

Supporting autistic people and people with learning disabilities in prison: Service evaluation and care pathway development

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Health services play a vital role in supporting people in prison who may be autistic or have learning disabilities, and reviewing how these services have been delivered and received has been an area of focus for the National Health Service (NHS).

The first part of this article summarises the findings from a service evaluation conducted by the University of Lincoln in prisons across the Midlands for NHS England. We provide an overview of the four main recommendations which came from this work, illustrated with quotes from some of the people we spoke to in this research. One of our recommendations was the development of a universal care pathway across the CJS which was commissioned by NHS England and conducted by REACH Out. The second part of this article explores the research undertaken to develop a set of universal pathways of care for autistic people and people with learning disabilities across the CJS. A summary of the findings is presented, and elements of the pathways are discussed. The article concludes with recommendations for practice and the implementation of the pathways in the future.

Service Evaluation

NHS England commissioned the University of Lincoln in 2022 to undertake an independent service evaluation across the prisons in the Midlands, specifically to understand if and how the guidelines published in 2021 were being implemented.¹ Fifteen

questions were asked during the review which investigated the prevalence of autism and learning disabilities, the screening and assessment practices, staff training and confidence levels in supporting people, access to support, specialist services and resources, use of medication, and information sharing.

Methodology

Literature review

As part of the evaluation, a review of existing literature was undertaken to understand what was known about support for autistic people and people with learning disabilities and to highlight areas of good practice.² The review included academic articles, His Majesty's Inspectorate of Prisons (HMIP) reports, Independent Monitoring Board (IMB) reports, and documents from relevant organisations including User Voice, Prison Reform Trust and the National Autistic Society. We found that prevalence rates were hard to determine due to varying definitions, recording processes, and issues with diagnoses being in place. Screening and assessments were not completed in a standardised way across the system and there needed to be more staff training to help increase staff confidence in working with autistic people or people with learning disabilities, which was found to be low in most of the literature. Good practice was seen in accreditation from the National Autistic Society but at the time, only three prisons had this. Support and access to specialist services varied but many of the reviewed pieces reported issues in this area and a

1. NHS England. (2021). *Meeting the healthcare needs of adults with a learning disability and autistic adults in prison*. Retrieved from <https://www.england.nhs.uk/wp-content/uploads/2021/09/B0707-meeting-the-healthcare-needs-of-adults-with-a-learning-disability-and-autistic-adults-in-prison.pdf>
2. Rogers, J., Kargas, N., Smith, L., Mason, R., Kusyk, I., & Hogue, T. (2023). *Services for Autistic Adults and Adults with a Learning Disability in Prisons: A Rapid Evidence Review* (Version 2). University of Lincoln.

specialist care pathway for learning disabilities was detailed but this was not the same for autism. Good practice was seen with the introduction of specialist units, but there were few mentions of specialist staff or champions. There was little information published on the use of medication or equitable access to healthcare services, no published information on joint care planning although it was acknowledged this is good practice, and little evidence on information sharing other than recommending this for screening and assessment. The literature emphasised the importance of lived experience when exploring barriers and facilitators to successful support. We acknowledge that the literature surrounding support for autistic people and people with learning disabilities has recently increased following various service evaluations across England and Wales and due to an increased focus on neurodiversity in the CJS. Therefore, the findings from this review may be different if conducted again, with wider search parameters.

Service evaluation

At the time of the evaluation, there were 26 prisons across the Midlands region of England, and of these, 24 engaged in a range of data collection activities including providing prevalence data, completion of a staff questionnaire, and engaging people in prison in focus groups or interviews based on participant preference. In addition, recognising that pathways into and out of prison affect the service people may receive, we circulated questionnaires for pre- and post-prison services including Criminal Justice Liaison and Diversion teams, police custody healthcare providers, the youth justice estate, and probation services.

We gained prevalence data covering the past 4 years from 22 out of the 26 prisons. We received 175 responses to the prison staff questionnaire covering 23 establishments, and 16 responses from the pre- and post-prison services. Sixty-six people in one of the 15 prisons visited joined one of 14 focus groups, and 29 people took part in one-to-one interviews. The people in prison who took part represented a range of gender

identities, ages, ethnicities, and time spent in prison, and reported autism, learning disabilities, or a combination of both alongside other mental health and neurodivergent traits. Full details of the review can be accessed in the published report or in the summary videos for easy access.^{3,4}

Findings and recommendations

A large amount of data were collected throughout this review, with the lived experience of both people detained in prison and staff working in them central to informing our findings and recommendations. We developed four core recommendations from our findings.

Recommendation 1: Develop a universal care pathway

Many people in prison felt the current support for autism and learning disabilities was lacking, and when comparing it to the community or other settings, they noticed the difference:

'If you struggle outside of prison, additional support is given. In prison, you're seen as being disruptive, you get punished or kicked off the course or IEP'd.⁵ It makes

you frustrated. You get punished for having additional needs, for 'being born a certain way' (Man in prison).

A lack of knowledge or joined up systems of working was perceived as a barrier for providing people with support they may need:

'People with LD and autism do not appear to have many reasonable adjustments made at court' (Pre or Post prison staff).

The data gathered suggested that a universal care pathway that sat across the whole of the CJS was needed. This care pathway would help to embed good practice and support with recording prevalence,

...a specialist care pathway for learning disabilities was detailed but this was not the same for autism.

3. Kargas, N., Mason, R., Smith, L., Rogers, J., & Hogue, T. (2023). *Independent review of services for adults with a learning disability and autistic adults in Midlands prisons: Report of findings for NHS England* (Version 2). University of Lincoln.
4. University of Lincoln. (2023). Meeting the healthcare need of adults with a learning disability and autistic adults in prison [Video]. YouTube. <https://www.youtube.com/watch?v=VhllrqjwSdU>
5. IEP'd refers to a previous Incentives and Earned Privileges scheme used in prisons in England and Wales, now replaced with an incentive scheme that has various levels depending on behaviour. This includes abiding by rules, taking part in work or other activities, working towards rehabilitation, and helping others. Examples of incentives include additional visits, more time out of their cell, and being able to spend more of their money. People in prison move up or down 'levels', depending on their behaviour.

facilitate the completion and sharing of screening and assessment outcomes, development of care plans which follow the person through the system, and allow the application of reasonable adjustments. This pathway would facilitate not only the sharing of information but improve organisation of and efficiency in the continuation of care, planned across multiple areas of the CJS and involving a range of appropriate agencies across these stages to facilitate multi-professional working and reduce duplication of work:

'I think it needs to be a more holistic approach. Relevant staff in these departments should be trained in valid tools and generally staff should have a better understanding of who to contact if they think someone should be screened. Awareness training should be provided for all staff so that they are better able to identify traits of autism. Screening/ assessments should also be shared more widely, for example on Nomis⁶. Information of this nature should be accessible to all' (Prison staff).

Recommendation 2: Enhance staff training

Staff working in the prisons, across various roles and organisations, told us they wanted additional training to help them best support neurodivergent people and raise their confidence in doing so. This included training in communication skills, recognising signs and behaviours associated with neurodivergence, how to work positively with behaviours, gaining consent particularly for information sharing reasons, how to make reasonable adjustments, how to carry out screening, and to understand what support is available from other departments or services. Co-produced training with people who are autistic or have learning disabilities was suggested to ensure the lived experience and real-world implications are at the forefront of discussions. Some of the people detained in prison believed that staff needed to want to care about the people they supported, so suggested training needed to also include empathy and compassion:

'As far as I am aware, there is no training for us specifically in this area or around what to do if the screening flags a potential concern' (Pre or Post prison staff).

'How to manage emotions, manage/set expectations, education around diagnosis, being consistent, keeping things simple, repetition' (Prison staff).

'Staff can learn through courses, through what reps say, through care plans and through their own research but it takes time and they need to care in the first place' (Man in prison).

Recommendation 3: Improve information sharing

Information sharing was found to be a significant barrier to providing joined up care and support for people. This included information from community support services into the prison and vice versa, but also the sharing of information between staff within a prison, with issues arising mainly due to working for separate organisations (such as healthcare, education, and His Majesty's Prison and Probation Service (HMPPS)). Recommendations for improvement included helping people in prison understand what they could or could not consent to in relation to information sharing.

'Not enough training given to enable information sharing of what we can/can't share or appropriate to share' (Prison staff).

'But obviously, they get in touch with your GP, well that's if they want to share your information. But it's not down to you but it should be down to you if you want to share it. So they should send a consent form to say, are we allowed to share your needs and everything with the prison you're in' (Man in prison YOI).

This recommendation would be integral to the operationalisation of the universal care pathway and sharing of screening or assessment outcomes and care plans. Understanding that this may be a significant issue to overcome, we suggest that a standardised process for regular multi-agency meetings to review people on the universal pathway may be a suitable compromise and was seen as good practice in some areas.

'Communication between [Criminal Justice Liaison and Diversion], Probation, Courts and police — ensure all the information is available to one another appropriately. Multiagency meetings' (Pre or Post prison staff).

Recommendation 4: Resources

Many of the good practice examples we heard about in our review demonstrated the positive impact adequate resources could have. Conversely, where

resources were not available, this had a negative impact on the person needing support:

'There [are] limited resources [for] adapted programmes which can address risk. This means men are stuck in prisons and not able to progress' (Pre or Post prison staff).

'We get into disputes with them over things like asking for headphones to make us feel calmer and we're told we can't have them. It's impossible to get anything authorised' (Woman in prison).

Resources included specialist support services as well as staff, including champions, peer-led initiatives (PLI), and neurodiversity leads in HMPPS staff groups, healthcare, and education. This was due to the perceived positive impact the new Neurodiversity Support Manager roles⁷ were having in some establishments at the time of the evaluation. We suggested that a resource for supporting PLIs, such as providing a framework or standard operating procedure, would also help due to having seen a proactive PLI in action who helped facilitate a large focus group, ensuring everyone's voice was included. In addition to services and staff, having resources for staff training, tools for screening, and resources for making reasonable adjustments (for helping with sensory sensitivities, educational needs, specialist interests, or adapted programmes) would be welcomed.

'Consistency, structure, smaller wings to reduce noise and becoming overstimulated, input from trained staff, accessible interventions, care plans where appropriate, dedicate groups to spend time with peers' (Prison staff).

Development of a Universal Care Pathway

We were invited by NHS England to present these findings at a Midlands Learning Disability and Autism

event. The event hosted 125 practitioners from a range of professions and roles who were actively invested in supporting neurodivergent people in the CJS. Presentations included the findings from our review and that of a similar one conducted in the young person's estate by the Council for Disabled Children. NHS England summarised the findings from both reports into 10 recommendations and two providers were commissioned to action three of these; to create a universal neurodiversity care pathway across the CJS, to develop a neurodiversity training package, and to provide a solution to sharing neurodiversity information across the CJS. The event demonstrated the interest people have for supporting neurodivergent people in the CJS across a range of professionals and roles, and introduced the work from REACH Out (discussed in the next section).

REACH Out were commissioned by the NHS-England (Midlands) Health and Justice Team to develop consistent, best practice pathways for autistic people and people with learning disabilities across the whole CJS. The pathways, developed between September 2023 and April 2024, were required to meet the needs

of children and adults across the East and West Midlands and aimed to structure service delivery across the CJS to provide standardised and high-quality care for autistic people and people with learning disabilities in contact with the CJS.⁸

The design project had five stages:

1. Review of the literature
2. Engagement of people with lived experience in co-production of the pathway
3. Engagement of key organisations
4. Focus groups to finalise universal pathways
5. Accessible pathway development with a visual designer.

Method

Relevant organisations were identified by creating a map of organisations involved in meeting the needs of autistic people and people with learning disabilities in the CJS in the Midlands, such as police, prison

6. NOMIS (National Offender Management Information System) is a centralised IT system used by prisons and probation to record information about people in prison / on probation.

7. Neurodiversity Support Manager roles were rolled out in prisons across England and Wales between 2021 and 2024 to help improve the experiences of neurodivergent people in prison through creating a whole-prison approach to neurodiversity.

8. Please contact author Dr. Sian Allen for details on the project and care pathways as these were not publicly available at the time of publication: Sian.Allen@covwarkpt.nhs.uk

custody, probation, and health services. A total of 148 staff with relevant experience and expertise attended workshops to discuss existing pathways and how to adapt and improve these for autistic people and people with learning disabilities in the CJS.

People accessing the services for whom the pathways would be for were contacted through existing networks of autistic people and people with learning disabilities, and those who were interested in participating in the project provided informed consent and were paid for their time. Eight people, four men, two women and two young people (both male) completed the service user journey mapping, where interviews about their experience of the CJS were conducted. Journey mapping allowed people with lived experience to describe their experience of the CJS, including relevant 'touch points' of contact with the CJS where interactions/interventions took place (whether positive, negative or neutral). It aimed to capture their lived experience in a visual map (produced with them during the sessions) to show their journeys through the system. Once journey maps were produced collaboratively, common themes were then identified by the project team.

Data from the literature review, the co-production stage, and from staff engagement was synthesised to produce new draft pathways, which included what works in existing pathways and new additions. Some of the new additions were based on existing pockets of innovative practice that was not currently generalised across the system. The final pathways were split into four sections, which could then be combined to form an interconnected complete pathway:

1. Police and the Courts
2. Prison custody
3. Secure hospital
4. Community release.

There was not necessarily a linear pathway for all individuals within the CJS, because people move from child to adult pathways and may 'loop' around parts of the pathway on multiple occasions. Separate pathways were developed to cover the journey through the CJS for children. The data indicated that many of the touchpoints and necessary actions were similar for male and female service users and therefore, instead of

developing gender-specific pathways, specific needs of women and girls were noted in change points and on the final pathways.

These newly designed pathways were then reviewed by people with lived experience and staff with relevant experience and expertise to produce the final pathways. In addition to the developed pathways, visually accessible versions were also created with a visual practitioner, and further developed with people with lived experience. The visually accessible pathways are available as stand-alone documents.⁹

Findings

There was not necessarily a linear pathway for all individuals within the CJS, because people move from child to adult pathways and may 'loop' around parts of the pathway on multiple occasions.

The final pathways have been developed, and the NHS-England (Midlands) Health and Justice Team are currently reviewing how these could be operationalised moving forwards.

The project identified that peer-led initiatives are necessary to improve peoples' journeys, and that autistic people and people with learning disabilities with lived experience of the CJS should be involved at all stages of pathway development and implementation. The importance of a consistent assessment approach was highlighted, and a screening and assessment flowchart was designed to guide this process. There are multiple opportunities in each pathway to intervene effectively, offering

appropriate screening and assessment, making reasonable adjustments and improving multiagency working.

Below, quotes from autistic people and people with learning disabilities who co-produced the pathways by sharing their lived experience of current pathways are included. Five key themes were identified from the data and these themes were built into the final pathways.

1: Communication with people involved with the criminal justice system: Information should be presented in a way that the person understands based on their individual communication needs.

'I had some support with understanding what would happen in court... given easy read documents, they told me what would happen... I knew what to expect'(Adult man).

9. Please contact Dr Sian Allen for access: Sian.Allen@cowwarkpt.nhs.uk

Information should be presented at multiple points in the pathway, as needed, and should be given at the right time. One person reported that in a police interview, them knowing about his neurodivergence really helped:

'The staff didn't rush, said they could give me more time to get things straight [and that others] drew out the caution with words and pictures, helped me a lot, was simple for me to read' (Young man).

2: Having the right support: Every person should receive the right support for them, depending on their needs and should feel safe and cared for.

'I had an officer who looked after me, she stood up for me and cared for me...Felt they cared for me and looked after me and calmed me down after I had a meltdown in court' (Adult, female).

This may include multiagency planning and support, requiring partnership working, peer support and well-planned transitions, with the person at the centre. Appropriate reasonable adjustments should be made, and any adjustments should be reviewed as the person moves through their journey.

'It's pretty cool at the AP [approved premises], [they] took me food shopping, showed me around the AP. Staff understand I have something about me that means I find it hard being with people' (Adult man).

3: Processes: Clear guidelines for screening and assessment are needed given the wide variety of screening tools that are currently used within the CJS, with guidance about how to use validated tools to conduct screening and assessment and when (such as including multiple opportunities for screens). It was not uncommon for screening for autism to have not taken place.

Assessments should be based on NICE (National Institute for Health and Care Excellence) guidelines. Staff should work with the person to develop a psychologically underpinned formulation of their needs

and behaviour to inform recommendations for reasonable adjustments and care planning.

'No one ever asked me if I had autism or asked why I was struggling. No one thought about autism as a possibility' (Adult woman).

Peoples' physical health needs should be met and seen as linked to their sensory needs as well as mental and physical wellbeing. Services should develop appropriate information sharing guidelines and systems to enable the safe and secure transfer of necessary information to avoid unnecessary repetition of assessments and ensure that accurate and up to date information is handed over. All services should comply with guidelines and relevant policies and ensure that quality assurance is truly embedded.

4: Resources: Staff should be well trained in how to work with autistic people and people with learning disabilities within the CJS, and should have access to ongoing mentoring and support.

'No help to understand or develop skills in managing overwhelm and escalations... was seen as a 'fighter' rather than anyone trying to understand' (Adult woman).

Employing specialist staff, such as learning disability nurses, Speech and Language Therapists, Occupational Therapists and psychologists, and developing a specialist team would allow knowledge and expertise to be generalised within systems and to improve outcomes. Whilst some of the care principles can be undertaken within existing services, it is noteworthy that the project found, in line with the above service evaluation, that resources are necessary to provide many of the care principles and that systemic and multi-systems changes would be required to develop the pathways outlined.

5: Environment: Often CJS environments are chaotic and stressful. Reducing sensory stimulus, making environmental changes such as providing quiet spaces and low stimulus areas, and reducing unnecessary transitions (such as between wings in prison) may support people to feel safe and to manage their sensory needs.

Staff should work with the person to develop a psychologically underpinned formulation of their needs and behaviour to inform recommendations for reasonable adjustments and care planning.

'Overloading noise, when lots of people talking at once it's like my heads like a balloon going to burst, I have to move away from there' (Adult man).

'Sometimes [prison custody] was very noisy. It was overwhelming, made my thoughts confused, I couldn't tell (what) was real and what wasn't' (Adult man).

In addition to the pathways produced, the themes and subthemes that emerged from the data and relevant change points have also been described and included in the main report.

Next Steps for Supporting Autistic People and People with Learning Disabilities in Prison

Based on the evidence from both pieces of work presented above, the care pathways have been developed but now need to be tested in practice. There are clear opportunities to implement and develop this multi-agency pathway across systems to achieve increased consistency and better outcomes for people, greater collaboration between agencies, and to develop skills and knowledge in staff. The pathways need to then be reviewed and refined to support ongoing development.

Whilst both pieces of work were commissioned by health services, for the recommendations of the projects to be achieved, a whole-systems approach will be required involving collaboration between health, HMPPS, His Majesty's Court and Tribunal Service, police, and social care. Given there is a cross-government working group focusing on this topic, established by the Ministry of Justice,¹⁰ it would be of benefit for this to be linked with their work moving forwards.

An overarching point is that autistic people and people with learning disabilities with lived experience of the CJS should be involved in developing and evaluating services. They should be included in developing peer support networks and should be employed within services to capture the reality of their lived experience. Partnering with pre-existing services that champion and amplify the voices of neurodivergent individuals in the CJS may be a way of

ensuring that people are included in all aspects of service design and delivery.

There were key recommendations highlighted across the reports to help implement and embed a universal care pathway and develop the support for autistic people and people with learning disabilities in the CJS. These included:

1. A diagnosis of autism and/ or learning disability should not be necessary to be on a learning disability and autism pathway. Access to autism and learning disability pathways should be needs-led and underpinned by a high quality, evidence- based psychological formulation of need rather than relying solely on diagnosis, especially as many people in the CJS are undiagnosed.

All relevant parts of the CJS should review the themes and change points on the pathways and produce individual guidance on how to implement these change points within services. To facilitate this, a self-audit tool for services could be developed. The development of a co-produced operational toolkit for practitioners could also support services to operationalise the evidence-based pathways.

2. To work with commissioners to develop a specialist forensic learning disability and autism team of clinicians to provide support to CJS services across the pathway in:

- (a) Developing psychologically underpinned formulations
- (b) Providing diagnostic support in complex cases
- (c) Conducting case consultation
- (d) Providing advice on reasonable adjustments
- (e) Providing advice on managing risk taking to account for neurodivergence.

Ideally, such a team would be jointly commissioned to work across the CJS pathway, including collaboration with health and justice teams, youth justice teams, police, courts, prisons, education, and social care.

3. For services to agree on which screening and assessment tools are most appropriate to use within the CJS for autism and learning disability. Specific consideration needs to be

There are many pockets of good practice currently and some of the necessary accessible documentation has already been created by services.

10. Autism All-Party Parliamentary Group details can be found here: <https://www.parliament.co.uk/APPG/autism>

given to the appropriateness of tools considering age, sex, race, culture, language spoken and level of language comprehension, and cost of measures. Guidance on available measures, based on current knowledge, for use with children and adults are available within the final project and in an additional review of the available tools.¹¹ In addition, health professionals should conduct the assessments for autism and learning disability and should receive training in using the appropriate tools as recommended by the NICE guidelines.

4. Develop a professional network for staff support and staff development for those working with neurodivergent individuals within the CJS. Ideally this network would have a clear facilitator, lead agency and lead professional/facilitator, and named, accountable professionals represented from each agency.
5. Develop a shared resource of easy read and accessible information (including videos, lived experience stories, easy read documents and links to relevant websites/ information) for autistic people and people with learning disabilities for use across the CJS pathway. There are many pockets of good practice currently and some of the necessary accessible documentation has already been created by services.
6. Develop a directory of services, across geographical areas and the different areas of the CJS and stages of the pathway. This directory would require quality assurance

measures to be in place and would include inclusion and exclusion criteria of each service; location of service; contact details; opening hours; clear referral process and links to any referral forms, including where these should be sent. An accessible version of this, with information relevant to autistic people and people with learning disabilities should also be compiled and made available.

Conclusion

Both pieces of work heard the experiences of autistic people and people with learning disabilities who had been involved in the CJS and noted the need for improvements in the support and care they receive. Staff who are supporting them are instrumental in this and investing in training would help to facilitate positive interactions that help build effective supportive relationships between people working and involved in the CJS. The provision of resources including physical items to manage sensory sensitivities, environmental changes such as residential wings for neurodivergent people, system wide screening tools, and staff training packages where staff are supported with adequate time to engage, would help encourage the good practice that has been seen across areas become more widespread. Having platforms to speak about and share the positive initiatives that areas have would help the move to a more system-wide approach to supporting neurodivergence. Co-production must be at the centre of all this work to ensure the experiences we heard are informing how to move forward.

11. Ramachandran, R., Kargas, N., Smith, L., Mason, R., Rogers, J., & Hogue, T. (2023). *Assessments and Screening Tools for Autism and Learning Disability in the Criminal Justice System: A Rapid Evidence Review* (Version 1). University of Lincoln.