

26 FOCUS THE ZONE

These kids will be

Hell is other people
- Jean-Paul Sartre

A

manda Curtis has heart-breaking familiarity with this notion, famously put by the 20th-century French philosopher and writer. But she

does not blame the people who treated her young son harshly, or who avoided and ignored him, causing him physical and emotional pain.

They did not know Philip is different to them, that he has Asperger's syndrome, an autism spectrum disorder characterised by repetitive, quirky and even obsessive behaviour and by difficulties with social interaction.

Determined to help her son and the many others like him - it is estimated as many as one in 110 children is diagnosed with Asperger's syndrome - today's guest in The Zone has written an unprecedented book: there are many books on the condition per se, but Curtis' is written primarily for the classmates of children with Asperger's.

In our interview, the full transcript of which and a short video are at theage.com.au/opinion/the-zone, she tells a story of courage amid anxiety and struggle, of creativity and collaboration. Above all, it is a tale of one of the most powerful emotions conceivable - a parent's love for their child.

A threshold question for the parents of children with Asperger's syndrome is whether to publicly disclose the situation. Curtis counsels that if the behaviour of the child with Asperger's is not clearly setting him or her apart from peers, then disclosure is not necessary. That was not the case with Philip, who was disturbing classmates, particularly by grabbing them and sitting disconcertingly close to them.

"For six months we thought we're not going to tell the parents and we're not going to tell the classmates he has got Asperger's. He's having therapy, he'll be OK. And he was not OK; the kids and parents did notice. It was just messy. It was awful.

"The principal suggested we hold a disclosure session and invite all the parents to the school to say 'our son has Asperger's and this is what we're doing about it and this is what it means'."

"And that was great. We had about 20 parents attend. But one of their questions was 'this is all good and we understand this now, but how do we explain this to our children?'"

This is how the book, *My Friend has Asperger's*, was born. Curtis has a background in business and was used to communicating with a range of associates - staff, suppliers, customers. She realised she could help her son by helping his peers and their families understand how and why he is different.

She and the school began by searching for such a resource - but failed to find it. Curtis started jotting down ideas for the book, and was spurred to write it when she saw Philip, when he entered grade one, continue to suffer the ostrac-



By Michael Short

WHO!
Amanda Curtis, author of pioneering book about Asperger's syndrome

WHAT!
Publicly disclose your child has the condition and is being bullied or ostracised

HOW!
Promote understanding and celebration by explaining to children why their classmate is different

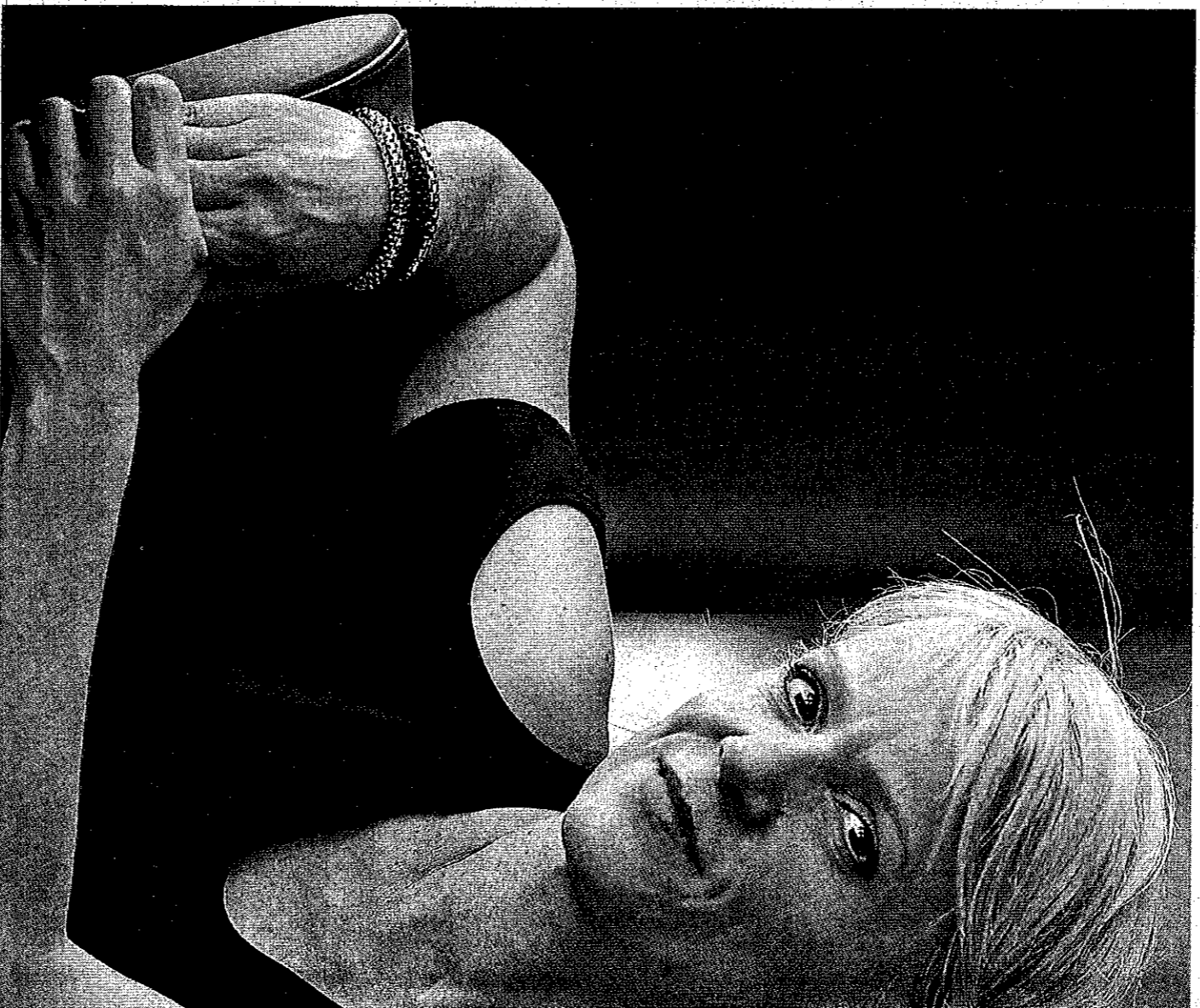
cism and teasing he encountered when he was in prep. She decided, too, to disclose Philip's situation by sending a letter and a mini version of the book (the full-sized version of which was to be read to the class by the teacher) to all the families in Philip's class.

She describes the decision as one of the hardest things she has ever done. She was terrified about adverse reactions. Her fears were, mercifully, misplaced.

"The next day I had a couple of mums coming to me teary-eyed saying 'we didn't understand, we did not know that there was a problem; we just thought that he misbehaved. Now we understand and now I'm telling my child to play with him and now we know what to say to my child to help yours.' So it was just overwhelmingly successful."

Previously, Philip would be left out. Suddenly his classmates were holding his hand, literally and metaphorically. Philip is much calmer now because he knows his peers understand him. His mother, too, is finding some peace and optimism.

As soon as the book came out, Curtis knew she was onto something special. *My Friend has Asperger's* is being embraced by schools. Curtis, in an enterprising flourish, sent it to Australian-born Crown Princess Mary of Denmark, who has passed it on to the Danish Ministry of Children and Educa-



Amanda Curtis' work is about creating peer tolerance.
Photo: Pat Scala

Curtis also contacted former Victorian premier Ted Baillieu, who handed it on to an adviser. Curtis says the government is indicating support, and she is hopeful the book will be added to school libraries.

The book has been praised by one of the world's leading authorities on Asperger's syndrome, Queensland-based, English psychologist Tony Attwood, who introduced Curtis to his book distributors. She has an agent in the US discussing publication there. And now she has been asked to produce a version for older students here in Australia.

Curtis' work is about far more than creating peer tolerance and acceptance of Philip and other children with Asperger's. "I want him to be celebrated. He's cool.

"They are not sheep, they are little leaders in their own right and we should be proud of that. . . . So I thought if I had to get my little boy accepted, education is the key and managing his stakeholders, which are his immediate peers and the parents.

"We underestimate the amount kids understand at the junior level in

primary school. They are intelligent and they are flexible. Their minds are not set yet.

"These kids get it. Once they have read the book, they think 'that is why that little boy flaps his hands when he's excited and jumps up and down!'"

Like so many others, Philip was not diagnosed until just before he started school. Curtis believes he would have encountered far less trouble had he and the family - been given therapeutic support early. She is passionate about the need for early diagnosis, early intervention and a co-ordinated approach by therapists.

She says these families need support. It can be draining dealing permanently with special needs. As many as four in five couples with a child with Asperger's break up. Curtis' marriage has ended.

"Had my son been picked up at three years old and been diagnosed then, there could have been a lot done at that age to prepare him for school."

Like so many parents of children with Asperger's, Curtis is profoundly tired, but she is pushing ahead, buoyed by the happy change her book has brought to her son's life. Frustrated by the lack of

All right

Leave him alone, he's just got Asperger's, he's quirky, he's fine.

communication she has often encountered between the various therapists helping a family with a child who has Asperger's, she is creating a series of workshops on bullying, psychology, disclosure and stress management (see link below). She will run the workshops with a team of specialists, including a psychologist, an occupational therapist, a speech therapist and a drama teacher.

Hell might be other people, but relationships can be heavenly. People with Asperger's are often totally without guile; they are characteristically unable to dissemble and lie. They tell the truth as they see it, unaware that so doing can sometimes be socially awkward. Their quirkiness and creativity and ability to focus forensically can be enchanting. These are the sort of things Curtis wants celebrated, the sort of things, too, that should be cherished in a friend.

Each day Curtis would drop Phillip at prep, she would feel fear, even anguish, for him. She knows bullying can intensify as children get older, and that as many as 80 per cent of children with Asperger's are targeted in secondary school, with 25 per cent physically

harmed. "I think about my little boy

entering a high school of 1500 to 2000 students, which is very different from the beautiful, gorgeous little school of 250 students at the moment. I think of the few times I was bullied or teased at school - and I was a pretty regular kid - and of him and his eccentricities and that he will stand out and be bullied.

"That frightens me. My goals is to get my book into as many primary schools as possible, and I can only do that with the help of parents, because disclosure needs to be driven by parents.

"If we can get as many children in junior school now using the word Asperger's like 'asthma', 'nut allergy' and all those other sorts of words as they are going through primary school through to high school, my little boy in high school will have a posse of peers around him, so that if he is bullied or pushed around he'll have a group that will say, 'Leave him alone, he's just got Asperger's, he's quirky, he's fine' and will help protect him."

disclosingsaspergers.com
specialintitpeopleseminars.com

HOT BUTTON

Our last guest was Braeden Lord, chief executive of Aussie Farmers Direct, which provides an alternative to the supermarket duopoly of Coles and Woolworths. Lord is seeking to grow his fledgling business at a time when the consumer watchdog, the Australian Competition and Consumer Commission, has escalated an investigation into Coles and Woolworths over suspected anti-competitive behaviour towards suppliers. Below are excerpts of Lord's chat session.

■ Aussie Farmers Direct is meant to be wonderful and sounds wonderful, yet I wish the article would point out there are huge areas they do not deliver to. For years I keep checking back and negotiate their website to find they still do not deliver where I am, even though there are over 80,000 people in our council, which is not too far out of Melbourne.

The lady from the corner shop BRAEDEN LORD'S RESPONSE
I am sorry to hear we cannot deliver to you ... YET. Many of our Milkos (franchisees) were customers to begin with. Once we have a dedicated community-minded person for your area, we will be certain to deliver. If you know someone in your area, have them check out the franchising section of our website.

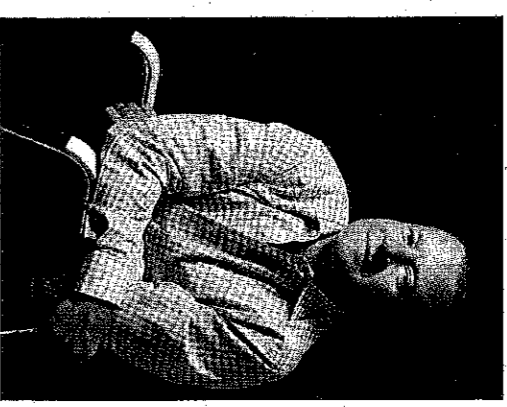
■ As someone who spent over 20 years in and around the dairy industry I can affirm to the massive takeover of Australia's milk production by overseas owners. ... And many smaller farmers have been dragged out of the market because of the low price of milk at the gate, no doubt pushed down by the drive of the big companies to get the lowest price for it so they can make some sort of profit before Coles & Woolies take their bite of the coin ... A serious look needs to be taken at this duopoly ... while there is still time to fix it.

Milkmaid - SWVIC
BL: Milk and bringing back the milkman is core to our existence and since having first-hand experience in operating a dairy we totally understand the importance of sustainable farm gate pricing. We are committed to long-term relationships with our dairy farmers.

■ Maybe you should talk to your body corporate about constructing a facility at the front of your apartment block to accept AFD deliveries. These guys turn up at 4am or 5am to deliver and most apartment blocks these days have security doors so they couldn't deliver even if they wanted to.

Harvey

ONLINE:
The full session is at theage.com.au/opinion/the-zone



BL: This is a tough one for us as access to apartments can be challenging however we have overcome this in the past. Our contact centre (1300 645 562) would be happy to assist.

■ The number of home-brand items on the shelves of Woolworths & Coles is becoming ridiculous, in some areas the old trusted brand has disappeared altogether. I don't want to buy home brands, it means some other business has been screwed to lower their price to enable the home brand to be sold at a lower price. I don't believe the claim that discounts are being funded from internal cost savings, you can tell how ruthless these companies are when they send small businesses broke by discounting until the small businesses can't afford to compete.

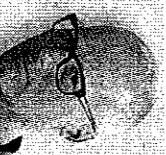
Peter - Caloundra
BL: Food retailing is certainly changing and we are at serious risk of losing choice and variety. We would encourage Aussie shoppers to spread their shopping dollars, particularly towards independent retailers who are proud to stock home-grown brands.

■ People who shop in this way at the duopoly are only short-changing themselves on taste and quality. Get back to supporting your local fishmonger and butcher. The meat at the supermarkets is far too young to be eaten.

David

■ I liked the idea and used them for quite a while. I stopped because the milk and juice was delivered about 1am, it had warmed up by morning ... not such an issue in the coldest part of winter, but it caused the milk particularly to go off quickly. They did supply a thermal bag but that didn't help much (the zip broke).

StivYarra



The Zone is about activism and advocacy, and seeks to bring fresh thoughts into the free market for ideas. It is collaborative, presenting arguments for moving from what is the case to what might be ought to be the case.

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EMAIL: michael.short@fairfaxmedia.com.au

ONLINE: theage.com.au/opinion/the-zone - for an edited video, full transcript of the interview and The Zone's entire archive

FACEBOOK: <http://www.facebook.com/michaeljshort>

LINKEDIN: <http://au.linkedin.com/in/michaeljshort>

CHAT: Amanda Curtis will be online for an hour from noon today.
NEXT WEEK: Professor Roz Hansen, head of the group planning Melbourne's future.