

# NeuroConverse

THE NEURODIVERSITY-FOCUSED ACADEMIC JOURNAL

Volume 2 Number 1  
November 2025



NeuroConverse







## FROM THE EDITOR

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### Visibility and Voice in Neurodiversity Research

This edition of NeuroConverse opens with a question that is as ethical as it is empirical, and as urgent as it is uncomfortable: what happens when the systems built to support young people instead expose their vulnerabilities? In Dr Neil Alexander-Passe's lead article, *Autism, School, and Crime: How School Can Lead Those with Autism into Crime*, we are invited to look unflinchingly at the institutional pathways that can push autistic students toward criminalisation rather than inclusion. His analysis, which is both rigorous and deeply humane, asks us to reconsider how schooling structures reward conformity and punish difference. It reminds us that moral responsibility in education lies not in compliance, but in understanding. Conformity is easy. Understanding takes courage.

The conversation then broadens with Charles Freeman's compelling and timely contribution, *If It Does Not Get Measured, It Does Not Get Done: Neurodivergence and Data*. Freeman exposes the "triple invisibility" of neurodivergent people – unseen to themselves, unseen to others, and unseen in public policy – showing how without data, invisibility thrives, as an absence of consistent data can perpetuate and worsen social and economic marginalisation (an observation which surely has repercussions for Dr Passe's lead article on *Autism, School, and Crime*). His call for a "neurodiversity evidence toolkit" bridges the qualitative and quantitative, advocating for an empirical visibility that respects lived experience rather than erasing it. Once again, this is an argument that resonates with Alexander-Passe's concern about how unseen differences can become unacknowledged systemic risks.

Finally, this issue concludes with a new section, *NeuroconVerse*, inaugurated by Jessica Dark's beautifully moving and inventive *Recognising Difference: A Neurodiversity-Affirming Poetic Autoethnography of Autism in Family Life*. Dark's work re-centres personal, transforming research into resonance. Through poetry, she reminds us that data and discourse are only part of the story: that difference is also felt, spoken, and even sung. In Dark's work, difference becomes cadence.

Across these articles runs a consistent thread of visibility and invisibility: of systems that misrecognise, of professionals, themselves often unrecognised, who strive to respond, of a

lack of data that reveals, and of the emergence of art that views in a different light, and so reframes. Together, they form a dialogue between structure and self, between measurement and meaning, and between science and story. This issue powerfully reaffirms the journal's commitment to an ethically engaged scholarship – one that listens to neurodivergent voices not as objects of study, but as co-authors of understanding. Together, the research, the struggle, and the voices become powerfully visible.

Martha Bloomfield



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Original Research Paper

DOI: 10.82005/NC\_02.01.01



# Autism, School, and Crime: How school can lead those with autism into crime

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Received 20 August 2025 / Accepted 16 September 2025 / Revised 03 October 2025 / Published 09 November 2025

## Abstract

**Background:** This paper explores the 'school-to-prison pipeline' and aims to raise awareness about the vulnerabilities of young people with autism in society.

**Methods:** This study employs an empirical review, with case studies, that combines insights from educational settings with empirical evidence related to autism and crime.

**Results:** The paper addresses the following topics: (1) risk factors for offending behaviour, (2) the involvement of police with individuals on the autism spectrum, (3) social naivety and the concept of 'joint enterprise,' (4) stimming and repetitive behaviours, (5) types of crimes committed by individuals with autism, and (6) the lack of training for arresting police officers regarding autism.

**Conclusions:** It is acknowledged that not all individuals with autism engage in criminal activities; in fact, many are highly vulnerable to becoming victims of crime themselves. When arrested by police officers, individuals with autism can experience elevated levels of dysregulation, often resulting in meltdowns that may be misinterpreted as threatening behaviour. This misperception places them at greater risk of facing charges of assault and being detained under mental health legislation.

**Keywords:** Autism, school, crime, mate crime, prison, joint enterprise

## 1. Background

The researcher is a neurodivergent educator with extensive experience in primary and secondary education (ages 5-18) in UK schools, where he served as a Special Educational Needs Coordinator (SENDCO). This paper is based on a new book by the author, which focuses on autism awareness and crime, and is part of a wider series exploring the 'school-to-prison pipeline' with those with dyslexia and ADHD (Attention Deficit Hyperactivity Disorder).

## What is Autism

Autism is a neurodiverse developmental condition that individuals are born with (National Autistic Society, 2025a). It can often be diagnosed at a very young age, as early signs, such as not crying or being content with their own company, can be observed, particularly in boys. In contrast, autism in girls may go undiagnosed until adulthood because they tend to exhibit different behaviours, often appearing quiet and reserved, and they may mask their traits by mimicking others (National Autistic Society, 2025a). Many people believe there are subsets of autism based on how symptoms manifest, which can be categorised as internal or external. These manifestations can be present in both males and females. Autism spectrum disorder/Condition (ASD/ASC) is one of the most common childhood-onset neurodevelopmental disorders. In the UK, the estimated prevalence in adults is about 1.1%, with relative consistency across studies (NCCMH, 2023). Comparing this estimated prevalence of autism in adults with that of children (1-2%), researchers suggest that autism is underdiagnosed among adults (Huang et al., 2020; O'Nions et. al., 2023). The proportion of males to females diagnosed with autism varies across studies but always indicates a greater proportion of males to females, mostly ranging from 3:1 to 5:1 (NCCWCH, 2022; BMJ Best Practice, 2023).

Autism is diagnosed as part of a medical process by a psychiatrist using screeners, interviews, and observations. There is a discussion about whether autism is a disorder (medical terminology suggesting something wrong with the person) or a condition (suggesting it's a human difference, and all humans are different, and that is okay), as noted by Morris (2024). Hence, the ASD or ASC abbreviations are options.

Those with autism see their autism as a major part of their personality, so they call themselves an 'autistic person' (Brown, 2025). Compare this with someone with dyslexia who sees this as a 'part' of their personality, who prefers to be called a 'person with dyslexia', as they are a person first and dyslexia is just one aspect of them. Brown (2025) interestingly notes that when we say 'person with autism', we convey that it is unfortunate and an accident that a person is autistic, that they would be better without autism, and would be neurotypical. However, when we say, 'autistic person', we recognise, affirm, and validate an individual's identity as an Autistic person. We recognise the value and worth of that individual as an Autistic person.

Autism manifests in various ways (National Autistic Society, 2025c):

- Problems with social communication and interaction
- Restricted or repetitive behaviours or interests
- Different ways of learning, moving, or paying attention
- Co-occurring conditions such as dyslexia, epilepsy, depression, anxiety, and attention deficit hyperactivity disorder (ADHD)
- Challenging behaviours like difficulty sleeping and self-injury

## Autism in a school environment

Individuals with autism often face challenges in mainstream education, where both social and academic skills are emphasised (National Autistic Society, 2025c). While they may excel academically, they often struggle with the social and environmental aspects of school life. The pressure to be sociable, make friends, and engage in group work and play, especially during breaks and lunchtime, can be daunting. Many would prefer to spend their time alone with a book, immersed in their own world. Unfortunately, this preference can lead to the perception that they are lonely and lack friends. As a result, adults may attempt to encourage them to be more social, which can create additional stress and anxiety, particularly if their autism is undiagnosed or not adequately supported (National Autistic Society, 2025c).

There are also environmental sensory challenges in mainstream schools. Classrooms with noisy children, very colourful rooms, and large gatherings can be highly dysregulated, e.g., dining rooms at mealtimes and assembly rooms. Autism specialist schools tend to have fewer students per class and are designed to minimise noise and clutter, thereby reducing sensory overload (National Autistic Society, 2025c).

Many young people with autism say they would be fine at school, apart from the other children there. They also comment that they find people illogical in their use of language. Most with autism struggle with illogical actions, and people say things they don't mean. They will hear what people are saying and accept it literally, so ironic language, jokes, and idioms often go unnoticed. If someone says 'It's raining cats and dogs', they will expect cats and dogs to fall from the sky (Leicestershire Partnership, 2025).

Understanding expression, the ability to read people, and how they feel is a known area of difficulty. Autistic young people struggle to understand both tonal range and read facial expressions, not knowing if others are angry or sad. They can find themselves reacting 'perceived' inappropriately to a person who is sad or angry, making them seem cold and without feeling (National Autistic Society, 2025c).

More boys are diagnosed as young children due to how they react to school environments, generally adversely, with meltdowns (reacting by unconsciously screaming, hitting out), compared to girls who will withdraw and stay silent, being perceived as distant, being in their own world (Loomes et al., 2017).

## 2. Autism and Crime

Before we proceed, the author wishes to note that not all young people with autism will get involved in crime; however, research indicates what happens when support networks break down, and vulnerable young people and older adults are left unsupported. Even when autistic individuals present as capable, especially high-functioning autistic individuals, they will still struggle in certain situations, which can lead to criminal activities, or their fascinations can lead them unintentionally into criminal activity.

This paper offers a review of current empirical evidence and does not present any new firsthand research. The choice of topics was informed by a broad study by the author, as the wider study evolved.

### An Introduction

Weinman (2023), an autism advocate in the USA, discusses the chances that a young person with autism could be arrested. She notes that most of the defendants she works with tell her they did not intend to commit a crime or harm another person. Rather, any criminal acts are a reaction to given situations. They acted in the only way they knew to protect themselves from a perceived threat. She offers several scenarios:

- You receive an alarming call from your son's school. The police are there to arrest your son for striking a teacher. You later discover that your son was reacting to something the teacher said.
- You and your son are at the supermarket. You proceed down an aisle with your son close behind. Suddenly, you hear a scream. You quickly turn to see a stranger face down on the floor, and your son nearby. A store employee calls the police, who arrest your son for assault. Later, you learn your child believed the stranger was staring at him.
- Your 20-year-old son is attracted to a girl he sees walking down the street. Being naïve and possessing the emotional maturity of a much younger child, he approaches her and inappropriately touches her buttocks.

## Risk Factors for Offending Behaviour by People with Autism

Allely (2019) and Howlin (2006) suggest the following explanation to better understand how those with autism can be drawn into criminal offences:

- **SOCIAL RULES:** Activities appropriate in childhood can be perceived as inappropriate in adulthood, e.g. picking up or tickling toddlers that belong to strangers.
- **FRIENDSHIPS:** Can have difficulties with developing and maintaining friends; their increased social naivety may leave autistic people open to manipulation by others, and a preoccupation/adoration for an individual could lead to stalking.
- **INTENSE INTEREST:** Convictions for arson have been found to have preceded by an interest in fires (e.g., Barry-Walsh & Mullen, 2004). Tantam (1988) describes an individual with a fascination with National Socialism, who dressed in Nazi uniform before assaulting a soldier. A fascination or 'special interest' could be fatal, e.g. fire or poison. Other examples can include a young man who had such an interest in washing machines that he would break into shops and people's houses to examine them!
- **Stimming:** Attempts to discourage certain repetitive behaviours, which are calming to them, could trigger reactive aggression from individuals with autism, accounting for the association between repetitive behaviours and aggression.
- **SOCIAL MISINTERPRETATIONS:** Bjorkly (2009)'s literature review of risk factors for violence in Asperger's Syndrome (high-functioning autism) found that 35% of violence towards others was reportedly attributed to social misinterpretations of the victims' intentions. Burdon and Dickens (2009) highlighted that impairment in understanding social cues may influence criminal behaviour in individuals with Asperger's Syndrome (high-functioning autism).
- **INTERNET/SOCIAL MEDIA:** The Internet provides a safe environment (degree of control); however, Internet/social media 'Friends' who validate skills and promise 'justice' and 'moral certainty' can influence an individual very quickly (Al-Attar, 2018; 2020). Technical skills coupled with social impairments can make an individual with autism a target for exploitation (Al-Attar, 2018; 2020).
- **SENSORY:** A strong dislike, such as the sound of a baby crying or a dog barking, might lead to an aggressive outburst (meltdown). A lack of knowledge of appropriate and inappropriate touching could lead to accusations of sexual harassment. Individuals may love the feel of a particular texture or material, such as velvet, and think nothing of stroking the back of the lady in front of them if she happens to be wearing a velvet jacket, which may have been seen as cute as a young child, but as an adult can be perceived as threatening.
- **UNEXPECTED CHANGE:** Unexpected violence and outbursts provoked by certain random and unexpected triggers in the environment, e.g. a fire alarm, a fire, roads being shut, or a train or bus breaking down.

The use of the term 'Asperger's' is now understood and commonly defined as high-functioning autism and is not part of the current use of language, being part of 'autism spectrum disorder'. It was removed from the DSM in 2013 (National Autistic Society, 2023; APA, 2013).

Hammond, Adkin, and Elma (2021) note remarks by Professor Simon Baron-Cohen that *"Autistic people are vulnerable to being misunderstood and to ending up in the criminal justice system, accused of crimes when they have had no criminal intent. It is vital that they have well-informed advocates and legal advice and that the police and the courts are well-trained to make reasonable adjustments for an Autistic defendant. Autistic people deserve proper support, especially when they make mistakes, given their disability"*.

Professionals and criminal justice professionals noted by the National Autistic Society (2020) that the main risk factors in school-aged autistic young people are: difficulties with socialisation, being

easily led, and aggression. 'Difficulty with socialisation' was reported as the highest-rated risk factor, followed by 'easily led or influenced by others'.

## Autism and police involvement

Davis and Schnunick (2002) argue that individuals with autism might also come to the attention of the police for the following autistic symptomatic reasons:

- Self-stimulatory and self-injurious behaviour such as hand flapping, pinching oneself, self-biting, repetitive actions, and thrashing.
- Wandering alone, e.g. dressed inappropriately for the weather, wandering alone, or darting into traffic.
- Peering into windows.
- Behaviour that may mimic drug abuse or mental illness.
- Bizarre or disruptive behaviour such as lining up objects, eating inappropriate objects, toe walking, and robotic-like speech.
- Hitting or biting people.
- Suspected child abuse, parents may be restraining their child with what may appear questionable force.

In situations involving interaction (e.g. an interview or questioning) with a police officer, Davis and Schnunick (2002) also comment that if the individual has diagnosed or undiagnosed autism, they could be seen as behaving in an extremely socially inappropriate way, causing offences without being aware they are doing so. They could be perceived as appearing aloof, rude, egocentric or insensitive. This could be due to a lack of understanding of how to react to unfamiliar situations and other people's feelings, difficulty interpreting and utilising non-verbal communication, and taking what is being asked literally in the interview. Being unable to understand the implied meanings or follow a lengthy set of instructions.

Regarding sensory difficulties, being touched, or reacting to extreme intolerance to certain sounds and smells or other sensory stimuli. This could include the sensory overload of being in a police car/van, interview room, or police holding cell.

A criminal intent study by the Welsh Assembly (2010) interviewed autism specialists, police officers, and autistic youngsters about their experiences with the police and their parents. Some said they had found themselves in situations where their social communication had led to misunderstandings. For example, one young man said, "I have been in trouble and they (the police) thought I was being cheeky, but I was just being honest. When asked by a police officer, '*Do you promise never to do this again?*'". One young man answered, "*No, I do not know if I will ever do it again*". In his mind, he did not want to make a promise that he was unsure he could keep. Another, when asked if he had been involved in a shoplifting incident, answered "*Yes*". He had not committed the crime, but he had been in the shop at the time when the incident occurred. His interpretation of the word 'involved' differed significantly from that of the police officer, which may have contributed to his arrest. Therefore, individuals with autism may appear to be behaving uncooperatively when they are trying to be as open and honest as they can be.

Autistic individuals sometimes comply with requests to please and make friends. It could be argued that they can be easily manipulated, making them vulnerable. For example, they may get involved with drug dealing because they see it as a way of making and keeping friends without thinking about or realising the consequences of their actions. Police, legal, and court professionals need to assess whether the person with autism understands that they have committed a crime. Sometimes, a person with autism will not realise that their behaviour could be classed as illegal. Conversely, an individual with autism may not understand that a crime against them, such as robbery or rape, has been committed.

The following examines various risk factors and vulnerabilities that may lead an autistic person to engage in criminal activity.

### **Social naivete and 'Joint enterprise'**

Being socially naïve may result in those with autism being easily led into criminal behaviour by others (Howlin and Moore, 1997). People with Asperger's syndrome (high-functioning autism) may seek out friendships with others to gain status without realising the risks associated with a particular group's community identity (e.g. criminal gangs, terrorist groups) and their vulnerability to exploitation (Shine & Cooper-Evans, 2016).

*"He was being taken advantage of and influenced by the wrong individuals."* Parent of an autistic young person (National Autistic Society, 2020)

*"They could be and still are influenced by others to fit in with a crowd; he didn't understand he was being used."* Parent/carer of an autistic young person (National Autistic Society, 2020)

They may also go with others committing crimes, to please them; however, if caught, they would make them equally guilty under 'joint enterprise' legislation (where persons who assist or encourage another to commit a crime are legally known as accessories or secondary parties in the crime committed). There have been recent cases of this with autistic individuals, but it has been very hard to argue their innocence, Alex is one such young man convicted for joint enterprise with undiagnosed autism, guilty of murder even though he did not kill anyone because he was 'in the wrong place at the wrong time'. (Henry, 2018; O'Brien, 2014).

Robins (2022), a special adviser to the UK's All Party Parliamentary Group on Miscarriages of Justice, notes *"The justice system cruelly stacks the odds against the neurodivergent"*. He says it striking how many cases in the sorry history of miscarriages of justice feature the wrongful conviction of people with significant cognitive impairment—for example, Stefan Kiszko, the shy Inland Revenue clerk with the mental age of a 12-year-old who served 16 years after being wrongly convicted of the murder of Lesley Molseed; or Stephen Miller of the Cardiff Three, mental age of 11, who confessed to killing Lynette White (after more than 300 denials); or any number of 'joint enterprise' cases in which autistic people (e.g. Alex Henry) have been convicted of murder under the controversial common law doctrine.

Barry Sheerman MP, chair of the UK's all-party parliamentary group on miscarriages of justice, challenged Justice Secretary Dominic Raab on the inequity of joint enterprise, which is often characterised as a 'dragnet'. As Sheerman points out, *"Many of the young people charged and convicted of joint enterprise are later found to be on the autistic spectrum"*, being undiagnosed throughout their school life and into adulthood. (Robins, 2022).

Case Study (Godfrey, 2022)

*The BBC News reported that an autistic 23-year-old man was arrested and jailed for being around a group of youths, known as a 'joint enterprise'. It is argued that he was not fully aware of the crimes being committed, and therefore, due to his autism, he was incapable of committing the offence and was not given a fair process in court when arrested, and whilst he is serving a prison sentence. His mother is working with lawyers, who allege institutional discrimination, to overturn a "miscarriage of justice". His lawyers said that the joint enterprise principle - in which guilt may be deemed by an individual's presence within a criminal group - was an option available to the jury at Mr Brown's trial, although the extent to which the jury applied it when making convictions was unclear.*

Robins (2022), Henry (2018), and O'Brien (2014) have all investigated 'joint enterprise' and note that it is very hard to argue an autistic individual's innocence, as it seems so unlikely a person would be so naïve, even with very eminent supporting expert witnesses like Professor Baron-Cohen.



## Stimming, repetitive behaviours

Repetitive/stimming behaviours often increase when an autistic person is feeling anxious or stressed (Howlin et al, 2004). Other examples of stimming may include pacing, spinning, tapping, or hitting an object, e.g. a person hitting/tapping their head or hitting their head on something.

For example, a young autistic man in his day setting wanted to shake everybody's hand whenever he saw them. This was potentially an issue, but generally manageable. The problem stemmed from the fact that he would constantly have his hand down his trousers as well! Combine the two, and suddenly, numerous issues arise. How he reacts to others not shaking his hand and running away or having strange reactions to him forcing his dirty hands in their direction, leads to confusion and meltdowns.

The type and intensity of the repetitive behaviour can make the difference between acceptable and unacceptable. However, there are other issues, such as age (Howlin et al., 2004), gender, the person's size, and even the autistic person's visible level of disability, which are also important. If a person appears to be the same as others, commonly referred to as acting 'normal', then there is an expectation that they will behave similarly (also acting 'normal'). The author appreciates that the concept of 'normal' is highly subjective, and this adds to the difficulties that autistic young people experience in society. It is better to use the term 'socially acceptable' behaviour than 'normal'.

In another example, a young child in public wishing to smell a person's hair or touch a particular type of clothing someone is wearing, because they like the material, may be seen as 'odd' or 'strange', but within the realms of acceptability. However, a 6-foot autistic adult male behaving in the same way may be interpreted very differently, maybe threatening. It might lead to police involvement and even criminal proceedings.

It could be argued that all stimming behaviours can easily be misinterpreted as unsociable or threatening, and should be discouraged by families, carers, or professionals in childhood. However, this is not always realistic or desirable for the autistic person. Attwood (2002) makes the point that autistic people often have very few enjoyable activities, so rather than stop all (unsocial/threatening) repetitive behaviours, a level of compromise is needed. For example, boundaries are set, such as this is a home or a bedroom activity, not one for outside.

Whilst this seems a sensible approach, as with most things, there is a level of risk involved. If an autistic adult finds themselves in a new and unexpected situation, e.g. their normal travel route is blocked, or a train is cancelled, this may lead to enormous anxiety and a need for comfort from a certain repetitive activity; the fact that they are not at home can become irrelevant due to their immediate situation. The use of stimming is used by many autistic people to avoid meltdowns; however, when prevented from being able to stim, this may lead to autistic meltdowns and possible explosive manifestations.

Case study (Purser, 2016)

*A young autistic adult with associated learning difficulties liked looking out of his bedroom window for long periods at a time, as he liked to feel the heat from the sun on him. The difficulty for others is that although there appeared to be no apparent or visible sexual motivation or gratification for this behaviour, the gentleman found the activity more enjoyable and relaxing naked. Neighbours started to complain to the police as well as the family. His parents were quite elderly and found it increasingly difficult to deal with his 'meltdowns' when he was stopped from undertaking this activity. A builder friend of the family suggested a film coating to go on the window, which meant the young man could still look out, but people could not see him; all parties were satisfied with this outcome.*

Many autistic people appear to be anxious about the police (Purser, 2016), and therefore, being confronted by them in an already volatile environment can lead to an escalation. If the behaviour



is seen as serious enough and the autistic adult is taken into custody, the anxiety levels are almost certain to increase further. Therefore, the stimming increases too, and there is a huge risk of a meltdown. If the police believe they are a danger to themselves and others, they may section the person so they can be moved to a hospital for psychiatric observation, as per many case studies (Bunn, 2024).

### Types of Crime Committed by Autism Individuals

The National Autistic Society's 'Youth Justice Report' (2020) studied 203 autistic people, 167 family members, 40 criminal justice professionals and 115 professionals working with autistic people outside the criminal justice system. The samples were made up of autistic people and their families who had been involved in the criminal justice system (aged 25 years and below). Participants indicated early concerns/risk factors in their children with autism in Table 1.

**Table 1:** Early parental concerns regarding acts that might lead to criminal activity (National Autistic Society, 2020).

Concerns	Percentage
Being easily led/influenced by others	66%
Violence and/or aggression towards others	52%
Being excluded from school	38%
Damaging property and/or fire setting	38%
Threats to harm or kill others	23%
Taking drugs and/or dealing drugs	20%
Stealing	17%
Inappropriate sexual behaviour	17%
Hacking personal networks and accounts	6%

Crimes committed by individuals with autism vary; a review of court decisions in Freckelton (2011) found that offenders with autism tended to disproportionately commit arson, computer offences, stalking offences, sexual offences, violence and neglect offences, and dishonesty offences. Common crimes manifested in those with autism are believed to be:

- Stalking
- Knife use and collection
- Computer crimes, stalking, and getting into hard systems
- Intense anger during a meltdown, hurting people
- Intense anger to kill people
- Carrying drugs after being befriended
- Sexual offences

Lindsay et al. (2019) and Fitzgerald (2013) suggest that evidence regarding the prevalence of offending in autism is equivocal; however, it is generally agreed that people with autism are more likely to be victims of crimes rather than perpetrators, especially victimisation (Collins et al., 2022). Nevertheless, people on the autism spectrum do offend, and it is therefore useful for management purposes to consider if there are any particular risk factors for offending behaviour in this population.

It has been suggested that autistic offenders may be more likely to engage in certain types of crime than others (King & Murphy, 2014); such as crimes against the person such as sexual offences, assault, and robbery (Cheely et al. 2012; Kumagami & Matsuura, 2009); and less likely to engage in property crimes such as burglary, arson and trespass, driving offences and drug offences (Cheely et al., 2012; Kumagami & Matsuura, 2009).

In terms of offences, the most common crime category found in an autism/crime study by Hofvander et al. (2023) was a violent crime, present in 75.5% of the prosecutions. Sexual crimes were the second most common crime, present in 16.1% of prosecutions. This is in line with previous studies where different interpersonal crimes are dominant among offenders with autism. These individuals commit various offences, but there appears to be a high proportion of violent offences, particularly arson and sexual offences (Hofvander, 2018).

### **Lack of training by arresting police officers**

Recently, Fallon (2021) reported that a school-based police officer in a UK school assaulted an autistic child having a meltdown at school. In this case, a police officer was seen threatening to kick the 10-year-old boy lying on the ground. The officer then grabbed him and dragged him along the floor into a room. This police officer resigned after losing a disciplinary hearing regarding this incident, highlighting the need for more autism training.

The following case studies suggest that autistic people are adversely affected by a lack of autism training in police officers, leading to arrest, where understanding would be more likely to result in a more positive resolution to situations.

Case Study (Powell, 2021)

*A national newspaper reported on a 12-year-old boy diagnosed with autism, on his first day at a school, being challenged for his trainer shoes, which were an agreed allowance for his autism. After he was challenged, he began to be dysregulated and pushed out, which resulted in a dinner lady being pushed. This resulted in it being classed as an assault, and the person was physically restrained by a police officer. Sharron Faiq says staff called officers in after 5ft tall Rayan, 12, pushed a dinner lady who insisted he change his trainers, despite the academy allowing him to wear them. This mum arrived to see her son restrained by a police officer. Rayan had been out of education since primary school due to classroom support funding problems. Sharron said, "The school called me saying there was a problem. I found Rayan pinned down in handcuffs on a table, being treated like a criminal." She filmed the incident, which has been watched more than 900,000 times on Facebook. Whilst not arrested, the school suspended Rayan and then removed him from its roll.*

Case Study (Robson, 2015)

*The parents of a 9-year-old autistic boy say they are launching a \$500,000 lawsuit after he was arrested at school and allegedly placed in handcuffs and a straitjacket. Brittany and Larry Granito said their son Colton's school called in police after the boy hit a teacher during a 'meltdown' despite having a crisis plan to deal with his occasional violent outbursts due to this condition. The couple from Sumner County, Tennessee, USA, claim their son has been traumatised ever since left in a straitjacket for an hour, locked in a prison cell, and charged with assault. The couple said the R.T. Fisher Alternative School should have followed the action plan last February, when Colton was eight, which lists his high-risk behaviours, including hitting and kicking, and how teachers should react, such as trying to reduce aggression with caring gestures or moving him to a safe area.*

## **3. Discussions**

### **Failed by schools**

The research discussed in this paper highlights the crucial role that mainstream education plays in the educational and social development of vulnerable young people with autism, whether

diagnosed or undiagnosed. It emphasises that autism is often misunderstood and that a lack of resources and awareness puts these young people at risk, not only of harming themselves but also potentially harming others.

There is a saying: "Once you have met one person with autism, you have met one person with autism". This underscores the need for a personalised approach. However, many schoolteachers believe they possess all the knowledge they need about autism and do not require further training. This belief is a common mistake, as educators are often seen as the experts in this field.

Mainstream education can be a challenging environment for students with autism, particularly for boys, who may express their struggles through more visible physical meltdowns. In contrast, girls with autism often withdraw and internalise their difficulties, which can lead to various mental health issues, compounded by a lack of diagnosis and support.

Case study (the author)

*In one school where the author taught, he encountered 15-year-old twin boys and girls. The boy had been diagnosed with autism at 3 years old and manifested his autism externally with explosive meltdowns. The girl's twin was perceived as fine; however, at 13-14 years old, she developed an eating disorder and began to have emotionally based school avoidance. After many meetings with her mental health worker and parents, noting her masking, the author suggested this might be a female presentation of autism, which was rejected by the health professionals present. However, it took many months to convince CAMHS (Child and Adolescent Mental Health Services in the UK) to reconsider autism, and after a long wait, autism was finally diagnosed. This began a journey to understand why she chose eating disorders as her autism coping-controlling mechanism.*

### **Misunderstood by society**

Autism, like many other invisible disabilities, often leads society to make judgments about those affected. When someone does not use a wheelchair, they are typically perceived as able-bodied. This perception places immense pressure on parents and caregivers of individuals with autism, as they seek the understanding and acceptance of others.

For example, when a child with autism has a meltdown in a supermarket, bystanders often judge the parent as a 'bad parent' who cannot control their child. Similarly, if a parent restrains their autistic child for safety in public, they may be viewed as harming their child, leading to concerns that they should be reported to social services. Such judgments can result in the exclusion of individuals with autism from society because conclusions are often drawn quickly and without consideration.

While this discussion focuses on the consequences of inadequate support structures, it is essential to recognise that many individuals with autism lead independent lives, getting married and raising children. However, there remains a percentage of those with autism who rely on support from family and social services as adults. This group may be more vulnerable to criminal activities, both as victims and potential perpetrators.

## **4. Conclusions**

The topics of autism, ADHD, and dyslexia are commonly investigated as part of the 'school to prison pipeline', as neurodivergent groups are commonly found in prison populations. They are a unique but large group in UK prisons, also reflecting their vulnerability to being involved in crime.

The examples discussed in this paper highlight the ease with which those with autism can be misunderstood by the public and the police, leading to an arrest. The sensory overload of being questioned and placed in a holding cell or a police van can lead to police officers using restraint

for their safety and perceived for the safety of the autistic person themselves. The resulting meltdowns leading from such situations will just exacerbate their vulnerability.

Social naivete and 'Joint enterprise' are a concern, as they can lead to criminal activities through innocent intentions, sometimes resulting in 'mate crime' when others take advantage of their naivete and exploit them as victims of crime.

Education is key for both the teaching and police professions, so they can quickly recognise key autistic traits and put in place the support structures needed. Along with suitable sex and relationship education for young people with autism. It is argued that this needs to be more explicit and offered in more sessions than the programmes currently offered in mainstream schools. However, as such explicit programmes with acting out scenarios and very explicit photographs can be uncomfortable for most teachers in schools, it is argued that autistic specialists should provide such programmes, and these should be part of ongoing preventative schemes.

This paper is an amended part of a new book, 'Autism Awareness and Crime' (Alexander-Passe, 2025), being the third in a book series investigating the school-to-prison pipeline (Alexander-Passe, 2023, 2024). This study was conducted by a neurodivergent researcher and involved individuals with autism and their parents, supported by empirical evidence.

#### Community Involvement Statement:

The subjects of autism, ADHD, and dyslexia are often examined in the context of the 'school-to-prison pipeline,' as neurodivergent individuals are disproportionately represented in prison populations. This group is significant and vulnerable, reflecting their susceptibility to involvement in criminal activities.

#### *Key points*

- It is known that many young people with autism have a tough time in mainstream schools and that many fall foul of school behaviour policies, leading to suspensions and permanent exclusions.
- It is also known that young people with autism manifest their dysregulation in school through meltdowns, which can cause harm to others and property, leading to removal from mainstream education and into alternative education.
- It was unknown how deeply mainstream and special education schools struggle to cope with those with autism, and how meltdowns could be treated as violent and criminal damage. Also unknown was how highly vulnerable autistic persons are due to their fascinations or 'special interests', which can lead to stalking and assaults on others. But also, how their vulnerability can lead them to be victims of crime, e.g. Mate Crime.
- It was also unknown how widespread the manifestations and traits of autism could lead to illegal and criminal activity.
- This paper offers a new understanding of how the many manifestations of autism can lead to possible criminal behaviours, such as sensory fixations leading to assaults, and the lack of awareness by police officers could lead to investigations based on autistic symptomatic behaviours.

#### **Ethical Consideration**

This paper was deemed not to require ethics committee approval as it did not include any research subject data. However, it is effectively a creative empirical review combining new sources of information.

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Original Research Paper

DOI: 10.82005/NC\_02.01.02



# Neurodiversity and Data: If it does not get measured it does not get done.

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Received 23 September 2025 / Accepted 11 July 2025 / Revised 23 September 2025 / Published 09 November 2025

## Abstract

Inadequate data, acts as a barrier, making it difficult for public bodies, to measure the impact of neuro inclusion policy.

The Neurodivergent (ND) community suffers from a problem of triple invisibility.

-ND people are frequently not visible to themselves - Most ND people are never diagnosed and therefore do not know they are neurodivergent.

-ND people are not visible to other people. You cannot tell if someone is ND by sight or casual observation.

-ND people are not visible in public policy. Without good data it is hard for public policy to measure differences between the experiences of ND people and other members of society.

While this issue of visibility is significant to the ND community, failure to recognise the significance of neurodivergence has a wider impact on the economy and society. For example, in the UK around 9m working-age people are not in employment. 2.6m are not working for health reasons. (Sky News , 2024) Many in this category are ND, not diagnosed at school and wanting to work. If they were able to work it would increase economic growth, reduce benefit bills and lift a pressure on the NHS. However partly because of lack of quality data Neurodivergence is rarely identified as a focus for employability policy.

This paper concludes with a call to action to researchers and advocates. The ND community should pragmatically build a data toolkit, which would embrace shared definitions, a shared approach to estimating the incidence of neurodiversity in the population, a shared approach to using survey data to estimate the incidence on neurodivergence in various settings and a shared convention on how to benchmark data.

**Keywords:** Neurodiversity, Data, Public Policy



## 1. Introduction

It is said if something does not get measured it does not get done. The lack of widely recognised data, relating to neurodivergence, acts as a barrier making it difficult for public bodies and businesses to measure the impact of neuro inclusion policy.

The Neurodivergent (ND) community suffers from a problem of triple invisibility.

- ND people are frequently not visible to themselves - Most ND people are never diagnosed and therefore do not know they are neurodivergent.
- ND people are not visible to other people. You cannot tell if someone is ND by sight or casual observation.
- ND people are not visible in public policy. Without good data it is hard for public policy or equality diversity and inclusion policy (EDI) to measure differences between the experiences of ND people and other members of society.

While this issue of visibility is significant to the ND community, failure to recognise the significance of neurodivergence has a wider impact on the economy and society. For example, in the UK around 9m working age people are not in employment. 2.6m are not working for health reasons. (Sky News , 2024) Many in this category are ND, not diagnosed at school and wanting to work. If they were able to work it would increase economic growth, reduce benefit bills and lift a pressure on the NHS. However partly because of lack of quality data Neurodivergence is rarely identified as a focus for employability policy.

Donald Rumsfeld former US Secretary of Defence said: (Wikipedia, 2002)

- There are known knowns. These are things we know that we know.
- There are known unknowns. Things that we know we don't know.
- But there are also unknown unknowns, there are things we don't know we don't know. This category tends to be the difficult one.

I think this statement sums up the current state of play when considering, the data set relating to Neurodivergence.

## 2. Understanding Terminology

Before considering the dataset it is useful to note, the language relating to neurodiversity, neurodivergence and neurominorities is contested and evolving.

An article in Psychology Today, 5 things you should understand about Neurodiversity by Erin Bulluss and Abby Sesterka, together with a comment posted on LinkedIn by Tony Lloyd then CEO of the ADHD foundation (Sesterka, 2023) illustrate this is a live debate. Personally, I am comfortable to describe myself as neurodivergent but can understand why people like Tony are uncomfortable with the term.

- The term Neurodiversity as Bulluss and Sesterka point out embraces everyone. 100% of the population. The term as one of its originators Judy Singer explains deliberately draws on the concept of biodiversity making the parallel argument that everyone's different thinking style is valuable and contributes to the richness of society. (Lutz, 2023)
- Neurodivergence and Neurominorities - The way some peoples brains work, differs sufficiently from the norms for them to meet the criteria for diagnosis for a range of conditions. In most discussions about neurodivergence these conditions include Dyslexia, Dyspraxia (DCD), Dyscalculia, Dysgraphia, ADHD, Autism, and Tourette's. However, this list is not exhaustive, and debate exists about other conditions which should be included on

the list. Nancy Doyle when compiling the genius within diagram included Mental Health conditions, Learning Disabilities and Acquired Neurodivergence. (Genius Within, 2025) Her logic being that if neurodiversity includes all thinking styles, and neurodivergence refers to people with thinking styles which significantly differ from the norm, the category should not be restricted to the seven or eight conditions usually cited.

- However, many ND people are not comfortable in identifying themselves as having a disability, let alone a learning disability. Disability Wales explains this point well

"Not everyone who is neurodivergent will identify as disabled. Many like the way their brain works.

They will probably still struggle with aspects of daily living or work, or both, but on the whole they are managing their lives, so they do not identify as disabled. " (Wales, 2024).

On the other hand, much of the employment protection ND people enjoy is embedded in disability rights legislation. If ND people choose not to identify as having a disability they may not benefit from this protection. In reality like many people with disabilities, ND people are disabled in some contexts and unaffected in others. This is consistent with the social model of disability. (IOSH, 2024)

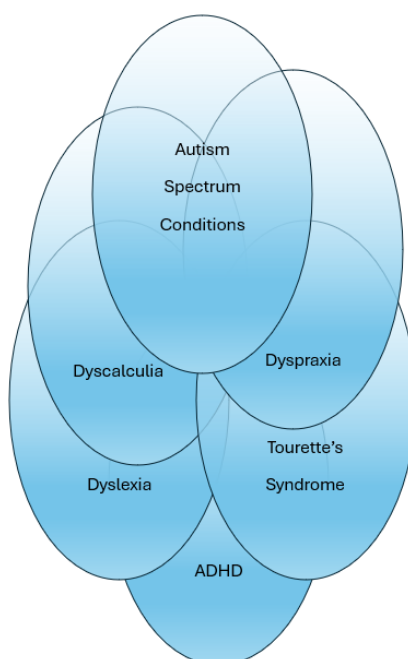
### 3. Known Knowns - What we think we know about the ND Data Set

The incidence of Neurodivergence in the population is frequently estimated to be 15-20%. This section explores the basis on which this figure has been estimated, and some of the reasons why this calculation may not reflect the actual situation.

#### 3.1 Calculating the incidence of neurodivergence in the population

Mary Colley in her classic diagram drew attention to the high level of overlap between conditions included in the Neurodivergent Family (Colley, 2009).

Overlapping Neurodivergent Conditions based on original diagram by Mary Colley



**Figure 1:** Overlapping Neurodivergent Conditions, based on a diagram by Colley (2009).

Professor Amanda Kirby notes Co-occurrence is very common and probably the norm with Neurodivergent Conditions. (Kirby, Neurodiversity 101 Co-occurrence, 2021) In an article she wrote with Mary Cleaton she includes a table including various estimates of neurodiversity in the population as well as estimates of co-occurrence.

**Table 1:** Estimated Co-occurrence of Neuro Developmental Conditions. (Cleaton, 2018)

Table adapted from Why Do We Find it so Hard to Calculate the Burden of Neurodevelopmental Disorders? (Cleaton, 2018)

			Proportion with Secondary Diagnosis %							
		Childhood Prevalence UK % from Kirby and Cleaton, National Charity estimates in brackets	ASC	ADHD	DCD	DLD	Dyscalculia	Dyslexia	ID	TIC
Primary Diagnosis	Autism Spectrum Condition ASC	0.6-3.5  (1-2 (NAS, 2023))		3-78	25-85	21	NE	14	15-51	8-60
	Attention Deficit Hyperactivity Disorder ADHD	0.5-2.2  (2 – 7 Ave 5 (ADHD UK, 2025) )	6		18-53	24	7-18	18-45	11-24	9-33
	DCD Dyspraxia Developmental Coordination Disorder	1.8%  (6% (FPLD, 2025)	6	19-53		>45	31-51	24-56	Na	<34
	DLD Developmental Language Disorder	>0.5-<2.2  (7.5 (DLD project, 2016)	4-8	18-61	30-71		62	48-87	<27	NE
	Dyscalculia	3.6  (6% (BDA, 2025)	NE	39	25-44	NE		26-48	NE	NE
	Dyslexia	2.3-6.2 (10 (BDA, 2025)	NE	18-50	16-53	NE	39-48		NE	8
	Intellectual	0.3-0.5 severe	10-28	18-55	NA	54-79	5	14-17		NE

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	Disability (Severe IQ <50 Mild <70)	2.2-2.5 Mild								
	Tourette's Syndrome	6	3- 22	26-82	13- 24	18	22-23	22-36	3	

NA Not Applicable, NE No estimate Available

The frequently quoted estimate that 15%-20% of the Population are neurodivergent (ICAEW, 2023), can be calculated by combining the incidence of the listed conditions in the population and discounting the degree of overlap between these conditions.

Table 2 sets out the calculation using Mary Colley's diagram as a starting point for a definition and national charity estimate of prevalence of individual conditions. The calculation looks something like this:

**Table 2:** Calculation of total ND population

Neuro difference	prevalence	Discount Co-occurrence	Non - overlap
Dyslexia	10%		10%
Dyscalculia	6%	Dyslexia	3.8-4.4%
Dyspraxia	6%	Dyslexia & Dyscalculia	2.9-3.4%
ADHD	5%	Dyslex & Dyscalc & Dysprax	1.4-3.4%
ASC	1%	Dyslex & Dyscalc & Dysprax & ADHD	0.1-0.5%
Total with co-occurrence discounted			18-22%

My calculation reaches a slightly higher estimate than the 15 to 20% regularly quoted figure, this is probably due to changes in the estimated level of co-occurrence changing through time. If TIC conditions were added to the calculation due to the level of overlaps the totals would not rise very significantly.

It is also interesting to note that in 2024 Birmingham University used a survey-based approach to estimate on a transdiagnostic basis the incidence of neurodivergence in the UK population . This survey estimated that 3.23% of the population had a formal diagnosis for at least one Neurodivergent condition and that 12.97% identified themselves to be neurodivergent (Apperly, 2024)

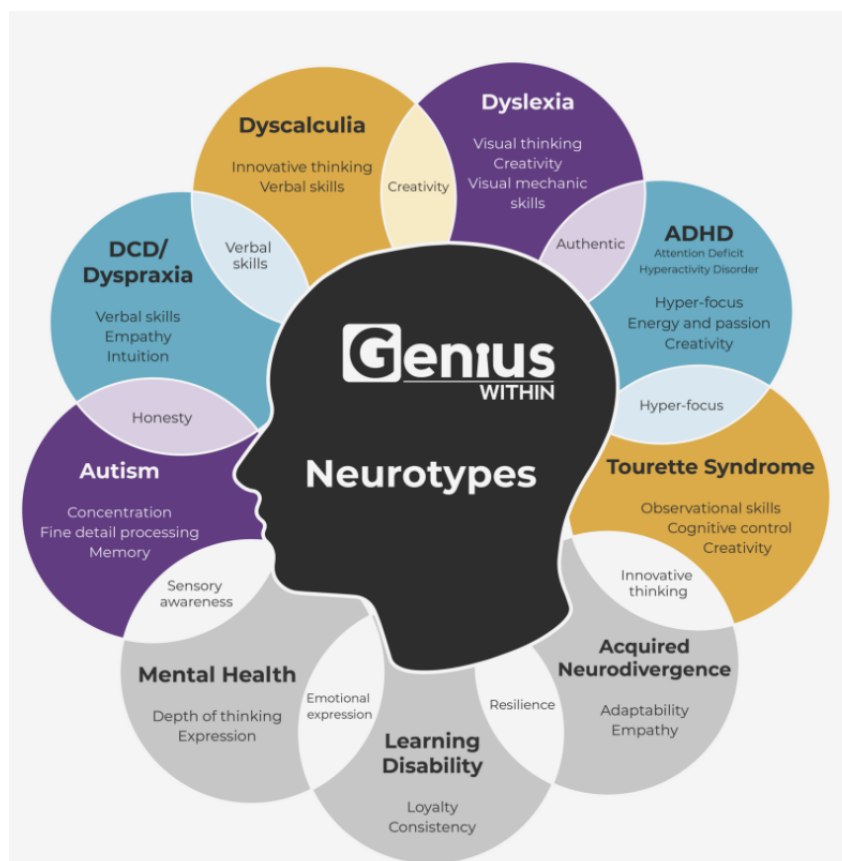
### 3.2 The reasons why the arithmetic calculation of neurodivergence in the population is problematic

This calculation of incidence in the population is however not straightforward. Professor Kirby points out several researchers who have identified different levels of co-occurrence between the listed conditions. (Kirby, Neurodiversity 101 Co-occurrence, 2021) Estimates of the incidence of individual conditions in the population also vary greatly depending on the organisation providing the data.

Furthermore, for some ND conditions the estimated level of incidence in the population is based on actual levels of diagnosis, while for other conditions it is based on a statistical projection. The National Autistic Society estimate 700,000 people 1% of the population are autistic. (National Autistic Society , 2025) This figure is based on numbers with a diagnosis. Some people believe the actual incidence including people who have not been diagnosed could be as high as 3% (Nion, 2023)

The Estimate of the incidence of Dyslexia (10%) and ADHD (5%) by contrast is based on a statistical projection of how many people meet the criteria for diagnosis. (British Dyslexia Association, 2022) However, the rate of actual diagnosis for dyslexia is far lower. Only 20% of Dyslexic pupils are diagnosed at school. (BBC, 2019). The figure for ADHD is similar with only 10%-20% of people with ADHD receiving treatment. (Doyle, 2022) The lower estimates quoted by Kirby and Cleaton tend to reflect actual diagnosis.

If the definition of Neurodiversity is widened in the way set out in Nancy Doyle's Genius Within Diagram the 15 to 20% estimate also needs to be extended. The NHS estimate more than 20% of the population have a mental health condition. (NHS England, 2025)



**Figure 2:** *What does neurodiversity mean?* From *What does neurodiversity mean?* by N. Doyle, 2025, *Genius Within*. Devised by Professor Nancy Doyle of Genius Within and derived from the work of Mary Colley. Reprinted with permission.

#### 4. Known Unknowns – Our understanding of neurodivergence is uncertain

Aside from the challenges of arithmetic discussed in section 3, the assertion that 15% to 20% of the population are Neurodivergent are unreliable for a range of reasons relating to language and logic. I will highlight; issues related to definitions, input data, and interpretation. My list is not exhaustive.

##### 4.1 Challenges with definitions

The terms Neurodiversity, Neurodivergence and Neurominorities do not have a medical definition. Language is constantly evolving, and no methodology has been agreed for quantifying their incidence. The following list outlines some of these issues.

#### 4.1.1 Lack of consensus regarding the conditions which count as being part of the neurodivergence family

The framing of neurodivergence as just including ASC, ADHD, Dyslexia, Dyspraxia and Dyscalculia as depicted in Figure 1 is uncomfortable. As Nancy Doyle argues, whether the term neurodiversity embraces natural differences across everyone in the population, and the term neurodivergence identifies people whose thinking styles differ significantly from the societal norm. It is logical for the term neurodivergence to not only include people with the conditions identified in Mary Colley's diagram but also cover people with other thinking styles which differ from the societal norm. (Genius Within, 2025)

Professor Amanda Kirby convincingly argues through her Balls in Bucket analogy (Kirby, Balls in Bucket, 2021) that many people with ND traits do not fit the diagnostic criteria for any of the individual ND conditions but will have similar traits, and experiences.

Professor Kirby also points out in a recent blog post "Neurodiversity 101 Newsletter, Navigating the landscape of neurodiversity, in awareness month", (Kirby, 2023), that many people have acquired neuro-differences or conditions which co-occur with ND conditions. These conditions often have similar impact to the normally recognised ND conditions; Professor Kirby therefore encourages the ND community to be more rather than less inclusive of people who may wish to be viewed as neurodivergent.

This advice resonates with me. One of my early diagnoses in the late 1960s referred to minimum cerebral palsy. All the educational psychologists focused on my dyslexia, but the minimum cerebral palsy label stuck in my mind. I wanted a more definite diagnosis as I was aware of my difference but was frequently being told by family, friends, the media, teachers, and health professionals that dyslexia did not exist.

A few years ago, Amanda Kirby explained to me, that minimum cerebral palsy would now be described as DCD or Dyspraxia (Kirby, Developmental Co-ordination Disorder (DCD), 2021) The notes in my diagnosis then started to make sense. In the same conversation I was made aware of the shared traits between DCD and Cerebral Palsy, as well as the way the definitions and diagnostic practice relating to the two conditions have evolved.

One of the strengths of the neurodivergent movement is how it unites people with similar experiences. These experiences of sometimes being perceived as being part of the mainstream and sometimes being perceived as having a disability are as important as meeting diagnostic criteria. However, this is delicate, from my experiences as a carer I noticed my mother with dementia undoubtedly had a thinking style which significantly differs from the neuro typical norm and was therefore neurodivergent. I am however unsure if people with dementia have the same shared experience particularly in education and the workplace which has unified much of the self-identified ND community over the past 25 years.

I am sure the concept of neurodivergence has further to evolve. My personal view is the group which identify with, and self-identify as being Neurodivergent. Is one of many neuro-tribes with a thinking style which differs from what is assumed to be the norm. The tile diagram of all these groups has not yet been fully mapped. (This continuing evolution is perhaps one of the key unknown unknowns of type referred to by Rumsfeld).

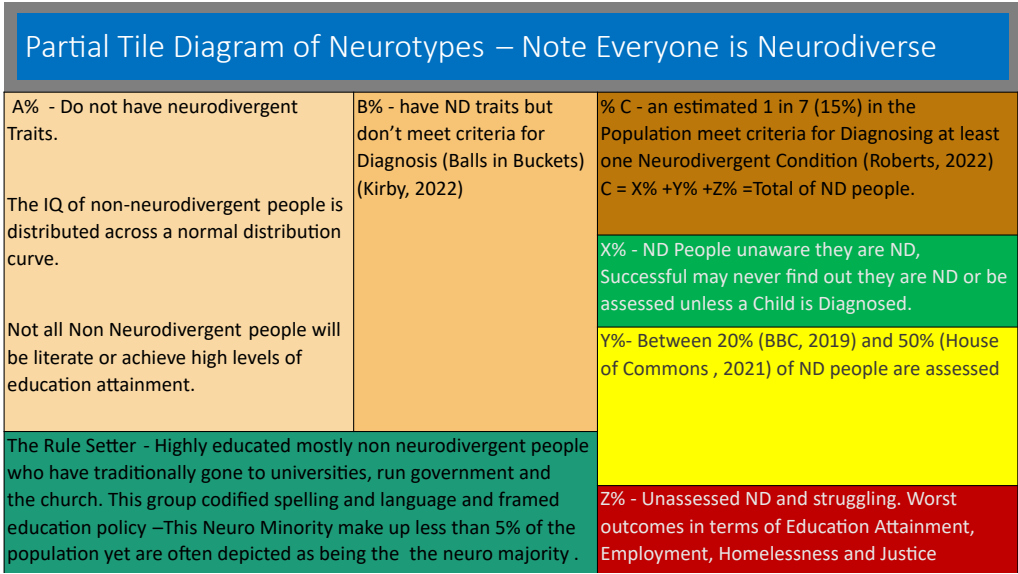


Figure 3: How can different neurotypes be mapped? (Freeman, 2024)

Neurodivergent people, on account of our different thinking styles, form a group on the margin of the labour force. On the one hand we do not have a profound disability which excludes us from work indeed most of us want to work. On the other hand, we experience disadvantage in the labour market and during our working lives are significantly more likely to experience periods out of work than most people in the population.

Those of us lucky enough to have a diagnosis, usually gained the diagnosis because in some way we (or one of our children) struggled. Usually, (but not always) the struggle leading us to diagnosis was with education or work. Post-diagnosis, most of us have also been able to achieve a level of success in education and at work when we have received appropriate support (reasonable adjustments).

Other people without a formal ND diagnosis or with other hidden disabilities or mental health conditions face very similar challenges in the labour market. They therefore share common experience with the ND community.

4.1.2 Different ND conditions are not consistently defined

Dr Martin Bloomfield in his Dyslexia Bytes Video Blog (Bloomfield, 2023) draws attention to the wide range of definitions used to define dyslexia worldwide. Definitions also change through time. ADHD was not recognised as a condition in the UK until 2000 (LancUK, 2016). The definition of Autism was expanded to include Aspergers Syndrome in the 1990s (National Autistic Society, 2024). More recently it has been recognised that labels such as low or high functioning can be damaging. (Katy, 2024)

This lack of consistency of definition makes it hard to compare data over time, or on an international basis or indeed between different studies in the same country. Good Quantitative data is therefore extremely scarce.

4.1.3 The Language used by official bodies is inconsistent

The UK Governments Disability Action Plan Consultation 2023-24 makes 13 mentions of neurodiversity (Gov.UK, 2023). Eight refer to the Department for Justice, which has a neurodiversity action plan. Other departments such as the Department for Health and Social Care, The Department for Work and Pensions and Department for Culture Media and Sport focus





exclusively on Autism. No Mention is made of Dyslexia or ADHD. The final Action Plan (GOV.UK, 2024) dropped the term neurodiversity altogether.

In its Outcomes for Disabled People Report the Office for National Statistics (ONS, 2021) publishes data relating to people with specific learning difficulties and autism but does not use the term neurodiversity.

The Higher Education Statistics Authority collects data relating to “students with a specific learning difficulty such as Dyslexia, Dyspraxia, or ADHD” and “students with a social or communication impairment such as Asperger’s syndrome or other autistic spectrum disorders”. (House of Commons, 2021) The Warnock Report in 1978 on the advice of the Department for Education avoided using the term dyslexia instead referring to specific learning difficulties (Dr Kirby, 2007). This term specific learning difficulty is still used by many education authorities.

This inconsistency in use of language across government departments and within official statistics makes it hard to compare published data and relate the available data to the term Neurodivergent.

## **4.2 Challenges with Input Data**

The base data relating to the diagnosis of each ND condition is based on arbitrary thresholds, Most ND people are never diagnosed so don’t know they are ND, and the methodology used in diagnosis has frequently been subject to class, gender, and racial bias.

### **4.2.1 Diagnostic thresholds for ND conditions are arbitrary**

The British Dyslexia Association (British Dyslexia Association, 2022) quotes an estimate that 10% of the population are Dyslexic. The European Dyslexia Association puts the figure at 9-12% with 2-4% experiencing a serious impact. (European Dyslexia Association, 2020) The Yale Centre for Dyslexia and Creativity (Yale Centre for Dyslexia and Creativity, 2022) uses a figure of 20%. The differences are explained by differences in definition and diagnostic threshold. The same differences are reflected in the range of estimates used in Table 1. Furthermore, as pointed out in Amanda Kirby’s balls in bucket analogy people 1% either side of a diagnostic threshold will have much the same traits (Kirby, Balls in Bucket, 2021). The point at which the threshold line is drawn for each individual condition is essentially arbitrary.

### **4.2.2 The estimates of ND conditions in the population, greatly exceed the number of people who have had a diagnosis or been able to access support**

A Birmingham University Study using a representative sample of 995 people aged between 17 and 77 found that only 3.23% of the sample had a formal diagnosis for any neurodivergent condition, however 12.97% of people in the sample self-identified as being neurodivergent. (Apperly, 2024) People with a diagnosis therefore make up less than 22% of the total estimated ND population.

On this basis, many ND people will not know they are ND and will therefore not identify as being ND in surveys or disclose to employers. The actual level of disclosure in employment surveys is likely to be further reduced due to the high level of stigma associated with neurodivergence and a fear that disclosure (even in a confidential survey) could lead to discrimination. (Achievability, 2017)

### **4.2.3 The diagnosis of individual ND conditions has historically been subject to significant biases**

A recent article in Scientific American highlighted the way in which cultural biases in the tests used to assess dyslexia frequently prevented black students from getting the support they required in order to fulfil their potential. (Carr, 2023) In recent years, the under diagnosis of



women and girls with ADHD and Autism has been highlighted. (Kirby, Where have all the girls gone, 2021) The Joseph Roundtree Foundation noted that the incidence of Dyslexia appeared lower in deprived areas than it is in more affluent areas. They speculate that this is down to under diagnosis. (Bart Shaw, 2016)

### 4.3 Challenges with Interpretation

Statistical Data relating to neurodivergence also needs to be interpreted with care. Low levels of actual diagnosis mean that comparisons with the estimated incidence in the population as opposed to actual number diagnosed may distort research findings. People with different ND traits may not respond to surveys in the same way, leading to differential response rates, and changes in diagnostic definitions and methodology together with lack of available data makes timeseries analysis challenging.

#### 4.3.1 Using the correct benchmark

Some reports use the estimated incidence of neurodivergence in the population (15 to 20%) as a benchmark against which to identify an over or under representation in a population. This approach is likely to lead to an unreliable interpretation of the data. The Birmingham study found that 3.23% of the population have a formal neurodiversity diagnosis and that 12.97% self-identify as neurodivergent. (Apperly, 2024) These figures might provide a more reliable benchmark.

The finding in the British Interactive Media Association BIMA equality survey show that over 20% of the interactive media workforce are neurodivergent. (BIMA, 2019) The report identifies a 50% over representation of ND people in the industry, compared to the benchmark of 15% in the population. In reality, it is likely that the over representation is significantly higher when compared to the number of people who have had a diagnosis.

Similarly, the finding that 7% of the games industry workforce are dyslexic. (UKIE, 2022) is likely to represent an over representation rather than an under representation. Despite the estimated incidence of dyslexia in the population being 10%. The number who identify as being dyslexic is considerably lower. Only 2% of the population have a formal dyslexia diagnosis at school. (BBC, 2019). While some others will gain a diagnosis after leaving school and more will self-identify, it is likely the community who are prepared to identify as being dyslexic in a population wide survey is far less than 7%. The 7% who did identify in the UKIE survey is therefore a high rather than low number.

#### 4.3.2 The response rate to surveys of ND people with different traits appears to differ

Responses to the Neurodiversity in Business, neurodiversity at work survey, prepared by Birkbeck University in 2023 (McDowall, 2023) attracted a disproportionately high number of responses from people with ADHD and Autism and a disproportionately low response from dyslexic people.

This can be explained in two ways:

- When actual numbers of people with a diagnosis are used as opposed to projected estimates of incidence in the population, the ratio between the different ND conditions flattens. The publicly quoted ratio is 1 Autistic Person (National Autistic Society, 2025) to 10 Dyslexic People (British Dyslexia Association, 2022). However, most of the 1% of the population with Autism have an actual diagnosis while only 20% of the Dyslexic population have a diagnosis. So the actual ratio of people with a diagnosis is 1 Autistic Person to 2 people with Dyslexia. (BBC, 2019)
- It has also been suggested that the differential response rate might be attributed to ADHDers and autistic people quite enjoying completing surveys, as opposed to dyslexic people who actively dislike filling in forms. This would also explain the relatively low

response by dyslexic people to many creative industry surveys (e.g. British Interactive Media Association Tech Inclusion and Diversity Survey (BIMA, 2019), Games Industry Survey (UKIE, 2022) UK Music Diversity Report (UK Music, 2022) and Inclusion and Diversity in VFX Animation and Post Production (Screen Alliance, 2019)). The Higher Education Statistics Authority HESA and many arts schools report large numbers of dyslexic graduate progressing into creative employment. (Rankin, 2015) These numbers are not showing up in industry surveys.

It may also be that dyslexic graduates find it easier to mask at work, than autistic graduates and are therefore less likely to disclose their neurodivergence. (The balance between the benefits of disclosure in terms of reasonable adjustment and the risks in terms of discrimination, will be different for each ND person).

#### **4.3.3 Comparisons through time are difficult**

The terms neurodiversity, neurominority and neurodivergence have only come into usage since the 1990s. The definitions of conditions which are generally regarded as being part of the ND family have also changed within the past 50 years. Professor Amanda Kirby suggests that frequently the diagnosis that an ND person receives depends on the lens through which they are viewed by a professional. (Kirby, Which Lens do you Look Through, 2022). Most ND diagnoses only pick up 1 or 2 diagnoses even though a person may experience overlapping traits. In my case my diagnosis in the 1970s was for dyslexia and dyspraxia. I almost certainly have dysgraphia but suspect I may have ADHD and possibly autistic traits, but due to definitions available at the time I was diagnosed, these traits were basketed within my dyslexia diagnosis.

### **5. Conclusions – Creating new knowns.**

#### **5.1 Absence of Evidence is not Evidence of Absence (Sagen, n.d.)**

The weakness of the data set relating to neurodivergence does not undermine the validity of ND lived experience either reported through anecdote or collectively in surveys.

The media frequently runs stories which cast doubt on the validity of ND experience. These often cause hurt and anxiety. The ND community should however be confident about the validity of their experience. The National Institute for Health and Care Excellence (NICE) and the National Health Service (NHS) recognise the validity of ND conditions including Dyslexia and ADHD. Growing quantities of anecdotal evidence point both to the successes and challenges faced by ND people.

ND experience is real. Collecting qualitative and quantitative data regarding the experience within the ND community is valuable it can also be a foundation for sound policy.

#### **5.2 Better Data would make neurodivergence more visible both within EDI work and public policy**

Professor Ludmila Praslova argues that ND people are the canaries in organisations and in society. We are the first to react to toxicity. (Praslova, 2022) Being able to track the way change impacts on ND people would therefore be valuable not only to the ND community but also to HR departments and policy makers.

While individual data sets for ND conditions e.g., autism, dyslexia and ADHD are useful. In my view we are also stronger together, not least as Amanda Kirby points out individual diagnoses rarely pick up the range of traits an ND person experiences. (Kirby, Neurodiversity 101 Co-occurrence, 2021)

In order, to strengthen the position of Neurodiversity as a dimension within both EDI policy and more generally within public policy a consensus on collecting and interpreting an ND data set is required.

### 5.3 Developing an ND data set is not impossible but will require pragmatism

Many organisations are already attempting to monitor neurodivergence within diversity surveys. The UK government until 2023 used the term within its disability strategy and action plan. However, the way surveys ask questions, accounts for differentials in response rates and interpreting responses is not consistent. This makes comparison between studies problematic.

Within the UK government, different departments use different language to describe neurodivergence.

For the neurodiversity movement to move forward, a more standardised approach to collecting and interpreting data is required. Such an approach would help employers, public bodies and the ND community.

The challenge requires pragmatism. A perfect definition of neurodivergence does not exist and we are still learning about the impact and incidence of neurodivergence and particularly undiagnosed neurodivergence.

The challenge is similar to that faced by the UK Creative Industry sector in the late 1990s. The then UK government decided it wanted to define a new industry sector, made up of many business groupings which had previously been viewed as separate - (Architecture, Advertising, Craft, Film & TV, Games, Publishing, Software Design, Visual and Performing Arts. These businesses were also fast evolving due to new technologies, much of the creative sector as exists now including digital marketing and immersive technology did not exist in the 90s . The sector faced similar shifting sands of definition to the neurodiversity movement.

The new sector was defined following the publication of a mapping document in 1998 (DCMS , 1998), and the development of the Department for Culture Media and Sport DCMS data evidence toolkit. (DCMS, 2004) Definitions and methodology have since evolved, but an authoritative data set has now emerged.

Now is the time for academics within the ND community to develop a data evidence toolkit for neurodivergence, which can be used as a template to authoritatively guide future research. This toolkit will not be written in stone and will need to evolve through time. Consistent data and a more standardised methodology would make it easier for the ND community to argue its case. The Birmingham University Transdiagnostic survey seems to pioneer this approach. (Apperly, 2024). Data will never be perfect, but through collective agreement it can be made good enough to be useful to the community and policy makers.

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Original Research Paper

DOI: 10.82005/NC\_02.01.03



# Recognising Difference: A Neurodiversity-Affirming Poetic Autoethnography of Autism in Family Life

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Received 23 September 2025 / Accepted 16 September 2025 / Published 09 November 2025

## Abstract

This article explores one family's evolving understanding of autism through a neurodiversity-affirming lens, guided by lived experience, poetic inquiry, and critical reflection. As both researcher and parent, I reflect on how my own autistic identity emerged while supporting my neurodivergent children—especially my middle daughter, whose internal distress was initially dismissed. Using Poetic Autoethnography and Poetic Ethnography, I weave together original poetry, personal narrative, and academic insight to examine how identity, recognition, and advocacy develop within everyday family life. This work adds to neurodivergent scholarship by centering lived experience and community-informed perspectives, and by promoting more inclusive and compassionate approaches to education, parenting, and research.

**Keywords:** Neurodiversity, Autistic Girls, Autistic Women, Poetic Inquiry, Adult Autism Diagnosis, Neurodivergent Families

## Introduction

This article explores my family's evolving journey of understanding autism through a neurodiversity-affirming lens. Drawing on advocacy reflections and poems written during pivotal moments, I use creative writing and poetry as primary data (Tarisayi, 2023). The methodology combines Poetic Ethnography, which presents life stories in poetic form, and Poetic Autoethnography, which examines personal experience through poetic expression. These approaches align with Hanauer's (2021) framework for poetic inquiry, capturing the emotional depth and authenticity of lived experience. Through personal narrative, emotional insight, and reflexive consideration, I connect our family story to broader cultural and institutional contexts, illustrating how relationships, environments, and systems shape identity and support. In doing so, this article presents a multifaceted account of personal transformation, inviting readers to consider how understanding, acceptance, and support evolve within the lived experiences of neurodivergent families.



## When Being “Good” Hides a Struggle

From a young age, my middle daughter displayed signs of sensory distress, heightened anxiety, and emotional overwhelm. Despite our early concerns, she was described by teachers as quiet, compliant, and academically able, traits that did not match their expectations of autism. She effectively withheld her neurodivergent behaviour during the school day, which made her significant struggles remain hidden. As an example of how she concealed her differences, I remember when she was about 9 years old and I asked her how she coped with the noisy classroom. She replied, “I let my ears hurt.” The thought of my daughter being in pain, without the support to express this among her peers and teachers, was heartbreaking. However, at home, she would no longer feel the need to hide; tensions would surface through meltdowns, disrupted sleep, and emotional exhaustion. I was met with the teacher’s disbelief, subtle blame, and repeated reassurances that she was “fine”. It took several years and ongoing advocacy for her to receive an autism diagnosis. By then, her needs had intensified, and the emotional toll was evident. In contrast, my son’s autism was recognised quickly; his traits were more externally visible and aligned with the standard diagnostic criteria familiar to professionals.

The difference between my daughter’s and son’s diagnostic journeys revealed how prevailing frameworks often reflect a male gender bias (Milner et al., 2019). Girls who internalise distress are frequently overlooked, even when they experience significant emotional and sensory challenges. These experiences emphasise the need for gender-sensitive approaches to recognition and support (Munroe & DeLeavy, 2023). For families like ours, delays in recognition can prolong distress and obscure opportunities to access affirming, informed strategies that could otherwise support wellbeing and identity development.

### ***Good Little Girl: Poem***

The following poem, “Good Little Girl,” was written in response to my middle daughter’s early years of being unseen. It speaks to the emotional labour of hiding neurodivergent characteristics, the pain of being misunderstood, and the strength it takes to hold it all in just to be perceived as “good.” Like many autistic girls, my daughter was praised for coping when in fact she was struggling to be heard. This poem gives voice to that experience and invites a deeper awareness of the different ways autism can present, especially in children who internalise rather than openly express their distress in public.

### **Good Little Girl**

This is a story of a good little girl who, despite specialists saying she's autistic.

The teachers mock, “Oh, another one,” and refer to an “epidemic”.

She isn't like the autistic boys, so it isn't autism they see.

Instead of support, they leave her alone, saying, “She is such a good girl for me”.

This is a story of a strong little girl who battles on day in and day out.

She learnt not to fuss about stomach aches and pains.

She would sneak off to corners where there weren't any games.

She always waited until the end of the day,

Before her tensions were released, so no one could say,

That she wasn't a good girl at school that day.

This is a story of a brave little girl who persevered with all her might.

The impact and scars that were left behind could not be outwardly seen from her fight.

Exhaustion, fatigue, low self-worth, and stress are the consequences she must bear.

The lack of support for autistic girls is undeniably unfair!

Unfortunately, our experiences of exclusion as autistic girls and women remain a challenge, leading to long-term mental health implications for many (Mandy et al., 2022). Recognition of these experiences is essential for developing more equitable approaches to identification, intervention, and care across childhood and beyond (Munroe & DeLeavy, 2023).

### **Reframing Motherhood Through Self-Recognition**

As our journey continued, the challenges my daughter faced did not ease with diagnosis alone. Like many families, the absence of post-diagnostic support meant that daily life continued to be difficult (Scattoni et al., 2023). Despite our best efforts, stress levels in our household were high. Navigating support systems, managing sensory needs, and responding to anxiety left us all feeling depleted. My children were struggling—and so was I. I often felt overwhelmed and frustrated that I could not be the calm, supportive parent I aspired to be. I had spent so much time worrying about my children that I had not paused to consider my own needs.

Like many families navigating a new diagnosis, I set out to learn everything I could about autism (Hughes et al., 2024)—not only from textbooks, but also from autistic advocates who generously shared their experiences and support strategies online. Along the way, I noticed familiar patterns in myself: sensory sensitivities, social exhaustion, and emotional intensity I had long overlooked. This gradual recognition brought an unexpected sense of clarity and began to shift how I understood both my children and myself. Over time, a realisation took shape that was both surprising and deeply affirming: I was not only parenting autistic children—I was autistic too.

With this understanding came a vital shift: to support my children in a meaningful way, I first needed to support myself. I could not expect them to embrace their identities or learn self-regulation unless I was willing to do the same. I needed to embody the calm, care, and acceptance I hoped they would come to feel within themselves.

### ***Closed Flower Bud: Reflection***

The reflection “Closed Flower Bud” emerged as I gained a deeper understanding of myself, my children, and the reality of our situation. It captures an epiphany moment (Hanauer, 2021) about the long-held habit of concealing differences, the inherited patterns of hiding neurodivergence, and the courage needed to begin revealing one's true self. This marked a turning point in my journey, both as a parent and as a neurodivergent person learning, gradually, to bloom.

### **Closed Flower Bud**

Growing up, my expression of difference was wrapped inside me like a closed flower bud waiting for spring - cocooned within a toughened shell and buried deep within. You may have only glimpsed this difference by spending time with me...time that the people around me didn't have. Instead, I was left a complete but closed bud for the whole of my childhood, teens, and twenties. Of course, I stood out as 'different', but my difference was never the subject of enquiry. Easily explained away by the unhelpful strategies my parents adopted to further strengthen the closure of their own armoured buds.

On birthing little closed buds of my own, wrapped in their own unique expressions of difference, I saw how closed they were. Initially, I tried to force their buds open...I knew there was no need to conceal their beautiful differences because I understood that what I saw in them was the difference I also held

within me - I wanted them to open their buds for the world to see because I thought that they were so incredibly beautiful, but the truth is that they had learnt to conceal their difference in the same way the generations of closed buds had done before them.

We see the other buds who do not carry this difference, and as they grow, their petals start to open - open for the world to see. But for us different buds we know that the colours held within us are not the same. We suffer in silence, we keep our buds closed, we do not talk about our struggle with sights, lights, and sounds. We get through our day tightening our buds, concealing our difference, and harbouring it as our personal secret.

We are different but we do not tell.

We do not tell you what our everyday is like because we are scared that in disclosing our differences you will dislike what you see!

So, we hide within ourselves.

As I watched my own little buds concealing their true self like their parents and grandparents before them, I thought to myself...how do I teach you to bloom?...how do I help you to see that your colours may be different from many of the other buds, but your colours within you are beautiful and bright?

I then took a look at myself, and I realised...I am just another tightly closed bud. In this realisation I learnt that you cannot teach other closed buds to bloom, without first blooming yourself.

I had to take it a petal at a time.

I learnt about my expression of difference little by little and then slowly showed it to the world. This was extremely painful at first because my bud had been closed for far longer than what was intended - but by exploring myself and using strategies to help me throughout my day - I slowly started the blooming process. The process that everyone with the same-coloured petals seemed to have done years ago, but non the less I was at last starting to bloom.

It was only through showing my children how I could manage my own blooming process that they could then start the process for themselves. I was honest with them, and I showed them that it was sometimes scary to show your true colours but in the long run, being open - and blooming into my truest self - is amazing!

Yes, my colours shine differently to many people and there are still some people who look at me and think 'what an odd-looking flower - she is not like the other flowers I see' but other people, the most loving people, the people I call my friends. They come to me to embrace my beautifully different petals and value the uniqueness that they hold.

So, if you are that closed bud, holding tightly to your difference, concealing them within and not wanting your true self to be seen - I invite you to bloom...the journey may not be easy, and the learning will take time but once the blooming process begins it's filled with self-love, self-care and sensory support that makes you a little stronger and your days a little brighter.

In the absence of meaningful recognition, families like mine are likely to encounter prolonged periods of uncertainty, emotional strain, and difficulty accessing appropriate strategies. Recognition of neurodivergence can offer a valuable lens through which to interpret experiences and foster a greater sense of self-understanding (Leedham et al., 2019).

### **From Personal Discovery to Research and Advocacy**

What began as a personal commitment to my family gradually developed into a broader academic and advocacy journey. My work now spans education and the workplace, underpinned by lived experience and a commitment to inclusive, community-informed research.

In education, I have explored the retrospective experiences of adult-recognised autistic women in secondary school, evidencing the strengths, impact, and missed support needs of a “lost generation” (Dark, 2022). I have dedicated time in my current and upcoming work to developing a neurodiversity-aligned understanding of autism (Dark, 2023) and inclusive research frameworks that value the insights and culture of autistic people (Dark, 2024). My current doctoral research in organisational psychology builds on this work, exploring the experiences of autistic women disclosing their diagnoses in the workplace. Across both fields, my research aims to contribute to more inclusive and responsive systems by centering the voices and experiences of our autistic and broader neurodivergent communities.

My journey has not always been easy; there have been moments when my perspective has been questioned or undervalued, yet these challenges have only deepened my resolve. With support from autistic advocates and others within the neurodivergent community, I have learned to value the integration of personal, professional, and collective insight. This journey has reinforced what many scholars and advocates have long asserted: that knowledge grounded in lived experience is not only legitimate but vital to meaningful change.

### ***Ode to Our Neurodivergent Community: Poem***

This final poem, “Ode to Our Neurodivergent Community”, is an expression of deep gratitude. It reflects the ongoing struggle many neurodivergent people face in being heard and understood within mainstream systems that prioritise conventional ways of thinking, communicating, and behaving. The poem honours the countless autistic and neurodivergent people who generously share their time, insight, and strength to uplift and support others.

### **Ode to Our Neurodivergent Community**

YOU say that we are not what society dictates as being 'right' or 'good'. That the empathy we display, is not shared in the way YOU think we should. YOU tell us that being different, is ultimately being weak. That we must conform to what YOU say, we must be more of what YOU seek.

Our sensitivities are seen as weakness in YOUR eyes. Our differences shamed by YOU as being less and our demise. We strive for recognition that our brains work at their best. We do not want our thinking to be the same as all the rest.

For different isn't lacking and different isn't wrong. The way the world is processed is beautiful and strong. The kindness that prevails and the sensitivities that are seen. They come from the most loving hearts that there have ever been.

I am sick of shouting 'help' to people who cover ears. My energy depleted from fighting for so many years. So much noise is made by many with little progress to be seen. They choose to not recognise all the suffering that has been.

So together we stand as a community and share our experience and strength as one. For no one knows neurodiversity better than the neurodivergent one. So, let's share what makes life easier, let's build each other up.

For the future must be paved by us and we will never ever give up!

I would not have come to recognise myself, deepen my understanding of how to support my children, or find the motivation to continue studying and working without the support of online neurodivergent communities. The shared knowledge within advocacy groups, social media spaces, and neurodivergent-led literature has been instrumental in expanding both public and academic perspectives on autism, moving beyond narrow, medicalised frameworks. This community-driven insight offers validation, practical strategies, and culturally attuned perspectives that are often absent from formal systems.

## Closing Comments

This article has explored my family's evolving understanding of autism through a neurodiversity-affirming lens, shaped by our lived experiences, emotional insights, and critical reflections. Engaging with poetic inquiry alongside narrative allowed me to examine these experiences in ways that traditional academic writing often overlooks. Adopting a creative approach to self-expression provided a space to express the layered and often unseen aspects of neurodivergent life, helping me to make sense of how we live, connect, and understand who we are as a neurodivergent family.

The contrast between my middle daughter's delayed diagnosis and my son's earlier recognition highlighted how gendered expectations and internalised distress influence access to support. These experiences led to a deeper questioning of diagnostic frameworks. They sparked a process of self-recognition that reshaped my parenting, professional focus, and identity as an adult-identified autistic woman. Throughout this journey, connection with the neurodivergent community provided vital insight, validation, and shared understanding, particularly when formal support systems proved limited. These relationships continue to shape my work, grounding both research and practice in lived experience and reinforcing the value of support rooted in deep listening, trust, mutual respect, and a sense of belonging.

While this article reflects the experience of one family, it contributes to a broader conversation within neurodivergent scholarship, one that values personal narrative to challenge assumptions and shape more responsive systems. This journey has been complex, yet it has offered moments of clarity, connection, and growth that continue to guide my work. Above all, it has shown me the power of being seen and heard in ways that reflect authentic identity. When recognition is offered with care, strengths become visible, opportunities emerge, and healing can begin, especially for those whose experiences have too often been overlooked. I offer this work as part of a continuing effort to build practices, policies, and communities that affirm neurodivergent lives and make space for each of us to be known, supported, and valued as we are.

**Acknowledgments** – I would like to extend my gratitude to my three exceptional neurodivergent children, who kindly gave permission for me to discuss our family in this article, and to the community advocates and scholars who have guided me on my journey thus far.

# NeuroconVerse

NeuroconVerse is a dedicated section of our journal that celebrates the many ways in which neurodivergent individuals express their understanding of the world. We recognise that creativity and insight take many forms, and that art, language, and emotion often reveal truths that conventional academic writing cannot fully capture. Through this section, we seek to give space to voices that communicate the experience of neurodiversity through poetry, song lyrics, short prose, visual art, and other expressive forms. Submissions may explore themes of identity, perception, challenge, or celebration, reflecting the richness and variety of neurodivergent experience. Our aim is to bridge the gap between scholarly discourse and lived expression, bringing academic readers closer to the human stories that inspire research, and helping the broader community to see neurodiversity not only as a subject of study, but as a vital, creative force within culture and society.



On Sunday, she tried to enjoy her  
time at home where she felt  
safe and sound.  
But tears ran down her face.  
She was tired of trying.  
Tomorrow was Monday and she had  
to try, and try all over again.

Kim Percy, Sunday from The Girl Who Tried (2024)







# NeuroConverse

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