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Knowledge and understanding of the autism spectrum amongst prison staff

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Introduction

There will be a number of individuals in the prison system at any given time who are on the autism spectrum. The size of this population is unknown as they may not be diagnosed and there is no mechanism to collect data on those who do disclose this information. Some have written about the incidence of offending and the autism spectrum^{1,2} but generally there is very little literature on the topic. Despite a literature search of electronic databases (IngentaConnect, International Bibliography of the Social Sciences, Social Science Information Gateway and Swetswise) little research, other than Myers in Scotland³, has touched upon the understanding of the autism spectrum by those who work in prisons. Talbot and Riley⁴ claim that people who work in the criminal justice system (CJS) do not always know how to support people with certain learning difficulties and the same is likely to be true within prisons. The nature of a prison environment will be particularly challenging for some individuals on the autism spectrum, although there may be some aspects of prison that suit some individuals (e.g. routine; predictability; social isolation; clear rules). This study set out to explore the knowledge that staff have on the autism spectrum, working within one particular prison.

Adjustments required to meet individual needs

In the report, *Fair Access to Care*, the Department of Health⁵ talks of the need for people on the autism spectrum to get the services they need. It is not clear whether prisons are included in this or not, but they

should be. Her Majesty's Prison service website⁶ does make reference to the duty of care of prisoners with disabilities, including autism. They emphasise how reasonable adjustments must be made to accommodate these prisoners, citing legislation in line with the Equality Act⁷. Debbaudt¹ recognises the need for law enforcement awareness campaigns but acknowledges that these need to be sensitive to the needs of the victim, the CJS, and the offender with autism. He believes national and international autism advocacy groups must become more involved in the CJS to organise, lobby and bring media and credibility presence to these endeavours.

Potential issues for a person on the autism spectrum living in prison

The needs of a prisoner on the autism spectrum should be assessed in relation to the three main areas affected, that is, in relation to their communication, their social understanding and their flexibility of thought and behaviour. In addition, some adults may experience difficulties in terms of their sensory processing and responses to particular stimuli⁸. They are likely to have problems in communicating their needs; in understanding the communication of others; in understanding the social and emotional behaviour of others; and in managing change and transitions. Their anxiety levels are likely to be high and their response to both staff and inmates may be inappropriate and misinterpreted as challenging. Bullying is a known phenomenon amongst the prison population generally and those on the autism spectrum are likely to be key targets of this. Prison staff need to be vigilant and however good the prisoner's level of functioning appears, carers should look for the areas of vulnerability and provide appropriate support⁹.

1. Debbaudt, D (2002) *Autism, advocates and law enforcement professionals: recognising and reducing risk situations for people with autism spectrum disorders*. London: Jessica Kingsley.
2. Murrie, D.C, Warren, J.I, Kristiansson, M and Dietz, P.E. (2002) Asperger's syndrome in forensic settings, *International Journal of Forensic Mental Health*. 1, 1, 59-70.
3. Myers, F (2004) *On the borderline? People with learning disabilities and/or autistic spectrum disorders in secure, forensic and other specialist settings*. Scottish development centre for mental health. 25 June 2004 (www) <http://www.scotland.gov.uk>
4. Talbot, J and Riley, C (2007) No one knows: *Offenders with learning difficulties and learning disabilities*, *British Journal of Learning Disabilities*. 35, 3, 154-161.
5. Department of Health (2006) *Better services for people with an autistic spectrum disorder. A note clarifying current Government Policy and describing good practice*.
6. HM Prison Service (2007) (www) <http://www.hmprisonservice.gov.uk>
7. Equality Act (2010) (WWW) <http://www.legislation.gov.uk>
8. Bogdashina, O (2003) *Sensory perceptual issues in autism and Asperger syndrome*, London: Jessica Kingsley.
9. Jordan, R (1999) *Autistic spectrum disorders: an introductory handbook for practitioners*. London: David Fulton.

Knowledge of the autism spectrum amongst other professional groups

Generally, the literature on how knowledgeable other professional groups are about the autism spectrum is relatively scant. Morton-Cooper¹⁰ argues that medical and nursing staff have patchy knowledge. Similarly, Preece and Jordan¹¹ found that the knowledge of social workers was insufficient. Kirby, Davies and Bryant¹² investigated teachers versus GPs knowledge of six specific learning difficulties, including Asperger syndrome. They found teachers fared better at defining the term, although both groups gave many incorrect responses.

The autism spectrum and criminality

Some of the literature supports an association between the autism spectrum and criminality, but not all. Haskins and Silva¹³ found that those with high functioning autism were over represented in criminal populations in the United States of America compared with their prevalence in the general population. Scragg and Shah¹⁴, in their Broadmoor special hospital study demonstrated similar findings and suggested that there may well be more people on the autism spectrum in prisons in the UK than is realised. However, there are many more researchers refuting these findings. Howlin¹⁵ doubts the findings of the study by Scragg and Shah¹⁴ as the numbers were very low. A significant body of research suggests that those on the autism spectrum are no more likely to commit offences than anyone else^{16,17,18,19}.

Design of the study

A survey was the main approach used amongst a group of prison staff. A questionnaire was devised and piloted to ascertain the level of awareness and understanding on the autism spectrum. Autism and Asperger syndrome were used as separate terms in the questionnaire. Confidentiality and anonymity of participants was made explicit. Ethical considerations and

official permission from the Deputy Prison Governor and the Primary Care Trust (PCT) employer were adhered to. Respondents were given time to read the consent form before signing and returning to the author, via the internal mail system. A month was allowed for the return of questionnaires.

A five point Likert²⁰ scale was used predominantly for the questionnaire. Occasional questions or statements asked for either/or responses as well. Likert scaling allowed respondents to specify their level of agreement to a statement. It is suitable for this diverse staff group as it provides them with a structure and is user friendly. However, there is no scope to get richer information on their exact knowledge or understanding, as in qualitative methods.

Sample

The sample consisted of 75 staff who worked with the prison population (see Figure 1):

Figure 1:

Staff who received the questionnaire

- Registered General Nurses (RGN) (Primary care in GP surgeries)
- Registered Mental Nurses (RMN) (In Patients (hospital))
- Dual diagnosis nurses (dealing with those with mental health and drug or alcohol problems) and a crisis intervention nurse
- Mental Health In- Reach team (RMNs and a social worker)
- Psychologists
- GPs and visiting psychiatrists
- Teachers
- Drug dependency team RGNs and RMNs.
- Probation officers
- Prison Governor
- Prison wing officers
- Prison workshop officers
- Chaplains

Independent Monitoring Board members (I.M.B). These are a group of ordinary, independent, unpaid members of the public who monitor day-to-day life in prison to ensure that proper standards of care are maintained.

10. Morton-Cooper.A (2004) *Health Care and the autism spectrum. a guide for health professionals, parents and carers*. London. Jessica Kingsley.
11. Preece, D and Jordan, R (2007) Social workers' understanding of autistic spectrum disorders: An exploratory investigation, *British Journal of Social Work* 37, 925-936.
12. Kirby, A, Davie, R and Bryant.A (2005) Do teachers know more about specific learning difficulties than general practitioners? *British Journal of Special Education* 32, 3, 122-126.
13. Haskins.B.G. and Silva. J.A. (2006) Asperger's disorder and criminal behaviour: Forensic-psychiatric considerations, *Journal of the American Academy of Psychiatry Law*, 34, 374-84.
14. Scragg, P and Shah, A (1994) Prevalence of Asperger's syndrome in a secure hospital, *British Journal of Psychiatry* 165, 679-682.
15. Howlin, P (2000) Outcome in adult life for more able individuals with autism or Asperger syndrome, *Autism* 4, 1, 63-83.
16. Ghaziuddin. M, Tsai.L.Y. and Ghaziuddin. N (1991) Brief report. Violence in Asperger syndrome: a critique, *Journal of Autism and Developmental Disorders* 21, 349-354.
17. Attwood, T. (1998) *Asperger's syndrome: a guide for parents and professionals*, London: Jessica Kingsley.
18. Woodbury-Smith, M.R., Clare, I.C.H, Kearns, A and Holland.A.J (2006) High functioning autistic spectrum disorders, offending and other law breaking: Findings from a community sample. *Journal of Forensic Psychiatry and Psychology* 17, 1, 108-120.
19. National Autistic Society (2005) *Autism: A guide for criminal justice professionals*. London: National Autistic Society.
20. Likert, R (1932) A technique for the measurement of attitudes. *Archives of Psychology* 140, 1-55.

Findings

The survey was conducted in the autumn of 2007. A total of 53 out of seventy five questionnaires were returned (71 per cent) which was an excellent return rate for this type of survey. The rate was probably enhanced as the author worked within the prison and so was known to many.

Knowledge of autism and Asperger syndrome

Thirty five respondents (66 per cent) said they knew what autism was and a smaller number of staff (49 per cent) said they knew what Asperger syndrome was. Ten years ago, hardly anyone would have heard of Asperger syndrome (Attwood¹⁷). But, it is perhaps those with Asperger syndrome who are more likely to experience prison, according to the present author's experience and that of others (Holland et al²¹ and the National Autistic Society¹⁹). The vast majority of respondents (83 per cent) agreed that autism or Asperger syndrome varies from person to person. Five respondents (9 per cent) disagreed or strongly disagreed and four respondents (8 per cent) did not know. Almost two thirds of respondents recognised sensory sensitivities in this population and almost one third did not. The senses staff thought were affected are shown in Figure 2: The most commonly affected sense was given as auditory, followed by tactile and visual.

Sight	18	(34 %)
Sound	31	(58 %)
Touch	22	(42 %)
Taste	11	(21 %)
Smell	9	(17 %)
Don't know	17	(32 %)

The general noise level in a prison, the potential for intimidation and confrontation, frequent fighting and disruptions cannot fail to have an impact on those on the autism spectrum. The potential for sensory overload is a real one and staff must recognise this.

The majority of respondents (85 per cent) thought did not think it was possible to detect autism or Asperger syndrome merely by looking at a prisoner. Six respondents were undecided and two thought that it would be possible. Eighty per cent of respondents recognised that eye contact in these prisoners would be different than most people.

Sources of information on autism and Asperger syndrome

Staff were asked where they got their information from (more than one box could be ticked). Respondents gave the following sources:

- Job contact
- Son being investigated for Asperger syndrome
- Friend has Asperger syndrome; friends child has Asperger syndrome; personal contact
- University, College, Teacher or Learning Disability Nurse training
- My own research
- Prisoner contact.
- Partner is a teacher.
- Information from my manager.
- Working with people with Asperger syndrome.
- Contact through my GP practice.

Six respondents did not specify where they got their information from.

Respondents were also asked which media sources they had gained information from. Television (30 per cent) and books (21 per cent), with only 6 per cent of respondents mentioning the Internet and newspapers.

Staff views on the likelihood of individuals on the autism spectrum offending

Only 6 per cent of staff thought there was an increased likelihood of offending in this population, with 51 per cent stating that this was not the case and 38 per cent being undecided on this issue.

Number of staff who thought they had worked with a prisoner on the autism spectrum

Twenty one staff (40 per cent) said they had worked with a prisoner on the autism spectrum, 11 said they had not and 40 per cent of respondents said they did not know. It is apparent that quite a number of staff may not know that some prisoners they work with are on the autism spectrum. This may have serious implications for the nature and outcome of their interactions. The knowledge deficits of staff indicate a need for in-prison staff training on the autism spectrum. A training programme geared towards a prison environment is recommended by the author and ideas for an information sheet are listed in **Appendix 1**.

Views on the stress levels of prisoners on the autism spectrum

Almost 80 per cent of respondents felt that the stress levels amongst prisoners on the autism spectrum would be higher than those of other

21. Holland, T, Clare, I.C.H. and Mukhopadhyay, T (2002) Prevalence of criminal offending by men and women with intellectual disability and the characteristics of offenders: Implications for research and service development. *Journal of Intellectual Disability Research*, 46 Supplement 1, 6-20.

prisoners. In terms of the most suitable location within the prison for these prisoners, 35 per cent of respondents felt that the prison hospital might be the best location, or in the segregation wing (6 per cent), but 59 per cent felt that the main prison wing would be fine. Over a third chose hospital admission but this may not always be best practice according to the *Prison Service Order 2855 — Prisoners With Disabilities*²². This mandatory prison instruction includes those on the autism spectrum and advocates 'normal' location if possible, so as to not miss out on accessing all of the prison regime. Only a small number (4 per cent) thought the segregation wing to be most appropriate. Debbaudt¹ advocates segregation first until an initial assessment is completed. Overall, it is crucial that a detailed assessment of the needs of each individual is made to determine provision, rather than provision which is allocated on the basis of the diagnostic label alone. One size does not fit all.

Implications and recommendations

The Director of the Prison Reform Trust recently stated,

*'The prison service is our least visible and, arguably, most neglected public service.'*²³

The need for a new and reliable evidence base for more appropriate care practices for those on the autism spectrum in our prisons is apparent. Moving away from prison staff being reactive in nature, as Lyon²³ suggests is the case at the moment, to reaching a better understanding through autism-specific training would be beneficial. If staff have some basic knowledge, they may then be able to appropriately and effectively assist prisoners on the autism spectrum. Disability awareness training (including autism) is not readily available for staff in prisons according to Talbot and Riley's⁴ 'No-One Knows' research. It is encouraging to note that Autism West Midlands, in the UK, is currently planning in-house prison staff training in their local young offenders institute (Hatton, personal communication).

Further research needed

Further research would be beneficial. A study examining the perspective of prisoners on the autism spectrum and their prison experiences would be useful. If practitioners consult with those who receive the service, then service provision is more likely to match needs. Gaining access to prisoners on the autism spectrum is problematic though, due to small numbers,

identification difficulties and ethical considerations, to name but a few.

Greater coordination of information and assessment within prison environments and a shared single assessment model within secure settings is advocated by Myers³. Collaboration amongst all criminal justice agencies, so all staff are informed and are able to assist and support prisoners on the autism spectrum throughout the criminal justice process, makes sense. A key worker to assess each prisoner's needs and to make appropriate provision as soon as possible would be of benefit. A screening tool or special needs assessment at the point of admission could be used for all prisoners. The initial information could be shared with the Disability Discrimination Officer (with the prisoner's permission) to follow up care. A multi-disciplinary network should be in place whereby continuity of support (perhaps including advocacy arrangements) are in place to help, especially with transitions (e.g. from prison to court). The Department of Health⁵ states that people on the autism spectrum sometimes get excluded from advocacy initiatives. Talbot and Riley⁴ found that it was the local prison for adult men that were the least likely of all prisons to have advocacy arrangements.

Concluding comments

Forensic services for those with learning disabilities have been slow to address the needs of those on the autism spectrum. It would be wise to make use of learning disability psychiatrists, competent in dealing with this population, in the assessment and treatment of offenders, as current learning disability services are not resourced to provide a service to prisons. Implementing a service would require dedicated funding which would have cost implications. More research is needed to justify a service such as this. A dedicated regional autism forensic unit could also be an option for those not managing a conventional prison placement. Services in prisons tend to have a radically different philosophy which is centred on security and control. The Equality Act⁷ stipulates that public organisations need to understand how their services are experienced differently by those on the autism spectrum and to make reasonable adjustments as a consequence. Realistically though, developing a clear service responsibility or policy focus on the autism spectrum in prison is a tall order.

To conclude, it is clear that we have an under-served population of vulnerable prisoners who may be misunderstood by a significant number of people looking after them. The results of this study form a first step, but

22. HM Prison Service (2008) Prison Service Order 2855. Prisoners with Disabilities (www) <http://www.hmprisonservice.gov.uk>

23. Lyon, J (2007) *Locked in a crisis*, 30.08.07 (www) <http://www.commentisfree.guardian.co.uk>

more extensive research and greater analysis needs to be done on a scale not permitted by this study. To conclude, Mills²⁴, the Director of Public Prosecutions, said,

'People with particular disabilities need help from everyone in the CJS, and we must all be on the alert to do the best we can for them.'

Appendix 1: Suggested information on the autism spectrum for staff working in prisons

Autism Spectrum – The Facts

Autism spectrum is an umbrella term which includes a range of conditions, including autism and Asperger syndrome.

Three areas of development are affected:

1. Communication.
2. Social and emotional understanding and interaction.
3. Flexibility of thought and ability to problem-solve.

These affect the way a person communicates and interacts with other people. Their intelligence may be average or well above average, but problems with social awareness and understanding remain.

What can you do to help?

1. Use the prisoner's name when you are talking to him.
2. Keep your language clear and minimal.
3. Wait and allow a little longer for information to be processed.
4. Listen to the prisoner. Ask direct, concrete questions.
5. Avoid abstract language. This prisoner takes things literally, so be exact.
6. Do not shout. This prisoner may be noise sensitive.
7. Be consistent. Tell this prisoner what is happening next.
8. Deal with one thing at a time.
9. Visual support often helps, so write things down if the prisoner is unsure.
10. Avoid crowds if possible.
11. Avoid queueing. (eg. wait until the queues are short or attend to this prisoner first or last).
12. Keep physical restraint to a minimum. This prisoner may be touch sensitive.
13. Allocate a key worker for support.

14. Keep to a daily routine and avoid change without warning.
15. Put rules and structure in place.
16. Offer purposeful activity (e.g. education or work).
17. Consider single cell accommodation or segregation on the vulnerable prisoner's wing.
18. Consider the befriending or anti bullying scheme.
19. Encourage daily exercise.

Everyday prison noises can be stressful and may cause pain and anxiety. This prisoner may plug his ears. If so, try to remove him to a quieter environment as soon as you can.

Invading personal space and touch can be stressful. If you have to search this prisoner or apply hand cuffs, please explain what you are doing first.

Remember!

1. Autism/Asperger syndrome is not a mental illness. It is a neurological difference in development.
2. You can not see it.
3. If the prisoner appears rude, aloof, or ignores you, this is not intentional. It is an aspect of his condition.
4. This prisoner may not look at you or he may have a different type of eye contact, because of his condition.
5. This prisoner may not be able to ask for help when he really needs it.
6. This prisoner tends to like rules, but be explicit with them.
7. This prisoner may get easily startled.
8. This prisoner tends to be anxious so offer explanations, reassurance and support.
9. Everybody is unique. No two prisoners with autism/Asperger syndrome will be the same.

24. Mills, B (1998) *Crown prosecution service: Criminal justice system must help people with learning disabilities.* (www) <http://www.cps.gov.uk> Archived press release 12.02.98.