

Bozo

Lugonja:

Hello and welcome to Piece of Mind, a podcast looking at mental health and psychiatric conditions and the science behind them. My name is Bozo Lugonja. I am the research coordinator for the National Centre for Mental Health here at Cardiff University in the Hadyn Ellis Building, and we are bringing you conversations from patients affected by these conditions alongside researchers working at furthering the understanding of an incredibly complex area of psychology, psychiatry and biology. In this episode, we are talking about ADHD. I would like to welcome our guests for this episode, Professor Anita Thapar, who is professor of psychological medicine and clinical neurosciences, and Zoe Piper, who will speak to us about her experiences with ADHD. Thank you very much, both of you, for agreeing to take part in this and speaking to each other and speaking to us about what ADHD is. I think it is probably best to start off with some introduction, basically as to what your experiences are and how you got involved with ADHD. So, Anita, how did you get involved with ADHD research and could you tell us a little bit more about what is ADHD, the causes and symptoms and prevalence and that kind of thing?

Anita

Thapar:

Yeah, sure. I really got interested in ADHD coming from two angles because I am a researcher and a clinician, and I was doing research on the different causes of child mental health problems and child difficulties. This is back in the early 1990s, and at that time, we did not know much about genetics and genetic contributions to these sort of children's difficulties. I remember being really struck because I had a clinic where I had a family with around 5 or 6 children, all of whom had ADHD and that has really stuck in my memory. And I got really interested then as to what was the genetic contribution. I mean actually, this was a time when I had just started research because I had really started mainly as a clinician, and we and other groups then found around that time ADHD was highly heritable. There was a strong genetic contribution. What I mean by that is that most medical conditions, ADHD included, are not entirely explained by genes, they are multifactorial, there are multiple genes and environmental risk factors, it is not a single gene, but nevertheless, ADHD like autism came out as very highly heritable. So that is really what got me interested then in pursuing more about the genetics. In terms of what ADHD is, it is a brain disorder that starts typically from early childhood although it might not present in that age group necessarily. The core symptoms are marked severe overactivity, when children are young, this could be that they are not able to sit still, fidget a lot. When people get older, that is more a feeling of inner restlessness, the physical overactivity is not as marked. There is also a severe concentration problem and also impulsiveness, acting before thinking, not being able to wait your turn. Most people recognise these symptoms, they are not sort of problems that we do not understand, and so sometimes that can result in misunderstanding, but there are lots of issues in medicine like that. When we talk about a diagnosis of ADHD, we are talking about this constellation, this cluster of symptoms that are really severe, at the severe end, and they have got to be interfering with someone's function,

so you know they are failing academically or in work. They are not being able to manage relationships. It has got to be interfering, and also another criterion is that you cannot have these symptoms just in one setting, it is not just say for example the child that is reported just at home, it has got to be present in other situations. For adults, it is a problem in work. So, we are talking about a severe set of problems.

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Lugonja: So Zoe, what is your experience with ADHD and could you just introduce yourself and some of the work you do?

Zoe

Piper: Yeah, my name is Zoe Piper, as you have already said, and I started the charity ADHD Connections around 4 years ago. That was started purely through need of desperation, of needing to find other people experiencing what I was. I have got a son who is now 14. He was diagnosed with ADHD at the age of 6, and even before that, 18 months to 2 years, our problems began, and I felt alone, desperate, isolated and just needed to find other families really who I needed support from them and they need support from me, and I got a great network now of families that we help support each other. I have learned so much from the families and I get a lot of help and support in terms of behaviour management, being able to ask questions and get advice and things like that, and that has been my strength through my journey so far.

Bozo

Lugonja: So I am sorry to interrupt you, but some of the symptoms that Anita says, does that relate to your son? Is that the kind of thing that you were noticing in him from early age?

Zoe

Piper: Yeah, definitely. Around the age of 18 months, there were things that I recognised in him, I did not know what it was at that time, but I struggled to manage his behaviour. He was like a bottle of pop, he was just on the go constantly. He would be quite relaxed then all of a sudden he would just explode into this Tasmanian devil really. He will be just going from this to that. I used to find behaviour such as repetitive things that he used to do and liked to watch certain films all the time, and that he really, really struggled in school. I mean he was 3 years old and expelled from his first school. He did not see consequences in his actions. I picked him up one day and he painted himself green. He ran out of school, "Oh, mum, I am the hulk." He was so proud of himself. However, it did not go down to wow the school. He then... obviously the older he got in a school environment, more was expected from him and I noticed then really that the concentration side of it was really, really having an impact on his education. I honestly believe that his education did not start until he was able to manage his symptoms and that then was through medication and that then allowed him the ability to concentrate for long enough to kind of get some work in there.

Bozo

Lugonja: So one of the things we try and do in this podcast is kind of like get rid of any misconceptions, myths or stigmas and it is really interesting that you both talked about how young an age the ADHD can be essentially diagnosed. And a lot of people would say, well, if a child is about 18 months or 2 years old or 3, are they not just misbehaving? Are they not just being, you know, kids or toddlers?

Zoe

Piper: I think that is why they leave kind of diagnosing until 6, 7, 8 and from then onwards. I think up until then they expect the maturity of the child to kind of grow out of certain behaviours, but unfortunately, if you have got a child with ADHD, those behaviours, they would not grow out to them on their own. They might be able to control a little bit more, but unfortunately, those behaviours that you have seen at 2 or 3 still carry on and that is where it impacts then in school and things like that.

Bozo

Lugonja: So we talked about it being primarily a childhood disease, but it can be diagnosed in adults as well. Is it being more readily diagnosed in adults as adults are more aware that perhaps they might have ADHD but they have never been diagnosed? Is that something you both came across or found?

Zoe

Piper: For me personally, I was diagnosed with ADHD three years ago, and off the back of my child having ADHD and as soon as my son's consultant said to me, "I think you need to go and be seen, I think you have ADHD and that is where Dylan got it from." It was just like a light bulb has just gone off and for the first time in my life, I understood myself. I understood why I behave in a certain way, why I struggled so much growing out with friendships and things like that, and it helped me tremendously to get that clarification of actually this is why.

Bozo

Lugonja: So the diagnosis helped you understand?

Zoe

Piper: Yeah, I mean some people say what is the point of having the diagnosis, you know, you are an adult now, what is the point. For me, it was being able to understand myself and why I am a certain way, so yeah, it most definitely helped me tremendously.

Bozo

Lugonja: Do you find often, Anita, is that a rare occurrence that people would be diagnosed in adulthood or is it more common now?

Anita

Thapar: It is interesting. ADHD and another child neurodevelopmental disorder, autism, that begin these brain disorders that start very early, people used to think children grow out of it. It is interesting because it relates to a

point that Zoe was making earlier that actually children change overtime as do teenagers, so generally, we become less active with age. People's concentration improves from the age of 2 till 18. So there is a general population improvement. Of course, people with ADHD, there is change, however, they do not catch up with people in the general population. There is still... lots of studies are showing there is still a lag and actually, follow-up studies that have followed up people with ADHD until adult, while some do improve, a substantial proportion remain with just a full-blown diagnosis or are impaired by what is called residual symptoms. So yes, I think there is a recognition now that actually this is not just something that people grow out of and as a result, people... there are two ways that this has become an issue for adult services. One is that children come out at the end of children services and then there is an issue of where do they go next, and that transition, a lot of people fall through the gap. And that is actually a really important issue at the moment. Services are beginning to pick up on adults, but it varies across the country. The second way is people who have perhaps had problems through childhood but they have never been picked up, particularly females, because with female ADHD and autism, there are certain types of characteristics, perhaps less behaviour disturbance that they might not get picked up and so the proportion of females picked up later tends to then be higher.

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Lugonja: So more females are being picked up later on and more males at a younger age, so does that feed into the misconception that it is largely a male disorder at a younger age?

Anita

Thapar: Basically, the studies have been done not of clinic population, so there is a male excess and for newer developmental disorders, ADHD, autism, epilepsy, there tends to be a male excess. So it is about 3 to 4 boys for every girl if you just look in the population. However, when you get to clinic, that rate then goes up to about 7 to 8 boys to every girl, which means the girls are not being picked up. However, that gap between boy and girl tends to be less in surveys at adult clinics, and there are two reasons. One is girls could get picked up. The second, unfortunate, is that boys who started off with very early severe problems could end up in services other than health services, and there is a lot of research on that. Sadly, they end up going, not everyone of course, but some will end up in prison services or in other sorts of... you know, they fall out of health services because obviously you need quite a lot of organisational skills to access health and once you are out of the educational system, then that can be difficult for some people.

Bozo

Lugonja: Yeah, absolutely. I think that is a very interesting point when you think about the societal pressures and why performing more research in understanding childhood developmental disorders we might be able to pick up on people who would quite sadly slip through the cracks or something like that to be able to help them at an early age to get them

into the services they need for them to be able to ultimately fulfil their potential. So Zoe, with your experience with ADHD, does that help you understand your son a little bit better? Do you feel like it is something that you share with him or...?

Zoe

Piper: It is definitely. We have got a bond like I have not got with my other children. We kind of just get each other. We kind of just look at each other and we know, and he has got like this little wickedness about him but it is really, really a positive one. I think for me, one of the biggest areas now that are letting him down is the education system. I feel that we got a fantastic CAMHS support and it does not matter what, you know, we seem to do with his medication and help at home and things like that. When he goes into the education system, that is where the biggest failing for me is because it is not understood, and I think that is one of the biggest areas that need looking at really.

Bozo

Lugonja: For anyone who does not know, could you say what CAMHS is?

Zoe

Piper: Sorry, it is the child and adolescent mental health service. So, for me, that is where his struggle is and what Anita said earlier about children falling through the gaps. I know he will be lucky to come out of school with only GCSEs. I would be very, very surprised if he did. So where does he go at 16, and if he does not carry on with an education, what does he do, and that is where I am really worried about him kind of getting into trouble, and he is more of a young adult then and it is his decision to take the medications, things like that, so that is going to be a massive test of time and I think a lot of patience and understanding is going to be needed at that time.

Bozo

Lugonja: How does the adult services compare to the child services?

Zoe

Piper: I mean I was seen last in clinic around two years ago. I mean, you are meant to be seen I think every six months and I went to a consultation with another adult who has now been diagnosed with ADHD and I was told that he does not have ADHD because adults do not get it. So I think services for adults are miles behind for that of children and I think all that the service is trying to do when you are a child. As you get to be an adult, that is where there is a massive problem. And to me, they need more than, they need a lot more guidance and a lot more reassurance to keep... well, to be just aware of their own condition and how to manage it. Not just through medication, but you know, through recognising their own behaviour. I mean, I do not take medication very often, I only take it when I know I have got to think before I speak and maybe today should have been a good day to actually take it. But you know, I choose just to recognise myself when to act appropriately and things like that.

Bozo

Lugonja: So do you think that there is a case of stigma still affecting ADHD? I mean, has the perception changed? Has it got better? Has it got worse? Or are we still in a place now where there is still a lot of stigma attached to it like they would have been with other conditions a long time ago? What you both think?

Zoe

Piper: Massively. It has still got a massive stigma over it. I do not know why because I mean more and more research is coming out that is showing it is a real condition. It is something that cannot be helped.

Bozo

Lugonja: That is an interesting one because that is one of the things I came across when I was reading about ADHD before, is that "ADHD is not real," it is just misbehaviour or something like that.

Zoe

Piper: I wish it was because you can help with behaviour. You can go to parenting classes, you can try and help your child in that way, but with ADHD, you can try and try and try as much as you want, it is not going to change that behaviour the same. It just takes a lot, lot longer.

Bozo

Lugonja: What do you think, Anita? Is it frustrating for you as a researcher when you are working in the field where people are saying "actually the condition you are working on is not a real thing."

Anita

Thapar: It is interesting because people do say that. However, I would say that was one of the reasons why I decided I would focus on ADHD research. When I went into psychiatry, because I was thinking should I do psychiatry or paediatrics after a medical student because I thought you can really make a difference here because there is so much stigma. And obviously people go into medicine to help people. I thought this is something. And then, I could see with ADHD, there is so much misunderstanding and stigma and I am really driven to do the research because there is not any point arguing about things and having sort of arguing in terms of opinions. You actually have to generate scientific findings and you know medicine is full of... if you look at the history of medicine, there's loads of examples of misunderstandings and faulty understanding of things and all sorts of odd understanding about different conditions. But the only way you're going to tackle this is through science and research and taking a dispassionate view as to what are the causes, how does it happen, what is going to help it. I do think that the stigma is still there. I mean, it does make me think, "Gosh, what must it be like for the people I've seen in clinic and their families and people do say we don't want to tell people." It is quite interesting because sometimes I see people even from the medical profession, they do not want to sort of tell people because I think it would be really helpful for people to know that you come from all strata and people don't want to discuss it, and you

know, there is a lot of I think stigma about doing the research. It isn't a cool disorder. I mean, even amongst the mental health disorders, and you know, sometimes my colleagues say, "why don't you work on autism? There's so much more funding there. It's cool. You know, you're a nice person. You don't get e-mails telling you 'oh, why are you doing this?'" But it makes me want to do it even more because I think well, what about the people who've got this?

Bozo

Lugonja:

Absolutely. That is a really good way of looking at it. The way I've looked at a lot of these conditions since working in mental health is when you go back 30 to 40 years and look at things like cancer, you look at things like AIDS, where there was these huge stigmas and misconceptions and misunderstandings, and now because they are mainstream and they are funded very, very well, people are quite happy to come out and say if they have had the condition, and it is only by knowing people with condition A, B, C, whatever, they have that human element and they understand that it actually can affect anyone. It is very widespread and a lot of these conditions are, especially mental health conditions. One of the things that we do at NCMH is that we always encourage people to get involved with the research, and one of the ways you can do this by getting involved is going onto ncmh.info and becoming a participant or get involved in our engagement. Anita, have you, and Zoe actually, you obviously both have been involved in research, how did you guys meet initially? You've known each other for a while beforehand. This isn't the first time you've met, is it?

Zoe

Piper:

No. I met Anita when I went to a seminar that Anita held in Cardiff University and from then, I've got my strength from the research that Anita has done. It has given me that fight to say no, it's real and this is why. If it wasn't for the work that Anita and her team had done, we would still be, we would be even further behind. At least now, we've got something concrete there to kind of show, and I'm so grateful from the first time that we've met and we've actually carried on then and had many conversations really about ADHD.

Bozo

Lugonja:

So obviously, it must help having people like Zoe get involved who actually had the experience with ADHD in the research and be able to kind of like explain to people how to get involved in the research. Do you think there is an issue with people getting involved, not just in ADHD research, but mental health research in general?

Anita

Thapar:

Yeah. I think it is really an important issue. I mean you highlight really well about cancer. I remember when I was a medical student, we did not say the word cancer, we said neoplastic growth. We used all sorts of abbreviations to avoid saying the word because there was so much stigma about it. Now, one in six people with cancer participate in research. We know much more about how it... you know what causes it,

having new treatments. HIV is another example where there was a lot of stigma, masses of research. This is what needs to happen in mental health, and I think one of the hardest things about mental health, I mean ADHD is a good example, is these are really stressful chronic conditions where actually there is not much support. If you had a chronic disease like diabetes, there would be constant monitoring, management lifestyle, and we have not got parity yet for mental health with physical health. I honestly believe that, you know, one of the ways that we've got to tackle this is through the science and the research. It is not the only way. I think what people like Zoe who are right on the ground are really important, not just for us to know about getting what it's like to have the experience of ADHD but also to provide support when there aren't enough services at the moment. But I think if we are thinking about the future and maybe the next generation, we do need the research and we want figures like 1 in 6 for ADHD and mental health. It is vastly lower, the figures for participation, and of course it is difficult because these are stressful conditions but until we have the most impaired or unwell people participating, we are not going to know very much about these conditions and then services aren't going to follow.

Bozo

Lugonja:

I think ADHD is something that growing up I didn't know much about. There were a lot more I think in terms of autism and Asperger's. I did understand to be honest because I had people in my classroom in school who had these diagnoses so you'd understand that you'd have a friend who may have it. But then ADHD was always something that no one really spoke about, so I think it is really important especially with what you do, Zoe, to be able to make it into the mainstream, into the media. Is there any positive or negative media depiction of ADHD that you've seen that you think you can give an example of that is good or bad or how can we improve it? How can we improve the image of basically someone saying actually I've got ADHD or let's do ADHD research, let's talk about the condition?

Zoe

Piper:

For me, I always encourage, especially my son to be proud that he has got it. I always tell him there's nothing to be ashamed of and that it makes him unique because he will achieve things in a completely different way to somebody without the condition. I just try to keep reassuring him basically that it's good to have ADHD in a way. I mean, I wouldn't have got to where I am now, I don't think, without it. It gives me drive, a lot of drive to do what I do. I think the media, it's always quite a negative reflection, I think the media gives quite negative, I mean the ADHD Foundation have just brought out a paper now and they found some really staggering information regarding ADHD and how it affects families. And I think a lot more work needs to be done on the ground to actually get across to government, schools, health boards, actually how it's affecting and what we need to actually improve cause there is so much more that can be done to actually turn it around.

Bozo

Lugonja: So that paper you mentioned, we can actually put that up in our website on our podcast page, so if anyone who's listening is interested in reading more about the paper from the ADHD foundation, do go on ncmh.info/podcast. All our podcasts are there and all the links to the things we talk about of chances to get involved in research, links to things like ADHD Connections that Zoe is involved with, it's all going to be on there. We're trying to use this as a resource and if anyone thinks of anything that we can add, feel free to e-mail us or Tweet us or get in touch with us directly and we can change and add things.

Going back to some of the research involved, you've spoken, Anita, about genetics, about social research, where do you see research going in terms of ADHD in the next few years and what are the best achievements so far that you would say?

Anita

Thapar: There are so many. You'll have me for over an hour. I think one of the interesting... Well, there has been a lot of changes even in the types, so why don't I just focus on what's changed in terms of our knowledge in the last 20, 30 years. One of the things, and I think it's interesting you raise the issue about autism because actually, autism, people do understand more about it but when I first trained, it was still, the term refrigerator the parents causing autism was not very far away. So I think it's a lesson as to how science coupled with real policy and drive can change.

Bozo

Lugonja: What do you mean by refrigerator the parents? I know I heard that before.

Anita

Thapar: People used to think that autism was caused by parents being cold towards their children. And schizophrenia, there were schizophrenogenic mothers, this was all in mind. This was in my early training, I do remember it being around. Things have changed. So in terms of the research, what do we know now? Well, one of the things is that we now conceptualise ADHD as one of a spectrum of neurodevelopmental disorders, so previously people said if you got ADHD, you can't have autism and vice versa. We now realise that these are quite closely associated conditions, people could have both and people might have features of one or the other if they've got one of these diagnoses, so that's one issue, that kind of realisation that ADHD is part of a spectrum of these disorders. So that's changed. People used to think ADHD can't occur if you've got an intellectual disability, that has also now changed, recognising that actually it can occur across all the cognitive ability spectrum. There's been quite a lot of research showing longer term outcomes. Whilst some people do, well, the figures are still sobering, highlighting that this is an important condition and big studies from Scandinavia have shown that ADHD is associated with premature mortality. Also ADHD can lead to substance misuse but that substance misuse seems to be less when there's treatment given. So this sort of 16 to 25 is quite an important age group. The recognition that ADHD can

persist into adult life. Also the genetic contribution to ADHD, that's changed in the last 30 years. I mean, just in the last few months, international efforts of which we are a part of in Wales have discovered particular areas of the genome, genes that are involved. This does not mean that we will be testing for people with specific genes because there isn't just one gene that ever accounts for these disorders. We also recognise there is a small group of people who might carry sort of rare genetic mutations which again that could have implications for the future, not for everyone but for some small group maybe who got ADHD and something else, perhaps they have gotten a learning problem or they've got a heart defect or something.

Bozo

Lugonja:

I think it's really important to like reiterate the work that we do with NCMH and here in Cardiff in the MRC Centre and with genetics and genomics, that only really happens when you have thousands upon thousands upon thousands of people giving samples and getting involved. You can't get these results with 10 or 20 people or the old school and equals 3 kind of thing. It has to be tens of thousands ideally. And when you say there is no one gene, there is no ADHD gene. There is no gene specifically for many diseases, so it's going to be a group of genes and also environmental factors that may implicate someone in having a high risk, but again you might have these genes but you might not end up developing this condition.

Anita

Thapar:

Yeah, and that would be true for diabetes or hypertension. You could have a relative with these conditions, doesn't necessarily mean you're going to get it.

Bozo

Lugonja:

So it's a lot more complex but genetics is allowing us to kind of understand a lot more about the groups of people that might be more prone to...

Anita

Thapar:

I think it's really important for anything involving the brain, genetics is really key because if you've got an illness or a disorder which is involving, I don't know, say the liver, you can actually get bits of liver. You can access liver tissue. We cannot access brain tissue, so the genetics is like giving us a window into the brain because you can do that by just getting someone's spit, and so that can give us insights into potential new treatments. It can tell us a bit about the nature of ADHD. As I've said like the genetics is quite important in recognising that ADHD is a neurodevelopmental disorder because we've shown that there is a big genetic overlap with conditions such as autism.

The other interesting finding that has come out in the last few years is that people, I mean anyone who knows people with ADHD who does the clinic, will say well I see a lot of social stress and social adversity, and I see relationships disrupted, that's what is causing the ADHD. But what's

really interesting is people who have done careful research have actually shown this seems to be a consequence of the ADHD. So people have used different designs because in science, you've always got to be sceptical until you see the same pattern of findings coming, using different sort of experimental designs, you don't believe it. So this finding has come out really using different designs. Actually, having ADHD and ADHD genetic liability can create risks, so for example, of having disruptive hostile relationship with say between a son and a mother, people say "oh that's what caused ADHD," but it actually looks like it's a consequence. Treatment studies show that when you treat them, this relationship improves.

Bozo
Lugonja: That's really interesting.

Anita
Thapar: That's quite important because then people can see, like you can take a superficial glance and say, "well no wonder they've got it," but actually if you look at the careful signs, you got to be really careful about cause and consequence.

Bozo
Lugonja: That's really interesting. I mean when we look at getting involved in research, Zoe, you said you worked with Anita's help. She has been giving you support, does taking part in research help you understand your own condition better and do you feel like you've got some kind of sense of ownership of the condition?

Zoe
Piper: Massively. I mean it is down to us now. I mean we've got the scientists, they've got the means, but we've got to be out to make ourselves available. It is a bit of blood or like Anita said, spit, and that is it. It literally takes 45 minutes of your time to actually help them, not just help them but it helps us. I think that is why my son was I think he was 8 or 9 when he did it and he was so proud of himself because he actually gave blood. Yeah, he was proud and it's important for children as well I think with ADHD for them to realise that there is something they can do, they can make change and it's only by us all standing together and by doing this research that we're able to get the results and to get that recognition out there that it is real. This is what we live with and we need help with a lot more understanding in order to help us more in the future.

Bozo
Lugonja: So one of the things we do at NCMH is that we've got a large tissue collection, so we've got blood and saliva we just mentioned. We have people taking part and we've got about 10,000 people who have taken part in the study. The majority of those people don't have ADHD. It's actually a very, very, very small amount so we are looking actively for people who have ADHD or families of people with ADHD who want to get involved, who might not have mental health condition or psychiatric condition. Those controls actually help us as well, so if you are

interested, please do get in touch with us on ncmh.info. There is an interview and you might give a saliva sample or blood sample depending on what you want to do, and the field team that we work with are incredible and I am personally responsible for the samples so I can be honest and say that we do really a good job with them.

Is there any kind of anything else that you would say in terms of research that we could do better, Anita?

Anita

Thapar:

I think we probably, as scientists, we have to highlight why research is important. I think sometimes it can be a bit scary to know what it's going to be used for and I guess perhaps it's interesting, when I talk to my Scandinavian colleagues, they suspect that in some countries, people are bit suspicious about authority. Well they tell me that they don't have quite the same issues, but I just kind of think that the most important thing is if we actually want to change things, you got to find out about it. And sometimes you don't know along the line how it's going to exactly help. I mean cancer, HIV, nobody knew exactly how it was going to help, but we have to do research and you know the easiest thing is to do research on people who are quite well, not on people who have got ADHD so it is really important to do the research. But I think we also have to be... it's important for scientists and for clinicians to really explain why we're doing it and why it's important.

Bozo

Lugonja:

And as I suppose bringing together the genetic and scientific research and the social research together to get a real...

Anita

Thapar:

Yes. It's not one of the other. I mean social factors are important for all of us. If we're poor, if we're hungry, if bad things are happening to us, it does not matter if you got diabetes, if you haven't got anything, it's going to make a difference. We're not saying by looking at genetics, we don't count any of the other things, but as I've said, it gives a bit of insight into the brain and the genetics also can sometimes help in working out the environment as well. For example, we have been using some of the genetic findings to look at some of the very early factors that a baby experiences in the womb, so ADHD because it's early, we tend to look at factors that happen very early.

Bozo

Lugonja:

Yeah, absolutely. So what do you think, Zoe?

Zoe

Piper:

I just think anyone who sat here or there listening to this and you are affected by ADHD in any way, you know just go and sign up for the research. Tell people about it because this is the future, this is the only way to get the services and to get, like I said before, recognition about this condition. And it impacts massively on family and having a child with ADHD causes family breakups. It's not a nice condition to live with at all.

You never know what you're going to get from one hour to the other. We need to give a lot more support and the only way to do that again, is by getting involved with the work that you do in here at the NCMH and I've been a part of it now for a couple of years and you're treated amazingly. You can have a look at the research and you can be proud that you've contributed to these findings.

Bozo

Lugonja:

Well, everything that we do really is down to our participants. I mean, if we didn't have any participants, we wouldn't have any samples, we wouldn't have any research projects and we have to say thank you to you and people like you who get involved for whatever reason because this entire building wouldn't really stand if we didn't have people taking part in our research and getting involved and actually making a difference to people.

We've spoken really, like, kind of touched on the fact that there's been a bit of a spur in the recent last few months that everyone has been involved with ADHD and international collaborations. What's brought that spur on and what has ignited in refreshed interest?

Anita

Thapar:

The main reason why we suddenly had a breakthrough in the genetics globally is because of our Danish colleagues. They had 16,000 people with ADHD to contribute data for, they did this through a national initiative. So basically, that's what has happened.

Bozo

Lugonja:

So literally, it's a case of people have gotten involved and we've got that rotated there because you have like a cohort there. Again, this paper, this Danish paper, we will put it up on our website so people can look at it.

Anita

Thapar:

It's a joint paper, I just want to say. We've got some wealth of samples in there, samples from elsewhere in Europe, there's a few from America as well. It's international, but as I said, the real boost really came from the Danes, but Wales made a contribution, not of that order of magnitude, yeah, a few hundreds.

Bozo

Lugonja:

That's fantastic. I mean with brand new technologies like DNA sequencing and genotyping, we're able to understand a lot more. Do you think that we're wholly going to be reliant upon genetics and genomics in the future or how do you see those technologies evolving to help us understand?

Anita

Thapar:

For any condition, you need a mixture of research approaches. That's what we do particularly well here, but as I said, the genes can also be used to look at environment. It can also give clues about potential treatments. For example, treatments already there may be used for

another condition that you could then use. So that's one issue. What's going to happen? We've only just started on the gene discovery pathway for ADHD for the reasons that you said, you need really large samples and the gene findings I've talked about, these are what are called common variants, that's one thing that all of us carry, they're quite common but just a cluster of them could result in basically an increased risk for ADHD. The other type of gene variation that is also associated with increasing your risk for ADHD are more rare. For example, we've found some years back that chunks of DNA missing or extra in your chromosome, that type, then observation was more common in people with ADHD and people are now trying to find more rare mutations, what we call rare mutations in neurodevelopmental disorders. That's worked really well for autism, we're lagging behind so far for ADHD, but that's another type of research. Why again, it gives us a bit of clue about the brain, what's going on in the brain, a bit about the biology. Also the potential, as I keep saying, none of these genetic findings we're going to have a gene testing, but there will be a small group of people with ADHD in the future that you may want to do testing for. Perhaps, they've got a more complicated picture. We've seen this for intellectual disability when I was training, not very long ago, we used to say that mild intellectual disability was due to social factors and now we do genome testing on all of them. Of course people with intellectual disability can be more socially disadvantaged but now genome testing is basically part of the NHS test for everyone because you will pick up a group with subtle rare mutations. It's not inconceivable in the next 20 years that this will happen for a disorder like ADHD.

Bozo

Lugonja: Excellent. So I think it would be good if kind of put things to a close to get back to Zoe's charity with ADHD Connections. So how can people get involved with your charity and how can people contact you?

Zoe

Piper: We've got a website for the charity. We've got a Facebook page which is just ADHD Connections. We've also got a closed support group there which people are able to talk and discuss issues and things like that. So yeah, just find us on Facebook or on the website really, which is just adhdconnections.org

Bozo

Lugonja: Excellent. Are there any other things that you guys would like to highlight to anyone who is listening?

Zoe

Piper: Educate educators a bit more for me. That's one of the massive, massive things that I'm trying to drive at the moment, is to make training for teachers or anyone dealing with children, you know Social Services and any third sector organisations. You know, they need help to understand a child with ADHD because at the moment they are getting penalised for having ADHD and I just think a lot more needs to be done about that really.

Bozo
Lugonja: How about yourself, Anita?

Anita
Thapar: I think schools are really important. I would agree. So for conditions like ADHD, autism, although I think it is changing for autism in a way that hasn't changed yet for ADHD. School is a really important environment, it is where you start and I would agree with that. I think there needs to be education, but I also think, as well as that, we also need research and more research and more research on ADHD and we can change things.

Zoe
Piper: But as well, from you know a parent's perspective, you told your child he has ADHD and that is it. I think that a lot more needs to be done in offering the parent more support and learning about ADHD. Giving us more strategies and ways to deal without our child and I honestly believe that working with strategies and working more closely with the health board and with education, we can manage the condition better and we haven't just got to rely on having medication. I mean, that's not the only thing that we are offered. NICE guideline says medication plus cognitive help but there's nothing, it' medication or nothing, and if we don't have medication, you're not even really offered any more CAMHS appointments. So it really is... we just need a lot more support in other ways as well.

Bozo
Lugonja: Great. I think it is a good time to bring it to an end. Just to say a massive, massive thank you to both of you for agreeing to take part in this and speaking to me and to each other about your experiences and to anyone who's listening. If you are interested in our podcast, they're all at ncmh.info. If you're interested in taking part as a participant, again try ncmh.info or NCMH Facebook page or Twitter page or Instagram even. I know Instagram. So I just want to say please review and rate and let us know what we can do better and what you found interesting and we're hopefully bringing you another podcast soon. Thank you very much and bye-bye.