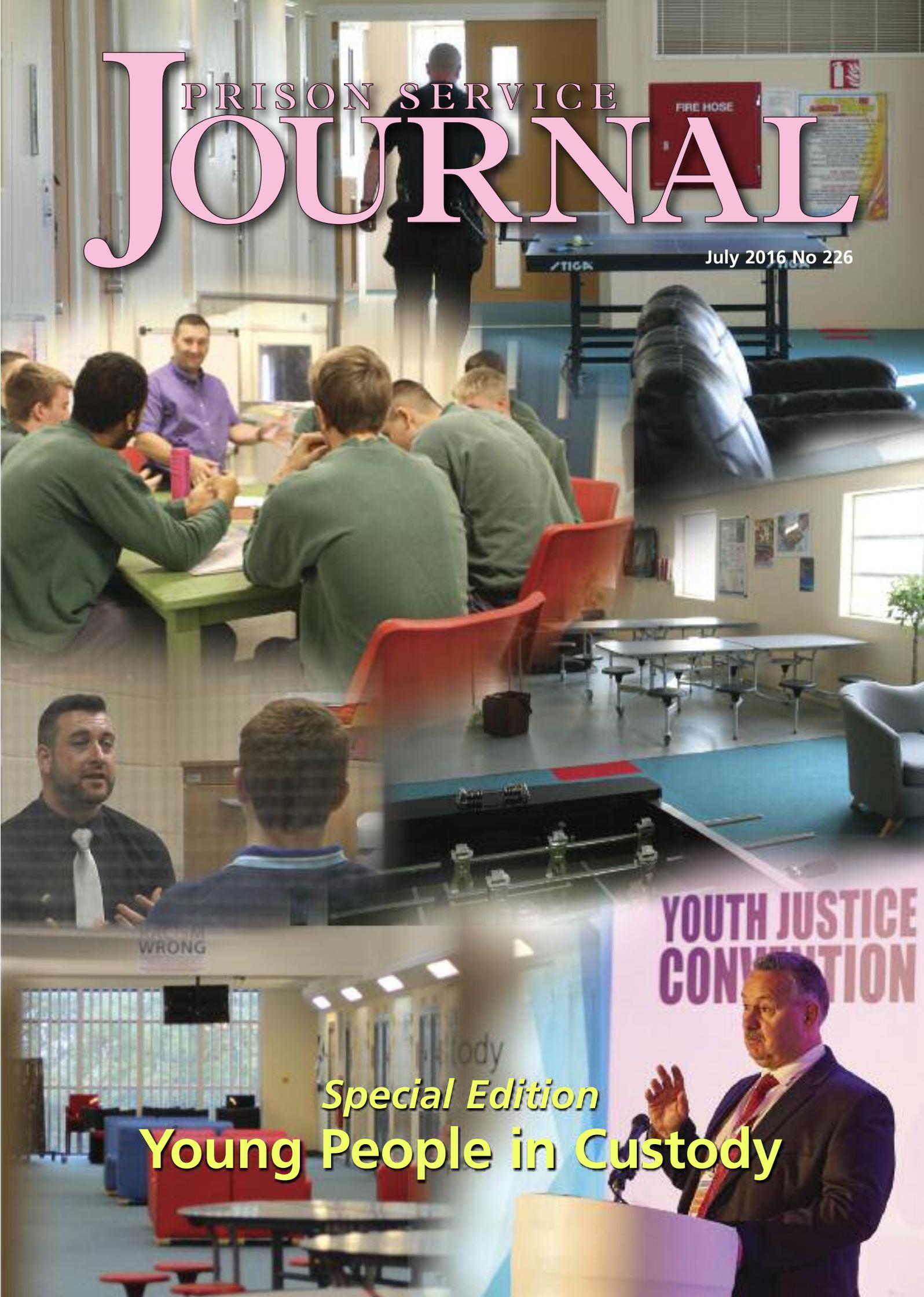


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WRONG

YOUTH JUSTICE  
CONVENTION

*Special Edition*  
**Young People in Custody**

# Improving the management of prisoners with autistic spectrum disorders (ASD)

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## Introduction

**Autistic Spectrum Disorders are lifelong conditions characterised by difficulties in social interaction and communication and often associated with restricted or repetitive patterns of thought or behaviour. The clinical expression of ASD is not uniform but varies between individuals, their stage of development, changing environmental demands and with the presence of comorbidities. However, people with ASD typically experience difficulties or misunderstandings in their daily lives as a result of their condition. ASD affects approximately 1 per cent of people.**

Increasing awareness of the disadvantages associated with ASD resulted in the development of the Autism Act 2009. This placed a duty on the Government to produce a strategy and statutory guidance in relation to people with autism. The initial strategy, 'Fulfilling and Rewarding Lives', was published in 2010 followed by the 'Think Autism' strategy as updated in 2014.<sup>1</sup> In addition to this specific legislation, people with ASD also benefit from the protection provided by the Equalities Act 2010.

The increasing recognition of the prevalence of autistic spectrum disorders and the difficulties experienced by people with such disorders has prompted those working within the criminal justice system (CJS) to consider how people with ASD experience and interact with the CJS.

This paper describes a collaboration between HMYOI Feltham and the National Autistic Society (NAS) to develop and implement standards and a framework for good practice to help support prisoners with autistic spectrum disorders within a custodial environment.

## Prevalence of Autistic Spectrum Disorders within the Criminal Justice System

There is much uncertainty and conflicting evidence about the exact prevalence of ASD amongst those coming into contact with the different parts of the CJS, and the prevalence amongst prisoners in particular. Problems arise due to differences in definitions, diagnostic methods used and populations studied. Most community studies have suggested that, in general, there is an average or lower than average rate of offending amongst people with ASD<sup>2</sup> although higher rates were found in one study.<sup>3</sup>

However, some studies of adult prisoners have suggested that the prevalence of ASD is greater than that found in the general population. No studies conducted in English prison populations have been published although several researchers have suggested that there are likely to be many individuals with unrecognised ASD in custody.<sup>4</sup> There have been no published studies of the prevalence of ASD amongst English adolescent offenders within secure settings or in the community. This deficit was noted in a recent report by the Children's Commissioner which made a strong recommendation for more research into the identification and management of neurodisabilities, including ASD, amongst young people who offend.<sup>5</sup>

1. Department of Health (2010) Think Autism: Fulfilling and rewarding lives: the strategy for adults with autism in England. London. Social Care Local Government and Care Partnership Directorate (2014) Think Autism: Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update.
2. Woodbury-Smith, M. R., Clare, I. C. H., Holland, A. J. & Kearns, A. 2006. High functioning autistic spectrum disorders, offending and other law-breaking: findings from a community sample. *The Journal of Forensic Psychiatry & Psychology*, 17, 108-120; Hippler, K., Viding, E., Klicpera, C. & Happe, F. 2010. Brief Report: No Increase in Criminal Convictions in Hans Asperger's Original Cohort. *J Autism Dev Disord*, 40, 774-780; Ghaziuddin, M., Tsai, L. & Ghaziuddin, N. 1991. Brief report: Violence in Asperger syndrome, a critique. *J Autism Dev Disord*, 21, 349-354.
3. Allen, D., Evans, C., Hider, A., Hawkins, S., Peckett, H. & Morgan, H. 2008. Offending Behaviour in Adults with Asperger Syndrome. *Journal of Autism and Developmental Disorders*, 38, 748-758.
4. McAdam, P. 2012. Knowledge and understanding of the autism spectrum amongst prison staff. *Prison Service Journal*, 26-30; 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, Edinburgh.
5. Hughes, N., Williams, H., Chitsabesan, P., Davies, R. & Mounce, L. 2012. Nobody made the connection: The prevalence of neurodisability in young people who offend. The Office of The Children's Commissioner, London.

Community and custodial studies of young offenders in other countries have consistently found increased rates of ASDs, although there is wide variability in absolute prevalence between these studies, with rates ranging from 5-21.4 per cent.<sup>6</sup> A recent systematic review<sup>7</sup> has been published which attempted to establish the main conclusions that can be drawn from the existing research. The authors expressed reservations about the possible confounding effects of the different methodologies and samples used, but concluded that 'it is likely' that people with ASD are over represented within the CJS. This recognition of the likelihood of a significant population of people with ASD within the CJS has prompted consideration as to how they may be identified and their needs addressed.

### Management of people with Autistic Spectrum Disorders in prisons

Custody is a challenging environment for most people and may well be especially so for people with ASD. It has been demonstrated that people with ASD find ordinary life in the community far more stressful than most people.<sup>8</sup> They may similarly experience disproportionately high levels of distress whilst in prison resulting in them exhibiting challenging behaviour and gaining less benefit from attempts at rehabilitation. In addition, the difficulties experienced by prisoners with ASD may adversely impact on everyday prison processes and result in inefficient or increased use of resources or other operational disruption.

The difficulties experienced by people with ASD can result in them attracting attention within a custodial environment, although the reasons behind their difficulties may be unrecognised.<sup>9</sup> They can be viewed as being purposefully disruptive, irritating or rude rather than their behaviour being attributed to distress or misunderstanding. Alternatively, they can be bullied but struggle to communicate this to staff and thereby fail to access available support.

In 2013 the National Offender Management Service (NOMS) commissioned the National Autistic Society (NAS) and other charitable bodies to conduct a review of the service

provided to prisoners with learning difficulties and disabilities.<sup>10</sup> Although the review found that staff had good theoretical knowledge of some aspects of autism, it observed that in practice, they often struggled to recognise those aspects in offenders and instead misunderstood their behaviour.

A number of researchers<sup>11</sup> have suggested ways in which prisoners with ASD could be better supported within a custodial environment. These suggestions have included: training to increase the ability of prison and court staff to recognise symptoms of ASD, the development of specific pathways of care for individuals with ASD in prison and the introduction of specialist wings for prisoners with ASD.

Recognition of the unique challenges inherent in developing effective ASD services within custodial settings and a wish to achieve a more pervasive cross-functional impact on the management of prisoners with ASD prompted the project described in this paper.

### Prison ASD Service

A specialist autism service has existed within the Healthcare Department of HMYOI Feltham since 2012. This has input from speech and language therapy, nursing, occupational therapy, psychology and medical staff. Assessments involve the young person, a parent/carer and staff members and comprise comprehensive developmental interviews together with the use of several specialist autism tools (typically the Autism Quotient Questionnaire — 50 (AQ50) and the Autism Diagnostic Observation Schedule (ADOS)).

If prisoners are identified as having an ASD, members of the mental health team work with education and discipline staff to develop an individualised care plan to support the prisoner during his time at HMYOI Feltham. Links are also made with services in the community to ensure ongoing care after release.

In 2014 the ASD service was audited using the Green Light Toolkit<sup>12</sup> against national standards. The results indicated that the service was operating largely at an adequate ('Better') level. However, it was evident from the findings that, in order

6. Kumagami, T. & Matsuura, N. 2009. Prevalence of pervasive developmental disorder in juvenile court cases in Japan. *The Journal of Forensic Psychiatry & Psychology*, 20, 974-987; Siponmaa, L., Kristiansson, M., Jonson, C., Nyden, A. & Gillberg, C. 2001. Juvenile and young adult mentally disordered offenders: The role of child neuropsychiatric disorders. *Journal Of The American Academy Of Psychiatry And The Law*, 29, 420-426; Stahlberg, O., Anckarsater, H. & Nilsson, T. 2010. Mental health problems in youths committed to juvenile institutions: prevalence and treatment needs. *Eur Child Adolesc Psychiatry*, 19, 893-903; Cheely, C., Carpenter, L., Letourneau, E., Nicholas, J., Charles, J. & King, L. 2012. The Prevalence of Youth with Autism Spectrum Disorders in the Criminal Justice System. *Journal of Autism and Developmental Disorders*, 42, 1856-62.
7. King, C. & Murphy, G. H. 2014. A Systematic Review of People with Autism Spectrum Disorder and the Criminal Justice System. *Journal of Autism and Developmental Disorders*, 44, 2717-2733.
8. Hirvikoski, T. & Blomqvist, M. 2015. High self-perceived stress and poor coping in intellectually able adults with autism spectrum disorder. 19, 752-757.
9. See case study in chapter 12 of Chief Medical Officer 2012. Annual Report. Our Children Deserve Better: Prevention Pays. In: Department of Health. (ed.) London.
10. National Offender Management Service 2013. Improving Services for Offenders with Learning Disabilities and Learning Difficulties: A Literature Review.
11. Woodbury-Smith, M. & Dein, K. 2014. Autism Spectrum Disorder (ASD) and Unlawful Behaviour: Where Do We Go from Here? *Journal of Autism and Developmental Disorders*, 44, 2734. 2741; Freckleton, I. 2013. Autism Spectrum Disorder: Forensic Issues and Challenges for Mental Health Professionals and Courts. *J. Appl. Res. Intellect. Disabil.*, 26, 420-434.
12. National Development Team For Inclusion 2013. Green Light Toolkit 2013: A guide to auditing and improving your mental health service so that it is effective in supporting people with autism and people with learning disabilities. Department of Health, London.

to achieve a higher standard of care for people with ASD, it would be necessary to reconceive the management of ASD within the prison from being primarily a mental health responsibility to an approach cutting across all functions and involving the whole prison.

### **National Autistic Society**

The National Autistic Society (NAS) is the UK's leading charity for people affected by autism. It has been running the Autism Accreditation programme since 1992. Autism Accreditation provides an autism-specific quality assurance programme for organisations throughout the UK and internationally. Successful achievement of the programme's standards is recognised by the award of a kite mark representing endorsement by the NAS. Regular oversight and ongoing audit are important components of the system. Achievement is evaluated by a moderated peer review system reporting to an independent Award Panel before Accredited Status is conferred.

Autism Accreditation has been achieved by a wide range of services including schools, colleges, adult day and residential services and secure hospitals. However, it had never been attempted by a correctional facility. The multi-agency applicability of the NAS Autism Accreditation appeared to offer a way to achieve our desired whole prison approach to the identification and management of ASD. Therefore an approach was made to the NAS to collaborate and develop standards suitable for a prison environment.

### **Achieving a partnership agreement**

A fairly lengthy period of liaison took place between the Accreditation Director of the NAS, the Governing Governor and the Health and Education management leads within the HMYOI Feltham before a partnership agreement was finally achieved.

Issues that arose during this period of liaison included querying why prisoners with ASD should be prioritised over prisoners with other difficulties, concerns regarding the extra work that might be involved, cost implications, how to make already overstretched staff available for training, ensuring that by increasing visibility of prisoners with ASD we did not increase their vulnerability, information sharing concerns, reputational risks and delays due to recommissioning of certain in-house services.

However, all these issues were satisfactorily addressed and a partnership arrangement was finalised in late 2014. This landmark project marks the first development of autism standards for prisons worldwide.

### **Project Aims**

The aims of this project were:

- To develop autism standards specifically for the secure estate.

- To improve partnership working within prisons.
- To ensure best practice is delivered across the estate.
- Better recognition of the needs of people with autism.
- Understanding the reasonable adjustments that can be put in place to support people with autism.
- To ensure best outcomes for people with autism.

### **Project Outline**

The project was divided into 6 sequential phases to take place over a 12 month period as follows:-

<i>Develop Standards</i>	<i>January – March 2015</i>
<i>Implementing Standards</i>	<i>March – July 2015</i>
<i>Self-audit</i>	<i>August 2015</i>
<i>External audit</i>	<i>September/October 2015</i>
<i>Accreditation</i>	<i>December 2015</i>
<i>Dissemination</i>	<i>December 2015 onwards</i>

### **Development of Standards**

The aim was to develop a framework of practice and a set of Autism Accreditation standards that were adapted to the realities of the environment, staffing and management in custody. The standards would set out appropriate adjustments and levels of understanding and awareness expected across the different functions within the prison.

A steering group was set up to oversee the project. It had senior representation from Mental Health, Primary Care, Education and Discipline functions at HMYOI Feltham and from the Autism Accreditation division of the NAS. It was chaired by a prison governor and met monthly. The first meeting was attended by the governing governor who made his support for the project clear and requested regular updates about the project's progress. This unequivocal top management buy-in was critical in giving the project credibility within the prison and helping to foster goodwill and commitment to achieving its aims.

It was acknowledged that the prison was not a homogenous institution and that it would not be reasonable to expect a single level of understanding and standard of practice across the whole establishment. Front line discipline and primary care staff should not be expected to have a specialist level of knowledge about ASD but a higher standard could reasonably be expected of staff working in mental health and education. As a consequence, the prison was divided into four areas for the purposes of the audit: Education, Mental Health, Primary Care and Discipline. It was agreed that each area would be audited separately and all four areas would need to meet the relevant standards in order for the prison to be accredited.

The steering group reviewed existing NAS Autism Accreditation standards and it was agreed that, with some modification, existing standards could be used for health and education. However, nothing existed which would be

appropriate to use as a framework to evaluate the Discipline function within the prison, so these standards were developed *de novo*.

In order to develop or optimise their respective standards, each of the four audit areas set up internal working groups which met regularly. The progress of these internal working groups was reported back to the monthly steering group meeting.

The steering group considered the impact of each standard at each stage of a person's journey through the prison from reception to release/transfer.

The key task for the discipline group was to develop a new set of 'discipline' standards which could be used to evaluate the sensitivity of the everyday prison processes and environment to the needs of people with autism. This was achieved by considering which aspects of everyday life within the prison were likely to impact on a prisoner with ASD and to develop frameworks of good practice around these. The processes inherent in the whole pathway from reception to release were identified and consideration given as to how they could be amended to improve the identification and support prisoners with ASD. The frameworks developed were then used as the basis for the new audit standards.

### **Autism Awareness Training**

An important aspect of the project was to begin a programme of increasing staff awareness about ASD throughout the prison. This involved educational sessions provided by in-house mental health staff, distribution of NAS information leaflets and setting up of display areas around the prison highlighting autism as an issue. It was decided that, in addition to providing regular whole prison training sessions, to appoint 25 'Autism Champions' who would undergo more in-depth training about ASD so that they could act as a resource for other staff. Staff from all prison departments were invited to register to become 'Autism Champions' and there was an enthusiastic response. Many came with valuable personal experience of ASD through having friends or family members with the diagnosis or having previously worked closely with offenders with ASD. Care was taken to ensure that champions were appointed from a range of departments. Champion training involved a mixture of face to face sessions delivered by mental health and NAS staff and online training using the NAS 'Ask Autism' online training modules.

Consideration was also given as to how ASD awareness could be increased amongst prisoners. Awareness raising events took place in Education and the library during April 2015 to coincide with World Autism Awareness Day. Comments made by prisoners after participating in these activities included:

*Autism — it's something that I will feel sorry for someone to have and will treat them better than normal people because they can't tell people what they need and how they feel.*

*I didn't realise it was a genetical disability, I thought it was to do with how your parents dealt with you when they were pregnant with you.*

*I think I have autism.*

It was felt that these events were an effective way of disseminating information about ASD to prisoners and it is planned to make them an annual occurrence. We introduced autism awareness training for all Listeners to improve their ability to recognise and support other prisoners with ASD.

### **Implementing the Standards**

Implementation of the standards had two aims. First to check the relevance and feasibility of the standards and secondly to determine how each function could demonstrate that it was meeting each standard.

No extra financial resources were available for this project and a high vacancy rate meant that existing staff were already working hard to achieve other targets (e.g. introduction of CHAT and the protected core day) whilst we were implementing the ASD project. It was recognised that it was important that the requirements of this project did not create an unnecessary additional burden.

One way that this was achieved was to examine all the meetings already occurring within the prison and seeing where ASD issues could be included as recurring items on the agendas (e.g. Equalities action team meeting). This meant that ASD issues were routinely considered during these meetings and the minutes of the meeting helped to provide evidence of those discussions. Similarly, we examined the data gathering that was already routinely taking place to see how ASD related information could be extracted. This way we helped to weave autism awareness into the fabric of the prison routine and minimised any duplication of effort.

It was agreed that some aspects of our autism modifications would be better captured through interviews with staff, service users and carers so it was decided that these should be included as part of the audit evidence as well as traditional paper gathering techniques.

### **Audit**

A comprehensive internal audit took place in August 2015. This was invaluable in highlighting any areas of weakness and ensuring that each area could adequately demonstrate the adaptations it had made to improve the identification and support of people with ASD.

The independent NAS Autism Accreditation audit took place in September 2015. The Accreditation team was composed of 3 people: two with high levels of ASD expertise and one with extensive prison experience.

The inspection comprised a 'walk through' of the prisoner journey by a member of the audit team, from reception, to induction units, to residential wings and

education/workshops. The audit also included opportunities to observe lessons and workshops as well as interviews with key staff across a range of functions. Several opportunities were provided for inspectors to speak to prisoners about their experiences. Paperwork such as policies and procedures, training packages and resources and prisoner and carer feedback were inspected.

In order to achieve accreditation, each area within the prison needed to meet at least 85 per cent of its standards and to have plans as to how it will achieve the remaining 15 per cent of standards.

The audit team presented their findings to the NAS Accreditation Panel which then convened in December 2015 to make a final decision. We are delighted to report that we were successful and have been awarded Autism Accreditation status by the NAS.

This is a great achievement but does not mark the end of the process as it is intended that a once every three years audit cycle will continue and that continuing improvements will be made. Staff from NAS Autism Accreditation will continue to support the prison between audits to encourage continuous development and provide oversight.

Developing and implementing the standards has involved considerable work, and it will be important to be sure of the effectiveness of this ongoing project. We intend to evaluate it using a range of outcome measures to ensure that the frameworks we have implemented are effective in improving the ability of the prison to support prisoners with ASD and to maximise opportunities to engage in rehabilitation.

Prisons are subject to a high level of scrutiny and accountability and the notion of being 'inspected' can be associated with a lot of stress for an establishment. However, our experience of the Autism Accreditation process has been extremely positive. We were allocated an Accreditation Advisor who supported us from the beginning to the end, shared a wealth of experience and learning from other organisations and made the whole process seem eminently achievable. The establishment has gained through the close cross-functional links that have developed as a result of this project and the benefits of this have extended had wide reaching effects.

### **Dissemination of learning**

As knowledge about the project has become widespread both the prison and the NAS have been contacted by a number of other prisons which have recognised the difficulties experienced by people with ASD within their establishments and are interested in learning from our experience. The work has attracted Ministerial attention and in March 2015 the

Prisons Minister issued a statement encouraging all prisons to seek Autism Accreditation (Ministry of Justice, 2015).

Network Meetings were held in June 2015 and December 2015 at which practical advice and learning points were shared with other prisons who had registered an interest in seeking similar Autism Accreditation. Discussion also took place to decide on appropriate ways to evidence meeting of standards. From June 2015, three other establishments joined the pilot to ensure that the standards are transferrable across the adult estate and to other prisons.

A group has been developed to share best practice across the other prisons participating in the Autism Accreditation process.

Pilots have also begun to develop similar standards with the National Probation Service and Community Rehabilitation Companies as well as the Police.

### **Implications for Practice**

The consequences of the successful implementation of these standards are likely to include reduced distress for people with ASD and improved engagement with rehabilitative and day to day prison processes. This is likely to offer prisoners benefits both within the custodial environment and post-release. It will also enable prisons to meet the duties imposed on them by the Autism Act and Equalities Act to make 'reasonable adjustments' to their services in order to ensure that people with ASD obtain fair access and effective interventions. The most recent progress report<sup>13</sup> for the Think Autism strategy mentions the development of these standards for prisoners with ASD as an example of good practice.

The implementation of these standards is particularly relevant for Young Offenders Institutions (YOIs). A new tool has been developed to improve the identification of health problems amongst young offenders, the new Comprehensive Healthcare Assessment Tool (Shaw et al., 2014), this incorporates a specific screen for ASD which is likely to lead to increased detection of these disorders. The CHAT is now compulsory for all receptions into youth custody (and there are plans to extend its use to Youth Offending Services in the future). Implementation of these autism standards in YOIs could ensure that a framework of good practice exists to support young people identified as having ASD by the CHAT.

Implementation of these standards is likely to require allocation of staff time and some costs in relation to staff training. Training costs can be minimised by using the prison mental health team to provide staff training. It is hoped that, once implemented, the new framework of care will mean that the prison is better able to meet the needs of people with ASD and result in less disruption to everyday processes, increasing overall efficiency within the prison.

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13. Department of Health (2016) Progress Report on Think Autism: the updated strategy for adults with autism in England, HMSO, London. [www.gov.uk/government/publications/progress-report-on-strategy-for-adults-with-autism](http://www.gov.uk/government/publications/progress-report-on-strategy-for-adults-with-autism) accessed 27 January 2016.