



USER VOICE

ONLY OFFENDERS CAN STOP RE-OFFENDING

‘NOT NAUGHTY, STUPID, OR BAD’

**THE VOICES OF NEURODIVERSE SERVICE USERS
IN THE CRIMINAL JUSTICE SYSTEM**

December 2023

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EXECUTIVE SUMMARY

This report brings forth the experiences of people who are diagnosed and self-diagnose as neurodivergent. As the health and criminal justice sectors are learning more about the experiences of neurodivergent service users, User Voice wants to bring their voices front and centre, and to give them real agency. Their quotes are unedited and based on their personal experiences.

As part of this study User Voice interviewed **104** service users across **11** prisons nationwide between September 2022 and February 2023. To gain as full a picture as possible, User Voice additionally surveyed **250** neurodivergent service users about their experiences in the criminal justice system. All interviewed or surveyed service users were either diagnosed or self-diagnosed as neurodivergent.

To provide as holistic a picture as possible, User Voice spoke to service users about their lives before they were involved in the criminal justice system. In early life, most service users we spoke to came from lower socio-economic backgrounds, over half had experienced abuse and neglect, and one third had been in care.

At a crisis point, service users often found that they did not have the needed support networks, and therefore as a result, many had turned to alcohol and drugs which then had led to a life of criminality. Many told us that due to their neurodiversity, they are easily manipulated, coerced, groomed, or susceptible to peer pressure.

This report shines a light on the lack of support for people who end up in the criminal justice system. **Half** of the service users who took part in this report told us they had been diagnosed before they turned 17 years old. Nine had been diagnosed between ages 17 – 26, and 17 when they were older than 27 years. None of them had been told how to live with their conditions.

This study finds a criminal justice system ill-prepared to help neurodivergent people. In police custody, only **2 service users** had adjustments made around their neurodiversity, whereas in prison, **15** said adjustments had been made. Because of lack of assessments and screening in prisons, we found that only few were receiving the support they needed.

We believe that lived experience has a crucial part to play in the formulation of policy and practice in every sector, whether it be criminal justice, health, or education. To benefit those who are neurodivergent, we advocate for more peer support as well employing staff with lived experience in neurodiversity. This would guarantee that services and resources are tailored to the needs of neurodivergent service users.

As prison populations grow, a commitment to more neurodiversity qualified health care staff is a must. The prison population would benefit from clinical psychologists in prison as well as better management of medication.

This report is a snapshot of people's lived experience. To drive true reform, we hope that more resources are given to projects that share the voices and experiences of neurodivergent people. To stop neurodivergent people ending up in the criminal justice system, we need to learn from those who have been there.

INTRODUCTION

In 2021, User Voice wrote a report commissioned by HM Inspectorate of Probation; we named it '[Neuro ... What?](#)' reflecting the fact that not many people knew much about neurodiversity. The report highlighted the issues and problems in relation to neurodiversity and the criminal justice system. We concluded that for too long the criminal justice sector has been ignoring an inconvenient truth: a significant proportion of people with a criminal record are neurodivergent.

Too little is known of how many people in the system are neurodivergent and its relationship with offending and reoffending. It is estimated that although only 15% of the general population has a neurodiverse condition, as many as half the people in the criminal justice system as a whole and 1 in 3 people in prison are impacted by neurodiversity.

User Voice gives a voice to the people in the criminal justice system (police, courts, prison, probation). Through their reflections and feedback, we deliver change. We were created by and are run by people who have been in prison and on probation. Lived experience means we engage empathetically instead of sympathetically. We exist to reduce offending by working with the most marginalised people in and around the criminal justice system to make sure that practitioners and policymakers hear their voices.

To accomplish this, we will illustrate their journey from early life, into adulthood and through the criminal justice system. This is the first time we will hear the voice of diagnosed and self-diagnosed neurodivergent people in the criminal justice system on such a large scale. We will find out how neurodiversity has impacted their lives, what support they have received and what should change so that people are better supported and understood in the criminal justice system and by the wider society.

User Voice believes that lived experience has a part to play in the formulation of policy in every sector, whether it be criminal justice, health, or education. The perspective of those who have been through the system makes them qualified to speak about where it can improve. Therefore, this report aims to create a shared language across the system and between neurodiverse service users and the neurotypical so we can achieve better outcomes.

This landmark report would not have been made possible without the support of NHS England and prison commissioners. User Voice would like to thank NHS England for commissioning this important and potentially life changing piece of work.

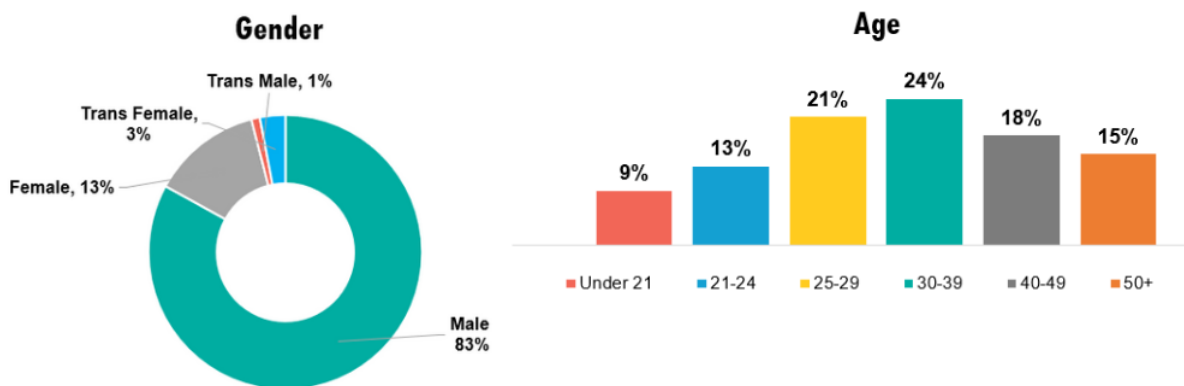
METHODOLOGY

User Voice interviewed 104 and surveyed 250 people about their experiences in the criminal justice system. Interviews took place between September 2022 and February 2023, and were conducted by people with lived experience of the criminal justice system. Interviews were conducted in 11 prisons across the country, and in the community. Where a condition is self-diagnosed/self-reported it is mentioned each time and is advised to be interpreted with some caution.

Service users were identified with the help of Neurodiversity Support Managers in each prison and prison management. All the interviewed service users were either diagnosed or self-diagnosed as neurodivergent. The decision to include that self-report was taken because User Voice wanted to give people the power to define their own lives.

To ensure that this project was peer led two advisory groups were set up: one with experts in the field of neurodiversity and another with people with lived experience in the community. Research and support materials were developed alongside the two advisory groups that included a discussion guide and questionnaire.

Number of people interviewed by gender and age:



Interview method	Number of participants
Male in-depth interviews	63
Male focus groups (8)	24
Female in-depth interviews	6
Female focus groups (3)	11
Total	104

Place of interview	Number of participants
Prison	94
Community	10

Neurodivergent conditions

The below table shows the self-reported conditions of the interviewed 104 service users by gender (87 men, 17 women).

User Voice read a list of conditions to all the service users and asked them to say which neurodiverse condition they have been diagnosed with or have self-diagnosed. Some conditions OCD, PTSD and Paranoid Schizophrenia were not on our list, and are not considered as neurodiverse conditions, but we included them because a notable number of individuals had been diagnosed with them and felt they were relevant to mention.

- 78% of the interviewed service users had been diagnosed with more than one neurodiverse condition (81 individuals)
- Half of the interviewed men had been diagnosed with or had self-diagnosed ADHD and 20% with ADD
- 24% of women had been diagnosed with or had self-diagnosed ADHD and 24% with ADD
- 40% of men had been diagnosed with or had self-diagnosed Autism
- Over a third of the men and 41% of women were dyslexic
- Almost half of the women and 25% of men were diagnosed with LDD
- A third of the women had domestic abuse related Acquired Brain Injury (ABI)

Condition	Men	Women
LDD	25% (22)	47% (8)
Dyslexia	34% (30)	41% (7)
Dyscalculia	10% (9)	12% (2)
Dyspraxia	10% (9)	6% (1)
ADHD	49% (43)	24% (4)
ADD	20% (17)	24% (4)
Autism	41% (36)	12% (2)
Developmental language disorder (DLD)	1% (1)	0
Speech and language disorders	5% (4)	3% (3)
Tic disorders such as Tourette's syndrome	5% (4)	6% (1)
Acquired brain injury (ABI)	13% (11)	29% (5)
OCD	8% (7)	6% (1)
PTSD	16% (14)	0
Paranoid schizophrenia	8% (7)	6% (1)

KEY FINDINGS

- Most of the people we interviewed have not been educated about their neurodiverse condition or how it impacts their emotions, feelings, or ways to communicate.
- The majority had continuously been labelled 'stupid', 'bad' or 'naughty' when they were children and lived their lives according to this label.
- The majority of service users we spoke to had experienced childhood adversity and/or trauma.
- Many have been over-medicated throughout their lives, and no other support for their neurodiverse needs has been offered.
- Many told us they are susceptible to peer pressure and/or manipulation which has got them in trouble and in contact with the criminal justice system.
- The majority have not been offered any adjustments or support in the criminal justice system.
- Criminal justice system staff and the NHS staff in prisons lack qualifications and information about neurodiversity and neurodivergent people and therefore are not able to provide them the support they need.

CHAPTER 1 – NEURODIVERSE CONDITIONS EXPLAINED BY SERVICE USERS

The stories of diagnosed and self-diagnosed neurodivergent people in the Criminal Justice System make for uncomfortable reading.

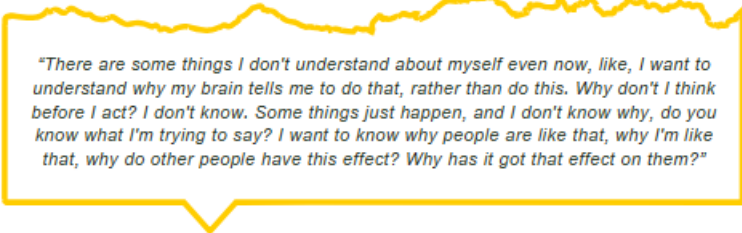
Utter incomprehension; shame; an inability to read forms let alone fill them in; communication hurdles with defending lawyers; assumptions of rudeness by judges and dismissal of any suggestion that neural health may be a mitigating circumstance; inability to remember appointments; frustration; anger; confusion. Neurodiverse service users simply cannot play the game. So, they lose.

Typically, neurodiverse service users have at some point interacted with the Police. They have been for many years our default mental health service and have been called in to exercise force in medical situations they are ill-equipped to understand.

The people User Voice spoke to as part of this study highlighted that this isn't just a criminal justice issue. It's a public health issue. If there was recognition and support for these conditions, then the link between neurodiversity and crime could be broken.

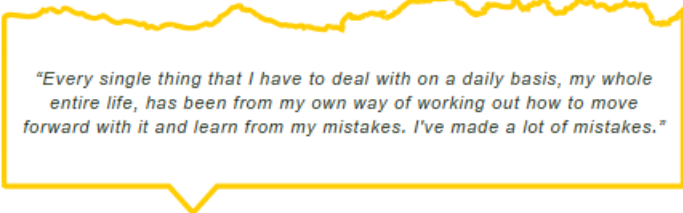
People identified the different stages of their involvement with the justice system and what needs to happen at each juncture. There is expertise across these stages, yet power is contained within institutions by different agencies, with different (if any) processes, screening, staff training and understanding. Most significantly, there is no agreement between different institutions – even between HMPPS and the NHS – about what neurodiversity is and so there can be no common, coherent, consistent response.

In this study, service users described being neurodivergent without being able to understand it felt to many 'like a mental imprisonment'. Only a few service users, who had actively searched for information, knew about their neurodiverse condition(s). Most had never been told about their condition, or how to live with it. They felt that the society's only solution had been to medicate, isolate, or incarcerate them.



"There are some things I don't understand about myself even now, like, I want to understand why my brain tells me to do that, rather than do this. Why don't I think before I act? I don't know. Some things just happen, and I don't know why, do you know what I'm trying to say? I want to know why people are like that, why I'm like that, why do other people have this effect? Why has it got that effect on them?"

Man, 19 with ADHD, LDD, dyscalculia & self-diagnosed autism



"Every single thing that I have to deal with on a daily basis, my whole entire life, has been from my own way of working out how to move forward with it and learn from my mistakes. I've made a lot of mistakes."

Man, 43 with ADHD, Autism, ADD, LDD & dyslexia

Service users explained to us how their confirmed or self-reported neurodiverse conditions had impacted their lives and continues to do so. They told us that in certain instances they had difficulties interacting with people or making friends because of their lack of understanding of emotions and feelings. A service user told us that emotions were 'like a foreign language' to him, whereas another explained how they cannot understand when people feel sad if something happens in a movie, because it is not real.

"They heard a song that made them feel sad, that is absurd. 'I watched a film and cried at it because the dog died.' That is absurd because the dog does not exist."

Man, 32 with autism

Feeling confused about the world and themselves was mentioned by several people in our outreach. This confusion led to years of anxiety and depression and is still an everyday reality for many. Service users told us they constantly overthink and ruminate on everything, which is exhausting and can lead to feeling paranoid about situations and people's intentions. Many said they would give everything to stop their brain thinking about an event or something repeatedly.

Most of the time, overthinking led to negative conclusions about people and situations, which in turn resulted in them hurting other people or themselves. Self-harm had become a 'coping mechanism' for many to stop them ruminating and to stop them from hurting others.

"With my ADHD, you know, I do a lot of things without thinking. That's the main reason. You know, I can be very hyperactive and things like that. I'll be hyperactive and not even know it myself. I could be all over the place. I could run around like a bull at things, and it's because I've got all that energy."

Man, 22 with ADHD & dyslexia

"Since eleven it was self-harming for me. It's always been the best way because you're hurting yourself, you're not hurting someone else. Even when I get thoughts in my head that say, 'That's the person that said it, go and take it out on them,' but then the last few self-harming instances have left me on life support."

Man, 43 with ADHD & ABI

Lacking the ability to concentrate was mentioned by everyone we spoke to who had ADHD. They expressed it as being "like a kid with 100 toys," or "like a furnace" or "like having a constant adrenaline shot." Having never ending constant energy and thoughts had impacted their whole lives. For example, a part of not being able to concentrate on anything was having no patience and a short temper or a fuse.

"It's relentless, it's never-ending, it's just constant, constant, constant. I have no control over it, even though everyone goes, 'oh, you're amazing, you do iron man, you do this, you do all these amazing things and should be proud of yourself', I sit and think, 'I'd give anything just to sit down and think.'"

Man, 43 with ADHD, Autism, LDD & dyslexia

Some said they had their ADHD "on level" with medication, however many either refused to take their medication because of how it made them feel or they had never found a medication that worked for them. Some were not able to take their medication because of other health issues (for example, severe asthma, cancer, and Tourette Syndrome).

Several mentioned that they were not allowed to get their ADHD medication in prison because it was classed as a controlled substance. They told us they were desperate to get their medication because they felt uncontrollable and constantly 'on the edge' in prison. They were trying to burn energy by overtraining and tiring themselves out.

"I sleep for an hour and a half, two hours, I'm up, I'll go back to sleep for an hour and a half, two hours. I'm fucking bad with it, do you know what I mean? Even though I trained all day yesterday, morning and afternoon, and I'm still fucking pinging awake, aren't I?"

Man, 45 with ADHD & dyslexia

"[I take] melatonin because I don't produce enough serotonin, so I might go 120 hours, five days with no sleep. Days and days and days. I'm on all sorts of different pills."

Man, 63 with autism & ADHD

"Make sure I'm busy all day and burn my energy so I'm tired in the evening, otherwise I'm angry and agitated."

Man, 23 with ADHD and OCD

"When I eat my food I sit down and eat my food, that's it, bam. I'll eat half my food, get up and then come back in, eat the other half of my food blah, blah, blah and do whatever I'm doing. ... It is painful for me. Not a lot of people understand. Unless you've been in my shoes you understand."

Man, 24 with ADHD

Noise, light, smells, or textures were a big issue for all autistic service users who explained that if they are not able to control the level of stimulants, they can get triggered and panic. These autistic panic attacks have been and are usually interpreted as aggression. Many had gotten in trouble with the police because of them. Fear of change and getting overwhelmed by change was a constant in autistic service users' lives.

"I try to calm myself down by reading and blocking noise out. Headphones and blocking my ears just so that the noise I hear is not too much. I just take tissue and push it down my ears, push it, push it, push it in. And then the wax in my ears start clocking up my ears and then I can't hear properly. That's how I do it so it's better basically."

Man, 21 with autism

During User Voice's outreach, only 16 service users we interviewed had been diagnosed with an Acquired Brain Injury (ABI), although many more said they probably had it too. Those who had been diagnosed did not know much about it, the overall sense was that no one had explained their condition to them, and that even the experts did not really know much about it. Those who were able to tell us about their condition said it has impacted their emotions, memory, temper and understanding of things and situations.

"What I've found right is, they don't really know fuck all about your brain do they? I've had a serious brain injury and my brain bled and they haven't told me anything. They don't fucking know, they don't know what's happened to me or what's likely to happen to me or how it's going to affect me. I've been told nothing and I'm the one it's happened to, so they don't know anything. If they did know stuff, they'd have told me, wouldn't they?"

Man, 41 with ABI

A third of women we interviewed had ABI, mostly through domestic abuse. The women told us that because of their brain damage they had also been diagnosed with dyslexia, schizophrenia, epilepsy and/or psychosis.

"I was in a domestic violence relationship with an ex-partner of 12 years, and I was hit quite a lot in my head, so now I suffer from epilepsy and seizures, and it's affected me where I can get very confused and forget what I'm talking about. I'm quite dyslexic because of it as well now and spelling or numbers. I also, a couple of years ago, had psychosis, where I had 4 different voices in my head telling me what to do, and the things that I'd see and hear I thought were very real, so I got put on antipsychotic medication."

Woman, 37 with ABI, dyslexia & dyscalculia

"The dyslexia was acquired with my brain damage. Prior to that I wasn't dyslexic."

Woman, 42 with ABI & dyslexia

"On a daily basis it's a struggle, well it's a fight. It's a fight every day, because I've got paranoid schizophrenia, short term memory loss because I've got a brain, hit round the head with a baseball bat, so I've got a bit of brain damage."

Woman, 34 with ABI & dyslexia

A couple of individuals with ABI were not comprehensible to us during our interviews, raising a serious question about them being in prison and not in more appropriate facilities where they could get the support they so clearly need.

CHAPTER 2 – THE DRIVERS OF NEURODIVERSE SERVICE USERS INTO THE CRIMINAL JUSTICE SYSTEM

EARLY LIFE ADVERSITY

- Over half of the service users had experienced abuse in their early life (47% men, 76% women)
- One third of the service users had experience of care (men 30%, women 24%)
- 38% of men and 29% of women had struggled with alcohol or drug addiction
- 71% of men talked about being labelled 'bad,' 'naughty' or 'thick' at school and acted accordingly (47% women)

It is widely accepted within the research community that the sooner neurodiverse developmental conditions are identified in children, and the sooner appropriate intervention is provided, the better the life opportunities are for those children. Children who are neurodivergent and have childhood adversity are recognised as more disengaged in society. This leads to their needs not being identified and them receiving less support.

"I moved out of my mum's, though, when I was, like, 13. I lived on the streets. Yes, I worked for myself, made my own money. I lived on my own."

Man, 25 with dyslexia, dyscalculia, ABI, OCD, & possibly ADHD

"So, when I first knew I think I was about 5 years old. I just knew I didn't fit in. Having adverse childhood experiences, so trauma that's happened to me as a child, I think a lot of that has moulded me. So, your mum not paying attention to you, you know, your parents abusing you, substance misuse, all of that then moulds you. So, that has an impact on how you view and see the world."

Woman, 33 with ADD & LDD

Most of the individuals User Voice interviewed for this project were from lower socio-economic backgrounds and therefore did not receive the support or resources that neurodivergent children from higher socio-economic backgrounds more often receive.

Most had felt different in their early years, often without understanding why. Many were not able to regulate their emotions and had problems communicating their opinions or feelings. Frustration about this led to anger and violence and was often misinterpreted by their parents, carers, friends, and teachers as being 'bad', 'naughty' or 'thick'.

"I've always been a bad kid, I've always been violent and aggressive, smashing things up. None of my family could control me, always calling me a spastic, retard."

Man, 31 with ADHD, dyslexia, ABI, LDD plus OCD

"I moved about a lot because nobody could understand me. Nobody could understand what I was doing, stuff like that, so I moved home after home after home. I went to like, a care, a boarding school down in [city name], and there they understood me and stuff like that, and then I moved back, and moved home after home after home again."

Man, 33 with autism, dyslexia, speech and language disorder & ABI

PARENTS

Many service users told User Voice that during their childhood their parents were using drugs or drinking. They told us how they did not receive much love at home, and how they were able to do whatever they liked without any consequences, without anyone telling them right from wrong. Some said their parents were busy working night shifts, trying to provide for their families, or had serious health issues and therefore not able to look after them all the time.

"I've experienced a lot of neglect from family. That's one of my big, main reasons of, like, my ADHD, because with neglect, I'd be on the streets at the age of five at 2am. I'd be breaking car windows and, you know, just laughing about it. You know, I'd be hitting people."

Man, 22 with ADHD & dyslexia

*"I've not had no men in my life, I've not had no dad, I don't know the c*nt. So I don't know where to fucking look, like, I don't know how to act like a man in these situations. I'm a manipulating c*nt myself, very manipulative because of what I've learnt, I know how to manipulate."*

Man, 33 with ADD plus PTSD

Many people User Voice spoke to suffered extreme abuse from their parents and their partners. Numerous service users also said how they spent their childhood living with different family members, being passed from family member to family member, adding to their feelings of abandonment and isolation.

"I got locked in a loft for 3 days by my parents. I had to watch my mum perform a sexual act on another man. My budgie was killed with a shoelace. They threw my guinea pigs up against a wall. Smashed a hammer over my dog's legs and then me and my sister were abused from the age of 5 until 7."

Woman, 31 with ADD & LDD

Several individuals told us that they had been diagnosed as neurodivergent at school or by social services but that their parents did not believe in these conditions due to stigma. Some parents believed they would 'grow out of it' and refused

all possible support or medication. These service users were left to survive without understanding their condition which for most were getting out of control and making them ever more frustrated and confused.

"I remember being sat in a doctor's office, a specialist office, when I was about 8, or 9. The doctor was asking me and my mum mad questions, and I just wasn't even paying attention. I remember her saying, 'This is what I've got to fucking put up with.' I remember the doctor saying something like, 'It's not really his fault, it's something to do with his head.' Then from there, things went tits up. I think she just wanted money, my old dear. She was doing the same for my other little brother, as well. It was mad, and I was the one that got pushed out, eventually."

Man, 28 with autism, ADHD, LDD, dyscalculia & dyspraxia

Some disclosed that their parents had pushed for diagnosis and did everything they could to get the right support, but nevertheless had ended up not being able to control or take care of them. Not one of the service users we spoke to remembers being sat down to discuss why they were behaving the way they were behaving, the only support they received had been medication. Medication without any other support had not been enough in controlling their emotions and feelings, or in teaching them how to communicate with other people.

"It took my mum and the mental health team in the school to push it through for 5 and a half years to fight it to get me diagnosed that I had ADHD. I wasn't sitting in classes, when I was in classes I was playing with the paper. ... They [CAMHS] are just like 'Here's your prescription, see you in 6 weeks' time'. That's not really helping that's just shoving pills down someone's throat, because they've not bothered to deal with us. To us it's like we've got a sign on our head saying we are different, we are weird, but we are not weird, we are not different, we are all human beings at the end of the day."

Trans woman, 29 with ADHD, plus PTSD and schizophrenia

SOCIAL CARE

One third of the service users we interviewed had been in care. They spoke about how their parents had not been able to control them, or not cared for. Some even said their parents had abandoned them and moved abroad leaving them behind for the system to take care of them. The most common experience was to be moved from care home to care home.

Most service users told us no one understood them, no one tried to explain why they were out of control or feeling confused. The only support mentioned was medication, which was often given without an explanation of why they were being medicated. Many also shared that they had experienced abuse in care.

"My needs were to deal with my trauma, to be able to sit down and really understand what my ADHD meant and why I was the way I was, and what I needed to do to be able to deal with that and cope better with that. In there [a care home], all they see you as, you're a kid, you're a kid who's a bit hyperactive, we'll give you some drugs, that'll shut you up, we'll put you in a corner and leave you to get on with it."

Woman, 29 with ADHD & ABI

"There was violence from my stepfather so I ended up in care [age 12]. ... I was put into a children's home, another children's home. I was moved from one to another and then when I was about 16 I got fostered. That broke down so I went back home with my stepdad. That broke down so I was then put into a working boys hostel. ... I was about 17. Then I went from there into my own flat. I wasn't shown how to manage my life from coming out of the care system."

Man, 57 with dyslexia & LDD

"I got abused in care as well ... So that lasted from the age of nine until when I got kicked out of care before my overnight birthday. And then I started coming to prison from the age of 14."

Man, 51 with autism, ADHD, dyslexia, dyscalculia, dyspraxia & LDD

DRUGS AND ALCOHOL

Negative early life experiences, as well as feeling confused and misunderstood, led to self-medicating for over a third of the people we interviewed. Many said they had started drinking or using drugs at a very early age (10-12 years old). Many isolated themselves and started drinking or using drugs to 'numb' their feelings or to 'block' their condition.

"Well I ran away from my care home ... we were up in these woods, because there was loads of woods round, and they sent a police dog after us. The police dog bit me, and I got nicked for running away, they took me back to the care home. All we were doing was up there smoking a bit of marijuana and a few drinks. I used to drink alcohol when I was 10 as well."

Man, 33 with autism, dyslexia, speech and language disorder & ABI

SCHOOL

Most service users had experienced special needs schools and classes, boarding schools, Pupil Referral Unit's (PRU), reduced timetables and exclusion. Research has shown that there are higher numbers of neurodivergent traits among children who are excluded from school but usually no screening or support, other than medication, is offered for these children before the final decision to permanently exclude them is made.

"When I was at school. I just knew at the time that I was just not right, people telling me I'm not right. I'm a good guy but I just can't stay still. I'm active 24/7, I can't lie down and get back up. I'm just fucking not right. I'm here, there bam, bam, bam."

Man, 24 with ADHD

Most participants said they were violent at school. Getting into fights, beating up other children, and destroying property. They were labelled the 'bad' boys or girls, a label that stayed with them. They told us that since everyone kept telling them they were bad, they started believing it.

Many said the label has stayed with them since school and persisted throughout the criminal justice system. They feel they are not seen as someone who needs help but as someone who is bad by nature. Sadly, to highlight this self-fulfilling prophecy, the very first thing many individuals told us when being interviewed was that they are a 'bad boy' or a 'bad girl.'

"School, I was beating people up. Just quite a loner at the start and then I turned into the class clown where I just made everyone laugh. ... Until 14. Got kicked out, thieving."

Man, 33 with ADD plus PTSD

"So in school you're bad, detention, and then you'd think, shit I'm not trying to be bad I'm just trying to do what makes me feel a bit better. Like, but because you get told you're bad, you believe you're bad."

Man, 29 with ADHD & autism

Many were sent to special needs schools or 'naughty' schools but only few ever got any support for their 'bad' behaviour. Some had teacher assistants sitting next to them in class, which often felt more embarrassing than supportive.

"They used to have to have a teacher sit with me because if I couldn't read something and that, I'd get fucking frustrated to fuck. If they tried to call me up in front of the classroom, I would go mad. I'd say, 'You trying to fucking embarrass me,' and I'd flip out and I'd walk out."

Man, 25 with dyslexia, dyscalculia, ABI & possibly ADHD

CHAPTER 3 – CRISIS POINTS; ENTRY INTO THE CRIMINAL JUSTICE SYSTEM

CRISIS POINTS

Many service users told us that they have lived their entire lives 'in crisis' due to neglect, isolation and a lack of understanding or support from their families and the institutions. By listening to these service users' life stories, it seems almost as if the education, healthcare, and social care institutions were looking the other way. These institutions seemed to wait for them to 'do the inevitable' and pass over into the criminal justice system, which the interviewees all did.

"I got abused in care as well ... So that lasted from the age of 9 until when I got kicked out of care before my 16th birthday. And then I started to coming to prison from the age of 14."

Man, 51 with ADHD, autism, LDD, dyslexia, dyscalculia & dyspraxia, plus PTSD and paranoid schizophrenia

Many said they turned to drugs and alcohol to cope, which in the end, when things got out of hand, had led to them to commit crimes such as stealing, robberies and assaults. Women service users' entry into the criminal justice system was often via domestic abuse and losing of children to social services, which then led to drug use and crime. Bereavement was also a trigger for many women, who felt they lost their support system and started to drink and take drugs to numb their feelings and emotions.

"Yes, I hadn't even really smoked a cigarette until then [22 years]. My daughter was born shortly after that. I'd got in a relationship, got married, and I wasn't dealing with it very well. Started taking drugs."

Man, 50 with ADD, dyspraxia plus OCD

"My mum used to say that I had problems, you know, in first school and that. Once I had to stay on an extra year at school, because a lot of the time people were saying things to me, but I wasn't taking it in. I couldn't understand it, and they were repeating questions, and I couldn't think. It's just like, I don't take in what I'm reading. But with my anger management and my anxiety and depression, I started suffering badly when my dad died, when I was a teenager, about 14. But at the same time as when my Dad died, I started getting on drugs, you know, through a first boyfriend."

Woman, 37 with dyslexia

Several individuals with ADHD said they stopped taking their prescribed medicine after leaving their care home or home. As a result, they could not control their emotions and thoughts which led to them being frustrated, angry, and violent.

"They gave me all of the medication. ... but my mum didn't want me to take them, because I was not myself, and I was, like, basically a zombie. I couldn't think straight in school or anything like that. I didn't have any support. And since I finished at nine, and I started committing crimes."

Man, 30 with ADHD, dyslexia & LDD

On the other hand, some discussed that being pushed out of the support systems after they left care, had left them going from crisis to crisis until they ended up in the criminal justice system. Some service users with ADHD stated that only having their medication, without any other support, was not enough for them to regulate their emotions and behaviour which often resulted in them offending.

"So obviously overnight I went from having all this support to being left in a 5-bedroom house on my own. It turned into a shithole. In fact, it burned down in the end, you know. Because I got exposed to drug-users which was how I got on the drugs. ... And after that I became homeless. And homelessness with a drug addiction that led to crime, that led to prison."

Man, 28 with ADHD

POLICE

- Of the 104 service users who were interviewed for this project, only 2 said police had made adjustments around their neurodiverse condition. That is 2% of the service users.

"They didn't take into consideration my ADHD, and when I came to the police interview, I told them that I'm meant to have an appropriate adult. They never gave me one."

Man, 34 with autism, ADHD, LDD & dyslexia

Service users told us that the police only reacted to their behaviour and never took the time to understand the causes of their behaviour. They felt that the police did not know enough about neurodiversity and the behavioural traits of neurodivergent service users. The police do not ask whether someone is neurodivergent. When someone tries to say that they are neurodivergent, the police either do not believe them or they do not care.

"I felt like I was-, well no one asked me anything, and the police didn't ask if I had any learning disability problems whatsoever. ... It just seems like that goes out the window when you're getting interviewed."

Man, 29 with autism, dyslexia, dyscalculia & LDD

"I think they weren't taking nothing really serious. I don't think they knew I had a brain injury, so they swung me round and took me out."

Woman, 26 with ABI and speech and language disorder

Service users felt they were being criminalised for their neurodiverse conditions. Autistic meltdowns were interpreted by the police as someone being aggressive or out of control due to drug or alcohol consumption. There was no understanding from the police that flashing lights, loud sounds and being approached by multiple police officers can be overwhelming for someone who is neurodivergent.

"... when I got arrested, I didn't react very well with it because it was uncomfortable for me. I don't like the police grabbing me, I don't like the police confronting me. It's uncomfortable for me, and I find them quite scary. And sometimes I feel as though the police are not trained very well with Autistic Spectrum Disorder. When you've got lights and loads of police officers coming at you, it's quite intimidating and scary, and it can give people with Autism quite a sensory overload."

Trans man, 35 with ADD, LDD, dyslexia, plus OCD

COURTS

- Of the 104 service users who were interviewed for this project, only 3 said the courts had made adjustments around their neurodiverse condition. That is 3% of the service users.

Service users told us that because of their criminal records, they feel they are perceived as not deserving of any support, and therefore their neurodiverse conditions are ignored in sentencing. Many felt that in the eyes of the system they are always just 'naughty kids.'

"I got a full psychologist's report done and when I went to court the judge picked it up, he had a flip-through and said, 'I don't believe a word of this, I'm not going to take it into consideration,' and then threw it over the side, literally just threw it."

Man, 28 with ADHD

"Because I go to court and when I go to court and then I don't get no help. They just look at my record. They just look at my record and then they will say 'I'm in the system, that I'm in and out of prison so they don't see me as a person that deserves help or person they should be helping."

Man, 51 with ADHD, autism, LDD, dyslexia, dyscalculia & dyspraxia, plus PTSD and paranoid schizophrenia

"My lawyer told me that there should be a lot of support for me because I'm autistic but there was none."

Man, 21 with autism

When asked what adjustments courts had made for them, most said there had been no adjustments at all. Service users described how judges and solicitors lacked knowledge and understanding of neurodiversity, and empathy towards neurodivergent people. Some individuals had their diagnoses changed to personality disorders, and the only 'adjustment' offered was being referred to cognitive skills course in prison.

"So I've met this industry professional over a period of a time who's saying you've got autism, and then I've met one guy for one hour, I've told him everything, and he says I'm more likely to have narcissistic personality disorder."

Man, 47 with ADD

Court hearings were described by service users as stressful because they were made to sit still, surrounded with people and noises and without being able to get up, walk around and/or hum. Some stated that court procedures had not been explained to them properly.

"When I was in the courts, stuff like that, every time-, I can't. Where there was so many people, my anxiety, my hand shakes. ... The barrister told the judge I suffer with certain problems, didn't do anything."

Man, 26 with ADHD, dyslexia & LDD

Some individuals said they had wrongly pleaded guilty without understanding what it meant because their solicitor had asked them to. This is an example of how some neurodivergent individuals can blindly trust people who they think have good intentions.

"I actually said to my Barrister, if I get sentenced, I'd like a hospital, and he went 'I'll try' but he didn't even ask. He went, as soon as the Judge said 26 months, he didn't even ask 'Can we do 26 months in a mental psychiatrist hospital where we can get the best help'."

Trans woman, 29 with ADHD

"A lot of people with autism are naïve to some things, don't see things coming and believe what authority tell them."

Male focus group participant

"I was terrified of going to court, I was terrified of the whole thing. I still had a psychosis, it was 2 days after I'd jumped from the police station the solicitor said, 'You haven't got a defence, plead guilty,' so I pleaded guilty because he told me to do it. That's an autistic thing."

Woman, 44 with ADHD, Tourettes, ADD & LDD

A service user with learning disabilities had been asked by his solicitor not to speak at a hearing because of their stutter, even though they would have wanted to tell their story to the judge. Another, dyslexic service user was told by his solicitor that he does not need to read all the court papers because he was taking longer than usual to read them. This resulted in incorrect information being put across to the judge which affected his sentence.

"The stutter as it's been pointed out to me by a guy in the prison later could be seen as a softening influence to make the jury like you. That had never occurred to me because all I see is a person that's not sure, there was no sureness in the complaint either. I have put the part about stuttering into a complaint to the solicitors that were responsible for that barrister and in the appeal, and he denied it, saying he did not give me that advice [advised him not to speak in court]. I don't blame him; I just took it as a chance to not speak because I was scared."

Man, 47 with speech disorder

A couple of individuals with ABI had been trialled and sent to prison although doctors had stated they are not fit for trial. We spoke to service users with ABI in prison who clearly should not have been tried in criminal courts because they were not even able to hold a conversation with one person in a quiet room.

CHAPTER 4 – LIFE IN PRISON

DIAGNOSED IN THE CRIMINAL JUSTICE SYSTEM

From our engagement, 9 service users had been diagnosed while in prison and a couple during their court case. In most cases, assessment was prompted by an outside service or prison education who had noticed something was not right. For some older service users, the trigger to be diagnosed came often from when the system noticed they were getting recalled after repeating the same behaviour.

"I was diagnosed with autism in early November of last year through the promptings of Prevent and HMPPS. ... Prevent took an interest and thought there were grounds for sending a psychologist to come and see me who then recognised autism. ... I would have loved a diagnosis [earlier in life] because it would have changed everything."

Man, 32 with autism

"Yes [was diagnosed in this prison one year ago], because they wanted to know what programme they could put me on, sort of thing. When I was out, before I got recalled, they knew there was something not right with me and that sort of thing. We were repeating the same things over and over."

Male focus group participant

To demonstrate the inconsistency of screening and assessments in the prison system, 1 service user with autism told us about how his autism diagnosis was done in prison whereas few others said they were told they could not be assessed for autism in prison because they needed to be observed in various environments, or because the prison did not have a licence for it.

"Firstly, it was, just, a load of questions, and then they had to ask loads of questions to my mum to see if I could do an ADOS test, which is the actual diagnosis. And then I did the diagnosis about a month ago. And then I've just got the piece of paper through saying, 'Yes'."

Man, 25 with autism

There were mixed experiences about being diagnosed while in court. A service user told us he was diagnosed with ADHD while he was being assessed for 'dangerousness', another said they had tried to get diagnosed while in court without success.

"Yes, I got diagnosed in jail. I tried getting diagnosed in court before, when I first came in, when I was going through the court to get sentenced, I tried saying, 'Listen something's not right.' And then it just never went anywhere."

Man, 29 with ADHD & autism

PRISON

- Of the 104 service users who were interviewed for this project, 15 said prison (previous or current) had adjustments made for them around their neurodiverse condition. That is 14% of the service users.

Confirmed or self-diagnosed neurodiverse service users face several challenges in prison; they are forced to share their space and to communicate with people who often also have different challenges in communicating and in regulating their emotions. They are forced to try to stay on the good side of prison staff, who often do not have enough understanding about the behaviour and needs of different neurodivergent people.

Service users told us that they did not have the freedom to decide or design their routines and activities that help them to manage life outside. Instead, they need to try adjusting their life and needs to prison schedules and activities. Some do this better than others. Finally, their health and medical needs are in the hands of the prison health care system, which is arguably not knowledgeable enough about, or fully resourced to support neurodivergent individuals.

"I think it's really hard to find a neurotypical person behind a door in a prison. We've all got something a little bit different going on, not necessarily to underline why we're here in the first place, but there's something not quite functioning in the normal way, whatever you want to say. But, like, the system throwing me in here, and I'm bumping into all kinds of different people that communicate differently, it's really made me stop and think, kind of, 'Okay, why is this person talking to me so aggressively when all he's asking for is a teabag? What's all that about?'"

Man, 47 with ADD

LIFE IN PRISON

Single cells were the most talked about and sought after adjustment in prison, especially amongst service users with autism. Most service users with autism preferred single cells to avoid sensory overload and confrontations, and to maintain their routines and cleanliness standards. Some mentioned they prefer single cells to avoid being manipulated by their cell mate, which had happened to some in the past where they were asked to fight, steal, or conceal to mention a few. Although some individuals spoke about the loneliness of being in a single cell, they still preferred it over getting into confrontations or being manipulated.

"There's one autistic person that got put in a cell with somebody else, and he got beaten up, because they put him in a cell with someone else. He should have been in a single cell on his own. You know what I mean? I think autistic people, if you come to jail, have single cells. Not being with people, because they like their own space, autistic people. They do like their own space."

Man, 33 with autism, dyslexia, speech and language disorder & ABI

"That's why I don't want cell mates, people I don't want to be involved in people's problems, because I get dragged into it basically. I would help them; I will do stuff for them."

Man, 21 with autism

Routines are necessary for many neurodivergent people; they provide stability and comfort. Many service users spoke about how they struggled with change in prison, whether it was in relation to a new cell mate, appointments, food, or anything that takes them off guard. Some individuals found prison life harder because they do not have the mechanism

to cope that they have outside. Whereas some found prison life easier because they did not have to deal with as many people and distractions as they do outside.

"I personally think that prison is helping me. Cos you know we wouldn't be able to have this conversation out you know. My autism was so bad I would not have been able to understand you properly. But coming to prison I had to force it, force it. Reading books, doing all these things."

Man, 43 with ADHD, autism, LDD & dyslexia

Individuals with ADHD told us that they needed more space, breaks, and opportunities to train (burn energy) to keep themselves calm. They told us that being locked in a cell when frustrated or angry only makes them more frustrated and angrier. Few mentioned they had received remedial gyms in other prisons which had helped them to control their energy and feelings. They were frustrated it was not offered in their current prison.

"In [prison name], don't forget, when I got my recall, I was getting eight gym sessions a week. So I could keep myself fit, and all that. But, you come here, you're getting one gym session a week, I've tried getting onto the doctors to say about remedial gym, because say I do have a punch-up out there, they always give me remedial gym, just to work off my energy and that. Here, you get fuck all. They just lock you up in a cell and don't give a fuck."

Man, 45 with ADHD & dyslexia

When we asked about helpful coping methods and distractions in prison, service users mentioned reading, music, TV, video games, drawing, games, matchsticks, and cleaning as some of the activities that can keep them engaged and help them to stop overthinking and ruminating on things.

Some individuals with autism said they will read everything they can get their hands on from books to user manuals, whereas some people with ADHD said they need to play games or do crafts that demand full concentration, so they are not able to think about anything else.

"I try and block it [his condition] out with drawing or music or TV, that's all you can do in prison, but outside, it's just booze and cars and stuff."

Man, 28 with autism, dyscalculia & ABI

"I do sing. But I rock and sing. It's all down to rocking, I like rocking to music. Because that's part of autism as well, I like rocking to music."

Man, 33 with autism, dyslexia, speech and language disorder & ABI

The gym is extremely important for many service user's mental health and is used as a coping mechanism in the prison environment. It is especially important to those with ADHD who need to burn excess energy to tire themselves out to be able to communicate with other people without irritation, and to be able to sleep at night. Those individuals, who do not like to interact with a lot of people, feel the gym is too crowded and therefore prefer to exercise in other ways like by running in the yard.

"Training is my medicine; I have to burn my energy."

Man, 35 with ADHD

Peer support was mentioned as a positive coping method by numerous individuals. There was a great appetite for more peer support schemes for neurodivergent people in prison, such as listeners and support groups. The common feeling was that a neurotypical person can never support and understand a neurodivergent person as well as another neurodivergent person.

Older service users, who had learned, often the hard way, to live with their conditions in prison and outside, felt that they could be helpful for other neurodivergent prisoners. Many expressed the wish or need to help others to help themselves.

"Look, I've been ADHD for 40 years, this is what I do to train my brain. You know, sometimes they pump you full of medication, or what's the other ADHD meds that are really popular? ... It would be quicker to get the help that I need if its peer led and I can get hold of it myself if I can get the answers myself. It's way quicker than putting an application in."

Man, 57 with LDD, dyslexia, autism & speech and language disorder

"Just knowing that if you've got a particular diagnosis or inclination that something is going on with you, you can go to someone that identifies the same as you in your neurodiversity channel and go, 'I'm really struggling today,' 'Have you tried this?' 'No, I haven't. I didn't even know that was a thing. I'll give that a go,' 'If you need me, I'm here.' A little bit like the listeners programme for people who are just generally suffering from low moods, stuff like that, but for neurodiverse people."

Man, 47 with ADD

COPING/ SURVIVAL METHODS

Routines and to-do lists were important for many people with autism and dyslexia, whereas training and exercise to burn energy was mentioned by most people with ADHD and ADD. Games that require extreme concentration like chess, sudoku and some video games were also mentioned as helpful.

"I don't know. I've just always, kind of, been like this. So there's three things that I can fully concentrate on in this world. That is Sudoku, chess, and the gym. Anything else, I struggle with. Sometimes I may need to do 2 things at once. ... Yes, you haven't got any choice but to focus on it, and because there are so many different ways of doing so many different things, Sudoku works. Chess works as well, it's the same thing. If you don't put your full 100% focus on it. And the gym, I just win in the gym."

Man, 36 with ADHD, ADD & dyslexia

Many service users had self-medicated to 'block out' their condition and calm themselves down. Only a few mentioned masking their condition and trying to appear 'normal'. One person said he is constantly loud to stop himself thinking about bad things and hurting people. Only a few mentioned controlling their behaviour as a coping mechanism.

*"Summer of 1996, I started medicating it myself.
... it kept me on a level."*

Male focus group participant

"I'm a loud person, but I'm not loud because I want to be heard. I'm loud because sometimes being quiet scares me. Because when I'm quiet is when I'm thinking bad things. The only times I've ever been quiet is when people seriously get hurt. So I'm normally loud."

Man, 19 with ADHD & autism

Many coped and survived by trying to avoid people and situations because they felt it was easier that way. The theme of self-isolation comes up throughout the interviews. This is because they had not properly learnt how to live as a neurodivergent person in a neurotypical world. The interviewees/service users rather had spent their lives isolating themselves from others to avoid problems and altercations.

"My way of coping with it is, I just completely avoid every situation to where I know I probably end up doing someone in. And I don't mean that as in, I walk around the wing aggressive, and I'm a threat to anybody. It's just people don't understand the stuff that I've got going on all day, every day. And there's that many different things that I'm having to deal with on a daily basis, like I come out of the cell and it's loud on the wing, I've got to go and do my job. I'm trying to move away from the crowds, so it's quiet while I'm doing my job, take my own time."

Man, 43 with ADHD, autism, learning difficulties & dyslexia

PRISON STAFF

Service users had several concerns about prison staff. They shared with us experiences of provocation and abuse from prison staff. They said officers do not always believe them when they disclose their conditions, and that misinformation or a lack of information about neurodiversity was common amongst the prison staff. A perceived stigma around neurodiversity was common when staff spoke to neurodivergent prisoners.

"Out of all the staff I've known in all the prisons I've been in, so thousands of staff, and I mean thousands, and tens and tens of thousands of prisoners, there's only, I would say, 5 members of staff in all these years that I actually got a lot of time for. That actually went out their way to try and help, and then they're ridiculed by staff for helping me. ... 'Are you going to help the spastic today Me!'"

Man, 63 with autism and ADHD

Worryingly, some individuals even disclosed that some staff know how to 'poke' them and use their triggers to elicit a reaction and to get them into trouble.

"I've figured them triggers out, but they won't, they keep using my triggers against me, it's not just staff its prisoners as well."

Female focus group participant

Service users told us that adjustments and support was not delivered systematically by all staff, and that some staff ignore adjustments on purpose. Service users with ADHD felt that their condition was still viewed as the “naughty boy syndrome” and therefore often dismissed as needing any support or adjustments.

"Naughty boy syndrome, how they used to treat it in the 90s. And it's always had that stigma within the prison service."

Man, 34 with autism, ADHD, LDD & dyslexia

"I cut my stomach. And they literally-, they just called me pathetic. The staff do, or 'attention seeker'. They don't know how to deal with ADHD. They don't know. ... A lot of the staff have got the attitude, 'We're not here as a social service. We're not a social service.'"

Man, 34 with autism, ADHD, LDD & dyslexia

Older service users spoke about how the role of prison staff has changed over time and that currently they only have time for locking up. They feel staff are lacking in communication skills, which is crucial for staff working in an environment with varying communication skills and needs. Another theme discussed by a few prisoners was the ‘us versus them’ situation where they feel the officers will always have each other’s back, no matter what the situation was.

"No, they've only got 1 job now. There's no communication with officers. It's just lock the doors and-, they're not allowed to. It's all changed now. They had a little key worker thing they used to do before, but that got scrapped. They couldn't fund, there's no staff. So, it's just lock the door, do your job, and go home."

Man, 36 with ADHD, ADD & dyslexia

"I don't kick off, or hurt anyone, or anything like that, it's mainly just coming out and telling the truth. A lot of people, officers especially, don't like the truth coming out. Some officers have been really horrible to do things behind people's backs, and then they get other officers to stand by, they'll all stick together, so it's like prisoners against officers, all the time. And I've had that through the whole prison."

Female focus group participant

Several service users mentioned positive encounters with staff members who had neurodivergent family members and who therefore knew how to support them. They felt these officers understand how difficult it can be to be in prison as a neurodivergent person.

"One of the staff members here, Mr X, he told me about his son who has ADHD. He's the only one who comes up occasionally and just talks you know, whenever he can. He actually realises the problem, he realises how hard this can be."

Man, 35 with ADHD, plus PTSD

The adjustments mentioned by the 14% of service users included single cells, being let out for a walk when they felt overwhelmed or frustrated, access to gym to burn energy, noise cancelling headphones, overlays, handwriting pens, and special plates so different foods did not touch.

MEDICATION AND HEALTH CARE

The lack of sufficient and systematic assessments as well as screening for neurodivergent individuals in prison meant that not many were receiving the support they needed. Many service users feel frustrated, angry, and even distressed about not getting the help they needed and have asked for.

"I've never had the help I need. Like, I'm not saying I'm a problem like that but, like, I'm so polite, I'm so helpful. I'm vulnerable in a way, like, I don't like even saying it but in a way I'm vulnerable because people know me to kick off, so, they know they can-, and I'll flip. Do you know what I mean? So, in that sense I'm vulnerable, very vulnerable."

Man, 24 with ADHD and autism

"And I've been told as recently as Saturday, so less than a week ago, they don't do assessments for any sort of neurotypically diverse issue within this prison. Even if they were to get an assessment done, the prison would not allow a specialist in, even if I paid for it. If by some miracle of God I did get an assessment done and I got diagnosed, they would not be able to give me medication because I wasn't prescribed it prior to entering the prison system. The problems being they're not commissioned to do any other assessments than personality disorder assessments."

Man, 28 with self-diagnosed ADHD

Most service users told us that medication was the only support they were receiving in prison for their neurodiverse conditions. However, too often they were given the wrong medication, too much or not enough medication (in comparison to what they were prescribed outside). In addition to this, medication is also given inconsistently to service users. Some individuals were not given the ADHD medication they had been prescribed outside because they were classified as controlled substances.

"I might find a situation actually quite traumatising, I might find an interaction with a nurse really difficult because I'm not- because I've walked away and they've not explained something to me properly ... Or helped me understand why my meds aren't there, AGAIN ... Erm with no good reason for it and I'm just confused. You're telling me I've got to take these medication."

Woman, 42 with dyslexia & ABI

"Do you know, for me to get medicated in here, I had to say, 'I'm going to hang myself, or you medicate me.' You know, that's what it came to. I actually got up onto the railing to try and hang myself before they said, 'Do you know what? We'll speak to the psychiatrist.' Hang on a minute, it's taken what? For you to see me go that bad, that mentally ill, that I've had to threaten my own life, for you to medicate me. It's not right. Everybody in here should have that first, initial assessment with the psychiatrist. Especially if they've got a past of mental health. Especially, such as, a past of bipolar, ADHD, you know, ASD, OCD, because if they're not right, and they were on medication before and they're coming in here rattling, and they don't get that medication, you've got a very, very serious, unpredictable person who could switch at any minute."

Woman, 29 with ADHD & ABI

"I think prison, more than me, needs to learn about ADHD and ADD, because the mentality of, 'Oh you're just naughty. You're naughty, you can't help it, he's got ADHD,' 'Oh, ADHD, here's another one, ADHD massive,' they're so dismissive of it as a condition. I mean, if I turned around and said I had AIDS, you'd give me my two tablets a day, and you'd treat me like a patient. But when I turn around and say, 'My minds not wired how your mind's wired, and I don't perceive things how you perceive things.'"

Man, 44 with ADD, dyscalculia, plus PTSD

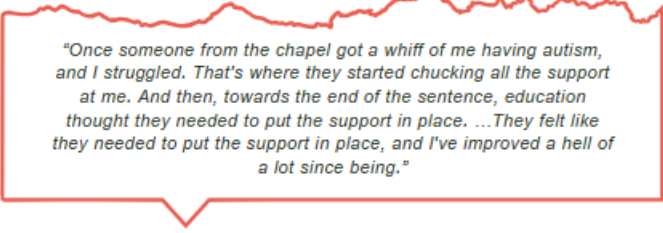
Service users spoke about the lack of sufficient access to health care and mental health services, and the lack of knowledge or qualifications relating to neurodiversity within these services. Those with ADHD especially felt that the prison system, and the whole criminal justice system, was dismissive about their condition and treated them accordingly.

"No one's done a meds review on me since the 26th April 2012. I haven't seen anyone from the mental health team since the 30th September 2014, Tuesday at 17 minutes past 2. No one. They've got a learning disability lady who came and saw me 6 months ago, never seen her again."

Man, 63 with autism & ADHD

Some service users had a positive health care experiences in prison when they had received support and adjustments for their neurodiversity. One person mentioned how it first took the chapel staff to notice his needs, after which other prison staff started to put support in place, and finally moved him into a single cell. Another individual spoke about a

mental health worker who had delivered a course that had helped him to manage his emotions better and therefore avoid getting into fights.



"Once someone from the chapel got a whiff of me having autism, and I struggled. That's where they started chucking all the support at me. And then, towards the end of the sentence, education thought they needed to put the support in place. ...They felt like they needed to put the support in place, and I've improved a hell of a lot since being."

Man, 29 with autism, dyslexia, dyscalculia & LDD

Those service users who were receiving support in prison said the support ended when they left prison.

CHAPTER 5 – NEURODIVERSITY ON PROBATION

Numerous service users told us that they were getting recalled often because no adjustments in probation had been made for them. Several individuals mentioned that they missed appointments due to changes in appointment times, locations, and officers. As change is a trigger for many neurodivergent individuals, adjustments should be made to accommodate their needs.

"I was struggling reading and writing. I was asking people out there. Long story short, by the time I got there I missed the bail store. I was supposed to be there at 6 o'clock. I couldn't find it. I was just walking up and down, asking people to read these instructions where you went. Couldn't find it. So, I got recalled. So, literally, it was a day out of prison. I went back to [area], phoned the probation office, and they said, 'Oh, your probation office doesn't sit in the office anymore. He only does home visits.' So, I was fucked. So, I was literally out, and they've recalled me."

Man, 59 with autism & dyslexia

"My biggest problem now is probation, outside probation, abusing me. Five times, no crime, nothing, not drink, or drugs, or anything, purely, 'Oh, he's been late here. He's been two minutes late. He was three.' Do you know what? One of the things when I got out, I got a voluntary job. I wasn't getting paid for it. I thought I'll do that, and then that will get me into employment. Do you know what they said to me? I was signing on once a day I had to go back to the hostel. They changed it as soon as I got the job, four times a day."

Man, 50 with autism & dyslexia

A service user told us that because his ADHD medicine was stopped, due to health reasons, just before he was released, he was not able to keep in control of things and plan his life. He was soon recalled.

"Before I got released on license, HMP staff had stopped my ADHD meds because I had major bowel cancer surgery where I had my large intestine removed. They never gave me- I was on Concerta XL and then they never gave me any other tablets for my ADHD. So then I was always-, I was just being distracted all the time, and not able to plan things properly. So then they recalled me because I didn't disclose my bank details or my alias name on Facebook within three days. But how can I plan things when I'm not on my ADHD meds?"

Man, 34 with autism, ADHD, LDD & dyslexia

Appointment times were said to be too short by some of the service users who had been previously rushed by their probation officers and therefore did not have enough time to go through all the issues and paperwork they needed to go through.

"Thinking 'hang on I've got another appointment in five minutes in another place', cause that doesn't help when I've still got three more letters to go through it. You know what I mean? I think with probation and that has gotta be more training and just, just maybe not even a probation officer maybe somebody who is just down there to talk to some people who's got some shit going on that can relate to some shit going on, it's about understanding."

Man, 47 with dyslexia, dyspraxia, plus paranoid schizophrenia

Service users told us that probation staff do not have enough knowledge or understanding about neurodiversity or the needs of neurodivergent people. Some said staff are often ignorant about their vulnerabilities, which had led them being housed in places where they had been manipulated and coerced.

Participants told us that they would often cause disruption to get the attention of prison staff so they could get the assistance they needed.

"I actually asked help from probation, I told them I've been made to do stuff I don't want to do. I showed them scars when I got stabbed in my own house, I told them everything. But there's no help."

Man, 22 with autism

"I got out, rang my probation officer, they put me in some crack house where people were injecting heroine and crack. I just lost it, smashed the place up. And I said to her [probation officer] to recall me and she said no you ain't done nothing wrong, so I videoed myself committing another burglary just to get to come back, to get help."

Man, 31 with ADHD, dyslexia, ABI, LDD, plus OCD

Some were frustrated about staff ignorance of their learning disabilities and difficulties when they were asked to go online to book appointments, sign onto courses and to fill out forms. A service user told us about his frustration of not getting onto a violence reduction course after trying to apply for years, whereas another service user with learning difficulties shared his experience of being called 'un-rehabilitatable' by a probation officer when he was in his teens.

"They [probation] keep telling me you've not done this, you've not done that, go online. I can't do none of that, I can't read and write, I can't do that. So I just miss all that and go 'fuck it'."

Man, 35 with ADHD, dyslexia, ABI & LDD

Reminders about appointments were mentioned as a good practice / adjustment in probation.

"Probation, only thing they supported me is that I forget about appointments and they actually send a text saying I have an appointment."

Man, 22 with autism

CHAPTER 6 – DIAGNOSIS AND TREATMENT

DIAGNOSIS

67 service users who were interviewed for this project spoke about their diagnosis in more detail. They were mostly those who took part in the one-to-one interviews because those in focus groups did not understandably want to share details that were too personal.

- Half of the service users had been diagnosed before they turned 17 years old (25 in primary school, nine in secondary school).
- 9 had been diagnosed between ages 17 – 26, and 17 when they were older than 27 years. 7 individuals did not disclose the age they were diagnosed.
- 29 individuals had been diagnosed while in school, 29 in the community, and 9 while in prison.

"I'm not ashamed of the condition. I celebrate it, I'll speak to people about it, I'll openly tell people of my disability. Up to my diagnosis I was obviously kind of ashamed of it and put in a box. But since I had the diagnosis and because of my children, and I have tattoos on my body with my children's autism with the jigsaw pieces in colour and stuff next to portraits and stuff."

Man, 43 with ADHD, autism, LDD & dyslexia

Everyone who had received a diagnosis said it had eventually been a relief, like a weight had been lifted off their shoulders. Diagnosis had given them clarity and assured them 'they are not mad'. They said it gave them, and people around them, one reason for why they had behaved the way they had.

"It [getting diagnosed] was like a big weight had been lifted off my shoulders because I knew that I wasn't mad. I used to sit there thinking, 'I'm mad, me.'"

Man, 40 with autism, ADHD, plus OCD

"At the time I first got diagnosed it was like a relief. Do you know what I mean? It took quite a lot of pressure off short-term because when sometimes you can think you're going mad and you think that you're struggling with all these things and they're not exactly what you'd imagine them to be. ... it's a relief that at least people can now have some understand the way you are in certain ways, in certain things, actually isn't your fault."

Man, 43 with ADHD, autism & dyslexia

"I was happy [to get diagnosed] because I was wondering what the hell was going on, because something wasn't right, my head wasn't there, I couldn't concentrate on my work, I was failing. I couldn't even sit my GCSE's."

Trans woman, 29 with ADHD

Some individuals with autism had not been happy or could not accept their diagnosis at first. They spoke about not wanting to be labelled as different to other people. Someone even said they felt insulted when a doctor gave them the diagnosis.

"For 12 years from 5th April 2002, Friday, to 5th June 2014, Thursday, I never even accepted that I had autism. Do you know what I mean, because it's another label. When you're labelled, when you've got this, that and the other or whatever, you're labelled. That makes you different to other people."

Man, 63 with autism & ADHD

Many spoke about how they would like to learn more about their condition and how to live with it better. They wanted a better understanding of themselves and the challenges they have as neurodivergent individuals when interacting and communicating with other people. Many were confused and not coping well.

"100% [would like to learn more about his condition], because then it can help me understand what things I need to take. Because I know I'm not right. What I do isn't right, and I don't want to be like that no more. So instead of just ticking me off and marking me off in a book in these counselling sessions, tell me what I can do to try and change the way I am."

Man, 47 with speech and language disorder, ABI, LDD & possibly autistic

Older service users wanted to learn whether their condition will change as they age. Those individuals whose children were diagnosed with neurodiverse condition(s) were more likely to self-learn about neurodiversity. Those who had self-learned more about neurodiversity felt it had benefited them greatly and helped them to live better with their condition(s).

"Yes [I would like to know more], how it will affect me further on in life as I keep growing older. Would it slow me down or would it be normal pace for me, or would it still be even quicker? ADHD, because you've got a faster metabolism as well, so I can't put on weight. I can put on the weight but I'll lose it instantly, that's because of my ADHD, I just lose my weight quite quick."

Man, 26 with LDD, dyslexia & ADHD

MEDICATION

Service users spoke in-depth about the extensive number of medicines they had been prescribed over the years to 'treat' their neurodiversity or the issues deriving from it or relation to it (see Appendix). Most had been over medicated with different medicines from anxiety and depression medication to insomnia and antipsychotic medications, to mention a few.

The experiences of being on different medications had been a trial and error and helped some individuals more than others. Medication had been the only support most service users had been offered as neurodivergent individuals.

"All the medication they have given me, it doesn't really help. It doesn't do anything, I end up being depressed, really depressed, anxious. I find it difficult to cope in prison."

Man, 41 with LDD, dyslexia, plus schizophrenia & PTSD

"I've been on medicine all my life, not all my life but from being probably 16 onwards, different antidepressants, Diazepam epilepsy tablets. ... sometimes they work, sometimes they don't. I suppose they help me sleep, if I need sleep sometimes they'll give me a medicine that'll help me sleep which is good."

Man, 28 with ADHD & autism

Service users with ADHD had a variety of experiences in taking medication for their condition. Some individuals had chosen not to take medication because of how it made them feel. A few individuals told us it feels like the medication for ADHD is more for the benefit of those around them and not for themselves.

"They put me on Concerta. ... I stopped taking them, they just made me go inside myself and I was like a little fucking scared cat in the corner."

Man, 45 with ADHD & dyslexia

Many service users talked about how their medicines from outside had not been continued in prison, which has caused them stress and anxiety. They criticised the prison system for not taking good enough care of people's neurodiverse conditions and mental health issues.

CHAPTER 7 – RECOMMENDATIONS FOR CHANGE

GOOD PRACTICE IN PRISONS

During our study, 3 service users gave HMP Pentonville's neurodiverse 'wing' as an example of good practice because it is less crowded, they have more freedom, and staff had better understanding of neurodivergent people. A service user mentioned Feltham YO1 where psychologists had explained to him about autism and identified triggers and coping mechanisms together. For example, he could ask the guards to lock his door or to take him for a walk when he was having a bad day.

"In Pentonville, the staff do understand. They give you more freedom. If you do teach these people, they'll hopefully give you more, like, freedom and more opportunities to not feel, I don't know. When was in Pentonville, they let me go to my friend's cell to just have time."

Man, 20 with autism, ADHD & LDD

"They explained everything to me, they said yes you got autism. They asked questions, they explained about autism. They tried to identify my triggers. They tried to identify how they could help me, they made a plan. ... The team in Feltham told me that there's no medication none of that stuff for autism, they told me it's not something to be worried about, it's not a disease. You are just special basically."

Man, 21 with autism

HEALTH CARE IN PRISON

Service users told us there are not enough health care staff who are qualified to understand neurodiversity, or opportunities to be assessed or screened for neurodiversity in prisons. Due to the complex issues many service users are facing; due to childhood adversity, trauma, and ill-supported needs, there is an urgent need for clinical psychologists in prisons. It was clear that many service users that we spoke with said they need more specialist help.

Individuals who had also served time in mental health institutions said that all the good work that was done in those institutions was undone when they were moved back to prison. Where the health care staff are not qualified enough to treat neurodivergent individuals.

"I need help. I need specialist help. I should not just be slammed in here all the time. If someone was to speak to me and give me some medication to chill me out I'd be fucking right. I'm just active. As soon as I open my eyes in the morning that's it I'm just like bam."

Man, 24 with ADHD

"They've got to train staff in understanding what the likes of Asperger's or OCD means because to them it's just a word. I've spent a lot of time at the SPD units, staff are trained there because they're all-, half of them are NHS staff that work on those units. It's the fact that when you come back to somewhere like this when you've done all your treatments, it's gone out the window because the staff here don't know anything about it."

Man, 43 with ADD & ABI

In fact, better assessment processes to determine whether someone should be in prison or in a mental health institution were called for by several service users.

"Me been coming to prison from the young age until now every time they send me to prison I always come out worse. There's no way I have been to prison and come out better. In life itself it's, like, most of these people in prison they're not supposed to be in prison they're supposed to be in a mental hospital. What are you putting them in prison for?"

Man, 51 with ADHD, autism, LDD, dyslexia, dyscalculia & dyspraxia

As part of health care and taking care of your physical and mental health, numerous individuals specifically wished for more opportunities to exercise and play sports, to help them burn excess energy.

"Here's the big problem with ADHD, we're all bored. We're all bored and we're all really hyper. You give us something like a sports hall or even just a soccer ball to kick about, we're going to burn ourselves out."

Man, 19 with ADHD & autism

TRAINING AND AWARENESS RAISING FOR STAFF

Most service users stated that the people working in the criminal justice system need to learn more about neurodiversity and the needs of neurodivergent people. They felt that ignorance, lack of information and misinformation have resulted in lack of empathy towards neurodivergent individuals. Many pointed out that there are a significant number of neurodivergent people in prisons, and therefore it should be taken into better consideration by the whole sector.

"The staff really need to because I think they'd be horrified to learn just how many women there are that have these problems."

Woman, 60 with ADD

"Well I want, I'm not being funny, I want prison officers to be more aware of autism. That's why I'm doing all this, because I want prison to be more aware of autism. You're getting a lot of autistic people in jail now, we are, a lot. I want them to do training on autism, I want them to be trained on autistic people as well, you know, because that's what they should be."

Man, 33 with autism, dyslexia, speech and language disorder & ABI

A few individuals reflected how significant it had been for them when an officer had taken a few minutes to ask how they are and listened to them. The importance of good communication skills among the criminal justice staff, especially prison staff, were mentioned as necessary throughout the interviews.

Many service users talked about their good experience with staff who had some personal experience of neurodiversity and were calling for more to be employed in the criminal justice system. Understanding of different conditions, and how they make people behave, gave these staff members the necessary empathy to work with neurodivergent individuals.

"The people that did understand me, like, when-, I've noticed the officers, like, one told me that his sister had autism and when I mentioned that I had autism, he knew how to deal with me and he was a lot better and I've got on with him ever since, you know, he treats me better. He's treated me with a bit of respect and knew exactly how to deal with me, but then others that don't, it's just-, it makes you laugh, really, you know?"

Man, 22 with ADHD, autism & tic

PEER SUPPORT AND SELF-LEARNING OPPORTUNITIES

Most service users were not only asking for more staff members with lived experience of neurodiversity, but they also told us they would like to be able to talk to their neurodivergent peers. More peer support was listed high on the agenda of what should change in the criminal justice system to make it more supportive for neurodivergent individuals. Diagnosed or self-reported neurodiverse service users felt frustrated having to explain themselves to neurotypical people.

"That really does go wrong there. You know, the lived experience is always, always the best key, but still having somebody that relates to people, you know what I mean, instead of someone with a clipboard and they, you know, it's just silly."

Man 47 with dyslexia, dyspraxia, plus paranoid schizophrenia

"I know sometimes they can get ex criminals going into prison, I'm thinking like a video call on one of the offending behaviour groups or something like that. Sometimes when you're speaking to somebody who just got training, yes, they're really good at their job, but haven't been in that person's shoes. Sometimes it helps speaking to somebody who's been in the same position as you have."

Man with autism, plus OCD

Peer support groups and listeners for neurodivergent people were suggested as good peer support models.

"Just knowing that if you've got a particular diagnosis or inclination that something is going on with you, you can go to someone that identifies the same as you in your neurodiversity channel and go, 'I'm really struggling today,' 'Have you tried this?' 'No, I haven't. I didn't even know that was a thing. I'll give that a go,' 'If you need me, I'm here.' A little bit like the listeners programme for people who are just generally suffering from low moods, stuff like that, but for neurodiverse people."

Man, 47 with ADD

What came across clearly from the 104 interviews was that only few knew enough about their condition(s) and how it impacted their behaviour, feelings, emotions, and communication skills. Only few had been taught about or had learned about neurodiversity, and therefore, most were desperate to learn more about it, and about themselves. Many said they would love the opportunity to self-learn while in prison if the materials were easy to access and meaningful.

"No I don't know enough. I would love to learn more, it would help me act in a certain way. Like I was watching a film in my special needs school ... about an autism boy, and it made so much sense. But it didn't show how he deals with it."

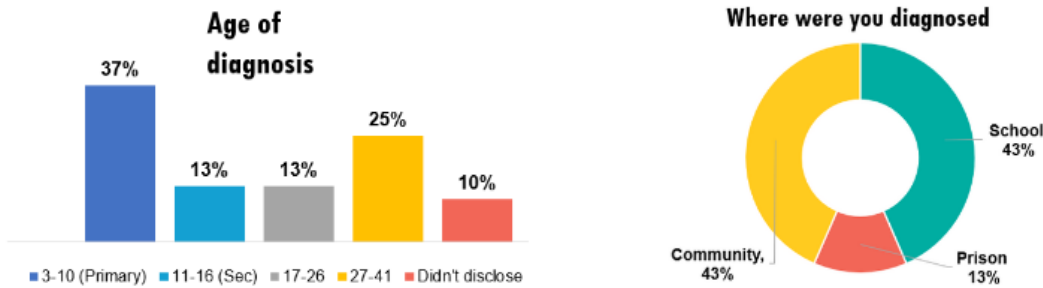
Man, 21 with ADHD, autism & LDD

RECOMMENDATIONS

- Where possible, prisons should provide single cells for those neurodivergent individuals who benefit from them.
- More one-to-one learning opportunities should be provided for neurodivergent individuals in prison who are not able to learn in group settings.
- More physical activities (i.e. gym and other sports) should be provided for neurodivergent individuals in prison who identify the need for exercise to stay calm, to sleep, and to burn energy to avoid being agitated.
- Prisons should organise more peer support activities (group sessions, listeners, champions) for neurodiverse service users.
- The NHS and the HMPPS should commission the coproduction of accessible and engaging self-learning resources for neurodivergent service users in prisons and the wider sector.
- Prisons should employ more NHS staff (including clinical psychologists) with qualifications and lived experience of neurodiversity.
- Health care induction in prisons should include more thorough and consistent assessments / screening / diagnosis for neurodiversity. The induction should also be provided for those in remand.
- The probation service needs to train staff so they are able to provide support that is adjusted to neurodivergent individual's needs. This especially should consider consistency, flexibility and service users' different literacy and digital literacy levels.
- The police should train all their staff to understand what support different neurodivergent service users need.
- Courts should offer better assessment for neurodiversity, and fully take into consideration service users neurodiversity diagnoses when sentencing. Additionally, more neurodivergent individuals should be considered for community sentences / tags when appropriate.
- The HMPPS and the NHS should consider employing individuals with lived experience of neurodiversity for roles that include interacting with neurodivergent service users.
- Everyone wants to learn more about their neurodiverse condition(s) and how to better live with them.

APPENDIX

67 interviewees, talked about where they had been diagnosed and at what age. (These were mostly people who took part in one-to-one interviews)



Medicines

The below table lists 45 medications that had been prescribed for the 104 service users we interviewed, and the number of individuals they had been prescribed to. The list is not comprehensive as some individuals did not remember the name of the medicines they were taking. We feel it is important to include this list to illustrate the fact that for most service users, medication was the only support they had received for their neurodiversity.

Medicine	Number people prescribed to
Mirtazapine	15
Concerta	12
Ritalin	11
Sertraline	7
Quetiapine	6
Atomoxetine	4
Risperidone	4
Citalopram, Pregabalin, Subutex, Methylphenidate, Propanol, Olanzapine	3
Promazine, Fluoxetine (Prozac), Propranolol, Aripiprazole, Medikinet, Lisdexamfetamine, Trazodone	2
Temazepam, Androvil, Anomoxotin, Melatonin, Diazepam, Lorazepam, Clonaxepam, Clopidol, Chlorpromazine, Haloperidol, Clozapine, Risperdal, Elvanse, Floxitine, Nortriptyline, Delmosart, Codeine, Solonex, Naproxen, Xenidate, Seroquel, Circadin, Gabapentin, Venlafaxine, Dosulepi	1

Prisons visited as part of the study		
HMP Forest Bank	HMP Wormwood Scrubs	HMP Ranby
HMP Northumberland	HMP Elmley	HMP Wandsworth
HMP New Hall	HMP Bristol	HMP Brinsford
HMP Brixton	HMP Norwich	

USER VOICE

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