Series 4 Summary

[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 summary

[00:00:28] **Sarah:** Right. Well, hopefully you've listened to all of our fantastic episodes now with each of our brilliant guests that we've had on for this neurodiversity series, which is, is it series four we're on Lesley?

[00:00:41] **Lesley:** Yeah, it's series four. Yeah.

[00:00:42] **Sarah:** Four series, wow! And as always, Lesley and I have come back together after doing all the recordings to have a general chat about the series and really try to pull out some of the key themes that we've seen and what our guests have talked about, and also to pull out some of the key messages for social work. It doesn't matter if you haven't listened to them yet, you can listen to this episode first and then dip into the other ones, but this is a kind of a summary really of what we've learned on this series.

So I think we mentioned this in the Introduction, but I think one of the really big things that comes out in this is the centrality of lived experience for understanding neurodiversity. And I think most, if not all of our guests talks about their own lived experiences, and the importance of centering autistic and neurodivergent voices within their research, within practice, within service design. And really doing that, which probably links to another theme, to challenge the misrepresentation or misunderstanding of autistic experiences within professional services. So I think that lived experience came across really strongly and the importance of framing that as the central part of research.

Well, for the researchers, for practitioners to think about the person that they're working with, all of it, it just came up again and again, didn't it?

[00:02:08] **Lesley:** Yeah. Because I think that for me with that, it's something I've been grappling with, because I think as I started my research journey, I was very much shown about, oh, you keep the personal and the professional separate, and I think that's a thing in social work, to try and separate those things out. But with neurodiversity, I think there's a really, really significant shift, that rather than the power being given to those that tell you what autism is and decide that that's what it looks like, that there's a real, genuine, authentic repositioning to say actually the person living, so the autistic person who lives with it, has an awful lot to say about that and should really be prioritised in that side. And I think that, for me, I feel like lived experience tends to be tokenistic in a lot of areas. You know, there's a bit of consultation done, people say this is "participatory" when it's not really, it is just a matter of I'm gonna tick a box and get some participation in there. But I think, for neurodiversity, I think that element, because there are so many of us in this area who are autistic ourselves, and therefore because of that, what we say about it or can share about it becomes really, really significant. And it's not lost on me that for many of us, we're in a position to be able to do that, not everybody is. But I think somebody asked me once about whether or not they should share about their diagnosis, and it's entirely an individual decision, but for me, I felt that I was in a position to share, and I was able to, potentially able to share it in a way where people might listen and might hear. So I think that that's been a really important part, and it means it's really messy, Sarah. That's my thing for this, is that now the personal and the professional is all mixed. And it's a little bit uncomfortable, I think, for some people, but I think that we need to just go with that, because the genuine and authentic lived experience is central. So that's what I am really keen about neurodiversity, because of the way that it positions the individual and that lived experience and what it's like to live that life. And valuing that. So yeah, that's come across massively. I think the challenge to the deficit, I was thinking just before about your experiences, because obviously you had your training, and I think you mentioned that in some of the episodes about your background and how autism was taught to you. And it's still being taught like that, that's the thing. It's still being taught as a deficit, as, you know, a neurodevelopmental and sort of pathologising it, in a negative way, from this deficit approach. And I would like to think, with this series, that social workers and those who offer training are listening, to be able to maybe access this material as a way to train in this area, rather than those older models that are outdated, and not helpful.

[00:05:28] **Sarah:** Yeah, and I think that's what our guests do really well within their research that they spoke to us about in this series, like really contesting those harmful stereotypes and moving away from that medicalised definition of autism towards this more affirming view. Because they talked, I can't remember which guest it was who spoke about being told, well, actually if you're autistic you lack empathy, so therefore you're not going to be a good social worker. So I think what comes across within all of the conversations is challenging some of those stereotypes, and actually showing a more positive view and the strengths, and as you say, moving away from that kind of pathologising view.

[00:06:10] **Lesley:** I think that was Jenni who did that. I think Jenni's research into the social worker and the social work experience, I think. And I remember seeing that coming up for students who then got Autism diagnoses. And then the question is, can you therefore be a social worker? And you absolutely can, because there's many of us that *are* social workers who didn't know that we were autistic.

[00:06:31] **Sarah:** Was it Jenni that shared the example of a social worker disclosing that she was autistic and then being asked if she'd done a risk assessment or something.

[00:06:41] **Lesley:** Yeah, yeah. There's really concerning things happening, I think just people don't quite know what to do. And I suppose that connects as well with Autism is a massive part of the neurodiversity movement, because this is where it emerges from, from the autistic experience, and now it's expanding wider to include, some people do and some people don't include *all* neurodivergence, both "natural", as in born with, or "acquired". So there's still steps, I think, for us to go to expand the definition further. I think that's what we're trying to do in this book as well. I'm gonna just like, it's like an advert for the book. We've got a book coming out!

[00:07:25] **Sarah:** I think some of our guests have contributed to the book, haven't they?

Lesley: They have.

Sarah: So then definitely, if people enjoy listening to them speak then they might want to explore the book as well.

[00:07:34] **Lesley:** Absolutely, yeah. And I think you mentioned about, because Sarah's done some helpful notes for us today, and one of the words that pops up is trauma. And it absolutely does. But I think for me, what I wanted to emphasise is within this framework, is that it's the trauma that comes afterwards, from this perspective, that you'll see trauma responses in people. Because of course, if you're living a life where you don't feel you fit or you are constantly told your way of thinking's wrong, your way of acting's wrong, and people don't, you know, you feel very, very misunderstood, then this has an impact. Because it's every day these sort of, you know, microaggressions is what neurodivergent people can experience all the time. And of course that's going to then lead to potential trauma. The thing for me about my experience was treating the trauma doesn't get to the actual issue, which is your brain works differently, and your whole body works differently, and that's not something you can change. So if we think about neurodiversity first, it acknowledges that everybody has a different way of living in the world. And so we need to think about it differently to try and prevent the trauma occurring. Because the brains are different, and why is that a problem? Difference shouldn't always be terrifying to people.

[00:09:02] **Sarah:** Yeah. I think that definitely came up so strongly in all the conversations, and links back to what we were just saying about pathologising. So instead of pathologising, actually affirming and acknowledging that there's just human variation. And if there are differences, then we need to *understand* those differences. So I know Hanna, I think a few used the metaphor of different languages, but Hanna in particular talked about that need for translators, as if one person is speaking one language and one another, and they're not understanding, nobody's wrong in that situation, you're speaking the language that you know, but we need to learn to each other's languages or use translators to help us understand each other. And it goes back to that importance of individualised care and support. So who is the person in front of me and what do they need?

[00:09:48] **Lesley:** Yeah, because that person-centred element has been a rhetoric that's been around for a really long time, but what concerns me is it's not really understood as a core concept, that is see the person in front of you rather than what, you know, people are jumping too far ahead. For me, we need to have more time to focus. Yeah. I feel like time, time comes across in all of our series. We need more time!

[00:10:18] **Sarah:** Yeah, if people are given more processing time.

[00:10:20] **Lesley:** Yeah.

[00:10:21] **Sarah:** Yeah. And for people not to equate that disengagement or that need for time, not to label it as disengagement or "resistance to services", but actually someone just needs a bit of extra time to process, to think about, to respond. So, yeah.

[00:10:36] **Lesley:** Yeah, yeah. And just across the board to give social workers, you know, the services across the board, they're so tightly packed at the minute because of the lack of investment and the lack of support, and it's becoming quite dangerous because I think linking back to that potential for trauma is so significant if you've got these systems that are just getting harder and harder for people who are different to engage in. And, you know, I see it as based on whether or not some people may very well have the capacity to manage that or the flexibility to manage that, but many, many, many more people do not. And we're really hurting people, and I don't think anybody intends that, that work in these services, but we do need to think about something, and I think that individual focus means that you *can* make a difference for that person in front of you. I think we talked about some simple things like just actually doing what you say you're going to do can be massive. You know, if you say you're going to get back in touch with someone, then do it. Even if you don't have the answer, just say, "look, I'm conscious that I haven't got this sorted yet, but I'm still working on it". Then people know.

[00:11:51] **Sarah:** And lots of things like that come up, not just in the neurodiversity research, but that comes up really strongly in the safeguarding research that I do, that people get told someone will get back to you, nobody does. It's a simple thing, but it means so much, and it just helps people have that clarity about what's happening.

[00:12:10] **Lesley:** Absolutely.

[00:12:12] **Sarah:** What other key messages do we have for social workers, Lesley, off the back of this series then?

[00:12:16] **Lesley:** So I think that I've pulled out from stuff that you've identified from it and from what's coming out, that trust-building thing, I think that's something, when social workers are working with people, the people they're working with are at a vulnerable point because they're accessing that service whether they want to access it or not. And being able to understand

the relationship aspect of that, so seeing that individual as a human being, a person in front of them who is not always going to act in the way that you expect them to act, because they're under stress already. So that goes across everybody, because you're putting people into a stressful situation. Social workers don't... I don't know how much we fully understand the impact that we have, like just us being there. And to think about how can I then build a, it doesn't mean you're going to become friends, but how do you build trust with somebody? And that connects then back to that, you know, do what you say you're gonna do, see the person in front of you. And to value that person, I think. Value the difference, and be open and curious *about* the difference, rather than scared that this is risky. You know, people are different, and I think it's quite interesting because the more I'm in in this world, the more I see, you *see* people. And I had a conversation with someone the other day about "I do see you". I think Hanna used the term "community assessment", which I loved. So rather than from a social work perspective, it's the idea of people within that community can see members of the community. Because you see the little bits and pieces that other people don't see. So that curiosity for social workers to see them, and those that are neurodivergent to utilise their knowledge that they're developing, to be able to see more and advocate more. So I think, for me, those were the key messages. I don't know if you've got different ones that you felt.

[00:14:16] **Sarah:** No, I think that's a really good summary of them. I mean, yeah, challenging that bias and discrimination. There was a point about separating support from safeguarding, particularly with the researchers that spoke about child protection and parent carer blame, you know, that the safeguarding-led approach can kind of escalate that distress and trauma, and actually, like you say, seeing that person, seeing what's happening and understanding that, rather than going in with a risk focus.

[00:14:49] **Lesley:** Yeah, because that risk bit is where the problem is, I think. That without the understanding, and especially autism is being perceived as a risk, and it doesn't need to be. And it isn't. It's just different, it just looks different. But of course, in the UK especially, we're starting to use terms like neuro-normative for the assessment process, that it's seen as this is what "normal" looks like. I used air quotes, and we're not on, we're not on video, are we? We're doing little air quotes. What normal is, and people assessing to that is problematic. So then if you go in with that risk lens, you escalate very quickly and don't then give the opportunity to understand what does the family look like in that environment, or what does somebody's life choices mean, for

adults with autism they're going to look different. They're going to look different for an ADHDer as well. They're going to look different. So the open curiosity is needed to prevent that escalation and going straight into safeguarding and risk.

[00:15:56] **Sarah:** Yeah. So I think it comes back, you know, there's lots of of messages within that, but the main one is just learn, be *open*, be *curious*, get to know the person. And I think within that as well, because your natural point when you're thinking build trust, get to know the person, might be spending longer there or visit more frequently, but that also was pushed back as actually that can be very stressful, that's not necessarily what we mean. But it is about understanding that, understanding how that person needs you to work with them, I think. And then all the rest of it will hopefully fall into place if you start with that, rather than starting with, they've got to fit in with my processes and my systems and my way of working.

[00:16:39] **Lesley:** Yeah. Yeah, absolutely. It's the individual, let's see the individual, let's see them, and be interested in them.

[00:16:47] **Sarah:** Yeah. I think that's a good message to finish on.

[00:16:51] **Lesley:** It's like a little drop mic moment. I've got a bit of blu-tak, I'll drop the blu-tak.

[00:16:57] **Sarah:** Just drop the blu-tak, and then walk off.

[00:16:59] **Lesley:** Because I am stimming and fidgeting while this is being recorded.

[00:17:06] **Sarah:** Well, I hope everyone's enjoyed this series. I hope this summary episode helps you to think about what some of the key messages are that you'll pick up in the individual conversations as well. And as always, just get in touch, let us know what you think. We love feedback, we love ideas. We haven't decided what our next series will focus on yet, so we are very open to people coming to us and saying, can you do a series on whatever you would like to learn about?

[00:17:33] **Lesley:** Yeah, I think we're gonna do some mini ones, we're gonna do some short ones. That's what we're doing in the next series, but we don't know what on yet.

[00:17:39] **Sarah:** Yes that's true, there are mini podcasts.

[00:17:41] **Lesley:** These are all very long. Mini, we're doing mini.

[00:17:43] **Sarah:** Yeah. And there won't be a theme across from them then, will there? They'll be short soundbites on different topics. Is that what we're thinking?

[00:17:50] **Lesley:** That's what we're wondering. So if we get some feedback, that might be quite helpful. So maybe we'll put ourselves out there to get input from, you know, ideas and thoughts from social work, and from social workers, to see what would be helpful. Because it might be that there's things we've done that would be helpful for us to summarise or, or... we don't know.

[00:18:12] **Sarah:** Definitely, we could get previous guests back in to say what they've done since, or anything, you know, let us know. We're open.

[00:18:20] **Lesley:** Or maybe there's an area that we haven't looked at yet that we should be looking at. And we're definitely up for listening to that. Yay.

[00:18:28] **Sarah:** Brilliant. Alright.

[00:18:29] **Lesley:** Excellent. That's, that's it. That's that series done. Thank you everybody for listening.

[00:18:36] **Sarah:** Yes. Hope you enjoy it.

Outro

[00:18:38] **Sarah:** You have been listening to the Portal Podcast, linking research and practice for social work with me, Dr Sarah Lonbay.

[00:18:44] **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.

[00:18:54] **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.

Bye.