

# CASER

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## Child Assessment Service Epidemiology and Research Bulletin

### Message from Subspecialty Division, Physical Impairment Team

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The prevalence of cerebral palsy (CP) remained unchanged for the last 60 years.<sup>1</sup> In Hong Kong, patients with cerebral palsy (CP) are largely being managed in the public sector including Child Assessment Service (CAS) and Hospital Authority (HA), by multidisciplinary teams consisting of various specialists including paediatricians, orthopaedic surgeons, neurosurgeons, nurses and therapists. Many established treatments for CP including selective dorsal rhizotomy (SDR) and intrathecal baclofen (ITB) are available in Hong Kong. Children with CP require various degrees of special educational support and prevocational support. However, the medical transition of this group of patients to adult care is not well established and there are few specific professionals dedicated to comprehensive management of transition to adulthood for individuals with CP.

In this issue of CASER, we will talk about the various joint clinics in CAS, which include Physical impairment (PI) clinics and various joint clinics with collaborators in HA (SDR clinics, Kowloon Physical Rehabilitation clinic (KPRC)). The transition clinic in CAS will also be introduced. This clinic was established to assess these adolescents with various medical, psychosocial and educational issues. Finally, various challenges in assessing children with CP with complex communication needs will also be mentioned in this issue. Methods of modification of the assessment will be discussed.

### Reference

1. Oskoui M, Coutinho F, Dykeman J, et al. An update on the prevalence of cerebral palsy: a systematic review and meta-analysis. *Dev Med Child Neurol* 2013;55:509-19. doi:10.1111/dmcn.12080

### An Overview of Services Provided by Physical Impairment Team in Child Assessment Service

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### Introduction

The prevalence of cerebral palsy (CP) remained unchanged at around 2.11 per 1000 live births for the last 60 years. The prevalence in term and preterm infants was unchanged.<sup>1</sup> Prevalence of CP was lower in Asian than whites and this disparity is unexplained.<sup>2</sup> The prevalence in Hong Kong was 1.3 per 1000 children. The age-specific prevalence rate varied from 1.04 to 1.50 per 1000 children. The low prevalence may be due to differences in study design or a genuinely low prevalence.<sup>3</sup> 55-70% of all children with CP are born at term and only 15-20% of these term infants with CP could be attributed to term birth asphyxia in developed countries. The majority born at term are due to brain malformation or perinatal strokes.<sup>4</sup> 30-40% of all children with CP are born premature with risk factors being extreme prematurity, periventricular leukomalacia etc.<sup>5</sup> Genetics factors including copy number variations and de novo mutations are a cause in 7-14% of CP.<sup>6,7</sup> In a recent study of 90 children with CP, 22.5% had normal intelligence, but 41.3% had moderate or severe intellectual impairment. Epilepsy occurred in 32.5% and attention-deficit hyperactivity disorder (ADHD) in 22.5%.<sup>8</sup> Emotional and behavioural problems are more frequent and these problems seem independent from the subtypes of CP.<sup>9</sup>

Gross motor function improves in most children with CP up to the age of 7 years at which time progress will plateau. From adolescence deterioration in function may be experienced.<sup>10</sup> One research on adolescents with CP showed 45% of those with CP, compared to 5% of controls, failed all examinations in elementary secondary school. The percentage of tertiary education attendance was 3.8%. Only 29% of adults with CP were engaged in open employment. 5% were in supported employment or sheltered

employment.<sup>11</sup> A longitudinal study found that a significant proportion of the children with CP aged 8-12 years old were at high risk of poor mental health. Over 40% showed borderline to abnormal range of emotional and behavioural symptoms.<sup>12</sup>

Transition from paediatric to adult care involves a Shared Management Model which was developed in 2000 by Kieckhefer and Trahms. It involves a philosophical approach for transition planning where there is a continuum of social, developmental, and health outcome achievements to help the child become an independent adult with gradual shift of responsibilities, with an anticipatory guidance approach in a developmentally appropriate manner.<sup>13</sup> Clear transition policies, guidelines, goals, and expectations should accommodate individual needs.<sup>14</sup> The support should be flexible and not be fixed to biological age. Personal, individualised information and support is required.<sup>15</sup> Common barriers to care included lack of accessible resources and lack of referrals.<sup>16</sup>

Physical Impairment (PI) team in CAS offers multidisciplinary assessment for patients with PI conditions including CP. Patients with complicated orthopaedics and physical problems will be assessed in our various joint clinics. This CASER issue aims to give a review of these joint clinics. Multidisciplinary team input is also required when they are transitioning from paediatric care to adult care. Various types of assessment for patients with complicated needs involve special modifications during testing. Cognitive assessment by clinical psychologists is one of the difficult evaluations which requires specialised skills, tools and preparations. The techniques will be covered in this issue.

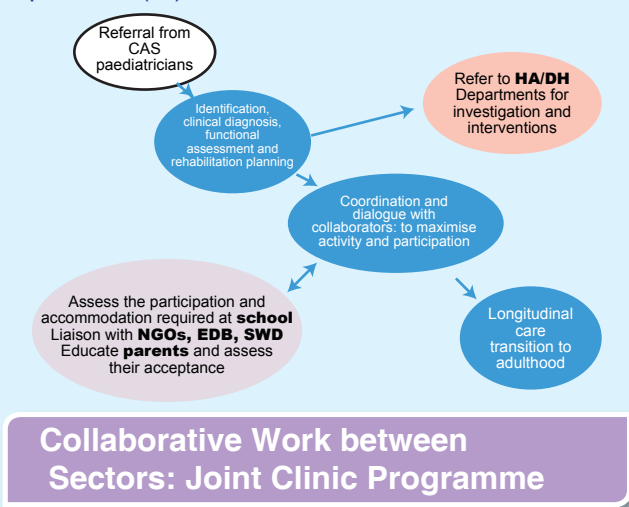
### Physical Impairment (PI) Clinics and Joint Clinics

PI team assesses and manages patients aged from birth to 18 years, with CP and other conditions leading to physical impairment, including neuromuscular diseases. The complex and diverse problems require a team approach. PI clinic doctors, physiotherapists and occupational therapists jointly assess patients. These clinics are held regularly at all the CACs. Usually the first assessment in PI clinic is before 2 years old and are referred by CAS paediatricians if a PI condition is suspected. PI team plays a part in the physical, functional and a life-long approach, and assesses the patient to confirm the diagnosis, look for any associated comorbidities and to evaluate cognitive, physical and functional levels based on functional approach of the International Classification of Functioning, Disability and Health Model (ICF).

After PI team evaluation, a rehabilitation and educational plan will be formulated to cater for the short, intermediate and long term goals. Medical management is based on the functional needs and age. Patients will be referred to paediatric clinics for workup as necessary. We actively collaborate with schools and parents to maximise children's activity

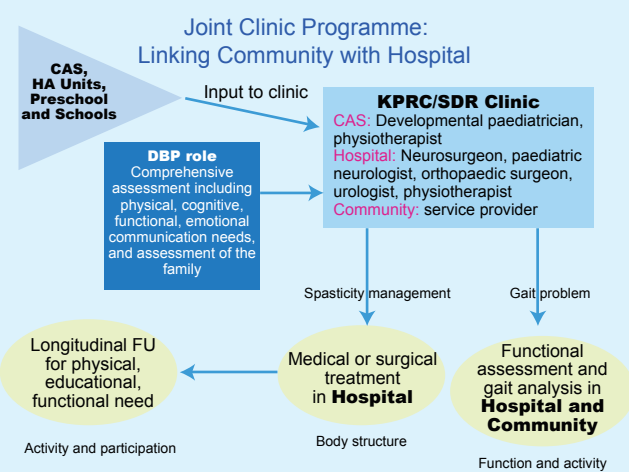
and participation. Adolescents with persistent and significant physical and/or psychological problems may be recruited to PI transition clinic for further assessment (Figure 1).

Figure 1. Management system of Physical Impairment (PI) Clinic



Patients with more complex and diverse problems may require a team comprising various subspecialties, therapists and orthotists. CAS plays a part in the physical, functional and a life-long approach from a developmental perspective, integrating assessments from multidisciplinary staff. Joint clinic with professionals from multiple specialties are hosted and coordinated by PI team (Figure 2).

Figure 2. Management system of Joint Clinic Programme



### Selective Dorsal Rhizotomy (SDR) Clinic

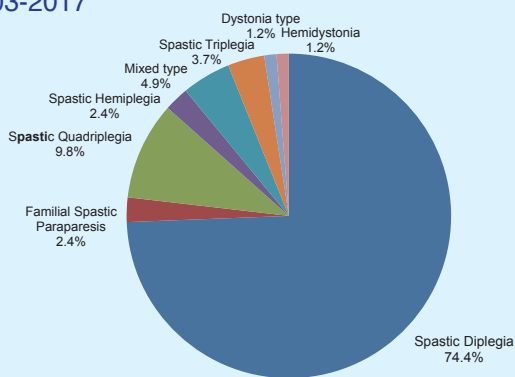
Poon YC Candice<sup>1</sup>  
<sup>1</sup> Physiotherapist

The SDR clinic was first held in March 1997 at Tuen Mun Child Assessment Center, with a total of 70 clinics held as of end 2017. This is a multidisciplinary clinic with developmental paediatrician, physiotherapist, paediatric neurologist, urologist, orthopaedic surgeon and neurosurgeon. In addition

to assessments related to SDR, the team provides recommendations on spasticity interventions when SDR is not the best option. There are regular reviews for post-SDR patients for continual care. They also serve to inform future screening and rehabilitation recommendations, and to provide data on long term outcome. Since 2015, a conjoint assessment programme was developed for potential patients for Intrathecal Baclofen (ITB). The first ITB trial was performed in early 2016.

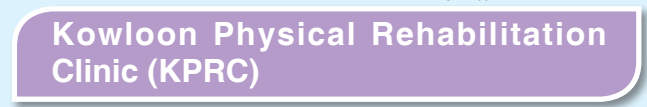
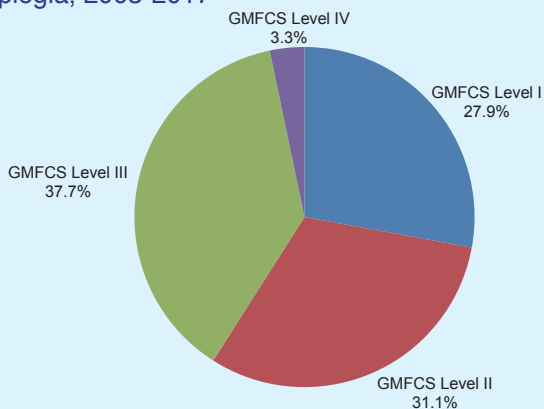
There were a total of 68 children known to CAS who have undergone SDR since 2003. 82 new clients were referred to the SDR clinic since 2003 until the end of 2017. Pre-school children accounted for 40% of cases and early school age another 40%. Case type distribution was shown in Figure 3.

Figure 3. Case type of newly referred clients (n=82), 2003-2017



The majority were clients with spastic diplegia and their Gross Motor Function Classification System (GMFCS) Level distribution was listed in Figure 4.

Figure 4. GMFCS level of newly clients with spastic diplegia, 2003-2017



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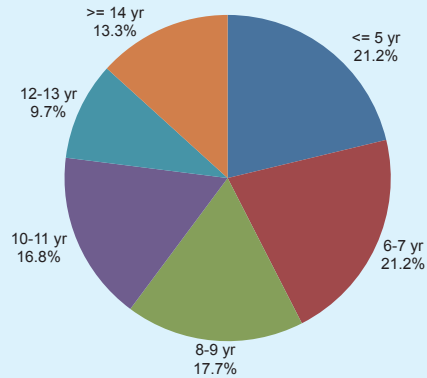
KPRC is a platform for clinicians to discuss the rehabilitation and management of clients with physical impairment. It was organised since 2009 with two clinics per year. There were a total of 21 clinics to date, with different clinicians from other units, including orthopaedic surgeons, neurosurgeons, paediatricians of the Hospital Authority.

physiotherapists and occupational therapists of the Hospital Authority, special schools and Non Governmental organizations (NGOs), who take care of the clients, are also invited. Overseas experts have also been invited to advise on management of cases with complex rehabilitation needs, and to provide a platform for learning and sharing.

Reasons for referral of clients to the KPRC clinic included 47 for tone management, 45 for consideration of orthopaedic management, 16 for post Selective Dorsal Rhizotomy (SDR) review, 13 for consideration of SDR, 3 for gait management and 3 for other reasons.

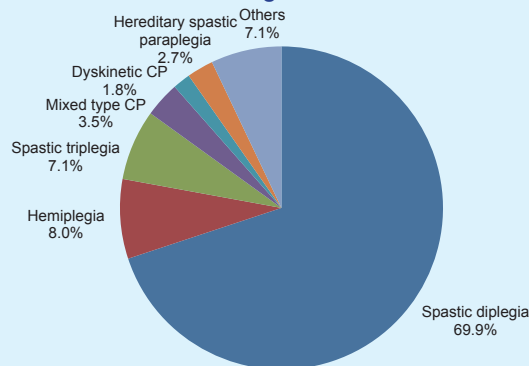
Age distribution of cases seen included 24 (21%) were preschoolers aged 5 years or below, 63 (56%) were primary school students aged 6 to 11 years and 26 (23%) were adolescents aged 12 years or above (Figure 5).

Figure 5. Age distribution of clients referred to KPRC



Diagnoses included 79 (70%) spastic diplegic CP, 9 (8%) spastic hemiplegic CP, 8 (7%) spastic triplegic CP, 4 (3%) spastic and dyskinetic (mixed) CP, 2 (2%) dyskinetic CP and 3 (3%) hereditary spastic paraplegia. Eight (7%) were associated with various conditions including Arthrogryposis Multiplex Congenita, metabolic diseases, Moebius syndrome, suspected peripheral neuropathy, post cerebral infarct, movement disorder and idiopathic tip toe walker (Figure 6).

Figure 6. Breakdown of diagnosis of clients



GMFCS levels of clients with CP include 24 (23%) were level I, 36 (34%) level II, 34 (33%) level III, 9 (9%) level IV and 1 (1%) level V.

Recommendations for clients included 9 who were considered suitable for SDR, 31 planned for orthopaedic surgery, 39 recommended for lower

limb botulinum toxin injection and 3 for upper limb botulinum toxin injection, 7 recommended to use oral medication, while 14 were referred to other clinics for further management. 20 were recommended for further investigations for diagnosis, 32 were referred for more intensive therapy, 31 were referred for equipment, e.g. orthosis. 14 were referred for gait analysis for future decisions, and 65 to be followed up at CAS PI clinic (Table 1).

Table 1. Type of recommendation made by clients

Recommendation	Number
PI clinic follow-up	65
LL Botox	39
Therapy	32
Orthopaedics	31
Equipment	31
Investigation	20
Gait analysis	14
Referrals to other clinics	14
SDR	9
Medication	7
UL Botox	3

### Transition Clinic

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In 2012, transition service was commenced in CAS for children with CP or other physical impairment conditions and with normal or close to normal intelligence, who were studying in mainstream school. The clinic aims to provide them with medical, psychological, educational, social and pre-vocational support and to connect them with available services. Patients over 12 years old may be assessed in the PI Pre-transition clinic. A conference with the full assessment team including paediatrician, clinical psychologist, physiotherapist, occupational therapist and medical social worker will discuss the case after the completion of follow-up evaluation, with the objective to make plans for further action. At the PI transition clinic, the full assessment team assess those aged 15 to 18 years 11 months old. We exclude those attending special school and those with severe mental health problems and attending psychiatric service.

### Scopes and Aims of Service

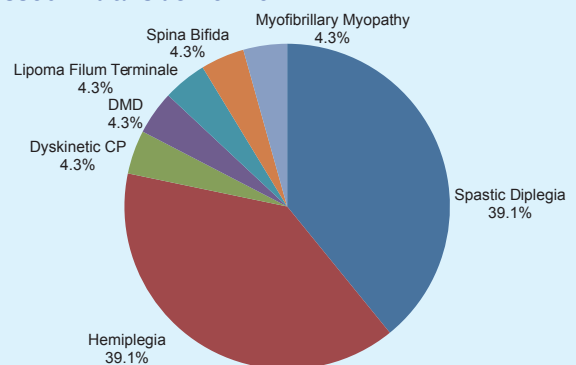
We identify the needs and provide assistance in locating suitable service. For educational transition, we coordinate with school support team, make recommendations and arrange for allowances accordingly. For the pre-vocational transition, we collaborate with other agencies working with these patients. We refer suitable patients to the programmes which provide training subsidies and supported employment. For the medical and physical aspects, we refer suitable patients to orthopaedic surgeons for follow up. We assess their social functioning, peer relationship and psychological well-

being. Our collaborators include school social workers and psychiatrists. We identify any financial needs for the patient and family. We assess if the patient can handle their own financial management. Funding will be sought as needed. Families with problems in family relationship can be referred to social services.

### Statistics for Transition Clinic

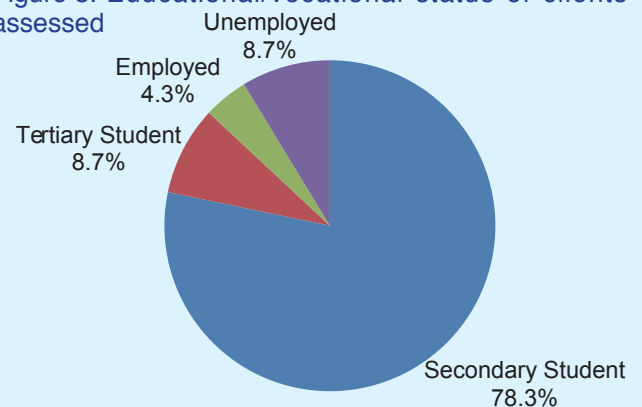
So far, 21 clients were assessed in CAS. The different types of physical impairment are shown in following Figure 7:

Figure 7. Type of physical impairment of clients assessed in transition clinic



The educational/vocational status is shown in Figure 8. They were mostly around 13 to 18 years old (78%) and some were above 18 years old (22%). 71% were male and 29% were female. Most (76%) of them are secondary school students.

Figure 8. Educational/vocational status of clients assessed



Most of the clients were assessed to have more than three problems categorised as in Table 2.

Table 2. Type of problem identified in clients assessed

Type of problem	Number
Musculoskeletal	18
Academic	7
Vocation	6
Socialisation	6
Parenting/family	6
Motor functioning	5
Psychological	4
Psychiatric	3
Respiratory function	2

The summary of management is in Table 3.

**Table 3. Type of management offered to clients**

Management	Number
Pre vocation	7
Joint clinic	4
Hand splint/ Orthosis	4
School liaison	4
Stretching programme	4
Parental counselling	4
Social service	3
Gait analysis	2
Liaison HA CP	2
PH school	2
Orthopaedics	1
Seating clinic	1
Surgery	1
Examination allowance	1
Self help support GP	1

There were 7 referrals for prevocational training. Some were referred to specialist doctor clinics and some for psychological service and counselling. Some referrals were related to the educational aspect.

In western countries, rehabilitation specialists are providing disability-related care to adults with CP. In the future, CAS PI team aims to start early for the transition process with a case manager system. We hope to gather knowledge and experiences of local health professionals as well as adult service providers (both primary and specialty care) in the community, so as to promote transition case service to the clients in need.

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## Challenges in Assessing Cognitive Function of Children with Physical Impairment

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Chen YK Theresa<sup>1</sup>

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### Challenges in Assessment

Children with physical impairment pose much challenge in assessment. Motor skills accounted for about 16% of the variance in the scores, whereas language / cognition accounted for 49% of the variance in many cognitive tests.<sup>1</sup> More than 70% of the items for children aged 9-24 months on the cognitive subscale of a common developmental measure would be unachievable by children with limited hand control.<sup>2</sup>

### Assessment of Choice-making Abilities

It is important to have an accurate identification of their choice-making abilities, i.e. the expression of personal preference and knowledge, which form the foundation for self-determination.<sup>3</sup> They may not be accustomed to the inherent expectation of most assessments or have little experience in responding to questions that are unrelated to the immediate environment. A conceptual model showed a progress of skills/ hierarchy of behaviours beginning with the ability to focus attention on a stimulus, moving from

general to specific signals to express preferences, and finally using specific signals to express concrete and abstract knowledge.<sup>3</sup>

### Selection of Assessment Tools

On the “Guidelines for Assessment of and Intervention With Persons With Disabilities” Guideline 14 published by the American Psychological Association,<sup>4</sup> it was pointed out that “depending on the context and goals of assessment and testing, psychologists strives to apply the assessment approach that is most psychologically sound, fair, comprehensive and appropriate for clients with disabilities”. A recent systematic review<sup>5</sup> aimed at identifying and evaluating a number of population-specific psychometric properties and clinical utility of intelligence (IQ) assessments used for children with cerebral palsy aged between 4 to 18 years old. Nine IQ assessments were reviewed which provide an overall score representative of global, verbal or non-verbal IQ.

- Columbia Mental Maturity Scale (CMMS-3)
- Leiter International Performance Scale - Revised (Leiter-R)
- Peabody Picture Vocabulary Test (PPVT-III)
- Pictorial Test of Intelligence (PTI-2)
- Raven’s Colored Progressive Matrices (RCPM)
- Stanford-Binet Intelligence Scales (SB-5)
- Wechsler Adult Intelligence Scale (WAIS-IV)
- Wechsler Intelligence Scale for Children (WISC-IV)
- Wechsler Preschool and Primary Scale of Intelligence (WPPSI-III)

There is no standardised cognitive assessment or reliable, valid data and population-specific norms for CP. They proposed a framework that facilitates clinical decision in choosing appropriate tools based on their motor and co-occurring communication/ visual perceptual impairments. For those with relatively good hands/ visual function but poor speech, non-verbal performance tests are more desirable.

Social adaptive functioning is also an integral aspect of evaluation in intellectual functioning.<sup>6</sup> Some commonly used social adaptive functioning scales are the Vineland Adaptive Behavior Scales-Second Edition, Adaptive Behavior Assessment System-Second Edition and Scales of Independent Behavior-Revised.

### Modification of Standardised Assessments

On the Guideline 15 by the American Psychological Association,<sup>4</sup> it elucidated that “a testing accommodation is a change in a test format or content, or some aspect of test administration, which makes the test accessible to individuals who might otherwise be unable to complete the measure but does not alter the construct being measured”. The guidelines proposed different ways of testing modifications.<sup>7</sup> All modifications adopted need to be accurately documented. Caution should be taken in interpretation of test findings. For children with complex communication needs, assessment might involve Augmentative and Alternative Communication device.

It is not easy to derive a standardised assessment protocol for all children with physical impairment. Better understanding of the nature of the child’s medical background, diagnosis, nature of communication, physical/ and or sensory difficulties, best possible modes of access and positioning is crucial. In sum, dedicated effort in developing a valid and reliable assessment protocol for this population is the way forward.

### Conclusion

More research is needed to evaluate the intermediate and long term effect of various new treatments for CP including SDR and ITB, on aspects of body structure and function, activities and participation.

In Hong Kong, the medical transition of clients with CP is not well established and there are few specific professionals dedicated to comprehensive management of transition to adulthood for individuals with CP. With patients surviving to adulthood and elderly age today, professional development is needed to address adult needs and medical complications which arise as patients grow older.

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## Recent Publications and Scientific Presentations

### Publications

Chan BMY, Chan CKY. Support service for children with anxiety problems and their parents in Child Assessment Service. *Brainchild* 2017;(18)1:24-26.

Cheung JMC. Attention bias modification: a new therapy for anxiety disorders. *Brainchild* 2017;(18)1:12-16.

Lo HPW, Lau VWY, Yu ESM. Clinical characteristics and developmental profile of child abuse victims assessed at Child Assessment Service in Hong Kong: A five-year retrospective study. *HK J Paediatr (new series)* 2017;22:88-96.

### Scientific Presentations

**Application of visual strategies in intervention and teaching of children with ASD** on 7 December 2017 at Diploma in Special Education (Special Learning Needs Education Course in Autism/Asperger's Syndrome), HKU SPACE by LAM Ling.

**Certification workshop of Copying Speed Test for Hong Kong Secondary Students – Part II report writing** on 24 November 2017 at Hong Kong Occupational Therapy Association by FONG Kin-han.

**Mathematics disability** on 8 November 2017 at Master Program of Educational and Child Psychology, The Hong Kong Polytechnic University by CHAN Mee-yin, Becky.

**Working with children with physical impairment** on 1 November 2017 at Master Program of Educational and Child Psychology, The Hong Kong Polytechnic University by CHEN Yuk-ki, Theresa.

**有特殊教育需要兒童的診斷及評估** on 18 October 2017 at Training Course for Special School Teachers, Centre of Special Educational Needs and Inclusive Education, The Education University of Hong Kong by SHEH Ching-Shan, Annie.

**Child assessment** on 12 October 2017 at The Spastics Association of Hong Kong by POON Wai-kei, Vitti.

**Developmental, behavioral and cognitive profile of neuromuscular diseases in Child Assessment Service and case illustration** on 6 October 2017 at The 13th Congress of Asian Society for Pediatric Research, Hong Kong College of Paediatricians by Dr CHOW Chin-pang.

**Functional impairment in childhood cancer survivors** on 24 June 2017 at The Hong Kong Paediatric Haematology and Oncology Study Group by Dr LIU Ka-yee, Stephenie.

**Understanding typical and disordered development in speech sound system (phonology) in children. How can teachers identify and support children with speech sound system problems in schools?** on 23 May 2017 at Thematic Course on Education of Students with Hearing Impairment and Speech and Language Impairment, The Education University of Hong Kong by NG Kwok-hang, Ashley.

**Autism Spectrum Disorder: what we know and don't know** on 14 May 2017 at Hong Kong College of Paediatricians by Dr LEE Mun-yau, Florence.

**Understanding the aim, scope, and procedures on screening and assessment of oral language functions in pre-school and school-age children. How can teachers identify children with oral language difficulties in schools?** on 11 May 2017; **How to enhance the oral language skills of school-age children with language impairment** on 12 May 2017 at Thematic Course on Supporting Students with SEN – Sensory, Communication and Physical Needs, The Education University of Hong Kong by CHAN Wai-ki, Amy.

**Understanding typical and disordered development in speech sound system (phonology) in children. How can teachers identify and support children with speech sound system problems in schools?** on 24 March 2017 at Thematic Course on Supporting Students with SEN – Sensory, Communication and Physical Needs, The Education University of Hong Kong by CHEUNG Sau-ping, Pamela.

**Understanding the aim, scope, and procedures on screening and assessment of oral language functions in pre-school and school-age children. How can teachers identify children with oral language difficulties in schools?** on 16 March 2017; **How to enhance the oral language skills of school-age children with language impairment** on 17 March 2017 at Thematic Course on Supporting Students with SEN – Sensory, Communication and Physical Needs, The Education University of Hong Kong by CHAN Wai-ki, Amy.

**Assessment of language abilities of school-aged children and HKCOLAS** on 13 March 2017 and 20 March 2017 at Master of Science in Educational Speech-language Pathology and Learning Disabilities programme, The Education University of Hong Kong by CHAN Wai-ki, Amy.

**Post-registration Certificate Course in Child and Adolescent Nursing: learning disabilities and dyslexia** on 9 February 2017 at Institute of Advanced Nursing Studies, Hospital Authority by LAI Yuen-kwan.

**Understanding typical and disordered development in speech sound system (phonology) in children. How can teachers identify and support children with speech sound system problems in schools?** on 25 January 2017 at Thematic Course on Supporting Students with SEN – Sensory, Communication and Physical Needs, The

Education University of Hong Kong by CHEUNG Sau-ping, Pamela.

**Understanding the aim, scope, and procedures on screening and assessment of oral language functions in pre-school and school-age children. How can teachers identify children with oral language difficulties in schools?** on 11 January 2017; **How to enhance the oral language skills of school-age children with language impairment** on 12 January 2017 at Thematic Course on Supporting Students with SEN – Sensory, Communication and Physical Needs, The Education University of Hong Kong by CHAN Wai-ki, Amy.

**Special family support service** on 9 January 2017 at JC A-Connect-Hong Kong ASD Conference 2017: Family Support and Development, Jockey Club Autism Support Network by Dr WOO Kai-fan, Estella.

**Special family support service** on 9 January 2017 at JC A-Connect-Hong Kong ASD Conference 2017: Family Support and Development, Jockey Club Autism Support Network by LAM Ling.

**Psychological assessment for children with special needs** on 24 November 2016 at Department of Psychology, CUHK by CHAN Mee-yin, Becky.

**Teacher workshop on enhancing motor perceptual functioning in primary school children** on 19 November 2016 at Hong Kong Council of the Church of Christ in China by NG Wai-fong.

**Application of visual strategies in intervention and teaching of children with ASD** on 10 November 2016 at Diploma in Special Education (Special Learning Needs Education Course in Autism/Asperger's Syndrome), HKU SPACE by LAM Ling.

**Post-registration Certificate Course in Child and Adolescent Nursing: physical development and related disorders** on 8 November 2016 at Institute of Advanced Nursing Studies, Hospital Authority Head Office and Child & Adolescent Mental Health Service, United Christian Hospital by Dr CHOW Chin-pang.

**General approach to clinical assessment of children: assessment of behavioural, social and emotional aspects of children** on 25 October 2016 at Department of Psychology, University of Hong Kong by CHAN Mee-yin, Becky.

**Intellectual assessment and assessment of adaptive functioning for children with physical or sensory impairment** on 4 October 2016 at M. Soc Sc. Programme, Department of Psychology, HKU by CHEN Yuk-ki, Theresa.

**Developmental coordination disorder and learning disabilities** on 28 September 2016 at Department of Educational Psychology, CUHK by CHUI Mun-ye.

**Augmentative and Alternative Communication (AAC) for people with learning disabilities and complex communication needs** on 16 November 2016 at Institute of Advanced Nursing Studies,

Hospital Authority and Tuen Mun Hospital of New Territories West Cluster by SIU Kit-ling, Elaine.

**Child assessment** on 6 October 2016 at The Spastics Association of Hong Kong by WONG Lai-wah, Polly.

**Case presentation** on 25 September 2016 at Spina bifida international forum by Dr CHOW Chin-pang.

**Assessment** on 23 September 2016 at Heep Hong Parents' Association by TSANG Fung-king.

**Mathematics difficulties: sharing on clinical experience and identification** on 19 August 2016 at Tsung Tsin Mission of Hong Kong by CHAN Mee-yin, Becky.

**Childhood developmental disorders 2: abnormal development** on 1 August 2016, 3 October 2016, 5 December 2016 and 13 February 2017 at Department of Paediatrics, The Chinese University of Hong Kong by Dr LEE Mun-yau, Florence.

**Public services for children with ASD and their families** on 8 July 2016 at Hong Kong ASD Conference 2016: Supporting Learning and Development by Dr LEE Mun-yau, Florence.

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