

**McCarthy, JM., et al. Screening and diagnostic assessment of neurodevelopmental disorders in a male prison. *Journal of Intellectual Disabilities & Offending Behaviour***

**Abstract**

*Purpose* The aim of the study was to identify neurodevelopmental disorders and difficulties (NDD) in a male prison. The study used standardised tools to carry out screening and diagnostic assessment of the attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD) and intellectual disability (ID).

*Method* The adult ADHD self-report scale (ASRS), 20-item Autism Quotient (AQ-20) and the Learning Disability Screening Questionnaire (LDSQ) were used to screen 240 male prisoners. Prisoners who screened positive on one or more of these scales or self-reported a diagnosis of ADHD, ASD or ID were further assessed using the Diagnostic Interview for ADHD in Adults (DIVA), adapted Autism Diagnostic Observation Schedule (ADOS) and the Quick Test.

*Findings* Of the 87 prisoners who screened positive for NDD and were further assessed, 70 met the study's diagnostic criteria for ADHD, ASD or ID. Most of those with NDD (51%) had previously gone unrecognised and a high proportion (51%) were identified through staff- or self-referral to the study.

*Value* The study demonstrated that improving awareness and providing access to skilled, standardised assessment within a male prison can result in increased recognition and identification of NDD.

**Keywords** attention deficit hyperactivity disorder; autism spectrum disorder; diagnosis; intellectual disability; prison; screening

**Abbreviations** ASRS, adult ADHD self-report scale; ADHD, attention deficit hyperactivity disorder; A-D, attention-deficit; ADI-R, Autism Diagnostic Interview-Revised; ADOS, Autism Diagnostic Observation Schedule; AQ, Autism Quotient; ASD, autism spectrum disorder; BME, black or minority ethnicity; CJS, Criminal Justice System; DIVA, Diagnostic Interview for ADHD in Adults; DSM, Diagnostic and Statistical Manual of Mental Health Disorders; GCSE, General Certificate of Secondary Education; H/I, hyperactivity/impulsivity; IAPTS, Improving Access to Psychological Therapies Service; ID, intellectual disability; IQ, intelligence quotient; LDSQ, Learning Disability Screening Questionnaire; NDD, neurodevelopmental disorders and difficulties;

NHS, National Health Service; NICE, National Institute of Health and Clinical Excellence; UK, United Kingdom.

## **Introduction**

The DSM-5 introduced a neurodevelopmental disorder diagnostic category which brought together conditions such as attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), communication/speech/language disorders, developmental coordination/motor/movement disorders, intellectual disability (ID) and specific learning disorders (such as dyslexia) (American Psychiatric Association, 2013).

This report focuses on three neurodevelopmental disorders: ADHD, ASD and ID. These conditions have an onset in early life and commonly occur together. For example, reports of individuals with ASD show rates of 28-44% for ADHD (Lai et al., 2014) and 20-30% of those with ID have ASD (Underwood et al., 2012). In addition to individuals with ADHD, ASD and ID, there are those with significant traits of these conditions who do not quite meet diagnostic criteria. This group, with broader 'sub-threshold' neurodevelopmental difficulties, may have similar vulnerabilities and needs, particularly within specific environments such as the prison system (Talbot, 2008). The Bradley report highlighted the current lack of appropriate early identification, intervention and access to specialist services for those with neurodevelopmental disorders or difficulties (NDD) across the Criminal Justice System (CJS) (Ministry of Justice, 2009).

When people with NDD are identified within the prison system they should receive support to access interventions through reasonable adjustments as required under the Equality Act (Parliament, 2010). This is consistent with the principle of equivalence, which has underlain the development of prison healthcare services across much of the world in recent years (Till et al., 2014). A recent review reported limited research on prisoners with NDD, however what evidence there is suggests that this group are not receiving services to meet their needs (Underwood et al., 2013).

The Operating Model for prison mental health and ID care takes into account the needs of special populations, which include individuals with ADHD (NHS Commissioning Board, 2013). Although this would include those with ASD this group is not mentioned specifically in the report, suggesting there is some way to go before the problems of identifying and managing this group in prison is seen as a priority for policy developers. A better understanding of the recognition and identification of NDD would provide evidence on who should be targeted for screening and further assessment.

The aim of this study was to identify prisoners with NDD in order to determine the best approach to the recognition and assessment of individuals with NDD within the UK prison system.

## **Method**

### *Setting*

The study was carried out between May 2012 and June 2013 in a London category C male prison with a maximum capacity of 798 prisoners (in the UK, category C refers to closed prisons for prisoners who cannot be trusted in open conditions but are considered unlikely to make a determined escape attempt). At that time, mental health care within the prison was provided by general practitioners, nurses, a primary care mental health team, a mental health in-reach team (comprising psychiatrists, community psychiatric nurses and a psychologist), an Improving Access to Psychological Therapies service (IAPTS) and a Substance Misuse Team. Healthcare staff in these teams were given information on the study and (where appropriate) access to the assessment tools. Information on neurodevelopmental disorders and their assessment was provided to staff on request and workshops with prisoners were held by the researchers. These workshops were attended by prisoners who were healthcare representatives and peer-to-peer supporters.

### *Participants*

Prisoners were eligible for the study if they were assessed as having capacity to give informed consent (see below) and could understand/speak sufficient English. Eligibility was assessed by researchers when they approached prisoners to take part and explained the study to them. The researchers had extensive experience of research recruitment and interviewing of adults with neurodevelopmental disorders. The study employed a purposive sampling strategy to maximise recruitment and increase representativeness; a similar number of prisoners were approached on each of the four main prison wings (97, 90, 87 and 92). A further 12 prisoners from the mental health inpatient wing were approached. The study approached newly arrived prisoners and some participants were recruited following self-referral or referral by prison healthcare or education staff. Ethical approval for the study was granted by the National Research Ethics Service Committee North East – Northern and Yorkshire (ref: 12/NE/0040) and National Offender Management Service approval was granted in March 2012 (ref: 50-12).

### *Procedure*

Researchers visited the prison 2-3 days a week, recruiting those who had arrived in the last four weeks and were present on the prison wings. Where possible, the study was explained to prisoners

in a private room. They were given a copy of a written participant information sheet and consent form which were presented in a simple, easy to read format/language. The researcher read out the participant information sheet and consent form, the prisoner was given time to read through the information themselves then the researcher checked whether they had any questions about the study. If they wanted, prisoners could take the information with them to discuss with others and make a decision later. Capacity to consent was assessed using a checklist to ensure that participants were able to: 1) understand the information about the study and what taking part would involve, 2) retain that information and use it to make a decision about whether to take part and 3) convey their decision. The researchers paid special attention to whether a prisoner's inability to understand the information may have been due lack of capacity or a language impairment (rather than because their first language was not English). If this was the case the prisoner was referred to healthcare services for further assessment.

Interviews were carried out in private rooms on the prison wings by the researchers (no prison staff were present). Participants who screened positive for ADHD, ASD or ID were asked to undergo further assessment and, if appropriate, to consent to referral to the mental health in-reach team for clinical assessment. Participants could refuse to be approached about the study and those who did consent could withdraw at any time.

### *Measures*

Participants with NDD were defined as those who: a) exceeded the threshold on one or more of the assessments employed by the study **or** b) self-reported having a diagnosis of ADHD, ASD or ID.

Participants with ND were defined as those who: a) screened positive for NDD **and** b) met the criteria for ADHD, ASD or ID on one or more of the diagnostic assessments employed by the study.

The screening thresholds employed by the study were: a score of <46% on the Learning Disability Screening Questionnaire (LDSQ; McKenzie and Paxton, 2006), a score of four or more using the six screening items of the adult ADHD self-report scale (ASRS; Adler et al., 2003) and a score greater than or equal to 10 on the 20-item Autism Quotient (AQ-20; Brugha et al., 2011), as recommended by the NICE (2014) Guidelines for Adults with Autism.

The diagnostic tools employed by the study were: the Quick Test (Ammons and Ammons, 1962) (with an IQ score of <85 indicating the presence of mild/borderline ID); the Diagnostic Interview

for ADHD in Adults (DIVA; Kooij and Francken, 2007) (with  $\geq 6$  symptoms of attention-deficit (A-D) or hyperactivity/impulsivity (H/I) as a child and  $\geq 4$  symptoms of A-D or H/I in adulthood indicating the presence of adult ADHD); and the Autism Diagnostic Observation Schedule (ADOS; Lord et al., 1989) and, where possible, the Autism Diagnostic Interview (ADI; Lord et al., 1994) (with the usual thresholds employed to indicate the presence of ASD). Adaptations were made to the standardised ADOS assessment as a consequence of establishment security rules. As a result it was not possible to take the following items on to the prison wings and therefore these sections of the ADOS were omitted: construction task, picture book, pictures, cartoon pictures and creating a story objects. All other sections of the module four ADOS assessment were completed and participants were asked to create a story without using physical objects as props.

### *Analysis*

SPSS v 22 was used to carry out two-tailed chi-square analyses of categorical variables and two-tailed t-tests of continuous data. Statistical significance was defined as probability (p)  $< 0.05$ .

### **Results**

The researchers approached 378 prisoners to take part in the study and 240 consented to the screening interview (see figure one). Of these, 15 were self-referrals who requested to take part as they believed they may have NDD characteristics. Prison healthcare and education staff referred 39 of the participants (n=30 and n=9, respectively). The remaining 186 participants were approached on the prison wings by the researchers within four weeks of arriving at the prison.

[TAKE IN FIGURE ONE HERE]

### *Participants with NDD: screening and diagnosis*

The study identified 87 prisoners with NDD according to the study criteria; 79 prisoners with NDD were identified by the LDSQ, ASRS or AQ-20 and eight screened negative on these tools but self-reported a diagnosis of ADHD, ASD or ID. There were 65 participants who screened positive for ADHD, 46 who screened positive for ASD and 33 who screened positive for ID (see figure one).

Diagnostic assessments were carried out for 56 (86%) of those who screened positive for ADHD, 36 (78%) of those who screened positive for ASD and 31 (91%) of those who screened positive for ID. For 15 participants there was not a complete diagnostic dataset: of these it was not possible to carry out any follow-up assessments on three participants.

Following further assessment, 70 participants met diagnostic criteria for ND. There were 54 who met the study's diagnostic criteria for ADHD. Thirteen participants met ADOS criteria for ASD and two were further assessed using the ADI; one met diagnostic criteria and one did not. Therefore, 12 participants met the study's diagnostic criteria for ASD. There were 24 participants who met the criteria for mild/borderline ID; three with an estimated IQ of <70 and 21 with borderline intellectual functioning (IQ of 70-84). One participant had a score of 108; this participant self-reported an ID diagnosis but did not screen positive on the LDSQ. He was removed from the sample screening positive for ID as an outlier, but remained in the NDD sample because he screened positive for ADHD and ASD.

As reported in McCarthy et al. (in press), the 87 participants with NDD were less likely to be of black or minority ethnicity (BME) (75% vs. 43%,  $p<0.001$ ) and were significantly younger (mean=31.3, SD=9.3 vs. 35.3, 11);  $p=0.006$ ) than the 153 participants without NDD. There was a great deal of crossover between the conditions as demonstrated by figure two:

[TAKE IN FIGURE TWO HERE]

#### *Participants with unrecognised NDD*

Just over half ( $n=44$ ; 50.6%) of those with NDD reported that they had an existing diagnosis or it was previously suspected that they may have ADHD, ASD, ID or 'learning difficulties'. These participants were compared with those whose difficulties had not been previously recognised ( $n=43$ ). Figure three demonstrates the extent of unrecognised NDD among the study's sample.

[TAKE IN FIGURE THREE HERE]

Participants with previously unrecognised NDD were significantly more likely to be from a BME background (35%) than those whose symptoms had been recognised (16%;  $p=0.0042$ ). Those with unrecognised NDD were also more likely to be have been able to both read and write (as assessed by the LDSQ) (93% vs. 68%;  $p=0.003$ ) and less likely to have been homeless before coming into prison (14% vs. 32%;  $p=0.048$ ).

ADHD had gone unrecognised in 38 of those who screened positive. Participants whose ADHD symptoms had been recognised had significantly higher LDSQ scores than those with unrecognised symptoms (mean=76.1 vs. 60.2;  $p=0.003$ ) indicating that those previously recognised had higher levels of functioning. Nine participants who screened positive for ASD had been previously

assessed for or diagnosed with ASD. There were no significant differences on the LDSQ or ASRS between those whose symptoms had been previously recognised (n=9) and those who had not (n=37). Only two participants who screened positive for ID had not been previously recognised as having some form of learning difficulty.

#### *Staff-referrals and self-referrals to the study*

Prison staff referred 39 prisoners to the study for assessment of NDD and 15 prisoners requested an assessment themselves. Of these participants, 87% of staff-referrals and 67% of self-referrals screened positive for NDD. In total, 51% of the 87 participants with NDD were identified by prison staff or by self-referral.

Participants with NDD identified by referral (n=44) were compared with those who were approached on the wings (n=43). Referrals were more likely to have educational qualifications at GCSE level or above (36% vs. 15%,  $p=0.06$ ) and had a significantly lower number of previous imprisonments (3.6 vs. 11.5,  $p<0.001$ ). There were no other statistically significant differences between the groups. Most of the staff or self-referred participants with NDD (82%) were identified more than four weeks after they arrived at prison.

#### *Validity of the screening methods*

The majority (96%) of those who screened positive for ADHD and were further assessed met the diagnostic criteria for Adult ADHD. Thus, our screening for ADHD appeared to be successful. However, a large proportion (67%) of those who screened positive for ASD and were further assessed did not meet diagnostic criteria. Thus, our screening for ASD resulted in a high number of false positives. By contrast, only 25% of those who screened positive for ID and were further assessed did not meet diagnostic criteria for mild/borderline ID; a fairly low rate of false positives.

### **Discussion**

The study identified a considerable number of prisoners with NDD, many of whom had previously gone unrecognised. Our previous report found that these individuals experienced significantly higher levels of social disadvantage compared with other prisoners (McCarthy et al., in press). In the current study, prison staff referred a high number of prisoners for NDD assessment and it was clear that healthcare staff did not feel that they could carry out these assessments themselves. Perhaps, this is one reason why offenders with NDD often go unrecognised in a prison setting (Chaplin et al., 2013). It also suggests that prison staff saw the need for specialised input for prisoners with NDD; they had not been previously referring individuals to the generic mental illness

provision for NDD assessment but welcomed the opportunity to refer prisoners to the study. Lack of capacity or ability to assess NDD is an issue not only for prison mental health services but mental health services in general (National Development Team for Inclusion, 2012). This study has shown that improved recognition of NDD can be achieved by a combination of increasing prison staff awareness and the use of standardised screening tools in face to face interviews.

The study highlights the need for training and increased awareness within the prison system so that all staff can recognise, understand and know how to work with prisoners who have NDD. However, training, awareness and screening are not sufficient without interventions in place that can help those with NDD including treatment for problems such as substance misuse. Screening is not sufficient without training of prison staff to recognise signs of NDD and know how to respond effectively to people with NDD. In addition the study verifies the high rates of concurrence of NDD in a prison population; so awareness training needs to include the ranges of NDD, ASD, ID and ADHD, as does any development in services for identifying NDD among offender populations.

It is likely that many of those identified with NDD had borderline levels of intellectual functioning or sub-threshold ADHD or ASD and may not meet clinical diagnostic criteria (Talbot, 2008). In terms of vulnerability, and the wider prison agendas of respect and resettlement, it would be useful to include this broader group with those who have a clinical diagnosis. This is because there are implications for day-to-day functioning on the wings (mindful of bullying), and for sentence progression (including taking part in offending behaviour programmes – such as enhanced thinking skills, or the sex offenders' treatment programme).

Improvements in prison healthcare should include the recognition of NDD as currently happens for prisoners with severe mental illness. Indeed, there is a need for recognition and management of NDD more broadly across the CJS, including police and probation services (Young et al., 2013; Young et al., 2014). Currently there are established pathways for prisoners with psychotic illnesses (see Jarrett et al., 2012) and, although NDD occur at greater rates than psychosis in the general population, there is no equivalent provision for this group. The mandatory assessment of functioning and skills for all prisoners from 2014 should offer the opportunity to improve the recognition of those with ASD and ID (see Think Autism; Department of Health, 2014).

In terms of the practicalities of screening for NDD, the ASRS administered face-to-face worked well, although it is acknowledged that this may not be the case if done in the pressured environment of prison reception. For ASD, the Autism NICE guidelines (2014) recommend two screens, the AQ-



10 and the ASDI. However there have been limitations reported on using the AQ as a diagnostic screen as opposed to identifying specific traits of autism (Hoekstra, et al, 2008, Sizoo et al, 2009). The LDSQ appeared to have good utility and appeared to identify prisoners with ID when used alongside self-reported information about existing diagnoses of ID or learning difficulties. In terms of confirming a diagnosis the study was unable to obtain a developmental history for prisoners. The measures used may be limited in establishing a diagnosis in the absence of clinical experience for those with complex or atypical presentations.

The main strength of the study was the use of standardised assessment tools administered during face-to-face interviews with prisoners by researchers trained in NDD assessment. Other studies have sought to obtain information on NDD using prison staff as informants or self-rating screening tools neither of which is likely to be suitable for prisoners with such disorders. However, a lack of clarity still exists in the field because different study methodologies and diagnostic criteria are often employed. To ensure consistency there needs to be greater agreement on measures particularly for studies with an epidemiological basis. More analysis is needed on the validity of screening methods in prison populations, particularly rates of false negatives (Silva et al., 2015). Future studies should include assessment tools that can identify a broader range of NDD such as developmental co-ordination disorder, specific learning disorders and communication/language disorders.

It appeared that those from BME backgrounds were particularly at risk of symptoms of NDD not being recognised. The screening methods used by the study identified more white prisoners with NDD than was representative of the broader prison population, despite a lack of sampling or referral bias. This was a similar finding to that of an ASD screening study in a prison in the United States (Fazio et al., 2012). It may indicate that the assessment tools used are not culturally sensitive, particularly in a prison setting or that those making referrals to the study were more culturally attuned to consider (or report) the presence of NDD in white prisoners.

The lack of screening, awareness and joint working is an issue throughout the CJS for those with NDD. If neurodevelopmental disorders can be identified earlier in the process e.g., the police station or court (as is the case for mental illness) this will provide information to inform decisions on appropriate disposal and support and as a result decrease the need for custodial sentences. NDD teams in police stations or courts could provide the emphasis for the introduction of a number of interventions including early identification, signposting, and case-management. This is necessary if we are to improve our understanding of what works for this group and how outcomes can be improved in terms of reducing contact with the CJS and accessing appropriate support.

In terms of accessing services on release, even for those identified with NDD, there is often disagreement on appropriate services, particularly given the lack of specialist services for this group. Even where specialist services for people with ADHD, ASD or ID exist, they are often not set up for those with an offending history or who are deemed high risk. With fragmented and incomplete NDD care pathways, it is often following a crisis that this group will come to the attention of general or forensic mental health services. Often service developments for this people with NDD in prisons, health and social care services are independent of each other and as a result many people fall through gaps in services. To address this there needs to be increased joint working between services and changes to current practices in the delivery of care pathways for this group of offenders.

### *Conclusion*

We found a significant number of male prisoners with NDD. Many had not been recognised, in the community or in prison. This situation is exacerbated by poor identification due to a lack of routine screening for NDD and awareness of these conditions by prison staff. However this is not just a prison issue; as the introduction of screening needs to be across the CJS e.g., in police stations or courts. The study confirmed screening tools that can be used in a prison setting to identify prisoners with NDD along with at risk groups e.g., those from BME backgrounds were particularly at risk of their NDD not being recognised. The screening tools used in this study require minimal training but are more effective in the identification of prisoners with NDD if used in face to face interviews in combination with awareness training for all prison staff.

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Figure 1: flow of participants through the study

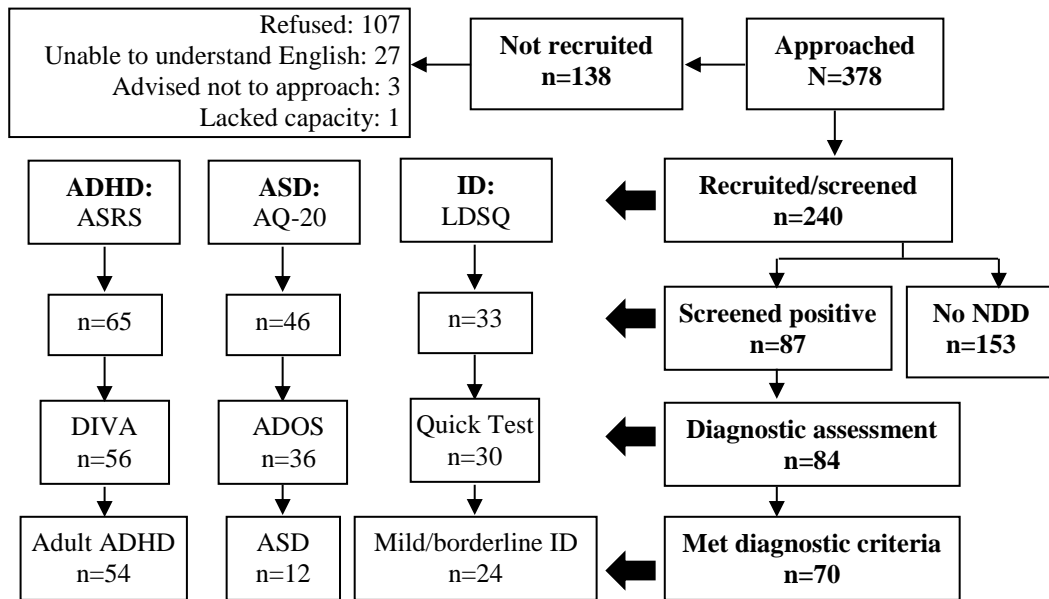


Figure 2: proportion of participants screening positive for ADHD, ASD and ID

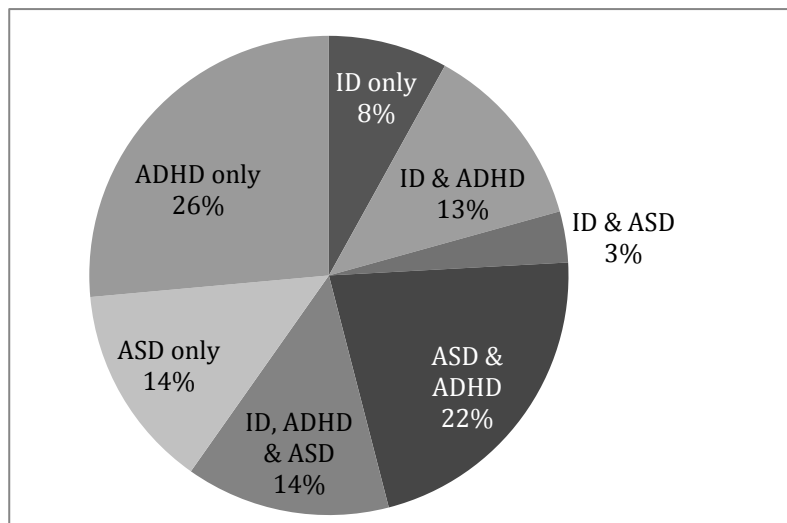


Figure 3: unrecognised NDD among the 87 participants who screened positive

