Series 4 Episode 3

Parent-carer blame in Autism services: A Conversation with Alice Running

[00:00:06] **Lesley:** Hello and welcome to the Portal Podcast, linking research and practice for social work. I'm your host and my name is Dr Lesley Deacon.

[00:00:13] **Sarah:** And I'm your other host and I'm Dr Sarah Lonbay. So we hope you enjoy today's episode.

Introduction to Alice Running

[00:00:28] **Sarah:** Welcome everyone to the Portal Podcast, linking research and practice for social work. I'm Sarah Lonbay, I'm here as always with Lesley.

[00:00:36] **Lesley:** Hello.

[00:00:37] **Sarah:** Hi Lesley. Today we're very grateful to be joined by Alice who has come to talk to us about some of her work for this Portal Podcast episode. Hi Alice.

[00:00:48] **Alice:** Hello. Hi.

[00:00:50] **Sarah:** Would you mind just giving us a quick introduction about who you are and what you do in the context of this podcast?

[00:00:59] **Alice:** Okay. So, I'm Alice, I'm a writer and author, and mainly I have a special interest in the use of parent carer blame within autism services and SEND provision. And my writing journey kind of started from lived experience as I was navigating my own pathway through SEND services for my children. I'm autistic, mother of neurodivergent children, and basically I've met blame every step of the way of trying to source provision, and that has just developed into a particular passion for social justice for me, and that underpins all my writing, all the study that I do, I'll say research, but in kind of a loose term, it's not technically academic research, but that feeds into some academic work that I do.

The “culture of blame” in SEND services

[00:02:06] **Lesley:** Your lived experience I think is incredibly valuable, and I know through our working together on things that you are currently really exploring that to how do you frame that for social workers?

[00:02:24] **Alice:** Well, blame kind of follows, or has followed me, and I can set this in a wider context later. But it has followed me along my journey of accessing support for my children. So right at the beginning, as I was raising queries with schools about whether my children were autistic, right at that start it was like, "no, they're not, it's because they've got a chaotic home life". They *don't* have a chaotic home life. "It's because you haven't set enough boundaries at home". I *do* set boundaries at home. "They're very well behaved at school". Yes, they are well behaved at school, they're well behaved at home, but that doesn't mean that they're not struggling to access a school environment. So that's one tiny part of it. But then, as their identity wasn't recognised early enough that then moved into difficulty in accessing the school environment, and that causing great distress for both my children. And then that was met with a response of, "oh, well one child is copying the other child". It's like, no, they're not. One child's gotten into school every day, with an extreme amount of distress, but is still in there, still going, it's like, "are you struggling at the transition to get them them into school?" "You're a lone mother, you're a single parent, we'll give you some resources to help around that". And it's like, well that's not the issue either. The issue is what's happening at *school*. So that's one context. And then when you get through all those sections, so when you've gone past assessment and when you've got an EHCP put into place, an Education and Health Care Plan, another aspect of that for me was, with one child, school not supporting that application and me having to do that as a solo parent, meeting resistance from every other professional, and other people within that arena, and fighting that and getting that. But even being successful in having needs identified and provision put into place, when that provision wasn't quite working, because it wasn't quite right, then that being turned around again by professionals and saying that I was obstructing the process, I'm not complying with their interventions and their support. No awareness that it was the *wrong* intervention and it was the wrong support for my child's particular way of being.

So that's just a short journey of the kind of blame I encountered, but that's mirrored up and down the country. So one of the big pieces of work that I did was with another parent, Danielle Jata-Hall, and we did a survey and we received over a thousand responses from parent carers up and down England, Wales and Scotland. And when we were asking about any blame that parent carers received from professionals when they're navigating SEND support for their autistic PDA children. And the responses were phenomenal. But one of the main issues was that the same types of blame, the same narratives, the same phrases were being used up and down the country. So that isn't about individual parenting, that's something deeper that's going on. And I think the level of blame and the type of blame that a lot of parents are receiving is really harming family life. So, you know, perhaps they successfully navigate one area of acquiring support, but then that goes on to become very traumatic later on for them, in terms of the blame that they receive. So a parent carer might, at the beginning of their journey of trying to access support, meet with a professional saying, "well, you're anxious, you're an anxious parent, this is impacting your child's ability to do X, Y or Z". And a parent may be "well, no I'm not an anxious parent", but the *end*, of trying to access support, they've become quite anxious, they've become depressed, or they've become isolated because of the way the system isn't putting the support in early enough, the *right* support in early enough, and it's almost like a cyclical, Catch-22 situation for a lot of parents.

Yeah, so I think a lot of the blame that I received has kind of stemmed from social work intervention, but perhaps their perception of me being informed by other professionals with less specific knowledge. And I think one of the key aims for me is to set it in a wider context, because it's not just happening to me, it's happening to families across the country, across the world, internationally as well. And I'm a bit of a pattern seeker, so to seek those patterns and to speak about those patterns, I think is the first step to change. Because it's so systemic, it's almost like it's a culture of blame that permeates every level. And there's so many functions to blame that I think exist, you know, it's about guarding resources, and it's about perceptions that have just maybe developed through a lack of understanding or a lack of experience based on wider perceptions of neurodivergence. So I try and set my experiences within that realm, looking at disability widely as a social justice issue, rather than an impairment issue. And that underpins all the work that I'm doing. In terms of the work specifically for social work, and social workers, I think I've just been given opportunities by *enlightened* professionals to explore this. So I've kind of grabbed those opportunities, just with the hope that it will make it easier for people accessing services in the future.

Defining PDA: From Pathological Demand Avoidance to Pervasive Drive for Autonomy

[00:09:39] **Sarah:** Thank you for that, and there's a lot to unpick with that. I've got a couple of follow-up questions, if that's all right. PDA was mentioned in another podcast, so I think I know what it means, but just for the benefit of our listeners, could you tell us what PDA is and how it fits into this conversation?

[00:10:00] **Alice:** So PDA, a lot of professionals use the Pathological Demand Avoidance terminology to describe it, and other people prefer Pervasive Drive for Autonomy. There's a debate.

[00:10:17] **Sarah:** That sounds a bit more positive.

[00:10:19] **Alice:** Yeah, it is more positive. There's a debate around whether, as a profile, as a distinct profile, as to whether it fits within the autism spectrum or whether it's a co-occurring condition, or whether it's a complete discrete condition. And research at the moment points to that it's within the profile of autism, and the characteristics are quite broad. So, you know, a PDAer may experience quite a lot of distress at being told what to do. They have a drive for autonomy, wanting to stay in control of their own lives and their own world. It's difficult to explain, I think, does that cover it enough? It's such a broad area and I don't like using clinical terminology to describe ways of being really. And I don't identify myself as a PDAer, so I don't feel like I have the authority to say exactly what the profile contains.

When support goes wrong: Generic vs individualised approaches

[00:11:46] **Sarah:** Yeah, that's fine. It's helpful just to have the abbreviation spelled out for us so our listeners can get a better idea, yeah, so thank you, that's great. And I wanted to ask based on what you were saying, because you were talking about how there's a lot of challenges in getting support for your children, and lots of parents are facing the same issue, and that then once you get that support it's not always the right support, but then you get blamed when it's not working the way that they think it should be working. As a parent you're blamed. And I'm just wondering, is the kind of support that's being put in place, how is that support plan developed? Is it quite generic, is that the issue? Or is it that they're not talking to you and your children, or other parents and their children, to understand what's happening, what's going on with those support arrangements? What's going wrong here? Because social workers are trained to work with the families to understand what's happening for them and what they need, but in this scenario it sounds like actually maybe that isn't happening, or something's going wrong so the support that's being put in place isn't appropriate or helpful for the family.

[00:13:07] **Alice:** So I'll try and narrow my response to social care, but it is broader than that, because obviously social care and social workers are informed by Education and Health Care Plans and potentially CAMHS, who are seen as *de facto* experts on autism even though it's a mental health service. So for us, even though there can be disability specific social workers, I think perhaps there is a view of autism generally, or neurodivergence generally, as being an impairment or a difference that needs to be "fixed", and that often the targeted interventions are about bringing an autistic or PDA child "up to" a non-autistic child's way of being. So almost like assessing it against a non-autistic benchmark. So for us, our goal was to get my child back into school regardless of the fact that a school environment was perhaps, well arguably *was not* the right environment for my child to learn in. So I think that's one aspect of it. I think also generic strategies are being applied, and I talk about this a little bit in a chapter I've written for Lesley's forthcoming book about neuro-inclusive social work, I think there's a tendency for professionals in general to look to a child's interests, an autistic child's interests and say, "oh, we'll use this to encourage engagement", and miss some of the nuances around that. So using my family's experience around interests in animals and, and dogs and things, we were given a wonderful intervention of a handler coming with a therapy dog once a week. But the *human* part of that was almost ignored. The fact that the human was difficult to engage with, for us, that was a stranger coming into our home, needing verbal communication, and missed the fact that the things that might have worked around "animal therapy", and I'm putting that in air quotes, may have just been the sensory issues, or the fact that with animals there's no demand to communicate with them on a verbal level. There's the play element, there's the element of being outside with an animal, an animal sitting on your lap, providing all those things. So it was kind of partially useful, but ultimately *not* useful because it didn't really tap into where the anxiety or the fear was. So it became a useless exercise. Does that make any sense?

[00:17:09] **Lesley:** Yeah, I completely get that, it makes complete sense. When I've read your work, Alice, I think for me what it really does highlight is that there's this, "oh yeah, let's use animal therapy, and let's send that in, that sounds great". Because I could give examples as well of that being used, but without understanding is that relevant? Just because that that young person likes animals doesn't mean that that's right for them, because it has to be very specific for that young person to be comfortable enough to engage.

Engaging with services as an autistic mother

[00:17:42] **Lesley:** And what they then don't understand is, and I I'm saying this from reading your work as well, Alice, is that extended sensory element of it. So they're never done in isolation, they're done in social environments, so any social environment is going to bring complication for an autistic person. And there's that lack of understanding that just because something's helpful in one context, it doesn't automatically mean it's helpful in another. And for me, Alice's work as well is about, what does autistic motherhood and mothering look like? What does autistic parenting look like? And that understanding is not there in social work. And so therefore they're not understanding the damage that they're then doing to people like Alice, like myself, to a lesser degree. But that element, and I think that's really powerful, that's coming through in what you are doing, Alice. Because then with that you are then being seen as being "difficult" and trying to "control" things, rather than the fact that just you understand your child better than they do. And you've encountered that going very badly, haven't you? Really difficult.

[00:19:02] **Alice:** Yeah. Yeah, so at one juncture, in terms of accessing support, you know, I self-identified as autistic for a long time prior to this, but meetings were becoming just impossible for me to access, as an autistic person. Just the duration of them, they were becoming exceptionally long, I wasn't able to focus, the pace of the verbal instructions and information that was being delivered, I couldn't keep up. And some of this was just like cumulative exhaustion, interacting with SEND services over, I think at this stage we're talking about seven years of trying to achieve something good. And that was wrongly identified as a mental health issue, because I was looking like I was dissociating from the room, when in fact I was just struggling to process all the information in a room that was just like, you know, next to a busy road, there was electricity buzzing, there were like five different faces and I'm trying to read facial expressions and understand what the implications were. And then something that I found really difficult was the way that information was presented to me, it wasn't given in a direct way, it was almost implied. So an example being like, professionals were having conversations around me about support groups or something they thought I could access, but I didn't pick up at the time, I didn't pick up that that's what they were doing, they were trying to informally introduce me to the idea. And it wasn't until I'd got my notes back, put in a subject access request, that I saw that I'd been labelled as "obstructive", and that I was difficult to work with, and I was refusing support, but I didn't know that that support had even been offered because it had been offered in such a roundabout way. And these labels, they stick with you. So I think the point I was trying to make was that I took the step to disclose, I got an official identification, an official clinical report about being autistic, and I used a bonafide advocacy agency, an autistic specialist, to come to meetings with me and request reasonable adjustments. And from that point in social care investigation became around how I parented and whether "my autism", and I'm putting this in air quotes again, whether "my autism" impacted my ability to parent, and so parenting capacity. And I mean just... I'm still shocked by that because... I think there's so many different things being conflated there, and it just shows how views around autism in general just haven't really shifted over decades really. We think we're modern and progressive, but then there's some very archaic views that spill over. And from that point in life just became very, very difficult. My son's, I don't want to say inability, sorry I'm just pausing to search for the right word. The narrative around accessing school became focused around how I was influencing that, rather than what was needed for my son to access learning generally. Which then placed barriers on being able to access the right support for my son, which was ultimately education at home. And so that took two years to sort that issue out, which is a whole level of stress, and trauma, for a family to go through.

The impact of bias and a path to positive change

[00:23:47] **Sarah:** That's huge, to feel like you've then been put under the microscope, and you're being blamed for what's happening. And it sounds like that shift happened when you disclosed that you were autistic. Have I understood that right? That then suddenly the shift was on your parenting and how you were parenting?

[00:24:06] **Alice:** Yeah. I think the shift had begun just slightly prior to that in terms that they were flagging my way of being as perhaps like a mental health concern. And I did have concerns that they were going to progress down that route. So I thought that declaring an autistic identity would offer some level of protection under the Equality Act for one. But it didn't, it just spiralled down another pathway. And I was really quite shocked at that, because it did distract from what needed to happen for a long period of time. I can talk on a more positive note though, and I do talk about this, it's written into quite a few chapters and articles that I've written, the *positive* spin of this is that how we came out the other side was that there were really good, informed professionals within that, and ultimately my case was transferred to another social worker, who had some more experience, and they brought in a lived experienced person who worked in capacity between parenting and accessing provision. And when that person with lived experience came into our little team, their knowledge was taken on board, and used really well to help us all move forwards. So there is positives there in terms of, you know, I always call it "autistic competency", really. It's not just about textbook learning, it's about learning and living, and believing and listening to the people who are autistic, who are neurodivergent.

[00:26:30] **Sarah:** Yeah. Because that begs, I mean it's great that that happened and that was a more positive experience, but it does beg the question about why *your* knowledge and *your* experience wasn't valid enough to be listened to. And I'm just wondering within what you're describing, you've given a really positive example, but were there any other examples where you felt like instead of being under the microscope and being blamed, that people were actually looking for strengths in your family and what could be built on rather than looking at, "oh, here's what you do wrong, you're obstructive", you know, those other negative experiences that you've described.

[00:27:08] **Alice:** Yeah. What was really interesting, I mean every authority has a different way of logging the information, doesn't it? So the minutes from a meeting, in that format that was given to me, there was a section that was a strength-based section, and in that strength-based section it was clearly identified that I had a good level of "autism knowledge", quotes again, and they drew that from some of the qualifications that I have, you know, paper certification. But yet in the professional-only notes it was almost an opposite belief that the professionals were working from, around me being, yeah, just obstructive and difficult to work with. So the two weren't tallying together. They weren't perhaps thinking about how the environments, or *their* way of communication, was impacting how I was able to communicate, and kind of that cross-transference of information was just not happening.

But within a much wider context I've had almost two parallel and different journeys through navigating services for my children. So my eldest, who's now at university, I didn't really experience blame in the same way at all. And that was because really early on, their SENCO was also a parent of an autistic person. And immediately, there was one occasion where I went into a meeting and the SENCO had said, "right, we're, we're just gonna listen to mum, we're gonna listen to what mum has to say, and we're gonna do what mum says". And from that point on, the journey was really quite simple, and all the needs were met, distress was minimised, etc., etc. But putting it back into a larger context, I think the difference is when you are parenting alone, I think that is significant, with how perceptions are formed and how professionals view you. Also at that time I wasn't able to work, I had to be at home for the children because the children weren't able to access school, you know, living in social housing, all those kind of subconscious biases that as professionals, professionals know to reflect on those biases. It's almost like they're so deep down that they still affect how you're perceived, and that affects the pathways that you go down, it affects the outcome. And going back to the study that myself and Danielle did in 2023, that was one of our key findings, a real significant statistic was that in the parents that had been subjected to safeguarding procedures, 76% of those were lone parents or neurodivergent parents. So yeah, I think there's an element of bias that's never been removed from the system.

Navigating a harmful system and the dilemma of “having sight of the child”

[00:31:09] **Sarah:** Yeah, I think there is a lot of misinformation about neurodiversity and some really damaging things floating around as well. You mentioned earlier about this idea of "curing" or "fixing" and I think there is still a lot of discussion, and actually linked to some very abusive practice . In relation to the survey that you did then, it sounds like what you found was the experiences of a lot of parents really echoed your own. Was there anything that you found from that survey that surprised you? Or were you sort of feeling like, no, this is what I already know.

[00:31:49] **Alice:** I think it was shocking. Yeah, the findings from the survey were definitely shocking. They weren't overly surprising. I think what was surprising was the extent to which parents were speaking about their experiences and how, I think the surprising element was relating to how impactful it was on life for them as a family, feeling like they had nowhere to turn and no one to trust. And one of the main themes, that parents were telling us, as people collecting the data, was just like the complete breakdown of trust between themselves and professionals, in particular social care. You know, them turning to home education, or moving countries in one instance, or moving to different parts of the country to get away from blaming narratives and bad practice. Because a lot of parents are speaking about this awful position that they found themselves in, and that they were mandated to perform certain interventions on their children, or be labelled obstructive. But knowing that those interventions, those strategies, would harm their children, would create distress in their children. One of the situations I found myself in, was that social workers wanted sight of my son, which is part of the guidance, part of the needs, that social workers need to see a child. And he complied with that initially, but then became more and more distressed about their appearance into the home. And eventually took himself into different rooms, behind closed doors. And that then became a real point of contention within the meetings, and how to get into the room, how to create that engagement, rather than just take a stand back and let him naturally come. And there was a really definitive moment where I was asked to just open the door, "just open the door and let me go in". And I just said, "no". I said, "no, I'm sorry, I'm not going to do that". And that, as a parent, was a really awful thing. I put the needs of my child first, but I mean, I was really, really, really putting myself at the forefront of blame, and being labeled as horrifically obstructive and abusive for doing that. But, you know, I stand by that decision, because what would've happened would've been an increasing amount of distress.

[00:35:08] **Lesley:** Yeah. They're seeing that as risky behaviour on your part, that's how they're seeing it, rather than seeing it as a parent understanding their child and their child's needs and understanding that that will be incredibly traumatic for their child to experience. And all of the practitioners, because I had similar experiences but with education home workers, all of them are not quite understanding their... I can't think of the right word, but they are causing a lot of the trauma and the pain, and that's really difficult I think, because, they don't intend to, as practitioners, going back to what you were saying earlier, Sarah, about, you know, you kind of think, well surely the social workers are wanting to work with parents and do the right thing. And even if you give them that benefit of the doubt, that yes of course that's where they're coming from, but they're not understanding that by not listening to people like Alice, and people who know their children, that the professional, and that's what I've read in some of your work, Alice, is that bit of the professional coming into the room or coming into the home, all of that, they are actually causing so much stress and not acknowledging that...

[00:36:28] **Sarah:** It's stressful for any family to have that kind of intervention. I mean, this is a really difficult and really troubling issue, isn't it? How this is playing out in practice is not working for anybody, because you are then put in the middle trying to safeguard your child, being blamed for not giving access, the child is stressed because they're still in the house, they know that someone's there, the social worker's panicking because they feel like they need to see the child and they're not able. So are there any solutions through this really difficult situation, do you see any ways of navigating some of this in a way that works better for everybody?

[00:37:13] **Alice:** I think ultimately it stems from provision for disability, or autistic provision, being lumped under safeguarding. And I think it needs separating out, even when you have a team that is disability specific, social workers always have, a safeguarding element. And yeah, I can understand, you know, in rare cases that will be needed, but for the majority of autistic families, that *isn't* what's needed. And it can just escalate a situation really, really quickly. In terms of relationship building, what we found is that the more effort that was put into relationship building, the more that presented as a demand, the more that stress was created in the household. Having to have conversations with strangers, because you can never really build that level of relationship where a professional becomes a friend. It's difficult. And you can be *friendly*, but to break down the professional–non-professional relationship it's impossible, isn't it? Because it's about power. And social workers will always have that power to instigate safeguarding, parents are always gonna feel that, "oh, my child may be removed". And I think perhaps provision for autistic families needs to be taken away from that context, and there needs to be a specific service for delivery of that, led in close consultation with autistic people. I mean, I talked before about cumulative exhaustion, but that's what it is. So personally, for me, I can write really, really well, but my verbal skills decrease the more I use them and the tired-er I become. So, you know, if you're having meetings twice a week, over periods of years, your ability to advocate, your ability to engage, your ability to, you know, *mask*, to a certain extent. So when social workers are coming in, you know, you're putting on your social side, you're offering drinks, you're trying to give them the best that you can give them in terms of your own engagement as a parent. And that's just draining. But for an autistic person, an autistic mother, that aspect takes much longer to recover from than it would a non-autistic person.

And I think this was another element that I was trying to advocate in terms of timescales within social care, is that for autistic people, we don't fit those timescales. So if you're going to prescribe a stepped increase, for example, along exposure to getting back into a school environment, or a stepped increase into engagement with a teacher, which is a really typical way of trying to get a child back into school or to engage with a professional, they eventually break down, because all you're doing is just piling on exhaustion, and piling, and you're not building in the recovery time in between. So, you know, a weekly visit may need to be a monthly visit to allow people to recover from that. And that, for me, advocating that maybe it may look like, "oh, you know, that's just trying to distance people into the house, she doesn't want the scrutiny, she doesn't want the oversight". But it's not. It's so I can engage at the level that you want me to engage, I need more time. And that goes for the mandated times to give assessments. So one of the lines of questioning as an autistic mother I had was, what does being autistic mean for you? How does it impact you on a daily life? And, you know, I would need, I would need three, three or four weeks to process that question, to give it the insight that it requires. But having to come up with an articulate answer to that on the spot was very difficult for me. And that's translated as, "doesn't have the understanding of self", or, "isn't really engaging with the assessment". It's very wide reaching.

[00:42:36] **Lesley:** When you were talking there, Alice, it was making me think of the assessment process and all of that. And I think it's about, obviously there's a bigger issue there about the timescales, but it's about how social workers interpret the information that they're looking for, because it just looks differently, from an autistic perspective, and putting, for want of a better word, "neurotypical" or "neuro-normative" expectations onto an autistic person in particular is going to cause damage. So it's about looking at things with, when they look at things, as much as they shouldn't have been necessarily, and obviously in your case when they're looking at parenting, they're not understanding what parenting looks like in a neurodivergent family. And it's that fundamental thing, because it's almost like it's the interpretation.

Misinterpreting Autistic family life

[00:43:35] **Lesley:** And for me, the professional is in the position to be able to not then put that onto an autistic family, that they could, and *should*, for example, consider things like emotional warmth. How does that look for an autistic family? And a lot of it is about side-by-side and about understanding, it's absolutely not hugs and kisses and eye contact and all of that very generic thing that they look for. It's not that. So I think for me it's onto those individuals who are looking at this to, we need more training of, yes but what *does* it look like? I remember that expression, Alice, when I talk about "what does it look like?" So what am I looking for if I'm trying to interpret what is emotional warmth? They need more information, and they need to be more open to listening to, okay, *this* is what it might look like in a family. And I think actually you've really helpfully done that in the chapter that I've just read, that you've done, reframing that, looking at you as "obstructive", okay, but *this* is actually what I'm doing as an autistic person. It's not obstructive. This is about being autistic.

[00:44:54] **Sarah:** It's about that understanding.

[00:44:56] **Lesley:** Yeah.

[00:44:59] **Alice:** When social workers are going into a home and assessing a home, and I'm not a social worker, so I only understand social work practice from the other side, and read reports, etc., some of the things that immediately spring to mind there would be how just like your home and the layout of your home is, as a neurodivergent person. So you can't really assess it on the same, well, you can't even assess it on "all neurodivergent people have a house that is similar", because everyone's mind is different. But for us, some of the annoyances that cropped up for me were, so they'd often focus on the amount of DVDs that my son has, which is one of his passions in life is films, and to this day he's still really passionate about films, so collects a lot of films. They're out in the living room. So that was associated with "mum not perhaps giving the right level of enrichment to the child", but missing the fact that behind the door are two shelves full of board games. So it's about just asking, you know, "oh, I see you've got a lot of DVDs there. Whose are they?" But being quite specific in your questioning. I think open questions can just, I mean I shut down with a lot of open questions because I don't know what you want from an open question. But given an opportunity to talk about that, you know, "well, my son's really passionate about DVDs". And also being mindful as to what is permitted in an autistic household. So for me, I let my children bounce on the sofa because it gives them lovely, immediate sensory feedback. And I recognise that if there is an unknown person in the house, and they are throwing themselves on the sofa, then that is a way of them regulating themselves, and I am not going to say, "stop doing that". I'm not even going to redirect them into something else unless they're at risk of hurting themselves. And that is another specific that can be interpreted as "not placing so many boundaries, the correct boundaries, etc." And I think those specifics are really good to talk about. And that's, as Lesley said, that's part of what I try and do.

[00:47:47] **Lesley:** I think those examples are helpful. Just those specific ones. It was like things like a misunderstanding of why you have lots of sensory toys. Like sensory play is a massive thing. There isn't a boundary of "okay, you only do that at this point as a child". It's actually that, you know, you do it all the time, and sensory play is a massive element. And something that doesn't look like a toy is actually used for play. There's a lot of misunderstandings, and I think that's why for me, your sharing these is a massive thing, that you're doing that is really important, because I think this is a way, potentially, for practitioners to be able to understand. Because there are some core things in there. It's like, it might not be DVDs, but collecting and lining up, I know lining up is a common perception, but collecting and focusing in on interests. So getting to know the child, but then you don't want them leaping on it and thinking, "ah, well, what we need to do is take them to the cinema" or something. It's like, no, don't go to the cinema, the sensory experience is horrible! It's about understanding, very much, the individual child. And *each* child, because they'll have a different experience, and understanding the family. I think it's just that when you go to a disabilities team, you already know that the disability is there, so I would expect that they would have better understanding. It's not always the case. My concern is that you probably didn't even encounter disability teams necessarily, or other people, unless you've got the diagnosis, you won't encounter them, and you'll encounter the generic social workers. And it concerns me that you've got two things there.

[00:49:33] **Alice:** Just on the point about disability social work teams, we were under a disability social work team.

[00:49:43] **Lesley:** So it wasn't, okay.

[00:49:44] **Alice:** Yeah. So I find it fascinating because I think I've spoken about this in one of my pieces, is that I assumed that that would mean specific knowledge, but it just means generic knowledge. And then perhaps the lens through which disability is viewed, is perhaps the tragedy model? May I go that far? It's to say that that might be an overriding view of some professionals, which makes it quite difficult to access the support that you need. Yeah, but going back, while you were speaking there, I just thought about, when you said not jumping on interests to try and create engagement for children, I think autistic children, and PDA children, can really spot when someone is being genuine, and when they are faking interest in your life. And I think that is a massive turnoff immediately. And I don't understand why a lot of social workers don't quite understand that yet. I think perhaps there's this misnomer that because autism is classed as a social communication disorder, and I, you know, I would challenge some of that, that autistic children can't have their own perceptions of people. And they do. They're there.

[00:51:20] **Lesley:** They do.

[00:51:20] **Alice:** They're clever.

[00:51:22] **Lesley:** They are. I completely agree, Alice, absolutely. They'll spot it a mile off, authenticity, genuineness. It's almost like the mistakes with saying things can be accepted if actually that person presents to you as authentic and genuine and interested rather than, you know, pretending to like computer games or DVDs and things like that.

Proposed changes for a more inclusive system

[00:51:50] **Sarah:** I was just gonna say, from listening to the conversation as well, that that's what's needed here. Because it sounds like a lot of the challenges that are being presented is when that listening and that authentic interest and that professional curiosity hasn't been there to understand what is life like for this family, and what do they need, rather than going in with assumptions and assuming, "oh, well, they're not giving me access to the child, there must be something terribly wrong".

I'm conscious of the time and there's one more question that I'd like to ask Alice, if that's all right. If you could make any change to the lives of neurodivergent people, what would it be and why?

[00:52:39] **Alice:** I think I've talked about this a little bit before, but to separate safeguarding from provision. And I think in terms of autism, and autistic ways of being, I think that convergence between safeguarding and understanding autistic lives is right at the start the of the assessment. Because it's a clinical assessment, and one of the guidelines for assessment is, is exclusion of all other possibilities. So right at the start, professionals are assessing safeguarding risk, and I think that record is kept, and the longevity of records attached to a child about parents, particularly, just stays with that child and is passed around. So an inaccurate observation can stay with someone for a long time without it being challenged. And then that then informs the perception of the next professional picking it up, and the next, and so forth. And it can escalate into a thing. And I think one final thing that I'd really like to see change is just how we perceive autistic families, just generally. And I think it's more useful to think about assessing autistic families through a cultural lens. You know, and viewing autistic ways of being as an identity, and how that translates into how you live your lives, and how that is *unique*. It's not "less than", it's not "concerning", it's a valued way of being. And I think it's almost like having respect for that, that that needs to build into systems.

[00:54:48] **Lesley:** Yeah.

[00:54:48] **Sarah:** That'll be a wonderful change to have, because viewing it in that way would shift that focus entirely from what's "wrong", and that "deficit", to actually understanding different ways of being, as you say. So, yeah. Is there anything else else you'd like to say that you haven't had a chance to yet, Alice, and particularly in relation to any messages for hopefully the hundreds and thousands of social workers that will be listening to the episode?

[00:55:20] **Alice:** I think I've probably said everything, but what I will end on is when we asked the thousands of parents in our survey what changes they would like to see, so I'll hand it back to the voices of the many. Accountability, like an actual, tangible way of ensuring accountability for mistakes made. And that's not to, you know, really put the blame back with professionals, it's to create a pathway of change. And training. Many parents were saying just more education, more training, needs to happen.

[00:56:07] **Lesley:** Yeah.

[00:56:08] **Alice:** But I think we all know that, I don't think that's news.

Conclusion

[00:56:13] **Sarah:** No, that's great though, thank you so much, Alice. We really appreciate you taking the time to come and speak to us, and I've learned so much from listening to you today, so thank you for that.

[00:56:24] **Alice:** Oh, you're welcome. Thank you for having me. It's been lovely to talk to you both.

[00:56:28] **Lesley:** Thank you, Alice.

Outro

[00:56:30] **Sarah:** You have been listening to the Portal Podcast, linking research and practice for social work with me, Dr Sarah Lonbay.

[00:56:37] **Lesley:** And Dr Lesley Deacon. And this was funded by the University of Sunderland, edited by Paperghosts, and our theme music is called, *Together We're Stronger* by All Music Seven.

[00:56:47] **Sarah:** And don't forget that you can find a full transcript of today's podcast and links and extra information in our show notes. So anything you want to follow up from what you've heard today, check out there and you should find some useful extra resources.

See you all next time.

[00:57:02] **Lesley:** Bye.