

Just because people have intellectual disabilities, that does not mean they cannot think. – Asia Community Service director Khor Ai-Na

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The majority of the learning disabled want to live independently, according to a survey by Penang-based Asia Community Service. LEE SOO HOON reports on the current debate surrounding this issue.

THE term "independent living" has long been associated with the global movement of people with disabilities. The term was coined in California in 1959 when a law was passed allowing counties to provide personal home services to people with disabilities in the community.

Although there is a great disparity internationally in the availability of services and support for people with disabilities, the philosophy of the independent living movement is more unified around the world.

The chairman of The Institute of Independent Living in Sweden, Adolf Ratzka, defines independent living as a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect.

"Independent living means that we demand the same choices and control in our everyday lives that our non-disabled brothers and sisters, neighbours and friends take for granted.

"We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, work in jobs that are in line with our education and abilities, start families of our own. Just like everybody else, we need to be in charge of our lives, think and speak for ourselves," says Ratzka.

The National Council on Independent Living which represents over 700 organisations and individuals with disabilities in the United States maintains that consumer choice, autonomy and control define the independent living movement. Its independent living philosophy holds that individuals

with disabilities have the right to live with dignity and with appropriate support in their own homes, participate fully in their communities, and to control and make decisions about their lives.

Asia Community Service (ACS), a charitable organisation providing services, training and support for children and adults with intellectual disabilities and their families in Penang, shares the universal worldview on independent living.

The concept is based on treating people with disabilities with respect as fellow human beings, accepting them for who they are, and giving them the freedom to make choices, says ACS director Khor Ai-Na. "Many adults with disabilities do not enjoy independent living because they are still living their parents' lifestyle or someone else's lifestyle. People tend to associate independent living with group homes, but that is not necessarily so.

"Independent living can take place right in the home of the family if the correct elements are there. Group homes on the other hand can turn out to be 'mini institutions' if residents are still being controlled or faced restrictions," she stresses.

"Just because people have intellectual disabilities, that does not mean they cannot think. The problems usually arise when we overlook their ability to think or rather do not trust them to make the right decisions."

In its survey among 38 adults with intellectual disabilities conducted in Penang during a workshop entitled *Towards Independent Living in the Community* last July, ACS found that

## Striking out on their own



Adrian Choo (left) making recycled paper with fellow trainee Teik Wei at the Step Training Centre in Relau, Penang.

60% of the respondents wanted to live on their own, while 40% favoured living with their parents. A large 45% did not mind living with friends or family members, and only 13% wanted to live in old folks' homes.

When it came to questions on coping alone in their own homes, at least 80% of the respondents could operate common electrical

and household appliances such as the fan, lights, television, radio, rice cooker, iron and washing machine. A huge 90% could cook instant noodles, 89% could make a hot drink and 75% could cook fried rice.

On the matter of choices and decision-making, 94% could decide independently on what clothes to wear and 92% could choose

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their own food and daily activities.

However, when it came to more challenging living skills, only 58% of the respondents could cross the road on their own, while only 51% were able to take the public bus or Light Rail Transit independently.

The issue of relationships and marriage generated much interest among respondents:

- 80% wanted to have a special boyfriend or girlfriend;
- 60% wanted marriage, 26% objected to the idea, 14% were unsure;
- 33% did not want children after marriage, 40% wanted between one and three children.

For 20-year-old Adrian Choo who has Down Syndrome, independent living means being able to take care of himself. To be independent also means to be happy, clever, hard-working and be an obedient child to his devoted mother.

He considers himself rather independent because "I can keep myself clean and tidy. I choose what clothes to wear. I help my mother with the chores at home."

Choo credits his mother for his growing independence as she was the one who taught him such skills as reading, cooking and keeping a diary.

However, one skill Adrian hopes to learn is to float in the water because he likes playing in the pool, a leisure activity that is disallowed for the time being. His mother, Gan Soo See, who is in her sixties, explains that he suffered ear infection on a few occasions after he went swimming.

"His hearing was affected and I had problems communicating with him," she says.

Gan confesses that she had difficulty letting

go of Adrian when he was younger because she was worried that he might have problems communicating with other people and that unscrupulous individuals might take advantage of his disability.

"Letting go in the early years was frightening. It was a gradual process. Of course, it helps if the parents have confidence in their child's carers," she says, in reference to the admirable work being done with her son by the ACS Step Training Centre in Relau, Penang.

However, there are still certain things that Gan has qualms over such as Adrian cycling along a public road and learning to take the public bus even though he had undergone the bus training programme with fellow trainees.

Besides having good independent self-help skills, Gan notes that her son can think independently.

"He is able to plan his own leisure activities at home. He will carry out his household chores with a full sense of responsibility but once he has finished, he will move on to leisure and will not let you get in the way."

Despite Choo's ability in certain aspects, Gan realises that it is impossible for him to be 100% independent. She hopes that he will stay with family members when she and her husband are no longer around to care for him.

"I understand the stress of caring for a person with special needs and do not want Adrian to be a burden to those caring for him. But I am confident that he will be a useful contributing member and not a handicap to his family."

"If that does not work out, Adrian can stay with friends in a well-run group home with

his family members helping to supervise him on money and health matters."

On the issue of marriage, both mother and son are equally excited. One cannot wait to find a girlfriend and get married. The other is terrified that it might happen.

"It will be so complicated. I prefer that he doesn't get married," admits Gan.

But if Choo had his way, he would rather settle down by 22. "First, I have to work and earn lots of money. Then I can buy a house for my wife," he says with a grin. He already has a girl in mind.

As far as seeking life partners is concerned, Choo is not alone.

Another fellow respondent, 32-year-old hemiplegic Basri Yob wants to marry a girl

who is gentle and hardworking.

Still, Khor Ai-Na concedes that the biggest barrier to independent living for people with intellectual disabilities is "other people's perception and attitude."

And that is something we can and must change.

■ *One Voice* is a monthly column which serves as a platform for professionals, parents and careproviders of children with learning difficulties. Feedback on the column can be sent to [dignity@tm.net.my](mailto:dignity@tm.net.my). For enquiries of services and support groups, call Malaysian Care (☎ 03 9058 2102) or Dignity & Services (☎ 03-7783 0849). Asia Community Service can be contacted at ☎ 04 658 5396.