

Interview between Speaker 1 (Meg) and Speaker 2 (Damian)

[Introductory music]

Welcome to the Two Sides of the Spectrum Podcast. A place where we explore research, amplify autistic voices, and change the way we think about autism in life, and in occupational therapy practice. I'm Meg Proctor from learnplaythrive.com.

Meg: Before we get started, a quick note on language. On this podcast, you'll hear me and many of my guests use identity-affirming language. That means we say, '*autistic person*,' rather than, '*person with autism*'. What we're hearing from the majority of autistic adults is that autism is a part of their identity that they don't need to be separated from. Autism is not a disease, it's a different way of thinking and learning. Join me in embracing the word '*autistic*' to help reduce the stigma.

Hi, and welcome to the *Two Sides of the Spectrum Podcast*! As an OT who teaches and trains other therapists in autism interventions, I really try to stay on top of research. But recently I was blown away by some new research done at the University of Edinburgh. The researchers did a study that looked at how autistic adults, non-autistic adults, and mixed groups shared information and built rapport. What they found was that when autistic people were working together to share information, they were just as effective as the groups of non-autistic people. And they also reported very similar levels of satisfaction with the social interaction. But when the groups were mixed between autistic and non-autistic people, it left everyone feeling stressed and misunderstood.

I'll link to some more details of this important study in the show notes. But here's the takeaway: We have for decades been saying that autistic people struggle with social skills and perspective taking. But the truth is, this goes both ways. While autistic

people may have difficulty demonstrating the skills expected by neurotypical people, those of us who don't have autism have just as much trouble accommodating the needs and preferences of autistic people. It's a problem on two sides of the spectrum. And while autistic people have been trying to bridge this gap for decades, we neurotypicals have a lot to learn.

This research was based on an idea created by Dr. Damian Milton. He calls it the, '*Double Empathy Problem*.' The idea of the Double Empathy Problem is what really inspired this podcast. Because I'm on a journey to work on my part of the empathy problem, and I want to take you along with me on that journey.

I actually teach an online course for OTs and other therapists called, '*The Learn Play Thrive Approach to Autism*'. And after reading Damian's research, I had to make some huge updates. Because like so many, I had been operating on the assumption that perspective-taking and social skills were simply things that we need to teach autistic people. When in reality, there is a cultural difference to be bridged between autistic and non-autistic people. This shifted both my framework and my interventions, and I'm very interested in what shifts this might inspire in your work.

In this episode, Damian talks about his path to becoming an autistic researcher, how he developed the hypothesis that led to this research, strategies to help OT's stay on target and in tune with their autistic clients, and so much more.

Dr Damian Milton is a part-time lecturer at the University of Kent. He consults with a number of organizations in the autism world, including chairing the Participatory Autism Research Collective. This interview was long and full of important insight, so I'm going to walk you through it point by point. We'll start with Damian's path that led him to study autism— Damian's son was diagnosed as autistic at 2. This led Damian to read more personal accounts of autism, eventually leading to his own diagnosis as autistic in his 30's. So Damian shifted his work from studying and teaching

sociology to focusing on autism. But he remained interested in social interaction, and breakdowns in social interaction.

At that time— and really, still today— there was the idea that autistic people lacked theory of mind, or the ability to understand that other people had different thoughts, beliefs, emotions, and perceptions other than one's self. And the idea is that if autistic people lacked theory of mind, this is where the social breakdown came from.

Damian heard this theory and it didn't sit quite right with him. He thought it was incorrect at worst, and a partial explanation at best. So he started to dive in a little bit deeper. Here's Damian talking about his very early research that he did to explore the question of autism and theory of mind.

Damian: I very much was interested in social interaction, but also from a lived experience, breakdowns in social interaction. It initially started out as just a theory and a different explanation. And some of that also came out in qualitative research that I was doing with both autistic children and adults, some of which was work I was doing with the *Autism Education Trust* in the UK. We talked to young children in schools, and used various materials and techniques for less verbal children, and some of the more verbal children had quotes like, *"95% of people don't understand me,"* and, *"Adults never leave me alone,"* and comments like these.

And they felt social understanding of sorts, and a serious mind— at least, a foundational one— but also struggled with social interaction and how others perceived them. So to me, it was logical if there was some kind of cognitive difference or perceptual difference, then one's experience of social life would be different too.

Meg: I want to pause here and highlight one thing Damian said: *"To me it was logical that if there was some sort of cognitive difference, then one's own experience of social life would be different too."*

When Damian said this it sounded so obvious. But I want to linger here for a moment, because this is not something most of us, including me, have really worked through before.

Imagine an interaction with an autistic peer that feels awkward. You walk away thinking, *“That was awkward, they didn’t have the social skills I expected,”* or, *“I really felt like they really didn’t understand me.”*

But what if they are thinking the exact same thing about you? What happens when we listen to the autistic perspective? Here’s Damian.

Damian: When it comes to social skills, I see that as a negotiated social reality. And so what's skillful and positive to one person may not be experienced as such by the next. When someone may say, *“Oh, I’m very empathetic and socially skilled,”* it meant to me they're anything but. [Laughs]

Meg: So social skills are *‘a negotiated social reality.’* It’s like when you travel to another country, and your usual wit and sarcasm suddenly leaves you sounding rude and out of touch, rather than smart and funny. It really helps to think about autism as a culture— then what Damian is saying becomes more familiar. What feels like good social skills for a non-autistic person may actually feel really uncomfortable and unnatural to an autistic person.

So then the question becomes, *“If we insist that the neurotypical perspective is the only one that matters, and that autistic people need to learn the skills to fit into the world as we have made it, what impact does that have on their health and well being?”*

Damian: Remedial attempts to try and make autistic people basically *‘less autistic’* to me tend to often do more harm than good, often just by stressing out the autistic person, or making them mask and having the stress of that. And that stress, I think, has to be taking into account with autistic people— well, or anyone. I think social disjuncture is quite different to just lacking theory of mind.

Meg: I want to break this down a little bit. *Theory of mind* is the ability to understand that other people have different thoughts, feelings, and experiences than you do. There's tons of research showing that theory of mind is present in most autistic people, but it may present somewhat differently.

Social disjuncture, however, is when there is a breakdown between two people in a social interaction.

So Damian and I talked about how social disjuncture isn't the same thing as saying that autistic people don't have theory of mind. If autistic people are in a near constant state of social disjuncture with neurotypical people, Damian discussed one thing that can really help reduce the stress.

Damian: One of the problems there, of course, is there may be a limited connection with others who experience the world the way you do, or in a similar way. So meeting other autistic people can be quite empowering if done well or at the right timing—sharing experiences and someone else saying, *"Oh, yeah, I understand that,"* or telling a story and it connects with you. And I think there's quite a lot between autistic people, even who've met for the first time, with that kind of connection starting to happen.

At the same, it's not using standard social etiquette perhaps. I saw a paper recently saying that autistic people were not empathizing more with each other because they were not showing motor synchrony with each other. And I was thinking, *"Well, does one have to copy physical movement in social interaction to feel this empathy thing?"*

Meg: Yeah, that sounds like a really limited definition!

Damian: And it's more— this is more how non-autistic people interact. It's like, *"Well, so what?"*

Meg: Did you catch that? *"So what?"* he said. So I asked myself, *"Autistic people socialize differently.... And perhaps we need to start by asking ourselves, 'so what?'"*

Also, I don't know if you guys have ever been in an autistic-only space, but it does feel very different from a mixed space. At two different points in my career as an OT, I've had leisure groups for adolescents who are autistic. When it was just the autistic kids, friendships flourished and social interaction abounded. It looked different than it might have for neurotypical kids. And absolutely no one cared. But when I tried to include neurotypical peers, the autistic kids, on the whole, shut down. It was awkward for the neurotypical kids, too. No one was having any fun.

It really highlighted for me what Damian is saying: Autistic kids need time to be in autistic spaces. I talked to Damian about my experience with having non-autistic kids (who I referred to at the time as '*peer models*' though I wouldn't use that language now) in my group, and here's what Damian had to say.

Damian: One of the issues for a lot of autistic people is predictability— predicting what's going to happen next, and for those things to be good things or perceived as good things, in a sense. A lot of peers will be perceived as a threat, either through past traumatic interactions or, "*These people are too brash, too fast, too loud.*" And you can instantly be, "*Oh, better back off a bit,*" and you may not— as you say, you may become more inhibited and shut-down from it.

In autistic spaces, one thing I've often noticed is how calm it is, and how people are kind of doing their own thing in a quiet, calm, and usually not very loud way. Occasionally you'll have a loud autistic person as it were, in an outburst, but it's actually quite uncommon and totally accepted when it does happen, because it happens in a kind of autistic way. That '*normal social interaction*', if you like, can often almost be a competition. If you've ever noticed that in a room full of people, how the volume of voices goes up and up? There's one or two voices which you can hear above all the others because they need to be the centre of attention. Its like, "*Bah, bah, bah!*"

Meg: Yeah.

Damian: And the autistic reaction to that is to back off, maybe observe and analyze who's the King in here, but often you'd just get overwhelmed sensorily and just need to leave. The idea of engaging with anyone there would be off-putting. So often, in terms of social skills, it seems that the autistic person's the one with the problem— *"He can't fit in, he needs to learn ways to do better"*. It creates exhaustion and personal cost to the autistic person, and how much is that coming the other way in an effort to understand autistic sensibilities, or their social ways and what they appreciate?

And to me, social interaction has to be a mutual effort. There's so much expectation placed on autistic people socially when they're already struggling in this area. It's interesting what you say, because this role model effect really doesn't work. If someone who's supposedly socially skilled learned off of them what you do and how to do it, it really doesn't work that way.

What's often quite useful is meeting other autistic people or older autistic people who can mentor you from that perspective, and say, *"Oh, this is what I did,"* or, *"It may not work for you,"*— as someone who understands what you're going through.

[Intermission begins]

If you're enjoying this podcast, you'll love my free 50 minute training. Autism-specific strategies that transform OT practice. In this training, I dive into the places where many OT's are getting autism wrong, why it matters way more than we realize, and four concrete strategies you can start using right away. We even talk in-depth about what we know now about autism learning styles, because when we can shift our perspective and truly consider how autistic kids think and learn, we can start generating more meaningful and effective interventions to help our clients find more joy, independence, connection, and acceptance in their lives. Visit learnplaythrive.com/masterclass to start learning right away.

[Intermission ends]

Meg: So this got me thinking: Why do we, as a culture, seem to have respect, or at least be developing some type of respect, for some types of differences but not for neurodivergence?

For instance, as a woman, I expect not to be asked to act less feminine, or to mask my femaleness. I can also expect to have access to female-only spaces. But why, for autism, is this different?

When I asked Damian, he said that it was because we have put autism into the '*Health issue category*'. It exists in a medical model, rather than in a social or neurodiversity model.

There is a lot to unpack here in this question of *Social model vs. Medical model*, and this is going to come up again and again on this podcast. But the short version is: In the medical model, autism is pathologized, and we must "treat the symptoms" and show progress. He recommends a shift to a neurodiversity model, or a social model. And if you aren't sure what that is, keep listening to this podcast. Because that's exactly what we're here to explore.

So I asked Damian one final question: "*What one thing does he want to see more of from OT's?*" Here's what he said.

Damian: I think with sensory perceptions and differences there, they're quite fundamental in autistic ways of being and in understanding that. But trying to remediate them is likely to cause problems rather than actually remediate them. Trying to desensitize an autistic person is generally a bad idea, and it's something they dislike. If it's to do with anxiety, one may be able to work on that in a very gentle way, but I would still give caution. If something is about unpredictability, making something more predictable can help. However, if something is predictably perceived as awful, that gets embedded quite quickly and stays that way throughout life, I would say.

There's some sensory issues I have where I really dislike the sensory input. A good example would be Parmesan cheese— I'm dairy-intolerant, so I don't really like dairy anyway, and so the smell of that stuff can turn my stomach at 20 meters. If that comes in the room, I would be shortly leaving afterwards. To me, no desensitization is ever going to make me put up with that stuff in a comfortable way— it's always going to be stressful, so I need to avoid it.

So I think there's a lot more than can be done in making adjustments around the autistic person and their likes and dislikes; and respecting that, because they can be quite extreme, as well as not having one's interests or sensory likes held back as if you're over-indulging. If you love swimming, then why not have lots of access to swimming? And so when things are felt positively, it can be a very good experience.

It's something I realized a few years ago about myself, is that I was very, very tactile, or sensitive. But there were some things in a tactile way I really liked, kind of sensory seeking, and other things that I detested and highly avoided. All of these came from a sensitivity, that some stuff was like, *"Oh, that's quite nice,"* or, *"Oh, that's horrible."* And for one autistic person to the next, that can be a very different profile, or the interest that comes from that.

For example, I'm also quite dyspraxic and have coordination issues. Many of my avoidances are practical things, or tactile sensory things. So the idea of gardening is like, *"Oh, horrible."* And yet, there was a program on UK TV a couple of years back called, *"The Autistic Gardener"* about an award-winning garden designer and gardener, and how he used his autistic ways in that sense. So you'll find people with very, very different personal likes and dislikes that come from experience, and how that autistic temperament responded to that stimulus at that point in their life.

I guess there's more one can do at an early age, so I am encouraging first and foremost motivation, rather than avoidance. But sometimes what people do is, *"Oh, that person is finding that thing difficult, so I'll give hours and hours a week on this thing."*

You're probably going to build up a mental barrier and block about this thing, and put people off.

One thing I say is, say, people who may have struggled with Math at school— so if I'm doing a talk, or some training, there's always some in the audience who do. And I say, *"Well, how would you like to do 40 hours a week of algebra and simultaneous equations?"* Their reaction would be, *"I'd run away, I'd fight, I'd scream."* So I'd say that they'd have a meltdown or be avoidant. So this is *exactly* how autistic people feel when you try and make them socialize with people they'd rather not. There's a lot more mutual respect to those perceptual differences and social interaction.

One intervention that is often used are cartoon strips and stories. But the way they're used is by often saying, *"You're doing it wrong, and you ought to be doing it this way instead,"* which has no mutual respect whatsoever of what this situation is like for you. One needs to start at that point: What's your understanding of this, how are you perceiving it? And that's rather difficult if someone doesn't have the words to express it, which is the case sometimes.

It means a lot more person-centeredness and humility in practice. It takes a lot of effort to understand the issues someone might have in a nuanced way, and that can be very difficult if a practitioner has very limited time with someone.

So with my son who's largely non-verbal, I would say with education practitioners, it takes about half a year to get to know him and develop that starting level of good rapport. Sometimes even then, personality clashes and it doesn't quite work. It's extremely difficult and takes a lot of effort sometimes to really understand the individual, but that's the message that needs to be heard: To not make assumptions, to put the effort in, and to be humble and that your interpretations are quite likely to be wrong.

Often we base them on our own experience; and non-autistic people trying to empathize with autistic people will make mistakes, thinking that if they were doing it

that way, they would be doing it for a certain reason. So you hear all kinds of things about autistic people— *"They're doing this to manipulate you."* What? What are you on about?

Meg: Yeah, that's my least favorite hypothesis for any child, really, that they're trying to manipulate you.

Damian: If you let them do that, then they get their own way, and what's wrong with that, occasionally? And so, in imposing what's right or wrong on someone, often the best stacks for it is the autistic person themselves— their own ways to self-regulate. Sometimes that can be difficult or dangerous, but often we're the best people at finding the solutions for ourselves. Sometimes not, but it's just respecting that and really working with someone and listening.

When someone is less verbal, being very aware of potential sensory issues is where autistic advocates and workers can come in useful. Something that I think other autistic people often pick up on a lot quicker are potential sensory hazards, and general things like that. That lived experience can be beneficial to practice for all autistic people, if used well.

Also, family knowledge. So my son might not be able to say what his likes and dislikes and sensory needs are, but his parents certainly give a good description from many years of that experience with him. Whatever the ideas and ideologies a parent might have, there's really key information and expertise there about that particular individual. One of the tricks is working better together with all the people around that individual, and respecting that we all have different expertise, and what the uses of that are. Sometimes I think the practitioners who don't respect that are partly having a defense mechanism through an anxiety about their own knowledge and expertise. The most humble practitioners are often the ones with the most experience.

A lot of the problems are socio-structural ones— how we organize work practices, things like these we should be looking at more. There's so much attention on the

autistic person or the autistic child and their development, when we should be looking at the systems and the people around them a lot more. Because that's something that we can really do something about. Social environments, school environments, things like these. I think the ideology of, "*Change the child, and society won't change*," is just wrong-headed.

Meg: I agree.

Damian says that trying to desensitize kids to sensory sensitivities is generally a bad idea. We can try making things more predictable. But some sensitivities are going to be embedded for life. And while there may be opportunities to help kids tolerate some of these experiences better, especially if the issue is anxiety, Damian says we should generally skip the desensitizing and accept that the input is stressful. This means more focus on accommodations and changes to the environment.

My personal OT practice has never been heavy on sensory interventions, so I'd love to hear from you. Each week in my Facebook group, *Learn Play & Thrive: Autism Resources for Professionals*, we reflect on the latest podcast episode. I'd love to have you join in share your thoughts and experiences on this in light of Damian's insight. I'll link to it in the show-notes.

Damian also talked about how many professionals tend to use our interventions to actually impose our way of thinking on our autistic clients. I love this idea that social stories, comic strips can be used to *learn about how our clients think*, not just to tell them how they *should* think or act.

In the end, Damian calls for *more humility and person-centered care*. To know that we're going to get it wrong. And to keep learning about our clients with empathy.

He also challenges us to stop putting all of the burden of change on the autistic person. Can we shape the physical or social environment to be more accommodating? Can

we set up the materials or change how we teach so that they are more meaningful, given the autistic person's strengths and ways of thinking and learning?

The next step for many OT's is to begin to understand autism with greater nuance so we can show up for our clients more respectfully and authentically, to empower and support them in their daily activities. And, at the very least, to meet them halfway, rather than asking them to be the only ones doing the hard work to thrive in this neurotypical world.

It's been so exciting watching my students in *The Learn Play Thrive Approach to Autism*, my online CEU course, make this shift. When they truly begin to understand and respect autism learning styles, their interventions and ways of teaching totally change. And their relationships with their clients flourish.

I remember when I learned that there was an alternative to behavioral interventions for autism. Previously, I'd been deeply unsettled by observing behavioral interventions. I'd said that working with kids on the spectrum "wasn't a good fit for my personality" but what I meant was, what I was seeing didn't feel kind, respectful, or ethical, and I didn't want to do it. But without these interventions, I was floundering and didn't actually know what *to do*. Learning to set up the environment, materials, and teaching approaches based on how autistic kids think and learn allowed me to love my work again, and to approach it with real respect for my clients.

Thought leaders like Damian are the people who create huge shifts in social paradigms. And therapists like you help bring that change to life in your work with clients. Thanks for listening, and thanks for the work you do.

[Ending music]

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share the episode with a friend or post it on your social media pages. Join me next time, where we will keep diving deep into autism.