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BRAINCHILD

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Special Issue on Augmentative and Alternative Communication (AAC)

7-year old Sum Sum using an AAC voice output device. A self-portrait.

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

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SPECIAL ISSUE ON AUGMENTATIVE AND ALTERNATIVE COMMUNICATION (AAC)

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The Hong Kong Society of Child Neurology & Developmental Paediatrics
BRAINCHILD – NOVEMBER 2011 ISSUE

Augmentative and Alternative Communication (AAC) in Hong Kong

This issue of Brainchild is devoted to Augmentative and Alternative Communication (AAC).

For many years, augmentative and alternative communication (AAC) in Hong Kong had been a veritable orphan in many senses of the world. It had no self-pronounced parents, no home nor regular centralized resources, and an uncertain future ahead. Most individuals who could have been benefited from AAC have never heard of it. Those who have been introduced to it face serious difficulties in making it a natural and permanent part of their daily lives. Among the serious challenges in this field, the isolated nature in which professionals using AAC are working poses a significant obstacle. For the most part, they work as individually keen staff within special education and work settings, learning on the job and having limited access to team collaboration, expert advice and administrative support. The multidisciplinary nature of an AAC team, encompassing speech therapists, occupational therapists, rehabilitation engineers, physical therapists, physicians, psychologists, social workers, nurses, health care workers and centre-in-charges, requires cross sector collaboration that may not be achievable for most front line professionals as part of their job duties.

The AAC Working Group under the auspices of The Hong Kong Society of Child Neurology & Developmental Paediatrics (HKCNDP) and under the powerful leadership of Dr. Catherine Lam (Developmental Paediatrician) and Miss Elaine Siu (Speech Therapist) germinated from small groups of professionals whose main focus was on children with physical disabilities. Seminars were organized, mainly by speech and occupational therapists, to share clinical experience in using AAC. Whilst reasonable interest was generated from these meetings, members remained a loose group. In 2007, a multidisciplinary group keen on pushing the AAC agenda gathered with the mission of fostering knowledge, skills, awareness and service provisions for children and adults with AAC needs in Hong Kong. This group was subsequently formalized to become the AAC Working Group of the HKCNDP.

This issue contains original papers from pioneer workers in this discipline. They clearly illustrate the evolution, objectives, service modes, research and future directions for AAC in Hong Kong. We thank Dr. Catherine Lam, Miss Elaine Siu and all contributors for their excellent effort and innovative work and sincerely hope that these articles will provide sufficient data and information to encourage all professionals dealing with children to make use of AAC and to promote its clinical practice amongst the community. Above all we need joint effort to do advocacy for manpower and resources support from the government and the community as a whole.

At the time when this issue of Brainchild is being put into print, we are most pleased to witness the inauguration of the China Society of Developmental and Behavioural Paediatrics. This is the fruit of years of dedicated work by an effective group of professionals in the specialty under the great leadership of Professor Jin Xingming, Professor Mao Meng and Professor Chen Ronhua with immense support from the management of Chinese Pediatric Society headed by Professor Gui Yonghao, Professor He Xiaohuand Professor Wu Xiru. This inauguration ceremony was held in Shanghai on 29th October 2011 and marked a significant milestone in the development of the specialty of Developmental and Behavioural Paediatrics (DBP) within the Mainland of China. Its establishment not only provides momentum for development of the DBP amongst professionals in China but also facilitates networking of subspecialists within the Asia-Pacific Region. Such close linkage of subspecialists within the region will definitely promote cross-pollination with great enhancement of subspecialty development. To all the good work of our Chinese colleagues, we would like to send them our best greetings and wish them every success in all their future endeavors!

I wish you all reading pleasure and best of health!

Dr. Chok-wan CHAN
Editor-in-Chief, The Brainchild
President, The HK Society of Child Neurology & Developmental Paediatrics
1st November 2011

An Overview of Augmentative and Alternative Communication Services in Hong Kong

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Communication is essential to our lives. Most of us naturally can express our needs, thoughts and views on any issue, any time, by speech. We can also create friendships and maintain intimate relationships through communication. People with severe speech problem experience difficulties in social participation through sharing their thoughts and ideas. They cannot even communicate with their doctors on health needs. Gradually because of their difficulty in expressing themselves effectively, they become passive and frustrated, with decreasing motivation to communicate. Furthermore, young children with learned helplessness because of communication impairment may become dominated by others (Basil, 1992). Augmentative and Alterative Communication (AAC) is viewed as a way out. It facilitates people using different tools to communicate with others for improving the quality of life.

Augmentative and Alternative Communication (AAC) are the words used to describe extra ways of helping people who find it hard to communicate by speech or writing. AAC helps them to communicate more easily. AAC includes many different methods. Signing and gesture do not need any extra bits and pieces and are called unaided systems. Others use picture charts, books and special computers. These are called aided systems. AAC can help people understand what is said to them as well as being able to say and write what they want.

From the website of International Society for Augmentative and Alternative Communication in 2010 March.

Today, AAC is not just for the people with developmental disabilities, (such as sensory impairment, cognitive disabilities, autism, etc.), with acquired communication disabilities (such as traumatic brain injury), or with neurological diseases. The potential users have been expanded across the entire age span. Recent AAC focus includes supporting individuals who lose their communication abilities in particular situations, such as in the intensive care unit or post medical procedures (Blackstone, 2009).

AAC service in Hong Kong has been available for decades. It helps many people who have communication difficulties to express their needs and gain self-identify. However, many potential AAC users still do not know about AAC. They have neither heard about it nor having any access to it.

In the past decades, a group of professionals share the mission and aspiration to improve the quality of life of people with communication difficulties through AAC, facilitating

expression, participation and communication. Frontline workers have paid great effort in improving AAC services in Hong Kong. Some invented new software for the Cantonese speaking population (e.g. REC-S1 Software communication board). Others adapted western AAC equipments (e.g. GoTalk and BigMac) and software (e.g. Clicker and Speaking Dynamically Pro) for Chinese application. However, these devoted professionals are scattered among different settings and do not have a common platform to share their experience and knowledge. As a result, work is constantly being duplicated and service providers cannot learn from each other's experiences.

Besides, most of the AAC equipment is expensive. People's needs on AAC are diverse and constantly changing, especially for developing children. No individual setting can be equipped with all required AAC equipment. AAC service providers prescribe AAC for their clients depending largely on the availability of devices in their setting. The quality of AAC service may be compromised and the continuity of the AAC service is unsustainable as the clients move from training centre to home to community, and from school to school.

In 2005, a group of professionals from different settings and backgrounds, sharing the same vision for supporting individuals with severe speech and communication disorders, came together to see what could be done. Most members are therapists working in special preschools and schools, others are from developmental paediatric teams and engineering departments. By 2007, a multidisciplinary group, keen on fostering knowledge, skills, awareness and service provision for people with AAC needs in Hong Kong, was formalized to become The AAC Working Group under The Hong Kong Society of Child Neurology and Developmental Paediatrics – a paediatric specialty association with focus on child neurology, developmental behavioural paediatrics and rehabilitation.

The first mission of the group was to understand the state of AAC service provision in Hong Kong. A territory wide survey was conducted. Results revealed the AAC service provision across different settings varied greatly depending on the availability of AAC devices, application, funding sources and service provider expertise (Siu E., Eric T., Dorene S., et al 2010). It also revealed the generalization of AAC devices application from the training room to community was minimal.The use of communication devices in community was also negligible. This situation was the same across settings. Information from the Hong Kong Census and Statistics Department 2008 (Census and Statistics Department, 2008) indicated that the prevalence rate for individuals with speech difficulties was 28,400 persons - about 0.4% of the entire population. Survey of AAC service provision of Hong Kong in 2010 reported that AAC use in the community was below 25%. Low frequency of AAC use in the community (under 25%) was reported in special schools for individuals with intellectual disabilities and, special schools for individuals with physical disabilities .Results of the survey also reported majority (72%) of the respondents, mostly speech therapists and occupational therapists, were not satisfied with their training on AAC specialty. A large number of them (67%) are also not satisfied with the current AAC services provision in their respective settings.

These findings reflect a rising awareness and desire by the community to improve AAC service in Hong Kong. It demands profession education, development of AAC technology relevant to Cantonese speaking population, and increasing official recognition and corresponding resource input.

For further exploring the day to day difficulties of AAC service provision at clinical settings, AAC working group collaborated with AAC service providers from preschool to adult settings and formed focus groups. It aims at addressing the different needs of people with communication difficulties. Subgroups are set up for AAC service providers of special preschools, for special schools for children with moderate grade intellectual disabilities, and for special schools for people with severe to profound grade intellectual disabilities and infirmaries. A high technology subgroup was also formed for meeting needs of people with high communication abilities but challenging physical conditions. Subgroup members openly shared their expertise and experience, with genuine wish to achieve transdisciplinary and cross sector liaison to achieve mutual goals.

Over the past several years, the AAC working group also established a website for sharing of AAC update to people who are interested in AAC (www.aac-hong kong.org). A repository of AAC materials and equipment is assembled and placed on the website, so that all users may readily obtain information and resource links during their work.

For the development of Cantonese specific communication system, the Working Group applied for and secured funding from the Queen Elizabeth Foundation for the Mentally Handicapped for developing a Cantonese communication application. It aims at increasing the access to communication devices for people with special needs by providing free and specifically designed software, coupled with new technology that can be easily acquired in the market at low cost, to enhance use in various institutions.

Successful provision of AAC service depends on various factors. Good collaboration among AAC users, AAC service providers, manufacturers and administrators are equally important. Collaboration among individual service providers is the first step. Further advocacy work on AAC products manufacturers, administrators at individual settings and the government is essential.

At last, AAC working group would like to offer our sincere thanks to all local AAC stakeholders and overseas experts for their great effort and generous support in contributing to the development of AAC service in Hong Kong all along. With the joint effort and hard work of transectoral and trandisciplinary colleagues, the future development of AAC service in Hong Kong is definitely promising.

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Augmentative and Alternative Communication (AAC)

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Speech is one of the defining human activities. People who are not able to speak are limited in their ability to demonstrate that they know or understand things and are in danger of having little control of their lives. This makes them vulnerable and they are at risk of abuse as they cannot report what has occurred.

The reasons for not being able to speak are many and varied. In some cases, lack of speech is a symptom of brain damage, but in others it is wrongly assumed that this is the case.

In the place of speech, a range of **alternative and augmentative communication** systems have developed over time and these are called AAC for short. The label AAC can be used for

- personal gestures that a family might develop for themselves, but that are not understood by others;
- a sophisticated signing system such as might be used by the deaf community;
- a written system such as a letter/word board for those who can spell and read;
- an iconographic system where a symbol represents a word or part of speech, this is useful for pre-readers or for those who are unable to develop literacy;
- a more concrete system where objects represent an activity or basic idea;
- a tactile system, for those who are both deaf and blind;
- an electronic communication system.

With the advent, and then improvement of information technology, small portable AAC systems have been developed. These can combine a range of input systems such as activation by a finger press, a switch press or even eye gaze. These inputs are then combined with a range of outputs such as sound and/or a letter or a pictorial display.

Any communication system has to be learned and for it to be successful it has to be understood by others. It is easy to underestimate the time it can take to acquire a new communication system. When a baby is learning to speak, all the family members are involved in modeling and responding to the child's attempts to pronounce words and then use them in the context of the language.

In the case of learning to use AAC, the family often needs the support of many other people as well. This might be a speech and language therapist to select and introduce the most appropriate system. If the person using the system has difficulty in accurately pointing to a letter, or forming a sign, then an occupational therapist might be required to find an alternative input system (such as a switch, overlay etc.). A teacher can assist in giving the user appropriate practice and challenge in using the new system. A rehabilitation engineer might need to integrate the system, its inputs and outputs into the user's mobility system. Others too might assist – the doctor, in recognizing that AAC is necessary and in referring the potential user on to the other team members; teaching and therapy assistants who might assist in the making of materials and giving practice in their use; a psychologist might be

able to help in assessing the AAC user's level of understanding and give an indication of the complexity of the AAC system that the user can manage.

Family members are still most important and it is their enthusiasm and support that has the greatest impact. They too are the people who tend to have to work hardest at setting the system up, using it in their daily lives and experiencing the frustrations as well as the joys when the system breaks down and/or succeeds.

Many parents of non-speaking children are hesitant and wary at first of using AAC. They are still wanting their child to speak and are fearful that using AAC will make the child 'lazy' and give up trying to talk. In fact, it has been shown that this is far from the case. Using an AAC system reduces the frustration of not being understood and in some cases, by taking the pressure off having to speak, speech spontaneously occurs. However, for other children, it is unrealistic to hope that they will ever speak, but they can still learn to communicate and then engage in education and the wider society through using an AAC system. Speech is far quicker than AAC and people will use it if at all possible. AAC only complements any communication the individual can produce themselves, it does not replace it.

A lot of effort goes into using an AAC system and therefore making the effort worthwhile needs considering, especially in the initial stages. Using the system to gain control over the user's life is often a motivating start. Selecting what clothes to wear, or food to eat, or book to have read, or game to play can give the AAC user control over a part of their life previously denied them.

Thinking of how a system can be used in the day-to-day life of the AAC user is also important. The vocabulary needs to be relevant to their daily experiences. The people around the user need to be trained in what to expect and how to respond and/or help. This can seem a daunting task at first, but with support those around the AAC user begin to see the impact and potential that the system can have. It becomes more rewarding to work with the AAC user and this in turn can increase the stimulation given to the AAC user.

When one considers the range of a speaking person's vocabulary and how they acquire the rules of syntax, it becomes obvious that making adequate vocabulary available is a constant demand on those supporting the AAC user. There is a balance to making lots of vocabulary available and to giving the user time to explore and learn it. This will also be dependent on the underlying ability of the AAC user.

Before AAC users had the reinforcement of a 'voice' in the form of an electronic communication system, people could pass by and pretend not to see the non-speaking person struggling to get a message across. Technology is seen by many people as an acceptable form of communication and with mobile phones, i-pads etc being used by everyone, the AAC user no longer stands out as someone different.

AAC is just one part of the revolution that is slowly taking place in the field of disability. However, it is an important part in enabling the disabled person to be heard, accepted and take their place in the wider community.

Communication Enhancement in Children's Hospitals: Practical Tools to Support Communication Vulnerable Patients

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Abstract

Hospitals around the world are coming to the realization that both the human and economic costs of the communication breakdowns and barriers that regularly occur within their walls are so high that they must be immediately and vigorously addressed. Many hospitals are also beginning to realize that the number of beds filled by patients with a variety of communication vulnerabilities is significantly higher than they once thought. Most hospitals, however, still lag behind in understanding how to address their patient-provider communication deficiencies in a comprehensive way, or how valuable the strategies and tools that speech therapists and audiologists bring to the table can be grappling with the converging communication contingencies they must resolve. This paper presents a framework for identifying and solving patient-provider communication barriers in children's hospitals, taking into account the convergent issues of patients and family members with communication vulnerabilities, second language issues, limited health literacy and cultural differences.

Introduction

Communication breakdowns among patients, their family members and healthcare staff can contribute to many more problems than most people realize. Deaths that result from medical errors, inadequate pain relief, extended hospital stays, increased costs, patient anguish and disorientation—all these and more can often be traced to breakdowns in patient-provider communication (PPC).[1-4] Current research clearly demonstrates that effective communication between patients and healthcare providers significantly increases the likelihood of (a) positive patient outcomes (b) accurate diagnoses and timely treatments, (c) patients and family members understanding and adhering to recommended treatment regimens, (d) greatly improved patient safety and (e) patient and family satisfaction with the care they receive.[5-6] Not surprisingly, effective communication between patients and providers across healthcare settings is increasingly seen as an important "risk management issue" and an essential component of quality healthcare and patient safety throughout the world.[7,8]

In the United States, for example, The Joint Commission, a nonprofit agency that accredits hospitals, recently introduced a new standard for hospitals (along with a useful implementation guide) entitled, *Providing Access to Effective Communication, Cultural Competence, and Patient-and Family-Centered Care)*.[9] It states: "successful communication takes place only when providers understand and integrate the information gleaned from patients, and when patients comprehend accurate, timely, complete, and unambiguous messages from providers in a way that enables them to participate responsibly in their care".[10] In the case of children, the standard also requires finding ways to communicate effectively with parents/guardians who are responsible for the health and well-being of their children. All hospitals must make a number of accommodations to achieve the new standard. These include the provision of interpreter services, assistive devices, referrals to communication specialists, staff training, modification of intake forms, *etc.*

The valuable implementation guide provided to hospitals (and available for free download on line) to help implement the new standard also makes explicit a new "standard," or definition of communication that takes into account that communication between provider and patient is not a one-way street. The guide, called a *Road Map*, requires, rather, the *joint establishment of meaning* between patient/families and health care providers.[1] It also describes a growing number of practical tools and strategies that are now available to help hospitals and other healthcare facilities deal with the many difficult and dangerous communication barriers that crop up in emergency rooms, in intensive care units, in acute care and rehabilitation hospitals, during discharge, and in so many other healthcare settings.

Unfortunately, these valuable tools, techniques and strategies are still far too rarely used to their maximum benefit. The good news is there are many simple and eminently practical ways to use readily available tools and materials to alleviate communication problems, including practical training protocols for health care practitioners, augmentative and alternative communication and other assistive technologies, and creative ways to tweak the hospital environment. The bad news is that only a very small percentage of those who need to know about these ideas are even aware of their existence, and current efforts to spread the word about them are quite limited.

Effective communication in pediatric healthcare facilities: Barriers and solutions

Communication barriers between patients, their families and health care staff can result from a variety of factors, as illustrated in Figure 1 and described in the case example below.

[1]The Joint Commission defined communication as "the successful joint establishment of meaning wherein patients and healthcare providers exchange information, enabling patients to participate actively in their care from admission through discharge, and ensuring that the responsibilities of both patients and providers are understood."

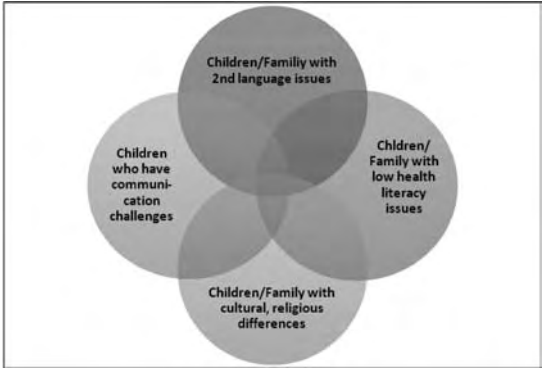

Figure 1. Converging factors affecting successful communication

LG is a 7 years old girl from Malaysia who began experiencing chronic headaches accompanied by nausea, vomiting and dizziness and was diagnosed with a 4th ventricle tumor. She was subsequently flown to a well-known children's hospital in the United States to undergo a craniotomy and resection of the brain. Her family spoke no English. As shown in the diagram, this family presented with second language issues; health literacy issues (the parents were unfamiliar with the U.S. system of healthcare) and cultural/religious differences (parents followed strict Islamic practices). In addition, after her surgery LG would be intubated while in the pediatric intensive care unit (PICU) and temporarily unable to speak. During this period, she needed a way to communicate with her family and hospital staff.

ICUs are especially prone to communication breakdowns. As John Costello and his colleagues have pointed out: the "broad criteria upon which critically ill children are admitted to the PICU suggest, in many cases, that these young patients will see their capacity for communication significantly diminished at some point during their stay. General ICU admission guidelines usually include children with: (a) severe or potentially life-threatening pulmonary or airway disease, (b) severe, life threatening or unstable cardiovascular conditions, (c) neurological conditions or diseases, such as seizures, spinal cord compressions, head trauma and progressive neuromuscular dysfunction, (d) hematology/oncology disease and (e) endocrine/metabolic disease. Many of these conditions are associated with communication vulnerability, because they involve airway patency and management of air gasses, impaired muscle function, strength and coordination and/or neuro-cognitive/neuro-linguistic impairment. Children in PICUs may experience one or all of the conditions that affect communication concurrently, or at varied times during their stay".[11]

LG illustrates a convergence of factors that required *multiple* communication accommodations. While providing an interpreter was obvious, that was not the only accommodation needed. More information about each factor and examples of potential solutions is offered below.

Children with communication challenges

Children who are admitted to the hospital may have (a) pre-existing, chronic communication conditions (*e.g.*, children with cerebral palsy, autism, Down syndrome, spinal cord injury, hearing impairment); (b) acquired conditions caused by the accident/illness for which they are admitted (*e.g.*, traumatic brain injury, meningitis) or (c) temporary conditions caused by a medical procedure (*e.g.*, intubation, sedation after surgery). Speech therapists and audiology professionals are specifically trained to deal with communication processes (speech, language, hearing) and associated challenges, particularly those caused by physical, cognitive and language impairments. These professionals can assess, treat and monitor a child's communication status before, during and after a hospitalization. They can also help train healthcare providers and family members to implement treatment protocols, such as adapted nurse call buttons, communication displays (commercial or personalized), talking switches, assistive listening devices, and can demonstrate strategies and train staff and family. Figure 2 shows a Pocket Talker used to help children or parents with hearing difficulties. Figure 3 shows a speech generating device (the Message Mate), which was used with LG during her stay in the Intensive Care Unit.

Figure 2. Pocket Talker

Figure 3. Message Mate 40

Language differences. When patients, family members and providers do not speak the same language, effective communication about a child's condition or treatment cannot occur. This means that the family is unable to give informed consent, understand instructions, participate actively in care regimes, *etc*. When family members are unable to read or write, they may be unable to fill out forms, sign legal documents, or benefit from written instructions; and when their understanding of basic health issues is limited, so is their ability to help their children or their providers.[12-14] Many hospitals now provide professional interpreter/translation services to patients with limited language proficiency. Research has shown that trained professional interpreters and bilingual health care providers positively affect quality of care, patient outcomes and patient satisfaction.[13] It is also true that no matter how well-intentioned a family member, friend or untrained staff might be, they should not be expected to provide accurate interpretations/translations of medical information. Thus, when in-person, on-site professional interpreting services are not immediately available, hospital staff are encouraged to use interpreting services delivered over the phone or through Video Remote Interpreting.[14-15] Augmentative and alternative communication strategies, tools and technologies can also help support interactions between patients/family members and providers who speak different languages. Figure 4 shows a bilingual communication display with pictograms. Figure 5 illustrates a child using a Talking Photo Album with key messages programmed in two languages. Figure 6 shows 3 of the 26 bedside messages, which can be read or recorded on a speech generating device in English or Chinese.[16]

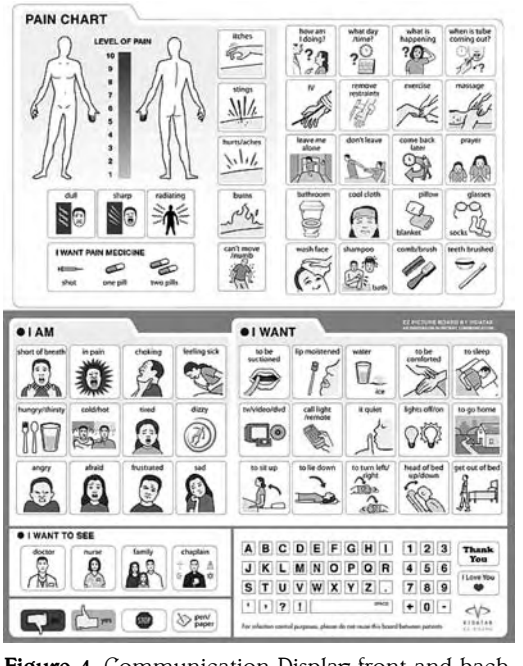

Figure 4. Communication Display front and back. Many boards are bilingual. Developed by Vidatak (with John Costello, Children's Hospital Boston)

Figure 5. Personalized Talking Photo Album

26 Key Bedside Messages: Sample from English & Simple Mandarin

1. I can indicate "yes" and "no". Please ask me yes and no questions.
   我能表示「是」與「不是」，請用「是」與「否」問題與我溝通。
2. Let me explain to you how I communicate.
   請讓我向你解釋我的溝通方法。
3. I am feeling quite a lot of pain; please help me.
   請幫忙，我感到很疼。

Figure 6. Bedside messages. Adapted for use in multiple languages

Low health literacy

Health literacy is defined as the degree to which individuals have the capacity to obtain, process, and understand [and act on] basic health information and services needed to make appropriate health decisions.[17] Low health literacy is prevalent among the elderly, children, minorities, people in poverty, those with lower levels of educational attainment and people of all ages with chronic diseases or disabilities. Limited health literacy currently accounts for many of the disparities in health care that different groups receive.[18] Obviously, the health literacy of parents, who make key medical decisions, affects the care children receive and should be of particular concern in pediatric healthcare facilities.

Hospital staff can help families with low health literacy by being respectful during all interactions while providing forms and instructions in "plain language" using graphics. Professional staff members need to use simple terminology (*e.g.*, say 'stomach' instead of 'gastrointestinal tract'). Also, pictures or videos describing an illness or upcoming procedure can increase understanding, reduce anxiety and may help empower a patient/family to ask questions. Professional staff should always use a "teach back" strategy (Weiss, 2007).[2] Figure 7 shows instructions for hand washing using plain language with graphics. Figures 8 illustrates instructions for an NPO (nothing by mouth) diet.

Figure 7. Easy to understand hand washing instructions

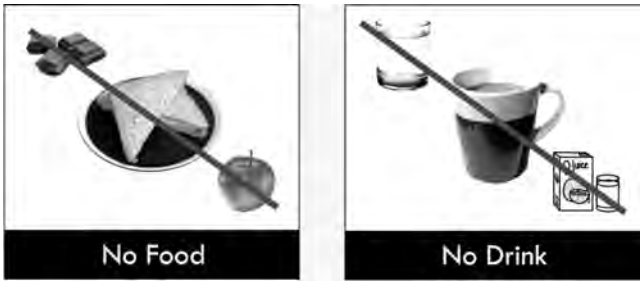

Figure 7. Easy to understand NPO instructions

[2]After providing instructions or information to a patient/family, the provider ensures understanding by asking the family to "Now please show me or tell me what to do."

Cultural and religious differences

While young children typically don't harbor strong beliefs about people based on race, ethnicity, culture or religion, older children and especially parents/guardians may have strong cultural and religious opinions and beliefs that can affect the medical care of their children as well as the parents' interactions with doctors and nurses. For example, LG's father expected doctors to speak to him, not his wife. He always served as the primary informant. The family requested that procedures not be schedule during traditional prayer times.

Admission procedures typically seek information about who is legally responsible for

decision-making, religious preferences, end-of-life directives and other issues (*e.g.*, dietary restriction, the gender of providers). Clergy and social workers may assist both patients and providers to arrange for accommodations during a hospitalization. Augmentative communication and assistive technology tools, strategies and technologies may help staff initiate these discussions using culturally sensitive language and graphics.

LG's communication plan took into account the convergence of factors affecting communication during her hospitalization, in the following ways:

- Before the surgery, the speech therapist, interpreter, LG and her parents worked on developing a digital speech generating device (Message Mate 40)™ with a symbol overlay and messages recorded in her native language and English.
- During her admission, the team developed a personalized picture communication board in both languages with text and pictures to help LG communicate with family, nurses and doctors.
- The speech therapist and interpreter worked with LG's parents to develop a communication board with vocabulary in both languages that enabled the parents to ask medical staff about her diagnosis, treatment, prognosis and care when the interpreter was not present.
- Nursing staff worked with the speech therapist and interpreter on message cards to promote daily nurse/family communication. Nurses could point to a message and the family could read it or in some cases, speak it to the child.
- The speech therapist and interpreter held training sessions with the family, as needed.

Throughout the admission, the family wrote down additional messages to communicate with nurses, *e.g.*, "I will be in the laundry", "I will be in the parent sleep space", "I need to speak with the interpreter". Later on, the interpreter added these to the message cards.

The surgery was successful and LG was discharged from the hospital. She and her family returned to Malaysia and her care was transferred to a rehabilitation facility near her home.

Summary and Available Resources

Improving patient-provider communication is an essential step toward improving the quality of health care and patient outcomes. Children's hospitals and rehabilitation facilities need to identify and address both the patient's and family' communication needs, being aware of and responsive to the variety of socio-cultural perspectives involved.

What are the most cost-effective and practical approaches, strategies, and tools for improving patient-provider communication in a children's hospital? The available literature citing proven and practical ideas is now growing. It is now possible to see, hear, read about and try out many of the tools, forms, communication boards, and strategies that have proven their value in the field, *and* to find the most useful sources of information. The authors have compiled multiple resources and references, which are now available on a special section of their web site called "Resources for Children's Hospitals," at www.patient:providercommunication.org.

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Assistive Technology and Augmentative and Alternative Communication for People with Complex Communication Needs

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Abstract

Augmentative and Alternative Communication (AAC) devices serve the needs of individuals with complex communication needs (CCN). In this paper, we aim to provide an overview on how assistive technologies (AT) are applied to support and facilitate the process of communication. AT innovations and new designs for enhancing effective and efficient communications will be discussed.

Introduction

Communication is an essential component of our daily life. Unfortunately, due to physical, neurological and/or cognitive impairments, Individuals with CCN are often deprived of the opportunity to communicate freely with others. In Hong Kong, over twenty-eight thousand people are diagnosed as having speech impairment and approximately 0.27% of the total population has no speech (Census and Statistic Department, 2008). In a recent report on AAC service provision in Hong Kong, Siu et al (2010) reported that about 50% of the professionals in special schools for physical and intellectual disabilities indicated that AAC devices were used in over 75% of therapeutic training sessions. However, applications of AAC outside school settings were found to be infrequent owing to the availability of AAC devices that each end user can get hold of. To allow full participation for users with physical limitations in communication, suitable ATs including input and selection controls as well as mounting systems for AAC devices are essential. In addition, technologies also play in an important role in the design and development of AAC systems that facilitate language learning, effective communication and speech generation.

Development of AT for AAC

In the past decades, many AAC devices (low, light and high technology) have been developed to ameliorate the communication needs of CCN individuals (Vanderheiden, 2002). Glimpsing back at the development of these technologies, set aside "low technology device" which does not involve any electronics, the first AAC device called POSSUM was developed in the early 60s (Arroyo, 1976). By using alphabet-scanning strategy, individuals with severe physical disabilities can utilize a pneumatic switch to operate an electrical typewriter to generate messages to communicate with others. However, this technique (orthography based approach) relies on spelling and only literate persons can benefit. For individuals with difficulties in spelling, picture/icon based symbols are used as an alternative. Core vocabularies or messages that are commonly used in daily communication

were embedded as voice messages in these pictures/icons. Moreover, in Chinese, there are over 3000 frequently used words/vocabularies. Selecting a suitable vocabulary from these symbols within a reasonable time limit is rather difficult if not impossible. In 1986, Baker (1986) introduced a polysemous symbol set (Minspeak®) which allowed CCN individuals to use a small set of symbols with multi-meaning icons to express themselves in a more effective manner. However, due to the complexity of the Chinese language, polysemous symbol set for Chinese is still under development.

AAC Technology

In general, AAC device is classified as dedicated or non-dedicated and with or without speech output. However, with the rapid growth of mobile technology, this classification may soon be diminished. Mobile device may soon replace the role of dedicated AAC devices on the market to serve individuals with CCN as these devices has high computing power and they are usually incorporated with speech generation device (SGD) for output. Moreover, in considering how ATs were applied to AAC, technology innovations in terms of facilitation of input and selection controls, displays and outputs will be discussed.

AAC devices are developed to facilitate optimal communication. The design of the human-machine interface is particularly important. Ease of access to the AAC device can enhance the fluency of communication. For individuals with CCN, the first challenge they face is how to access the device and perform selection with limited physical function. This barrier is usually bridged by the use of input device, usually an ability switch. Depending on the severity of the physical impairment, the input device can be a special sensor with switch function that detects small body movement (i.e. finger, toe, eyebrow, eye ball or cheek), muscle activities (i.e. electro-oculogram, EOG) or even brain signals (i.e. P300 signal from the electroencephalography, EEG). Once the user gains control of the input, the next crucial step is to make selection from the AAC device. Depending on the type of language representation system that an AAC device adopted, the display technology would vary. Generally speaking, there are 3 types of display technologies used: static, dynamic and hybrid. Static display technology refers to a fixed grid of selection items. As these choices of selection are fixed, users can easily remember the physical locations of each item and selection can be made rapidly. On the contrary, the number of choices is rather limited in number. Therefore, some AAC devices incorporated multi-pages of overlay to the fixed grid to expand the vocabulary base. Users have to manually switch the AAC to another level when a new grid was used. This configuration is in between a static and a truly dynamic display. Dynamic display refers to a refreshable screen, where the display items for different contextual scenes will change in a logical manner according to the user's selection. These changes are programmable to fit different communication scenarios, and can greatly increase the number of core and fringe vocabularies stored in the AAC system. For hybrid display, it incorporated a specific area of static icons for core vocabulary/items, and a dynamic display area to present extended selection of vocabularies or words. The advantages of using dynamic or hybrid display is that the AAC user does not need to memorize the storage locations of the many different communication icons available in the system.

To be able to control/select items available on an AAC device, CCN individuals that cannot perform direct selection would require the system to prompt him/her to make a choice of selection. This is usually done by means of scanning. Basically, the system will seek input from the user as choices of selection are presented to the user one at a time. In a static display system, a small light is usually positioned at the corner of the target item. When this light is turned-on, the user can activate his/her ability switch to make selection. However, this process is time demanding and communication rate is greatly reduced. To speed up the process, row-column/column-row scanning was used. Another alternative way to perform faster input is to use encoding techniques. Specific codes are used to represent different alphabets and input is made by generating these codes via a number of ability switched. The Morse code is an example of this technique.

The output of the AAC device serves as the ultimate interface for communication. In daily activities, verbal communication is the most frequent way for information exchange. In AAC, augmented speech is usually generated in either digitized or synthesized form. Digitized speech refers to recorded speech and synthesized speech is electronic generated voice. Digitized speech is limited by the availability of pre-recorded messages stored in the system. Also the utterance generated from combined selection of communication icons in sentence making would sound quite unnatural. In contrast, synthesized speech (also referred to as text-to-speech, TTS) is more powerful and can almost speak out any word/sentence with reasonable natural utterance. However, there are still limitations. For example, speech generation is dependent upon the availability of TTS engines in a particular language and on a particular platform (i.e. Windows, iOS, Android...etc). Also, to best represent the AAC user, the generated speech should be of appropriate gender with an age match. Modern technology has greatly improved the voice quality of both digitized and synthesized speech output. Furthermore, under legal requirements for equal opportunities, many software manufacturers have now incorporated TTS engines in their platforms. Examples included the "Narrator" in MS-Windows and the "Voiceover" in Mac iOS. Although these TTS systems are primarily used as screen readers for individuals with visual impairment, they can also be used as speech output for AAC software run under these platforms.

Hardware mounting is an important piece of technology, which greatly influences the successfulness of an AAC intervention. Communication happens anytime and anywhere. Be able to carry the AAC device along and provide prompt response is essential in daily function. For individuals with CCN and severe physical disabilities, mounting the AAC device and the ability input switch in a functional orientation is not a simple task. If the mounting fixture is too rigid, it may prohibit some daily routines, including feeding and toileting. If mounting is too flexible, the AAC device may be knocked out of the user's line of sight/control or damaged due to impact. To affix the ability switch, gooseneck type mounting or Loc-line flexible tubing are commonly employed. Other mounting fixtures (i.e. DAESSY Mounts, USA; GUS mount, USA...etc) are also commercially available. In some situations, custom made mounting device have to be fabricated to suit specific needs.

Mobile technology

The advancement of mobile technology and the popularity of these devices in the past few years have opened up new perspectives in device selection by AAC users. This technological bloom has also bombarded the industry to develop new of AAC software for integrated use. Nowadays, communication has got beyond face-to-face interaction. Through the internet, people exchange information and perform chatting real time (i.e. MSN, Twitter, skype...etc). Mobile device has all the advantages to meet this demand. Because of its popularity, the price of these devices is affordable. They are originally designed for internet access and with speech generated device built in. Some AAC software developers have already developed some applications (Apps) for AAC users (i.e. Proloquo2go (AssistiveWare, USA); EZ speech, (Gus Communication Device, USA)...etc). However, the human-machine interface for individual with CCN is still limited. There are some interface products being available on the market (i.e. RJ Cooper, USA).

Other AT contributions

Learning to communicate and resuming communication are the two vital roles of AAC intervention. AT also contributes significantly in facilitate language development as well as performing assessment and training. For children with CCN, AAC device plays an essential role in his/her language development. The contribution of AT is in the architectural design of the AAC system. This is a team effort of many professionals and the key players are speech therapists and rehabilitation engineers. Technology innovations will focus on supporting children's literacy development and facilitate social engagement. To facilitate reading and writing in early childhood, AAC software is designed to be highly flexible, allowing ease of vocabulary expansion, changes of contextual scenes, integration with external devices for classroom participation etc. The technologies involved are dynamic displays with communication links to other computer peripherals via wireless connections. An example is the InterAACt® (DynaVox Mayer-Johnson, USA) a language framework that allows construction of context dependent language to facilitate progression of communication ability levels during growth. In the InterAACt® framework, efficient communication is achieved by using reusable words, phrases and sentences; communication precision is facilitated by selecting from a list of core and categorical words together with user input from keyboard; by using a consistent layout of communication buttons, resistance during transition of communication levels is minimized; ability to easy customization in creation of communication templates and importing image/graphics caters the different needs of the end user and finally, seamless interface to external devices (i.e. environmental controls and computers) allows fully connection with the environment. In terms of reading and writing, software like Kurzweil 3000™ (Kurzeil Educational Systems Inc., USA) allows AAC user get access to electronic books and get hold of web materials and even communication with other on the internet platform.

Conclusion

The field of AAC is keep evolving as technology innovations proliferate. The successfulness of any AAC-AT interventions depend on how end-users find the equipment

satisfy his/her demand in daily routines. These include how technology can be more portable, enabling effective communication with doctors and care givers as well as keeping new friends (O'Keefe et al, 2007). Although mobile technology with dynamic display and embedded SGD output seems to offer an immediate solution, its effectiveness of use by individual with CCN remains to be investigated. So far, the positive outcome of adopting mobile devices for AAC application is by those who are literate and technology lovers. There are still many other concerns remain to be addressed for CCN users. Besides, more evidence based research of the cost effectiveness of using mobile technology for AAC applications are needed. Nevertheless, advancement of AT will continue bringing new and greater opportunities to improve communication for individuals with CCN.

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Meeting the Challenges of Providing Appropriate Augmentative and Alternative Communication Devices for People with Disabilities in the Community

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In Hong Kong, the majority of people with speech dysfunctions are living in their own homes while some others are institutionalized within hospitals or hostels. It is widely accepted in the international rehabilitation community that augmentative and alternative communication (AAC) devices may empower the needy clients to overcome their handicaps in communication. According to Lloyd, Fuller and Arvidson (1997), AAC is defined as:

"1) The supplementation or replacement of natural speech and/or writing using aided and/or unaided symbols...The use of aided symbols requires a transmission device. 2) The field or area of clinical/educational practice to improve the communication skills of individuals with little or no functional speech." (p. 524)

AAC devices can be gadgets being used by ordinary people, such as paper and pencils, fax, smart phones or personal computers. They can also be design-for-disable equipment such as electronic speech synthesizers with visual displays that carry distinctly different shape and form from ordinary gadgets.

We echo with Lindsay's (2010) observation that there is a high level of unmet needs and underutilization of AAC devices. For an example, half of Canadian children aged 5-14 with communication disabilities had none of their needs met (Statistics Canada, 2008). This discussion paper reflects our clinical observation and judgment about ways of meeting the challenges leading to unmet needs and underutilization of AAC devices.

A common challenge towards effective adoption of AAC devises is the lack of support from the clients' significant others, such as their family members, teachers or friends. According to Lindsay and Tsybina (2011), these significant others have already developed specific ways to communicate with the clients. It is likely that they might find AAC devices to be odd or inhuman. Thus, involvement of these important people in the selection of appropriate AAC devices can decrease future frustrations and prevent underutilization of the AAC devices. An extra challenge for Chinese AAC device users is the compatibility of the western developed technology for incorporating Chinese linguistic contents, such as Chinese texts, Mandarin or Cantonese speech output.

However, the information given in product catalogues is usually insufficient for anyone to make adequate selection of the appropriate equipment. Both the clients and their significant others need product samples so that they can gain a good understanding about the strengths and limitations of a device. Thus, it is important to have a well-organized product demonstration service that provides a wide range of samples for hands-on exploration and also produces web-accessible video documentaries for reviewing the features in action.

Due to the highly limited market share for stand-alone design-for-disable AAC devices in Hong Kong, technical support for these items are rare or none. To ensure that local technical supports are readily available, efforts should be spent to explore the appropriateness of consumer products, such as ordinary personal computers, smart phones or tablet PC to test whether they can meet the needs of people with disabilities by adopting some specific settings. In fact, nearly all consumer PCs and smart phones carry some accessibility features for people with disability. When these features are proven to be inadequate, the clinicians should consider assessing those design-for-disable software and accessories that are compatible with consumer products. Stand-alone design-for-disable products should remain the last resort as they are usually more expensive and lack of local technical support.

Another challenge is the portability, mounting and battery capacity issues. It is basically important that the users can carry the AAC devices to their desired operation environment, such as bedside, wheelchairs, classrooms, public transport or shopping malls. Thus, devices of appropriate size and weight, the availability of sufficient battery capacity, adequate mounting and protective accessories are important. For examples, it is essential to consider whether the device can be mounted firmly at the user's wheelchair or whether there is a portable stand that can position the device with adjustable angles at a desk.

A prevailing challenge faced by the needy clients is their financial constrains. Many of them cannot afford to pay for the costs of those ever-changing technology. Thus, they need financial subsidy for getting those devices available now and in the future, as their needs may change or more appropriate technology may emerge. It will be desirable if there can be a public-funded long-term loan service that can allow the users to change for updated devices.

The last but not the least challenge is the perceived image of the AAC device from the perspective of mainstream culture: whether the device represents the stigma of underprivileged disability or the pride of being a smart consumer. In this connection, using specialized software within an ordinary smart phone or tablet PC may be more acceptable for people with disability than using a gadget that ordinary people may associate it with extraordinary conditions.

Conclusion

Clients and their significant others are required to face lots of challenges in the selection, purchase, operation and maintenance of AAC devices. Collaboration among the users, their multi-disciplinary clinicians, IT experts, and funding donors serve to decrease unmet needs and underutilization of purchased devices.

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Experience of Free Augmentative and Alternative Communication Resource Sharing in Hong Kong – Computer Rehabilitation Resource Station (C-Rehab)

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Communication and Augmentative and Alternative Communication (AAC)

Communication is a process of information conveyance which requires a sender, a message and a recipient. Successful communication means that a recipient completely receives the sender's message, which is important for survival, relationship development, and emotion expression. Human communication can be classified into nonverbal, visual, oral and written communication. Gesture, body language, facial expression and eye contact are representations of nonverbal communication. Visual representations, for example, photographs, signs, and drawings, to convey messages are visual communication. Oral communication and written communication refer to spoken verbal communication and written communication respectively. People with various disabilities may have different level of difficulties in communication. Thus another form of communication is needed for them to express needs and ideas. That is augmentative and alternative communication (AAC).

Local Free Resource - C-Rehab

Computer is a machine processing logical operations, and it is very common in Hong Kong. It is a useful assistive device as well as an AAC device. With the development of internet, communication is no longer limited by time and location. The Hong Kong Jockey Club Community Project Grant: Computer Rehabilitation Resource Station (C-Rehab) is a free AAC resource for people with various disabilities. C-Rehab (http://crehab.emv.org.hk) is an on-line training website specially designed for people with intellectual disability and elderly. It provides well-designed therapeutic training programs to enhance their daily living skills and general knowledge so as to achieve independence and community integration. In addition to a wide range of training programs, C-Rehab consists of other services such as "Student Zone", "Photo library", "Teaching Materials DIY", "Rehabilitation Information", and "Therapist Blog" etc. The application of the training programs and services of C-Rehab to meet the needs of people with disabilities is illustrated below.

Index Page of C-Rehab

Autism and Communication Book

People with autism have impairments in communication and social interaction, but they are strong in capturing visual images. If they have difficulties to deliver both verbal and written messages to recipients, visual communication such as photographs or pictures are suitable media to convey their ideas. Communication book is common tool for people with autism to convey messages to others. Users can point to photographs and words in communication book to express their needs and ideas. One of main services in C-Rehab - "Photo Library" consists of clear and colorful photographs in area of food, beverages, clothing, public transport, and cooking utensils etc. Teachers or parents can download the photographs freely and design their own communication book.

Photographs of daily objects inside "Photo Library"

Oral Motor Delay and Blowing Exercise

People with mild intellectual disability or physical disability may have oral motor delay. Oral motor delay may affect one's oral motor control, chewing, speaking or language development, hence oral motor training is needed. Blowing exercise is a useful oral motor training. It can be in form of playing woodwind and brass instruments, singing, blowing paper boat, or blowing bubbles. Computers equipped with microphones and suitable training programs can also provide interactive blowing exercises. C-Rehab has designed several training programs to train blowing abilities. The activities include blowing bubbles, petasl, dandelions, or acting as wolf in the story "Three Pigs and the Wolf". Progress records and reusability are the major advantages of computerized oral motor training.

Exercise blowing in a simulated environment in C-Rehab

Severe Intellectual Disability and Emotion Expression Game

People with severe intellectual disabilities cannot meet the demands for normal developmental functioning including in speech development.They have difficulties expressing feelings and emotions verbally. Self stimulating or self injurious behavior may occur when they try to fulfill their emotional or sensory needs. C-Rehab provides a series of interactive sensory stimulation training programs, which can facilitate these individuals to express themselves by pressing a single switch, through which they could receive visual and auditory stimulation. The ultimate goal is to prevent self injurious behavior. Different topics are provided to suit various needs and interests, including for example, flower gardens, oceans, forests and Hong Kong scenery.

Interactive sensory stimulation training program to smooth emotion

Physical Disability and Scanning Function Training

People with physical disabilities may have limitations in fine motor control, and have to put great effort in using standard computer keyboard or mouse access devices.A cross scanning function program is developed such that the input of a bundle of information may be done through the using of a single switch. The program can scan either row by row or column by column. Users only need to select the mode by pressing one switch, and finally select the character using the same method. C-Rehab has several training programs equipped with this scanning function. Users can learn the concept of scanning function and practice its use.

One step on cross scanning

Scanning function inside C-Rehab's training program

Provision

Apart from C-Rehab's AAC programs illustrated above, other topics are further developed to suit the needs and interests of people with disabilities. Programmable, interactive and cultural specific communication board software is an option other than conventional communication book for people with autism. Moreover, software training programs have precise body motion or eye blinking detection function, to train people with physical disabilities to practice their head control or eye blinking. C-Rehab also hyperlinks with another free AAC resource developed by our Association, namely Rehabilitation Software Encyclopedia, in short Resopedia. Freeware and shareware for people with disabilities are collected and illustrated at the site. AAC software, such as text-to-speech program for people with visual impairment, word prediction program for people with specific learning difficulties are also available. Computers thus have multiple usage, and application on AAC development can greatly benefit people with disabilities.

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Challenges of Assessing Children with Physical Impairments and Complex Communication Needs using Standardized Assessment Tools: from a Clinical Psychologist's Perspective

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Clinician's challenges in assessing children with physical impairments and complex communication needs

Assessing children with complex communication needs and physical impairments, such as the cerebral palsy and those with severe dysarthria are of paramount challenges to clinicians. The challenges can be of many folds as follows.

Firstly, the motor and various sensory difficulties of children with cerebral palsy may limit the applicability of standardized tests and interpretation of test findings need to be with mandatory caution. Secondly, the time limit imposed in the test procedure may penalize children with motor impairments. Sometimes it is difficult to judge whether test failures of children with motor impairments are due to their cognitive deficits (such as slow processing speed) or physical disabilities.

Thirdly, cognitive skills can be difficult to be assessed directly in young children with significant motor or sensory impairments, because the tasks on standardized measures of cognitive skills for young children emphasize motor behaviors. Some research suggested that more than 70% of the items for children aged 9-24 months on the cognitive subscale of a common developmental measure (Bayley, 1993) would be unachievable by children with limited hand control, regardless of their underlying cognitive skills (Cress, 2001).

It was suggested that for persons with complex communication needs using Augmentative Alternative Communication (AAC), cognitive and language skills in particular may develop at rates discrepant from other types of developmental skills. Miller (1999) found that children with developmental disabilities had very different profile of nonverbal cognition, and receptive and expressive language skills, depending on etiology and experience.

Taken children with different types of cerebral palsy as an example who represent a key proportion of our AAC cases, the presentation of their clinical profiles are rather varied, and there is a lack of precise information on the cognitive and neuropsychological functioning of children with different types of cerebral palsy.

Right-hemiplegic children (with left lateralized brain lesion) display deficits on measures of syntactic awareness and sentence repetition, and higher order language function; however their ability in receptive vocabulary may be intact. Clinical experience also support that

children with cerebral palsy seem to have greater difficulty to build up abstract concepts such as colors and numbers, whereas they are more capable to learn verbal concepts which they have more exposure in daily lives.

Children with extrapyramidal cerebral palsy have been found to display a wide range of intellectual abilities, with many of these individuals scoring in the normal range (Lou, 1998). Because of severe dysarthria of the muscles involved in speech, some of these children may have delays or deficits in language skills (Fennell & Dikel, 2001).

Modifications of assessment made necessary

Despite the above difficulties, a major and ultimate goal of a clinical psychologist in the AAC team is to go beyond standardized cognitive testing in order to measure the "trapped intelligence of the child, tapping his/her best potential. In other words, we hope to explore the able mind from the disabled body and understanding their learning and training potentials.

In most cases, modifications of standardized tests may be necessary due to the child's various communication and physical difficulties. Modifications may include adaptation of administration procedures and presentation of testing materials format depending on the child's nature of difficulties. For children with cerebral palsy who have good hands and poor speech, performance (non-verbal) testes are more desirable. If the situation happens to be the opposite, verbal tests shall have the priority.

When serious physical limitations exist, modifications of the standardized testing procedure may be necessary. By the same token, for some children with cerebral palsy with significant movement difficulties, a motor-reduced test may be used. A motor-reduced test requires the barest minimum of motor output for a response. The examinee merely points or gestures (use of head-movement and eyes pointing) to indicate the correct answer among alternatives.

For examples, for a verbal test originally aims to tape a child's fund of picture vocabularies by naming, the child will be asked to point out the pictures of objects (or any form gestures) from different options instead when the names of objects are provided by the examiner. (i.e. becomes a receptive vocabulary understanding and picture identification task). Besides, examiner would also take into consideration of the child's hand function and access in order to determine the spacing and layout of testing materials being presented. Instead of using the original stimulus books, the examiner may manipulate the choice of answers to be 1 out of 2, 1 out of 4 or 1 out of 8 according to the child's ability. Thus, assessment becomes a dynamic process, and it also provides a platform for examiner to determine the entry level point for designing AAC tools suitable for the child's ability.

In terms of clinical practice, the selection of standardized tests largely depends on the child's abilities and physical limitations as well as upon individual tester's preferences.

Examples of non-verbal intellectual assessment for children with better hands that are commonly used in our clinical setting are: the Comprehensive Test of Nonverbal Intelligence (CTONI), Test of Non-verbal Intellgience-3rd edition (TONI-III), Merrill-Palmer Scale of Mental Tests, and Columbia Mental Maturity Scale. For children with good verbal functioning, the Weschler Intelligence Scale for Children-Fourth Edition (WIS-IV), Leiter International Performance Scale-Revised, and Stanford Binet Intelligence Scale Fourth Edition (SB:FE) are the commonly chosen tests by clinicians.

In most cases, due to the children's expressive or physical constraints, not the whole battery can be administered thoroughly. In such a case, interpretation of test results should be made with caution, and estimation of the child's cognitive functioning could only be estimated with clinician's best "educational guess" based on more than single assessment tools. Moreover, for children with significant motor impairment, assessing children's receptive language skills and basic pre-academic concepts will be one of the major focuses of cognitive assessment.

Some researchers (Ross & Cress, 2006) suggested that as receptive language skills can be assessed with fewer physical restrictions than early cognitive developmental measures, it may provide an achievable benchmark of skills against which other developmental skills can be considered. Children with severe expressive impairments may have a discrepancy between expressive and receptive communication skills, due to greater motor, modality or accessibility constraints on producing rather than understanding other intended message (Beukelman & Mirenda, 1998). In such children, receptive communication may reflect more closely a young child's communicative and procedural competence than estimates of his or her non-verbal cognition or expressive language.

Apart from cognitive functioning, social adaptive functioning is also a part-and-partial aspect of evaluation in order to ascertain the child's intellectual ability (DSM-IV text revised, APA). In our clinical setting, the commonly used social adaptive functioning scales are the Vineland Social Maturity Scale, as well as State of Independent Behavior-Revised (SIB-R). These scales were administered with the parents or caregivers as informants.

On parent's side, the AAC team will also examine the parents-child communication patterns, parent's motivation and skills, so as to identify the family's strengths and limitations, as well as the family's readiness in adopting AAC on their children. On top of assessing the child's intellectual potential, another purpose of AAC assessment was to identify whether the child is potential candidate user of AAC. Thus, a child's other aspects of cognitive functioning, such as attention span, their alertness to environment will be assessed. Moreover, other factors, such as the child's communication intention, modes of communication preferred or habitually used by the child, as well as the child's motor/access constraints will also need to be evaluated formally or informally.

It will be more valid to assess the child's understanding of functional vocabularies by interviewing his/her parents, teachers and caregivers who have more chance to observe

and interact with the child in daily life across various naturalistic settings. In serving this purpose, our team has designed a pre-assessment questionnaire in order to tap the child's communication pattern and vocabularies inventories in daily lives by interviewing the school personnel, parents, and caregivers. Our team may also arrange home and school visit if necessary in order to observe the child in a more unobtrusive and socially valid situations.

The importance of a multidisciplinary assessment team

Our AAC assessment team in the Child Assessment Service composes of multi-disciplines, including Paediatrician, Physiotherapist, Occupational therapist, Speech therapist, as well as Clinical Psychologist. Given the complex nature of most clients, involving multiple impairments, our team needs to work closely well before and during the whole assessment process.

Before assessment could be formally conducted, a team intake conference and preparation meeting will be arranged in order to understand the nature of child's medical background, diagnosis, nature of communication, physical and/or sensory difficulties.

On the day of assessment, physiotherapist will help to set up the physical settings, such as making the child's seating or positioning more conducive to the child in performing table tasks. An occupational therapist will focus on mounting and hand access of the child (such as choose of using different access, such as Big Mac, or E-trans-frame display), and speech therapist may suggest the mode of responds (such as scanning) that best allow the child to indicate the answers. Clinical psychologist will also work closely with speech therapist in examining the child's verbal functioning, comparing the results derived from intellectual assessment with those by speech therapist.

Referral logistics

With a review of our AAC registry entry data since 2003 to 2010, we have so far served 57cases with AAC needs, covering children with physical impairments (40 cases), syndromal cases (6 cases), pure mental retardation (6 cases), and children with Autism Spectrum Disorders (5 cases). The trend of AAC team in moving to serve wider client groups is indicated.

Currently, we identify potential clients who may benefit from AAC as those with any communication disorder presenting with discrepant receptive and expressive language ability (with no or unclear speech), regardless of the client's age, cognitive function or medical diagnosis. Parents/caregivers with high motivation and who are keen to improve the child's communication with AAC are on our top list of priority. It is found that children who are well supported by school, or early training settings (such as special schools, Early Training and Education Centre, Special Child Care Centre, Integrated Child Care Centre), and with caregivers' strong involvement in the children's training are significant factors contributing to successful implementation of AAC and positive outcomes in the children's training.

Conclusion and Future direction

Given the complex nature of children who need AAC, there is a lack of standardized assessment protocol tailored-made for potential AAC clients. Certain modification of testing procedures and presentation formats of testing materials are necessary, though undesirable. Clinicians in interpretation and implications of test findings need to be caution. Moreover, it is recognized that collaborative work by multi-disciplinary assessment team, and caregivers is imperative in assessing children with complex communication needs. Dedicated effort in developing a valid and reliable assessment tools for this population in the future is deemed necessary. A standardized computerized program addressing this need in order to reduce the motor and expressive demands of examinees might be considered.

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Use of Augmentative and Alternative Communication in a Special Child Care Centre – a Case Sharing

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Background information

C. is a charming little boy studying in a special childcare centre. He was diagnosed of spastic quadriplegic cerebral palsy when he was one-year-old. Marked increase in muscle tone could be found on four limbs together with truncal hypotonicity. C's communication development was delayed. At the age of three, he understood many object names and action words and he could respond appropriately to "yes /no" questions. However, he could produce only two vowels /a/ and /e/, and one consonant-vowel combination of /pa/. Despite this, his motivation to communicate was very high. He was able to use his sound production, together with eye gaze, head nodding and shaking, to draw others' attention, to request and to reject. However, with these limited means of expression, he could only request for things that were in his immediate surroundings. And even though he was very sociable and frequently made use of vocalizations to draw others' attention, he could hardly keep the interaction going as he could say nothing to those people. Often adults needed to guess what he would like to say and ask questions like "do you mean you want to have some more juice?" to clarify his needs. In short, communication was passive and inefficient at that time.

Implementation of AAC

AAC was first introduced to C. at three. It was in the form of a voice output communication device with four choices (see picture 1). C. could use his fist to press on the device and a pre-stored message would be played then. C. was so excited when he first explored the device. He kept pressing and pressing the device like it was a new cause-effect toy for him. It took only two treatment sessions for C. to understand that pressing on the picture meant delivering that message to others. Once this was understood, he was very motivated to make use of the communication device to express his wants and needs in different situations. Use of the communication device was first introduced in two lessons, during which his motivation to communicate was highest. A great deal of collaboration was done with C.'s teacher in planning C's cookery and play lessons, to enhance communication opportunities for him. In the cookery lessons, C. could make use of the device to choose ingredients he wanted for making snacks. He enjoyed making choices and combining ingredients in his own way. In the past, C. was quite passive in the play lessons as he needed much assistance in manipulating the toys. With the use of communication device, he could tell others exactly what he would like to do with the toys. He could tell the teachers whether he wanted to put the doll on a swing or a see-saw.

After learning to use the communication device to communicate wants and needs, C. learnt to say some more things with his device. Ability to make comment with the device was targeted. In the cookery lessons, C.'s teacher would provide opportunity for C. to comment on the snacks that all the students made. C. would deliberately say that his peers' snack was

"stinky" and "bitter" while his snack was "yummy". To learn to report events was another focus of learning for C. In the play lessons, the teacher would ask every student to share what they had done at the end of the lessons, and C. was encouraged to use his communication device for reporting. With the use of the device, C. shares with his peers that he had made some fried rice with beef and corn, and that he had used the microwave oven to cook some soup. Without the aid of communication device, C. would not have had the means to express ideas of that complexity.

In addition to expansion in communicative functioning, use of AAC promoted C.'s linguistic development. C. was now learning to construct sentences for expression. He could make short sentences like "pour milk", "give daddy", and "mommy wants". Without the use of AAC, C. might not have had the chance to develop his potentials to this extent.

Picture 1 Voice-output device with four choices

Difficulties encountered in implementation of AAC

Even though C. was progressing satisfactorily, the following difficulties were encountered:

1. **Lack of resources**

C. was now using a voice output communication device with 8 grids (see pic 2). As only 8 messages could be presented in each page, it took a lot of time in turning pages until C. could choose the vocabulary he wanted. Due to limitation in fine motor control, C. needed to rely on others to turn pages for him, which was not very efficient sometimes. As such, C. should try and will likely benefit from more advanced communication devices, such as those with dynamic display. However, the prices of those devices were simply unaffordable to an ordinary special childcare centre in Hong Kong.

Picture 2 Voice-output device with eight choices

2. **Need of further parent education:**

In preschool centers, it was very common for parents to be skeptical about the use of AAC. Most parents worried that the use of AAC would have a negative impact on their children's speech development, as the children would "not have to use speech with AAC". So, even though they might not reject the use of AAC at school, they were unwilling to borrow the AAC devices for home use. Generalization of AAC learning to home environment was really difficult. More work on parents' education was needed to breed true understanding and acceptance towards the use of AAC by preschool children.

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A Case Report on Augmentative and Alternative Communication (AAC) Intervention for a Preschool Child with Dystonic Cerebral Palsy

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Case Background

WC was first identified as a potential AAC user at the AAC clinic of Hong Kong Child Assessment Service (CAS) when he was 3 years 7 months. His antental history was uneventful. Frequent arching of back was reported at the age of three months. MRI finding revealed periventricular leukoencephalopathy. He was diagnosed with dystonic cerebral palsy and borderline to mild intellectual delay. No significant sensory problems were evident. He had drooling and difficulty in initiating speech. His phonetic repertoire was limited. Aside from acupuncture therapy, he was not on any medication at the time of AAC intervention. He studied in a special child care center and received traditional speech training such as oral motor training, speech training and training on increasing his ability to understand pictures of common objects. The parents were supportive in training and expected him to have progress on speech, hand function and mobility. They had no worries about his cognitive abilities and verbal comprehension. Daily communication at home was said to be satisfactory.

Assessments in Child Assessment Centre

The initial AAC assessment involved a physiotherapist, occupational therapist, paediatrician and speech therapist. With the help of a special corner chair with occipital support, abduction pommel, pelvis strap and the foot rest, WC could remain seated for more than 30 minutes to complete the presented table tasks. He was right – handed. He could reach out with his right hand to all directions with mild compensatory movement. The left hand has more limited active reaching out range. Total flexion pattern was obvious when he used the left hand. He failed to keep his hands flat on table with mildly flexed fingers when wrist was in neutral position. Isolated finger movement was weak but he could point with good accuracy at picture cards of 9 inches size with the right index and middle fingers loosely opened. He was also able to activate an adapted battery operated toy with a specific pressure adjustable switch. The paediatrician considered WC's health status stable for AAC intervention. A questionnaire was sent to the parents on evaluating their child's current communication function (e.g. Can your child understand past events and how did you know?) and their expected outcome of the communication training. The child's communication abilities and the carer's interaction style were assessed by clinical observation of the mother-child interaction in activities such as playing with form boards and mother's verbal interaction with the child. The findings indicated that the child's verbal comprehension ability was estimated to be around 2years 6 months. Expressive means relied mainly on limited body language (e.g. nodding and shaking head), eye gaze and facial expression. He was slow to respond and passive in initiating interaction, especially in front of strangers. The parents

seemed to understand their child's limited expressions well. They were responsive to their son's expression but were controlling in the interaction. They learnt about AAC intervention from the story of a well known AAC user - Professor Stephen Hawking. They hoped their son could be understood by other people other than themselves. They showed particular interest in computer access training and agreed to participate in the AAC intervention, even though they emphasized the importance of speech training. After the initial assessment, there were five other reviews and one school visit within a three year follow up period. All the assessments and visit were initiated by the AAC team of Child Assessment Service. At one of the assessments when the parents were ready to purchase a VOCA for their son, a local voice output communication aids (VOCAs) manufacturer and the child's preschool therapist were invited. Liaison with the preschool therapists about the AAC intervention was arranged each time after an AAC assessment .

Intervention

Intervention focused on introduction of a communication book, the use of voice output device, parent training on the use of AAC means and computer access. Training on computer access will not be discussed here. During the three years of AAC intervention, speech training at preschool continued to be provided. WC could speak not more than five intelligible words with ease before he left the preschool.

Communication book

As the preschool speech therapist was not familiar with AAC intervention, the speech therapist of Child Assessment Service helped to produce the first preliminary, direct- pointing communication book, with due consideration of WC's motor and cognitive abilities as well as basic communication needs. Information about the design of the layouts and developmental stages (Latham, 2004) were shared with the preschool speech therapist and the parents. The design and the application of the communication book were reviewed in each session. Both the father and therapist acquired computer skills for upgrading WC's communication book. The number of icons increased to over 450 and were categorically organized (e.g. ACTITIVITY and ACTION/ PEOPLE/ TRANSPORT, etc) by the time of the last review during preschool. However, the use of icons in real life communication context was inadequate and it was restricted to a small portion related to places, food, WC's personal tools and toys. WC could spontaneously direct his parents to bring out the communication book for making requests for toys, indicating places to go and requesting objects that he wanted by pointing one icon. The parents actively encouraged him to make choices (e.g. the food to be bought in the supermarket). The communication book was used to enhance WC's communication as well as to serve as a dictionary. However, the inclusion of quite a number of icons was in fact redundant for WC's needs, and reduced his efficiency in locating the icons needed.

Voice output device

At the initial assessment, WC played with the Big Mac as a toy and did not realize how it could "speak" for him. However, it was loaned to the preschool speech therapist

with suggested activities such as giving command in classroom group activity. Parents understood how it could enhance WC's participation in activities such as story telling after demonstration in the second AAC assessment. WC showed more interest in voice output device. Tech –Speak 32 (VOCA) was loaned to him at the second assessment. The AAC Team believed that Tech –Speak could further enhance WC's communication in group activity and distant communication. Messages such as "I want to try" and "I'm smart to do it!" could be pre-recorded for enhancing the communication dynamics in the classroom. Customer – driven assessment approach (Rackensperger, Krezman and etc., 2005), that was found to be important in selection of an appropriate devices for AAC users, was difficult to be applied in Hong Kong situation where non-profit making AAC organizations were rarely available in Hong Kong. Parents learnt about AAC devices from private agents or therapists mostly. By the third AAC assessment, WC was reported to be able to link up two to three icons from the Tech-Speak to talk to his father while he was driving. He also initiated to let the therapist know that there was something wrong with the Tech-Speak by pressing the icon that was out of order and another icon "don't know". The parents finally self approached the local agency to purchase a Smart-Speak 32 that could be considered as an advanced version of the Tech-Speak 32. On the last review at preschool age, WC could automatically swab to use the Smart – Speak or the communication book with parents' physical support. He could answer simple wh-questions by using a single icon. Use of the VOCA was mainly limited to making request of daily routines at preschool. The parents rarely used it at home as they were worried that their child would lose opportunities to learn speech and oral language.

Parent training

At almost each assessment session, the examiner gave WC's parents information about the expressive language development, means for AAC application and communication partner interaction skills (e.g. modeling the use of the communication book). Written summaries were prepared for the parents. The Operational issues of the Smart - Speak 32 was followed up by the VOCA manufacturer. On the training content mentioned above, parents often failed to give modeling on the use of icons. For example, they rarely pointed to the icons while they were talking to WC. Expansion or extension of WC's single icon expression were uncommon. They usually expected WC to follow their speech for locating the icons, from which to construct a sentence. It was also common for preschool speech therapists to conduct drilling on identification of the individual icons, before using them with other AAC users and communication partners in life communication.

Summary and Conclusion

WC received AAC intervention together with speech training with the collaboration of preschool speech therapist and the CAS AAC team. After three years of follow up, WC made little progress on speech. Daily communication mainly relied on the AAC means and the natural non-verbal means such as eye gaze. Reviewing the case management of WC, several points are worthy to be highlighted.

a. Apart from including the motivating icons for communication, such as the child's likes and dislikes, the purpose of the aids should be clear to the trainers and the parents during the assessment process (Johnson R. M. ,1997). Specific training goals such as communication with particular people at particular social situation are needed to be targeted before expanding the content of the communication book.

b. It is common that parents preferred speech training over the AAC intervention, especially at young age. However, when they could be shown that their child's motivation to communicate and the expressive ability was improved, they would accept AAC intervention in parallel with speech training or facilitation. It is important for parents and children to have trials on certain voice output aids before they make decision in accepting and rejecting to use the device. Thus, there is a need for Hong Kong to develop a local loan library for AAC devices.

c. Application of AAC in school activities was a challenge for local speech therapists and teachers. A communication aid apparently can serve more than requesting for snacks, toileting or a walking aid in the school routines. Use of theme based layouts can be a way to increase the classroom participation of the non-verbal students. More training for the frontline workers on AAC application in education settings is needed.

d. More continued parent training on interaction skills is needed in AAC intervention as the non-speech language system is new to the parents. Modeling is important for the development of expressive language of normal children. Children with AAC needs also learn to express using their AAC means by modeling from the parents, teachers and trainers. Language facilitating strategies such as use of open-ended questions should be encouraged. The content of communication partner training program may be taught in more structured way (Kent-Walsh & McNaughton, 2005) so as to increase the treatment efficiency and effectiveness.

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Application of Augmentative & Alternative Communication in Special Schools for Students with Physical Disabilities

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Communication needs of students with physical disabilities

The communication needs and strategies to enhance communication abilities of students with physical disabilities will be illustrated by the two following cases.

Case 1: SS

SS, a non-verbal student with moderate mental disability, has difficulty to use hand signs to express because of his limited mental ability and fine motor coordination. He was admitted to a special school for the physically disabled when he was six. At that time, he used actions to express basic needs, such as touching the body part to indicate toilet needs. He responded to yes/no questions with vocalization "aa" to indicate "yes", and shaking head to indicate "no". He showed the ability to understand simple commands. Adults tended to ask "yes/no" questions to elicit responses from him. Thus he was perceived as a passive respondent in communication. In addition, his peers might not be able to understand the idiosyncratic means of his expressions. Adults usually played the "interpreters" role to translate his expressions to his peers. Thus, communication with peers was limited.

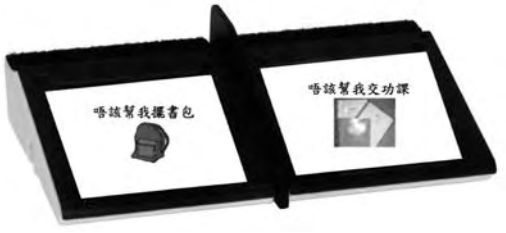
Stage 1: Training SS to use communication pictures to represent ideas

Through daily routines, the ability to use communication pictures to request was established. He was asked to get the items he needed during lunch by choosing the communication pictures.

Communication in routines empowered him to have a sense of control in daily activities. Communication boards with choices of more rice/ soup/ different types of fruit, etc, enabled him to play an active role in his daily living.

Stage 2: Increasing chances of communication by using light tech devices

SS's communication needs could not be met by using communication boards only. His peers might not be able to read pictures and understand the symbolic meanings of pictures; light tech device, a two-choice partner plus voice output device was also prescribed to facilitate communication abilities with his peers. He could ask his peers to help him in the morning routines. His peers responded to his request by helping him to hand in the homework. Similar light tech device with more choices was prescribed for other communication functions.



In addition, a step-by-step communicator had been mounted on his walking aid to encourage him to share his communication ideas. The first recorded message let him call for others' attention; the second message was the event happened so as to enable him to share.

Contexts to train up his communication skills to comment on others were included in the intervention. Communication pictures representing "beautiful/ugly", "good/bad" and "happy/unhappy" were included to enable him to have different communication functions.

Case 2: Macy

Macy, a 10-year old non-verbal girl with borderline intelligence, was admitted to a special school for physically disabled when she was six. She was diagnosed to have spastic quadriplegic with dystonia at birth. By the time she was there, she could sit in a wheelchair with support. She was responsive in expressing herself through facial expressions and blinking her eyes to represent a "yes/no" choice. Her limbs control was highly limited. She could neither press a single switch nor perform any reliable hand function. Macy was a girl having strong communicative intention; she always looked for someone to read her mind. Obviously, her eyes blinking and facial expression was not sufficient in meeting her communication needs. Thus, the speech, occupational therapist and physiotherapist worked together to help Macy in various aspects included posturing, mounting of equipment, establishing a reliable access mode and identifying her communication needs in different situations. Her intervention, in these 4 years, could be divided into the following stages:

Stage 1: Her use of a single-scanning voice-output device

Macy was found to be able to turn her head to the left to press a single switch. Thus, a voice-output device with 8 grids was mounted on her wheelchair desktop. She could elicit a response by her head when the scanner moved to a preset message of her choice. This light-tech voice-output device could help her to express

her daily needs in school. With multiple layers of messages, she could also participate in classroom learning in responding to teachers' questions.

Stage 2: Her use of a step-scanning voice-output device

The 8-grid communication device was seemed to be able to meet Macy's basic communication needs in the first few months. However, as she was more proficient in operating the scanning system, she could take quicker turns in communication. Her communication partners were more eager to talk with her, and she requested to "talk" more. The 8-grid device was no longer sufficient to meet her needs. Another device, with 32-grid on each layer in a step scanned mode, was prescribed. Macy was now able to make quick choices with her 2 single switches (one on each side) mounted. The speed in responding was now under Macy's control by using the step-scan mode. The scope of communication content was also widened with 32 choices provided in each layer.

Stage 3: Her use of a lap top with communication software and a cross scanner

The light-tech communication device, no matter it was 8 or 32-grid could only offer limited choices for Macy. Further, she was reliant in swapping through different layers of messages in the device. In order to overcome these limitations, on top of building up Macy's independence in communication, a lap top with a communication software named Speaking Dynamically Pro was prescribed. Speech therapist could design different layout for Macy. Number of choices and layers could be designed flexibly, as long as it could meet her communication needs in different situations. Macy could also use her head switch to control the cursor through the cross-scanner program. This program enabled her to operate the cursor as if operating a mouse click. Macy was also learning to type words (in Chinese and English) using on-screen keyboard, this allowed her for further development in using a text-to-speech engine in enabling a free communication.

Difficulties in access and academic learning

Apart from the communication needs of students with PD, they engaged difficulties in accessing communication devices and learning aids because they are not capable of using ordinary peripherals to access computer, thus diminishing their opportunities of digital inclusion (數碼共融), not only the basic need of communication but also the human right of access to information (The International Bill of Human Rights, 1996).

Decision tree solutions for students with physical disabilities for access and academic learning

The first study of human and computer interface (HCI) was presented by a group of professionals at the Association for Computing Machinery's Special Interest Group on Computer–Human Interaction (ACM SIGCHI) Conference in 1992 (Hewett et.al., 1996). Wong (2004) applied the concept of HCI in the intervention of computer access solution for people with PD. It illustrates the ***GAP*** between human factors and system factors of people with PD in computer access – 'Assistive Technology (AT)' and 'special computer access solution' should be recommended to bridge the gap.(fig. 1)

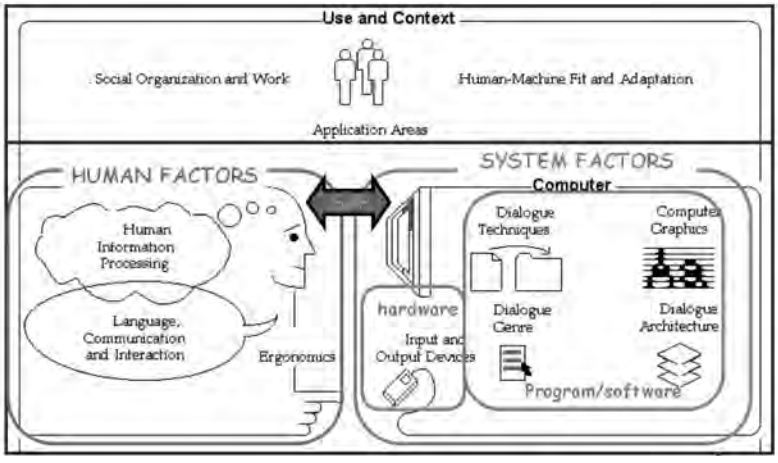


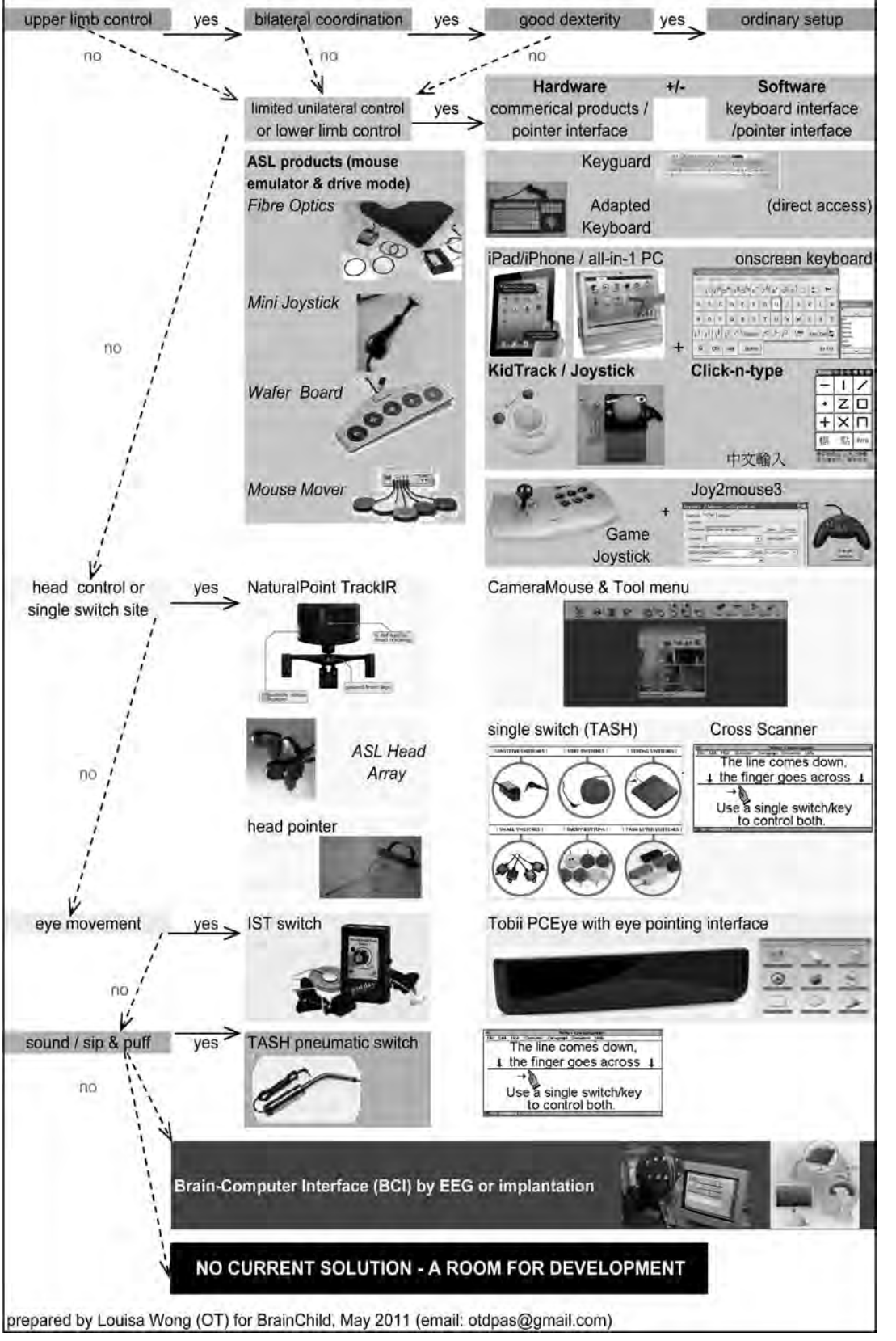
Fig. 1 – the gap between human factors and system factors (Hewett et. al.,1992) modified by (Wong, 2004).

There are two paradox of access solution for people with PD. From the point of view of ergonomics, people with PD are often too physically impaired to activate mechanical input devices for direct access. Most of them also have speech impairments, which further restrains them from accessing computers or enjoying information technology through sound-activated systems. Thus, people with PD might need indirect access, nonmechanical or nonhandheld pointer interfaces (dialogue architecture) to use language-free applications (design approaches) for their learning and literacy needs.

Figure 2 illustrated a proposed decision tree for access solutions for PPD. The priority of AT /AAC intervention should be:-

direct access > onscreen keyboard > scanning;
bilateral control > unilateral control > switch(es);
ordinary peripherals > keyboard interface +/- pointer interface;
mechanical switch > proximity switch > sensor switch;
durable & replaceable > fragile & irreplaceable; and
easy to carry over > delicate & complicated.

Fig. 2 **DecisionTree for Access Solutions for Students with PD**



prepared by Louisa Wong (OT) for BrainChild, May 2011 (email: otdpas@gmail.com)

The ultimate scenario of digital inclusion will empower people with severe and multiple PD to active participate in communication, recreation, and continuous learning with equal opportunity (Man & Wong, MS Louisa, 2007).

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Augmentative and Alternative Communication in Special School for Children with Severe Mental Disabilities

在嚴重智障兒童學校運用輔助溝通工具學習的情況

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Abstract

Caritas Jockey Club Lok Yan School is a special school for students with severe and multiple handicaps. Because of their physical and cognitive limitations, it is difficult for them to acquire verbal communication skills and build up social relationship with others. A school-based language developmental milestone is thus developed to guide our teachers and related professionals to form appropriate learning goals and intervention strategies for our students. **Alternative and Augmentative** Communication (AAC) is a powerful system for enabling students to realize their physical and cognitive capacities in a supportive environment. Evidences show that applying AAC can facilitate effective communication throughout one's stages of language development. A multi-disciplinary approach is adopted for choosing suitable communication modalities, further adjustment to individual's needs and generalization to the prevailing social situation. Extensive training with AAC devices is highly recommended to help students to bridge a gainful transition from special school to adult service.

明愛賽馬會樂仁學校是一所服務嚴重智障兼有多重弱能學生的特殊學校。大部份學生的基礎能力較薄弱，例如專注力短暫、少有溝通意慾、社交能力薄弱。他們亦未能掌握和運用適當的溝通模式，難與週邊的人及照顧者表達其需要，從而影響其生活質素。

本校對學生語文能力的發展非常重視，故在二零零三年開始，推行了「密語話集」訓練計劃來促進學生的溝通能力。我們因應學生溝通能力的不同發展階梯，擬定目標，為學生選擇適切的溝通模式及輔助溝通工具進行學習。

以下我們透過兩名學生的個案，介紹不同能力學生在溝通訓練及使用輔助溝通工具學習的情況。

（一）學生小強

小強因受智能及多重弱能限制，以致溝通能力及溝通意慾較低。他與大部分嚴重智障兼多重弱能學生的溝通發展一樣，處於早期的語前溝通階段，主要以面部表情、肢體動作或發聲來表示需要。

然而，小強表達的模式並不限於此，他的一個眼神、一個姿勢、動作或不同長短的音調，也可能是表達著不同的需要和內容，這全依賴熟悉他的人一一去解碼和演繹。為了讓他可以更清晰、明確地表達意願及需要，除了鞏固他已有的前符號 (Pre-symbolic) 能力外，我們亦會使用輔助及另類溝通工具，協助他與人溝通和互動。

處於語前溝通階段的學生 (即：反射期或啟蒙期)，雖未能理解語句的意思，但透過運用溝通器可協助學生學習和領會因果關係，亦可作為引人注意的一種手段，及為進入下一階段學習 (如：自我表現期、互動期等) 作準備。例如在玩耍時，施教者會把一個連接已錄有「我想繼續玩！」溝通器的提起式操控桿放在小強手中，然後刻意在玩耍中途停下來，鼓勵他拍動溝通器以示意繼續。雖然他未能理解「我想繼續玩！」這句說話的意思，但他能理解按下溝通器後，可繼續玩耍這因果關係。

按下溝通器的動作雖然簡單，但對小強來說是一項艱鉅的工作，幸好得到校內跨專業團隊的協作，為他設計一個提起式的掣鍵，讓他能更有效地與別人溝通和建立關係，甚至操控一些簡單的玩具作玩樂。

由於小強尚未能掌握符號的概念，為鼓勵及加強其對表達的理解，我們與他溝通時，多會輔以實物來表達，而這些實物的內容主要是其日常接觸的物件 (如：杯、匙羹)。透過這些練習，讓他慢慢理解物件與表達內容的關係，從而協助他建立有意識的溝通行為。

（二）學生小文

小文屬腦麻痺兼嚴重智障及四肢痙攣，但聽力和視力正常。入學初期，他已能專注班內情況、理解別人簡單說話和提問、會引人注意、與別人打招呼等。小文的表達模式主要包括簡單的動作 (如將頭轉向一邊表示「好」)、面部表情、及發出簡單單音回應別人等。經過數年的學習，小文漸由自我表現期及互動期發展至實物辨認期，他能運用實物和相片來與人溝通，也能理解自己、環境及生活中所經驗的各種事物。他亦能以伸手觸摸來揀選相片並輔以發聲作確認，從而表達自己的需要、選擇及喜好。

目前，小文在認知發展和語言理解方面均不斷提升，對一些抽象概念 (如符號、文字) 的理解，亦逐步建立。故此, 以往的相片溝通模式已不足應付需要。經校內跨部門專業團隊商討後，決定為他更新溝通簿 (包括人物、地方、食物、個人情感、數字、文字等)。透過施教者提供的兩張線條圖，小文可運用右手輕觸其中一張溝通咭，並發出單音來表達確認。現時，他已能有效運用此溝通簿與人溝通，在輔助下表達心中所想，可自主決定，因而提高的生活質素。

隨著小文表達能力的發展，跨部門專業團隊正探討為他設計電腦溝通簿。期望他能運用特別的電腦輸入裝置來操控電腦溝通簿，讓他能更獨立自主地表達自己的需要和興趣，更容易及主動與人溝通和建立關係，在未來生活進一步突破他的障礙，活得更自主和開心。

結語

從以上兩個個案可以看到，若協助學生發展溝通能力，是需要細意掌握其可發揮的能力及跨專業團隊的緊密合作。每個學生都是獨特的，其遇到的溝通障礙亦是個別的。在過程中，如何擬定學生的學習目標、選擇適切的溝通模式和輔助溝通工具，均需要了解學生的獨特處境及情況，並協助他們把有關能力發揮出來和應用在日常生活中。隨著專業團隊的努力及科技的日新月異，相信我們可以為學生提供更好的支援，讓他們更向前跨進一步。

此外，我們亦應從學生的長遠發展著眼。運用適合的輔助溝通工具，把學生已建立的溝通能力基礎，延展至學生的成人階段，讓其雖然面對成長和生活的轉變，仍能掌握和運用已有能力，與周遭環境互動並與人建立情意，讓生活變得更充實。

Augmentative & Alternative Communication (AAC) in Hospital for Persons with Mental Challenge

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Abstract

People with severe to profound intellectual disabilities often have limited speech or even no speech to communicate with others. They possess limited communication skills and are more likely to communicate with nonverbal means, such as gesturing, facial expressions, eye contact, and body movements. Some of them have weak communication intent. Their wants and needs, which are communicated through their facial expressions and behaviours, are subject to their caregivers' interpretation. In fact, individual expressions are difficult to be understood and they may be diverse in different contexts. The use of AAC is to provide a clear communication between residents and their caregivers. Other strategies, such as object of reference, communication passport, are also employed to increase the communication opportunity in clinical setting. It is hoped that an effective communication can reduce the occurrence of residents' challenging behaviour and to improve their quality of life. However, barriers in communication still exist, such as tight manpower and knowledge deficit. Staff training is crucial to identify the communication needs of individual residents.

Introduction

In Hong Kong, the prevalence of intellectual disability (ID) is about 1-2% of the general population. Among persons with ID, the percentage of severe and profound intellectual disability shares 5%. Though the intelligent quotient (IQ) for severe and profound grades is 20-35 and below 20 respectively, persons who are unable to go through an intellectual assessment or beyond the capacity of expressing themselves are automatically categorized into severe to profound ID, including individuals with profound intellectual and multiple disabilities (PIMD). Therefore, persons with severe to profound ID are an extremely heterogeneous group in terms of functional abilities and behavioural patterns. Due to scarcity of medical resources, only the lowest ID stratum with difficulty of community integration is eligible for long-term hospitalization. Mental Handicap Unit provides infirmary care for this group of people who are aged 16 years and above.

Most of the residents in Mental Handicap Unit are non-ambulant with restrictive limbs movement due to contracture and deformity. Their daily living activities are mostly assisted by or dependent on personal assistants. They have an overall risk of developing medical complications such as seizure disorders, gastro-esophageal reflux, and recurrent pulmonary infections. Almost all require regular medications to control epilepsy, prevent gastrointestinal bleeding, and sedate maladaptive behaviours. In addition to profound intellectual and physical disabilities, challenging and self-stimulating behaviours, as well as visual and hearing impairments are frequently reported. Additional associate diagnoses include autism, and mental illness (Hospital Authority Mental Handicap Infirmary Service, 2003).

Use of AAC

Most people with severe to profound ID are unable to understand or comply with requests or instructions. Their communication attempts are often ignored or neglected. For relatively able persons, they always use the quickest way to express themselves, for instance, take or do the things that they like without asking for permission, or persistently nagging for the things that they want if they can use simple words or utterance with gesture. Immediate gratification is their primary goal to satisfy their demands; subsequently, they are being labeled as having challenging behaviour because they do not follow the rules and patterns of the daily routines. If appropriate communication training and opportunities are provided, the challenging behaviours of individual residents will be decreased.

In fact, majority has little speech, like vocalizations, or even no speech. They have to communicate through nonverbal means e.g. eye contact, gestures, facial expression and body language to convey their needs or feelings. However, these expressed contents are highly reliant on people around them for interpretation. Some residents can recognize familiar people and have strong relationships with their key caregivers. More than one type of AAC strategies will be introduced to them, depending on their capability to understand, as well as their interests to communicate. Communication systems for this group of residents generally rely on photographs, object of reference and real objects. For example, a picture or a real pack of drink will be presented when asking the question "would you like a drink?". This is to facilitate the association between picture / object and the interaction context. Daily activities / necessities and favorite foods are things that frequently motivate their learning interests.

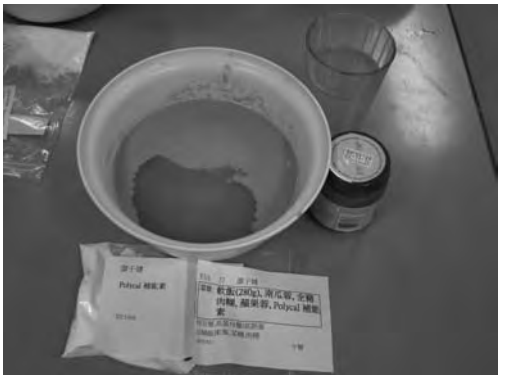

Figure 1. Photo of individual own meal can trigger the interest of the resident

Figure 2. Pictures of foods often draw residents' attention for further interaction

Figure 3. Some residents are able to recognize familiar faces to show their attentiveness with immediate environment

Figure 4. Object of reference is employed to indicate individual preference through visual gazing

Figure 5. Photo of activity area can orientate the resident to accessible environment

For residents who are unable to communicate intentionally, they are perceived as passive since they can hardly take initiatives to express their needs. They are often excluded from mutual communication. In fact, a sensitive caregiver can provide communication opportunity for them. For instance, they look miserable and may cry if they feel discomfort, they show satisfaction if their needs are met. Based on these reactions, they can be involved in choice making, like, to smile when they want to wear blouse with bright color. The communicative intention of a non-verbal person can be increased by training the caregivers to interpret the subtle body language efficiently or introducing a communication passport to guide their interpretation, including modes of communication or gestures that are frequently adopted in daily life.

Figure 6a. The communication passport of a resident

Figure 6b. The communication passport provides essential communication tips of individual resident

Communication is an interactive process. It is important for all involved carers to be familiar with the normal communication patterns of individual residents in areas of form, content and use (Brodin & Stancheva-Popkostadinova, 2009):

Form – how does the person express himself or herself?
Content – what does the person really express / say?
Use – in what contexts does the person communicate and with whom?

Sometimes, people with severe to profound ID may understand more than they can express. No matter the person can communicate intentionally or not, s/he should be assumed being competent to interact through verbal or nonverbal means.

- Focus on one theme at a time and provide adequate time for the resident to respond
- Beware of the effects of medicine that may influence the resident's attentiveness to communicate
- Pay attention to usual pattern of response
- Ensure accessibility of communication device if the resident has learned to use it
- Never pretend to understand, this may cause frustration of the resident and s/he may refuse to communicate further
- Speak slowly and use appropriate language based on individual's capability i.e. simple and clear words; visual information e.g. pictures, diagrams, signs and gestures
- Try alternative strategies if the person does not understand e.g. photo and real object
- Use appropriate tone and voice volume to show respect

Barriers to Effective Communication

The speech therapy service in adult settings is heavily loaded by the assessments of dysphagia. The training on communication is needed to be emphasized as it is important to minimize the occurrence of challenging behaviour.

Most often, the communication breakdown will lead to frustration of residents and uncooperativeness to treatment regime, such as refusal of taking medication, and display temper tantrum. Currently, communication needs are first identified in a training unit and followed by individual training. However, the learned skills are difficult to execute in clinical setting because it takes time to communicate with this group of residents. Under the pressure to complete daily routine and special assignment, staff is less likely to comply with the communication protocol.

Previous research has demonstrated that staff in day and residential services have difficulty in adjusting their communication modes to suit the person with ID. The findings of McConkey et al.'s (1999) study indicated that frontline staff of institutional setting tend to use directive and instructional contents to interact with their residents rather than engage in social conversations, like chatting. Even when they are communicating with predominantly non-verbal residents, like those with profound ID, majority of staff often fail to adjust their language to the resident's level of understanding. Generally, direct care staff would not provide opportunity for enhancing communication with their residents and they seldom attempt to identify or understand residents' non-verbal behaviours. In addition, staff perception to their roles is also contributing to ineffective communication because staff may assume that they are paid to do a job rather than to engage in conversation. Hence, behavioural control and task completion would be their major target in clinical duty (Lowe & Felce, 1995; McConkey et al., 1999).

Presently, some sensitive staff can identify ways to communicate with the residents, who show comparatively higher cognitive functioning than others, verbally or nonverbally in clinical setting. However, residents without communication intent will only receive basic nursing care routinely.

Conclusion

Communication is the most important basic need in all human beings. For this reason, all people have the right to communicate and express themselves. The absence of verbal communication results in an increased reliance on caregivers to interpret their needs and choices through nonverbal cues.

The use of AAC is encouraged to base on individual capability. It is hoped that the communication opportunity can reduce the occurrence of challenging behaviour and promote their quality of life by meeting their needs and wants. However, the utilization of acquired communication skills is limited due to busy routine, tight manpower and knowledge deficits. Staff training on effective communication strategies with severe to profound ID should be considered as a mandatory prerequisite for staff recruitment. If communication is indispensable for everyone, the service provision of speech therapy for adults with severe to profound ID should comprise a wider scope on effective communication training.

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Augmentative and Alternative Communication: Emerging in Hong Kong and the Way Ahead

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For many years, augmentative and alternative communication (AAC) in Hong Kong had been a veritable orphan in many senses of the word. It had no self-pronounced parents, no home nor regular centralized resources, and an uncertain future ahead. Most individuals who could have benefitted from AAC have never heard of it. Those who have been introduced to it face serious difficulties in making it a natural and permanent part of their daily lives. Among the serious challenges in this field, the isolated nature in which professionals using AAC are working poses a significant obstacle. For the most part, they work as individually keen staff within special education and work settings, learning on the job and having limited access to team collaboration, expert advice and administrative support. The multidisciplinary nature of an AAC team, encompassing speech therapists, occupational therapists, rehabilitation engineers, physical therapists, physicians, psychologists, social workers, nurses, health care workers and centre-in-charges, requires cross sector collaboration that may not be achievable for most front line professionals as part of their job duties.

The AAC Working Group under the auspices of The Hong Kong Society of Child Neurology & Developmental Paediatrics (HKCNDP) germinated from small groups of professionals whose main focus was on children with physical disabilities. Seminars were organized, mainly by speech and occupational therapists, to share clinical experience in using AAC. Whilst reasonable interest was generated from these meetings, members remained a loose group. In 2007, a multidisciplinary group keen on pushing the AAC agenda gathered with the mission of fostering knowledge, skills, awareness and service provisions for children and adults with AAC needs in Hong Kong. This group was subsequently formalized to become the AAC Working Group of the HKCNDP.

One of the first missions of the Group was to determine the state of AAC service provision in Hong Kong. Official statistics from the Hong Kong Census and Statistic Department 2008 (Census and Statistic Department, 2008) indicate that prevalence rate for individuals with speech difficulties was 28,400 persons - 0.4% of the entire population. A territory wide survey was conducted by this group on Hong Kong's AAC services, results from which are published in a 2010 paper in the journal of the International Society for Augmentative and Alternative Communication (Siu E., et al 2010). Application of AAC was low, students needed to share devices such as over 100 students sharing one effective device in special schools for intellectual disabilities, and generalization of use across teaching sessions and beyond the school setting to the home and community was extremely low, with up to 100% rarely or not using AAC in the community. Professionally, respondents in the survey were not satisfied with the training they received in AAC use, and the lack of locally

developed Cantonese language-based AAC systems for user friendly application renders their work at the front line daunting and difficult to sustain.

Against this background, the AAC Working Group set for itself a blueprint for tasks it needed to address in the following years. Establishment of an expert service team in Hong Kong to meet service needs in all settings is a high priority. For this, professional education, development of AAC systems relevant to Hong Kong's language and culture, and seeking official recognition and resource input, were identified as essential. A website for the AAC Working Group was set up (www.aac-hongkong.org) to increase communication and sharing among users. AAC resources in Hong Kong were gathered and posted on the website's resource library, along with linkage and information on international resources. Subgroups were formed to work on respective AAC settings: for children in preschools and moderate grade intellectual disabilities special schools, for those in severe to profound grade intellectual disabilities settings, for individuals with high communication abilities and severe physical disabilities requiring high technologies. Through these focused activities, the Working Group was able to reach out to a wider range of professionals, and to recruit them into its work.

International connections are of paramount importance to Hong Kong at this stage, when our practitioners are trying to catch up with standards of overseas AAC centres. Contacts are made through personal connections as well as networking at international meetings, including the International Society for Augmentative and Alternative Communication (ISAAC) and American Speech-Language-Hearing Association (ASHA) conferences. These are expected to be strengthened and formalized in the coming months and years, when international experts are invited to participate in this formative work in Hong Kong. Efforts will be made to enable overseas training for Group members in the near future.

Funding is critical to stable progress for this Group's work. In 2010, the Working Group successfully applied for a grant from the Council of the Queen Elizabeth Foundation of the Mentally Handicapped, to support the development of an effective and locally relevant Cantonese language-based AAC system suitable for use by children with communication disabilities. Further support will be sought to acquire hardware, in form of readily available portable computer technology, to stage the AAC system developed. It is the aim for the system software to be made freely available to all users in Hong Kong, and for the hardware with the system installed to be made available to as many preschools and special schools as possible. Ultimately, it is the vision of this Group that a Hong Kong AAC Foundation can be formed and maintained, for supporting research, development and services.

Looking ahead, the work for the AAC Working Group is vast and uphill. Training for Hong Kong's AAC team workers needs to be fortified and carefully planned. These include adequate undergraduate teaching and practicum, especially for speech therapists and occupational therapists, and inclusion as a knowledge item in paediatric, physiotherapist, psychologist, nurse and special education training. Systematic continued education activities should be organized by tertiary institutions and professional bodies, while training at overseas

AAC expert centres should be made accessible to active professionals through the support of respective employers and scholarships. On the practical front, platforms for professionals from different sectors to work together on individual cases, with employers' endorsement, are essential, as there is no one mature team yet in Hong Kong which covers all aspects of AAC assessment, prescription and follow up – from language and communication to seating and mounting needs, rehabilitation engineering, medical, intellectual and psychological assessments, special education and social work support. Professional and public education is essential, as was demonstrated in the territory wide survey on AAC. This Group plans to host a week long Conference on AAC in 2012 in Hong Kong, including seminars, workshops, clinical case presentations and sharing, and exhibitions of hard and software by the commercial sector. Sustained efforts in research and development for AAC systems in Cantonese for the range of ages and abilities are critical to success, and require strong input from academic, clinical as well as business perspectives.

In the education sector, catering for diverse needs in education is an important agenda to the government. To achieve this, support for learning and communication for severely communication impaired students should be given serious attention. On the medical front, a Centre of Excellence in Paediatrics is currently under development for Hong Kong. The presence of an expert AAC team within the Centre that has expertise and experience working together, is essential to live up to the expected tertiary care for children with serious illness related AAC needs.

The World Health Organization's International Classification of Functioning, Disability and Health (ICF) and its Child & Youth version (ICF-CY) emphasize the importance for persons with disabilities to participation as fully in the community as possible. For some children, AAC is the key. With the entry into force of the United Nations Convention on the Rights of Persons with Disabilities in Hong Kong, the Government has stated its commitment to defend the rights of persons with disabilities by creating an environment of equal opportunity in all aspects of life, through introduction of legislation, drafting and implementation of policies. Indeed, in the last analysis, the government's visible support and wide public awareness are ultimate keys to success.

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