Series 4 Episode 5

Reframing Autism through lived experience and a new language: A Conversation with Hanna Bertilsdotter Rosqvist

[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 Hanna Bertilsdotter Rosqvist

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

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

[00:00:34] **Sarah:** And today we are joined by Hanna. So Hanna, if you could introduce yourself for our listeners please, that would be great.

[00:00:41] **Hanna:** Yeah. Thank you for having me. I'm Hanna Bertilsdotter Rosqvist, and I'm a professor in social work in Sweden, but I'm a sociologist by background. So I have to say that my practice experience is mostly from being a member of the autistic community and that I'm an activist in the Swedish autistic community.

[00:01:01] **Sarah:** Great. Well, it's really great to have you today joining us as a guest. So welcome, welcome to the podcast and it's nice to meet you.

A path to autism research: From queer studies to community activism

[00:01:09] **Sarah:** So just to start us off, could you just tell us a little bit about your background? and you said you're an activist in the autistic community, so

how did you come to be in that community and working in that community and doing research around neuro diversity?

[00:01:25] **Hanna:** Yeah, I think my original background is from the gay community, because I'm a bisexual person, so I was kind of starting my research career in queer studies, or gender studies. And then I needed, after my dissertation, I needed to do something else because I kind of needed to change place. And my former partner is a psychologist, so he introduced me to the issue of autism. But then you have to be mindful that this was a psychological perspective in 2007, so it was quite early by then to do assessments in Sweden, as not the first ones, but it was not that big yet. So it was a kind of emerging question. And he found himself, as an expert in the field, to be that kind of expert to really know what autism is about from a practitioner perspective. And I was a sociologist coming from queer studies, so I was kind of, "oh, this is exciting, I'm kind of thrilled about this", because I knew, and I saw, there was a lot of similar issues between the autistic community and the kind of discussion around neuro-normativity and neurotypical dominance and so on, and the queer community about heteronormativity and gender, cisgender, whatever. So I think I felt like, "oh, it's just a jump into a very close field". You can use similar perspectives. And I was acquainted with Crip theory because I was having comrades and friends looking at Crip theory and disability studies, it was not that far. But then I went to this fieldwork where I met autistic people, not just a kind of professional perspective, but really autistic people. And I was doing ethnographic fieldwork in a small school. And they, after three months of fieldwork, they said, "you are autistic yourself". So I got some kind of community assessment. And that was really strong, that I didn't go to the formal investigational assessment process, but I got a community recognising me as "you are the same as us". And my self-identification process, which was starting then at 2009, and I continue working on that. A lot of my early research, a lot of early publications, should be read as my own process of kind of figuring it out, sooner or later, that okay, this is me. And sooner or later I got into first starting to feel confident enough that I could say openly I'm autistic. But that took some time, I think it was 2016 or 2017 when I felt like now I can kind of start to "come out". And when I was really into, for instance, this work of mine, *Neurodiversity Studies*, we started that in 2018. So it was quite new for me at that time to really be confident and feeling comfortable in being an autistic autism researcher. So that's my background.

[00:04:32] **Sarah:** Thank you.

The “community assessment” and “coming out”

[00:04:32] **Lesley:** Can I go back to something you said that I found really interesting there Hanna? Because you talked about community assessment, because I'm thinking social workers in the UK listening will think of a different thing. But this is, if I'm right, you are saying that this is the members of the autistic community almost seeing you and accepting you as "you are one of us".

[00:04:53] **Hanna:** Yeah.

[00:04:54] **Lesley:** I really like that. Yeah.

[00:04:55] **Hanna:** Yeah. I think you can talk about it as "peer assessment".

[00:04:59] **Lesley:** Yeah, okay.

[00:05:00] **Hanna:** But I like to see it as actually it's not just self-identification, it's a community assessment, so people really acknowledging each other and saying, "you are one of us". It doesn't have the same power, of course, as when it comes to epistemic power, but I think it's the same as with the gay community, that in the beginning, in the early 20th century, it was like the sexology physicians who were assessing gay people, that you're probably homosexual. And then the community started to develop, and people could get into the community and they said, "well, welcome, welcome to the club, or the gay community".

[00:05:40] **Lesley:** Yeah, that's really interesting to see it in that way.

[00:05:45] **Sarah:** I was just interested because you said there is that community assessment and a sense of being brought into that community and feeling part of it. But you said you didn't have the confidence to "come out", I think you put it, until several years later. So you don't have to talk about this, because we're here to talk about your research and this is your personal journey, so if you don't want to answer it or you want it taken out of the podcast that's fine. But I was just interested about what changed for you? What helped you to feel that shift, that actually it was okay to tell people that you were autistic?

[00:06:18] **Hanna:** I think partly it's *because* I'm autistic, I needed to do bottom-up research in order to be able to get into the sense that, okay, I can talk about myself as autistic now. So I needed to do a lot of research before, and at that time, 2009, it was just in the beginning of critical autism studies. So what's happening now, mostly in the UK and USA, it's like it wasn't happening at that time. So there wasn't that amount of openly autistic researchers. I think I'd heard of Damien Milton, but they were almost not existing at that time. And so I think we'd heard about three possibly open autistic PhD students, and he was among them. But this was before he was formulating his double empathy problem, which he was publishing in 2012. So we kind of were a little bit lost, and there was mostly, I wouldn't say nice, but some kind of nice neurotypical researchers out there who wanted to do something else. They wanted to listen to the movement, but there were very few openly autistic researchers out at that time.

[00:07:28] **Sarah:** Yeah, okay, thank you for talking about that.

An epistemic awakening: Challenging the professional gaze

[00:07:31] **Sarah:** And, what's your research about that you've joined us to talk about today?

[00:07:37] **Hanna:** I think I started with a sense that I am coming with my ex-partner's, the psychologist, his firm investment in his knowledge, that he's really thought that he knows this, he's the expert in the field, in a very practiced sense. He knows, he is encountering a lot of autistic people and giving them a formal diagnosis. And when I came back to him in the evenings from my fieldwork and tried to discuss with him that there's something else here I see, these autistic people talking about themselves in another way, he said, "well, they don't know because they don't, they *can't*, that's part the diagnosis or their functionality, that they can't know themselves". So this was a kind of very epistemic moment in my mind, to see that this is totally, these are two different paths, and they're not speaking to each other, mainly because the professional side don't recognise this other voice as autistic voices are not recognised as epistemic, or viable.

[00:08:43] **Lesley:** Yeah, so you're saying that from that sort of psychological perspective, the idea is that an autistic person can't understand themselves, almost can't get to know who they are, and it's almost like then they're being

told who they are. Rather than it coming from actually within the individual who *can* obviously know who they are and know about themselves.

[00:09:05] **Hanna:** Yeah, you can talk to other autistic people, because that was among the strengths in that first fieldwork of mine. It was like there was a *group* of autistic people, so I was encountering different kinds of people, but they were in the same kind of social sphere where they started to form an autistic self in that collectiveness. There was an autistic space, a very early one in Sweden. And also the teacher, there were two teachers who were neurotypical, and then there was a helping PE teacher, she was autistic, and she supported that kind of translation between the autistic pupils and the teachers, and that was so interesting also because I met with her some months ago, and she said that was such a hard time for me because they didn't really, they kind of acknowledged me as a translator, but it was too early in some ways. There were a lot of people around her who kind of thought that, well, are you really sure? Is this really the thing that... there was kind of a tension between her position as an openly autistic adult trying to translate between the autistic pupils, students, and the neurotypical teachers.

[00:10:14] **Lesley:** What were the sort of things that came through at that time, Hanna, around how these autistic young people understood themselves and knew about themselves?

[00:10:24] **Hanna:** It was mainly by reading non-autistic people's books about them. So it's like there was a particular kind of education where they were, for one year they were going to be taught to be in-formators, or advocates, or to be able to talk about autistic people and autism from an insider perspective, but still with the backing of neurotypical understandings of autism. So it becomes like they read books or learn about autists from neurotypical perspectives, and then they should illustrate those things from their own experiences. But there was nothing about the fact this is an *alternative* knowledge.

[00:11:07] **Lesley:** Yeah.

[00:11:07] **Hanna:** But it was more like illustrative of neurotypical ideas. It's very strange.

[00:11:13] **Lesley:** Yeah, so like the neurotypical view and not really recognising that there is a different one.

[00:11:19] **Hanna:** No. Just examples that the typical literature on autism, saying that autistic people may have difficulties with meeting the eyes. And this is so for me too.

Explaining the double empathy problem

[00:11:28] **Lesley:** Can I just jump back? I'm just thinking for our listeners, because obviously our listeners are social workers in the UK, and I know it's not directly yours, but you mentioned it about Milton and the double empathy. And to be honest, I think our practitioners would benefit from understanding a little bit about that, if that's okay, Hanna? To just explain what we mean by the double empathy.

[00:11:54] **Hanna:** I can't describe it very briefly, but I would think about this, in a practitioner way I would think about this as different languages. And when I do a lecture in Norway, which I did a half year ago, I could illustrate that, that in some way, as a Swedish person, I'm supposed to be understanding Norwegian because they're quite "close" languages, we are in some way "brothers and sisters". But I don't understand. So I prefer to speak in English to this Norwegian audience. Because then we can at least see that we won't be really understanding each other if we try, it'll be miscommunications. It's safer to understand it as different languages, and we will need to do translation between them. And there's no fault, there's no fault of a Norwegian person to speak Norwegian. And it's no fault of mine to speak Swedish, because that's part of how it is. But we can try to communicate across languages. And I think that's the same thing here. The double empathy problem is no problem, as no one is *owning* the problem, but we have communication difficulties because we're experiencing the world differently.

[00:13:00] **Sarah:** That's a really, really nice and really, really clear way of explaining, Hanna, thank you.

Researching from the body: Embodiment and new language

[00:13:06] **Sarah:** And in terms of your work then, because you said was it your ex-partner who had his particular view about autism and neurodivergence, but you were out in the community and seeing something different from that learning that you had yourself previously had as well?

[00:13:24] **Hanna:** Yeah.

[00:13:24] **Sarah:** And we've talked about this with different guests on the podcast, because I trained originally in psychology and what I was taught about autism was very different as well. So I'm just wondering, is that what inspired you to start researching in this field more? That actually you were noticing, hang on a minute, this doesn't look right, there's something else that I'm seeing here that isn't acknowledged in our current thinking. And if so, where did that route take you? What did you start to look at or start to do?

[00:13:54] **Hanna:** Yeah, I think of it as you're in a space, you're in whatever space, a lecture hall, and you feel that something's just not right. It smells, something in a corner, something is not right. But everybody's telling you, "no, everything is fine, we have the right light, we have the blah, blah, blah". No, I smell something! And I think I went with that feeling that something is smelling here, and this became a focused interest of mine of course. So I jumped into it, then I couldn't get out of it because I really have to understand what is that smell, because they're letting me know there's no smell, there's nothing to worry about. But no, it's not. It's something here. And you were so *sure* that there was nothing there. I'm going to say "no, don't you feel that smell?"

[00:14:39] **Lesley:** I think I would smell it as well. I like that explanation of it, because it is that thing of thinking, "no, that's not right, there's something wrong here". But then other people are telling you that, "no, no, there's nothing, it's fine". I think that's quite a common thing for the autistic experience, being told, "no, no, it's fine", you know, "you don't experience it like that". I quite like the idea of, yeah, there's a smell there and it's wrong. So what was the smell? What did you find out? I'm loving how this conversation is going.

[00:15:17] **Sarah:** What could you smell, Hanna?

[00:15:18] **Lesley:** What could you smell Hanna? What was it?

[00:15:22] **Hanna:** As for one thing, I do a lot of things, but among the things I am very interested in the body. And this was very much about, "well, it's not about the body, it's about, social interaction", or "it's about communication", or "it's about restricted repetitive behaviours". And for me, no, it's not about that, because it's about my embodiment, it's how I experience the world. So when we talk about autism, it's very much about cognitive experiences. I'm supposed to be thinking like this or that, and that is part of it. But I'm more into, "but how does it feel in my body?" So I think that is a path I'm kind of

continuously walking on. So I can't really say "this is it", it's more like I'm gradually unmasking my sense of my body. And I think that's part of what the whole community is doing. We are naming our different experiences of our bodies, as we are unmasking. Because it's very easy, when you are in this world to constantly mask, which means you don't understand, you don't acknowledge your own experience of your body.

[00:16:27] **Lesley:** Yeah, I think that's a really helpful way of putting it. Because it's bringing in mind I think, and I will, Sarah, if you haven't heard this term, and for listeners, we will explain what it means, but the idea of *alexithymia*, is what that makes me think about. So, I've had that described *to* me as, in effect, like dyslexia, but of emotions. So not being able to read your emotions. And I think that's probably a good example of what you're trying to say about, "yes, but what do emotions feel like in an autistic body?" Is that right, Hanna?

[00:17:05] **Hanna:** Yeah, but I don't like the term alexithymia.

[00:17:08] **Lesley:** No, I know, I know, I gathered that!

[00:17:12] **Hanna:** Yeah. So I think it's very much about being humble, I think, to see that we don't have a lot of words right now. We are trying to demolish what used to be the truth. What used to be the obvious things. Which my partner was really, "this is it, this is the truth". No, it's not. We need to demolish everything and start to build up something new. And then it's in very small, small, small steps, and we gradually experience and construct new names for our experiences. And then I think we will, in hopefully not that far future, we will get into something which is something about this emotionality. But it's not alexithymia, it's something else, but I don't know yet. It's an alternative emotional processing. And it's coming, for me at least, it's very much a bodily thing. Which means, and it's also connected to, as I'm processing, not in a neurotypical way, I'm processing in a bottom-up, detail-oriented way, it's hard sometimes to put a top-down concept on my feelings, because it doesn't work with me. I can feel a lot of feelings in my body, a lot of things are happening in my body, but I'm not sure if I can put a big concept on that. "Happy". It's too top-down. So I need smaller words, and smaller more detail-oriented words. And that is also part of the process, that we need to develop those words, which fit more into our experiences.

[00:18:45] **Sarah:** Yeah. I love how you've explained, you've got a lovely way of explaining things, Hanna, it's so clear, and the examples you use, it really is

illuminating. Because I love what you've just talked about in terms of what yourself and other autistic researchers are doing, that you are chucking out that very rigid and very deficit-based thinking, and actually trying to reframe and reshape that in a way that's grounded in your experiences. Because you are the only ones that can tell the world what it's like to be autistic. So having these things imposed on you, and in a way that's often very deficit-based and pathologising, I think. And I think that seems to be something that all of the researchers that we've spoken to have in common, is that need to reframe, to reshape, to regrow things from the bottom up, from their experiences, and to create that awareness in practitioners and in the wider public around, "actually what you've been taught might not be right, here's another way of thinking about things".

The insider-researcher: Where activism and research intertwine

[00:19:50] **Sarah:** So do you find, because you did mention before that you're an activist, so is that part of your research? Is your activism and your research quite intertwined?

[00:19:59] **Hanna:** Yeah, I can't see the difference, and that is part of why if you are an insider-researcher, you are living in the community. So it's not a choice. My friends are all AuDHD or ADHD or autistic people. And so it's like a family thing. It's like chosen community, or chosen family. So for me it's like, when I'm doing things in research, it's not like I'm listening to the community, I'm *part* of the community. So that's the difference, when you formulate articles talking about community research priorities, it's like, "yeah, but this is part of my friendships, this is part of my Facebook...", I'm a member of Swedish Facebook group for autistic and ADHD women, and we talk a lot. And I also use my knowledge in different ways to respond to discussions in those Facebook groups. So I think we also are formulating right now, as in Sweden, I think in the UK you've travelled much further than in Sweden, unfortunately. So in Sweden it's still like, people don't acknowledge or really realise there's a lot of autistic professionals among social workers, it's still like, "no, it's just clients". No, it's not. But in the community, in those Facebook groups, I think we are marginally constructing some kind of neurodivergent professionality, where we are supporting each other from a community social work approach in some way. So it's not just that I'm sharing experiences, it's also like I'm teaching, I'm doing psycho-education.

[00:21:31] **Lesley:** Yes. The awareness-raising around that I think is quite interesting. I presented recently on what my research is and realised it's not something I can separate, I can't separate myself out of this because I'm part of it. It's not like you're researching something objectively, you're researching something that is your living as well. And bringing those research elements to that is an important part of that for me, that I like about this neurodiversity paradigm. That it's giving, the power is shifting, from that top-down to actually the people that are living through. I think that in social work, I think that we're not doing enough to recognise that it's colleagues as well as the service users, that the people in the communities are the people that work in social work as well. And I think we're not quite there with that. Well, "not quite", we've got a long way to go!

Implications for social work: Neurodivergent practitioners and the need for "translators" and processing time

[00:22:28] **Sarah:** I wonder if there's something for social workers to learn from autistic researchers, because as you've pointed out, a lot of social workers will themselves be neurodivergent and working with neurodivergent people. And I just wonder, Hanna, from your experience, with being an autistic researcher, it's all intertwined, isn't it? Whether you have any kind of thoughts about that for social workers in terms of how they might draw on that in practice or how they might reflect on that experience?

[00:23:03] **Hanna:** I think it's a lot of things here, and we are trying to develop that actually in our current work with the book, the *Neuro-Inclusive Social Work* book. And so there's a lot of work being done at this moment, but in Sweden I think a lot of the problem is the masking, that students in social work, or social workers who are also neurodivergent, they don't come out because they're so afraid, and they're also aware that there are actually discrimination cases. So it's not like you're just afraid of something which is not real, it's really real, so the few people coming out, they have to be really, really strong, and really, really in stable positions in order to be able to do that. But I think my *hope* is that social work will acknowledge that it's similar to other minority work situations, that we need to work with the communities and we need to have social workers, of course, having experiences of being part of that minority themselves. Because it's really hard, again back to the translation thing. To be a neurotypical social worker trying to work with neurotypical clients is not a big thing, because you have the similar kind of communication. But if you're back to the Norwegian and Swedish person, if I'm going to do

social work with a Norwegian client, it's really hard if I don't understand Norwegian. So I think that is a kind of simple thing, that we need to have better "translators". And mostly it is neurodivergent people who are the best translators between your neurotypical social workers and neurodivergent clients. Neurotypical social workers also need to understand that they need to "learn neurodivergent".

[00:24:41] **Lesley:** Yeah. I like the idea of it being a language, like we need some sessions. Because when I do my workshops, I find that supporting social workers to put themselves into the shoes of the people they work with, and how they would feel if they were receiving some of the services, can be really helpful for them to then start to realise that they would find that very difficult, very challenging, and start to explore in themselves that there are differences in themselves that they haven't fully understood. So through the work I do, I get a lot of people then "coming out" at the end because they start to realise, "but my brain's like that, that's how I think". And it's a very comforting thing that those of us that can speak up, I think with the activism side, it's helpful that we do, so that it makes it easier for people who are struggling. Because you're right that that issue with this discrimination against social workers who are neurodivergent is happening. They end up on action plans in the UK, so they have an action plan because they're not doing what the neurotypical expectation or the neuro-normative expectation of "this is what you should do as a social worker", and they're doing it slightly differently, and the space for that has not been created.

[00:26:04] **Sarah:** I think that's an interesting point that you've raised, Lesley, that you're expected to do things and operate in a particular way, there's no acknowledgement that actually there are different ways of doing things that are equally good.

[00:26:18] **Lesley:** Yeah. It's not controlling the journey of somebody's learning, or how somebody does it.

[00:26:23] **Sarah:** Yeah, you arrive at the same outcome. The process is different, and that should be fine. And I just wonder, Hanna, because I'm just trying to think about our social work listeners, and you've given some really nice examples, and I love that idea of a translator, and I'm trying to think what that looks like in practice. Is this something that you've explored as an idea for practitioners then?

[00:26:50] **Hanna:** Not really, but I think a lot about pacing, that sometimes while we are living in, I wouldn't say a fast-paced society, but it's like you're supposed to, if I imagine myself in a meeting with three or four professionals, and they're all going to assess me or discuss with me possibly interventions in my future life, and I'm just filled with my anxiety. Currently I'm just filled up with different feelings in my body, I'm not really given time to either process my feelings or what they're saying. So it becomes an incomprehensible moment, even for me as in, I'm used to reading, I'm an academic, it still would be overwhelming to be in that kind of situation. So for me it's like basic, you need to make other kinds of meetings, which is enabling people to process and talk in their own way. And if you don't do that, it's pointless. It's like you can have a lot of meetings but you won't get anywhere because the person isn't able to communicate or let you know what is actually needed. And you will assign the person different kinds of interventions which are not needed, because you don't understand the need, because you didn't allow for processing time.

[00:28:05] **Sarah:** Yeah, that's absolutely crucial, because social workers do operate from that principle of inclusivity and working with the person, so if they're not doing that in a way that actually allows that, that's a huge miss, isn't it? I'm just wondering with this, is that the same for people who are ADHD? What kind of, are there differences in terms of that translation or differences in practice that would be helpful for that?

Epistemic authority and neurodiversity research

[00:28:32] **Hanna:** I think so, but we don't know yet. Because I think the autism research has come much further than the ADHD research. So maybe the AuDHDers can support us here! I'm an AuDHDer too, but we haven't yet come across what that would be. But of course, sensory and social accessibility is central for both groups, but in different ways.

[00:28:56] **Sarah:** Yeah. So much of the research then is led in the field of autism rather than ADHD at the moment, yeah.

[00:29:04] **Hanna:** Yeah. Unfortunately.

[00:29:06] **Sarah:** Is there more emerging?

[00:29:08] **Hanna:** Yeah, I think so, but that is part of the problem, that I think AuDHDers are leading ADHD research now, as they're coming up with different new things. And also when I think about our work with the book also, it's a lot of AuDHDers in the book. But when it comes to "clean" ADHD, I think they are fewer in academia, and fewer are openly ADHDers among the researchers. So I think they are a bit years behind the autistic autism researcher group.

[00:29:40] **Sarah:** Okay.

[00:29:41] **Lesley:** Yeah, that makes sense.

[00:29:43] **Hanna:** Yeah. Because they also are quite angry about autistic privileges when it comes to epistemic authority and when it comes to neurodiversity, that it has been a lot of autistic-centredness in defining neurodiversity or experiences of neurodivergence.

[00:29:58] **Sarah:** Okay. So there's quite a lot of work to do in terms of looking at neurodiversity as a whole, from the sounds of it, and a lot of learning still to come.

[00:30:07] **Lesley:** There is a lot to do, yeah. Because I work with pure ADHDers quite often actually, and it's sort of learning, with the workshops we do, we're learning that differences and experience. So I've got the person that I present with, I share, "this is what it looks like from me as an autistic person", and then she presents, "this is what it looks like from me as an ADHDer". But I think it's difficult with the idea of the pureness of it as well, because we're a little cocktail of neurodivergence, so you sort of have a bit of this and a bit of that and a bit of the other, and it's like a sort of smorgasbord, that would be the right word? You know, just a little bit of everything.

[00:30:48] **Sarah:** That just makes me think of cheese.

[00:30:50] **Lesley:** Yeah, I feel hungry now. Yeah. Yeah.

Neurodiversity and differences in experience

[00:30:53] **Sarah:** So what are the key, I know we're going maybe slightly off topic here, but what are the differences, if we're talking about neurodivergence, I know there are differences between people who are

autistic, ADHD, but if we're saying also that actually lots of people have just lots of traits across, what are the key differences in experience?

[00:31:15] **Hanna:** Sometimes it's about being monotropic, and you're getting into the rabbit hole and you can't get out it. You may be stuck in certain ideas as, for instance, back to the situation where I'm meeting a lot of professionals, and they are starting to bring in different kinds of discussions, and I get focused on one. And I can't really absorb all of them because I'm focused on one. And I think that is more an autistic experience. But I would say that the ADHD experiences would be more like being able to be more a "bird view" point of view, but will be still very overwhelmed by all those kinds of stimulations. It's not like you can keep on being in the bird view. That is also part of, I think, a neurodivergent experience, that you need to have an interest-based attention. You can't just focus because you're *supposed* to, but you have to keep on being interested, otherwise you will un-focus.

[00:32:12] **Lesley:** Yeah. Interest-based attention, I think it's really interesting you saying that Hanna, because I do think that does seem a key thing within neurodivergence, that just because there's an expectation that you *should* be able to concentrate or focus on something doesn't mean that you can, unless you are interested in it. And then the interests are different depending on the individual. So there's no helpful manual really, is there, to say "right..." I think, certainly with the book, with what we're working on, there's that hope that we can do these toolkits and things like that, and I think that's really challenging because it's so individualised that, to me, it goes back to what social work is about, which is about those individuals and seeing that person for who *they* are, rather than how they conform or do not conform to an old teaching on what autism or ADHD looks like. It's seeing the nuances in that.

I've got two questions.

Expanding the discourse: Triple empathy

[00:33:13] **Lesley:** Is that okay? Can I ask them both, Hanna, and you decide which one you want to answer first, in what order? Okay, so one is then, because it's come up through the book we're doing, triple empathy. I'm interested in knowing a little bit more about that side of it, just because I think your explanations are brilliant and I'm sure you've got another one to come for that one.

[00:33:34] **Hanna:** Oh, yeah.

[00:33:35] **Lesley:** And the other side to it was about your research into autism and sexuality, and the relationship side of things, and just what you think's important about that, that social workers should know about. Mm-hmm.

[00:33:51] **Hanna:** I think the triple empathy problem is I don't know it enough.

[00:33:56] **Lesley:** Okay, that's fine.

[00:33:56] **Hanna:** So yeah, so for me it's mainly that it's a problem when you have your professional experience and knowledge and you are from the other neurotype, and you're supposed to be workers. It's not just two people trying to communicate, but then you also have this hierarchical relationship, that it's a professional wanting to do something to a client. And if they don't understand each other, for me, that is a kind of triple empathy problem. But the problem is put on the client, the client is represented as non-obedient or a "problem client" who can't accept or can't be, I wouldn't say supported, but when you come to talk about "therapy-resistant" people, for me that is a kind of triple empathy problem, that you're not reflecting upon your own professional communication, but you put it on the client to be the problem if the therapy is not working.

[00:34:52] **Lesley:** Yeah, that makes sense.

[00:34:54] **Sarah:** I just wanted to check I've understood that, because this concept of triple empathy is new to me. So when you said before double empathy, it's like you've got two people speaking two different languages, and that's the neurodivergent versus the neurotypical language. So is triple empathy when you introduce the third language of that professional role and everything that that carries with it, which creates another layer of translation that's needed? Because that level is probably there in a lot of practitioner service user interaction.

[00:35:27] **Hanna:** Yeah. So it has been introduced, has been developed, that concept has been developed in a health professional context.

[00:35:38] **Lesley:** Yeah, that makes sense to me, that there's a third language that's in there, between those two, there's an extra layer, the professional language, and the way they see it and the way they talk. And I see that with

the challenges, to me, with the idea that the answer, certainly in the UK, is "let's do some CBT", but the CBT language of that is not done within a neurodivergent space. So therefore then they put on the client that it's their fault that they're not moving along quickly enough in the six to eight sessions that they're allowed. And yeah, that's it, it's their fault. And then you get referred back in. That's great, thank you for that, Hanna. Because it's just come up recently and I was trying to get my head around it as well, and I think that's helpful. So, yeah.

Neurodivergent sexuality

[00:36:25] **Lesley:** So in terms of your research into the sexuality side of things, what do you think is important about that?

[00:36:32] **Hanna:** I think because I was doing a lecture on some, I don't know, conference some months ago, I think it was for some kind of educators, and for me it's like, when we are assuming a lot of things, again, we have a neurotypical frame when it comes to sexuality and gender, so we are assuming a lot of things when we are looking at autistic people doing sexual stuff. We assume, or look at it from a neurotypical, heteronormative version, mostly, perspective. And sometimes we don't then acknowledge some sexual practice autistic people do, because it doesn't fit within our ideas of neurotypical sexuality. So for me, when I was doing a book last year together with two autistic researchers, and it was a lot about naming the nameless so it can be thought. So we have a lot of experiences in our bodies, and what we do, and our desires, but sometimes we don't acknowledge them as sexuality because they're not fitting in the *ideas* of sexuality. And then you have to understand that those ideas are neurotypical, based on the kind of top-down ideas of how you're supposed to be naming your sexual attraction, whatever it is. And then it's like, "no, that's not sexuality, no, that's not either, that is bad". A lot of ideas, because they're outside of that kind of ideas, and then we need to grab them back and say, sexuality for us is something else. Sometimes it's connected, it's a similar thing which neurotypicals talk about, similar to gender, sometimes it's a kind of similar thing, but sometimes it's just another thing. But it's about pleasures.

So I would like more to talk about sensory pleasures, where among them there could be things which we now think about as sexuality. But if you're a sex educator, and trying to teach autistic students, or young people, sexuality from a neurotypical perspective, some of them will think, "well, I'm not a sexual

person at all, because I don't like those things you're assuming me to like". So then we miss the sex education part because we don't teach people to explore their bodies and their sensual pleasures, and learn then, of course, how to communicate your desires or what you need and your boundaries. So this book tries to kind of reformulate ideas of sexuality and gender from an autistic perspective.

But then it's also taking different kinds of inspirations, and I think a lot of inspirations can be taken from the BDSM community, because they have a lot more words and languages for sensory experiences. So I think that was also part of the book, that there are a lot of people in that book was coming from the BDSM community and were also neurodivergent. So they took the kind of, again, toolboxes they have been learning from the BDSM community, and put them into a neurodivergent framework, and then started to explore that, or also develop new words. And sometimes they'd be in the BDSM community they'd be talking about crashes as when you are a "top" (dominant) or a "sub" (submissive), you are crashing after a session. And that's similar to a meltdown or shutdown. It's like, very similar experiences, but then it's kind of normalised. Sometimes things are getting too much, you get overwhelmed, either as a "top" or as a "bottom" (submissive), and that's very useful to translate when it comes to autistic sexuality. And then it's back to pacing, that we need other words, but we also perhaps need other pacing things as processing time. That means that sexuality can't be in the kind of "scripted" way where you assume things are going to happen at a certain pace, and we can't assume it's supposed to be about this and that, but we have to open it up. Otherwise, people or educators would think that a lot of autistic people are asexual. And I think some of us are, but I don't think it's really that problem. I think the problem is that we don't acknowledge all possibilities of autistic sensory experiences or sensibilities.

[00:40:35] **Lesley:** Yeah, absolutely. I think that's quite an interesting element, because I think that sexuality, and generally within disability, is something that has a, I mean there are people exploring it obviously, but I think that there's a lack of understanding, for want of a better expression, from practitioners, to understand that individuals are sexual beings as well, and that that can be important to them, when they're supporting them. It's almost like that side of it gets sort of ignored, like we don't want to talk about it, rather than understood and explored with the individual, and to support that individual. Yeah. I need some more processing time with that one.

[00:41:18] **Hanna:** Yeah, that is a basic thing, need more process time for everything.

[00:41:23] **Lesley:** Yeah, just, just generally! I suddenly get stuck and just go, "oh, that's interesting, can't quite work out what bits I want to pull out from that, but..." I feel like we need an extra, "and here's some additional questions that we asked afterwards when Lesley had processed".

[00:41:42] **Sarah:** We could do that, definitely. Yeah, I just think it's great that you are researching that and thinking about it. Because I think Lesley's right, this is a completely different example, but my research is with older people predominantly, and sexuality gets ignored in our older population as well. I think people just assume that you hit a certain age and you're not interested anymore, and suddenly anyone over 65 is completely asexual, which just isn't reality. So it's really good to be thinking and talking about it and pushing back against that discourse, and saying actually this isn't the case, it just might look different, or it might not look in the way that neurotypical and heteronormative discourse says that it should look. So I'm pleased to hear that that work is happening and we're researching in that space as well, and understanding it and pushing boundaries around that.

[00:42:38] **Lesley:** Because when you think of quality of life for somebody, it's what's fulfilling to *them*, isn't it? It's not about a society expectation of that, it's an individual, from that individual, what is important to them, and wanting to be able to engage with that.

[00:42:54] **Sarah:** Yeah, that's the really crucial point isn't it? It's not coming in and making judgements and assuming that you know what someone wants and needs, but actually really stopping to listen and learn from the person that you're working with. And I know you said before, Lesley, about the book that you're both involved in, around neurodiversity and social work and wanting to come up with some toolkits, and very likely there will be some broad messages that might cut across that you can give, but it sounds like that just stopping to learn and understand, and having that time and space for processing and translation, is really important.

[00:43:32] **Lesley:** Processing time is *really* important. Giving any individual time, because mostly when you've got a professional involved it's already stressful, so even stepping out of neurodivergence into working with *all* people, it's a stressful time, so you've already got people in a difficult time in

their lives, so anything that professionals can do to give time and space to individuals to understand what's happening. I really feel like people in certain professions just do get stuck in this new language, and use shorthand, all these acronyms so they can be quicker. Rather than thinking, actually, I can't assume that everybody in this room understands what I'm saying, and just using clear language. I'm gonna advocate for clear language from now on. I already do.

[00:44:30] **Sarah:** You do, you're very good at that actually, so it's always appreciated by everyone in the room.

Final recommendations and a vision for the future

[00:44:35] **Sarah:** I'm conscious of the time, Hanna, and I definitely want to give you a chance to say anything else that you'd like to say, but I do have a couple of final wrapping-up questions as well, if that's okay.

[00:44:46] **Hanna:** Yeah, I think it's better, because I also start to get tired. So it's easier if you question me and question me. Ask me, then I can focus on that.

[00:44:54] **Sarah:** Brilliant. Well, two final questions then. The first one, do you have any key recommendations for social workers? I know you've talked through a few things within this conversation, but is there anything particular that you'd like to highlight?

[00:45:08] **Hanna:** I think it's back to the language thing, that if we acknowledge autistic people or neurodivergent people to be a language minority (similar to deaf people), I think it would be very helpful, because then of course you need to, I don't know, there's a lot of languages choice, you can learn Spanish or Swedish, whatever, and you need to go through them in order to learn Spanish. You can't just say "I'm a Spanish speaking person" without learning the language. So that would be helpful, to just acknowledge those kinds of language barriers, and not focus on *cognitive* barriers. Because when you focus on cognitive barriers, it's like, "oh, you should understand this". "No, I can't". "Why?" I still am a competent person who can talk about myself and experience and reflect, but I can't really speak in your language because I don't speak that language, or I speak it very poorly. I *can* speak neurotypical language, but it's costly. So as a client I would prefer if we can speak in my language, as neurodivergence, then you would be more supportive with my high needs or whatever. I can't also be assumed to be speaking neurotypical

language. So I think it's about energy consumption, and that if you want to have a good meeting with the person, you need to think about how to do an energy efficient meeting. So you don't put that person into a completely cognitive burden, as a situation where you just burn that person in energy. When I think about barriers in my imagined meeting with a group of social workers, it's like, oh, are you not going to even get to the core of my needs? Because you are posing so many barriers before we can get to that core. You'll drain my energy before we get to it. And that's a kind of, it's a non-efficient use of my energy, and you have to be aware that I may last one hour, and after that I need to go to home and have a sleep.

[00:47:05] **Sarah:** I love that way of framing it, just because it puts it so clearly, and I think, like you said at the start, it just shifts it away from this blame narrative or this idea that someone's at fault for, you know, it's actually there's no one to blame here, there's no one at fault here, there's no problem here. We're just speaking two different languages, so we need to come together and understand each other. So thank you, thanks for that recommendation.

And the final question then is, if you had a magic wand, you could make a magic change for neurodivergent people, what would that change be and why?

[00:47:45] **Hanna:** I'm going to start to go into therapy actually, with a Swedish AuDHDer therapist, and she's interested to develop neuro-affirmative therapy in a Swedish context. So I'm going to be her... say, when you're a client, but also a test person experiment, kind of thing.

[00:48:05] **Lesley:** I think guinea pig is the expression.

[00:48:07] **Hanna:** Yeah, so I'm going to be a guinea pig, and I'm very much looking forward to it, because first I know she's my AuDHDer, and I know she's having that kind of framework that she really wants to make a situation which is working for me. So before the meeting, we are going to meet up next week, I have said that these are my accessibility needs. And she said, "okay". And that is so helpful. So I don't have to come to the situation with a lot of anxieties that I will be the problem, because I don't have that kind of functionality, that I'm supposed to be understanding this or that. But I just said, this is my accessibility needs, can you produce a space for me, which is working for me? And then we can do the core things. Then we can talk about my needs, as the more therapeutic kind of needs.

[00:48:55] **Lesley:** I like the idea of "create a space for me". I like the idea that that's an important thing, because that's the, the difference with, in the UK we talk about the "reasonable adjustments", which is just about, okay, well it's going to be the neuro-normative space and then we'll add a few bits, rather than actually that universal design element of creating the spaces with that difference in mind, with the individual in mind. And I think, yeah, that's really helpful to think. There's not enough to support, I think, within psychological services, for the neurodivergent brain. I don't think it's, I was surprised by that, I thought it would be understood more, but it's not.

[00:49:35] **Sarah:** Yeah, yeah.

[00:49:37] **Lesley:** Oh, that's been really brilliant, thank you so much Hanna.

[00:49:40] **Sarah:** Yeah, thank you Hanna. Really, really enjoyed hearing from you today. It's been great. We really appreciate it and yeah, thank you for spending the time with us today, it was nice to meet you.

[00:49:52] **Hanna:** Bye-bye then.

Outro

[00:49:53] **Sarah:** You have been listening to the Portal Podcast, linking research and practice for social work with me, Dr Sarah Lonbay.

[00:50:00] **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.

[00:50:10] **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.

[00:50:25] **Lesley:** Bye.