

FASD with Tristan Casson-Rennie and Jan Griffin

transcript

Chantal Boyle:

Welcome to the Sunflower Conversations with me Chantal. Today, we're going to be discussing foetal alcohol spectrum disorder, FASD. Joining me today is Tristan. How are you, Tristan?

Tristan Casson-Rennie:

Hi, I'm very good. Thanks for having me.

Chantal Boyle:

So Tristan established FASD, Ireland, a not-for-profit that aims to raise awareness and provide support to families living with FASD in Ireland. And we also have with us Janet Griffin. How are you, Janet?

Jan Griffin:

I'm very well, thank you.

Chantal Boyle:

So, Janet is mum to Rossi. Rossi was born with FASD and joins us today to share their experiences as a family. Tristan, could you tell us what is FASD and how might it affect someone?

Tristan Casson-Rennie:

Simply put, FASD is an abbreviation of foetal alcohol spectrum disorders. We have an 's' on the end, simply because it's an umbrella term that is used to describe a number of conditions that can be caused by drinking alcohol during pregnancy, or when indeed planning to get pregnant. There are a number of comorbid conditions that affect people with FASD. And when I say that a number, I mean there are currently 428 conditions can be associated with the condition of FASD. So, I'm not going to list them for you now, but the most common one would be ADHD, of which 70% of people diagnosed with FASD will have in some degree. It does affect all sorts of attributes of human functionality. And so, what I tend to say to people is, if you have a concern about your child and you recognize that you may have been drinking through pregnancy, then look up FASD and see how many boxes you can tick before going to seek advice.

Chantal Boyle:

Is there an outward trait, physical features, which would indicate that they have FASD because of certain physical features?

Tristan Casson-Rennie:

So, physical features are only prevalent in 10% of diagnosed people with FASD, and that's simply because of when the alcohol was consumed through pregnancy. So, it's really really not dependent on facial features. And, believe it or not, up until about maybe 18 months ago, most of the CAMHS, the children and adolescent mental health service, were not diagnosing FASD, unless [crosstalk 00:02:40] the child presented with facial features. That has now changed.

Chantal Boyle:

How many are we talking about? What are the statistics for UK and Ireland? Do you know?

Tristan Casson-Rennie:

So, we tend to talk about the prevalence in society, because the numbers are scarily large. In Ireland, we are the third highest country in the world with FASD. We have 4.75% population. So, that's a significant number. The UK, not quite so high, but the UK is currently sitting in the top 10 though. And that has a prevalence of 3.2, 4% of the population. So, it's still a significant number. We're still talking about around two million people in the UK with FASD and a good number, I think around 40,000, in Ireland.

Chantal Boyle:

40,000. Those are quite big numbers, aren't they?

Tristan Casson-Rennie:

They certainly are. And I had a conversation recently as yesterday with our Minister for Education, and we were doing comparative numbers of people with autism, as opposed to people with FASD. Ireland has a very close relationship with the autism community. And I highlighted that 1% of the Irish population will be on the spectrum of autism, as opposed to 4.7, 5% having FASD.

Jan Griffin:

Rossi is my birth son, which is a super important point to get across here, because a significant amount of children with FASD will be in the adoptive area or the children in care. And the figures that Tristan was just talking about, they're massive, two and a half times more common than autism.

Chantal Boyle:

Do you think that there's an under-diagnosis because of all of those comorbidities, the 428? Do you think that potentially a lot of children are diagnosed with something else and maybe the FASD has not been picked up on?

Tristan Casson-Rennie:

I think the situation is slightly different between the two countries. The case in Ireland is very much more that people with FASD live in birth families, and there is a huge stigma attached to that. Current statistics would suggest that 82% of women in Ireland drink alcohol while pregnant. And my experience of living in the UK, is that as Jan said, most of the children identified with FASD or have a diagnosis of FASD would traditionally be in or experience of the care system. The UK is now moving towards recognizing that there are children in birth families with FASD, but that's still very, very new...

Tristan Casson-Rennie:

So, we are both in that domain where we are saying, we understand there is a stigma attached. However, there can be no blame or shame here, because society has grown up very much since the '50s post-war, thinking that drinking alcohol was very acceptable. And indeed some hospitals, particularly in Ireland, would be pushing trolleys of stout through the maternity wards saying, this is to help the mother and baby so that they don't suffer anemia. So, we have to educate society now to say, we understand the risks. They are significant risks. They cause a lifelong disability. So, please do not drink alcohol of any quantity when pregnant, or when planning to be pregnant.

Chantal Boyle:

Jan, if you can tell me a little bit about Rossi and how old he is. You said that you are his birth mother.

Jan Griffin:

I'm birth mum to Rossi. Now, there's a lot more of me's out there than is spoken about. And that's where I'm trying to get out there that you don't get shot. Rossi's now 20. He was a surprise package. I'd already gone through the change. I'd had a cardiac arrest, a long history of things happened to me. And was told that I could no longer have children. And I was okay with that. I've got two other children neuro typical, and just carried on with my life. I was a builder. I found out that when I was actually around about four months, that I was actually pregnant. I was a bit poorly. I had to go into hospital. Not to a second did I think that I was actually being pregnant. I was told that there was a nonviable, the want of a better word growth and was offered a termination or a class as a D&C...

Jan Griffin:

And obviously I was hugely shocked and I didn't go ahead with the termination, but I carried on. Now, they couldn't quite work out how far along I was. They told me that I needed to be exceedingly careful of cats. It was a big thing, toxoplasmosis. So, I nearly split up from my partner, cause I wanted to boot the cat out. As you cannot possibly have the cat here, that could possibly endanger the baby. Discussions on smoking and cheese and eggs. I then found out that I was worried about the tablets I was taking as well. So, I was very stressed and that time the doctor actually said to me, look, we can give you sleeping tablets to help de-stress you, or you can have a little tot of whiskey or brandy. And I'm not really a spirit drinker. My life was going to a building site, building something, going to the pub at lunchtime, having a couple of pints, going to the pub after work, having a couple of pints, going home, making sure the older two were okay...

Jan Griffin:

And so you're going on weekends, having friends over things like very normal, living the best life of a 40 year old woman and Rossi was then born. He was very tiny five weeks early, but nothing was really picked up that anything was wrong with him. And I then started the very long journey of 12 years, collecting labels. Autism one, ADHD another, febrile convulsions, behavioral issues, lots and lots of different things. All of which didn't fit Rossi. None of them fitted Rossi at all. And it wasn't until he was 12/11 years old, that I was still seeking to find out what missing part of the jigsaw was. And I read about a young lad on the Surrey and Borders, NHS. Which, is a chap called Raja Mukherjee. A consultant, was one of the only people that could diagnose FASD. And I read a story about this young man called Andrew...

Jan Griffin:

I read. And I thought, oh my goodness, me that's Rossi. And everything clicked. It was like, if I was four months pregnant, still didn't really know how long I was, but you work out two pints a day at lunchtime, bottle or two of wine at the weekends. I'm thinking, oh my goodness. And it literally was looking at that computer screen. Like somebody had taken a brick and lobbed it as hard as they could through my screen. And there was two things that happened. One was that the view now was so clear and the contrast went up and it was so obvious. The other part that happened, was all of the pieces of glass came and hit me. And so that pain of all those shards of glass hitting me with the knowledge that I'd caused my child, this damage.

Chantal Boyle:

That must have been a very hard thing to process. Particularly, when you said that your own doctor pretty much prescribed you brandy to calm your nerves and help you get to sleep.

Jan Griffin:

But, he knew I was a builder. It just was not a thing. Hats were a thing. And there's so many women out there that have got a child with ADHD or autism, and they're not quite fitting the bill. They're being given an EHCP or whatever there might be in Ireland, but it's not quite working. And they don't realize lots of people haven't actually heard of FASD. They can't even say it. FASD what? So, it was a horrendous shock, but I absolutely knew a hundred percent. That's when the journey started. That's when the battle began.

Chantal Boyle:

Would you mind, just for our audience explaining what an EHCP is please?

Jan Griffin:

It's in the UK. I'm not sure about Ireland. It's called an Education and Health Care Plan. In the olden days, it was a statement of needs. They swapped it up to Education and Health Care Plan, which means that it lists every difficulty your child might have. Every disability. What the provision might be to assist with that difficulty and what outcomes we hope to get from that support.

Chantal Boyle:

And would you say it's from that plan that helped you to recognize that these wasn't the correct diagnosis? It wasn't the full picture, because you weren't able to tick off all of those action points on there.

Jan Griffin:

Absolutely. I'm sure Tristan will tell you as well with his children, that there's huge differences. There's a lot of similarities because it is overlapping. It is an umbrella. So, Rossi does have autism, and he does have ADHD, but he also has FASD, which is brain damage, organic brain damage, which means that the neural pathways, the gray matter in his brain didn't migrate across. So, therefore, those pathways weren't built. He's got nodules in his brain. So, he has a huge issue with memory. You can teach him once in one day, he will have it pinned down, but tomorrow it's gone.

Chantal Boyle:

You experience that as well, Tristan with your boys.

Tristan Casson-Rennie:

Yes, I do. There's a plus to it for a lot of neuro typical parents to neuro typical children, look at my own son and say, wow, that's just incredible. I wish my child was a bit like that. So, typically if you go to bed on a grudge with a child, they will wake up on with the same grudge. But with a child with FASD, they will just have that reset button pressed and overnight, and they'll wake up and tomorrow is a

fresh day. The other point to make really is that the neuro pathways are definitely, they don't join up. So, we experience on average, a 22 second delay from an instruction being given to the action being taken. So, to a parent that is aware of their child, having FASD and aware of these delays, then that can be incorporated into our parenting style...

Tristan Casson-Rennie:

But just imagine for a second, a teacher in a class of 30 children walking in and asking the children to please sit down and be quiet, and it takes your child 22 seconds to process that, and the message may or even get through to where it needs to go. And your child is still standing there laughing, joking, or trying to settle. And that then causes significant problems with the education system. And now we have, fortunately in the UK, the educational healthcare plan, which are very good. If you can get one and there's a big if there, because they're not mandated for every child with special educational needs or with FASD. But here in Ireland, we have a pretty dire situation at the moment where the National Council for Special Education, the NCSE as its known doesn't recognize FASD is a disability...

Tristan Casson-Rennie:

Although, we have a significant number of children in every cohort. So, if 600 babies a year born in Ireland got FASD, the NCSE refuses to recognize that FASD exists. And that leads those children into a revolving door of attending education, being excluded, going back into education, being expelled, trying to get back into education getting refused, and then going into the judicial system, homelessness, crime. And it's a cost to the individual, the young person. It's a huge cost to them because their life opportunities are lost. But, it's also a massive cost to society because society has to attempt to pick up the pieces in adulthood, where actually with the right supports in place through education, we can allow that person with FASD to lead a somewhat independent life into adulthood.

Chantal Boyle:

That's where it starts though isn't it? It starts at, your nurturing as a child, and then when you are out of your family home, you need to be nurtured by your education care provider. And that's really very shocking to hear that's not recognized this condition in Ireland. I am assuming that FASD Ireland is campaigning hard, strong, and fast to get that changed.

Tristan Casson-Rennie:

Yes. Our reason of existence is simply that we want the government to acknowledge FASD. We want to raise awareness. We want support for the families, children, young people, adults with FASD, the other underlying message

for us is to increase the level of education around drinking alcohol through pregnancy.

Jan Griffin:

I mean, it's only just being put into the NICE guidelines in the UK. Hopefully Southern Ireland will now take that on.

Tristan Casson-Rennie:

The last questions are asked at Prime Minister's questions. So, the PQs here in Dail Eireann. The last question was asked about FASD and the Minister for Health, at the time, said quite simply FASD isn't an issue here in Ireland. We only have one or two children every year born with FASD. And they are born to alcohol dependent women. Roll forward five years to just after we were established, so far anyway I've managed to have seven PQs asked on our behalf of Dail Eireann. So, I've got seven in six months, as opposed to none in five years. Those questions are still coming back from the Minister of Health saying, we do not have a problem here in Ireland. It's only with women who are alcoholics, and we put our interventions in while the baby's being carried, and we try to stop the women from drinking, and then the baby can grow up normally. So, we have so much work to do here in trying to change the opinions, but also to educate even ministerial level.

Chantal Boyle:

Is it recognized globally?

Tristan Casson-Rennie:

Yes. It's fair to say. There are significant organizations in Canada, America, Australia, New Zealand, that have a very loud and powerful voice. I can tell you, for example, if you go into an off license in Canada, there are notices on the countertops, at the till, the cash point. Saying if you are pregnant, do not buy alcohol. And it's on the bottles. It's everywhere. Here in Ireland, similarly, legislation was put through Dail Eireann onto statute in 2018. The Public Health (Alcohol) Act of 2018 to say exactly that to happen. To say that labels must be placed on all containers with alcohol and warning notices put up. And none of that has been put into use. So, it's on statute, but it's currently sitting up at the European Courts because I believe that a couple of countries in Europe objected, and we could have prevented many many of those in Ireland if we had that legislation in practice. If, it was put into use. It's in law, but it's not enforced.

Jan Griffin:

Overall, you're talking possibly 26,000 children a year. It's a lot of misbehaving children in classes, misunderstood.

Chantal Boyle:

Misunderstood and not supported. So, as a parent Jan, what have your biggest challenges been?

Jan Griffin:

I think with Rossi, it was a case of he was different. He wouldn't engage very well. He would be very perseverate on things that he would just get fixed on things, very autistic traits really. But the one that really stood out, was the one where he didn't learn via consequences. He didn't learn that he put his hand on there, it was hot. He wouldn't do that again. He would do it. And again and again. And the fact that he could not do numbers, he couldn't do his times table. The only way I could get him to learn was by doing everything musically, kinesthetically. I realized early on that was absolutely pointless trying to cut off those corners of Rossi, because he was who he was. If you can't do maths, nevermind, we'll get you out of maths lesson and we'll try and do it a different way...

Jan Griffin:

And I've always been that way possibly, because I'm probably on the spectrum, myself, not FASD but the autism spectrum. So, I recognized his difficulties and I was damned if I was going to let him suffer the way that I did. So, I being the way that I am, I managed to persuade the teachers that it might be better for them to help him in different ways. So, argue, learn the law, got the code of practice, read it cover to cover, particularly .9 .6...

Jan Griffin:

Did course with IPSEA, which is the Independent Parents Special Education Needs team, did a course with them. Learned everything I could so that I could then go to the educational authority and get the help that he needed. It was a huge battle. It was through persuading them that it would be easier for them if they let me do this, or if they didn't let me do this, then he wouldn't be in school. Rossi was actually quite happy to go in school with his pink wig. I asked him this morning, I said, didn't you find that you were so different to people, didn't you just, he said, I wasn't. It was everybody else. That was different. I was okay.

Chantal Boyle:

Excellent. I like that response.

Jan Griffin:

But that's this wonderful thing about having Rossi being 20 now, and he's very eloquent. Most of the children with FASD, the expressive language is amazing. It's what goes in, that's the issue. As Tristan said, I can yell and scream at him and get

really upset. I'm upset for days after about an hour. Not even that 10 minutes, once he's in his bedroom he's whistling.

Chantal Boyle:

You are listening to the Sunflower Conversations with Chantal. To share your story details are in the show notes. Can I ask you about that memory thing, in that it's a short term memory loss, but does that mean because your children are able to learn in some shape or form, for example, they know how to talk and they know how to walk. They haven't forgotten that. How does that short term memory loss work in practical terms?

Chantal Boyle:

Can I ask you about that memory thing, in that it's a short term memory loss, but does that mean, because your children are able to learn in some shape or form, for example because they know how to talk and they know how to walk. They haven't forgotten that. How does that short term memory loss work in practical terms?

Tristan Casson-Rennie:

So, for example, if the child with FASD is in a maths' lesson and they are taught a way of doing algebra, something I know very little about, and the lesson focuses on, this is how you do algebra and all the way through the lesson, they would grasp it. And by the end of the lesson, they would know it inside out. They would come home and you'd say, what did you do today? Went to school. Okay. What lesson? Maths. What did you do in maths? I don't remember. I can't remember that. So, that's, the usual answer is I can't remember. The next day then they would go to school and they would have maths and pick up from yesterday's lesson. And they wouldn't know the first thing about algebra because that was yesterday. But if you roll forward a week, the week later that would've been committed to memory and it's about going back to what I said earlier at the 22 second delay. The message can go in, but it can spend a significant time trying to find the filing cabinet in the brain where it needs to go.

Chantal Boyle:

Yes.

Tristan Casson-Rennie:

The same would be said of any lesson in school.

Chantal Boyle:

Yes.

Tristan Casson-Rennie:

Is that if it's not delivered in specific bite size chunks, then it can be floating around for a long on time until it finds the right filing cabinet. And that's best described as for a neuro typical person, you would say, go and have a shower. And that person would go and have a shower. For a neuro diverse person, a person with FASD, you would say, go and have a shower. And they wouldn't. And then maybe 22 seconds later, they might, but they only might go and have a shower if that message has then gone into the right place.

Jan Griffin:

There's nothing else distracting them.

Tristan Casson-Rennie:

Exactly. And actually, if you said after 10 seconds, I told you to go and have a shower, that message overwrites, the first message, which causes confusion. And particularly in a child with FASD, that can then cause red mist. And when I say red mist, we then talk about things like meltdowns. So, we're very keen as parents to remember that we deliver our messages of, can you go and brush your teeth please, as just that rather than, can you go and brush your teeth, wash your hair, get your school bag ready and be downstairs in five minutes. Because that's overload. It's too much. You can tell a child with FASD every single morning that they need to brush their teeth and they will still forget the next day.

Chantal Boyle:

Jan, how has those behaviors interacted with his older, you've got two older children, haven't you?

Jan Griffin:

Having not found out until he's 12. We had those years of Rossi just being Rossi. We're very accepting family. It doesn't matter to us who you are, what you are, why you are colour you are doesn't matter. We're just very diverse, very open family. So, Rossi was always different. Always. He wanted to be a girl when he was seven and he was always the princess in the film. He could never be the prince. He was always drawing, writing, singing, all these different things. The older two, I used to let him get away with a lot more than well, because he was a special child, as in special needs because he was born early...

Jan Griffin:

He was tiny. He was so out there different. And the older two were older. They used to think that I kind of spoilt him a bit because I would always just give in. It was natural for me to go, okay. He hasn't got that. So, I need to find a different way to get him to get that. And so I would spend a lot more time still not

knowing it was FASD. I'd accepted all the other labels gratefully because it did open the door. They used to think I spoilt him and they'd get crossed with him. And particularly my daughter, because he would go in and decide that particular make up was exactly what he needed...

Jan Griffin:

Yes. And so he would have it. And no matter how many times, even now do not touch things that do not belong to you. As far as he's concerned, nobody has it in their hand. And so those were huge problems for a daughter. When we found out it was FASD, I then faced another one of don't be silly. Don't be silly mom. People like you don't have children with foetal alcohol. It's people with needles hanging out of their arms, they're alcoholics, they're poverty stricken. The way I speak as well was also something that became actually a barrier for me...

Jan Griffin:

I would say to the consultants at the hospital, are you sure it's not because I drank when I was pregnant and they no, no, no, no, no, no. That would affect the back part of his brain. And it's only as he's got older, it's only as FASD has been more talked about, particularly in the UK, I've got more involved, Rossi's got more involved. He's writing a book with a friend. It's now that people are being educated. And it's just getting people to say, listen, we need to get it out there to young people in schools, both girls and boys, because the boys have to support the girls with the non-drinking, with the planning of pregnancies and all the rest of it to say it could be you.

Chantal Boyle:

Absolutely. And hopefully this is what this podcast will help to also do raise awareness amongst everybody. And what's socially, now he's older, how does he interact with the world? Does he have friends? You mentioned he's writing a book with a friend. How is his social life?

Jan Griffin:

He does really want to socialize, but he does do massive faux pas all the time. He's a qualified makeup artist. He is amazing. He really is amazing at that. He's a fantastic singer, he's brilliant at acting. He's got this whole side of him, which has driven him forward. And he said that it's the creative side of him that has helped him get through. It doesn't matter, it does matter, the two things that really annoy him are his lack of ability with abstract thinking, which is budgeting time, clocks time and his memory and organization skills. He absolutely hates it with a passion, but he's beginning to recognize it and accepting it. And so he recognizes now that he'll always need a peer moving forward I think we are getting there in slow process. The loads of layers, they have very spiky profiles, certain areas there three or four years old and other areas he's full on 20 years old, which he keeps telling me.

Chantal Boyle:

Are there any specific treatments for a child or adult with FASD medication?

Tristan Casson-Rennie:

There's no golden bullet as such. It's very much based around individual need and any of the comorbidities that are recognized with the condition of FASD. So, for example, if a child does have ADHD as one of those facets, then there is medication available to help the child to try to get the ADHD to control. But as with any medication, it's just a sticking plaster. It covers over what's going on underneath and medications do wear off...

Tristan Casson-Rennie:

So, it's important to consider a more holistic approach. So, one where we put strategies in place to support, where the adults and peer group around the child were aware of the circumstances, the behaviors, the situations, and that they know how to read the room rather than taking exception to it. I have come across some early work from Canada that is doing trials with a natural protein that's found in the brain. I'm actually using that with my own son at the moment. And that is like a miracle. We have almost a different child over the last two years. There is a white paper that has come out of Canada and they have identified a natural protein. It's one that the brain makes when we take a knock or a bang to help to repair the brain ourselves. And they have found in trials, very early trials, but five years worth of trials that this protein is helping. It's not helping everybody.

Chantal Boyle:

Would you mind if I asked an example of pre taking this supplement and now?

Tristan Casson-Rennie:

Absolutely. So, pre taking the supplement, every ask, so every kind of "can you go and do this, can you go and do that" would usually lead to an altercation. And within three months of taking this supplement, there's certainly a lot more compliance happening. The good thing is at the moment, there's so much research going on around the world that whilst there is no cure for FASD, because it is absolutely lifelong, it's about how the brain was formed. We haven't yet learned to grow new brains in test tubes. So, what we have to do, is we have to live with what nature provides. And we have to build strategies to help us as a family cope with that. But there are various things on the horizon that they help us, well will help our children and young adults and people living with FASD to have better lives, more manageable, more independent lives...

Tristan Casson-Rennie:

What I would say is that if people think that their child may have FASD, the first thing to do is to talk to the SENDCO school. The Special Educational Needs' Coordinator, because they will have lots of ideas around support and the strategies for the child, if FASD is a potential flag. But also the route to diagnosis, again, we don't have one in Ireland per se, but we're catching up with the UK. The root of diagnosis is usually from the SENDCO to a referral, to the community pediatrician, to a referral to CAMHS, Child, Adolescent Mental Health Service. And from there, it kind of goes into the specialist arena of FASD.

Jan Griffin:

There's a new pathway as well, which is called ramping up.

Chantal Boyle:

What I'm picking up here from both of you is that you've both educated yourselves in order to get to where you've got to. So, it's a lot, isn't it? You have a child, you think you're just going to be a parent that's hard enough, but then to then become a basically, a doctor, pediatrician, an education specialist, a SENDCO specialist, you really do need...

Jan Griffin:

Law specialist.

Chantal Boyle:

Law specialist. Yes.

Tristan Casson-Rennie:

You're right Chantal, you have to learn to be a pediatrician, a counselor, a therapist, a specialist, an educator. You have to learn to be able to walk into a school and not be treated as a neurotic parent, which happens, letters from teachers. I have letters from people who have FASD who are in their forties and just need help, but don't know where to get that help. Where they've gone to see their GP and the GP said to them, don't be stupid. You haven't got FASD, you're 37, it only affects foetuses and that's from a GP. I get those letters and are able to help to support those people, to show them what they can do and where the support is. And now the conversation turns to how do we work with employers so that people with FASD can sustain employment and can make a positive contribution to that employer.

Chantal Boyle:

Do you see individuals with FASD living independent lives, or are they still generally supported by family or a carer or something like that?

Tristan Casson-Rennie:

I think up to now, it's fair to say that at 99.9% of people with FASD remain at home with a parent or carer. And that's simply because, and I can only talk about Ireland really, because that's my experience. And I think that's simply because there has been none to little recognition. And of course one of the difficulties we have in Ireland is we have a fairly high suicide rate. And we also have a fairly high prevalence of FASD. And the average age of mortality here for people with FASD is 34. So, the two numbers correlate.

Chantal Boyle:

Yes.

Tristan Casson-Rennie:

And that's not FASD that kills them, but it's society that does. It drives people to suicide because they can't live independently. And so I suppose one of the indicators that I look for in terms of the impact we can make is to try to help decrease the numbers of prevalence of FASD. And in turn, over the years will decrease the numbers of suicides in the country.

Jan Griffin:

In England, we have what's called supported living. Now to get supported living, you have to have a social care assessment. A major here is the support worker. Does that support worker understand FASD.

Chantal Boyle:

As you say, like the support workers need to be trained in FASD don't they, each disability health condition has different demands and needs. And it's important that whoever is kind of giving that caring provision, understands that and supports it. It sounds to me from everything that we've discussed, that although it's come a long way with the hard work of the charities, there's so much more that needs to be done. It's so layered, isn't it, that recognizing it at a very young age. Schools being able to support it, nursery care provision, being able to support it. So, that then influences a family situation dynamic whereby everybody else in the house understands that it's going to take their sibling a bit longer to understand that you can't have my makeup, or that yes, I've told you once, but I'm going to have to keep telling you, and they so many different layers...

Chantal Boyle:

And then, like you say through to the point, well, adolescence, that is a really difficult age for every human being anyway, teenage years are so difficult. So, yes, it must make it immensely hard. And then as we go through to independent

living and employment and employers, understanding that there's a contribution to be made by this individual.

There is a stigma attached to the condition, which then friends, people, parents from maybe seeking a advice, talking to their friends. We all do it, when you have a child. You do look at another child and you compare their development. And if maybe one is walking and yours is still bum shuffling or whatever, then you're thinking, "oh gosh, am I not a very parent? Why isn't my child at that stage?" So, I can understand why these things are being pushed under the carpet, but it doesn't help anyone does it?

Jan Griffin:

And put alcohol into the fray as well. Oh no, "absolutely not! I never did that."

Tristan Casson-Rennie:

And it doesn't help anyone when the social stigma drives the parent to request the wrong diagnosis. And that's the battle we have here currently, is that the difficult conversation are not being had by schools, by healthcare workers, pediatricians, specialists, doctors, CAMHS, the national educational psychologist service. They're not having these conversations with parents because they're difficult conversations. Also, because the NCSE isn't recognizing FASD is a disability. It's driving CAMHS and the National Education Psychologist Service to misdiagnose with ADHD or Autism so, at that the child is at least is getting some help in school.

Chantal Boyle:

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Tristan Casson-Rennie:

If the woman's been out all week and it's Friday night, and she goes out with her mates after work and says "well I'll just have glass of wine and then I'll go home", is that alright? I said "absolutely not, it's not okay. One drink, one drink will cause FASD."

Jan Griffin:

My mother, Irish background. I always had a drink. I was told a pint of Guinness was good for you, cause of the iron. And I'm like, mother, "do you realize that you would need 10 pints of Guinness for one milligram of iron."

Chantal Boyle:

My mum said the same thing to me. Is okay to have a Guinness, I don't actually like Guinness. But, this guidance of no alcohol. It's very clear. It's very easy to understand. There's no like, well, I'm not sure if this is a large glass or a small glass.

So, Jan, what do you see lies ahead for Rossi and his creative career?

Jan Griffin:

He's at Longcross Film Studios at the moment, which is brilliant. They film Call the Midwife there, which means he's studying. The only downfall again is the employability part of it. It's the 10, I've made a document, which I give to people now with a 10 point easy read for employers, how to help Rossi be the best him for them. If all of the planets align nicely and gets a really nice partner and things like that, I think he could be a very accomplished makeup artist or even writer or any of those things. Then we are now going to do this road trip from the top of John o Groats down to Lands End. So, he's going to meet a lot more people as well. So, I'm hoping through one of those avenues, he'll be safe. And that's my main thing, is his safety.

Chantal Boyle:

Where can people affected by FASD can they head to learn more to support themselves or their family member?

Tristan Casson-Rennie:

Across the two countries of Ireland and the UK, we have our own website, which is fasdireland.ie. And in the UK you have nationalfasd.org.uk. If you're in Scotland, you've got the national FASD Hub. One of the best things in the UK right now for people living with FASD.

Chantal Boyle:

I want to thank you both for spending an hour with me today, to talk to me about FASD, to really understand what it is and how it can impact a person and what things need to be done. But I think for me that the most important message that I've pulled out of what you both have to say is that education around this and stigma. Guys, forget the stigma. We need to let go of the stigma.

Chantal Boyle:

If you would like to share your Sunflower story or conversation with us email conversations@hiddendisabilitiesstore.com. Find out more about us or listen to this recording again by checking out our insights page at hiddendisabilitiesstore.com. You can also find us on Facebook, Instagram, Twitter,

YouTube and LinkedIn. Please help, have patience and show kindness to others and join us again soon. Making the invisible, visible with the Hidden Disabilities Sunflower.