Rationale and evidence for taking a person-centred approach to screening in prison

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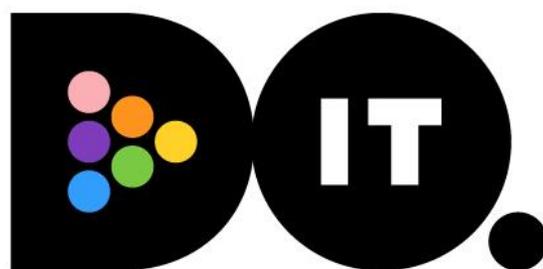
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Introduction

There is increasing recognition of Neurodiversity in the prison context. Neurodivergent traits are generally associated with the following conditions: ADHD, Autism Spectrum Disorders, Dyslexia, Dyscalculia, Developmental Coordination Disorder (DCD, aka Dyspraxia), Developmental Language Disorders, Tic Disorders (including Tourette's syndrome) and Intellectual Disability (ID, aka Learning Disability in the UK).

The need to identify and support people in prison with neurodivergent traits has been explored by the *No One Knows* series of reports (Jacobson, 2008; Loucks, 2007a, 2007b; Loucks and Talbot, 2007; Talbot, 2007, 2008; Talbot and Riley, 2007) which used the term learning difficulties and disabilities (LDD), the *Bradley Report* (Bradley, 2009) and the *Coates Review* (Coates, 2016). These have highlighted that neurodivergent traits are far more common among people in prison yet are frequently unidentified. Lack of identification may increase the likelihood that individuals are: unable to cope with prison routines; unable to access rehabilitative courses; victimised within prison; and at greater risk of reoffending

(Bradley, 2009; Coates, 2016; Jacobson, 2008; Loucks, 2007a, 2007b; Loucks and Talbot, 2007; Talbot, 2007, 2008; Talbot and Riley, 2007).

Common conditions, such as Attention-Deficit/Hyperactivity Disorder (ADHD, including ADD), Autism Spectrum Disorder (ASD, an umbrella term including Autism and Asperger syndrome), Developmental Language Disorder (DLD, including speech and language difficulties) and Tic Disorders (including Tourette's Syndrome and Chronic Tic Disorder) have been shown to have a considerable impact on individuals' vulnerability within prison (Allely, 2015; Bryan et al., 2007; Gudjonsson et al., 2007; Young et al., 2009).

Following DSM-5 criteria (APA, 2013), these conditions, are all grouped under the term Neurodevelopmental Disorders (NDDs).

Following advocacy by people with these conditions, we refer to NDDs as Neurodivergent conditions (see Glossary) and use the neurodiversity to mean the different ways we all think, move, act, process and communicate.

In the past two years there has been greater emphasis on the needs to support neurodivergent people moving through the justice system.

In (2020) the Ministry of Justice has stated that:

"Neurodivergent offenders often have speech, language, and communication needs. Consequently, this cohort can experience difficulties understanding and processing complex information, particularly in stressful circumstances, such as whilst serving a community sentence.

They are required to understand the processes and their sentencing requirements, as well as be able to communicate proficiently with a wide range of individuals. There is a risk that this cohort face extra challenges when trying to comply with criminal justice processes and procedures."

A Smarter Approach to Sentencing by Lord Chancellor and Secretary of State for Justice, Ministry of Justice, September (2020)

In addition, in 2021 the Ministry of Justice undertook a review of evidence called

"Neurodiversity in the Criminal Justice System":

"A programme of awareness-raising and specialist training should be developed and delivered to staff working within criminal justice services. For frontline staff this learning should be broad-based, mandatory, raise awareness of neurodivergent conditions and how they impact on communication and be supported by practical strategies for working with neurodivergent people.

More specialised training should be provided for staff whose roles require it. The programme should be developed and delivered in consultation with people who have personal experience of neurodivergence. "

In 2021, The HM Inspector for Probation the paper by Kirby was written: *Neurodiversity a whole child approach for youth justice,* again highlighting the need for robust screening and appropriate training in prisons and throughout the youth justice systems as well.

In May 2022 the Ministry of Justice published the report: " Not another brick in the wall:

"Data shows that over 30% of prisoners have a learning difficulty or learning challenges. However, we heard that this figure is likely to be an underestimate and that the true scale of the issue is not known, as prisons rely heavily on prisoners declaring themselves to have learning needs. The current screening process is not adequate to identify prisoners with additional leaning needs.

We recommend that the Ministry of Justice introduce a consistent assessment process for every prisoner when they enter the prison estate.

We believe that there is a strong case for every prisoner to receive an assessment for learning needs from an educational psychologist, or at the very least a more intensive form of screening, and we recommend that the Ministry of Justice prepares a cost appraisal for implementing such an approach."

Prevalence of Neurodivergent traits

Neurodivergent traits are common within the general population. For example, among UK children estimates of the diagnosed prevalence of ADHD range from 0.5-2.2% whereas for Dyslexia these range from 2.3-6.2% (Cleaton and Kirby, 2018). The diagnosed prevalence of Neurodiverse conditions among children and young people in the UK ranges from 0.5-2.2% for ADHD to 2.3-6.2% for Dyslexia (Cleaton and Kirby, 2018).

Much higher prevalence rates are found within populations of vulnerable young people particularly juvenile prison populations (Hughes et al., 2012). For example, UK studies report ADHD rates ranging from 10.8% among all young people in Liverpool Youth Offending Services (Lewis and Scott-Samuel, 2013) to 74.2% of those serving custodial sentences for four or more offences in a regional secure training centre (Rayner et al., 2005).

The prevalence of neurodivergent traits in adult prison populations has been between estimated to be approximately 33% (Coates, 2016). However, there has been a paucity of high-quality prevalence

data (Coates, 2016). Also, as previously noted, counts of LDDs do not generally include individuals with ADHD, ASD, DLD or Tic Disorders and thus are underestimates of the prevalence of Neurodiversity.

Female populations

Whilst comparatively few studies have focused on female prison populations, A range of neurodivergent traits appear to be highly prevalent in this population, too. For example, 59.4% of a sample of 69 women in Newhall Secure Female Prison, Yorkshire met diagnostic criteria for adult ADHD when screened (Farooq et al., 2016). Among a random sample of 60 females in Her Majesty's Prison (HMP) Styal, 8.3% had ID (IQ<70) and a further 31.6% had borderline ID (IQ 70-79) when screened (Mottram, 2007).

Females in prison also have low literacy and numeracy levels, some of which may be attributable to Dyslexia and Dyscalculia, respectively. For example, 47% of women entering prison in England in 2014/15 did not have Level 1 literacy skills and 77% did not have Level 1 numeracy skills (Creese, 2016). These are

skills levels expected of typically developing 11-year-old children.

It should be noted that many of the women in these studies had not had their needs identified **before** they were screened for research, indicating these women's diagnoses were highly likely to have been missed before and after they entered prison.

By using Do-IT Profiler in a female prison population we, along with research colleagues have published research (2020) which has examined the data has shown that despite high numbers of females having varying patterns of neurodivergent traits most do not come into prison with a diagnosis. Many have been diagnosed with mental illnesses. Neurodivergent traits were significantly associated with history of self-harm, history of attempted suicide and mental health diagnoses. In total, 32% of women also reported at least one head injury as well.

Defining Neurodivergent traits and conditions

One of the key issues regarding Neurodiversity is that diagnosis is made on the basis of a set of symptoms – using, for example, include DSM-5 (APA, 2013) and ICD-10 (WHO, 1993) international sets of criteria.

Other factors, such as Adverse Childhood Experiences (ACEs, including childhood abuse) and head injuries (potentially causing Traumatic Brain Injury (TBI)) may also result in attention, concentration, social, memory, cognition and/or other difficulties that can mimic Neurodivergent traits and conditions (Babikian et al., 2015; Chang et al., 2018; Van Der Kolk, 2005; Yang et al., 2016).

Conditions relating to Neurodiversity, TBI and ACEs are also highly co-occurrent (Cleaton and Kirby, 2018) and symptoms of one may be misdiagnosed as another (e.g. Bishop et al., 2008).

There is increasing evidence that the combination of neurodiversity and adversity has an even greater impact

(Dinkler et al, 2017; Ruchika,et al, 2021).

This complexity of these two elements is particularly relevant in a prison context, where many individuals may have a history of head injury (Hughes et al., 2012), been a victim of childhood abuse (McDaniels-Wilson and Belknap, 2008; Williams, Papadopoulou, et al., 2012) and/or a victim of domestic violence (McDaniels-Wilson and Belknap, 2008; Prison Reform Trust, 2017) as well as having one or more neurodivergent traits.

We have seen from thousands of data sets in prisons gathered using Do-IT Profiler, that many people get missed gaining a diagnosis because they don't fit into one diagnostic box or another neatly.

Providing accurate, appropriate, and targeted support requires comprehensive, and holistic screening and assessment.

This must include gathering information relating to a history of traumatic brain injury during child and adult life and other adversity (including being in care; risk of homelessness, exclusion in school otherwise misdiagnosis may result.)

Lack of identification of neurodivergent traits and conditions

As previously mentioned, many people who are neurodivergent fail to have their condition(s) ever diagnosed.

Lack of identification may be attributable to the route to diagnosis. There are various routes to gaining a diagnosis of one or more Neurodivergent conditions, which can be inconsistent and variable across the UK and internationally and for many very difficult to access (e.g., Jones et al., 2014).

This is particularly true of individuals with multiple co-occurring conditions (Brett et al., 2016; Kentrou et al., 2018) and especially where individuals have co-occurring neurodivergent traits alongside mental health condition(s) (Barkley and Brown, 2014; Takara et al., 2015), both of which may apply in the prison context.

Missed diagnoses

There are many reasons why a person's Neurodivergent traits and condition may have been missed and undiagnosed prior to entering prison. Parental engagement with health and educational services may have been limited while the person was in school, resulting in little or no access to screening or assessment processes (Astle and Bathelt, 2019; Hamed et al., 2015). Additionally, many people in prison may have missed much of their education, for example through school exclusion, and some will also have moved around the system (e.g., because of being a Looked After Child and/or Young Person (LACYP)) (Jacobson et al., 2010; Oak Foundation, 2019). One or more of these factors may result in the person being less likely to have gained a diagnosis.

High levels of underdiagnosis may be related to the well-documented 'postcode lottery' that affects provision of diagnostic services in the UK (Lamb, 2018). The diagnosis an individual receives remains, in many cases, determined by the services provided by their local healthcare board (Ross, 2018), the knowledge and biases of their parents and of gatekeepers such as teachers and GPs (Miyasaka et al., 2018), the particular specialists that are seen (Astle and Bathelt, 2019) and the ability of the individual and/or their parents to access services (Keenan et al., 2010). In particular, some less well-known conditions, such as DCD and DLD, often fail to be considered and assessments for these may be particularly difficult to access (Missiuna et al., 2006).

Misdiagnosis

Misdiagnosis is also a considerable issue affecting individuals with Neurodiverse conditions. For example, ADHD (Horton-Salway, 2011), ASD (Midence and O'Neill, 1999), DLD (Ripley and Yuill, 2005) and other Neurodiverse conditions are frequently misdiagnosed as 'bad behaviour'. In other cases, Neurodiversity may be misdiagnosed as another condition (e.g., Aggarwal and Angus, 2015). Confusion may also occur when history of head injury is not considered, as TBI can result in 'secondary' ADHD as well as symptoms that mimic ASD and ID (Babikian et al., 2015; Chang et al., 2018; Compton et al., 2017; Keenan et al., 2008;

Max et al., 2005a, 2005b; Yang et al., 2016). In particular, some children may appear to 'recover' from their TBI(s), as the behavioural impact may not become apparent until adolescence (Tonks et al., 2017). In these cases, symptoms are infrequently correctly attributed to the TBI.

Female populations

Females appear to be at particular risk of under- and misdiagnosis of Neurodiverse conditions, although so far this has only been investigated for ADHD (Nussbaum, 2012) and ASD (Loomes et al., 2017). Females with ADHD more often have the predominantly inattentive type (Biederman et al., 2002; Gershon, 2002), which is usually associated with less disruptive and externally-obvious symptoms (APA, 2013). Females with ADHD are also less likely than males to exhibit physical aggression and other externalising behaviours (Rucklidge, 2010). Likewise, females with ASD generally present differently to males. They tend to have more age- and gender-typical restricted interests (Hiller et al., 2014) and often mimic peers' social interactions, although without necessarily understanding them (Dean et al., 2017; Lai

et al., 2017). Additionally, females with ASD tend to have higher levels of social motivation (Sedgewick et al., 2016) and lower levels of repetitive behaviour (Harrop et al., 2015; Mandy et al., 2012; Van Wijngaarden-Cremers et al., 2014). These differences in presentation likely contribute to the under- and misdiagnosis of Neurodiverse females.

Prison systems and staff may assume that those who have neurodivergent traits will arrive in the justice system already diagnosed and be able to articulate their difficulties and ask for appropriate help. In fact, this is rarely the case. Many young people and adults entering the Justice System may not have any formal diagnoses (or, alternatively, may have diagnoses for some but not *all* the challenges they experience) (Kirby et al, 2020).

Additionally, diagnoses in a prison context may often be based on 'behaviours' or a psychological framework, such Conduct Disorder or Borderline Personality Disorder, rather than considering NDDs and/or history of TBI or ACEs.

Young people missed

There are many reasons why a people may have been missed or misdiagnosed prior to entering prison.

Parental engagement with health and educational services may have been limited when people were young, resulting in no access to screening or assessment processes. Additionally, many young offenders have missed much of their education, for example through school exclusion, and some will have moved around the system (being a Looked After Child and/or Young Person (LACYP).

Potential impact of missed diagnoses and misdiagnosis

Neurodiverse individuals typically experience cumulative adversity – increasing, accumulating negative experiences over time. This includes a range of poor psychosocial outcomes relating to offending behaviour, physical and mental health, education and employment (Cleaton and Kirby, 2018).

Offending behaviour, criminal exploitation, and false confession

The impact of having one or more Neurodivergent traits or associated conditions, with or without TBI, may render individuals more vulnerable to offending behaviour, being coerced/manipulated into offending behaviour and/or impulsively or falsely making a confession. For example, it is recognised that individuals with ASD are less risk-aware and less socially protected, even compared with individuals with Down's Syndrome (Fisher et al., 2013). Children with ASD are significantly more socially vulnerable than typically developing children (Sofronoff et al., 2011) and this extends into adulthood (Jawaid et al., 2012).

People with ADHD are more likely to commit reactive and/or opportunistic offences, more likely to be apprehended and less likely to appreciate the seriousness of their actions (Harpin and Young, 2012). Additionally, people with ADHD may not trust their memory during police interrogation, resulting in responses that appear evasive (Gudjonsson et al., 2007). This is concerning, as evasive answers are often used to differentiate truth-tellers from

liars and thus differentiate innocents from guilty suspects (Masip et al., 2018). Additionally, people with ADHD may also be more motivated to comply with requests and avoid conflict, resulting in greater rates of false confession (Gudjonsson et al., 2008, 2012a).

However, the association between criminalisation and Neurodivergent traits and condition extends beyond ADHD. People with ASD are at increased risk of being manipulated or exploited by others in order to commit crimes, due to their social vulnerability and elevated levels of compliance (Payne, 2017). One survey found 37% of people with ASD had been forced or manipulated to do something that they did not want to by someone they considered a friend – this included criminal behaviours (National Autistic Society, 2014). Recent criminal trends have also targeted Neurodiverse people. For example, County Lines drug supply chains often exploit people with learning and developmental disorders (NCA, 2019). In particular, individuals with ID may be targeted for 'cuckooing', a process where drug dealers take over and sell from a vulnerable victim's residence which often involves intimidation and violence (Spicer et al., 2019).

Mental health and Neurodivergent conditions

People with neurodivergent traits are at increased risk of mental health difficulties (Cleaton and Kirby, 2018). These include common conditions such as Anxiety Disorders and Depression, but also a range of other conditions such as Eating Disorders, Obsessive-Compulsive Disorder, Personality Disorders and Schizophrenia (Cleaton and Kirby, 2018).

Neurodivergent conditions are also associated with elevated risk of suicide. Suicidal ideation, suicide attempts and suicide completion are all more frequent in individuals with ADHD (Impey and Heun, 2012) and individuals with ASD are 7.6 times as likely to die by suicide as general population controls (Hirvikoski et al., 2016). Individuals with Dyslexia and/or Dyscalculia are 2.2 times as likely as controls to have ever attempted suicide (Fuller-Thomson et al., 2018). As well as suicide attempts, Dyslexia is also associated with self-harm and suicidal ideation (Alexander-Passe, 2016), as is ID (Giannini et al., 2010).

This association between Neurodivergent traits and conditions and

poor mental health has profound implications for the support and management of people in prison, particularly females.

There is no reliable data regarding the number of people in UK prison who have mental health conditions – the most recent figure dates from 1998 when the prison population was significantly smaller and awareness and recognition of mental health was much less widespread (NAO, 2017). However, in the general UK population, 1 in 6 people have a depressive or anxiety disorder and approximately 1 in 4 have any mental health condition, 6.7% have ever attempted suicide and 7.3% have ever self-harmed (McManus et al., 2009, 2016).

Self-harm and suicide is a considerable and growing issue in prison populations, particularly in the female estate (Bartlett and Hollins, 2018). From September 2017 to September 2018, there were 92 self-inflicted deaths as well as 52,814 self-harm incidents committed by at least 12,467 self-harming individuals in English and Welsh prisons (MoJ, 2019). Between 2008 and 2018, the total number of prisoners in England and Wales decreased by 0.2%[1] (MoJ, 2009, 2018) but the rate of self-inflicted deaths in prison increased by 47.6%[2], the rate of self-harm incidents increased by 230.0%[3] and the number of prisoners who self-harmed increased by 182.9%[4] (MoJ, 2013, 2019).

It is also possible that self-harm incidents in prison may also be becoming more physically harmful: in 2008, 5.5%[5] of self-harm incidents in prisons in England and Wales required hospitalisation but by the September 2017 to September 2018 period this had increased to 6.0%[6] (MoJ, 2013, 2019). Hospitalisation rates can be affected not only by the severity of injury but also by the type of injury and the availability of medical services in the prison in question. Thus, they are not a clear marker of how physically dangerous

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[1] From 83,200 prisoners in 2008 to 83,005 prisoners in 2018.
[2] From 70 self-inflicted deaths in 2008 to 92 self-inflicted deaths between September 2017 to September 2018. Note: the latter may be an underestimate, as the number of deaths 'awaiting further information' prior to being classified has also increased markedly.
[3] From 24,119 reported self-harm incidents in 2008 to 52,814 reported self-harm incidents between September 2017 and September 2018.

[4] From 6,521 individuals recorded as having self-harmed in 2008 to 12,467 individuals recorded as having self-harmed between September 2017 and September 2018.
[5] Of 24,119 self-harm incidents in this year, 1,337 required hospitalisation.
[6] Of 52,814 self-harm incidents in this period, 3,179 required hospitalisation.

self-harm incidents are. However, this issue is worth further consideration.

Substance misuse and Neurodivergent conditions

Many neurodivergent conditions are also associated with increased risk of substance use disorders (Cleaton and Kirby, 2018). Individuals with ADHD (Capusan et al., 2019; Flory and Lynam, 2003; Knop et al., 2009; Sprafkin et al., 2007; Wilens et al., 2011) and ASD (Butwicka et al., 2017; Hofvander et al., 2009) are both more likely to have substance use disorders than individuals without these conditions. One study found that individuals with ASD were 3.9 times as likely to have a substance use disorder, 4.6 times as likely to have an alcohol use disorder and 5.6 times as likely to have a drug use disorder compared to their relatives without ASD (Butwicka et al., 2017).

In the case of ADHD, substance misuse may be an attempt to self-medicate symptoms (Gudjonsson et al., 2012b). In this situation, treating the underlying ADHD can result in reduced substance misuse relapses, improved housing status and increased employment

rates (Bihlar Muld et al., 2015). These factors are all associated with reduced recidivism (Hopkins, 2012; O'Hagan and Hardwick, 2017; Williams, Poyser, et al., 2012). In adolescents with ADHD who do not have substance use disorders, long-term, appropriately titrated pharmacotherapy is associated with significantly reduced rates of alcohol, marijuana and other drug use (Hammerness et al., 2017). This suggests that optimising the diagnosis and management of ADHD may assist in preventing, as well as treating, substance use disorders with potential consequences for offending behaviour.

As well as those with ADHD and/or ASD, individuals with ID are also at increased risk of substance use disorders (Chapman and Wu, 2012; Van Duijvenbode and Vandernagel, 2019). This occurs despite the prevalence of alcohol and drug use being low in this population (Chapman and Wu, 2012). Within the population of people with ID, substance use, and thus also substance use disorders, were more common in those with mild (IQ 50-69) or borderline (IQ 70-85) ID than those with ID that is moderate, severe or profound (IQ<50) (Chapman and Wu, 2012). This is

particularly relevant for prison populations. Recommendations state that individuals with ID should generally be diverted to forensic ID, medical or social care services rather than being sent to prison (Mansell Committee, 1993; Parkin et al., 2018; Reed, 1992). However, individuals with mild or borderline ID are often undiagnosed and/or do not disclose their diagnosis due to stigma (Wieland and Zitman, 2016). Thus, many may end up in prison. For example, one study of 140 randomly-sampled prisoners from HMP Liverpool found that, when screened with the WAIS[7], 7.1% had mild or moderate ID and a further 23.6% had borderline ID (Hayes et al., 2007).

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[7] Wechsler Adult Intelligence Scale, a widely-used IQ test for adults (Wechsler, 1999).

Current diagnostic and support systems

Categorical or dimensional?

The current diagnostic systems categorise individuals as having distinct, categorical, symptom-based disorders (ADHD, ASD, Dyslexia, etc.). However, a categorical approach like this ignores the fact that Neurodivergent conditions appear to be inter-related and often co-occur with each other (Kaplan et al., 2006, 1998, 2001) as well as other common, potentially confounding factors such as TBI and ACEs. They also co-occur commonly with mental health conditions as well such as anxiety and depression.

As well as commonly co-occurring, Neurodivergent conditions also commonly exist at a *sub-threshold level*. This is because they are based on dimensional, not categorical characteristics – similarly to other human characteristics such as height, any cut-off between 'normal' or 'typical' and 'abnormal', 'disordered' or 'atypical' is arbitrary. It is quite common, for example, for individuals with ADHD or DLD to have what is described as 'Autistic tendencies' – i.e. sub-threshold ASD (Conti-Ramsden et al., 2006; Green et al., 2015). Some individuals, despite having

functional difficulties in many areas (e.g., attention, social communication, reading, mathematics, memory), do not reach the diagnostic threshold for any of the conditions associated with these difficulties.

Having specific diagnostic thresholds can result in inequitable provision of support and services, as they mean diagnosis functions as an 'all-or-nothing' model.

They also rarely consider other contributing factors such as TBI, abuse experiences and family disadvantage when diagnosing.

Cumulative Adversity and Neurodiversity

The cumulative challenges experienced by someone with symptoms of multiple Neurodivergent conditions at a sub-threshold level may be functionally more impairing than the challenges experienced by someone who meets diagnostic criteria for, and has symptoms of, a single condition only. However, without a diagnosis, individuals with a number of different sub-threshold Neurodivergent traits that don't fit within a specific diagnostic box are rarely

deemed eligible for educational or medical support even if their overall needs are potentially greater.

In a prison context, this may be why so few people have received diagnosis – their pattern of needs doesn't fit the current, categorical service model.

This has been demonstrated in males, females and youth offending contexts in prisons using Do-IT Profiler and in independently published work.

The challenge when we work in silos

Another challenge facing Neurodivergent people is that services often operate in different professional silos, both within and outside the Justice System. For example, Dyslexia, Dyscalculia and, to some extent, DCD 'sit' within education, ADHD 'sits' in mental health services and ID may be separated from both into Learning Disability provision.

This means that the individual's whole profile is rarely fully explored. Thus, the diagnoses people receive more often reflect the professionals that they have seen rather than the actual difficulties that they have (Astle and Bathelt, 2019).

Alternatively, a prison may run an effective learning disability screening programme and service, without recognising that this fails to identify or support individuals with other, equally disabling conditions such as ADHD, ASD, DLD and TBI. These challenges may have at least as much impact on an individuals' overall health and wellbeing (Bihlar Muld et al., 2015), their ability to engage with rehabilitative courses and, potentially, their likelihood of reoffending (Chang et al., 2016; Ray and Richardson, 2017).

In other cases, screening programmes are run that cover many conditions but only effectively identify those who have previously had a diagnosis and/or support. This clearly misses the majority of people moving through the justice system who have had their neurodivergent traits missed again and again because they don't live in stable home settings, or have access to consistent health provision e.g., GP services.

As previously described, many if not most neurodivergent individuals either have no diagnoses or do not have diagnoses for *all* the difficulties they have. Additionally, many people *with* diagnoses do not receive any support following

diagnosis (e.g. Braiden et al., 2010; Crane et al., 2016; Jones et al., 2014). Therefore, if one weights a screening questionnaire too strongly towards questions about previous support, even people *with* diagnoses may not meet screening criteria.

Working in silos and focusing on particular conditions has severe consequences, as many if not most Neurodivergent individuals have more than one Neurodivergent condition (Cleaton and Kirby, 2018). Even if all of an individual's diagnoses are, eventually, made, working in silos means delays may be exacerbated. For example, if a child with DCD, ASD and Dyslexia was referred to a clinic because of social communication concerns, they would (after reaching the top of the, typically very long, waiting list) receive a diagnosis of ASD. However, they would then have to be referred to a motor disorders clinic, with another very long waiting list, to be diagnosed with DCD. Later, perhaps after a few years at school, their reading difficulties might become increasingly obvious and they might be referred to an educational psychologist for a Dyslexia evaluation, with yet another long wait. By this point, years without adequate

support could mean the child has developed nascent mental health difficulties, disaffection with school and/or a negative relationship with their parents. They may have spent years unable to access the curriculum, with long-term consequences for their educational and employment outcomes, as well as offending behaviour. In contrast, if they had initially been referred to a comprehensive Neurodevelopmental clinic, they could have been screened and monitored for all Neurodivergent traits and conditions, resulting in timely diagnoses, earlier initiation of support and potentially better long-term outcomes.

Siloes within the prison services

Another issue associated with the separation of services into silos is that data-sharing is frequently inadequate if it happens at all. Thus, for example, in a prison context the mental health team may not inform the substance abuse team about an individual's ADHD diagnosis, even though this may affect their likelihood of drug relapse (Bihlar Muld et al., 2015). Equally, education may not inform either the mental health team or the substance abuse team about the individual's Dyslexia, resulting in the individual being given self-help materials

that they cannot read. This lack of joined-up thinking and working has the potential to severely affect people in prison.

All the above models (i.e., single-condition 'siloed' services, Neurodivergent specific services and services that rely on prior diagnosis/support to identify service users) are highly unlikely to be sufficiently comprehensive, equitable or fair. They fail to recognise the reality of the conditions they purport to assess – i.e., that Neurodivergent conditions are complex and interrelated, they have high levels of symptom commonality with other conditions such as TBI and they are frequently undiagnosed and misdiagnosed. Thus, these systems risk leaving the most needy individuals unidentified and unsupported, consequently rendering them highly vulnerable to within-prison victimisation, unlikely to cope with prison routines, unlikely to be able to access rehabilitative courses and at greater risk of reoffending (Bradley, 2009; Coates, 2016; Jacobson, 2008; Loucks, 2007a, 2007b; Loucks and Talbot, 2007; Talbot, 2007, 2008; Talbot and Riley, 2007). Unfortunately, these appear to be the predominant service

models, both within the community and within the Justice Sector.

Paper-based screening tools

Around 50% of people in prisons in the UK are functionally illiterate, i.e. have a literacy level equivalent to age 11 years or lower, and 20% have a literacy level equivalent to age 9 years or lower (Creese, 2016). Other research has highlighted that 50% of the prison population are thought to have a language disorder (Anderson et al., 2016). This means that reading, understanding, and completing documentation is limited for this population.

Despite these known difficulties, paper-based assessments have often remained the dominant mode of screening for Neurodivergent conditions. Scribes and readers may be provided, or assessments may be carried out in interview format. However, this is not only expensive but also may be inappropriate. Having a reader assist with a paper-based assessment may place a larger cognitive burden on the person being assessed, resulting in inaccurate assessment. Additionally, the participant may feel embarrassed at having to ask for questions to be repeated or words to be defined. They may also be afraid of

disclosing potentially stigmatising information, such as an inability to read, when a stranger is physically present. Thus, paper-based assessments risk inaccurate results and may increase the likelihood that an individual's difficulties are missed.

A paper was published in the Prison Service Journal in 2017 outlining the rationale for computer-based screening systems by Kirby.

Prison staff knowledge of neurodiversity and neurodivergent conditions

A further issue that has been highlighted in government reports in the past couple of years is the level of prison staff knowledge about terms and words associated with neurodiversity and neurodivergent traits. Very few studies have assessed the knowledge levels of prison staff. However, those that have been carried out suggest that improvement is required.

One study investigated the knowledge and understanding of ASD among 53 prison staff (McAdam, 2009, 2012). One-third reported they did not know what Autism was and half did not know what Asperger's Disorder was. Over a third thought that offenders with ASD were most appropriately located in a secure hospital, even though research indicates this may not be the ideal location. Nearly 20% of the staff were unaware or unsure of whether the presentation of ASD varied between individuals with the condition.

The only other study investigating prison staff awareness of Neurodiversity was carried out more than 10 years ago and investigated 'LDD's in general. There, around a fifth of respondents felt that, due to a lack of awareness, people in prison who had 'LDDs' were subject to abuse by prison staff (Talbot, 2007). The study predominantly asked open-answer questions and did not test staff's specific knowledge about any individual condition.

A different approach: taking a person-centred, needs-led approach

As described above, categorical approaches to the diagnosis and support of Neurodivergent individuals have many serious shortcomings. An alternative to these, are dimensional approaches – approaches which consider an individual's unique needs, rather than determining whether the individual fits certain diagnostic criteria and providing support only if these diagnostic criteria are met. Dimensional approaches are needs-led rather than diagnosis-led.

A shift away from categorical approaches towards more holistic, profile-based, dimensional approaches have been suggested by some psychiatrists (NIMH, 2014). This approach creates a formulation-based assessment and management plan based considering an individual's needs, whether they group neatly into diagnostic criteria or not.

The key areas of challenge for that individual are identified with respect to their current social and physical environment and appropriate, holistic support is provided. This approach could be taken in a prison context too.

Dimensional approaches are also typically person-centred – they put the person first and consider them as an individual rather than a category ,label or type – e.g., 'Sam, who has strengths in A, B and C but requires support with X, Y and Z and' rather than 'another young male prisoner with ADHD'.

Person-centred approaches are often based on a biopsychosocial model of disability (see Glossary). This model incorporates the best aspects of two previous models of disability: the medical model and the social model (Engel, 1977, 1980). It is based on the idea that disability is the combination of differences in people's bodies (bio-), differences in people's minds (psycho-) and the mismatch between people's needs and the physical and social environment that they live in (social).

By taking a person-centred approach using the biopsychosocial model, we can better support neurodivergent people, particularly in the prison and community contexts, resulting in better outcomes for all. For example, a person with Autism might become violent when unexpectedly transferred between cells, wings, or prisons, resulting in injuries to staff. A traditional approach, if the

individual either lacked a diagnosis or if staff did not understand the diagnosis, might be to sanction the individual and/or increase the number of staff involved in these transfers. However, this is unlikely to affect the behaviour in this case and the additional staff might cause the person to become more agitated, resulting in them becoming even more violent. An alternative approach would be to recognise that individuals with ASD often respond well to routine and may be more resistant or fearful of change. Therefore, unexpected transfers are more likely to provoke a response in someone with ASD than someone without ASD. A more appropriate response might be to discuss transfer procedures, where possible, with this individual and ensure that they are always informed in advance of any cell or prison changes. Additionally, the individual might be shown pictures or videos of their new cell or prison or introduced to key new staff in advance, to help them cope with the upcoming change and visualise their new location. This would result in reduced stress for the individual, improved rapport between the individual and staff, reduced likelihood of staff injuries during transfers and reduced staffing requirements during transfers. Kirby and Saunders wrote about how to successfully facilitate an embedded whole prison approach (2015).

Do-IT Profiler has been successfully used in many prisons in the UK and in some prisons since 2013. 10s of 1000s of screenings have taken place with people using the system of all ages and all abilities.

Accessible and effective profiling of complex adversity

As discussed above, there is a clear need for timely, practical, and comprehensive profiling of both males and females in the Justice System, using dimensional, needs-led, person-centred approached. This will allow staff (and the individuals themselves) to gain a thorough understanding **each person's** specific strengths and challenges. To do this, more holistic screening and support approaches are required, as needs and suitable interventions will vary between individuals (and over time).

One challenge to delivering this sort of approach to screening and support has been how to practically capture this information, especially if there are no specialists available to undertake this work.

Accessible, voiced, computer-based screening solutions can be self-administered and can automatically and immediately generate functional guidance as a first step to providing support. As scores and personalised initial support recommendations are automatically generated, the administrative burden of screening participants is greatly reduced

and the risk of errors during manual data-entry or scoring is eliminated. Computer-based screening solutions also allow information to be easily communicated to relevant stakeholders across the prison, breaking down silos and allowing easier interdisciplinary working. Overall, they have the potential to identify rapidly, efficiently, and comprehensively the most vulnerable.

This may save time and allow better conversations about support needs and recommended interventions to occur earlier in an individual's pathway through the Justice System, improving outcomes in this high-demand context.

Conclusion

Only once an accurate picture of overall adversity is created can steps be made towards ensuring targeted support in prison is comprehensively and routinely provided. Accessible, computer-based screening solutions provide a cost-effective means of doing this. The identification and targeted support of people in prison with Neurodiverse conditions and related adversity will enable them to gain equitable opportunities to access education and employment programmes whilst in prison

and ensure that they are given suitable preparation for resettlement. Starting this process earlier both within the community, for example in schools, and on initial contact with police and the Justice System could reduce offending pathways. However, without this, we risk continuing to imprison Neurodiverse people and continuing to let them leave prison unprepared and at high risk of further adversity and reoffending.

Author biography

Professor Amanda Kirby MBBS MRCGP PhD

Amanda is an emeritus professor at the University of South Wales and an honorary professor at Cardiff University. She has clinical and research experience and founded and ran a transdisciplinary clinical and research team for 20 years relating to neurodiversity. She is a qualified GP and has a Ph.D. relating to emerging adulthood and neurodiversity. She has initiated and run a Masters in SEN programme.

Amanda is also the founder and CEO of Do-IT Solutions, a tech for good company that provides neurodiversity screening and web-based support tools for schools and for adults in education and employment.

Amanda has been on government advisory boards (e.g., Hidden Impairment National Group) as well as advising UK and international charities in the field of neurodiversity. This includes being a patron of the Dyspraxia Association in New Zealand, and Chair of Movement Matters UK. She is also the current chair of the ADHD Foundation and works closely with many other charities working in this area

She has written 10 books and more than 100 research papers in the field and her latest book published in 2021:'Neurodiversity at Work, Drive Innovation, Performance and Productivity with a Neurodiverse Workforce' has won the Business Book Awards 2022 for EDI. Amanda has been voted one of the top UK HR Thinkers in 2022 and also won the Lifetime Achievement Award at the National Diversity Awards in 2023 as well as being voted in the UK Power 50. She has a new book on Neurodiversity in Education coming out in 2023 with authors Paul Ellis and Abby Osbourne.

Amanda has lived experience of neurodiversity first hand, as she sees herself as neurodivergent as well as being a parent of neurodivergent children, and grandchildren. Amanda's passion to make changes in society and increase the chances of showcasing talents for neurodivergent children and adults especially in work settings remains as strong as it was 30 years ago.

Glossary

Acalculia – an acquired condition that affects understanding of mathematics and related concepts that use mathematics, e.g. money, time, positional directions. Caused by an Acquired Brain Injury. General intelligence is not affected. If mathematical skills are compromised since childhood with no apparent cause, see Dyscalculia.

Acquired Brain Injury (ABI) – an injury to the brain resulting from an external cause rather than a genetic, developmental, or degenerative condition. For example, injury caused by trauma (see Traumatic Brain Injury), stroke, meningitis, encephalitis, or poisoning.

Adverse Childhood Experiences (ACEs) – experiences that occurred before age 18 years that are known to have an adverse effect on long-term physical health, mental health, health-harming behaviours and other outcomes. Typically include: physical, verbal, emotional and sexual abuse; neglect; parental divorce/separation; parental death; domestic violence; parental mental illness; parental or family member alcohol abuse; parental or family member drug use; and parental or family member incarceration. Some studies also include other adverse experiences, e.g. poverty.

Alexia – an acquired condition that affects understanding of written language, i.e. reading and writing. Caused by an Acquired Brain Injury. General intelligence is not affected. If reading and writing are compromised since childhood with no apparent cause, see Dyslexia.

Apraxia – an acquired condition that affects gross motor skills (e.g. running, dancing, riding a bike, driving), fine motor skills (e.g. using cutlery, tying laces, buttoning, handwriting) and balance. Caused by an Acquired Brain Injury. If motor skills are compromised since childhood with no apparent cause, see Developmental Coordination Disorder (DCD).

Asperger's Syndrome – see autism spectrum disorder (ASD). This historic term was generally applied to individuals with ASD who had average or above-average intelligence, no language delay and no delay in learning everyday skills such as dressing and feeding oneself. This term was taken out of the DSM-5 categorisation in 2013.

Attention-Deficit Disorder (ADD) – see Attention-Deficit/Hyperactivity Disorder (ADHD).

Attention-Deficit/Hyperactivity Disorder (ADHD) – a developmental condition that affects attention, activity and impulsivity levels. This categorisation is based on DSM-5 criteria, whereas the related condition Hyperkinetic Disorder is based on ICD-10 criteria. Between 1980 and 1987, ADHD was officially called 'Attention-Deficit Disorder (ADD) with or without hyperactivity'. There are three types of ADHD:

- **Predominantly inattentive** – where there are few hyperactive or impulsive symptoms but significant inattentive symptoms.
- **Predominantly hyperactive/impulsive** – where there are few inattentive symptoms but significant hyperactive and impulsive symptoms.
- **Combined** – where there are significant inattentive, hyperactive and impulsive symptoms.

Autism – see Autism Spectrum Disorder (ASD). This historic term was generally applied to individuals with ASD who had below-average intelligence, language delay and/or delay in learning everyday skills such as dressing and feeding oneself.

Autism Spectrum Condition (ASC) – see Autism Spectrum Disorder (ASD).

Autism Spectrum Disorder (ASD) – a spectrum of developmental conditions that affect social communication, social interaction, sensory sensitivity and flexibility of behaviour and

thought. This umbrella term includes Autism and Asperger's Syndrome. Autism Spectrum Condition (ASC) is a synonym of Autism Spectrum Disorder.

Biopsychosocial model – a model through which disability can be understood. This model takes into account how the condition affects the person's biology (e.g., genetic differences, physical differences, pain, fatigue), the affect the condition has on the person's mind (e.g. anxiety, depression, fear of stigma) and the interaction between these two aspects and the person's physical and social environment. It considers disability to be a combination of all of these aspects. E.g., someone with two above-knee amputations may not be disabled by their amputations *per se* but may be disabled by phantom pain, depression triggered by their change in life circumstances and/or the lack of ramps and lifts at their first-floor workplace.

Categorical approach – an approach to describing characteristics of people or objects. This approach groups these characteristics into categories, e.g., 'tall' versus 'short' or 'blue' versus 'green'. This approach works well with some characteristics (e.g., a switch is either on or off) but does not work well for characteristics which lie along a spectrum (e.g. different cultures disagree on whether certain shades are 'blue' or 'green'; a person who is considered 'short' in the UK in 2019 might be considered 'average height' in China in 2019 or in the UK in 1319).

Chronic Tic Disorder (CTD) – a Tic Disorder. CTD is diagnosed when someone has motor **or** vocal tics for **more than** 1 year, starting before age 18 years.

Developmental Coordination Disorder (DCD) – a developmental condition that affects gross motor skills (e.g., running, dancing, riding a bike, driving), fine motor skills (e.g., using cutlery, tying laces, buttoning, handwriting) and balance. Dyspraxia is the term most commonly used in the UK, especially colloquially. However, DCD is the internationally-recognised official term.

Developmental Language Disorder (DLD) – a developmental condition that affects receptive language (understanding spoken language you hear), expressive language (language you speak), semantic language (understanding meaning in spoken language, e.g., jokes, euphemisms, metaphors) and/or pragmatic language (using spoken language appropriately in social situations). Historically, this was called Specific Language Impairment (SLI). It is an umbrella term that includes DSM-5 diagnoses such as Language Disorder and Social (Pragmatic) Communication Disorder and ICD-10/11 diagnoses such as Expressive Language Disorder, Mixed Receptive-Expressive Language Disorder and Social Pragmatic Communication Disorder. However, it is less broad than the umbrella terms Speech, Language and Communication Needs (SCLN) and Speech, Language and Communication Difficulties (SCLD).

Dimensional approach – an approach to describing characteristics of people or objects. This approach does **not** group these characteristics into categories, e.g., 'tall' versus 'short' or 'blue' versus 'green'. This approach works well for characteristics which lie along a spectrum with only arbitrary dividing lines between them (e.g., different cultures disagree on whether certain shades are 'blue' or 'green'; a person who is considered 'short' in the UK in 2019 might be considered 'average height' in China in 2019 or in the UK in 1319).

DSM – the Diagnostic and Statistical Manual of Mental Disorders. A system of diagnosing psychiatric illnesses, published by the American Psychiatric Association. The current edition is DSM-5 and was released in 2013.

Dyscalculia – a developmental condition that affects understanding of mathematics and related concepts that use mathematics, e.g., money, time, positional directions. General intelligence is not affected. If mathematical skills are compromised due to an acquired injury, see Acalculia.

Dyslexia – a developmental condition that affects understanding of written language, i.e. reading and writing. General intelligence is not affected. If reading and writing are compromised due to an acquired injury (e.g., stroke, Traumatic Brain Injury), see Alexia.

Dyspraxia – see Developmental Coordination Disorder (DCD). Dyspraxia is the term most used in the UK, especially colloquially. However, DCD is the internationally recognised official term. If motor skills are compromised due to an acquired injury (e.g., stroke, Traumatic Brain Injury), see Apraxia.

Hyperkinetic Disorder – see Attention-Deficit/Hyperactivity Disorder (ADHD). Hyperkinetic Disorder is a diagnosis made based on ICD-10 criteria whereas ADHD uses DSM-5 criteria. It is equivalent to a severe version of combined ADHD.

ICD – the International Classification of Diseases. A system of classifying diseases, published by the World Health Organisation. The current edition is ICD-10 and was first used in 1994. Latest edition (ICD-11) - 2022.

Intellectual Disability (ID) – a developmental condition that affects global intelligence and everyday functional skills, e.g.,,self-care. Learning Disability is the term most used in the UK. However, ID is the internationally recognised official term and avoids confusion as Learning Disability in the USA is equivalent to Learning Difficulty in the UK.

Learning Difficulty – an umbrella term used in English and Welsh education, particularly post-16 education. Equivalent to Specific Learning Difficulty (SpLD). Generally, includes Dyslexia, Dyscalculia and Developmental Coordination Disorder (DCD). Sometimes, Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD) and/or Developmental Language Disorder (DLD) are also included.

Learning Disabilities and Difficulties (LDDs) – an umbrella term used in English and Welsh post-16 education. Includes Learning Disability and Learning Difficulties. I.e., it generally includes Intellectual Disability (ID), Dyslexia, Dyscalculia and Developmental Coordination Disorder (DCD) but sometimes may also include Attention-Deficit/Hyperactivity Disorder (ADHD), autism spectrum disorder (ASD) and/or Developmental Language Disorder (DLD).

Learning Disability – a term used in English and Welsh education and health services. In this context, equivalent to Intellectual Disability (ID). However, in other nations (e.g., USA) it is equivalent to the UK term Learning Difficulty.

Neurodevelopmental Disorders (NDDs) – an umbrella term. Includes Attention-Deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Developmental Coordination Disorder (DCD), Developmental Language Disorder (DLD), Dyscalculia, Dyslexia, Intellectual Disability (ID) and Tic Disorders.

Neurodiversity – a term coined by Judy Singer in the late 1990s. It is the way we differently all think,move, process, communicate and act differently.

It is has been associated with Neurodevelopmental Disorders. The term Neurodivergence recognises that differences in represent normal, naturally occurring variations in human brains/minds rather than abnormal 'disorders'. In this respect, Neurodivergent traits and conditions are social categories, and should not be stigmatised or eliminated.

Person-centred approach – an approach to diagnosing, treating and/or managing physical and mental health conditions and Neurodiversity. This approach considers *all* of the challenges the individual person faces and how these challenges may change over time and with different environments. Diagnostic pathways and interventions are tailored to the

individual person rather than being a one-size-fits-all approach based on a standard response to suspected or confirmed diagnoses.

Provisional Tic Disorder (PTD) – a Tic Disorder. PTD is diagnosed when someone has motor **and/or** vocal tics for **less than** 1 year, starting before age 18 years. If the tics persist for more than one year, the condition is reclassified as either Chronic Tic Disorder or Tourette's Syndrome, as applicable.

Specific Language Impairment (SLI) – a historic umbrella term, equivalent to Developmental Language Disorder (DLD).

Specific Learning Difficulty (SpLD) – an umbrella term used in English and Welsh education, particularly compulsory education. Equivalent to Learning Difficulty. Generally, includes Dyslexia, Dyscalculia and Developmental Coordination Disorder (DCD). Sometimes, Attention-Deficit/Hyperactivity Disorder (ADHD), autism spectrum disorder (ASD) and/or Developmental Language Disorder (DLD) are also included.

Speech, Language and Communication Difficulties (SCLD) – a broad umbrella term used in Welsh education. Equivalent to the English term Speech, Language and Communication Needs (SLCN).

Speech, Language and Communication Needs (SCLN) – a broad umbrella term used in English education. This includes difficulties due to Developmental Language Disorder (DLD) as well as stammering, stuttering and difficulties that stem from autism spectrum disorder (ASD), hearing impairment and other causes. Equivalent to the Welsh term Speech, Language and Communication Difficulties (SLCD).

Tics – abnormal, repetitive, non-rhythmic, unintentional movements (motor tics) or vocalisations (vocal tics). These can be simple, e.g., eye blinking, sniffing, or complex, e.g. echopraxia (imitating another person's actions) or palilalia (repeating words one has previously said). Tics are described as semi-voluntary or involuntary – they are suppressible but irresistible – suppression results in an irresistible urge and eventual expression of the tic.

Tic Disorders – an umbrella term, including developmental conditions characterised by tics. Includes Chronic Tic Disorder (CTD) and Tourette's Syndrome. Provisional Tic Disorder (PTD) is sometimes also included in this umbrella term, although this is not the case in this report.

Tourette's Syndrome – a Tic Disorder. Tourette's Syndrome is diagnosed when someone has motor **and** vocal tics for **more than** 1 year, starting before age 18 years.

Traumatic Brain Injury (TBI) – a sub-category of Acquired Brain Injury (ABI). An injury to the brain resulting from trauma to the head or face (e.g., from a traffic accident, fight, sports injury, etc.). TBI, particularly if severe or repeated, can result in long-term symptoms that mimic aspects of Attention-Deficit/Hyperactivity Disorder (ADHD), autism spectrum disorder (ASD) and Intellectual Disability (ID) in particular. Symptoms may also sometimes include Acalculia, Alexia and/or Apraxia. TBI severity is classified based on symptoms immediately post-injury (e.g., tested using the Glasgow Coma Scale) or, if these are unknown, duration of unconsciousness:

- **Mild**: Glasgow Coma Score of 13-15 and/or less than 10 minutes loss of consciousness.
- **Moderate**: Glasgow Coma Score of 9-12 and/or between 10 minutes and 6 hours loss of consciousness.
- **Severe**: Glasgow Coma Score of less than 9 and/or more than 6 hours loss of consciousness.

– an injury to the brain resulting from an external cause rather than a genetic, developmental or degenerative condition. For example, injury caused by trauma (see Traumatic Brain Injury), stroke, meningitis, encephalitis or poisoning.

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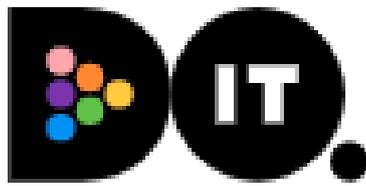
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