

## FASD with Jacob Casson-Rennie

Speaker 1:

Welcome to The Sunflower Conversations, where we explore The Hidden Disability Sunflower and its role in supporting people with hidden disabilities.

Chantal Boyle:

Welcome to The Sunflower Conversations with me, Chantal. Today, I'm joined by Jacob. Jacob is 16 years old and lives with his parents in Ireland. Jacob's parents head up FASD Ireland, and also The Hidden Disability Sunflower Ireland. Jacob has foetal alcohol spectrum disorder, which is known as FASD. Hi, Jacob, how are you today?

Jacob Casson-Rennie:

I'm good, and yourself?

Chantal Boyle:

Yeah, I'm good, thank you. I know that you have just finished school for the day, so I hope you're not too tired.

Jacob Casson-Rennie:

Oh, I'm all good.

Chantal Boyle:

So, as I mentioned, you are currently in school, yeah?

Jacob Casson-Rennie:

Yeah, I am, fifth year, so I don't know what the equipment is there, but going into second last year of school.

Chantal Boyle:

Okay, so is that your A-Levels?

Jacob Casson-Rennie:

That's the A-Levels, yeah. It's A-Levels.

Chantal Boyle:

And do you enjoy school?

Jacob Casson-Rennie:

I probably enjoy it more than most people my age, because when we're away from the school, I just want to be back in school. I love learning. I love taking in new information. I just enjoy it a lot.

**Chantal Boyle:**

That's brilliant. That is quite unusual. No, it is really good. And can I ask this, does the school support your needs, as you have FASD?

**Jacob Casson-Rennie:**

I mean, I would say so. I mean, I get an SNA, which helps me through the class, and a lot of the teachers are incredible in how it takes me longer to process certain things that they're saying and stuff. They're more than happy to go and repeat it again or explain it in a different way so I can understand it. So a lot of the teachers are very, very good in making sure I actually understand what's going on and that I'm processing it correctly and stuff.

**Chantal Boyle:**

So you mentioned there about processing. Can you tell me, what is living with FASD like for you? What does it mean to you?

**Jacob Casson-Rennie:**

I mean, especially for me, I know myself, doing things immediately when people ask. A lot of school is, "I've asked you to do this. Do it now," and I find it very difficult to even get that. It's like Swiss cheese. The brain's like Swiss cheese. You have your little holes in it and you're at A, and the teacher's instructions at B, but there's a little hole in the way, so you've got to go around to C and then to D and then come back to B to get there. So it takes that time, which is what we call the 21-second delay. It takes a time in between an instruction to then actually get it done. So I have a habit of saying no to a lot of things that I'm asked, not in a, "I'm not going to do this." In a, "No, my brain hasn't fully processed what you've asked me to do yet. I need time to give you the answer you want."

**Jacob Casson-Rennie:**

So it's a lot of struggle on processing things and making sure I do things in the correct way, and remembering things. But memory is a big thing, like lists. I need stuff written down. If I get asked to do something, any more than three things, I remember the first two, and then it's just a struggle to remember the rest.

**Chantal Boyle:**

Are they the two main things, would you say?

**Jacob Casson-Rennie:**

Definitely my two main things, remembering and processing instructions immediately.

Chantal Boyle:

So therefore, it's really important that the school is able to understand your needs to support you?

Jacob Casson-Rennie:

Absolutely. They definitely do, especially with my teaching assistants and SNAs. They're incredible for reminding me of things that I'm meant to be doing in class and helping me to... Reminding some of the teachers that might forget, because teachers are teaching the class of however many kids, and always keeping that in the back of their mind that I need extra time, and sometimes it's just hard for them, especially in the more writing-heavy and work-heavy subjects, so like sciences and English and stuff. It's a lot of the SNA reminding me that I'm supposed to be doing this question, or that we're meant to do all of these questions when they list out, can you do A, B, C, D, and then go to question 7 and do B and C. I remember the first lot, but they remind me the other questions I'm meant to do.

Chantal Boyle:

So does your learning support, do they come accompany you to every lesson [inaudible 00:04:32] one in each subject?

Jacob Casson-Rennie:

The lessons I need. There are some classes like Art and Biology and certain other stuff, like PE and stuff. A lot of the classes, I have them, but might not need them. They're there in case I need them. Especially in our school, we have a fair amount of children with additional needs in school. So we have enough SNAs and teaching assistants to look after the kids, but where it doesn't mean that we can have one in every single class, which is fine for me, but not for some of the kids. They might need it in every class, but I need it in certain subjects more than others. So I can manage in my subjects that I really love and I have that passion and drive, because I can kind of just push in and just go, "You know what?" I just ignore everything my brain is telling me, "Just do it," and a lot of the subjects where it's kind of just one thing.

Jacob Casson-Rennie:

You get told, "Draw this." That's fine. That's, "Draw this." I can do that, or, "Do this experiment." I'll figure it out as I'm going along. It's not, "Do this, then do this, then do this."

Chantal Boyle:

Yeah. It's those several step process.

Jacob Casson-Rennie:

Yep.

Chantal Boyle:

And when do you think that you became... 'cause you're 16, you're a young, young man. When do you think you became aware of what your needs were? Because you explained that so well about the Swiss cheese, and the holes, and trying to get from A to B really articulately. Do you remember when you became aware of, "Okay, this is what I need, and this is why I'm struggling?" 'Cause it must have been super frustrating before then.

Jacob Casson-Rennie:

I think the whole way through primary school, I had not a notion of what was causing anything, to be honest. I'd say my knowledge and my ability to explain to people and help people to understand how I go is from Dad starting up this company and getting the knowledge to everyone else, that then it's come straight to me, because even for us, it took us a long while to figure out exactly what caused those things. So I'd say it's over the last year, maybe two years, but the time building up to starting the company and throughout the time of having the company.

Chantal Boyle:

Are there any other challenges that you faced, maybe, in school or outside of school?

Jacob Casson-Rennie:

I think, mostly, the key things that I struggle with, then everything else I can just shove under and just get away with not really focusing on too much, but I think the biggest problem I have with it is my rugby and my sports. Once you're in the height of a game, you've got all that pressure of the game going on. You've got all this stress. You've got to remember your job. You've got to remember to be in a certain place. And in rugby, it's a lot of people telling you what to do, 24/7. So you've got to listen to one person and listen to another person and it [inaudible 00:07:36], so then I tend to get really frustrated, and then I tend to get cards and stuff. But I think, especially, there has to be credit given to my coach for the last four or five years who's worked really closely with Dad to work on figuring out a coaching style that works with children with additional needs.

Jacob Casson-Rennie:

So he's become a very helpful coach, because at the start, he'd not a notion what was going on, but with working with Dad and getting to know me more over the four or five years I've been playing with him, it's gotten a lot easier for me to play in matches. I don't get into trouble as much. I don't get as many yellow cards or red cards because we've figured out ways of working around it.

Chantal Boyle:

So when you play rugby, have you had any injuries?

Jacob Casson-Rennie:

I've had quite a few injuries. I've dislocated my shoulder, slipped my knee cap, I've broke my ankle in total about five times and I broke these three fingers and sprained most of them. But I think another thing to do with my condition is acknowledging pain and actually going, "Actually, maybe I should take a break," and that determination, just wanting to keep on going. So I know a lot of my injuries, I've had them, and I've just carried on playing because it's harder for me to sit down on a sideline and watch people do something I love than I'd rather play through the pain because I'm actually doing something I love, 'cause [inaudible 00:09:07] sit and watch people.

Chantal Boyle:

And is that something that nobody can stop you, like your coach can't?

Jacob Casson-Rennie:

If I feel an injury, and I know the coach is going to go, "Actually, you're going to sit out," I'm not going to tell the coach. I'm just not 'cause that's going to risk having to come off the field.

Chantal Boyle:

Yeah.

Jacob Casson-Rennie:

I'm not willing to do that. I care too much about the team. I want to do everything. I play a big role in the team, so without me there... I replace people's positions. I play in my position, but I also replace every other injured player. So me being injured, then we're kind of stuck for positions. So I always feel that pressure of, "Okay. I have to keep playing. I have to be okay to play."

Chantal Boyle:

When you were little, do you remember feeling pain?

Jacob Casson-Rennie:

I know from one very important moment I can remember from my childhood, as well as one... I still lived with my mom. I was, well, maybe four, maybe just turned four, and she asked me to get something out of the oven. And I went over to the oven, opened the oven door and just stuck my hands into the oven and grabbed this tray out of the oven and burnt the down here, by both sides of my hands. And I just took them out, put them on the thing and-

Chantal Boyle:

Oh my gosh.

Jacob Casson-Rennie:

... the oven door closed the door and was like, "Okay," and went back and sat on the thing, and then she saw my hands and was like, "What the hell did you do?" And I just never-

Chantal Boyle:

Oh, wow.

Jacob Casson-Rennie:

I mean, another time that happened, we used to go to church a lot, and my mum was big in to the church, and I always used to go 'cause my friends would go and we played football in this little pitch that they had for us. There was a spiky post and a drain pipe and a brick wall behind it. We used that as a goal, and we used the poster as a goal. I was playing in goal. I've always played in goal. I'm too clumsy to play be out field, I always trip over the ball. And I dived to save this ball, and I slammed it right here on my head on the spiky post and cracked my head open, blood pouring out my head, gushing out my head and I wiped it off, carried on going for about half-an-hour.

Jacob Casson-Rennie:

My mum comes out to check on us and goes, "What's happened to you?" And there's just blood on my [inaudible 00:11:30], all in my hair and still stuck on my hair, and all up my sleeve, and then I got rushed to the A&E, but I just didn't realise, it was like, "Okay," and brushed it off and carried on going.

Chantal Boyle:

Well, that's potentially really, really dangerous, isn't it?

Jacob Casson-Rennie:

It is very dangerous. I mean, it can cause some serious, serious damage, but it's a sense of that person knowing that they know they do it. I know I do it. Sometimes I don't sense pain, but then I see it, 'cause if I injure myself, I'm not going to feel it, but I'm going to see it.

Chantal Boyle:

Yeah.

Jacob Casson-Rennie:

If I see it, it's whether I actually go, "Actually, I might need help for this," or "Actually, you know what? I'll survive."

Chantal Boyle:

Wow. That's really interesting. I have a very low pain threshold. Very, very, very, very low, so I can't imagine what that must have been like. Gosh. Have your hands healed up?

Jacob Casson-Rennie:

Oh, my hands are perfectly fine now. That's a good 11 years of healing now, 11, 12 years of healing.

Chantal Boyle:

Good.

Jacob Casson-Rennie:

They're all good. Back to normal.

Chantal Boyle:

Good.

Jacob Casson-Rennie:

The joints are still all a bit... They all wiggle out of position, but... I mean, my right-

Chantal Boyle:

Jacob's wiggling his hands and his fingers and showing me how they-

Jacob Casson-Rennie:

My right pinky isn't actually attached to its knuckle anymore. It's kind of just there. The knuckle is above where the finger is.

Chantal Boyle:

Yeah. Wow. Ouch. But not ouch for you.

Jacob Casson-Rennie:

That label of 'naughty child' was something I had immensely growing up. It was always, "Oh, yeah, you're just dust, and you're just messing about," and I think even now the teachers know that, but even now, still, because of my condition, there's certain allowances that are made to help school... who make it an equal environment as a less stressful environment to make it as comfortable it is for other students. And I think other students see it as, "Oh, he's getting away with this. He's getting away with that," so I've still got that label within the students of, "Oh, he just gets away with everything. He messes about and doesn't get told off for it," 'cause they don't see it. Now I have, especially, I know in my friend group, they know so well, and they're so interested in learning about this company and what my parents do, and every time I explain it to them, to different guys, they're rather impressed by it, and they go, "Wow, this is actually really handy, and this makes a lot of sense."

Chantal Boyle:

Because that is the frustrating thing, isn't it, for you, in that you are literally doing the best that you can, and sometimes what can happen when there's frustration, it can boil over, and what can seemingly outwardly seem like a negative way? And then you can be labeled with a red card or maybe when you were younger as a naughty child, and it's not what your aim is at all. You're not just having a temper tantrum.

Jacob Casson-Rennie:

The adults are getting better at it. The kids still have a lot of learning, because we work to educate everyone, but the first part is educating the adults. And then I think it's also we need to educate my age group on this because I've got to live with those people around, and they're still going to have labels. They're still going to put labels on people. So it's just about getting out to the adults so the adults can educate the children.

Chantal Boyle:

Yeah, I think knowledge is power, isn't it? And if you know what ways to interact with an individual, what are triggers, what would actually deescalate a situation, then that's the best thing to do, isn't it? And your learning support, they know how to do that, and your parents clearly do because they've set out The FASD Ireland.

Speaker 4:

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Chantal Boyle:

Just tell me a little bit about what FASD Ireland does.

Jacob Casson-Rennie:

It's such a common thing in Ireland due to the fact of, back in, maybe, '70s, '80s, it was common for women to drink through pregnancy. It was just, "Oh, have a glass of red wine or Guinness for the iron for the babies." It was just a thing that was done. But now, it's about getting the message out and actually getting mothers of children to feel less guilty about... Actually, accepting the fact that they did, and that their child might need support. But I think it's taking time here, and the ministers and my parents are working really hard on getting it out there. So Dad's working really hard to get in that... put out there and that we need to actually forget about this whole embarrassment, this whole feeling guilty for doing it and accepting the fact that these things have happened, and then working towards getting it recognized, and just everyone accepting these facts.

Chantal Boyle:

So that would be your message to any parents who are a bit concerned and are not, maybe, going forward for a diagnosis to get support for their child?

Jacob Casson-Rennie:



Absolutely. I think it's pivotal that people need to get the diagnosis for their children because the wrong diagnosis can lead to the wrong medications and the wrong support. Evidently, it's going to be wasting support 'cause it might not help at all a single bit. So it is really important that you get the diagnosis for what you have. So a lot of it, growing up, the misdiagnosis of ADHD, and also now, I do have ADHD, but to a lesser degree. It was never an idea of, "Oh, you might have FASD." It was always, "Oh, let's just go with ADHD." It's easy to just diagnose with just ADHD, ADHD.

Jacob Casson-Rennie:

So that's what another thing that Dad's working for, is getting that as one of the first diagnoses we get ticked off, rather than going, "Oh, let's check ADHD first." If you check FASD first, then it's easy to go, "Actually, yeah, such person does," or you know they don't. Okay, maybe they do have ADHD, whereas if you go through ADHD first, then to FASD, a lot of symptoms of FASD can be found in ADHD, so people are going to be going, "Oh, well, that's just ADHD," and then they don't actually go any further into looking at it.

Chantal Boyle:

Yeah, yeah. It sounds like they're doing fantastic work, and that you're very proud of them.

Jacob Casson-Rennie:

I'm very proud of them. It takes a lot of work, and I can see the stress and the time that they're putting into this. Dad is coming into work ridiculously early in the morning and leaving ridiculously late because he's so dedicated to getting the people the help that they need and the support they need. And both of them, I mean, after the brain injury of my other father, he's still getting back to work. When he was recovering from his injury, he was still like, "How is work going? Is there anything with work I can help?" So they're really just adamant on getting this out there because they care so much.

Chantal Boyle:

Yeah. It's a real commitment. Well, I mean, you can see. So you're doing well at school, you're in a rugby team. What are your hopes for the future when you leave school?

Jacob Casson-Rennie:

When I leave school, I hope to go to college and study behavioural psychology.

Chantal Boyle:

Wow.

Jacob Casson-Rennie:

Yeah. And as a child with learning difficulties, the amount of work that has to go into getting the grades needed for that, and people have always been growing up and like, "Oh, well you're not going to make it through school, and it's because you're always messing about,"

and this, that, and the next thing. And I think, as a person that's gone through a lot of these situations, I want to work with children, especially, and children that have been through traumas... child, because of personal experience, because I can help with those things. It makes more sense to me to have a person who's had those experiences and have all the training, all of this, help someone with that, rather than someone that's learned everything that they know out of a book.

Chantal Boyle:

I couldn't agree more. I think lived experience is so valuable, isn't it? So that you have the empathy, you've got the understanding, you know exactly where that young person is coming from. You've got the tools already, haven't you?

Jacob Casson-Rennie:

It's key. I mean, a lot of younger people want to relate to the people they're talking to. If you can relate to someone that you're talking to, and go, "Actually, this person actually understands and they know how I'm feeling. They know physically how it feels. They know mentally how it feels, because they've been through all of it, whereas a lot of the professionals, they know what it's like from other experiences from other people, but they don't know what it's like to live it. They don't know what it's like to go through all that trauma and all that stress."

Chantal Boyle:

So having FASD doesn't mean that you can't have a fulfilling life? It doesn't mean that you can't succeed in the things that you enjoy?

Jacob Casson-Rennie:

Exactly, definitely. It's the same as anyone else. You work for what you want. Yes, it's going to take extra time. You're going to need extra support. But if you put your mind to it, you will get where you want to. And I think that's another key thing, determination. A lot of us are stubborn. If we want something, we're going to get it, so-

Chantal Boyle:

Is that one of the traits, is it?

Jacob Casson-Rennie:

I know it's especially one of my traits. If someone's asked me to do something, and I can do it, I will do it. Yes, it's going to take me longer. I'm going to have to put in more work, but I'm still going to get there.

Chantal Boyle:

Yeah. Well, that's it. If you've got the desire, the determination, nothing's going to stop you. I understand from your dad that you do a little bit of part-time work for FASD Ireland and Hidden Disability Sunflower. What things do you do when you're working?

**Jacob Casson-Rennie:**

I did some of the media, so the TikToks and the other stuff for Hidden Disabilities Ireland. And I do a lot of the postage for all of the stuff that comes through into Ireland, so every order that's placed through FASD Ireland, it comes through our office and I package it, and make sure it's going to the right address, and then post it at the post office. So I do all the posting, the making sure it gets safely from the office through the post office, and then the media for that. And a lot of my stuff is in Copenhagen. A lot of the photos of the Hidden Disability are in Copenhagen. And so, I've done quite a lot of work with these guys.

**Chantal Boyle:**

Fantastic. So we've got FASD Awareness...

**Jacob Casson-Rennie:**

September 9th.

**Chantal Boyle:**

Yes, in September the 9th?

**Jacob Casson-Rennie:**

Yes. And that was another thing. Everybody is encouraged to support the National FASD Awareness Day by wearing red shoes on the 9th of September.

**Chantal Boyle:**

Brilliant. Okay. Well, we'll make sure we can try and get that message out to everyone. So we're going to come to the end of our chat. What is the main thing that people around you can do to support you or somebody else with FASD, do you think?

**Jacob Casson-Rennie:**

I think one of the key things is time. Just be patient. The people like me, we can do it. We're capable of doing it. We just need that time to get there, and support is... especially, it's incredible to have the Sunflower lanyard to help with that note, so that people know that we might need extra time or need support in certain areas. So the main thing that people can do is just give time and offer help, if it's needed. Don't just immediately help. Don't go and try and take over. Just offer that help and that support, 'cause if that person needs it, they'll take it. If they can do it, they will do it. But at least they know that they have someone that is going to help them.

**Chantal Boyle:**

That's brilliant. Thank you so much, Jacob. I hope that this has not been too tiring for you after your long day.

Jacob Casson-Rennie:

It's been okay.

Chantal Boyle:

Was there anything else that you wanted to say, to share with people?

Jacob Casson-Rennie:

I think just the whole of the Sunflower lanyard and FASD Ireland, we have a lot of products showing that. It's just, if you see it, do offer your hand, don't just overlook it, because people might not show their stress in a more open way, or their discomfort in a open way. If you see it, do offer your help, because you never know how anxious or how uncomfortable somebody someone is in a certain situation. So just always offer your help.

Chantal Boyle:

And be kind.

Jacob Casson-Rennie:

Yeah.

Chantal Boyle:

Okay, right. Well, thank you very much, Jacob. And I look forward to sharing this podcast with everyone.

Speaker 1:

If you'd like to share your Sunflower story or conversation, please email [conversations@hiddendisabilitystore.com](mailto:conversations@hiddendisabilitystore.com). Find out more about us, or listen to this recording again by checking out our insights page at [hiddendisabilitystore.com](https://hiddendisabilitystore.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 Disability Sunflower.