

ADHD Developmental Coordination disorder and sensory processing with Justin Wesolek

Speaker Key:

CB Chantal Boyle

JW Justin Wesolek

VO Voice Over

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

CB I'm Chantal, and joining me on The Sunflower Conversations today is Justin Wesolek, who has ADHD, developmental coordination disorder, and sensory processing issues.

Justin joins us from the US, and we are going to discuss how he uses his experiences to advocate for people with disabilities. So, hello, Justin.

JW Hi, Chantal. Pleasure to be with you today.

CB Yes, it's great. Thank you so much for making time for us. So, let's start off by finding a little bit about you. Can you tell me a bit about yourself and where you're studying?

JW Sure. So, my name is Justin. I am a, I guess now a graduate as of last Saturday, of the University of Wisconsin-Whitewater, in Wisconsin, in the United States, here.

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I just got my Master's degree in higher education leadership. Before that, I got a Bachelor's degree in political science.

While I've been here, I've also been on our Whitewater Student Government in various roles for the last five years, as the Speaker of our Student Government Centre for the last two of them, three terms. Really, that role enabled me to do all kinds of just great things for students with disabilities.

I've been on the UW System President's Advisory Committee for Disability Issues for a couple of years. I've advocated for students with disabilities in various ways on-campus. So, this has really been a passion point of mine since really arriving here at UW-Whitewater, a school that also has a special mission for students with

disabilities.

CB That's amazing. It sounds like you are in the right place. So, let's talk a little bit about your health condition. We'll start off with ADHD. What does ADHD feel like for you? I know that it can vary. All disabilities, health conditions can vary from person to person. So, interested to find out what ADHD feels like for you.

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JW Sure. So, what it's really like for me is, I have the combined type, so I have both the inattention piece of it and the hyperactivity piece of it, not so much of the impulsive part that some other people get.

But really, it's just hard for me to focus on a day-to-day basis. That's the main symptom of it, just on things like schoolwork, but also things I enjoy. Before I started taking medication, I remember I was telling somebody, it's so hard to watch TV shows that I enjoy. And people were like, what do you mean? That should be fun.

And I'm like, it's fun, I enjoy it, but with the exception of video games, focusing on any one thing for a really long time has always been pretty difficult, unless I get really far down the rabbit hole of whatever it is of the day.

The hyperactivity piece, I was never the kid that ran around and bounced off the walls. It was more so, for me, just fidgety, restless all the time, always wanting to do something.

So, that half of it isn't quite as prevalent, but it's still pretty prevalent. I'm very fidgety. I always like to be playing with something, doing something. Medication's helped a lot with that, but yes.

CB I think when we met before, did you have a lot of pens? Did you say pens or something?

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JW Yes, that's always been my big thing, especially before I started taking something for it. I would just take pens apart and put them back together 40 times in a meeting. Just would break them apart, put them back together. Break them apart, put them back together. It was just something repetitive to do.

CB Are you able to listen and take in what's being said whilst you're doing those repetitive things?

JW Yes, I think it actually helps, strangely, and I don't know that that makes a lot of sense, but it does.

Otherwise, I would be just spaced out doing something, but if I'm, I don't know, playing with something, flipping something over, I don't want to say it's completely involuntary, because it's not. It's not like I don't know I'm doing it, but it's just

something I do, and that helps somewhat.

CB Yes, it helps you to actually focus on what else, the other things that're happening.

JW Yes.

CB And you've mentioned that you take medication. So, the difference when you take medication, you notice, is what?

JW Yes, it's not like it all just goes away completely, but it's certainly helpful. I can definitely pay attention a lot better. I don't take my pens apart at my desk, so it really helps with the fidgety piece of it.

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And just I can focus on things I do enjoy and things that I don't, too, which is helpful because we all have to do things at work, school, whatever, that we don't all love doing all the time.

So, that's been really helpful for me. I started taking that when I got up here at college for the first time, and that's been really helpful. I wish I had a time machine and could go back.

CB So, you feel like it would have really been of benefit when you were younger?

JW Yes, 100%.

CB And is that just to do with the educational setting or social settings, or everything?

JW Really everything. I have a short-acting version of the medication, so I don't have to take it all the time every day, but I choose to. I can take up to three doses a day for 12 hours, and it's really just helpful. It's helpful to be able to enjoy the world around me just a little bit more differently.

CB What is developmental coordination disorder? What does it mean?

JW Sure. So, if I'm not mistaken, this is something you all, generally speaking, call dyspraxia I think in the UK. We don't much use that term in the US. We use the DSM-5 version, which is called developmental coordination disorder.

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So, what is that? It's really a gross and fine motor impairment. For example, the most noticeable fact, by far, is my handwriting is abysmal. You do not want me to write on a whiteboard or write anything.

I have a really hard time with handwriting. Other little daily activities like opening ketchup packets, cutting with scissors, that can be a real challenge sometimes. But those are the finer things.

And then gross motor, I have really bad balance and just general spatial awareness. It's not a real strong suit of mine. It doesn't affect driving or things like that, and I can still do some things.

I can ice-skate, roller-skate pretty well, and play hockey, but riding a bike, for example, is something I can just never learn how to do, to this day, even. So, really, it's an overall motor coordination problem.

CB I spoke to somebody recently who has dyspraxia, as you say, that's what we call it in the UK, and she was saying that even trying to go into a toilet, so a restroom with her backpack on, causes her a lot of stress. Because the confined space with the backpack on, she's bashing into everything, because she really struggles with that spatial awareness, and she can end up actually hurting herself.

JW Yes, I definitely have been known to have a bump or a bruise or a scrape, or a trip and fall on a sidewalk, once or twice. I don't know that I've had that specific issue, but just certainly really tight navigating spaces is not something I have a very great grasp on.

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It's not severe for me, to the point where I can't do a lot of those things, but a lot of things just require cognisant effort, focused effort, that I don't think other people have to do.

I don't think people focus very much on standing upright, straight. And that's something that requires a little bit of thought. Or focus on writing or opening a ketchup packet, that's something that takes thought for me.

CB So, the final health condition that I mentioned at your introduction was that you have sensory processing. Can you explain a bit more about how that affects you?

JW Sure. So, I don't have a super severe sensory processing disorder, but I certainly have, I have one. This affects me in different and strange ways that don't really seem connected, but they certainly are.

I'll just give a few random examples. So, denim, the feeling of denim is one of the biggest ones. Blue jean material. Justin does not wear blue jeans, suffice to say. It's something that I would be completely distracted all day, so it's a textile thing.

Ankle socks, too, short-cut socks, for whatever reason, that position on the bone of your ankle, it freaks me out.

I don't know how people do that. No. Keep ankle socks away from me. So, those are a couple of things in that space.

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Light photosensitivity. This is a strange one for me. Bright lights, like at a concert or

wherever where you'd expect bright light, it doesn't really bother me, but anytime light comes into the corner of my eye that's a bright light, it really bugs me for some reason.

I always have to turn it off. If I'm watching TV in front of me here, lights that are off to the side, either which way, really bother me if they're not at the right angle. I don't know that I could even tell you what the right angle is, but whatever the right angle is. So, photosensitive in that regard.

Sunlight. I wear sunglasses every day outside. It doesn't really matter if it's as cloudy as can be and you can see sunlight or not, if you can make some sort of a shadow from sunlight, I wear a pair of sunglasses.

It really just bugs me. It doesn't give me a migraine, or I don't get sensory overload from those kinds of things in the traditional sense perhaps, but it's just a constant annoyance. It's like somebody's, I don't know, poking you constantly, is probably the best way I could describe it, with sunlight.

Other things? Super high-pitched noises, that's a plug your ears and don't listen. They really bother me. I have really good hearing, which is a good thing for that, but I can hear high-pitched noises and then they really bug me.

Generally, too loud of environments if I'm trying to focus on something, that probably plays a little bit into the ADHD part of it, too, but those are a bother. I do have a case from here, Loop Earplugs.

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CB Are they good? I've seen lots of people advocating for them.

JW I love them. So, I didn't actually know about these until last year. I used to wear earplugs a lot when I had to take tests and stuff in elementary school, and I grew out of that. But then, someone was like, hey, you know there're high-tech earplugs, so you can still hear things, that aren't like your traditional foam earplugs?

And they've been super helpful. So, I have two different pairs of them, with an adjustable setting, and they're really good for just taking down extra noise a little bit.

I don't wear them on a daily basis, but they're helpful in certain circumstances, or if I'm just generally overwhelmed that day, they're really nice to have around. So, they sit on my dresser and I can grab either pair of them, depending on which I need. Those are really helpful.

I'm trying to think about other things with sensory processing in general. Just I do like a weighted blanket. That's something that really calms me, hyposensitive, flipping to the other side of the coin for a second, in that regard. It's just a really good feeling.

I always like tight stuff, like hugs, whatever. And then, so when somebody suggested

trying that, I was like, that's really helpful and it calms me down.

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Other things? I don't like really tight, Dri-FIT clothing. I can wear a polo. This is a polyester material. But if it's too tight, that really bothers me. Those are my main suite of symptoms. I don't have any food sensitivities to speak of. There're certain foods that gross me out.

CB Smells? Some people have smells, don't they?

JW Yes, that doesn't much bother me. Really strong perfumes and stuff, I don't love, but they don't bug me like the others. It's really light, textures, sound.

And I forgot to mention one, too. I'm not a huge fan of confined spaces. Again, it's not something I can't do, but it's just not very comfortable. I like to have a little bit of space to move around in, and being really confined is just not super fun. I don't love being in the middle seat of an airplane, is something that I try not to do. I always try to have a window seat or an aisle seat, if possible.

CB Yes, the feeling of being trapped.

JW Yes. And if I know I'm going into it, and it's the same thing with a lot of these, if I know I'm going into an environment where these are going to occur, like a concert, I can do loud noises or any of those things where there's high-pitched noise. But if it's just unexpected in my day-to-day environment, and I don't have time to think about it and prepare for it mentally, then it really bothers me.

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CB Have accommodations been made to support you whilst you're studying? And if so, can you tell me about them?

JW Yes, so I think to answer that question, I'll tell you a little more about UW-Whitewater. So, this is the school since the 1970s, I believe, that is the Wisconsin school for students with disabilities.

Now, it's not exclusively a school for students with disabilities, I should say, but it is one that has the special mission to serve them. So, about almost 15% of our students have some disability, whether that be visible or invisible.

So, this school is and always has been on the cutting edge of accommodations, and even one step further, what we call universal design, where your environment, whether it be virtual, digital, physical, spatially, really is meant to include everybody as much as possible.

Some of the ones I've had, I have a lot of different kind of exam-type accommodations, from extra time to being able to type or have a scribe, to a private room. I'm able to take breaks from classes, or whenever I needed to. I'm trying to

think of other ones.

I forgot to mention one thing in the light sensor suite. Blue light, cool-colour-temperature light that's a little bit more bluish than yellowish, they're a bother to me, so I've always had all my office lights changed out to be a more yellow, warmer temperature.

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So, that's something that they've always been really good about. But really, it's an ask for what you need here.

CB I was going to say, these accommodations, because there's quite a lot there that you've mentioned, that all seem very easy to do and to support you with, are these things that you've said, look, this is going to help me?

Or do they come up with a list and say, you can tick these things? Or how? Or has it been just through dialogue? How have you achieved those accommodations?

JW A little bit of both. I had to make the initial ask and turn in documentation and whatever, and then from there, it was a very natural, free-flowing dialogue. I came up with some of the ideas. They came up with some of the ideas.

And they've evolved over time, as just you thought, this would be helpful. Or ironically, sometimes you don't know what is going to be helpful until somebody suggests it. And then you're like, so that's helped you before? Why don't maybe I try that? And then you're like, that's really helpful. That's what happened with the Loop Earplugs, for example.

CB It's great, though, because it sounds like it's a space that really values inclusiveness, and therefore you are able to then be more open about your needs, and so is everybody else. That's what they often say, is that sometimes making these accommodations will help other people. Sometimes, whether they have a disability or not, it can be to the benefit of more than one person.

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So, having this great space where you can share your access needs is really important.

What's a typical day like for you, then? Do you get up and take your medication, first of all? How's a day for you? Make sure you don't put your blue jeans on, denim jeans?

JW Yes, both of those things. I don't even own a pair of blue jeans, so we don't have to worry about that problem. But no, I usually get up, take my medication, and then just go about whatever my day's going to be. I tend to keep a packed calendar all the time.

CB You are listening to The Sunflower Conversations. Remember to hit subscribe. So, with your medication, does that help you at all with the sensory processing and the developmental coordination disorder? Or does it literally only affect the ADHD?

JW I would say it literally only affects the first one. I have not heard, that I've read in literature before, I've read a lot of disability literature from experts, and they say that helps some people. It has not helped me with those much. I think there's probably some correlation there of, if you're paying more attention, you're slightly less likely to trip over something.

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CB Yes.

JW But I can tell you, I still can't stand on one foot and walk on a tightrope very well, suffice to say.

CB Okay, and then what do you think of the Hidden Disabilities Sunflower, and how do you see it supporting people?

JW I think it's a fantastic idea. We have done a really good job here at UW-Whitewater of talking about, disabilities are not always visible, they're not something you can see. In fact, the majority of them are probably ones you wouldn't notice, majority by type and by people with them, I think is a fair statement to say.

And the Sunflower's a great extension of that. I learned about it from just Googling around one day, after a PACDI, the Advisory Committee for Disability Issues for the System, meeting. And that was something that was really neat to find.

I understand it's a whole a lot bigger in the UK than it is in the US. Now, recently the airport I usually fly out of to go on vacation a lot, which is the Rockford Airport, just joined the Disability Sunflower Programme.

CB Brilliant.

JW I just saw the signs for the first time when I was there.

CB That's great.

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JW In, I don't know, January, February, whenever that was. So, that was neat to see. I did get a pin from there. It's somewhere buried in my desk drawer right now. I'm sure that that will claw out somewhere.

But it was my first experience in person with it. But I think the programme is great. I think there're people who have different needs and different reasons, and to just get that little bit of understanding without having to, I don't know, ask for it, without having to somehow make something invisible visible, with a magic wand, I'm not really sure how one does that, but that's really been neat.

One thing I think I would really like to see is, I just was on the website two days ago, just getting ready for this, and I noticed there's a huge list of hidden disabilities, and that was the first time I've seen that since I visited the website, and that was really cool.

I think the icon selection I would like to see, if I had a magic wand, expanded ever so slightly. I know, something for confined spaces and textiles and...

CB I think there is a sensory processing one.

JW There're ones for a couple different sensory issues, but there're not ones just for a more generalised thing, or for confined spaces and stuff. I know, for example, I don't love waiting in super long lines that are super tight spaces with a lot going on in them.

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CB Yes.

JW And there's one that says, I have trouble standing for a long time. And that's not how I would describe it myself. It's not a problem with standing. If I was sitting in a computer chair, it wouldn't make any difference.

So, I think the expansion of the list has been phenomenal. I would love to see an expansion of even more icons for people. But I love the Sunflower Concept Scheme, whatever you want to call it, and I think it's really a great tool that I would love to see expanded.

Again, my understanding is, in the UK, it's a very recognised symbol, and I know that the Special Olympics in Germany this year are going to recognise that for the first time. And I know that, as a result of that, we're hosting Special Olympics Wisconsin here at Whitewater next month actually, and I know there's already been some conversation with administrators about, you might see this.

I don't know that there's been super robust dialogue yet, but it's at least been tossed around a couple of times. I got a briefing memo in my email about Sunflower, two weeks ago I think it was, and I was like, that's neat because I've already read about that, so that was good to see.

CB Yes, in places of education it's really important to be able to be recognised. So, yes, it'd be great if we could see Whitewater becoming members of The Sunflower, and supporting their staff as well as students, because disability affects everybody, doesn't it?

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JW For me, airports is a great first step in the US. I think educational institutes, both K-12 and universities, would really be another huge stepping stone. That would be, if I had a magic wand, my next big push.

Because then people who are of a younger generation get used to seeing that, and their parents get used to seeing it, and I think it naturally flows into the world. Then stores, first responders, you name it, start to see more of that.

And I know one of our arenas here, Fiserv Forum in Milwaukee, that's this brand-new beautiful arena, has sensory bags that you can pick up, and they have two sensory rooms now for people who want to use them.

And I think that beginning to see that stuff in business spaces is going to really play hand-in-hand with this. The Sunflower continues to grow, and I think there's a natural tie-in there that's going to be really great for a whole bunch of different reasons.

CB Absolutely. Definitely, yes. The Sunflower lanyard would be a wonderful inclusion to have in a sensory backpack, for people when they visit entertainment places, leisure. And you're right about the airports, it's a good way for it to start. It started in the airport here, in Gatwick Airport, and it's a great way.

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Because obviously, you get on an airplane at one point and then your destination, so it's good to have it that it's recognised in your arrival airport as well.

And with regard to the icons, we always welcome feedback, so I'll pass that on to the team. So, if you have any other ideas, do pop them over to us, and we'll see how we can work them or incorporate them.

JW Absolutely.

CB So, finally, what can society do to remove barriers for people and improve inclusivity, do you think, Justin?

JW Great question. I think this is a really complicated question to answer, shocking, by the fact it hasn't been solved, I know.

I think in America, I'll talk about specifically, we really have done a fairly good job since the Americans with Disabilities Act, of being accommodating, whether that be through elevators and building codes with ramps, to automatic door openers on doors, to all kinds of different things in that regard.

Especially for physical accessibility, there are grants for blindness and deafness a lot of the times, and state tax credits, and I think there's even a federal tax credit, if I'm not mistaken.

So, those are all great. I think we're doing great in those spaces. I think expanding some of those programmes beyond the rigid, original definition of disability, I don't even know that it was the original definition ever, but just the way people thought of it back in the 1970s, to the next level.

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One thing I always talk about is, I wish more rooms had a dimmer switch. In my room here, I have controllable lightbulbs through my cell phone, so I can dim mine down anytime I want, or change the colour to a million different colours, ridiculous stuff.

But I think dimmer switches on lights, updating building codes and ADA compliance to include stuff for sensory spaces, things like that I think are really the next natural evolution of things.

I think we've done a really good job with restrooms and physical spaces, but I think it's time to get a lot more intentional with universal design in both web accessibility and in sensory profiles of areas.

We're never going to be perfect, and so many people have so many different needs, and there's some onus, that if you need something then just ask. But I think there are some things that if I walked into a certain building and said, hey, can we dim the lights a little bit? They'd go, we can't do that.

Now you've run into a problem. And for me, that isn't that severe, but I know people who really struggle with that and wouldn't be able to access that space without it. So, I'm fortunate enough that that wouldn't be a barrier in that regard for me.

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But I think the next step is to really move into the next generation of thinking around disabilities, and how we can continue to be inclusive to more invisible disabilities and how those work.

CB Yes, absolutely. And hopefully the Sunflower will be a part of that to companies and businesses and individuals opening up that conversation about what their access needs are, and help stimulate that conversation moving forward.

JW Absolutely.

CB So, Justin, thank you so much for your time today, and I've thoroughly enjoyed having a chat with you.

JW Thank you very much, Chantal. I enjoyed it the same. Take care, and I look forward to seeing the Sunflower everywhere I go someday.

CB Yes, me too. If you have enjoyed this conversation, please hit subscribe to The Sunflower Conversations Podcast.

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and show kindness to others. And join us again soon, making the invisible visible with the Hidden Disability Sunflower.

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