

# The experience of prison by individuals with neurodivergence:

## A lived experience perspective

This article brings together two separate interviews conducted with two neurodiverse individuals who have had experience of imprisonment. In doing so it brings to the fore the lived experience perspective which is so vital to hear. The interviews are presented together to represent perspectives from individuals with different neurodiverse traits, and to reflect on how a diagnosis whilst in prison may impact peoples' experiences differently (one of the interviewees was diagnosed in childhood, the other following imprisonment).

### Interview 1

*Usman Anwar is currently a member of the HMPPS workforce employed as a National Lived Experience Lead in the Resettlement and Reducing Reoffending Team. Here he shares his experience of custody and navigating that with neurodivergence. He is interviewed by Dr Helen Wakeling, a Chartered Research Psychologist and founding partner of KTA Research and Consulting.*

The interview took place on Tuesday 1st October 2024.

**If you're happy to please can you tell me about your neurodivergence? If you've been diagnosed, what is the diagnosis and when was that made?**

I have Attention Deficit Hyperactivity Disorder (ADHD). My neurodivergence is ADHD. Less on the hyperactive side of things, and more on the attention and distraction side of things. I get easily distracted. The diagnosis was made in 2021 or 2022. It wasn't a diagnosis by the NHS. It was picked up by one of my managers at the time. She saw signs and then she did a workplace health assessment, which led to an external psychology assessment. I went to a private clinic. I had a fully qualified clinical psychologist who did the assessment and walked me through the tests, and then came up 'yes, this is the diagnosis — we believe you've got ADHD'. Which is the first test I passed full marks by the way!

**And how did you feel when you got that diagnosis?**

I was a bit shocked at first. It's funny because you think that this just what happens to other people. Like I was aware of neurodiversity, but I always used to think that happens to other people, and I need to help other people, and you don't necessarily relate it to yourself. And then when I was being told 'yes you have ADHD', I was a bit shell shocked.

And then once I started to get to grips with it, I thought, ok what's ADHD? Let me learn a bit more about it. Let me educate myself a bit more. The more I started to learn, the more I felt like I was reading a book

about myself. I started thinking ok, yeah, I do that. Oh, so that is why I do that. Ok so this is why I feel like that. And you start to kind of learn about yourself. But you also come to the realisation that it's not so bad to be diagnosed because it's actually an answer to certain things and the way you've been doing things for years. I only got diagnosed in my adult life, so I started to imagine how this could have helped back when I was younger. Do you know what I mean?

**Yes, absolutely. So, you weren't diagnosed when you were living in prison? Can I just take you back to that point. What was your experience of prison life?**

So, I've been to prison on two separate sentences. For the first sentence I served around 2 years, and for the second sentence just under 4 years. The first time was when I was 17, and it was a shock to the system, because you are now living in a new reality, a new regime. You can't do what you want, you have to wear prison clothes, and you are forced into this setting which is not the most supportive. And it's not conducive to those with neurodiversity. That was my first sentence. In my second sentence it was a bit easier in one way because I had some familiarity, so I adjusted more easily. I was still undiagnosed, but I was able to better adjust to the processes and systems. But there were still things which frustrated me and irritated me more than they would a normal [neurotypical] person.

**And can you remember your first night and first few weeks in prison? What were they like?**

I can. You know, ironically, no matter how long passes, you will never forget your first night in prison.

It's vivid in my memory. I was in Rochester prison. You're given these clothes, you're given a big orange blanket, a thick kind of fire blanket. You're taken to a room where you can touch the walls with both hands. And there's a toilet. There's a little TV with no remote. It's not a welcoming environment and it's one you have to get accustomed to really quick. You have to adapt, you have to accept it really quick, otherwise that can get to you for the rest of your sentence. And I was lucky in the sense that I actually knew someone that was already there. Looking back, maybe that wasn't the best of things because I got in trouble, but it did help because there was a sense of familiarity, and especially being neurodiverse, new environments, new people, uncertain environments, can kind of make you want to run.

### **So how did you adapt over time to prison life?**

Like any 17-year-old, I rebelled a lot, so I was pushing back to the system, so to speak. Always questioning, why are you asking me so many questions? I already told this to the probation office, and now I'm telling you — why do I have to keep repeating myself? I didn't take the time to stop and think, what is this person actually wanting from me and trying to help me with? And I was very resistant and disengaged. But then there was also an element of a bit of a bravado and falling in with the crowd because that's what all your peers do as well. I was lucky in the sense that a lot of my peers from my area in London knew other people in the prison. So some people knew of me, and my standing in the community kind of carried on with me in prison. That did kind of help with my adjustment. But it was more the processes and the systems and the regimes which I couldn't get accustomed to.

### **In what way did you find processes and systems difficult? Could you please expand on that?**

In prison there are domestics — you have to wake up and be up at this time, and be ready at your door, even if you've got nothing on. You have to wear uniforms. I didn't like that. I've got my own clothes, why can't I wear them? Also having to repeat everything multiple times. You do your competency examination for English. I did one in Belmarsh prison. I did one in Rochester prison. And I was asked to do

another one in Chelmsford prison. I didn't understand why they had to get me to do this again and again. And because I didn't understand why, I immediately shut down and refused to complete it again. It's processes like that I couldn't get my head around. Instead, I would refuse, stand strong, get in trouble and get sent to the block. Nobody explained it to me. I understand better now why I did that. But now I'm living *with* my neurodiversity, not against it, and I'm making the best of me now.

### **How well did HMPPS support your needs when you were in prison?**

If you're talking standard duty of care, then they did that. I was fed, I was able to get my clothes, there was a minimum standard of care. If you're talking neurodiversity-wise, then there wasn't any support. Not for me when I was in prison. There were no neurodiversity staff, and no one looked for the underlying cause of my behaviour. And I'm just one of many. There are many adults in prison with undiagnosed autism. And it sometimes seems like they did the minimum but didn't support with my additional needs. There was no formal plan to support me, no one spoke to healthcare to get a formal diagnosis. I think that's prevalent across the system and is something we need to improve.

### **How would things have been easier if you had been diagnosed when you were in prison?**

I would have been less in trouble, and down in the segregation unit less. I would have definitely got more out of it and been able to achieve my equivalent GCSEs quicker, which would have given me a better standing in the community. When Rochester prison got converted into an adult prison, and they started taking in adults, there was more opportunities like Open University and further education, which (had I engaged with) would have then helped me on my first release because I would have had more qualifications and groundings. But because I was undiagnosed it looked like I was just being resistant to certain processes and procedures. This wasn't just in the custodial setting, but in the school setting as well as college. I wasn't supported because I was unaware of my neurodiversity. No one took the time to be like, 'look, the reason you can't focus or the reason you're being distracted is because you've got this. Do you mind taking a test?' There was no one that was concerned about me

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enough to put in the effort to check where my issues stemmed from. In the school setting, the court setting, and even the custodial setting no one stepped up to say that I was showing signs of neurodiversity, showing signs of ADHD. I was distracted, talkative, didn't get simple facts that are simple for most people. It takes me a bit longer to do things. It will take me an hour to do something that will take others 10 minutes. I store information differently. I've read Harry Potter twice as I forgot it the first time I read it. It's a good thing in a way because I can watch a movie again like it's the first time I've watched it. But you know in different environments, and particularly those detrimental to my life, it would be good to be aware of what structures I could put in place to keep my life improved and live with my neurodiversity rather than live against it.

**And how do you think having the diagnosis would have changed the way you behaved in prison?**

I know what difference a diagnosis has made to me now as an adult. I wasn't a bad child or a rude child, I'm not like that. I was diagnosed a few years ago and someone took the effort to walk me through why I sometimes don't get things, suggesting that it's a good idea to take notes, or this is a good way to retain information, because I learn differently from neurotypical people, and now I'm aware of that. When I'm in meetings or in a work environment and doing work tasks and I don't get something, I speak up and say can you repeat that or check that I've understood something correctly. And then I write it down. You carry shame with neurodiversity, and before if I didn't understand something expressed in a meeting or work environment, I'd bite my tongue and not do the work, and then make excuses, which increases anxiety, and makes you want to run away and hide. But now with the awareness that I have, the structures I have put in place, and the education I have around ADHD, I don't do that. If I had that awareness and information back then I might have been able to put myself on a different path so I could walk away from situations. In frustrating situations now, I need to breathe. Whereas in prison I'd react immediately, and get myself fired up, and put in the block, arguing with everyone and causing more issues and tension. My neurodiversity wasn't seen. No one bothered to put in the effort to say 'wait hold on, this is not a bad child, he

is having difficulties, let's have a chat with him'. Instead, it was put down to me being a troublemaker. I was a show off in college. In custody I was a prisoner acting up so was punished. There was no point when someone actually bothered to ask if there was another reason why I was behaving as I was. Could there be an underlying cause for the behaviour? In my case it was my neurodiversity which gave me a fun start to life!

**We've talked about what things were like in prison, what about when you were released from prison? What was your experience of release from prison like?**

The first time was a bit crazy, but the second time was much better because I had reached a point in my own life when I needed to do things differently, so I started to get myself in the mindset of trying to change, gain employment and stuff. But looking back it was still difficult because I was unaware of my diagnosis and my distraction. So, when I was applying for jobs and getting frustrated about not hearing back, I would go and do something which doesn't support me and my progression. But I did finally get a job and settled into it well. But when I was on probation, I had seven different probation officers, and one thing that's particularly unnerving to someone with ADHD but also showing some traits of autism, is inconsistency. I had seven probation officers, and I had to keep repeating my story and journey to each of them. I couldn't understand why I had to keep repeating myself and why they didn't just pass notes on to each other. And then when Covid hit, most of the conversations then took place over the phone which made it harder in some ways. I didn't really get support with employment either.

**And if your probation officers had known about your ADHD diagnosis, how do you think that might have helped?**

It would have definitely helped with the relationships I had with them. Sometimes with my ADHD I do speak without thinking, which has caused some issues with probation staff. Had the staff known about my neurodiversity issues they might have been more understanding of this sort of behaviour. I think if probation were aware of my neurodiversity and were educated in how the condition can manifest itself it

would have made my relationship with them better, but also my management and supervision on licence way easier.

**What do you think the prison service can do to better support people with neurodivergence?**

Firstly, I'd say to support the people in prison you have to be aware of neurodiversity. And it's not just for the prisoners, it's also to support staff with neurodiversity and the recognition of that neurodiversity. When I was in prison there was an SO [senior officer] who rather than jumping to punishment when I did something wrong, which is the usual reaction from staff, he took the time with me to talk the issue through. He was basically practicing neurodiversity awareness without knowing that's what it was. He was communicating clearly, allowing me to take a moment, repeating explanations, and not reacting straight away. I'm a very animated person and talk with my hands. One time I actually got an adjudication for talking with my hands because the staff felt threatened. That's just the way I talk. But this SO, he was practising neurodiversity skills. And it turns out that he had someone in his family who was neurodiverse, which is why he was more practiced at doing this.

So, raising awareness and providing training for staff is important. Staff communicating clearly and knowing the signs of different neurodiverse conditions could help. Understanding that someone is not going to hit you with his hands, that is just how he talks, and it is not someone's fault if they need to be told two or three times the same piece of information. Staff need to be patient and tell people with neurodiversity information two or three times or even write it down for them. Doing this could mitigate a lot of things that would otherwise result in punishment. I once had a meeting with an SO and a Governor, and when I'm nervous sometimes I walk off, or rock backwards and forwards in my chair. This can be interpreted as being rude but I'm not meaning to. I do this to make myself feel comfortable in a setting that is uncomfortable. And if staff had understood this about me it would have been better.

I also think that we need to focus on prison culture. If we can create a culture that's more accommodating to those with neurodiversity and support people to get diagnosed, then we can create a more rehabilitative prison. We also need to support staff with neurodiversity too. If you support your employees and make sure they're well supported and getting the things they need with regards to their

health, then they'll be more equipped and willing to pay forward that support to people in prison.

**HMPPS have introduced some changes in prisons which aim to better support people living in prison with neurodivergence. For example, neurodiversity support managers have been introduced to provide support to people in prison, and they have also introduced specialised wings for people with neurodivergence in some prisons. How helpful do you see these sorts of things to be?**

I do think they're good initiatives and it is recognition from the Service that neurodiversity is important, as there is a higher intake of people who are showing signs of or are diagnosed with neurodiversity now. But I think it's only part of a good initiative. I think they also need to do better assessment and diagnosis in prison. Take the time to observe behaviours and identify signs people are showing. Take the initiative to get people diagnosed and offer that support they need. There are so many people undiagnosed in prison, and their issues are put down to bad behaviour or trauma. But if you dig down a bit deeper and take time to understand peoples' backgrounds, you'd get a better understanding of individuals, of the underlying causes of their behaviour but also, you'd build more positive relationships. Treat people as individuals with individual needs.

So better assessment and diagnosis 100 per cent but also link that in with post release care as well by doing better at information sharing. Improve continuity of care into the community by sharing information across organisations. If we want the best for individuals and to make the best support plan, we need to be sharing information from prison into probation and other services that someone might access in the community. Like 'this is what we've learned about so and so, he doesn't like this, he tends to show this, he finds things easier when...' and so on. And this should all start in schools and colleges. If someone comes into prison and has a history of PRUs [pupil referral units] and other difficulties from school, then this information should be passed on to the prison. Someone doesn't just arrive at prison without a history. Often it will start with a child, whose parents have left, social services have let them down, local authorities have let them down, police have let them down, youth services have let them down. It's a joint effort. All of these services need to be working together, and where issues of neurodiversity are identified this should be passed on between these services.

## Interview 2

*Kirsty is currently on probation and has an Autism Spectrum Disorder (ASD) diagnosis. Here she shares her experience of custody. She is interviewed by Tassie Ghilani, the HMPPS Reducing Reoffending National Lived Experience Lead.*

The interview took place on Friday 18th October 2024.

### **If you've been diagnosed what's your diagnosis and when was this made?**

Around the time of my diagnosis I was in a mainstream school, and it was obvious to everyone that I needed special education. My mum fought tooth and nail for me to get help and that is when I got diagnosed with my ASD.

With my diagnosis, I struggled with things like understanding and processing information. I have to be told one task at a time. I can't be given loads of information at once. I need people to simplify things for me so I can understand better and easily. I'm quite sensory, so loud noises can be quite triggering, especially when I am around a lot of people, but I feel like I am getting better with that.

### **What was your experience of prison life in relation to your neurodivergence?**

Personally, for me, I thought it was quite difficult because a lot of things go on in prison, so things like the clashing of the gates, the keys, the noises, the banging. It is sensory overload and was a big trigger for me.

### **Can you remember the first time you went into prison? What was your first night like or your first few weeks?**

So back in 2019 I was on E wing, an induction wing, and it was very traumatising because it was my first time. I didn't know what to expect. A lot of things were going on and my mental health declined. In terms of my neurodiversity, it was really, really difficult trying to grasp things and the regime. But I got through it by just having resilience and just trying to get through it myself. As I was doing things the more I felt 'ok, and that maybe I can actually do it'. It is difficult and it is really hard trying to adjust to the routine.

### **How did probation support you? Or did you have any licence conditions in place that were a bit tricky to think about?**

I was able to go to the open prison in York - HMP Askham Grange, and I did what I needed to do there, and 6 months prior to being released they set you up with what you need in the community. Resettlement planning was something that I felt was really important. I met my outside probation officer while I was there which made it easier when I was released.

### **How well did the Prison and Probation Service, support you in terms of your needs?**

I think the prison environment do what they can, but I think there's things that needed to be done, or maybe in place before I was on probation. But I had a really good relationship with my probation officer, and she met my needs in a way that other people haven't so that was really refreshing. I think there needs to be more done in custody, but I can't fault my probation.

### **So, in terms of how things could be better in prison, what do you think those things would be?**

I think maybe just having workshops or rooms in custody about neurodiversity. So, then the knowledge and the education are there for other people as well as the residents and as well as the staff. I think that might be good.

### **What things made it easier for you in relation to your neurodivergence?**

The PIPE [Psychologically Informed Planned Environment] unit was really good and so was speech and language therapy — that was really beneficial for my neurodiversity needs. Working on communication definitely helped me. I guess my personal officer as well did help me with a few things at the time.

### **Is there anything that made things harder for you?**

It was difficult when they would just drop things on you, like I wouldn't even know I had an appointment or meeting or interview. It becomes confusing and difficult to process when they don't tell you in advance. I feel like, with neurodiverse people, they have got to know [in advance]. You need staff to let you know what's happening so you can adjust your feelings and emotions in yourself. So for someone to just tell you there and then, it's a bit of a shock.

### **Specialised neurodiversity wings have been introduced as well as neurodiversity support managers in prisons. Do you feel things like this will be helpful to people in prison?**

I think that would be beneficial. Yeah, definitely. I mean the PIPE unit was similar to this and it was very helpful for me having the specialised staff with understanding of neurodiverse needs.