

FAMILY MOVES OVERSEAS TO OBTAIN RIGHTS BASED SERVICES

Jonah Maxwell and his Family ABC TV 7:30 Report, 19 August 2009

A New South Wales family have made the gut-wrenching decision to leave the home and friends they love and move to the UK because they say Australia cannot provide the support and services they need for their autistic son.

It is estimated that 500,000 Australian families are affected by autism.

Many of them struggle not just with the needs of an autistic child or adult, but with the huge costs associated with the array of therapies required.

For the Maxwell family, that struggle came to an end last week when they decided Australia was not the place to provide the support and services needed for their autistic son.

"Our whole lives have just been packed up today and put into that truck and it's gone," father Kevin Maxwell said. "It's very surreal."

"This is really exciting for us because we really hope that we can get something better for Jonah. But the other side of the equation is it's sad.

"Things have to be pretty severe for us to give up that sort of a home base, that foundation, and go to the other side of the world."

Jonah Maxwell was born a normal, healthy boy, who up until the age of two was happily reaching every developmental milestone.

"He had all his skills," Mr Maxwell said. "He spoke. He'd talk. He knew colours, and then around two years 10 months we noticed a big regression.

"He just started losing a lot of those skills. He became more withdrawn, starting speaking less, and over a number of months he just became more and more withdrawn."

Jonah was diagnosed with childhood disintegrative disorder, a rare and severe form of autism.

"It was a shock," Mr Maxwell said. "I remember [my wife] Annette calling me up at work and I had to leave work and come back. It was devastating.

The diagnosis of autism was the start of a difficult journey for Jonah and his family.

He needed a range of specialist treatments and therapies, and they all came at a cost.

"I couldn't put an exact amount to it, but between lost wages and therapy bills, Jonah over the last three years has probably cost us \$80,000 to \$90,000," Mr Maxwell said.

Nicole Rogerson, the founding director of the advocacy group Autism Awareness, is also the director of the Lizard Children's Centre, a private clinic for autistic children.

Her son Jack has autism.

"I make a joke that the one thing you need when you have a child diagnosed with autism is a good strong credit card," she said.

"But you know, it's true. You need to get intervention for that child. There needs to be a lot of hours. That's where the money becomes involved.

"Children with autism have a pervasive developmental disorder. It affects every part of their life.

"So, their ability to speak and to communicate, their social skills, their ability to go to the toilet, their ability to eat a range of foods.

"In order to get them back from where they are, we need to remediate everything. So it's really important that they have as many hours as possible in intervention."

Last year the Federal Government announced details of its long-awaited funding program for children with autism.

The \$190 million package provided families of autistic children with an annual payment of \$6,000 for two successive years, up to the age of six.

But it still fell short of what is required to meet the Government's own best-practice guidelines.

"It's giving parents access to maybe once a week they see a speech pathologist, they see an occupational therapist maybe, but essentially it is only really going to mean a child is getting two or three hours at the most of early intervention a week," Ms Rogerson said.

"The Federal Government published their own reports saying children need a minimum of 20 [hours].

"So whilst it's great, and I don't mean to sound like it's not helpful to some families, unfortunately \$6,000 is simply not going to do it."

End of the road

Bill Shorten, the Parliamentary Secretary for Disabilities, says the Federal Government has, for the first time, provided literally thousands of dollars plus allied and professional health services to children.

"What I can't say is that we've reached the end of the road or we've solved the problem because we simply haven't," he said.

When the Government's autism package was announced, Jonah Maxwell, who had turned six and was attending full-time school, was not entitled to assistance.

But earlier this year the Government expanded eligibility for the program to include children like Jonah.

It was to be assessed on a case-by-case basis.

"We thought great, here is a hope - \$6,000 - it will just pay for his speech therapy bill for a year," Mr Maxwell said. "It really got our hopes up.

"But then to be rejected on the fact that he goes to full-time school, it just doesn't make sense.

"It was so frustrating and that was one of the driving issues or results I guess that tipped us over the edge and thought we're going to have to look to other places to live.

"It is just not affordable. It's not happening here in Australia."

When Mr Maxwell began making inquiries about the support available to autistic children and adults in the United Kingdom, he was surprised by what he learnt.

"The primary difference is that the local authority has a statutory duty of care," he said.

"They have to look at the child.

"Jonah has been at school here at an autism-specific school for a year-and-a-half.

"The NSW education department know him. They know of his paperwork. They've never come and seen him. They've never sat down with us and said, "Right, your child has a disability. What can we do for you? Where should we go for this?"

"When we go to the UK, within three months - we've been told it should only take two months - the local council have to sit down with us, assess Jonah and come up with an education plan for him."

No choice

Mr Maxwell has given up a full-time position as a producer at the ABC, but he says it is the sacrifice made by his two older children that pains him most.

"They're brilliant. You just look at them, the way they interact with Jonah, they love him and they do understand.

"They've seen what's happened. They've cried with us. They know how hard it is."

The family believe they do not have a choice.

"The education system in Australia, in my opinion, does struggle with children with autism," Mr Shorten said.

"The challenge for providing greater support for parents of children with autism is the challenge that all carers and all people with impairment face.

"That is the rest of the community doesn't always want to know, and what we have got to do is keep debating within government and within the community at all levels of government and say, hey, this child with an impairment needs more support."

But for the Maxwells, the time for debating is over. And as they say goodbye to Australia, Mr Maxwell is convinced his family are the lucky ones.

"We've got an option," he said. "We have a plan B. We can go to England.

"God knows how many tens of thousands of families are out there suffering.

"They haven't got a plan A. They haven't got a plan B. The system's deserted them.

"We have to give the best possible chance we can to our son."

LISA Comment: Australians have a right to health services, but not disability services! Limited intellectual capacity, intellectual disability, for example, is not considered under health. So there is no entitlement to support services!

Australian families with a member with an intellectual disability must beg, crawl and lick bureaucratic boots for their family member to receive any services - a few reactive hand-out crumbs at best.

Yet countries like Britain, New Zealand, Holland, Denmark, etc, provided pro-active rights based services from the time a person is diagnosed with a disability, for as long as they have a disability.

