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## Seminar on Advocacy Issues in Regional Areas: Hong Kong Experience

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### Introduction

With advancement in our understanding of the neurobiological bases, clinical features and evidence-supported interventions for Developmental Dyslexia, it is imperative that services for and interests in affected individuals are informed accordingly. Rights are embodied under the United Nations Charter for Children's Rights and the Disabilities Discrimination Ordinance (DDO) in Hong Kong since 1995. In order to achieve these, we need to have alignment of definitions among professionals, accurate identification and diagnosis through validated screening and assessment tools and the work of integrated multidisciplinary teams, as well as accountable management plans. In line with these, there must be parents who understand their children's condition and needs, school teachers who have appropriate preparation and ongoing in-service training, enlightened education administrators, as well as widespread public awareness and acceptance of the disabilities. Adverse complications associated with undiagnosed or improperly managed children with Dyslexia include school failure and drop out, eroded self esteem, juvenile delinquency, substance abuse, and a future life of unemployment and underachievement. Effective legislation and government policies, plus close partnerships among professionals, stakeholders and the public are foundations for success.

### Evolution

Specific Learning Disabilities (SLD) are problems that have intrigued professionals throughout the years. There are people who believe that SLD only involves problems with reading, while there are those who understand Dyslexia

merely as a writing problem with mirror inversion of alphabets. Furthermore, many feel that SLD, although a major and documented problem in Caucasians, may not exist in the Chinese population due to cultural and language differences. Yet numerous Hong Kong children and parents suffer daily as a result of this condition with limited recognition and support.

In 1996, the Hong Kong Society of Child Neurology and Developmental Paediatrics (HKCNDP) hosted a meeting on SLD at Queen Elizabeth Hospital with speakers from the medical, psychological and special education sectors. The meeting was well attended by professionals who were convinced of the presence of such problems in our community and agreed that something had to be done. The past seven years saw an increase in awareness in the topic in Hong Kong as evidenced by the long list of visiting guests invited by the various organisations to address the subject, and by the growth of a variety of therapies offered for treating the condition, including prism lens, coloured-glasses, auditory stimulation, sensory integration and so on. Each claims that his/her method is superior to the others and local parents often suffer both loss of time and money in the hope of finding panaceas for their children's problems. While such therapies have public appeal, many cannot be supported by empirical evidence or theoretical soundness. The lack of unified definitions, local data and cooperation between professionals on management further adds to the confusion.

Sporadically, some activities on the subject have already been started locally. A Subspecialty Group on SLD was set up under the Child Assessment Service (CAS) of the Department of Health, Hong Kong Government to study the problem within their service. A Working Group was formed between the Special Education Section of the Education Department and CAS in an attempt to arrive at professional consensus and congruent management practices for children with SLD in Hong Kong. Parent groups such as the Hong Kong Association for SLD (HKASLD) were established as self-help organisations with

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**President, The Hong Kong Society of Child Neurology and Developmental Paediatrics, Hong Kong, China**

CW CHAN

support from various individual professionals, while charitable organisations such as the Pathways Foundation have pioneered services for children with SLD which may eventually become prototypes for application at mainstream schools. However, despite the efforts of these groups and parties, advancement on this issue remains very limited.

### **Workshop on "SLD: Setting the Scene in Hong Kong"**

In November 1998, the Hong Kong Society of Child Neurology and Developmental Paediatrics successfully hosted another meeting on the subject "*SLD: Setting the Scene in Hong Kong*" whereby speakers from developmental paediatrics and education psychology reviewed the current situation in Hong Kong, addressed the subject conceptually and conveyed the message clearly and forcefully that something needed to be done without delay. After careful and earnest discussions at the meeting, professionals from over ten disciplines working in this field agreed unanimously on the following:

1. That SLD does exist in Chinese people using the Chinese language;
2. That SLD comprises a heterogeneous group of conditions and that unified definitions are mandatory for meaningful study and management;
3. That education rights of children with SLD (as stated by the WHO Declaration of Children's Rights) have to be addressed and respected;
4. That a multi-disciplinary working party should be established to tackle the problems in a comprehensive manner; and
5. That in view of the urgency of the problem in Hong Kong, the approach to this problem should sequentially include immediate measures, long term objectives and the setting up of policies for future practice.

### **Workshop on "SLD 1999: The Way Ahead"**

The workshop on "*Specific Learning Disabilities 1999: The Way Ahead*" is a continuation on the previous activities. It consisted of a one-day workshop hosted at the Queen Elizabeth Hospital on 2nd March 1999. Two world experts on the subject, Dr. Drake Duane (neurologist) and Professor Leong Che Kan (psychologist-cum-special educator) were invited to address the audience at the Plenary Session on "*Overview of the State of Practice and Research in SLD*". These successfully set the scene on the subject and the

audience was deeply impressed by the speakers' vast experience and the latest development on SLD at the international arena. This was followed by Seminar I on "*SLD: Local Experience in Hong Kong*" with papers presented by local clinicians and Seminar II on "*SLD: Current Practice in Hong Kong*" where speakers including a neurologist, a developmental paediatrician, a psychologist and educator, an administrator, a legislator and a parent addressed the problem from their respective perspectives. The highlight of the workshop was a Panel Discussion Session on "*SLD: The Way Ahead*" hosted by speakers from Seminar II together with Dr. Drake Duane, our international expert. During the open forum the following areas were discussed:

1. Understanding of SLD from individual profession's perspectives;
2. Current practice on SLD within their specialties;
3. Measures urgently required to tackle the problems in Hong Kong; and
4. Proposals for short and long term plans to solve the problems.

Through these exchanges and constructive debates, the Panel was able to arrive at preliminary recommendations and practical consensus. Professionals present agreed that joining efforts are mandatory. A document "*Resolutions from the Workshop*" was adopted at the end of the meeting by all professionals present. This will henceforth become a basic reference for all professionals dealing with SLD in Hong Kong. In order to keep the day's important information and discussions on permanent record, the Council of the Hong Kong Society of Child Neurology and Developmental Paediatrics resolved to publish proceedings of the workshop to commemorate this important occasion and for future reference.

### **Evaluation of Existing Problems Facing SLD in Hong Kong**

Despite the terms *Specific Learning Disabilities (SLD)* and *Dyslexia* having been known to Hong Kong for over three decades, they remain a mystery to most professionals in the region, seeing this as a problem of letter mirror-reversal. Over the past eight years, through the enthusiastic efforts of the Hong Kong Society of Child Neurology and Developmental Paediatrics, a series of academic activities on the subject were organised through which professional attention was attracted to the topic. These resulted in significant local progress in the understanding of the

problem: *that SLD and Dyslexia do exist in Hong Kong in Chinese people using the Chinese language, and that serious and responsible attitudes as well as a multidisciplinary approach are essential for tackling the condition.* In view of the urgency of the matter in Hong Kong, the approach to a solution should sequentially include the following areas:

1. Taking stock of current situation and needs for early action;
2. Immediate measures for current problems;
3. Long term measures including policies and legislation; and
4. Government and community input of manpower and resources.

### **1. Current Situation and Needs for Early Attention**

- 1.1 *Low awareness of condition* in Hong Kong's medical, allied health and education communities;
- 1.2 *Non-uniformity of definitions*;
- 1.3 *Inadequacy of local data*: incidence, characteristics of conditions, etc.;
- 1.4 *Limited communication* between involved professional groups;
- 1.5 *A likely significant number of children with undetected learning disabilities* in the community; and
- 1.6 *Inadequacy of local research-supported practice tools and intervention guidelines.*

### **2. Immediate Measures for Current Problems**

- 2.1 To establish a theoretically sound set of terms and classification for SLD, which is acceptable across professions in Hong Kong, input from medical neuroscience, psychology, education, psycholinguistics and other specialties are essential in this process.
- 2.2 To understand the current state of the condition and practice through:
  - 2.2.1 *Compiling existing local data* on the incidence and nature of SLD for local children;
  - 2.2.2 *Sharing information on current professional practice* used in detection, investigation, evaluation, educational and medical managements, etc.; and
  - 2.2.3 *Gathering information on current operational structures*, both within individual professionals and departments and between them.
- 2.3 To identify urgently needed measures and tools to identify, evaluate and help children with SLD through the following actions:
  - 2.3.1 *Study of current systems* whereby children with SLD are brought to professional attention;

- 2.3.2 *Identification of key areas for improvement* for currently available methods of evaluation and diagnosis;
- 2.3.3 *Identification of areas where timely, early management* (treatment, education, remediation etc.) *are critically needed*, and how these can be improved in the short term; and
- 2.3.4 *Identification of essential points where cooperation is urgently needed* between professionals and service departments.

### **3. Areas for Long Term Future Planning**

- 3.1 Professional Aspects:
  - 3.1.1 Planning of systematic collection of *local epidemiological data*;
  - 3.1.2 Determination of *research directions for assessment tools*;
  - 3.1.3 Establishment of *protocols* for intervention, and for measuring progress and intervention effectiveness;
  - 3.1.4 Establishment of long term structured *definitive channels for professional communication*; and
  - 3.1.5 Identification of *training needs for professionals* in respective fields, and review of local institutions' role in such training.
- 3.2 For children with SLD and their families:
  - 3.2.1 *Promotion of public awareness*, correct concepts and acceptance;
  - 3.2.2 *Promotion of peer support groups* for psychosocial support, sharing of information and advocacy; and
  - 3.2.3 Through professional support, *promotion of parental skills* in dealing with their children's specific needs.
- 3.3 Policies and Legislations
  - 3.3.1 *Review of administrative guidelines for diagnosing SLD* and children's access to special help;
  - 3.3.2 *Review of current structures* within the education and medical system, which provide remediation and support;
  - 3.3.3 *Review of sources, diagnostics parameters and logistics* through which official data on SLD are compiled;
  - 3.3.4 Taking up of an *active role in helping government to formulate effective and fair public policy and legislation* in relation to these children's right for appropriate educational and therapeutic support.

#### **4. Government and Community Input of Resources**

Proper recognition of the problem together with appropriate and timely input of manpower, resources and blessing from the government, non-governmental organizations (NGO), and academic institutions is mandatory and essential for the ultimate success of all aforementioned objectives. Details of the input will be worked out in the course of time.

#### **The HKCNDP Working Party on SLD**

The Working Party was established by the Council of the Hong Kong Society of Child Neurology and Developmental Paediatrics at the November 1998 Council Meeting with the following terms of reference:

1. To set the scene in SLD for Hong Kong;
2. To obtain unified definitions amongst professionals in Hong Kong;
3. To study local incidence and relevant statistics;
4. To promote communication between local professionals;
5. To share experience with overseas experts; and
6. To establish strategic plans for tackling the problem in Hong Kong.

#### **Recent Achievements by HKCNDP for SLD in Hong Kong**

##### **1. Interaction with Public Authorities and Education Field**

Over the years, The Hong Kong Society of Child Neurology and Developmental Paediatrics has been very active on scientific and professional affairs related to SLD. In collaboration with The Hong Kong Association for SLD (HKASLD), we hosted a Special Workshop for Teachers at the Hong Kong City Hall on 12th May 2002 to provide basic information, concepts and clinical features on SLD for frontline workers at school. We participated at a joint meeting with the Equal Opportunity Commission of Hong Kong on 22nd June 2002 at the Hong Kong Convention and Exhibition Centre on education rights of children with SLD. We also proactively met with the Hong Kong Examination and Assessment Authority on 29th July 2002 to advocate a formal system for accommodations for children with SLD at public examinations, and with principal officers of the Special Education Service of the Education and Manpower Bureau (EMB) of the Hong Kong

SAR Government on 7th October 2002 on service provisions in school for SLD. All meetings yielded constructive results and we are pleased to witness fruitful actions as a consequence.

On 19th October 2002, the Society was invited by Mrs. Fanny Law (Permanent Secretary of EMB) together with Dr. Margaret Chan (then Director of Health), local experts on SLD, and senior officials from Special Education Service of EMB to provide views on the nature and needs of Hong Kong's students. We are pleased to witness two major projects as a spin-off from the meeting: a "Course on Children with Special Educational Needs (SEN)" to cover primary and secondary school representatives, and a "Position Paper on A Service Model for Children with SLD in Hong Kong". The SEN Course was subsequently organised by our Society and commissioned by EMB. It was delivered through the contribution of over 50 academics and professionals in related fields and lasted over a period of five months (from February to June 2003), including interruption by the Severe Acute Respiratory Syndrome (SARS) endemic. The Course was attended by over 2,000 school principals and teachers from primary and secondary schools with lectures and practicum which promulgated clear messages to promote understanding on principles and management of SEN children in mainstream schools. At the same time, we are pleased to report that, with enthusiastic participation of scholars and disciplines from different sectors, the Position Paper is now ready and has been submitted to the HKSAR Government for consideration of the policy-makers.

##### **2. Academic and Professional Activities**

The Society is proud to have successfully hosted *the 2002 International Conference on Dyslexia in Children Using the Chinese Language* on 26th-28th October 2002 in Hong Kong with a focus on Functional MRI (fMRI) and Advocacy Issues. We are pleased to witness eight keynote experts from the United States, Singapore, Taiwan and the Mainland of China, as well as 20 local speakers gathering in Hong Kong for academic and professional exchange. The comprehensive programme attracted participation from more than 400 attendants covering a large range of professionals including medical, nursing, teachers, educational and clinical psychologists, speech, hearing and language pathologists, social workers, administrators, policy-makers, legislators, parents and others. We were honoured to have Miss Anna Wu, Chairperson for the Equal Opportunity Commission of Hong Kong, address the audience at the Opening Ceremony on rights of children

with SLD in Hong Kong. The Conference set a platform and milestone for exchange of experience, sharing of knowledge, collaborating of research and future professional cooperation.

At the service level, we are pleased to have developed a CD-ROM on "A Phonetic Approach to Reading English for Cantonese Speaking Children", edited by Dr. Catherine Lam, and are encouraged to witness its being well received by professionals and parents.

### **Role of Paediatricians in the Management of Dyslexia**

With Dyslexia being a multidisciplinary problem, it often falls upon the paediatrician the task of identifying developmental problems. He/she should also be a member of a medical/educational team for diagnosis, ascertainment of medical causes, severity of deficit, strengths and weaknesses, and formulation of individual educational remediation programmes. While remediation, accommodations and Individualized Educational Plans (IEPs) are provisions expected from educational specialists, school principals and teachers, the paediatrician should be proactive in providing advice where appropriate and through surveillance of implementation processes. The paediatrician should also endeavour to coordinate activities amongst professionals from multiple fields working on Dyslexia, and to establish agreed definitions and promote research. Most important of all, the paediatrician has the intrinsic duty, as *Child Advocate*, to safeguard the welfare and rights of children with this disability.

As a Child Advocate for Dyslexia, the paediatrician should be fully aware of problems: low awareness, lack of coordination amongst professionals, plethora of unsubstantiated interventions, and fear of stigmata and labeling. He/she should attempt to initiate effective solutions to these problems. Special focus should be placed upon professional preparations, strategic measures needed to arouse public awareness and initiate legislation and government policies, introduction of local screening and assessment tools, and promotion of effective educational support at schools and public examinations. In essence, the paediatrician should work as a *professional advisor*, *coordinator*, *advocate* and *close friend* of individuals with Dyslexia, inherent duties of a paediatrician in all child health problems.

### **Conclusion**

A Child Advocate is one who pleads or raises his/her voice in favour of, to defend or recommend publicly, to stand beside, to promote actions and to effect changes for the benefit of children.

To deal with the challenge of Dyslexia, the first step must be to see it, to recognise it and to understand it. Dyslexia is not a developmental lag that children will grow out of. It is an inherent biological difference causing a disorder of function, despite normal and adequate opportunities, resulting in a disabling situation especially in education. The disorder must be assessed and carefully diagnosed by professionals in the field. A course of action can only be formulated on the basis of knowledge.

To view Dyslexia, especially mild cases, as a maturational lag, lack of discipline or motivation on the part of learners, would be deceiving the public and denying these children the opportunity of help. Support for children with Dyslexia is not a matter of discretion. Today in Hong Kong, it is a matter of the child's rights.

Advocacy is to effect change. Change requires social commitment from the community and policy and financial commitments from government. Change is necessary not only because it is the decent thing to do, it is a legal obligation.

Of all levels of human rights, the most basic are rights to life and to survival. An extension of these is the right to individual development through education in a civilised society. Development of the individual is an investment in human capital. It leads to self sufficiency and productive citizens, in turn reducing social and economic burdens.

In Hong Kong, we have already aroused public interest. We need coordinated scientific activities, collaborated research and agreed definitions for Dyslexia amongst professionals. We concur with the trial use of new screening and assessment tools. We attempt to mobilise local resources, lobby legislators and government policy-makers, provide in-service and pre-service teachers with professional support, substantiate parental work, and work in coordination with NGO for the welfare and interests of children with Dyslexia. Given the range of information and services that can address the full scope of their needs and to promote their strengths, talents and potentials, every individual with Dyslexia should have the opportunity to lead a productive and fulfilling life, from which society will ultimately benefit.