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The Hong Kong Society of Child Neurology & Developmental Paediatrics
Brainchild - May 2003 issue



Message from the President

Dr. CHAN Chok Wan

At the time of preparation of this May Issue of Brainchild, Hong Kong is at the peak of the Severe Acute Respiratory Syndrome (SARS) attack, with all frontline health professionals dedicated in unison to combat the Coronavirus infection. The Virus has all but paralysed the community and the medical system, yet we are pleased to witness the infection being controlled with the gradually decreasing daily new cases. It is also encouraging to witness our children being less affected in terms of disease incidence, morbidity and mortality. While apparent recovery is being observed on these affected children, child neurologists and developmental paediatricians should bear close vigilance to possible long-term effects of the infection on function of the immature brain. This is an important mission for all members of this Society, and I am sure we shall be able to offer more information on these aspects to colleagues from other disciplines in our future publications.

Modern understanding and management of children with Physical Impairment has always been a major interest of our Society members. Over the past, we have hosted scientific activities on the subject including our Annual Scientific Meeting 1996 under Dr. Joe Watt on Physiatry, a number of Bimonthly Meetings on this theme, and the recent Neurodevelopment Conference on 25th February 2003. The latter Conference on "Management of Children with Cerebral Palsy" was convened by Dr. Sophelia Chan and participated by guest experts (Dr. KY Yam, Consultant Neurosurgeon from Tuen Mun Hospital and Dr. WM Wong, Consultant Orthopaedic Surgeon from Alice HML Nethersole Hospital) as well as a packed roomful of multidisciplinary guests. To further promote our activities in this area, the Editorial Board designates this May Issue to Physical Impairment with Dr. Sophelia Chan as Guest Editor.

The current issue contains *The First Report by the Working Party on Cerebral Palsy* under the leadership of Dr. Sophelia Chan, Dr. Tsui Kwing Wan and Dr. Winnie Yam. The Working Party has covered much groundwork on the subject and is now ready to launch a territory-wide surveillance for children with cerebral palsy in Hong Kong. The project obviously will need concerted efforts of special schools, Department of Health and Hospital Authority services, and the special education section of Education and Manpower Bureau (EMB) that supports mainstream schools, to ensure as wide a coverage as possible. We would like to take this opportunity to thank all parties for their cooperation

and assistance and look forward to valuable results and statistics in the near future. Also inside this issue are excellent articles including *Botulinum Toxin A Injection to Children with Cerebral Palsy: A Local Experience*, *A Standard Protocol for the Assessment of Spastic Upper Extremity and Its Application*, *Use of Electrical Stimulation under the Principles of Conductive Education: A Case Study in a Child with Spastic Diplegic Cerebral Palsy*, *Use of a Lycera-based Garment in Facilitating Postural Stability in Children with Cerebral Palsy*, and *Training Rehabilitation Staff in Mainland China* all contributed by local professional experts. Members will surely be interested in reading through *The Summary Report on the Questionnaire for Parents of Children with Physical Handicap* conducted by the Child Assessment Service of the Department of Health in collaboration with the Hong Kong Association of Parents of Persons with Physical Impairment, a newly registered parent self help group. The report provides important insight on the medical condition of these children, service available to them, and long term needs including systematic improvement in Hong Kong for access, transport, and rehabilitation equipment provisions. This successfully conducted local survey culminated in a conference attended by leading practitioners and senior government officials and paves direction for proper management of children with physical impairment in the future. I congratulate colleagues for their immense contributions.

At the Society level, we are pleased to report that the Working Party on Epilepsy Surgery under Dr. Dawson Fong and Dr. Sharon Cherk is now working at collecting local statistics on Intractable Seizures and at preparing Protocols for Children indicated for Epilepsy Surgery. Results will provide important guidance to our management of Childhood Refractory Epilepsy in Hong Kong.

The Working Party on Specific Learning Disabilities (SLD) continues to work on promoting public awareness, professional development, policy formulation and advocacy issues for individuals with SLD. We are proud to witness production of a CD-Rom on "A Phonetic Approach to Reading for Cantonese Speaking Children" edited by Dr. Catherine Lam, and its being well received by professionals and parents. The Special Course on Children with Special Educationally Needs (SEN) organized by our Society and sponsored by the Education and Manpower Bureau of the HKSAR Government targeting over 2,000 school principals and teachers from primary and secondary schools is well attended despite a short interruption by the SARS epidemic. We hope to complete the Course before end of June 2003 and are confident that lectures and practicum delivered therein will serve to promote understanding on principles and management of these children in mainstream schools. At the same time, the Working Party is still working diligently on *The Position Paper on a Service Model for Students with SLD in Hong Kong*, at the request of the Department of Health and the Education and Manpower Bureau of the SAR Government. We are fully aware of the honour endowed on us and the important mission we have to achieve. With the enthusiastic participation of scholars from different sectors of institutions and professionals from multiple disciplines, we are near completion of the Paper. The draft paper will be sent to Society members and relevant experts in Hong Kong for consultations before submission for consideration by the policy makers.

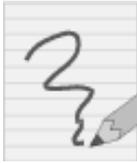
The 11th Asian Congress of Paediatrics, hosted by the Thailand Paediatric Society at Bangkok in November 2003, will offer interesting symposia, seminars, workshops and free papers sessions on general paediatrics, child-health related specialties, and paediatric subspecialties including child neurology and developmental paediatrics. Colleagues are strongly recommended to submit papers in time and attend the Congress so as to familiarize yourselves with recent advances as well as to cultivate friendship with associates and friends from regional countries.

Back in Hong Kong, SARS poses a monumental challenge to all health professionals and academics. We are proud to witness efficiency and determination of our colleagues in fighting this battle despite frequently limited resources and adverse working situations. I appeal to all of you to also provide your best efforts in this mission with the Hong Kong Society of Child Neurology and Developmental Paediatrics. Most important of all, please do take good care of yourselves.

I wish you all reading pleasure and best of health!



Editor-in-Chief, Brainchild
President, HK Society of Child Neurology & Developmental Paediatrics



Education Section

Botulinum Toxin A Injection to Children with Cerebral Palsy: A Local Experience

Nerita NC CHAN

Physiotherapist, Department of Physiotherapy, Tuen Mun Hospital

Introduction

Botulinum toxin type A (Botox) has been widely used in children with cerebral palsy (CP). The major goal is to decrease spasticity and improve motor function. With an intensive physiotherapy training program, we hope to maximize the effect of Botox intervention and achieve a better functional gain.

Botox injection to the spastic muscle has been introduced to the clients in NTW region since 1998. Children with spastic CP and matched our selection criteria were initially screened in our Botox Clinic. A detail pre-injection and post-injection assessment including muscle tone, passive range of motion, physical function (GMFM) and the observational gait analysis were then arranged. Post-injection, all children have to undergo a 3 months intensive physiotherapy-training programme with three sessions per week.

We have performed more than 50 injections, and we would like to share our experience and some of our observation on the effects of Botox with our co-workers.

Common Type of CP and Muscle for Botox Injection

From our data, the most common type of CP for Botox injection is spastic diplegia (Figure 1). The most common muscle group for injection was gastrocnemius.

Effect on First Dose

At the screening assessment, we ensured the potential candidates have predominant spasticity rather than soft tissue tightness or structural deformity that affected the gait. Post injection, we observed a transient decrease in equinus pattern but the effect was not long lasting. The equines gait pattern would usually resume in two months time, but usually with some improvement in posture and physical function when compared with the pre-injection status.

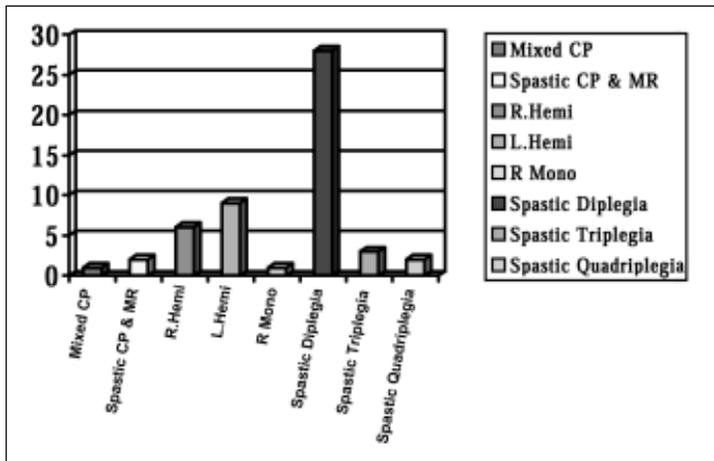


Figure 1. Number of children received Botox injection.

Effect on Repeat Dose

Both therapists and parents have the similar impression that the positive effect of the repeated second dose was not as obvious as the first one, even though the dosage has been increased.

Selection of Clients

As we all know, the selection of suitable clients is very important for good spasticity management. We chose those children with predominant spasticity that affects physical function, and also those with satisfactory muscle power. It is more controversial for those children who have very low axial tone and strength, but with high spasticity of antigravity muscle, as one might be afraid to decrease their function by taking away the muscle tone. However, from our experience of one child with spastic diplegia with truncal hypotonia but lower limb spasticity, we observed that the early spasticity management is beneficial to him. Please see the following case discussion.

Case Study

CP is a premature graduate born in China with birth weight of 1.8 kg at 31 week of gestation. He was diagnosed spastic diplegia. He started to receive physiotherapy training in Hong Kong since 2 years old. On the initial assessment at the age of two (8th September 2000), the boy had very limited motor function with a very low basic postural tone. He was unable to maintain sitting posture and his trunk muscle was weak. When putting him into standing position, both legs would go into an extension synergy with leg crossed. There was severe knee recurvatum of 20°. He could not maintain standing posture by himself. After physiotherapy training, his trunk muscle control gradually improved. He was then able to maintain in standing position with support on a rollator. However, he still had severe knee recurvatum and he could not bend his knee to step forward (Figure 2). The hyperextended knee pattern was due to significant spasticity of the calf muscles that locked the ankles in plantarflexion position with compensated knee recurvatum. No tiptoe standing was presented because of weaknesses in both calf and quadriceps muscles. After our initial assessment,

we decided to give Botox injection to both calf muscles (dosage: 1.7 u/kg/muscle). Immediate after the first injection (date of injection: 21st February 2001), the child was able to bend his knee and make the first step. From the GMFM charting, we could clearly demonstrate a mark improvement on both standing and walking dimension after the injection (Table 1).

Post-injection, physiotherapy training was concentrated on the strengthening of trunk and antigravity muscles with neuromuscular



Figure 2. Standing posture with recurvatum knee.

Table 1. Gross Motor Function Measure (First Botox injection was given on 21/02/01)

GMFM	08/09/00	13/12/00	09/02/01	Botox	27/03/01	23/05/01	30/07/01
				↓			
%	%	%	%		%	%	%
Lying	90.2	100	100		100	100	100
Sitting	41.7	48.3	55		65	73.3	73.3
Crawling	7.1	9.5	9.5		16.7	16.7	31
Standing	0	0	0		5.1	7.7	7.7
Walking	0	0	0		0	1.4	1.4

electrical stimulation to calf muscle. Mother also carried out intensive home training. The child was able to make step and walk with support on a Kaye walker. He still needed a lot of assistance to support his pelvis and trunk. Scissoring gait was marked suggesting significant hip adductors spasticity. Second Botox injection was given to bilateral gastroc-soleus (dosage: 2.5 u/kg/muscle) and hip adductors muscle (dosage: 2.5 u/kg/muscle) on 12th December 2001 i.e. 8 months after the first injection. Post-injection assessment showed significant improvement in GMFM score again (Table 2). Both the walking base and the stride length

Table 2. Gross Motor Function Measure (Second Botox injection was given on 12/12/01)

GMFM	03/12/01	Botox	02/01/02	11/01/02	29/04/02
		↓			
%	%		%	%	%
Lying	100		100	100	100
Sitting	78.3		78.3	78.3	85
Crawling	33.3		40.5	40.5	52.4
Standing	15.4		15.4	15.4	20.5
Walking	1.4		1.4	2.77	15.3

have increased (Figure 3). As he was able to walk more steadily on a Kaye walker and performed more walking exercise at home, his muscle strength has further improved.



Figure 3. Walking with support on Kaye walker.

As spasticity came again around 6 months post-injection, a third dose was given on 18th December 2002 i.e. one year after the second injection. The injection was given to bilateral medial hamstrings (dosage: 3 u/kg/muscle) and gastro-soleus muscles (dosage: 3 u/kg/muscle). Post-injection, there was noticeable improvement in the step length as he could extend his knee more fully during the swing phase of the gait cycle.

Currently, the child is able to walk independently on a Kaye walker at moderate speed. He can extend his trunk and maintain an upright posture in walking. The trunk and antigravity muscle power are still not strong enough to perform all the transitional movement; therefore, continuous training on the rotational trunk control is needed for him.

Conclusion

Botox injection to decrease spasticity was proved to be effective in improving gait and motor function of children with CP. As the effect is transient, it is important to incorporate post-injection intensive physiotherapy training to achieve a better functional outcome. Selection of suitable candidate and muscle group for injection, as well as setting appropriate goal are important factors in affecting the outcome. Early spasticity management with Botox injection to younger children is frequently preferred as it opens up early opportunity for the children to learn the normal movement pattern before their deviated movement pattern is developed. Last, but not least, active participation of both mother and child in the training program is most valuable throughout the habilitation process.

A Standard Protocol for the Assessment of Spastic Upper Extremity and Its Application

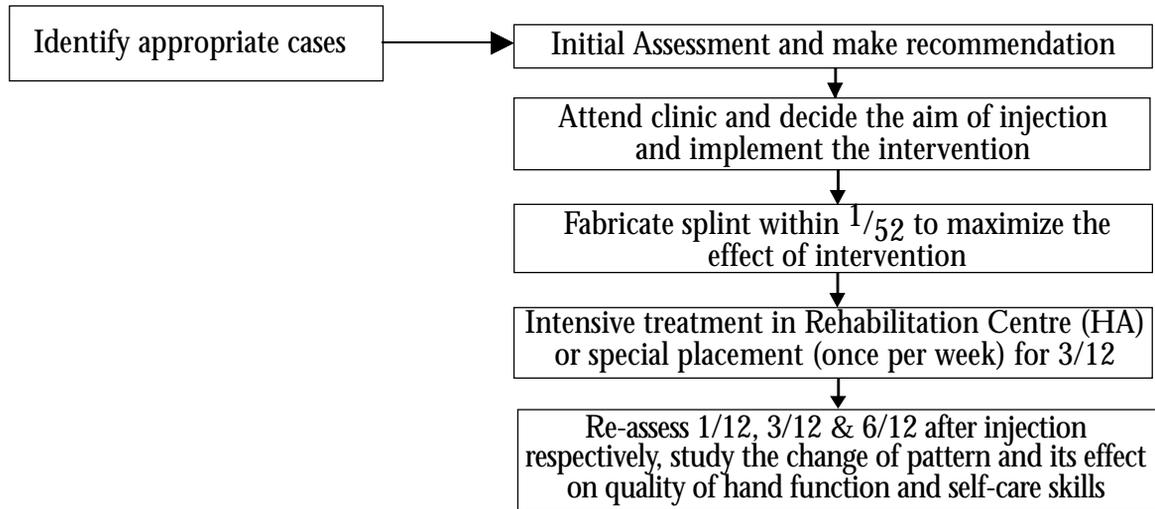
Sanne SL FONG, Alice KWO, Anita FONG, Anna WU, Barbara CHAN, Cecilia LEUNG,
Doris TING, Freda YEUNG, Hellen YANG, Magdalene POON, Sally LIU, Winnie FOK
The Child & Adolescent Working Group , OTCOC

Occupational therapy for hands has been recognized as a specialty within the profession since the 1940s. The survivor rate of those with congenital, systemic or neurological afflictions of the upper extremity also is producing significant number of persons needing help because of dysfunction in daily use of their hands. In addition, in the recent decades, there are increasing varieties of therapeutic intervention of spasticity in order to improve upper extremity function, prevent or correct deformities. The advance in technology and therapeutic intervention creates a challenge to occupational therapist service in the hand rehabilitation. However, the instruments to provide baseline evaluation of the upper extremity function are still controversial among individual centres. In view of the need to have a widely acknowledged and comprehensive assessment to document the effectiveness of intervention programs in Hong Kong, the Child and Adolescent Working Group, OTCOC has developed a commonly accepted guideline on the implementation of Spastic Upper Extremity Assessment in 2002.

Since change in biomechanical capacity of the hand can be quantitatively measured, recorded and traced, these results seen to be regarded as the bench marks of success. However, a successful result cannot and should not be derived merely in degrees of ROM, grip strength or sensation. The patients and their relatives tend to measure the success based on satisfaction in the quality and the quantity of both appearance and performance. Only through purposeful activity, qualitative performance, effects of interruptions in daily tasks and routines allows the patient and their relatives to view the performance in something to which he can related and to monitor his own achievement in overcoming the effects of the impairment. In the rehabilitation of hand function, domain of concern of occupational therapy is not only managing the physiological sequelae, but also self-image, self-care, and restoration of the work-play continuum.

The Spastic Upper Extremity Assessment has adopted standardized tools. The scope of regular assessment includes active range of motion, abnormal muscle tone (Modified Asworth Scale), grip strength, sensibility, grasp & release pattern (include Zancoli's Classification of Spastic Hand), functional use of hand (with developmental issue addressed), hand grip pattern and speed of motion (Jebsen Hand Function Test), with the presence of clinical photos for longitudinal evaluation. This is especially true to document the upper extremity function which influences play and activities of daily living, and thus developmental progress for the children with cerebral palsy.

The following flow chart shows the suggested Assessment Protocol :



This paper aims to present the suggested assessment protocol. The use of different standardised tools is illustrated with a single case study (Appendix), data before and after Dysport injection is presented. Result after intensive splinting program and rehabilitation training is discussed.

Conclusion

The Case Study illustrated our standard protocol of assessment of spastic upper extremity. The content includes physical condition, sensibility, quality of hand grip in performing self-care tasks. In order to observe the effect of therapeutic intervention longitudinally, a "pre-treatment" assessment, then follow at 1 m, 3 m and 6 m intervals is suggested. The Spastic Upper Extremity Assessment Form can provide a visual comparison of the effect of any intervention program. This is helpful to the team when making clinical judgment. With a clear documentation of patients' performance, we can monitor our treatment provided as well. Since most of the items provide quantitative values, the assessment protocol provides us a pre-requisite of evidence-based service.

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Appendix

Princess Margaret Hospital Occupational Therapy Department Spastic Upper Extremity Assessment Form			HCY OCC- 02 - 1XXXX9 Diagnosis: Triplegia, with Rt hand involved										
BW: 18 kg		Affected side (Rt)/ Lt		21 Aug 02 (Pre-injection)		2 Oct 02		21 Nov 02		18 Feb 03			
				Rt		Lt		Rt. 1/12		Rt. 3/12		Rt. 6/12	
AROM	Thumb Extension (0→6) thumb vs 5th MC to ≥2 cm lateral to palm		6		6		6		6		6		
	Thumb Abduction (0→3) measure palmer abduction range 0→≥2 cm		3		3		3		3		3		
	MCPJ ()°		Full		Full		Full		Full		Full		
	Wrist (Ext/Flex)°		55°/75°		35°/70°		0°/85°		20°/85°		30°/80°		
	Elbow ()°		15°~130°		0~130°		10°~135°		0°~135°		0~130°		
Forearm (Pron/Sup)°		Full/40°		Full		Full/55°		Full/70°		Full/40°			
TONE		Thumb (Ext/Flex)		0 / 1		0 / 0		0 / 1		0 / 1		0 / 1	
Modified		Thumb (Ab/Ad)		0 / 1		0 / 0		0 / 0		0 / 0		0 / 0	
Asworth Scale (0,1,1+,2,3,4)		Fingers (Ext/Flex)		0 / 1+		0 / 0		0 / 1		0 / 1		0 / 1	
		Elbow (Ext/Flex)		1 / 2		0 / 0		1 / 1		1 / 1		1 / 1	
		Wrist (Ext/Flex)		0 / 2		0 / 0		0 / 0		0 / 1		0 / 1	
		Forearm (Pron/Sup)		3 / 1		0 / 0		0 / 0		1 / 0		1 / 0	
Grip Strength (R/L) in kgf		Power Grip Kgf		7.0		13.0		2.00		4.0		1.00	
		Lateral pinch Kgf		2.0		3.5		1.75		2.0		1.25	
		Pincer Kgf		1.6		3.5		1.10		1.5		1.75	
Sensibility (R/L)		Stereognosis (0, 1, 1, 2) Discriminate 12 objects		1		2		2		2		2	
		Two-point Discrimination (0, 1, 2) (Discriminate <5 mm to >10 mm)		NA		NA		NA		NA		2	
Grading of grasp & release of a film capsule													
Supination		0 if no		1 if yes		0 ①		0 ①		0 ①		0 ①	
Elbow position		Flex		Extend		flex extend		flex extend		flex extend		flex extend	
Grasp	primitive squeezeae	1 2		1 2		1 2		1 2		1 2		1 2	
	palmar	2 3		2 3		2 3		2 3		2 3		2 3	
	radial palmar	3 4		③ 4		3 4		3 4		3 4		3 4	
	radial digital	4 5		4 5		4 ⑤		4 ⑤		4 ⑤		④ 5	
Release	against surface	1 2		1 2		1 2		1 2		1 2		1 2	
	Into 15 cm container	2 3		2 3		2 3		2 3		2 3		2 3	
	Into 5 cm container	3 4		③ 4		3 ④		3 ④		3 ④		③ 4	
Total score (max. 10)		7		10		10		10		10		8	
Upper Limb Function Assessment (a / b / c / d) (independent use of hand – no functional use)		c		a		c		b		c			
Zancolli's Grasp & Release Pattern (I / IIA / IIB / III)*		IIA		I		IIA		I		IIA			
Parents Assessment -1 = worse 0 = no change 1 = better 2 = much better 3 = very much better						-1 0 ① 2 3		-1 0 1 ② 3		-1 0 ① 2 3			
Side Effect 1 = Ecchymosis 2 = Fatigue 3 = Flu-like illness 4 = ↑ pain 5 = ↑ or excessive weakness in injected body part 6 = Rash						1 2 3 4 ⑤ 6		1 2 3 4 5 6		1 2 3 4 5 6			

Appendix (Con't)

		Units / muscle	Date		Units / muscle	Date
Injection	Adductor pollicis brevis	100 unit Dysport	27.8.02	<u>Rt Brachioradialis</u>	100 unit Dysport	27.8.02
	Flexor Dig. Profundus			Biceps	80 unit Dysport	27.8.02
	Flexor Dig. Superficialis			<u>Rt Pronator quadratus</u>		
	<u>Rt Flexor carpi radialis</u>			<u>Rt Pronator teres</u>		
	Flexor carpi ulnaris			Pectoralis major		
				Others		

Clinical Photo

21 Aug 02	8 Oct 02 (1/12 after injection)	21 Nov 02 (3/12 after injection)	19 Feb 03 (6/12 after injection)
			
			
			

Date	Comment	Therapist
21 Aug 02 (Pre-injection)	Chun Yan's Rt hand performance was severely impaired. Fair sensibility had limited performance in functional tasks. Significant hypertonicity of the Rt. forearm pronators made her difficult to perform tasks like using spoon and unscrewing caps of bottle. Dysport injection to Rt. forearm pronators, Rt. FCR, Rt. BR was recommended.	Sanne Fong
2 Oct 02 (1/12 after injection)	Post-injection training program include weekly hand function training and night time static splintage to keep the Rt. hand in functional position and forearm in maximal supination as tolerated. Much reduction in hypertonicity of thumb adductors, finger flexors, pronators and elbow flexors was observed. Power grip and pinch was impressed as weak. Endurance in weight bearing activities was fair. Grasp & release were easier than before. Mild improvement in functional use was observed such as able to use spoon & scoop food with Rt hand. Yet, the total impairment score still fell in the moderate range. Continuation of intensive training and night splintage were essential at this stage.	Sanne Fong
21 Nov 02 (3/12 after injection)	Improvement in active wrist extension, elbow extension and forearm supination was noted. Chun Yan felt much easier to perform the tasks during assessment. There was only mild increase tone in forearm pronators. Hand function has improved from moderate to mild impairment. She was much more efficient in completing the tasks in Jebsen-Taylor Hand Function Test. Difficulty in holding and orientating a spoon for simulated feeding was still present related to increase in forearm pronator tone. Continuation of the night forearm supination splintage and hand function training in school was recommended.	Sanne Fong
18 Feb 03 (6/12 after injection)	6 months after the injection of dysport to Rt FCR, BR & PT, Chun Yan has shown improvement in the efficiency of grasp & release pattern. The performance in sub-tasks of Jebsen-Hand Function Tests like picking up objects, stacking checkers and picking up large objects have sustained improvement. In addition, Chun Yan has achieved new skills like cutting with a knife using diagonal grasp, using five finger pinch and lateral pinch and demonstrated two-point discrimination at 6 months post-injection. There was some return of hypertonicity in the injected muscles limiting the active wrist extension, elbow extension and forearm supination again. This explained her wrist drop when she tried to release objects precisely into containers. Continuation of nighttime splintage and hand function training in school was recommended. Further assessment 6 months later would be essential to evaluate the longer-term effect after the injection last as well as to monitor the training progress.	Sanne Fong

Appendix (Con't)

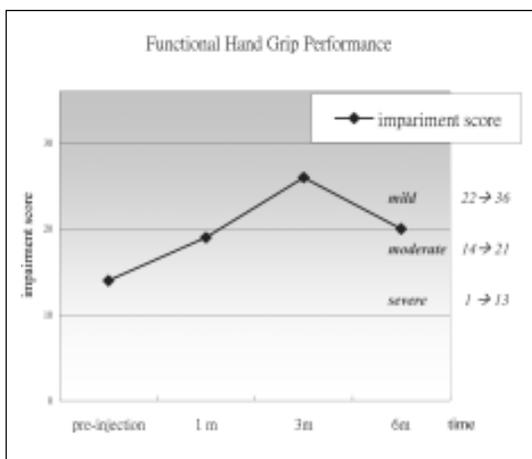
Functional Assessment

Date	Pre-injection		1/12	3/12	6/12
	21.8.02		2.10.02	21.11.02	18.2.03
Jebson-Taylor Hand Function Test (min' sec")	Rt	Lt	Rt	Rt	Rt
Writing	3'45"36	1'37"77	NA	NA	6'47"25
Turning cards	22"84	9"06	23"38	19"78	21"58
Pick up objects	NA	12"42	4'45"	53"88	1'11"61
Simulated feeding	NA	38"13	46"60	3'14"70	NA
Stacking checkers	24"73	8"03	23"52	20"46	17"16
Pick up large objects	NA	7"88	NA	1'05"57	1'05"77
Pick up large heavy objects	NA	9"47	NA	NA	NA

Functional Hand Grip (Eliasson et al)

Transverse grasp	2.5 cmØ horizontal bar in mid-air & place on table	0 1 ② 3 4	0 1 2 3 ④	0 1 2 ③ 4	0 1 2 3 ④	0 1 2 ③ 4
	Move a 2.5 cmØ vertical bar from one pegboard position to another	0 1 ② 3 4	0 1 2 3 ④	0 1 ② 3 4	0 1 2 ③ 4	0 ① 2 3 4
	Lift a glass and pretend to drink	0 ① 2 3 4	0 1 2 3 ④	0 ① 2 3 4	0 ① 2 3 4	① 1 2 3 4
Diagonal grasp	Hold a knife and cut paste into pieces	0 ① 2 3 4	0 1 2 3 ④	0 ① 2 3 4	0 1 2 ③ 4	0 1 2 ③ 4
Five finger pinch	Pull a sleeve on & off unaffected arm	0 1 ② 3 4	0 1 2 3 ④	0 1 2 ③ 4	0 1 2 ③ 4	0 1 2 ③ 4
Tripod pinch	Unscrew 2 cmØ cap	0 ① 2 3 4	0 1 2 3 ④	0 1 ② 3 4	0 1 2 ③ 4	0 1 2 3 ④
	Unscrew 7 cmØ cap	0 ① 2 3 4	0 1 2 3 ④	0 1 ② 3 4	0 1 2 ③ 4	0 ① 2 3 4
Lateral pinch	Grasp a vertically orientated plate (5 x 5 x 1 cm) in mid-air & place on table (supination)	0 1 ② 3 4	0 1 2 3 ④	0 1 ② 3 4	0 1 2 ③ 4	0 1 ② 3 4
Pinch	Pick up a small cube & touch the chin with it	0 1 ② 3 4	0 1 2 3 ④	0 1 2 ③ 4	0 1 2 ③ 4	0 1 2 ③ 4
Total score		14	36	19	26	20
Impairment (severe 1→13, moderate 14→21, mild 22→36)		moderate		moderate	mild	moderate

0 = cannot grip the object; 1 = grips object but cannot complete task; 2 = grips object using an awkward grip & motion but complete task; 3 = grip object using a slightly deviant grip & motion but completes task; 4 = grips object using normal grip & motion & completes task



Zancolli's Classification of Grasp & Release Pattern

Pattern I

The fingers can actively extend with the wrist in less than 20° of wrist flexion.



Pattern II

II A
have positive voluntary extension of the wrist when the fingers are flexed. The extensors of the wrist are active and have good voluntary control.



II B

unable to extend the wrist when the fingers are flexed; the extensors of the wrist are very weak or paralyzed.

Pattern III

There is a severe flexion deformity of the hand. Hand sensibility is usually poor.



Use of Electrical Stimulation under the Principles of Conductive Education: A Case Study in a Child with Spastic Diplegic Cerebral Palsy

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Background

Neuromuscular electrical stimulation is the application of electrical current transcutaneously to innervated, superficial muscles to stimulate muscle fibres. It is usually applied as an adjunct to physical therapy in the management of children with neuromuscular impairment to reeducate muscle, strengthen muscle and improve gait.¹⁻⁴ It is recommended that electrical stimulation be used while the child is engaged in task-specific, goal-directed activities so that the child can take an active role in the process of motor learning.⁵ This approach is consistent with the principle of conductive education. Conductive education adopts an educational model instead of a medical model in the habilitation of children with neurological impairments. It believes that active learning through a holistic approach and a facilitative learning environment are the keys to success in the habilitation of children with disabilities. A description of the use of electrical stimulation under the principle of conductive education is illustrated in the following case example.

Clinical Application

HY was a five-year-old girl diagnosed with cerebral palsy, spastic diplegia. She had normal intelligence. She ambulated with two quadripods independently indoors and outdoors. Due to spasticity in the calf muscles, she walked with a toe-walking gait which was partially corrected by a pair of AFO. She was a boarder and went back home in weekends.

The physical training that HY previously received in the Conductive Learning Centre was delivered in the form of group motor programmes and daily functional routine training. The motor programmes and daily routine training focused on education on postural awareness as well as body and movement concepts; control and coordination of ankle, knee and hip movement; standing balance; gait training; stretching; and motor planning. Electrical stimulation was added to HY's physical training when she was five years old. Electrical stimulation was implemented in a strengthening and endurance programme.

Before electrical stimulation was administered, an introductory session was given to the staff, explaining the use of electrical stimulation and how it was implemented in the daily schedule of the child. A familiarisation session was given for the child to know the function of electrical stimulation and be familiar with the sensation of electrical stimulation. Electrical stimulation was used an average of three times a week. Each session took about 40 minutes in the morning free play time when the boarders finished breakfast. Electrical stimulation was not given within the group motor programmes since the former focused more on strength and endurance while the latter focused more on coordination and balance. Electrical stimulation was applied to bilateral calf muscles while the child was engaged in gait and pre-gait activities including rising on heels, stepping up and down a low

stool, exercising on the stepper, walking on the treadmill and walking on the ground. Besides actively involved in the core physical training, the child was also given responsibility to help prepare the material and apply the electrode pads on the muscles, set the time for training, solve the problem of getting in and out of the treadmill or stepper, clean up the legs after treatment finished, and give feedback during and after treatment. The child received electrical stimulation within the conductive education setting for a period of eight months.

Response Select (Empi, Inc., USA) was used for electric stimulation. The protocol of electrical stimulation was based on the guidelines recommended by Carmick.⁵ Typically electrical stimulation is used where the amplitude of the stimulation is sufficient to elicit muscle contraction within the child's tolerance. However, HY could only tolerate the stimulation on a sensory level, that is, at an amplitude lower than that resulting in a muscle contraction.

Progress on gait was recorded by videocamera and analysed by Photoshop software. Progress on gross motor abilities was assessed by Gross Motor Function Measure (GMFM) which is a standardised assessment to test gross motor functional changes in children with cerebral palsy. Since the operation of electrical stimulation involved getting the child out of her peer group during the morning free play session, a survey was distributed to staff to help observe the influence of electrical stimulation on the psycho-social behaviour and learning routine of the child.

Results

Physical Aspect

Before electrical stimulation was used, the child has been receiving physical training from conductive education programmes. Continuous improvement was made the one-year conductive education programme. The child progressed from using a posterior walker to using two quadripods to walk, indicating an improvement in postural stability and balance. Also the child has attained the ability to walk without support for a few steps and the ability to climb up and down stairs holding onto rail. Moreover, gait was improved in terms of increased step length. However, there was no change in foot contact area during gait and walking speed.

When electrical stimulation implemented in strengthening and endurance programme was added, further improvement was made in gait and motor abilities. The mean step length of the left foot increased from 35 cm to 40 cm, and the right foot from 28 cm to 36 cm. Gait also demonstrated improvement in increased area of foot contact. In the initial contact phase of the left foot, the frequency of landing on toes or forefoot was reduced; instead, there were more occasions on landing on flat foot while landing on heels was occasionally observed. In the mid-stance phase of both feet, forefoot contact was no longer observed; instead, there were more occasions of nearly full foot contact. Walking speed was slightly increased from 0.11 m/s to 0.14 m/s. Besides, GMFM showed a further gain in motor abilities. HY could maintain free standing for more than 30 seconds, as compared to a previous record of 5 seconds; she could also attain standing from sitting on a chair without using arms, as compared to the previous need of using arms. There was only minimal change in the range of movement in the ankle joint and tone of the calf muscles.

Psycho-social Aspect

The staff working with HY commented that while administration of electrical stimulation during the morning free-play time did take up some of the child's time to play and interact with other children, there was no adverse effect shown in the psycho-social behaviour of the child. As well,

although sometimes the child was slightly late for the first lesson, the influence on learning was minimal. When the psycho-social and cognitive learning goals of the child set for this year were reviewed at the end of the training period, nearly all the goals were fulfilled, indicating that the training didn't bring along any adverse effect on the child's learning.

Discussion

Effectiveness of Electrical Stimulation

It was shown in this case example that electrical stimulation together with strengthening and endurance training refined gait and motor performance in children with spastic diplegia, built on the substantial physical improvement gained from conductive education programmes. Especially, electrical stimulation helped to increase foot contact area during gait. This result is consistent with the results of other studies which demonstrated positive effect of electrical stimulation on gait and motor abilities in children with cerebral palsy.^{1-4,6} However, the improvement shown in this case example could not be attributed solely to the effect of electrical stimulation since both electrical stimulation and strengthening and endurance training were delivered to the child at the same stage. Strength training programmes are known to be able to increase strength and motor activities in children with cerebral palsy without adverse effects.⁷

In this case example, only the sensory level of the electrical stimulation was used. In fact, during the process of selecting appropriate candidates for electrical stimulation, one of our children even demonstrated an adverse response of tensing up the muscles of the whole body when the sensory level of electrical stimulation was given. Previous studies on electrical stimulation used the motor level electrical stimulation to demonstrate the effect of electrical stimulation on children with physical impairment. The age of the children in these studies were as young as twenty months of age.^{1,3,4} However, there has been no report on the use of electrical stimulation on children who cannot tolerate the motor level electrical stimulation. Recently, a number of studies investigated the use of low amplitude sensory stimulation as a treatment alternative. Investigators are especially interested in the effect of therapeutic electrical stimulation (TES), a night-time delivery of low amplitude electrical stimulation, which claims to be able to improve motor abilities in children with cerebral palsy through improved muscle bulk.^{6,8} However the effect of TES is controversial.⁹ Apart from being used as the TES protocol, the sensory level electrical stimulation can be used as a facilitative tool through its sensory input to enhance sensory awareness. A few children reported to us that the tickling or tapping sensation allowed them to 'feel' the muscle in use. For those children with poor perception of movement and without adverse responses toward the sensation of electrical stimulation, the sensory input is likely to facilitate motor learning.

This case example indicates that electrical stimulation implemented in strengthening and endurance programme is beneficial to children with spastic diplegia, specifically in the improvement of area of foot contact during gait. Even though electrical stimulation may not be used at the motor level in some children, its sensory input may serve to facilitate sensory perception of movement in these children, provided that these children demonstrate no adverse response toward the sensation of electrical stimulation.

Implementation of Electrical Stimulation in a Conductive Education Setting

Besides that the electrical stimulation with strengthening program itself brought about therapeutic effect on gait and motor ability, this case example also illustrates that the way the program introduced to the child and her learning environment could enhance the management of the child in a wider scope.

When the electrical stimulation with strength training programme was introduced in the Conductive Learning Centre, it was not regarded solely as a physiotherapy programme that only the physiotherapist involved could play an active role. Instead, it was introduced in a holistic manner, paying respect to the transdisciplinary team approach. First, the introduction of the modality to the staff working with the child helps to enhance transdisciplinary understanding on the management of the child and facilitates team cooperation in administrating the programme. Second, the child was requested to be actively involved in an all-round manner in the training session, based on what she has learned in the conductive education environment, including a sense of self-responsibility, knowledge on body concept and movement concept and motor planning. As such, the child had all-round benefits, besides the motor benefit, under the educational principle. Third, the training sessions were carefully scheduled so that it would not interfere or interrupt the child's core learning time. The child in this case example had satisfactory psycho-social development and her major learning goal was on the physical aspect. As such, her psycho-social development was not affected by the reduction in free play time with peers. Besides, since HY had a higher functioning ability than her peers, it is necessary to provide her with more specific and more challenging motor tasks apart from the group motor programmes. However, for children whose learning goals involve social interaction as well, in order not to interfere the core learning time including free play session, their motor group programmes and daily routine have to be re-structured so that the training with electrical stimulation and strengthening could be implemented in the programmes.

This case example illustrates that, first, conductive education and electrical stimulation with strengthening programme could be compatible and complement each other as long as the educational principle and holistic view of management are well taken. Second, in order to obtain optimal results from the electrical stimulation programme, appropriate candidates should be selected; mainly are those who do not have adverse response toward electrical stimulation and whose major learning goal is on the motor aspect.

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Use of a Lycra-based Garment in Facilitating Postural Stability in Children with Cerebral Palsy

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Begin with a Story

Truncal, pelvic and shoulder girdle instability is often a big hurdle to the development of independent mobility and upper limb functions of children with cerebral palsy. Some years ago, we observed an unexpected "side-effect" of a pressure garment worn by a schoolboy with spastic quadriplegia after accidentally scorched his groin region by hot water during bathing. The pressure garment covering the lower trunk and hips gave some stability to his "wobbly" pelvis and allowed him to free one hand from support while standing. This task was impossible for him before wearing the pressure garment. The "side-effect" aroused our interest in looking into the use of lycra to tackle the problem of proximal stability in children with cerebral palsy.

Literature Review

In reviewing the literature, it was found that Blair, et al.¹ had experimented on lycra material to make a lycra-based dynamic total body splint called UPSuit. They reported that the splint provided joint stability and tone inhibition. The best result was achieved in children with hypotonia or dystonia. This splint consists of multiple layers of lycra fitted next to the skin with plastic reinforcement to provide the required dynamic pull and support. The difference between the UPSuit and the conventional rigid orthoses is that it provides support and control whilst allowing movements. Hence, it allows active learning of more normal functional movements. However, the splint was complained to associate with significant practical problems such as inconvenience of putting on and keeping hygiene.² In considering the climate in Hong Kong, comfort and tolerance would be another issue.

Other versions of dynamic splint based on the concept of UPSuit was tried by other investigators such as in Hylton and Allen's case study³ where they use a thinner lycra material to make what they called the stabilizing pressure input orthosis (SPIO). It was again a whole body garment.

Gracies, et al.⁴ investigated the mechanical effect of these lycra-based garments. Their experimental garment consisted of a series of circumferential lycra segments sewn to form a sleeve tightly fitted to the whole upper limb with a pull in the direction of supination. They demonstrated that a low-tension sustained torsion was exerted to the arm and forearm in the desired direction.

Clinical Trial of the Dynamic Postural Garment (DPG)

Based on the literature review and the observation of the child mentioned in our story, we selected two cases from the Jockey Club Conductive Learning Centre of the Spastics Association of Hong Kong for a clinical trial on a lycra garment which we called the Dynamic Postural Garment (DPG)

(Figure 1). The garment consisted of a single layer of lycra covering the shoulder region, the trunk, the pelvic region and the thighs to produce circumferential and compression pressure to the axial and proximal joints. This is similar to the effect of approximation given manually to elicit an active cocontraction of the axial musculature so as to gain truncal and pelvic stability.



Figure 1. Child NKT having DPG on.

Subjects

One case (CYX) selected was a four-year-old boy with hypotonic CP and moderate mental retardation. He demonstrated a generalized hypotonicity and the tone was only slightly raised in exertion. He was a supported sitter with good head control but poor truncal stability and with kyphotic back. Propping with the upper limbs was weak even with arm gaiters and the grasp was also weak and not sustained. In supported standing with a ladder frame and manual assistance, there was a constant sway of the pelvis to either side and locking of the pelvis in the posterior tilted position showing the poor cocontraction of the axial musculature. The DPG was expected to elicit more active muscle work of the axial joints.

The other case (NKT) was a 3 year-old girl with athetoid CP and normal to limited intelligence. Her basic muscle tone fluctuated from normal to slightly hypotonic. She sat with support and occasionally could prop both hands on floor to maintain sitting balance. However, she got little confidence to sit independently without adult beside her. She showed little attempt to reach out with both hands. She tucked her elbows to the side of the body for stabilization when doing manipulative tasks. This limited her use of the hands in a more functional position as well as limited her ability to push the ladder frame (the walking aid she used) in assisted walking. The DPG was expected to give her more proximal fixation around the shoulder girdle and the trunk giving her confidence to attempt sitting independently and releasing the fixed posture of the upper limbs for reaching and pushing.

Wearing Regime and Training

CYX started the trial in September 2000 and off the garment in June 2001. In the first week, the garment was worn for one hour as an adjustment period. The duration was gradually increased to 2.5 hours per day thereafter. The garment was off during mealtime and sleeping time.

NKT started the trial in June 2001 and off in August 2001. The DPG has been worn for 5 weeks. The duration of wearing the garment was increased gradually from one hour per day to 2.5 hours per day. The much shorter duration compared with CYX was due to less skin tolerance in NKT.

Both cases continued their training in Conductive Education programmes which include learning in transfer skills, hand tasks, play skills, self-care skills and daily routine of walking, toileting and feeding. All the activities emphasized active movements and participation as well as understanding of the task and good postural requirements. The flexibility of the DPG material allowed movements and it did not hinder the active learning part of the programmes.

Data Collection

Video on gross and fine motor activities was taken in the natural environment during the training programmes and daily routine. Video was taken before wearing DPG, immediately wearing it and at the end of the trial period. The content was analyzed according to activities including rolling, prone on elbows, 4-point kneeling, sitting on floor, sitting on stool, standing, sitting on stool to standing, walking, reaching with the upper limbs and basic grasp and release of the hands.

Results

CYX showed functions improved immediately after wearing the DPG:

1. The frog position of the legs in lying was reduced;
2. The upper limb actively took part in the assisted rolling with the shoulder showing more self-controlled movement;
3. The head could maintain in the upright position in the forearm-supported prone position for a longer time and the head could turn from side to side to follow toys with sound;
4. Hands could prop on the floor without arm gaiters to maintain sitting for a second and with arm gaiters, sitting balance could be maintained up to 2 minutes;
5. In sitting, the trunk maintained in the upright position more frequently;
6. Sideways and forward sway of the pelvis was reduced in supported standing.

NKT also showed improvements in the following functional activities:

1. She could sit on the floor on her own without support for an increased period of time;
2. She showed confident to sit on a stool without adult beside her;
3. She could reach out with both hands in different directions in the sitting position;
4. She could maintained a 4-point position which was not achieved before;
5. Her shoulders were more forward with elbows extended in standing pushing onto a ladder frame;
6. "Athetoid dancing" of the legs was reduced in standing position;
7. Walking was improved with better pushing of the ladder frame and weight shifting between the two legs.

Conclusion

The project was a very preliminary trial of two cases on the lycra-based garment. Encouraging results were seen in both cases indicating an improvement of proximal stability on wearing the garment. The investigation will be continued to work for a more systematic assessment for correlating the findings. Colleagues who are interested to try this garment out are reminded to some contraindications. Subjects with uncontrolled epilepsy and poor respiratory function should be excluded. Skin sensitivity to the lycra material should be observed before a longer wearing regime is adopted. Reduced muscle strength in prolonged wearing is also theoretically possible. Constipation and urinary frequency is also some complications mentioned in some investigations.

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Training Rehabilitation Staff in Mainland China

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For many years, the Hong Kong Society for Rehabilitation (HKSR) in its capacity as a WHO Collaborating Centre, with the contributions of many volunteer experts, has organized rehabilitation courses in China. Our approach is a little different from other projects in that our students come from all over the country and we are not aiming to establish a long-term relationship with one centre. We aim to transfer knowledge and skills that are immediately useful and relevant although the outcomes are left up to the students' commitment.

Background

In 1989, we started targeting mainly doctors and nurses working in hospitals, by running one-year "Certificate Courses in Applied Rehabilitation" in co-operation with the Ministry of Public Health. While, the project was very successful over its seven years, in "sowing seeds" of rehabilitation throughout China, and we continue to maintain this network of trained and enthusiastic professionals, very few of the graduates were working with children.

In fact, it quickly became obvious that disabled children were in general misunderstood and neglected. Certainly, there were isolated professors, teachers and parents doing wonderful jobs, and many of the readers will have connections with these people. However the majority of parents spent all their resources visiting hospitals looking for answers, coming away with little more than very thick medical records. Fortunately, through the efforts of many people in China and from outside, there have been great changes in the last decade.

Introducing Conductive Education for Children with Cerebral Palsy

We were fortunate to have the services of a Sister Joan O'Connor as our volunteer, and while supervising our certificate courses in Wuhan, she began working with a group of children with cerebral palsy. After long years with the Spastics Association in Hong Kong, she was the ideal person to introduce the Conductive Education (CE) approach to the Mainland. In particular, the many children's welfare institutes welcomed CE and there are now many excellent models of good practice.

It is interesting to speculate on the success of CE, especially in the institutional situation. My personal view is that the structured approach appeals to leaders and front-line workers alike. The group methodology keeps more children occupied. The songs, repetitions and focus on the conductor or teacher, are very similar to the Chinese preschool classroom. In addition, the original stimulus for Prof. Andras Peto to develop CE in Hungary was the need for children to be active and functionally independent if they were to attend schools. This is also true of China, where large classes, squat toilets, stairs, and no special assistants for disabled students, will certainly be with us for many more years. However, even for a child to be considered a "success" in the welfare institute, he or she must be able to manage independently. Staff appreciate the CE focus on functional independence.

Child care staff, whether nurses, teachers or rehabilitation workers can learn the basics of CE quickly. In addition to measurable functional improvements, they also recognize the changes in the child's personality, including interest in the environment and other children, increased communication and free play activities. As the staff gets more experience and growing commitment to rehabilitation, they begin to implement a "daily routine", emphasizing that all situations are learning and practice opportunities for the child. This means that not only the "rehabilitation staff" but also all the child-carers start taking responsibility for stimulating and encouraging the child's development.

Of course, there are also many challenges. What happens when the child seems to "plateau" physically? Are the childcare staff able to progress the individual treatments and group activities? What about the child with unique needs such as visual impairment, epilepsy, dislocated hips or particular learning disabilities? And even, relatively concrete conditions such as contractures require increased problem-solving and special arrangements outside of the group situation. Ultimately, can the child move on from a CE class to a school or classroom-learning situation. Is an educational environment even available? How can CE be translated to a community centre. Will parents accept the functional-oriented CE classroom over a one-to-one passive treatment approach?

To fill in fundamentals and broaden the knowledge and skills of front-line staff, last year we set-up a two year "adult education diploma" with the China Civil Affairs College of Administration and the Beijing Children's Welfare Institute. It is not ideal being only two-seven week semesters separated by a year, when the participants return home but must complete assignments. We have 135 trainees attending in 3 batches; 75% from orphanages and 25% from community centres. The project will be completed in December 2003 and we are now studying the opportunities for similar but less costly options for continuing education for child-carers already on-the-job.

China is now training rehabilitation therapists in 2-year certificate courses ('zhong zhuan'), 3-year diploma courses ("da zhuan") and finally two sites have started bachelor degree courses (Nanjing Medical University and Capital Medical University in Beijing). However, it is clear that many graduates will go to hospitals and the paediatric aspect of the curricula is usually not well developed. China must ask the question: why not train a paediatric therapist from the beginning, instead of following the expensive western model of first training a PT and OT, followed by post-graduate courses to specialize in child rehabilitation?

HKSAR Training Strategies

HKSAR focuses on continuing education. Our broad strategy of training aims to give staff the practical tools as well as positive attitudes with which to practice rehabilitation. In reality, what they do with those tools is their responsibility. We all know that it also depends greatly on their working situation and the leadership they receive. It also depends on the trainees' own initiative, commitment and courage. It is our experience that while some go back and immediately blossom, others hibernate and sometimes only after we have given up (almost), are ready to take the steps, as other colleagues are trained or a new leader takes over. We can all relate to this, even in our Hong Kong situation.

Thus our training strategy is more than running courses. The main components include:

1. **Short Courses** for front-line child-care workers on CE and on other aspects according to requests from centres. We tend to run courses at centres that have good programmes for observation and

- practice during the course and always invite the local staff, including front-line workers, (not only professors) to assist with teaching, practise and discussion sessions.
2. Providing follow-up visits for the most active trainees. These usually include clinical teaching, advising the staff on their programmes, and talking to the leaders to raise their awareness of rehabilitation. It often also includes giving a talk to staff and perhaps to parents. Our Hong Kong volunteers who help us with these follow-up visits have to be prepared to be flexible and practical, as well as to take part in the inevitable banquets. Many readers will have their own such friendly but often exhausting experiences.
 3. Educate the leaders by organizing short observational visits to other centres in the Mainland and Hong Kong. The aim is to increase awareness of the potential of disabled children given access to rehabilitation and education. The chance to see Hong Kong's services will often stimulate increased support for rehabilitation. We are selective in these invitations so as not to waste everyone's time and effort. While it is difficult to measure outcomes, the opportunity is highly appreciated by many staff who are now key leaders in the change process we are all seeing.
 4. Cultivate teachers and consultants by upgrading the skills of the best trainees, and then inviting them to teach and perform follow-up visits.
 5. Encourage mutual help and support among front-line workers through small group meetings and a simple newsletter (starting in 2003) for child-care staff.

While there are certainly disadvantages to running such broad training programmes, our unique strength lies in our network of trainees, working in community-based programmes, private centres, welfare homes and hospitals throughout China. While at present, and in the future, HKSR relies on the strong volunteer ethic of so many Hong Kong professionals, we are also now able to make use of the experiences and enthusiasm of staff in the Mainland. In fact, often they are leading us.

There are many Hong Kong individuals and organizations promoting child health and habilitation in China. We hope that together we can support a more accessible and accepting environment for disabled children.

Related publication from the WHO Collaborating Centre for Rehabilitation:

1. O'Connor and Yu, "Moving Ahead" (English), Springer, 1998, HK\$220
– A step-by-step manual based on CE approach, with 1500 illustrations.
2. O'Connor and Yu, "引導式教育 – 伴兒同行" (Simplified Chinese), the Hong Kong Society for Rehabilitation, 2002, HK\$100
3. Tongji Hospital, WHO Collaborating Centre and the Hong Kong Society for Rehabilitation
WHO Collaborating Centre, "促進腦癱幼兒的發育" Promoting the Development of Children with Cerebral Palsy (Simplified Chinese), 2002, free
4. Tongji Hospital, WHO Collaborating Centre and the Hong Kong Society for Rehabilitation
WHO Collaborating Centre, "促進脊柱裂和腦積水嬰幼兒的發育" Promoting the Development of Children with Spina Bifida and Hydrocephalus (Simplified Chinese), 2002, free
5. Posters on Child Development (Simplified Chinese), the Hong Kong Society for Rehabilitation, 2001, free/donation
6. Hong Kong Conductive Education Songs (in Putonghua): by the Angel Choir, 2000.
– Cassette and songbook, free

All of the above are available from: HKSR: who@rehabociety.org.hk or Tel: 2817-2651

「肢體弱能人士問卷之調查」簡報

香港衛生署兒童體能智力測驗服務
香港肢體弱能人士家長協會
二零零二年十二月十二日

本問卷調查的對象是肢體弱能兒童的家長。調查是由香港衛生署兒童體能智力測驗服務(中九龍評估中心)及香港肢體弱能人士家長協會聯合設計及進行，更得香港理工大學物理治療系協助收發問卷及研究分析。

於二零零一年七月及十一月期間，共發出 414 份自填問卷，給與曾接受評估服務的肢體弱能兒童家長及各家長會的會員，回收及有效的問卷共 296 份，佔 71%。

斷症：
大腦麻痺症 61%
肌肉營養不良症 2%
脊髓肌肉萎縮症 2%
脊柱裂 1%
不清楚 / 沒有填寫 35%

年齡：
超過九成在 12 歲或以下

性別：
58% 男，41% 女，1% 沒有填寫

將斷症為大腦麻痺之問卷資料(共 181 份)再作深入分析：

基本資料

- 大腦麻痺種類：
痙攣型 77%；多動 / 徐動型 6%；混合痙攣及徐動型 4%；震顫型 2%；
不清楚 11%
- 視力問題：
斜視 29%，散光 / 近視 / 遠視 33%；弱視 8%，失明 2%
- 聽力問題：
弱聽 9%
- 智力表現：
正常 37%，有限智能 8%，輕度弱智 9%，中度弱智 12%，
嚴重弱智 17%，發展遲緩 10%，不確定 7%
- 行為問題：
有行為問題 15% (包括自閉症傾向，過度活躍等)
- 溝通方法：
語言 77%；非語言 20% (溝通板 16%，手語 14%，電腦 11%，
身體語言 58%)
- 室內 / 戶外活動能力：
獨立步行 42%/34%，需要別人扶或用協助器步行 22%/17%，
自行運用輪椅 2%/1%，需要別人協助運用輪椅或手推車 32%/43%，
沒有填寫 2%/5%
- 進食能力：
自行進食 46%，大部份情況下自行進食 13%，在別人協助下能自行
進食 11%，需要完全由別人協助進食 28%
- 穿衣能力：
自行穿 / 脫簡單衣物 28%，大部份情況下能自行穿 / 脫簡單衣物 10%，
在別人協助下能自行穿 / 脫簡衣物 21%，需要完全的照顧 39%，
沒有填寫 2%
- 其他疾病：
癲癇 / 抽筋 33%，口肌 / 吞嚥問題 13%，大便困難 12%，呼吸系統
問題 10%，小便失禁 5%，大便失禁 5%

對醫療，康復訓練及教育服務的意見

對以下服務的滿意程度(%)：

	十分滿意(%)	滿意(%)	不滿意(%)	十分不滿意(%)	一般 / 沒有意見(%)
專科覆診 N=180	8	72	10	1	9
評估服務 N=167	8	76	1	5	5
學前訓練及教育 N=181	13	63	3	2	19
學齡教育 N=104	11	72	9	1	7
物理治療 N=167	8	75	12	0	5
職業治療 N=153	7	67	15	1	10
言語治療 N=93	4	71	14	2	9
復康用具 N=181	4	55	15	2	24

改善項目：

	輪候時間 N=181	治療時間及頻率 N=181	治療環境 N=181	治療設備 N=181
物理治療	20	44	10	14
職業治療	20	47	10	17
言語治療	37	43	0	7
	頻密程度 N=181	覆診形式 N=181	地方安排 N=181	其他 N=181
專科覆診	12	39	19	30
評估服務	41	26	9	24
	輪候時間 N=181	耐用程度 N=181	價錢問題 N=181	資料提供 N=181
復康用具	26	18	34	13

家長的期望：

- 縮短輪候時間
- 多一些機構可提供價錢相宜的復康用具
- 提升製造復康用具的質素，注意外觀，舒適及耐用程度
- 有一些兒童復康用具的陳列室給家長參考

社群參與

家長認為對孩子最重要的事項：

自理能力(35%)，活動能力(20%)，訓練 / 治療安排(14%)，醫療安排(13%)，情緒 / 行為表現(8%)，讀書表現(6%)，社交康樂活動(2%)，工作 / 就業機會(2%)

消閒活動及文娛康樂活動或進修班的參與：

	是	否	沒有意見
參加消閒活動			
快餐店，酒樓用膳，商場購物，遊戲機中心 / 兒童樂園，公園遊玩，郊遊活動	86%	7%	7%
參加文娛康樂活動或進修班			
圖書館，社區中心，青少年中心，游泳池，私人機構或會所	54%	35%	11%

家長的期望：

- 有關機構多舉辦肢體弱能兒童可以參加的活動及興趣班，特別在暑假期間
- 能特設一些適合肢體弱能兒童玩樂的地方
- 在介紹旅遊地方的單張上，註明是否適合輪椅使用者
- 定期接收一些有關弱能人士的活動訊息
- 增加類似傷健中心的機構及資源中心，提供各項文娛活動給殘障人士參加

外出面對的困難

當與孩子外出，你是否面對困難？ 是 70% ，否 22%

當與孩子外出，面對的困難： 交通問題 46% ，通道進出口問題 28% ，公眾人士接受問題 23% ，其他 11%

困難程度： 非常困難 17% ，十分困難 17% ，少許困難 31% ，沒有意見 34%

家長的期望：

- 所有公共交通設施，可以上落輪椅及手推車
- 巴士公司儘快更換有低地台巴士，以方便輪椅使用者
- 加強巴士司機對弱能兒童的認識
- 在地鐵站街道圖上註明輪椅出入口
- 加強巡查商場或其他公共地方，以確保有足夠的扶手電梯，出入口通道有斜坡設施及有足夠的輪椅人士洗手間
- 在加建公共設施及作城市規劃時，會考慮弱能人士的特殊需要
- 有融合教育學校的校車，應加設低地台或低樓梯級，讓一些行動不便的兒童容易上落

社會的接納

非常接納 5.5% ，十分接納 61% ，不接納 22% ，十分不接納 1% ，沒有意見 11%

家長的期望：

- 公眾人士不要帶著歧視的眼光去看這班可憐的小朋友
- 政府應多作宣傳，讓社會對弱能人士多些了解和接納
- 政府應從公民教育做起；在學校，老師要對學生講解；在家庭方面，家長要對小朋友灌輸一些正面的知識，讓每個人都可以瞭解及接納這些有特殊需要的兒童，令他們可以得到平等的待遇
- 多在大眾傳播媒介，如電視、報紙、電台等對弱能、弱智人士作正面的報導，如他們怎樣勇敢地面對生活上的困難和在各方面取得的成就
- 多鼓勵普通學校的學生，參觀和參與特殊學校的活動，或者到特殊學校作義工，使能接觸及正確認識他們
- 希望各專業人員繼續支持及輔助有需要的家長及兒童，把他們的熱誠廣泛渲染各人，讓大家都接受及支持這群有特殊需要的孩子

Working Party on Cerebral Palsy in Hong Kong

First Report



Under the auspices of the Hong Kong Society of Child Neurology & Developmental Paediatrics (CNDP), a Working Party on Cerebral Palsy was formed in 2002. The aim of the Working Party is to study the extent of problems of cerebral palsy in Hong Kong.

The Working Party is under the advice of Dr. C. W. Chan, President of the Society, and is led by Dr. Sophelia Chan, Dr. Winnie K. L. Yam and Dr. K. W. Tsui. We are honored to have Ms. Ashley Yu to be our Consultant Statistician as well.

The Working Party is currently planning a study on the school-aged children with cerebral palsy. The study includes two phases. The first phase is to find out the local prevalence rate of cerebral palsy in Hong Kong for children aged 6-12 years old. In Hong Kong all children age 6 to 12 years old are studying in primary schools, we therefore have contacted the Education and Manpower Bureau (EMB) enquiring the total number of children with cerebral palsy in various types of special schools as well as normal schools (P1-P6). The preliminary response from the EMB is positive and encouraging. The second phase of the study includes detail investigation on the subtypes of cerebral palsy as well as the associated neuroimpairment, activity limitation and participation restriction, adopting the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) model.

On 12th March 2003, the working party has presented the study plan to the CNDP members and has raised great discussion after the presentation. Comments and suggestions from the floor were highly appreciated.

We believe that the local prevalence rate and detail profile of cerebral palsy is important to us and such data has not been reported in any medical literature locally. It is therefore important for our working party to continue work on the two-staged study. The information from the study will serve as a foundation to guide more focused future clinical researches, as well as to provide some evidence for our policy makers, service providers and family of children with cerebral palsy in the planning, delivery and advocacy of service.

In the best interest of children with cerebral palsy, the Working Party looks forward to the continued support from all the healthcare workers and educational professionals working with children with cerebral palsy. Active support from the school teams is crucial to our success in the completion of the study.

17 March 2003



Useful websites

www.KIDSMOVE.ORG

Kidsmove—Worldwide Education and Awareness fro children's movement disorders

www.wemove.org

Worldwide Education and Awareness For Movement Disorders

www.fhs.mcmaster.ca/canchild

Canchild Centre for Childhood Disability Research, McMaster University

Activity Announcement

**International Conference on Cerebral Palsy
April 30-May 3, 2003
Quebec City, Canada**

To ensure the quality of the content of the Conference, the international Scientific Committee has determined thematic sessions that bring together international leaders from each field of expertise. This meeting will be an excellent opportunity to exchange on various themes: (a) issues in service delivery; (b) client-oriented goals / approaches; (c) early diagnosis and classification; (d) surveillance and advances in identification of risk factors; (e) measurement issues; (f) intervention strategies; (g) fitness and health; (h) promoting autonomy through technology; (i) activity, motor behaviour and function; and (j) brain to movement. Each topic will be covered extensively during the three days of the Conference, in oral and poster presentations on the most recent scientific developments related to the health and social integration of persons with cerebral palsy. Although most presentations will be performed in English, some will be in French. Simultaneous translation from French to English will be available. Read more... www.crupu-ul.ca

**57th Annual Meeting of the American Academy for Cerebral Palsy and Developmental Medicine
September 10-13, 2003
Montreal, Quebec, Canada**

The Program Committee meets in March, and the final Program will be available around the middle of June. Both the Program and Online Registration will be available shortly thereafter via this web page. Deadline for abstract submission has passed. Read more ... www.aacpdm.org

**15th Meeting of the European Academy in Childhood Disability
October 2-4, 2003
Oslo Kongressenter, Norway**

From Research to Clinical Practice

The 15th meeting of the EACD addresses all professions working in the area of habilitation of children. Seminars, lectures, free papers, posters and videos cover a great variety of topics predominantly concerning children, partly also adolescents and adults.

Abstracts for consideration:

The EACD Scientific Programme Committee is now accepting abstracts for consideration for presentation at the 15th Annual Meeting. Read more... www.eacd2003.no