

## { AUTISM }

# MINDS FROM ANOTHER WORLD

What happens when autistic children grow up? Where do they go? And who will look after them once their parents are no longer around? **Oliver Roberts** looks at a growing problem that has few solutions in sight

Photographs: **Dave Southwood**



IT'S just past 2pm on a hot Wednesday afternoon in Lakeside, Cape Town, and Jarred Flügel is cycling towards Narnia. There's a pile of books on the handlebars and he's pedalling like mad. The base of the stationary bike shifts on the wooden floors. Sunlight bleaches in through the window to his left. The flywheel hums.

We know he's heading for Narnia because that's what he told Roxie Kotze.

"I still get moments when I look at Jarred and wonder about the world he dwells in," Kotze says. "Then he'll look at me and say something like, 'Gap Student Roxie, how loud is your ponytail's lever?'"

Kotze, 22, is one of Jarred's carers. "Gap student" is the label Jarred gave her. Jarred is autistic. And, at 27 years old, he's one of a number of

adults with the disorder who come to the enrichment centre at this church hall every weekday. The centre forms part of The Academy for Adults with Autism, an organisation established in 2007 by Jarred's parents, Dudley and Debbie Flügel and two other colleagues, in response to a dire need for places where autistic adults can go to be stimulated and cared for, and a forum where other parents can receive support and information on autism. The enrichment centre caters for a maximum of seven adults, to ensure proper care. Daily classes are limited to four adults.

The prevalence of autism, or autistic spectrum disorder, is on the increase worldwide, occurring in roughly one in every 68 children today. Most of these children are sent to special schools where early intervention at least provides them with the chance to master basic

skills and perhaps learn how to read and write. However, once he or she turns 18 and leaves school, the autistic child faces a major problem: nobody knows what to do with them.

"Facilities, workplace opportunities, respite or residential centres for adults do not increase with the increasing numbers leaving school," Debbie says. "When there have traditionally been virtually no such facilities to begin with, this

**'The burden on families becomes much more than can be tolerated'**

problem starts to reach devastating proportions since the burden — emotional, financial and societal — on families, communities and countries becomes much more than can be tolerated."

Autism is a complex developmental disorder that presents itself during the first three years of a person's life. It affects normal brain function, and people with autism typically have problems with non-verbal communication and social interaction. They struggle with concepts such as empathy, are often averse to physical contact and are hypersensitive to sounds, smells and lights. Their speech is affected, too. Either they don't speak much or they repeat words and nonsensical phrases. Many develop obsessions and physical tics.

Autism is a relatively new diagnosis. The first person to be diagnosed, Donald Gray Triplett, an 81-

year-old American, is still alive. He was diagnosed in 1943. There is a lot about autism that remains a mystery. Also, because each individual with the disorder displays a completely different set of behaviours, any significant progress beyond a certain stage of development is difficult, if not impossible.

"Each has their own strengths and weaknesses, and it's important for us to make use of these things to help with their weaknesses," says Ashleigh Fortune, occupational therapist at the centre. Jarred calls her "Mother Ashleigh".

The things she refers to are aids such as puzzles, beadwork, play dough and Jarred's self-propelled Narnia rocket.

"Because they're adults, the most important thing is to get them independent in their daily living," Fortune says. "So it's general things like toilet hygiene, food prepara-

tion, knowing to wash your hands. These are basic things that we don't even think about but they need to be reminded all the time."

On my first morning at the centre I go for a walk to a nearby park with Jarred, Debbie and Kotze. Before we leave, however, there's a briefing in the kitchen. Apparently Jarred likes to collect things when he walks.

"So he walks with his hands in his...?" Kotze says to him.

"Pockets," Jarred replies. It comes out pa-ock-ets. He's playing with the word, chewing its syllables.

"What's the other rule? Jarred? What's the other rule? You're going to listen to?"

"Ta-ooo..."

"Oh dear, we can't go walking then."

"Ta-ooo..." He pushes out the words like they're objects stuck in his throat. Different shapes for different things. "Roxy."

"And if you don't listen, we come...?"

"Straight back to the hall."

Jarred charges ahead with Debbie at his side trying to keep up. She has to maintain a constant eye, and a near-constant physical and emotional hold, on her son.

"They don't realise the consequence of running after a truck, for

**'J is in a good mood. Had a good day. Slept for an hour, woke up laughing'**

example," Debbie says. "Jarred has done that."

At the park, Jarred heads straight for the swings. There are four of them and Jarred must have a go on each because that's how his mind works. Sometimes there are kids on the other swings. Kotze says it's "very rare" that Jarred actually pushes anyone off the swing he wants to go on next.

We watch Jarred swinging. The chain grinds against the top of the frame. The southeaster is roaring. The beige mountains in the distance loom over everything. For a moment, nobody says anything. Jarred is swinging wildly now, leaning his head far back and reaching for the sky with his feet. When he speaks he often covers his mouth with his hand because he spits. He was only fully toilet trained at the age of seven.

"Being the mother of a person with autism hurts like hell," Debbie says. "But we have to do the best we can and that is what I am doing. The highs are very high and the lows are very low."

When I suggest that she seems a strong and brave individual, she says, "I am not always strong. I don't know how anyone can be. I'm just trying to do what I am capable of with the resources I have. I am very dependent on others to get me through tough days."

Debbie has two other sons, Ross, 19, and Brett, 25.

Debbie has invited me to supper with Jarred and Dudley that night. Jarred knows about the arrangement. It's been the main theme of the day so far.

"Oliver Roberts, are you coming to the restaurant?" he keeps asking. Or he'll say, "I suppose you'll cancel your restaurant, Oliver Roberts."

On the way back from the park, Jarred spots an elderly man walking along the road and goes up to him, really gets into his space.

"Would you like to come to the rest-aurant?" Jarred says.

The man is obviously a little startled at first but when he realises what's going on, he politely declines. Other strangers are not as kind. Debbie recounts a recent episode when she was in a queue at the supermarket and Jarred asked the man in front of her if he'd ever been stung by a bee (Jarred himself had been stung that day). The man turned around and told Debbie to "control her child".

As we get closer to the centre, we pass a row of houses with barking dogs. Jarred is largely unaffected by the noise. Debbie says when he was younger this kind of racket "freaked him out". She also tells me that Jarred seems excited that I'm here.

"Is that dog a busy dog?" Jarred says.

THE restaurant is unexpectedly busy. This isn't great news for Dudley and Debbie. All those voices, the clattering of cutlery. It could send Jarred over the edge. He seems fine though. He eats a pizza, we all eat pizza, and he asks if I can chatter-chatter like a monkey. Jarred asks if my rental car can roar like a lion. He asks if I can hoot like an owl. The other diners are aware that Jarred is there, that something isn't quite right, but nobody is looking.

Dudley and Debbie talk about the piece of land they're thinking of buying to build a kind of compound for autistic adults. Perhaps four separate cottages, two people per cottage. They tell me about their lives, how they left the Eastern Cape for Cape Town when they were in their early 20s. They laugh about it now, remembering. They were young and wild. What were we thinking, just up and leaving like that with no job waiting? You could do that in those days though, couldn't you?

Dudley says he sometimes wonders what their lives would be like if they hadn't had Jarred. Different, of course, I say. But then you wouldn't be here, running this centre for desperate parents.

"Is your car a little imp?" Jarred asks me.

Debbie has to take the ice out of Jarred's glass before he'll drink his soda because he doesn't like cold things. Dudley and Debbie recall various embarrassing incidents

**Jarred asks if my rental car can roar like a lion. He asks if I can hoot like an owl**

with Jarred, like the time he urinated in an aisle at Woolworths or slapped a woman's bottom as she bent down to try on a pair of shoes.

The Flügel's tell me it's difficult to send an autistic child to a place for, say, those with Down's syndrome, or similar kinds of intellectual disabilities because autism is so specific and so different from other disorders that specialised care is needed. There just isn't enough of that available. The academy is a non-profit organisation whose basic operating expenses have been funded for the past two years by the National Lottery Distribution Fund. The rest comes from trusts and corporations and an annual R100 membership fee. Extra fees are charged to attend the enrichment centre, but Debbie insists that anyone requiring support or referral is not dependent on them being a member at all.

I follow the Flügel's to their house



CONNECTING: Ralph is attended to by carer Ashleigh Fortune at The Academy for Adults with Autism

for coffee. When I pull up in the driveway and get out of my car, Jarred says, "I've been expecting you, Oliver Roberts."

RALPH, who I meet at the centre the next day, is also 27. He wasn't born with autism. He developed it when he got tick-bite fever at 18 months. The high body temperature damaged his brain. He is not as verbal as Jarred but he can read and write pretty well. He's able to send e-mails to his family.

"I am working very hard," reads one. "I built a 200-piece puzzle."

Ralph is exceptional with directions. Over a period of two weeks Ralph's father taught him how to take the train from his home to the centre. This is how different one autistic person is from another.

A trait of Jarred's is that he can remember the faces and names of people he met five or 10 years back, just like that. Another of Jarred's gifts, I think, is his sense of humour and, I noted, irony. On day two, he decides to label me "King Oliver Roberts", and calls me this for the rest of my stay.

He also spits at me. On the second day Jarred comes right up to me and unleashes a light spray of saliva onto my face. Kotze reckons it's because he's observed me talking to her and has become a little jealous.

Brett, 33, is at the centre today, too. He is tall and blond and shakes my hand to say hello. A greeting of sorts takes place, sure, but there's hardly any recognition of it from Brett. Meeting an autistic person is like greeting a room of 100 people and expecting the same engagement you feel when meeting someone one-on-one.

"A doctor once told me that if you have a handicapped child, you have a handicapped family, and it's so true," says Marcelle, Brett's mother. "You're constantly walking on egg shells, waiting for the next outburst. You put your big mask on, people look at you and nobody, but nobody, knows the pain behind the mask."

A major worry for all parents of autistic children is what's going to happen when they're no longer around to look after their child.

Marcelle's husband, Nick, is British and they have managed to get Brett a British passport. If necessary, in the future, Brett might have to be flown to the UK and spend the rest of his life in a home there. Marcelle describes this as "another option".

Options. You'll notice that parents of autistics are always talking about options, about what works and what doesn't. Diets. Supplements. Medication. There are drugs such as Prozac to keep the anxiety down, and other meds, like Risperdal and Tegretol. Some parents have used them and had success, as much success as can be rationally hoped for. But there are also horror stories of ignorant practitioners over-prescribing and the child shooting off in a whole new direction of chaos.

Trevelyn Lodge is a home for the intellectually disabled in Vredenburg in the Western Cape. Andrea

**As a boy, James would say things like, 'Can you put a peach on a spark plug?'**

sent her son James there a couple of years ago. James is now 22. Andrea and her husband knew something was wrong when James became obsessed with vacuum cleaners. When he started talking, he'd say things like, "Can you put a peach on a spark plug?"

Now that James is in a home, the family visit every six to eight weeks, and James comes back for a four- or five-day stretch at home. It's not an easy decision, sending your child away like that (Andrea has a daughter too) but when I ask Andrea if she struggled at all with the resolution, she is brutally, admirably, honest.

"Things became considerably easier for me and the rest of the family after James went to Trevelyn," she says. "I suddenly had a different lease of life, suddenly I could do all sorts of things I didn't have time for before and I wasn't exhausted all the time. I almost want to blank out that time of my

life when I was bringing him up because it's quite hard to think, 'Did I go through all that?' I feel that a big part of my life was spent just sorting James out."

One of the things Andrea did when James went to Trevelyn was learn how to write poetry. When her son turned 21, Andrea wrote a poem about it. She said it helped her a bit.

Maria is a mother who knows about over-medication. She reckons one specialist almost killed her son Lucas with the cocktail he gave to him. Lucas, she says, "went crazy".

Lucas is 27 and lives with Maria in Johannesburg. She describes the problem of the ratio of autistic adults to suitable homes for them as "a ticking time bomb, a tsunami". She's planning a move to Cape Town in the future. She wants to be part of Debbie's plans for a compound.

"There are no facilities, especially for the difficult cases. And parents are ageing. So until we plan how to take care of them as adults, they are not going to be independent. This is the drama we are in."

DEBBIE keeps a sort of diary about Jarred. A day-by-day account of his demeanour, his behaviour, his changes. One entry reads: "J is in a good mood. Had a good day. Slept for an hour, woke up laughing."

The evening I arrive back in Johannesburg from Cape Town I get a text from Debbie: "Some Saturday night info for you Oliver. Jarred is sitting in his room listening to his favourite song. Google the words sometime. *Ten Million Fireflies* by Owl City. He's asking me to sit with him and sing it while it plays on his CD player."

And so the first verse goes: *You would not believe your eyes if 10 million fireflies lit up the world as I fell asleep / 'Cause they'd fill the open air and leave tear drops everywhere / You'd think me rude, but I would just stand and stare.* **LS**

● For information on The Academy for Adults with Autism, visit [adultswithautism.org.za](http://adultswithautism.org.za) or e-mail [Debbie and Dudley Flügel on info@adultswithautism.org.za](mailto:Debbie and Dudley Flügel on info@adultswithautism.org.za)