**Interview Details**

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

Interview date, time, location: 25/04/2023, 06:30-07:30pm, video (Microsoft Teams)

Interviewer: KT (“I”)

Interviewee: Participant 2 (“P2”)

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: So my first question is in relation to the research topic is can you tell me how it was like for you when your child got the ADHD diagnosis?

P2: Um.

I guess a relief, really. That's probably the first thing that came to mind.  
That kind of acceptance and realisation that XXX's brain is not neurotypical, and a lot of the stuff that she struggles with would then be able to help her with. And then probably…. Yeah, I'd say that was… mostly it was hard, a little bit overwhelming.

Because with any sort of diagnosis you you know you feel.  
A huge amount of emotions, don't you?

But um.

I'm slightly aware that she might still be here, so I'm not answering this question fully, but she's just about to leave and go out so.

Um, yeah, probably relief in the, in the first instance.

I: Yeah, um and thinking about that diagnostic appointment, how did you feel about the information that you were given? At that time.

P2: Um.  
Again, it was…  
It was also a bit of a blur really, and the way that it was done for us is, XXX had her assessment in one room with the clinical psychologist and a specialist occupational therapist, and then XXX and I were in the room next door with a psychiatrist and I'm guessing now I've worked out in my head they were doing the autism assessment bit and the psychiatrist was asking us questions all the way from conception all the way through to now. So we were building that kind of ADHD profile of a child that's struggled but…

They then... We then went to the waiting room and they discussed for 30 odd minutes, I think. And then they bought XXX and I in separately first and then told us.

And then we processed it. We asked the questions that we wanted to at the time and then they brought XXX in and then they explained what they'd found to XXX… obviously in a slightly different way.

I: Hmm.  
Yeah.

P2: Sorry, my wife is adding extras. She's just said something. But yes, she said that she was seen by the psychologist as well, and I think I said that. Yeah, the clinical psychologist and the OT.

I: Yeah.

P2: So yeah, they brought us all together. They explained what they'd found that XXX fit the diagnostic profile for both ADHD and autism.

I: Yeah.

P2: And gave us a bit of time to process it. And then.  
That was it, really. It was quick. It was. It was very quick.

As I said, probably a bit overwhelming and we were all a little bit stunned and a little bit shocked but.

I: Hmm.

P2: As I said, we weren't entirely sure that the autism diagnosis was coming our way, but… With the ADHD, we were expecting that.

I: You were expecting it?

P2: We're then left and then two weeks later they sent us a draft report and of which there was a couple of small errors that we needed amending. And then we've recently…  
Two days ago, got the full final report, so very recently.

I: Right, yes.

Did you know much about ADHD before? Before XXX got the diagnosis?

P2: As I said, we probably suspected it with her since she was seven-ish.  
Seven years old.

I guess maybe being nurses and having scientific brains, we both did a huge amount of research.  
Read lots of books, lots of resources.

But often XXX would struggle when she was with her peers, so they'd be able to sit at the dinner table and eat with a knife and fork, and sit still and not move before the end of the meal. And XXX would be within 10 minutes upside down under the table and not able to use the knife and fork, and struggled a bit more socially. So I think, probably…  
Yeah, about kind of 6-7. We thought that there might have been something slightly different.

I: Yeah. And just taking you back to the bit where you said that you guys did quite a bit of research, you read some books, you sort of looked up things when you noticed that it might be that. Tell me a little bit more about your thinking behind that and how you were feeling.

P2: And I think one of the first books we read was called the Out of Sync Child and…  
And I'm not sure how we came across that book originally. And we also have an adult friend who's got ADHD and a couple of friends whose children have got ADHD. That came a little bit later.

So we read that book and initially it was all very, very sensory for her. Everything was too much and the expectations of being still were too much, loud noises, and she was just so hectic and frantic and all over the place and couldn't concentrate. And it was when she started school that things were very noticeable.

I: Yeah.

P2: At four years old, she was… So she was four in the \*\*\*, and then she started school in September. So she was a very late summer baby. We “um-ed and ah-ed” with keeping her back a year, and because she wasn't developmentally ready, but we didn't.  
And I think at that time you couldn't, I don't know whether you know much about how the school system works, but you couldn't keep a child back and let them start from the beginning. They had to miss the next year, so if she missed the reception, she'd start in year one and that wouldn't have been ideal for her either. So we went with it. And unfortunately now they've changed it. And you can hold a child back a complete school year. That would have done her the world of good, but that wasn't possible then. So we sent her off to school at kind of…

I: Yeah.

P2: …Four years old, knowing that she wasn't ready, and that's when we really started to notice a difference,

I: Tell me emotionally what that was like for you, that emotional side for you as a parent noticing that they might struggle and what this was like for you internally as a parent.

P2: Ohh it was horrible.  
She she went to nursery from nine months old because XXX went back to work and she was in pretty much three days a week. Six hours a day. So she was used to being away from us as her parents.

But school was different.

In the expectation of her being able to sit in a classroom at four years old when she couldn't explain how she was feeling and the overwhelm of the noise and everything, it wasn't very nice.

I: Yeah.

P2: But it didn't sit right with us, and even from when she was tiny, my wife and I thought she'd be better off being home-schooled or she'd be better off in a system that wasn't strict. All the kids in the class and teach them in one way. And don't get me started on the education system because I have issues…

I: Yeah? And I guess the way that the system operates and how it looks after our children, did that have an impact on how you felt as a parent?

P2: Yeah. Um.  
Right from the beginning to me, it doesn't feel like they taught her as a person, as her own entity. She was always clumped in with a classroom and they've got this very stereotypical right from the beginning. You sit down, you listen, you absorb from the teacher. And if you can't learn like that, then you haven't really got a chance.

And still now actually if, you know, if I could move to a country where schooling was very different, I would but…  
I just see it as a babysitting service. You know, we send our kids to these establishments and the government get us to go out to work all day, and we'll pick up at the end of the day, and they churn out a little robot that should be able to, you know, survive in society as it is, and I don't really like any of this, but it wouldn't feel nice as a parent. It still doesn't feel nice really.

I: Yeah.  
Yeah. And taking you back a bit to that first question that I asked you about the bag of feelings you were telling me about the huge mix of feelings and that relief was the first one. Was it a sense of relief?

Because I guess you confirmed some…

P2: Yeah.

I: The I guess what you thought might be going on emotionally. What else was there?

P2: I think with anything I went through, it was a huge amount of emotions in one go. Grief in a way, because this child that I had all these hopes and dreams for might not be able to achieve those things, but I know she will. But at that time it was painful. And loss again for that kid that is going to be slightly different to the one that I thought that I might have. And again, I don't mind that at all.

I think I didn't get emotionally upset, but my wife cried. It was quite overwhelming for her. This has been a long a long journey for us.

I: Hmm.

XXX's been under CAMHS in the NHS for her diagnosis since she was seven.  
Umm, that's five years of build-up. And then I also felt a little bit lost because I now no longer had to fight for something that I have been fighting for for so long. And we often find that even now we spend our evenings talking about what's coming next or…  
But we don't need to do that anymore because we now know that this is the type of brain that XXX has, and now we've just gotta put our focus into helping her in other ways. But yeah, relief definitely was my most overwhelming one. And actually, if, if I'm honest right at the beginning, I didn't want any of this. I just wanted to make it all go away and I wanted for her to be that neurotypical kid that fits into society. And XXX and I used to, we didn't fight but we used to have a difference of opinion that I work in general health and XXX works in mental health, and she was very much for the “we’re doing this is for her mental health”. This is gonna make things easier for us as a family. And I was like, “no, I don't wanna know”. It's not medical. It can't be fixed. Ohh. I went into kind of a bit of a denial, but.

Flipping that on its head at the day of the diagnosis, I felt much more relief and.

I: Yeah.

P2: Kind of calm. And then XXX was the one who was like, ohh, what do we do now?

I: Yes.  
Ohh.

P2: So it was quite strange and I think both being women as well, we both are quite emotional. So there wasn't that traditional masculine like “ohh get on with it” type of person. So you know we probably made it worse.

I: You sound like a wonderful team. Actually, it sounds like you were supporting each other. Going through the motions at different times and you were really solid throughout… As unit, so really well done, it is a really difficult thing to go through because of all the things you've listed. It is huge. As the implications, as you say, for her life and longer term are big, aren't they?

So it is understandable that all these feelings you had were there in that moment. So tell me a bit about this assessment process, you mentioned you've been under services for about 5 years, right? CAMHS and child health. So tell me about specifically the ADHD assessment and what that was like for you as a process.

P2: Okay.  
So XXX was referred to CAMHS via myself and XXX and school when she was six and a half, seven.  
I believe it was her year 2 school teacher who finally saw what we saw. So she saw a child who was desperate to learn, who was very, very keen to please. Enjoyed being in the classroom setting at that point, but really, really struggled to focus and concentrate and she couldn't keep on track. She would often need constant... They used to call I can't remember the way they used to but they used to have to pull her attention back to the work very, very frequently and if left, XXX would just disappear off into her little world where she'd be daydreaming, or she'd be doodling or dancing in her head and doing all these other things that weren't learning in class. So she then developed an almost like her stem. She became a little bit flappy and when she disappeared into this world, she would completely lose focus.

And then when she was put back to whatever they were learning about and she couldn't remember what had been talked about.

So that led us to that. She also became highly anxious at that time, didn't wanna separate from XXX. And struggled going to school.  
Refused to read because there was a lot of pressure around which colour books you were and at what level your reading was, and they used to compare the children to the other classroom children and XXX found that really difficult.

And so it was at that point she was referred to CAMHS and she undertook the “controlling worries” group.  
Which had quite a lot of older children. It actually… she was the youngest one. It was a joint group and there were about eight or nine children, and it was a programme where she went every week.  
And that really, really helped. It showed her how to deal with how she was feeling.  
Um.

And inside this child there's a really quite grown up person that really struggles with the world.

So that was when she was seven. She did that. And at that point we were told that she would be put on the neurodevelopmental pathway.

And then that was when she was seven.  
We then waited 3 years.  
I think… since she was discharged because they said that maybe with the control and worries group should be OK, things settled down at school and then they got worse again and then she was in year 4.  
Trying to remember the year that this was…

This was at a different school because the relationship with the first school completely fell apart.  
Um, they didn't see a child that we saw. They weren't able to help us. And so we moved school. So we moved her to a different Junior School just 10 minutes up the road, the same Academy with a different head teacher, and they saw a child that was struggling. So again she was referred to CAMHS. Then when she was 8 years old, I think.

I: Yeah.

P2: And then once she was referred back in, they finally put her on the ND pathway. They then changed how the whole process works. And they've changed from a diagnostic-led to a needs-led service. So they got rid of the ND pathway and they implemented this tool called the ND profiling tool. But because XXX had already been referred in, she stayed on the pathway.  
We hounded them absolutely hounded them because every time we rang, they were, we were told she was 187th on the list. You've got another 18 months to wait and eventually we got a phone call to say that they were going to do something called a QB test.

I: Yeah.

P2: You may have heard of that. They attach the camera on the child's head and they have to… anyway… She scored off the scale on the QB test.

It said that her inattention was more than 99% of every other child on the test, so it very, very highly indicated ADHD. So with that, they were then going to put her in the next queue.  
For assessment by psychiatrists. And it was at that point with the QB test she was in year 7. And so yeah five years. So that was three years between that referral and the QB test. And then we were told there was gonna be another 18 months wait.  
And at that point, it was just too much for us. So we researched private.

We spoke to CAMHS and they gave us the details of the one that they outsourced to and because they're overwhelmed and they've got the huge waiting lists. So we went privately to the one that they recommended.

I: Yeah.

P2: And as I say, yeah, just last week we got the final report.

I: So it's been a long journey. What you're describing, with lots of steps in a very sort of quite a complex sounding process. Thinking about that in a nutshell, can you describe to me you as the parent trying to navigate this, what that was like for you?

P2: It was horrific, absolutely horrific.  
I'm educated and I found it absolutely soul destroying because I have this young person who I'm responsible for who was telling me that they weren't coping.  
Um, I can't use any more words than that. I would not wish what we've been through on anyone.

The support was non-existent every time we tried to make a phone call or contact someone or e-mail. It took weeks to get a response.  
And I work for the NHS myself and I know that we're massively overstretched and…  
But we never, ever felt like we would be listened to.

I: Yeah.

P2: I would, I would almost say it was traumatic, really, for all of us.

I: Ohh, I'm sorry to hear that. That's really sad and I guess coming with this experience from your perspective, what would be some of the… have you got any recommendations for our services? What do you think they can do better? You were just saying you never felt listened to. What can they do to change?

P2: I know there's waiting lists and I know that the services are massively oversubscribed, but just that.  
Just feeling heard and feeling listened to rather than… Be abrupt. “Ohh yeah, you're 187th on the list and we'll get back to you when we can”. And then nothing more. And we were signposted on very few occasions for some books and some literature and some… And you know, kind of different organisations that may be able to help us, but when you're feeling already at a loss for what to do that doesn't help you. You don't really have the energy to look into those things when just getting your child up to go to school was hard enough in itself.

I: Hmm yeah.

P2: But then again, I don't know how you can fix it because there's no money, so you can't say I want 10 more educational psychologists or 15 more psychiatrists. Because where I live, there is this one educational psychologist for the whole city. And I live in a massively overpopulated city and…  
And I think there are two prescribing psychiatrists that deal with ADHD and the medicine side of stuff.  
And there's a nine and a half-ten month wait for a child to even be seen to get the medicines prescribed. So if you're gonna go down that route…  
Yeah, I don't know. I don't know what to say really. I just feel that it's a rubbish system.

I: It makes sense and it's really helpful to hear your honest views about it. And I guess how has the ADHD diagnosis made a difference to you as a parent?

P2: Um.  
It it, it's really, really changed things. XXX's owning her quirks and she now is able to understand why she behaves in some of the ways that she behaves in.  
She's taken... She's nearly 13 and she's a typical teenager and that she's taken to now calling herself special, which initially I thought was.

A bit odd, but actually she explained it to me the other night and she went “no, I don't mean special as in, she does an impression of \*\*\*. This really bad and non-PC but.

I: It's OK.

P2: She does this thing and I'm like, no, no she's like, “I don't mean that special. I mean special as in I'm different”. So she started to to kind of embrace that and she is absolutely wild when she's on top form. Today, for example, she came home from school and she was 110, like she was off the scale ADHD wild but…  
And then she had her school friend with her, and she was able to say “Ohh. I'm like this because of this” and it just gives her that kind of, almost like a “It's OK that this is how you are”. Whereas before she used to be really upset that she was different or get really crossed with ourselves. She still does. Absolutely, but…  
And yeah, it's helped her. Definitely.

I: How does it make you feel when she's gained an understanding of herself when she's being more kind to herself and starts to like herself with her own quirks? How does that make you feel?

P2: It's just great. It's… It's what you want as a parent, isn't it? You… all you want is your children to be happy and…  
You know, there's typical parent things: I want her to be polite and I want her to be kind and I want all of those things of which she is. But her happiness is the most important thing. And if she's happy, I'm happy.

I: Yeah.

P2: It does have like a complete knock on effect and I think I guess like with any parent that's what you want, isn't it?

I: Yeah. And I'm wondering…

P2: But yeah, it also makes me. It makes me proud, actually, that she's finally realised that she's the kid that I've always thought she was.

I: Ohh, that's lovely. That's so nice to hear. XXX. That's lovely. Good. Well done, XXX.  
And XXX, in terms of your own confidence in your parenting skills, has the ADHD diagnosis made any impact on that, on how you see yourself as a parent?

I: Um, yeah, I guess it has. Um.

There are things that I've learnt along the way, you know, things that I might have picked up from my parents when I was younger and I used to say to XXX. Yeah, you constantly nag. Stop doing that. Make sure you say thank you. Make sure you say please and all of that, the niceties that you teach your children and speak properly and pronounce your letters properly. And actually I know that she knows all of that stuff, but I don't need to tell her every time. And I we now pick our battles as well. We only you know they're… there are hard rules. No, no swearing and no rudeness and absolutely no real back chat and nastiness. But other than that, it seems a much happier household. We're not constantly bickering.  
Um.

Yeah. I don't know. I think we've always done quite a good job. She's quite a spoiled single child. Very much wanted, you know, she was an IVF baby and…  
Yeah, it's good. It's actually a really good time. At the moment, I think.

I: Ohh, that's fantastic. That's so nice to hear.  
Thank you for sharing again, I'm just looking at my little prompts on the left that I've not missed out anything. If you just bear with me one second.

I'm curious in that appointment where they gave you the diagnosis and they said “right, she does have ADHD”. What's the first thing that went through your mind? Do you remember?

P2: The very first thing.  
I think I probably thought.  
I'm gonna swear now. I probably thought like “ohh shit” like they've confirmed what we've always thought and.  
I think because it came alongside the autism diagnosis as well, it was a bit different to how I expected to feel, but.

I: Yeah, yeah.  
Ohh.

P2: I would go back to just that relief of the last five years of fighting a battle were actually over, although they aren't because we've now got to go back to CAMHS and ask for medication and stuff, so we're ready for the next battle. But.  
OK, that probably was…  
“Oh my God. Am I going to get some of my life back? Am I going to get some of my time back with my wife?” In some of this stuff that we enjoy doing rather than reading through reams and reams of evidence and books and…  
Yeah, it was definitely a really tough time.

I: Yeah. And another thing I forgot to ask is, has there been any negatives of getting an ADHD diagnosis, do you think?

P2: For XXX the ADHD? No, none. She always… We've always been open with her and we've always said that we think that her brain works slightly differently.  
Um, we were very open family, we've talked. She knows about her conception and all of that stuff, so that wasn't a surprise at all. And she actually took that because she was like, I think she said, “well, I already knew that anyway”.

I: Yeah.

P2: But again, you know you got the flipside of the autism one and that did cause some trouble because she was saying, “well, I'm not a special kid”. I'm not autistic.

I: Yeah. Yeah.

P2: Autistic boys who were very robotic and she's like “I'm not like any of that” and she's very.

I: Yeah, girls are like that.

P2: Able to not seem autistic, if that's makes sense. Girls are quite good at hiding it and masking it.

I: Yeah.

P2: Um.  
But the more we speak about it openly.  
And the more she sees that she is, she's even told her friends now, which is amazing.

I: Wow.  
Hmm.

P2: And she didn't want to. She was happy for them all to know that she had ADHD because she likes being bouncy. She likes being the clown and the centre of attention.  
And with that, she doesn't need much sleep, and she's always up early in the morning, and she's always on the go. And her friends yawning away in the corner after a day at school. And she's like, come on, come on, let's go on the trampoline and constantly wild.

I: Yeah.

P2: But um, the autism one? That was a bit different. She was like, I don't want anyone to know cause I'm not. She went through a phase of calling herself a bit of a weirdo. And I'm like, you're not. You're not. It's just your brain. You're the same person. But I heard her say ohh, that's because I'm autistic the other day and I didn't think I'd hear her say that. So she started to accept that one as well. Bless her.

I: Wow, yes.

P2: But yeah, the ADHD was fine. She knew it was coming.

I: Great. Yeah. Really positive. Is there any final thoughts or comments or questions that you might wanna share that you think I might not have asked you about?

P2: No, not really, I think I've that the drive for me to do this was if this can be used to help a broken system that destroys families.  
That's why I wanted to do it, because now we're all very cohesive and XXX's happy and XXX and I's relationship is good. But when you're going through the trauma of fighting for your child, it's awful.  
Um, we were arguing a lot, XXX and I… to the point that we even ended up possibly separating at one point, and it would have been over this. This is what caused us all of our difficulties.

I: Wow.

P2: Um, so yeah, I just feel it needs to be. It needs to be fixed, but then so does the whole of the education system. So I don't think it's gonna be fixed overnight.

I: Yeah.

P2: What I hope is we're still in limbo ourselves is that we've had to submit our private diagnosis to CAMHS and.  
Hopefully because we used a service that they accept, they will accept that diagnosis and then put her on the waiting list for ADHD meds.  
At the moment XXX doesn't want them. She doesn't want to change. She's happy how she is.  
But we would like to have that ability for her to have them. It was recommended in the report of private report that she did try them to.

I: This is it.

P:3 The slow active fast acting ones. Well, she's at school to help with her attention and concentration, but she said no at the moment and we'll be absolutely guided by her.

I; Yeah.  
Hmm.

P2: But maybe for her exams later, when she's older, she might see a benefit to them then and…  
I've just had no clarification from anyone anywhere as to whether that is even gonna be possible, or whether we're gonna have to buy her prescriptions privately.

I: Yeah.

P2: So that's where we're at next. But if I could make this journey any easier for anyone, just one person. If I could make it nicer because…  
You've got groups on social media about, you know, lots of people, all in the same position and then you speak to older people who say, oh, oh, they say ADHD and autism. That wasn't diagnosed in my day. What's going on now. And actually it probably isn't that there wasn't autistic people with a ADHD, it's just that they were probably hidden away. In the asylum, and they weren't looked after appropriately. And now it's becoming, well, people like you and experts making it more aware that… There are lots of people with these conditions that exist in the system. That just doesn't work for them.  
But yeah, it's just that fight, wasn't it?

I: It hasn't worked for you as parents either, as you tried to advocate for your for your child and I'm really sorry to hear that. Obviously it was so stressful going through it that it pushed your… you know, your relationship with your with your wife to the point where you were even considering separating that just really, really sad to hear. And it must have had an impact on XXX as well. If that was happening. So I'm really pleased to hear that you… This has passed. This is in the past.

P2: Yeah. No, we are, yeah. It's a good place.

I: Well, that's good. Um, but yeah, thank you so much for spending some time with me and sharing your experiences. I will pause the recording now as we finish the questions and then I'll talk you through sort of what happens next basically, right.