

Neurodiverse and Tourette Syndrome with Kez Symcox

Chantal Boyle:

Hello. I'm Chantal. And joining me today is Paul Schriever, my colleague. How are you doing, Paul?

Paul Shriever:

Very well, Chantal.

Chantal Boyle:

And also with us is Benedict Symcox, who we are both really excited to talk to. I'm going to jump right in and ask Benedict to introduce yourself, please.

Benedict Symcox:

Hi. Well, thank you so much for having me. I'm really excited to bring the two things that we do together, because it feels like it fits. My name is Benedict Symcox, and I'm chief exec of Family Voice Surrey. Family Voice is a we're a charitable incorporated organization as of the last four years or so. And we, more importantly, are Surrey's Parent Carer forum. To explain that a little bit, every local authority has, or nearly all of them, have a parent carer forum, and those were part of the 2008 Aiming High For Disabled Children initiative. The idea being that if you can incorporate lived experience into policymaking, then you're likely to come out with better services for the people that you're trying to support. And it's been a really successful initiative. There's so much evidence that shows that actually if you listen to parents, if you listen to children who have additional needs, then you're more likely to be able to put in place services that work. And usually you end up as a local authority spending less money. We sit at that intersection between listening to parents and speaking to the local authority.

Chantal Boyle:

Are you a charity?

Benedict Symcox:

Yes.

Chantal Boyle:

How big and how many staff? And can you tell me how the organization is set up?

Benedict Symcox:

I can, yes. We anticipate, it's always very difficult to actually be very specific about the number of families affected by additional needs. Our remit is to represent the lived

experience of families who have a child with additional needs, age naught to 25, whether they have a diagnosis or not, whether they have such tree support in place or not, and any disabilities. That includes mental health. It includes physical health. It includes neurodevelopmental issues. It's a really broad remit. We estimate that there's probably an excess of 30,000 families in Surrey that are affected. Our membership at the moment is about 2,400 and something.

Chantal Boyle:

What type of support would do you guys offer to the families?

Benedict Symcox:

That's a really good question, Chantal. If you can be told or find out that there is a parent carer forum that you might get some help from. That can be the gate into other things. We're not an advocacy service. We're not a support group of such, which for all of us who work for Family Voice, our parent carer's ourselves. And it's one of the hardest things that we deal with is that we can't fix people's problems. However, we do a lot of signposting. We know most of the charities in Surrey. We know a lot about how the statutory systems work so we can [inaudible 00:03:17] people.

Benedict Symcox:

We also, in the last few months, what we found is parents really want more specific communities. I know my daughter talks about a lot is what you want when you have a diagnosis or what do you think something is wrong, is you want to find people who are experiencing a similar situation. We have a group specifically for parents whose children are 16 and over. We have another one for whose kids are not to fall. We have, at the moment, we have one for parents whose children have Down Syndrome, another for global developmental delay. Another one is for restrictive food intake, and so it goes on. And again, with those groups, we're likely to bring in speakers with more specialisms. We're offering as much training as we can.

Paul Shriever:

Can I just ask a question about how people come or contact you? Is it normally through a local service? Rather than coming directly to you, typically people will go through something. Because if it was me and I had a child, I would think I'll talk to my council or somebody local and say, I need help.

Benedict Symcox:

I wish. I think probably the most common place that people hear from us is through Facebook, through friends, so it's word of mouth. That said, we're really pleased. In the last year, Surrey County Counsel now on any... If you have a caseworker, so if your child is at that high level of need, every letter has our details at the end. What we're hoping to do is work with schools, so that if a school identifies a child with an additional need, one of the first things they'll tell the parents is this is your parent carer forum. Communication is the biggest problem in our world.

Paul Shriever:

You have a relationship with schools, with doctors, with all of those places where people might ask for that help?

Benedict Symcox:

We have a very good relationship with the local authority, and we have a very good relationship with the senior strategic health bodies. Getting to people like GPs or pediatricians or schools is much harder because every school is an autonomous thing. I mean, I'm sure you can imagine the inbox of any head teacher is about that big. And so that's one of the things that we have been working towards. I have plans. My hope is that through... You mentioned, Chantal, earlier about our structure. We have about 2,400 members. We have just under five full-time equivalent members of staff, but that's spread through about 15 of us. We have our core operations team, and then we have coordinators. We aim to have one coordinator per borough, and there are 11 boroughs in Surrey, and that allows us to have a really good local presence. And that's been really, really key to hearing from parents.

Chantal Boyle:

How do you get your funding?

Benedict Symcox:

A very good question. Every parent care form gets a funding from it's a central government fund that's organized through a charity called Contact. And that's a fantastic charity for any family that has a child with an additional need. They do a whole load of things. There's loads of support through contact, and they can help put you in contact with other families with similar syndromes, for example, similar conditions. The bulk... It's the biggest part of our funding in one pot comes from Surrey County Council. We have a very clear agreement with them that strongly emphasizes our independence. We have no value to them unless we are independent, unless we are free to challenge. And at the same time, it's true that some parents feel that they wonder how we can then be independent if our funding is comes from Surrey.

Benedict Symcox:

Number one is our purpose is to be independent and to challenge. And secondly, actually, because they fund us, they have to use us. And if they weren't funding us, they would get away without using us so much in a way. When you've got some teeth in the game or whatever it is, you have to use us. But we've got a good relationship, and that notion of challenge is absolutely imperative. And then we do what a lot of charities do is we fundraise, and we apply for various grants, either from a community foundation or from the national lottery or from other bits and pieces. We had a good bit of funding through various COVID grants last year.

Chantal Boyle:

You said that everybody who works within the organization is a parent carer. Your children have additional needs? Would you mind sharing a bit more about that with us?

Benedict Symcox:

I have three offspring. It feels wrong to call them children now, because they are between nearly 18 and 21. And between them, I need to be a bit careful because a couple of them are cagey about coming out. But between the three of them, we cover autism, mental health difficulties, neuro developmental issues. We have Tourette's. We have ADHD. We have medical needs. We've done tube feedings, and we've got heart problems, and we've got asthma, and we've got a little bit of learning difficulty thrown in.

Chantal Boyle:

That's a very long list.

Benedict Symcox:

In my line of work, it's really, really helpful, because I've got a wide experience.

Chantal Boyle:

Yeah. I mean, you're a self-taught expert, aren't you?

Benedict Symcox:

That's what we... I mean at the end of the day, that's our purpose as the parent care formers, we are parents by experience.

Chantal Boyle:

It's not just paying lip service, because that's the company I work for now. You live and breathe it, you understand it. And is it difficult keeping your work life and home life separate?

Benedict Symcox:

Yes, it is. And I think on the one hand, it's been really helpful to have an outlet to make my brain work. On the other hand, I feel like I live, breathe, eat, drink disability, and it's exhausting.

Chantal Boyle:

Are your families and yourself aware of the Hidden Disability Sunflower?

Benedict Symcox:

Yes, we do a lot of work. One of our coordinators, Kim, I think she put us in touch, because she's been a real advocate of the Sunflower scheme. I've been aware of for a long time, and we do promote it on a very, very regular basis. It's one of these amazing tools that there's

something beautifully simple about it is that you can use it. I know when my kids were younger, I wore one without telling my children what it was, because had I told them that was one in particular who would have absolutely said no.

Benedict Symcox:

I found that one of the places that we used it really successfully was an airport. And again, one of them really hated it, but I was able to say yes, but your brother actually is, he's in a wheelchair. We have to use this lane. And so this just simplifies things. But the ability to use it in the way that suits your individual circumstance, I think for me is a real strength of that little, little lanyard. When you think of how far it's come and how well known it now is, it's beautiful, a it's lovely. It's lovely, not have a symbol of a broken human. We struggle so much with symbols of disability, and it's often that wheelchair, isn't it. But actually, first of all, most of the disabled people don't use wheelchairs, and then you've got those, like my son, who uses a wheelchair and then gets out of it. And that really blows people's minds. But how do you symbolize somebody who has a disability? Actually, there's something about that little sunflower that's really quite lovely.

Paul Shriever:

I think also the fact that you're finally addressing something that is about being inside you, that it's hidden. I still can't believe that it's taken this long for somebody to come up with something for it.

Benedict Symcox:

Sadly, that's the experience of so many families and people with hidden disabilities is they are treated as though they're making things up, that they are seeking attention. And that's the hardest thing to see, I think is you have people who are putting so much effort into doing the simple tasks of living. And when they don't cope, they're treated as being weak. And actually the kids that I come across and the families I come across are the strongest people I've ever seen.

Chantal Boyle:

Have you got any advice for anybody listening now?

Benedict Symcox:

If I look back to me nearly 20 years ago, when things were really quite critical, I would say, it'll be okay. Just breathe. Get through the next 30 seconds. If you need to go and lock yourself in your bedroom or lock yourself in the loo, I did that a lot, go and do that for 30 seconds. Come out. It'll be okay. That's the only thing for me that allowed me to take the next step.

Chantal Boyle:

How can families get in touch with Family Voice Surrey?

Benedict Symcox:

We have a website, which is going to get better. We need a new one, but it's a good place to find us. We're called the Family Voice Surrey dot org. We're also on Facebook. A lot of our activity happens through Facebook. We have a Facebook page which is Family Voice Surrey. What we tend to do when somebody joins us is we put them in touch with their local coordinator, and on our Facebook, we've got all of our events available to our members. And on, again through the website, you have our phone number and our email addresses and all that.

Chantal Boyle:

Thank you for your time today, Benedict. If there's anybody out there who is into web design and is looking to do some pro bono work, please do get in touch with Benedict Symcox. Her website needs updating, and we've heard how time consuming applying for these funding pots is. Thank you for sharing what it's like. And I'm sure that the listeners will enjoy listening to it as much as we have enjoy speaking to you today. Thank you.

Speaker 4:

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