



By Ivy Kwek and Yam Phui Yee

Beating childhood learning difficulties

Making early intervention count

Opposite page:
The play therapy room
in Pusat BOLD-PSDC
is a welcoming and
safe space for children,
especially those
undergoing trauma, to
express themselves
freely.

Right: The Focus on
Literacy programme
helps students learn to
read using creative aids
and flexible teaching
methods.



Daniel Lee

Motherhood has been very tough for Mei Sing*, as both her sons have learning difficulties. She blames herself for the "misfortune". Her older son has signs of Attention-Deficit Hyperactivity Disorder and the younger one was identified as ADHD with learning difficulties at the age of four. "I was lost when I had my first child, because no one explained what to do about his special needs."

DESPERATE and helpless, Mei Sing searched for professional help and friends recommended the BOLD-PSDC Centre in Island Park (Bureau on Learning Difficulties), Penang. She enrolled six-year-old Andrew* in BOLD's Transition to School programme and later, Focus on Literacy for primary school students.

Heartened by Andrew's progress, Mei Sing sent her elder son, Alex*, who was in Year Five, to BOLD. By then, Alex had been labelled a "retard" and "very naughty boy" by his teachers.

Despite his hyperactivity, Alex was timid and quiet, "like a robot", said his mother. Within a year at BOLD, he became calmer and more expressive.

"I lost a lot of precious time with Alex – that's my big regret. At that time both the teachers and I knew nothing about ADHD and I kept caning him. The years of torment eroded his confidence," Mei Sing confessed.

Indeed, helping children with special

needs is a battle against time. Early intervention is as important as early diagnosis.

"Every child deserves a chance – children have the right to access diagnosis and intervention," stated BOLD president Dr Tan Liok Ee. In 2002, in a census carried out by the Socio-Economic and Environmental Institute (SERI) on learning difficulties among Year One pupils in Penang, researchers found that 9.41% of them had learning difficulties. These students were not physically disabled, but they learn in different ways compared to normal children. Following conventional teaching methods, their difficulties are often overlooked and their behaviours misunderstood.

The findings affirmed that BOLD was on the right track in its pursuit to assist children with learning difficulties and related conditions such as ADHD and autism. Set up by the Penang Education Consultative Council (PECC) in 1998,

BOLD is now a registered society. It currently conducts early intervention programmes, play groups and play therapy for children aged three upwards, and a literacy programme for school-going children. There is also a parent support group to help them cope with the challenges of parenting a child with learning difficulties.

The play group targets three- to five-year-olds with delayed development or difficulties in social, communication or language skills. BOLD's therapy room boasts a collection of toys which children can play with freely on the condition that no one and nothing gets harmed. A child who is unable to recognise anger towards his mother may come in and throw a soft toy to the floor. "This gives them the freedom to be themselves and express what they cannot, outside," explained a staff member who has been working on play therapy for many years.

Under the Focus on Literacy (FOL) programme, volunteers – most of them housewives – help students learn to read in Bahasa Melayu, Mandarin or Tamil using creative aids that combine touch, sound and visual senses, and flexible teaching methods. "Only with the ability to read and write, can the children progress in their learning process," said Dr Tan.

BOLD also has a well-stocked library of books on learning difficulties that is open to the public. Those who live on the mainland can access its catalogue online and the books will be taken over to its centre in Seberang Jaya.

Just last year, BOLD teamed up with Asia Community Service (ACS), another Penang-based NGO, to provide a wide

Yam Phui Yee



Pusat BOLD-PSDC president Dr Tan Liok Ee: "Do we want to be a society that only rewards the best; or do we want take a humane approach in ensuring the welfare of the weaker ones?"

Below: The First Step Intervention Centre.



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range of services for those with special needs, from babies to young adults. The ultimate goal is to help them become independent individuals. Their joint project, First Step Intervention Centre, conducts massage sessions for babies and a range of programmes including school preparation classes for six-year-olds. The ACS Stepping Stone Work Centre, meanwhile, gives meaningful employment to young adults with disabilities. Members, as they are called, earn a living from cooking and baking, paper-making, recycling, weaving, and candle- and soap-making.

Mei Sing eventually quit her job as an office administrator to be a full-time mother, determined to give her children the best and to learn to accept their needs. Alex has difficulties socialising, so she encourages him to participate in group activities such as camping, basketball and choir practice.

As the super friendly Andrew struggles to cope with changes, she exposes him to as many real life experiences as possible. She lets the boys help with household chores, as it develops problem-solving skills and lets them identify with their parents' hardships which ultimately gives them a sense of satisfaction and achievement.

"Even if they create a mess after mopping the floor or roll up a T-shirt into a bun when trying to fold clothes, I let them be," said Mei Sing. A special child needs a lot of love and encouragement but there must also be times when discipline is observed. She and the boys draw up rules together and agree on the punishment if they do not comply.

First Step and Pusat BOLD are not daycare centres – they impose a strict rule that a parent or caregiver must accompany the child for most classes. "It is also a good exercise for the parents to understand their child's needs, and to overcome society's stigmas

against children with learning difficulties," said Dr Tan. Children with learning difficulties can learn, they just learn in different ways.

"We don't provide a five-day week programme or we would be a kindergarten. We encourage parents to find a local kindergarten and we support them through the process," said ACS executive director Khor Ai-Na.

Khor is working on providing itinerant support for kindergarten teachers but she laments that it is a challenge because of the lack of trained staff. Although a number of organisations for children with learning disabilities have sprung up in Penang, the fact remains that these are not enough. Families that live far away from the centres and cannot afford transportation costs often lose out.

The consolation is that people are becoming more and more aware of learning difficulties and other disabilities, compared to the 1990s. More hospitals are offering multi-disciplinary therapies now. There is no official data but it is estimated that there are some 14,000 persons with disabilities in Penang, and 4,000 of them have intellectual disabilities.

Dr Tan hopes the government can focus more on training and human resource development, rather than only focusing on the hardware. Perhaps then we will see more families like Mei Sing's getting help as early as possible, no matter how difficult their situation.

Although the present situation is far from ideal, Dr Tan acknowledged that children with special needs in Penang are luckier than those in other states. "We have many NGOs with a long history such as the Cerebral Palsy (Spastic) Children's Association of Penang and St Nicholas' Home for the visually impaired. Over the past 10-12 years, we've also seen many new ones sprout up, such as ACS, Two Way Centre, and BOLD.

"Besides, our General Hospital is also one of the most equipped hospitals in the northern region in terms of facilities and professionals who work with children," said Dr Tan. "I must say that BOLD would not have existed if not for the previous state government's effort to initiate the Penang Education Consultative Council, which has done much to benefit the people. I must give credit to the current state government for continuing the good work," she added.

** Names have been changed to protect their privacy.*

Ivy Kwek is a research officer with SERI.

Yam Phui Yee learned more about our education system when her dyslexic student was struggling with Year Two work, weeks before sitting for the UPSR.



Best friends S. Sharren (left) and Ernest Teoh, who is visually impaired, are proof that a disability need not be a barrier to genuine friendship, education opportunities and the good things in life.

Below: Asia Community Service executive director Khor Ai-Na insists on not providing five-day daycare service for children with learning difficulties so that parents will have to look for kindergartens where their special children will gain more from interacting with normal students.



BREAKING BARRIERS

Why the Malaysian education system needs to become more inclusive

ERNEST TEOH is a new student in SK Jalan Hamilton but he has already found a best friend in S. Sharren, an old friend he met when their parents attended a gathering. Ernest's face lights up when he talks about Doraemon, Crayon Shin Chan and his favourite subject, Science. Ernest wants to be a lecturer when he grows up. The 10-year-old boys love car racing, cracking jokes and laughing out loud. When asked about their favourite activity, both exclaimed, "Walk around!" "And play!" one of them added. From the way they bantered and completed each other's sentences, you would not notice any barriers between them until the boys got up for their walk and Sharren gently placed Ernest's palm on his forearm. Ernest was born blind.

"Sharren is very good to me. He always shows me how to do my homework and takes me from class to the resource centre," said Ernest. SK Jalan Hamilton is the first primary school in Penang where visually impaired students can study in the same classroom as their "seeing" friends, following a scheme that began this year. Here, Ernest studies in the same class as children with normal vision and writes with a Braille, the "typewriter" his classmates are fascinated with.

"He types very fast. When we were writing the first sentence he was already writing the fourth," said Sharren, beaming with pride as he spoke about the places he had shown Ernest. It was only within the last one-and-a-half decades that the term "inclusive education" became more understood in Malaysia, when the nation became a signatory to the Unesco Salamanca Statement 1994 – possibly the most important international policy on the subject. With inclusive education, every child gets equal opportunity to learn in the same class regardless of his or her abilities or disabilities, gender, background and so on. This means that the education system in its entirety adapts to reduce learning barriers to meet the needs of the students.

The "inclusion" practised in Malaysia is actually functional integration, whereby disabled children who are considered "educable" are placed in a school for non-disabled children but often tucked away in a special class. Depending on their abilities, these students join in some or all classes with normal students based on the existing curriculum, which means they are forced to conform to the mould or risk failure. Although the Persons with Disability Act 2008 enshrines the right to education for all disabled people, it does not override the Special Education Regulations 1997 – a hotly debated law for its definition of "educable" and who decides if a child is so.

This is the inclusive education advocates' aim: scrap the need to label the child in order to fit him into the system and change the system so that every child can study in the same class.

"We don't believe that you should have those with Down Syndrome on one side, and those with autism on another side. If you can't accept them as children, you can't accept them as adults. And society seems to think that if you can keep them out of sight, that's better," said Dr Tan.

"Our society tends to practise elitist thinking," she added. "It is an issue to ponder: Do we want to be a society that only rewards the best; or do we want to take a humane approach in ensuring the welfare of the weaker ones?" A special child learns important social and life skills when she interacts with others under normal conditions. An inclusive classroom gives him/her opportunities that a special classroom or special school, cannot.

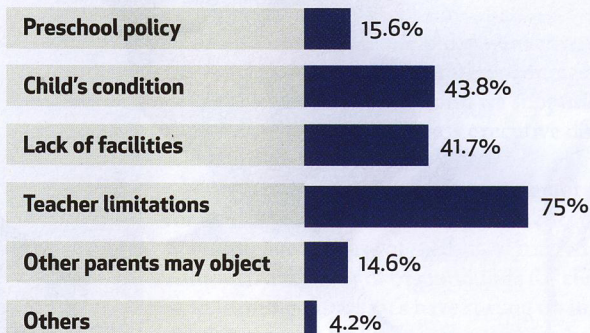
Contrary to the fear among many parents that a disabled student will hamper the academic performance of the class, Khor said they should look at the positive aspects instead. "If a teacher can break down the task for a child with special needs, she'll be a better teacher because of the creativity and skills involved. In the end not only the child benefits but the whole class as well," she explained.

On top of the struggle to come to terms with their children's conditions, parents with disabled children also have to deal with rejection by preschool operators. In the Inclusive Preschool Education in Malaysia survey by ACS, 156 out of 191 private preschools surveyed received enquiries to enrol a disabled child, and 96 (61.54%) of these were turned down mainly due to teacher limitations (see chart).

The survey also highlighted that the key to inclusive education was collaboration between parents, teachers and professionals who can support teachers in their work. ACS is now looking into itinerant support for kindergartens in the state. "If there are 700 preschool operators in Penang and each school enrolls a (special) child, we'll be out of business," said Khor with a smile. Having children with learning abilities in the same class sounds like a daunting task for any teacher, but it need not be the case with proper training and support.

Of course, the Education Ministry has to spearhead the change and this is where parents can play a proactive role in calling for an inclusive education. In Norway, Canada and many other countries, parental pressure has helped make inclusive education possible.

Reasons for turning down enrolment of children with special needs



Source: Inclusive Preschool Education in Malaysia, Asia Community Service. 2007.

Here in Penang, Ernest's father, Alvin, has been pushing for equal education rights for disabled children and today we see the first three visually impaired students studying in a mainstream primary school in Penang.

Inclusive education requires a massive transformation of the Malaysian education system and Khor reckoned that it would take another 10 to 20 years of careful planning before it took off. This is also a fight against time – our children's. The earlier they are in put in an inclusive environment, the easier it is for them to embrace each other. Sharren's younger brother has Down Syndrome. Ernest's mother noticed that unlike other people (adults included), Sharren knows how to take care of her visually impaired son and believes it has to do with Sharren's experience with his own disabled brother.

Ernest has to adjust to a more demanding curriculum and a new group of friends in the school. After attending a school for the visually impaired for a few years, he was reluctant to attend a mainstream school at first. But his parents knew it was necessary to give him a chance to lead a "normal" life.

Do we dare imagine how many children have been left behind because we lack the will to change the system or are not proactive in holding our leaders accountable? "Mainstreaming is so possible in kindergarten and primary school," said Khor.

When we accept that children with different disabilities and abilities can live and learn together, we are essentially teaching them to live as humans. And that's a powerful lesson. Will the children be able to cope? Just look at Ernest and Sharren. ●

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Tel: +604-398 4358

First Step Intervention Centre
227, Jalan Pemancar,
Gelugor, 11700 Penang.
Tel: +604- 658 5396
www.asiacommunityservice.org

ACS Stepping Stone Work Centre
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For more information on volunteer opportunities and community-based organisations in Penang, log on to www.penangcares.net.

STEPPING STONE

Nestled in the quaint Pulau Betong area of Balik Pulau is the ACS Stepping Stone Work Centre which offers meaningful employment to persons with disabilities. The workers, who are called 'members', clock in at 9am using punch cards that bear their name, initials, picture, number or any symbol that they can recognise as theirs. Not all of them are able to identify letters. Then, a busy day begins as the 22 members head for their workstations to bake, cook, weave, paint batik, sort out items for recycling, pound banana tree trunks into pulp for paper, and mix various chemicals to make soap.

As employees, the members receive a monthly salary and RM300 disabled worker's allowance from the Welfare Department each. Given support, training and equal employment opportunities (which is their right), persons with disabilities can live as dignified, productive and contributing members of the society.

The government needs to take the lead by ensuring the 1% quota employment for disabled policy is implemented in every department, while private companies should seriously consider adopting this practice. Not many realise that companies are entitled to double tax deduction for remuneration paid to employees with disabilities.

What kind of jobs can they do? Well, certainly more than assembly line work. *PEM* chatted with Stepping Stone members, Diana Mariawa Din and Izwan Talib. Diana has cerebral palsy while Izwan has intellectual disability.



Diana Mariawa Din, 25

What does your work involve?

I'm a trainer in the weaving section and my job is to help other members if they have problems while working on the loom. At the end of the month, I type out a report for my section. I've been here for seven years. When I was a beginner, it was so difficult to set up the loom and when the thread got stuck you had to untangle it, you must not cut it. It was frustrating!

The craft items made here are also sold at the Little Penang Street Market at Upper Penang Road.

What's the experience at the bazaar like?

I had never taken a bus in my life and never left Balik Pulau. When I took a bus to town for the first time I was very afraid I'd get lost but the ACS staff guided me. I was shy when I had to sell things at the bazaar. Now I'm getting better at it. I feel very happy when someone buys our products.

You are the president of the Mutiara Voice Club. What does the club do?

We speak up on our rights such as the right to study with our normal peers, right to work and we help the people like ourselves. We have organised a bungalow stay and jointly organised the 3rd National Self-Advocacy Conference with ACS last year. We hope to express what we want to the government and the public because there are very few channels for us to do so.



Izwan Talib, 25

What do you do at Stepping Stone?

I started in the kitchen when I came here seven years ago. Then I moved on to other sections – batik making and weaving. Now I'm under the recycling section. In the mornings my friends and I cycle around the village to collect recyclable items and the villagers know us by now. I also make paper from banana tree trunks.

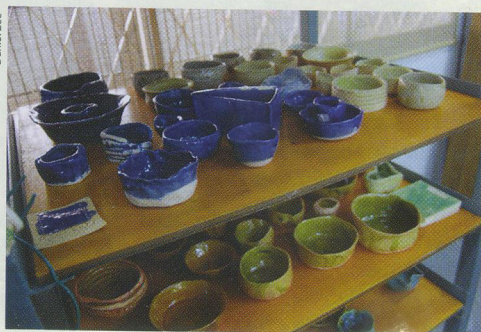
Describe what it's like working at Stepping Stone?

It's fun and I've made a lot of friends. If I don't work I'd be sitting at home doing nothing, and I won't get *EPF*. We must work so that we can save money to buy things.

Who do you live with?

I started renting a house nearby with a colleague last year. It's much easier than for me to live with my family in Teluk Bahang and travel every day.

**Last year, Izwan gave a speech on independent living for people with disabilities in the 3rd National Advocacy Conference.*



Some of the craft items are sold at bazaars like the Little Penang Street Market, where the ACS Stepping Stone Work Centre regularly displays things made by its members.

Text by Yam Phui Yee. Photos by Daniel Lee.