

# FAMILY POST

Expatriate parents of autistic children  
have limited treatment options >PAGE 6

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# Needs of the few

It's tough raising an autistic child. But for expatriate families in Hong Kong, the options for special needs education are even more limited, writes **Oliver Chou**



A music and art workshop for autistic children at the Children's Institute of Hong Kong. Photo: Jonathan Wong

## THE ENGLISH WAY

Special education institutions for English-speaking autistic children

**Autism Partnership**  
36 autistic students  
1:2 teacher/student ratio  
HK\$18,500 monthly fee  
1-2 months waiting period  
Charity status/private

**Child Development Centre**  
140 autistic students  
1:3 teacher/student ratio  
HK\$150-\$6,000 monthly fee  
4-5 months  
Charity status/partially subvented

**The Children's Institute**  
18 autistic students  
1:1 teacher/student ratio  
HK\$30,000 monthly fee  
1 year waiting period  
Charity status/private

**The Springboard Project**  
16 autistic students  
1:3 teacher/student ratio  
HK\$13,200 monthly fee  
Waiting period based on individual interviews  
Charity status/private

Global public health crisis and a fast-growing epidemic: these were the stark terms used by experts at an international summit held here last weekend to describe the cost of autism. The descriptions are backed up by grim figures. In South Korea, as many as one in 38 children are diagnosed as having autism spectrum disorders.

The US Centres for Disease Control and Prevention reports prevalence at about one in 88 youngsters in the country. Hong Kong doesn't have an official estimate, but groups say the number ranges from 70,000 to 200,000, depending on the screening criteria.

For their parents, no amount of research or statistics can compare with the stark realities of raising children who will struggle all their lives to make sense of the world. There are long waiting lists to get into the special needs facilities in Hong Kong, from assessment centres to schools, whether private or government subsidised.

English-language services are even more limited, which makes for a desperate group of expatriate parents, especially if their child is among the more severely impaired.

Alison Ridley strived for years to get help for her son Jack, now six.

The Polytechnic University lecturer counts herself lucky that Jack secured a place last year at the Jockey Club Sarah Roe School, a centre for children with learning difficulties under the English Schools Foundation.

"Sarah Roe offers a very rich special needs curriculum at the basic ESF price. Having messed up Jack's opportunities for early intervention, I am just happy that he is happy there," she says.

Her son enjoys the school trips and activities, such as riding. But Ridley says she never ceases to think that he would have been much better off if they had chosen to return to her native Britain, where there is better access to therapy, or to go deep into debt to pay private therapists for the recommended 30 hours of one-to-one sessions a week when he was younger.

"There is permanent guilt from not having provided the right amount of help at the right time, and permanent fear of having consigned a child to dependence on parents who will not live forever," she says.

Ridley, who has lived in Hong Kong for 16 years, started noticing signs after Jack turned one. He didn't seem to interact with people around him and was obsessed with spinning objects, such as fans, and

having things in order (all his toy cars had to be lined up). At first, she and her husband put it down to childhood quirks. They began consulting doctors because Jack barely spoke, but had to wait months to see a psychologist and get a diagnosis from a child assessment centre.

Ridley used that time to surf the internet for clues and soon worked out what her son's condition was. She says all the research indicated that if Jack was to realise his potential to function more fully in society, early intensive intervention was necessary. This meant between 25 and 40 hours of therapy per week.

A neurological development disorder, autism affects individuals to greatly varying degrees. To observers, they may seem locked in a world of their own. Some may display vocal tics or actions, such as hand flapping or rocking.

Because sufferers process information differently, most have trouble linking words with meaning or expressing themselves. They can fail to read emotional signals from faces, and find it difficult to interact with others and understand their differing perspectives.

But research indicates that with early, intensive treatment, most can improve their ability to relate to others. Treatment can also enable them to care for themselves as they grow older. The window for successful treatment is typically between the ages of two and four.

As working parents of modest means, Ridley and her husband were ready to send their son to a public facility.

But Jack had trouble expressing himself even in his mother tongue, so a service catering to English speakers was crucial. There were only two such centres in Hong Kong, however, and both involved long journeys and equally long waits.

Meanwhile, the family tightened their belts. Ridley took on extra weekend work to pay for Jack's 15 hours of therapy each week. They also sent him to a private speech therapist. But it was hard to find one who didn't require an hour's journey for a half-hour session.

By the time he was 3½, Jack was still "non-verbal" and not toilet trained. He was often up at night, spinning around the flat from 1am to 4am, upsetting his brothers. At the time, Ridley recalls, "all the family had some dark shadows under their eyes".

Agonising over his isolation, they tried sending him to kindergarten. But this proved to be a mistake. Jack could not communicate or learn routines, and was ejected after three weeks for being disruptive.

Options for expatriates in Hong Kong looking for special needs education are limited. There is Sarah Roe, which has 64 slots, and a handful of other institutions that cater to English-speaking autistic children. Among them are The Children's Institute of Hong Kong (TCI), which is a non-profit school.



Children who need special education will have to learn Cantonese first. That's discrimination

DR JEREMY GREENBERG (ABOVE)



There is also the partly subsidised Child Development Centre (CDC). A bilingual special education institute for children under six, the CDC serves many English-speaking children. About half of CDC's 280 students are autistic. Its chief executive, Virginia Wilson, rates Hong Kong as being 30 years behind the West in facilities for autistic children.

At last week's Autism Summit, sponsored by Goldman Sachs in collaboration with the CDC and US-based research institution Autism Speaks, several speakers acknowledged the city's overall inadequacy of services for special needs children.

"We still don't know enough about it here, and our facilities, from screening to diagnosis, are insufficient," says Equal Opportunities Commission chief Lam Woon-kwong. "It was not until very recently that we had a better diagnosis mechanism. Even now, we are not sure of the number of children in need. Support is lower than justifiable for an advanced economy like ours."

While applauding the government's principle of integrating autistic children into the mainstream education system, he says that "execution has fallen considerably behind what is needed largely because of a lack of infrastructure, lack of training for teachers, and lack of supporting professionals."

Secretary for Food and Health, Dr York Chow Yat-ngok, expects the city's autism figures to rise as the criteria for diagnosis have broadened. Consequently, more resources will be allocated

for special needs children. But a holistic approach is needed to address their needs.

"It's not just health care," Chow says. "There is also pre-school service, then school to follow. So it is a long-term project. But it has to be dealt with at the early phase before it becomes a burden on society."

That's cold comfort for expatriates such as Ridley, who challenges the notion that parents should have to pay a high premium for the choice if they seek English-language services for their special needs children.

"The special needs debate in Hong Kong is far from being about choice. It is about basic rights," Ridley says.

TCI director Dr Jeremy Greenberg agrees. "Expatriates living in Hong Kong pay taxes like the locals. But when they have the need for special education, their kids will have to learn Cantonese first. That is very hard for a five-year-old who doesn't even have a first language. That's discrimination."

The US introduced notions of "free appropriate public education" and a "least restricted environment" for all children, including the handicapped, into its education system during the 1970s.

But Greenberg says Hong Kong has no such rule for children with special needs. He argues that the dearth of special education facilities for expatriates will hamper the city's competitiveness.

"I get [overseas] phone calls every week from people saying their companies are planning to move them to Hong Kong and they have a kid with autism. I feel terrible telling these parents that they have to be on the waiting list for one year."

"These people are the brightest in multinational companies. But without the facilities for special

education, they will go somewhere else and Hong Kong is going to lose out," adds Greenberg.

The government should expand the infrastructure, such as schools and the health care system, which have to grow along with the economy, Greenberg says. At the moment, it is lagging far behind.

"The government owns all the land. Instead of just selling to developers to build small but expensive apartments for huge profits, it should take some land and build schools for both regular and special education."

Several special education institutions struggle with the problem of space. The CDC only recently managed to extend its lease at Matilda International Hospital through to 2014.

Autism Partnership, a bilingual special education institution that runs five English-speaking classes, is on the lookout for new premises.

Lam insists that the charge of discrimination does not apply in Hong Kong's provision of special needs education, although society lacks awareness of the plight of

autistic people. "The situation is not deliberate. It's that the system is insufficient for everybody, local and expatriate. There is a shortage of professionals. Overall as a system, we need to invest more in this very under-developed field."

Lam estimates that it will probably be "another couple of decades" before a sound infrastructure is in place to meet Hong Kong's special education needs, including that for autistics.

Would it take a top official with a personal stake to speed changes, as Greenberg suggests?

Certainly, two key organisers of the summit, Elizabeth Chen, managing director of Goldman Sachs (Asia), and Wilson of the CDC, are mothers of autistic children.

"To be a parent of children with autism is beyond the imagination of many normal families," Chen says.

"That's why I feel very strongly about this cause. I hope the local community and policymakers can be more understanding of autism and those who are affected, and be supportive of families in need." oliver.chou@scmp.com

## Intensive therapy appears to foster 'social bloomers'

Generva Pittman

Many autistic children with social and communication problems benefit from intensive therapy, and about 10 per cent "bloom" socially as they grow older, US researchers say.

Most of the children in the study who benefited were white and came from wealthy homes. This may reflect a difference in access to treatment, the study says. Also, few of them had intellectual disabilities in addition to their social problems.

Autism is a spectrum of disorders marked by a group of symptoms, all arising from atypical brain development that causes problems with socialisation, communication and behaviour.

One in 88 US children have autism, ranging from severe communication and intellectual disability to much milder symptoms seen in children with Asperger's syndrome.

"Most children get at least a little better over time," says Christine Fountain, an autism researcher at Columbia University in New York, whose study was published in the journal *Pediatrics*.



Autism awareness day was April 2

Although the disorder can be mild or severe, in general children with autism have trouble communicating and making friends. Many avoid eye contact with people, hampering their ability to understand what others are thinking and feeling.

For their study, Fountain and colleagues followed the growth of nearly 7,000 autistic children, aged two to 14. The children had undergone at least four evaluations in which staff recorded their social and communication difficulties and their repetitive behaviour.

The researchers found that especially when it came to social and

communication scores, most children improved over time. Of the children, about 10 per cent saw rapid improvements, moving from severely affected to high functioning. The researchers call them "social bloomers".

But they noticed that many of the "bloomers" had white, well-educated mothers. Minority children with less-educated mothers or children with intellectual disabilities were very unlikely to make rapid gains, they say.

The researchers did not have information about the specific treatment each child received. There is limited evidence on what type of autism treatment might be helpful, but behavioural therapy typically includes language- and communication-based exercises.

Some children are also given medication which includes antidepressants.

Johnny Matson, an autism researcher at Louisiana State University, says the findings reinforce evidence that children with autism and a normal IQ improve more from intensive therapy than those who have

both autism and intellectual disabilities. Matson, who was not involved with the study, says gaps in improvement based on parents' race and education are probably linked to access to good-quality treatment.

But he says "those gaps are narrowing very rapidly" because of laws requiring insurance companies to cover intensive treatment for all children with autism.

Fountain says the findings point to the importance of providing equal access to the best autism treatment for minority and less well-off children. Some states in the US provide services to all children with autism regardless of their families' ability to pay, but others do not.

She says children's specific conditions and symptoms may play a role in their long-term improvement, but the treatment they get also is likely to be important.

Fountain and Matson say parents of autistic children should be persistent in making sure their kids get the help they need.

They both agree that parents should be optimistic. Reuters