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**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 – Shanghai October 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.

### **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.