



Working together with parents in the preschool years (Part 1)

by Dr Avril Brereton

Most professionals working in Early Intervention have quite a lot of interaction with the parents of the children they are working with. During early childhood, a child may be suspected of having autism or if diagnosed, it is likely that the diagnosis is fairly recent. In Australia average age at diagnosis is about four years of age. Clearly, for those parents on lengthy waiting lists, this is a stressful time. However, how parents are thinking and feeling *after* diagnosis can vary widely.

Reactions to diagnosis

Reactions to the diagnosis of autism vary from family to family just as the road that leads each family to diagnosis can be different. In some cases the parents are aware that their child is slow in achieving developmental milestones, for example at 3 years of age their child may have no speech, and instigate the assessment and diagnosis process themselves. For others, concerns may be raised by a relative who knows the child well or a professional such as a preschool teacher who expresses concerns about the child's play or social skills and suggests some further assessment.

For some parents the wait has been long (up to two years from the time they first had an idea that something may be wrong with their child) and for them a sense of relief comes with the diagnosis when they finally find out what the problem is, that it has a name and that the process of accessing appropriate services and support can begin. Some parents have read widely and already have a strong suspicion that their child has autism by the time the formal diagnosis is made. In these families, some intervention plans may already be in place and the parents are well on the way to adjusting to their child's difficulties.

The diagnosis may come as a shock to some parents who did not seek an assessment but were referred by a health professional or preschool teacher. They may not believe it, be angry with the professionals who have made the diagnosis and reject it totally. Some parents may be overwhelmed by feelings of sadness and guilt. Some families we have worked with are initially more concerned about the reaction from members of the extended family and worry about how to tell *them* rather than thinking of their *own* feelings at this time.

Here is a father's reaction to his son's diagnosis (Printed with permission)

The first day I was very emotional. I couldn't even start the car to go to work. I stayed home that day. I then thought I had gotten over that initial feeling but have found it coming back to me especially when I see a movie, TV shows or even hear or read stories about autistic adults. For some stupid reason I place Jez in their shoes and think that is how he could end up and that's when the odd tear builds up in my eye. But partial denial, the old he'll be OK, he'll fight this and nobody will even know he's autistic, creeps back into my mind. But unfortunately there will always be that doubt. I know if I talked about my feelings with anyone I would be a blubbing mess. Being a six-foot man, I don't think you are meant to do this.

I find him both frustrating and amazing. Frustrating for both him and me, when he's trying to tell me something, and not being able to understand what it is he is saying. It is frustrating for me because I can hear the frustration in his voice. But I find him amazing in what he can draw and remember, like the alphabet and counting to 20, spelling certain words and streetscapes he continually draws. It is these amazing things that make me feel good inside and these are the things I tell people at work what he can do. With the news a couple of weeks ago about him being in the 20% group of autistic children that are intellectually normal and has the capacity of learning was a great weight off my mind. But then I have this stupid feeling, is he an exceptional copier and all the things he did on the assessment day, did he do it with his own intellect or was it routine? But I know it was his intellect. Like I've stated before there is always something there in the back of my mind. With anxiety I'll always have that burning question. Who'll look after him when I'm gone? But I know he'll be OK (I hope). It's been hard writing this (emotion wise) but I've surprised myself and done it. But this is how I feel from the first day until now. How I feel later, who knows? We'll just have to see how Jez grows up.

Responses and reactions to diagnosis may vary from one parent to another but what *is* common to all families is the need for:

- accurate information about autism
- accurate and up to date information about services available to them.

It is important that preschool and child care staff have access to up to date information about local services. Here are some useful websites:

Autism Victoria

<http://www.autismvictoria.org.au/home/>

ECIS

<http://www.office-for-children.vic.gov.au/children/ccdnav.nsf/childdocs/-AC92DB94286EC4AACA25700A007CC5F4?open>

Association for Children with a Disability

<http://www.acd.org.au/>