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Citation for final published version:

Chaplin, Eddie, Rawat, Amina, Perera, Bhathika, McCarthy, Jane, Courtenay, Ken, Forrester, Andrew, Young, Susan, Hayward, Hannah, Sabet, Jess, Underwood, Lisa, Mills, Richard, Asherson, Philip and Murphy, Declan 2022. Prisoners with Attention Deficit Hyperactivity Disorder: co-morbidities and service pathways. International Journal of Prisoner Health 18 (3), pp. 245-258. 10.1108/IJPH-03-2021-0020

Publishers page: http://dx.doi.org/10.1108/IJPH-03-2021-0020

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Prisoners with Attention Deficit Hyperactivity Disorder: Co-morbidities &

Service Pathways

Abstract

Purpose

Effective diagnostic and treatment pathways for ADHD are needed in prison settings due to

the high prevalence of ADHD and comorbidities in the prison population.

Methodology

Two studies were carried out in two prisons in London. Firstly, data was collected to

understand prevalence of ADHD and the comorbidities. The second study used quality

improvement (QI) methodology to assess the impact of a diagnostic and treatment pathway

for prisoners with ADHD.

Findings

22.5% of the prisoners met the diagnostic criteria for ADHD. Nearly half of them screened

positive for autism with a higher prevalence of mental disorders amongst prisoners with

ADHD compared to those without. The QI project led to a significant increase in the number

of prisoners identified as requiring ADHD assessment but a modest increase in the number of

prisoners diagnosed or treated for ADHD.

Originality

High rates of neurodevelopmental disorders in the prison population needs to be addressed.

Despite various challenges, an ADHD diagnostic and treatment pathway was set up in a prison

using adapted QI methodology. Further research is needed to explore the feasibility of

screening for ADHD in prison and examine the effectiveness of service delivery models.

Keywords; ADHD, Prisoners, Comorbidities, Service pathways, Neurodevelopmental

Disorders, Quality Improvement

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BACKGROUND

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder with a world prevalence of 5.9% in youth and 2.5% in adults (Farrone *et al.*, 2021). 40% to 60% of children diagnosed with ADHD have symptoms that persist into adulthood with significant psychosocial impact, comorbidity, inadequate healthcare access and impacts on society (Faraone *et al.*, 2021, Volkow and Swanson, 2013). There is well-established evidence that ADHD is associated with criminality (Barkley *et al.*, 2004, Mannuzza *et al.*, 2008, Mohr-Jensen *et al.*, 2016, Satterfield *et al.*, 2007). A meta-analysis found that the prevalence of adult ADHD in incarcerated populations was 25.5% (Young *et al.*, 2015). A study of female prisoners in the UK found that 41% of female prisoners met the diagnostic criteria for adult ADHD with high levels of impairments secondary to ADHD (Farooq *et al.*, 2016).

Studies have shown an association of ADHD with poorer outcomes for people within the criminal justice system. These include higher arrest rates, convictions, incarceration, aggression in prisons, and poor engagement with probation (Mohr-Jensen *et al.*, 2016, Young *et al.*, 2015). Studies have also found positive outcomes in offenders receiving treatment for ADHD. Using data from the Swedish National Register, Lichtenstein *et al.*, 2012, investigated over 25,000 people with ADHD who received medication to treat ADHD. They reported a significant reduction of 32% in the criminality rate for men and 41% for women when using medication to treat ADHD compared to periods when not receiving medications. Apart from the individual benefits of improved quality of life for those prisoners treated for ADHD, there are other important and wider societal implications in developing a structured pathway to identify prisoners with ADHD and offer treatment.

The UK Adult ADHD Network (UKAAN) consensus paper discusses various strategies to screen, diagnose, and provide interventions to prisoners with ADHD (Young *et al.*, 2011). The consensus statement also identified barriers within the prison and criminal justice system, such as inadequately trained mental health staff, lack of appropriate screening and diagnostic tools, availability of appropriate multimodal interventions for the treatment of ADHD in prisoners (Young *et al.*, 2018). Furthermore, though NICE guidelines state that prisoners should be assessed and treated for ADHD, they only provide recommendations on managing ADHD in the general population with no definitive guidance on a pathway that will work in a custodial setting.

Despite the evidence for a significantly high prevalence rate of ADHD in the prison population and the effectiveness of treatment, (National Institute of Clinical Excellence Guideline [NG87], 2019) our literature search showed there is no published evidence on screening, or diagnostic and treatment pathways for prisoners with ADHD in the UK.

AIMS

In this paper, we describe two studies conducted in two prisons in London, England. In the first study (study 1), the aim was to identify prisoners with ADHD with a focus on describing comorbidity and vulnerabilities of this group of prisoners.

In the second study (study 2), using QI (quality improvement) methodology (Taylor *et al.*, 2013), the aim was to measure the practicability and effectiveness of a specialist ADHD diagnostic and treatment pathway for prisoners. A secondary aim was to identify the barriers to accessing treatment for ADHD in custodial settings.

Reference will be made to the screening and diagnostic strategies used in both studies.

METHODOLOGY

Study 1 describes the methodology to describe the characteristics of prisoners with ADHD in a prison in South London. This was granted ethical approval by the NRES Committee North East – Northern & Yorkshire (ref: 12/NE/0040) – and NOMS approval (ref: 50-12). This study was funded by grants from Guy's and St. Thomas' Charity (Grant Reference (G101019) and St. Andrew's Healthcare, Northampton, UK. Study 2 describes the methodology behind a QI project subsequently carried out to develop and assess the impact of a specialist ADHD diagnosis and treatment pathway in a prison in North London.

Study 1- Approach to Identification & assessing comorbidity

The study took place in a male London resettlement prison with a capacity of 798 prisoners. The researchers approached 378 prisoners, of whom 240 consented to screen for ADHD and subsequent diagnostic assessment if they screened positive. Recruitment took place over a

one-year period. As well as a review of case notes, screening for ADHD was completed using the six item Adult ADHD Self-Report Scale (ASRS-v1.1) (Adler *et al.*, 2006). The diagnosis of ADHD was confirmed using the DIVA 2.0, Diagnostic Interview for ADHD in Adults (Kooij, 2012). The Mini International Neuropsychiatric Interview (MINI v.6.0.0; Sheehan *et al.*, 2010) was used to confirm ICD-10 diagnoses and the presence of suicidality and self-harm. The Learning Disability Screening Questionnaire (LDSQ) was used to screen for Intellectual Disability and the Autism Quotient 20 (AQ-20) was used to screen for autistic traits. Chi-square tests were used to analyse categorical and continuous data, respectively, using SPSS v 22. The study recruitment strategy and information on ethical approval is available in McCarthy *et al.*, 2016.

Study 2 – QI methodology in measuring the practicability and effectiveness of an ADHD Pathway

This study was in a male London prison with a capacity of 1300 with approximately 33,000 movements a year through its reception. An overview of the ADHD pathway for the prison was created based on the NICE guidelines (Figure 1), while taking into account the structure and regime of the prison system in providing health care. Prior to developing the pathway, there was no assessment process for ADHD in the prison. Prisoners with probable ADHD (identified by a previous diagnosis in their medical records) were booked on an ad hoc basis to a general psychiatric clinic. A QI project was developed to measure the effectiveness of the ADHD pathway in identifying and managing prisoners. Data was collected and reviewed on a monthly basis for a year from April 2019, the beginning of the project. Data collected from April 2018 to the end of March 2019 (the pre-QI period) were compared with data collected during the QI period.

{Figure 1 here}

Aim of the QI Project

The aim for the QI project was to develop an effective ADHD pathway and increase the number of prisoners diagnosed and treated for ADHD by 50% in the year from April 2019 compared to the previous year. This was considered to be a specific, measurable and achievable target as per QI methodology. As per QI methodology, factors (or drivers) that would influence the diagnosis and treatment of ADHD in prison settings were identified. They

included 'primary drivers' which had a direct impact on the aim and 'secondary drivers' which had an indirect effect (Figure 2).

Strategies identified to help deliver the aim of the QI project

'Change ideas', or strategies, were then considered to address these drivers. For example, one change idea was to provide ADHD clinic appointment letters to the prisoners. They were delivered directly to them by a staff member. In this way, not only was the prisoner made aware of the appointment but also the reason for it. Another change was to provide training sessions for staff including prison officers, probation staff, accommodation placement staff, chaplaincy, substance misuse support staff, teachers, and trainers. All the drivers and change ideas were mapped out on a driver diagram (Figure 2) to enable the connections between the aim, the drivers, and the change ideas to be easily understood. This then helped to focus on implementing new strategies to deliver the aim of the QI project (Taylor *et al.*, 2013).

{Figure 2 here}

Process of referral to the ADHD service and assessment

Due to the high number of prisoners entering the prison system every day, it was agreed that the criteria for referral to the ADHD service was:

- prisoners with a historical diagnosis of ADHD or conduct disorder (as indicated in their existing clinical records),
- 2. prisoners with no previous diagnosis but who presented with symptoms such as hyperactivity on screening.

For screening, the plan was to use the Brief-BAARS (Young *et al.*, 2016) for its brevity and reliability. Any staff member in the prison was able to make referrals to the ADHD service. The referrals were usually made via the prison computerised system, but also via paper or in person, to the in reach team. The referrals were then discussed in the weekly in reach MDT team to decide if the referral be accepted and booked into the ADHD clinic.

Prisoners who screened positive for ADHD were booked for a full assessment in the joint ADHD clinic, which was staffed by a psychiatrist with special interest in ADHD and a psychiatric nurse. The assessment included a full psychiatric history and an objective assessment using the DIVA-5 (Diagnostic Interview for Adult ADHD; Kooij *et al.*, 2019).

After diagnostic confirmation, prisoners who required medication to treat ADHD were provided with psychoeducation, followed by monitoring in line with NICE guidelines. In the event that medication was declined, not indicated, contraindicated, ineffective, not tolerated, or only caused partial remission, they were invited to a weekly psychosocial support group for people with ADHD.

Data collection and variables measured

Data was collected for a period of 12 months prior to the QI project and then monthly for 12 months during the QI project to assess the effectiveness of the pathway and interventions. The variables that were measured include the number of; i) referrals to the ADHD service, ii) staff trained to assess for ADHD, iii) ADHD clinic appointments (including re-bookings), iv) non attendees to the ADHD clinic, v) prisoners assessed for ADHD, vi) prisoners diagnosed and vii) prisoners commenced on treatment for ADHD. This data was obtained by going through the minutes of the weekly in-reach MDT meeting where all referrals to the team are discussed, looking at the ADHD bookings on the prison computerised system and going through the computerised medical record of each prisoner referred to the ADHD service.

Implementation of 'change ideas'

The QI team met regularly with the wider mental health team to review the data and the pathway. Change ideas were implemented, discarded, or adapted as necessary following each review. A note was made when the change ideas became effective. The plan was to ensure that change ideas were implemented one at a time to more accurately measure their impact on the data. As this process occurred, it was mapped out into PDSA (plan, do, study, act) cycles (Taylor *et al.*, 2013). For example, a change idea was to deliver letters to the prisoners providing an appointment date and explaining the reason for the appointment to decrease rates of ADHD clinic non-attendance. This plan was continued as long as the rate of non-attendance decreased during the study. If the non-attendance rate had not decreased, then the change idea would have been adjusted accordingly. Data were analysed for demand, capacity and flow through the pathway, which then led to the implementation of strategies to overcome existing barriers.

RESULTS

Study 1- Identification & assessment of comorbidity

Of the 240 who participated, 65 (27.1%) screened positive for ADHD. 54 (22.5%) met the diagnostic criteria for ADHD. Of these, 28 had a previous diagnosis of ADHD, 19 (35.2%) of whom were diagnosed in childhood and 9 (16.6%) in adulthood, of these over 80% had combined-type ADHD.

The comparison of prisoners with a diagnosis of ADHD (49) versus those with no neurodevelopmental disorders (ND) (69) represents those with complete datasets for mental health assessment.

Over 60% of the ADHD prisoners were in the 20-29 age group compared to 36% of those with no NDD. The ADHD prisoners were significantly more likely to be white (81.6%, n=40), whereas those with no NDD prisoners were of both black and white ethnicities (44.9%, n=31), (see table I).

{Table I here}

Considering socio-economic factors and educational attainment, ADHD prisoners were more likely to have poorer educational outcomes in literacy and national state examinations (GCSEs). However, they were no more likely to be homeless or unemployed compared to other prisoners (see table II).

{Table II here}

Neurodevelopmental comorbidity

20 (40.8%) prisoners with ADHD screened positive for Intellectual Disability and 24 (49%) with autistic traits. 15 (30.6%) screened positive for both Intellectual Disability and autistic traits.

Mental illness and personality disorder comorbidities

Prisoners with a diagnosis of ADHD had a significantly higher risk of mental health problems compared to prisoners with no NDD. The current rates of mental health problems were ADHD v no-NDD: 31 (63.2%) v 12 (17.4%), (X^2 = (n=118) 28.03, p>001), with lifetime rates of 41 (83.7%) compared to 29 (42%) of those without NDD (X^2 = (n=118) 20.59, p>001). ADHD prisoners were ten times more likely to be diagnosed with antisocial personality disorder,

depression and mania/hypomania than prisoners with those with no NDD. Prisoners with ADHD were significantly more likely to be dependent on alcohol and illegal substances, with over 60% diagnosed as either dependent on alcohol or other illicit substances (see table III).

Risk of self-harm and/or suicide behaviours

ADHD prisoners were ten times more likely in the past month to have thought about self-harm in comparison to the non NDD group, whilst 4 (8.2%) reported having tried to take their life. The ADHD group were significantly more at risk of lifetime attempts with almost two thirds having made an attempt 32 (65.2%) compared to 8 (11.6%) of non NDD prisoners (see table III).

{Table III here}

Study 2 – Rates of Referrals & Assessments: Pre QI & during QI project

Baseline data (pre-QI data for a period of 12 months) and QI data (data for 12 months during the QI project) were collected. The data collected included the number of ADHD referrals and assessments, ADHD appointments offered, non-attendees to clinics, prisoners newly diagnosed, and those commenced on treatment for ADHD (see table IV). Initially data was also collected on the number of screens carried out, however, due to the inconsistency in its implementation and its interpretation, as well as the lack of documentation on the prisoners' medical records, this data was not subsequently collected.

Pre QI Project (April 2018 to March 2019)

During pre-QI period, 45 prisoners were referred to the prison mental health team for ADHD diagnosis and/or treatment. This is much lower than what is expected given the high prevalence of ADHD in the prison population and the average number of prisoners at any time in the prison of up to 1300. Of the 45 referrals, 13 already had a diagnosis of ADHD and were thus for review only. 32 were referred for a full diagnostic assessment. Out of this group, 14 had an ADHD assessment and 13 (93%) were diagnosed with ADHD.

Of those with a positive diagnosis, only 8 (61.5%) were started on treatment. There were various reasons for this, for example prisoners requiring physical investigations such as an

ECG before treatment could be started. Some were released from prison before they were seen again for treatment, while others did not wish to take medication for ADHD as they believed that their symptoms had limited negative impact on their lives.

Looking at the number of appointments, during the pre-QI period 72 prisoners were offered appointments compared with the QI period where 282 were offered an appointment in the ADHD service. The appointments were for both new assessments and reviews of those already diagnosed with ADHD.

During QI Project (April 2019 to March 2020)

During the QI period, 169 prisoners were referred for ADHD assessment (again lower than expected). Out of this group, 51 had ADHD diagnostic assessment. 40 (78%) of 51 prisoners received the diagnosis of ADHD and 25 (62.5%) of those diagnosed with ADHD received treatment. As indicated in table IV, there was an increase of over 200% (from 8 to 25) in the number of prisoners diagnosed and treated for ADHD compared with the previous year. There was an increase of 267% (from 45 to 169) in the number of referrals in the QI period compared to the pre-QI period.

The reasons why those referred for an ADHD assessment did not undergo an ADHD diagnostic assessment (before and during the QI period) include prisoners being released or transferred to another prison prior to their appointment date. This is often the case in a remand prison where the turnover of prisoners is high. Another significant reason is the high rate of non-attendance at the clinic (50%). There are many potential reasons for this and may include prisoners not receiving their appointment slip, the prisoner not understanding what the appointment slip is about, the prisoner having conflicting appointment times, the prison being in 'lock-down' meaning all movements of prisoners are halted or the prisoner simply forgetting about the appointment. As all the prisoners have to attend the clinic holding room at the same time, regardless of their appointment time, even if the prisoner attended the appointment, it was sometimes the case that the prisoner wished to return to his cell as he did not wish to stay in the waiting room.

{Table IV here}

DISCUSSION

What these two studies tells us

To our knowledge there have been no studies describing the implementation of an ADHD pathway in prisons in the UK. Although pathways have been designed for research purposes (Asherson *et al.*, 2019), this has not been done previously for clinical practice. In addition, the findings highlight the high rates of mental illnesses, alcohol dependence and self-harm behaviour in prisoners identified with ADHD. A striking finding was that nearly half of prisoners with ADHD screened positive for autistic traits and 40% screened positive for intellectual disability. These results indicate that this is a complex group of prisoners with multiple comorbidities (McCarthy *et al.*, 2016; McCarthy *et al.*, 2019).

The number of prisoners who underwent a full diagnostic assessment for ADHD in the pre-QI period was 14, while in the QI period, the number of these assessments increased to 51. This parallels with the increase (276%) in the number of referrals received for ADHD assessments in the QI period compared to the pre-QI period. The increased awareness occurred secondary to discussions with the various health members during team meetings in the prison about the ADHD pathway and educational events on ADHD. These events included an academic session at the prison with staff from ADHD services in other local prisons and small group teaching by the psychiatric nurse on screening for ADHD. Also, prior to the QI period patients for ADHD assessments were booked on an ad hoc basis to be seen by a prison psychiatrist (with expertise in ADHD) in a general psychiatric clinic and there was no process for screening for ADHD. During the QI period a more structured method via a service pathway was used to improve the number of referrals and assessments for ADHD. This included a dedicated ADHD clinic run by the prison psychiatrist and a psychiatric nurse.

In the pre-QI period, 8 prisoners were treated for ADHD with medication compared with the following year where 25 prisoners were treated. This is an increase of 212%. It is important to note that not all the prisoners diagnosed with ADHD received treatment for it. This was particularly challenging in the current prison as it was a remand prison, therefore prisoners are often released before being seen again in clinic and thus this presents as a missed opportunity to treat. Though information about the diagnosis could be forwarded to the community GP, often prisoners are not registered, and GPs are highly unlikely to commence

treatment without specialist training. It is likely that because of the nature of ADHD, prisoners would not be connected with local health services.

Challenges in implementing an ADHD pathway in prisons

It is important to review the barriers to creating an ADHD pathway in a prison setting. The initial and most pertinent barrier in receiving referrals for the ADHD service, from our experience working in prison, was the lack of awareness of ADHD symptoms among prison staff (Young et al., 2018). Another theme was the lack of interest or the scepticism amongst both prison and health care staff of ADHD being a valid diagnosis amongst prisoners and one which is treatable in a prison setting. There was also a fear of stimulants used for treatment because of the potential for prisoners to misuse the medication, despite evidence showing that this is not the case (Young et al., 2018). This may have hindered staff training opportunities and may have been the reason for differences in opinion amongst staff on screening for ADHD. Some staff were in support of the idea of screening prisoners for ADHD, whilst some were dubious about prisoners' intentions to get a diagnosis.

Other significant challenges in the ADHD pathway were the high number of prisoners not attending clinic appointments. As seen by the results, the rate of non-attendance at the clinic was 50%. This was observed in both the pre-QI period and during the QI. There are a variety of reasons for this issue, much of it related to the organisational structure of the prison system which determines how the appointment system works and how prisoner movement within prison is carried out effectively and securely. Issues relating specifically to non-attendance in ADHD clinics include the disproportionate rate of illiteracy and intellectual disability as seen in study 1 so the prisoner may find the appointment notice hard to understand, they simply forget the appointment, or misplace the appointment notice (with forgetfulness also being a core feature of ADHD). The study attempted to overcome the non-attendance rates by delivering appointment letters directly to the prisoner. These letters gave a simple explanation of what the appointment was for and what it entailed. As the letters were delivered, a verbal explanation of what the appointment was about was also given. The monthly data indicated that during this period of delivering appointment letters, there was a reduction to 30% in the number of clinic non-attendances, However as the number of

referrals to the ADHD service increased, delivering letters became unsustainable because of the increased workload, and thereafter the non-attendee rates returned to their original level.

Ideally, a prison ADHD pathway would screen all prisoners for ADHD, given that the rate of ADHD is 4-5 times higher in the incarcerated population. However, it was predicted that screening all prisoners would result in a significant increase in the number of referrals for diagnostic assessment of ADHD. Due to the limited number of staff trained to assess for the disorder, it was not feasible to assess all of them. If a waiting list was operated, many prisoners would have left the prison before their appointment time. NICE guidelines recommend that all prisoners are screened for ADHD but in busy prisons, this can be impractical at the point of reception when prisoners enter the prison. High numbers of prisoners enter the prison in the evening, usually from the courts, when they are seen by the reception nurse who screens them for various medical conditions and substance misuse. Prisoners may then be referred to a GP if required. Both have very limited time to see each prisoner coming through. Even if the reception staff agreed to spend a few extra minutes to screen for ADHD, a significant number of prisoners would have been using illicit substances or in withdrawal states making the screen unreliable.

Strengths and limitations

A strength of these studies is the use of the screening and diagnostic interview for ADHD by researchers and clinicians trained specifically in their use thus increasing reliability. Another is the benefits arising from QI methodology, which is designed to be used continuously to further identify barriers and improve services. In prisons, multiple agencies and disciplines are involved in the provision of healthcare services to prisoners. Hence, by ensuring multiagency representation in this study, we were able to both identify and overcome some barriers to service provision in this area.

QI methodologies are likely to help ensure a realistic approach to the development of treatment pathways in complex environments such as prisons. Their inherent flexibility can allow services to consider how challenges can be overcome in real time. However, prisons are institutions that are required to deal with multiple priorities and which have well-recognised

difficulties delivering safe and effective services. This has recently been compounded by the national policy of austerity in England and Wales (Ismail, 2020), increases in rates of self-harm, violence (Slade, 2019) and dual harm, and the reality of the Covid-19 pandemic (Kothari *et al.*, 2020). Additionally, prison regimes often prioritise security over healthcare needs, and given these limitations we found it necessary, at times, to modify the standard QI methodological approach to ensure optimal service implementation.

Another important limitation of study 2 is the overlap of confounding factors and change ideas in practice, making it difficult to ascertain which change idea had the greatest overall impact. Central London prisons are amongst the busiest in the country, and these are complex environments in which operational changes can frequently occur. Some such changes may have influenced the results presented above. For example, prisoners and staff's movements may have been restricted at times for security reasons, preventing screening activities or clinic attendance.

Future recommendations

The results of the studies have several clinical and policy implications for the health service working within the criminal justice system. The high prevalence rates of ADHD in prisoners, together with increased rates of comorbid autistic traits and intellectual disabilities, indicate the need to screen and diagnose for all neurodevelopmental disorders within offender populations. This is in order to understand and respond appropriately to the complex presentation of this group.

To facilitate the screening and diagnosis of prisoners for ADHD, autism and intellectual disability, the inclusion of staff with expertise in neurodevelopmental disorders in prison mental health services is an imperative. Consideration needs to be given whether these services should be integrated within existing mental health in reach teams or be a separate structure with their own funding. This has service design and financial implications on issues such as staffing levels and in particular costs. To convince funders that the costs of implementing such services is worth undertaking it would be necessary to show that the services have an impact in reducing the social and financial burden of people with neurodevelopmental disorders who engage in offending behaviour. Further work can develop

or adapt current ADHD service pathways across prisons by engaging in qualitative studies and long-term quantitative studies in prison on the outcomes of treating prisoners with ADHD. This has been previously described for the development of mental health pathways and services for prisoners with mental illness (Forrester *et al.*, 2018; Forrester and Hopkin, 2019). Qualitative studies are required particularly to understand the barriers in implementing an ADHD pathway in prisons. It would be important, as a baseline, to conduct a survey to gain a more detailed understanding of current ADHD services and pathways in prisons at a national level in England and Wales, and within the other devolved UK nations.

The QI project showed that the main barrier to diagnosing and treating prisoners with ADHD was the process, or rather the absence of process, of screening prisoners for ADHD. Indeed, a core component of the QI project was the recognition of symptoms to facilitate referrals to the ADHD service. Hence, the use of specific neurodevelopmental screening is a future priority and its feasibility and timing should now be submitted to research using randomised or quasi-randomised trials as highlighted by others in the screening of mental illness in correctional settings (Martin *et al.*, 2013). Is it feasible, for example, to introduce such screening at prison reception, alongside screening for a range of other physical and mental health disorders, and alcohol and substance misuse or withdrawal, or would it be better implemented at a later point, but still within the early stages of imprisonment. And what is the relationship between existing screening tools for major mental illness and the need to identify those who present with distinct, or comorbid, neurodevelopmental conditions? Could a screening tool be developed which helps screen for all three neurodevelopmental disorders, one which is both quick to implement but also reliable? In these questions is the next set of likely research priorities.

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