because of its properties in assessment of general development and cognitive functioning (Edwards, Frost & Witham, 2006). Similarly, SGS has also been used to assess psychomotor and cognitive development in children below 6 years of age after long term exposure to anticonvulsants in pregnancy. SGS helped to highlight the delays in interaction, hearing and language domains among those children when their developmental milestones were monitored over a period of time (Adab et al, 2004). In monitoring the progress of developmental milestone, SGS was used to follow up the developmental milestone of a case of attention difficulties and holoprosencephaly as it provided specific areas of developmental deficit and made documentation more accurate (Heussler et al, 2002). In exploring the benefits of early intervention programme to pre-school children with motor impairments, SGS was chosen because of its scoring system where differences in scoring enabled the researchers to ascertain the

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acquirement of new skills (Woofson, 1999). SGS has also been used as a screening tool to ascertain the developmental outcome of newborn infants treated for acute respiratory failure (Kambekar et al., 2006). Its use has also been compared to other developmental assessment tools for early detection and diagnosis of autism spectrum disorder in young children (Chakrabarti et al., 2005).

1.2.4 Early Intervention Programmes

When comparing early intervention programmes, it has been noted that there is considerable diversity in the population being surveyed, the purpose of intervention, the approach used and the indicators of success (Bruce, 2003). Well conducted evaluation of programmes in early intervention centres has been scarce, particularly for this region. Moreover, the effectiveness of early intervention programmes has been well established. Despite that, there are very few studies that compare its effectiveness in different settings. The early intervention programme has been shown to improve the family's ability to reconnect with mainstream societal services (Carpenter & Barry, 2007). De Souza (2006) and colleagues conducted a survey on compliance to early intervention programme for high-risk babies in India in a clinic-based programme and showed moderate compliance of only 59.2%. The researchers recommended that early intervention programmes should be community-based to provide easy accessibility, especially for high-risk infants. A randomised control study looked at the effectiveness and cost of a community-based intervention and a hospital-based intervention and found no significant differences between the community and hospital-based groups in terms of outcome measures and costs (Harrington et al., 2000). Another study conducted a prospective randomized trial to
look at a community-based parent training as compared to a clinic-based individual parent training programme for families of pre-schoolers at risk for disruptive behaviour disorders. Their results showed that those attending the community-based programme reported greater outcomes and better maintenance at follow-up. Furthermore, a cost analysis proved the community-based programme as six times more cost effective as compared to the clinic-based programme (Cunningham et al, 1995).

Another survey on formal assessment practices in Florida showed that multiple assessment tools were used to assess various domains in child developmental milestones, using age appropriate instruments. It was shown that there is great complexity in implementing the assessment systems for young children in child care. This study, therefore not only attempts to introduce a new developmental assessment tool but also endeavours to look at differences between the early intervention programme in the clinic and the community so that improvements can hopefully be recommended based on its findings.

1.3 Scope of study

This study proposed to use the Schedule of Growing Skills which had been modified for the Malaysian setting. Being a new method, it was validated first in a pilot study. In addition, this study also aimed to look at differences in children with special needs attending the early intervention programme in clinic-based and community-based centres in Kuching. This is the first known study to look at such method and differences in developmental assessment in Malaysia.