

'Before My Brother Came... I Lived Off Sandwiches'

Adapting the Prison Service to ensure equality for neurodiverse prisoners

Elizabeth Davison is an Assistant Private Secretary to the Permanent Secretary of the Ministry of Justice and an ambassador of the Unlocked Graduates programme.

The researcher was a Prison Officer at a Category B remand prison in central London. This is a challenging environment, with a diverse prisoner population which is often changing. Staff have little time or training to accommodate the needs of neurodiverse prisoners, yet often make their best efforts to do so. Officers have been seen writing application forms, giving tours of the wing, ensuring that prisoners too afraid to shower in general association get showers outside of this. Countless lunch times have been given up printing outlines of animals for prisoners to colour in, or pictures of motorbikes to decorate cells with and emailing in-reach with a long list of welfare concerns. Equally, there have been instances of misunderstandings which have escalated into use of force. A prisoner being given an instruction they might not fully understand, disobeying it and being put behind their door (again). Officers learn in training that your duty as a prison officer is to, 'prevent victims by changing lives' and to 'reduce reoffending by rehabilitating the people in our care through education and employment'. Yet the literature discussed in this report reveals that there are many areas in which the Prison Service is failing to give adequate adjustments and support to neurodivergent prisoners. There needs to be systematic changes across the entire prison-estate to ensure equality of experience for the neurodiverse prison population. In local remand prisons, issues of gang violence often take the centre-stage and there is not the same funding and opportunities to look for solutions for problems faced by neurodiverse prisoners. Yet, the remand prison is perhaps one of the most important areas to get this right. It is the first place that neurodiversity

could be identified and support can be put in place. The remand prison is also an emotionally taxing part of the prison experience, where prisoners: negotiate prison life, face court and sentencing, learning the norm of emotional restraint which acts as a 'collective coping function'.¹ This research looks at some of the key areas of prison life which are directly affected by neurodiversity and in the second part looks at some potential solutions and recommendations.

Introduction

There is no universally accepted definition for neurodiversity and as such the range of conditions that fall under this bracket is diverse and there is a variation in the impact any one of these conditions has on daily life. It is not a perfect term and scholars have, more recently, recognised that the 'neurodivergent' identity can be problematic if it assumes a common experience of neurodiversity. Although the term is broad, it is the preferred one for this study as it rejects the medical model of disability, engaging instead with the social model, where neurodivergent people are considered part of a normal variation. The term rejects the use of stigmatized terms such as 'deficit' and 'disorder'.²

The literature presents that there is a disproportionate representation of neurodiversity in the prison population. It is difficult to estimate the exact figures because there has been no consistent data gathering at local or national level. Again, the broad term 'neurodiversity' presents some problems in capturing data as different neurodivergent conditions are measured using different criteria. The 2021 Review of Evidence commissioned by the then Lord Chancellor, Robert Buckland, used the 'working conservative assumption' that around 50 per cent of the adult prison

1. Crewe, B., Warr, J., Bennett, P., & Smith, A. (2014). The emotional geography of prison life. *Theoretical criminology*, 18(1), 56-74.

2. Shah, P. J., Boilson, M., Rutherford, M., Prior, S., Johnston, L., Maciver, D., & Forsyth, K. (2022). Neurodevelopmental disorders and neurodiversity: definition of terms from Scotland's National Autism Implementation Team. *The British Journal of Psychiatry*, 221(3), 577-579.

population experiences 'some sort of neurodivergence challenge.' This data presents overwhelming evidence that a large proportion of the prison population has some sort of neurodivergence which will directly impact their experience of the prison system. Yet, there is a dearth in literature which highlights neurodiverse prisoners' experiences, with little progression towards improving these experiences. Whilst there is some evidence of good practice, this tends to be singular to individual establishments, with very little cohesive improvement across the prison estate. It is imperative that there is improved research, from which we can advise the prison service and its staff what reasonable adjustments could be made to ensure equality for all prisoners. This first part of this review will look at four key areas which act as 'barriers' for neurodiverse prisoners in having an equal experience of the prison system.

Barriers for Equity

There is consensus amongst scholars that there is a lack of sufficient screening for neurodivergence, which leaves many unidentified.³ This is problematic as, theoretically, once neurodivergence is recognised, future interactions can be adapted to the specific needs of the individuals and further investigations can be made. One study showed that fewer than 50 per cent of prisoners in the target group had undertaken screening or assessment to determine the presence of learning difficulties and disabilities⁴ and another found that they could identify several prisoners with neurodevelopmental disorders and difficulties (NDD) who had previously gone unrecognised due to a lack of capacity and ability to assess NDD.⁵ Previous governmental research has reflected this evidence and recommended that 'urgent consideration should be given to the inclusion of identifying learning disabilities into the prison health screen'.⁶ Over a decade later, the Criminal Justice Joint Inspectorate recommended that 'common screening

tool should be introduced, supported by an information sharing protocol.' The gap between these recommendations highlights that the screening process in prisons has had no significant improvement in the last decade.

When talking about access, it is important to address how the prison perceives responsibility. It is argued that prisoners are 'taught' to engage with institutional goals and take personal responsibility for their actions through a combination of threat and opportunity. An example of this is the Incentive Earned Privileges (IEP). Launched in 1995, IEP's give prisoners the opportunity to benefit from 'good' behaviour and therefore responsibility for their own sentence progression and rewards. However, there is a disconnect between these normative expectations of self-governance and the prison system's ability to respond to the challenges and barriers for neurodiverse prisoners.⁷ Therefore, neurodiverse prisoners are at a structural disadvantage.

Sentencing and sentence plans is one area which could reveal serious consequences of not having equal access to information. The literature indicates that there are some neurodiverse prisoners who receive complex sentences, the terms of which, they are unable to understand. Without guidance on the requirements, they need to meet in order to be released, the lack of reasonable adjustments in this area, can literally translate into longer sentences for neurodiverse prisoners. In a seminal study, prisoners were asked if they 'knew when they could go home'. One in ten said they didn't, a number that doubled for those with a possible or borderline learning disability.⁸ Decisions around prison progression and release is complicated for a large part of the population, their 'mechanics bewildering... an opaque form of fortune telling' leaving prisoners feeling powerless and dehumanised.⁹ Sentencing is an area which has the potential to instil a sense of powerlessness amongst prisoners. If the

If the sentence or sentence-plan is not presented to prisoners in a way that they can understand, a sense of 'powerlessness' translates into direct discrimination.

3. McCarthy, J., Chaplin, E., Underwood, L., Forrester, A., Hayward, H., Sabet, J., ... & Murphy, D. (2015). Screening and diagnostic assessment of neurodevelopmental disorders in a male prison. *Journal of Intellectual Disabilities and Offending Behaviour*, 6(2), 102-111.
4. albot, J. (2008). *Prisoners Voices*. Prison Reform Trust, London.
5. See footnote 3
6. Bradley, K (2009). *The Bradley Report: Lord Bradley's Review of People with Mental Health Problems or Learning Disabilities in the Criminal Justice System*.
7. Gormley, C. (2022). The hidden harms of prison life for people with learning disabilities. *The British Journal of Criminology*, 62(2), 261-278.
8. See footnote 4.
9. Crewe, B. (2015). Inside the belly of the penal beast: Understanding the experience of imprisonment. *International Journal for Crime, Justice and Social Democracy*, 4(1), 50-65.

sentence or sentence-plan is not presented to prisoners in a way that they can understand, a sense of 'powerlessness' translates into direct discrimination.

A recurrent theme throughout the literature is the inaccessibility of prisons 'paper-based regimes' which relies on written applications to make food choices, arrange visits, lodge complaints, purchase from the prison canteen.¹⁰ Further, when an individual with possible learning difficulties was interviewed, he stated: 'Before my brother came, I just used to tick it and hope for the best. I knew 'a' was sandwiches, so I lived off sandwiches. The officers won't fill your menus out, they say just ask a prisoner.' This is particularly poignant as it highlights one of the most basic rights in prison, the ability to make your food choices.¹¹ This further highlights the power a prison regime has over people to undermine their autonomy and prohibits them from making decisions about their own lives. The literature points to the structural inaccessibility of the system for neurodivergent prisoners. They are subjected to normative expectations in making requests without the diversity of needs being considered and access to information in an accessible format. Without these adjustments being met, daily life can become challenging for neurodiverse prisoners who face oppression through 'daily denials'. This deeply entrenched structural discrimination has the potential to leave neurodivergent prisoners without access to their basic rights in prison, but also force them into risky social relationships and social exclusion.

Mental health is also a key concern as literature reflects that neurodivergent prisoners have a greater propensity to mental health problems such as psychosis, anxiety, depression, personality disorder and thoughts of suicide and self-harming behaviour that neurotypical

prisoners.¹² A study in 2019 found that of the 87 prisoners who screened positive for neurodevelopmental difficulties, 69 had concurrent mental health issues.¹³ In addition, it was found that 44 per cent of prisoners who had screened positive on The Learning Disability Screening Questionnaire (LDSQ) had a current mental health problem. Of this group, 25 per cent had thought about suicide in the last month and 63 per cent had attempted suicide in the past.¹⁴ These are significant statistics across two separate studies, revealing that this group of prisoners are a disproportionately vulnerable in terms of having concurrent mental health difficulties. Despite the principle of 'equivalence of care' in prison medicine, it is understood that mental health services 'are not adequate', there is a high proportion of prisoners with unmet need for treatment.

The behaviour of neurodivergent prisoners is often perceived by operational staff as 'difficult'.¹⁵ Despite a large population of neurodivergent prisoners, there is only a brief mention of neurodiversity in initial prison officer entry level training (POELT). Staff need to be trained in identifying and interpreting different behaviours and being able to adapt to these, ensuring reasonable adjustments are made.¹⁶ This is consistent with a study which found in their survey that most staff said they were 'not very confident' on supporting prisoners with learning difficulties and disabilities, with no staff involved in the survey responding they were 'very confident' either. These staff identified the main obstacles to providing support as shortages in resources, staff training and awareness. It was noted that staff attempted to adjust where they could — mainly around taking more time with individuals that needed it.¹⁷ The amount of knowledge you have about neurodiversity can affect the way staff respond to and

Understanding of the prisoners' various conditions, found them challenging and their behaviour challenging, whereas the staff with more information, saw this behaviour as part of the prisoners' formation.

10. See footnote 7.

11. See footnote 4.

12. Crocker, A. G., Proki, A., Morin, D., & Reyes, A. (2014). Intellectual disability and co occurring mental health and physical disorders in aggressive behaviour. *Journal of Intellectual Disability Research*, 58(11), 1032-1044.

13. McCarthy, J., Chaplin, E., Forrester, A., Underwood, L., Hayward, H., Sabet, J., & Murphy, D. (2019). Prisoners with neurodevelopmental difficulties: Vulnerabilities for mental illness and self harm. *Criminal behaviour and mental health*, 29(5-6), 308-320.

14. Chaplin, E., McCarthy, J., Underwood, L., Forrester, A., Hayward, H., Sabet, J., & Murphy, D. (2017). Characteristics of prisoners with intellectual disabilities. *Journal of Intellectual Disability Research*, 61(12), 1185-1195.

15. Criminal Justice Joint Inspection (2021) Neurodiversity in the Criminal Justice System: A Review of Evidence

16. Kirby, A., & Saunders, L. (2015). A case study of an embedded system in prison to support individuals with learning difficulties and disabilities in the criminal justice system. *Journal of Intellectual Disabilities and Offending Behaviour*, 6(2), 112-124.

17. Loucks, N., & Talbot, J. (2007). *No one knows: identifying and supporting prisoners with learning difficulties and learning disabilities: the views of prison staff in Scotland*. London, UK: Prison Reform Trust.

interact with a prisoner. Further, research has found that officers who had a lesser understanding of the prisoners' various conditions, found them challenging and their behaviour challenging, whereas the staff with more information, saw this behaviour as part of the prisoners' formation. Thus, this awareness allowed them to manage their emotional reaction to a prisoner.¹⁸ This is important as it would aid the formation of a strong working relationship between prisoner and officer. Lack of staff training and knowledge has clearly been understood to be an issue over the past decade, yet there is a dearth of literature around successfully adapting the prison setting to be inclusive for the neurodivergent population.

Recommendations

In this section, five recommendations are made identified by reflecting on the main themes of the literature review. It is recognised that due to the breadth of the term neurodiversity, these recommendations are generalised, there is no one-size fits all intervention or adaption. The impact of estate-wide adjustments such as easy-reads, and communication could have little impact without a person-centred care plans and appropriate support with individualised communication needs. Crucially, an effective screening tool is needed in order to understand what specific needs individuals have and to start gathering data to make a more targeted response.

1. Screening

A common screening tool which is implicated across the whole prison-estate should be used. The screening tool should identify both the challenges and strengths of the person, contextualised within the prison environment. There have been pockets of good practice identified within the current prison estate. HMP/YOI Parc uses the 'Do It Profiler' a modular computer system, which screens for neurodiversity. At HMP/YOI Parc they supplement this with a basic educational skills test and an assessment by a learning disabilities nurse. The Do-It Profiler can provide staff

with care and support strategies which are 'written to be able to be implemented in line with the Five-Minute Intervention (FMI) approach'. Producing a strategy for staff is a key deliverable for a screening tool, without which the tool would not improve the outcome of the prisoners' experience. It is therefore particularly important that the Do-It Profiler assimilates to FMI (a strategy which teaches officers to turn conversations into interventions) as it reduces the amount of new training needed. The Do-It Profiler will offer advice for every new profile, therefore developing staff knowledge on successful adaption approaches over time. Another success HMP Parc is the way the Do-It Profiler is incorporated into the induction process. Prisoners will complete the assessment on the Do-It

Profiler in the first 48-hours on the induction unit, with prisoner Peer Support Mentors on hand to support the process if needed. This is important as it mitigates the problems of self-identification in reception, which is a potentially very stressful and emotional environment, thus helping to identify more prisoners with support needs at earlier stages. This reflects recommendations in previous reviews, which emphasise that effective screening tools need to improve the rates at which we identify support needs.¹⁹

2. Care Planning

Person-centred care plans should be created with a joined-up approach between residential, healthcare and education staff. Effective screening should identify the needs of neurodiverse prisoners and reveal areas of day-to-day life which may need adapting to ensure its accessibility. Individual Care Plans could be an effective way to ensure that neurodiverse prisoners needs are understood and being met through any reasonable adjustments. Whilst generalised adaptations are useful, care plans are an example of how prison staff can ensure a person-centred approach. A care plan would ensure individualised support is given to neurodiverse prisoners by advising staff on how best to support them — e.g., making allowances such as showers outside of allotted association time. This exhibits an approach which looks at the 'whole-person' rather than the 'offender' which can help the development of positive

Producing a strategy for staff is a key deliverable for a screening tool, without which the tool would not improve the outcome of the prisoners' experience.

18. Cooke, E., Stephenson, Z., & Rose, J. (2017). How do professionals experience working with offenders diagnosed with personality disorder within a prison environment?. *The Journal of Forensic Psychiatry & Psychology*, 28(6), 841-862.
19. Bradley, K (2009). *The Bradley Report: Lord Bradley's Review of People with Mental Health Problems or Learning Disabilities in the Criminal Justice System*.

self-identity. This is compatible with existing literature on desistance which emphasises the importance of the professional relationship as a powerful 'vehicle for change', enabling self-realisation and personal growth.²⁰ Care plans are being used in the prison estate; however, these are generally 'owned' by mental health services, often not shared with residential staff and at times, prisoners themselves were not aware of their care plan. This contradicts a person-centred practice which is based around skilled 'interpersonal processes, which focus on the need to understand an individual's needs, perceptions, and motivations in life. Some exceptional practice is being seen at HMP/YOI Parc, who have implemented 'Supported Living Plans' (SLP) for those with additional needs. SLP's are a means of information and supporting residential staff in appropriately caring for neurodiverse individuals. An SLP can be opened by any member of staff, but healthcare input is always required, and an initial assessment is made by a Learning Disabilities Nurse. Residential staff are the 'owners' of the SLP as the highest level of interaction with prisoners and can therefore best identify the individuals needs for additional support, but they are supported by specialist areas such as health, learning and skills. This exemplifies a joined-up approach to care planning which puts the neurodiverse prisoners' needs at the centre. Where Care Plans have been successful in residential and hospital settings, the approach ensures that the voice of the resident themselves is consistently involved to ensure that care is matched. Care planning in prison should place the neurodiverse prisoner and their voice at the centre, with the residential staff 'owning' the plan with the input of healthcare staff and ideally a Learning Disability Nurse.

3. Easy Reads

Easy Read alternatives to all applications, to be co-produced with neurodiverse people. These should be homogenous across the prison-estate and supported by staff training for individualised needs. One of the key themes throughout the literature review was the inaccessibility of prison structures. This recommendation focusses on creating accessible

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information which could be rolled-out throughout the prison estate to ensure continuity across a prisoner's journey through different estates. Accessible information aims to modify the content and the method of delivery so that the meaning is understandable for neurodivergent people. Accessible information promotes active participation and allows neurodiverse prisoners to be self-determining (where possible) within the custodial environment. In order to make the 'paper-based regime' more accessible, the prison estate could implement 'Easy Reads'. These are characterized by plain language, simple layout and format and the use of images to illustrate key messages in the text.²¹ There have already been some successes in using this model within the CJS. The Hampshire Constabulary custody centre developed Widget Symbol custody sheets which explained information about rights and entitlements for people entering custody.²² Staff who used this felt that improved understanding, supporting better relationships whilst preventing escalation of incidents. Service-users felt that this kind of support could have a space within standard procedures and practices as it explained essential information without jargon. One user explained that the symbols meant they 'could understand it straight away and I'd know what was going on'. The British Institute of Learning Disabilities (BILD) was commissioned by NOMS to produce a set of Easy Read Leaflets, however, access to these is limited, and some are now outdated. To ensure that Easy Reads were effective and accessible, it would be important that these were co-produced with neurodiverse people. This approach is integral in reflecting the voice and agency of the neurodiverse community, which in the social model of neurodiversity, foregrounds the capabilities of neurodiverse people, therefore addressing the power imbalance.²³

4. Communication

Staff training in how to adapt their communication to match the needs of the neurodiverse prisoner. Verbal communication is another central element of access. It gives an individual autonomy and can open opportunities for learning, mutual support and being

20. McNeill, F. (2006). A desistance paradigm for offender management. *Criminology & Criminal Justice*, 6(1), 39-62.
21. Turnpenny, A., Caiels, J., Whelton, B., Richardson, L., Beadle Brown, J., Crowther, T., ... & Rand, S. (2018). Developing an easy read version of the adult social care outcomes toolkit (ASCOT). *Journal of Applied Research in Intellectual Disabilities*, 31(1), e36-e48.
22. Parsons, S., & Sherwood, G. (2016). Vulnerability in custody: perceptions and practices of police officers and criminal justice professionals in meeting the communication needs of offenders with learning disabilities and learning difficulties. *Disability & Society*, 31(4), 553-572.
23. Dowse, L. (2009). 'It's like being in a zoo.' Researching with people with intellectual disability. *Journal of Research in Special Educational Needs*, 9(3), 141-153.

part of a community.²⁴ Prison staff should have awareness and communication training which will enable them to recognise when an individual has a communication difficulty and teach staff to adapt their communication in order to better support these prisoners. It is important for staff to realise that they're behaviour, actions and the way in which they communicate can impact a prisoners' behaviour. Making small adjustments in our approach, e.g., checking for understanding, could impact the outcome of an individual's behaviour. Staff training should highlight how communicational breakdowns in a prison setting can have very real consequences on the lives and sentences of a prisoner. One study demonstrated that prison staff often assume prisoners understanding of jargon and the details of what is required of them, which can leave neurodiverse individuals feeling anxious, frustrated and embarrassed.²⁵ This could also contribute to reoffending, one participant in their study returned to prison after failing to comply to the conditions of his license, which he did not understand. Communication guides could be a useful tool to give to staff; these would highlight simple changes neurotypical staff could make to meet the needs of a neurodiverse prisoner. The prison service could adapt guides that are already in existence, such as the examples beneath which are adapted from Mencap and United Response communication guides.

Interventions

Rehabilitative support in terms of adapted interventions or initiatives to provide holistic, long-term support for neurodiverse prisoners is currently very limited. Studies have shown that there is a correlation between neurodiversity and poor outcomes in rehabilitative interventions.²⁶ This is problematic, particularly for prisoners who must meet specific requirements in their sentence plans in order to progress. It is argued that engagement is a key variable in treatment outcome and prisoners with low intellectual ability have a limited capacity to engage due to 'deficits in cognitive ability.' Under the principle of 'risk, need, responsivity', these interventions are not being delivered in a way in which the neurodiverse prisoner can benefit, therefore it is ineffective through not meeting responsivity. It is recommended that there should be adapted programmes which promote

inclusion of the neurodiverse population in prisons. There have already been some successes in adapting accredited programmes. For example, the Foundation for People with Learning Disabilities adapted the Thinking Skills Programme. Working with voluntary agencies might be one approach that could be successful for future programme adaptations, as it ensures great understanding about the experiences of neurodivergent people and thus adjusts the services in accordance with their needs. There is a need to expand the suite of interventions for neurodiverse prisoners and in doing so it is useful to look at successful frameworks such as the Good Lives Model (GLM).

Conclusion

There is a growing body of literature which demonstrates the potential impact neurodiversity has on prison experience. Reviewing this literature has demonstrated where prison structures fail to consider the needs of the neurodiverse prison population, revealing that they are at a structural disadvantage despite the legal obligation of protection. There are barriers present which affect the daily living of neurodiverse prisoners as well as the ability to engage in sentence plans and purposeful activity. The most concerning outcomes of these barriers are the negative effects on mental health, increased vulnerability and longer sentences. It is an institutional failing of the prison service to not meet their legal obligation to make reasonable adjustments for this overrepresented population of prisoners. Without proper screening, the onus falls on the neurodiverse person to ensure that prison staff understand their needs and then to navigate a prison structure which is not adjusted to meet them. Government reports and bodies have made recommendations which have remained consistent over the past decade demonstrating that there has been little progress made. Although there are some examples of excellence, these are singular and not system-wide which also impacts the consistency of experience across the prison estate. This review began with reference to the remand prison, where it is most important to identify neurodiversity and follow-up diagnosis with personcentred care plans. It is recognised that general recommendations such as improvements to communication and staff training will only be effective when followed-up with person-centred planning.

24. Nind, M., & Seale, J. (2009). Concepts of access for people with learning difficulties: towards a shared understanding. *Disability & Society*, 24(3), 273-287.

25. Houston, S., & Butler, M. (2019). 'More than Just a Number': Meeting the Needs of Those with Mental Illness, Learning Difficulties and Speech and Language Difficulties in the Criminal Justice System. *Irish Probation Journal*, 16.

26. Newberry, M., & Shuker, R. (2011). The relationship between intellectual ability and the treatment needs of offenders in a therapeutic community prison. *Journal of Forensic Psychiatry & Psychology*, 22(3), 455-471.