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Locally Made Paediatric Rehabilitation and Seating Systems for Cerebral Palsy Children in Sarawak

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ABSTRACT

Introduction	Children with cerebral palsy (CP) are often prescribed Rehabilitation and Seating Systems (RSS) to assist in daily activities, posture improvement and prevention of muscular-skeletal complications. In Sarawak, a special project to produce RSS was started under a partnership of a Japanese physiotherapist, health department and the community using local material.
Aim	To document the RSS project and to determine usefulness and cost-affordability of these systems for cerebral palsy children and their families.
Methods	The details of RSS manufactured were retrieved from the clinic notes and secretary file. Parents of children who received the seating systems between July 2004 and September 2008 were invited to complete a 5-point Global Parental Perception Questionnaire (GPPQ) between December 2008 and January 2009.
Results	277 RSS were manufactured between July 2004 and February 2011 (which included modified wheel chair, wooden chair, corner chair, buggy chair and standing frame), and used by children all over Sarawak. Parents of 73 children who used the seating systems completed the 5-points GPPQ. Ten families required full sponsorship. Children spent more time sitting up and brought outdoor more often after the systems became available. Majority of parents reported positive experience in their children with sitting ability, smiles, interaction with people, learning skills and easiness of doing physiotherapy. No change was noted with passing of motion drooling / oral secretion. Most parents agreed that the cost was affordable and worth paying.
Conclusions	A community based initiative to manufacture RSS by using locally available material and skill, at affordable price for the parents was feasible and useful for the family/children with CP.

Keywords	rehabilitation and seating systems, cerebral palsy, complication, physiotherapy

INTRODUCTION

Children with Cerebral Palsy (CP) have motor dysfunction and postural problem. Parents of children with CP in all age groups and with Gross Motor Function Classification System (GMFCS) II to IV identified more priorities on daily activities, especially those related to mobility [1]. The GMFCS defines functional status by categorizing children with CP into one of five different levels of function primarily on the basis of skills in sitting and walking (Level I children walks without restriction but limitations in advanced skills only; whereas in Level V, self-mobility is severely limited even with the use of assistive technology) [2]. Few studie shave shown that the adaptive Rehabilitation And Seating Systems (RSS) were able to improve postural alignment [3,4,5,6], upper-extremity function [4,5,6], head control [6], speech sound [7] and oral-motor function [8], as well as improving quality of lives and preventing muscular-skeletal complication and aspiration when the child sits better.

However, in many parts of Sarawak obtaining RSS for these children was not easy. It often meant ordering and shipping in from West Malaysia, and sometime from overseas. These RSS were therefore costly, and they might cost 3 to 10 thousands ringgit depending on the types and complexity. These prices were not easily affordable by most of the Malaysian families, when 38% of Malaysian family only had monthly income of 3 thousands ringgit or less [9]. Material used by the imported RSS might not be suitable for the humid and warm Malaysian weather. Although the ordinary wheel chairs were cheaper and readily available, children sizes were not easy to obtain and they were not custom made for individual child. As a result, Lau King Howe Memorial Children Clinic (LKHMCC), Sibu where the authors were based, had only prescribed less than 5 RSS for the 150 children with CP between the years 1998 and 2004 [10].

With these challenges and wills to overcome them, a special project onmanufacturing RSS for children with CP was initiated in Sibu, Sarawak in 2004. With the skills and guidance from late Mr. Tatsumi Kondo (1965 – 2010, a Japan International Corporation Agency physiotherapist working in Sarawak between 1996 and 2000), Association for Children with Special Needs Sibu (ACSNS) initiated and operated a workshop in manufacturing custom-made RSS for children with CP at affordable cost. Mr. Kondo learnt carpenter skills in Japan between 2000 and 2003. In this workshop, locally available materials such as ordinary wheel chairs, wood, cushion and some second-hand buggy-chair frames brought in from Japanwere used to manufacture the various RSS needed by local children. The assessment also involved local paediatricians, public health nurses and physiotherapist from LKHMCC. The expertise skills were transferred to the local carpenter employed by ACSNS. A policy in sponsoring these system was laid down, of which 50% of the production cost was borne by ACSNS. Further support (e.g. payment by installment) or sponsors (e.g. referral to Social Welfare Department, various local charitable organizations or individuals) would be provided to those families who need more financial assistance.

AIMS

To document the RSS project between July 2004 and February 2011, as well as to study effect of RSS on time spent by CP children sitting up and being out-door, and to determine usefulness and cost-affordability of these systems for children and their families.

METHODS

The details of RSS manufactured were retrieved from the clinic notes and ACSNS secretary file. Parents of children who received the seating systems between July 2004 and September 2008 were invited to complete a 5-point Global Parental Perception Questionnaire (GPPQ) between December 2008 and January 2009. The questionnaire covered areas such as time spent sitting up and being out-door, usefulness of RSS for children and their families, and the feasibility of this partnership program. Basic demographic data of the family were also collected.

DATA ANALYSIS

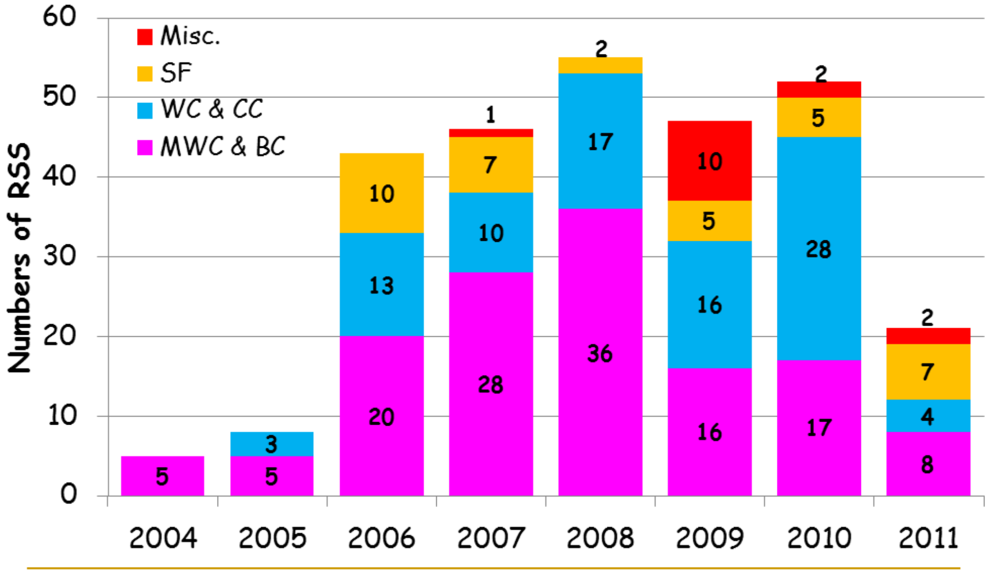
The data was analysed using Microsoft Excel 2010. Statistical analysis involved descriptive analyses of the children demographics, and the results from GPPQ. Further statistical analysis was conducted using χ^2 tests in qualitative data. A p value of equal or less than 0.05 was considered statistically significant.

RESULTS

There were 277 pieces of RSS manufactured and produced under this special project between July 2004 and February 2011, which included modified wheel chair (modified from ordinary wheel chairs, with cushion-seat and spine support, as well as head support if necessary), wooden chair (wheeled cushion-seat chairs with spine and/or head support), corner chair (simple seating system without wheels), buggy chair (custom-made chairs from second-hand frames from Japan), standing frame (consisted of supine and prone boards). Other miscellaneous rehabilitation systems such as climbing bar, balancing beam and wheeled trolley were made when needs rose. Chart 1 summarised the total numbers of RSS manufactured under this special project in Sibu. In addition to children from

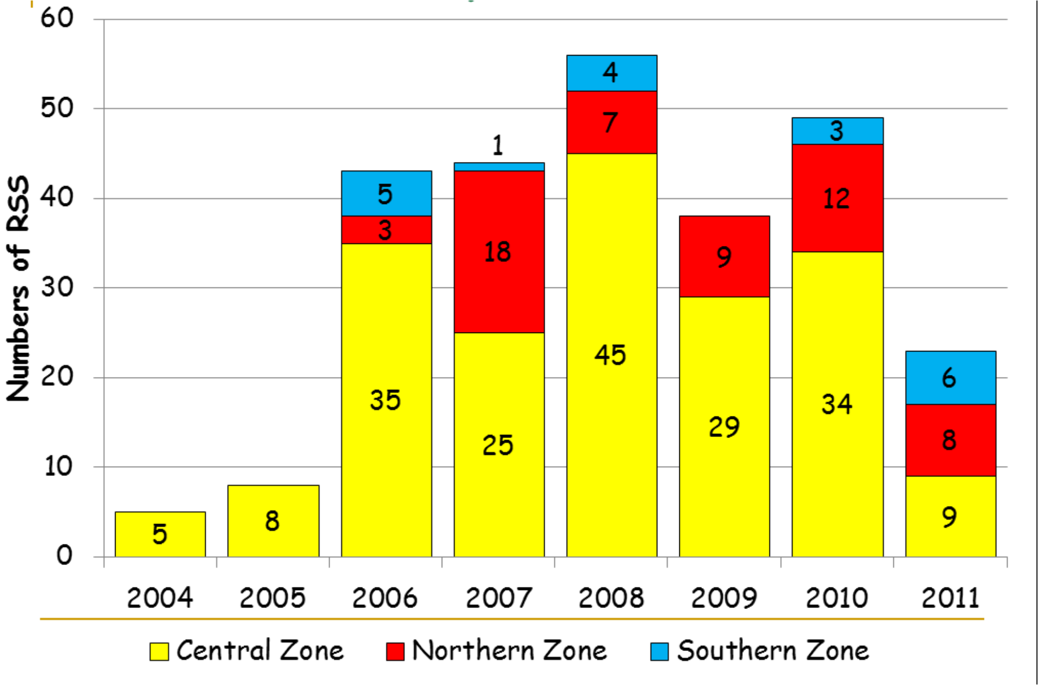
Sibu and the surrounding areas, these RSS had been used state-wide in Sarawak (Chart 2). Central Zone of Sarawak consisted on Saratok district of Betong, Sarikei, Sibu, Mukah, Kapit and Bintulu divisions. Southern Zone included Betong, Kuching, Samarahan and Sri Aman, whereas Northern Zone included Miri and Limbang divisions.

Chart 1 Numbers of Rehabilitation and Seating Systems Manufactured in Sibu, Sarawak between July 2004 and February 2011



MWC = Modified Wheel Chair, SF = Standing Frame, BC = Buggy Chair, CC = Corner Chair, WC = Wooden Chair

Chart 2 Distributions of Rehabilitation and Seating Systems in Sarawak between July 2004 and February 2011.



Parents of 73 children who used buggy chairs (n = 10, mean age 6.2 ± 3.0 years), modified wheel chair (n = 41, 8.1 ± 4.0 years) and wooden chairs (n = 22, 5.8 ± 3.5 years) completed the 5-points GPPQ (76.4% of the respondents were mother, and 27.4% of the respondents never or only completed primary school education). Thirty-seven respondents (50.7%) reported monthly income of the family was less than one thousand ringgit, where as 43.8% had monthly income between RM1000 and RM3000. Among these 73 children, 64.4% were male, and 87.7% had level V CP according to GMFCS. Table 1 summarised the cost of seating systems paid by the families and their method of payment. Only 10 families (13.7%) required full sponsorship and majority of families (64.4%, n = 47) were able to made their payment in full by installment or at once.

Table 1 Cost and Types of Seating System Manufactured and Method of Payment

Types of Seating System		**Buggy Chair (n = 10)**	**Modified Wheelchair (n = 41)**	**Wooden Chair (n = 22)**	**Total (n = 73)**
Median Cost		RM790.00	RM520.00	RM260.00	-
Payment	in full / by installment	5 (50%)	23 (56.1%)	19 (86.4%)	47 (64.4%)
	paid partially (by installment)	3 (30%)	10 (24.4%)	3 (13.6%)	16 (21.9%)
	sponsored fully	2 (20%)	8 (19.5%)	0	10 (13.7%)

Eight of the parents who completed the GPPQ (11.0%) reported that their children never sat up before the formal seating system were available (Table 2). However after the systems became available, 2 of these 8 children (25%) sat less than 4 hours in a day and 6 of them (75%) sat between 4 and 8 hours in a day. Forty-nine children(67.1%) only sat less than 4 hours in a day before the systems were available. After the systems became available, 51.0% of these 49 children (n = 18) sat between 4 and 8 hours in a day, and 12.2% (n = 6) sat longer than 8 hours. There was a significant difference (p = 0.03) in the sitting-up time before and after the systems became available (excluded the > 8 hours group before systems were available).

Table 2 Sitting-up Time for Children Before and After Seating Systems Became Available (n = 73)

Before Systems Available		**After Systems Available**		
Duration	**Number**	**< 4 hours**	**4 – 8 hours**	**> 8 hours**
Never	8 (11.0%)	2 (25.0%)	6 (75.0%)	0
< 4 hours	49 (67.1%)	18 (36.7%)	25 (51.0%)	6 (12.2%)
4 – 8 hours	13 (17.8%)	0	7 (53.8%)	6 46.2%)
> 8 hours	3 (4.1%)	0	0	3 (100%)

The questionnaire also studied 51 parents whose children were using buggy chairs and modified wheel chairs for the frequencies of children brought outside the houseor their room in the long house (Table 3). Before the systems were available, 41.2% (n = 21) of the parents never or only brought their children outside the house / room on monthly basis. After the systems became available, 8 of these parents (38.1%) brought their children outside the house / room 1 or 2 times a week, and 19.0% of them (n = 4) did it on daily basis. Nine parents (42.9%) remained infrequent or never in bringing their children outside the house. There was a significant difference between the frequency being brought outside the house/room before and after the systems became available (p < 0.001).

Table 3 Frequency Being Taken Out Door for Children Who Were Provided with Buggy Chairs and Modified Wheel Chairs Before and After Seating Systems Became Available (n = 51)

Before Systems Available		**After Systems Available**		
Duration	**Number**	**Never/ Monthly**	**1 – 2 Times Weekly**	**Daily**
Never / Monthly	21 (41.2%)	9 (42.9%)	8 (38.1%)	4 (19.0%)
1 – 2 Times Weekly	15 (29.4%)	2 (13.3%)	11 (73.3%)	2 (13.3%)
Daily	15 (29.4%)	0	2 (13.3%)	13 (86.7%)

Table 4 summarised the results of GPPQ. Majority of parents reported that their children could sit longer (n = 61, 83.6%) and better (n = 59, 80.8%) after the systems became available. However most parents reported no change in terms of passing motion (n = 54, 74.0%) and disagreed with improvement in drooling and oral secretion (n = 47, 64.4%). Majority of the parents reported that their children smiled more and seemed happier (n = 62, 84.9%) as well as interacted with people and surrounding more (n = 60, 82.2%) after the seating systems became available. Parents also reported that it became easier to perform lower limbs physiotherapy (n = 43, 58.9%) and their children were more able in performing upper limb function (n = 31, 42.5%). Lastly, 64.4% of the parents (n = 47) reported that their children learnt skills faster after the seating systems became available.

Table 4 Global Parental Perception Questionnaire (n=73) for Various Conditions of the Children after the Seating System Became Available

Conditions surveyed	Strongly Agree	Agree	No Change	Disagree	Strongly Disagree
Can sit longer	17 (23.3%)	44 (60.3%)	11 (15.1%)	1 (1.4%)	0
Can sit better	19 (26.0%)	40 (54.8%)	14 (19.2%)	0	0
Can pass motion better (less constipation)	4 (5.5%)	14 (19.2%)	54 (74.0%)	1 (1.4%)	0
Has less drooling /oral secretion	1 (1.4%)	1 (1.4%)	24 (32.9%)	46 (63.0%)	1 (1.4%)
Smiles more and seems happier	12 (16.4%)	50 (68.5%)	11 (15.1%)	0	0
Interact with people and surrounding more	11 (15.1%)	49 (67.1%)	13 (17.8%)	0	0
Easier to perform lower limb physiotherapy	5 (6.8%)	38 (52.1%)	30 (41.1%)	0	0
Easier to perform the upper limb function	5 (6.8%)	26 (35.6%)	42 (57.5%)	0	0
Learn new skill faster	7 (9.6%)	40 (54.8%)	26 (35.6%)	0	0

The parents who have paid for their seating systems (n = 47) were also asked to comment on the costs and usefulness of the systems, and these were summarized in Table 5. Majority of the parents agreed that the cost paid by them were affordable (n = 27, 57.4%) and worth paying for their children (n = 42, 89.4%). Thirty-eight of these parents (80.9%) would pay for another similar systems should their children outgrow the current systems (Table 5). Majority of the parents again reported that the systems were highly recommended for other children with similar conditions (34.2%, n = 25 strongly agreed; 63.0%, n = 46 agreed), and only two parents did not comment on this question.

Table 5 Costs and Usefulness of Seating Systems Purchased and Paid by the Parents (n = 47)

Costs and Usefulness of the Systems	Strongly Agree	Agree	No Comment	Disagree
Cost paid was affordable by most parents	1 (2.1%)	26 (55.3%)	11 (23.4%)	9 (19.1%)
Cost paid was worth paying for the child	16 (34.0%)	26 (55.3%)	4 (8.5%)	1 (2.1%)
Re-purchase another similar system with similar cost shall the child outgrow the current system	38 (80.9%)	-	8 (17.0%)	1 (2.1%)

*No parents reported any of the conditions by “strongly disagree”.

DISCUSSION

Many studies have illustrated the usefulness of RSS in children with CP. They enhance the quality of lives of children and improve their daily functions. However, in clinical practice the prescription was challenging as explained in previous paragraph. This paper has illustrated the importance of positive partnership programme between the health professionals and community in developing RSS that were much needed by the children with CP at affordable costs and suitable for the needs of children.

Parents were generally happy with the seating systems in terms of daily function and children’s skills based on the GPPQ as reported in this paper. Sitting upright promoted dignity of the children, besides preventing from all the complications associated with improper sitting and lying. In addition, they promoted happiness and created potential for positive interaction with people, as documented by the parents in GPPQ. It was therefore leading to improvement of quality of life. RSS also enhanced physiotherapy and learning of new skills, which were important for children with CP.

However, parents were not satisfied with the drooling (oral secretion) and passing of motion. When children sat up more, it was normal to expect them drooling more because of gravity as compared to when they were lying supine all day long. When lying supine, oral secretion was likely to go posteriorly in the pharynx and aspirated into the lungs if the children do not have good swallowing mechanism. Majority of children in this study were classified as GMFCS Level V (87.7%), i.e. those with no means of self-mobility skills, and most likely to have the severe spastic quadriplegic type with associated swallowing incoordination. Therefore, it was not surprise to note the disagreement by the parents with regards to drooling and oral secretion. Sitting up do not seem to affect motion frequency, as noted by parents in this report.

Nevertheless, with the RSS provided to the children, we are unsure if these RSS prevented health risks such as aspiration, vitamin D deficiency and pathological fractures in these children. Education for children with CP was a complicated matter, require multi-disciplinary team effort. RSS alone does not replace this effort. It is very hope that RSS does improve the mobility and sitting ability of these children, and making them more accessible to schools, as well as participating more in outdoor activities. This shall form the future research question.

CONCLUSIONS

A community based initiative using locally available material and skill at affordable price was feasible and useful for the family/children with CP. The program has ensured transfer of skills to local workers, and health professionals. Significant number of children with severe CP had gain benefit from the RSS in sitting up and being outdoors after the systems became available. Parents have also noted much positive differences in the children daily lives and learning experience.

LIMITATION

This was not a controlled study and we acknowledge that self-reported questionnaire may prone to bias. The data collected were largely categorical and statistically they were not ideal.

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Without the kind and unselfish act of Mr Tatsumi Kondo (Tokyo, Japan), hundreds of children in Sarawak would not have benefited from these RSS. Sadly Mr Kondo passed away in Japan on 8 January 2010 due to unexpected illness. We would also like to express our sincere thanks to the parents and children participating in the study, and family/parents that supported the project, the clinic and the association. Invaluable support had also been granted from staff of LKHMCC, especially Habsah Razak, Imor Jawa and Chua Soh Yian who assisted as research nurses; committee and staff of the ACSNS, and other non-governmental organizations / individuals for sponsoring some of the RSS and donation for the project.

REFERENCES

1. Chiarello LA, Palisano RJ, Maggs JM, Orlin MN, Almasri N, Kang LJ, Chang HJ. Family priorities for activity and participation of children and youth with CP. PhysTher 2010 Sep; 90(9): 1254-64.
2. Palisano R, Rosenbaum P, Walter S, et al. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Dev Med Child Neurol 1997. 39:214-223.
3. Washington K, Deitz JC, White OR, Schwartz IS. The effects of a contoured foam seat on postural alignment and upper-extremity function in infants with neuromotor impairments. PhysTher 2002 Nov; 82(11):1064-76.
4. Reid DT. The effects of the saddle seat on seated postural control and upper extremity movement in children with CP. Dev Med Child Neurol 1996 Sep; 38(9):805-15.
5. Myhr U, von Wendt L. Improvement of functional sitting position for children with CP.Dev Med Child Neurol 1991 Mar; 33(3):246-56.
6. Hulme JB, Gallacher K, Walsh J, Niesen S, Waldron D. Behavioral and postural changes observed with use of adaptive seating by clients with multiple handicaps. PhysTher 1987 Jul; 67(7):1060-7.
7. Hulme JB, Bain B, Hardin M, Mckinnon A, Waldron D. The influence of adaptive seating devices on vocalization. J CommunDisord 1989 Apr; 22(2):137-45.
8. Hulme JB, Shaver J, Acher S, Mullete L, Eggert C. Effects of adaptive seating devices on the eating and drinking of children with multiple handicaps. Am J OccupTher 1987 Feb; 41(2):81-9.
9. Puah P. Half of Malaysian households earn below RM3,000 a month. The Edge. Available at http://web.archive.org/web/20080711130341/http://www.theedgedaily.com/cms/content.jsp?id=com.tms.cms.article.Article_af703730-cb73c03a-1b092820-e338574e.Archived from the original on 2008-07-11. Cited by http://en.wikipedia.org/wiki/Economy_of_Malaysia. Cited on 1 January 2011.
10. Department Report for 2004, Department of Paediatrics, Sibu Hospital, Sarawak, Malaysia.