

Vision impairment: after the diagnosis

This is a transcript of the Raising Children Network video available at http://raisingchildren.net.au/articles/vision_impairment_diagnosis_video.html. Child health specialists talk about how early intervention can help children with vision impairment learn and develop. Parents talk about early intervention and how it helped their child's development. Health specialists say it's important to stimulate a child's other senses, and support children who will be Braille readers.

Louise Brennan [*Paediatric Orthoptist*]: Once the parents get the diagnosis that there is a vision impairment, it's really important that they seek help from agencies really, early on.

Depending on where you live in Australia, there's lots of different organisations and they really vary state to state. In most of the country, Vision Australia is involved with families as well as Guide Dogs. And then in states such as New South Wales there is the Royal Institute for Deaf and Blind Children. In South Australia there is Can Do for Kids, and in Western Australia there is the Association for the Blind.

Sue Silveira [*Orthoptist and Research Fellow, Royal Institute for Deaf and Blind Children*]: Early intervention is a fairly broad term that will encompass all areas of support for the child and family. One of the key things that we're looking for all the time in children is where are they up to in their development. Are they where they should be? Have they fallen behind in particular areas? So early intervention will target those areas that they need support in.

Louise: Once parents get in contact with an early intervention service, often what will happen is they will actually be given a home visit by a team that might include an orthoptist, an occupational therapist, and they will come and assess the child to see if they are eligible for services. And this is often based on what level of vision does the child have?

Leah [*Mother of three, one with vision impairment*]: The ophthalmologist that was there put us in contact with the Royal Institute of Deaf and Blind Children. And through there we had a case worker assigned to us. Ivy has OT once a fortnight where we have a lovely occupational therapist come to the house and spend time with us, showing us things that we can do to help maximise her vision.

Louise: In the presence of vision impairment, the child really has to be using their other senses to learn about their environment. So some things that parents can do is use a lot of verbal cues, and really chatting to their child and explaining everything they're doing. So if you're lifting a baby out of the pram, just say that Mummy's unbuckling you now, Mummy's lifting you out of the pram, we're going to have a cuddle, and really commenting on what's coming next. That's what's really important about commenting.

Leah: Prior to diagnosis, little things would cause her to be heartbroken. And I would think 'Why on Earth is she crying?' Kids would come screaming past her and she would

startle. Her startle reflex was just amazing. And she would just cry and cry and cry. And looking back on that you now understand that when you can't see someone coming, to all of a sudden have someone zoom past you, with noise, is very overwhelming. So both of my children have had to learn to be much quieter.

Louise: The use of touch is really, really important. Children that have trouble seeing different textured things need to have a lot of touch. On their hands, on their feet and generally on their body. Spiky things, soft things, bumpy, all those different textures. Because they don't have the visual feedback to learn about what they are, it's really coming down to touch.

Having a black background, or very dark coloured like navy blue, a plain background to have your baby's toys on, on a play-mat, is really important. It's very simple for the child to look at, and also not to have the area cluttered, so just one really good toy at a time.

Leah: We have a lot of toys that are very brightly coloured, that light up, that make noise. I never, ever looked at a toy before thinking 'What is this going to give my child?' It was always 'This looks pretty cool. They'll play with it. Brilliant.' Now when we look at it, it's 'What's Ivy going to get out of this toy? What's going to stimulate her vision the most?'

Louise: One of the early decisions that has to be made for a child is what level of vision impairment do they have? Are they going to be a Braille user or are they going to be able to use assistive technology, or low-vision aids? If the decision is made they are going to be a Braille user, there's different preschool programs and pre-Braille skills that they'll be taught by early childhood teachers, particularly those that are trained in Braille.

Fatima [*Mother of two, one with vision impairment*]: I spoke to the people at the Deaf and Blind Institute and they said she's probably going to need to learn Braille. I'm probably going to have to learn Braille as well. Because I don't want her cheating on her homework [laughs], and things like that. So, that's how that started initially, I think. And then they were, pretty much from the beginning they have little books, the little baby books that have the labels with the Braille on them.

Louise: What we also need to remember is that approximately 60-70% of children with a vision impairment also have additional disabilities. So this can make early intervention quite challenging in many ways. So not only would the child be having help from an orthoptist, they'd also be having help from an occupational therapist, to help them with grasping objects, with their posture, and trunk control. And also with a physiotherapist, for movement. And definitely with a speech therapist as well, to help them along the way. Because there are some characteristic problems that children with vision impairment can have with their speech, if early intervention is not happening.

Fatima: Simra also has, along the way she's had speech therapy, not just for talking but also for feeding and swallowing. She's also had physiotherapy – she's almost four years

old and she's still not walking on her own. She has a walker to assist her. And then the OT [occupational therapist] she gets from the RIDBC as well. So the physiotherapist and the speech therapy are the two main things she's had.

Leah: With the occupational therapist coming fortnightly, they come for a school term. It's for one-hour sessions, which is more than enough time. A twelve-month-old in a one-hour setting is quite intense, but she enjoys it, it's a really friendly environment. We play a lot of games; we sing a lot of songs. Everything is very purposeful, but it's also lovely. It's a reassuring time, every fortnight I get to sit and listen to someone tell me she's improved from the previous fortnight.

Sue: Ultimately children with vision impairments will reach developmental milestones. It's very positive and that's what early intervention will provide those children with. They'll do it in a different way and they'll do it in their own time but they certainly will get there. They will have trouble getting there if they're not having early intervention and support.

Leah: I'm very, very lucky to have a very supportive husband and a very supportive family. Now, I don't even think about it. Life has just returned to normal.
