

# Reassessment on the Development of Children with Disability in Malaysia

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## SUMMARY

This is a cohort study investigating the profile of children with disability registered with the primary health care clinics in Malaysia. The purpose of the study was to determine whether reassessment on the development of children with disability under rehabilitation should be done at three months interval or six months interval. Secondary data from the pilot project conducted by the Family Health Development Division, Ministry of Health Malaysia was used in this study. The study was carried out for seven months from 1st August 2004 until 28th February 2005. A total of 168 disabled children followed up for six months were selected in this study. Schedule of Growing Scale (SGS) II was the tool used for analysis. Results showed a statistically significant difference in the mean total SGS score at six months interval but not at three months interval. The result suggests that reassessment on children with Down Syndrome, Autism, Cerebral Palsy, mental retardation and delayed speech under rehabilitation should be carried out every six months while children with gross developmental delay and slow learner might need a longer interval for reassessment.

## KEY WORDS:

*Developmental Reassessment, 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 capacities'<sup>1</sup>. Ten percent of the population in any country around the world has some form of disability and it has been estimated that among the 10% population with disability, one third are among children less than 15 years old<sup>1</sup>. Translating this statistics into the local setting, Malaysia would have an estimated 800,000 children less than 15 years old with some form of disability that requires special care. The Malaysia National Health and Morbidity Survey 1996 reported that 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 to manage children with disability<sup>3</sup>. They carried out activities to provide rehabilitative services for these children. As of December 2004, there were a total of 98 health clinics in Malaysia providing rehabilitation services for children with disability<sup>4</sup>. There were a total of 1,569 disabled children below the age of seven years detected at the health clinics in the year 2004<sup>4</sup>. In Malaysia, the 'Children with Special Needs Programme' was implemented to provide special health care for children with disability.

Studies from developed countries have used different developmental assessment tools to describe the developmental achievement among children with disability<sup>5-7</sup>. Most of the studies concentrate on one particular disability and on one particular skill area. There were limited studies on reassessing the developmental achievement among these children undergoing rehabilitation. In Malaysia, there has been no study done to reassess the development of children with disability under rehabilitation.

The objective of this study was to determine any significant difference on the development of children with disability reassessed at three months and at six months according to ethnic group and types of disabilities.

## MATERIALS AND METHODS

This study looks into secondary data from a study conducted by the Family Health Development Division, Ministry of Health Malaysia. The study period was for seven months from 1st August 2004 until 28th February 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 every month using the Denver Developmental Assessment Test (DSST) II chart and Schedule of Growing Scale (SGS) II over a period of seven months. The study included only children who were assessed at baseline, three months and six months later. All children who attended the clinic throughout the study period were included in the study. All nurses were being supervised by the respective Family Health Specialist or Maternal Child Health Officer in the clinic.

In this study, the SGS II was used for analysis. SGS II was validated in 2006 in a pilot study conducted by the Family Health Developmental Division, Ministry of Health Malaysia. SGS II is a developmental screening tool and it provides

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information on whether the child is developing normally and identifying which skill areas is the child delayed in using a scoring system.

The inclusion criteria in this study include all cases from the pilot study being assessed at three different time intervals (baseline, three months and six months interval). The exclusion criteria include cases from East Malaysia, cases that are not Malaysian and cases whose age at baseline assessment was more than 144 months (12 years old). This study included cases from four states chosen randomly involving 36 primary health care clinics. The four states include Kelantan with six clinics, Perak with eight clinics, Johor with eight clinics and Selangor with fourteen clinics.

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>. Total SGS score from all the eight skill areas for each case at three different time intervals were used in the analysis. The higher the SGS score in the skill area the better the child is at performing that skill.

The purpose of this study was to determine whether reassessment on the development of children with disability under rehabilitation should be done at three months interval or six months interval. Data was analyzed using the Statistical Package for Social Sciences (SPSS) Version 11 programme.

## RESULTS

A total of 168 children with disability were assessed at three different time intervals (baseline, three months and six months). Malay were the majority (90.4%) followed by Chinese (4.8%) and Indian (4.8%). There were 100 (59.5%) males and 68 (40.5%) females. The mean age of the population was  $53.3 \pm 2.4$  months. There were 56 (33.3%) cases from Kelantan, 44 (26.2%) from Perak, 40 (23.8%) from Johor and 28 (16.7%) from Selangor. Down syndrome and Cerebral Palsy accounted for over 70% of the type of disability among the population (Table I).

Table II showed the difference in the mean total SGS scores at baseline and three months interval with baseline and six months interval. Using 'paired T-test', there was a statistically significant difference in the mean total score at assessment conducted at six months interval ( $p < 0.001$ ) but not at three months interval ( $p = 0.165$ ). The 95% Confidence Interval of the difference at six months interval was between -5.014 and -1.796.

Table III showed the mean total SGS scores according to ethnic group at baseline, three months and six months interval. The mean total scores was highest among Malay ethnic group and lowest among Chinese ethnic in all the three different time intervals. In general, the total mean SGS scores increased from baseline to three months interval and six months interval. Paired *T*-test showed that statistically

significant differences were noted for Malay and Indian ethnic at six months interval while Chinese ethnic at three and six months interval when compared with baseline data.

The mean total SGS scores at baseline, three months and six months intervals were compared in relation to the different type of disability (Table IV). In general, the mean total SGS scores at baseline was highest in delayed speech cases (147.00), followed by Down syndrome (101.84) and lowest in mental retardation cases (3.00). Using paired *T*-test, there were statistically significant differences in the mean total scores at three months interval for mental retardation while statistically significant differences at six months interval were noted for Down syndrome, Autism, Cerebral palsy, mental retardation and delayed speech.

The mean total SGS score at baseline, three months and six months for Down Syndrome was compared according to age group (Table V). The age groups include infant period (1 - 12 months), toddler period (13 - 60 months) and child period (61 - 120 months). There were statistically significant difference in the mean total score at three months for age group between 61 and 120 months while at six months it was across all the age group.

## 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. In Malaysia, CWSN programme has expanded greatly where most clinics in all the states provide the service. A baseline developmental assessment is carried out for each child with disability registered at every clinic. Reassessment on the development for each child is carried out at three months interval. An audit on the case notes of the cases in selected clinics revealed that only 20.2% of the cases were reassessed every three months. The main reason given by the nurse in-charge of the clinic was lack of human resource and time.

The problem with overlapping categories between Cerebral Palsy and other disabilities have been considered in the study. Among the 48 Cerebral Palsy cases, there were 10 cases of Cerebral Palsy with mental retardation, five cases of Cerebral Palsy with delayed speech and three cases of Cerebral Palsy with gross developmental delay. In these cases, the main disability which was Cerebral Palsy was entered into the analysis as the type of disability.

In this study, the ethnic distribution of cases was biased towards the Malay ethnic compared to the same age group 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>11-13</sup>. Down syndrome was the commonest

Table I: General characteristics of the children with disability (N = 168)

General characteristics		n	%
Age at first assessment (months)	1 -12	12	7.1
	13 - 24	16	9.5
	25 - 36	24	14.3
	37 - 48	44	26.2
	49 - 60	24	14.3
	61 - 72	8	4.8
	73 - 84	12	7.1
	85 - 96	4	2.4
	97 - 108	4	2.4
	109 - 120	20	11.9
Ethnicity	Malay	152	90.4
	Chinese	8	4.8
	Indian	8	4.8
Gender	Male	100	59.5
	Female	68	40.5
State assessment done	Kelantan	56	33.3
	Perak	44	26.2
	Johor	40	23.8
	Selangor	28	16.7
Type of disability	Down Syndrome	76	45.2
	Slow Learner	4	2.4
	Autism	16	9.5
	Cerebral Palsy	48	28.6
	Mental Retardation	4	2.4
	Delayed Speech	16	9.5
	Gross Developmental Delay	4	2.4

Table II: Comparing mean total SGS score at baseline and 3 months with baseline and 6 months

	Mean total score at baseline	Mean total score at 3 months	Mean total score at 6 months	Paired difference*			Statistical significance	
				Mean	95% CI of the difference		t	Sig (2-tailed)
					Lower	Upper		
Total score at baseline – 3 months	86.07	87.05	-	-0.976	-2.359	0.407	-1.393	0.165
Total score at baseline – 6 months	86.07	-	89.48	-3.405	-5.014	-1.796	-4.177	<0.001**

\* Statistical testing using paired T-test

\*\* Statistically significant at  $p < 0.05$

Table III: Mean total SGS score at baseline, 3 months and 6 months according to ethnicity

Ethnicity	Mean total score at baseline	Mean total score at 3 months	Mean total score at 6 months
Malay	88.34	89.03	91.18 *
Chinese	57.00	64.50 *	69.50 *
Indian	72.00	72.00	77.00 *

\* Statistically significant at  $p < 0.05$  using paired T-test

Table IV: Mean total SGS score at baseline, 3 months and 6 months according to types of disability

Type of Disability	Mean total score at baseline	Mean total score at 3 months	Mean total score at 6 months
Down Syndrome	101.84	103.47	104.42 *
Slow Learner	98.00	96.00	87.00
Autism	97.00	95.75	98.00 *
Cerebral Palsy	45.83	47.92	53.25 *
Mental Retardation	3.00	9.00 *	21.00 *
Delayed Speech	147.00	146.75	152.25 *
Gross Developmental Delay	53.00	40.00	49.00

\* Statistically significant at  $p < 0.05$  using paired T-test

Table V: Mean total SGS score at baseline, 3 months and 6 months for Down Syndrome by age group

Type of Disability	Age Group (months)	Mean total score at baseline	Mean total score at 3 months	Mean total score at 6 months
Down Syndrome	1 – 12	8.00	9.81	16.80 *
	13 – 60	87.81	87.04	89.81 *
	61 – 120	101.67	105.58 *	106.88 *

\* Statistically significant at  $p < 0.05$  using paired T-test

type of disability in this study followed by cerebral palsy. Several studies from different countries support this finding<sup>13-15</sup>.

There was a statistically significant difference in the mean total score at six months interval in all types of disabilities. This suggests that improvement on the development among children with disability is a slow process<sup>16-18</sup>. Studies done in the United Kingdom and the United States on children with Down syndrome and Cerebral Palsy showed that improvement could be observed only six to nine months after rehabilitation<sup>6,7,14</sup>.

Developmental improvement among children with disability in all the major three ethnic groups was noted at six months interval after rehabilitation. The study also showed that significant improvement was noted at three months interval for the Chinese ethnic group. Lai FM *et al.* showed that the Chinese ethnic children with Down's syndrome in Singapore had better developmental improvement compared to children of other ethnic groups<sup>15</sup>.

Delayed speech cases had the highest mean total scores across all the three different time intervals. This observation was understandable because majority of the cases have minimal or no disability except for speech and language. Mental retardation cases had the lowest mean total scores across all the three different time intervals. This finding was expected because the cases will have difficult in accomplishing the task examined using the SGS II tool. Improvement could be seen at three months for mental retardation cases. This result was in contrary to that reported by Garcia-Navarro ME *et al.*<sup>5</sup> and Bell R *et al.*<sup>14</sup>.

## CONCLUSION

Early detection and intervention is essential for a child with disability to achieve a better quality of life. Children with Special Needs Programme was initiated in Malaysia with the emphasis on rehabilitative services being provided at the primary health care level. Although well planned and effective rehabilitative activities had been carried out for these children, reassessment on their development were rarely done. The planned procedure was to carry out a reassessment every three months. Failure to comply was mainly due to lack of human resource and time. This study illustrates that reassessment for children with Down Syndrome, Autism, Cerebral Palsy, Mental Retardation and delayed speech on rehabilitation should be done every six

months while children with gross developmental delay and slow learner might need a longer interval for reassessment. This result could be utilized by the higher management within the Ministry of Health, Malaysia and other countries to reevaluate the reassessment period of children with disability from three months to six months to cope with the problem of lack of human resource and time.

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