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Special Tenth Anniversary Issue on Specific Learning Disabilities



Ice-cream Party

Drawing by
a 7 years-old girl with Dyslexia

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





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SPECIAL TENTH ANNIVERSARY ISSUE ON SPECIFIC LEARNING DISABILITIES

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The Hong Kong Society of Child Neurology & Developmental Paediatrics

BRAINCHILD – NOVEMBER 2004 (TENTH ANNIVERSARY ISSUE)

Message from the President

This year is the Tenth Anniversary of our Society. The Council is planning a series of celebration programmes to commemorate this important milestone including publication of an *Anniversary Monograph*, hosting of the *Anniversary Scientific Conference* in conjunction with the Society's 2004 Annual Scientific Meeting on Rehabilitation, convening a special *Workshop on the Subspecialty Evolution of Developmental Paediatrics* with panel speakers from neighbouring regions, organization of the *Keynote Delivery cum Anniversary Banquet evening event*, and the launching of HKCNDP *souvenirs for members*: an elegant set of silk ties and scarves. We are pleased to witness the current issue of Brainchild (the Anniversary Edition) being devoted to Special Learning Disabilities (SLD) with special focus on Developmental Dyslexia which account for 80% of SLD in the community. This, being an important subject within the subspecialties of Child Neurology (CN) and Developmental Paediatrics (DP), is one of the prominent areas where our Society has achieved outstanding results and put our name onto the map for Dyslexia internationally by virtue of our active promotion for professional cooperation and collaboration in the Chinese language speaking regions.

Dr Catherine CC Lam, our Guest Editor for this Anniversary Issue, is to be commended for the comprehensive coverage of papers collected in the current publication. The papers on "Developmental Dyslexia: A Complex Syndrome that can be understood" and "All Our Children" by Professor Albert Galaburda, Professor of Neurology from Harvard Medical School and Professor Leong Che Kan Emeritus Professor from the Dept. of Ed. Psychology & Sp. Ed., University of Saskatchewan, Canada are masterpieces from world experts on the subject. Excellent connotations from both scholars set the scene for the issue followed by outstanding papers on "Services for Hong Kong's Children with Developmental Dyslexia" (Dr Catherine Lam), "Dyslexia: Some Local Clinical Experience" (Ms Becky Chan, Kelly Lau and Lucia Tsang), "Identification study on students with Specific Learning Difficulties (SpLD) in Schools for Social Development of the Society of Boys' Centres (Ms May Chan), "Towards building an educational and assessment accommodation home-school support model for children with dyslexia and their families: Interim Report" (Dr Sandra Tsang et al), and "Advocacy Issues in Dyslexia in Hong Kong" (Dr CW Chan) illustrate how multidisciplinary, transdisciplinary and interdisciplinary teams can coordinate and work together effectively for our children with these life-long constitutional disabilities and how remediation, compensation, accommodation and resources support at school, in the family and within the community can help individuals with dyslexia to adapt to learning, socialization and career fulfillment during adulthood.

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 of 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 wide spread 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 between professionals, stakeholders and the public are foundations for success.

Over the years we have successfully convinced professional in Hong Kong about magnitude of the problems for dyslexia. We are very encouraged to witness the Department of Health (DH) and the Education and Manpower Bureau (EMB) of the Hong Kong SAR Government have taken up enlightened attitude towards our children with dyslexia and are also impressed by their willingness to devote resources for this good cause. We are especially pleased to be told that communications are also currently provided for these children at high stake open examinations by the Hong Kong Examination and Assessment Authority (HKEAA). However in order to expedite good results for good accommodation we need to have effective, efficient and quality screening and assessment services as well formative accommodation data at school. At present the bottle-neck seems to occur at the levels of assessments and accommodation at school with good Individualized Educational Programmes (IEP). We should endeavour to find means to tackle these hurdles. The former might be partially solved by collateral quality assessment services proved by Non-governmental Organizations at cost affordable by parents and the latter by re-arrangement of school setups with small class teaching and resource support under the supervision of experienced educational psychologists. With the joint efforts of trans-sectoral and transdisciplinary professionals, the future for our children with dyslexia should be promising and we should be able to provide an optimal environment for them to learn and to adapt into adulthood.

I wish you all reading pleasure and best of health!



Dr Chok-wan CHAN

Editor-in-Chief, *Brainchild*

President, The HK Society of Child Neurology & Developmental Paediatrics

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All Our Children

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Editor of *Annals of Dyslexia*

It is an honor to be asked by the editor of this special issue of Brainchild to help celebrate the tenth anniversary of the HK Society of Child Neurology and Developmental Paediatrics (HKCNDP) by writing a short piece. It is with some trepidation that I do so as a psychologist-cum-educator with experience as a clinician and a long-time research interest in developmental dyslexia and processes of reading and spelling.

Ten years mark a milestone in the growth and development of a professional organization and call for celebration and reflection. I would like to offer my very sincere congratulation to HKCNDP, its President, Council and members for the many faceted achievements in the professional field, in public awareness and education. In the last six years or so I have been privileged to take part in, and contribute to, seminars, workshops and a large-scale international conference on dyslexia held in Hong Kong under the auspices of HKCNDP. Health professionals, educators and parents all benefit by these activities. In this congratulatory note I confine my thoughts to some issues on children's learning and their development with particular reference to Hong Kong.

Pre-School Children

The beginning of another decade is Janus-like; it offers the opportunity to look back and look forward. A good starting point in looking back is the systematic and detailed study of a Hong Kong developmental screening system for pre-school children by Baber, Chan, and Hutchison (1982). This study is significant, particularly in the context of the late 1970s and the early 1980s, in providing indicators for the developmental assessment of Chinese children during the pre-, peri- and post-natal periods, incorporating familial factors, vision, hearing, motor, language and social skills. The authors quite rightly point out that the screening system should help all those "interested in the health and welfare of Chinese children", not only in Hong Kong but also in other parts of the world (Baber et al, 1982, p.v.).

It is laudatory to note that this pioneering work in screening and assessing Hong Kong children, particularly those at-risk for developmental disorders, has been followed up over the years with refined instrumentation by the Family Health Service and the Child Assessment Service of the Department of Health (CCC Lam, personal communication, September, 2004). A systematic screening over time should provide cumulative records of the developmental trajectory of children at-risk for subtle speech and language impairment and subsequent reading and spelling disorders, in addition to those with visible disabilities. These screening records of developmental milestones, gross and fine motor skills, cognitive, speech and language factors should help in early diagnosis, remediation and intervention of children at risk for various kinds of developmental disorders.

This kind of systematic early screening of children finds a parallel, albeit with greater theoretical and methodological sophistication, in the early development indicator (EDI) designed in Canada as a survey tool for assessing readiness for school by kindergarten teachers in these areas: social, emotional and physical health and well-being, communicative skills, cognition and language (Hertzman & Power, 2003). Hertzman and Power emphasize the significance of early life and its impact on learning in school years and on health in adulthood. According to these authors the keynotes are: latency (the earlier the better); gradients of

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development as early signs of the brain's plasticity; cumulative effects of advantages and disadvantages over time in terms of exposure to risk factors; and pathways as intervention at strategic points such as transition from kindergarten to primary, secondary, tertiary education and the world of work.

Longitudinal Prospective Studies of Young Children

In the above context of early health and welfare of children we may want to note similar development in my adopted country Canada and elsewhere. The very comprehensive Canadian national long-term study of development and health known as National Longitudinal Survey of Children and Youth (NLSCY), begun in the mid-1990s with a random sample of 22,000 children aged 0-11 and continuing every other year with newborns at each cycle, has yielded significant data to guide policy makers, health and education professionals. According to one of the lead researchers, who has helped to design the longitudinal study and analyze its results, the data of NLSCY show that environment makes a difference and these differences translate into developmental inequalities with deleterious consequences (Hertzman, 2000, May, 2004). Hertzman, a professor of health care and epidemiology, is emphatic that there should be universal access to opportunities for development, care and learning of children and the focus should be on children's environment, rather than a one-on-one service.

Directly in my research area of developmental dyslexia, the ongoing Jyvaskyla Longitudinal Study of Dyslexia documents the development of a group of 107 children at risk for familial dyslexia compared with 93 controls from infancy to their current age of about 7 and in the first grade (H. Lyytinen et al, 2004). These researchers report on brain event-related responses including ERPs to categorical speech perception and processing of specific temporal features of the Finnish language as precursors of dyslexia. From the comparison of the developmental characteristics of the at-risk and control groups Lyytinen et al show the importance of environmental effects including parent-child symbolic play and language interactions between parents and children and also the predictive power of some core language measures, both phonological and morphological specific to the highly agglutinative Finnish language. This prospective, fine-grained study serves as another noteworthy exemplar for similar investigations in Hong Kong and elsewhere.

Enhancing Children's Environment

This emphasis on improving children's environment is particularly applicable to Hong Kong in that the school milieu is on tests, examinations in meeting so-called high standards and much less on learning per se and the children's health and welfare. There are recent reports in the local media that the education authorities find in their inspection of some 17 kindergartens that many of the daily activities consist of rote learning of characters and English in the forms of drills and writing to dictation. Where then is the joy of learning for young children?

If the above on the wrong kind of teaching of young children is based on media reporting, there are some sobering statistics on how Hong Kong children learn and how they compare with children in other countries. The recent Progress in International Reading Literacy Study (PIRLS 2001) involved over 150,000 grade 4 students in 35 countries, including those from Hong Kong (Tse, Lam, Lam & Loh, 2004). PIRLS assessed reading comprehension on both literary and informational aspects and collected extensive home, school and national context data on these students. The participants in Hong Kong scored at the very top in reading characters and words, sentences and writing in grade 1, but ranked only 14th out of 35 in grade 4 reading. It is interesting to ask why there is this big drop from both the policy and teaching perspectives.

Related data show that Hong Kong ranked 35/35 in early family reading activities; 28/35 in educational resource index, 28/35 in terms of homes with 200 or more books; 22/35 in home newspapers. These bald comparative figures may not tell the full story. However, they do suggest that home environment and parenting do play an important role in literacy acquisition. If anything, parents in Hong Kong generally

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spend what time they can to help their children in their homework, to get higher marks in schools. The important thing is whether this parent-child-care partnership model is most conducive to children's education, health and general well-being. Parents in Hong Kong need help from health and education authorities and non-government organizations to educate their children in the real sense of the word. A more appropriate parenting model is one of family-as-educator model where parents help young children to develop their gross and fine motor skills, their social, cognitive, receptive and expressive language skills and book-reading knowledge (Snow, Burns, & Griffin, 1998).

Summary and Suggestions

I would urge very strongly the authorities should place a high priority on early childhood health and education, and should upgrade care-giver and teacher education in these areas. Above all, the considerable resources available from such sources as the Quality Education Fund should be directed to long-term, interdisciplinary, multi-site studies of the development of children along the lines of such notable investigations as NLSCY in Canada and the Jyväskylä Longitudinal Study of Dyslexia in Finland. Directly in dyslexia research and practice Leong (1999) made a modest proposal of a framework for diagnosis and its implementation. In all these activities – research, practice and public policy – HKCNDP has a very important role to play to advise health, education and other services in child development and provision for young children.

In their very powerful book synthesizing the latest findings of the minds of children in the context of human development [a book that should be read by all working with children], Gopnik, Meltzoff and Kuhl (1999) liken child development to the ship of Ulysses in need of constant repairs in the course of the long and hazardous life journey and they emphasize the overall quality of experience is more important than just timing at a particular point in life. In the Hong Kong context, it is not just stuffing facts into children's heads at a very early age to get a head-start, and cramming for tests and examinations that are important. In the translated words of Montaigne "It is better to have your head well organized rather than full". May these and what is discussed in the preceding paragraphs be the goals of the endeavours of HKCNDP for the next decade?

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Developmental Dyslexia: A Complex Syndrome that Can Be Understood

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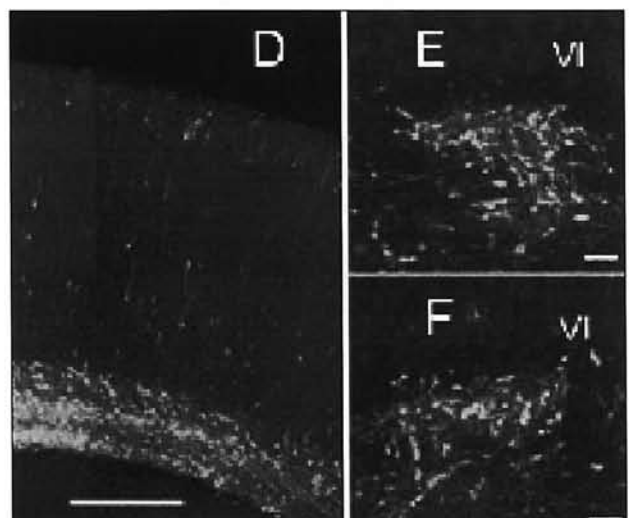
Introduction

Developmental dyslexia is the most common specific learning disorder in children, yet its underlying causes are not well understood. Neurophysiological and neuroanatomical findings indicate that dyslexia is associated with alterations in both neocortical function and structure¹⁻⁴. The pattern and timing of such neurobiological changes suggest that developmental dyslexia may be caused in part by alterations in early brain development and neuronal migration^{2,5}. In addition to neurobiological correlates, there is substantial evidence that dyslexia susceptibility associates with multiple genetic loci^{6,7}. In the present brief review, I will outline the main steps between a proposed genetic mutation and a linguistic deficit often accompanying developmental dyslexia.

Genetic Background

Dyslexia susceptibility loci have been shown to be present on the X chromosome as well as autosomal chromosomes 1, 2, 3, 6, 11, 15, and 18⁶⁻¹¹, and the first candidate dyslexia susceptibility gene, DYX1C1 (also known as EKN1), is located on 15q21^{11,12}. *In utero* interference with the translation (RNAi) of DYX1C1 protein edisrupts both the migration and morphology of developing neurons¹³ (Figure 1). Cellular and biochemical experiments indicate that DYX1C1 functions within the cytoplasm of migrating neurons, interacts with the migration gene LIS1, and regulates the association of LIS1 with the cell motor protein dynein. These results established DYX1C1 as a novel neuronal migration protein, and linked dyslexia susceptibility to molecular mechanisms underlying neocortical development. The results also suggested that the disorder of neurodevelopment and migration associated with dyslexia is only one possible outcome in a range of mild to severe disturbances of cortical development related to altered genes involved in neuronal migration, which also includes Lissencephaly Type I. Given the growing number of genes discovered to be involved in neuronal migration and cortical development, an important focus of on-going and future studies is to determine whether proteins coded by genes within other dyslexia susceptibility loci play similar roles in neuronal migration and development.

Figure 1: Results of an experiment using interference RNA directed at the dyslexia susceptibility gene DYX1C1. The left panel shows a sheet of post-mitotic neurons (green fluorescence) that failed to migrate to the overlying cortex by the time of birth. The right panels show subcortical clusters of neurons that survived into the first week of postnatal life after failing to migrate.



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Neuroanatomical Background

Abnormal migration and developmental genes such as *DYX1C1* are capable of triggering a cascade of anatomical changes likely to be responsible for the cognitive and behavioral deficits seen in developmental dyslexia. Work on the mechanisms of function of the altered *DYX1C1* gene indicates that the gene has both cell autonomous and non-cell autonomous effects on cortical development¹³. Thus, while cell autonomous mechanisms explain the abnormal interactions between young neurons and the radial glia along which they must migrate to the incipient cerebral cortex, and the resultant periventricular migrational arrest (Figure 1), additional non-cell autonomous effects lead to focal disorganization of the layering of neurons in the developing cortex. Other non-cell autonomous effects may lead to breaches in the external glial limiting membrane, which results in the production of layer I ectopic collections of neurons and glia (ectopias)⁵ (Figure 2). Experimental induction of ectopias by physical means in rats or mice, such as by freezing injury to the surface of the cortex at post natal day 0 or 1 (P0, P1), can reproduce these same effects and lead to layer I ectopias and focal areas of microgyria in the affected cortex^{14,15}.

Induction of ectopias by physical means triggers changes of a widespread nature in other areas of the cerebral cortex as well as in the thalamus (Figure 3). These changes include alterations in the types and proportions of neuronal types and in patterns of neural connections^{12,16-21}. Evidence exists for decreased cortical inhibition in affected cortical areas^{22,23} and for anomalous connections between injured cortex, adjacent cortex, and even homotopic and non-homotopic cortex in the contralateral hemisphere¹⁸. With respect to the thalamus, abnormal afferent and efferent connections between injured cortex and thalamus result from the induction of cortical ectopias¹⁸, and there are changes in the numbers of large and small neurons in specific thalamic sensory nuclei, even when they do not directly project to the area of affected cortex²¹.

In the lateral geniculate nucleus, the average size of neurons in the magnocellular layers was found to be reduced by 30% in the brains of dyslexic individuals²⁴. In the medial geniculate nuclei, dyslexic human brains showed a shift toward smaller neurons, which again could be produced in experimental animals by induction of cortical ectopias by freezing injury at P0^{21,25}. Of additional interest was the finding that despite comparable severity of the cortical injury and resultant cortical malformation, female rats, unlike their male counterparts, did not develop the predicted changes in thalamic neurons²¹. This indicated that

Figure 2: The left panel (A) shows a distortion of the cortical layers by a layer I ectopia (asterisk), which resulted from an experiment locally interfering with the function of *DYX1C1* in a rat embryo at day 13. The right panel (B) shows a cell stain of a similar malformation seen in the brain of a dyslexic individual.

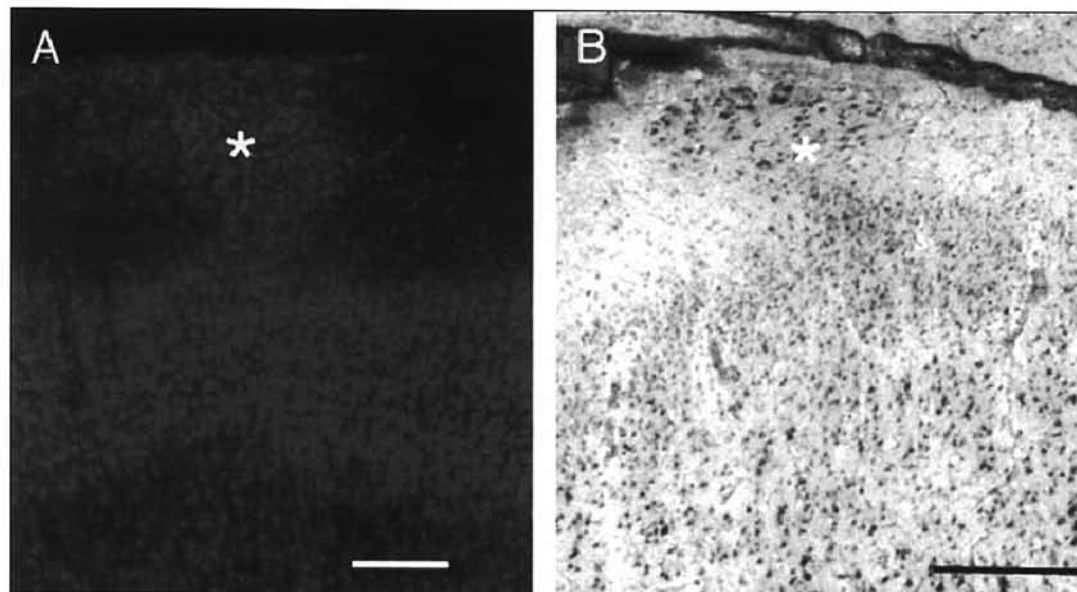
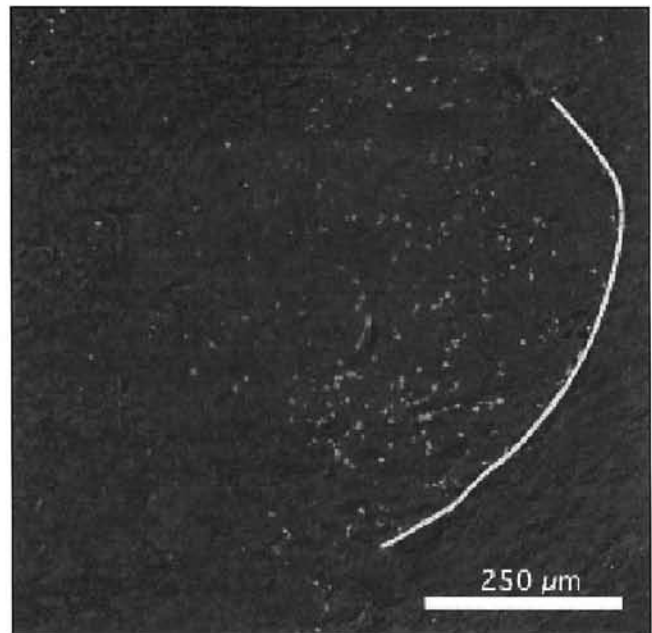


Figure 3: Light-green fluorescent dots represent dying neurons in the ventrobasal complex of the rat thalamus following induction of microgyria in the newborn cerebral cortex. Cell death is felt to be the principal mechanism by which proportions of neuronal types in the thalamus change in cortical malformations.



females are more resistant to the secondary changes in the thalamus that result from induction of cortical malformations at birth, as compared to male rats. However, the pattern of male reaction to cortical injury could be induced in the females when the latter were exposed to the male sex hormone testosterone²¹.

Behavioral Consequences

In alphabetic languages phonological problems describe the majority of children with developmental dyslexia²⁶. This is usually demonstrated by tests addressing conscious awareness of the phonological structure of words, such as rhyming or phoneme deletion tasks and pig-latin games. The origin of these metaphonological deficits is not known, but some experts believe that they result from abnormal auditory perceptual processing during critical stages of phonological development early in childhood²⁷⁻²⁹. A variety of temporal auditory processing problems have been reported, some that concern rapid sound changes, others involving slow auditory transitions (see review and critique by Ramus³⁰.

Behavioral and cognitive aberrations can also be demonstrated with the use of functional imaging methods, such as PET and fMRI. The application of these tools often discloses differences in activation of cortical areas between good and poor readers, which involve perisylvian cortices, inferior prefrontal regions, temporo-parietal junction cortex, and the so-called 'word-form' area located at the border between the temporal and occipital lobes on the left side^{31,32}. These are also areas where ectopias have been shown to be present in dyslexic brains^{5,33}. In languages such as Chinese, the details of the dysfunctional activation may differ in quite an interesting way, reflecting a different relationship between the orthographic code and semantics^{4,34}.

Induction of cortical malformations in neonatal rats leads to temporal processing auditory deficits similar to some described in children with developmental language impairment. Affected animals show difficulties with processing rapidly changing sounds, which can be demonstrated in operant conditioning, oddball, and evoked potential paradigms^{17,21,35-41}. Of further interest is the finding that only those animals with induced cortical malformations that also demonstrate changes in the thalamus exhibit the temporal processing deficits, and this group is composed of only males, the females being resistant to thalamic changes. Exposure of pregnant dams to testosterone leads to females' acquiring thalamic changes, like the males, and, also like the males, temporal processing deficits. Therefore, the temporal processing deficits are linked to the secondary thalamic changes rather than to the initial cortical malformation.

Pathway: From Gene to Behavior

Several susceptibility loci on the human genome have been linked to the phenotype of dyslexia, but only one candidate gene has been identified and studied so far. At the same time, several forms of developmental dyslexia must exist, which affect different components of language processing and perhaps also non-linguistic abilities involved in reading. Of the Western form of dyslexia, the phonological type is the most common and a tentative pathway now exists that can explain the phonological core deficit beginning with a gene mutation. Thus, I propose the following scenario to explain phonological dyslexia in people who carry the DYX1C1 mutation or another mutation affecting neuronal migration and cortical development in a comparable manner.

Initially there is a mutation in a gene crucial for proper neuronal migration and cortical development, such as DYX1C1. A mutation in such a gene leads to cell autonomous and non-autonomous neuronal migration problems. These may begin with subventricular neuronal migration arrest, some of which may not be demonstrable later in life because of shortened survival of subventricular, poorly migrated neurons. The abnormal process of neuronal migration, because of secondary effects on the health and integrity of radial glia, may also end with disruptions in cortical layering and ruptures in the external glial limiting membrane (which is made up of the foot processes of radial glia). The latter changes comprise the main anomaly in cortical development as it concerns dyslexia, which includes the generation of layer I ectopias. Either the generation of ectopias or the underlying cortical changes lead to changes in cortico-cortical and cortico-thalamic connections, which in turn produce secondary cell changes in the thalamus. These thalamic cell and connectional changes lead to problems with auditory temporal processing, which in turn disrupt development of normal phonological representations and processes during language development. Weakness or anomaly of phonological processing in turn results in problems with phoneme-to-grapheme mapping-the core problem in developmental dyslexia.

Outstanding Questions

Although a rough pathway can be drawn between a mutation in a neuronal migration and development gene and a complex behavior such as phonological dyslexia, there are several areas where additional information is still needed.

Several chromosomal locations may independently be responsible for genetic phenotypes. This may affect people unevenly according to ethnic/genetic background, such as one may account for most dyslexics in one geographic or ethnic group but a few cases in another. We have already seen this phenomenon with regard to DYX1C1, where involvement of Finnish dyslexics is different from dyslexics in the UK or in Canada^{9,11}. The question remains as to whether the different genes are all neuronal migration genes or they affect cortical development by interfering with different developmental molecular pathways, either pre- or post-migratorially.

We thus far have inconclusive evidence for the statement that neuronal migrational errors lead to non-cell autonomous changes in layering and ectopia formation in the overlying cortex. Additional work needs to be done to specify the steps by which secondary cortical malformations follow the impairment of subcortical neuronal migration directly linked to the gene mutation.

Another set of questions relates to the exact mechanisms, described at cell biological and molecular levels, for the abnormalities in cortico-thalamic interactions, felt to be crucial in the proposed step for abnormal phonological development. We do not as yet know what signals are involved in transforming a cortical injury into an abnormal thalamus. Changes in programmed cell death are likely involved, but more data are needed to rule in or out other contributors.

Another outstanding question has to do with the variation that may exist in the anatomical underpinnings of dyslexia. The only neuronatomical studies published thus far have been done of Western individuals most likely suffering from phonological dyslexia. Other forms of dyslexia in Western languages (surface, deep), and dyslexia in non-syllabic languages like Chinese, may in fact be associated with different neuroanatomical substrates, which need to be characterized.

The possibility that some aspects of the dyslexic phenotype are learned, rather than acquired *in utero*, would suggest that brains will be found with functional anomalies not caused by underlying neuroanatomical defects. Modern neuroimaging tools will permit the discovery of such cases, and further developments in *in vivo* imaging will disclose details of the underlying neuroanatomy heretofore not possible to conceive. High strength magnets and especially designed imaging protocols are even presently disclosing details of cortical anatomy previously only possible to see in *pos mortem* or biopsy tissue^{42,43}. Nonetheless, it is clear that an important proportion of dyslexics do indeed have unusual brains from birth or before, which can be understood on the basis of comprehensible errors in cortical development beginning with a single gene mutation.

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Dyslexia: Some Local Clinical Experience

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Introduction

"Dyslexia is a specific learning disability that is neurobiological in origin. It is characterized by difficulties with accurate and/or fluent word recognition and by poor spelling and decoding abilities. These difficulties typically result from a deficit in the phonological component of language that is often unexpected in relation to other cognitive abilities and the provision of effective classroom instruction." (The International Dyslexia Association, 2003). Similar to other dyslexic children all over the world, children with dyslexia in Hong Kong often have unsatisfactory academic achievement, which is not commensurate with their potentials for learning. Very often, doubts, confusion and frustration ensue, with much suffering for both children and parents before learning difficulties are identified, formally diagnosed and referred for appropriate remedial and accommodation services.

In this article, we report preliminary findings of a study on the clinical profiles of children diagnosed with dyslexia at the Child Assessment Service (CAS), Department of Health from 2003 to 2004. The clinical features of these children will be described and the flow of assessment, interim support and referral to appropriate services will be discussed. Although not all medical and health professional disciplines are involved in the formal diagnostic assessment or treatment of children with dyslexia, their awareness of the condition, early identification and bringing it to appropriate attention, will often lead to an important turning point in the lives of these children and families.

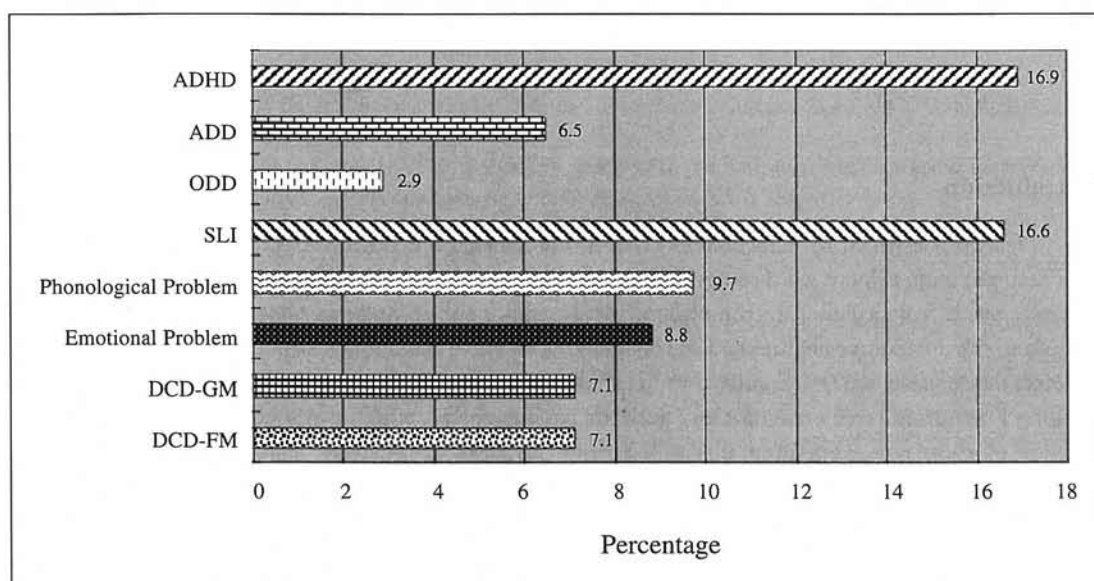
Clinical Profile

In the recent study on the clinical profiles of children diagnosed with dyslexia in CAS during the period from September 2003 to August 2004, data from 308 children were analyzed. Among them, 76% were boys with the boy to girl ratio around 3 to 1. This is consistent with the findings in prevalence of more boys than girls as reported in DSM IV-TR. Over 50% of the children were diagnosed at the age of 6 to 7 years old. In other words, their learning difficulties became obvious in early primary school years. The chief complaint in the referral mostly involved learning or learning related problems (over 60%). In recent years, the specific referral complaint of suspected "Specific Learning Difficulties" (SLD) or "Dyslexia" was applied increasingly, reflecting a heightened awareness of the condition among primary care physicians. Meanwhile, the most common complaints from parents related to dismal performance in dictation and spelling, despite great efforts by child and parent in preparation. Over 60% of the children reported failing marks in dictation, and it was common, especially for those studying in higher grades, to repeatedly obtain zero marks. Although some children managed to obtain passing grades in dictation and spelling, efforts spent on preparation were usually greatly out of proportion to the results obtained.

Co-morbidity was common in these children with dyslexia (Figure 1). The most frequent co-occurring condition was attention-related difficulties. 23% of the cases had either Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD). 16% of the children had Specific Language Impairment (SLI). With Hong Kong still lacking a validated assessment tool for Cantonese verbal language, this figure may well be an under-estimation, although it still represents a significant increase from earlier reports (Lam, 1999). Meanwhile, 14% of the dyslexic children were found to have Developmental

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Figure 1: Co-morbid Conditions



Coordination Disorders (fine or gross motor), and 3% to have an Oppositional Defiant Disorder. These co-morbid conditions compounded onto presenting dyslexia symptoms, further exacerbating difficulties in academic performance, and contributing to negative impressions on the part of their teachers.

Clinical Presentation

In evaluating children suspected with dyslexia, in addition to general intellectual assessment, we will assess these children's specific literacy skills and emotional aspects.

Reading

In reading, these children showed difficulties in reading single words at respective grade levels, and cannot read passages fluently. Common reading errors include:

➤ Associative or semantic type

e.g. 警察 → 差人
秩序 → 規則
狐狸 → 豺狼
防火 → 消防

➤ Errors which are orthographically similar to the target words

e.g. 探望 → 深望
紅燈 → 紅橙
犧牲 → 義性
葡萄 → 蘿蔔

Dictation

In dictation and spelling, they failed to recall many words that have been learned and rehearsed before. Common dictation errors in Chinese include:

- Addition or omission of word parts or strokes:

e.g. 春 春 季 季
天 天 節 節

- Left-right reversals/substitution of word parts:

e.g. 知 知 排 排
道 道 隊 隊

- Errors that are phonologically similar to the target words:

e.g. 海 海 速 速
洋 陽 度 到

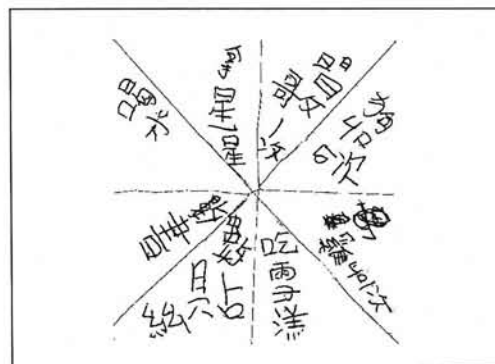
- Others:

e.g. 自 自 克 黑
己 自 服 衣

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Some interesting error pattern can be noticed in the following game paper (Figure 2) designed by a girl with dyslexia studying in Primary Two. Readers are recommended to note the three different versions of the word 「次」.

Figure 2: Paper for the game of "East South West North" (東南西北) designed by a P2 girl with dyslexia



Medical and health professionals who come into contact with these children can also identify signs of reading and spelling difficulties. As the first step, we would like to suggest that history taking includes the child's learning history – especially in word recognition and learning to write during pre-school years. Over 60% of cases in our study reported word recognition problem in pre-school years. Observations reported by parents and teachers on the child's literacy acquisition, and a careful review of the child's schoolwork to search for clues of error patterns in his/her handbook or dictation books usually provide important information. Informal assessment on the child's reading skills by requesting him/her to read words chosen from his current text book/homework may also be revealing.

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Emotional Aspects

Our recent study on the socio-emotional functioning of children with dyslexia and their parents did not identify significant emotional difficulties in these children when compared with non-dyslexic children of the same study level. However, the parents with dyslexic children were significantly more stressed on the Total Parent Stress Score, as well as in three subscales of Parental Distress, Parent-Child Dysfunctional Interaction and Difficult Child. Nevertheless, emotional difficulties of dyslexic children were reported from time to time by their parents in our interview with them. Their frustrations in word learning are best illustrated in the following scripts by two young boys with dyslexia:

- i) 「有無搞錯，唔記得咗呀！上次記得呢邊，唔記得個邊，今次記得個邊，唔記得呢邊。」
("How come I forget again! Last time, I recalled this side of the word and forgot the other side; this time I recall the other side but forget this side.") This was recorded when he was doing his revision in preparation for the dictation next day.
- ii) 「每當我寫一個字的時候，我以為是錯的，那字就對；我以為是對的，個字就錯。啲字搞到個頭好痛」("Every time when I write a word, it is right when I think it is wrong. But it is wrong when I think it is right. Words make me confused and cause me headaches.") This was recorded when the boy expressed his feeling in word learning with his mother.

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Management by Multi-disciplinary Team of CAS

Our team in CAS typically includes the developmental paediatrician, clinical psychologist, optometrist and medical social worker. Speech therapist and occupational therapist may be involved in the assessment if the child demonstrated difficulties in language functioning and fine motor control or handwriting.

Assessment by the clinical psychologist covers the cognitive assessment to gauge the child's intelligence level and its profile, as well as achievement levels and cognitive processes involving in word reading and writing. In addition to ascertaining the diagnosis of dyslexia, the clinical psychologist goes through differential diagnosis and exclusion of other co-morbid conditions, including emotional and behavioural problems. After conclusion of diagnostic evaluations, interim support will be provided. These include parent workshops which aim to help parents better understand the nature of their children's learning difficulties, basic principles of word learning strategies, ways to improve parent-child relationships, as well as related community resources. Recently, direct group training on word learning skills for early primary school children with the use of game approach are also conducted. Parents are invited to attend the groups so that they can learn the skills and apply to daily home training.

In response to the Education and Manpower Bureau's policy of "Whole School Approach", and School-based Support for children with Special Education Needs (SEN), a summary of assessment results will be sent to school after our formal assessment. Referrals will be made for remedial services, as well as recommendations for accommodations in the classroom. Today, schools' responses remain rather varied, but in general, with the teachers increased awareness of the problem, positive feedback from schools are noted.

Conclusion

In Hong Kong, as in other developed countries, the major business of a school-aged child is to study and play. The "mission" at this developmental stage involves studying hard in order to achieve and feel good about oneself; and to play happily and to enjoy him/herself. However, to children with dyslexia, the road to success and life satisfaction is not as easy. Substantial assistance and understanding from the parents, teachers and health professionals are crucial for their academic pathways and psychological health.

Dyslexia is not a disease and there is no medical cure for it. What is certain is that early diagnosis and early supportive measures are important for dyslexic children to be able to read at age level. The role of the primary health care professionals is to identify these children as early as possible and to refer them for formal assessment. For those children suspected to have multiple developmental disorders, referral should be made to Child Assessment Service where multi-disciplinary team approach is employed. Timely confirmatory diagnosis and referral to appropriate services will significantly improve future life experiences of children with dyslexia and their parents.

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Services for Hong Kong's Students with Developmental Dyslexia

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Nature of Dyslexia

The Greek prefix *dys* refers to *difficult* or *hard*, and *lexia* refers to *words*. Dyslexia characterizes significant word recognition and spelling difficulties in affected individuals. It is one of several distinct specific learning disabilities, in contrast to the more general terms "Specific Learning Disabilities (SLD)" or "Learning Disabilities (LD)" used to describe larger sets of individuals with listening, speaking, reading, writing and mathematics difficulties. Epidemiological studies show that dyslexia constitutes at least 80% of the SLD/LD population (Lyon, 1995), and because of its long reaching effects, the most important condition with SLD/LD in terms of public health impact.

This definition which draws from the relationship of biological and psychological underpinnings with behaviour, is in contrast with both the International Classification of Diseases (ICD-10, World Health Organization, 1992) and DSM-IV (American Psychiatric Association, 1994), which apply operationalized criteria in their definition of a reading disability. The National Institute for Child Health and Development of the United States reported an approximate prevalence of 10% of school-aged children being affected to varying degrees (Lyon et al 1993), with 3-5% believed to be severely affected.

Current Situation for Students with Dyslexia in Hong Kong

Presence of Dyslexia in Chinese and Hong Kong

In studies of reading disabilities, it is widely believed that dyslexia in different languages share biological bases that are related to regional brain dysfunctions associated with deficits in written language processing, with ensuing difficulties in decoding respective scripts. Recent fMRI findings on reading disabilities in Chinese (Siok WT, Perfetti CA, Jin Z, Tan LH, 2004) show that while details of the dysfunctional activation in Chinese may differ from that of alphabetic languages, biological abnormalities are responsible for deficits in mapping word form (morphological and orthographical aspects of reading) to its sound and meaning. Recent studies (Ho CS, Chan DW, Lee SH et al, 2004; McBride-Chang C, Chun PW, Shu H, Zhou A, Wagner R, 2003) also suggest that difficulties in morphological awareness and orthographic knowledge contribute significantly to problems encountered in Chinese reading disabilities.

Local experience suggest that up to 10% of students fall within the disorder criteria for dyslexia in the HK Test for Specific Learning Difficulties (Ho CSH, Chan DWO, Tsang SM, & Lee SH, (2000), and that 2-3% within these have severe difficulties.

The serious educational consequences of undiagnosed and unsupported dyslexia are extensively documented. In addition, children with dyslexia who are not provided the appropriate and timely educational and social support are highly susceptible to delinquent behavior and other negative social outcomes. In a 2002 Hong Kong study (Chan WC, 2002) conducted in P.3 and P.4 of a Special School for Social Adjustment (attended by children with emotional and behavioural problems) showed that over

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50% of these classes were identified positively for dyslexia – a figure in alignment with international outcome studies for negative social outcome of young persons with dyslexia. Further extension of this study to all grades of their school in 2003-04 resulted in similar observations (Chan CK, 2004).

Since increase in public awareness over the past 5 years, there has been remarkable rise in the numbers of referral for assessment and support at both the Department of Health (DH) and the Education and Manpower Bureau (EMB). However, it is believed that many are still not receiving attention because of the limited awareness within schools to identify these students, especially those in higher elementary grades or in secondary school.

Identification of Students with Dyslexia

To date, there are no systematic measures to identify students at risk for or with dyslexia in Hong Kong. Current channels include:

- (1) Developmental screening for children 5 years or under at the Family Health Service (FHS) of Department of Health may identify children with at risk signs of dyslexia (such as symptoms of early language delay). There is no system for these at risk children to be followed through into primary schools when literacy problems arise.
- (2) The Student Health Service (SHS) of the Department of Health screens students from P.1 to S.7 for physical and mental health well being. If information obtained from parents/students raises the possible presence of dyslexia, students may be referred to EMB for further assessment and action.
- (3) Teachers may use EMB's Observation Check List for Teachers (OCT) for P.1 Pupils at the end of P.1 or in P.2 if the student shows signs of school failure. This checklist includes items on various aspects of learning. In the past, upon receiving this report from schools, EMB will determine eligibility for resources under its remedial support programmes. In recent years schools are empowered to decide on utilization of its own remedial placements, while EMB will advise on difficult cases as indicated.
- (4) In 2000, The Hong Kong Specific Learning Difficulties Behaviour Checklist for primary school pupils (Hong Kong SLD Research Team 2000) was made available to schools to assist teachers in identifying students suspected to have specific learning disabilities.
- (5) From 2004 September, a new Primary One Checklist screening for Learning Abilities was launched, where Chinese, English, mathematics, social adaptation, verbal language and motor abilities of P.1 students are checked at the end of the first semester in December/January to identify any learning problems and additional educational needs. Teachers are expected to provide additional support to those identified as at risk, and to refer out those who are identified to have significant difficulties. School and teacher readiness for taking up this role is variable.

Assessment for Diagnosis

- (1) Teachers and special support personnel within schools refer students with learning problems and suspected dyslexia to specialist sections of EMB for further workup.
- (2) Students and parents may also be referred by medical doctors or psychologists to the Department of Health's Child Assessment Service, or may directly approach other non-profit making or private services for diagnostic assessment. These include evaluations by medical, allied health, educational, and social work disciplines, according on the setting. Depending on which discipline(s) are assessing the student, follow up support in school may need to be requested from other outside supporting educational specialists.

- (3) There is no locally agreed operational “severity benchmark” above which active remediation and accommodations should be provided. In view of the high prevalence of this condition, this poses a critical issue of resource and support service gate-keeping, in contrast to other much less common but more visible conditions such as autism or physical and sensory impairments.

Educational Needs of Students Diagnosed with Dyslexia

1. In 2003, a new model of supporting students with special needs in mainstream schools was launched by the EMB. Through this, a “Whole School Approach” is advocated and supported by a funding system, whereby a learning support team within each school is set-up to be responsible for identifying, supporting and monitoring the progress of students with various special educational needs in the school. With this model, resources from previous special programmes including “Intensive Remedial” or “Inclusive Education” support will be replaced and faded out. The future success of this model will depend on the effectiveness of each school’s identification and subsequent work with affected students. Formally qualified special educators are not available in most schools for organizing and leading learning support teams, nor for delivering interventions for students with dyslexia.
2. Specialist support to schools’ learning support teams may be requested as indicated. These include:
 - Regional Educational Office (REO) personnel who provide overall support to schools within its region, including support for students with dyslexia through their educational psychologists and education inspectors.
 - School based educational psychological services are an alternative source of support in a small percentage of schools that engage their own specialist support. English School Foundation (ESF) schools or private schools may also have additional special educational support for their dyslexic and other special needs children.

Accommodations in Learning and External Examinations

With increasing awareness of needs and rights of students with dyslexia taking open, high stakes O-Level and A-Level Examinations, the Hong Kong Examination and Assessment Authority issued a pamphlet in 2002 reminding schools of the channels for providing necessary accommodations to students with dyslexia at these examinations. Understanding of these issues in secondary schools, and students’ access to the required updating on diagnosis and documentation of accommodations during secondary forms are very limited. Many students approaching Form 5 O-Level examinations still face difficulties in obtaining documentation needed for open examination accommodations. This issue applies to Primary 5 and Primary 6 school assessments where results are handed in to the EMB for use in territory wide secondary school placement exercises.

In Hong Kong, the Code of Practice on Education issued by the Equal Opportunity Commission in 2001 lays out principles for reference by administrators and educators in the management of students with disabilities, including dyslexia and specific learning disabilities.

Practices in Other Countries

In the UK and USA, as well as many other developed countries, including to varying extents in Japan and Taiwan, educational and civil laws govern the provision of services to students with dyslexia/Learning Disabilities, monitoring:

- Special educational support eligibility ascertainment
- Access to services and resources

- Mode and quality of delivery of services
- Support in open examinations

The Individual with Disabilities Education Act (IDEA) of the United States (1997) stipulates that Individual Educational Programmes (IEP) must be provided to students with special needs (including dyslexia), to allow the student to receive educational benefit. To meet IEP recommendations, additional funding is to be made available through educational authorities to support individual student needs accordingly.

Proposals for Service Development to Support Children with Dyslexia in Hong Kong (Figure 1)

Support to children diagnosed with dyslexia should be safeguarded by laws and policies on special education and disabilities. All parties serving students with serious reading difficulties need to recognize that this condition constitutes a disability that falls under the ambit of Hong Kong's Disability Discrimination Ordinance, and that due support of these children is a legal obligation. Public education has to be conducted regularly to promote understanding of these concepts.

Identification: As for all developmental disabilities, early identification and intervention are critical to ultimate success in remediation and habilitation. Early identification requires public and professional awareness, presence of tried out instruments to aid surveillance and diagnoses. Data on early predictors and longitudinal outcome from prospective outcome will provide evidence based criteria for early and continuing intervention

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Educational support: Multiple levels of service are needed for these children after diagnosis, including:

- specific reading and language therapists who provide direct remediation on reading difficulties, including outside of regular classroom sessions
- regular teachers who have basic understanding of the condition and are able to provide general teaching adaptation and accommodations
- a special learning support team within the school to provide overall administrative and educational support to students with special needs, including maintenance of special needs registries, monitoring of progress and securing of additional resources.
- professional support from outside the school as indicated, including by educational psychologists (for government or aided schools – EMB or contracted out services) who deliver regular and continual support over the years to the school's learning support team as these children progresses in grades, and face changing educational challenges.
- potential role of special classes/schools for students with dyslexia, *currently unavailable in Hong Kong*, which could help children with severe dyslexia who are not benefiting from mainstream curriculum at that point because of severe reading problems. Intensive specialist attention could be provided to them at these special settings, together with adapted teaching measures to ensure continuous upkeep with grade level education contents, so that when these children return to mainstream schools they could follow on with curriculum appropriate to their age.

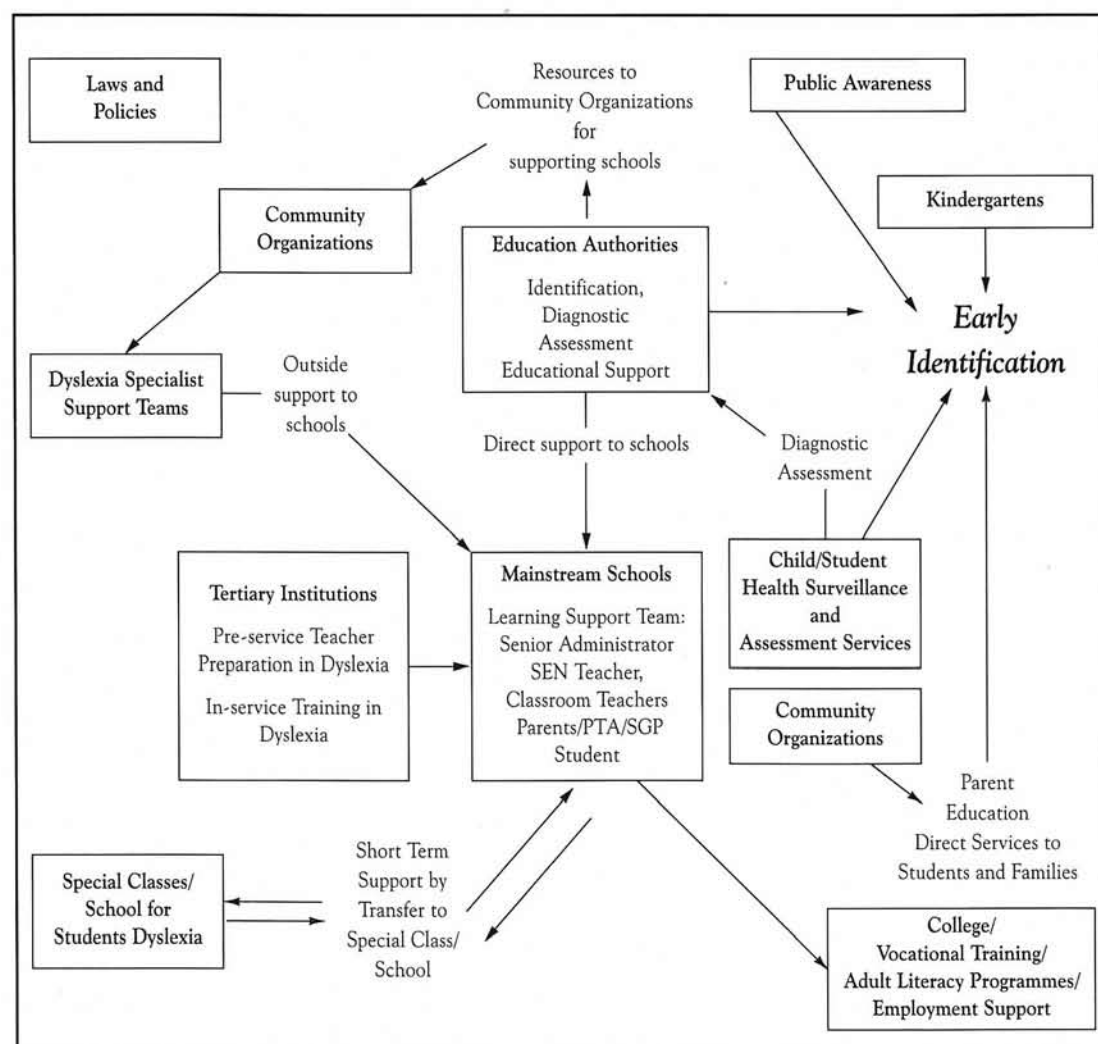
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Examinations: Provision of level playing fields in open examinations needs to be ensured for students with dyslexia, so that they could demonstrate what they know of the subjects tested. Much publicity still needs to be provided to Hong Kong's students, parents, and school administrators, to raise their understanding of the principles, availability, and measures to secure accommodations in secondary school allocation assessments, HKCEE (O-Level) and HKALE (A-Level) examinations.

Tertiary education: Children and young people with dyslexia have normal intelligence and are capable of completing tertiary education and further. Some may be gifted in specific aspects and go on to great achievements given the opportunity. Tertiary institutions in Hong Kong, as in developed countries, have systems whereby students with special learning needs, including dyslexia, may be supported during their college years. Students should be given due guidance when they apply for universities at the end of secondary school, so that necessary knowledge of their rights, documentation of needs, and expectations are in place.

Vocational training and employment: At school leaving, dyslexic students who do not have the option to proceed further in mainstream education may opt for vocational training. Guidance services for these students are needed in Hong Kong. Most are simply regarded as failures in the education system, expected to go the route of "bottom rung" students when looking for further educational opportunities or employment. Furthermore, dyslexia is a life-long condition that may or may not be compensated in adulthood through training and the educational process. Many dyslexic adults remain undiagnosed. Adult literacy programmes as in Western countries should be promoted, through which affected individuals living in today's literate society could be rescued from lives of low expectations and achievements, to become productive citizens of Hong Kong.

Figure 1: Generic Service Model for Supporting Children with Developmental Dyslexia



Research Needs

- Although dyslexia has been known and studied in western countries for many decades, it is still a new subject to Hong Kong. Research needs cover a wide range of aspects, including
- Local epidemiological data
- Developmental trajectory of Chinese dyslexic children
- Neuropsychological and neurophysiological processes underlying Chinese dyslexia
- Clinical characteristics of dyslexic Chinese children using Cantonese
- Tool development to facilitate identification and diagnostic assessment
- Intervention programmes and outcome studies for Chinese dyslexia

Role of the Paediatrician and Other Medical Professionals

Paediatricians and medical professionals who serve children are their guardians, watching out for their health and developmental needs. It is therefore the task of paediatricians and medical professionals to familiarize themselves with developmental disorders, such as dyslexia, that not only impact severely on development and learning, but are amenable to remediation with successful life outcomes. Paediatricians who suspect dyslexia in their patients should be knowledgeable of referral and service systems in their community, and take action to ensure that the necessary support is being engaged. Ongoing guidance to the family as they go from stage to stage would be invaluable. The vision of these children's greatly improved chance of self-fulfillment and life success as a result of timely intervention will no doubt provide ample gratification for all those who take these extra steps.

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Acknowledgement

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Towards Building an Educational and Assessment Accommodation Home-school Support Model for Children with Dyslexia and Their Families: Interim Report

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Background and Objectives

In Hong Kong, the educational and psychosocial adjustment needs of children with dyslexia were only better understood by parents, teachers and other helping professionals in the 1990s. By 2002, some assessment tools for early identification were developed but most teachers and parents still lacked the sensitivity and initiative for case finding. Home-school support to promote their confidence, learning attitude and skills were piecemeal or even absent. Educational and examinations accommodations like reduced homework and extra time allowance for completing written assessments which were standard provisions overseas (Ramjhun, 1995) were not introduced nor accepted by the Education authorities. Students with dyslexia continue to get poor grades, and many proceeded from school underachievers to adult occupational failures. This research is designed to develop and implement an indigenous home-school cooperation model to promote the psychosocial functioning of children with dyslexia and their families. The model was launched in 3 primary schools and 3 secondary schools on their junior forms students with dyslexia. Each student was assisted over three academic terms (about 18 months) in the main language subjects through an Individualized Educational Program jointly designed by the student, concerned parents, teachers, social worker as well as the research team members. It is expected that the experience of setting up such home-school cooperation prototype can facilitate other schools to adopt the model to support children with special educational needs.

Theoretical Underpinnings of the Model

Development of the current model is enlightened by concepts and evidence regarding the importance of the ecosystem (Nicolson, 2002); the significance of home-school cooperation on children development (Epstein, 2001), Positive Psychology (Seligman, & Csikszentmihalyi, 2000), and evidence on the rehabilitation of educationally challenged children. There were integrated into a number of guiding assumptions. First, early identification and support to children with specific educational needs is helpful and necessary (Lindsay G, 1995; Education Department, HKSAR, 2001). Second, such children will benefit from individualized educational programs (IEPs) jointly designed, implemented and monitored by the child, parents and teachers concerned. Third, the IEP meeting provides a platform for objective and sustainable home-school cooperation to advance the children's study attitude, results, as well as psychosocial functioning (such as the promotion of self-esteem and reduction of behavior problems). Such

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home-school cooperation is more effective than teacher-led pedagogical efforts (Epstein, 2001). Fourth, principles of positive psychology and strength-based approach should be able to energize the IEP team to maximize the gains out of the program progress. Finally, the experience of using such a model to support students with dyslexia should be a springboard for the school to apply the model to support other students with special educational needs. The experience can also be disseminated to other schools to facilitate their implementation of integrative education in Hong Kong.

Method

Three primary schools and 3 secondary schools volunteered to join the study. The target subjects were 20 junior primary and 22 junior secondary school students with dyslexia from these schools, their parents and their Chinese and English subject teachers as well as school personnel assigned to serve the team. Quantitative and qualitative data were collected to chart the progress of the development and implementation of the home-school support model, and the attitudinal and psychosocial changes of the concerned parties. The study spanned over a two year period. The first term was used for preparation. Intra-subject evaluative data were taken at the beginning of the second term and the end of the fourth term during which three rounds of IEP design and implementation have been completed. The dependent variables included the self-esteem and study attitude and performance of the students with dyslexia; the parents' perceived stress and behavior problems of the target children; the teachers' attitude towards integrative education and their perceived confidence in teaching such students. The intervention included the IEP meetings (which instilled positive thinking and modeled problem solving and negotiation skills for the concerned parties); educational and assessment accommodations for the students, as well as training programs (like study skills groups or esteem-boosting camps) for the students, parents and teachers. The actual schedule of the project ran as follows:

- Phase 1: Preparation (Sept 2003 to Jan 2004): development of research, assessment and intervention package; identification and confirmation of target schools and target cases.
- Phase 2: Baseline assessment and 1st IEP (Jan 2004 to July 2004): baseline assessment on the target schools' provisions and preparations for integrative education; assessment on attitude of parents and teachers to children with dyslexia; design and implementation of first IEP for the target students; teacher and parents training
- Phase 3: 2nd IEP (Sept 2004 to Jan 2004): design and evaluation on second IEP for each target student; more training
- Phase 4: 3rd IEP and final evaluation (Feb 2005 to July 2005): design and evaluation on third IEP, collection of end of project evaluative data
- Phase 5: Report writing and experience dissemination (July 2005 to October 2005): data processing and report writing, dissemination seminars to teachers and other professionals and parents.

One Year Progress of the Project as in September 2004

1. Early identification and intervention was achieved in Phase 1 when the research team provided resources in case finding. In Hong Kong, proper diagnostic tool for children beyond age 10 and a half is not yet developed, and first identification of children with dyslexia beyond that age was very controversial if not impossible. The project made a significant achievement by successfully involving some 15 Hong Kong educational and clinical psychologists to endorse the inclusion criteria for secondary school cases into the project.
2. The academic, clinical and psychosocial profile of the participating students constituted a comprehensive data base enabling the longitudinal study of their journey through education in Hong Kong. This database will also facilitate their application for assessment accommodations in public examinations to ensure their rights for equal opportunities in assessment.

3. By early 2004, functional home-school support teams were established in each of the 6 seed schools. Each team was led by a senior teaching staff and case managers were appointed to monitor the IEPs of 2 or 3 students, thus making the monitoring work more manageable and reliable. Teacher and parent training were offered in mid 2004 to all the schools. By September 2004, it was evident that the school personnel in all the participating schools had a full mastery of the rationale and operation of the home-school cooperation model and the IEPs. All schools initiated case-finding at the beginning of the 2004-5 academic year and started IEPs for the confirmed cases and applied the monitoring system devised in this project to those cases even though they were not included into the current study. One secondary school even extended the IEP system to other junior form students with specific educational needs. It is obvious that all participating schools appreciated the project and could not hesitate to generalize it to other relevant students
4. The inclusion of junior primary and junior secondary students provided natural comparative data on how age affects the students' understanding, ownership and commitment to the IEPs. The project confirmed that age was an important but not sufficient factor dictating the students' commitment to the IEP. The students' self-esteem and personality and perceived competence as well as availability of family support are also critical factors warranting attention.
5. The team has conducted a number of talks and work shops to around 400 teachers, over 40 social workers and over 100 parents to disseminate the experience gained from the study.

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Conclusion

As an initiative to activate home-school resources to alleviate children with dyslexia from misunderstanding and insufficient educational support, the research team is pleased about the progress in engaging the schools in this research, devising the evaluation instruments and database, and attracting due attention from the parents, teachers and students from the concerned schools. Although the sample size was not very large, the project has generated massive quantitative and qualitative data regarding the effectiveness of different strategies to support children with dyslexia. The future challenge for the team is how to sustain the commitment of the participating schools and cases to launch and keep records on the IEPs as agreed. The team hopes that the experience gained from this project can benefit affected children and attract appropriate understanding and support from significant adults in their ecosystem.

Acknowledgement

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Identification Study on Students with Specific Learning Difficulties (SpLD) in Schools for Social Development of the Society of Boys' Centres

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Society of Boys' Centres

Introduction

"Learning disabilities" is an umbrella term used to describe a group of disorders due to the dysfunction of central nervous system. These disorders involve difficulty in development and utilization of skills such as listening, speaking, reading, writing, reasoning or mathematics.

According to the Orton Dyslexia Society Research Committee, "dyslexia (the term to be interchangeable with SpLD and reading disabilities) is a specific term used to describe a type of learning disability that involves impairments in reading, spelling, and writing ... they are not the result of generalized developmental disability or sensory impairment. Dyslexia is manifest by variable difficulty with different forms of language, often including, in addition to problems with reading, a conspicuous problem with acquiring proficiency in writing and spelling" (The Orton Dyslexia Society Research Committee April, 1994). An unexpected underachievement is thus commonly observed among the dyslexic children. And more important, reading disabilities affect at least 80% of the learning disabilities population constituting the most prevalent type of learning disabilities (Lyon, Fletcher, Shaywitz, Shaywitz, Torgesen, Wood, Schulte & Olson R, 2001).

In spite of the diverse views on the underlying causes of dyslexia, it is believed to manifest in various languages. The incidence is about 10% (Symthe, 1997). Similar finding with 10-11% of incidence is also noted in Hong Kong (Kwan, Ho, Chan, Tsang & Lee, 2003). Based on this rate, there are about half a million of primary students who are suffering from different levels of SpLD. Since it is the "invisible difficulties", these students are not easy to be identified and thus proper interventions can be delayed (Schwab Foundation for Learning, 2000).

In Western, there are ample researches on the nature of deficit of SpLD. The phonological-deficit hypothesis has been a dominant view. However in recent years, the multiple-deficit hypothesis is widely adopted, proposing that the dyslexic child to have more than one aspects of cognitive deficit. Half of them may have three or more aspects of deficit (Badian, 1997). The multiple-deficit model is also found to be more relevant to the learning of Chinese. Rather than the phonological awareness, phonological memory or visual perceptual skills, deficits in rapid naming and orthography are found to be more detrimental to reading acquisition in Chinese (Ho, Chan, Tsang, & Lee, 2002).

Dyslexic students, without proper identification and intervention, are expected to endure years of school failures (Lyon, 2002). The resultant academic frustrations are detrimental to their psychological development. They are more anxious and exhibit more psychosomatic illness than their peers (Mcrgalit & Zak, 1984). As they are less likely to be accepted by their peers, they are at an increased risk of being bullied and teased (Eaude, 1999). They are found to have higher rate of having depression as well (Bender & Wall, 1994). In order to defend themselves against the misunderstanding and the frustration in learning, their excessive anger may turn into conflicts and acting-out behavior in schools (Abrams, 1986).

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Apart from the emotional disturbance, the dyslexic children and adolescents are noted to have more behavioral and social problems (Fergusson & Lynskey, 1997; Ryan, 1992). The distinguished longitudinal study by McKinney and colleagues (McKinney, 1989) found that elementary students with concomitant learning disabilities and behavioral disorders displayed a declining pattern of academic progress and a typically increase in maladaptive behavior over time. The other study of McConaughy (1986) also reported that boys with learning disabilities showed significantly lower levels of social competence and more behavior problems compared to normative samples of boys in the same age range. A study in Hong Kong also finds that the group of older children (P.4 to F.1) obtained significantly higher scores in the Child Behavioral Checklist (CBCL) than the younger group (P.1 to P.3), indicating that the secondary problem of emotional/behavioral is likely developed in children with dyslexia (Chan, 2002). Thus, it is not surprising to notice that there are higher rate of school dropout, juvenile delinquent and criminal acts among dyslexia than the general population. Recent studies have demonstrated that more than half of the young institutionalized delinquents have serious difficulties with written language (Hilton, 1996; Jensen, Lindgren, Meurling, Ingvar, & Levander, 1999; Moira, 2001). However, the claim that dyslexia is more prevalent among prisoners than among the general population is fundamentally flawed in terms of sample bias. It is difficult to discriminate whether the reading difficulties are innate as in dyslexia, or consequences of being imprisoned. The complex background of the prisoners also complicates the relationship between dyslexia and the emotional/behavioral problems.

28 *A study on the concomitance of emotional/behavioral problem and SpLD in School for Social Development in Hong Kong*

It is difficult to discern whether emotional/behavioral problems cause or worsen symptoms of dyslexic, or whether dyslexia puts children at risk for emotional/behavioral problems. Although it may be impossible to definitely state any direct relationship, it is necessary to identify the association between dyslexia and emotional/behavioral problems, especially at their earlier age and in school setting.

A study on the concomitance of emotional/behavioral problem and SpLD in School for Social Development (SSD) in Hong Kong was administered in 2002 (Chan, 2004). There are seven Schools for Social Development (one type of special school) in Hong Kong, five for boys and two for girls. All students were previously enrolled in ordinary schools. Due to emotional and behavioral problems, they were then referred to the SSD. Students can be referred throughout the school year. Three of the seven SSD serve primary students from P.3 to P.6, two of them being run by the Society of Boys' Centres. Mainstream school curriculum is adopted in these schools and the students are expected to re-integrate in the ordinary schools when their emotional/behavioral problems improve.

The study was administered during April to October of 2002. The aims of the study are to document the incidence of SpLD in P.3 and P.4 students in these schools, as well as the nature of deficits in them. The result is essential for understanding the correlation between SpLD and emotional behavioral difficulties, as well as for identifying directions in early interventions.

Subjects

All of the P.3 and P.4 students, 62 in total at that time, in the two SSD of the Society of Boys' Centres are assessed in the study. 21 of them are P.3 students while 41 of them are in P.4.

Tools

- (1) The Hong Kong Test for Specific Learning Difficulties in Reading and Writing (HKT-SpLD) (Ho, Chan, Tsang, & Lee, 2000) is used to assess student's ability to read and write Chinese as well as their underlying cognitive profiles. The HKT-SpLD consists of three literacy tests (with tests on Chinese word reading, Chinese word dictation and one-minute word reading); one rapid naming task

(to name digits as quickly as possible); three orthographic tasks (to discriminate left-right reversals, make lexical decisions and determine radical positions); two phonological awareness tasks (to detect onsets and rimes) and three phonological memory tasks (with tasks to repeat words and non-words in sequences). The twelve subtests would generate one composite score in the literacy domain and five composite scores in various cognitive domains namely rapid naming, orthographic knowledge, phonological awareness and phonological memory. There are local norms from children of 6 years old up to 10 years 6 months. Hence, if the age of the student is above ten and a half, his performance is still be measured by the norm of 10 years 6 months.

- (2) Test of Visual Perceptual Skills (Non-motor) Revised. Gardner's (1996) Test of Visual-Perceptual Skills (Non-motor) Revised was used to gauge the participant's visual perceptual and memory skills. Four subtests including Visual Discrimination, Visual Memory, Visual Spatial Relationship and Visual Closure were selected for administration in the study. These tests required participants to discriminate visual figures from within a set of similar alternatives, memorize visual patterns after a brief exposure, detect visual figures with a different spatial orientations and to imagine completed patterns from partial ones. Together, subtests would yield one composite score in the cognitive domain of Visual Skills.

Results

Ten subjects are excluded due to below-average intelligence or the presence of specific psychiatric problems such as autistic features. With two other marginal cases and one case with insufficient assessment information, 49 subjects are included in the final analysis. Results reveal that

1. 30 of them (61%) are found to have SpLD (Table 1). The incidence largely exceeds that in the general population 10-11%. The result suggests that there is very high correlation between emotional/behavioral problems with SpLD.

Table 1: Number of students assessed to have SpLD

	Number of students having SpLD
P.3 (n=17)	9 (53%)
P.4 (n=32)	21 (66%)
Total (n=49)	30 (61%)

2. In line with the previous finding of Ho, Chan, Tsang, & Lee (2002), higher rate of deficits in rapid naming and orthographic knowledge are found among these students.

Table 2: Nature and severity of deficits found in the students

Scale Score	Rapid Naming	Orthographic Knowledge	Phonological Awareness	Phonological Memory	Visual Perception
1-4 (Deficit)	8	8	1	1	0
5-7 (Weak)	12	9	12	11	7
	20/30 (67%)	17/30 (57%)	13/27* (48%)	12/26* (46%)	7/26* (27%)

* Only 26 or 27 of the 30 students have taken that sub-test

3. Of the 61% of students found to have SpLD, 7 (23%) exhibit only one aspect of deficit and 9 (30%) two aspects of deficits, leaving almost half of them (47%) showing three or more aspects of cognitive deficits. The finding may suggest that the more severe SpLD with multiple areas of cognitive difficulties may cause students to present early with problems of maladjustment, as in these young primary school children.
4. Out of the identified dyslexic students in this study, only two of them are known cases. This implies that identification for dyslexic students is really limited at the present moment.

The statistics in school year 2003-2004

The findings from the above study are quite alarming to the schools in the study. It appears that up to half of new comers are likely to have SpLD. Today, an initial assessment on the Literacy subtests of the HKT-SpLD will be administered to each of the new comer. Those who are at high risk would be placed in a class that provides students with tailored Chinese curriculum, with purpose of promoting reading and writing abilities in these students.

The statistics on the incidence of SpLD in the two schools is collected annually since 2003. For the year 2003-2004, 46% of all the primary students (P.3 to P.6) in the two schools (227 in total) are found to have SpLD (Figures 1 & 2). Furthermore, the incidence in the lowest form (P.3) is much higher than the upper ones (74%), with the least in P.6 (35%). The results are consistent with previous findings. In addition, less than ten cases have already been identified before admission in SSD.

Figure 1: Statistics of the school year 2003-2004

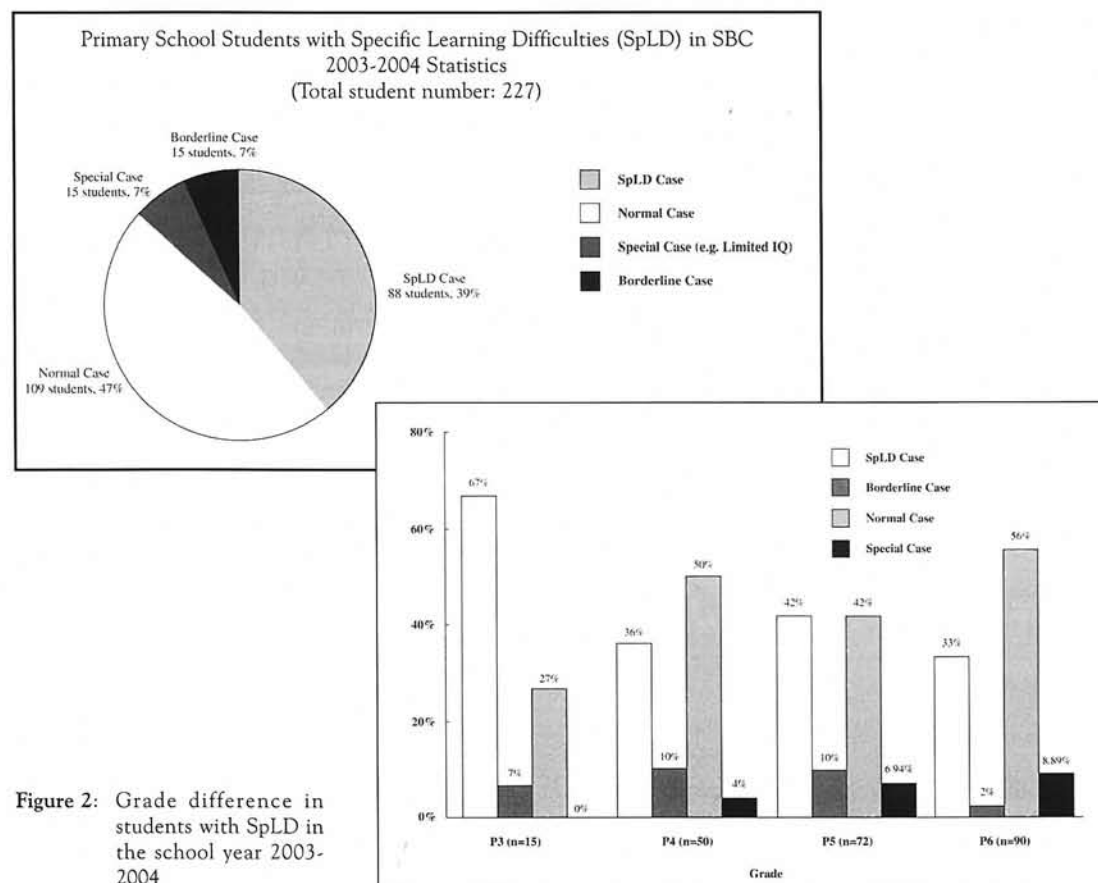


Figure 2: Grade difference in students with SpLD in the school year 2003-2004

Conclusion

The study and follow up statistics on the prevalence of SpLD in the SSD reveal that early identification and necessary interventions are far from sufficient at this stage. More effort on early identification and interventions are very vital for the development of these children.

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Advocacy Issues in Dyslexia in Hong Kong

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Chairman, Working Party on SLD, HKCNDP

Problems Facing SLD In Hong Kong

Despite the terms *Specific Learning Disabilities (SLD)* and *Dyslexia* having been known to Hong Kong for over five 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 including the Workshop on "SLD: Setting the Scene in Hong Kong" in November 1998, Workshop on "SLD 1999: The Way Ahead" in March 1999, and the Annual Scientific Meeting on Developmental Dyslexia in December 2002 and others were organized 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 the Chinese race and language, that through "Resolutions from the Workshop" an agreed definition on SLD by all professionals was produced, 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
4. Government and community input of manpower and resources

1. Current Situation and Needs for Early Attention

- 1.1 *Low awareness of the condition* in Hong Kong's medical allied health and education communities though the public is already well informed through public health education and the media.
- 1.2 *Low awareness of the definitions* by professionals despite its being well agreed by local experts
- 1.3 *Inadequacy of local data:* incidence, characteristics of conditions etc.
- 1.4 *Limited communication* between involved professional groups (lack of trans-sectoral cross pollination).
- 1.5 *A likely significant number of children with undetected learning disabilities* in the community.
- 1.6 *Inadequacy of local research-supported practice tools and interventional 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.
 - 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 system* 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.
 - 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*.
 - 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.
 - 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.

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4. Government and Community Input of Resources

Taking into consideration that individuals with SLD should enjoy their own rights embodied under the United Nations Charter for Children 1989 and the Disabilities Discrimination Ordinance (DDO) in Hong Kong since 1995, proper recognition of the problem together with appropriate and timely input of manpower, resources and blessing from the government, non-governmental organizations (NGO), academic institutions are mandatory and essential for the ultimate success of all aforementioned objectives. All adults should be fully aware that appropriate and adequate provision of remediation, compensation, accommodation and resources support at school, in the family and within the community is not something to be regarded as charitable or compassionate but should be taken up as duty and obligations of the Government and failure of provision might result in litigating procedures at court for proper fulfillment of their rights.

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 (HKCNDP) 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
6. to establish strategic plans for tackling the problem in Hong Kong

Achievements by the Working Party for SLD in Hong Kong

1) Interaction with Public Authorities and Education Fields

Over the years, The Society has been very active on scientific and professional affairs related to SLD and dyslexia. In collaboration with Hong Kong Association for SLD (HKASLD), we have hosted a Special Workshop for Teachers at the Hong Kong City Hall on 12th May 2002 providing basic information, concept 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 advocating a formal system for accommodations for children with SLD at public examinations, and with principal officers of the Special Education Service of Education and Manpower Bureau (EMB) of the Hong Kong SAR Government on 7th October 2002 on service provisions at 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 (the 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 organized 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 message 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 for submission 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 26-28th October 2002 in Hong Kong with focus on Functional Magnetic Resonance Imaging (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 and hearing 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, addressing 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 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 member of a medical/educational team for diagnosis, ascertainment of medical causes, severity of deficit, strengths and weakness, and formulation of individual educational remediation programmes. While remediation, accommodations and Individualized Educational Plans (IEP) 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 endeavor 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 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 recognize 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 maturity, discipline or motivational issue, 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. Changes depend largely on *professional readiness, evidence-based practice, resources availability, and social justice*. Change requires social commitment from the community

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and policy and financial commitments from government. Change is necessary not only because it is the decent thing to do but it is a *legal obligation*.

In Hong Kong, we have already an aroused public. We need coordinated scientific activities, collaborated research and agreed definitions for Dyslexia amongst professionals. We concord with the trial use of agreed new screening and assessment tools. We attempt to mobilize local resources, lobby legislators and government policy makers, provide in-service teachers and teachers in-preparation with professional support, substantiate parent work, and work in coordination with non-governmental organizations (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.

