Parent Stories: ASD diagnosis and reactions from others

This is a transcript of the Raising Children Network video available at http://raisingchildren.net.au/articles/asd_parent_stories_diagnosis_video.html. Parents talk about their feelings following a child’s diagnosis of autism spectrum disorder or ASD. Grief and anger are common, but they also say getting past the first few days and doing some research made them feel more positive. Parents also describe how they were affected by other people’s reactions to their child.

Natasha [Mother of four, three with autism spectrum disorder]: My feelings from diagnosis to now would have to probably start with some of those feelings of grief. We feel a lot of sadness for what your child may not achieve, because it is, once you hear your child has whatever it may be, you do instantly sort of think, “So what does the future hold?” because you’re just hearing what they’ve got, but you’re not able to stop in that moment because it’s a pretty scary, overwhelming thing, just in that very moment.

Kerry, mother of two, son Campbell (7 years) has ASD]: In the beginning, going from anger and just shock. “Where do you start? What do we do? How could this happen to us? Why us? Why us? Why me?” I remember times of just being very cross and wanting a big pity party, I wanted everybody to feel sorry for us.

Mariela [Mother of Beth (14 Years) who has ASD]: For me, when she was little, we just survived. We just worked out how to help her and nothing ever fazed us, we just plodded along. And that’s my theory, plod along.

Kerry: You do go through this strange mourning, grieving of a, “Well, is this child ever going to do this? This? This?” And then you come to the realisation where you go, “Well, you know what, whatever he achieves, don’t put that pressure on him. Don’t put that pressure on yourself.”

Natasha: Once you move past those first few days, I guess, and start to do a bit more research, there’s a lot of relief because you can see that it doesn’t mean the end of something, it’s just the beginning of something new. Once you have that diagnosis there’s, over time I guess, a gradual understanding of why they react in certain situations and you start to learn skills to either avoid those situations because you know that it’s just not going to be helpful. Or you can start to learn to put things in place to make those situations more pleasant for everybody.

FRIENDS AND SUPPORT

Natasha: Initially I was always worried about what people thought of my kids and I worried that they’d judge my parenting because the kids couldn’t sit still and they did cry a lot and they struggled to mix in social situations.

Kerry: There have been people on our journey who have made us feel very unwelcome and it’s been very challenging and who you’ve had to kind of distance yourself from, or
even strangers who will say comments. Strangers, who will just make a comment about your child, and they’ve got no idea. But then there’s been others who just get it, and we’ve had angels just come out of nowhere who’ve just come and supported us and helped us. We’ve been so lucky and so blessed. It’s very strange.

**Mariela:** It’s who you are. People that know Beth, and accept her autism, are the ones that help her flourish. Are the ones that are happy when she writes a word, are the ones that are happy when she does something really nicely, or just happy to be with her.

**Kerry:** Trying to correct everybody, it’s very challenging sometimes because not everybody really understands the condition, so I think they want to approach you and try to talk about it, but they talk to you about something that they’ve seen on, “Oh, I saw this on “Rainman”. Is Campbell a savant?” It’s like, “Well, not every autistic child is going to be a savant. They’re not like that.” It’s all those misconceptions that you have to try to get people to really understand what autism actually really looks like, and that it’s different for every single child.

**Natasha:** As the kids have got older, and they’ve had a lot of therapy and done a lot of work to learn how to manage those interactions and they’ve got better at it, I can see that people can see the difference.