

**SUBMISSION FOR**  
**INQUIRY INTO SERVICES FOR PEOPLE WITH AUTISM SPECTRUM DISORDER**

BY CHRISTOPHER REID, FATHER OF A CHILD WITH AUTISM

Thank you for taking the time to read my submission and for caring about wanting to improve services in this area.

I would like to focus my remarks on the fourth term of reference, namely:

d) evidence of the social and economic cost of failing to provide adequate services

because I believe I have a unique perspective in this area through the experiences of my daughter, Claudia.

**THE EXTENDED PATH TO DIAGNOSIS OF AUTISM**

Claudia was born in 2008 in Indonesia, where I had lived and worked as an English teacher since 2004. She is our first and only child.

For the first year, she seemed to be a normal, happy child, despite her parents' lack of experience. Claudia was slow to start walking and this caused her mother some concern, but this was like her father and eventually she did.

However, by age 2 she still had little vocabulary. She would point at things she wanted rather than ask for them; she would tap her cup on the table continuously to signify she wanted a drink; any time she was upset she would scream or bite something. My wife often shared her concerns with me; initially I discounted them as an overreaction, but eventually we asked her paediatrician – we saw him regularly because in Indonesia they administer immunisations – for his professional opinion.

The paediatrician recommended a specialist in early childhood development at a well-known international-standard hospital. (Like in many developing countries, Indonesian public hospitals aren't the best place for good healthcare).

We went in with high hopes... but after a couple of sessions, all the specialist could tell us is that Claudia had a "developmental delay" in certain areas, but not what was causing it.

We thought that maybe Claudia's lack of speech development was caused by a hearing problem. In 2011 when Claudia was three, we made a three-month trip to Australia around my work, so got a referral for a hearing assessment. However, the waiting list was over two months, so by the time we got the results – Claudia aced the test – we couldn't investigate any other possibilities because it was time to return to Indonesia.

It was only 15 months later – in December 2012 – on our next trip back to Australia that we could get an appointment with a paediatrician. Claudia was already 4½ when we got the diagnosis of autism and we knew what was going on. By this time, Claudia had effectively flunked her Indonesian pre-school and was continuing to regularly exhibit many challenging behaviours.

**OUR INDONESIAN EXPERIENCE**

While some parents are understandably distraught by a diagnosis of autism, for us it was a relief to know what was going on. However, returning in Indonesia presented several related issues.

My wife and I discussed how we would discuss Claudia's condition with our friends and family in Indonesia. We agreed that it would be on a "need to know" basis, due to a number of stereotypes, prejudices and misconceptions that exist around mental illness and autism in Indonesia.

In Indonesian culture, children are seen to be a divine blessing upon a family and are expected to surpass their parents' achievements in life. Children with illnesses of any kind are by extension seen to be not blessed, or a divine judgment on something the parents had done wrong.

It is also thought that mental illness is contagious in the same way as a physical illness, so parents don't want their children to be in the same class as difficult children. Claudia's Indonesian pre-school had a paragraph in the fine print of the enrolment conditions – couched in nice language - about how the school retained the right to expel your child if it had a mental illness.

Also, due to inadequate facilities in Indonesia, people with mental illness cannot be adequately controlled by their families, communities or the police. This is one reason why a disturbingly large number of them are shackled indefinitely to a bed or another place as a "solution"; despite it being outlawed decades ago, few are ever prosecuted, probably due to the extenuating circumstances.

#### COMING TO AUSTRALIA

We came to live in Australia in July 2013, when Claudia was 5.

It would be easy to give this story a happy ending and say how Claudia is all better, but it would be a cop-out and untrue.

Don't get me wrong; the early intervention therapy has certainly made a difference. Claudia can communicate how she feels and what she wants, which has helped reduce the challenging behaviours. She does not get upset as easily as before and her parents now have tools to reduce her separation anxiety. Unlike before, she is also to do several self-care skills by herself, such as dressing and eating.

Similarly, the teachers at her special school are amazing and have helped Claudia to be more patient, to work together with other children and to develop resilience.

The principle behind the early intervention funding for children with autism is that kids who have therapy at a young age will have better outcomes later in life. Yet, the problems don't cease at age 7 and children certainly don't get cured; it is a lifelong condition that needs ongoing treatment and support.

When the funding for free therapy was used up a little before Claudia's 7th birthday, it still felt like the job was only half-done.

Also, while we can still get some reimbursement from Medicare on a health plan of 15 sessions per year – 10 for mental health and 5 for general health - it is still completely inadequate for Claudia's needs. We have private health insurance, but the low level of reimbursement is a disincentive.

We have had to reduce Claudia's therapy because we can't afford to fund it at the same frequency by ourselves.

Similarly, I had hoped to continue doing the same stay-at-home job I did for the last two years I was in Indonesia because it allowed me to be there for Claudia when required, but it wasn't possible to

support my family this way. I now have a day-job in the city which is a better financial outcome, but means I can't be as practically supportive to Claudia and my wife as I would like to be.

As a new migrant to Australia, my wife cannot apply for any social security benefits - including carer's payment - until two years after she obtained her permanent residency, which will be in August 2017. She feels stuck because her additional needs caring for Claudia appears unvalued, but then she also can't get a job that allows her to be at home when required.

We applied with our local council for respite care; after an assessment, we were told we could have four hours/month. This seemed not enough to be worthwhile.

A common feature of children with autism is difficulty with toilet training. Claudia still has issues in this area and there are few places for assistance; the continence support service for our "area" of Melbourne is in Ringwood, 20km away from where we live, in Chadstone. Visits during office hours are not easy to arrange, even with the assistance of other family members with transport.

I have tried to think of creative solutions to helping all parents of children with special needs pay for the therapy and other medical needs. My personal favourite was an idea, based on meeting another parent with a kitchenware business: an equivalent of the Yellow Pages featuring only the businesses of parents with children who have special needs. I wrote a detailed proposal to the principal of Claudia's special school. While the school administration was supportive, after a long wait the Department of Education knocked it back on legal grounds, i.e. that the Department could be deemed responsible for any negative outcomes.

Similarly, I don't think that parents of children with special needs get sufficient support in looking after the children, or themselves. Parents are themselves having difficulty dealing with everything, yet often everyone asks how the kids are going, not about the parents. I wouldn't be surprised if parents of children with special needs have higher levels of stress, depression, separation/divorce, etc.

#### IN CONCLUSION

Our experience in Indonesia shows what can happen if support services for people with autism are inadequate. They include prejudice, ostracism and negative stereotypes which effectively exclude people with autism from mainstream education, employment and opportunities.

I firmly believe that the more we invest in helping children with autism, the greater the opportunities they will have later in life and the less support they will need as adults. Even in financial and economic terms, it might save state and federal governments money in the long run.

As her parent, I won't be around in Claudia's life forever. Personally, my hope for Claudia isn't the typical thing that she will become a doctor or lawyer, but more practical: that one day, Claudia can look after herself and not require support.

At the moment, Claudia's ability to obtain these skills is governed not by her ability to learn them, but more around her parents' capacity to pay for the therapy to help her gain them.

Anything that this committee can do to improve services for people with autism spectrum disorder would be appreciated.

I am keen to play a role in helping children like Claudia. If the committee would like to discuss this submission or related issues with me, I will gladly make myself available.