Brainchild

The Official Publication of HKCNDP

Hong Kong Society of Child Neurology & Developmental Paediatrics
香港兒童腦科及體智發展學會

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Hong Kong Society of
Child Neurology & Developmental Paediatrics
香港兒童腦科及體智發展學會

The Council

The Editorial Board

Address
c/o The Federation of Medical Societies
4/F, Duke of Windsor Social Service Building
15 Hennessy Road
Wanchai, Hong Kong

Website
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Hong Kong Society of
Child Neurology & Developmental Paediatrics
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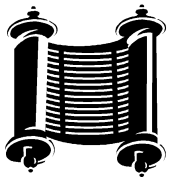
Cover

The cover picture is a print from C. C., a little patient of Alice Ho Miu Ling Nethersole Hospital.

The Hong Kong Society of Child Neurology & Developmental Paediatrics
Brainchild - August 2001 Issue



Message from the President

Dr. CHAN Chok Wan

We are pleased to witness Brainchild proudly advancing into its third issue. On behalf of the Hong Kong Society of Child Neurology and Developmental Paediatrics, I would like to thank all members of the Society for their enthusiastic response and to all professional colleagues and friends of the Society for their constructive comments. With these supports, we are confident that Brainchild will become the informative and representative publication that we need.

In the current issue, we have included presentations from our bimonthly scientific meetings on Optic Neuritis and Epilepsy Surgery as well as a paper by Dr. Wu Shun Ping on Computer and Epilepsy presented on behalf of our Society at the FMSHK Annual Scientific Meeting 2001. All these excellent scientific papers together with abstracts in the section on Journal Watch serve to fulfill our primary mission of promoting academic development within the subspecialties of child neurology and developmental paediatrics. We are pleased that consequent to exchanges at these scientific meetings, the Society Council has resolved to convene a special Working Party on Epilepsy Surgery, with Dr. Dawson Fong as Convenor and Dr. Sharon Cherk as Honorary Secretary, to study the magnitude of the problem in Hong Kong, formulate indications for surgery and make recommendations to relevant local authorities for delivering this service effectively in Hong Kong. This is the third working party appointed by the Council; the other two, designated to Cerebral Palsy and Specific Learning Disabilities, are currently working efficiently and effectively.

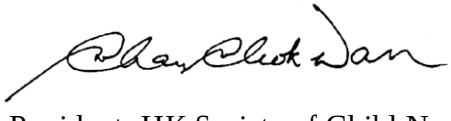
Also included in this issue is the full text of the submission of our Society to the Commissioner for Equal Opportunity which I am sure reader will find it appropriate and relevant for children in our community. I would particularly like to share with readers the Society's opening statement in this submission that "*The Hong Kong Society of Child Neurology & Developmental Paediatrics comprises of a body of professional persons dedicated to the promotion of standards and practice in the fields of child neurology and child development, and to promoting welfare of children under their disciplines' purview. The Society welcomes the preparation of this Code to provide guidelines to the public and educational establishments in interpreting the Disability Discrimination Ordinance (DDO) 1995. As children's*

advocates, the Society would like to provide its professional views to the Commission with the hope that welfare of children with disabilities and special education needs may be further promoted". We are pleased to witness that the Code has been passed by the Legislative Council in July 2001 and will continue to work closely and proactively with the Equal Opportunity Commission to ensure that the spirit of the Law and Code are put into real and effective practice.

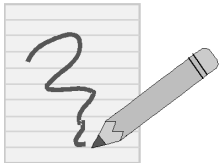
Developmental Dyslexia is a major problem in Hong Kong and preliminary local data converge on an incidence which is no different from that of countries elsewhere. We are pleased that the effort of the Working Party on SLD has successfully aroused awareness of Hong Kong's professionals and administrators to its lifelong and disabling problems. We are further encouraged to report that many concrete projects by various sectors are underway to tackle the problem. One question that is always asked is what difference there is between developmental dyslexia in children using the Chinese language and those using alphabetic such as English? In order to study this very important issue, the Society will be hosting an International Conference on "Developmental Dyslexia in Children using Chinese Language: fMRI and Advocacy" in Hong Kong in October 2002, whereby world authorities on the subject together with experts from regional Chinese speaking areas (China, Taiwan, Singapore, and Hong Kong) will be invited to assemble here to update knowledge, share experience, exchange concepts and formulate strategic plans to jointly address the problem. We sincerely hope that this meeting of minds will serve as a platform for further understanding this intriguing subject and developing solutions to helping Chinese dyslexic individuals. More details will be forthcoming in due course and we look forward to your keen support.

Last, but not least, we are pleased to present our Annual Scientific Meeting on 14-18th October, 2001 on Paediatric Neuro-Ophthalmology under the directorship of Professor Peter Savino of Medical College of Pennsylvania and Hahneme and Director of Neuro-Ophthalmology, Wills Eye Hospital, USA, together with generous contributions from local experts in the area of developmental paediatrics and ophthalmology. The full programme promises a very fruitful meeting for all participants. Please watch out for further details from our posters or via our Society Website at http://www.fmshk.com.hk/hkcndp for early registration.

We wish you all reading pleasure and look forward to your support and comments. Thank you.



President, HK Society of Child Neurology & Developmental Paediatrics



Education Section

Optic Neuritis in Children: Clinical Presentation, Treatment and Outcome

Dr. WU Shun Ping
Department of Paediatrics, Queen Elizabeth Hospital

Optic neuritis can be defined as an involvement of the optic nerves by inflammation, degeneration or demyelination leading to an impairment of function (Riikonen 1988). The aetiology of optic neuritis is heterogeneous. While the association of optic neuritis with multiple sclerosis is well established in adults, it is less frequently a presentation of multiple sclerosis in children. Morales et al (2000) reported in a series of 15 patients presented to the Department of Ophthalmology, University of Miami School of Medicine, four (26%) developed multiple sclerosis. More often optic neuritis is associated with febrile viral illness several weeks before presentation. Post-infectious optic neuritis has been reported following measles, mumps, chickenpox, rubella and Ebstein-Barr virus infection. Other rarer causes include systemic lupus erythematosus, toxins (like methanol), bacterial infection (like cat-scratch disease and Lyme disease) and immunization.

The clinical presentation in children was typically 2 weeks after a febrile illness. Visual symptoms come on suddenly. Central scotoma is present in around 40%. Visual acuity can vary from mild impairment to compete loss of light perception. But the majority had severe impairment of visual acuity; 84% presented with visual acuity of less than 20/200. Complete blindness is usually complete within 12 to 48 hours of onset. 56-66% of children suffered from binocular optic neuritis (Brady et al 1999, Morales et al 2000). Eye movement can elicit eye pain. Over 70% of children will have acute papillitis with swelling of the optic disk. The rest are retrobulbar in location and thus fundoscopic examination can be normal.

Most patients received treatment. In two recent reports from the USA, intravenous methylprednisolone were given in around 80% of patients. Optimal recovery, defined as a final visual acuity of 20/40 or more, can be achieved in more than 50% of patients. The favorable prognostic factors are:

(1) Binocular involvement
(2) Young age (<6 years old)
(3) Normal optic nerve finding on MR imaging, without nerve swelling, hyperintensity or gadolinium enhancement
(4) Freedom from associated features e.g. transverse myelitis

The Department of Paediatrics, Queen Elizabeth Hospital has admitted 6 patients with optic neuritis since 1993. Amongst these patients there were 5 females and 1 male. The age of presentation varied from 4 years to 12 years. Half of them had preceding fever or vomiting illness before. Interestingly 2 patients presented with epileptic convulsion, one of which was a status epilepticus leading to significant brain swelling. Onset of visual impairment started about 2 weeks from the initial illness.

All patients reached the nadir of visual acuity within 1 week of onset. Half of the patients had monocular disease. One patient presented with a central scotoma in one eye. In bilaterally affected patients the involvement of the eyes are usually symmetrical. One patient presented with impaired colour vision and she failed Ishihara test. The rest presented with global reduction in visual acuity. It ranged from complete loss of vision to a markedly reduced visual acuity.

Half of the patients had papilloedema on presentation. Eye pain was not reported in any of them.

Regarding the investigation to the cause of optic neuritis, 3 patients underwent lumbar puncture. All cerebrospinal samples showed normal protein, glucose, and bacteriological culture and were negative for oligoclonal band. One patient was positive for antinuclear factor at 1:40. She did not develop any other feature of systemic lupus erythematosus. Five of the 6 patients had MR examination of the brain. Three patients had abnormal hyperintensity of the optic nerves. It is associated with an increased risk of poor recovery, defined as a final visual acuity of less than 20/40. Two out of 3 had a final visual acuity of less than 20/40.

One of the 6 patients developed transverse myelitis 20 days after onset of optic neuritis. She presented with generalized weakness, brisk lower limb tendon jerks and Babinski sign. MR Brain showed patches of hyperintensities over the medulla and frontal area. MR spine was not performed. She received 3 days of pulsed methylprednisolone and then continued with oral prednisolone. Transverse myelitis resolved 10 days later. Her serum showed a 32 fold increase in antibody titre against influenza A. The clinical diagnosis is thus Neuromyelitis optica (Devic's disease) and it was thought to be related to influenza A infection.

Another patient who presented with impaired colour vision in one eye had a relapse 7 months after an initial complete recovery of visual acuity. She received a second dose of oral prednisolone which lasted 27 days. Her final visual acuity was 20/30. There is residual red-green deficiency. Her right eye also showed a pale optic disk compatible with optic atrophy.

If we count the number of eyes, out of the 7 eyes in these 5 patients who attended regular follow up till plateau of recovery, 2 out of these 7 did not recover completely. Assuming the one lost to follow up is also incompletely recovered, the rate of complete recovery is about 55%.

Three of these patients received pulsed methylprednisolone followed by oral prednisolone. The number in brackets represent those who recovered completely, It can be seen that the treatment of steroid did not yield conclusive result. However statistical evaluation did not show significance.

Optic atrophy is associated with incomplete recovery, as is abnormal hyperintensity of the optic nerves. Two of the older patients (12 years old) had complete recovery, while the 2 younger patients of 4 years did not recovery to a visual acuity of 20/40. Recovery is not associated with binocular involvement as elucidated from other studies.

Upon follow up there was no patient who developed remitting-relapsing neurological abnormality to suggest the diagnosis of multiple sclerosis.

It can be seen that optic neuritis is a heterogeneous group of disease. About half of the patient will recover completely. It cannot be concluded if steroid has made significant impact on the eventual outcome of the disease. Abnormal MR finding is associated with incomplete recovery, which is often manifest with optic atrophy upon long term follow-up.

Optic Neuritis in Children

Dr. LIANG Chan Chung
The Hong Kong Eye Hospital

Optic neuritis is inflammation of the optic nerve. There are several causes of optic neuritis in general:

(1) Demyelination. This can be an isolated process or the systemic presentation of multiple sclerosis.
(2) Direct infection. Inflammation can be caused by bacteria or viral infection. This is an uncommon cause.
(3) Parainfectious. This is the commonest cause in children. It is thought to be immunologically mediated and is usually preceded by a viral infection 1-3 weeks before.
(4) In systemic disease. For example SLE and sarcoidosis.

Assessment

Optic neuritis usually presents as an acute loss of vision, either unilateral or bilateral. Besides visual acuity, the visual field as well as the contrast sensitivity can also be affected. The most sensitive parameter for documenting optic nerve dysfunction is by abnormal colour vision and a relative afferent pupil defect (in unilateral cases). MRI and lumbar puncture are not routinely performed in adults with optic neuritis. They are however very helpful in children. Visual evoked potential provides little additional information except in complicated cases.

Course of the Disease

Optic neuritis typically follows a course of rapid visual loss for 2-3 weeks and then a recovery phase usually within 3 months of the onset. Most patients will have satisfactory recovery of visual function but some suffer certain degree of residual damage of visual function.

Differential Diagnosis

The typical disease course makes optic neuritis quite distinguishable from other causes of optic neuropathy. However conditions like papilloedema, compressive optic neuropathy, infiltrative optic neuropathy (by leukemia or lymphoma) can sometimes cause confusion.

Management

It is reasonable to offer observation only as the visual function will return in most of the cases. According to the Optic Neuritis Treatment Trial (ONTT), systemic intravenous methylpredniolone followed by oral steroid can hasten the visual recovery, although the final visual outcome is not affect by treatment. To treat or not is a balance between the benefit of treatment and the side effects of corticosteroid. In general, treatment is recommended in children because of the different aetiologies from adult and a high response rate.

Prognosis

The prognosis of optic neuritis in children is good. The majority achieves satisfactory visual recovery but residual deficit does occur in some cases. Most of the cases with unsatisfactory recovery have bilateral involvement. Multiple sclerosis after optic neuritis is less common in children than in adult. The chance is higher in recurrent attacks or if the presentation is at an older age. Bilateral simultaneous optic neuritis carries a lesser chance of multiple sclerosis probably because it indicates an immunological origin rather than a primary demyelinating process.

Difference between Adult and Children

Adults	Children
• Majority female	• No sex predilection
• No preceding illness	• Usually preceding viral illness
• Unilateral	• Simultaneous bilateral
• Retrobulbar	• Swollen disc
• LP/Serological tests not required	• LP commonly performed
• Slow action of steroid	• Quick action of steroid

Seizure Outcome in Children after Temporal Lobectomy

Dr. SIN Ngai Chuen
Department of Paediatrics, Prince of Wales Hospital

Temporal lobe epilepsy is an important and common epilepsy syndrome in childhood. Seizure of temporal lobe origin tends to persist. Epilepsy has long been considered a "medical" illness, reflecting the view that surgery should be considered a last resort for patients that had failed any and all non-surgical approaches.

With the realization that the temporal lobe and the amygdalohippocampal complex have a higher susceptibility to seizure induced brain injury and that they are the common sources of medically intractable complex partial seizures (occur in children in approximately 30% of cases) with major adverse impact on patient's intelligence, cognition, behaviour, language and psychosocial morbidity, medical epileptologists nowadays are referring an increasing number of patients for early surgical intervention.

Temporal lobectomy was pioneered by Wilder Penfield and colleagues at the Montreal Neurologic Institute in the 1930s. Although the specifics of a pre-surgical evaluation vary slightly between centres, consistent features are a thorough non-invasive electroencephalographic study in an attempt to localize the origin of seizures, detailed neuro-imaging to identify structural and functional abnormalities that may correspond to the seizure focus, and physiological testing if there is any concern that the involved cortex may serve critical functions. If the site of origin of the seizures or the functional significance of the involved cortex is in question, invasive monitoring is then pursued. Based on the result of the above evaluation, rational therapeutic decisions can then best be made by the epilepsy team, incorporating multidisciplinary expertise and perspectives.

Of 152 patients combined in three reported paediatric series, over 2/3 of patients became seizure free after surgery. Unlike other adult series, gender, side of surgery duration of epilepsy, age at surgery, unilateral MRI abnormality, concordance of inter-ictal and ictal epileptiform discharge and histopathology results did not predict seizure-free outcome in children.

A retrospective study of the long-term outcome of a large cohort of 29 children with medically intractable temporal lobe epilepsy who had standard temporal lobectomy performed at the Hospital for Sick Children, Toronto between 1995 and 1999 showed that pre-operative absence of mental

retardation in children predicted excellent seizure-free outcome (100% positive predictive value for seizure-free outcome $P<0.012$). Cognitive outcomes of our patients showed that almost 1/3 of children improved in both verbal and non-verbal intellectual functioning after either left sided or right sided temporal lobectomy. There was no deterioration in verbal skills for those who had left sided surgery. A prior history of febrile convulsion was associated with mesial temporal sclerosis in our series ($P<0.023$). Dual pathology did not predict seizure outcome in this study.

In view of the poor long-term prognosis of intractable temporal lobe epilepsy in children and favorable seizure and cognitive outcomes after surgery, all children with medically intractable temporal lobe epilepsy should be considered potential candidates for surgery. In appropriately selected patients with temporal lobe epilepsy, surgical "cure" or at least significant improvement of the seizure disorder is a realistic goal.

Epilepsy and Computer

Dr. WU Shun Ping
Department of Paediatrics, Queen Elizabeth Hospital

(Presented at the Annual Scientific Meeting of the Federation of Medical Societies of Hong Kong, 10 June 2001)

Computers are often regarded as a potential trigger of seizures. The computer can be divided into the processor and the computer screen. The screen, which is basically the same as a television screen, is the main culprit.

Computer screens generate images by a cathode beam scanning across the fluorescent screen forming interwoven lines called raster. They refresh at a rate of 50-60 Hz, and the rate is known as flicker rate. Some software, especially computer games, also entail flashing or produce certain repeating patterns on the screen.

Amongst patients with epilepsy, about 5% demonstrate some form of photosensitivity as recorded on electroencephalogram. Photosensitivity has a highest prevalence in teenagers. Considering that about 0.5% of the general population is epileptic, it can estimated that about 1 in 4000 people is susceptible to photic induced seizures. The characteristic flicker rate that provokes EEG changes and clinical fit is 15-18 Hz. The flicker rate of computer screens is too high for most epileptic patients, hence working with computer with programs that do not flash is usually safe.

The advice given to photosensitive patients is to watch the screen in a well-lit room at a distance of 1-2 meters. Smaller screen size and covering one eye are also useful measures. However when working with computers the screens are usually viewed at a short distance. Computer users also tend to spend long hours in front of the computers. Illumination of the workplace is thus very important in reducing the photic intensity.

Video game epilepsy is a condition closely related to computer induced epilepsy. It was first reported in early 1980s. It is believed to be a distinct type of epilepsy. It is most prevalent in teenagers. Photosensitivity was not always demonstrated on EEG. Different patient would fit to different video games. Male patients out-numbered female by 4 to 1. Most of the patients do not have television-induced epilepsy. These patients often have underlying epileptic syndromes, including complex partial epilepsy, juvenile myoclonic epilepsy and juvenile absence epilepsy. It was proposed that

video game epilepsy is a kind of reflex epilepsy in some patients, but for others there might be other non-photic factors like emotional excitement, fatigue, sleep deprivation and intense mental activity that might add up and culminate in a seizure.

For non-photosensitive epileptic patients, a recent study showed that there is no increase in seizure occurrence when they engage in video game compared with other leisurely pursuits.

So far the evidence regarding the safety of computer use in epileptic patient is limited. There has been no definitive recommendation from major epilepsy association and institutes of occupational health warning the hazards of seizures for epileptic patient, photosensitive or otherwise.

In conclusion, computers do not trigger seizures in most patients with epilepsy. Caution should be exercised nonetheless. Sleep deprivation, fatigue and computer software that produces excessive flashing should be avoided.

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Journal Watch

Role of Vision on Early Motor Development: Lessons from the Blind

Prechtl HF, Cioni G, Einspieler C, Bos AF, Ferrari F
Dev Med Child Neurol 2001;43:198-201

For a better understanding of how vision contributes to the development of movement and posture, the effect of early blindness was studied. Video recording of 14 totally blind infants was examined. The infants were selected on two criterias: 1. Severe blindness. 2. No evidence of brain damage.

During preterm and term period, as in sighted infants, the early-blind infants showed normal complex, fluent general movements involving whole body.

The first sign of motor delay occurred at around 2 months postterm with clear delay in head control. Head lift in prone position was poor or absent. Abnormal head lag was noted during pull from supine into sitting position, which continue until 6 to 7 months ' postterm. The infant could not keep its head in the horizontal plane when tilted sidewards, forwards, or backwards from an upright suspended body position, until the end of the first year. This insensitivity suggests a delay in vestibular function due to the lack of visual calibration of the labyrinthine function.

All normally developing infants have a spontaneous "fidgety movements" pattern at postterm age of 9-15 weeks, in which they move their arms and legs with graceful, small movements. In all the blind infants, the "fidgety movements" were exaggerated in amplitude and jerky in character, and their presence lasted longer than in sighted infants, until 8 to 10 months postterm. There was long-lasting ataxic instability during free sitting. These ataxic movement including trunk and head often lasted till 12 to 14 months postterm. With visual projection to the cerebellar vermis and cortex, it could be assumed that a lack of this visual input leads to a delay in cerebellar control of balance and hence leads indirectly to a very prolonged period of postural instability, expressed as ataxia.

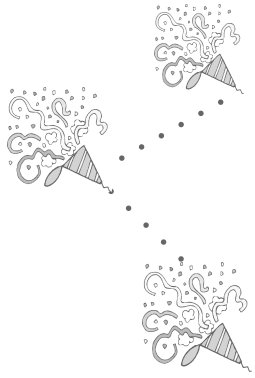
Fine motor manipulation of objects also appeared immature and clumsy. This suggested a delay in the development of proprioceptive system, which lacks integration with vision.

During motor development, vision provides important feedback to the vestibular and proprioceptive systems. Consequently, motor development is impeded in cases of early blindness. Strategies to compensate for the lack of vision-mediated calibration of the vestibular and proprioceptive systems should be emphasized in early therapeutic interventions for blind infants.

(Reviewed by Dr. Sophelia CHAN, Child Assessment Service, Department of health)

News of Society

Welcome New Members



The Council would like to welcome the following new members:

Affiliate Members:

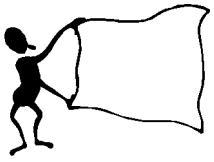
Miss Chan Mee Yin Becky
Miss Cheung Chi Wah Amy

Web Site Update

Our web site www.fmshk.com.hk/hkcndp is being regularly updated. The latest additions include:

(1) Registration forms and call for abstract submissions for the Annual Scientific Meeting 12-15 October 2001.
(2) Information to the public on Neurofibromatosis by Dr. Winnie KL Yam.
(3) Our latest newsletters and Society Publication "Brainchild".

The log-in name for the Members' Area is "member" and the password is "cndp238".



Special Announcement

Hong Kong Society of Child Neurology and Developmental Paediatrics
2001 Annual Scientific Meeting Neuro-Ophthalmology - First Announcement

We are proud to announce our scientific meeting of the year 2001, which will take place on 12-15 October with the theme "Paediatric Neuro-ophthalmology". Our Course Director will be the world famous Professor Peter Savino,

The year's meeting will be held on the evening of 12 October (Friday), the morning and afternoon of 13-14 October (Saturday & Sunday). A Public Keynote Lecture will be delivered, together with a Banquet, on the evening of 15 October (Monday).

As a member of our Society, the meeting is free for you but prior registration is essential. A nominal registration fee of $200 will be charged for non-members. Attached please find the registration form. You may also choose to return the registration form later when further details of the Annual Scientific Meeting are announced.

We would also like to take this opportunity to invite members who would like to participate in the local presentation session to approach Dr. Winnie KL Yam at e-mail address: wklyam@hotmail.com & Dr. KW Tsui at e-mail address: kwingwan-tsui@i-cable.com for further details.

Members are invited to submit abstract for the presentation session for topics on child neurology and developmental paediatrics, not limited to the topic of paediatric neuro-ophthalmology. Attached please find the "Call for Abstract".

The Annual Scientific Meeting is an important occasion for academic and social exchange between medical and allied health professionals in Hong Kong, and the Society counts on your support for our future. Please mark your dairy!

Hong Kong Society of Child Neurology and Developmental Paediatrics

Call for Abstract

A session in our 2001 Annual Scientific Meeting will be allocated for oral & poster presentations. This session is planned with the purpose of providing a platform for academic, clinical and especially front-line workers to share their experience in any of the areas of child neurology, developmental paediatrics and rehabilitation. Physicians and allied health professionals who generally have limited time and support for scientific presentations are strongly encouraged to participate, as this will be conducted among our good friends and co-workers. Our course directors and local experts will be invited as adjudicators. Prizes and souvenirs will be awarded to the winners of the presentations. Abstracts of presentations should be submitted latest by 1 September 2001. Participant will be notified by 15 September 2001 if his/her presentation is accepted.

Notes on submission of abstracts

1. All abstracts must be typed in English, using 10-point size Times New Roman in the format below. Do not indent paragraphs.
2. Authors are encouraged to submit abstracts in electronic format. Abstracts should be saved in MS Words 6.0 or later version in a 3.5" floppy disk. The disk must be labeled with the name, phone number and e-mail address, if any, of the sender, and the MS Word Version used. Authors are reminded to ensure the floppy disk is virus free.
3. The disk should be sent with this form to Dr. KW Tsui at Paediatric Department, North District Hospital, Fanling. Authors may also choose to send the abstract as an attached file by e-mail: kwingwan-tsui@i-cable.com. (Please still fill in the reply form for details and send as an additional word file)
4. Title should be in Block Letters. Type Author(s) name(s) in lower case, underline the presenting author, omitting degree and qualifications.
5. Abstracts should be submitted to Dr. KW Tsui latest by 1 September, 2001. A receipt will be faxed back to the author when the abstract and this form are received. Late submissions will not be considered. Accepted abstracts will only be printed in the Abstract Book if the presenting author has registered by 15 September, 2001.

Abstract Reply Form

Name: _____ Title: _____

Specialty/Allied Health: _____

Address: _____

_____

Phone: _____ Fax: _____ E-mail: _____

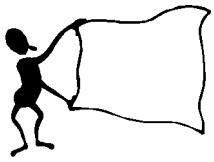
Format of presentation preferred:

Oral
- Overhead projection
- Slide
- Digital/computer presentation

Poster

Either oral or poster

Title
Authors and Institution
Abstract (200 words or less)(on attached sheet or as attached file to e-mail: kwingwan-tsui@i-cable.com)



Activity Announcement

9 August 2001 (Thursday)
Room 6, First Floor, Block E, Queen Elizabeth Hospital, 8 p.m.
Case Management Study Group Meeting. Topic: Movement disorders in Sleep
If you have any patients with strange movements at sleep that you would like to discuss amongst neurologists, please inform Dr. SP Wu at wusp@ha.org.hk or fax 2384 5204 at least one week prior to the meeting so that your case can be brought up for discussion.

14 September 2001 (Friday)
Lecture Theatre, M Block, Ground Floor, Queen Elizabeth Hospital, 8 p.m.
Bimonthly Scientific Meeting. Topic to be announced

12-15 October 2001 (Friday-Monday)
Queen Eizabeth Hospital
Annual Scientific Meeting on Neuro-ophthalmology

20-25 September, 2002, China
Joint Congress: The 9th International Child Neurology Congress & The 7th Asian and Oceanian Congress of Child Neurology
The joint congress will be the first to be held in China and probably the one closest to home. Congress will run from 20-25 September 2002. The first announcement is already out. Members who are interested in submitting entries please visit the web site: http://www.ciccst.org.cn/icnc2002

Response to the Equal Opportunity Commission

On the Code of Practice on Education under the Disability Discrimination Ordinance

March 2001

The following is the response submitted by the Council to the consultation of the Equal Opportunity Commission on the Code of Practice on Education under the Disability Discrimination Ordinance. The full text can be downloaded from our web site at www.fmshk.com.hk/hkcndp.

The Hong Kong Society of Child Neurology & Developmental Paediatrics

The Hong Kong Society of Child Neurology & Developmental Paediatrics comprises of a body of professional persons dedicated to the promotion of standards and practice in the fields of child neurology and child development, and to promoting welfare of children under their disciplines' purview. The Society welcomes the preparation of this Code to provide guidelines to the public and educational establishments in interpreting the Disability Discrimination Ordinance (DDO) 1995. As children's advocates, the Society would like to provide its professional views to the Commission with the hope that welfare of children with disabilities and special education needs may be further promoted.

Response to the Document

(Proposals for this Commission's action are printed in bold and italics)

(Section 4.1)

Definition of Disability in different sectors vary. We feel that this will unavoidably lead to confusion and altercation, especially since a number of professional bodies are involved in determining the presence of a disabilities within children, which in turn would entitle them to various protections through this Ordinance. *The Society proposes that the meaning of "Disability" here, versus its meanings in other related Acts, and in various administrative and professional uses, be further elaborated. This Ordinance's meaning of "disability" should be understood in contrast to WHO definitions and concepts which are used in Hong Kong's White Paper for Rehabilitation: "impairment" or body structure and functions which refer to body structural and functional impairments, "disability" or activity limitation which refer to limitations of an individual's activities because of his bodily impairments, and "handicap" or participation limitation which refer to limitation in societal participation because of an individual's disability (refer WHO definitions of impairment/disability/handicap, and WHO ICIDH-2 definitions of body structure & function limitation/ activity limitation/participation limitation). We feel that for the purpose of this Code, "disability" should be interpreted as "participation limitation": meaning that the child's disability directly and adversely affects educational performance and thus requires special educational services. We are convinced that deviations in interpretation by different key players will guarantee future dispute, when statements documenting a child's disability are contested amongst professionals, the school and his parents. Unification of Chinese translation of such terms is also required for Hong Kong.*

(Section 4.1.2)
"Specific Learning Disabilities (SLD)" is preferred to "Learning Disabilities". The latter is still often used with various meanings, especially in United Kingdom related practices where it may refer to learning difficulties resulting from any condition, including all degrees of mental retardation. Both the United States Office of Special Education and Rehabilitation Services (OSERS) and the United Kingdom Department for Education and Employment (DfEE) include "specific" in their use of the term when referring to the specific language based learning disabilities which include dyslexia, differentiating it from others in their list of disabilities which require special education attention. Currently, "specific" is included by Hong Kong's medical, educational and academic bodies in their professional and operational communications.

(Section 4.4)
Equal opportunity for education for disabled children DOES NOT merely mean access to and through the school door and to the same education process that non-disabled children receive. Low expectations for children within special education and an insufficient focus on applying research proven methods of teaching for children with different disabilities have made equal opportunity for them to access the general curriculum to the maximum extent possible an unrealizable goal in Hong Kong.

Equal opportunity to access education for a disabled child means that this child is entitled to an education in the least restrictive environment within a continuum of programmes, that is individually designed to meet his unique needs, and from which he receives educational benefit.

We feel this point cannot be overemphasized and should be clearly stated in the Code. Clear examples of children with non-visible disabilities should be quoted here to enable education establishments to understand the nature of these cases. This particularly impacts on children who are today taught in mainstream schools but not given the necessary special educational support.

A note is made here regarding specific learning disabilities (SLD) for the Commission's reference in relation to this Section:

Recent figures form the United States OSERS shows that of the over 5 million children receiving special education services under their Individuals with Disabilities Education Act (IDEA), the largest group, about 2.5 million children, have specific learning disabilities including dyslexia. United Kingdom DfEE reviews show that children with SLD are on their schools' registers for special education, although many may not have a "Statement". Given widely researched and comparable incidences of SLD in these countries, this group of children constitutes a very significant portion of those who are eligible for special education and to protection under DDO. Preliminary research and clinical data show that a similar epidemiological situation is present in Hong Kong. With the rapidly growing awareness in Hong Kong of these conditions and of their potentially devastating effects on children's education, increasing demand will arise for equal opportunity to access educational curriculum in mainstream schools through specific programmes which address the needs of children with disabilities. Increasing dispute will be inevitable between parents and schools until the latter is made aware of and are equipped to manage these conditions).

(Section 5)
While parents should not be "encouraged" to seek litigation at times of dispute with educational establishments, it is precisely this right that the DDO is here to serve. Parents should be given guidelines regarding which parameters in the educational experience of their disabled children are critical features

under the jurisdiction of this Ordinance and Code. Parental misinterpretation of the Code, poor preparation when seeking help after feeling discrimination, unrealistic expectations, etc. are all preventable.

We propose that the Commission add a section under "Implication of the DDO in Education" to guide parents on how they should act when there is dispute between them and the schools. The guidelines should include the critical items a parent should expect from educational establishments: (1) direct access, (2) acknowledgement of valid evaluation "statements" of the child's disabilities and special needs, and (3) presence of a corresponding and effective special education programme designed to meet the special needs of his child. We feel that the list of responsibilities for parents and students in Section 21.4 does not at all suffice in addressing these important aspects.

(Sections 6.1.1, 6.1.3.3.1, 13.4.1)
Admission to mainstream schools for children with non-visible disabilities are particularly vulnerable to abuse. School administrators must have the professional skills to understand a disabled child's strengths, weakness and needs. Admission based on past achievement records and admission achievement tests are currently the most common methods of selection. Low achievement results are most often interpreted by schools as demonstrating abilities below that reasonably required by their educational establishment. (6.1.3.3.1 and 13.4.1 liable to be interpreted in this fashion). Achievement tests, in reality, do not address the children's underlying causes for poor performance, and bar them from accessing further effective education.

1. *Clear codes of practice at admission selection should include statements (with examples) which disallow admission refusal solely on the basis of "poor academic achievement". Professional knowledge in childhood disabilities by school personnel involved in the admission process is required to allow understanding of these children's conditions and needs. Furthermore, unjustifiable hardship cannot be claimed on the basis of teacher resources, be it in professional readiness or manpower, if (1) teachers' professional competence should be reasonably expected from an educational establishment qualified to operate in Hong Kong, and (2) the Government will provide, as expected, the resource support to schools to cater for diverse learning needs.*

2. *The Education Department should be responsible for helping parents at transition points - moving house and school district, transition from kindergarten to primary or from primary to secondary schools - to identify schools most likely to benefit their disabled children's educational needs. The current practice of providing parents with a full list of schools in the district and asking them to try their own luck adds to these children's barriers to equal opportunity for effective education.*

   Today, the Hong Kong Education Department together with a number of professional and lay bodies are advocating for early pervasive inclusive education. Should limitation of resources or teachers' preparation be accepted in the meantime by these bodies as causes for inadequate educational services for disabled children within mainstream schools, they can only be held answerable for misguided and irresponsible judgement.

(Section 11.4)
All educational establishments, including primary, secondary and tertiary institutions, should have policies related to disability discrimination.

It is proposed that a generic version of school policy on disability discrimination for use by all schools be drafted by the Commission as an appendix to this Document, while large establishments may draft their own policies which expand upon but not contradict principles laid down in this guideline.

(Section 13.5)
Educational establishments which interact with applicants with special needs should be equipped with the professional skills to understand their needs as well as any evaluation documents on their disabilities that parents may bring along to the school. Often times, school personnel who fail to fully understand the contents of reports may arrive at erroneous or biased conclusions. Today, local professionals and even authorities have often advised parents, in good will, to withhold showing such documents at admissions application.

Demonstration of a recognized evaluation documents testifying to a child's disability and special education needs should be welcomed and not become a barrier to admission. It is the hoped that all children in future will be identified early, whereupon finding and recommendations are documented before they approach schools for admission. Parents should be able to feel assured in this process and not endeavour to hide information on their children's special needs. This point should be highlighted here, if the Code is to truly exert its effect. It should be made understood that blatant direct discrimination is in place when a child is denied access after the school's viewing of a disabled child's evaluation reports.

(Section 14.4)
Tailoring of curriculum to meet specific needs of children with disabilities often call for professional skills that are beyond those of a regular class teacher. Special needs support teachers are not available in every school, and they reasonably in turn too, are often limited in skills and knowledge base for designing and implementing such programmes. This problem is further exacerbated when the range of diversity of children's special needs rise with the increasing trend of inclusive education in Hong Kong. The Education Department's Special Education Support Services as well as its Curriculum Development Institute should be responsible to develop tools in consultation with research based methods which are effective for specific disabilities. The Department should also be responsible for guiding and propagating the use of such tools in schools for these children.

In Section 21.1.2.3, the responsibility for developing different specific tools for accommodating and teaching children with different disabilities must primarily rest on the Government. This is distinct from "development of curricula of different subjects with regard to the needs of students with disabilities". Children with different disabilities require not only access to core educational content through the above measures, but specific remediation and training programmes designed for their areas of deficit. The latter are tasks which require support from special education expertise.

(Section 21.1)
While commendable efforts have been made by the Commission to solicit views from stake holders during the past year, the Society noted that there still remains a significant lack of awareness today, by the public and key players alike, of this Ordinance and Code, and more importantly, of the critical principles that should underlie this law and code. *The Society feels that every effort should be made by the Government, in collaboration with professional and advocacy groups, to promote and explain these documents and principles to parents, relevant professionals and administrators as well as the public, not just at the Code's launching but on a perennial basis.*

(Section 21.1.4.4)
No amount of appeal to education establishments will work until an accountability system is in place. One source of monitoring will come from parents as awareness of rights and readiness to call schools to task is increased. Alternately, government dedication to monitoring and supporting education establishments in their implementation of recommended practices is a more positive approach. *The Code should call for routine review by school inspectors for school compliance with the Code, and for difficulties encountered and support needed in implementing it.*

(Section 21.3)
Teachers' Training Institutions have the responsibility to provide adequate instruction on special education issues: the nature of the various disabilities, their respective special needs and teaching programmes, related administrative, policy and advocacy issues etc. Grossly inadequate emphasis in Special Education in today's teachers' training curriculum is noted, resulting in teacher graduates who may be insufficiently prepared to bear the responsibilities that this Code imposes on them. In-service training for both regular and special education teachers are also required to strengthen their knowledge and skills after they come into contact with these children in school.

The Government, in its funding role for tertiary institution programme development to meet society needs, has the duty to ensure that good quality special education pedagogy is given due emphasis. Without this, effective special education support in regular schools will become mere lip service.

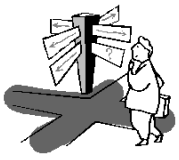
(Section 1.3)
A committed schedule for revision of this Code should be made in light of experience and public understanding. These revision efforts should draw upon the participation of professional bodies involved and knowledgeable in the field.

A statement in this direction would be reassuring to all parties in that this Code, after trial, would be further improved upon to suit the needs of Hong Kong.

Additional Comments

1. In order that there is professional alignment in definitions, evaluation procedures and diagnostic criteria which document children's disabilities, the Commission should request the Government to call for a collaborated effort by key professional bodies to draft commonly agreed protocols for assessing and measuring the severity of individual disabling conditions. This would minimize arguments and confusion which are observed today regarding "eligibility" of a child with a disability who is referred for special services after evaluation.

2. As evaluation and special programme recommendations require professional skills subsumed under specialized disciplines, it is suggested that the Commission call for the Government to consider designating institutions/professional disciplines which it deems suitable and eligible for making the diagnosis of certain disabling conditions to take up this role. These are particularly important for those conditions where direct measurement of biological functions such as visual or hearing levels are available, or where conventionally accepted parameters such as the intelligence quotients are in place. Only by doing so will practice be truly aligned and quality controlled, and the spirit of equality in the Law and Code be realized.



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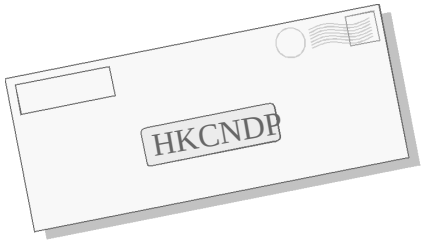

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