ORIGINAL ARTICLE

Neuroimpairment, activity limitation, and participation restriction among children with cerebral palsy in Hong Kong

香港腦麻痺兒童的神經缺損、活動限制及社群參與障礙的情況

HSS Chan 陳凱珊
PHB Lau 劉佩香
KH Fong 方健嫻
D Poon 潘美英
CCC Lam 藍芷芊

Objectives. To study children with cerebral palsy in Hong Kong, their neuroimpairment, activity limitation, and participation restriction in society. Parents' opinion on current medical and rehabilitation services was also sought.

Design. Systematic survey using questionnaires.

Setting. Four associations in Hong Kong: Child Assessment Service, Hong Kong Association for Parents of Children with Physical Disabilities, Association of Parents of the Severely Mentally Handicapped, and Hong Kong Physically Handicapped and Able-Bodied Association.

Participants. Parents of children with cerebral palsy.

Main outcome measures. Neuroimpairment, activity limitation, and participation restriction.

Results. Information from 181 children with cerebral palsy was analysed. Among them, 56% were boys. The mean age was 7 years 6 months (standard deviation, 3 years 11 months). The most common diagnostic type was spastic cerebral palsy. Co-morbidities in children with cerebral palsy were common. Limitation in daily activities including mobility and self-care tasks was considerable and this posed great stress to parents when taking care of their children. Children's participation in both social and leisure activities was regarded as a low priority. A high percentage (70%) of parents reported difficulty in travelling. The reasons involved problems in transportation, building access (entry and exit), and attitudes of the general public. These environmental factors restricted the social participation of the children and their families. Over 75% of parents were satisfied with the current medical and rehabilitation services.

Conclusions. Children with cerebral palsy have multiple and complex needs. The findings of this study may serve as a reference for parents, service providers, and policy makers to work in partnership to achieve a more comprehensive health-care service for children with cerebral palsy and to facilitate better integration into the community.

目的：了解香港腦麻痺兒童之神經缺損、活動限制及社群參與障礙的情況，及探討家長對本港醫療及復康服務的意見。

設計：以問卷調查形式作系統性探討。

安排：兒童體能智力測驗服務、香港肢體弱能兒童家長協會、嚴重弱智人士家長協會，以及香港傷健協會。

參與者：腦麻痺兒童的家長。

主要結果測量：神經缺損、活動限制及社群參與障礙的情況。

Key words:
Activities of daily living;
Cerebral palsy;
Developmental disabilities;
Disability evaluation;
Learning disorders

關鍵詞：
日常活動；
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Central Kowloon Child Assessment Centre, Child Assessment Service, Department of Health, 147L Argyle Street, Hong Kong
HSS Chan, MRCP, FHKAM (Paediatrics)
PHB Lau, MCSP
KH Fong, PDOT
CCC Lam, FRCP, FHKAM (Paediatrics)
Department of Rehabilitation Sciences, The Hong Kong Polytechnic University, Hunghom, Hong Kong
D Poon, M Phil, PDPT

Correspondence to: Dr HSS Chan
(e-mail: sophelia_chan@dh.gov.hk)

結果：181 個腦痲痺兒童中，五成六為男孩，平均年齡為 7 歲 6 個月（標準差，3 歲 11 個月），大部份斷症屬痙攣型腦痲痺，腦痲痺兒童一般患有相關的疾病。很多腦痲痺兒童在活動及自我照顧能力方面都有明顯的限制，故大部份家長認為照顧兒童成為一項沉重的負擔。兒童參與社群及文娛康樂活動的安排有較低重要性。七成家長表示在與腦痲痺兒童外出時經常面對困難，主要原因包括交通、通道進出口及公眾人士接納等問題。這些環境障礙限制腦痲痺兒童及其家人參與社區活動的機會。七成半家長對現有醫療及復康服務表示滿意。

結論：腦痲痺兒童的需要是多方面及複習的，建議家長、有關服務機構及政策制定者參考本調查之結果，共同協商制定更全面之醫療復康服務，促進腦痲痺兒童及其家人更能融入社會。

Introduction

Cerebral palsy is a complex disease, and the affected children need multiple and variable care. From June 2001 to June 2002, the Child Assessment Service (CAS) in conjunction with the Hong Kong Association for Parents of Children with Physical Disabilities (HKAPCPD) conducted a parental survey that focused on children with cerebral palsy. It aimed to study neuroimpairment, activity limitation, and participation restriction of these children. Parents' opinion on local services was also sought.

Methods

A questionnaire was completed by parents of children with cerebral palsy. Information was sought in five areas: (a) basic epidemiological data; (b) level of neuroimpairment, activity limitation, and societal participation; (c) need for rehabilitation equipment and home modification; (d) parents' opinion on current medical and rehabilitation services; and (e) parents' major concerns (Appendix). Fifteen parents who were not involved in formulating the survey questions completed the questionnaire as a pilot study. A revised questionnaire was produced based on their feedback.

Questionnaires were sent out to the parents of children with physical disabilities. The parents were recruited from CAS, HKAPCPD, the Association of Parents of the Severely Mentally Handicapped (APSMH), and the Hong Kong Physically Handicapped and Able-Bodied Association (PHAB).

Statistical analysis

Chi squared test and Fisher-Freeman-Halton exact test were used to analyse the questionnaires using the Statistical Package for the Social Sciences (Windows version 10.0; SPSS Inc, Chicago [IL], US). The Department of Rehabilitation Sciences of the Hong Kong Polytechnic University supported the data analysis.

Results

A total of 420 questionnaires were sent out to the parents of children with physical disabilities. Two hundred and ninety-six questionnaires returned, with the response rate of 70%. A total of 181 parents identified their children as having cerebral palsy.

Neuroimpairment

Among 181 children, 56% were boys and 91% were younger than 12 years old. The most common diagnostic type was spastic cerebral palsy, but most parents were unaware of the topographical involvement. Diagnostic type of cerebral palsy was unknown in 11%. The two most quoted causes of cerebral palsy were prematurity and asphyxia (Table 1).

The most common associated medical problem was epilepsy (32%) followed by oromotor and swallowing problems (12%), constipation (11%), urinary or bowel symptoms (11%), and respiratory problems (10%). Developmental problems were also common: 48% were mentally retarded or had global developmental delay and 20% were non-verbal communicators. Visual problems were present in 63% of children. Behavioural disorders and hearing impairment were present in 15% and 13%, respectively. Only six of the 36 non-verbal children used a low-tech augmentative alternative communication device such as communication books or boards. Hand signs were used by five children and the others relied on simple means such as gestures, vocalisation, or crying. No child used a high-tech augmentative alternative communication device at home.

Activity limitation

Mobility

Children's mobility was rated according to four functional levels: independent walker, assisted walker, independent wheelchair user, and assisted wheelchair user. Most (64%) of the children were walkers indoors (42% independent, 22% assisted). The percentage dropped to 51% (34% independent, 17% assisted) outdoors. This was associated with an 11% increase in assisted wheelchair users (from 32% to 43%). Sig-

Table 1. Neuroimpairment of children with cerebral palsy

	No. of children (%)
Sex*	
Male	56
Female	43
Age (years)*	
0-2	7
3-4	19
5-6	18
7-8	19
9-10	15
11-12	13
13-14	3
15-16	2
17-18	1
19-22	2
Type of cerebral palsy	
Spastic cerebral palsy	77
Dyskinetic cerebral palsy	6
Spastic dyskinetic cerebral palsy	4
Ataxic cerebral palsy	2
Non-specific cerebral palsy	11
Possible aetiology	
Prematurity	35
Asphyxia	24
Head injury	9
Congenital brain anomalies	7
Central nervous system infection	5
Unknown	18
Others	2
Cognitive performance	
Developmental delay	10
Limited intelligence	8
Mild mental retardation	9
Moderate mental retardation	12
Severe or profound mental retardation	17
Normal	37
Unknown	7
Additional health or developmental problems[†]	
Epilepsy	32
Oromotor and swallowing problem	12
Constipation	11
Respiratory problem	10
Urinary incontinence	5
Bowel incontinence	5
Urinary retention	1
Visual problems	63
Hearing impairment	13
Cognitive impairment	63
Behavioural disorder	15
Non-verbal communication	20
Visual performance[†]	
Amblyopia	13
Squint	29
Refractive error	34
Blind	3
Undergone squint surgery	9
Wearing corrective spectacles	28
Normal	38
Hearing performance[†]	
Hearing impairment (different grade)	13
On hearing aids	2
Normal	87
Communication performance[†‡]	
Verbal communicator	77
Non-verbal communicator	20
Use of augmentative alternative communication device	3
Use of hand sign	3

* Data were missing for one questionnaire
[†] Respondents could choose more than one item
[‡] Data were missing for three questionnaires

nificant differences were found between intellectual level and walking ability for both indoor (χ^2=42.93, df=4, P<0.001) and outdoor (χ^2=49.18, df=4, P<0.001) environment. A high percentage (indoor, 65%; outdoor, 64%) of assisted wheelchair users functioned at a moderate-to-severe level of intellectual disability. On the contrary, a high percentage (indoor, 70%; outdoor, 73%) of independent walkers had normal intelligence (Table 2). Only two independent wheelchair users used a powered wheelchair and had normal intelligence. No child could use a self-propelled manual wheelchair.

Self-care activities

Self-dressing was considered a more complex task than self-feeding. Sixty percent of children needed help with dressing, whereas 39% needed help with feeding. Only 28% of children could dress or undress themselves alone or with minimal assistance, whereas 46% could eat with minimal or no assistance.

Societal participation

Eighty-six percent of children participated in common leisure activities such as going to restaurants, shopping malls, and playgrounds. Only 54% of children participated in recreational activities such as attending public libraries, swimming pools, or youth centres. Seventy percent of parents had difficulty in going outdoors with their children because of problems with transportation (47%), poor access to buildings and railway or subway stations due to entry/exit problems (28%), and discrimination by others (23%). Parents found it difficult to get buggies or wheelchairs onto public vehicles, such as buses, minivans, and taxis, especially those not equipped with fixed ramp or parking space for wheelchair. Rehabus service was limited and required booking months in advance. Entry to and exit from Mass Transit Railway stations and buildings that had only escalators or stairs were the main access problem. Society was perceived to be ‘non-accepting’ and discriminatory by 23% of parents (Table 3).

Need of rehabilitation equipment and environmental modification

Eighty-five percent of children required rehabilitation equipment including leg braces (58%), standing frame (32%), special wooden chair (31%), leg gaiter (31%), arm gaiter (28%), buggy (25%), arm brace (16%), walking frame (11%), manual wheelchair (10%), spinal brace (6%), crutches (5%), and others (9%). Structural modification to the home to facilitate independence in daily living activities was carried out by 29% of patents. Such changes ranged from minor additions such as adding hand rails (22%) and ramps

Table 2. Comparison of intelligence level with indoor/outdoor walking ability*

Intelligence level	Indoor walking ability			Outdoor walking ability		
	Independent walking No. (%)	Assisted walking No. (%)	Wheelchair using† No. (%)	Independent walking No. (%)	Assisted walking No. (%)	Wheelchair using† No. (%)
Normal intelligence	46 (69.7)	12 (34.3)	9 (19.6)	38 (73.1)	15 (57.7)	11 (17.2)
Limited intelligence and mild mental retardation	14 (21.1)	9 (25.7)	7 (15.2)	11 (21.2)	4 (15.4)	12 (18.8)
Moderate-to-severe mental retardation	6 (9.1)	14 (40.0)	30 (65.2)	3 (5.8)	7 (26.9)	41 (64.1)

* Significant differences were noted between intelligence level and walking ability indoors (χ^2=42.93, df=4, P<0.001) and outdoors (χ^2=49.18, df=4, P<0.001) [Fisher-Freeman-Halton test]

† It includes both independent wheelchair users and assisted wheelchair users

Table 3. Societal participation

	Yes (%)	No (%)	No entry (%)
Participation in leisure activities	86	7	7
Shopping mall	81		
Chinese restaurant	77		
Playground	76		
Fast food restaurant	73		
Game centre	61		
Countryside	59		
Participation in recreational activities	54	35	11
Swimming pool	44		
Library	32		
Community centre	15		
Private organisation/club	15		
Youth centre	7		
Difficulty in participating outdoor activities	70	22	8
Slightly difficult	31		
Difficult	18		
Extremely difficult	17		
No entry	34		
Reason of difficulty in participating in outdoor activities			
Transportation problem		47%	
Entry/exit problem		28%	
Public acceptance		23%	
Others		11%	
Societal acceptance			
Extremely accept		6%	
Accept		61%	
Unaccept		22%	
Extremely unaccept		1%	
No entry		10%	

(1%), to major renovations such as changing bathtub to shower (11%), changing toilet setting (7%), and wall removal (2%).

Services

Over 75% of parents were satisfied or extremely satisfied with the local medical and rehabilitation services (Table 4a). The most popular subspecialty clinic was paediatric neurology, followed by paediatric orthopaedics, ophthalmology, and the general paediatrics clinic. Thirty-two percent of children needed to attend three or more clinics for follow-up, whereas 39% attended two or more hospitals. Nonetheless, 7% of children received no follow-up medical care. Multidisciplinary joint clinics and outreach school clinics were rarely mentioned, whereas 92% of children had attended the CAS. Physiotherapy was the most commonly accessed therapy, followed by occupational therapy and speech therapy. In primary school–aged children, 75% attended special-needs schools, with the majority in schools for the physically handicapped and schools for children with severe mental retardation. Only half of the 20% of children attending mainstream schools were supported by inclusive education, peripatetic, or remedial services (Table 4b).

A need for improvement in subspecialty clinics was identified by one third of the parents. Several

Table 4a. Parents' opinion on the services

Service	Extremely satisfied (%)	Satisfied (%)	Dissatisfied (%)	Extremely dissatisfied (%)	No entry (%)
Preschool education (n=181)	13	63	3	2	19
School-aged education (n=105)	11	72	9	1	7
Physiotherapy (n=166)	8	75	12	0	5
Occupational therapy (n=154)	7	67	15	1	10
Speech therapy (n=93)	4	71	14	2	9
Subspecialty clinic (n=181)	8	72	10	1	9
Child Assessment Service (n=167)	8	76	10	1	5
Rehabilitation equipment (n=154)	4	55	15	2	24

Table 4b. Attendance of educational, medical, and rehabilitation services

	Percent
Subspecialty clinic follow-up	
Paediatric neurology	56
Paediatric orthopaedics	37
Ophthalmology	37
General paediatrics	35
Neurosurgical	16
Paediatric surgery	8
Ear, nose and throat	7
School clinic	6
Multidisciplinary joint clinic	5
Child psychiatry	1
Child Assessment Service	
Attended	92
Never attended	8
Therapy training	
Physiotherapy	92
Occupational therapy	85
Speech therapy	51
No. of subspecialty clinic attended for follow-up	
0	7
1	25
2	35
3	19
4	11
5	1
6	1
No. of hospitals attended for follow-up*	
0	7
1	52
2	32
3	6
4	1
Equipment and home modification	
Need rehabilitation equipment	85
Need home modification	29
Major modification	20
Minor modification	23
Current educational service	
Preschool education service (EETC, SCCC, ICCC, NKG, NNY)[†]	42
Regular primary school	14
With support	8
Special primary school	44
For physical handicapped	20
For mild mental retardation	3
For moderate mental retardation	3
For severe mental retardation	14
Other special school	4

* Data were missing for four questionnaires

[†] EETC denotes early education and training centre, SCCC special childcare centre, ICCC integrated childcare centre, NKG normal kindergarten, and NNY normal nursery

Table 5. Suggested area for improvement

Areas that need further improvement	Yes (%)	No (%)
Subspecialty clinic (n=181)	33	47
Follow-up frequency	12	
Follow-up mode	33	
Location	19	
Others	30	
Child Assessment Service (n=167)	23	57
Follow-up frequency	41	
Follow-up mode	26	
Location	9	
Others	24	
Physiotherapy (n=166)	38	45
Queueing time	20	
Treatment environment	10	
Equipment	14	
Treatment time and frequency	44	
Others	12	
Occupational therapy (n=154)	38	40
Queueing time	20	
Treatment environment	10	
Equipment	17	
Treatment time and frequency	47	
Others	6	
Speech therapy (n=93)	29	46
Queueing time	39	
Treatment environment	0	
Equipment	7	
Treatment time and frequency	43	
Others	11	
Rehabilitation equipment (n=154)	32	38
Waiting time	26	
Durability	18	
Cost	34	
Information availability	13	
Others	9	

suggestions were made: (1) better continuity of care: the child should be followed up by a dedicated case doctor who knows the child and the family well. (2) Better access to existing services: more flexibility in arranging appointments, shorter waiting list and waiting time, longer consultation time. (3) More respectful and supportive care: discourage unfriendly attitudes and encourage professionals to respect parents' and children's concerns when deciding on a management plan. (4) Better coordinated care: arrange more integrated multidisciplinary joint clinics and school outreach clinics to limit the number of visits to different clinics and hospitals.

Parents wished to have more frequent follow-up for their children and a longer time allocated for meetings with staff to discuss findings of the assessment and rehabilitation plan, as well as to have a more detailed assessment summary. Parents also suggested longer and more frequent therapy session, with a higher therapist-to-child ratio. The cost of prosthetic and orthotic equipment was considered high by most families. Parents suggested that orthoses should be more durable, weigh less, fit well, need less time to manufacture, and need less re-adjustment. They also suggested that more readily available rehabilitation equipment resource libraries should be set up (Table 5).

Table 6. Comparison of parents' concern and priority*

Parents' concern	Priority		
	High No. (%)	Medium No. (%)	Low No. (%)
Independence in self-care activities and mobility	116 (45.8)	42 (18.5)	5 (3.5)
Medical follow-up and therapy training	74 (29.2)	63 (27.8)	22 (15.4)
Emotional and behavioural stability	28 (11.1)	39 (17.2)	8 (5.6)
Academic performance	20 (7.9)	37 (16.3)	21 (14.7)
Social participation and leisure	11 (4.3)	35 (15.4)	31 (21.7)
Employment	4 (1.6)	11 (4.8)	56 (39.2)

* Parents' concerns are shown to be associated with priority (χ^2=247.34, df=10, P<0.001)

Parents' major concern

Over 70% of parents rated their children's self-care activities and mobility, along with therapy training and medical care, as high priorities. Over 45% of these parents rated independence in self-care and mobility as the most important concerns. Social participation was rated as important by incredibly few parents (<5%), and 21.7% rated social participation and 39.2% rated future employment as a low-priority concern (Table 6).

Discussion

Cerebral palsy is the most common physical disability in children.[1] It is a neurodevelopmental condition and affects many aspects of a child and the family's daily life. The World Health Organization international classification of functioning, disability and health[2] (ICF) [Fig] has moved cerebral palsy away from a 'consequence of disease' classification[3] to a 'health focus' classification. In contrast to the traditional view that disability affects only the individual patient, the new model recognises that disability is a social construction and involves interaction of the affected person with the community or society. In addition, it highlights participation as an important outcome of health.[4] In this survey, the ICF framework was adopted to study children with cerebral palsy, their neuroimpairment, and to determine to what extent this limited their daily activities and restricted their participation in family and community life. Environmental factors were also analysed.

The most common diagnostic type was spastic cerebral palsy. Parents who were unknowledgeable with regard to the diagnostic type of cerebral palsy might be due to inadequate medical information or the difficulty in diagnosing cerebral palsy. The pattern of neuromotor findings change during the first few years of life and also vary with different clinical types and severity. Muscle tone may evolve from hypotonia to hypertonia as the child grows and the clinical differentiation between dystonia and spasticity is sometimes complicated. The diagnostic type of cerebral palsy is considered stable only after the child reaches 5 or 6 years of age.

A Canadian study reported that 75% of children with cerebral palsy had a learning disorder or developmental delay, 41.6% had communication and speech delay, 29% had visual impairment, 10% had hearing impairment, 14% had behavioural disorders and 27% had epilepsy.[5] This study confirmed their findings that cerebral palsy usually came with co-morbidities. Thus, recognising and managing the many important co-morbidities in cerebral palsy is as important as treating the motor disabilities.[1,4]

Learning disability is highly predictive of restriction in mobility.[6] In this study, there was a statistically significant correlation between intellectual level and walking ability (indoor and outdoor). Other factors such as the severity and type of cerebral palsy, parental coping, and environmental obstacles also affected a child's motor performance. Activity limitation was found to be strongly associated with participation restriction.[6] More than half of the children in this study had limited mobility and required assistance to use public transport. There was a strong correlation between this mobility limitation and the high percentage (70%) of parents who expressed difficulty going outdoors with their children. The problem was

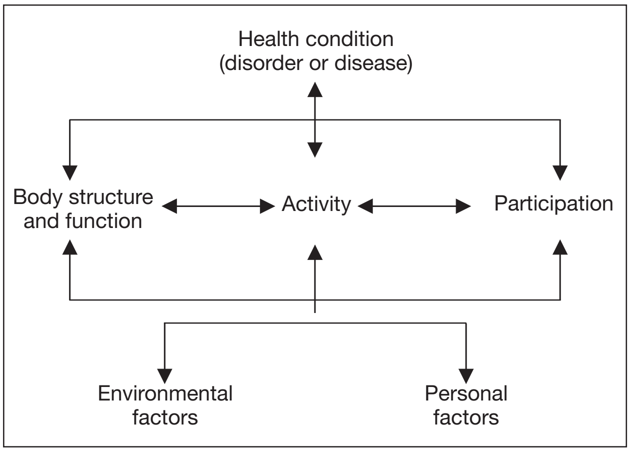

Fig. The international classification of functioning, disability and health model

compounded by major environmental adverse factors such as inaccessible transport and attitude of the general public.

The use of an alternative augmentative communication device or power mobility was rare in this study population. Most children relied on conventional rehabilitation therapy that aimed to correct the primary impairment and promote more ‘normal’ movement patterns. Recently the goals of rehabilitation has shifted from eliminating deficits to enhancing function across all performance domains.[7] Adaptation of the task or environmental modification can help achieve functional independence and good quality of life, despite physical or mental impairment.[4] More liberal use of assistive technology may also enhance a child’s independence and social participation. Early introduction of power mobility to preschool-age children has been shown to have a great positive impact on their social, language, and play skills.[8] Early introduction of augmentative alternative communication for children with verbal expressive difficulties can help promote the development of language. This dispells the myth that augmentative alternative communication devices inhibit normal language development.[1] Technology is constantly advancing with an increasing number of devices becoming available to assist disabled children and adults with activities of daily living. The use of such technology is an important aspect of rehabilitation that can aid family participation in social activities. Nonetheless, as devices become more sophisticated, special training may be needed to use them. Their availability may also be limited if costs are prohibitively high.

Parents identified four main concerns for their children: self-care ability, mobility, therapy, and medical care. Many children needed supervision or assistance to perform everyday activities such as dressing and feeding, and many parents relied on daily therapy and treatment to enable their children to achieve simple daily tasks. Participation by children in leisure and social activities that would enhance social development were, surprisingly, considered unimportant by many parents. This may have been due to time constraints of the parents or a lack of awareness of the importance of social development. The possibility of future employment was not an immediate concern as the children were young, but may become a concern as they grow up.

The most commonly accessed services were physiotherapy, occupational therapy, prosthetics and orthotics service, and visits to paediatricians. Most parents were satisfied with the local medical and rehabilitation services. The important role of both structural elements (accessibility to existing services) and process elements (presence of respectful and supportive care, continuity and coordination of care) in parents’ satisfaction has been previously identified.[9] In contrast to what most believe, the outcome of care is not as important as satisfactory service provision. In this survey, parents identified a need for improvement in both structural elements (shorter waiting list and time, longer consultation time, more intensive training, more frequent follow-up, higher therapist-to-child ratio, and better quality of rehabilitation equipment) and process elements (more friendly attitude and having a dedicated case doctor who is familiar with the child and the family) of services. Parents requested more multidisciplinary joint clinics and school outreach clinics to decrease the need to travel. Greater parental satisfaction with care has been shown to be associated with a comprehensive and integrated programme of medical and psychosocial services that encourages family involvement and partnership with service providers in making decisions and offers coordination of services, health education, and support.[10]

There are several limitations in this study. First, children with milder forms of cerebral palsy might not be well represented. Usually children with more severe functional limitation would attend medical and rehabilitation services more consistently. Second, the information was based mainly on preadolescent children. There was little information on the health and functional status of adolescents, or parents’ satisfaction regarding current services for adolescents and adults. Third, this study was carried out from a convenient sample rather than a population-based study. The findings may not represent all children with cerebral palsy and their families in Hong Kong. It should nonetheless give an indication of the current situation as most children with cerebral palsy are referred to CAS for further evaluation.

Conclusions

The ultimate goal of rehabilitation is to maximise children’s potential and to assist them to participate fully in school, home, and community. Level of participation has a tremendous impact on quality of life and is a vital part of childhood development.[11] Participation enables children to understand society’s expectations and to acquire the physical and social competencies needed to function and flourish in their home and community.[12] Satisfaction with participation is an important predictor of life satisfaction.[13] It is therefore important for parents, service providers, and policy makers to realise the ultimate goal of rehabilitation: to assist children to participate fully in their family and community, and to understand the major factors that promote or limit such participation. A child's participation is affected by his/her own, family, and environment factors.[11] Positive child factors include their feelings of competence (eg in athletics, academics, etc) and their functioning in physical, cognitive, communicative, emotional, behavioural, and social aspects. Positive family factors include the presence of supportive family demographic variables (eg high income and education), good family functioning with better parent well-being, and family preferences related to recreation and skill-building activities. Environmental factors include the presence of supportive physical and institutional environments (such as absence of restrictions physically and socially) and the presence of supportive relationships with other people. Environmental factors and family factors are more important in promoting children's participation than the characteristics of children themselves.[14] This study revealed that physical environmental barriers combined with lack of parental encouragement to participate socially were the two major adverse environmental factors that limited children's participation.

The following findings may be helpful to parents:

1. Although the needs of an individual child with cerebral palsy vary, the complexity of their needs is something that many families have in common. Joining a parent support group allows parents to share information, to interact with others who have the same experiences and family stresses, and to become involved in advocacy work to improve services.[15]
2. Children's needs are often long-term and complex. Families should be empowered with adequate information to plan for their children's continuous needs.
3. Parents should not place too much emphasis on their children achieving normal function. Accommodative strategies and the use of assistive technology should be encouraged to enhance their social participation and quality of life.

For service providers and policy makers, the following may be helpful:

1. The information obtained by this survey may assist in developing programmes that address gaps in the current service delivery.
2. Children with cerebral palsy continue to experience physical problems with access. Government policy and legislation must ensure a more wheelchair-friendly environment in all public transportation, stations, buildings, facilities, and other public areas.
3. Children with cerebral palsy receive services from many different organisations such as educational institute, hospitals, child assessment services, and out-patient training centres. Such services should be coordinated.
4. Parents' opinion on services should be taken into account to ensure delivery of family-oriented services.
5. More resources should be allocated to supply augmentative interventions such as mobility aids, alternative communication devices, and related technical tools. These enhance children's functional performance and thus participation in the community.
6. More education should be provided to raise public awareness and acceptance of people with different kinds of disabilities.
7. Professionals should empower parents with necessary skills and teach the importance of early social participation and environmental modification to enhance the overall functioning and quality of life for children.

This is the first study of children with cerebral palsy in Hong Kong that has used the ICF framework[2] to study neuroimpairment, activity limitation, and participation restriction, as well as how these elements relate to each other and affect parental priorities. Parents' opinion on current local services has also been analysed. The information from this study provides relevant reference for parents, service providers, and policy makers in advocating improvements in services for children with cerebral palsy.[16] As cerebral palsy cannot be cured, the World Health Organization's model focuses on 'function and health'. It offers an important framework to guide modern thinking about goals of rehabilitation.[1, 2] Parental values and goals are important components of a child's rehabilitation plan.[17] Parents and service providers should work in partnership built on mutual respect to create a better environment for children with cerebral palsy in Hong Kong.

Appendix

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References

1. Rosenbaum P. Cerebral palsy: what parents and doctors want to know. BMJ 2003;326:970-4.
2. World Health Organization: International classification of functioning, disability and health. Geneva: World Health Organization; 2001.
3. World Health Organization: International classification of impairments, disabilities and handicaps. Geneva: World Health Organization; 1980.
4. Majnemer A, Mazer B. New directions in the outcome evaluation of children with cerebral palsy. Semin Pediatr Neurol 2004;11:11-7.
5. King S, Law M, King G, Kertoy M, Hurley P, Rosenbaum P. Children with disabilities in Ontario: a profile of children's services. Part 1: Children, families and services. Ontario: CanChild Centre for Childhood Disability Research; 2000.
6. Beckung E, Hagberg G. Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. Dev Med Child Neurol 2002;44:309-16.
7. Graves P. Therapy methods for cerebral palsy. J Paediatr Child Health 1995;31:24-8.
8. Butler C. Augmentative mobility: why do it? Phys Med Rehabil Clin N Am 1991;2:801-16.
9. King G, Cathers T, King S, Rosenbaum P. What makes parents satisfied and dissatisfied with rehabilitation services for their children? Child Health Care 2001;30:111-34.
10. Stein RE, Jessop DJ. Does pediatric home care make a difference for children with chronic illness? Findings from the Pediatric Ambulatory Care Treatment Study. Pediatrics 1984;73:845-53.
11. King G, Law M, King S, et al. The participation of children with physical disabilities. Ontario: CanChild Centre for Childhood Disability Research; 1999.
12. Brown M, Gordon WA. Impact of impairment on activity patterns of children. Ach Phys Med Rehabil 1987;68: 828-32.
13. Kinney VB, Coyle CP. Predicting life satisfaction among adults with physical disabilities. Arch Phys Med Rehabil 1992;73:863-9.
14. Jackson EL, Burton TL. Understanding leisure and recreation: mapping the past, charting the future. State College, PA: Venture Publishing Inc; 1989.
15. Law M, Stewart D, King G, King S, Terry L, Chiu J. Many roads to one place: the effects of parent support groups for parents of children with special needs. Phys Occup Ther Pediatr 2001;21:2-3.
16. Child Assessment Service. Press conference on "Parent Survey on Children with Cerebral Palsy". Hong Kong: Brainchild; 2003:24-6.
17. King S, Kertoy M, King G, Rosenbaum P, Hurley P, Law M. Children with disabilities in Ontario: a profile of children's services. Part 2: Perceptions about family-centred service delivery for children with disabilities. Ontario: CanChild Centre for Childhood Disability Research; 2000.

肢體弱能人士服務問卷調查

請在適合的□加上√(如有需要可√多項)

I. 基本資料

1. *孩子資料*
出生日期：______年___月___日　性　　別：□男　□女
來港定居：□自出生　□自___歲 (___年)　家中排行：□獨生　□第___
另有___名兄弟姊妹有特殊需要

2. *主要照顧者*
□母親　□父親　□祖/外祖父母　□兄弟姊妹　□傭工
□宿舍職員/專業人員　(□長宿/全宿　□五日寄宿)　□其他 (關係____________________)

3. *斷症：*
□痙攣型大腦麻痺症　(□半身(Hemiplegia)　□下肢(Diplegia)　□四肢(Quadriplegia)　□三肢(Triplegia))
□多動/徐動型大腦麻痺症
□混合痙攣及徐動型大腦麻痺症
□震顫型大腦麻痺症
□肌肉營養不良症 (DMD—Duchenne Muscular Dystrophy)
□脊髓肌肉萎縮症 (SMA—Spinal Muscular Atrophy)
□脊椎裂
□其他____

4. *斷症成因：*　□先天異常　□早產嬰　□缺氧　□腦膜炎　□腦炎　□腦創傷
□不清楚　□其他____

5. *視　　力：*　□正常　□弱視　□斜視 (□曾作手術改正)
□ 散光/近視/遠視 (□需要配帶眼鏡)　□失明

6. *聽　　覺：*　□正常　□弱聽 (□不需要助聽器　□需要1部助聽器　□需要2部助聽器)
□曾接受耳窩移植
□其他____

7. *智　　力：*　□正常　□有限智能　□輕度弱智　□中度弱智　□嚴重弱智　□發展遲緩　□不確定

8. *行　　為：*　□正常　□有行為問題 (□自閉症傾向　□過度活躍　□嚴重情緒失調　□自毀行為)
□其他行為問題 (請說明：______________________________)

9. *溝通方法：*　□語言　□非語言方法 (□溝通板　□手語　□電腦)
□其他溝通方法 (請說明：______________________________)

10. *活動能力* (請√最相近情況)

室內	戶外
□獨立步行	□獨立步行
□需要別人扶或用協助器步行	□需要別人扶或用協助器步行
□自行運用輪椅	□自行運用輪椅
□需要別人協助運用輪椅或手推車	□需要別人協助運用輪椅或手推車

孩子是否因活動能力而阻礙參與日常活動
□否　□是：　程度：□少許　□一般　□十分　□非常
(請說明：____)
家居是否需要為孩子而改動 (如拆牆、改如廁、沐浴地方…)
□否　□是：　□已改動 (請說明：_______________________________)
□未改動 (請說明：_______________________________)

11. *進食能力：*　□能自行進食　□大部份情況下能自行進食
□在別人協助下能自行進食　□需完全由別人協助進食

12. *穿衣能力：*　□能自行穿/脫簡單衣物
□大部份情況下能自行穿/脫簡單衣物
□在別人協助下能自行穿/脫簡單衣物
□需完全由別人協助穿/脫簡單衣物

13. *其他疾病：*　□癲癇/抽筋
□口肌/吞嚥問題(請說明：_________________________)
□呼吸系統問題(請說明：__________________________)
□小便失禁
□小便困難(需用藥物或喉管協助)
□大便失禁
□大便困難(每次大便相隔多於三天或需用藥物通便)
□其他____

II. 醫療服務 (如有需要可√多項)

1. *專科覆診* (現所需之專科覆診)
□兒童普通科(醫院名_____________)　□兒童腦科(醫院名_______________)　□兒童外科(醫院名_______________)
□腦外科(醫院名_________________)　□骨科(醫院名___________________)　□耳鼻喉科(醫院名_______________)
□眼科(醫院名___________________)　□兒童精神科(醫院名_____________)
□學校會診(合辦機構及專科：_____________________________________)
□醫院會診(合辦機構及專科：_____________________________________)
□其他專科____
你對專科覆診的滿意程度：□十分滿意　□滿意　□一般　□不滿意　□十分不滿意
你認為以上服務是否需要改善：□否

□是 — □頻密程度____________________
□覆診形式____________________
□地方安排____________________
其他____________________

其他意見：____

2. *評估服務*

孩子是否曾到兒童體能智力測驗中心進行評估：□是 □否(請跳至第3題)
第一次到兒童體能智力測驗中心接受評估的年齡__________
最後一次到兒童體能智力測驗中心接受評估的年齡________
你對評估服務的滿意程度：□十分滿意 □滿意 □一般 □不滿意 □十分不滿意
你認為以上服務是否需要改善：□否
□是 — □頻密程度____________________
□覆診形式____________________
□地方安排____________________
其他____________________

其他意見：____

3. *醫藥/手術*

□長期服用藥物 (所針對病症名稱：____________________)
□為腦積水而置的分流管
□氣管造口術 □需要呼吸器協助 (□全日 □晚上)
□胃造口術 □鼻喉
□間歇性導尿
□用藥物灌腸放便
□骨 科 手 術：□肌腱及軟組織 (即放筋) 手術
□手 — 在____歲 □腳 — 在____歲
□骨性手術
□手 — 在____歲 □腳 — 在____歲 □脊骨 — 在____歲
□局部注射治療：□肌肉注射：肉毒桿菌毒素 (鬆筋針) (Botulinum Toxin) — 在____歲
□用酚作神經阻斷 (Phenol block) 在____歲
□脊後根切斷術 (Selective dorsal rizotomy) 在____歲
□其他手術____
你對醫藥/手術治療的滿意程度： □十分滿意 □滿意 □一般 □不滿意 □十分不滿意
你對醫藥/手術治療的意見：____

III. <u>教育訓練服務</u> (請√出曾或現正接受訓練的地方，如有需要可√多項)

1. *學前訓練及教育*

□早期教育及訓練中心，自____歲至____歲
□普通幼兒中心，自____歲至____歲
□普通幼稚園，自____歲至___歲
□幼兒中心兼收弱能兒童計劃 (混合位)，自____歲至____歲
□幼稚園兼收弱能兒童計劃 (混合位)，自____歲至___歲
□特殊幼兒中心，自____歲至____歲
□特殊幼兒中心(宿位)，自____歲至____歲
□特殊學校預備班，自____歲至____歲
□其他____________________
你對孩子所接受訓練的滿意程度：□十分滿意 □滿意 □一般 □不滿意 □十分不滿意
你對孩子曾接受之學前教育的意見：____
____

2. *學齡教育*

□主流學校 — □沒有特別輔導服務：自 ___ 歲至 ___ 歲
□巡迴輔導服務：自 ___ 歲至 ___ 歲
□啟導班：自 ___ 歲至 ____歲
□融合教育：自 ___ 歲至 ___ 歲
□特殊學校 — □肢體弱能學校：自 ___ 歲至 ___ 歲
□嚴重弱智學校：自 ___ 歲至 ___ 歲
□中度弱智學校：自 ___ 歲至 ___ 歲
□輕/中度弱智學校：自 ___ 歲至 ___ 歲
□輕度弱智學校：自 ___ 歲至 ___ 歲
□其他：______________________________
現就讀年級：__________
你對孩子所接受訓練的滿意程度：□十分滿意 □滿意 □一般 □不滿意 □十分不滿意
你對孩子現接受之教育及訓練的意見：____

3. *治療訓練*

3.1 物理治療
孩子是否曾接受物理治療：□是 □否 (請跳至題目3.2)

年歲	訓練機構		
0至2歲	□早期教育及訓練中心	□醫院門診	□其他________________
2至6歲	□早期教育及訓練中心 □特殊幼兒中心	□醫院門診	□其他________________
6 歲以上	□學校	□醫院門診	□其他________________

孩子是否曾接受水療：□是　　□否　　□不清楚
你對孩子接受水療服務的意見：____________________________________
你對孩子所接受治療的滿意程度：□十分滿意　　□滿意　　□一般　　□不滿意　　□十分不滿意
你認為物理治療服務是否需要改善：□否
□是 — □輪侯時間________________________
□治療時間及頻率 (每__星期__次，每次__小時)
□治療環境________________________
□治療設備________________________
□其他___________________________
其他意見：____

3.2 職業治療
孩子是否曾接受職業治療：□是　　□否 (請跳至題目3.3)

年歲	訓練機構		
0至2歲	□早期教育及訓練中心	□醫院門診	□其他________________
2至6歲	□早期教育及訓練中心 □特殊幼兒中心	□醫院門診	□其他________________
6 歲以上	□學校	□醫院門診	□其他________________

你對孩子所接受治療的滿意程度：□十分滿意　　□滿意　　□一般　　□不滿意　　□十分不滿意
你認為職業治療服務是否需要改善：□否
□是 — □輪侯時間________________________
□治療時間及頻率 (每__星期__次，每次__小時)
□治療環境________________________
□治療設備________________________
□其他___________________________
其他意見：____

3.3 言語治療
孩子是否曾接受言語治療：□是　　□否 (請跳至題目3.4)

年歲	訓練機構		
0至2歲	□早期教育及訓練中心	□醫院門診	□其他________________
2至6歲	□早期教育及訓練中心 □特殊幼兒中心	□醫院門診	□其他________________
6 歲以上	□學校	□醫院門診	□其他________________

你對孩子所接受治療的滿意程度：□十分滿意　　□滿意　　□一般　　□不滿意　　□十分不滿意
你認為言語治療服務是否需要改善：□否
□是 — □輪侯時間________________________
□治療時間及頻率 (每__星期__次，每次__小時)
□治療環境________________________
□治療設備________________________
□其他___________________________
其他意見　：____

3.4 另類治療：
孩子是否曾接受另類治療：□是　　□否 (請跳至題目4)
□針　　灸，自___歲至___歲：每星期___次，每次___小時，每次收費約____
(效果：□有進步　　□無進步　　□不確定)
□按摩推拿，自___歲至___歲：每星期___次，每次___小時，每次收費約____
(效果：□有進步　　□無進步　　□不確定)
□脊　　醫，自___歲至___歲：每星期___次，每次___小時，每次收費約____
(效果：□有進步　　□無進步　　□不確定)
□其　　他，自___歲至___歲：每星期___次，每次___小時，每次收費約____
(請說明______________)　(效果：□有進步　　□無進步　　□不確定)
□其　　他，自___歲至___歲：每星期___次，每次___小時，每次收費約____
(請說明______________)　(效果：□有進步　　□無進步　　□不確定)

4.　復康用具/家居輔助器材 (請√出你的孩子現時所使用及擁有的器具)
□矯形支具：□手扎　　□手托　　□腳扎　　□腳托　　□腰封　　□其他______
□助行器　：□手動輪椅　　□電動輪椅　　□助行架　　□拐杖　　□手推車
□特殊坐椅：數量__張 (用途：□如廁　　□沐浴　　□餵食　　□訓練)
□輔助器材：□企架　　□企床
□其他____

總括而言，你對孩子復康用具的滿意程度：□十分滿意 □滿意 □一般 □不滿意 □十分不滿意
你認為以上服務是否需要改善：
□否 □是 — 改善項目：______________________________
改善建議：□輪候時間______________________________
□耐用程度______________________________
□價錢問題______________________________
□資料提供______________________________
□其　　他______________________________
其他意見：______________________________
____

IV. 社群參與

1. 你認為以下有關孩子的事項，按其在你心目中的重要性，作出排列，最重要的給予 (1)…，如此類推
_______ 活動能力
_______ 讀書表現
_______ 自理能力
_______ 工作/就業機會
_______ 情緒/行為表現
_______ 訓練/治療安排
_______ 社交康樂活動
_______ 醫療安排
_______ 其他 (請說明______________________________)
2. 你有否與孩子參加以下消閒活動：
快餐店 ：□沒有 □有 (每___月___次)
酒樓用膳 ：□沒有 □有 (每___月___次)
商場購物 ：□沒有 □有 (每___月___次)
遊戲機中心/兒童樂園 ：□沒有 □有 (每___月___次)
公園遊玩 ：□沒有 □有 (每___月___次)
郊遊活動 ：□沒有 □有 (每___月___次)
其他 (請說明)：______________________________
3. 你有否與孩子參加以下文娛康樂活動或進修班：
圖書館 ：□沒有 □有 (每___月___次)
社區中心 ：□沒有 □有 (每___月___次)
青少年中心 ：□沒有 □有 (每___月___次)
遊泳池 ：□沒有 □有 (每___月___次)
私人機構或會所：□沒有 □有 (每___月___次)
其他 (請說明) ：______________________________
你認為以上服務是否足夠：□不足夠 □少許 □一般 □十分 □非常足夠
你對社區服務的意見或需要：______________________________
4. 當與孩子外出，你是否面對困難：
□否 □是 — 程　度：□少許 □一般 □十分 □非常
困難所在：□交通問題 (請說明：____________________)
□通道進出口問題 (請說明：______________)
□公眾人士接受問題 (請說明：____________)
□其他 (請說明：________________________)
5. 你覺得社會是否普遍接納你的孩子：□非常接納 □十分 □一般 □少許 □不接納 □沒有意見
6. 其他意見/建議 ______________________________
____

~~~ 多謝閣下撥冗填寫這份問卷，謹此致謝 ~~~

若你有興趣參與我們的協會或繼續得到我們的消息，請你填寫以下資料：
收信人姓名：______________________________
聯絡地址 ：______________________________
____
____
電話 ：______________________________
傳真號碼 ：______________________________
電郵地址 ：______________________________