Series 4 Episode 2

Neurodiversity, victimisation and mate crime: A Conversation with Amy Pearson

[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 Amy Pearson

[00:00:25] **Sarah:** Hello everyone and welcome to the Portal Podcast. I'm Sarah Lonbay, your host, joined as always by Lesley.

[00:00:32] **Lesley:** Hello.

[00:00:33] **Sarah:** Hello, hi Lesley. And today we've got Dr Amy Pearson from Durham University joining us as our guest to chat to us about her research. So Amy, if you wouldn't mind just introducing yourself and who you are and what you do, that would be great.

[00:00:49] **Amy:** Yes, hello, thank you for having me. So as you've said I'm Amy Pearson. I am a developmental psychologist at Durham University, so I'm part of the Centre for Neurodiversity and Development, and I do research around the experiences of neurodivergent people, specifically usually working with autistic people, but I do a little bit of research with people who are ADHD, dyslexic, dyspraxic as well, and my work mostly focuses on experiences of relationships and things like victimisation and then aspects of identity and identity management.

Amy's research and personal journey

[00:01:28] **Sarah:** Brilliant, thank you very much. And we'll jump straight in. I think one of the first things we are really interested in hearing about is just a

little bit more about your background to the work. So how did you come to be doing this research?

[00:01:41] **Amy:** So I had, I think, a bit of a strange journey through to where I am now. So I started my career as a cognitive developmental psychologist. So I did my undergrad in psychology with cognitive neuroscience, and then a master's in neuroscience and neuro imaging, and a PhD in cognitive psychology looking at how autistic and non-autistic children and adults understand the world from different visual viewpoints. And I got interested in autism because my younger brother is autistic. He was diagnosed when he was around 8, which was a late diagnosis back in the nineties. Now that's, I think, a pretty early diagnosis by the standards we have, but at the time that was late, and my mum really had to fight for it. And while I was at university, I became really interested in autism, and that's kind of what prompted me into to moving into autism research. I did an internship with a researcher who I later did my PhD with, Dani Ropar, I worked in a school for autistic kids for a while trying to get some experience. But I had like a really very traditional understanding of autism and what it was. Like, I think by comparison to today, I had a very deficit-based understanding. And when I finished my PhD, I started to really question the thinking I had and how I conceptualised autistic people, I was reading a lot more work from autistic people themselves and starting to engage more with advocates. And it really shifted how I was thinking out of that very traditional lens into a more neurodiversity-affirming perspective. So understanding neurodivergence and autism specifically as part of that, as natural variation, right? As something that doesn't mean that you are "impaired" or "deficient" just because the way that you do things isn't like the dominant, neurotypical majority. Through the interactions I had with other autistic advocates and other autistic people, I also ended up starting to realise things about myself that made me feel like I had a lot in common, and I went through the diagnostic process in my early thirties and was also diagnosed as autistic. And that was kind of a... so I was an autism researcher before I knew I was autistic. Which is, I think, not often the case for researchers. So it's been a rather weird journey, I think, to where I am now from where I started.

Redefining Autism: From deficit to difference

[00:04:04] **Lesley:** There's a couple of things that I was just interested in, in what you were saying about the way autism used to be defined, I think it's helpful that, because it's mainly social workers that we're aiming this at, could

you say what that old version was, of how it was seen, and then how you would say it now?

[00:04:23] **Amy:** Yeah, so I think that, I mean there's a typical script, isn't there? Because it's what used to be written, and is still written in many textbooks now, people still get taught this in their degrees, but "autism is conceptualised via a triad of impairments in social communication, social interaction, and repetitive and restricted interests". So the idea that autistic people lack communicative skills, we lack social skills, that we don't understand other people's minds, that we don't experience empathy, a lot of really actually very damaging narratives have been constructed around autistic people and our experiences. And now, I mean my understanding of what autism is, is shifting all the time, and this is, I think, one of the hardest questions I get asked anytime I do a talk, "so what is autism?" And I'm like, " how long have we got?" What is autism? What are autistic people? Understanding autistic people might be a little bit easier, but autistic people, at the moment our best understanding is that we differ from the neurotypical population in the way that we seem to process information, in the way that we interact with other people, we might speak differently, use gestures in a slightly different manner, we might move differently, we allocate our attention differently, so tend to have a very kind of singular focus, as opposed to spreading our attention more evenly across other things in our environment. And we do tend to have really strong and passionate interests, which can sometimes be a little bit restrictive. There are so many different domains. I think the main thing is that we tend to think, it's really hard to describe autism without the comparator, so we say like, "autistic people differ to neurotypical people, and these are the ways in which we differ". It's really hard to define what autism is, or define what autistic people experience, without taking that into account. But the best way I think I can do is to say we have a unique social communication style, a monotropic, attentional focus, so that kind of more singular focus, and a different way of moving throughout the world. And sensory experience. Actually, that's the biggest and probably most important thing to mention, is that autistic people tend to have really different sensory experiences compared to non-autistic people. And that can include hypersensitivity, so being really sensitive to sensory input; being hyposensitive, so needing *more* sensory input in order for it to register, or a mixture of the two. And for most people it's really fluid, so you might be really hypersensitive to noise, but then you could go to a really, like I was at Sam Fender at the weekend, which was loud, but it was fantastic, I chose to be there, I had control over choosing to go into that environment, and so being somewhere

really loud was great. If I was walking down like Northumberland Main Street in Newcastle on a Saturday afternoon without headphones though, by comparison, I'd want to claw my own eyeballs out. So it's that choice.

[00:07:25] **Lesley:** Yeah, I'm just laughing because obviously we're quite similar, and it's nice to hear, in some respects, the world described as I experience it as well, rather than hearing it described as what it's not. That's quite a nice way of doing it.

Critiquing gendered interpretations of Autism

[00:07:47] **Lesley:** My other question with it, because obviously you just said there before Amy, about being a bit different that you were in autism research but then didn't find out you were autistic until later. But then the experience of being a female, as an autistic, that, obviously as myself, a late-diagnosed autistic woman as well, some of the challenges there, around the way autism was seen as being almost like the "male brain" idea.

[00:08:14] **Amy:** Yeah, I have big issues with the gendered interpretation of autism, and that's true for both the "extreme male brain" theory, which posits that autistic people have a version of "extreme maleness" that, "You know who struggles with empathy? Men. You know, who's really good at systemising? Men." So autistic people must somehow just be like extremely male in terms of how our brains function, which is utterly ridiculous, and the evidence for it is really inconsistent. Like, are we systematic? Yes. Could the theory have had a better name? Absolutely. But I also take issue with some of the recent framings around autism, having a female autism phenotype. So the idea that autistic women are kind of qualitatively different. And I'm like, well, yes, because we're women, not because we're autistic women, it's not a different kind of autism, right? It's that how you live in the world, how you experience the world, how other people perceive you is impacted by those other aspects of your identity, and gender is a huge part of that. I think to suggest that autistic women, it's somehow a special kind of autism and that's why we've missed it, I'm like, Hmm, is it that or is it clinical bias? Because that seems a lot more of a simple explanation there.

[00:09:35] **Lesley:** That's the one I like. I mean, there's a lot of clinical bias, isn't there? So, you know, when it comes to a lot of the way we understand things from that health and medical perspective have largely been based on white

male experiences, so that's missed an awful lot of other experiences of the same things.

The Lingering dominance of the deficit model

[00:09:56] **Sarah:** I just had a follow-on question from yours about, we've possibly spoken about this before, Amy, but I started off studying psychology as well and was taught about autism in very much that same framing. And obviously, like you say, that has shifted a lot, and there's a lot of people doing a lot of really good research, which has moved it away from that really horrible kind of deficit focus and that triad of impairments or whatever it was called. And then I'm just wondering how dominant that new understanding is? Because, you know, my research is in health and social care, and I'm not sure how much that research and that thinking has kind of infiltrated the systems and the structures that we're embedded in. And do you have any sense of how much that deficit model has been put to bed? Or is it still being used?

[00:10:53] **Amy:** No, that's a great question. It is still so prevalent. Like I exist in a little bit of a bubble, in that I, you know, surround myself with researchers who have really similar perspectives to me. And then I go to big autism conferences and, you know, so the International Society of Autism Research, INSAR, has an annual conference and I would say two thirds of the work that gets presented at that, if not *more*, is biology, it's genetic, it's still very deficit based, like intervention work, how can we "fix" autistic people? Mm-hmm. I think we are seeing the implementation of neurodiversity into more services, but I don't necessarily think the understanding is there. So I think some people are using the terminology, but they're using it like, you know, when people use the term "neurodivergent conditions", I'm like, it's just a new word for developmental disorders. You think it just sounds nicer, that euphemism treadmill of, like, you're just using the same kinds of intention behind the term, but the term sounds a little bit fluffier and nicer. I think there are pockets of people, in things like health and social care and education, who have a really good understanding. But I think those people are in the minority at the moment. And we need really quite a focus on *up-to-date* training being implemented in a variety of different organisations and services that is co-designed and co-led with neurodivergent people, because I think that's the only way we're going to see actually real tangible change on the ground, instead of, you know, an afternoon, a day maybe of doing the Oliver McGowan training and coming away and having no time to reflect on that, no kind of supervision in terms of how you implement that in practice. So I think we've

still got a huge way to go. Things are changing, but it's by no means the dominant paradigm yet.

Exploring the scope of neurodiversity

[00:12:58] **Lesley:** No, that's really interesting what you're saying there, Amy, because I've just, with the practitioners that I do practice research with, they looked at neurodiversity and they looked at what people like practitioners within social care understand by it. And the Oliver McGowan training they did mention, they weren't getting the second part of it, which I understand is where you actually then have training with an autistic person. So like a really key part was being missed. And a conflation of autism with learning disability.

[00:13:27] **Amy:** Yes.

[00:13:28] **Lesley:** We see a lot that it's "autism and learning disability". And yes there are, of course there are, but there's also a whole other space where autism is sitting. But it's also confusing, I think, because there's the other side to it is a little bit... I wonder what you thought about this, Amy, that there's almost like a dominance of autism in neurodiversity. Like the autistic voice is quite loud in that. I don't know if you think that.

[00:13:59] **Amy:** Yeah, no I do. And like, so I mean the reason for that it, like why it makes a lot of sense, is that a lot of the work around neurodiversity, theoretically, and a lot of the early advocacy emerged from autistic circles. So there were lots of non-autistic people *included* in those, often, like what I think were referred to as "autistic cousins", but now it's like, that's people who were ADHD, it's dyslexic people, it's other disability advocates. But I think a lot of the initial advocacy work going on was driven by people like Jim Sinclair, back in the early nineties. And so I think it's kind of the *uptake* among autistic people, particularly online, it's gathered a lot of traction and I think that's why we've seen so much more, I think advancement, in terms of how the theory is used in autistic circles. But it's also led to a lot of people using "autistic" and "neurodivergent" interchangeably. Which is fine, as long as you acknowledge that neurodivergent doesn't just mean autistic, which some people take it to, and you're like, no, so many more people come under that umbrella, like it's so broad. Or at least for me, so I was recently part of a project that I'd started on a few years ago with a group of other neurodiversity researchers. At the time we started, we had like, I think, one neurotypical person, but we ended up, they didn't have time. And so everyone on the project was neurodivergent, but

in different ways. And we were doing some work around what we thought "neurodiverse" was as a concept and what we thought it *should* be. And so we generated a bunch of statements and then developed a Q-sort, and then all took part in the Q-sort, and then looked at what kind of clusters we had in terms of our knowledge and what we believed neurodiversity was. And there were some really clear distinctions among us. So I have a really broad view of what I think neurodivergence is and who should be included in that, and I think my view aligns with Kassiane Asasumasu, who generated the term, like, it's broad, if someone feels like "neurodivergent" fits them as a descriptor, then they should be able to use that. But some people very much felt that it was *only* to be used by people with developmental diagnoses. And they were like, "no, neurodiversity, neurodivergence, is autism, ADHD and dyslexia, and that's it". And I was like, I *wholeheartedly* disagree with that, and I think that's a really unhelpful view. But I can also see, given like as I was saying before, like that, "okay, well this is just a new term to describe developmental disorders", how someone might come to that conclusion. Very frustrating, but people are allowed their opinion.

[00:16:51] **Lesley:** Yeah, of course. I just wonder, because, I think I'm similar to you, Amy, in that I see it very broadly and I just see it as if the concept fits with other, not necessarily conditions that you may be born with but maybe are acquired, in your life, I see that as a concept it fits, like you've got things like acquired brain injury or complex PTSD and OCD, and those things that can come later, the concept makes sense because it's about seeing it as just a *difference* rather than seeing that it's always about fixing the problem, which some problems they *can't* be fixed. So it's living in a positive way with it. So I think that's probably your influence on me actually Amy, to be fair, because I think I came to all of this through you quite a bit, because I didn't know. But, just a quick question, where you said a Q-sort, what was that? Sorry, you used a term, I didn't know what it was.

[00:17:55] **Amy:** Yeah, so it's a really interesting method that aims to explore subjectivities about a particular topic. So you generate a list of statements and then everyone ranks the statements, they like sort them into the order of what they think is most important and least important. So I think we had like one factor, which seemed to be people who had very limited ideas around what it was, and a group of us who were like, it includes anybody who think they're included, and then some people who were kind of a little bit unsure. So it kind of allows you to cluster together those subjectivities to come up with some

kind of understanding, as small groups, of what that might look like. Like the conceptual understanding of something.

“Mates” research: Victimisation, compliance and mate crime

[00:18:38] **Lesley:** No, that's helpful, thank you. We were gonna talk about your "Mates" research a little bit. Is that okay Amy?

[00:18:47] **Amy:** Yeah, absolutely.

[00:18:48] **Lesley:** Do you want to tell us a little bit about your research?

[00:18:51] **Amy:** Yeah. And I'll tell you a little bit about the background, because I think that's particularly relevant for your listeners. So I became interested in victimisation around 2016, 2017, I was starting to shift away from my cognitive work and thinking about what I wanted to do. And I knew I wanted to do something that was going to be meaningful for autistic people. And I was seeing a lot of anecdotal discussions, online reports from people who'd experienced significant victimisation from people close to them, so like romantic partners, other relationships. And I was like, wow, there's not really any research about this, and I don't really understand why we're not asking people about their experiences, why we're not trying to figure out why this is happening and what we can do about it. And around the time that I was thinking about starting to develop some research in that area, I had a master's student start, at the University, in psychology on the conversion masters, Sam Forster, who has a background in social work. So Sam had been a social worker for years and had decided to come back to do a conversion masters, and in her work she'd supported a lot of autistic adults who'd experienced mate crimes, so violence and victimisation from people they were supposedly friends with. And so she really wanted to do some work around that. And I was like, okay, this is perfect, let's do something. And that was really the start of it. So we interviewed five autistic adults, did like a really small scale qualitative study just exploring their experiences within relationships, their perceptions of what mate crime was, and whether they'd ever had any experiences that they thought might fall under that label. And the findings were really, really interesting. So they talked a lot about their identities and about feeling like they had to mask from other people, like they had to constantly engage in stigma management, and really felt like they couldn't be their authentic selves. And it was really, really overloading for them. So it was like the cognitive pressure, just the sheer amount of things you're having to think of when you

are having to think about how other people think of you and what you're saying and how you're perceived, and then manage that. It's really, really draining. And then they spoke about really negative social experiences growing up. So experiencing bullying more frequently, and also this idea that they thought that mate crime was worse than bullying, because when someone bullies you, like, you know they don't like you, bullies don't like you, and that's why they're doing it. But if someone pretends to be your friend, like that's really insidious. And then one of the participants in particular talked about some experiences of being, what she describes as being taken advantage of by a friend. But I think kind of a leaning into this experience of mate crime, so someone kind of systematically always forgetting her purse when they went out together so that she would always have to pay, and like this gathering to the point of this girl, like moving things into a house and then refusing to take them, and then her dad having to get involved. And something she said really struck me, which was that she didn't like saying no to people, because she didn't want to be perceived as rude, and that everyone thinks autistic people are rude, so she works extra hard not to be. And that, I think, was the thing that just sparked the ongoing snowball of research. Because autistic people are often subject to intervention from an early point in life, regardless of whether they're diagnosed or not, there are pressures to blend in, to act like other people, and to meet other people's expectations, to comply with what other people want. But that's particularly heightened where we have people involved in intervention, which is compliance based, when you're taught to ignore your own interpretations of the world and your own internal experiences and just do what you're told. And I was like, this is so dangerous. We're effectively training people to be victimised by teaching them that their own agency, that their own boundaries are completely pliable and they should always do what other people say before they take their own needs into account. So we carried on with another two studies looking at victimisation broadly. So we had another online study where we asked a larger number of people about whether they'd ever been victimised by someone they know, and whether they'd ever been taken advantage of by someone they know. And again, we found aspects of polyvictimisation, so most people had had that happen in multiple relationships across their lifespan. It wasn't limited to one person or one instance. We also found that, again, heightened compliance, people complying because they felt like they couldn't say no, but also because of really complicated things like power dynamics in relationships. So, you know, being victimised by parents, by caregivers, and feeling like there was a really complex power structure there that they couldn't quite breach. And that it was really hard, because people had had such fraught relationships growing

up there was almost this sense of normalisation of violence that had made it really difficult for them to trust their own intuition and also to recognise when someone else was being abusive. And then we snowballed that into a second study where we looked at the impact that that had on people, and kind of what they needed for support, what might make them feel a little bit safer, what kind of therapy might help, what they would like from people. And we again saw similar things coming out about compliance, but this experience of normalisation was really rife. So people felt like it was just part of autistic life, part of autistic experience, that this is the way things are. And that because of the way that other people perceive autism and perceive autistic people, because of that, that stigma leads to expectations of being treated like you are less of a human than other people. And that would lead again into masking. So people talked about feeling like they had to hide who they were, be really inauthentic in order to stay safe. And as a trauma response. So something they felt like they *had* to do, rather than like a way to build relationships because they wanted to fit in. And that people also really felt, a lot of the time, like there was some things that helped them access, I guess recovery and starting to move forward, just needing an understanding of themselves, of autism, and also their experiences, and having good quality relationships.

Barriers to accessing support and justice

[00:25:34] **Amy:** But people also talked about some real barriers in accessing support as well. So basic things like, you know, having to call a helpline, is going to be inaccessible for a lot of autistic people.

[00:25:46] **Lesley:** I'm just laughing. I hate phone calls. I hate them!

[00:25:49] **Amy:** Having to use the phone is so difficult. But also things like, really at a structural level, so people talking about, you know, calling the police and the police not believing them because they don't make eye contact and it's seen as dishonest, as their body language being really misread by people. And that kind of structural violence just contributing towards further trauma and the idea that people just, there was no point trying to move on because they weren't going to be believed, they couldn't access help. And so, yeah, and then we, after that, did a follow up. So we were looking specifically at intimate partner violence. So that's our most recent piece of work. And that was looking at how people, or how autistic people make sense of the experience of intimate violence and abuse. And then what can be done to better increase support. And we had really similar findings come out to the first studies, but a

big focus in terms of support around resourcing, which we really, really need more than ever. It's not just those structural barriers, but it's how we address them. So the need for actual resources to go into services, training for staff, and ongoing supervision for staff so that they can really make sure they're implementing their knowledge effectively. And a really high need for good quality relationship education among autistic young people. Young people more broadly, but accessible sex and relationship education for young people, so that we aren't seeing things normalised, like people get to develop a better knowledge about their own sense of boundaries, autonomy, and what healthy relationships look like.

[00:27:36] **Sarah:** Yeah, that's so important isn't it? I was just thinking, because you touched on it briefly, but with what you're saying, obviously there are so many barriers to help-seeking within that as well, particularly when you think about the mate crime, because if it's someone who you should be able to trust and who should be caring for you doing this, how are you going to put your trust in an anonymous service? So presumably there were a lot of barriers, and did much come up in terms of data around people who did, in any of the studies, that people who did try to access different services? I know you touched on some of that in what you were saying.

[00:28:12] **Amy:** Yeah, people really struggled with it, and to be really blunt, and also really bleak, the experiences some people had reaching out to disclose was also really harrowing. So disclosures to people like the police, again, being disbelieved, not being taken seriously, but also interactions with other support services. We had some people who've talked about, you know, reaching out to report domestic abuse and being told that it wasn't bad enough for their service to be able to support them at that point in time. Which again, I think comes down to under-resourcing. But obviously it's really difficult, yeah. And people also trying to disclose to friends and family members and then also being disbelieved by them as well. So like a massive issue with just their testimony not being taken seriously.

[00:29:02] **Lesley:** Yeah. Some of those barriers with that, I think in other stuff that I've done, and in my own experiences as well, the lack of resources means that the system seems to become so rigid. And you've then got this problem with the autistic needs for their own rigidity means that they can't adapt. And I'm seeing a lot more of having to access private services because it's the only way to then actually have some flexibility, which is really concerning because

that means that that's only available to some people who have the resource to be able to do that.

[00:29:46] **Amy:** Yeah. And that actually, it really chimes in with one of the things that participants talk about, which really stuck with me. So it was someone who had, they had other mental health difficulties they were experiencing, they had an eating disorder, and so they were accessing inpatient support for that at the same time as effectively leaving an abusive relationship. And when they were leaving the hospital, they were trying to get housing set up, they were trying to make sure that everything was as clear, as certain, as possible so they could minimise the distress with that transition. And they asked for their discharge to be delayed so they could ensure that that was all done. And the hospital, the doctors effectively told them that they weren't taking recovery seriously. And I was like, this understanding of how people think, and the lack of ability to apply knowledge about autism, autistic people alongside knowledge of mental health, that's leading to real, actual trauma among the people who are accessing those services, like their distress is being misread as being challenging. And it's just contributing towards further mental ill health. Which is why I think we need a huge shift in how services understand and interact with people, particularly in inpatient settings, I think that's really, really crucial. But yeah, it was one of those things that just like, it, it always sticks with me. Because I'm like, you're meant to go into services to recover, to get better, and a lot of people are actually getting worse.

Co-occurring conditions and the pattern of misdiagnosis

[00:31:22] **Lesley:** I have a question, because I don't know if you know about these things, but because you mentioned that person having an eating disorder and is there, and it might not be your research, Amy, but is there more research around the relationship between autism and eating disorder? Do you know a bit about that?

[00:31:36] **Amy:** Oh yeah.

[00:31:37] **Lesley:** Oh good. Could you tell us a bit about that? I find that really interesting, because I feel like, is it being... a lot of mental health things, they're *not*, they're autistic responses.

[00:31:50] **Amy:** Yes. So there's a really growing body of research around autism and eating, and autism and eating disorders. So what we're seeing, a lot

of this actually, the works come from people who've worked in clinical services, I know Will Mandy, who is a researcher at UCL, has done some work around this, because they're seeing effectively a heightened number of patients in eating disorder inpatient services are autistic, or displaying autistic characteristics and are later going on to be diagnosed. And so there's a real growing interest in effectively what that relationship might be caused by, whether it's things like heightened distress and coping among autistic people, whether some eating behaviour is driven by factors that we wouldn't necessarily expect in "typical" conceptualisations of eating disorders. So whether things like restricted food preferences might be contributing, sensory differences have a huge impact, so people really restricting what they eat because of things like texture and smell and having a really overwhelming sensory experience around food. And that aspect, which we obviously do see in kind of typical eating disorder research, but that control around food and that kind of tendency towards very obsessive and rigid thinking among people can also contribute. So yeah, it's something that we are seeing a really large growth in the research coming out around this. Mm-hmm. Because it's only like in the past few years, I think people have really gone, "oh wow...". I've got actually a really lovely colleague at Durham who's doing some research around autism and eating, not looking at eating disorders, or she has done some research around eating disorders in the past, but just looking at what we know about autism and eating at the moment. Liz Evans, so she does absolutely fantastic work, and from a really nice neurodiversity-affirming approach as well. So it's nice to see a growing body of literature there.

[00:34:03] **Lesley:** It's just so interesting, because that again connects with the practitioner research where there's kind of the idea of, and we were talking with another guest about this, about the idea of Borderline Personality Disorder, and how practitioners are starting to see the re-diagnosis of people with autism. That we're actually seeing that there's been a theme that's been missed, across services, which is why I think this is so helpful to have this so that we can hopefully share this with practitioners. Because I think the desire is there to be helpful, but they're acknowledging that they're not getting the information.

[00:34:45] **Sarah:** Or if they are, which information are they getting? And what kind of training is available?

[00:34:49] **Lesley:** Exactly.

[00:34:50] **Sarah:** Because, as we've discussed before, it may not be the right training. So what information are people accessing? Or if you trained years ago, is your thinking underpinned by models and frameworks that have been debunked? What's actually happening for practitioners right now? What are they accessing? How is it being taught in the curriculum? All of those questions I think are important.

Current societal challenges for neurodivergent people

[00:35:21] **Lesley:** Absolutely.

[00:35:23] **Sarah:** But to follow up on what you were talking about, Amy, one of the questions we'd like to ask is around what particular challenges you think neurodivergent people are facing at the moment and how you think social workers might help to respond to those?

[00:35:37] **Amy:** I mean, it's so pressing at the moment. Look at the situation we've got with disability and PIP (Personal Independent Payments). I think there are some massive issues at the moment, and I think this does link in with how we conceptualise autistic people. There's some really challenging thinking coming out around disability, and how disabled people contribute towards society. And I think it's leading to really tangible problems for autistic people. So autistic people in the UK are classified as having a disability. This gives people, well I say it gives people access, in theory it gives people access to support to apply for things like PIP, and that helps to, in some way improve the quality of life of people. And I think having a hostile conceptualisation of disability is, it's really challenging, because we're doing all of this work at the moment to try and combat stigma, to improve autistic lives, employment, education, improve services and healthcare. And so we're really pushing for different forms of thinking. And then at the same time, we seem to be having this pushback in terms of like, "people are overdiagnosed", "people just need to get into work", "people just need to try harder". I mean it's like repetitive thought, isn't it? Every few years we have the same things coming up. And I think that makes it particularly difficult at the moment, because we are seeing shifts in thinking, and then almost like a fight back against that. So I think that's *really* difficult for people. And that difficulty is obviously reflected in the services we have. So the education system isn't fit for purpose. We know this. We have so many young people in particular who are outside of the school system, are *involuntarily* not accessing formal school education because the environment is inaccessible, the way they're treated isn't particularly

supportive. We see people in healthcare are more likely to experience complications as a result, we see people more likely to experience fatality for going in for things like routine treatment, that people in the workplace are more likely to be bullied by their colleagues, that they're more likely to experience being put on things like a "personal development plan". Neurodivergent people generally are having a pretty crappy time in society. Like it's not great. And so we have a real need to have people's knowledge updated as quickly as possible, but I don't think knowledge alone is all we need.

Strategies for changing mindsets and overcoming bias

[00:38:29] **Amy:** Like we can provide people with information, but that's not, you know, I mean the internet exists. There's lots of misinformation online, but we also have so much information at our fingertips. Now we can access things easier than ever before, but I think the big thing that we need is breaking down of our own biases, which is so much harder. You know, we, society is based around the needs of the majority, and getting people to understand that, okay, that works for some people, not even all people in the majority, but it actually really doesn't work for other people. And what if, radical thought, we try to make things more accessible for *everybody*, like might that not be a little bit better? And I think people find that really, really difficult to get their heads around sometimes. Like, why does someone have to make eye contact with you? You know, it's such a small thing, but a lot of people are like, "well, they should be able to do it", but why? Why does it matter? You can have a conversation with someone side-by-side, you don't have to look at them, like why do *you* need that? And getting past that is really difficult, I think that bias is really, it's really entrenched. And I know firsthand, obviously from my own shift in thinking, like when you have to challenge the way that you've thought about something and realise that the way that you've thought about something and talked about something is really actively harmful, like you feel bad as a result of that, but you feeling bad for a limited time is not more important than the humanisation of other people. Being able to recognise that actually, yeah, that you *were* hurtful, but what you can do from that is actively make a choice not to do that in future, is more important than being like, I need to not have my feelings hurt by this.

[00:40:21] **Sarah:** Yeah. It is so difficult because people can be very defensive, can't they? And then they're not open to looking at that situation and thinking,

well actually what could I have learned? What could I do differently? And so you end up with a block. Because it's a shift in thinking that's required.

[00:40:38] **Amy:** Yeah. It's such an important point as well. And I think that actually it links in really nicely, I think with, like we were saying at the beginning, like autism's really hard to define, but we always end up breaking it down to differences in the brain. And I think that's because people, when we talk about the brain, find it more tangible, like that's a tangible thing that's different. And so it almost makes it easier for people to think, all right, well this is biological, it's essentialist, so therefore we must do these things to make things better. And it's that intangibility, actually *those* are the important things we need to change, but it's so much harder to explain that to people.

[00:41:20] **Sarah:** And I think that there is that thinking around, well, why can't the person just do it? You know, why?

[00:41:27] **Lesley:** That word "just" always comes out.

[00:41:30] **Sarah:** You do hear that, because it is intangible. You know, if it's a sensory, well you know, everyone else can manage it so... because if you can't put your finger on something really tangible and say it's because of this... So there's a lot of work to do in terms of changing mindsets and helping that understanding.

[00:41:52] **Lesley:** I do a little image when I've gone to do some workshops, I show the image of kids in a school and then just put a circle around it, and explain the circle is the social rules that are leading. You know, this is where the problem is, it's not physical, it's that, and you can't see it, but it's there. And it just helps a little bit, in some way, to help people think. Because that's the bit for me. Because if you've had a background in psychology or in sociology, you see these things and that's part of your education. But when I've talked to family about it, I realise that's just not the way they're thinking. And like you were saying, you're in your bubble, I think we're all in our little bubbles, aren't we?

[00:42:33] **Amy:** I've had similar things. So I've done some sessions with therapists, like who were counsellors who are wanting to develop their knowledge about neurodiversity, and I talk to them about that reflective questioning. So like, think about a time when you felt misunderstood by somebody or misinterpreted, how did it make you feel? Think about a time

when you were trying to communicate your needs and someone really wasn't getting it. What did you do? How did you find a solution? How did that make you feel? And I think sometimes when people are prompted, they're like, "oh... oh, okay".

[00:43:06] **Lesley:** I have that every day, ten times a day, I have it all the time.

[00:43:12] **Amy:** I've got a friend, a colleague, who is a researcher, but also is a therapist and does training. And she was talking about doing some training with other therapists and talking about things like really, really rigid schemes of support and intervention. And she was like, how would you feel if you'd had a really stressful week and you came home and you poured yourself a glass of wine and someone took that out of your hand and was like, "oh, you can't have that glass of wine now, you've got to wait twenty minutes until you've thought about your day, and then maybe you can have the glass of wine". Like how would you feel if you had to go away and fill in a chart, and every time you did something someone was noting that down and deciding whether that was a reasonable reaction to the situation or not? And they were like, "well, obviously I'd be furious". And she's like, "well then how are you not seeing how that's going to make someone else in your services furious?" Like, why don't they get the same dignity that you do?

[00:44:06] **Lesley:** I think people struggle with that idea. That's why I find that the whole misconception about empathy, which I know when you're in your bubble, you know, we all talk about actually no, autistic people, yes we have empathy, yes it's just it might look different, it's all there, but outside people don't see that. Thinking yourself into other people's shoes, that actually I think that a lot of autistic people are doing that to try and understand other people, they're thinking about, you know, analysing so much more of that person and the environment and getting a lot more information. And I just think that element of supporting practitioners to think about what would it be like if a social worker turned up on *your* doorstep and questioned your parenting? How would *you* feel? All of those things are just, I think, are helpful, because I think we get so set in our own little worlds and think everything fits with that, but actually it doesn't. And someone's experiences, you don't get to control that, if that's how they felt it. So actually thinking yourself into someone's shoes I think is really a helpful way of doing it to, to think about, yeah, but how would you feel if this is what happened? And, you know, I get that it's difficult to understand and I'm talking years of having had it said to me and then gone away and done a course and done some more research and then ended up,

you know... So yes, it's a lot of work. But I'd like to think with social workers that there's an appetite and a willingness there. And I think there is, because I think certainly they want to do the right thing. Nobody really goes into that profession because they want to hurt people, you know? I don't think so. I think that as social workers, they want to do it, but I think it's about getting the right information to them to begin with. I know what you said, Amy, yeah knowledge is not the only thing, because they want like a toolkit. There isn't a toolkit, you can't have it.

The impact of late diagnosis for individuals and practitioners

[00:46:10] **Sarah:** Yeah, I was just thinking about what you said before, because you mentioned that pushback, and we've seen this haven't we, like "people are just getting diagnosed all over the place" and, "oh, actually the centres are just doing it to get money", and this kind of discourse happening. And obviously, my understanding of this is that actually it's just people are understanding themselves better and therefore seeking these things out. But there is obviously a sense of lots of people going through that process later in life, and I'm just wondering how that plays into these shifts in our understanding, and into practice as well. Because practitioners themselves are, they're part of our general population, they're not a subset of their own, so there'll be lots of practitioners who are themselves neurodivergent and perhaps have only come to that realisation later on themselves. So I don't know if you can speak to that a little bit, Amy, if there's anything, it's not really a question, I'm just firing a comment at you and asking you to say more...

[00:47:19] **Amy:** No, it's such an important thing though. Like, it's so, so important and I think that's something that we're going to see more of. So there are going to be people who've been working in these areas for years who only through recent developments and knowledge have gained that self-understanding and have started to recognise their own ways of doing things, their own needs, and the way that they think. Really interestingly, some of the people I've spoken to who've had similar experiences, like they've managed in their careers to develop such a good rapport with people that they've worked with who are neurodivergent, they've been using neuro-affirming skills in their work because they've been like, "oh, well how would I deal with this, what would I do?" But I think that, I mean that's fantastic. But I think as our knowledge increases, we are going to see more people in a variety of professions who are recognising that that fits with their world experience. And I think that can only be a good thing. Like, it's a lot of work for individual

people, the processing of recognising that you're neurodivergent and then kind of making sense of your experiences later in life, it's a huge thing. Like, I think it really can't be understated. It's a long process, it's a really intense process for many people. And I also think, relatedly, a lot of people come to that through not just the increase in public knowledge, but an increase in knowledge of, and the experience of, burnout. So we're seeing huge numbers of professionals who are only really diagnosed after they finally just cannot cope anymore. All of the skills that they've built up just kind of fall away because there's just that constant need to be doing more and more and more, workloads are increasing, resources are decreasing. Most people are struggling within those systems. But for people who struggle with other aspects of the world, who've managed to maybe build up some coping mechanisms around those systems, once those demands just can't align anymore, it's too much. So, yeah, I think like, I don't know... it all comes down to the same thing, right? That need for increased knowledge and need for increased support. But I also think that then having those people embedded in organisations and services who can help to promote that kind of thinking on the ground is great. That often isn't how people are experiencing things in practice. I think people are often seen as disruptors, as difficult, for the way that they try and encourage a more humanising perspective. So yeah, I think it can be really, really challenging.

[00:50:06] **Sarah:** Yeah. I was wondering as well, with the research that you've done, and this might not be something that you can answer, but do you see any differences in people's experiences and needs depending on whether they've always known that they were neurodivergent or whether they've come to that realisation in later life? I mean, the experience of being neurodivergent will be broadly similar, but obviously their life experiences and how they've interpreted those might be quite different. And did you notice any kind of differences in your work around that?

[00:50:37] **Amy:** That's a really interesting question. So a lot of the people who've taken part in my work have been late-diagnosed, and I think that's because primarily doing work during COVID, people are online, a lot of people who are online in big advocacy circles are late-diagnosed because they've come to that looking for information. But in some of the research we've done around victimisation, what we've seen is that that label doesn't really seem to matter, so people are still experiencing the same stigma, it just has a slightly different name. So it's like, autistic people who know they're autistic are picked on because "they're a freak", and people who are autistic but no one knows they're autistic, they still get called a freak, they grow up feeling like there's

something wrong with them, they're mistreated by other people. And really interestingly, in one of the recent studies we'd done around intimate violence, one of the participants was early-diagnosed and the rest were late-diagnosed, and the only person who had a diagnosis early in life was the only male participant we had. And the late-diagnosed women in the study felt like their experiences would've been different if they'd have been diagnosed earlier on in life. And I was like, but they wouldn't, because this person has had the same experiences that you have had. And I think there's that idea that an earlier identification can act as a bit of a panacea sometimes, I think it's easy to think that I could, and actually people are experiencing the same things regardless. So I think a lot of the challenges are very similar. I think there are unique challenges for both groups. I think, you know, people who have a diagnosis, again, are more likely to be enrolled in things like compliance based interventions, which have a really, really harmful impact on people, really traumatic, But then they might also be more likely to get particular forms of support, in school, that can help people with certain outcomes. Likewise, some of the people who are diagnosed later in life, the expectations that other people have of them are higher because they haven't got a label that people perceive negatively. So they might be socially odd, but people aren't doubting their capability or their capacity because of the diagnosis that they have. So I think there are kind of swings and roundabouts for both groups, but a lot of the core experiences are really, really similar.

Conclusion: A vision for a more accepting society

[00:52:58] **Sarah:** Yeah, which makes sense of course, yeah. Thank you. I think we'll probably need to start wrapping up, so I've got one more question that we'd like to ask you, if you could make any change to the lives of neurodivergent people, what would that change be?

[00:53:15] **Amy:** Oh. One change? That's a...

[00:53:18] **Sarah:** You can have multiple changes.

[00:53:20] **Lesley:** You can have many.

[00:53:21] **Amy:** I'm just like, make everything, everything better for them.

[00:53:23] **Lesley:** If you could just click your fingers and it's all sorted.

[00:53:27] **Amy:** And there would be magic society understanding and lower stigma like that? I would take that in a heartbeat. Yeah, I would like to see a society that includes and supports and accepts neurodivergent people for who they are. I would like to see a place where people felt it was safe to be their authentic selves, where they felt like their needs were being met, and that they had better opportunities to thrive and flourish than they do now.

[00:53:59] **Sarah:** That's a wonderful change. I would like to see that too.

[00:54:02] **Lesley:** I like that. That feels like it's drawing together on a very nice positive perspective, even though it's a wish, it's a dream.

[00:54:13] **Amy:** We've got to keep working for it, right? Like we've got to keep hoping that we can improve things, even if it's bit-by-bit.

[00:54:21] **Sarah:** Yeah, and I think recognise how far you've come already, because you have, you've done, as an individual, as a collective, there's so much change already happened that's really, really positive. And yes, there's a long way to go, but it can feel disheartening when you only look at the journey that's still to come. But reflecting on the journey that's already happened is, is also really positive.

[00:54:45] **Amy:** We talked about this a little while ago. We were talking about the education system and kind of what would be needed to change things. And a colleague of mine was saying, like, "but this is such huge changes needed, like, can we ever get there?" And I was saying that it reminds me of, and I haven't read Ancient Greek or anything like that, but like Theseus and his ship, and the idea that you can replace individual parts of something, when it gets to the point where it's no longer any part of the original is there. And maybe it's like that, you know? We make so many tiny changes over time that do have a tangible impact that eventually the whole system has changed and we just didn't realise because it wasn't one huge paradigm shift. It's just those little incremental things that we can improve that will eventually lead to those big changes for people on the ground.

[00:55:37] **Lesley:** I like that way of thinking, because I think that if you've just changed even if it's just one person's mind, you've changed something. And I like the idea of the ripples, where you throw the pebble in and it ripples out. A tiny, tiny pebble can still cause all of that, can't it? And I think that is the way to do it, I think. Because then the more you do that, then that spreads out, and

then those people continue to go up in their jobs, become strategic leaders with that ethos. So I think it will happen. Because I think that's what we're doing with these podcasts as well, and very much work with practitioners and not *at* them, and not do things *to* them, but work *with* them in the same ethos that we're talking about with neurodivergent people, then practitioners. It's just a human approach, isn't it? And I like that. I like that example . Thank you so much, Amy, for talking to us today. It's been brilliant. There's lots to think about and I'm gonna spend some time with that.

[00:56:41] **Sarah:** Yeah, thank you. Thanks for giving up the time. Really appreciate it.

Outro

[00:56:45] **Sarah:** You have been listening to the Portal Podcast, linking research and practice for social work with me, Dr Sarah Lonbay.

[00:56:52] **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.

[00:57:02] **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.

[00:57:16] **Lesley:** Bye.