**Interview Details**

Project Title: Parents Experiences of their Child Receiving an ADHD Diagnosis in England

Interview date, time, location: 05/04/2023, 05:30-06:30pm, video (Microsoft Teams)

Interviewer: KT (“I”)

Interviewee: Participant 4 (“P4”)

THE BEGINNING OF THE INTERVIEW FOCUSES ON DEMOGRAPHIC INFORMATION AND FAMILY CONTEXT. IN ORDER TO PROTECT PARTICIPANT IDENTITY AND IN LINE WITH REGULATION AROUND DATA PROTECTION, THIS SECTION HAS BEEN WITHHELD PRIOR TO DEPOSITING THIS DOCTORAL THESIS DATA INTO THE UNIVERSITY REPOSITORY.

I: OK, thank you. Well, our, I guess first more ADHD related question is … So can you tell me how it was for you when XXX got the ADHD diagnosis?

P4: I think I felt quite relieved because I hadn't really ever considered ADHD to be an issue like… but there was always something. So XXX is lovely but he's very boisterous and I can be at the bottom of the stairs. He can be midway down the stairs and he'll just go mummy and he'll jump on me. He's 13 years old, he weighs 14 stone and he's 6 foot tall, you know, like and no appreciation. Whether it will be like “that is not, that's not a good idea”.

And so I always got like these little like, you know, I'd get bruises and injuries and different things. Not because he of him being willingly kind of maliciously like point wanting to hurt me but just things like jumping to sit on my lap and and having like a lack of spatial awareness being quite impulsive, being quite hyperactive. You can never have a drink around him because he took it over like... Initially when he cause he's been permanently excluded from primary school when he was sick and then he went to a special needs primary school. So there was a lot of…. And lots of other difficulties with his mental health and self esteem. And and I guess once he'd got into, like, a stabler place, I started noticing that he wasn't wilfully having tantrums and meltdowns. It was more that.

He was having quite impulsive behaviour, so it I guess he would. It was quite late on that for me that I started thinking that maybe that was an issue.

And then when he got diagnosed, I was quite relieved because I think one of the things that I hear from parents of children with ADHD is that their kids get termed naughty and that's that. That is what I wanted to get away from because even though he's doing that behind me, which is irritating…

Just doing it, just say hello.

I: Of course. And that's the different story, isn't there? The story, the, the one maybe beforehand around being naughty and in that sense of relief that you are describing when you got the ADHD diagnosis and thinking ohh it was something else.

Yeah. OK.

P4: Yeah. Yeah, cause I always had that sense of he couldn't do it rather than he was refusing, like I always felt like he wanted to please. And that sometimes he was quite upset when he hadn't pleased. But he didn't really have the skills that he needed. So, like, you might say, all sit there and don't touch anything and then five seconds later he's, you know, touching everything and you just think like, I just said that and he, you know, he'd be like, ohh, I'm really sorry. And I felt like he was sorry. And I felt like he didn't. He hadn't wanted to do it.

He just couldn't quite help himself.

I: Yeah.

P4: So yeah, in some ways it was just a relief.

To have like a kind of an explanation.

I: That's really nice to hear. And on the specific, you know, when you were saying about some, some people would say ohh, he's a naughty child. Tell me a bit more about that, sort of who, what was the context there?

P4: When his school once asked me if I thought he might be a psychopath, which I was just like what? You know, no, I mean he's not malicious. He would never hurt anybody and you know. And you know people.

In indoor play areas you know and I think he… he's never really even … like in terms of like societal norms, like being able to sit at the table and where everyone had finished eating. You know, it's just like those sorts of expectations of him. I've always had to be like. He can't do that. That isn't an explanation uhm expectation that is appropriate for him because he just he couldn't do it.

And. Someone, I think. That there's always been people and I think lots of people say it's your parenting, you know? Well, you know, my children would sit at the table until, like, you know, everyone's finished eating it from five years old. They were doing that would be. Yeah. And it makes you feel really rubbish to think. And that I couldn't get him to do those things. But also I had that sense of… It wasn't because he wasn't willing, but that was something he really struggled with. So I think I eventually learned to kind of bend with him to kind of say, well, you know, sit for 5 minutes and then you can, you know, then you can go play.

I: Yeah.

P4: But I was constantly battling against people who, because of the lack of an explanation, explanation of why kind of made me feel crap about him and the fact that he couldn't do those sorts of things that would class as good like those good behaviours.

I: Yeah.

P4: But also I mean it's had a massive impact on him… in terms of, you know, looking into people knocking things over.

His mental health is much better now, but if you know for a while, he certainly sort of said. “I am. I'm bad. I'm naughty. I'm scary. People are frightened of me”.

I: What was that like for you? What was that like for you?

P4: What was it? I think it that made me very, very sad and also quite frightened because kids are supposed to be happy. You know, they're supposed to be playing and not really a kind of aware of that so far. You know, you got plenty of time to be miserable when you're an adult, don't you? You say you know, so when you've got a young child and they're kind of saying cause he would say things like I just I don't want to wake up. I don't wanna wake up tomorrow.

And.

That way, that's really, really sad, and it made me quite frightened. Um. Ohh.

Of what kind of what that would mean for him and whether or not you know what would that be like in the future for you to deal with. Also he never said that he wanted or that was gonna hurt himself but it still made me feel quite frightened of or for that, that decline in his mental health and wellbeing.

I; Yeah, that makes complete sense. I'm so sorry that you've had these difficult experiences.

And just taking you back a little bit, when you were telling me about other people saying things that made you feel a bit rubbish. Can you tell me a bit more about that feeling about what that was about?

P4: I think mums are judged by their children, so if you've got children who are well turned out, you know nice and tidy and clean and well behaved, then you're a good mum. And I think that, you know, just things like in an indoor play area like pushing a kid out the way and you know, you kind of like being really boisterous and not wanting to share and snatching things off people and you, you're getting judged as well, you know. “Haven't you told your child not to do that?” And you think? “Yes, I have mentioned it about 1000 times, but it's not sinking in”. But yeah.

I think it's those sorts of drip feed of comments on like a daily basis. And then I started to get really uptight. And so lots of no lots of you cannot do that. No, you will not do that. And that really impacted on our relationship and that made it a lot worse.

I; Yeah.

P4: And I think we ended up having familial play therapy for like it's like attachment for bonding and because it got to a point where even if, um, we're not asking him to do something, he wouldn't do it because he didn't like me very much because I was constantly telling him off, constantly moaning at him, and I was stressing myself out trying to make him into what I deemed to be kind of acceptable or normal.

Um. Say it was a bit of a carnival journey to let it go, you know, to let…

I; Very difficult.

P4: Yeah. Ohh.

I: Very difficult and it sounds like you've done a really good job. It's not easy. It's really hard.

Um and going back to the diagnosis and getting the diagnosis.

P4: Ohh.

I; To what extent did you feel like you understood the information that you were given?

At that sort of ADHD diagnostic appointment and we can think about both, if that's helpful, both the private as well as the NHS one.

P4: Ohh yeah.

I think.

The private one, I mean. Um, I did have it like a feeling of is he just saying this because I'm paying him? Like, you know why? I was thinking like cause he was agreeing with everything I had said. Like, you know, I saw that what you were saying and I agree with you and I'm just I was thinking are you saying this because I'm, you know handing you money?

He didn't use as much kind of like …, although his report was quite extensive and we've a lot of his report took a lot of digesting.

I; Yeah.

P4: Um, because there was. It was a lot of information in it.

And I think the NHS one, they were really good.

Explaining it in a way and also I kind of trust them a bit more, which I know sounds stupid because I thought well, you know, you know if you're saying it then it has to be true, you know.

And.

But I think.

I think both of them though, was a kind of a lack of what you do now..

I; Ohh, OK, tell me more about that bit. The lack of what you do now.

P4: Yeah, I don't know what I expected and perhaps I was naive, but I kind of felt like.

They would kind of say, well, okay right, he's got ADHD. Here are your options. We can look at these medicines. We can look at these therapies, these treatments, but there wasn't that.

And I think that when the NHS, because I asked about medications and I was told that the school have to embedded in all of the different strategies and then they have to see how that works and only if it's having a significant impact on his day-to-day life could they consider medication. Not like I particularly wanted it.

To medicate him. But I was worried about him being excluded from school.

I: Hmm.

P4: Because I think you know, we were kind of on last chance, you know, with schools. And I was really worried and I wanted, I guess, what I wanted was for them to do something or for something that would alleviate some of the symptoms so that I could have feel less worries that he would be permanently deleted from school.

Um, and they really they didn't. You know, there was nothing really.

I: Hmm. Yeah.

P4: Ongoing, it was kind of like here. The diagnosis. Here's the information about it.

I: Yeah.

P4: You know, kind of go off and, you know, get on with that kind of thing.

I: Yeah, that's interesting, isn't it. If you could make a recommendation for them, what would you say that they could do to improve the service?

P4: I think it could be created. They should keep you open for longer so there.

So they could kind of you could e-mail or, you know, or phone them up and say this is happening. I'm on the bit worried. What do you know? What do you think I could do?

And they did put me on to the parent factor, which is like an ADHD parenting course.

I: Hmm.

P4: Which was… I'm still waiting to go on it, but that'll be good. Even just to meet other parents. Really it will be good, but. Yeah, I think if they could just not close you immediately so you could go back to them and ask their advice.

I: Hmm.

P4: And who? Even if I'm in the SN school. So in some respects they kind of know what they're doing. But I think if he was in a mainstream school, he might be the first kid with that presentation. So I do think that maybe they ought to like check in with the school in terms of do you know what you're doing?

And because I think that that's the hardest part. I mean his school have changed loads and they do lots of sensory things with him now and they'd give him lots of movement breaks.

And um, yeah. So they kind of chunk things down for him. So he'll do sort of 15 minutes of an activity and then he can switch it off and do something else, which has helped because I think it's that.

You know you will sit there, you will, you know, do their that they find so difficult. So his school have put those things in place, which is nice. But I do wish they'd allowed us to stay open to them for longer. So that if any, if anything, had gone wrong or if I had any kind of queries about things that I could have spoken to them.

I; Hmm. That makes complete sense. What you're saying. Absolutely. Yeah. And I'm curious to know, did you know much about ADHD before this whole process?

P4: Not really, no. To be fair, I kind of thought it was the hyperactivity or that that was my kind of war. ADHD was, was and Cause I was when I started reading about it I thought cause XXX can focus really wonderfully on stuff that he's interested in. In fact, you can't get him to stop focusing on it.

And I cause I was thinking well because he can do that. Then that means he doesn't have ADHD.

And I think it was only kind of going through the process.

I: Yeah.

P4: That was actually quite a lot of different presentations or of it. And you know, just because one person might just be bouncing off the walls like there are lots of different types of presentations of it. So I really didn't know.

I: Yes, it sounds like you've done lots of reading afterwards, which must have helped you know and you him as well when you’re parenting.

P4: Ohh. Ohh yeah yeah.

P4: And um, what do you think about the whole ADHD assessment process and I guess we could do again the private versus the NHS, not that we're like clashing them against each other, but it's interesting to hear both, yeah.

P4: In the end, I mean the private was quick and that's cause um, I had said to CAMHS about doing an ADHD assessment and they said they would do it.

But it was kind of like how long is a piece of string type thing. You know, we'll get to round to it when we'll get round to it kind of thing. And I'd wanted the information to inform the local authority into choosing a school. So I couldn't really wait for that and that's why we went private and I guessed the private is quick so it's like he fitted us in fairly quickly and um and I guess he got to spend quite a bit of time with XXX, which was nice and he spent quite a bit of time with me talking to me.

Yes, that, that was the good bit. But I think that the NHS was much more… the multidisciplinary like things were, there was more people involved.

Um and I thought… That was quite nice because you it wasn't just, um, one person. You got the input of a few different people and they spoke to his school and first of all, they got information on the primary and then the senior school.

Um, which kind of brought them in on it and cause they.

They get to see him in a different setting and.

But I mean, I think that you know the NHS it, it didn’t look into the background for months. It took quite a long time.

I: Yeah.

Hmm.

P4: But you know, they were. They were thorough. You can't really argue that they didn't do a good job. It's just that it's the length of time. They were very, very cautious because they were very reluctant. Whereas the private practitioner? He was kind of like, you know, it's fine. I've seen the education psychology report, I've seen. People have been talking about him being overactive right the way back, I'm willing to say that he has it, but the NHS practitioners they were much more hesitant and much more courteous.

And of not wanting to give a diagnosis for something that could have been attributed, and obviously they were thinking that cause he's had cochlear implants since he was 18 months old. So he can hear and he has been hearing since he was 18 months old.

But they were still concerned cause they didn't really know much. They didn't know enough about deafness to know how much of that would have impacted on his listening and attention in kind of skills.

Hmm.

I: Yeah, that makes a lot of sense what you're saying and just picking up on something that you mentioned there when you were talking about the NHS assessment and how the waiting, you know that it took a longer amount of time. Tell me what that was like for you as a parent.

P4: Um, frustrating. I think that's the overriding thing. It was. It was frustrating.

You know, you’re kind of like chasing it up. And I found it difficult to get hold of national deaf CAMHS. And I was ending up ringing them up saying you need to speak to them. They can't get hold of you. And I was having to kind of, like, try and push it on and wrangle people and find out where they were with different things and get them to talk to each other and chase the school up for them to fill the questionnaire. And all of that kind of stuff. So.

There was a lot more stress than a lot more kind of frustration.

I: Yeah.

P4: And I think it's, you know, I know that it's an inexplicably long time though, you know, you think like what are you doing? How long can this take?

And yeah, so I did find it quite stressful and quite frustrating.

Um, it's kind of, you know, to go through that and the chasing and all the other time it kind of took.

I: Yeah, makes complete absolute sense. You know, to me what you're describing and again, thank you. You know, it's your own thoughts about that. And I'm just looking at my little list and I'm thinking… have you got any thoughts about anything that we've not spoken about yet that you think is really important about this topic? And I've not really asked you.

P4: Yeah, when I can be hones. Only thing is I keep thinking of the way ADHD impacts on mental health and I think.

I mean, I know we touched on it, but I do think that when you have a child who's continuously getting told off and even if you're not continuously thinking about it, cause you're conscious of it like you know, just society as a whole. You know, just sort of and at school and out, like kind of get…

I think that they get it quite rough. Kids with hidden disability, cause it's quite a hidden one like they can speak perfectly. They can behave in a way and I know for my son, I kind of feel like it's like to delay development in some areas because it's almost like a toddler in in some areas where, like they can't sit still like a little kid can't sit still.

I: Yeah.

P4: And asked how come when asked how I think of it like he's still learning those skills in those areas, but I guess.

From an outside perspective, I get there's a lot of people who feel like.

Um.

He should have those skills because of his age.

Even strangers.

Um.

Can kind of say all that kid needs are good hiding. I've had that from like a random person. Um.

I: Ohh.

P4: And you think, by the way, that's illegal. You know, it’s illegal to hit your kids. Did you not see the memo on that one?

I: Ohh.

Hmm.

P4: And I think that all of those things have, they've impacted on my mental health and my wellbeing and they've impacted on XXXs and some of my friends I've got who got kids with ADHD. I think that that's something we all kind of have in common.

And.

I: Yeah.

P4: Plus a lack of understanding and having kids who look like they should be able to do things that they really do struggle to do.

Ohh. Yeah, yeah.

I: Yeah, it completely, you know, agree with everything you've said. This is so really sad actually, isn't it? Um, that society has such expectations from, from the kids in that they are misunderstood. Aren't they often really misunderstood? And that can have an impact, as you say, a real impact. And I guess I'll, I've decided I wasn't going to ask, but I will ask these questions are so if it's a bit repetitive…

Has the ADHD diagnosis made a difference?

P4: It's made me more confident just to say to people actually he's got ADHD and he's gonna really struggle with that and it's made me more confident.

And just to kind of plan like, you know, when we've gone out, we went out with my mum for Mother's Day. I planned something that was outdoors. I planned something that would be a lot of, you know, physical, running around, like doing things. Like we went to the beach. We went and saw the squirrels, you know, and went to the aquarium because I know it sounds like a day for him rather than a day out for me. But I enjoy seeing him happy. And I planned something that took into account the fact that he was going because we've done it before, where we’ve done like a family meal.

Got round in a busy pub and um.

And it's just not gone very well. So I guess it's,… it's confidence to be able to say to people actually know he's not going to be able to do that and it's confidence just kind of think well, I need to accept that he isn't gonna be able to do it and plan. So that I’m taking into account those things. And so I think I it's just I've given myself permission.

To kind of you know.

Not have those expectations on him. Not to say that I don't.

And want him to build. I mean, look, you know, he's left me alone for a good, like, 15 minutes, hasn't he? You know, we're. Yeah, we're building on his ability to tolerate boredom, to find constructive things, to do that don't involve, like, cutting the curtains off or anything. That was strange.

And.

But you know it's given me that confidence to say.

These are the things that he's gonna struggle with and people need to make allowances for that.

Ohh.

I: What a great you know, difference that’s made in you and in in turn for him and for his day-to-day life in in various different situations as well.

Any final thoughts?

P4: Now I hope that your research study helps kind of highlight this news, yeah.

I: I really hope so too.

Ohh, thank you, XXX. It's been wonderful. Let me just pause the recording. Bear with me and I will tell you about the debriefing sheet and voucher and so on. Right.