Series 4 Episode 1

Neurodiversity and Fabricated or Induced Illness: A Conversation with Cathie Long

[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 Cathie Long

[00:00:28] **Sarah:** Hello everyone and welcome to the Portal Podcast, bringing research to practice for social workers. I'm your host, Sarah Lonbay, I'm joined as always by co-host Lesley Deacon, and today we're very happy to have Cathie Long with us to talk about neurodiversity and social work and the research that she's been doing. So Cathie, can I ask you just to introduce yourself for our listeners and tell them a little bit about yourself and your background and why you're doing what you're doing?

[00:00:58] **Cathie:** Okay, yeah. So, I am Cathie, I'm an independent social worker and I've been an independent social worker for 15 years, and full time as an independent social worker for 10 years. I have a background in mental health, I was a forensic social worker, which I absolutely loved. And I've worked with people with learning disabilities and substance misuse, older adults, lots of different areas of social work. So I consider myself very generic. And I started off in childcare, in child protection. And so now I predominantly work with neurodivergent people. I do assessments for Education, Health and Care Plans as an expert witness, I do Capacity Assessments for the Court of Protection, I do Care Act Assessments, lots of different things. And aside from the main social work practice, I've written publications, I train, done lots of podcasts and seminars. so I'm pretty busy, really.

A personal and professional journey into Neurodiversity

[00:02:09] **Sarah:** Yeah, sounds like it. Thank you. And could you tell us a little bit about the background to your work with or about neurodiversity and how you became interested in that area?

[00:02:23] **Cathie:** I don't know, it's sort of evolved. I think sometimes things find us. So, I really didn't have any interest in neurodiversity, it wasn't something I understood or knew about. Before I qualified a social worker, I worked in a day centre for adults with learning disabilities, and so I've probably met lots of neurodivergent people there, but didn't know it. Probably they were not diagnosed at that point because that was in the early eighties. And what happened was, for me was my son, age 10, was diagnosed as autistic. It took me a long time to see it, I didn't understand it, I didn't know really what being autistic meant. And I was working for the local authority that delivers his services. And at some point I was seconded to do some research to look at setting up an autism service within county. So that started my interest, and I was incredibly naive, there were things I really didn't know, understand, I just went in with an open mind and decided I would listen and try and get it. And then going back into my mental health work, I started to see people coming into the service, and I thought I'm wondering if they're autistic, there's just some sort of sense in me. And often they were, and this caused huge battles with the medical profession, particularly psychiatrists, because their diagnosis is "what's right". However, one of the psychiatrists actually ended up apologising, saying, "you're always right". I wasn't always right, but that's what happened. The service was set up and then I decided to do an MA in autism. And it was something I thought, I trained as social worker, I had a diploma in social work, I didn't do a degree, I never felt I needed a degree, but because I love teaching and lecturing I needed to do something. So I missed out a degree and went straight to an MA. That was really hard work, and I was convinced I wouldn't pass it. I absolutely, I was saying to my supervisor, I just want 1% above the pass mark. And she said, "Cathie, you will pass". And I'm thinking, "no, you don't know me, I will not pass". And I did, and I got an outstanding achievement award for my dissertation. So, yeah, and I was stunned, absolutely stunned. And so I had to tell myself that I can do this, I'm not stupid, which is the message I'd been given in school. And I say that because part of my journey here is that through all this process I've discovered that I'm autistic with ADHD, and I had absolutely no awareness of that whatsoever. So, that's really my journey.

The issue of misdiagnosis: Autism and personal disorders

[00:05:35] **Lesley:** I think that's a common journey to be honest, from being within the community myself as well, that journey of realisation and then the research into it almost, like you said, doing the Masters to try and understand it sounds like something I hear quite often from people as they try to explore what it means for them and their families.

[00:06:00] **Sarah:** And also, what you were saying about misdiagnosis is something I've come across as well. Particularly I've heard about misdiagnosis of Borderline Personality Disorder, for people who were in fact autistic. So that's interesting that you picked up on some issues when you were working in the mental health setting as well.

[00:06:21] **Lesley:** And especially with women.

[00:06:23] **Cathie:** Yeah, no, it's true. I mean, it's another area that I've been doing a lot of work with, and training with, and one of the areas I'm really interested in, and I've been researching, with my colleague, Dr Judy Eaton, who's a clinical psychologist, is about where predominantly women are misdiagnosed with, Emotionally Unstable Personality Disorder, which used to be called Borderline Personality Disorder. And the amount of stigma that women and girls who are diagnosed with an emerging personality disorder, the amount of stigma they experience. Because having worked in a mental health team, I know how people with a diagnosis of personality disorder are treated as attention seeking, difficult, manipulative, you know, "they're not really ill", "they're making it up", and that was this stigma, all the time. Now I tended, as a forensic social worker, to work with some of these women who had gone into the forensic services when things have gone very wrong for them. And I saw them very much as other women who had strengths and struggles. I didn't see them as a disorder. But also the research shows that up to 80% of people diagnosed with a personality disorder are women. Which is very concerning.

[00:07:58] **Sarah:** Yeah. And that's really interesting what you were just saying as well, because that label is stigmatising and it sticks to the person, doesn't it? And they carry it with them. So you lose sight of the person. To label someone as disordered is an awful thing to do anyway, but then for that to stay with them, and that changes how everyone views them, it changes the way they interpret their behaviours, their communication. So it's really good to see some of that challenged, and different ways of thinking about these things emerging as well. But I didn't know that, that 80% of people with that diagnosis or label were women, that's new to me.

[00:08:36] **Cathie:** Yeah, yeah. And that really applies to autistic women because a high percentage are misdiagnosed with personality disorder. Yeah. And so they receive that, you know, there's discrimination in services because of that misdiagnosis. So somebody might have a misdiagnosis in their teenage years and be in their forties, fifties, diagnosed as autistic. And that label, that original label, will stick. And I know from experience how social workers can pick up that misdiagnosis and work with somebody as if they are personality disordered. So it's almost like keeping them at arm's length, not engaging with them because they might attach to me and they are "difficult" and "problematic", when that's not the case.

[00:09:31] **Sarah:** And beyond that, working with them in other ways that are probably really detrimental if someone is autistic. So not recognising what they might need, you know, in their environment, in their care from that professional. There's a whole host of issues with that.

[00:09:47] **Lesley:** There is, this is something that's come through with the practitioners that I do research with. So they talk to other practitioners, currently social workers and social care professionals, and they are making these observations, that they're seeing mainly women coming through their services and then starting to get this re-diagnosis from Borderline Personality Disorder to autism. And they're starting to notice that and think about how are we treating them? How are we engaging with these people? And I think women as a particular group have been, like I don't like the word "personality disorder", as if it's something that's probably just a thing that a lot of people have, I don't like being told that somehow your personality is wrong, that you're not "right". And for me, getting the autistic diagnosis helped me understand that no, no we're just different. Just different.

[00:10:47] **Cathie:** I agree, I can't remember the quote, but there's a quote about, you know, there's no one sort of brain that's held in the basement of the Smithsonian Museum that, you know, you compare all of the brains to. And I think equally there's no one perfect personality that you say "this is the perfect personality, and we compare all others to this personality, and *you're* disordered, and you're not". I would very much say that when somebody presents with what is described as Borderline or Emotionally Unstable Personality Disorder, they are trauma responses. And we also know that a lot, and I can say it myself, that a lot of people growing up autistic in a society that's not geared towards autism experience trauma. You know, my secondary education was the worst time in my life. I understand why now. I came out of

school with the equivalent of one GCSE, which is why I never thought I could get a master's, and I only wanted 1% above the pass mark. and I've had to undo that sort of script, and think "I'm not stupid".

[00:12:01] **Lesley:** Yeah, it is about unlearning, and unlearning the masking element that you've done throughout your whole life to try and fit in with something and not know who you are. And I get why the trauma comes through from that. I think that's a common theme, especially for those of us who are late-diagnosed, because you've been through so much.

Understanding Pathological Demand Avoidance (PDA)

[00:12:27] **Lesley:** I'm just thinking about how you and I got to know each other, which was through the PDA Society, which is a problematic term and they admit this themselves as well, it's Pathological Demand Avoidance.

[00:12:39] **Sarah:** Okay, I've heard about this, but can you tell me what that is? Because I'm sure other people won't be totally clear.

[00:12:46] **Lesley:** No, they won't be totally clear. And it's not totally clear, because as a member of that research network, it's going through transitions as people try to understand it more. But I think it was, is it Elizabeth Newson was the first person to identify it, and we can put some links to those articles, and it started as this almost distinct profile within autistic individuals. That, I think, is starting to be questioned around it, and the pathological element, because it's not a diagnosis, that's where you have problems. Because as practitioners, practitioners need a diagnosis in order to know what to then do and what services can be offered. So when there isn't, you get this inconsistent response, and the complexity of PDA means that the autistic rule book that almost practitioners will follow doesn't apply and doesn't work with those individuals. So you need a much more individual-focused strategy because it's, and you jump in Cathie, if I'm getting this wrong as well, but the demands in life trigger a fear response and it's like a panic.

[00:13:55] **Sarah:** So it's everyday demands?

[00:13:57] **Lesley:** Everyday, yeah. For some people, yeah, the idea of, "oh, just brush your hair" or "just brush your teeth", "just get up", "just drink some water". You know, "if you're thirsty just drink some water". It's that idea that they create a very significant challenge for individuals and even though they

want to do things themselves, they find they then *can't*. And it was through that...

[00:14:23] **Sarah:** Like a feeling of being, sorry I'm just trying to understand it, is this about feeling overwhelmed because there are so many of these demands put on us every day? Is that, is that what it is?

[00:14:33] **Lesley:** I mean, it can build up to that, but it's the mere trigger of a demand, any demand, can absolutely knock someone, and school is not a safe space for these individuals I think. Cathie, would you agree that's a safe thing to say?

[00:14:49] **Sarah:** It's nine-to-five demands, isn't it? Sit down, do this, read this, write that.

[00:14:53] **Lesley:** Put your hand up when you need the toilet, wear these itchy clothes, you know, do this, do that, walk this way down a corridor and be told off when you get it wrong.

Exploring the crossover between Autism and ADHD

[00:15:03] **Sarah:** And is this something that's linked to ADHD and, because you mentioned it in context of autism, is it with ADHD that people experience this as well.

[00:15:15] **Cathie:** So I'm very aware of, being autistic with ADHD, I'm very aware of that sort of space in the middle where ADHD meets autism and I would describe it as my ADHD brain is that very creative, loads and loads of ideas, or you want to do all sorts of different things. And then my autistic self is the part for me that wants order and calm and not to be interrupted. And so then they can clash. And I think there is research starting to evolve looking at the interface between autism and ADHD and whether that plays a part in Pathological Demand Avoidance, or a demand-avoidant profile. And so because it can be absolutely overwhelming to have this part of our brains that sort whizz off all over the place, and then part of us that just... "just", there's no "just", I think we should abolish the word!

[00:16:18] **Lesley:** I know I was using the word "just" purposefully then.

[00:16:21] **Cathie:** A part of us that *needs* to have calm, order, everything running smoothly, no pressure whatsoever. Except there are points, and I experience this, when that clash means I have to stop and I cannot do anything. And I just, I just, *don't do*, you know, I might be under a weighted blanket, watching back-to-back Netflix or something to calm.

[00:16:53] **Sarah:** Yeah, yeah. And I'm just gonna say at this point that, so this isn't my area of knowledge or research, I've learned a lot from Lesley because we spend a lot of time just talking in Lesley's office, just chatting away. so I'll probably ask some really obvious, basic questions in this conversation.

[00:17:11] **Lesley:** Oh no, we like questions, we like them Sarah, these questions are the autistic world, because that's how I think, that's how we feel in most situations, that we ask those questions. That's why I think it's great to have somebody like yourself who doesn't know it. You will be in the place of the autistic here, Sarah, I know you're not.

[00:17:33] **Sarah:** Yeah, okay.

[00:17:33] **Lesley:** But you're gonna be neurodivergent for a moment and ask some basic questions for the listeners.

[00:17:42] **Sarah:** I think we're swapping roles because our last series was about research with older people, which isn't your area Lesley.

[00:17:49] **Lesley:** I didn't know what was going on!

[00:17:51] **Sarah:** So this will be my turn. But I was just wondering when you were saying about, and you don't have to talk about your own personal experience, you can answer this however you want to, but I'm hearing more and more about people who do have a diagnosis of autism and ADHD, or have both. Are they really two distinct things? Or is there crossover with them?

[00:18:14] **Cathie:** I think, I can't answer that completely from a factual analysis because I think that's an area that really needs to be researched. I mean it was believed, not that long ago, that somebody couldn't be autistic and have ADHD. Or they couldn't have ADHD and be autistic. So the two were very separate. And I think they are, this is my experience, they are separate conditions or "ways the brain works", and yet, you know, I've got one brain, so they're both in there, and I have to find ways to manage the part of me that

needs calm to the part of me that, it's sort of like a part of my brain that needs to be fed and stimulated and, you know, and that's why I love learning and doing all the things that I do. So I think, yeah, there probably is, there must be, a crossover between the two. It's something I really think needs to be researched.

[00:19:19] **Lesley:** It does, doesn't it? Yeah, it does need to be researched because that's what connects with this, as you were talking about, with the personality disorder diagnosis. Because you can have both of them, and the battle that, as you say Cathie, between the brain that wants order and the brain that wants and thrives on chaos is a daily battle, that could indicate why there would be challenges with that. And why people external to that, like practitioners, would struggle to understand it because it is an emerging understanding of how these different conditions, which are very, very different, so having them in one brain is a challenge, I think that's probably fair to say. So in that sense, I think it's really understandable why practitioners are struggling because the field is not up-to-date yet, but there's so much knowledge out there about the lived experience. Because I think this is where it's shifted, because that lived experience is what's out there now more than the diagnostic, that's behind. Because of the way people present, I mean I get it constantly now on my feeds that I'll get autistic and ADHD feeds of people, and people showing, you know, this is what it's like in my brain, this is what happens. So there's a real positive with that, but there's also a danger then in the power that practitioners have. And that's where something that, you know, I remember it was quite a long time ago I actually did, Cathie won't remember, but I did have Cathie for a phone call as a consultant when I was going through things, trying to understand what this PDA profile was, trying to understand, how to make sense of it. I did an Open University Learn course, like you were saying, Cathie, you went and did your Masters, and I did mine on autism and understood it. And then the training that I then got was *way* behind where my knowledge was. So instead I wanted to understand more about PDA, and when I went into that, the amount of parents in that group, I was the only one that didn't have Child Protection involvement. Which was really worrying, and really concerning as to how this lack of understanding of PDA meant that they were blaming parents for the behaviour. You know, like it's the parents' fault for not getting the child into school, it's the parents' fault for the child having outbursts. You know, it's "bad parenting". And it's not. And that's when I think I then got to know Cathie through the PDA society, and where you, your research has taken, seen what can happen there.

Blaming mothers

[00:22:07] **Cathie:** Yeah. And you know what, it's just, it's not even bad parenting, it's deemed as bad *mothering*.

[00:22:13] **Lesley:** That's true, yes.

[00:22:16] **Cathie:** Because it's the mother, who again is blamed and, you know, things like, well, lack of boundaries. And what we do know about working with somebody who has a PDA profile, or is PDA, is there can't be, you can't cannot implement boundaries. You really have to have a different approach to parenting where the person with PDA and the family is sort of like everyone has to revolve around that person. They need to be in control, which goes against the sort of neurotypical approach to parenting. Parents are in charge, parents set the boundaries, that's what keeps the child safe and happy and they thrive. And the PDA situation, it's different, you know, parents feel like they are treading on eggshells around their child, as in "if I do this, they will become extremely distressed or stop functioning or get very angry or physically aggressive". There has been more highlighting recently of child aggression towards parents because it doesn't come into Child Protection. So when a parent says "my child is beating me up", it's not a Child Protection issue and becomes more of a parenting issue. And yet this is a reality of what lots of families experience. It's very hidden because there's a lot of shame and sort of feeling that, you know, we're not like other people, we need to keep it quiet or we won't be understood.

Fabricated or Induced Illness (FII)

[00:23:56] **Sarah:** So is this what your research is about, Cathie? Is it about parenting and working with children?

[00:24:03] **Cathie:** Okay, what I've been looking at, it's huge actually, it covers, it's just like my fascination, because I have a very, very strong sense of justice, and I'm sort of experiencing, in my work, huge injustice. I cannot put into words what's happening at the moment. So what I'm looking at is working with families where they have children with disabilities, it's not all neurodivergence, it might be physical health problems, genetic disorders and genetic differences, etc., a whole lot of things. And there are thousands of families across the UK, and actually across the world, but we'll focus on the UK, where the parents are being accused of what's called Fabricated or Induced Illness. And that is a condition, it's not a diagnosis, and I *fundamentally* say it is *not* a diagnosis. It is

linked to what used to be called Munchausen Syndrome By Proxy, which is now known as Factitious Disorder Imposed on Another. However, it is not the same because it's not a diagnosis. And Fabricated or Induced Illness is when it's believed that a parent, usually the mother, is exaggerating or making up their child's difficulties, or making their child unwell, for their own gain. And it might be emotional gain, it might be financial gain, getting benefits, getting services. So this is happening, and there's been quite a bit of research recently, Cerebra at the University of Leeds have done some research, and other people, and a high percentage, at least 50% of mothers accused of FII are autistic. So that's huge. And you can have people in a relationship where, you know, there's a mother and a father, and the mother's accused of FII and the father's not. You know... why? And so what happens in this situation is that it comes under child protection, usually under emotional harm. A high percentage of referrals to social care come from education. So if a child isn't able to go into school, so Lesley you were talking about PDA, a PDA child might come to a point where they can't go to school, and so the parents are blamed for that, or the mother's blamed for that. Or a child is in school, they're autistic, ADHD, masking beautifully, and they appear fine in school yet they don't *feel* fine. And when the child gets home all hell lets loose, you know, like we all do really, we're more ourselves in our home environment. And so the school are saying, "well, the child's fine in school, they're not at home, therefore it's a family referral to social care". And another thing which is really concerning is a huge number of referrals for FII come after a parent's made a complaint. So a complaint will trigger the referral. And, you know, I've seen that as quite blatant sometimes. One mother I worked with made a complaint against a child and adolescent mental health service psychiatrist, immediately an FII referral was made to social care and said "this mother's personality disordered". Because one of the criteria, again, which links into here, is with the Royal College Guidance, which has been updated fairly regularly, is one of the criteria is if the mother's got a Borderline Personality Disorder they're more likely to have FII.

[00:28:37] **Lesley:** I just realised they can't see, the listeners can't see our shocked faces. But we're just sitting here in stunned silence about that, because that's horrific Cathie, that's horrible.

[00:28:49] **Sarah:** Yeah. So what you're saying is that predominantly mothers are being accused of this, but being accused incorrectly because actually other things that are going on in the family are not being recognised or picked up on or believed.

[00:29:05] **Cathie:** Yeah. It is huge, absolutely. So I've been working with a human rights lawyer, as some of my colleagues have as well, who are seeking to challenge what's happening from a human rights perspective. And he, when we got together to talk about it, I said, "I'm not putting my email out there because we will be swamped". So he put his, and I haven't got the time to reply, so he put his email out there and we sort of advertised, publicised what he's doing. And the last time I'd spoken to him, which is in the middle of March, he'd been in contact with over 750 parents accused of that. That's far too many, but there's many, many more than that.

[00:29:56] **Lesley:** Yeah, and it's like that because in the work I do I look at the earliest stages of the processes, like where this can start, where the mistakes are made early on through this lack of understanding, through not looking at, when you don't understand how neurodivergence presents in people and how that compares to how practitioners have been taught to assess. To see parenting in a particular way, to see childhood in a particular way, and it looks different. It *is* different. But rather than seeing that as just, "okay, so that's different, but that's this family", they see that as a *risk*. And that risk, that concern, that *fear* starts to escalate. And that's the bit where they end up in those experiences that you're talking about Cathie, where it just keeps going, because then that's like, I remember in my training they talked about it being this "anchored reasoning", that once you've got hold of something you keep looking for the evidence to back that up, and you'll *find* the evidence because you are looking at it in the wrong way. So of course it'll be there because that "difference" will always be there, because it's neurodevelopmental difference.

[00:31:11] **Cathie:** But also if you think of the system for getting an EHCP, an Education, Health and Care Plan, that is meant to be a system to support children with additional needs to access education however they need it, and it should not be on the basis of a diagnosis. And yet parents are forced to, you know, *effectively* forced, to go and get lots of different assessments. So it might be a speech and language therapist, educational psychologist, occupational therapist, all of this to get the child an EHCP. And one of the criteria for Fabricated or Induced Illness is subjecting a child to multiple assessments.

[00:32:02] **Lesley:** Oh gosh.

[00:32:03] **Sarah:** They can't win.

[00:32:04] **Cathie:** Ticks that box straight away. And then there can be things like not attending appointments. So a child might have a CAMHS appointment, can't attend, you know, it could be a child with PDA, or difficulties transitioning from A to B, or they're having a bad day. And so that's another tick box. A parent speaking up for a child. One of my children was, as a young child, a selective mute, didn't speak outside of the house, didn't speak at school, so we had to speak up for him because he couldn't do it himself. And so that's another tick box for Fabricated or Induced Illness. So many, many parents are falling into this, and the consequences are horrific, really, really horrific. I mean, children are in care and they don't want to be in care, parents have had their children removed, for *years* on some occasions, some haven't seen their children for a really long time. And then a child might be removed from a parent and then suddenly all the accusations are dropped, and then the child is back home and they have a very angry young person in the house who's traumatised by what's happened. It's horrific.

[00:33:28] **Lesley:** It is.

[00:33:30] **Cathie:** It is. And there was a big consultation in March at St George's House, Windsor Castle, which I was part of, and FII was described as a sort of modern day witch hunt, and akin to the Post Office scandal. And it is huge, it is really huge, and people are suffering. And yes, there will be parents who exaggerate, will make up their child's difficulties, and yet the system we have is too broad. So too many people are being caught up in this.

[00:34:06] **Sarah:** So is there any value in keeping that lens, or keeping that eye on FII? If, I mean, are most of the cases then in fact *not* cases where parents are...

[00:34:21] **Cathie:** No, I mean the research has shown that most cases end up being quashed quite quickly. And so there have been calls for the Royal College of Paediatrics and Child Health to revise their guidance, or to put their guidance on hold, or to withdraw it. I mean, what I would really like to see happen, as a social worker, is for a complete independent review of all the evidence, somebody, you know, a team of experts who are impartial to look at this, look at the research, look at what is going on, listen to the voices of families affected by FII and create a guidance which encapsulates neurodiversity and difference so that, and there will be people that are missed, there will be families that are missed, and sadly, in the social work profession, it's when we miss that one family and something tragic happens that we end

up being named and shamed and blamed. But at the moment the system isn't working and it's costing probably millions and millions and millions in terms of social care budgets, and the court system, because a lot of these end up in court.

[00:35:41] **Sarah:** This is really news to me, I haven't come across this, so as part of your research are you trying to raise awareness of this as an issue then? Because it sounds horrific.

[00:35:54] **Cathie:** Yeah. I didn't do it on my own, but I was the lead author in the British Association of Social Workers Practice Guide on Fabricated or Induced Illness. And so I feel that offers a really balanced perspective about FII. And I also, with my colleague, and she was the lead author, Dr Fiona Gullon-Scott, we published an article in the British Journal of Social Work, there have been other articles published recently as well, particularly one by my colleague Professor Andy Bilson, who's a professor of social work, and he's looked at, he reviewed lots of cases and his findings are that I think there's been one death where FII was a genuine concern, and the rest aren't, so there isn't a high mortality rate, which is what is being cited by the Royal College of Paediatrics and Child Health. So yeah, it is an area that I'm very, very involved in, I've written book chapters and there's a new book chapter coming out in July, I think, which I've worked with a couple of colleagues to talk particularly about social work practice and FII.

[00:37:20] **Sarah:** OK yeah, because presumably this is an issue for health and social care practitioners more broadly because doctors, nurses, they'll be working with people and perhaps making these assumptions as well. It won't just be coming through to social workers.

[00:37:37] **Cathie:** Yeah, the fundamentals of social work practice is when we train as social workers we learn about the social model, and then there's the social model versus the medical model. And this is a clear example where there's a medical model that says "a person who behaves like this is, they have this condition". There isn't a diagnosis called Fabricated or Induced Illness, without looking at the social aspects, and there needs to be a balance between the two. We need a medical model and we need a social model. We need to find a middle way.

[00:38:21] **Lesley:** And it's not in the media though, I think that's one of the things, it's something that, because I'm obviously aware of it through knowing

you Cathie, and I remember doing the education for social workers and the guidance around FII, but not something that people really talked about very much. And I don't think it's sort of... the awareness element is within academia and some elements of practice rather than actually broader, because these are miscarriages of justice in many respects, like you're talking about bringing in human rights. If you've had 700 people contact, that's actually massive considering how bad that's got for families, because this is then causing trauma to all members of that family, potentially. And it's an example of systems causing that. The systems that are created *apparently* to help are actually causing it. Like the EHCP you mentioned, and we started before recording talking about the Personal Independent Payments applications, that systems are very adversarial and risk averse, and they put *so much* pressure onto the individuals who are already in difficult places and they make it even worse. I don't know what my point for that is.

[00:39:46] **Cathie:** Yeah, well I think the worst bit about this is when a parent is accused, a mother is accused...

[00:39:53] **Lesley:** A mother. Yeah...

[00:39:56] **Cathie:** ...they, because they're meant to be exaggerating or making up their child's difficulties, they don't get any services.

[00:40:03] **Lesley:** Yeah, of course.

[00:40:04] **Cathie:** So they don't get their social care support that's needed, they don't get the health support that's needed.

[00:40:13] **Sarah:** They're disempowered, they're being punished for their circumstances and by being accused of something that's incorrect and they're not being able to access support that they should be able to access.

[00:40:25] **Cathie:** And actually the support is for the child. And so their child or children are not getting the support. So, you know, it's harmful. I mean, effectively, I think being accused of FII can cause more harm in the long run. And I think in itself it can be, it is an irony that it can be a child protection issue when a family is wrongly accused of this, or the trauma that it causes everybody. So it leaves families in positions where they might not be able to work any longer so they can get into debt and poverty, having to pay huge fees for expert reports, legal representation. I've worked with families that have

spent an excess of 200,000 pounds on getting themselves out of an FII accusation. I'm also working with families at the moment where there are a few where their child is in hospital, through a genuine medical condition, and for other reasons they've been accused of FII, and sort of "parent blame", and there are people that have been *arrested*, the police have turned up, the medical team have called the police because of them. That's horrific. So yeah, not only are they having to manage a child who's very unwell, but they're also subject to an investigation.

[00:41:58] **Sarah:** And presumably in the small percentage of cases, whatever that might be, where that *is* what's happening, it's support that's needed there as well, and not these punitive measures of being arrested and punished, because there's something going on for someone to want to put their child through that, if it is a genuine case.

[00:42:23] **Cathie:** Yes, I mean my colleague, Dr Fiona Gullon-Scott talked about this, there's an FII awareness week, it's the first week in May, and we were presenting, and she was saying that when it's believed that somebody has Factitious Disorder Imposed on Another, there is a very, very thorough diagnostic and assessment process, which doesn't rely on one practitioner. And so it's really gaining a psychological profile into somebody, a bit like a forensic psychiatric assessment, so looking at their past behaviour, current, and how that person might behave in the future. However, with FII it can be one person saying "FII", everybody else jumps on the bandwagon and it *sticks*. And the parents don't get a psychological assessment to look at what's going on with them. They are accused.

Key messages for social workers

[00:43:25] **Lesley:** I feel like I need some processing time with all of that, Cathie, but I'm thinking for the practitioners, what would you want to say? So you've got social workers, lots of social workers, generic practice, they don't have the level of expertise in complex issues, which is one of my bugbears, that it's so generic that it means these complex issues are missed. So what key messages would you say to them to help them with what should they be doing?

[00:43:56] **Cathie:** Well, I think fundamentally as social workers, I mean I qualified in the early nineties, I don't know what things are like now, however as social workers, I was trained to question and challenge, and it was to

challenge *any* kind of discrimination. And so I think as social workers we have that authority to be able to do that. That's what we're trained to do. So it is being that voice that dares to question, okay, you're saying this, where's the evidence? You know, what is it? Is it your instinct? I mean, instinct can be right, you know, is it your instinct? Are there facts here that support the case? What is the evidence? So I think it's going in with that. I also am very aware that social workers working in local authorities and other statutory services, there's an immense amount of pressure and the workload's really high, and it is difficult to give the reflective space to think about what is really going on here. And so that is needed as well. It needs us to be able to step back and think, and to work with families where it could be suspected that FII is happening, to work with them, hold that in mind and work with them, and be honest and gradually build up a bigger picture, which is not *solely* through that lens of FII. It's "what is going on here?" Understanding. And also there can be the pressure from management that "we haven't got any money, we can't afford any services", or whoever that comes from. And it doesn't have to be about providing lots and lots of expensive services. It's about listening to parents, listening to the child, understanding what's going on, and being honest when you can't deliver everything because it's not possible. That is a lot. I'm saying that requires a lot from a practitioner if they're working with, you know, they have 40 or more cases, you know, families they're working with on their caseload. But that is what's needed.

[00:46:22] **Lesley:** Yeah. And that open curiosity side to it, isn't it, like you were saying about what else could it be, rather than sticking with "it's this" and finding that evidence to back it up, but what else could it be? What other alternatives are there to what could be going on here?

[00:46:41] **Cathie:** I think one of the other things that I find, and I know I'm quite forthright in saying this, is I can be working with parents and you have a mother accused of FII and I'm very quickly thinking they're autistic or they have ADHD. And so neurodivergence can be missed. And what we do know is, my ADHD consultant said there's a very strong genetic link to ADHD in families. I also know that's relevant with autism. And so if we have a child who a parent is suspecting could be autistic, it's very likely that one or both parents are neurodivergent. From my own experience, and I find this fascinating, is my friends that I've had throughout my adult life, most of them are neurodivergent, and it's almost like we attract people that are like us. And so it's not unusual to have neurodivergent couples, I sort of describe it a bit like I have a dog, she's a bichon frise, she doesn't know she's a bichon frise, she

doesn't know what she looks like, because if she sees herself in the mirror, she barks because she's with a dog. And yet when she's on the beach running, she will instantly know another bichon frise. She will just go to them. And so I think it is a bit like us as neurodivergent people, we sort of go to people that we feel safe with, that get us.

[00:48:23] **Lesley:** Yeah, you gathered them throughout your life. Gathered them together.

[00:48:27] **Cathie:** Yeah. And I've got so many neurodivergent friends that are just, you know, that's how it happened.

Conclusion: The importance of being heard and understood

[00:48:37] **Sarah:** Okay. I think we've got time for one last wrap-up question, Cathie, if that's okay. If you could make any change to the lives of neurodivergent people, what would it be and why?

A big question.

[00:48:49] **Cathie:** Yeah, it is a very big question, and it's a lovely question. It is about being listened to, being understood, and *really* listened to, not being seen as a bunch of deficits, because if you read the DSM-V, the diagnostic criteria, there are a lot of deficits, we are not deficits and we have some brilliant capabilities, and I do, and yet some huge struggles at times as well. And one doesn't outweigh the other. So it's about accepting people as they are. And I think the huge issue is about double empathy, where autistic people will really work hard to try and understand somebody who isn't autistic, but this needs to be two-way, it needs to be two-way communication. And when we don't get something we don't understand it's to say it, not sort of assume. I also work, as well as a social worker I work as a psychotherapist and I'm working with neurodivergent people who so often it's like, "I've got it wrong again, I've got it wrong". And I say, who makes up the rules? It's neurodivergent people who make up the rules about how we communicate. So it can be things like saying someone will come back to them, you know, saying they'll contact them and then they don't. And it's do what you say you're gonna do. And if you can't do it, just say, "I'm really sorry I can't get back to you by the end of the week, something's happened, I'll get back to you next week, if you don't hear from me come back to me". It's that sort of thing. It's really important.

[00:50:45] **Lesley:** I would love practitioners to do that, I would love them to do that Cathie, and it's such a tiny thing.

[00:50:51] **Sarah:** This comes up so much, yeah. I'm doing some research at the minute around adult safeguarding, and this is just coming up time and time again about people saying, lots of different people contacting them, saying they'll get back to them, they don't get back to them, and people just feeling so... neurodivergent, neurotypical, it doesn't matter, for everyone, that would make life so much easier, you know, if people follow through with what they say they're going to do and are clear about their communication.

[00:51:17] **Cathie:** Yeah. And if they can't do it, just say so. Because it leaves a lot of wondering and a lot of anxiety. And that can also, I've seen this as well when neurodivergent people are anxious, or *anyone's* anxious, can get aggressive and more abrupt. And so that creates another set of problems. So it's just clear communication, that's the key.

[00:51:46] **Lesley:** I like that.

[00:51:46] **Sarah:** Thank you so much. This conversation, honestly, it's been, I don't know what word to describe it, because it's not positive, but it is been really inspirational to hear about the work that you're doing, and how you've identified this issue and what you're doing to try and address it. Because it's huge, what you've shared with us today, and I really appreciate you taking the time to come and speak to us.

[00:52:10] **Cathie:** Yeah, thank you.

[00:52:11] **Lesley:** I just want to echo that. I just always feel like, like I want things to change for people. It's very important that things change, because when I look at those things, I think I could have ended up having those negative experiences if things had been different. And I'm very aware of that. And that's horrible. It was horrible enough to experience things without them... I mean, I just can't even imagine how I would feel in those situations, in those parents' situations, and particularly those mothers. And it's not about this idea of virtue signalling and things like that, it's about this genuine, horrendous things are happening to people in society that wider society is not aware of. And this is just one of those issues. And it's really concerning that these things are happening. And I don't think, to go back to the practitioners, we know why people go into social work is *not* to do that harm. They don't go

in for that. And that's *not* intentional. But I think, as practitioners, we need to acknowledge how our practice is being received by people, and what it's like to be on that other side of things that, that you would never want it to be like that, that's not what you wanted to do.

[00:53:35] **Cathie:** But that's, you know what, as somebody I worked with many, many years ago when I was working in the local authority, said, we just need to keep chipping away on the inside. And that's what we do. We just keep chipping away, and that can make a difference. Because we can't change the world, but we can do our bit.

[00:53:53] **Sarah:** Yeah.

[00:53:54] **Lesley:** Excellent.

[00:53:55] **Sarah:** That's a lovely positive thought to end on there, Cathie. Thank you.

[00:53:59] **Cathie:** Okay, thank you.

[00:54:01] **Sarah:** Shall we say bye to our listeners then and we can finish up? So thank you for listening. Thank you for coming in, Cathie. Or not coming in, joining us virtually.

[00:54:12] **Cathie:** Thank you both, yeah.

[00:54:14] **Lesley:** Thank you.

Outro

[00:54:15] **Sarah:** You have been listening to the Portal Podcast, linking research and practice for social work with me, Dr Sarah Lonbay.

[00:54:22] **Lesley:** And Dr Lesley Deacon. And this was funded by the University of Sunderland, edited by Paperghosts, and our theme music is called, *Together We're Stronger* by All Music Seven.

[00:54:32] **Sarah:** And don't forget that you can find a full transcript of today's podcast and links and extra information in our show notes. So anything you

want to follow up from what you've heard today, check out there and you should find some useful extra resources.

See you all next time.

Bye.