**Interview Details**

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

Interview date, time, location: 03/04/2023, 06:30-07:30pm, video (Microsoft Teams)

Interviewer: KT (“I”)

Interviewee: Participant 1 (“P1”)

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: I think we've covered sorts of the foundation at this point. Thank you for for being open and sharing. So I guess my first question on topic would be, can you tell me how it was for you when XXX got diagnosed with ADHD?

P1: It made me angry, to be fair, because we we'd sought help for him for years since he was about two years of age. Even his first childminder, so it made me feel angry because obviously the private route isn't cheap.

Um and then to have the the NHS obviously dispute the diagnosis to then feel the need to do it all over again.

I: Hmm.

P1: Yeah, it's it's a very frustrating process for parents, like a ridiculously long process.

I: Yeah. Yeah. No wonder you felt angry.

Can you tell me what was running through your mind when you got that private diagnosis initially? Like, what was some of the thoughts that came to mind?

P1: Just kind of thought I it was what I suspected for years and and just kind of yeah that hopefully now that things will at least look to move forward a little bit in terms of like support wise.

Relieved as well because and I I don't mean this to sound horrible, cause obviously I work for the same organisation. There is a lot of parent blaming that takes place. I think for too long there are a lot of stupid hurdles that you have to go through. There are a lot of parenting courses that you get sent on that we know actually aren't beneficial tactics for children with neurodiversity.

I: Hmm.  
Hmm.

P1: So it's. Yeah, I'm not very complimentary about the NHS pathway for it because I think we know from the children's and family act 2014 actually that that was introduced to be stating about why timely support is very much needed for the child and their family. But to me it gets delayed for as long as possible because it's a cost saving exercise.

I: Okay, that’s really, really challenging. You're describing lots of parts to it, but ultimately a really frustrating battle. And if you could make any recommendations to the services, what would you do?

P1: I guess it's actually abide by um. How NICE guidance and how the Children and Families Act actually states that, you know, services should be undertook because with NICE guidance the child is it's either six or seven and the behaviour seen in two different settings.

I: Okay.

Yeah.

P1: That's not it. That is the key thing. I mean, the impact it's had on my son's education, it's not OK.

I: Yeah, absolutely. So the delaying that you're talking about and you also mentioned waiting times earlier. Can you tell me a little bit more about that aspect of it all?

P1: Um so for CAMHS we just literally, we kept getting turned down. XXX’s first childminder struggled with him when he was approaching 2. She tried to seek early help early, terrible days. His first school. I think school sometimes aren't that helpful. The school SENCO.

I think has a lot to do as well with how swiftly the process goes for parents. My son's first school wasn't that good. They were not helpful, I think because my son academically he's always done OK. They weren't interested, schools aren't interested.

Yeah. Whereas then his second SENCO said “we'll see”. We started asking for help. When XXX was two, he turns 11 in July.

And he's been diagnosed privately in 2022. He's had ticks for three years now. Motor and vocal tics. Again, CAMHS, delayed doing any kind of a referral because apparently there aren't tic disorder services here.

They delayed it so once the referral actually went in, we were seen very quickly and obviously then the Tourette’s diagnosis has, like come, but obviously he had his private assessment last August we had CAMHS have been assessed CAMHS then as soon as he had his private diagnosis and it came back and it said that they then straight away said that they would then have to reassess him again but prior to that they kept turning him down for an assessment. So what then?

I: Ohh.

P1: It makes no sense because privately, we've been told that he has got it. So, yeah. Then we're awaiting next week for CAMHS outcome.

I: OK, so that's a bit up in the air.

P1: Nine years waiting.

I: Yes, very, very long time. Just devastatingly long time. Um, and I guess I'm hearing the anger. When you got the diagnosis, was there any other feelings when you initially got the diagnosis or apart from also? What other feelings were there for you?

P1: A bit of a relief as well that I guess that it was over in a sense that you know, we weren't. Yeah, just I don't really know. Like, you just can't. Really. I I think as well because for us it had been going on for so long just yeah we were just relieved just angry. Just kind of wanting to know like what was gonna happen next in terms of like support wise.

I: Hmm.  
Hmm.

P1: Yeah, cause I I'd always been quite anti medication, but it was kind of one of the first things that we were offered for XXX. So kind of hesitant as well because I didn't. Yeah, like it kind of really hesitant to actually be giving my son medications.

I: Hmm.

P1: And then, yeah, just further annoyed when speaking to CAMHS, who then say that they have to reassess him all over again. Cause we're still currently paying private for his prescriptions.

I: Very frustrating.

So thinking about the private diagnosis, to what extent sort of do you? Did you understand the information that they gave you at the time? How, how was that for you?

P1: To be fair, they were really, really good. I mean, even now we have 3 weekly contacts with them. They send you links for various different like support and training things that they do about like managing your child and their ADHD. They're very good with obviously like the medication reviews and stuff. So to be fair we’re actually really well supported, but I kind of expect that from any kind of a private route because I guess.

I:1 Hmm.

P1: It's different, isn't it, when you're actually paying for a service compared to the NHS service, which is quite quite bad, but still, yeah, like the lady was absolutely lovely. Like she really clearly explained things to me and my son.

And yeah, like.

I: Hmm. Hmm. Hmm.

P1: Everything was very clearly explained about the different areas and stuff and about where he scored and what he scored on.

Um, yeah, I like, can't fault it to be fair.

I: Yeah, that's really helpful. Thank you. And that's just made me think, did they tell you about his ADHD profile, whether he's sort of a combined type both in attentive and hyperactive?.

P1: Yeah, she said that his… Yeah, that he is combined ADHD I think out of like their scoring system was like 52 and he was like 48.

I: OK.

P1: Yeah, they were really, really good. Like they they took background information from me, they took background information from the school. I had a theme provided by his social worker. So I myself felt kind of confident that it was a good assessment because they actually also used. It is not like I just went to a private service just, you know, filled out some questionnaire and then that that was it. They got a statement from the school. I got a statement from the social worker background information.

I: Hmm.

P1: So you've actually got the chronology to be kind of building things off on.

I: Yeah, OK great.

Um, I guess with that you're telling me about the assessment process.

And how this was sort of my next question which you've answered, but I'm wondering did you have many appointments in person or was it virtual, what was the set up like?

Hmm.

P1: No. See all of this was done virtually because I find that actually quite a lot of places, even XXX’s Great Ormond St appointment, it's a lot of things are actually still being done virtually now. I think a lot of services are actually moving things forward that way. So now we yeah, just sent them over like the reports and assessment and then had another assessment afterwards and that was it.

I: OK. Yeah. And do you and again you've sort of answered this question. So sorry if it feels a bit repetitive, but I just wanna capture this clearly. Again, did you know much about ADHD before the diagnosis, would you say?

P1: Yeah, I think because of my background in work, I did seven years in a learning disability setting. I yeah, had quite a good working knowledge. I think of, yeah.

I: Yeah. No, that that's really helpful. Thanks, P1.

And I know that you said earlier you mentioned.

Because we were paying, we sort of were expecting a good service. Then we sort of got a good service then you sort of compared that to the NHS and how that would have been. Can you tell me a little bit more about this sort of the distinction between the two, your thoughts on that?

P1: I think in in terms of like I mean, especially now having also been through the NHS diagnosis route as well and just waiting outcome, I think the level of communication how you’re communicated with.

Um.

You’re treated more respectfully, to be fair down the private route and it shouldn't be that way. But then I also do get like you know like the NHS is stretched in like every service, it's the same where I am.

But I do think that because it is like anything, isn't it, even though the NHS isn't free and I hate when people use that term because it isn't, but because of how.

Yeah, it's, I guess private companies are just better.

It's a different relationship, isn't it? It's a completely different dynamic and I guess that you just kind of do like any service that you go to see, you always expect a certain, you know, good, friendly level of service. And personally, I've just never experienced that from the NHS and CAMHS never at all. The lady to be fair that did his QB test was lovely. But outside of that I think it's very poor standard of communication. I think sometimes they're very rude to parents as well. And I haven't experienced that from \*\*\* at all, like, they're really helpful emails and stuff and you're responded to within a timely manner.

Yeah.

I: Yeah. No, that's really helpful. It's good to hear your honest views about this. And I know I asked you earlier about what would be your recommendations of how they could improve if if we split it into the two. So in terms of private assessment and diagnosis or outcome.

Do you have any recommendations for them?

P1: Um, I guess that testing has to mirror NHS because that's what surprised me is that when we picked somewhere like it did make sure that it actually had links to the NHS. So I would have thought somewhere that is under the NHS, right to choose should have to and should have to use kind of a very similar diagnostic criteria to what the NHS does. However, we were told by CAMHS that like the reason as to why they wouldn't accept it is because it's not the same.

I: Hmm.

P1: Diagnostic criteria. So I was quite alarmed to actually how how can you have private companies that are under an NHS right to choose pathway. So you can have private and NHS patients use them.

Um, but then when it comes to the NHS, then actually taking on that diagnosis, they're refusing it because it isn't done to NHS standard.

It's frustrating as well because then it's yeah, it even though the XXX’s diagnosis now has been accepted on his EHCP and it's accepted by his school, it's currently not been accepted by CAMHS. So to me that, that and obviously still issues mainly for us the fact that any kind of support and his medication I have to get from the private route which is extremely costly.

I: Yeah, of course. Yeah. And you mentioned that you’re waiting for an outcome, is that to do with whether they will accept or not or is that to do with something else?

P1: CAMHS have now assessed him for ADHD themselves, so they have actually undertook their own assessment now. He had his QB test done a couple weeks ago. We had two other appointments with them. CAMHS were also supposed to attend the Great Ormond St appointment with us, but didn't.

I: Ohh OK.

P1: Yeah. So where XXX should be going to their formulation this week and then they will tell us if they feel that he's got ADHD.

I: Yeah, okay.

Wow. So now focusing on the NHS CAMHS sleeve. What would your recommendations be for them and how they could improve the service for assessment and communicating outcome?

P1: Guess it's just to do it appropriately. I mean, like we all know that, you know, there are always going to be people that abuse systems in any system. And I know that, you know, NHS staffing and access has a massive impact on things. But for me it still doesn't justify the way that sometimes parents are responded to. I mean like if you ring up CAMHS, the receptionist at times can just be horrific. If you send e-mail communications you can be waiting over a week for anything back again.

That rationale as well for kind of refusing, even though XXX hit what I would define as the NICE guidance criteria for the fact that school were backing up what I was saying. I was saying these behaviours were at home as well, his social worker said she saw these behaviours.

I: Yeah.

P1: CAMHS, which are still like “no, doesn't fit the criteria”. No further explanation for it at all. So then to all of a sudden like “he's privately got diagnosed and then yes, we're going to assess him”. To me it's just, it's a very poor standard of care. Like it's just delaying things unnecessarily.

I: OK, yeah, and um.

In terms of.

Um.

Since getting here and getting the diagnosis… And you've mentioned some bits around this question already, but will ask you a bit more explicitly how has this diagnosis made well, has it made a difference, I guess?

To him.

P1: Massively. Mainly I think because um... And I think it has been the medication, it has completely changed… like he's on that I can never pronounce it right XXX. So the non-stimulant one because they said that stimulants potentially can made it worse. So even though we still have that, he gets very restless, his tics are getting worse as he gets to pre-puberty.

I: Hmm.

Yeah.

P1: He still doesn't really cope within a mainstream class. You can kind of reason with him better. He's able to kind of concentrate a little bit better than what he did before. He's kind of, he's not as impulsive. We have found that his texts aren't as bad as what they were previously. So I think that that for him it's just gave him a better quality of life. To be fair because he's not standing out as much among his peers.

Um, which hopefully means he goes to secondary school soon and that's always been our biggest concern… that you know, we want him to go to a mainstream school, we want him to be able to engage with his peers.

Sometimes he's a bit too much for other people and he doesn't always see it. Where we're finding that how he's able to kind of interact with people. It isn't as impulsive, so it's made the world of difference going from not being in school to only having one internal exclusion this whole year is just remarkable. It's the best school year that he's had by far.

I: And what's that meant for you?

P1: It's meant that I've not kept getting constant phone calls at work. I've actually stopped doing permanent nights and I'm doing a few more day shifts. Now I don't feel as kind of worry taking him to school, that I'm gonna get a phone call in half an hour's time to come and pick him up. I feel better that he seems better within himself, seeing that he's kind of making stronger friendships this year, hearing back from his school like how he's doing.

Yeah, it's like a massive weight just off my shoulders.

Yeah.

I: Ohh, it's so nice to hear that. Obviously not just for him. Bless him. He's done well, hasn't he? But obviously has a big impact on you too. And how you organise your life, which is positive. And that's not to disregard the really what the challenges you've told me about in terms of this assessment process.

I: You've told me lots about the… what it was like to go through the private assessment and experience what it was like. I guess the NHS is ongoing still.

For you as the mom of XXX… Thinking “I need to get him assessed”… What has that been like for you from an emotional and psychological point of view?

P1: I had to educate myself in family law to get my son home. I had to fight to get his EHCP at both education tribunals.

Um, it feels like everything is a constant, unnecessary battle.

I: Hmm.

Yeah.

P1: It's yeah. As a parent, I shouldn't feel that I have to protect myself from the local authority and from a very shoddy system. I don't. Yeah, it's been absolutely hell. To be fair. Like it's just been horrible. It's just nice that we finally feel like it's starting to get behind us. It's like it's one thing after another sent on, like, pointless courses, just constant hurdles to have to jump over.

I: Hmm.

Hmm.

P1: Um, yeah, it's an absolute joke of a system. To be fair, it's an absolute joke of it. It's within like special educational needs and disability. I mean, I don't know whether it crosses over onto your projects and stuff, but actually 83% of children in foster care are actually suspected to have some kind of form of additional needs. There is a really good researcher called Andy Bilson, and he does quite a lot about how the child protection system is very overreactive and we do find that in too many cases now, parents seek help with their children because they suspect it as additional need and they face parent-blaming for too long rather than support and it does nothing but further destroy families. Like absolutely nothing. I mean XXX’s social worker now is lovely. She's absolutely amazing. But we've had some that have just been ridiculous. Absolutely ridiculous. I mean my son's experienced abuse in a pupil referral unit, he was restrained. He was secluded.

I: Yeah.

P1: Um, all that information was hidden from me.

Had I been listened to when he was younger, had we been appropriately supported? Had they, because for years they just tried to say ohh it's nothing, it's just mum overreacting.

I: In.  
Hmm.

P1: He he would have been through all all of that. It's just left me, yeah, ridiculously angry. I I've got a Council Ombudsman complaint that I won a couple weeks ago as well about their treatment of my son whilst he was under their care. Parents shouldn't have to go through these lamps because ultimately it took time away that I should have spent with my children. It's kind of took. I've yeah, absolutely disgusted in the system. I've got no words at all.

I: Yeah, yeah.

P1: I've got, yeah, it disgusting. Absolutely disgusting.

I: And it makes complete sense why you're angry.  
And you know, given what you've just told me what's happened? It's. Yeah. And I'm really sorry to hear that. It's not been easy.

At all. And I guess to sort of finish things off, um, is there any other thoughts or comments that you might have that you think we've not really talked about that you feel it's important to do with the topic?

P1: No, I think it definitely is a topic that needs to be looked into because you know we… we know statistically about neurodiversity and actually how you get a lot of people kind of… there is a lot of scepticism around ADHD. And I think for a lot of people it's, you know, it's horrible as a mum that for a long time it's just looked at the ohh, you are just a bad parent or you've just got a naughty child or you're just not putting in place proper boundaries when we actually know that, you know, there are a lot more people that have various different invisible kind of conditions.

Um, so now it's just, yeah. Like, I'm quite happy to help. To be fair, it's, you know…

I: Ohh, that makes complete sense. What you're saying in certainly one of the main reasons why I chose this topic and I'm really really thankful… for you know… for taking time to answer my questions and what I'm going to do now is I'm going to stop the recording and then I will explain… I'll send you like a debrief sheet afterwards and I'll explain about the vouchers and all of that stuff, but right, let me just pause this.