WHO WILL CARE FOR RUSSEL & KENNETH?

THE Tan brothers, Kenneth (right, with a neck brace), 48, and Russel, 50, live, eat and play at the residential facility of Bishan Home for the Intellectually Disabled. Both of them have autism spectrum disorder which is not formally diagnosed: Kenneth is verbal – meaning he talks - while his brother Russel is not.

At the home, activities like music classes, karaoke sessions and daily living skills lessons fill up much of their day.

They were born at a time when autism was not a known diagnosis. At the age of four, Russel was diagnosed as retarded by a professor of paediatrics.

Both children were later informally diagnosed by their mother, Dr Dixie Tan, 74, a former MP and then a practising medical doctor. “When Russel was about 10, we heard this word and it was Dr Tan. He ticked all the boxes for it.”

Kenneth, who has an IQ of 58, is the higher functioning of the two brothers. He was similarly diagnosed with Asperger’s syndrome in adulthood.

Kenneth prefers to be at his family home where he has more freedom. But Dr Tan does not think he is capable of living independently, citing examples of how he got into trouble with the police for taking a cassette tape from a store.

“Kenneth is an unhappy man, he can’t get what he wants,” Dr Tan reflects. “But on the other hand, Bishan Home gives him the structure... gives him the protection.”

When the boys grew into adulthood, she started looking for long-term placement for them because she and her husband did not expect to outlive them.

“I was always on the lookout for a good place where they would have a reasonably happy life, where they could fit in nicely,” says Dr Tan. She placed both of them under Bishan Home’s residential programme when it started in 1999. The Tans have two sisters, Grace, 46, and Jacinta, 45, who live and work in East Malaysia and Britain, respectively.

“At times they have expected them to sacrifice themselves for their brothers,” Dr Tan says. “I didn’t feel it was fair.”

To take care of the fees and medical expenses both now and in the future, she bought annuities two years ago that provide an amount to her sons annually for the rest of their lives.

She raised money for this by downgrading from their semi-detached home to a condominium apartment.

Bishan Home charges $1,500 a month for each resident, but families are eligible for up to 75 per cent in government subsidies. Out of 130 residents, 11 have or are suspected to have autism.

“Now, I feel very relaxed that I have done everything I could and put everything into place,” she says.

She now spends long stretches of time in Britain, taking care of her three-year-old grandson.

Growing old is a big uncertainty

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concentrating and is unable to hold down a job.

Each day at the DAC, Nicholas gets about four hours of physical education, recreational therapy such as swimming, and skills training in cooking or art.

For all parents in Mr and Mrs Yeow’s situation, there is thankfully some good news on the horizon. In September, St Andrew’s is due to open a $23 million autism centre at Elliot Road to expand its current intake of adults with autism. It will then be able to take in about 300 clients up to the age of 55 – more than 10 times its current intake – and employ up to 150 teachers.

By next year, it plans to convert its existing premises at Raffles Institution to a respite centre, for parents to drop off their adult children for a few nights a year just to get “some time to rest”, says Dr Taylor.

But Mr Yeow knows that this will not provide a long-term solution for his children. When Nicholas turns 55, he will have to leave the day care centre.

There are still no long-term residential or group homes catering specifically for adults with autism here, although the Ministry of Community Development, Youth and Sports Enabling Masterplan (2007 to 2013) has outlined plans to widen the range of residential care options for people with disabilities.

Experts say it may take some time before adult autism residential or group homes, like the ones in the United States, Britain and Europe, get built.

The state’s focus is currently on children with autism.

Dr Lynen thinks that it’s all about priorities. “The Government needs to look at the whole lifespan of the condition.”

Dr Taylor agrees.

For housewife Yvonne Koh, 49, help and support cannot come a moment too soon.

Her only child Benjamin, 23, still needs directions and supervision to shower. His life runs like clockwork and follows a set daily routine, but from the time he wakes up at 6am to the time he closes his eyes at 10pm, he is never left alone.

“We don’t foresee him living on his own,” says Mrs Koh, whose husband is a retired airport station manager.

“I worry that if I fall sick next time, there will be no one to look after Benjamin. I hope there will be a home for him in the future.”

WHAT IS AUTISM?

AUTISM spectrum disorder (ASD) is a lifelong developmental disorder that affects the way a person communicates and relates to others. The degree of impairment ranges from mild to severe. ASD is an umbrella term which includes:

- Autism
- Asperger’s syndrome
- Pervasive developmental disorder – not otherwise specified (PDD-NOS).

ASPERGER’S SYNDROME, PDD-NOS

People with Asperger’s syndrome display attributes identical to those with autism, but in a milder form.

Those with PDD-NOS have some of the characteristics of autism but do not fit all the diagnostic criteria.

It is sometimes referred to as atypical autism.

The exact cause of autism is unknown although some research suggests it may be linked to genetic factors.

AUTISM VICTIMS HAVE:

- Abnormal social development

They struggle to develop social relationships and may be unable to relate to others.

They have difficulty recognizing or understanding other people’s emotions and expressing their own.

They can also fail to understand social or unwritten rules about what is appropriate or expected in given situations. For example, they may stand too close to others as they do not understand the social norms governing personal space.

- Communication deficits

They have trouble comprehending both verbal and non-verbal language.

Many have a very literal understanding of language and are unable to grasp abstract concepts.

They can find it difficult to use or understand facial expressions or tone of voice, jokes and sarcasm, and common figurative phrases, like describing something as “cool” to mean trendy, not of a low temperature.

Suffers tend to repeat words, show abnormalities in rhythm and pitch, and use abnormal gestures.

- Restricted and repetitive interests and behaviour

They tend to engage in repetitive play patterns, like collecting and lining up objects, or develop a preoccupation or attachment to random things.

Many tend to resist change and are resistant on routines. The amount of difficulty experienced by sufferers varies from person to person.

People with autism have no marked physical abnormalities and look like the average person on the street.

Autism strikes males far more commonly than females, at a ratio of about 4:1. Singapore has about 24,000 people with ASD, with about 5,000 under the age of 19.

There is no known cure for autism.