

# Pathways to Services for Children with Cerebral Palsy in Selangor and the Federal Territory, Kuala Lumpur

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## SUMMARY

Cerebral Palsy (CP) describes a group of chronic conditions affecting body movement and muscle coordination caused by damage to one or more areas of the brain, occurring at any time during foetal development to infancy<sup>1,2,3,4</sup>. This research was carried out to learn how parents of children with cerebral palsy (CP) had found and accessed services provided for them in Selangor and Kuala Lumpur. It was based in the Spastic Children's Association of Selangor and Federal Territory (SCAS&FT) among 96 of 201 parents of children who use the facilities and services provided by the SCAS&FT through questionnaires and face-to-face interviews. There was a satisfactory level of availability and accessibility of contacting and using the services provided by SCAS&FT in terms of respondent satisfaction. However, parents had varying levels of awareness of the different classes and activities carried out by the school. Efforts to improve knowledge regarding the services available for children with CP in the general population and among parents of these children should be promoted.

## KEY WORDS:

Cerebral palsy, Services, Paediatric, Selangor, Kuala Lumpur, Malaysia

## INTRODUCTION

Cerebral palsy (CP) is the major cause of prenatal and perinatally acquired disability, occurring once in every 800 births<sup>1</sup>. It is a disorder of movement and posture due to damage from a non-progressive lesion of the motor pathways in the developing brain.

Research has found that CP is seldom due to a single cause but rather the end result of multiple causal pathways<sup>1,2,3,4</sup>.

Management consists of helping the child achieve maximum growth and development potential with physiotherapy, occupational therapy and speech therapy as the first line of management<sup>5,6,7,8,9,10</sup>. Correct management if given early enough in life can bring great benefits although not an absolute cure. These therapies may be reinforced with medication, surgery and braces to improve nerve and muscle coordination and prevent or minimize dysfunction,<sup>11,12,13,14,15,16</sup>.

The SCAS&FT was chosen for this study as it is the largest school for children with CP in Malaysia. It caters to about 200 children who live in Selangor and the Federal Territory

which are the most densely populated states of Malaysia consisting of almost four million people<sup>17</sup>.

The aim of this study was to evaluate the extent of awareness among parents regarding the facilities and services available for children who are born with CP. The specific objectives were to determine the following:

- The level of awareness of parents regarding the services provided for children with CP by SCAS&FT
- The ease in making contact for these services and using them
- Parent satisfaction with the facilities provided
- Parents suggestions to improve on the services or facilities provided by SCAS&FT

## MATERIALS AND METHODS

Self-completion questionnaires and short face-to-face interviews were carried out among 96 out of 201 parents who had children attending facilities and services provided by the SCAS&FT. A larger sample was not attainable due to time limitation and poor response rates of parents who did not attend the school with their children.

A pretest of the questionnaire had been carried out among several parents of the same population as in the final survey. Since the changes had been minimal, the completed questionnaires of these parents were included into the sample.

(See Appendix – Questionnaire)

### Questionnaire Design

There is little previous work in the area. Questions were chosen based on their face validity to cover issues which seemed likely to be important to parents, to the children and to the school, given the constraints of using a postal questionnaire. The questionnaire consisted of two sections. The first section contained two questions regarding the general information of the parent responding to the questionnaire such as their race and family income.

The second part of the questionnaire was directed to obtain information regarding the child's age, when and how they first realised their child had this disability, the use of services and facilities provided by SCAS&FT, how they discovered SCAS&FT, how they contacted the school, the difficulties they encountered contacting the school, awareness of the facilities provided by the school, satisfaction with facilities and their

This article was accepted: 7 November 2007

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suggestions to improve on the services and facilities of the school.

This questionnaire was in English and Bahasa Malaysia. To facilitate understanding of Chinese parents who were unable to read either language, the questionnaire was read out in Chinese by a native speaker.

All but one of the questions had been structured in a closed-ended manner with boxes to tick their answers. The last question of the survey was an open-ended question requesting parents to suggest the services and facilities that they felt needed improvement.

Data were analysed by the Statistical Package for Social Sciences Version 11.0 (SPSS)<sup>18</sup> programme. The main tools for analysis were simple graphics and cross-tabulations with a  $\chi^2$  test. Where the expected number of cases in a cell in a table was very low, the Fisher's exact test was used with a p value calculated by Monte-Carlo simulation.

## RESULTS

Ninety-six out of 201 parents completed the questionnaire, a response rate of only 48%. The majority of the students were Malay (N=33) and Chinese (N=46), followed by Indians (N=9) and other races (N=7). More than 60% of the students come from families that earn less than RM3,000 monthly, and the average income amongst participants was RM 3,033 (Open ended range: below RM1,000 – above RM10,000).

More than 76% of respondents had indicated that they had suspicions that their child had CP when they were less than 13 months old. Of these children, 75% were first identified by a child specialist or a doctor, while 22.9% were first noticed by their family.

A large minority (40.4%) of the respondents had used other services prior to attending SCAS&FT such as other special needs schools, paediatric and physiotherapy services from hospitals, physiotherapy clinics and traditional treatments (massages/acupuncture).

Seventy percent of respondents said that they had learnt about the facilities provided by SCAS&FT through doctors, medical staff or counsellors. Another 22.9% had found this out through friends or relatives (3.1% from other parents, 4.2% from newspaper articles, physiotherapist etc). 58.5% of parents had been introduced to SCAS&FT by other parents or healthcare professionals. This was followed by 31.9% of respondents who first contacted the SCAS&FT by telephone. The remainder had been introduced from their child's previous schools or from friends.

### *Service Availability and Accessibility*

Just under 95% of respondents had not experienced any difficulties in getting in touch with SCAS&FT. However, parents who said they did had some difficulties, seemed to have trouble getting their child enrolled rather than getting in contact with the centre. 86.8% of respondents had stated that they did not have to wait long for their child to start using the facilities provided (indicating good availability and

accessibility to services). Some parents did complain of a long wait to use these facilities. Unfortunately, the duration of their wait was not documented.

### *The Levels of Awareness*

More than 70% of parents were aware of the clinical and therapeutic services such as physiotherapy, occupational therapy, speech therapy, and music and movement activities, provided by SCAS&FT. The level of awareness of the Early Intervention Group of classes, sports (track and field, swimming, and horseback riding) and singing groups was lower at between 55% and 69% for the individual services.

The awareness of the other classes (Functional Academic Classes, Living Skills Classes, Care Group, Pre-Vocational Class and Vocational Class), gardening activities, art and craft activities, and other services (transportation, meals for children, staff assistance) were all below 55%.

The level of awareness of services provided was similar in most of the services among parents of different races and income groups. However for some facilities parents from the highest and lowest income groups were more aware than the middle-income families, (the Early Intervention Group of Classes (Fisher's Exact Test = 9.169, d.f. = 4, p= 0.045), awareness of Functional Academic Classes (Fisher's Exact Test = 11.690, d.f. = 4, p= 0.014), awareness of Music & Movement Activities (Fisher's Exact Test = 13.739, d.f. = 4, p= 0.004), awareness of Singing Activities (Fisher's Exact Test = 8.847, d.f. = 4, p= 0.050)).

### *The Levels of Satisfaction with the Facilities Provided*

The majority of parents found that all the services and activities provided by the centre to be of satisfactory levels although the facilities that were most favoured were physiotherapy, occupational therapy, speech therapy, the Early Intervention Group of classes, sports activities, music and movement activities, and singing activities. These services had more than 60% of satisfied or very satisfied respondents. There were few differences in the level of satisfaction expressed with the services according to family income or ethnic origin.

Some suggestions for improvement in the services are shown in Table II.

## DISCUSSION

The survey would have been more representative of the target population, parents of children with CP in Malaysia, if a larger number of parents had been involved in the questionnaire. This could have been achieved by carrying out the survey in more than one school or by personally delivering the questionnaires to the homes of students whose parents did not respond by post.

However, from this study it was found that the ethnic composition of the students attending the school was similar to that of the surrounding community. There are no accessible regional income figures, but the income distribution is believed to be representative of that in Selangor.

Table I: The Level of Awareness and Satisfaction with the Services Provided

Service	Awareness	Satisfaction		
		Not Satisfied	Neutral	Satisfied
Physiotherapy	84 (87.5%)	8 (9.6%)	10 (12.0%)	65 (78.3%)
Occupational Therapy	69 (71.9%)	14 (19.4%)	13 (18.1%)	45 (62.5%)
Speech Therapy	74 (77.1%)	10 (14.7%)	13 (19.1%)	45 (66.2%)
Early Intervention Group	56 (58.3%)	5 (10.7%)	10 (21.3%)	32 (68.1%)
Functional Academic Classes	33 (34.4%)	4 (12.1%)	10 (30.3%)	19 (57.6%)
Living Skill Classes	41 (42.7%)	9 (23.1%)	8 (20.5%)	22 (56.4%)
Care Group	32 (33.3%)	7 (24.1%)	9 (31.0%)	13 (44.8%)
Pre-Vocational Class	26 (27.1%)	3 (13.0%)	9 (39.1%)	11 (47.8%)
Vocational Class	30 (31.3%)	5 (21.7%)	8 (34.8%)	10 (43.4%)
Sports	61 (63.5%)	8 (17.0%)	9 (19.1%)	30 (63.8%)
Gardening Activities	27 (28.1%)	5 (20.0%)	7 (28.0%)	13 (52.0%)
Art & Craft Activities	44 (45.8%)	4 (10.0%)	13 (32.5%)	23 (57.5%)
Music & Movement Activities	70 (72.9%)	5 (7.5%)	9 (13.4%)	53 (79.2%)
Singing Groups	64 (66.7%)	6 (9.5%)	9 (14.3%)	48 (76.2%)
Other Services (Transport, Food, Staff Assistance)	43 (44.8%)	-	-	-

Table II: Suggestions for Improvements

Area	Suggestion	Support (%)
Teaching & Support Staff	- More teaching and support staff - More speech and occupational therapists - Improve staff motivation - More specialised teaching skills and teaching methods	21 (53.8%)
Teaching Materials, Equipment or Classes	- Upgrade tables and chairs to accommodate individual needs - Increase number and variety of activities	12 (30.8%)
Facilities for Parents' Use or Parental Support	- Teach parents ways to reinforce their child's education at home - More motivational courses and counselling facilities for parents and guardians	6 (15.4%) 2 (5.1%)
Transportation Facilities	- More bus routes	2 (5.1%)
Speed Up Intake of Students	- For children who were outpatients	7 (17.9%)
Other Facilities	- Onsite medical staff, better wheelchair access etc.	39
Total No. Respondents		

Most parents had realised that their child might have CP before they were 13 months old and had had minimal difficulties with contacting SCAS&FT and with accessing and using the services provided. It is also noted that SCAS&FT represents the first service used by almost 60% of these parents.

There was a high level of satisfaction with the classes and activities carried out by the school. There was a very high level of awareness of the traditional clinical services provided by the SCAS&FT. However awareness of the more vocational skills, aimed at older children was less satisfactory. This may have implications for independent living, the future placement of and employment prospects of these children.

Respondents made many suggestions for service improvements. A similar study was had been carried out by The Cerebral Palsy Association of Western Australia<sup>19</sup> regarding satisfaction with services using a questionnaire based on "The Measure of Processes of Care"<sup>20</sup> which is a well-validated self-report measure of parents' perceptions of the health services they and their child(ren) receive. Despite the differences in the questionnaires, it had similar findings. Although parents had received a satisfactory level of specific information about the facilities used by their child (scoring 5.4 out of 7), there was poorer level of understanding of general awareness of other facilities (4.2 out of 7).

Work should be done to improve dissemination of knowledge in the general population and amongst parents of children with CP about the services available. A study should be carried out among parents whose children with CP are not using special care services specific for their child's needs. Reasons for not using these facilities should be addressed to extend accessibility to aid and manage all children with CP.

#### ACKNOWLEDGEMENT

I would like to thank to my supervisor Dr. Anthony Staines, the Human Research Ethics Committee of University College Dublin, Dr Choong Yoke Lan, Mr. Lim Teck Sun, Puan Laila P. Mohd., Puan Fauziah bt Tahar, all the teaching staff and their assistants in the SCAS&FT and to the parents for their contribution in making this research a success.

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