

All about disability diagnosis

This is a transcript of the Raising Children Network video available at http://raisingchildren.net.au/articles/disability_diagnosis_video.html. Child disability experts talk about what to do if you're concerned about your child's development. Parents of children with disability talk about their own experiences of getting a diagnosis.

Elizabeth McGarry [*CEO, Association for Children with a Disability*]: Once you have a diagnosis, you have a written assessment saying what your child actually has. Then there's a line in the sand, and you can really start to work on finding the best supports.

Christine Cameron [*psychologist, Parenting Research Centre*]: The process of diagnosis and assessment can be very different, depending on the child. Sometimes that can be relatively quick. They might have one appointment and come out with a diagnosis. Other times it can be quite a long process, where they have to visit a number of professionals, or teams of professionals, and go through a whole lot of interviews, assessments, et cetera.

Elizabeth McGarry [*CEO, Association for Children with a Disability*]: I think one of the most important things is for families to trust their intuition. And sometimes that's easier than other times, particularly if this is your first child.

Leah [*Mother of three, one with vision impairment*]: It took me, with mother's instinct, and me pushing, to get a diagnosis. It has taught me to be a little bit more persistent. I'm Ivy's advocate for now, until she can talk and tell everyone else what's going on. So mother's instinct is definitely something that is always good.

Elizabeth: While you're waiting for a diagnosis, ring up and see how you're going on the list, always suggest that you're available if there's a cancellation. And just continue to appreciate your child at the same time. And try and keep life as regular as you thought it would be, as much as possible.

Christine: If a parent is worried about their child or how they're developing, or other people have commented about how their child is going, they need to talk to people like maternal and child health, or the local GP. Go to somebody that they're comfortable with already. Take some time to explain what it is they're worried about.

Associate Professor Jan Matthews [*Psychologist, Parenting Research Centre*]: It's always a good idea to seek a second opinion, and not to be cautious about doing that, or reluctant to do that. Most professionals will understand that parents need to check the information they've been given is the sort of information they need.

Elizabeth: Definitely go for a second opinion. Make sure you do see a paediatrician, and that will be a referral from your local GP.

Christine: Sometimes, people come up with a relatively clear and specific answer. And other times a child might end up with a diagnosis of developmental delay, or what's often called global developmental delay. Some children with have that more general

diagnosis until they're about six or ready to start school. When a child is almost ready to start school, they're often reassessed quite formally to make plans for appropriate schooling and so on. And it's at *that* time, often for the first time, that a diagnosis of intellectual disability may be made.

Sandra [*Mother of three, one with hearing impairment*]: Now that you know, you're able to make things better. Don't let anybody fob you off. As soon as you know, you know that things have got to move forward. Then once the flurry of that stuff is done, you really know that you're moving forward.

Christine: Once parents have a diagnosis, that gives them some idea of what the future may hold. There's no template saying if your child has this diagnosis, this will be the outcome, or this will be what your child's life is going to be like. It's a bit like when any child is born, you make assumptions about where the child's going to be in 10, 20 years' time, which you don't really think about a lot, but if your child has a diagnosis of some sort of delay or disability, you suddenly kind of go 'Oh, what does that mean in 20 years' time?' And so parents will often start worrying about what's going to happen in 20 years' time, whereas parents who don't have a child with a disability just assume it will be fine. And I think that can be very frustrating or stressful, for the parents to try to plan their kid's whole life when they're only 18 months or six months, or two days old, or something.

Fatima [*Mother of two, one with vision impairment*]: In terms of the future, we don't look to far ahead, because I think that's one of the things we did initially: 'Who's going to marry our child?' instead of 'How are we going to get through the next couple of years?' And I think that's really important, that we just take it step by step and a few days at a time, or a day at a time.

Nicole [*Mother of two, one with cerebral palsy*]: Someone explained to me it was just like you have your life written on a whiteboard. You just need to kind of wipe that off and rewrite things. So, it might feel like the end – at that moment when you're given that diagnosis and when you're going through the trauma of such a life-changing event – but things can change. And they do. But it doesn't feel like that in the beginning – it's really very, very hard.

Elizabeth: Really we find that families go through a grieving process because they're now facing a situation – and their child is facing a situation – that is different to what they expected their life would be, and their child's life would be. So all those grieving processes of denial and anger and working right through to acceptance, is a process that many families go through. And continue to go through, as the child grows.

Nicole: It's important that you do go through the process of emotions. Because by letting yourself do that, you're allowing yourself to be human. But you're also allowing yourself to get to that place where it does get better, and it does get easier.

Fatima: I put an email together about us, and about Simra saying she had this condition, and this is what was happening. So rather than all my family and friends, whether it's here or overseas, find out from word of mouth or gossip or anything, they're actually hearing it from me, directly. Everyone really appreciated that and I think that helped me – it was quite therapeutic for me as well, to know that I had so much support from family and friends.

Christine: Take one step at a time, one day at a time. That's hard when you're worried about the future, but it is really important. To enjoy your child, to remember that this is a family we are talking about. It's not all about the child. It's about getting a balance between everybody's needs. Thinking about your own needs and remembering that if you're not looking after yourself, there's no way you can adequately look after your child. Parents sometimes think 'Oh no, that would be selfish, I can't do that.' But it's critical. You are the most important person in your child's life, regardless of whether they have a disability or not. So you need to look after yourself.

Mike [*Father of two, one with cerebral palsy*]: If you have all the feelings of guilt and all the feelings of anger and things that sometimes bubble up, you have to be strong for Kennan to get through. And Kennan has to face a lot of things – you have to give him the strength to face those things.

Elizabeth: Sometimes, once a family has received a diagnosis for their child, they can be inundated with information, and often they'll be numb, and they actually can't take it in. But it's important for families to keep that information, because you might need to go back to it.

Nicole: When you first get a diagnosis, all you see and all you hear is cerebral palsy. But as time goes on, it becomes your child, the situation becomes 'this is my son, who has cerebral palsy,' but it doesn't define who he is.

Kati [*Mother of three, one with Down syndrome*]: Don't doubt for a minute that your little child is going to make a big impact on the world, in their own way. And our job is just to love them and help them. And you'll need to give them a lot of help. But, in the same breath, there's a lot of help out there for you too.
