Specific Learning Disabilities (SLD): A Paediatrician's Role

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 ten years, through the enthusiastic efforts of the Hong Kong Society of Child Neurology and Developmental Paediatrics, a series of professional activities on the subject including the Workshop on "SLD: Setting the Scene in Hong Kong" in November 1998, the Workshop on "SLD 1999: The Way Ahead" in March 1999, the Annual Scientific Meeting on Developmental Dyslexia in December 2002 and others, were organised. These activities have attracted the attention of the profession to this very important subject. As a result, there has been significant progress in the local understanding that SLD and Dyslexia do exist in Hong Kong Chinese. Through "The Resolutions from the Workshop 1999", an agreed definition on SLD by all professionals from intersectoral and multidisciplinary sources was produced (an innovative achievement of Hong Kong professionals and the first of its kind in the world even up to this date), together with proposals for responsible attitudes and transdisciplinary approach which are essential for tackling the disabilities. Professionals have started to accept SLD as a constitutional and heterogeneous group of disorders consisting of four major disabilities, namely developmental dyslexia (dyslexia), specific language impairment (SLI), specific disability in mathematics (Math-LD) and developmental coordination disorder (DCD). Dyslexia occurs in 80% of affected subjects and individuals with SLD can have one or more disabilities in combination. This obviously creates lots of confusion for those unfamiliar with the topic. Dyslexia has been comprehensively studied with strong evidence showing this being a genetic disease with foci at the DYX1C1 on 15q21 and KIAA0319 on 6p7 both are responsible for neuronal migration occurring before 20-week gestation. The disability is thus congenital in origin and occurs prenatally.

With advancement in our understanding of the neurobiological bases, clinical features and evidence-supported interventions for developmental dyslexia, it is imperative that service providers for affected individuals be well informed. Rights of children with SLD are embodied under the United Nations Charter for
Children's Rights in 1989 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 transdisciplinary teams, as well as accountable management plans. In line with these, there must be parents who understand their children's condition and needs, school teachers who have appropriate preparation and ongoing in-service training, enlightened education administrators, as well as widespread public awareness and acceptance of the disabilities. Undiagnosed or improperly managed children with Dyslexia can lead to school failure and drop out, eroded self esteem, juvenile delinquency, substance abuse, and unemployment and underachievement in adult life. Effective legislation and government policies, plus close partnerships between professionals, stakeholders and the public are foundations for success.

On looking back over the past decade, there were several significant milestones for success of work on SLD in Hong Kong. These include the formation of the Working Party on SLD by the Hong Kong Society of Child Neurology and Developmental Paediatrics in 1997 and the alignment of Definition for SLD by multidisciplinary professionals in 1999. Coaching and guidance from visiting world experts on the SLD including Professor Che-Kan Leong (Educational Psychologist from Canada), Professor Drake Duane (Child Neurologist from USA) and Professor Albert Galaburda (Neurologist from Harvard Medical School, USA) from 1999 to 2001 had enriched professionals with knowledge, research, ideas clinical advice in evidence-based approach to management. The International Conference on Dyslexia in Children using the Chinese Language 2002 affirmed for the first time beyond doubt that dyslexia does exist in the Chinese Language.\textsuperscript{8-14} The contemplated legal actions against the government by parents of children with SLD in 2003 provided momentum for action. Furthermore, the inclusion of SLD as one of the disorders within the Rehabilitation Programme Planning (RPP) under the Rehabilitation Advisory Council in 2006 represented official recognition by the Government of the existence of SLD as a disability. Such recognition enables children with these life-long disabilities to have access to management including remediation, compensation, accommodation and resources support at school, in the family and within the community. This also helps individuals with dyslexia to adapt to learning, socialisation and career fulfillment during adulthood. The final catalysts for the recent achievements include the launching of the Position Paper for Future Direction of SLD in Hong Kong 2006 and the direct investigations of the Ombudsmen on the assessment and services for SLD in Hong Kong in 2007.

Modern child health covers medical, educational and social sectors. Admittedly SLD especially dyslexia is a major education problem. However, it also involves domains in developmental paediatrics (developmental behavioural neurology) and public health. Thus paediatricians, being champions in child health\textsuperscript{15} who are fully aware of children's needs, are in the best position to play the vital roles as one of the primary healthcare workers in the community for early identification of SLD transdisciplinary assessment, formulation of the individualised educational programme (IEP) and in the co-ordination and evaluation of the effectiveness of the IEP for this disorder. Paediatricians should always play the key role as child advocates for our children with special needs (which in this case is SLD). It is thus imperative that paediatricians of the 21st century should equip themselves with the most up-to-date knowledge and informtion on the subject so that they can provide timely and accurate counseling and support to individuals with SLD and their families.

Over the years we have successfully convinced professionals in Hong Kong about magnitude of the problem of dyslexia. We are very encouraged to witness that the Health and Food Bureau (HFB) and the Education Bureau (EdB) of the Hong Kong SAR Government have taken up an enlightened attitude towards our children with dyslexia and are also impressed by their willingness to devote resources for this good cause. We applaud the immense contributions of Dr. York Chow (Secretary for Health and Food), Mrs. Betty Ip (Deputy Permanent Secretary for the Education Bureau)
and others for their benevolence to our children. We are also pleased to witness the current special provision for children with SLD at high stake examination of Hong Kong Examination and Assessment Authority (HKEAA). Despite these encouraging progress, we are still facing problems of shortage of teachers with expertise on the subject, education at tertiary institutions and job opportunities in the community. While we need to provide appropriate measures and resources to help children with SLD to overcome their disabilities, it is even more important that we should focus on their strengths which could be in the field of fine arts, sports, designs and other creative and innovative domains as well as to provide opportunities for them to excel in their talented areas. This will ultimately build up their future career!

In order to help to achieve good results for accommodation we need to have effective, efficient and quality screening and assessment services as well as 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 (NGO) at a cost affordable to parents and the latter by small class teaching and resources to support the supervision of the management of children with SLD by psychologists. With the joint efforts of trans-sectoral and transdisciplianry professionals, the future for our children with SLD/dyslexia should be promising and we should be able to provide an optimal environment for them to grow, learn and adapt into adulthood so that they can be useful member of our future community. "Healthy children for healthy world"

References

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