**Collaboration video Script**

Prof Jackson: “I'm Jonathan Jackson and I'm the head of optometry at the Royal Victoria Hospital or Belfast Health and Social Care Trust and I've been working in pediatric low vision and children's ophthalmology and optometry for probably 30 years.

Let's think about how these kids are supported firstly within the secondary care sector.

We have a really good team internally but in addition to that we have great working relationships with the voluntary sector and various organisations that are out there in community that aren't necessarily within the secondary care health sector.

So it's whenever we talk about the prognosis and the development of the child's vision, that's where working with voluntary sector partners is really helpful because as you can imagine, you know, a parent coming to see me on the first or second visit and I give them a whole lot of information it's, it's so upsetting that we haven't been able to say great, we're going to make it better that a lot of the information we give will have just disappeared and they'll have missed it.

In specific clinics we have a really great bunch of folks who are called our Eye Care Liaison Officers or our ECLOs and we have pediatric ECLOs and they really help to put parents minds at ease and help and support them through the process when we're running about trying to do tests and things like that.

We also have particularly in the pediatric low vision service, we have a QTVI or specialist teacher for visually impaired and their role is to liaise with everybody else in the education sector in order to get the information out as to what's happened in the clinic with the child, what level of vision that they've got, what magnifiers they need, what they're supposed to do with their glasses.”

Sara: “I'm Sara McCracken from Angel Eyes NI. We became involved with the Family Insight Project right from formation.

We've been working with RNIB for many years and together we came up with a project plan to support parents and children and young people through family support and education advocacy.

The Family Insight Project has provided really good support for children right from birth upwards and education is very much part of that journey, along with family support.

No one support sits in isolation of another and it's only having all of those support mechanisms around that child can we really make the biggest difference and the biggest impact to children.

So we bring our expertise but we also connect people, connect professionals, connect support services, think out of the box about how to support children, how to make the biggest impact.

We're experts at being resourceful. We have to be, that's how we operate and that improves the overall impact that we have for our children and young people.

I think knowledge is power and one of the things that our stakeholders and our partners can do to improve the support for our families is really that communication and communicating with them.

That can start with the referral into the voluntary services to get the parent started in the journey. Nothing works effectively in isolation and it only works really well whenever all of those services come together and I think that's, you know, testament to the Family Insight Project that we've seen that working really really well.

I think one of the things that I find the most reassuring is talking to parents and hearing their stories of how wonderfully supported they have felt with RNIB, with Angel Eyes and that was something that just simply didn't exist before the project started.

Michelle: “My name is Michelle and I have a little girl called Elodie, she's 10 years old. Elodie is registered blind. She was born with a rare eye condition. She has got Microphthalmia which means small eyes and she also has condition called Coloboma which means missing so the bits of the back of her eye, the retina, it didn't form properly.

She is registered blind but she can see a little bit of light out of one of her eyes.

When Elodie was born I would say the first few weeks, I suppose we were a bit troubled about her eyesight.

We did feel something was wrong and it was about six weeks before we did get the, the actual diagnosis that, that she was going to be blind.

One of the things that I wanted to know from the health professionals was everything. When Elodie was born I wanted to know, I want to know about braille, I wanted to know when she would learn it, I wanted to know where you get books and I didn't really have anybody to ask.

I don't think anybody knew anybody that maybe that was on the same journey at that time because there's so few blind children being born here.

As a parent you're always thinking what's next, what's ahead and your little babies in your arms. You've maybe their whole life planned in front of you and suddenly that the plan I had was gone.

She was in my arms and I can remember thinking, I had a list of careers that she could do.

I thought as long as she'd have children before she was in her twenties there'd be time enough for my retirement and I could retire and help her and my husband's going, ‘she's six weeks old, calm down’.

But I just think that's a mother's prerogative, you know, to worry and to plan but I always think, if we had those people to speak to, that that would have greatly helped us.

Prof Jackson: I've seen some of these children so many times that I look on the families as being friends and I know them.

So what aspects of my work over the last number of years give me the greatest sense of pleasure?

That's a question which I ask myself from time to time and I can tell you definitively the answer to that.

So when I get a young man or young woman coming to me at 18, after having been in my clinic for 17 years. And been provided with contact lenses, given low vision aids, encouraged through the school system and helped to maximise their education, and they come to me and say, ‘listen I'm going to university in Edinburgh next month’ and you know it's brilliant, ‘I'm going to study accountancy’ or whatever it is, I think fantastic, that's just really good news.

Those things give me immense pleasure or whenever I see a five-year-old who came to see me with some of my specialist colleagues who I work with in for example the NOVIC clinic.

And we see the child three or four years later on and that little child who had fairly profound cerebral visual impairment and had major disability challenges to deal with and we see them responding to different visual targets and we see them engaging with them and we see their language development I mean that's just fantastic and that's why I get out of bed in the morning.”

Cherie: “My name is Cherie Coyle and I have two daughters. One is Freya age eleven and one's Abbie aged eight. Freya has OCA one and Nystagmus.

When we were told about Freya's condition the clarity from doctors would have been the main thing that we wanted just to know what we were dealing with because we knew about Albinism but we, I really didn't know it affected people's eyesight, I just thought it was their skin and hair.

So there was a lot of that that we needed clarity about, about her eyesight.

We got in contact with the RNIB through the eye liaison officer at Freya's eye appointments and then we went to certain events like family

The benefits of meeting other families is fantastic for Freya and for us as well.

Freya meets other children just like her and we also get talking to other adults and get tips and them from us as well so we found it really beneficial to go to these things.

Karen at Angel Eyes gave me support with Freya's education moving to secondary school. Helping me sort out her statement that needed refreshed again and also anything that I thought that wouldn't be in place for Freya going to secondary school. It was a huge relief to have her.”

Freya: I'm Freya Coyle and I'm 11 years old. I was born in the hospital with a condition called Albinism.

It makes me not see that far and it makes me have white hair and I also have a condition called Nystagmus. It makes my eyes like move side to side a bit and I can't really concentrate on like one thing.

I do like drama and singing and dancing and like acting, like that type of stuff.

I hope I get to be an actress. I hope to have like a nice house and I hope there would like be driverless cars in the future.”

Prof Jackson: “I think we've come a long way over the last 10 years in terms of collaborative working. I think both in terms of statutory and voluntary sectors working together and being prepared to share information about individual children and specific cases as long as consent is agreed.

I think we've also come a very long way in terms of professions working together. Where ophthalmologists, orthoptists, optometrists, ophthalmic nurses work together and we're not as precious about the things that maybe 10 years ago we would have thought oh, that's a task that's specific to my profession.

I honestly don't believe we're as precious about that sort of thing anymore and another way where I think collaboration has improved is the relationship between primary care and secondary care and whereas COVID has been devastating for us in healthcare and social care. One has to look for the positives that has come out of challenge and without a shadow of a doubt COVID will have changed the way we do certain things to the better and one way is how those of us who live in our secondary care world liaise with primary care, primary care optometry, primary care pharmacy, primary care general medical practice and I think that will be for the benefit of services overall.

I as a clinician can only do so much to help the vision impaired children and their parents and those that work with them to maximise the child's visual potential and that's exactly the same for my colleagues, the ophthalmologist, the orthoptists, the other pediatric optometrist that I work with,we can only do so much and the need is much greater than that.

So what we need from those in the health trusts, the health boards, the planners, the commissioners, the department of health and our political lords and masters is the support and the funding and the resources to be able to deliver what we deliver, what we can deliver to best effect and to be able to deliver more of it so that waiting lists aren't so bad, so that the time we can spend with children and their parents and helping them tackle these huge challenges is maximised.

So yeah, really what I'm doing is I'm appealing to our MLAs and our politicians in Westminster and to those in local councils to actually support us and help and work with us to deliver the best possible services for these children who we love and their parents.”

Sara: “So I think going forward it would be wonderful for our statutory partners to recognize the benefits that come when working with voluntary services.

We are in a climate where funding is not getting bigger for our statutory services and they're overworked and they have big waiting lists and we're hearing that in the media, both in education and health and I think anything that we can do to support the family through that journey and to support our statutory colleagues in health and education would be very much welcomed and I hope this project has demonstrated to our stakeholders just how good and how many benefits there are when we all work together as a collective.”

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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.