“My name's Collette Kerr. I'm one of the sight loss counsellors with the Need To Talk project in RNIB in Northern Ireland. There are lots of different eye conditions and the different eye conditions are going to affect each individual differently.

 But there are some overarching themes, especially with children and young people when an eye condition is involved. One of the things can be treatment. It can be quite intimidating, it can be quite frightening for a child to have to go into a hospital environment and meet all these new professionals.

So counselling and emotional support can be really helpful there just to help prepare them. Again, that's about building up that advocacy, that self-advocacy, and that finding your voice and having that independence of being able to stand up for yourself.

Some of the transition periods in the child's life as well, can present unique challenges to them. A lot of people kind of forget almost that children move from education into university. Or into work or into young adult life, which can again throw up all of its own challenges and its own issues and difficulties that the person has to face. We offer our services to anybody aged 11 and up.

We also offer our services to not only the person who has sight loss themselves, but also anybody that's supporting them. They can very often be given their diagnosis and sent on their merry way basically. Just sent off to deal with it and to live with this new condition or this change in an existing condition.

They might be experiencing worry about their diagnosis, what it means for them, what it might mean for their future, or for the future of their child.

Getting that emotional support, particularly if it's at the point of diagnosis or if the point of change, means that the parent or the siblings or the Grannies or the Grandads or friends aren't feeling that I have to go through this on my own.

I have to shoulder all this on my own. I can be given all this medical information. I can be given all these printouts from Google. I can be given all these leaflets, but who's going to listen to me? Who's going to listen to our experience of this? Because the child isn't just isolated. The child is part of a family unit.

So you really have to remember that there are so many people around this child or this young person, and it's like ripples, you know? It's like waves reaching out further and further.”

“My name is Laura McCauley. I am the Project Coordinator for the Family Insight Project. I have been responsible for the family support element of the project. So the project has two elements to it, the education and family support. And over the period of the project, I've been running the family support element.

The family support element of the project, the main focus of that is early intervention. So we would be there at first diagnosis or when a family is referred to us, usually from the hospital setting. We would carry out an assessment of needs. So finding out really what is happening with the family at that time and what their needs are. And that could include peer support groups, talking with other families.

Some of the main concerns that families would come to would be again, if it was first diagnosis, it would be kind of, I suppose just the acceptance of a new diagnosis and everything that meant. Often, I think people's minds went to worst case scenario. So it was about providing the information to say, look, you know, while this isn't ideal it's going to be okay. There is support. There are things that can be put in place.”

“My name's Lisa and my husband's John, and we have a daughter called Rebecca and Aaron who has Down Syndrome. When Aaron was born, he was taken immediately to Neo-Natal and my husband went up to check and see how things were. And we were told then that he had cataracts. And I just remember feeling shocked and confused to be honest, thinking "How can a baby have cataracts?"

You know, it was only something that old people get. And when his consultant came to see him the next day, she straight away said, "You know, he will need surgery." It would be two separate surgeries. And that basically his sight depended on us keeping his glasses on. And that was quite scary, because if his eyes did get progressively worse, would that be our fault?

So we were just under a lot of pressure. So we had to basically tape Aaron's glasses to his nose to ensure that they were kept on, because there were far too big. The ones that were issued from the hospital were too big for a wee tiny 9-week-old baby.

So when we first had Aaron, obviously he had so much going on, so many health complications and in and out of hospital and lots of surgeries. There was no advice, no signposting, there was no real, advice on what charities were out there, what was available.

We really thought we were on our own. From a health professional there should be more leaflets in the eye clinic, there should be more posters. There should be more sign posting for families, it's a scary journey.

And if you're going through the surgeries, the scary eyedrops, up through the night doing eye drops, you know. There should be some kind of signposting to offer families support. I just feel like that could be a wee bit better. And new families who have just been diagnosed.

I'd say just reach out, get support, reach out to Angel Eyes, reach out to RNIB, the support is phenomenal. Everything that we have had so far has just helped and benefitted our life so much.”

Collette: “So I think going forward, what is needed is a specialist sight loss support service. There are specific challenges that are faced with people who have sight loss. And it's really, really important that those needs are met at an appropriate time in an appropriate way. It's lovely for a parent to be able to hear that from a professional, that I know what you're talking about. I know where you're coming from and I understand these particular terms.

While I'm not medically trained, I do understand what you're talking about. It's lovely for a professional to be able to come along and see that individual, see that person, see that child, see that young person, see that family member and go "I can see you. I can hear you." "I know what you're saying." "And I hear what you're telling me."”

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Family Insight is a five-year project led by RNIB Northern Ireland. Working in partnership with Angel Eyes NI, supporting families in living and learning.