

The Hong Kong Society of Child Neurology and Developmental Paediatrics

## **Annual Scientific Meeting 2012**

### 16-19 November 2012, Hong Kong

## Augmentative and Alternative Communication



# Programme-at-a-Glance

Date	Time	Session	Торіс	Speaker	
	18:30 – 20:00				
16 Nov 2012 (Fri)	20:00 - 22:00	Seminar I         Augmentative communication to meet the needs of children with severe communication difficulties in the hospital and community		Dr. John Costello	
	10:30 – 11:00	Registration			
17 Nov 2012 (Sat)	11:00 – 12:30	Seminar II	Introduction of augmentative and alternative communication Augmentative and alternative communication & intensive care unit/acute care: changing roles for speech-language pathologist	Dr. John Costello	
	12:30 – 13:30	Seminar III	Message banking: pre-op intervention and intervention for children and adults with progressive diseases impacting speech production	Dr. John Costello	
	13:30 – 14:30	Light Lunch			
	14:30 – 16:00	Seminar IV	When a patient can't speak: supporting communication during critical illness and at end of life (clinical cases/clinical lessons)	Dr. John Costello and Local Discussants	
	16:00 – 16:30	Seminar V	The gadgets and technology for augmentative and alternative communication in the hospital	Dr. John Costello	
	08:30 – 09:00	Registration			
	09:00 – 10:30	Seminar VI	Augmentative communication assessment and intervention: profiles and strategies	Dr. John Costello	
	10:30 – 11:00	Coffee Break			
	11:00 – 11:30	Local Presentation I	ocal     Introduction of augmentative and alternative       resentation I     communication working group		
			Patient with "Locked-in" syndrome – in memory of the late Miu Miu	Ms. Louisa Wong	
18 Nov 2012	11:30 – 13:00	Seminar VII	Augmentative and alternative communication and errorless co-construction of language	Dr. John Costello	
(Sun)	13:00 – 14:00	Light Lunch			
	14:00 – 14:30	Local Presentation II and III	Augmentative and alternative communication intervention for a client with severe intellectual disability and autism	Ms. Chi-yan Lo	
			Augmentative and alternative communication intervention for a student with physical disabilities and aphasia	Ms. Louisa Wong	
	14:30 – 16:30	Seminar VIII	Cortical visual impairment and clinical considerations for assessment and intervention with augmentative and alternative communication	Dr. John Costello	
	18:30 – 19:00		Registration		
19 Nov 2012 (Mon)	19:00 – 20:00	Keynote Lecture	Breaking the silence for children with complex communication difficulties	Dr. John Costello	
	20:00 - 22:00		Chinese Banquet		

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#### Synopsis

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## Welcome Message



We are pleased to present Augmentative and Alternative Communication (AAC) as the theme for the Annual Scientific Meeting (ASM) 2012 of our Society. This is being chosen for a number of factors. Firstly, with rising awareness, we are feeling increasing need to address the knowledge and service gaps for many children with serious communication difficulties in local hospitals, schools and the community. Secondly, our Society has established an AAC Working Group since 2005 whereby a multidisciplinary group including paediatricians, speech therapists, occupational and physical therapists, rehabilitation engineers, nurses and special educators can learn and work together on AAC services, research and development

as well as professional education (working group's website: http://www.aac-hongkong.org/). This group reckons that expert teaching, guidance and advice is necessary at this point to bring their work forward in Hong Kong. Last but not least, Hong Kong is preparing for it first children's hospital to be opened in several years' time (hopefully in 2018 at Kowloon Bay). Children with the most serious medical problems will be referred for treatment, followed by complex rehabilitation planning for a number of years. Systems to address communication needs of children during hospital stay are new to Hong Kong, and we are keen that the hospital's planning, from hardware to professional preparedness to culture promotion, should be commenced at this timely moment. There is keen interest from the children's hospital commissioning team on this upcoming AAC training opportunity. Our course director Dr. John M. Costello, MA, CCC-SLP, is the Director, Augmentative and Alternative Communication Program, Department of Otolaryngology and Center for Communication Enhancement, Children's Hospital Boston, Harvard University, Boston, MA, USA. With his immense knowledge, experience and expertise on the subject, we surely will be able to promise all participants a successful meeting of minds.

In order to make full use of the memorable occasion, we are privileged to host the ASM together with the Hospital Authority for wider promulgation of our message to all colleagues within the public sector. At the same time, we are ready to welcome experts on Developmental Behavioural Paediatrics (DBP) from China to join us at the Meeting. Through years of effort and collaboration, we are most pleased to witness inauguration of the Chinese Society of Developmental and Behavioural Society in Shanghai in 2011. We are most encouraged to learn that experts on DBP from China will join us at the ASM and to have cross-pollination with us on the area of AAC. We also plan to host a separate Professional Meeting for the Joint DBP Group to review our current achievements and to explore further areas of collaboration of our specialty in the future.

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I would like to take this opportunity to thank Queen Elizabeth Hospital and the Hospital Authority for providing us with the meeting venues and the following key figures for contributing to the success of this Annual Scientific Meeting: Dr. Wai-kwong Chak, Dr. Catherine Lam, Ms. Susanna Lee, Dr. Stephenie Liu, Ms. Elaine Siu, Dr. Kwing-wan Tsui, Dr. Theresa Wong as well as all speakers at the Meeting. Special thanks are due to Dr. Hin-biu Chan, Dr. Lily Chiu and colleagues from the Hospital Authority for their effort and dedication in coordinating the ASM and the Commission Course on AAC for the Hospital Authority. Wyeth (Hong Kong) Holdings Limited is to be commended for their support via an Educational Grant as well as to Ms. Melissa Leung and Ms. Sigourney Liu of UBM Medica Pacific Limited for their support (both local and colleagues from China) and all registrants for their active participation which are always vital for the success of this Meeting. For all your support, I say thank you and I look forward to having your continual support in all future activities of our Society.

I wish you all a fruitful and enjoyable Annual Scientific Meeting 2012!

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**Dr. Chok-wan Chan** President Hong Kong Society of Child Neurology & Developmental Paediatrics

### **Council Members**



### The Hong Kong Society of Child Neurology and Developmental Paediatrics

(2012 - 2014)

President:	Dr. Chok-wan Chan
Vice President:	Dr. Catherine Chi-chin Lam
Honorary Secretary:	Dr. Stephenie Ka-yee Liu
Honorary Treasurer:	Dr. Theresa Yee-ling Wong
<b>Council Members:</b>	Dr. Wai-kwong Chak
	Dr. Florence Mun-yau Lee
	Dr. Tim Kam-tim Liu
	Dr. Kwing-wan Tsui
	Dr. Eric Kin-cheong Yau
	Dr. Sam Chak-ming Yeung

## **Organizing Committee**

Chairman: Dr. Kwing-wan Tsui Members: Dr. Wai-kwong Chak Dr. Hin-biu Chan Dr. Catherine Lam Ms. Susanna Lee Dr. Stephenie Liu Ms. Elaine Siu Dr. Theresa Wong

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### **Course Director**



**John Costello** has been a speech-language pathologist specializing in the area of Augmentative and Alternative Communication at Boston Children's Hospital for 28 years. He is the Director of the Augmentative Communication Program and the founder of an internationally unique dedicated program for Augmentative Communication in the Pediatric Intensive Care Units and Acute Care Settings. He pioneered the model of bedside message banking for patients who will have a temporary loss of speech and has now applied that same concept to adults who will experience a permanent loss of natural speech. In addition to being a full-time clinician and director of the outpatient and inpatient AAC Program at the hospital, he teaches graduate

level courses in Augmentative Communication at Boston University, Emerson College and the MGH Institute of Health Professions. John has lectured widely Internationally on topics of AAC in the hospital setting, AAC at end of life and AAC assessment and intervention considerations in the outpatient setting.



#### Dr. Chok-wan Chan

Specialist in Paediatrics, President, Hong Kong Society of Child Neurology and Developmental Paediatrics

#### Dr. Hin-biu Chan

Chief of Service, Department of Paediatrics and Adolescent Medicine, Service Director (Information Technology & Telecommunications), United Christian Hospital

#### **Dr. Catherine Lam**

Consultant, Child Assessment Services, Department of Health

#### Ms. Chi-yan Lo

Speech Therapist, Po Leung Kuk Law's Foundation School

#### Ms. Elaine Siu

Speech Therapist, Co-convenor of the Augmentative and Alternative Communication Working Group, Hong Kong Society of Child Neurology and Developmental Paediatrics

#### Dr. Kwing-wan Tsui

Senior Medical Officer, Department of Paediatrics and Adolescent Medicine, Alice Ho Miu Ling Nethersole Hospital

#### Ms. Louisa Wong

Occupational Therapist, Hong Kong Red Cross Princess Alexandra School

#### **Dr. Theresa Wong**

Specialist in Paediatrics, Honorary Treasurer, Hong Kong Society of Child Neurology and Paediatrics

#### Dr. Eric Yau

Associate Consultant, Department of Paediatrics and Adolescent Medicine, Princess Margaret Hospital

# Programme

Date: Venue: Chairpersons:	16 Nov 2012 (Friday) Lecture Theatre, G/F., Block M, Queen Elizabeth Hospital, 30 Gascoigne Road, Kowloon Dr. Chok-wan Chan and Dr. Kwing-wan Tsui
18:30 – 20:00 20:00 – 22:00	Registration and Light Dinner Seminar I Augmentative communication to meet the needs of children with severe communication difficulties in the hospital and community Dr. John Costello, USA
Date: Venue: Chairpersons:	17 Nov 2012 (Saturday) Room 205S, 2/F., Hospital Authority Building, 147B Argyle Street, Kowloon Dr. Hin-biu Chan (morning sessions); Dr. Eric Yau (afternoon sessions)
10:30 – 11:00	Registration
11:00 – 12:30	Seminar II Introduction of augmentative and alternative communication Dr. John Costello, USA
	Augmentative and alternative communication & intensive care unit/acute care: changing roles for speech-language pathologist <i>Dr. John Costello, USA</i>
12:30 – 13:30	Seminar III Message banking: pre-op intervention and intervention for children and adults with progressive diseases impacting speech production <i>Dr. John Costello, USA</i>
13:30 – 14:30	Light Lunch
14:30 – 16:00	Seminar IV When a patient can't speak: supporting communication during critical illness and at end of life (clinical cases/clinical lessons) <i>Dr. John Costello, USA</i>
16:00 – 16:30	Seminar V The gadgets and technology for augmentative and alternative communication in the hospital <i>Dr. John Costello, USA</i>
Date: Venue: Chairpersons:	18 Nov 2012 (Sunday) Lecture Theatre, M/F., Hospital Authority Building, 147B Argyle Street, Kowloon Ms. Elaine Siu (morning sessions); Dr. Catherine Lam (afternoon sessions)
08:30 - 09:00	Registration
09:00 – 10:30	Seminar VI Augmentative communication assessment and intervention: profiles and strategies Dr. John Costello, USA
10:30 – 11:00	Coffee Break

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# Academic Accreditations

College/Association	16 Nov	17 Nov	18 Nov	19 Nov
Hong Kong College of Paediatricians (cat A)	2 points	5 points	6 points	1 point
Hong Kong College of Family Physicians (cat 5.2)	2 points	5 points	5 points	1 point
Hong Kong College of Physicians (passive)	0.5 point	1.5 points	2.5 points	0.5 point
Hong Kong College of Radiologist (cat A)	2 points	4.5 points	6 points	1 point
MCHK CME Programme (passive)	2 points	5 points	5 points	1 point
Hong Kong Occupational Therapists Association	1 point	2.5 points	3 points	0.5 point
Hong Kong Physiotherapy Association	2 points	5 points	5 points	1 point





### Queen Elizabeth Hospital 伊利沙伯醫院 16 November 2012

Hospital Authority Building 醫院管理局大樓 17 – 18 November 2012



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### Eaton Smart, Hong Kong 香港逸東「智」 酒店 19 November 2012



# Augmentative communication to meet the needs of children with severe communication difficulties in the hospital and community

Dr. John Costello, USA

Seminar I

The inability to communicate is devastating to the psychosocial, emotional and educational development of a child. In the hospital setting many people become communication vulnerable for the first time due to medical interventions. The inability to communication can have many negative outcomes including:

- poor medical outcomes related to medical error,
- increased need for medication and sedation due to patient anxiety and frustration and,
- a patient's belief that the medical staff is providing poor quality of service as they cannot take the time to try to understand the needs of a patient with severe communication difficulties.

As indicated in the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and entered into force in Hong Kong in 2008, there is a charge to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity". Furthermore, there is increased focus internationally on the new standards from The Joint Commission which highlight that effective communication is: The successful joint negotiation of meaning wherein patients and health care providers exchange messages, enable patients to participate actively in their own care from admission through discharge and ensure that the responsibilities of both patient and provider are understood. To be effective, communication requires a two-way process (receptive and expressive) in which messages are negotiated until the information is correctly understood by both parties".

While considerations for communication support are vastly different for children in the community as opposed to the intensive care or acute care setting, this discussion will overview how implementation of unaided strategies such as sign language and gestures, as well as low tech, mid tech and high tech aided strategies can be used to support language learning and the psychosocial and emotional needs of children who are nonspeaking in the community. Further focus will highlight how appropriate assessment and implementation of augmentative communication in the hospital may also support improved patient participation, patient and family satisfaction and possible medical outcomes in the intensive care and acute care medical settings.

### Introduction of augmentative and alternative communication

Dr. John Costello, USA

Seminar II

In the past three decades, the field of augmentative and alternative communication has experienced monumental growth and change. While starting as a field that focused primarily on face to face communication for persons with physical impairment or in some instances for persons with mild to moderate intellectual disability, it has evolved into an area of practice that supports effective communication for *all* persons with complex communication needs in *all* settings. Further, mainstream technologies have broadened the scope beyond interpersonal communication to include web based options such as email, internet communication, blogging, Skype, face time, Facebook, twitter as well as an ever-expanding palate of physical access options and wireless solutions such as GPS integration and blue tooth.

Along with this expanded view of communication comes an international focus on the rights of people with disabilities, application of the World Health Organization's ICF-CY (International Classification of Functioning, Disability and Health – Child and Youth Version) and a specific focus highlighting the basic right to communicate.

# Augmentative and alternative communication & intensive care unit/acute care: changing roles for speech-language pathologist

Dr. John Costello, USA

Seminar II

The inability to communicate in a hospital setting can be terrifying for the patient but may also negatively impact patient care, recovery and satisfaction. With an increased focus internationally on the needs of the patient who is 'Communication Vulnerable', the Speech–Language Pathologist has a unique and pivotal role in the assessment and implementation of AAC strategies to meet patient needs. This lecture will explore the considerations for AAC as it relates to the patient's type of communication vulnerability, developmental stage and an overview of the clinical feature matching process. The need for the Speech–Language Pathologist to be present and available in the hospital setting AND be skilled in the assessment and application of augmentative communication will be highlighted.

# Message banking: pre-op intervention and intervention for children and adults with progressive diseases impacting speech production

Dr. John Costello, USA

Seminar II

Patients who will remain intubated/ventilator dependent after surgery or who have other conditions imposed on them that will impact the ability to speak (tracheostomy, mandibular fixation, etc.) as well as patients with progressive neurodegenerative diseases (Amyotrophic Lateral Sclerosis, Muscular Dystrophy) and headneck cancer requiring total glossectomy and total larnyngectomy may be good candidates for Message Banking in their own voice.

Voice banking and message banking have been recommended for many individuals who will lose the ability to speak, yet the practice and the terms themselves are understood differently by many speech-language pathologists and physicians. This can lead patients and families to be confused or misinformed about their potential options and may cause them to have unrealistic expectations. To add to this dilemma, the concept of voice banking is referenced on the web in confusing and conflicting ways, leading patients who face a temporary or permanent loss of speech to be confused and poorly informed. Indeed, as early as 1988 the term voice banking was used by this center in a pediatric pre-operative model of AAC in the Intensive Care Unit. But as technology has evolved, it is important to evolve the terminology as well.

Through case video and case presentation, this session will detail a model for introducing and implementing 'Message Banking with a patient's own voice', developed in both a pediatric and adult clinical practice at Children's Hospital Boston. Each step of the model for pediatric short term AAC system needs *and* adult permanent AAC system needs will be delineated. In addition, terminology and classification of vocabulary selection will be highlighted. A link to a web-based downloadable Preoperative Message Banking Guide with full details of each step of the process will also be provided.

Case presentation will illustrate process, technologies and protocols for functional clinical implementation.

## Seminar IV

## When a patient can't speak: supporting communication during critical illness and at end of life (clinical cases/clinical lessons)

Dr. John Costello, USA

Communication enables us to relate to the world around us, yet for many persons living with life threatening illness at the end of life, there is little support to communicate. As an AAC specialist on a Pediatric Advanced Care Team, focused on improving the quality of life in children with advanced illness, it is evident that well planned AAC support cannot only create meaningful opportunities for personal communication at the end of life, but can support patients to clearly participate in life determining decision making.

The scope of augmentative communication services for persons with life threatening illness is as diverse as the individuals. For some, tools and strategies to support active decision making regarding care and quality of life is critical while for others the ability to share their experience with the hope of helping another and making meaning out of their own illness, is of primary concern. While for one person, the ability to engage in conversation beyond the realities of life threatening illness is paramount; another is most interested in remaining emotionally connected with loved ones. Age, medical status, life experience and self-awareness of medical status and course are variables that contribute to this disparity.

Several augmentative communication strategies used to support quality of life, and lessons learned from each individual using AAC, will be detailed. Eye gaze tools, single switch speech output tools, simple communication devices, non-electronic communication displays and family directed profiles of a patient's communication strategies will be highlighted.

Through review of current issues, case discussion and video presentation, this seminar will explore AAC strategies to support meaningful communication for optimal quality of life for persons living with life threatening illness.

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## The gadgets and technology for augmentative and alternative communication in the hospital

Dr. John Costello, USA

This brief overview will highlight low tech, mid tech and high tech tools that may be used by patients during varied stages of recovery in the hospital setting. The framework of three profiles of patient communication vulnerability in the ICU/acute care setting as described by Costello (2010) will be used to organize this discussion.

### **Seminar VI**

# Augmentative communication assessment and intervention: profiles and strategies

Dr. John Costello, USA

For more than 20 years the field of augmentative and alternative communication has embraced a 'person first' approach that focuses on identifying current and anticipated strengths, abilities and needs of those with complex communication needs (CCN). These characteristics are then matched to the feature set offered by available augmentative communication hardware, software and strategies. This process, dubbed "feature matching" by Shane and Costello in the 1990's provides a framework for clinical decision making based on a set of rules and pertinent questions that cuts across several assessment domains that includes patient, family, medical, motor, cognitive, sensory, linguistic, social, cultural, educational, behavioral and financial areas (Shane and Costello, 1994). When successfully executed, this process yields clearer insight into AAC tools and strategies needing further investigation through a strategic evidence-based, clinical trial.

This session will provide an overview of domains of assessment and feature matching considerations with a focus on intervention considerations for three categories of communicators: Emerging, Context Dependent and Independent, as described by Dowden (1999). Supporting demonstration of communicative competence in each of these categories requires both engineering opportunities that are truly motivating to the non-speaking person and providing intensive receptive language models through natural and aided language stimulation. In addition, the need for countless opportunities for expressive language practice without judgment of performance *before* expecting consistent intentional expressive communication with AAC to be achieved, will be highlighted.

### Introduction of augmentative and alternative communication working group

Ms. Elaine Siu, Hong Kong

Augmentative and Alternative Communication (AAC) refers to different strategies that assist people with severe communication needs to express themselves efficiently. It includes a range of aided to unaided, high tech to low tech equipment and measures.

An AAC interest group was first formed in 2005, consisting of professionals concerned with communication needs of persons with complex communication difficulties. Members included doctors, clinical psychologists, occupational therapists, physiotherapists, speech therapists and rehabilitation engineers, who met regularly at professional and case sharing events.

In 2007, The AAC Working Group was formed under the Hong Kong Society of Child Neurology and Developmental Paediatrics, with missions to develop and enhance AAC services in Hong Kong through professional advancement, resource development, public education and advocacy. It aims at providing a platform for people who work with persons with complex communication needs to share knowledge and clinical experience.

In 2008, The AAC Working Group conducted a survey on AAC services in Hong Kong to obtain an overview of the local scene. Research findings were published in the Journal of International Society Augmentative and Alternative Communication in 2010. The survey reflected a rising awareness and desire of the community to improve AAC service in Hong Kong. It called for profession education, development of AAC technology relevant to the Cantonese speaking population, increase in official recognition of the need, and strengthening of resource input.

Over these past years, a website (www.aac-hongkong.org) was created for sharing AAC knowledge and free resources. Seminars were run with presentations from local and oversea speakers. A repository of AAC materials and equipment for professional access was established, such that therapists could try out their intervention plans for their patients.

With technological development, tablet computers became popular among the field of special needs services. In 2012, the AAC Working Group developed the first Cantonese communication application (Apps) with funding support from the Queen Elizabeth Foundation for the Mentally Handicapped. The Apps will be launched in December 2012 for professionals' free download and use.

Putting its mission into practice, the Working Group collaborated over the past five years with a range of service providers and stakeholders who serve individuals with complex communication needs. Subcommittees were formed to focus on children in special preschool centres and special schools, and on individuals with moderate to severe intellectual and physical disabilities in activity centres and hospital settings. This is an essential step forward for the Working Group, and results are encouraging. We firmly believe the key element for success lies in the close and cross boundary collaborations among different parties.

Finally, the Working Group would like to express its sincere thanks to all local and overseas experts for their generous support. With joint effort, the future of communication access for persons with special communication needs is bright and promising.

Augmentative and Alternative Communication (17)

### **Local Presentation I**

### Patient with "Locked-in" syndrome - in memory of the late Miu Miu

Ms. Louisa Wong, Hong Kong

The growth of neoplastic neuroma over the spinal cord and cranial nerves caused Miu to gradually lose motor control. By 2010, Miu has lost both vision and hearing abilities, at which time she learned tactile sign language. However, even tactile sensation was lost in the later stages, rendering her a living person captured within a body with no communication access. She finally lost the drive at communication and living.

#### **Questions for discussion:**

- 1. What are the residual abilities of a patient with Locked-in-Syndrome that can facilitate communication? How can these be assessed?
- 2. Are there concrete communication media for these patients?
- 3. By what means of communication can one comfort patients with Locked-in Syndrome and sensory loss?
- 4. How can the communication partner facilitate communication when the patient withdraws from interaction?

# Augmentative and alternative communication and errorless co-construction of language

Dr. John Costello, USA

For persons learning to use two-dimensional representations for expressive communication, language opportunities are often limited to the vocabulary set and context created by adults. This provides limited opportunity for a child to learn the power of inventively manipulating language. It also does not consider what is known about early language use of typical children in which syntactic paraphrasing or re-casting is done by adults without knowledge of the young speaker's true communicative intent. Through a very simple strategy of using a Veltex board, lots of symbols on Velcro, a white board, color markers and a little imagination, you can make language come alive and help your student learn that each symbol/word is powerful manipulation of meaning! Further, students can quickly experience the impact changed word order has on meaning.

## **Local Presentation II**

# Augmentative and alternative communication intervention for a client with severe intellectual disability and autism

Ms. Chi-yan Lo, Hong Kong

YW, a 20-year-old young man was diagnosed with autism and severe intellectual disability. He was a Picture Exchange Communication System (PECS) user at level VI. He was able to make requests and to share what he sees through his PECS communication book. However, as his needs increased and vocabulary expanded, his communication book became thicker and heavier. For independent and more effective communication, YW may need different systems, for which he was introduced to different speech-generating devices. The dilemma was that extensive time and effort was required to learn a new system, and acquired skills were easily forgotten when out of practice.

#### **Questions for discussion:**

- 1. How can one determine which AAC system or combination of systems is appropriate for YW?
- 2. How can the effect of intervention to YW be maximized with limited mental resources?

# Augmentative and alternative communication intervention for a student with physical disabilities and aphasia

Ms. Louisa Wong, Hong Kong

Leslie suffers from Mitochondrial Myeloencephalopathy and Dystonia, resulting in aphasia, spastic quadriplegia, contractures and limited motor input. Being an ambitious teenager, Leslie has motivation to express himself by colour-code eye pointing. However this has been found to be passive, restrictive and inefficient.

#### **Questions for discussion:**

- How can a more reliable response mode be established? (Leslie does not have a reliable control site, as his eye pointing, use of vocalization and facial expressions are inconsistent).
- 2. How can the mounting site of the for eye pointing colour board be optimized? (As a result of his unpredictable dystonic movements, it is difficult to determine the positioning of the colour board to facilitate accurate eye pointing).
- 3. How can Leslie's colour coding system be improved? Are there alternative systems and update AAC technology suitable for Leslie to enhance his communication? (It was noted the colour-code eye pointing system cannot meet the needs of Leslie for complex communication.)

#### Co-author:

Ms. Michelle Cheung, Speech Therapist, Hong Kong Red Cross Princess Alexandra School

## Seminar VIII

# Cortical visual impairment and clinical considerations for assessment and intervention with augmentative and alternative communication

Dr. John Costello, USA

"He inconsistently can make a choice from a field of two." How many times has this been the progresses report statement for your student who has Cortical Vision Impairment, complex communication needs and significant motor impairment?

Cortical Visual Impairment (CVI) refers to visual impairment due to damage to the visual cortex, the posterior visual pathways or both. CVI is a working diagnosis secondary to many medical conditions including Periventricular leukomalacia (PVL), Asphyxia, Hypoxic-ischemic encephalopathy, Intraventricular hemorrhage, cerebral vascular accident, traumatic brain injury, structural abnormalities and other conditions such as damage due to seizure activity, metabolic disorders, etc. Secondary to this damage, the individual can have difficulty in processing and/ or understanding visual information. On examination, however, the eye may appear 'normal.' Instead, CVI is diagnosed most often by a vision specialist who assesses for presence of specific visual characteristics. These characteristics include:

- Color response: usually can see bright colors and may prefer single color objects.
   Visual motor responses: child may have significant difficulty performing multiple r
- Movement response: use motion to gain attention; if it is stagnant it may not be seen.
- Latency of response: it may take time for vision to 'click in,' requiring wait time. With increased consistent experience, wait time decreases.
- Visual fields: may show distinct visual field preferences, may not use central vision at all.
- Complexity: complexity of object or background may make using vision difficult. Competing auditory information (lots of verbal cues) may cause person to stop using vision all together.
- Visual motor responses: child may have significant difficulty performing multiple motor tasks including looking and reaching, looking and pushing switch, etc.
- Light gazing and non-purposeful gaze: competing light from window or overhead lighting will compete with visual attention to task.
- Distance viewing: child has viewing success within a limited area and outward expansion may be supported over time.
- Visual novelty: may have difficulty viewing objects/materials that are new or do not have preferred features.

When a speech language pathologist reviews vision assessment information for a child who has CVI, traditional vision assessments often state that the child 'appears' able to use his or her eyes. Further, standard visual assessments frequently state that the eye is 'normal' and the eye examination was 'normal.' With this information, augmentative communication intervention strategies adopted are typically visually based. Furthermore, when observing the child's apparent visual behavior combined with visual assessment information, strategies investigated often require a child to visually track, shift gaze between options and fixate and attend to representations. In addition, frequent verbal cues and prompts are provided to help keep the child 'on task'. For a child with CVI, each of these expectations/interventions will assure failure. Consequently, these same children are often identified as being 'pre-symbolic', 'unable to attend', 'unable to be engaged', 'easily distractible', 'behaviorally involved', 'emerging communicators' or simply 'inconsistent'.

Through multiple video and case example, this seminar will detail characteristics of CVI, assessment process and intervention successes which support social participation, increased lexical diversity and meaningful communication through simple and complex partner- assisted auditory visual scanning systems. Intervention strategies and materials that first focus on enhanced language opportunities with a secondary consideration of encouraging increased use of vision will be detailed.

### Breaking the silence for children with complex communication difficulties

Dr. John Costello, USA

The field of augmentative and alternative communication has changed dramatically in the past three decades. While far from gone, many social and attitudinal barriers for persons with complex communication needs have been minimized. Policy changes have included increased national and international attention to the rights of people with disabilities, adoption of United Nations Standards and in many parts of the world, new hospital standards of care for people who are communication vulnerable. At the same time technology has become more full functioning, universally accessible and often mainstream, making it more socially acceptable and ubiquitous.

Through case review, this session will highlight that with all of the social and technological changes, persons with complex communication needs continue to rely on the clinical acumen of speech-language pathologists and medical team members to perform thorough clinical assessments. Feature matching the needs and skills of a person to the most appropriate communication tools and strategies remains critical in the classroom, the home or the hospital bed. This will not occur for people with complex needs unless it is recognized that <u>all people communicate</u> and have the right to intervention. There may be different profiles of communicators with vastly different motor, intellectual and sensory needs and skills but they all must first be given the opportunity to learn, participate, succeed *and* fail before they can become effective communicators.

## **Record of Past Annual Scientific Meetings**

Since the inauguration of our Society in 1994, Annual Scientific Meetings were held each year:

2011	Date: 18 – 21 November 2011 Theme: Paediatric Neuro-Radiology Course Director: Professor Paul Griffiths, UK Keynote Lecture: An Approach to Imaging Children with Cerebral Palsy
2010	Date: 26 – 29 November 2010 Theme: Neuro-Immunology Course Director: Professor Russell Dale, Australia Keynote Lecture: Auto-antibodies in Paediatric Neurology
2009	<ul> <li>Date: 13 – 16 November 2009</li> <li>Theme: Autism Spectrum Disorders: Updates on Management</li> <li>Course Director: Professor Lonnie Zwaigenbaum, Canada</li> <li>Keynote Lecture: Complementary and Alternative Medicine in Autism Spectrum Disorders: Public Forum</li> </ul>
2008	Date: 21 – 24 November 2008 Theme: Neuro-Genetics Course Director: Professor Alan Percy, USA Keynote Lecture: Exploring the Neurogenetics of Mental Retardation
2007	<ul> <li>Date: 16 – 19 November 2007</li> <li>Theme: Energy Crisis of Nervous System</li> <li>Course Director: Dr. Ingrid Tein, Canada</li> <li>Keynote Lecture: Approach to the Diagnosis and Management of Muscle Cramps, Exercise Intolerance and Recurrent Childhood Myoglobinuria</li> </ul>
2006	Date: 10 – 13 November 2006 Theme: Attention Deficit Hyperactivity Disorder Course Director: Professor Drake Duane, USA Keynote Lecture: Treatment of ADHD: Medical Behavioural and Educational and Prognosis
2005	Date: 11 – 14 November 2005 Theme: Neuromuscular Disorders of Infancy, Childhood and Adolescence Course Director: Professor Royden Jones, USA Keynote Lecture: Childhood Neuromuscular Disorder from the Perspective of Adult Neurology
2004	Date: 19 – 22 November 2004 Theme: Paediatric Rehabilitation Course Director: Dr. Chok-wan Chan Keynote Lecture: Evolution of Developmental Paediatrics in Hong Kong
	<b>Course Director:</b> Professor Robert Armstrong, Canada <b>Keynote Lecture:</b> Developmental Paediatrics in the 21st Century

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2003	Date: 19 – 22 September 2003 Theme: Paediatric Neurocritical Care Course Director: Dr. Robert Tasker, UK Keynote Lecture: Head Injury and Neuroscience – Inside Fragile Minds
2002	Date: 8 – 11 March 2002 Theme: Paediatric Neuro-Ophthalmology Course Director: Professor David Taylor, UK Keynote Lecture: The Apparently Blind Child
2000	<ul> <li>Date: 8 – 11 December 2000</li> <li>Theme: Language Development, Learning Disorders and Brain Plasticity: Research and Clinical Implications</li> <li>Course Director: Professor Albert Galaburda, USA</li> <li>Keynote Lecture: Language Development, Learning Disorders and Brain Plasticity: Research and Clinical Implications</li> </ul>
1999	Date: 20 – 22 November 1999 Theme: Paediatric Neuro-Epidemiology Course Director: Dr. C. M. Verity, UK Keynote Lecture: What Happens to Children who Suffer with Febrile Convulsions
1998	Date: 14 – 16 July 1998 Theme: Paediatric Epilepsy Course Director: Professor Brian Neville, UK Keynote Lecture: Epilepsy: A Potential Reversible Cause of Developmental Disability
1997	Date: 11 – 13 November 1997 Theme: Neonatal Neurology Course Director: Professor Alan Hill, Canada Keynote Lecture: Brain Injury in Premature Newborn – An Overview
1996	Date: 29 October – 1 November 1996 Theme: Paediatric Neurorehabilitation Course Director: Professor Joe Watt, Canada Keynote Lecture: Recent Advances in Paediatric Neurorehabilitation
1995	Date: 14 – 16 November 1995 Theme: Neurometabolic Diseases Course Director: Professor Kenneth Swaiman, USA Keynote Lecture: Update on Neurometabolic Diseases in Childhood

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