

Series 4 Episode 4

Co-designing social work training for working with older Autistic adults: A Conversation with Laura Lennuyeux-Comnene and Rebecca Charlton



[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 the guests and the COAST project

[00:00:25] **Sarah:** Hi everyone and welcome to the Portal Podcast, linking research and practice for social work. I'm Sarah and I'm here as always with Lesley.

[00:00:33] **Lesley:** Hello.

[00:00:34] **Sarah:** And today we're very lucky to be joined by Laura and Rebecca. And if I can ask you both to introduce yourselves and say a little bit about who you are and where you've come from, that'd be great. Laura, do you want to start?

[00:00:48] **Laura:** Sure. Okay, so my name is Dr Laura Lennuyeux-Comnene. I work as a postdoctoral research assistant at Goldsmiths University on the COAST Project, so that's Co-designing Autism Social work Training, and yeah, we're here to talk about that amongst other things.

[00:01:11] **Sarah:** Brilliant, thanks Laura. And Rebecca?

[00:01:14] **Rebecca:** So I'm Rebecca Charlton, I'm a professor of psychology at Goldsmiths University of London, and my work is generally looking at the experiences of people as they get older. And more recently we've been doing a

lot of work understanding the middle aged and older age experiences of autistic people.

The researchers' journey to the topic

[00:01:32] **Sarah:** Brilliant. Well, thank you both very much for introducing yourselves, and for giving up the time to come and speak to us today about your work. We really appreciate it. We'd like to know, before we dive into the details of the research and what you've been doing, we are always really interested to know what brought you to the topic and what your background is and how you came to be researching in this area.

[00:01:55] **Rebecca:** So as I said, my background's really in ageing research, so I did my PhD in cognitive and brain changes that happen in older people, and then went on to do some work with older people with late life depression. And really this working with older autistic people came about just through a conversation with a colleague who does a lot of work with autistic people. And I said, "what happens when autistic people get older?" About sort of 12, 15 years ago. And she said, "we just don't know". And so that's just really sort of started a whole branch of interest for me about how we know so little about the experiences of autistic people, but other people who have neurodivergent conditions that we just don't know what happens as they get older. And so I think these are really important questions, that we understand everybody's experience of ageing.

[00:02:45] **Sarah:** Yeah, absolutely. Thank you for that. And Laura, how about you? How did you come to be working in this area?

[00:02:51] **Laura:** Well my journey is probably a bit more circuitous. So I started back in 2000, 2001, I was a volunteer with my local National Autistic Society branch, and I worked mostly with parents, and we did events together and all that kind of stuff. And I thought, okay, actually I wouldn't mind going back to studying and finding out a bit more about this. So I went back and did a post-grad in psychology, and then I thought, well, I really like this research business, so I went and did a bit of internship and research assistant work in lots of different labs that were working with autistic people. Actually, funnily enough, I started with babies, and then the next job was with children, and then the next job was with adults, and now it is with older people. So it's sort of, it's kind of...

[00:03:40] **Sarah:** Worked your way through the life course!

[00:03:41] **Laura:** As I've got older, so have some of the people I work with, which I think is quite funny. So I did a PhD in psychology, and my focus was on anxiety in autistic people. So you will notice that mostly I'm talking about autism. And then as I went along this concept of neurodiversity became more and more part of my vernacular, in a way, and I started becoming more aware of this, particularly because autistic people that I came across with children and adults alike tended to have co-occurring conditions. And it was more about thinking about the whole person and actually how do these things come together. And then, once I'd finished my PhD, this opportunity came along and I was really happy about that, because I thought, great, I'm gonna do something applied, something that'll have a really positive impact in autistic people's lives. And I've been working for almost two years on this project, and obviously I love it, so it's been a really, really positive experience, and I hope it will have really positive impact on autistic people's lives too.

Co-designing training for social workers

[00:04:49] **Sarah:** Yeah, thank you, that leads us nicely into the next question, could you tell us what is the research about and what are you aiming to do?

[00:04:58] **Rebecca:** So the project is working with autistic older people and social workers to co-design training for social workers to work with autistic older people. So this came about from some work that was done by another co-PI on the study, Mary Stewart, who's at Heriot-Watt University, and her initial work, in the initial findings, looking at what older autistic people were concerned about, what was needed and where there were gaps, and then she and I and a group of other academics worked together to do a little bit more work of looking at where the biggest needs were. And that work really showed that not only do older autistic people think that training's needed, so do social workers. So there's this real sort of coming together of different groups of people acknowledging the fact that this is a gap, and that social workers really felt like they needed more support to understand and better work and better support older autistic people in their jobs. And so really that's where the project came from. And the project we're working on now is funded by the National Institute of Health and Social Care Research, and we have been working for, as Laura said, nearly two years now, sort of really *co-creating* this work, so working with autistic older people, social workers and social care providers who act as co-researchers on the project. So they have been involved

in really refining the questions, setting the criteria, deciding what the training's going to look like, and really being part of the team who designs the training. So we've done all of that, and we've designed all of our training, including some podcasts, and we are now at the stage where we are evaluating that training. So we're asking social workers and social work trainees to complete the training, and then we'll do a proper evaluation so that we can show that it's having an effect. because obviously we don't want to roll this out if it isn't quite there yet, or if there are things that still need adjusting. And as part of the evaluation, older autistic people will be evaluating the social workers to see what *they* do to make sure that this is really having an impact on the lives of older autistic people.

Understanding older autistic adults and late diagnosis

[00:07:13] **Sarah:** Brilliant. Well, I can't wait to get into it and hear more about what that training involves, but I'm quite interested, before we do that, to unpick a little bit with you, who are older autistic adults? I guess in terms of what age range are you looking at and thinking of as being older? But also, my understanding is there's been a growth in people coming to the realisation later in life that they are autistic. And obviously lots of people know that from a young age as well, so with the people that you're working with, what's their kind of journey to understanding that for themselves? And what kind of age are we looking at?

[00:07:58] **Laura:** So the first thing I think that I can answer is where you asked us about the ages of the older autistic people. So I think there are lots of different definitions of what "older" means, particularly in social care "older" can usually mean something around 65 plus, and somewhere else it can mean something different. When you turn 50, you start getting all the Saga advertisements, so maybe you do become part of that older generation. But I think there's some research that shows that some things happen earlier with autistic people, and also we wanted to kind of consider that *journey into* older age. So rather than sort of, "okay, now that you're already older...", it's like, "what does it feel like to *become* older, and what support do you get along the way?" So that's why we went for "older" meaning 50 plus, in fact. So when we did a call out for older autistic people to join us, we asked for people who were over the age of 50, and the age ranges of our community researchers, they start at around, I think the youngest is 53, and then the oldest is I think now about 73. So it's around that sort of age. And we wanted to make sure that we reached as many people as possible, that was one of the challenges, that it's

actually quite difficult to find the right people, because one of the reasons why they might be difficult to reach is because they're difficult to reach! So it's equally difficult for us to encourage people to get on board. But we've done reasonably well, we wanted to make sure that we went across the breadth of the country as well, because otherwise there was a danger that we're going to be quite London-centric, and clearly those are going to be different experiences to somebody who lives in a different part of the country or in a very rural area, they'll have different experiences. And then we wanted to make sure we had a mix of genders as well, to make sure that we captured those experiences. So that's our cohorts, and then I think we have two different kind of community research involvement. One of them is really a group who helps us to steer the project in the right direction, and who oversees a project really. And then the other group, where we talk about subjective experiences and subjective ideas about that training and how that might be beneficial. So that was one question, and then you asked me something else, and I've already forgotten you see, because I got so kind of "we're here".

[00:10:38] **Sarah:** It was about your participants, in terms of being autistic, whether you're tending to see with older adults that they have realised that later in life or whether...

[00:10:49] **Laura:** Oh yes. So I would say yes, *all* of our participants realised later in life that they were autistic, that they got a later life diagnosis. So again, the "later" is a little bit fluid, obviously if somebody who's in their fifties, they're gonna have it, sometimes it was literally a year or two before they became involved with the project, somewhere in their mid-forties, perhaps. One of ours, he got his diagnosis I think when he was about 70, so quite late again. There are different reasons why that happened. The autistic participants who were female at birth, they may have thought about it because of their children, when their children became diagnosed, they started thinking about it. But the other experience was that they may have had mental health difficulties, and they will have gone that way in seeking support, and then their therapist or their GP even might have suggested, actually maybe there's something else going on as well. So they may initially have had another diagnosis, and then came to the realisation that something else was happening. And that was for both men and women, actually.

The lost generation: Diagnosis rates and family connections

[00:12:03] **Rebecca:** Yeah, I think it's worth saying that in some ways our group of people who are taking part in this research are a little bit unusual in that they have a diagnosis. And we know that actually once you get over 50, about 90% of autistic people *don't* have a diagnosis.

[00:12:19] **Lesley:** Yeah.

[00:12:19] **Rebecca:** So we are really scratching the surface here with the experiences of older autistic people. But for this project, actually everybody who's taking part as co-researchers *does* have an autism diagnosis. But we know that that's unusual.

[00:12:36] **Lesley:** Yeah, because with the family connection side of things, is there something you can say for our listeners, Rebecca, a bit about the genetic sides with autism?

[00:12:45] **Rebecca:** Yes, I could. And that's often, sometimes when *older* people go for a diagnosis, it's often their grandchildren, not their children, that sort of triggers people looking for a diagnosis. So we know that there is a strong genetic component, so autism and other neurodivergent conditions too. So you often see that autism or ADHD is common in families, it's a very complex relationship, and genetics isn't my area, but there are lots of different things which interact both in terms of genetics, but also in terms of other environmental factors which may have an input too. So we know that autism runs in families, we tend to see autistic parents of autistic children, so somebody may be autistic themselves and have autistic family members, both older and younger. And I think that's important to remember too, that you may have people who are in middle age who are, or even older, who are looking after autistic parents who don't have a diagnosis and autistic children who do, so. Although of course, everybody in the family isn't going to have a diagnosis or isn't going to be autistic, but there do tend to be strong genetic components of autism.

[00:14:07] **Sarah:** I was just going to ask about what you said about, I think you said 90% of older adults may be autistic but not have a diagnosis, and I was just wondering about that. Is that people who are aware but have decided not to go through a formal assessment? Or is it people who may not be aware about neurodiversity and therefore not be thinking about that for themselves? What's happening with that? Because that's quite a high figure, isn't it?

[00:14:35] **Rebecca:** So that comes from a paper that was published just last year, with Liz O'Nions as the first author, and what that study did was, it took GP health records from about 10,000 people, so representing quite a large proportion of health records in the UK, and estimated that if we take a fairly conservative estimate, that 1% of the population is autistic, and we look at how many people have a diagnosis across a whole bunch of different GP records, and look at it by age bands, what does that look like? So do we see similarities in the rates of diagnoses in what we expect to see and what we actually see? And so looking at that data, what they showed was that in young children and into sort of young adulthood, the rates are more or less where you'd expect them to be. But once you get into middle age and older, then we're not seeing very high rates of diagnosis. And that's not really surprising, if we think about it, because if we think about when autism became a unique criteria in the diagnostic manuals that psychiatrists used largely for diagnoses, that was 1980, DSM-III, when autism was first uniquely identified. And so according to those criteria, somebody who was diagnosed as a child under those criteria in the 1980s will only now really be in their late forties. So it's not really a surprise that we don't know very much about middle aged and older people, and it's not really a surprise that those diagnostic rates are low. But the impact of that is that we don't really understand life course effects for these people, and what it's like to *not* have a diagnosis and go through your whole life often struggling and having lots of barriers in your way. So that may have knock-on effects into later life, which I think is really important to understand.

[00:16:27] **Sarah:** Yeah, that's really interesting. I do some work with older people, that's what my research focuses on, and it's not about neurodiversity, but I did meet one of my participants recently, he told me, he's in his seventies and he'd recently, been diagnosed and been through an assessment and realised that he was autistic and he was doing quite a lot of reflection on his life through the lens of this new information that he had about himself. And so that's quite huge, isn't it, for someone who's lived their whole life not knowing something really important about themselves.

The impact of late diagnosis and challenges in social work

[00:17:03] **Rebecca:** Yeah, and that's something that we hear people say quite often actually, that receiving a diagnosis in later life just allows people to look back on things through a completely different lens and to sort of really understand how they've reacted in certain situations, how other people have reacted in certain situations, and to sort of have a much more complex

reflection. And sometimes that can be really positive, because people can really forgive themselves for things that have gone wrong, which really were not in any way their fault. But it can also raise a lot of issues around people feeling like there are missed opportunities, and so it can be a bit challenging in those ways too.

[00:17:41] **Lesley:** Yeah, I feel like you're talking about my life as well. Because I'm one of those late-diagnosed people, so I completely connect. I'm just curious about social work, and what could be seen as "best practice" in this area. Were there experiences before this that were brought to light that were concerning? Or has it come very much just from, "we don't know what's going on, we need to find out".

[00:18:12] **Rebecca:** I mean, I think that it's a little bit of both. When we start talking to people, there are definitely examples of things not quite working. And I think one of the challenges is that, I mean you'll know, you'll know better than me, that sometimes social work teams can be slightly siloed, right? So you have an older age team who know a lot about older age and frailty and maybe dementia. You have an autism team who are often dealing with children and families, and maybe *aren't* looking at older age very much. But getting teams to talk to each other and to share their expertise and experience is really what we need to be doing, because most people feel like they're having a bit of a gap. So even people who work a lot with autistic people may not have worked that much with older people. People who work with older people often have had very little experience with people who are neurodivergent or who are autistic. And so it's really about bringing together that knowledge that's there and making sure that people are able to share it so that you can deliver a "best practice" approach.

Key findings: Collaboration and reframing skills

[00:19:20] **Sarah:** Thank you. And what are the important things that have emerged from the work that you've been doing?

[00:19:26] **Rebecca:** I think one of the most important things that I thought we would struggle with doing this research project and bringing people together to co-design training was that there may be really big disagreements between what autistic people thought was important and what social workers thought was important. And we have had surprisingly few of those challenging conversations, because everybody understands the limitations of the systems

people are working in. And so it really was very positive about coming together to find a way forward and to find a solution that was going to work in practice. There's no point designing a whole bunch of training if it's going to be really expensive, it's going to take two weeks and no one's ever going to ever do it, and it's going to sit in a cupboard somewhere. It has to be something that can fit into social workers' lives, and then have a really sort of positive experience. But also a lot of the time, when we're sort of slightly reinventing, we're not trying to reinvent the wheel here. Social workers have a lot of these skills already, and they know what they should be doing. I think it's just about framing it in a way that helps them sort of *remember* to do them in that situation, in that moment, because social workers are highly skilled professionals. So it's not that we want to retrain them, it's just about slightly reframing and a little bit of giving people tools to enable them to enact those things that they will be doing anyway in best practice, when they're not under pressure. So it's just about support really, more than anything else.

[00:20:55] **Sarah:** Yeah. And is that linked with giving some confidence around, because you're rightly saying that they might have skills in one area, but not have so much knowledge or understanding of the other. So that training I'm sure will give a bit more confidence too around working with older autistic adults.

[00:21:15] **Rebecca:** I think that confidence, and confidence to sort of maybe step outside of your normal frameworks of working, I think was something that really came across, that people sort of needed to really feel that they had the support around them to do something which maybe wasn't completely typical and wasn't A, B, C, in order to support someone.

[00:21:38] **Sarah:** Yeah. And that seems to be really important from the conversations we've been having for this podcast, that expecting people to fit into a very static framework doesn't work. So it's about understanding how that practice can look different to fit better with the people that you're working with. Yeah. And how about you, Laura? What do you think were the really important messages or findings from the work?

[00:22:06] **Laura:** Yeah, so obviously I agree with Rebecca. I too was expecting a certain amount of friction when the groups came together, and there was a lot less of that. There was a lot more kind of synergy and understanding, and there was a lot of recognition from the older autistic people's point of view that yes, we know social workers are under a lot of pressure. And then from

the social workers who were involved in the project, they also understood some of the barriers that older autistic people may face, and particularly that kind of idea of older autistic people falling through the cracks because they didn't fit into one or the other of the models, again it's going back to that idea of siloing that we were talking about earlier, particularly if you had co-occurring conditions and you didn't really fit into that preexisting idea about what autism is. And that's where a greater understanding of neurodiversity is key, so that you don't kind of try and fit the person to a model of what you think an autistic person should be or look like. And to always keep an open mind. And in the Care Act, it's very clear that you don't need a diagnosis, it should be about needs, needs-led, and all of those things. But then when you're in that situation, you kind of forget and you go, "okay, autistic, here we go, that must mean this and that and the other". And the training is largely about reminding people to keep an open mind and to *ask*, because even within neurodiversity, each individual is unique, and to really bear that in mind, I think that was the main finding.

Exploring intersectionality and family dynamics

[00:23:44] **Lesley:** Just going back to something that you were saying, Rebecca, about the reframing of skills. I had a little moment there where things click, because that's exactly how I write about social workers and research, that they *can* do it, they know *how* to do it, you just need to give them the confidence to reframe their skills as research and give them the time to do that and the support. So that's really helpful for me actually, to think about supporting social workers, to reframe the skills they have to understand neurodiversity. So not obviously just with older people, but across the board. But I've just got a couple of questions about, and it's for either of you really, but where's ethnicity within this? Have you managed to look at the intersectional experiences across that? And then also the parents of autistic children whilst also caring for an older parent? So I'm just wondering on those two fronts, what have you found or what's been some of the barriers to that?

[00:24:43] **Laura:** So as I mentioned before, it was quite difficult to reach out to people. And we were very conscious of that because we wanted to make sure that we had a good representation of autistic experiences, and we know, well, we know, we understand from research that yes, there are differences in diagnostic rates, let alone differences in access to support and all of these different things, if you don't fit into this kind of "model" of this, you know, "little white boy", let alone anything else. So there are many difficulties and we

did do our best to reach out to that. One of the community researchers is of African origin, she's an autistic person, and she's been very helpful in continuously reminding us of that actually, that that adds an extra layer to her experiences and the experiences of her adult "child". Because as a young black male, he's got that first, and then everything else on top that's going to be, that's going to make his navigating the world just that little bit more challenging, is something that we have to be mindful of. So yeah, that is something that we think about quite a lot. And of course from when we started the project, of course, we were thinking about the intersectionality of age and autism. So that's like the compounding of those experiences. So not only do you have the sort of ageism, and then you also have the stigma that is sometimes associated with being autistic. And then how do those two fit? And to what extent are those experiences compounded in terms of that stigma or those challenges that you may face in navigating the world. So that's where we were coming from, but also understanding that actually intersectionality did come from Crenshaw. And it did come from those different experiences as a black woman. So it's that intersectionality of race and gender. So we were mindful of that while slightly, kind of, borrowing it, let's say, to understand those experiences of older autistic people.

[00:26:51] **Sarah:** Thank you.

[00:26:51] **Laura:** Yes, there was another bit, and now I'm so bad at these things, I've already forgotten the other bit of the question.

[00:27:00] **Lesley:** Sorry, yeah, it was me thinking about some of the challenges, just using myself as an example, entering into that age group where you've still got a young child who's navigating systems and then you've got an older parent as well. I just wondered if that was something coming through for those adult entering, what is it, journeying towards older age, is what I'm seeing it as!

[00:27:23] **Laura:** Yes, so firstly the older side, they no longer had parents, so they didn't really think about, I mean it's not that they didn't think, but that didn't come up in our conversations. I think we did have a conversation with someone who did, who had autistic offspring and parents who were now significantly older and they suspected that they probably were, but they never had that conversation, and it probably wasn't going to happen. So yeah, that's as far as that sticky middle thing that happens, that's as far as those conversations went. But we did have conversations with people who were

either being cared for by their partner, or they were carers of their partner, who may or may not have different difficulties or challenges in their lives. And so the conversations were around what happens when something happens to either of us, to the other one, because there was this kind of mutual support going on that sometimes isn't seen. So in terms of that carer's role, either it is invisible, and so they don't understand that actually you have responsibilities, or it is a bit *too* visible, so that the caring responsibility is seen as being taken care of. So they don't get the support that they may need in advance of that support no longer being available. So it's like that double thing. I don't know if I'm making that very clear, but that's what I'm thinking about.

[00:29:03] **Rebecca:** Yeah. I mean, I think that it is very challenging, and I think as Laura was saying, that those challenges of caring, you know, looking after yourself and your own needs, looking after your child's needs, maybe dealing with a parent who's getting older, and much older in some cases. And I think those diagnostic differences across those generations are also quite significant. So, as Laura described earlier, most of the people who are helping us as co-researchers in this study are between about 50 and their early seventies. But when you've got people who are older than that, who are sort of into their eighties and maybe even nineties, the chances of them having a diagnosis is almost nil. And people's reactions to wanting a diagnosis is very different generationally as well. So I think there are lots of challenges happening there at those sort of intergenerational spaces.

[00:29:57] **Laura:** Yeah, I was thinking as well that some older people may still have those ideas of what autistic people are like themselves, so they also imagine a little boy who has particular behavioural presentations, and they think, well I'm not like that, so I'm definitely not autistic. And so that's also part of it, just that kind of understanding of what it means.

[00:30:24] **Lesley:** Yeah.

Messages from older autistic adults to social workers

[00:30:25] **Sarah:** Yeah, I imagine that's a challenge, yeah. And from the older adults that you're working with, what were their main messages for social workers?

[00:30:33] **Rebecca:** I think largely about understanding that they are whole people with unique lived experiences, where they may have had various jobs

through their lives at quite a high level, they may be very skilled in certain areas, but that doesn't mean that they may not need support in certain aspects of their lives. So that understanding of them as a whole person, where there are things they can do very well and excel at, but also things which are challenging. And I think that, that complexity of those different levels of need in different situations, is something where I think there were the most challenges. So people often described either them being slightly infantilised, so people treating them like they were children and not giving them any agency or control, or the other way, assuming that because they were very skilled and had held down a job in a certain area, that they didn't need help with anything. And so there would be sort of two extremes. And I think really the main thing that people really want is an understanding of them and their needs as a whole person, but also understanding that they have often had lifelong, a very difficult and often trauma-based experiences that influence how they interact with social care, with medical doctors, and with a lot of other situations.

[00:31:47] **Sarah:** Yeah. And that's so important, isn't it? Because that's going shape that relationship from the start.

[00:31:54] **Laura:** Yeah, very much so.

Systemic challenges for social workers

[00:31:57] **Sarah:** And you were saying that there weren't any sort of big challenges around what the older adults were saying and what the social workers were saying. I mean, you must have got a sense from social workers of what they think the challenges are for them as a profession, and can you speak a little bit about it from their perspective?

[00:32:20] **Laura:** Yeah, I can certainly have a go. I would say a lot of the challenges had to do with structural challenges, and with systemic challenges really, to do with, well, they had their ideal of what they were, what they knew they should be, wanted to be as social workers, you know, social workers don't go in there for the fun of it, because they want to make a positive difference in people's lives, they really want to do the right thing, they want to have that right approach. But then they just simply don't have the time, they don't have the resources, and they're very much sort of pushed to produce results, to resolve cases, to move on to the next one. And so I'd have a conversation where someone would say, I would say, "oh, so how would you approach this situation?" And they would say, "oh, I would do this, and then I would

absolutely do this". And then I'd say, "oh, so and then how do you do it?" And they'd say, "oh gosh, well actually in real life it's kind of like this, and I don't like the fact that it's like this, but I don't have, I can't do it any other way". So I think those were the main challenges really. There were some where there were some kind of differences in understanding, because, particularly around kind of understanding dementia and where that might kind of, how do you know, how do you distinguish, and all those different things. And that is quite a nebulous area anyway. So there was some lack of confidence around that, some lack of confidence around finding the right approach, because often social work can be evidence-based, and you have to kind of show proof, you have to show paperwork to do these things. And so if you didn't have a diagnosis, you couldn't offer the right support because you didn't have proof that that's the support that they needed. So sometimes there were those kinds of barriers. And, you know, if you have to see lots of different people all the time with different presentations, different needs, it's quite difficult to get your head around that. So with time pressure you want to have a neat little kind of guide that says, in all circumstances, when you meet someone, this is what you do. And of course, that's not what happens, and that's not what's needed, and that's not what would be beneficial. It's about keeping that open mind and about asking the right questions. And having the confidence to do so, and having the confidence to take your time to pause, think, reflect, because eventually you know that that's going to save time. But in the *moment* it's kind of, you want to do it now and you just have to give yourself permission to reflect, to think, and to take your time. And ask all those questions in order to get it right.

[00:35:08] **Lesley:** That's really helpful actually. I was just thinking that connects so nicely with our other podcasts as well, about what can social workers do? Because they are in a very, very busy profession. They are struggling. The resources are being removed, and the perception of time is a thing that comes through a lot, doesn't it? They *do* need the time, so almost giving them permission to just think, okay, you don't have to solve it in that moment, you can take a step back and regroup and find the answers. And I was just reflecting there as well, in my own head, about how in some respects it feels easier for me because I have got an autistic brain, so I get it, and I get like realising when you talk to other autistic people that you completely get what's going on there and you see it. And I can't see that from the outside. I can't see what that looks like. I just know how I've experienced it. And normally that's quite traumatic, the way it's been presented. But I'm now looking at it from, so how do they feel about helping, and doing something? So

social workers, what we've agreed in this, and all the way through our series, is social workers want to help. That's not why they went into this, to do the harm that may happen inadvertently. So just, it's more of a thought really, that that's a really helpful way of putting it, I think, for our listeners. I hope so, anyway. It made sense to me, did it to you, Sarah?

The interaction of autism and ageing

[00:36:35] **Sarah:** It did, yeah, really helpful. And I think I was wondering as well with what you've been saying, and I think you mentioned something related to this earlier, Rebecca, but have you learned much about the interaction between autism and ageing overall? And are there things that are very distinct for older adults that you might not see, I know we talked about that in terms of lack of diagnosis in later life, but are there other things like that that have come up that you think are important to mention?

[00:37:09] **Rebecca:** I mean, I think that there's still a lot we don't know about how ageing impacts autistic people. I mean, the number of studies has increased in the last five years or so, but it's still in the hundreds, so there's still a lot that we don't know. I think there are some important things to think about, and they're quite broad really. So there are issues around the cognitive changes we'd expect to see in typical ageing as somebody gets older, so what are the cognitive changes we tend to see? And what we don't really understand fully is how they may interact with difficulties or areas of challenge that autistic people have, particularly in executive function. So the ability to plan and organise and start and see tasks through to completion. They're all areas that we know become more challenging as people get older. And we know that a lot of autistic people, all struggle with those kind of tasks in their day-to-day lives. So there's a real risk that actually as people get older, those challenges may intersect in some way, but we don't have a lot of data on that. And the results that we do have in terms of looking at what cognition looks like in older age for autistic people are very mixed. So some studies show really, sort of the same pattern of change as you would expect in any older adults, we don't really see very big differences. Then other studies show that older autistic people are at higher risk of developing lots of different neurodegenerative conditions, so different types of dementia, they're at higher risk of various health conditions. And so what we have here are a real breadth of different studies, not many, but that are showing very different results. And the challenge with that is, well, what are you looking at, and what are the differences, and why are they there? And partly I think the differences

are related to who's taking part in those studies. So if you have a study where somebody's asking you to come in and do a couple of hours of cognitive tests, and then you're going to come back next year and next year and next year, you're going to be pretty well, you're going to be pretty cognitively able even at the start. And then when you have looking at medical record data, where we are seeing these bigger differences and these larger risks for things like dementia, then actually they're people who are already receiving support. These are generally US studies where we've got, you know, Medicaid and Medicare data. So, you know, they're a very different group of people. And the problem is that we don't have enough data to really understand where these differences are, and sort of what that means for an individual. So what is the risk of an individual in this situation? So I think there's still lots of questions that we need to ask and answer around cognition and cognitive changes as people get older. I think separate to that, I think that autistic people often have had lifelong challenges, including difficulty with depression, anxiety, and they are going to continue into later life, and then they have knock-on effects. So I think there are real challenges there about supporting people as they get older in the face of that, and understanding that whole lifespan approach to a moment that you are seeing in time, but understanding that that reflects a lot of different experiences across somebody's life.

Future plans and a magic wand for change

[00:40:34] **Sarah:** Yeah, thank you. Thanks for that. And have you got plans to keep working in this area? Because I know you're evaluating the training currently, so what are your next steps? Have you got more research in this area to follow on?

[00:40:50] **Rebecca:** Well, so the first step is to complete this evaluation, and hopefully we'll show that it has a positive effect. And then what we'd like to do, really, I think we focused on social workers because in some ways they're really important points in this whole process of people accessing social care. But there are a lot of other people who work in these areas around an individual where this kind of training can just be adjusted in order to sort of fit those people, so whether it's social care practitioners, or receptionists in GP surgeries, you know, people who you're going to encounter. So really it's about education and then sort of getting the right support and support material in place to help everybody better support autistic people, particularly as they get older.

[00:41:38] **Sarah:** Fantastic. Yeah, thank you. I'm conscious of the time and how long we've been chatting for, so our final question is if you could make any changes to the lives of neurodivergent older people, what would it be and why? And perhaps you can both answer that question individually? Although you might have the same answer, I don't know.

[00:42:05] **Rebecca:** So I think for me, I think one of the biggest things, if I could wave a wand and change today, it would be to reduce barriers that are built into systems in order to allow it to be easier for autistic people to access services. So more flexibility about communication, about how somebody has to access an appointment, about how somebody has to reach out in order to make an appointment in the first place. You know, I don't understand why we're insisting on phone calls in a world where we have access to text and internet and technology and anything else that people can use. So if I could change one thing, it would be those barriers to even getting in the door in the first place.

[00:42:48] **Sarah:** Great answer, thank you. I can see Lesley nodding to that one as well.

[00:42:53] **Lesley:** When you say the word phone calls, I think this came up in another podcast.

[00:42:56] **Sarah:** It did, yeah. That's why I was like, I thought you'd be on board with that change.

[00:43:00] **Lesley:** I love it, definitely, let's have it.

[00:43:02] **Sarah:** Thank you. What about you, Laura?

[00:43:06] **Laura:** Yes, I agree with those structural barriers, I think they should, that would be great. If I could have a magic wand, I would do that. I would, well yes, if I had that magic wand I would probably increase the availability of people who could support older autistic people to access those services in the first place. I think that there's, there's an assumption often, with autistic people who do get access to social care, that they are going to be able to fill in all the forms, that they're going to remember to do all those things, that they're going to be, and actually more support in that area would be wonderful. But at a very basic level is just to not make assumptions for people, not to make assumptions about them, to not think that because they think

they know what being neurodivergent is, or they *do* know about that person's individual unique experience, that they actually ask, that they listen, and then that they work together to come up with solutions. And that's the most important thing I think, is just ask, listen, and work together.

[00:44:17] **Sarah:** Fantastic change. Thank you. And is there anything else that you haven't had a chance to say that you wanted to share today for our listeners, who are hopefully social workers, although we know lots of other people listen to the podcast as well.

A call for participants

[00:44:35] **Rebecca:** If you're interested in helping us evaluate the training we've developed, then please get in touch, we'd love to hear from you.

[00:44:40] **Laura:** Mm, yeah, absolutely. It'd be great because we rely on you to make this the best it can be, so get involved, we'd love to have you on board.

[00:44:52] **Sarah:** Fantastic. Well, your details will be in the show notes that go out with this podcast, so if anyone listening is thinking they'd love to help, then you can check there and we'll have contact details for Rebecca and Laura, amongst other things.

[00:45:05] **Laura:** Thank you so much.

Conclusion

[00:45:06] **Sarah:** No, thank you, thank you so much, it's been absolute pleasure speaking to you and hearing more about the work you've been doing.

[00:45:13] **Lesley:** Yes, Thank you.

[00:45:15] **Rebecca:** Thank you so much.

Outro

[00:45:16] **Sarah:** You have been listening to the Portal Podcast, linking research and practice for social work with me, Dr Sarah Lonbay.

[00:45:22] **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.

[00:45:33] **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.

[00:45:47] **Lesley:** Bye.