

DEAL COMMUNICATION CENTRE Inc.

Breaking the Silence:

Developing communication strategies for
children in China who cannot talk

A project funded by
The Australia-China Council
Department of Foreign Affairs and Trade
2008-2009



BREAKING THE SILENCE

Background 2007

In October 2007 I was invited to give a keynote address on Non-speech Communication at the inaugural international conference on Rehabilitation of Children with Cerebral Palsy held at the Shanghai University of Traditional Chinese Medicine. My host was Professor Kexing Sun. After the conference I was asked to visit clinics for children with cerebral palsy held at two teaching hospitals. It is my experiences during these hospital visits, described below, that led to an extended project funded by the Australia-China Foundation.

Both the hospitals had well-equipped speech therapy clinics with well-trained speech therapists, but none of the therapists had any knowledge of the communication techniques which are commonly used here to assist children who can hear but who cannot speak. They literally had never seen even the most basic items, such as cards with YES and NO (in Chinese characters of course) for children to point to, to answer questions.

The electronic communication aids I was carrying, which allowed the children to 'speak' by pressing pictures for what they wanted to say, stunned them. They had presumed that children without any speech also lacked understanding. To hear them answering questions and composing sentences like "Cats are tame animals. Lions are wild animals." (of course in Chinese) was totally unexpected.

The first clinic I visited closed for the day immediately after seeing me work with just 2 children, to allow the staff to talk to me about the implications of what they had seen and about ways of making or obtaining similar equipment. The second clinic remained open late into the evening with queues of desperate parents wending their way through the corridors waiting to see me.

Following these sessions Professor Sun discussed setting up a joint project to provide non-speech communication training to therapists, therapy students and parents and we approached the Australia-China Council for funding.

As a result, in 2008 DEAL received funding from the Australia-China Council for two visits to Shanghai to provide training in non-speech communication to parents, teachers and therapists, the first of which took place late in 2008 and the second of which took place in June 2009.

Our partner institution was the Shanghai University of Traditional Chinese Medicine, where we have been working closely with Professor Kexing Sun.

Shanghai November – December 2008

Visit hosted by Professor Kexing Sun from the Shanghai University of Traditional Chinese Medicine.

Summary

- Arrived in Shanghai on Monday morning 24.11.2008.
- Spent 9 days working with 28 children with cerebral palsy, autism or other developmental disabilities in Putuo and Shanghai Pearl Hospitals and a special school.
- Conducted hands-on training sessions for speech therapists at both the hospitals and delivered an in-service for staff at the special school.
- Met with Director and Rehabilitation Co-ordinator of Yue Yang Hospital to discuss holding a conference on AAC in 2009.
- Delivered two 2-hour plenary presentations at the International Seminar on Speech Therapy which took place at Putuo Hospital over the weekend of Nov 29-30 and was attended by more than 100 local therapists. After each presentation I was literally mobbed by therapists desperate to get the laminated communication boards I had taken to give away.
- Set up a small library of communication equipment and software at Putuo Hospital for use by therapists.
- Departed Friday evening 5.12.08

Highlights 2008

During the December visit I met many fascinating people, including Yi Lin, a smart young lady of 15 with cerebral palsy who can walk - just - and talk - just - very unclearly. She cannot use her hands. She has never been to school and her mother is dyslexic. Nonetheless she has learnt to augment her dysarthric speech by writing with a pen held in the toes of her right foot.



After returning to Australia I successfully obtained funding for a computer system for Yi Lin. A few years ago that wouldn't have helped her but the mobile phone has changed everything! Today young Chinese are incredibly rapid text messagers using predictive Pinyin, the phonetic representation of Simplified Chinese based on the roman alphabet. Similar software is also available on laptops, making it possible to type Chinese characters and words far more quickly than previously while using a standard keyboard.

In 2008 all I could do was to give Yi Lin a Pinyin textbook and line up her 14-year-old brother up to teach her Pinyin. With an expanded keyboard (which she'd use with her toes) attached to a laptop, a keyguard to stop her hitting 2 keys at once, and a screen reader or text-to-speech program (yes, they do exist for Simplified Chinese) to read aloud what she typed, she'd be able to type and talk.

The complete kit that Yi Lin needed cost about \$3,500 in Australia – which is much cheaper for this kind of equipment than Shanghai – and Deal obtained donations to purchase a kit to deliver on my next visit.

Communication aids

During my 2008 visit a major US communication equipment manufacturer – Liberator/Semantic Compaction - who is interested in marketing communication aids in China was in regular phone contact and sent over laminated communication boards for me to distribute at the seminar.

I also carried a selection of cheap electronic communication aids recorded in mandarin and a number of bi-lingual low-tech communication boards and folders which I'd created using Boardmaker software. These formed the basis of the small equipment library I set up before leaving.

On this visit I bought a printer and set up a cottage industry making extra communication boards and folders for individual children in my hotel room with the assistance of the tertiary students who were my interpreters. I left the printer and distributed PDF files of the communication boards so the therapists could print more as needed.

Seating



Every child who couldn't walk who came to see me was carried by a parent, regardless of the child's age or size. Questioning established that the government does supply wheelchairs, but one size fits – or doesn't fit - all. A 5-year-old with spasticity and extensor spasm gets exactly the same off-the-shelf chair with no straps as an adult who has a broken leg. I spoke with the Rehabilitation Director of Yue Yang Hospital about the need for appropriate seating, which they recognise and are working on, but a rapid resolution seemed unlikely. Given the environment and the poverty, it appeared that an adjustable insert for the standard funded chairs might be the quick and dirty solution. I followed this up with my international contacts on my return to Australia.

Shanghai – Beijing June 2009

Dr Kexing Sun (Kevin) met me at Shanghai Pudon airport on the evening of Sunday June 14th. In the 12 days before he drove me back to the airport to fly to Beijing on Friday June 26th, I worked with 25 children with cerebral palsy or autism at Putou and Shanghai Pearl Hospitals, 7 of whom I'd seen previously in 2008.

Sadly Yi Lin, the 15-year-old with CP who writes with a pen held in her toes, for whom I'd set up a laptop with special software and an expanded keyboard funded by donations, wasn't among them. Putou Hospital had lost contact with Yi Lin and her family, and Kevin and I spent considerable effort trying to track her down. In the process we did two TV interviews, one of which aired twice on a local station, and the other of which was shown four times on the most popular channel in Shanghai - to put this in perspective, greater Shanghai has a population roughly the same as Australia. I was quite glad that I was in Beijing before it went to air. Unfortunately at this time nothing has been heard of Yi Lin.

However, there is positive news. The first Non-Speech Communication Resource Centre in China will open in the next few months in Shanghai. During my visit Dr Sun and I met twice with Dr Wang Ya Gang, Manager of Patient Services at Quyang Hospital in the Hongkou District of Shanghai. Dr. Wang was interested in establishing a multi-disciplinary rehabilitation centre (now open) and had set aside a complete floor of the hospital to accommodate it. On our first visit she was very excited to see Augmentative Communication (AAC) aids and hear about their use. She immediately decided to incorporate an AAC Resource Centre in the Speech Therapy department.

We also discussed the possibility of the centre sponsoring the local manufacture of a cheap, highly adjustable wheelchair which was designed in Norway and is being made for US\$100 or US\$150 (depending on complexity) by an agency run by one of my colleagues in the Phillipines.



This chair would be an immense improvement on the current situation for Chinese children with CP, who either use nothing, and are carried everywhere, or sit in large adult chairs with no straps or modifications to adjust them to the child's size. Apart from the obvious practical problems, the lack of supportive seating significantly impacts on the children's ability to control their bodies and to use communication aids.

On our second visit to Quyang Hospital we were joined by Nigel Duckett of Liberator Australia who demonstrated the electronic aids that Semantic Compaction/Liberator are adapting specifically for use in China. Dr Wang had invited Professors from two other interested universities together with the CEO of Tiger Electronics, the largest manufacturer and distributor of speech therapy aids in the Shanghai area, to meet with us, with a view to future co-operation.



A Springboard Lite communication aid programmed in Mandarin. When you press a Pixon symbol the screen changes to offer more choices

There was much enthusiasm for the AAC Resource Centre, which will include a library of aids to loan to patients and other therapists. The only obvious impediment is the lack of therapists with an AAC background. Nigel and I spent some time canvassing different training models including sponsoring local therapists with good English in placements in Australia or the US, or having overseas AAC specialists conduct training for more therapists in Shanghai.

Between the two meetings at Quyang Hospital Dr Sun and I met with Hui Tiong Yu, Director of Rehabilitation at the Shanghai Disabled Persons Federation (a government agency) and her deputy Wang Hai Dong. The concept of non-speech communication and AAC was totally new to both of them. Initially Ms Hui appeared to think that it was a fad of countries too lazy to teach all their children to speak. Conversely she thought that any children who didn't speak lacked the cognitive ability to do so – ironically later we saw that Speech Therapy and IQ Testing were

constructed, but most could not at this stage. The whole process taught me something about Chinese language structure and which words are unnecessary – HIS, HER, A, and THE among others, which is why they may cause problems when Chinese speakers learn English as a second language.

While a few severely disabled children used eye-pointing to select the cards, most of the children used their hands. Their eye-hand co-ordination and hand pointing appeared much better than we usually see at Deal in children with similar speech difficulties. That may be because the children who are brought to Deal are those who have not succeeded with standard AAC because they have more severe neuro-motor impairments, or it may be due to the acupuncture and other therapies used in China. Certainly the children with autism seemed significantly calmer. In every session I sat opposite the child, in the regular therapy position, not next to the child, as I would usually need to at Deal in order to provide support or control.

On Friday June 26th I flew to Beijing to deliver a plenary presentation on basic AAC entitled *Communication Aids Programmed in Mandarin* at the 2nd Chinese International Conference on Speech Therapy co-sponsored by the Beijing Rehabilitation Medical Association, Hearing and Speech Branch, and the University of Minnesota at Duluth. Partly as a result of Deal's input the conference included four plenary presentations on AAC, with the other speakers being Dr Tianxue Snow Yao, Prof. Stephen Calculator and Dr Carol Goossens, who are all well known in the international AAC field. Later Chinese speakers espoused the establishment of the first professional association for Chinese speech therapists so it's obviously likely to be some time before China has an association devoted to non-speech therapy!

Since my return to Melbourne on June 29th I have exchanged many emails with Dr Sun and other stakeholders in China, Australia and the United States in regard to the opening of the AAC Resource Centre later in 2009.

A letter from Dr Sun is attached – obviously significant assistance with both training and equipment is going to be needed for the centre to be functional.

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To whom it may concern,

In the second half of 2009 Quyang Hospital in Shanghai will open a comprehensive rehabilitation centre under the direction of Dr Wang Ya Guang .

Dr Kexing Sun of the Shanghai University of Traditional Chinese Medicine, Dr Zhao Ming Huang of Eastern Normal University, Shanghai, Dr Rosemary Crossley, Director, Deal Communication Centre, Melbourne, Australia and Dr Mark Mizuko, Professor & Department Head, Communication Sciences & Disorders of the University of Minnesota are working on the development of an Augmentative Communication (AAC) Resource Centre, to be included in the Speech Pathology Department of the new rehabilitation centre.

This will be the first Augmentative Communication Resource Centre to open in China. It will include a library of electronic communication aids for loan to families for trial and training. Any assistance you can give to enable the Centre to provide a comprehensive service would be greatly appreciated.

Yours sincerely

Kexing Sun
Course Director of Rehabilitation Teaching-Research Section
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