

# Assessing the Development of Children with Disability in Malaysia

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## SUMMARY

This is a cross-sectional study investigating the profile of children with disability registered with the primary health care clinics in Malaysia. The purpose of the study was to assess the developmental stage of children with disability. Secondary data from the pilot project conducted by the Family Health Development Division, Ministry of Health Malaysia was used in this study. The study period was for six months from 1st August 2004 until 31st January 2005. A total of 900 disabled children were selected in this study. Schedule of Growing Scale (SGS) II was used for analysis. Results showed more boys than girls were affected with a ratio of 6:4. The mean total SGS score increases as the age of the child increased. The score was highest in delayed speech cases and lowest in cerebral palsy cases. The performance among children with delayed speech was the highest while children with cerebral palsy were the lowest. There was a statistically significant difference between the major ethnic groups in delayed speech and attention deficit hyperactive disorder.

## KEY WORDS:

*Developmental Assessment, Child Disability, Schedule of Growing Scale (SGS) II*

## INTRODUCTION

According to the World Health Organization (WHO), children with disability could be defined as 'any child unable to ensure by himself wholly or partly, the necessities of a normal individual and or social life, as a result of a deficiency either congenital or not, in his physical or mental capabilities'<sup>1</sup>. WHO stated that 10% of the population in any country around the world has some form of disability. It has been estimated that among the 10% of the population with disability, one third are among children less than 15 years old<sup>1</sup>. Translating this figure into the Malaysian population of 24 million, there are about 800,000 children less than 15 years old with some form of disability that requires special care. In the Malaysian National Health and Morbidity Survey 1996, the prevalence of disability among 6 to 14 year olds was 5.8% while the prevalence of impairment among 0 to 14 year olds was 4.8%<sup>2</sup>.

The awareness and interest in rehabilitation programme for children with disability in Malaysia began in 1981 following the establishment of the inter-ministerial committee to plan for early detection, management and placement in

appropriate schools<sup>3</sup>. Since 1986, Public Health Nurses have been trained in the management of children with disability, following which activities have been carried out by them to provide rehabilitative services<sup>3</sup>. As of December 2002, there were a total of 93 health centers in Malaysia providing rehabilitation services for children with disability<sup>4</sup>. In the year 2002 alone, there were a total of 1,387 disabled children below the age of seven years detected at the health clinics<sup>4</sup>. In Malaysia, the 'Children with Special Needs Programme' was implemented to provide special health care for children with disability.

Studies from the developed world have used different developmental assessment tools to describe the developmental achievement among children with disability<sup>5-7</sup>. However, most of the studies concentrate on one particular disability and on one particular skill area. In Malaysia, there has been no study to quantify or score development among children with disability.

The objectives of this study were:

1. To describe the characteristics of children with disability attending primary health care clinics.
2. To score the developmental assessment among children with disability using an appropriate assessment tool.
3. To determine any significant difference in the developmental assessment score among children with disability in the three major ethnic groups.

## MATERIALS AND METHODS

This is a cross-sectional study investigating the profile of children with disability registered with the primary health care clinic in Malaysia. Secondary data from the pilot project conducted by the Family Health Development Division, Ministry of Health Malaysia was used in this study. The study period was for six months from 1st August 2004 until 31st January 2005. A total of 40 nurses in charge of children with special needs programme were selected to participate in the study. Each nurse was required to examine 10 children with special needs per month using the Denver Developmental Assessment Test (DDST) II chart and Schedule of Growing Scale (SGS) II for six months over the study period to assess the developmental state of these children. Each nurse was trained on the use of DDST II chart and SGS II. Universal sampling method was used by the nurses to select the cases where every child that visited the clinic was selected until the quota of 10 cases for each month has been reached. Through

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out the study, the nurses were supervised by the respective Family Medical Specialist or Maternal Child Health Officer in the clinic. Types of disability were diagnosed by Family Medical Specialist based on the 'Standard Operating Procedure' of the primary study.

In this study, the SGS II was used for analysis. SGS II was validated this year (2006) in the pilot study conducted by the Family Health Development Division, Ministry of Health Malaysia. SGS II is a developmental screening procedure which was based firmly on the well-known and well-respected developmental sequences designed by Dr Mary Sheridan<sup>8</sup>. Supplemented by a few well-tried items not included in Mary Sheridan's work, SGS II was the fruit of several years of research, development and trial on children throughout the United Kingdom. It provides information on whether the child is developing normally and identifying which skill areas the child is delayed in.

The inclusion criteria in this study include all of the cases from the pilot study. The exclusion criteria include cases from East Malaysia, cases that are not Malaysian and cases at age at assessment of more than 144 months (12 years old). In order to prevent repetition of cases being entered into the analysis, cases who were evaluated more than once during the study period were only entered once in reference to the earliest assessment date. This study included cases from four states involving 36 primary health care clinics. The four states include Kelantan with six clinics involving six nurses, Perak with eight clinics involving eight nurses, Johor with eight clinics involving eight nurses and Selangor with fourteen clinics involving fourteen nurses.

The scoring system for developmental assessment in the SGS II was assessed in eight skill areas. The skill areas include locomotor, manipulative, visual, hearing and language, speech and language, interactive social, self-care social and cognitive. In each skill area, there are several skill sets. The score achieved for the child within the skill area is the sum of the scores of the single most advanced item in each skill set<sup>8</sup>.

The purpose of this study was to assess the developmental stage of children with disability. Data was analyzed by using the Statistical Package for Social Sciences (SPSS) Version 11 programme.

## RESULTS

A total of 900 children with disability attending rehabilitation provided by the primary health care clinic were included in the study. The mean age of the cases was 57.5 months. There were 546 (60.7%) males and 354 (39.3%) females. Malays were the majority (80.2%) followed by Chinese (13.6%) and Indian (6.2%). There were 322 (35.7%) cases from Selangor, 212 (23.5%) from Johor, 198 (22%) from Kelantan and 168 (18.7%) from Perak. With respect to the type of disability, there were 27.8% Down syndrome, 22% cerebral palsy, 12.9% gross developmental delay, 8.7% slow learner, 7.6% delayed speech, 5.6% autism, 4.4% attention deficit hyperactive disorder, 3.3% mental retardation and 7.8% others (Table I).

The mean total Schedule of Growing Scale (SGS) score tends to increase as the age of the child at assessment increases.

This holds true in almost all the types of disability with the age group from 0 to 96 months. The mean total SGS score was the highest (ranging from 84.0 to 174.0) in delayed speech cases and across the age groups while cerebral palsy cases had the lowest score (ranging from 25.9 to 49.9). Pearson correlation,  $r$  was used to establish the association of age with SGS score among the different types of disability. The  $r$  value ranging from 0.167 to 0.695 was statistically significant at  $p < 0.05$  for all the types of disability except autism ( $r = 0.063$ ) (Table II).

Table III showed the percentage of mean SGS scores in relation to the mean achievable scores according to the chronological age of the cases. A higher percentage means that the child's developmental age is closer to their chronological age ability. Delayed speech scored the highest percentage (ranging from 61.0% to 99.4%) in seven out of the eight skill areas while cerebral palsy scored the lowest (ranging from 14.7% to 36.9%) in all the eight skill areas. Among the different skill areas, cognitive skill had the lowest percentage (ranging from 14.7 to 60.2) in all the types of disability except for delayed speech. There were statistically significant differences in the mean score among the different types of disability for all the skill areas.

The mean total SGS score among the three ethnic groups were compared in relation to the different type of disability. There were statistically significant differences in the mean total score among the three ethnic groups for delayed speech and attention deficit hyperactive disorder (Table IV). Post hoc test using the 'LSD' method was used to determine which mean pairs were significantly different. For delayed speech, significant differences were detected among Malay-Indian ( $p < 0.001$ ) and Chinese-Indian ( $p = 0.001$ ) mean pairs. As for attention deficit hyperactive disorder, significant differences were detected among Malay-Chinese ( $p = 0.038$ ) and Malay-Indian ( $p = 0.015$ ) mean pairs.

## DISCUSSION

Children with disability (special needs) are a group of children that require special health care needs and services. They have a chance of achieving a better quality of life if special care through early detection and intervention is provided for them. The Early Intervention Programme (EIP) was initiated by the WHO in 1986 for this group of children. EIP has evolved to the Children with Special Needs (CWSN) Programme with the emphasis on decentralization of rehabilitation services to primary health care. This was to ensure that the services provided were as near to the child as possible. CWSN programme has expanded greatly in Malaysia where most clinics in all the states provide the service. However, no efforts have been made to quantify the developmental assessment for each case and this makes evaluation of the progress of the cases extremely difficult.

The problem with multiple disabilities in a child has been considered in the study. Among the 900 cases, there were 67 cases diagnosis with a combination of disabilities. Seventeen cases had cerebral palsy with mental retardation, 16 cases cerebral palsy with delayed speech, 13 cases Down syndrome and slow learner while 21 cases Down syndrome with mental retardation. In these cases, the main disability was entered into the analysis as the type of disability.

Table I: General characteristics of the children with disability (N=900)

General characteristics		n	%
Age at assessment (months)	1 – 24	216	24.0
	25 – 48	222	24.7
	49 – 72	164	18.2
	73 – 96	134	14.9
	97 – 120	102	11.3
	121 – 144	62	6.9
Ethnicity	Malay	722	80.2
	Chinese	122	13.6
	Indian	56	6.2
Gender	Male	546	60.7
	Female	354	39.3
State assessment done	Kelantan	198	22.0
	Perak	168	18.7
	Johor	212	23.5
	Selangor	322	35.8
Type of disability	Down Syndrome	250	27.8
	Autism	50	5.6
	Cerebral Palsy	198	22.0
	Attention Deficit Hyperactive Disorder	40	4.4
	Slow Learner	78	8.7
	Mental Retardation	30	3.3
	Delayed Speech	68	7.6
	Gross Developmental Delay	116	12.9
	Others	70	7.8

Table II: Mean total SGS score according to age group (in months) and types of disability

Types of Disability	Age group (months)	0 - 24	25 – 48	49 – 72	73 – 96	97 – 120	121 – 144	Pearson Correlation, r
		Max Score: 96	Max Score: 145	Max Score: 185	Max Score: 192	Max Score: 192	Max Score: 192	
Down Syndrome		37.1	86.5	111.4	115.3	135.0	126.7	0.695 *
Autism		65.0	113.0	98.1	104.6	126.7	85.0	0.063
Cerebral Palsy		25.9	38.7	38.0	49.9	49.4	46.0	0.167 *
Attention Deficit Hyperactive Disorder		N/A	85.7	130.2	138.1	145.3	183.0	0.558 *
Slow Learner		40.0	97.6	112.0	158.3	140.8	176.7	0.783 *
Mental Retardation		3.0	N/A	74.1	N/A	99.2	120.5	0.645 *
Delayed Speech		84.0	123.2	151.8	135.7	147.0	174.0	0.649 *
Gross Developmental Delay		49.7	74.9	109.3	130.0	155.0	62.0	0.584 *
Others		34.1	102.2	107.1	114.7	93.5	56.0	0.498 *

N/A = Not Available

\* Correlate is significant at the 0.01 level (2-tailed)

Table III: The percentage of mean SGS score to mean achievable score corresponding to chronological age according to types of disability and different skill areas

Types of Disability Skill Areas	Down's Syndrome	Autism	Cerebral Palsy	Attention Deficit Hyperactive Disorder	Slow Learner	Mental Retardation	Delayed Speech	Gross Develop-mental Delay	Others	One-Way ANOVA F score
Locomotor	71.3	83.7	15.9	88.1	90.1	64.0	97.3	56.3	55.1	90.052 *
Manipulative	62.0	55.1	24.0	70.8	77.0	48.1	90.2	62.9	62.0	51.824 *
Visual	70.4	63.9	36.9	77.2	82.1	56.2	87.2	73.6	70.9	39.980 *
Hearing & language	61.0	47.5	36.0	61.8	71.9	40.9	75.8	64.2	59.7	24.688 *
Speech & language	51.6	46.7	26.2	59.8	74.9	36.7	61.0	53.3	48.6	33.102 *
Interactive Social	70.8	55.2	30.3	79.7	81.0	54.3	89.1	67.9	66.5	43.907 *
Self-care Social	71.2	65.7	25.0	78.6	85.6	49.8	99.4	54.3	65.2	53.768 *
Cognitive	6.1	38.8	14.7	59.0	60.2	30.5	71.2	44.4	43.9	28.401 *

\* Statistically significant at  $p < 0.05$

Table IV: Comparing mean total SGS score among ethnic groups according to type of disability

Type of disability	Malay	Chinese	Indian	One-Way ANOVA	
	Mean total score	Mean total score	Mean total score	F score	p value
Down Syndrome	85.3	85.9	85.7	0.215	0.807
Autism	101.0	113.0	101.9	1.654	0.202
Cerebral Palsy	40.5	40.6	41.0	0.291	0.748
Attention Deficit Hyperactive Disorder	142.6	110.0	132.0	4.743	0.015 *
Slow Learner	126.7	155.0	128.8	0.614	0.544
Mental Retardation	84.0	98.0	83.9	0.156	0.856
Delayed Speech	127.4	121.3	124.0	8.690	<0.001*
Gross Developmental Delay	72.2	61.2	71.43	1.083	0.342
Others	78.5	61.6	73.4	0.732	0.485

\* Statistically significant at  $p < 0.05$

In this study, the ethnic distribution of cases was almost similar to the distribution in the general population<sup>9,10</sup>. There were more male compared to female cases with a ratio of 6:4. This ratio is consistent with other studies<sup>11-12</sup>. Down syndrome was the commonest type of disability in this study followed by cerebral palsy. Several studies from different countries showed that Down syndrome and cerebral palsy were the common disabilities in the study population<sup>13-16</sup>.

Delayed speech cases had the highest total score across all the age groups. This observation was understandable because the majority of cases had minimal or no disability except for speech and language components while cerebral palsy scored the lowest. Hutton et al and Krigger et al showed that the majority of children with cerebral palsy has moderate to severe developmental delays in all skill areas<sup>17,18</sup>. In general, the total score increases in all types of disability as the age increase (especially from 0 to 60 months of age). The developmental skills of a child will increase or improve as the child grows<sup>19</sup>.

The percentage of mean SGS score to achievable score provides a useful figure to evaluate the deficit in a child's development. Delayed speech had the highest score in all skill areas except for speech and language. This is expected as such a child would have a significant developmental delay in that specific skill area. Cerebral palsy cases generally suffer from global developmental delay affecting all the skill areas and they had the lowest score. The scoring system for the cognitive skill area under the SGS II was different from the other skill areas. It was scored by a simple item count. The score was recorded as the highest item performed only. Children with such disability normally have a short attention and concentration span<sup>20,21</sup> coupled by the fact that this skill area is performed last may result in underscoring of this skill area.

Down syndrome was the commonest type of disability in this study. Speech delay cases obtained the highest score while cerebral palsy obtained the lowest. There were significant differences in the mean scores among the three ethnic groups for delayed speech and attention deficit hyperactive disorder. This study has provided useful information on the developmental assessment among children with disability. The study has quantified the assessment by providing a scoring system. This result could be used as a baseline for other similar studies in Malaysia. The implementation of the SGS II in all primary health care clinics could be used in the evaluation of outcome and impact of the programme and also the progress of individual cases.

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