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Message from Subspecialty Division

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This issue of CASER is on one of the most well-recognised problems observed in the field of developmental paediatrics - developmental delay and mental retardation.

Developmental delay is a term that is commonly applied to preschool children whose developmental levels are substantially behind the average expectations of children of the same age in two or more developmental domains.¹ These domains include cognitive and intellectual, gross motor, fine motor, language, social and adaptive development.¹ Significant delay is taken to refer to scores 1.5 to 2.0 standard deviations (SD) below the mean on norm-referenced age-appropriate developmental tests.² At Child Assessment Service (CAS), borderline delay is taken to refer to scores 1.0 to 1.5 SD below the mean of Griffiths Mental Developmental Scales.³ Due to rapid growth and development during infancy and preschool years, the clinical presentation and outcome of children with developmental delay can be highly variable. Very often, developmental delay represents an early warning sign of later developmental problems, such as mental retardation and other developmental disorders.

Mental retardation (MR), on the other hand, is a developmental disability characterized by significant limitations both in intellectual functioning and adaptive behavior as measured by standardized intelligence tests and parent reported scales on adaptive behavior.⁴ In the United States, the prevalence rate is estimated to be around 1% in the population.⁴ According to the data from Census and Statistics Department in 2001, the local prevalence of mental retardation is estimated to be around 0.9 to 1.3% of the general population.⁵ However, local statistics for the paediatric population is still lacking.

The feature topic of this issue is divided into three parts. The first part is on the profiles of children with developmental delay and mental retardation diagnosed in CAS. The second part is a summary report of a local study on the cognitive outcomes of preschool children with developmental delay just before entering primary one, and parental choice of primary school placement. The final part is a discussion on recent trends in educational intervention for children with mental retardation.

Local Profile of Children with Developmental Delay and Mental Retardation

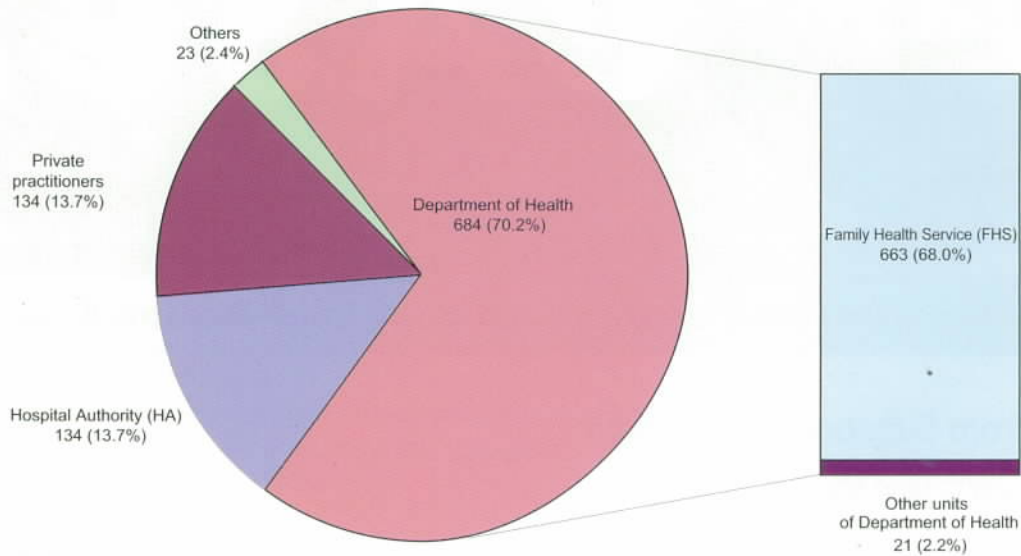
Lau WY

Children with developmental delay and mental retardation represent a substantial proportion of clients served by CAS. In 2004 and 2005, among the 6,439 new referrals received by CAS, 22.7% (1,463) were diagnosed to have developmental delay or mental retardation. From CAS case analysis, the characteristics of these children will be described in the following section.

Sources of Referral

Figure 1 shows that Family Health Service (FHS) is the major source of referral, accounting for approximately 68% of the cases referred. Other common referrers include the Hospital Authority and private practitioners.

Figure 1: Number of children with developmental delay and mental retardation by source of referral

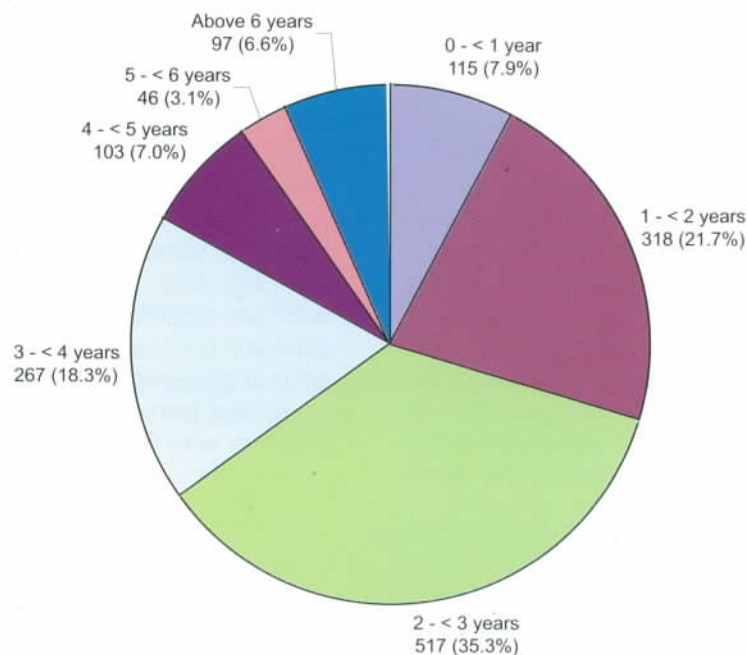


Age at Referral

Children with developmental delay are often identified in the pre-school years. The majority (93.4%) of these children are referred before the age of 6. One third (35.3%) are referred

for assessment between the ages of 2 years and 2 years 11 months, and nearly one quarter (21.7%) at an even earlier age between 1 year to 1 year 11 months old (Figure 2).

Figure 2: Number of children with developmental delay and mental retardation by age at referral to CAS

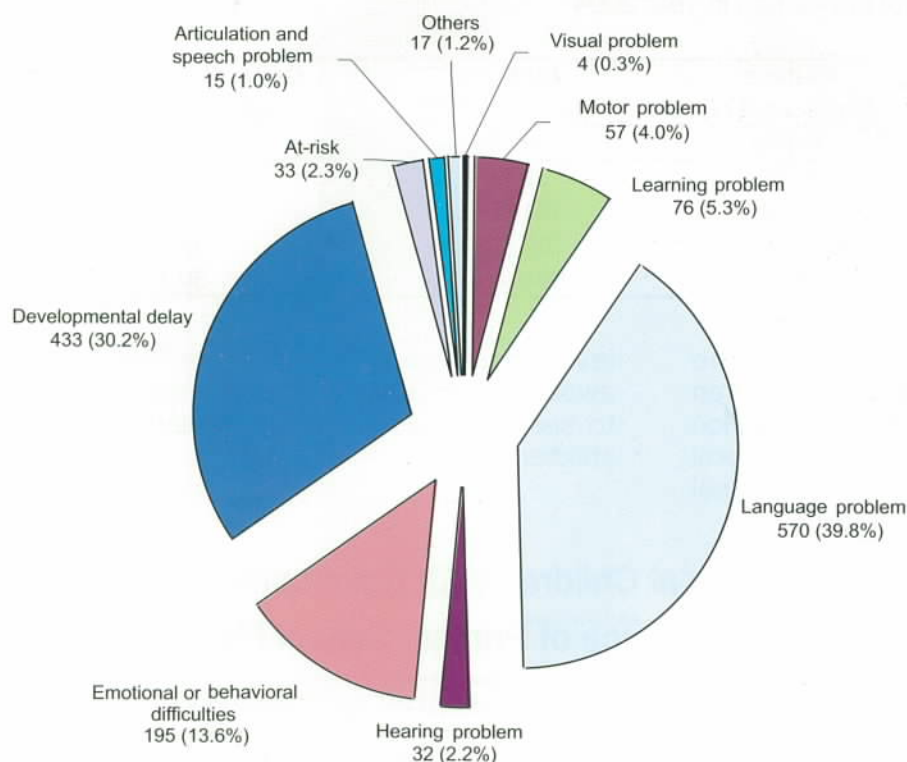


Reasons for Referral

The most common reason for referral (39.0%) is language delay. A possible reason may be that verbal language is an easily observable and important area of development, and failure in achieving the milestones is very likely to draw the attention of parents or medical

professionals on potential developmental problems. Global developmental delay (29.6%) is another major reason for referral. The third most common reason for referral (13.0%) is emotional or behavioral difficulties (Figure 3).

Figure 3: Number of children with developmental delay and mental retardation by referral reason



Diagnosis and Gender Ratio

Among the children of this group, two thirds are assessed to having borderline developmental delay, and the remaining one-third having significant developmental delay. The male to female ratio is about 3:1 for both groups. This ratio is relatively high compared to 1.5:1 reported in the United States.⁴

Socioeconomic Background

To reflect the socioeconomic status of this group of children, education level and occupation of their parents were analyzed.

As shown in Table 1, around two thirds of the parents of children with developmental delay or mental retardation have completed secondary school (60.9% for fathers and 65.0% for mothers). About one fifth of them have achieved matriculation level education or above (21.8% for fathers and 16.6% for

mothers). Around 10% are at primary school level or below (10.5% for fathers and 10.7% for mothers). In the general population of Hong Kong, less than half finished secondary school level (46.7%), a quarter have matriculation level or above (26.7%) and another quarter have an education level of primary school or below (26.6%).⁶ These statistical figures appear to show that parents of this group of children represent a somewhat higher educational level.

Table 1: Distribution of education attainment in parents of children with developmental delay and mental retardation and general population in year 2004

Educational Level	Fathers (Total = 1,341)	Mothers (Total = 1,360)	General Population of Hong Kong
	N (%)	N (%)	%
Primary or below	141 (10.5)	145 (10.7)	26.6
Secondary school level	817 (60.9)	884 (65.0)	46.7
Matriculation or above	293 (21.8)	224 (16.6)	26.7
Others and unknown	90 (6.8)	107 (7.9)	---

Nearly 60% of the fathers of these children are employed as non-manual workers (57.7%), comprising of "managers and administrators," "professionals," "associated professionals," "clerks" and "service workers". This is in contrast to the corresponding figures in the

general population of Hong Kong, where only 39.2% of people have non-manual jobs.⁶ Interestingly, about half of clients' mothers (48.2%) are unemployed or non-working (Table 2), possibly reflecting the need for mothers not to work in order to take care of their children.

Table 2: Distribution of occupation in parents of children with developmental delay and mental retardation and general population in year 2004

Occupation	Fathers (Total = 1,272)	Mothers (Total = 1,220)	General Population of Hong Kong
	N (%)	N (%)	%
Manual workers	263 (20.7)	39 (3.2)	21.6
Non-manual workers	734 (57.7)	461 (37.8)	39.2
Others and unknown	206 (16.2)	132 (10.8)	0.1
Unemployed or non-working	69 (5.4)	588 (48.2)	39.1

In summary, our data show that the socioeconomic status of parents of children with developmental delay or mental retardation were somewhat above those of the general population. Perhaps with higher educational

level, these parents were more likely to be aware of their children's problems and keen to seek early advice and guidance for their children.

Cognitive Outcome of Preschool Local Children with Developmental Delay at Pre-primary One and Their Parental Choice of Primary School Placement

Tang ML

According to a cohort study done recently in Child Assessment Service (CAS), children with various degrees of developmental delay at initial diagnosis were found to have different cognitive outcomes on subsequent follow-up. Children diagnosed to have borderline developmental delay during the preschool period had a near 50% chance of catching up in terms of cognitive function at the pre-primary school stage. However, if a child had significant delay at initial diagnosis, there was more than 80% chance that the child would have cognitive impairment at primary school level. A substantial percentage (40%) of parents with children with mental retardation chose mainstream schools rather than special primary schools.

This is the first local outcome study on children diagnosed with developmental delay in preschool. The study focused on the cognitive outcomes at primary school entry of young children with developmental delay.

Pre-primary Cognitive Outcomes

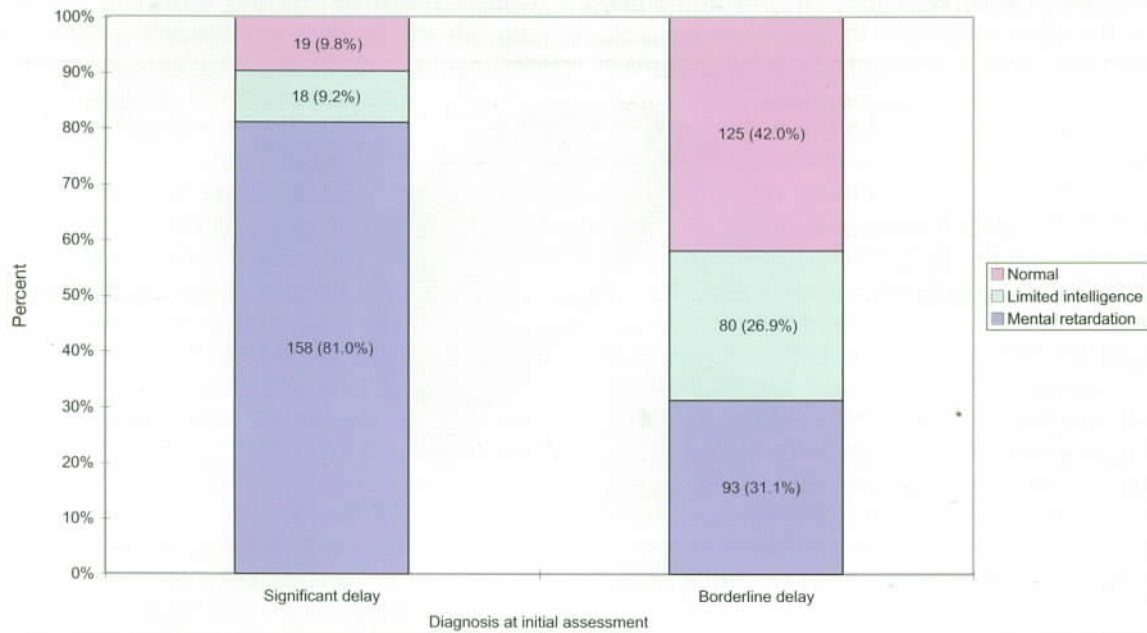
At initial diagnosis, 298 children (60.4%) were evaluated to have borderline developmental delay, while 195 children (39.6%) were found to have significant developmental delay at mental retardation (MR) range.

At pre-primary assessment of children with borderline delay, 125 children (42.0%) were found to have normal intelligence (low average or above), 80 children (26.9%) to have limited

A retrospective cohort was retrieved from the database of CAS from the year 2003/04. 493 children who met the following inclusion criteria were included in the study: (i) aged 5 to 6 years old in the year 2003/04, (ii) less than 5 years of age at initial diagnosis and (iii) undergone medical evaluation of developmental delay by developmental paediatricians in CAS. This cohort all received preschool training in Early Education and Training Centre, Integrated Child Care Centre or Special Child Care Centre. They were then reassessed between the ages of 5 to 6 years old, undergoing either a detailed developmental assessment (using Griffiths Mental Developmental Scales³ by the developmental paediatrician) or an intellectual assessment (using Hong Kong Wechsler Intelligence Scale for children⁷ by the clinical psychologist). This age was chosen because it represents the age before primary school entry, and is a key childhood developmental and social milestone at which successful adaptation is essential for future success.

intelligence, and 93 children (31.1%) to have mental retardation (Figure 4). On the other hand, among the 195 children with significant developmental delay, 158 children (81.0%) were found to have mental retardation, while only 18 children (9.2%) and 19 children (9.8%) were found to have limited and normal intelligence respectively (Figure 4).

Figure 4: Cognitive outcomes at pre-primary assessment



Parental Decision in Primary School Placement

In principle, all children diagnosed with MR are best supported in special schools catering for children with MR; whereas children with limited intelligence should be provided with intensive remedial service in mainstream schools. However, the pattern of our cohort showed a different picture when parental decision was taken into consideration.

Figure 5 shows the results of primary school placements for children diagnosed with limited intelligence after pre-primary assessment. Around half (49.0%) of the parents declined to notify the school principals and the Education and Manpower Bureau on the necessity of remedial service in their new schools.

Figure 5: Parental decision in primary school placement for children with limited intelligence

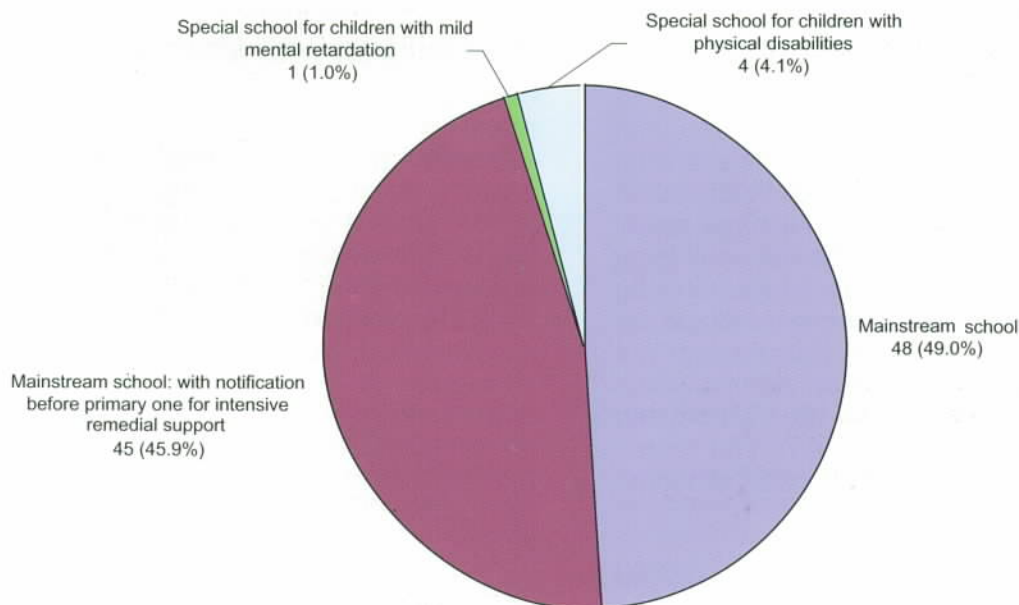
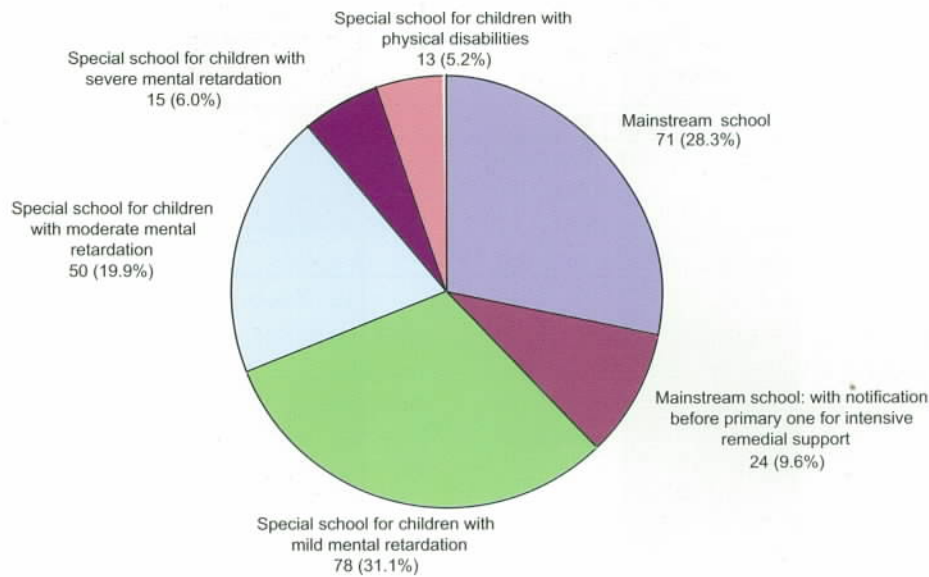


Figure 6 shows the pattern of primary school arrangements for children diagnosed with mental retardation. Around 40% of the parents preferred that their children be integrated into

mainstream schools, with nearly three quarters (71 out of 95) of these declining referral for intensive remedial service at mainstream schools.

Figure 6: Parental decision in primary school placement for children with mental retardation



These results showed that parents of children with MR preferred integrated education in mainstream schools. A substantial percentage of parents had reservations with placing their children in special schools, whilst others were concerned with the possible stigmatization of being a "special educational needs" student in mainstream schools. Decisions on school placement were not correlated with socioeconomic status of parents in this study ($p > 0.05$), although this observation may be affected by limitation of the sample size.

As a significant proportion of parents with mentally retarded children did not notify mainstream schools on their special

educational needs, resource allocation will be difficult and the challenges faced by the teachers in mainstream schools when managing these children with "hidden" demands will be great.

This study highlights the significance of initial diagnosis of developmental delay in predicting the subsequent cognitive outcomes at pre-primary school level. Also, since a substantial proportion of parents with mentally retarded children favoured placement in mainstream schools, the need for notifying and providing support to mainstream school teachers in managing the educational needs of these children must be addressed.

Recent Trends of Educational Intervention for Children with Mental Retardation

Chen YK

Today, there is a widely accepted view from both Western and Asian countries that children with mental retardation should have equal opportunity to receive education in a least restrictive environment, such as a learning environment within the general education system.⁸ In light of such philosophy, the concepts of social integration, full inclusion and inclusive education have been introduced to the general education system. The format and progress of such pursuit varies amongst different countries.

Schools in Western countries (e.g. United States and United Kingdom) are now facing the new and dynamic conceptualization of "inclusive education," which refers not only to the location where children with mental retardation receive education, but also to making relevant supportive services easily

accessible to these children.^{9,10} This concept poses a significant challenge to the teaching model of the general education system: curriculum design, resource allocation and teacher training.^{10,11} Moreover, it also leads to a re-evaluation of the traditional system of special education.

With the multi-professional support available in the United States, there is an increasing trend to integrate children with mental retardation (including those with severe impairments) into local mainstream classes.¹⁰ In European countries, such as the United Kingdom, an intermediate view of retaining special schools as part of the wide spectrum of service provision for children with special educational needs and behavioral difficulties is adopted.¹⁰ Similar trends are also evident in the education systems of Asian countries such as Japan and

Korea. More and more children with mental retardation are now placed to mainstream schools with a decreasing rate of enrollment in special educational services, including special schools or special classes located in mainstream schools.¹²⁻¹⁴

Hong Kong is now facing similar issues and challenges in meeting educational needs of children with mental retardation since the introduction of inclusive education in 1997.¹⁴⁻¹⁶ Based on the beliefs of social equality and least restrictive learning environment, local mainstream schools are encouraged to include these children in regular classroom and are struggling to balance between providing general education and specialized educational services to address their special needs. Teachers in local mainstream schools need to tackle the educational demands of these children under the constraints of limited resources, large student-teacher ratios, as well

as inadequate support on curriculum design and classroom management.¹⁶ Meanwhile, the introduction of inclusive education also poses a special challenge to the whole special education system. Local special schools are now facing a critical stage of service change and need to review their roles in supporting children with mental retardation. New service models, such as special resource centres and out-reach supportive services to teachers of mainstream schools, are developed. To facilitate the future development of educational service for children with mental retardation, further efforts are needed to address issues such as providing in-service teacher training on the characteristics of children with special needs and relevant teaching skills, service collaboration among special schools and mainstream schools, as well as parent education on their active participation in the process of inclusive education.¹⁷

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Publications

Chan HSS, Chan N, Poon C, Yiu B, Yam KY. Selective dorsal rhizotomy in Hong Kong: a multidimensional assessment of outcome. Abstract of the 4th World Congress for Neurorehabilitation, Journal of Neurorehabilitation and Neural Repair 2006;20:113.

Lam L. Diagnostic issues of preschool children with Autism Spectrum Disorders: challenges for clinicians. Brainchild 2006 Feb;6(2):9-13.

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Yam WKL, Chan HSS, Tsui KW, Yiu BPHL, Fong SSL, Cheng CYC, Chan CW. Prevalence study of cerebral palsy in Hong Kong children. Hong Kong Med J 2006;12:180-4.

Scientific Presentations

The following presentations were conducted between January and June 2006:

Selective dorsal rhizotomy: a multidimensional assessment of outcome on 15 February 2006 at the 4th World Congress for NeuroRehabilitation (WCNR) by Chan HSS, Chan N, Poon YC, Yiu-Lau PH, Yam KY.

Intervention and support for children and adolescence with mental retardation - local scene on 17 February 2006 at the Hong Kong Society of Child Neurology and Developmental Paediatrics Neurodevelopmental Conference by Tang ML, Chen YK.

Hong Kong Cantonese Oral Language Assessment Scale (HKCOLAS) seminar and workshop on 25-26 March 2006:

- **Administering HKCOLAS and Test of Hong Kong Cantonese Grammar** by Ng KH.
- **Textual Comprehension Test** by Chan BW.
- **Lexical-Semantic Relations Test and Expressive Nominal Vocabulary Test** by Chan WK.
- **Word Definition Test** by Man YH.
- **Hong Kong Cantonese Articulation Test: phonological development** by Cheung SP.
- **Nonword Repetition Test** by Cheung SP.

Psychological assessment of cognitive and emotional aspects of children with SLD on 26 May 2006 at the Certificate Course on Specific Learning Disabilities Course Programme by Chan MY.

Screening and assessment on 26 May 2006 at the Certificate Course on Specific Learning Disabilities Course Programme by Lam CCC.

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Paediatric traumatic brain injury: acute management, cognitive rehabilitation and school reintegration on 8 June 2006 at the Hong Kong Society of Child Neurology and Developmental Paediatrics Neurodevelopmental Conference by Cheung CP, Lau MT, Ng MY.

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Next Issue

The next issue of CASER will be released in December 2006. The feature topic will be on Autism Spectrum Disorders.

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