Adults with autism and the criminal justice system

A report from Overview & Scrutiny

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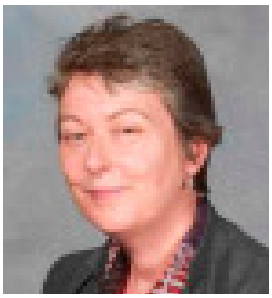
Preface



Councillor Karen McCarthy,

Member of the Health & Social Care Overview & Scrutiny Committee

I have heard about many examples of autistic adults and their families under terrible stress, and met some of them in my ward. A constant worry for them is that the autistic person who feels they have not done anything wrong can get into trouble with the police at any time. All too often the autistic person will be frightened and stressed, and unless the police are autism-aware and help the person manage the stress, the attempts to reduce their own stress will be misinterpreted, leading to the police apprehending them.

I was pleased that we found that some police officers were heroes. A parent told us of one who had spent hours patiently talking with and advising her autistic adult son who was desperate because he was being victimised by people in his neighbourhood. And though many of the stories shared with us about encounters between autistic people and the police showed lack of autism awareness leading to bad outcomes, three of them showed wise, sensitive policing and positive outcomes.

Before the inquiry began I had the impression that autistic people get into police encounters, and into courts and prisons, more often than the average non-autistic person. We learned that those impressions were true: they are seven times more likely to encounter the police, and at least three times more likely to be imprisoned. Yet few of them intended to do wrong or realised that they were doing that.

Autistic people are very vulnerable. They see and take in far more details than the rest of us do, but find it difficult to make sense of those details. They take words literally and cannot work out others' motives, so false 'friends' can involve them in crime without them realising that.

I hoped we would find that all criminal justice agencies and the mental health trust would have reliable, comprehensive data that would enable us to trace the extent of the challenge. Unfortunately that was not the case: some had almost no data, and others had incomplete and inaccessible data about how many autistic people to whom they had responsibilities. We identified the need for better data as a basis for better commissioning and better safeguarding.

I am delighted to hear of the planned new Specialist Autism Resource Centre (SPARC) due to open this year in Edgbaston. It is a positive and very welcome development.

I hope that this report will be useful to many of those who are affected by autism, whether they are autistic themselves or care about somebody who is. I hope also that the criminal justice agencies and mental health trust will do all they can to make their staff aware of autism and what that awareness means for their own behaviours and practices.

Councillor Karen McCarthy

Member for Selly Oak, and Lead Member for this inquiry.

Summary

Our original assumption was that if we could identify and arrange to meet better the un-met or ill-met needs of autistic adults, fewer of them would get into trouble with the criminal justice system or be misdiagnosed as having mental disorder.

We found that there is little reliable data on the numbers of autistic people who are:

- Apprehended and detained by the police, who are the "front end" of the criminal justice system;
- Encountered by the Crown Prosecution Service, which decides which cases should come to court;
- Seen by the courts themselves;
- In the prisoner population; or
- Referred to the secondary care of the Mental Health Trust.

Many autistic people and the agencies that serve or interact with them could benefit from a Birmingham-wide database of all those diagnosed with autism, or better still a West Midlands or national database. The current lack of solid data hampers commissioning and leaves many people with autism unable to prove their diagnosis in order to minimise trouble or obtain the support they need.

Witnesses told us that most autistic people have and follow a strict moral code and are unlikely to break the law, and most of those that do break the law neither mean to nor understand that what they are doing is a crime. They are much more likely to be victims of crime than to be criminals.

The key factors that can reduce the number of autistic people who get into trouble with the criminal justice system are (1) early diagnosis which gives access to support services; (2) training of the majority of front-line police officers in autism awareness; (3) offering fixed activity routines – wherever possible, paid employment - that could fill much of the autistic adult's day and that they will feel safe doing, to minimise the risk of other people exploiting their vulnerabilities; (4) enabling them to know where and how to obtain advice and support services when needed, particularly around the various transitions in their lives; and (5) to develop a social care advice, guidance and coaching pathway to which courts could divert autistic offenders as an alternative to giving them criminal convictions.

The key stages to serve the general needs of most people with autism are (1) to get the numbers of people known to have autism together in a single data file or database and provide the number totals to Joint Commissioning so they can commission appropriate services; (2) to look out for more 'concealed' diagnoses being unconcealed, and add them to the database, as commissioned services become more available; (3) to improve and extend diagnostic services: use the SPARC diagnostic service, continue to raise GPs' awareness via the Clinical Commissioning Groups, and develop a clearly-understood, widely-publicised diagnostic pathway; and (4) as diagnoses rise in quality and quantity, to add the numbers known to have autism into the database, ready to drive the next round of commissioning.

When talking with witnesses we have shared with them our draft proposals in the hope that they will act on some of them during, rather than after, the inquiry.

Summary of Recommendations

	Recommendation	Responsibility	Completion Date
R01	That Joint Commissioning involve Autism West Midlands in discussions with clinical commissioning groups concerning the creation of a definitive West Midlands list of all notified diagnoses of autism and how best to capture more diagnoses and optimise the relevant agencies' use of the list	Cabinet Member for Health & Wellbeing	June 2013
R02	That autistic adults be encouraged and where possible supported to obtain and carry an Autism Attention card	Autism West Midlands, and Cabinet Member for Health & Wellbeing	June 2013
R03	That all agencies interacting with parents, carers, teachers or support workers ask them to record any triggers they know that tend to create high stress in the autistic person, to define those triggers on a card and to encourage the autistic person to keep and use that card with their Autism Attention card	Autism West Midlands; Cabinet Member for Children & Family Services; & Cabinet Member for Health & Wellbeing	June 2013
R04	That all young people with a diagnosis of autism be given support for their transition to adulthood, even where they are not attending school	Cabinet Member for Children & Family Services	June 2013
R05	That a pathway be developed to support autistic students to complete degree or professional courses	Cabinet Member for Health & Wellbeing	June 2013
R06	That staff in each Accident & Emergency unit be provided with the AWM guidance note *A&E staff: dealing with patients with autism*	Cabinet Member for Health & Wellbeing, and NHS Trusts with A&E units	June 2013

R07	That Joint Commissioning commission creation of a referral pathway to develop social skills in autistic offenders, and once it is ready, make magistrates and judges aware of this so they can, where appropriate, make a disposal order to that pathway instead of a criminal conviction	Cabinet Member for Health & Wellbeing	June 2013
R08	That a diagnostic pathway for autism be developed, introduced and publicised to GPs, Psychiatrists and Psychologists whose work includes diagnosing autism	Cabinet Member for Health & Wellbeing	September 2013
R09	That the Health & Wellbeing Board asks each Clinical Commissioning Group operating in Birmingham to set out its plans and target dates for ensuring that its GPs have enough knowledge to diagnose autism or possible autism	Cabinet Member for Health & Wellbeing	June 2013
R10	That the Police and Crime Panel, supported by a letter from the Cabinet Member for Health & Wellbeing, ask the newly-appointed Police and Crime Commissioner to include in the Police and Crime Plan how and by when the majority of front line police officers will be trained or self-trained in autism awareness sufficiently to support them when interacting with autistic people or those whose behaviours appear to be autistic	Police and Crime Panel, and Cabinet Member for Health & Wellbeing	March 2013
R11	That Birmingham & Solihull Mental Health Foundation Trust prepare a plan for its community psychiatric nurses to be trained on autism awareness and autism diagnosis	Cabinet Member for Health & Wellbeing & Chief Executive, BSMHT	June 2013

R12	That letters – and, six months later, follow-up letters - be sent to the Bar Council and the Law Society, asking them to arrange for any criminal justice professional in Birmingham who has neither been trained nor scheduled for autism awareness training to visit the Autism West Midlands website and download the advice guides most relevant to their work, then read and discuss them with others	Chair of the Health & Social Care Committee	March 2013 then September 2013
R13	That Autism West Midlands be invited to report to the Council's Health & Social Care Overview & Scrutiny Committee at its last meeting in 2013 on how they perceive the picture of support for people with autism, including a report on how SPARC has been used in its first year	Chair of the Health & Social Care Overview & Scrutiny Committee	Invitation to be sent by 1 November 2013, to report to HOSC in December 2013.
R14	That each Birmingham City Council directorate and NHS Trust prepare plans to designate two jobs that add value to the organisation and which can be designed to be filled by autistic people	Cabinet Member for Health & Wellbeing; Cabinet Member for Children & Family Services, Cabinet Member for Development, Jobs & Skills	June 2013

1 Autism and the criminal justice system

An adult with Asperger's Syndrome was arrested and taken to …… Police Station in Birmingham. On being booked in he produced his Autism West Midlands 'Attention Card' to make officers aware of his condition but the Custody Sergeant threw it on the floor and refused to treat him as vulnerable.

Note: Except where indicated otherwise, stories and quotes shown in italics in boxes in this report were provided by the Criminal Justice Sector Development Lead from Autism West Midlands.

1.1 Introduction

1.1.1 It is estimated that about 500,000 people in the UK have an autistic spectrum disorder (ASD). It is also estimated that 65% of autistic people also have a mental health disorder and that 50% have a learning disability. Autism is sometimes wrongly assumed to be a form of one of those. But it is neither: it is a lifelong developmental disorder, so cannot be treated or cured.

1.1.2 'Autism' literally means 'a state of being alone'. People with autism have problems all their life with social interaction, social imagination and social communication, and many have severely restricted interests and highly repetitive behaviour. The spectrum of autistic disorders ranges from low-functioning classic (Kanner – pronounced 'Connor') autism where the person's attention is locked into their own thoughts, with no speech and minimal interaction with anything or anyone around them, to high-functioning autism or Asperger syndrome, with which people can live relatively independently. High-functioning autistic people may have high intelligence: Albert Einstein, considered the greatest scientist of his time, is thought to have been on the autistic spectrum.

1.1.3 This inquiry is not intended to address all or even most aspects of autism because it would take several years to do that justice. Instead it focuses on minimising the number of adults at or near the high-functioning end of the spectrum who get into trouble with the criminal justice system or are referred inappropriately to secondary mental health services. The aims are to improve the quality of life for them and those who care about them, and potentially to reduce the total cost to the public purse.

1.1.4 We explored how the prison identifies and copes with autism for several reasons, even though people are already in trouble by the time they get there. Comparing the numbers of people with autism in the general population and who encounter each part of the criminal justice system might indicate where more autism awareness is needed. We had received conflicting evidence about whether autistic people find prison routines

comfortingly safer and more predictable than life outside, or whether they want release as soon as possible, so wanted to explore that. In the event we could not achieve either: prison managers did not know which prisoners were autistic. However looking at why so few incoming prisoners were diagnosed highlighted that mental health nurses lack the training to diagnose autism. We learned why the under-diagnosis was not corrected later. Finding the annual cost of keeping a prisoner helped us estimate the public purse savings from reducing the number sentenced to prison.

1.1.5 Autistic people have, to varying extents, weak *central coherence* (the natural predisposition people have to place information in a context in order to give it meaning); poor *executive function* (the mechanism to enable us to move our attention from one activity or object to another flexibly and easily, allowing us to plan, organise ourselves and to solve problems); problems with *theory of mind* (the ability to appreciate the mental states of oneself and other people); and *context blindness* (an inability to understand the shifting social context for one's actions and the actions of others).

1.1.6 As a result, many autistic people find everyday interactions extremely stressful. One sufferer explains that: "*To me the outside world is a totally baffling, incomprehensible mayhem which terrifies me. It is a meaningless mass of sights and sounds, noises and movement, coming from nowhere, going nowhere*." Another says "*I feel like an alien visiting a world I don't understand and that doesn't understand me - everything is random, unpredictable and frightening*."

1.1.7 To add to these problems, the combination of characteristics makes autistic people very vulnerable to being abused, bullied and misused by other people. Such data as exists concerns children: research sponsored by the National Autistic Society suggests that in any year, between 35% and 75% of autistic children are bullied, compared with 4% to 10% of other children. Autistic adults are also very vulnerable to being bullied but whilst we have been given anecdotal evidence of individual adults being very badly mistreated, including being robbed and assaulted, we have no data on what percentage of the total population of autistic adults suffers bullying. We were told by Autism West Midlands that everybody with autism lives in a constant state of heightened stress.

1.1.8 There are many more people at or near the high-functioning end of the spectrum than at the low-functioning end. They may appear to be capable because they have good use of language and will seem to others to be normal in most situations, but their understanding is still limited by the problems outlined above. They are the ones most likely to get into trouble with the criminal justice system.

1.1.9 Many high-functioning people are classed as having Asperger syndrome. The National Autistic Society says opinions differ as to whether that syndrome and high-functioning autism are the same or different disorders. The differences seem to be that in Asperger syndrome there is no delay in language development in childhood, while

children with high-functioning autism may have had significant language delay; and that those with Asperger syndrome are more likely to have difficulty with fine motor skills. However the fundamental presentation of the two conditions is largely the same. This means that treatments, therapies and educational approaches should also be largely similar. In general literature the terms tend to be used interchangeably.

1.1.10 Often three gaps occur as autistic children become adult: namely a time gap, a financial gap and a support gap.

1.1.11 Whilst they are at school, its routines provide structure to their weekdays, so once they leave school the structure ceases, and a time gap opens. Witnesses told us that many newly adult people with autism become fearful of leaving their home, which hampers their access to support. Many autistic people need safe, active routines to fill much of their day, with support available if needed.

1.1.12 The second is a financial gap: if the carer – usually a parent - has been able to get paid work whilst their autistic child was at school, they may have to give up that income in order to be on hand to provide support and safeguarding full time. Also those who claimed child benefit lose it once the child becomes 16, and very few autistic people qualify for employment or disability allowances. Once the planned welfare reform becomes law autistic people may struggle with the assessment process as many do not feel safe leaving the house or meeting new people.

1.1.13 Most of the support services the autistic child received, including the support they need to interact with the outside world, were linked to their education. So a support gap starts to open at 16 if they leave school then, and opens wider when they become 18, since very few of them meet the eligibility criteria to receive adult social care services. Sometimes the support framework disappears earlier, for example if the autistic child is excluded from school. It seems unlikely that the autistic newly-adults' needs for support suddenly disappear, so unless they or their carers can find new replacement support services some of their needs for support will remain un-met or ill-met.

1.1.14 Our starting assumption is that if we can identify those un-met or ill-met needs and find ways of meeting them better, fewer autistic adults would get into trouble with the criminal justice system or be misdiagnosed with mental disorder. That would improve theirs and their carers' quality of life, and also potentially mean a net saving to the public purse.

2 Numbers of people with autism

2.1 National statistics

2.1.1 Autism affects between 1% and 2% of the national general population. For several years the overall proportion was thought to be 1%, based on 1.8% of males and 0.2% of females being autistic. Now that more cases are being diagnosed it is thought that the proportion is closer to 2%, in part because there is under-diagnosis of females with autism. A press article about autistic women, in Appendix 1, shows possible reasons for the under-diagnosis.

2.1.2 We know that people whose autism is at or near the low-functioning end of the spectrum cannot look after themselves for long in public without help. Autism West Midlands said that half of all those with autism have no speech. In public they will almost always be supported and accompanied by a carer or support worker who could speak on their behalf to anyone, including the police and the courts. So they are unlikely to get into trouble with the criminal justice system.

2.1.3 Because those on the high-functioning parts of the autistic spectrum are more likely to be away from a carer or support worker, they are more at risk of being led into crime or of being arrested if their actions in public seem out of control.

2.1.4 Based on research in the USA, the National Autistic Society reports that autistic people are on average seven times more likely than others to come into contact with the police, either as victims, witnesses or alleged criminals.

2.2 Birmingham statistics

2.2.1 National statistics applied to Birmingham's population of just over a million suggest it has between 10,000 and 20,000 people with autism.

2.2.2 Census data show that 26% of Birmingham's population is 18 or younger so we estimate that in Birmingham there are between 2,600 and 5,200 autistic children and between 7,400 and 14,800 autistic adults.

2.3 Police data

2.3.1 The ways the police may find that someone in their custody has autism is through victim or witness statements, custody records, crime reports, or requests for an appropriate adult. If so, that information is noted on the manual records of prisoner

characteristics that are held locally in each of ten local policing units (LPUs), of which there are four in Birmingham.

2.3.2 Unfortunately the key information, which should be indicated by ticking a box on one of several forms, is not computerised, summarised or reported anywhere.

2.4 Court data

2.4.1 Around 98% of criminal cases start and finish in the Magistrates' Court. Others start in the Magistrates' Court but finish in a higher court – usually the Crown Court - where a jury decides guilt or innocence. There are some offences so serious that anyone charged with them is either bailed or remanded in custody by the Magistrates' Court, but the case is sent to the Crown Court straight away.

2.4.2 One of the Council's principal solicitors heads a legal team that has close contacts with the courts. She told us that the courts only record or keep information that they need, so there is no system of recording how many witnesses or accused people are autistic.

2.5 Prison data

2.5.1 Her Majesty's Prison Birmingham holds adult male prisoners, both convicted and unconvicted. It has certified normal accommodation for 1,112 prisoners and operational capacity for 1,450. The actual number of prisoners is close to or at its operational capacity: an inspection report by HM Chief Inspector of Prisons showed that at 15 December 2011 it had 1,442 prisoners, so there is a degree of overcrowding. The current contract to run the Prison is held by G4S Care and Justice Services.

2.5.2 Research suggests that a high proportion of prisoners have learning disabilities, mental disorder or substance abuse problems, so prison systems focus on those three issues rather than autism, which affects far fewer prisoners.

2.5.3 There are several ways by which prison staff might find that a prisoner has autism. On arrival a new prisoner goes to a first night centre and is assessed by an NHS general nurse, who may also call in an NHS mental health nurse if mental health seems to be an issue. However a general nurse is unlikely to have been trained to recognise autism symptoms and our Mental Health Trust witnesses confirmed that autism awareness is not part of the standard training for mental health nurses. Most of the nurse's findings remain confidential and are not disclosed, but prison staff are notified of any special needs for which provision needs to be made. The police or court may have passed on the message about autism, through a Prisoner Escort Record document.

2.5.4 The prisoner might say he has autism, but many new autistic prisoners will be very stressed by the unfamiliar situation and may not be in a state to communicate well. If, later, an autistic prisoner attends an educational class it is possible that the teachers

will diagnose autism, and if they do, should report that to prison staff. Prisoners are asked to agree to the prison obtaining copies of their medical notes from the GP. Only some prisoners authorise this: others do not feel it is appropriate in case knowledge of their vulnerabilities spreads and make them targets. So there will be cases where autism may be diagnosed neither at entry, nor afterwards.

2.5.5 Prisoners known to have autism might be placed under section 43 of the Prison Regulation Act, which means they are vulnerable. This makes three other options available, namely move to a Vulnerable Prisoners wing which is away from the mainstream prisoners, being moved to a hospital wing, or being moved to a more suitable prison.

2.5.6 Rule 43 is thought of as a 'last resort' only used for prisoners such as sex offenders who are at risk of violent assault by others who dislike their offence: most prisoners would see Rule 43 as a punishment. The hospital option is unlikely to be appropriate because autism cannot be treated or cured, though its co-morbidities (other disorders), if any, might be treatable. Transfer to a more suitable prison may not help if it takes the autistic prisoner away from the practicable visiting range of their family or carer. None of these options has to be taken if the prisoner can be adequately safeguarded without them.

2.5.7 If a vulnerable prisoner is being bullied or misused by other prisoners the Prison Mental Health Team follows this up, and if the matter cannot be resolved the prisoner is put into 'A' wing, which looks after prisoners who struggle to cope with custody.

2.5.8 The Prison's Deputy Director said there are on average ten prisoners with 'severe' autism – that is, those who display obvious symptoms most of the time - but he did not know how many others had autism. [Note: Clinicians rarely use the 'severe' term in relation to autism].

2.5.9 Autism West Midlands told us that between 4% and 7% of prisoners are autistic. This is based on one study finding of 7%, and other studies finding smaller percentages but saying that prison staff and governors viewed those as underestimates. The Deputy Director agreed to make enquiries amongst other managers and staff and tell us an average of their estimates, using any reliable data they have. The average estimate was that there are about 80 autistic prisoners including the ten with 'severe' autism. 80 prisoners are 5.5% of the total prisoner population of around 1,450. We note that by coincidence this falls exactly half way between the research findings.

2.5.10 The Learning Prison report says "A former prisoner who re-offends costs the criminal justice system an average of £65,000 up to the point of re-imprisonment: it then costs an average of £40,992 a year to keep them there." So imprisonment of someone with autism who did not realise they were committing a crime is not only a disaster for the individual and anyone who cares about them but a major cost to the public purse.

2.6 Mental health data

2.6.1 Overall we found that at present the Trust has no reliable information about the number of patients referred to it who have autism, either as well as or instead of mental disorder. Further information on mental health and autism is given in the 'Mental Health and Autism' section of the report.

2.7 Data scarcity

2.7.1 In summary neither the police, courts, prison nor the mental health trust have reliable, accessible data on the number of autistic people with whom their organisation interacts. This makes it difficult to plan services. As a result some people whose autism makes them uniquely vulnerable go through criminal justice or mental health experiences that they can barely, if at all, understand or cope with.

2.8 Databases: too many or too few?

2.8.1 We found that several organisations had incomplete databases listing the autistic people they served. Service providers are reluctant to recognise the need for a database: Birmingham Commissioning team asked 300 of them for information on the numbers of autistic people they served, but only 13 responded to the survey. If there were a comprehensive national database listing everyone diagnosed with autism it would be of use potentially to autistic people or their carers or support workers when accessing support or care services for them, and to all parts of the criminal justice system, mental health services, hospitals and GPs, and social care staff.

2.8.2 The Council's Joint Commissioning staff are talking with GPs to see if a reliable database could be created. A Birmingham-only list would be of some use, but a West Midlands list would be better, and the ideal is a national list, perhaps held by the National Autistic Society or by the NHS. The Information Commissioner may need to be informed once plans are ready, and use of the list will need to comply with Data Protection Act rules. As a first step, it was agreed that from Monday 22 October 2012 any of the Council's Social Care service users who is known to have autism will be recorded on Care First Six, the social care service user database, and the database is set up to accept this.

2.8.3 Autism West Midlands has what might form the basis for a West Midlands-wide list. There needs to be discussion about which organisation will hold the definitive list; how all the agencies that might diagnose autism – including parents and GPs – can be told why, how and to where they are invited to send diagnoses so that they are added to the list; and how the existence of the list can be notified to the many agencies that could validly use it, including benefits agency staff, the police, the mental health trust,

the prison – in order to adequately safeguard autistic prisoners - and other providers of service. Data protection rules will need to be complied with and thought will be needed as to how to minimise the risks of the data being shared inappropriately. We recommend:

R01: That Joint Commissioning involve Autism West Midlands in discussions with clinical commissioning groups concerning the creation of a definitive West Midlands list of all notified diagnoses of autism and how to optimise its usefulness to families affected by autism and to the agencies that serve or can potentially serve them.

2.8.4 If an organisation issues autism alert/attention cards without requiring proof of diagnosis, people who do not have autism could obtain one: for example someone intending to commit a crime might obtain and use a card to avoid being sentenced if caught and arrested. We were told that the police tend to disregard such cards if presented, as they do not prove autism. In contrast, each card issued by Autism West Midlands is backed up by a database record confirming the diagnosis, providing the autistic person has agreed for their record to be on it. So if anyone in the West Midlands, for example a police officer, wants to check whether someone who shows a card and claims to be autistic is telling the truth, they can phone AWM and check. By May 2012 AWM had issued cards to 1,350 Birmingham adults. This suggests that between 80% and 90% of Birmingham adults with autism do not have a card. We recommend:

R02: That autistic adults be encouraged and where possible supported to obtain and carry an Autism Attention card.

2.8.5 The advantages of consenting to their record going on a database needs to be explained in straightforward words to autistic people and their carer or support worker where relevant, to maximise the numbers that consent and can benefit from it.

2.8.6 Once a West Midlands list is created it could form the model for a national (England or England and Wales) list, perhaps held by a national organisation like the National Autistic Society, or by the NHS.

3 Transition

3.1 School pupils

3.1.1 Currently 1,600 children in Birmingham have a special needs statement with autism as a primary need. Statemented children with other primary needs may also have autism, and some autistic children may not be statemented. It has been noticed that in recent years as the numbers of children diagnosed with autism increases, the numbers diagnosed with mild learning disability decreases, suggesting that a proportion of autistic children were misdiagnosed before. Also the ratio of boys to girls diagnosed with autism is changing. Whereas national statistics suggest females are only 10% of those with autism, the percentage diagnosed in Birmingham's statemented children has steadily risen from 14% up to 28%, so diagnosis of autism in girls has increased, and will impact on commissioning plans as that pattern continues into adulthood.

3.1.2 Our witnesses from the Children, Young People and Families Directorate (CYPFD) told us that low rates of referrals for diagnosis come from inner city areas with a mix of cultures. There is concern that in certain cultures if a community finds that a family includes someone who is autistic it may stigmatise that family and not consider its sons – and in particular its daughters – as being suitable for marriage, so families with one or more autistic members may seek to conceal the fact. CYPFD focuses on diagnosing the children and providing support for them, rather than seeking to challenge the cultural attitude.

3.1.3 The CYPFD does not have any data suggesting an increase in police contacts in the teenage years.

3.1.4 In some cases a seemingly small feature of the environment such as a colour, sound or smell can trigger off stress, sometimes extreme stress, for someone with autism. That can tip them into acting abnormally to try to reduce the stress, which in turn may bring them into contact with the police. Some autistic people do not have any particular triggers, while others have one or more. If a member of school staff or a support worker or carer has learned what the normal triggers are for a particular autistic person it would be helpful if they could list these on a card and ask the autistic person to show it with their Autism Attention card if they are approached by the police. As far as possible the trigger information should be shared with all professionals who might interact with the autistic person. They may also be able to coach the autistic person to avoid those triggers or to become less stressed by them. We recommend:

R03: That all agencies interacting with parents, carers, teachers or support workers ask them to record any triggers they know that tend to create high stress in the autistic person, to define those triggers on a card and to encourage the autistic person to keep and use that card with their Autism Attention card.

3.1.5 Though in some cases the 'trigger difficulty' can be resolved on an individual basis as described above, unfortunately it cannot be solved on a general basis. So if an autistic person suddenly shows signs of acute stress in public and does not carry detail of the trigger, there may be no clue to the police or to anyone else as to what triggered off the stress or how the trigger could be identified and avoided.

3.2 Preparation for transition to adulthood

3.2.1 Many schoolchildren assessed as autistic will receive support organised via the school. As they approach school leaving age they should get help, preparation and advice including signposting to other sources of service. The Common Assessment Framework is used, with transition pathway plans from when the children are 14 years old, and the plans are reviewed annually. The Autism Education Trust has developed a set of 43 National Standards with funding from the Department for Education in England, to describe the key factors common to good practice for pupils with autism. The Standards have been designed to enable staff in educational settings to find the extent to which the needs of pupils with autism are addressed, by analysing policies, systems and whole school development work. Some of these standards focus on transition to adulthood. They were published in April 2012.

3.2.2 Sessions focus at first on social skills, money management, communication and interaction. These include social care topics. There is also an evidence-based parenting programme called Cygnet, offered by the Disabled Children's Social Care Team, the Communications & Autism Team, and Child & Adolescent Mental Health Services. This programme is designed to help parents manage children with autism and a range of the associated challenges. For statemented children, there is a duty for child care up to age 18.

3.2.3 There may be many reasons why children with or without autism may not attend school, for example if they are in hospital, suspended from school, or educated at home. They are at risk of not receiving enough transition support. We are concerned that the stories we received from parents of autistic adults do not mention their children having received any transition support. One parent witness was asked directly whether her son, who had repeatedly been excluded from his school, had had any support for his transition to adulthood. She told us he had not. We recommend:

R04: That all young people with a diagnosis of autism be given support for their transition to adulthood, even where they are not attending school.

3.2.4 The Services in Complex Children (CAT) team will ensure that the National Standards for autism are developed and applied to services and settings and this implies good transition at all key stages including to Adult Services. The new SEN reforms identify that each local authority will publish its "Local Offer" and transition pathways to adulthood will be clearly laid out in the document. However it needs to be remembered that many people with autism will not qualify for Adult (social care) Services. Education Welfare and Integrated Family Support Teams may help in ensuring that every child, including non-attendees, will be supported through transition.

3.2.5 As the young person reaches 18, the focus changes to supporting independence, employment and training. The Disabled Children's Social Needs Team hands over care after six months of planning with Adult Transition Social Workers, who begin to plan for the handover when the young person is 17½. Meetings are held weekly. Negotiations are progressing with the NHS to bring forward assessments from 18 years old to 17 years old for funding of care. Assessments at the handover stage include the whole family's needs. Some special school provision covers the period until the young person reaches 19 and they are able to remain at the school until the end of that school year. Since 2011 it has been agreed that the Adults & Communities directorate will fund the care element. Both directorates, Adults and Children, are developing closer service integration to meet transition needs.

3.2.6 From April 2011 local authorities have taken on a duty to provide short break services – formerly known as respite care – that included autistic children. Increasing demand shows that the service is highly valued: 1400 short breaks were accessed in 2008, and this had grown to 6,000 in 2011.

3.3 Later transitions

3.3.1 Autistic adults may go through other transitions after the one to adulthood. Transition involves change, and autistic people tend to find change very stressful unless they are introduced very slowly to the need for it and given a vision of what the end result will look like.

3.3.2 A common transition is moving from living with family and carer to living alone. Autistic adults who continue to live with their parent or parents may eventually need support or to move out when their parent(s) die or become too old or unwell to support them. Other autistic adults may need to move away earlier either because they want the independence or because their family can no longer cope with their stress-driven aggression. The ideal is that they find suitable affordable accommodation in an area where there is little risk of them being victimised or mis-led into crime; near to a centre where they can take part in activities that will provide structure to much of their waking

hours and that will change rarely and slowly; and that advice and guidance, when needed, is readily available to them from someone they trust. Of course, that ideal is hard to find.

3.3.3 Where an autistic adult needs social accommodation potential sources of advice and help include the Council's Housing Support Service on 0121 303 0439, the Council's Learning Disabilities team on 0121 303 2202, and Autism West Midlands on 0121 450 7574. Others include housing associations: many of these offer care and support services as well as specialised and general housing. The Council's Housing Support Service can advise on the availability of accommodation-related help funded by Supporting People.

3.3.4 Private accommodation normally needs a financial indemnity to be deposited, plus some rent paid in advance. An Internet search for 'Private flats for rent in Birmingham' will show several websites that offer flats at a range of prices and locations.

3.3.5 CYPFD witnesses said the Council recognises it is short of expertise on how best to support children or young people with autism if their parents die. That issue is being addressed. We will ask the Education & Vulnerable Children Overview & Scrutiny Committee to track progress on this matter by asking for a progress report from CYPFD.

3.3.6 Autistic people who continue to live with their parent or parents may abruptly or gradually over several years face a different transition. This is the change from being helped and supported by parents, to having to support them because they are old and infirm or have dementia. This is very challenging for an autistic person who cannot recognise or imagine what others think, feel or need. Autism West Midlands and Social Care can provide practical advice if contacted.

3.3.7 Another is the transition to education. Most colleges and universities encourage group work to enable students to interact and learn from each other, and encourage students to ask questions and state their answers and views on the issues being learned. All this is very difficult for autistic students, even if they are highly intelligent and well-read. A few manage to complete courses, including degree or professional courses, but many more drop out of courses because they cannot cope with the pressures to socialise. Several bodies mentioned in the 'Sources of support' section of this report could help autistic students. The Council's high level supportive programmes are available but are not specifically aimed at autistic students. OSSME, the Outreach Educational Support service, might be able to help them, as might Autism West Midlands.

3.3.8 A support pathway might enable more autistic students to complete their university professional courses. It might identify what learning techniques and environments the student would be able to benefit from and those that the student would find very stressful. It could be sent to universities or other course providers when the autistic

student enrols, and the student could bring a copy with them when they attend. If commissioned, the University of Birmingham might be willing to develop a draft. We recommend:

RO5: That a support pathway be developed to assist autistic students to complete degree or professional courses.

3.3.9 Our CYPFD witnesses said that Independent specialist colleges were more likely to be able to cater for special needs like autism. A new computer-based education provision was piloted from September 2012 for young people who have difficulty accessing normal education provision. Under this scheme there are several training providers who could obtain additional funding to provide specialist support.

3.3.10 If it is known in advance that an autistic person will have to stay in hospital and has a responsible person who understands and accepts the need to prepare them for that event they can greatly reduce the stress experienced when it happens. However sometimes the need to go to hospital is not apparent beforehand. Pain may show someone has a significant injury or illness. But autistic people do not show the normal responses to pain and may not be able to or think to communicate it. So if they are injured or ill others may not realise this until it is serious enough to mean the person has to go to hospital – usually to the accident & emergency unit first - suddenly, without time to be fully prepared. This abrupt transition to hospital will be confusing and frightening for the patient. Autism West Midlands has produced a downloadable guidance note designed for A&E staff treating someone with autism and it would be prudent to take copies when going to hospital. We recommend:

R06: That staff in each Accident & Emergency unit be provided with the AWM guidance note *A&E staff: dealing with patients with autism*.

3.3.11 The other common transition is that from being unemployed to being in a paid job. Again several bodies in the 'Potential sources of support' section can assist with this.

4 More people with autism get to court

4.1 *Mens rea*

4.1.1 A criminal court cannot legally find an accused person guilty of a crime unless the court can establish that there was *actus reus*, meaning that they carried out the criminal act, but also *mens rea*, (Latin for 'guilty mind'). Depending on the nature of the offence, the relevant guilty state of mind might be 'wilful', 'reckless' or 'negligent'. Broadly it means that the accused intended to carry out the act, knew that it was likely to have harmful consequences, and either wanted those consequences to happen or did not care whether they happened. Sometimes a failure to act may be a crime, if the law requires the action to be carried out.

4.1.2 Most autistic people cannot understand or imagine the effects of their actions on others. Thus it should be very rare to prove *mens rea* for an autistic offender. The percentage of the general population that is autistic is thought to be 1-2%. So it might be expected that the proportion of autistic convicted prisoners would be lower than that. Unfortunately the reverse is true: overall the figures in the Prison Data section of the report suggest that compared with an average person in the general population an autistic person is about three times more likely to be imprisoned.

4.1.3 A presentation accessible from the National Autistic Society website quotes prisoners about going into court: "*I was upset, I didn't know why I was there*". "*I understand that I've done something wrong, but I'm still unsure as to what that is*". "*I got sent to prison, which I didn't even know.*"

4.1.4 Autistic adults are much more likely to be victims of crimes rather than to be criminals.

4.2 The Crown Prosecution Service

4.2.1 The Law Society is responsible for training solicitors and the Bar Council is responsible for training barristers. All solicitors and barristers have to do Continuing Professional Development (CPD) learning each year, but this does not necessarily include autism awareness.

4.2.2 The Crown Prosecution Service (CPS) employs about 2,500 prosecutors and has provided autism awareness information to all of them. Defence solicitors, defence barristers and some prosecutors are self-employed and paid by the hour, which makes it difficult to train them. However recently the government has said it plans to create

a Crown Defence Service, and if that employs significant numbers of defence counsel it will make it easier to raise their autism awareness.

4.2.3 Another of the CPS roles is to decide which serious cases submitted by the police will go to criminal court. Its decision on each case will be based on an evidencial test and a public interest test. The evidencial test is whether the evidence provided by the police gives a realistic chance of a successful prosecution: if it does not, the case will not go to court because it would waste the court's time. The public interest test considers whether the alleged offender is so vulnerable that prosecution would have a very adverse effect on him or her, but it also considers whether a failure to prosecute would endanger the public.

4.2.4 The CPS is very reluctant to prosecute vulnerable people such as those with autism, and wherever possible tries to seek a disposal order for treatment rather than a criminal sentence. Our Autism West Midlands witness said that though autism cannot be treated, the prospects for an autistic offender can be improved by developing social skills. However few, if any, councils had referral pathways for autistic offenders yet and that Social Care should design these, giving courts the option to make a disposal order to social care interventions that would reduce the risk of re-offending. We recommend:

RO7: That Joint Commissioning commission the creation of a referral pathway to develop social skills in autistic offenders, and once it is ready, make magistrates and judges aware of this so they can, where appropriate, make a disposal order to that pathway instead of a criminal conviction.

4.2.5 Courts can make disposal orders for restorative justice but unfortunately autistic offenders are unlikely to benefit or learn from that because they lack empathy and understanding: it would be necessary to tailor the intervention to the autistic offender's abilities.

4.2.6 If the police give the CPS medical evidence that a witness is unlikely to cope with the normal court environment the CPS may advise the court that special measures are needed for that witness. The court decides whether or not to act on that advice. The range of possible special measures includes changing how court officials are addressed, removal of wigs, giving evidence by video link, or giving evidence via intermediaries, who are often trained speech therapists. Special measures are used only rarely and usually only for witnesses with learning disability. It is very rare for special measures to be used for a defendant.

UPDATE 31 October 2012

summarising an email received by AWM CJD Development Lead

Autism West Midlands' Criminal Justice Development Lead reports receiving a tentative request from the Department of Health National Autism Lead to present a series of training sessions to staff from the Ministry of Justice, particularly their court services, at a series of regional events

in November and December. If confirmed, finalised and agreed he will train Ministry of Justice court staff for the region in Birmingham on 30 November 2012.

4.3 Autistic defendants have problems in court

4.3.1 However autistic defendants may have all sorts of problems in court. Unless they have been given prior visual images of the court they may be so overwhelmed by the strangeness of the court environment and see its details without understanding its overall purposes, that they may close down and not communicate, or try to reduce their panic by behaving abnormally.

4.3.2 Even if not overwhelmed they are likely, when questioned, to give answers that they think the questioner needs or wants them to give, so they will say "Yes" if they think a yes is needed, even if the true answer is "No". If the same question is asked at different stages of the trial their answers may differ, based on what they thought was expected at the time it was asked, and this risks the judge and/or jury assuming they are lying. They tend to take language literally so unless the question is very short and simple they may not understand it. Their anxiety means that if they do not know an answer they will make up something and say that, rather than saying "I don't know", which they fear might get them into trouble. Autistic people tend on average to take 11 to 15 seconds to take in and understand new data so they are slow to answer questions. That slowness, plus their tendency to display inappropriate facial expressions because they do not understand the social rules, may be wrongly assumed to be signs of contempt. Their reluctance to make or sustain eye contact may give the impression that they are acting guiltily.

4.3.3 But if the judge and counsels know or guess that the defendant has autism they will try to see beyond these behaviours and help the defendant to understand the questions and tell the truth. If questioned appropriately, autistic people can be good witnesses since many have almost photographic memory – our Autism West Midlands witness likened their memory to that of a video recorder – so can remember and repeat accurately the details of incidents better than other witnesses could, even though the autistic person may not fully understand the meanings of the incidents.

4.3.4 If someone with autism commits a criminal act but lacked *mens rea*, he or she has a chance of being given a non-criminal disposal order the first time it comes to court. But autism does not always stop criminal conviction: if the crime is repeated, thus proving that the court's previous action was not enough to protect the public, the offender is very likely to be sentenced.

5 Why more get to court

5.1 Compulsive interests taken to extreme

5.1.1 Autistic people often develop a strong interest and fascination with one or more of the topics they understand and target their behaviour on it: as they find out more about it their interest becomes obsessive, because they feel safe with it. They may be unable to imagine how their obsessive behaviour affects others and that can lead to other people being inconvenienced or alarmed and eventually calling in the police when the behaviour does not stop.

5.1.2 If the autistic person has computer skills he or she is able to explore all aspects of the topic they are fascinated by, and if the fascination is compulsive that may lead to them to developing ways of legally accessing or illegally hacking into databases that might hold data about the topic, which might include company, business or government databases. The companies or government may use the law to stop the hacking, and perhaps to punish the hacker in the hope of deterring others. So the autistic hacker may be arrested and tried.

5.1.3 Our Crown Prosecution Service witness told us of another autistic man who was obsessed about winning. Since many people with autism have balance and co-ordination problems in addition to other physical disadvantages, few engage in sports. Though he could not win by playing football the man could win by supporting a winning football team. He did not support the team, just the winning. He spent a lot of money buying many teams' tops. When going to a match he would wear the home team's top, but underneath it he also wore the opposing team's top. If the home team started to lose, he would stop shouting support for it, take off his top to reveal the other team's colours, and start shouting support for that team. This enraged the home team's fans who were all around him so fights broke out and the police were called. When this kept happening at further matches he got into trouble with the police.

5.1.4 *A youth with Aspergers was arrested in ……. for handling stolen bicycles. His 'Special Interest' is bicycles and local youths are aware of this and take advantage by stealing and selling them to him. The OIC* (Officer in Charge) *has changed 3 times and none of them have any understanding of ASD and why this leads to 'Special Interests' which are obsessive. They keep re-bailing him resulting in extreme anxiety and confusion due to his condition.*

5.1.5 Sometimes a satisfactory solution can be found by negotiating boundaries. The Crown Prosecution Service witness told us of an autistic man who was fascinated with kitchen

plumbing and taps, and started spending whole days in a retail store's kitchen and bathroom sections, handling and manipulating the taps and fittings on display. This made other customers uneasy and several complained to the store's management. Eventually it was agreed that the man could come into the store and handle and look at the taps and fittings for half an hour each morning and half an hour each afternoon, at defined start and finish times. He kept to the bargain, and harmony returned to the store. One aspect of support that some autistic adults need is help in negotiating compromises with organisations.

5.2 Becoming highly stressed

5.2.1 Witnesses told us that autistic people are much more likely than others to reach a state of sensory overload, particularly when in strange situations, strange places and with people they don't know, whom they perceive as invading their personal space or making demands that their brain cannot interpret. Their inability to put details into context means they can be mentally overwhelmed by a seemingly huge volume of sensory stimuli that seem to be random and unpredictable.

5.2.2 It may be hard for people who are not autistic to understand what it feels like to be deluged with data and sensory stimuli. Two images taken from a PowerPoint presentation 'Incredibly different or differently credible?' by Sue Mulcahy, Jacqueline Wheatcroft and Laurence Alison for the University of Liverpool and downloaded from the Internet might give a visual impression. The first image is a slightly blurred picture of a man's head and shoulders (in this case, Richard Madeley's). Whereas we could see someone else clearly and make a swift assessment of his or her mood and state of mind, autistic people see much more detail and can pick up multiple and ever-changing messages from the person's face, so the other person's motive and purpose is blurred. Autistic people tend to avoid eye contact because it is hard work for them to keep interpreting the changing signals they pick up from other peoples' eyes. If they are on the higher-functioning half of the autistic spectrum and not over-stressed they can distinguish sufficiently between the various signals to recognise voice, and after a short delay allowing them to interpret what has been said, to respond.

5.2.3 But if someone has low-functioning autism the second picture may be a better illustration. In addition to confusingly large quantities of sensory stimuli coming at them from the other person they are also taking in data from all aspects of the environment around them that our subconscious would choose to ignore. They see that lights are increasing or decreasing their luminosity, and that they are quietly humming, with the humming varying in tone. They see subtle variations in colours, shades and textures and hear many small sounds. Some people with low-functioning autism pick up so many different changing sensory stimuli that they cannot identify voice as the key signal, so will not answer it, which is partly why about half of all people with autism have little or no speech.

5.2.4 Physical sources of stress could include, but not be limited to, being in pain; being too hot or too cold, or being hungry or thirsty. Autistic people who are in pain, even intense pain, do not usually behave as other people in pain will behave. They may not mention, hold or guard the hurt area. They may have a favourite item of clothing that they wear in all and any weather conditions so may need something to cover them if they could be cold. They may need food or drink. If the physical need can be recognised and met, it may allow the autistic person's stress levels to drop.

5.2.5 If a high-functioning person with autism is in an unfamiliar situation and place and is frightened because they cannot understand what others want them to do, they too are likely to be so overwhelmed with data coming at them that they become very stressed.

5.2.6 When their brain approaches overload it instinctively shuts down most of its cognitive processes to prevent it being damaged. Only the oldest, most primitive part of the brain remains active. This includes the 'fight or flight' system, so if the person cannot flee from the unbearable stress they are experiencing they must fight to try and end it. This may seem to others to be unprovoked aggression, rather than a purely defensive action. If police attend their normal response to aggression is to try to physically restrain the aggressor. That response may be appropriate for a non-autistic aggressor but is wholly inappropriate for one who is autistic: they will just panic more, fight harder and if this doesn't work, may go into 'total shut-down' where they cannot communicate or respond to others' communications, potentially for days.

5.2.7 Here is an account of a real case reported to us by Autism West Midlands. It illustrates an incident in which several agencies could have identified the possibility of autism and modified their behaviour accordingly, but none did.

Case 'A'

Diagnosed at age 7 with Asperger Syndrome (high functioning autism). Now 19 years old.

Sequence of events:

About 22.15hrs Saturday ---- May 2011 'A' was walking home from the ------- Public House situated about a mile from his home with a long term friend with whom he is comfortable. They had consumed 2 drinks.

'A' was subjected to a violent attack by 2 persons who hit him in on the head with a brick and stamped repeatedly on his head as he lay on the floor. He was robbed of both his mobile telephone and his wallet (containing his Autism West Midlands 'Attention Card' amongst other things). An eye witness in a neighbouring house called police and ambulance. The Command & Control log may well contain information about the caller's initial belief that 'A' was dead as he was apparently unconscious and not moving.

'A' was conveyed by ambulance to A&E at ------- Hospital for treatment.

He received stitches to his wounds and regained consciousness. At this point, in addition to possible concussion and shock he began to suffer what is referred to as 'sensory overload', which is common in people with autism. He had awoken in a strange place, surrounded by strangers unable to make sense of why he was there and what was happening. Due to his autism, unpredictable situations, change and unfamiliar people / places all cause confusion, extreme anxiety, fear and an overwhelming need to escape from this situation to somewhere familiar.

He could not phone home for assistance as his mobile was stolen, he could not produce his 'Attention Card' to make staff aware of his difficulties or provide contact details as his wallet was stolen. He did the next best thing and told them he was autistic and needed to get home and requested a lift. When this failed to meet with cooperation his ability to process information became more impaired due to the effects of sensory overload increasing as he tried to think his way out of the situation (an extremely difficult if not impossible task for someone with autism even when not in a heightened state of anxiety).

His resultant behaviour was entirely predictable and consistent with people with autism in such a heightened state; it is likely he had gone into a 'meltdown' which can have the effect of putting the person into a complete black-out where they are unable to have full control over their actions and cannot calm themselves down. As a consequence, he began shouting as most of his mental functions had closed down and the only fully functioning part of the brain became the original part concerned with the primal 'fight or flight' survival function.

At this point Hospital security staff became involved. They physically restrained 'A', this being the worst thing to do with an autistic person in this situation. As explained his whole body and mind at this point was in 'survival mode' and predictably he fought as his confused mind would interpret restraint as a threat to his life.

It was at this point that a police officer became involved and, with the security staff, wrestled 'A' to the ground, where he was forcibly restrained and handcuffed. During this action his wound was re-opened and he was then forcibly restrained as a further 5 stitches had to be administered. The officer requested assistance.

A total of 5 officers then placed what 'A' later describes as 'tape' around his legs, but which we suspect was an approved restraint belt. He was thrown into the rear of a police van and taken into custody at --------- police station. It is not known what offence is recorded on the custody record as reason for detention initially.

He was detained in total for around 17 hours. Although his parents were informed of his arrest and informed the custody sergeant of his autism, they were still not allowed to attend custody to see him and assist in reducing his anxiety and fear until officers were ready to interview. His father was then allowed to act as 'Appropriate Adult' for the interview.

He was subsequently charged with 2 x offences of 'Assaulting a Constable in the execution of his duty'. He appeared at ---------- Magistrates Court on Wednesday --- June and entered a plea of 'Not Guilty'. The case was adjourned and came to trial in November. Below is the outcome:

- *'A' appeared at ---------- Magistrates Court on Friday --- November 2011 to stand trial. The case was to be heard before a circuit Judge.*
- *The Judge at the request of the defence allowed 'A' to sit with his parents behind the defence counsel rather than having to sit alone in the dock.*
- *It was clear the Judge had studied the case papers in advance, in particular the psychiatric report. He asked if the prosecution would be 'offering no evidence' as it appeared to him that it was not in the public interest to pursue a prosecution in this case.*
- *The CPS prosecutor wanted to continue the trial but was advised by the Judge to seek guidance from his superiors and briefly adjourned to allow this to happen.*
- *On his return the prosecutor insisted he had been told to continue. At this point, the Judge pointed out that were he to do so, given the assessment by the psychiatrist, he would expect the defence to submit a request for investigation into an 'abuse of process' by the CPS.*
- *A second brief adjournment for the prosecutor to seek advice was allowed.*
- *On his return the prosecutor 'offered no evidence' on behalf of the prosecution and the trial was halted.*
- *In summing up the Judge recognised the difficulty police faced when confronted with apparently difficult or violent behaviour, however he felt that once the facts became known he did not understand why a decision to prosecute was still taken.*
- *The defence counsel thanked AWM for the support and advice provided to 'A', his family and the defence team in this case which had assisted in ensuring that a vulnerable teenager was not unnecessarily prosecuted.*

5.3 Co-morbid conditions

5.3.1 We know that a proportion of autistic people also have mental disorders. The best known research study establishing what that proportion might be was sponsored by the National Autistic Society. It covered only autistic people who had committed serious criminal offences: it was found that 65% (65 out of the 100 offenders studied) also had mental disorders. They had one or more psychopathology conditions including psychosis, attention deficit hyperactivity disorder (ADHD), personality disorder or other neurological disorder.

5.3.2 It is unknown whether that percentage also applies to the whole autistic population, or to just those at or near the higher-functioning end of the spectrum, or perhaps it only applies to the original hundred people because there was something special about them. However it seems that most autistic people who commit serious crimes do so because they misunderstand social situations and act inappropriately, or others misinform them and lead them astray, rather than because there is something special

about them. Autism West Midlands reports that 71% of autistic children also have another mental disorder.

5.3.3 We note that the '65%' figure is also used in many reports about people with autism as being the proportion who also have mental disorder or learning disability. The Department of Health 2010 report 'Towards "Fulfilling and Rewarding Lives" says that 50% of people with autism have learning disability.

5.3.4 Where autism is not the only condition it may be the non-autism condition – or some interaction between the two conditions - that leads to committing the crime. For example ADHD is an impulsive disorder which might lead to committing a crime just on impulse.

5.4 Being helpful to 'friends'

5.4.1 It is relatively easy for criminals to befriend someone with autism to involve them in crime. In one case (see Appendix 2, Story 1) reported to us an autistic man with Asperger syndrome was asked by his 'friends' to come with them into a shop, then they took items from the shelves and put them into his pockets, so that if spotted or arrested only he would be at risk, while they could claim they were not involved. The autistic man only recognised that he was being co-operative, doing what his friends asked him to do: he couldn't understand that the whole event was theft, or imagine the effect on the shopkeeper. Fortunately in this case the shopkeeper saw that the man was being victimised, so instead of contacting the police he contacted the man's family.

5.4.2 There are many other ways autistic people could be involved in criminality without realising it. For example they could be persuaded to be helpful by keeping (stolen) items at their home, or by waiting outside a building that their 'friends' are visiting (burgling) and calling out if anyone else is coming.

5.4.3 Any organisation becoming aware that this is happening should consider whether it can provide effective support or whether it needs to network quickly with others that may be better placed to do this. The ideal is holistic support including, if possible, drawing the autistic person away from people providing inappropriate influences.

5.4.4 Part of the solution may lie in supporting the autistic person to engage in structured routine activities that will give a pattern to his or her day and reduce the opportunity for being misused by false friends. Some of the organisations listed in the 'Potential sources of support' section can assist with this.

5.5 Following the norm, where crime is the norm

5.5.1 Autistic people raised in a family or community where criminality is the normal practice may come to see that as the rule and normality that they should seek to copy, in order

to avoid trouble with the family or community. Criminal behaviours can be copied and eventually learned.

5.6 Aggression at home

5.6.1 Autistic adults living with their family or carer may sometimes act aggressively to reduce their own loneliness, frustration and misery. Where behaviour that would be an arrestable crime if committed in public is committed at home on siblings or parents, the police are unlikely to want to arrest, though they will warn, at first informally. But if it is repeated the police could apprehend and potentially arrest and detain.

5.6.2 If there is no arrest and detention the usual outcome in that situation is that the parent(s) will eventually decide their autistic son or daughter must move out. Potential sources of help in finding housing are set out in this report's 'Potential sources of help' section.

5.7 Misunderstanding social situations, and panicking

5.7.1 We were told of one case where an autistic young man regularly had to travel across his city (not Birmingham) by taxi. He was obsessed with stories of kidnapping and abduction and constantly worried that he might be kidnapped and killed. One day the taxi driver took a very different route from normal because he'd heard there were major traffic jams in the city centre. He didn't explain to the passenger why he had changed routes. The passenger believed he was being kidnapped and, in panic and fear for his life, attacked the driver. The passenger was charged and convicted. This might have been avoided if the support worker or carer had told the taxi company about the fear of being kidnapped and the need to explain the reasons for any re-routing.

5.7.2 In Birmingham taxi drivers have already been given basic autism awareness training and further training will be given before the end of 2012 to deepen their understanding.

5.7.3 Another case involved an autistic woman whose young son was very keen on the children's character, Noddy. Just before Easter she had heard that there were chocolate Noddy eggs in a supermarket. She went there with her support worker but found there was only one left, at the back of the shelf. She picked it up and rested it near the front of the shelf whilst she was reaching for a different Easter egg on a higher shelf. As she was doing this, an elderly woman came and picked up the Noddy egg, put it down again, moved away briefly, then returned and picked it up again. The autistic woman said it was hers, and politely asked the older woman to give it back. The older woman refused. The autistic woman was stressed and could not work out

what else to do to end the stress other than by getting the egg, so she pushed the older woman, who unfortunately fell over.

5.8 Hearing that another category of people is worthless

5.8.1 Most autistic people have and follow a strong and rigid moral code (or possibly moral construct) that prevents them from knowingly committing a crime. They rely on and feel safe with rules. They may become stressed and potentially angry if anyone around them seems to be breaching the code or rules, though this by itself seems unlikely to result in contact with the criminal justice system.

5.8.2 Perhaps because of this strong moral code, adults with autistic spectrum disorders are less likely than others to commit very serious crime. However despite the code there are a few cases where autistic people have committed serious crimes up to and including murder. In at least some of these cases the autistic person has read or heard other people say, perhaps often, that a particular person or category of people is worthless and better off dead. Because the autistic person believes literally what they read or what others say he or she may then, on encountering that person or someone from that category of people, think it is right to take things from them (because they are 'worthless') or even to kill them (to make them – or the world - 'better off').

5.8.3 We were told that autistic children in mainstream education in secondary schools had been discovered taking a special interest in fascist and anti-Nazi websites. There is concern that it is difficult to break such obsessions and consideration is being given to introducing special training to address that problem.

5.9 Problems with diagnosis

5.9.1 Autistic people may be stressed by any one or more of a wide range of social situations, changes that interrupt their 'safe' routines, or environmental triggers. When stressed they may adopt behaviours including self-harming that contain or may reduce their stress. If the stress is acute they may try to run away, or 'shut down' and cease to communicate; or try a range of other behaviours, including words. But if none of the techniques reduce or end the stress they may use physical violence as a last resort. To others these behaviours seem to be abnormal and unpredictable. If their autism is undiagnosed or others involved do not understand what the diagnosis means, the autistic person is likely to be apprehended and taken to a police station.

5.9.2 The National Autistic Society website gives access to the following table. It shows that many traits of high-functioning autism and Asperger syndrome (left and middle columns) are also features of the general (non-autistic) population (left and right columns).

Trait or behaviour	Asperger's % affected	Non-Asperger's % affected
Circumscribed, unusual interests	95	43
Impaired non-verbal expression	91	38
Pragmatic abnormalities	67	14
Semantic or syntactic abnormalities	30	7
Clumsiness	91	36
Autistic disorder in childhood (where history available)	100	0

5.9.3 Autism, learning disability, mental disorder and brain injury may each give rise to and in many cases share some behavioural differences that mark them from other people. So often if a person is identified as behaving differently from others the difference may be diagnosed or misdiagnosed as having any one or more of those conditions.

5.9.4 It is harder to diagnose high-functioning autism or Asperger syndrome than to diagnose low-functioning autism. This can lead to disagreement as to whether an alleged offender is autistic or not, and if the court is told or decides the alleged offender is not, it will not accept autism as part of the defence arguments. Even if it is accepted that the alleged offender is autistic the police and/or counsel or the judge may not know enough about autism to realise what it means in relation to the alleged offence. The CPS told us of one defence counsel who announced in court that the defendant is autistic, but when the judge asked the counsel how he or she wanted that to influence how the case progressed, the counsel could not explain.

5.9.5 Since diagnosis of autism, particularly Asperger syndrome, is known to be tricky, an agreed and well-publicised diagnostic pathway would help. It should provide a framework for judgments that build up towards diagnosis and help ensure that all the key issues are considered. The National Autistic Society website gives access to a diagnostic pathway developed by Liverpool Asperger Team and another developed by Bristol Autism Spectrum Service, plus guidelines for any organisation thinking of creating a new one. Perhaps Birmingham Autism Partnership Board could lead on and co-ordinate an analysis of the Liverpool and Bristol pathway models, consult with other experts, and adapt and accept one of the models for use in Birmingham, and lead on publicising it once it is ready. We recommend:

R08: That a diagnostic pathway for autism be developed, introduced and publicised to GPs, psychiatrists and psychologists whose work includes diagnosing autism.

5.9.6 The prospects for someone with autism who is correctly diagnosed early in childhood are usually much better than those for someone diagnosed in or after their teens, by which time they may already have been misled into crime. An email from a young man lucky enough to have been diagnosed early is shown in Appendix 3. The correlation pattern between late diagnosis and trouble with the criminal justice system has been evident in many of the cases reported to us.

5.9.7 Though having been properly diagnosed is an advantage in most situations, there are some in which it may be a disadvantage. If prisoners find out that another prisoner is diagnosed as having autism, there is a risk that some will misuse that prisoner. The other situation was highlighted in one of the parent's stories in appendix 2. If support services for people with learning disabilities or mental disorder are well developed and readily available, but services for people with autism are not, being diagnosed with autism may reduce access to services. Fortunately that is changing for the better: the Council's Joint Commissioning Team has recognised the needs of autistic people and started commissioning for services to meet those needs. Birmingham Autism Partnership Board has been set up to keep autism on the agenda. And many third sector and private bodies, including those listed in the 'Potential sources of support' section and in Appendix 5 of this report can provide support.

5.9.8 There are about 25,000 GPs in England. On average each GP has around 1,800 patients, and since at least 1% or more likely 2% of the population is autistic, a typical GP would have at least 18 or more likely nearer to 36 autistic patients. If well-informed about autism, GPs could do the early diagnosis, and could refer the child to a secondary specialist – a psychologist, psychiatrist, or a hospital's neurology consultant - if they need confirmation. There will also be a diagnosis service at the SPARC, described in section 10.2 of this report.

5.9.9 The Royal College of General Practitioners offer a web-based training module about diagnosing autism. Yet only 709 GPs (fewer than 3%) had used the module during its first year. Perhaps GPs did not notice or were too busy to pay attention to the link. However some GPs in Birmingham have asked for more training: one of our commissioning witnesses said there had been a request for autism training combining e-learning and a workshop-based session. This is being commissioned. We recommend:

R09: That the Health & Wellbeing Board asks each Clinical Commissioning Group operating in Birmingham to set out its plans and target dates for ensuring that its GPs have enough knowledge to diagnose autism or possible autism.

5.9.10 Studies indicate that the prevalence of autism seems to be the same in all ethnic groups and socio-economic classes.

5.9.11 Commissioning witnesses told us of a recent study which suggests that the Somali community has seen increases following changes in diet. However as at October 2012 no other published study has shown that diet and autism are linked.

6 Autism awareness training for police

6.1 Investments so far

6.1.1 Twice in the last ten years West Midlands Police has invested funds to raise awareness of autism. In 2004, when funding allowed it, every police officer was given an Autism West Midlands Autism Alttention Card and about 300 police officers were trained by Autism West Midlands. In 2008 further funding enabled four or five copies of a poster about the Card and what to do about it to be taken or sent to each police station for permanent display.

6.2 Stories suggesting need to change front-line behaviour

6.2.1 However the three following anonymised anecdotes provided by Autism West Midlands suggest this awareness-raising has not been wholly successful:

6.2.2 *A 17 year old with AS was having an argument with his girlfriend in the street in ……. Police intervened and he produced his 'Alert Card'. The officer looked at it, stuck it in her pocket and proceeded try to manhandle him into the police car. Due to his heightened state of anxiety he refused and was forcibly restrained and arrested and subsequently charged with assaulting the police, despite not having committed an initial offence warranting arrest.*

6.2.3 *An Autistic male who lives in supported accommodation became agitated whilst out alone and began shouting and swearing in the street. Officers from …… attended and took him home but still insisted on giving a first warning for a public order offence despite the staff at the home explaining he could not help it or understand their warning.*

6.2.4 *An adult with Asperger's Syndrome was arrested and taken to …….police station for interview. The officer from the LPU was shown the 'Alert' and stated he knew nothing about autism or the card. The mother who had accompanied her son to the station produced the Autism West Midlands poster about the card which were distributed throughout the force in 2008/9 and asked for it to be put up as the officer said he had*

never seen one. The mother was then allowed to act as appropriate adult and assist the officer.

6.2.5 Our Autism West Midlands witness told us that on average he receives about three communications per week from autistic people or their carers about interactions with the police, and most of them concern interactions where police acted inappropriately because they lacked awareness of autism. He provided us with a total of 14 stories about police handling of encounters with autistic people. Three of them showed wise, sensitive police behaviour and good practice. However we were disturbed that the other 11 stories (including the six included in this report) were critical – some very critical – of police behaviour.

6.3 Cascade offer declined

6.3.1 We asked about the level of autism awareness in police forces. Autism West Midlands said that they had offered autism awareness training to several forces. The offer was, for a once-only fee of £250 per force, to 'train the trainers' and offer them replicable training packages, including a PowerPoint presentation, which could be cascaded throughout each police force. The main cost is that of trainees' time. This had been taken up by several forces including Warwickshire Police, Cheshire Police, West Mercia Police, British Transport Police, Greater Manchester Police and the Metropolitan Police. Cheshire Police has already cascaded the autism awareness training throughout its workforce, so its autism awareness is high and likely to remain high. In the others, the cascading is underway. The commitment to have the training done was led by each force's top management team.

6.3.2 We were told that the trainer made the same offer to West Midlands Police (WMP), but received no response. Eventually, in November 2011, he met an Assistant Chief Constable, who told him that autism awareness training is not a priority for WMP.

6.4 Financial pressures

6.4.1 We were given evidence from two WMP staff, namely the superintendent with lead responsibility for advising the WMP command team on equal opportunities and disabilities, and the equalities, diversity and human rights manager. WMP has recently had to reduce its budget by £120 million, so all sections have had to lose budget and staff, many staff had had to alter their roles, some police stations had closed, and many poorly-staffed detention centres were being reduced to three well-staffed ones. WMP has had to reduce its employee numbers from about 14,500 employees to 12,000, including 7,000 front-line officers. Now as far as is possible all training has to be delivered by e-learning, though it was acknowledged that that method was not

ideal. All proposals for training have to be supported by a detailed business case, which may or may not be approved.

6.4.2 The superintendent said if we provided her with the detail behind the critical stories she would ensure 'service recovery' takes place for the 11 critical or very critical stories, and would also send a copy of all 14 stories to the equalities officers in each of the ten local policing units. We asked Autism West Midlands to supply her with that detail.

6.4.3 She also said that some further training is planned: Autism West Midlands will do a development day in October for one of the Local Policing Units. Also some small teams of staff who are not first-response officers will be trained in autism awareness.

6.5 Cascading or e-learning?

6.5.1 We hope West Midlands Police will reconsider its approach to raising autism awareness. E-learning, particularly where each topic ends in a test, engages short-term working memory for long enough to pass the test but is lost soon afterwards, so is unlikely to affect behaviour. According to the Atkinson-Shiffrin multi-store memory model, "…memories can reside in the short-term "buffer" for a limited time while they are simultaneously strengthening their associations in long-term memory. When items are first presented, they enter short-term memory, but because it has limited space, as new items enter, old ones leave. However, each time an item is rehearsed while it is in short-term memory, it is also increasing its strength in long-term memory. The longer an item stays in short-term memory, the stronger the association becomes in long-term memory." So certain processes, experiences or felt needs can act as 'push factors' that hold transient learning in working memory long enough to make it register in long-term memory from which it can be mentally accessed as needed, and modifies behaviour.

6.5.2 One push factor is the opportunity to practice what has been learned very soon afterwards in the main job role. There are up to 20,000 autistic people in Birmingham, each perhaps seven times more likely than other people to come in contact with the police. So they are the equivalent of 140,000 average people in police workload. Yet it cannot be guaranteed that an officer will encounter one of them soon after completing e-learning.

6.5.3 Another push factor is a post-learning discussion. Soon after e-learning several learners get together and discuss what they have learned, how they will put that into practice, and how it would have altered their previous handling of encounters if they had known about it then. However post-e-learning discussion groups need to be actively organised and those who are likely to be part of the discussion need to do their e-learning at about the same time. If they are not actively organised they are unlikely to occur.

6.5.4 One advantage of the cascade offer is that in order to train other people each trainer has to learn the subject thoroughly and well enough to be able to handle any questions or challenges. That felt need transfers the learning into their long-term memory. At each level of the cascade, more knowledgeable trainers are created, so the learning is durable, and can easily be repeated for new recruits.

6.5.5 The following table sets out the learning options.

LEARNING METHOD	EFFECTIVENESS FACTORS
e-learning.	Costs little but tends to have no effect on behaviour unless pushed into learners' long term memory by some other process, experience or felt need (a 'push factor').
e-learning plus the push factor of "How are we going to use this from now on?" discussions for groups of e-learners.	Costs little but needs a group of learners to do their individual e-learning at about the same time so discussions can be organised soon afterwards. If this is achieved, it can affect future behaviour. Takes staff time to organise and take part. Behavioural effect tends to be less if there is a significant delay between the e-learning and the discussion.
Read relevant AWM guidance notes and keep them accessible as a reference.	Costs very little. Affects behaviour only if reader is interested and motivated to use the learning in practice.
As above plus an organised push factor.	Costs very little. The push factor may cost, but ensures the learning lasts and changes behaviour.
Cascade 'train the trainers' sessions throughout the relevant parts of the force, including the push factor of trainer-guided "How can we best use this from now on?" discussions amongst trainees at each session.	Initial once-only cost of £250 plus cost of staff time during the sessions. But maximises the effect on behaviour and ensures there are well-informed trainers at each level of the cascade, and training kit for them to use, so training/learning can easily be replicated when needed in future. Learning tends to be more durable because of this.

6.6 Autism awareness and front line police officers

6.6.1 Doing service recovery for 11 cases might help the individuals involved. Sending copies of the 14 stories to the equalities officers in each Local Policing Unit will help spread the

message, but its impact will depend on how effectively the equalities officers can get the key messages to all front line officers and make the messages 'stick'. Also although all training in autism awareness helps to some extent, the training of staff who do not have first-response roles is unlikely to reduce the numbers of autistic people who are apprehended unnecessarily.

6.6.2 It is a challenging task to train the majority of 7,000 front line police officers, but they are the ones who have to decide quickly – and sometimes under intense pressure - how to behave when encountering someone who is or may be autistic. All first-response officers would benefit from the awareness. Every police force faces severe financial pressures, yet several smaller police forces, one similar sized one – Manchester Police, and one much larger one – the Metropolitan Police – have accepted and acted upon the Autism West Midlands 'cascade' offer.

6.7 Potential savings

6.7.1 Once the training has improved first-response police behaviour it will create savings. There will be savings to the police in that fewer autistic people will be apprehended, transported, interviewed and detained. Autistic people are unlikely to perform well in police interviews, which will mean that fewer will get to court, making savings for the court and police. Each time this is prevented it will save an estimated £13,000 per alleged incident. Because they are also unlikely to perform well under questioning in court, fewer who get to court will go to prison. Preventing someone from being jailed unnecessarily will save nearly £41,000 per year for the prison service.

6.7.2 The source for the £13,000 figure is a 2002 report by the Social Exclusion Unit 'Reducing re-offending by ex prisoners' which says each offence costs the criminal justice system £13,000 and that the average ex-offender re-offends five times before being sentenced again, costing the system £13,000 x 5 = £65,000. The source for the £41,000 is 'The Learning Prison' report.

6.7.3 So the total saving to the criminal justice system could range from £13,000 up to £106,000 - and perhaps more, since five offences is just an average rather than a limit - per autistic person who can be enabled to avoid being apprehended unnecessarily.

6.7.4 We recommend :

R10: That the Police and Crime Panel, supported by a letter from the Cabinet Member for Health & Wellbeing, ask the newly-appointed Police and Crime Commissioner to include in the Police and Crime Plan how and by when the majority of front line police officers will be trained or self-trained in autism awareness sufficiently to support them when interacting with autistic people or those whose behaviours appear to be autistic.

6.7.5 Appendix 4 is a copy of an article written by a senior American Police Crisis Management and Defensive Tactics Instructor who is father of an autistic son. It aims to raise the autism awareness of front line police officers and sets out 28 practical guidance principles. Though some of the equipment and practices referred to are American, most of the principles would also be helpful for front-line police in this country.

UPDATE 31 October 2012
summarising an email received from AWM CJS Development Lead
On 17 September the Autism West Midlands Criminal Justice Development Lead provided four training sessions to about 50 West Midlands Police (WMP) staff on a West Midlands Police Continuing Professional Development day. The newly-appointed WMP Head of Learning & Development sat in on one and as a result asked him to 'train the trainers' of WMP on 8 November and provide the package for them to incorporate into their current training programmes and deliver as stand alone sessions to operational staff. The training will be cascaded throughout WMP including the front line officers. It is expected to take about 18 months before the full impact can genuinely begin to be recognised. By that time it is hoped that the development of services, frameworks and practices proposed in this report will be completed. Once in place, the proposed social care referral pathway in particular will need to be shared with WMP Learning & Development Department so that the pathway presents a referral option instead of criminal prosecution.

7 Mental health and autism

7.1 Misdiagnosis and non-diagnosis

7.1.1 Any of a range of conditions may make people behave abnormally at times. They include autism, brain injury, learning disability or mental disorder. A high proportion - the National Autistic Society says 65% - of people with autism also have a mental disorder. Some abnormal behaviours are common to autism and mental disorder. If a mental health specialist assesses someone behaving abnormally and who has both autism and a mental disorder, the likelihood is that only the mental disorder will be diagnosed, unless the patient says he or she is autistic or shows strong evidence that he or she has autism, or the assessor has been trained to recognise and diagnose it.

7.1.2 Several councillors have mentioned to us that they have learned or heard of people with autism being misdiagnosed as having mental disorder if they have no other conditions, or being correctly diagnosed with mental disorder but their co-morbid autism being missed. Some are not correctly diagnosed until late in their life. Recently one of the Council's cabinet members was told by two mothers that their autistic sons had been unjustifiably 'sectioned', meaning assessed then compulsorily detained for inpatient assessment and treatment under the Mental Health Act (MHA), literally the MHA 1983 as amended by the MHA 2007, when the mothers thought they should not have been.

7.1.3 From figures in paragraph 2.5.9 of this report it is likely that Her Majesty's Prison Birmingham has between 58 and 102 prisoners with autism. However when asked, its management could only identify ten autistic prisoners. This strongly suggests that neither the general nurse nor the mental health nurse who between them assess incoming prisoners are trained to recognise or diagnose autism.

7.2 Birmingham & Solihull Mental Health Foundation Trust

7.2.1 GP's (primary health services) treat about 90% of mental health problems affecting their patients. But about 10% of cases are outside the GP's ability to diagnose and treat adequately, and or require specialist skills the GPs cannot obtain. Those cases are referred to the secondary care of Birmingham & Solihull Mental Health Foundation Trust.

7.2.2 Wherever possible the Trust tries to reduce or treat the mental health problem to make it manageable enough to enable the patient's care to be safely discharged back to the GP. The Trust is 'block funded' so its income is not affected if the number of patients being treated changes. The Trust employs psychiatrists, psychiatric nurses,

psychologists and other specialist staff, and can prescribe drugs that can be very dangerous and need patients to be tested frequently to ensure the drugs are doing more good than harm.

7.2.3 The Trust is only commissioned to treat mental disorder, not autism, because that is untreatable. Any patient found to have autism instead of mental disorder would be quickly discharged back to the GP's care, and Autism West Midlands would be notified.

7.2.4 Trust witnesses told us there have been many cases where police have been involved with patients. Most are where a patient behaves aggressively at home. If the patient has autism as well as mental disorder the aggression may or may not be attributable to autism. There is usually no wish for the patient to be arrested and after the police leave the family remains at risk, not knowing where to turn next.

7.2.5 Patients with autism who transfer to or resume education at a college are likely to need a support worker to provide reassurance and guidance, but the Trust does not supply that service, because it is not commissioned to do so. An organisation listed in the 'The support autistic adults need' section of this report – OSSME - may be able to provide this service.

7.2.6 The Trust's patient database has recently been redesigned so that it has provision for recording if patients have autism. This is a positive and welcome step, but it will take time for this information to be captured and recorded.

7.3 Assessing under the Mental Health Act

7.3.1 A MHA assessment is carried out by an Approved Mental Health Professional (AMHP) and two medical doctors, of whom usually one knows the patient well and the other is a psychiatrist. The AMHP is an experienced social worker, psychologist, occupational therapist or nurse, with extra training in MHA assessment, appointed or reappointed by an AMHP panel to act on behalf of the local social services authority. The local social services authority that has a legal duty under the MHA to provide an AMHP service in Birmingham is the Council. The guidelines for appointment or re-appointment of an AMHP are contained in the MHA Code of Practice.

7.3.2 Where people appear to be so mentally unwell that they present a risk to themselves or to others and do not agree to being assessed as an inpatient or to undergo treatment the MHA enables them to be compulsorily detained for those purposes if a MHA assessment shows this to be necessary as a last resort. This decision to detain is sometimes referred to as 'sectioning' because specific sections of the MHA determine the maximum detention periods. Detained patients have rights for a review of their detention by a Mental Health Review Tribunal and the hospital managers. The nearest relative, as defined by the MHA, can also appeal to the hospital managers for the patient to be discharged.

7.3.3 The MHA includes autistic spectrum disorders in the range of conditions that may justify MHA assessment and may lead to compulsory inpatient assessment and sometimes compulsory inpatient treatment.

7.3.4 Under section 136 of the Mental Health Act (MHA) a police officer can transfer a patient to a place of safety (POS) for up to 72 hours to allow the carrying out of a MHA assessment. The Mental Health Trust has a POS suite in the Oleaster Hospital, and Parkview Clinic has a POS suite for young people. A designated police station may be used as a POS instead, though their use for this purpose is diminishing.

7.3.5 Patients who are so mentally unwell that they need specialist or intensive treatment can be admitted as informal inpatients in a psychiatric hospital or psychiatric ward if they agree to this. They are normally discharged when the treatment has been completed and has brought about improvement. Since they are there voluntarily they can discharge themselves earlier than this if they wish. However a voluntary admission could still result in a formal admission using the relevant parts of the MHA if the medical multi-disciplinary team consider that it is not safe for the person to be discharged. In that case there will be a formal request for a MHA assessment.

7.3.6 Just over 2,000 MHA assessments were done in Birmingham in 2011-2012. The assessors can decide to detain the patient for up to 28 days for inpatient assessment and treatment if necessary under Section 2 of the Act, or, following detention under Section 3 or section 37/41 of the Act, for up to six months for inpatient treatment and continuing assessment.

7.3.7 Community treatment orders (CTOs) may be used as an alternative to inpatient treatment if the patients agree to receive medication and treatment in the community under supervision. If the patients then refuse their medication or defaults on any part of the CTO plan whilst in the community they cannot be made to become an inpatient unless they are again becoming a danger to themselves or others, in which case the CTO can be revoked. So some patients who would previously have had repeat formal admissions may now be being re-detained in hospital through the revocation of a CTO, following a recall to hospital. CTOs can be renewed as well.

7.3.8 We do not know whether the sons or daughters of the two parents mentioned earlier just had autism or whether they had mental disorders as well. If the doctors and AMPH assess that the patient has autism instead of mental disorder compulsory detention will normally be inappropriate. This is firstly because the autistic person will tend to calm down once the immediate sources of stress are reduced, so the crisis will fade; and secondly autism cannot be reduced or cured by hospital treatment. More usually the GP (who may have been one of the two doctors who carried out the MHA assessment) and Autism West Midlands will be consulted and once the patient seems to calm down he or she would be referred back to the GP's care.

7.3.9 More often when autistic people are subject to MHA assessment it is because they have co-morbid serious mental disorder, and it is the co-morbid condition that justifies the MHA assessment and possible decision to detain.

7.3.10 The Mental Health Commissioners told us that very few patients who have autism were given a MHA assessment in 2011-2012. Those found to have no co-morbid mental disorder would be referred back to their GP.

7.4 Autism is not a mental disorder

7.4.1 Some of the Trust's patients have schizophrenia, a serious psychotic disorder. Most of its harmful symptoms can be managed effectively by appropriate drug treatment. Before the early 1940s anyone with the symptoms we would now recognise as autism would most likely have been classed as having schizophrenia, or learning disability. This started to change with Leo Kanner's seminal 1943 paper defining low-functioning autism and Hans Asperger's 1944 paper defining high–functioning autism. However up until the 1970s many people with autism were still being misdiagnosed as having schizophrenia.

7.4.2 Some current organisational practices rest on the enduring widespread assumption that autism is part of mental health. Several witnesses have told us about situations in which a mental health nurse, normally a community psychiatric nurse (CPN), is the first to be called if someone who may have autism needs assessment or behaves abnormally. Yet CPNs are not normally trained in autism awareness or diagnosis. Thus misdiagnoses can occur, often with adverse consequences for the person with autism. Autism West Midlands or possibly the National Autistic Society might be willing to assist with designing and delivering cost-effective training that would help the CPNs. The Trust would need to assess whether all or only some of its CPNs would benefit from training. We recommend:

R11: That Birmingham & Solihull Mental Health Foundation Trust prepare a plan for its community psychiatric nurses to be trained on autism awareness and autism diagnosis.

7.5 The effect of co-morbid autism on treatment

7.5.1 When the Trust knows a mentally-ill patient also has autism, treatment regimes are modified as necessary. The bulk of the Trust's patients are encouraged to work in teams for therapy and confidence-building, but if a patient has autism he or she would find that stressful and would be found other ways to learn. Work with young patients approaching adulthood involves talking with a psychiatrist through problems, and that too would not suit autistic patients because it is difficult for them to imagine scenarios,

so the step may have to be missed. The Trust can help reduce the anxiety of autistic patients but is not able to meet their ongoing autism needs, so it would signpost them to Autism West Midlands.

7.5.2 If the Trust does not know about the autism the treatment regime will be purely for the mental disorder, so may have adverse consequences for the patient.

8 Community healthcare trust and autism

8.1 Birmingham Community Healthcare NHS Trust

8.1.1 The Trust delivers NHS care services in the community to patients across Birmingham. Its website shows a long list of conditions for which the Trust provides services but as at October 2012 the list excluded autism. This is because the great majority of support services that autistic adults need, such as advocacy, employment preparation and support for living independently, fall under the broad ambit of social care rather than that of the NHS: no drugs or surgery can 'cure' autism.

8.2 Learning Disability Service

8.2.1 The Trust's learning disabilities (LD) service includes six consultant psychiatrists, about six psychologists and between 40 and 50 community nurses. In total around 2000 cases are open to LD services. About half of these are open to psychiatry: each psychiatrist has an active case load of about 150 patients.

8.2.2 The LD service has a single point of access for referrals of patients. Most patients are referred to the Trust by GPs, though others including social workers, neighbours, family members and patients themselves can also refer. Referrals are discussed at a weekly meeting and either accepted, accepted for initial assessment only, or rejected.

8.3 Co-morbid autism

8.3.1 One of the Trust's consultant psychiatrists acts as its autism lead and also serves on the Birmingham Autism Partnership Board. He estimates that half of all patients known to the LD service also have autism, and since those 50% take up 80-90% of the psychiatrists' and psychologists' time, "A lot of colleagues agree that autism is our main business." He said that the LD service has between 500 and 1,000 patients with autism but all are supported because of their co-morbid LD.

8.3.2 If a patient is found to have autism instead of LD the patient will be discharged and the Trust will notify the patient's GP. It will also try to notify the Council's social workers. He said it is already very difficult to contact social workers via their single point of access and he is concerned that as the Council has to make further substantial savings contacting the social workers might become impossible.

8.4 Offenders and autism

8.4.1 The Trust has a LD forensic consultant with a case load of about 80 offenders, each of whom has at least one criminal conviction. His broad aims are to support and guide patients away from re-offending, and for those who re-offend, to assess them before or during a court case and advise the court as to whether the accused had *mens rea* or not. The consultant psychiatrist acting as the Trust's autism lead said it is likely that most of those 80 LD offenders also have autism.

9 The support autistic adults need

9.1 Support needs of adults with autism

9.1.1 This chart was provided by Autism West Midlands. 'OSSME' is Outreach Support Service to Mainstream Education, accessible at Web address www.autisminitiatives.org 'CJS' means the criminal justice system or criminal justice sector.

NEEDS	SPECIFIC	CORE	GENERAL
LEVEL OF NEED FOR INDIVIDUAL	URGENT		NON URGENT
NUMBER OF PEOPLE WITH NEED	LESS		MORE
	Specific educational needs Involvement with CJS Prison Involvement with emergency services Life Crisis e.g. Hospitalisation, Homelessness, Sectioning, Bereavement, victim of crime/abuse Needs of the elderly	Diagnosis Daily Living Health – physical, mental Employment Finances Education Needs of carers	Friendships Relationships Sex Confidence Gender and sexuality Fitness Healthy Eating Hobbies and Interests
SERVICES	SPECIALIST	CORE	GENERIC
DIRECT SUPPORT	Support to access specific services. E.g. OSSME Emergency Placement facility Step-Down service Forensic unit Crisis call-out support Legal advice Counselling Nursing care for the elderly	Residential services Supported Living/Domiciliary Care/Outreach Respite/Short Breaks Family support Education – Pre 16 and 16-18 Transition Employment services – to get into work and stay in work Financial advice Advocacy Speech and Language therapy Psychology Occupational Therapy GP services Hospital and healthcare services Mental health services	Social activities Interest activities (e.g. book club/craft club) Information and Signposting Support Groups Relationship (dating) service Sexual advice
INDIRECT SUPPORT (Inc. Preventative)	Research Training Awareness Raising Family Support Consultancy CJS & Emergency Services development work	Research Training Awareness Raising Family Support Accreditation Lobbying	Research Training Awareness Raising Family Support

10 Potential sources of support

10.1 Web-Based services

10.1.1 A free and readily accessible Birmingham-based source of support for autistic people and for others needing to know about autism is **Autism West Midlands**, phone number 0121 450 7582, website www.autismwestmidlands.org.uk. Amongst the website resources are downloadable information and advice guides, each designed to be useful for anyone dealing with a particular issue concerning autism, or for particular professionals – including criminal justice professionals - dealing with people with autism. The full list of advice guides is shown in Appendix 5. We recommend:

R12: That letters – and, six months later, follow-up letters - be sent to the Bar Council and to the Law Society, asking them to arrange for any criminal justice professional in Birmingham who has neither been trained nor scheduled for autism awareness training to access the Autism West Midlands website and download the advice guides most relevant to their work, then read and discuss them with others.

10.1.2 Another free source is the **National Autistic Society** website www.autism.org.uk and telephone number 0808 800 4104. Its website gives access to information and advice on a range of matters including possible housing solutions, benefit entitlements, diagnosing complex needs, living with autism, leisure & environment, communicating & interacting, employment, and the criminal justice system.

10.1.3 It gives access to a document called 'Autism: a guide for criminal justice professionals' prepared by the National Autistic Society but also approved by the Association of Chief Police Officers. Our witness from the Crown Prosecution Service (CPS) has supplied a copy of this to every judge, and to every prosecutor it employs.

10.1.4 Many commercial websites offer autism-related advice, information and services. An internet search gave a long list of choices. Two dissimilar examples we picked at random from the list are Living Autism and Fairway Training. We do not imply anything about their competence or service quality.

10.1.5 **Living Autism**, website address www.livingautism.co.uk telephone number 01138 150 210, acts as a network, matching supply and demand. It invites individuals seeking autism accommodation or therapy services to register with them and set out the services they need. It also invites organisations to register with it if they can supply autism-related services. The aim is to introduce the individuals to the organisations that may be able to meet their needs.

10.1.6 **Fairway Training Healthcare**, telephone 0845 450 3971, gives half-day training courses on a wide range of topics including for individuals and families living with autism. Its web address is http://www.fairwaystraininghealthcare.co.uk

10.2 Specialist autism resource centre (SPARC)

10.2.1 Autism West Midlands' new offices in Edgbaston will house a new specialist autism resource centre (SPARC). The centre, due to open this calendar year, will offer a range of services for anyone affected by autism. Birmingham City Council and Walsall Borough Council have both committed to providing start-up funding. Funding for equipment was provided from other sources including a charitable trust. SPARC will be run as an independent charity involving local authorities, clinicians, the University of Birmingham, and Autism West Midlands.

10.2.2 A prime aim is to provide a safe place where people affected by autism can come for help, advice and understanding. It will also help to empower, engage and upskill autistic people. There will be a specialist assessment and diagnostic centre linked to face to face advice and signposting to local advice and provision. People with autism will be able to book specialist advice and have access to occupational and speech and language therapies.

10.2.3 SPARC will have drop in facilities including information services for anyone affected by autism, access to internet terminals to help find or keep employment, a library and a social area with refreshments. There will be a state of the art sensory room, fitted with a range of lights, textured fittings and audio equipment for both play and relaxation. As most people with autism struggle with social communication, interaction and imagination, this room will be used to develop skills across the autistic spectrum. The centre will also be a hub for raising public awareness, continuing Autism West Midlands' work in training families, professionals and employers about the condition. To avoid the issue of social isolation, the new centre will be a haven where people on the autistic spectrum can go to get support, relax, be active and learn.

10.2.4 We have high hopes for SPARC and we would like to receive feedback from AWM in a year's time on how the overall picture for support for people with autism has developed, and in particular how SPARC has been used. We recommend:

R13: That Autism West Midlands be invited to report to the Council's Health & Social Care Overview & Scrutiny Committee at its last meeting in 2013 on how they perceive the picture of support for people with autism, including a report on how SPARC has been used in its first year

10.3 Employment

10.3.1 Employment can benefit most adults including many of those who have autism. It provides pay; routines and activity that give structure to their weekdays; a sense of self-respect from doing something valued and useful; and, if the employers are autism-aware, the possibility of being with others without being pressured to socialise with them more than the employee finds comfortable. People at or near the high-functioning end of the autism spectrum tend to be very good at using computers so can add value in roles where those skills are the main ones used.

10.3.2 However survey data suggests that only about 11% of autistic adults are in paid employment. Autism West Midlands said it can take between 12 and 18 months to prepare an autistic person for their first paid job.

10.3.3 Fortunately there are at least three readily-accessible sources of focused support. Our commissioning witnesses told us that Shaw Trust, based in Digbeth, assists autistic people to get paid employment and supports them to maximise the chances of keeping the jobs. Autism West Midlands also offers advice and support to autistic employees and their employers. The National Autistic Society website gives access to a report "The undiscovered workforce" that identifies the value autistic people can add to organisations employing them. Autistic people who could potentially work, or their carer or support worker on their behalf, could contact those three sources of support to find how best to obtain and then keep paid work.

10.3.4 The Council's Joint Commissioning staff are trying to secure the support of the Chamber of Commerce to employing autistic people. The council and the NHS are large employers in Birmingham and each has the capacity to modify jobs so that autistic people could fill them. However though neither organisation is recruiting at present or perhaps in the foreseeable future, jobs could be planned now, ready for when recruitment starts to pick up again. It may be best to start with a few jobs – say a target of one or two jobs per directorate, and to find what works well, before expanding to larger numbers. It would be wise to seek legal or human resources advice to ensure compliance with the relevant employment law, and to discuss the plans from the outset with Autism West Midlands.

10.3.5 At present recruitment processes in the Council involve interviews and assessments of social skills even when they are barely relevant to the core duties of the post. Interviews can be very stressful for an autistic person. As a result, autistic people who would be very efficient at doing, for example, computer-based data input, detailed analysis and output, do not get the job because they cannot meet recruiters' social expectations. We recommend:

R14: That each Birmingham City Council directorate and each NHS Trust in Birmingham identify two posts that could potentially be filled by people with autism

10.3.6 These would not be new or extra posts but an analysis of two or more existing posts to identify the core job components and develop, for future use, a recruitment process that tests only the abilities relating to those core components and is stripped of unnecessary barriers. It may involve rethinking practices. For example, if an autistic person performs well at using the computer, it should not be necessary for him or her to have to attend meetings as well. Someone else could go to the meetings instead.

10.3.7 We know that this is possible. The Complex Children Team in Access to Education currently employs two members of staff who have autism and we have been told that others are employed by Service Birmingham.

10.4 Commissioning & Birmingham Autism Partnership Board

10.4.1 Autism has until recently received little commissioning support unless it is co-morbid with one or both of mental health and learning disabilities, each of which affect much larger numbers of people. To improve this situation, Birmingham Autism Partnership Board was created to raise the prominence of and provision for autism.

10.4.2 Meeting quarterly, it is chaired by a consultant psychiatrist and includes autistic people, carers, and staff from the Council, Birmingham Community Healthcare Trust, Birmingham & Solihull Mental Health Trust, Connexions, voluntary organisations and – soon – advocacy and other specialist groups. Its aims are to develop local strategies and services, support and monitor their development, and to share information about the developments with networks serving people with autism. So it both influences the joint commissioning team and spreads news about what it achieves.

10.4.3 It has set up several sub-groups, including training and awareness; identification, diagnosis and assessment; transitions; and improving access to services and/or employment.

10.4.4 Similar Partnership Boards have been set up for Mental Health and for Learning Disability.

10.4.5 Commissioning money provided start-up funding for SPARC.

10.5 Voluntary & Third Sector

10.5.1 Birmingham Voluntary Services Council (BVSC) kindly provided a list of third sector organisations that have autism as their main focus. Some of these organisations can

provide support services directly, while others can assist autistic people to access other services. The full list is shown in Appendix 5. BVSC has over 1,000 other organisations on its database, and it may be that some of them could offer some autism support even though it may not be their prime role. BVSC's web address is http://www.bvsc.org/

11 Conclusion

We cannot assess how many fewer autistic adults will get into trouble with the criminal justice system or be misdiagnosed if their needs are met more effectively. However it seems likely that there will be some. By finding meaningful routines and activities that autistic people can access during the day there is less risk that they will associate with false 'friends' who might deceive them into criminality; by reducing the number of circumstances where autistic people are likely to experience acute stress there will be fewer occasions when their stress-induced abnormal behaviour brings them to the attention of the police; and by helping them negotiate compromises there will be fewer whose compulsive interests will be carried to excess. If GPs and community mental health nurses learn autism awareness fewer people will be undiagnosed or misdiagnosed. And if the police succeed, as we hope they will, in raising the autism awareness of all first-response officers, the numbers of autistic people apprehended unnecessarily will fall. The end results will be improvements in the quality of life for many autistic people and those who care about them and in time a reduction in the total cost to the public purse.

Source data

This list covers all documents read as background to the report excluding those reproduced in the report.

1. Autism West Midlands Website www.autismwestmidlands.org.uk [Many downloadable documents]
2. National Autistic Society Website www.autism.org.uk [Many downloadable documents]
3. Autism Resources Website http://www.autism-resources.com/autismfaq-hist.html
4. Websites re transfers from working memory to long term memory www.human-memory.net/types_short.html. Also several other Websites found by a Web search for the Atkinson-Shiffrin Memory Model
5. Oral and written evidence given to the Committee at or in preparation for the formal evidence-gathering event on 22 August 2012. It includes:

   Children, Young Peoples & Families Directorate leaflet summarising support to children with autism and mentioning 'signposting' to other sources of help;

   RosenBlatt, M. (2008): I exist – the message from adults with autism in England *National Autistic Society*

   Report by the Comptroller and Auditor General (2009) 'Supporting people with autism through adulthood' *National Audit Office* HC 556 Session 2008-2009 5 June 2009 pp.1-59.

   The National Autistic Society guide to criminal justice professionals.

   A police email dated 7 August 2012 referring to current training initiatives to raise autism awareness in West Midlands Police Force.

   'When two worlds collide' an article by Nigel Archer about the issues that can arise when people with autism come into contact with the police and courts

   List of 13 examples of interactions between West Midlands Police and persons with Autistic Spectrum Disorders, provided by Nigel Archer.

4. Oral and written evidence given to the Committee at the formal evidence-gathering event on 3 September 2012.
5. Written or emailed evidence given to the Lead Officer before, between or after the two evidence-gathering events.
6. Allen, D., Evans, C., Hider, A., Hawkins, S., Pickett, H., & Morgan, H. (2008) Offending behaviour in adults with Asperger syndrome *Journal of Autism Development Disorders* Vol.38, pp. 748-758.

7. Bishop, D. (2008) An examination of the links between autistic spectrum disorders and offending behaviour in young people *Internet Journal of Criminology*

8. O'Brien, R. (2010) The learning prison *RSA*

9. Browning, A. & Caulfield, L.S. (2011) The prevalence and treatment of people with Asperger's syndrome in the criminal justice system. *Criminology and Criminal Justice, 11,* 169-184.

10. Brugha, T., Cooper S.A., McManus S., Purdon S., Smith J., Scott F.J., Spiers N., & Tyrer, F (2012) Estimating the prevalence of autistic spectrum conditions in adults – extending the 2007 adult psychiatric morbidity survey *The Health and Social Care Information Centre* The NHS.

11. Burdon, L. & Dickens, G. (2009) Asperger syndrome and offending behaviour *Learning Disability Practice* November 2009, Vol.12, no. 9, pp.14-30.

12. HM Chief Inspector of Prisons (2012) Report on an announced inspection of HMP Birmingham 9-13 January 2012.

13. Chown, N. (2009) 'Do you have any difficulties that I may not be aware of?' A study of autism awareness in the UK police service *International Journal of Police Science & Management* 2010 Vol.12 no.2 pp. 256-273

14. Summary of responses to 'Key questions (disability analysis) HMP Birmingham 2012'

15. de la Cuesta, G., G. (2010) A selective review of offending behaviour in individuals with autism spectrum disorders *Journal of Learning Disabilities and Offending Behaviour*, Vol. 1 Iss. 2, pp, 47-58

16. Curry, K., Posluszny, M., and Kraska, S. (1993) Training criminal justice personnel to recognize offenders with disabilities *Office of Special Education and Rehabilitative Services News in Print*, (Winter 1993).

17. Fermin, I. (2012) Autism Needs Assessment *Birmingham Autism Board, Learning Disability and Mental Health Joint Commissioning & Birmingham Public Health Information and Intelligence*

18. Jacobson, J., & Talbot, J. (2009) Vulnerable defendants in the criminal courts: a review of provision for adults and children *Prison Reform Trust*

19. Mayes, T.A. (2003) Persons with autism and criminal justice *Journal of Positive Behavior Interventions* Vol.5, no.2, Spring 2003, pp 92-100.

20. Mills, R. (2012) PowerPoint presentation: Offending behaviour in autism- why do some individuals with autism get into trouble? *Research Autism* June 2012. The National Autistic Society, downloaded from www.researchautism.net

21. Austin, C., & Skirrow, P. (undated) PowerPoint presentation: High risk and offending conduct in adults with Asperger syndrome – *Liverpool Asperger Team*.

22. Myers, F. (2004) On the Borderline? People with learning disabilities and/or autistic spectrum disorders in secure, forensic and other specialist settings *Scottish Executive Social Research*.

23. Roy, A. (2012) PowerPoint presentation: Improving autism services in Birmingham *Birmingham Autism Partnership Board*

24. The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales.

25. Summary for the new arrangements for police governance and accountability in England (a briefing sheet produced in Birmingham City Council for internal use).

26. Table headed Summary of average and total cost estimates, by crime type and cost category, downloaded from the Home Office web site.

27. Notes of first evidence-gathering event on 22 August 2012.

28. Notes of second evidence-gathering event on 3 September 2012 [Note: the names of the person with autism and their mother must be redacted before the document is copied or shared]

29. Inquiry Outline: Meeting the needs of adults with autistic spectrum disorders (ASD). [Note: this was the original terms of reference for the inquiry, but since then the lead Member, the title of the inquiry, the lead officer and some of the timescales have changed.]

30. Letter dated 23 March 2012 from Richard Burden MP to Peter Hay, Director of Adults & Communities, and Eleanor Brazil, the then interim Director of Children, Young People & Families, headed 'Autism Strategy Birmingham City Council – Strategic Directors for Children & Adults'.

31. Letter dated 25 July 2012 from Birmingham City Council's Cabinet Member for Health & Wellbeing to Richard Burden MP headed 'Autism Strategy Birmingham City Council'.

32. Terms of reference for Birmingham Autism Partnership Board (BAPB).

33. Draft minutes of BAPB meeting dated 11 July 2012.

34. The Intervention Ziggurat (diagram of a series of possible interventions to help autistic people cope). Provided by Nigel Archer. The original source was Aspy, R., & Grossman, B. G. (2011). The ziggurat model *Shawnee Mission*, KS: AAPC Publishing; www.aapcpublishing.net; used with permission.

35. 'Integrated Services for Children with Special Needs.' A report by Birmingham City Council's Assistant Director for Children with complex Needs to the (former) Vulnerable Children Overview and Scrutiny Committee dated 28.11.2011.

36. Video by John Simpson, a West Midlands-based 20 year old with Asperger syndrome. www.creativeeducation.co.uk/videos/watch-video.aspx?id=1532

37. Care Quality Commission's 2011 annual report on the Mental Health Act http://www.cqc.org.uk/sites/default/files/media/documents/cqc_mha_report_2011_summary_final.pdf

38. Prof. Huw Williams (2012): Repairing shattered lives: brain injury and its implications for criminal justice *Centre for Clinical Neuropsychology Research*, University of Exeter

39. Department of Health (2010): Towards "Fulfilling and rewarding lives" The first year delivery plan for adults with autism in England. First published 2nd April 2010. Published to DH website, in electronic PDF format only. http://www.dh.gov.uk/publications

APPENDIX 1: Autistic women: a life more ordinary

Downloaded from The Telegraph Website.

Lauren, Selina, Cara and Kelly are all women on the autistic spectrum

Charlotte Moore 12:01AM BST 21 Sep 2008

Why do women make up only one in four of those diagnosed as autistic? Could it be that they are simply better at pretending not to be? Charlotte Moore meets a group of women for whom 'normal' is an alien language that they battle to learn.

I am in Godalming, Surrey, sitting with a group of pleasant, personable women who have come together, as they do each month for an all-women's night, to share news, views and experiences. You'd imagine that the room would be alive with a babble of voices, but it's not. The gossipy, reciprocal flow of normal female conversation is absent, and so far not one of them has asked me, a stranger, a single question about myself or what I am doing here. The stilted atmosphere would strike outsiders as disconcertingly weird, but these women are oblivious to the awkwardness. They are autistic, and for them this is normality.

'We are not real women according to any of the known guidebooks… [But] we are not from another planet. We tricked you… We are from right here, Planet Earth.' So writes Judy Singer, one of 19 contributors to Women from Another Planet? (2003), an anthology written by a group of women on the autistic spectrum who met on the internet. While Singer, her co-authors, and the women gathered around me in Surrey, may not be from another planet, they do constitute a distinct minority. According to current statistics one in 100 British people has autism (I am myself the mother of two autistic boys), and one in four of those is female.

Ever since autism was first identified in the 1940s it has been accepted that autistic males heavily outnumber females. In Autism: Explaining the Enigma (2003), Uta Frith, a leading developmental psychologist at University College London, says that among those with the most severe autistic symptoms the ratio of men to women is four to one, rising to 15 to one among those with Asperger's syndrome (a variant in which autistic behaviours are less extreme and verbal ability is higher). But she goes on to speculate, 'It is worth considering whether girls are less likely to be detected… Girls are often considered to be more verbal and more compliant than boys in educational settings, and therefore might show better compensatory learning.'

She raises a vital question. Are women less likely to have autism, or are they under-diagnosed and slipping through the net because they are better than their male counterparts at adapting to social situations? The contributors to ‘Women from Another Planet?’ believe the latter. Most of them were not formally diagnosed until adulthood, if at all. Most lead apparently 'normal' lives in that they study and have jobs and sometimes husbands and children. But all feel profoundly 'different'; they write of the terrible, damaging strain of attempting to conform to social expectations.

The two psychologists who first investigated the condition (independently of each other) were Leo Kanner and Hans Asperger. The work they did more than 60 years ago set the pattern for the way we still see autism, and it happened that Kanner studied few female patients and Asperger none at all. Could it be that this led to

a false assumption that autism was overwhelmingly a male disorder? And do autistic women, as Frith suggests, often fly beneath the radar because of their ability to mask their difficulties?

Certainly, social stereotyping can lead to autistic behaviour going unnoticed. A woman who depends heavily on a dominant husband and has little life outside the home may well escape scrutiny. In school, while autistic boys are typically loud, disruptive and destructive, girls can be quiet, passive and compliant, but mentally absent; and students who give no trouble are less likely to be flagged up by a busy teacher. It has also been suggested that autism could be one possible cause of traditionally 'female' problems such as anorexia. Christopher Gillberg of the National Centre for Autism Studies at the University of Strathclyde explains, 'A girl may be withdrawn and uncommunicative without attracting attention, but when she develops a calorie fixation it becomes a serious problem. Counting calories may be a manifestation of autism. Some women could be going undiagnosed.'

Simon Baron-Cohen, the director of the Autism Research Centre at Cambridge, has pioneered the theory that autism is caused by a testosterone surge in pregnancy, affecting the child's brain development, leading it to be born with an 'extreme' male brain - strong on systemising, weak on empathy. This, he believes, can affect both males and females. Autistic girls, he has said, often have 'tomboy' traits, and feel 'more compatibility with typical [not autistic] males simply because typical males may be more willing to adhere to the linear, step-by-step form of thinking and conversation. This is echoed by the internet group: 'We may have more in common with [non-autistic] men than we do with [non-autistic] women, for it is women who are more often the social gatekeepers, who scrutinise our manners, care more for them than for our minds, and want to keep us out of the club.'

The need, then, is growing for 'clubs' of a different kind, spaces where autistic women can communicate with others who share and appreciate their differences. The Godalming club which I have visited is a pioneering experiment by the careworker Bettina Stott. She had run a mixed-sex social-skills group for people with autism for some years, but two years ago, at the request of some of the female members, she started an all-women group, which meets once a month. 'Our ladies are very vulnerable,' she tells me shortly before the meeting starts. 'They tend to fall in with what men suggest. In their own group they can discuss topics in a different way. It gives them a chance to talk honestly about their autism, and to learn about the way society works; they may adhere to social structures, but often they don't understand what they're for.' Group meetings begin with informal socialising, then move on to a structured discussion of a topic - anxiety, empathy, bullying - guided by careworkers. Stott feels that autistic women are more able to see things from another's point of view than autistic men, and are more emotionally responsive. Many of them have been misdiagnosed in the past with psychiatric illnesses or learning difficulties. 'Autistic tendencies are often overlooked,' she says.

Stott introduces me to four of the women who regularly attend the group - Lauren, Selina, Cara and Kelly. Lauren, 32, was not diagnosed until she was 23. She now lives in a supported flat, and accepts that she needs help with most practicalities, but loves it when her support workers are on holiday. 'It's bliss. I need time to chill out on my own,' she says. For autistic people, prolonged social contact is exhausting, and as I talk to the girls it emerges that the group is popular because it provides contact with other women, but within a definite time limit.

Selina, 27, also speaks of valuing her own space. She lives alone, works in Sainsbury's and keeps in touch with friends from previous jobs and from the special school she attended. She seems quite comfortable with one foot in the mainstream world, the other in that of special needs. She plays the clarinet, goes on theatre

trips and watches television. But her autism has caused her trouble in romantic relationships, and when a recent boyfriend became over-controlling the careworkers from the women's group had to step in to help. She's now single, but hasn't ruled out 'meeting Mr Right'. But, I ask, wouldn't Mr Right invade the privacy she enjoys? She smiles. 'I don't know. Maybe.'

On the subject of marriage Lauren says, 'I know I'll never be a mum,' but 20-year-old Cara, who works part-time with pre-school children (a job she loves), is not so sure. A good-looking girl who likes parties, music and Manchester United - especially Ronaldo - Cara has also had boyfriend problems. Most autistic people find physical contact acceptable only on their own terms, if at all, and the careworkers helped Cara to understand that she could choose to say no to unwelcome advances.

Kelly, 25, well-presented with careful make-up and a cherry-red jacket, is doing a course in travel and tourism. The others seem reluctant or unable to think beyond the present, but Kelly says she has ambitions; she doesn't like the English climate and wants to work in Spain, in the tourist industry. She has a pleasant, earnest manner, has done a particularly good job of mimicking non-autistic behaviour. However, like all the others she has experienced bullying in mainstream settings and relishes the fact that at the women's group differences are fully accepted. 'People pick on people who are different because they're scared. They're like sheep,' she says. 'Society wants to put you in a box.'

All four women agree it is harder for a woman with autism than for a man, though they can't explain exactly why. This is one of the difficulties of talking to autistic people: they find it easier to talk about concrete realities - bus routes, football, a broken clothes-horse - than about issues or theories. When I ask Cara whether there are any advantages to being autistic, she says it got her to the front of the queue at Thorpe Park. I try to find out more about Lauren's relationship with her family; she says her father is going to fix her clothes-horse, so they have 'a bond'.

The women have few conventionally feminine interests. Selina stacks shelves in the health and beauty aisles at Sainsbury's, but she has no particular interest in those products. All seem to lack that instinctive understanding of social behaviour that to most women comes as naturally as breathing. Nevertheless, they have found ways to operate in society, difficult though these accommodations may have been. The Godalming women's group is an immensely useful response to a newly perceived need: to support women who, however high their academic intelligence, struggle with the social skills that most of us take for granted. More and more women like Lauren, Selina, Cara and Kelly are now seeking diagnosis, relieved to have found an explanation for a set of characteristics that in the past would have been dismissed as 'weird', and relieved to understand why they have had to struggle so hard to conform to normal social expectations of female behaviour.

When the first of my two autistic sons was diagnosed in 1994, someone told me that autism was more prevalent among Jews (my sons' father is partly Jewish). This notion probably arose because many mid-century psychiatrists and psychoanalysts were Jewish, so interest in and awareness of unusual mental states was higher among Jewish families, who were therefore more likely to seek consultations for their children. Similarly, Asperger believed autism to be more prevalent amongst the professional classes, failing to see that it was simply more likely that such a parent would seek his advice. We now know that autism is not related to ethnicity, income or social class. Are we about to find that it is not as strongly linked to gender as has been supposed, that there are more autistic women out there than we imagine?

The women in the internet group certainly support a reassessment of diagnostic criteria. They want to reject the pressure to conform to a limited and limiting range of acceptable female behaviours. 'Bear witness,' writes Judy Singer, 'to the violations of human rights we have suffered: the torment in the playground; the discrimination by employers on social grounds in jobs where social skills should not be part of the criteria; the pressure from families to act normal, to be more feminine, to have children.'

Understanding of autism in males has increased dramatically over the past couple of decades. Now, it seems, it is time to take a fresh look at the way autism manifests itself in women.

8 The National Autistic Society's helpline is 0845 070 4004. For more information, visit www.autism.org.uk

APPENDIX 2: Parents' stories

Each is anonymised to protect the originators and their families.

Story 1

Parenting and autism spectrum conditions

Parenting children with autism is a challenging and rewarding job that demands skills that are not always innate but can be learned by an eager and willing student. Parents learn quickly from their children, the problems often begin when we attempt to transfer our knowledge and learned experience onto an outside world that is ill prepared to meet and greet our children with special needs, the danger when we fail is social exclusion and isolation that lead to an inevitable decline in expectations of life and rob our communities of the capacity to learn from and help each other. We need to learn how to transfer our experience fast, autism is now estimated to affect 1 in 100 people in the UK (NAO p7[1]) for reasons presently unknown but often attributed to better detection and diagnosis (where are all the undiagnosed adults who have previously slipped through the net?).

There are many theories as to potential causes of autism but no clear cut proof which fuels suspicion among parents, the public debacle involving a respected authority on autism Andrew Wakefield[2] is just one example of the fear and suspicion that surrounds autism and gives rise to our distrust of authority and subsequent damaged relationship with professionals. It is within this atmosphere of fear, doubt and disbelief that we attempt to raise our children, how can we prepare them for life on the 'outside'?

I have struggled in my attempts to 'feed' my children into a system that has little understanding and recognition of their needs. There is a ten year gap between my sons. I would like to say that the education system is sufficiently changed in ten years and in a better position to detect and meet needs than it once was but wheels are slow to turn, I heard many of the same remarks from teachers and unforgiving Headteachers in both experiences though possibly attitudes were a little more PC the second time around. My eldest son was described by his junior Headmaster as 'A born hod carrier' (which resulted in a rare brief but explosive visit from his father); a child psychologist some years later described him as 'A bloody genius' with an IQ of 180! The unhelpful bad parenting paradigm was upheld for reasons unknown and my son left school at 15 without any qualifications.

I have left no stone unturned in an effort to get an educational rethink that might meet the needs of these very intelligent young men but my efforts are often thwarted and here's the thing; it matters not how determined I am because I can see past the façade of armour plating that they employ to save their eroding sense of self-esteem that school had pummelled out of them, often by the time I have found a professional (and they are out there) who is willing to look beyond the obvious and fight their corner with me, the young person has succumbed to the belief that they are a square peg in a round hole and therefore unwelcome in the world. At the age of 15 when identity formation is at its most crucial, convinced that they are so different and abhorrent, they will cascade into other co-morbid conditions that will confound the efforts of most parents and professionals. Whilst other children are making their transitions into the world of work experience and social life, our children are at home in the autism wilderness with curtains drawn and doors firmly closed (often

reinforced with furniture) and we begin to mourn their developmental losses instead of celebrating their successes. We ourselves begin to take stock; along the way to here we have lost families who couldn't help themselves but direct unwanted and inappropriate parenting advice at us with no realisation or understanding of why their interventions do not work, friends gave up, despairing of us as we became immersed in the demands of autism. We fall into the pit of depression that we transmit to the young adult reinforcing their feelings of hopeless, uselessness, not only has the world failed to meet their needs but now we, as their parents have lost our sense of efficacy. We look to psychological services (oh the stories I could tell you!) they observe *our* shortcomings and assume that that's how it's always been, and we remain on the treadmill of learned helplessness that no medication or behaviour modification programme on earth will assuage.

The experience of autism between my children is vastly different. My eldest son was not diagnosed until the age of 22 and only then as a result of private consultation as no-one in the NHS would undertake diagnosis, it seemed crucial at the time as he was tumbling into problems, I did not realise that a diagnosis of autism would further exclude him from treatment, services or any kind of helpful understanding. He was later relieved of his diagnosis by an NHS psychologist who had no knowledge of his developmental process or on-going health conditions but felt he could do without *the label*. He was subsequently seen by an expert in personality disorder and returned home enraged after his first appointment, having been informed that he had a 'personality disorder' which is acquired and would have grown through the experience of having been loved too much or too little in childhood, but worse – he actually had no memory of his childhood to call on for proof one way or the other.

Sadly I am not the only parent to have had such accusations levelled by a professional whose patient has arrived as a result of insufficient understanding leading to misdiagnosis. The experience led to a break down in our relationship, the onset of violence brought about a descent into a new realm of existence as he tumbled into psychological territory for which there is simply no help. Body dysmorphic disorder, mood disorders, psychosis and obsessive compulsive disorders fuelled the fires of hostility leading to estrangement as he turned against himself and his family, I sought to protect myself and his younger siblings from his rage. Much of his mental health problems were exacerbated by his poor diet, the processed carbohydrates leading to opiate like effects when unavailable, often led to violent outbursts. Cravings like this are unaccounted for in autism but I have watched three generations of my family traversing the chaos of unhelpful neurology resulting in mood disorders linked to poor diet, their physical health is equally appalling, our morbidity is frightening.

I am unsure if it was his experience of psychological services or an on-going trait that led to his development of secrecy as second nature, like permanent paranoia (feared above all else in my family due to risk of schizophrenia) he avoids form filling at all costs, if needs be choosing to squat in empty buildings rather than report to the job centre as unemployed or homeless. During his descent into violence at home I sent him to a local hostel, he was entitled to help from various housing associations but his unwillingness to fill in a form and refusal to allow me to advocate for him resulted in homelessness and hunger. At 15 he had left school to work in an engineering environment returning each day like a child miner covered in black grease but determined to prove his value in the world of work. After 18 months he was invalided out with a hemopneumothorax from which he almost died. He will suffer with lung problems all his life. There followed years of recovery providing the coveted opportunity to hide away from the world, his mental scars are still

as evident as the physical ones though the physical trauma is easier for people to understand, they can see the full extent of it, it's only skin deep. Although injured at work he never applied for benefits unable and unwilling as he was to apply himself to the necessary form filling, we lived meagrely.

I began to study psychology with an eye on autism and abnormal psychology that has pitted the experience of generations of my family in a very real attempt to help myself and my children; somehow I needed to find a way to ease them into a world as at times unwelcoming as they are unwilling. I learned some techniques that I could not only apply to our overall family situation but most importantly that I could teach them to apply themselves in the privacy of their own confines. As he responded, his confidence grew he took the brave step of applying for jobs and managed to secure a job that seemed a good fit. He was quickly promoted which rankled senior staff so equally quickly let go to appease them. It was after his farewell drink that he set off home in a taxi and quickly became lost and disoriented that resulted in a brush with the law. I met with him several weeks later and was horrified at the bruises and obvious broken bones that were the result of a night in custody, the police officer thought he was being smart-no visible evidence of his Asperger's syndrome (AS) to alert him to his disability and he would not offer any. A long period of depression and withdrawal resulted in a breakdown and I had no choice but to bring him home and try to help him rebuild his self-esteem. It took 3 years. Now he looks for live-in jobs in hotels as a night porter, his constant enemy is promotion and day work, he must learn to be less able as promotion brings him into contact with a steady influx of people which after a period of 3-4 months results in burn out and his hasty departure. His future is very uncertain, he will never reach his potential, we will never know what his potential might be, he will undoubtedly come into contact with the wrong side of the law again as he leads an intransigent existence as I am not always able to accommodate him at home.

My youngest son was diagnosed with AS, ADHD and OCD at 13, the transition to senior school as often, proved the catalyst that evidenced his disability for all to see, painfully. Where my eldest son was resistant of diagnosis my younger son welcomed it feeling that it gave him a better understanding of himself, don't be fooled into thinking he *accepted* it head on, it was something of a quietly contentious nature for some 6 months before as a family we could begin to talk openly about.

One of their most notable differences is my youngest son has a moral character which underpins everything he does, integrity, good moral judgement and good humour are his constant companions without which he will flounder. Whilst they share many of the common issues of autism like attention to detail, a preference for working alone or at a respectful distance, a quiet uncluttered environment, a need for personal space, fear of changes, tactile sensitivity, perfection etc, their personalities are vastly different, it would be difficult for me to imagine my youngest son falling foul of the law by any means.

The transition from CAMHS to adult services at 17 was painful due to the relationship that he had built up with his therapist who had watched him mature and shared his frustration at his difficulties in education. I noticed a strong reluctance to embrace adult services which was an occasional home visit from a community psychiatric nurse, though he was struggling with elements of OCD and became socially phobic, he resisted medication so the role for an adult mental health team was limited. Their letter of discharge to our doctor reflected the fact that when he presented with

mental health issues it would be best not to mention his autism to the adult mental health service as it might be unhelpful in gaining treatment.

My youngest son has battled with social phobia for similar reasons to my eldest, his identity is impacted by the awareness of his differences that set him apart from his peers though he has a more secure sense of himself as a good and worthwhile person, he now accepts that his journey will be *different*. His GCSE's were disrupted as school failed to meet his needs despite his individual support plan, everything fell into disarray as support arrived too late, he was devastated and became very ill suffering anxiety resulting in agoraphobia. At school he was used in the illicit activity of others who would take him to the shop and fill the lining of his jacket with goods, being ever helpful he would allow them, thankfully a store manager observed and reported what was happening and an unwitting descent into crime was averted. Vulnerability will be his enemy-my eldest son would have been doing rather than helping! We have embarked on a pilot scheme to enable him to take his GCSE's which will be delivered through a virtual academy, with exams sat in a designated college with sufficient awareness of his needs, if successful this will enable a new educational option for others in similar circumstances. We did access funding for 3 years at a specialist college but the intake that year was mainly of students with higher than average needs and once again but for opposite reasons he found himself in a minority which further impacted on his self-esteem. He attended an IT academy, and on presentation of his very badly written up Learning Support Plan was refused, however when represented at a later date by a mentor with no mention of disability he was welcomed with open arms and graduated with top scores in the academy expecting to receive an ipad like the previous year's winner, however, the manager having discovered his disability hissed at him on his departure that when she discovered how he had managed to come first she would strip him of his certificates. First prize went to the most improved candidate. He returned home devastated, this was one of the worst blows to his self-esteem and it rendered him housebound for 2 years, his anger turned inward resulting in physical health issues with more long-term implications. People in positions of authority carry so much weight for people with autism I wish they had a measure of the destruction their ill thought out words and behaviours had and how it is to live with the results.

My daughter who is only mildly biologically affected by autism has nevertheless struggled with the demands of autism within the family, I have spread myself far too thinly in her direction actually feeling as though I was stealing time to spend with her on much loved ordinary activities like shopping and cinema trips. I say stealing as much of my life as a parent is spent attending to the greatest presenting need of the hour with not much allowance for either leisure activity or forward planning, it is a very needs must existence that can be fraught with anxiety, stress and depression that research bears out results ultimately in chronic health conditions which is why it is so important for the cost to be quantified in order to stem the flow of avoidable diseases in the future as a result of constant stress. That is not to suggest that fathers don't also experience stress and depression, but often fathers are absent either at work or due to family break ups. My daughter has learned that attention is sadly linked to need as I am discovering, is this ascent into autism or the result of neglect as a result of autism in others?

Public services are struggling to catch up with the demand for an autism friendly approach. Whilst awareness is growing fast there is a desperate need to look at attitudes of ignorance and indifference. My responsibility for my children will not end when I die, it will continue for as long as they live, as a parent is it imperative that I teach them skills for independent living to enable them

to live not just survive. In living rewarding independent lives they are better able to contribute to society and not just depend on it. People with autism, with the right guidance can excel in areas that might at first seem prohibitive; they may need a great deal of encouragement to engage, a mentor-especially an expert in their field can have a powerful influence on a young person with autism-there is huge scope here for a service offered by retired or semi-retired professionals who thrive on a challenge, experts carry a lot of weight, would that it could be in a positive way. I have heard it said by professionals that 'you have to wait for the mother to die to introduce services to the child' yes there are parents out there who seem to be locked into unhelpful battles of will and determination to keep outsiders at bay, but just consider some of the attitudes above and multiply them by 100 and understand that some parents have been indirectly abused by the system through their children, (look at Winterbourne View [3]). Some parents have been poorly parented themselves in families where autism may have been a factor before we discovered its prevalence and so may not know any difference, many parents live in ignorance and fear unable to determine that their child might have a problem until it is too late and they are presented with an angry young adult whose needs were missed at school and worst of all at home leaving society to pay the price.

Beware the rebuttal of the person centred approach-it may not be accepted as intended as it is so far removed from the norm and is often perceived as patronising better to strive for caring compassionate attitudes that lead to inclusion, they do exist, as much as I have been confronted by professionals who confused Asperger's with mental health problems I have been gifted with a connexions PA who through her affirmative attitude of awareness seems to have accomplished the impossible for my youngest son who will now get to take his GCSE's and regain his self-confidence and access mainstream education and the world of employment where he will make an outstanding contribution, if we could all display her level of commitment and interest and determination there would be no end of possibilities.

It is difficult to encourage parents new to autism to look for the child's talents and not concentrate too heavily on their deficits the nature of diagnosis would defy this statement. Much of our attention is focused on possible causes of autism; while the jury is out I believe we need to learn and to teach how to live with it in order to halt the alarming descent by our youth into illegal activity and dereliction. We may need to revise our attitudes and embrace the fact that many of these children are born without the apparent need to please us, they often don't have an inherent need to communicate with us so we need to learn how to communicate with them-not just in words but in our actions and lifestyles that precede us but of which they are so obviously aware. I am strongly advocating for more interventions that help mothers to help their children, mothers are the first line of defence for a child, better educated healthy mothers make strong advocates for children who will grow into healthier adults with better expectations of life where isolation is seen as the disease and inclusion the cure.

1 (2012)Progress in implementing the 2010 Adult Autism Strategy. (p7)
2 http://www.guardian.co.uk/society/2012/jan/05/andrew-wakefield-sues-bmj-mmr
3 http://www.learningdisabilities.org.uk/our-news/blog/11-08-05/
The Department of Health Publications, policy and guidance on autism:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122847

Progress in implementing the 2010 Adult Autism Strategy.
http://www.nao.org.uk//idoc.ashx?docId=aa73991d-d024-4eca-8c6a-6cff163b014e&version=-1
Tony Attwood's website: http://www.tonyattwood.com.au The Discovery of "Aspie" Criteria

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Story 2

'**A**' came and told us her story. Her son, '**B**', was diagnosed with autism when he was ten years old. His diagnosis included semantic pragmatic disorder, meaning he takes all spoken language literally, and obsessive compulsive disorder (OCD). He is now 21, but has an appearance and mental age of someone who is 14 or 15. When young, he was prescribed risperidone to treat his tendency to tantrums, aggression and self-injury. Unfortunately a side effect of the medication was that he put on so much body weight that he had to have two hips replaced, and is now frightened of falling. Like most autistic people, **B** also has problems with balance and co-ordination.

A said **B** does know right from wrong, but he began shoplifting when he was young. Luckily his doctor helped to keep him out of trouble by explaining to police that his conditions meant he could not realise or imagine the effects on others of his actions.

Because **B**'s tendency to tantrums, aggression and self-injury made him an awkward pupil, instead of rising to the challenge of giving him a good education anyway his school kept excluding him. **A** gave an example: on one occasion **B** picked up a pencil but didn't know who it belonged to. Since nobody claimed it he started using it. The school excluded him for two days for this. Eventually the Parents in Partnership organisation helped when **B** was being excluded repeatedly.

But because his vulnerability was obvious to other young people they picked on him unmercifully whenever they could. This frightened and stressed him until he became very angry and then physically aggressive. With age he soon became much stronger than his mother or sister. The aggression was mainly against **A** and things in her house. It hurt **A** and endangered her daughter, who was four years younger than **B**, and also increased the risk that the family would lose the house. As the aggression continued it became clear that **B** would have to move out and live somewhere else. **B** has been before the Youth Court and also the Crown Court. The decision to make him move out was very painful for **A**, because she loved both of her children. The friend whom **A** brought when she told her story works for the Domestic Arms Charity, which helps families where the parent or parents are being assaulted by their children.

B had been attacked and robbed often in the ward where they lived, so he was rehoused, firstly into C. House at the other side of the City, then a B&B which was also across the other side of the City, then a private rented flat in Moseley that was in very poor condition, then a top floor flat in Maypole where he felt very unsafe, and then a ground floor flat near to his home ward. In each of those places **B** had been picked on, attacked and robbed, suffered break-ins, and was constantly terrified. Now he lives in the ground floor flat people keep stopping him in the street and trying to pressure him to grow cannabis there. A particular police constable has been very helpful and has talked with **B** for hours, helping and advising him, which has in turn reassured **A**. **A**'s daughter has moved out to live away because she feels unsafe with **B** living near her. **A** still feels under constant threat from **B** but above all wants to help him and find some way of giving him a better quality of life free from acute stress and persecution from others, in which case the violence is likely to cease.

Social services are unable to help **A** because her son no longer lives at her address. Autistic people generally learn best by what they see, so if the date, time and place of a future appointment is written down on a card and given to **B** when he visits any office or centre, he is likely to remember and keep the appointment. St Andrews Health Care runs a 10 week course for offenders. Unfortunately like most offices or centres, St Andrews staff just speak the appointment date and time, so **B** cannot keep it in his head, and misses the repeat appointments. Thus he does not receive all the benefits for which he is eligible, and was unable to complete the St Andrews course. **B** has been on probation for a year, but **A** cannot tell what this has achieved for him. Probation services are only able to run their own fixed programmes, which are designed for the majority of offenders, whose needs are quite different from those of autistic offenders. Because of data protection law, probation staff will not talk to **A**, who could understand them, but will talk to **B**, who cannot understand or remember what they say. So neither knows what probation is doing or whether B is meeting its reporting requirements.

When asked, **A** said she had not been given any advice or signposting to alternative sources of support either before **B** left school or at any time since.

To add to **A**'s stress, she has a mother with dementia.

A would love there to be a local support centre for families coping with autism; wishes data protection laws would be interpreted to allow agencies to share with a carer information about an autistic person who cannot understand it them self; wants schools to use exclusion only as a last resort when there is no alternative, rather for their own convenience; and wants all agencies to raise their awareness of autism, and design and introduce flexibility into their programmes and systems to give autistic people at least a reasonable chance of complying with or completing them.

APPENDIX 3: Story from a young man with early-diagnosed Asperger syndrome

First can I just say that since the age of 5 I was in a number of different classes and groups and at different institutions to help me work on my social interaction skills. So although I am on the ASD spectrum I am a lot more polished socially now than I would have been if I hadn't been diagnosed from an early age.

The thing about ASD people having high IQ, speaking well and having a wide vocabulary but still finding it hard in social interaction social communication and social imagination: often I find it's because of the fact we are so socially difficult we're often not used to people using it around us, as often we may only talk to people who deliberately try to avoid that.

On the social imagination front when I was younger at the 2004 euro I heard the term dark horse used for the first time and asked my mum but where's the dark horse? Later in the tournament I then said to my mum then Germany must be the white horses as I associated the term with the colours of the kit as that was the only logical conclusion I could make from the dark horse.

On the being lied to often I believe I would find it difficult to know if someone is lying anyway, but I believe I have never been lied to, to help someone else's agenda. But that is probably because of the environment: I am around at school for the most part.

In term of understanding my own actions affecting others I do struggle to think beforehand. For example relationship break ups saying my point but not having a consideration for how that effects her opinions (that's probably a normal thing at my age but just thought I'd say) or conversations often over text where I misinterpret something they say, and react in the wrong way such as being too verbally aggressive if I feel threatened.

APPENDIX 4: Teaching American police how to deal with those with autism

Downloaded on 1 September 2012 from
www.policeone.com/corrections/articles/1705010-The-Autism-tsunami
The report has been slightly anglicised to assist understanding.
July 07, 2008

Treatment, Care & Custody
with Joel Lashley

The 'Autism tsunami': 1 in 150 births are currently on the autism spectrum; 3 out of 4 are male; half are nonverbal or profoundly verbally limited. They are seven times more likely to encounter the police than a person who is not diagnosed with an Autism Spectrum Disorder (ASD).

Driven by the natural desire to connect with their sons and daughters with autism, parents work tirelessly to communicate, mostly through trial and error. When my autistic son was growing up, this trial and error was just about all we had to rely on. But now things are swiftly approaching a critical mass. Parents of "the first wave" are trying to pass on what we've learned to the next generation of mothers and fathers — as well as the police and corrections officers who will undoubtedly come into contact with autistic people, and for whom mental health and autism training is increasingly critical.

By "first wave" I am referring to the massive increase of young adults with autism; a statistical wave created by what appears to be a perfect storm scenario of concurrent contributing factors, including increased diagnoses, increased incidence of autism, over-taxed and drying up community resources and a maturing front-line demographic of individuals with autism.

Autism is a Greek derivation meaning "state of being alone." (Pat Rogers, Children's Hospital of Wisconsin)

Just last May, I was invited by NEMRT (North East Multi-Regional Training) to attend a police instructor certification training seminar called "Autism Awareness and Roll Call Briefing Trainer" in Chicago. The State of Illinois has wisely joined Indiana and Kentucky in requiring autism awareness and related subject control training for its sworn law enforcement personnel. The conference was well attended by academy instructors and police crisis intervention team members, of the Chicago Police Department and various other police instructors from throughout Illinois.

The autism tsunami

The class was led by Dennis Debbaudt, the premier autism and law enforcement issues expert who authored the book, Autism, Advocates, and Law Enforcement Professionals; Recognizing and Reducing Risk

Situations for People with Autism Spectrum Disorders. In my opinion, all first responders, parents of children with autism, and persons on the autism spectrum, should read his book. (For more information on classes, please visit Autism Risk & Safety Managment.)

Mr. Debbaudt's co-presenter, Dr. Stephen Shore, is author of the book, Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome, and co-author of the Dummies series book, Understanding Autism for Dummies. (Also visit www.autismasperger.net.) During his presentation, Dr. Shore referred to the first wave phenomenon as the "autism tsunami." He estimates the average age of these autism-boomers at somewhere between 17 and 19 years of age.

Consider this: the Center for Disease Control estimates 1 in 150 births currently are on the autism spectrum and possibly still rising. 3 out of 4 are male. Half are nonverbal or profoundly verbally limited. They are seven times more likely to encounter the police and at least three times more likely to be victims of violent and/or sexual crimes. 4 out of 5 police calls will involve unusual or dangerous, not criminal, behaviors that will often be difficult to manage or interpret. Two out of 5 will be prone to seizures, and a good deal of them will be hypotonic (low-muscle-tone), making them prone to positional asphyxia and musculoskeletal injuries. To top it all off, many of them will appear to be oblivious to pain, while others will shrink, as if in pain (perhaps real pain), to your slightest touch.

28 principles to guide you

In the previous article, I tried to build a picture of recognition for subjects who may have an intellectual or developmental disorder, including autism. Once you've encountered a subject who you think might have a cognitive impairment, here are a few principles to help you out.

1. **First be safe.** Use your Verbal Judo principles of SAFER® and make sure they are unarmed.
2. **Persons with ASD are as diverse as neurotypical people are.** People with autism are as varied in levels of intelligence, language ability, and personality as anyone else. Start out simple. Then find out how well they can communicate and adapt to that level.
3. **Manage your back-up.** Make sure you have back-up because you may need them just like on any other call. Have your back-up stay back a few extra feet and stay quiet. Their presence is added stimulation you don't need right then! They should be alert, out of direct sight, and out of mind.
4. **Don't interfere with "self-stimming."**

   Everyone self-stimulates — we drum our fingers, tap our feet, and other quirky things when under stress or just bored. Since their sense of nonverbal communication is not like ours, persons with autism will exhibit what looks like bizarre self-stimulating behaviours, like hand flapping, twirling their body, rocking, jumping in place, handling an object and other things.

Stimulating can also be auditory in the form of humming or other sounds by mouth, or repeating a single work in rapid succession, "*Yes, yes, yes, yes, yes.*" Stimulating is a natural behaviour we all do to calm ourselves down or focus our concentration. Let it go and keep talking. It's helping you out more than you know.

Persons with autism and/or persons in crisis abhor strange voices and sounds. Only one responder should do the talking and don't allow unnecessary talking around the subject. (Pat Rogers, Children's Hospital of Wisconsin)

5. **Move them away from the scene, or move the scene away from them.** The point is to reduce outside stimulation. Give them less of everything — less sound, less light, fewer words, fewer voices, fewer people, fewer distractions. Radios, sirens, pagers, beeping medical equipment, flashing lights and all the trappings of public safety and emergency medicine are exactly what will send your subject with autism into crisis.
6. **Allow for acclimatisation.** Once you've moved them, allow them to acclimatise. Everyone acclimatises to new surroundings. We simply look around the room. People with autism will often walk around the room touching things. Just watch and make sure they are safe.
7. **Don't expect eye contact or other appropriate body language.** Their lack of, or some might argue "unique" sense of, instinctive nonverbal communication will be unnerving. They usually won't look at you or wear an appropriate expression. They may spontaneously smile, frown, scowl, or wear a blank expression. Don't look for too much meaning in what you see on the face.
8. **Don't equate the inability to speak with deafness or illiteracy.** Even if your subject is nonverbal, they are likely to hear and understand some or all of their own primary language. In the case of nonverbal subjects with autism, your spoken commands may be your only means of communication. Most of them can probably read. Try short written notes if your spoken words aren't "getting through."
9. **Don't read meaning into words alone.** Gauge your success by their physical responses to your commands, not their words. If you ask them to sit, they might say the word "sit" before or after they physically comply. They might say, "Starbucks" because their mother always tells them to sit down during their daily trip to Starbucks. They may talk about something seemingly way off topic, like a TV show or their favourite restaurant.

    They may repeat what you say back to them. Immediate repetition of what another person has said or is saying — a behaviour called "echolalia" — is a common autistic trait. Repeating is thought to be their way of attempting communication with others from behind the curtain of the profound loneliness many of them feel.

    They also might answer yes then no to the same question. Higher functioning individuals might quote the law to you when you are interfering, in their mind, with their right to move freely. Be prepared to read between, over, and under, the lines.
10. **Use a normal volume of voice until you gauge their reaction.** If your voice appears to startle or frighten them then decrease your volume. If your first attempts to communicate have failed, you can try increasing your volume slightly. Sensory input is often impaired. A low volume may be

expectable, while a "normal" volume might hurt their ears. Or they might be hearing impaired, like my son, Colin. You'll have to be adaptable until you get things rolling.

11. **Keep your tone of voice soft and unthreatening.** They will likely not be able to interpret emotion from your voice, but in case they can, you want to sound unthreatening. Slow your pace and speak clearly.
12. **Use an economy of words.** Keep your commands brief, clear, and literal (no figures of speech). Speech is a form of stimulus. Persons with autism and/or persons in crisis abhor strange voices and sound. Only one responder should do the talking and don't allow unnecessary talking around the subject.
13. **Give them extra time.** The persons with autism will usually need more time to process your words and react to them. Silently give them up to 15 seconds to act or respond to your commands or questions. You can go onto the next thing once they've answered you.
14. **Dispel their fear.** They don't know what you want from them. All they know is that you are in their face. Tell them, "I am here to help you," "I will take care of you," or "I will take you home," depending on the situation. Anticipate the problem and alleviate their anxiety.
15. **Say "good job" to kids and adults alike.** This is something I learned from Clinical Nurse Specialist Norah Johnson, RN, in Education Services at, Children's Hospital of Wisconsin, with whom I've partnered in developing behaviour challenges training related to patients with autism spectrum disorders. It may sound odd to say "good job" to an adult, but it represents praise they likely to be familiar with from childhood and perhaps even in their current living situation. By praising them with the phrase "good job" you're building rapport and validating for them that they are doing what you want.
16. **Use unthreatening body language.** If they are able to interpret body language, and most will not be able too, they will not respond to your command presence. Most will not understand it and some will only feel threatened by it. Remember, you were trained to use a command presence as a means to gain compliance. Your command presence, or alpha posture, is not appropriate to use for persons with autism or anyone in crisis. It will most likely only backfire on you.

    Instead of a command presence, keep your hands at belt level, gesture slowly, and move slowly. Be relaxed but alert.
17. **Model the behaviours you want to see.** Persons with developmental disabilities may not understand the subtleties of most nonverbal communication, but they usually will respond to your mood and the gross-motor movements of your body — either negatively or positively.

    So, if you want them to be still, then be still. If you want them to be calm, then be calm. Want them to stay back? Then maintain an appropriate space from them and from your partners. If you want them to sit then try modelling sitting. Just as they might echo your words, they might echo your behaviours.
18. **Personal space is relative.** Stay out of tip-off or kicking range as trained. Proximity is a form of nonverbal communication like any other body language. Since persons with autism spectrum disorders often do not have an instinctive sense of personal space, they might invade yours. Be ready for it. **Guard your weapons.** They can be attracted to shiny or otherwise interesting objects. If you have foreknowledge of what you're getting into, then leave your badge, name tags, pens, and other non-essential items in your squad car. Keep your hands empty — there will be time for notes later.
19. **Look for a cause.** In my experience I've met kids with autism who did things like put their head through a bus window because they couldn't tell anyone they had a bad ear infection. I've met some who severely slapped their own bare skin, probably just because they were cold. When I covered them with a blanket the behaviour stopped. I've seen kids who were combative just

because they were hungry. A cup of applesauce can make acting-out behaviours disappear magically.

20. Many teachers have talked about the "terrible hour" meaning that time in the afternoon when some kids with autism will act-up. Often when a brief nap was introduced, the behaviours ceased. First see to basic needs: pain, cold, heat, thirst, hunger, and fatigue, and then see what happens.

Persons with ASD are as diverse as neurotypical people are. People with autism are as varied in levels of intelligence, language ability, and personality as anyone else. (Pat Rogers, Children's Hospital of Wisconsin)

21. **Striking out is communication.** Facial expressions and other body language have limited or no meaning to persons with an ASD. If we get too close, or come up behind a person, we can expect to get a dirty look over the shoulder. The dirty look means "stay back" and is often an unconscious and instinctive, rather than learned, behaviour. For persons with autism, that instinct will often translate into a backhand or choking movement. They can't say it with their mouth, or show it on their face, so their instinct is to physically strike out with their hands.
22. **Tell them the "rules."** This is a tip I got from Dr. Steve and Dennis Debbaudt — when I did, it was like a light bulb went off over my head. People with autism are all about routine and the "rules." Law-abiding neurotypicals, like you and me, fear and/ or respect the law. Persons with ASD rely on and respect the rules. So for example, say, "Sir, the rules say I have to put these handcuffs on you."
23. **Quiet hands and feet.** "Quiet hands" is a common command used to manage children with ASD in the home and school setting. Its one many children and adults will be familiar with. If one is striking out or kicking, try the "quiet hands" or "quiet feet" command in a stern moderate tone.
24. **Biting is a common defensive behavior — don't get bitten!** Biting is probably the most basic mammalian defensive reaction. When attempting to physically control persons on the autism spectrum, stay clear of the mouth. The human bite is very dangerous and I've seen persons with autism severely bite their own loved ones. The best defence against a bite is to prevent it by stabilizing the subject's head before the subject's teeth can make contact with your body. If you do get bitten, mandibular or hypoglossal pressure points are worth a try, but I've seen them fail on a subject with autism. In the event that they are severely biting someone, there are other passive techniques for breaking off a bite that are beyond the scope of this article. But considering that biting is a common behaviour for autistic persons in crisis, it may be time for public safety people to learn additional passive bite releases.
25. **They have an alternative sense of fear.** People with autism may exhibit an irrational fear of, or be attracted to, glass. They are often attracted to bodies of water and have no fear of drowning (I taught my son to swim at a young age, and I suggest it to everyone. Work with his or her doctors and learn how to proceed).

    Certain sounds and sights may frighten them, perhaps even some odours or textures, but at the same time they might have no fear of opening a door in a moving car or darting into heavy traffic. Wandering off is a big problem with ASD kids and some adults. A lack of fear of strangers places them in all sorts of dangerous situations.
26. **They have an altered sense of pain.** Many persons on the autism spectrum can be repulsed by certain textures and calmed by others. Irritation from certain fabrics has been described, by some persons with autism, as painful. They might have a broken arm or other severe wound and not exhibit a pain response, such as screaming, crying, or guarding. Some may be comforted by a bear hug, but the same person might shriek at a soft touch on the shoulder, as if in pain.
27. Pain compliance will not work reliably, either because they can't feel it, or because they can't make the causal connection between your actions and the pain. For instance, they likely won't get the

connection between their action (biting) and your action (pressure point). Rapid Multiple Officer Stabilization involving the manual control of the limbs, e.g., Star Tactic (biting caution) and the blanket-escort hold, is your best method of controlling the actively violent unarmed subject that you suspect might have autism.

Wrist compression come-along tactics may injure the subject without ever achieving the desired result of compliance. When you "crank down" on the wrist, they might not wince or cry-out even if you break their wrist! They are also hypotonic [meaning their muscles have less tone and tension than most people's] making them more susceptible to injury from wrist compression. Children and elderly subjects are also very susceptible to this type of injury.

A baton strike may be useful as a means of disarming or creating dysfunction, should such a level of force become necessary. However be prepared for a baton strike to fail as a method of pain compliance or psychological control. Be ready to change your method and/or level of force quickly, depending on the circumstances.

An initial TASER® Probe Deployment will likely cause momentary incapacitation, creating a short window of opportunity in which officers can quickly move in and stabilize an autistic subject armed with an edged or blunt force weapon. Remember, one must presume that pain compliance resulting from a drive stun with the cartridge removed will be unsuccessful. Again, persons with autism may even feel the pain intensely without making the causal connection between his action (holding a weapon or potential weapon) and the pain created by your drive stun without the cartridge. They also may not understand that a TASER® is a weapon. If the subject with ASD fails to comply when you point a gun, TAZER®, OC canister or other weapon at them it could be for several reasons, such as: A.) They don't understand what the weapon can do or even recognize it as a weapon. B.) They need several seconds (up to 11 or even 15 on average) for them to understand that you are pointing a weapon at them, C.) They don't care that you are pointing a weapon at them because they are in crisis.

If your subject has an altered sense of pain, OC Spray will also likely fail as a means of control. Remember that they are likely to be hypotonic and have respiratory problems already. Consider that before using pepper spray. As one fire-fighter/paramedic put it to me recently, "Once the cops pepper spray an autistic guy or maybe someone with a diabetic reaction, and nothing happens, they usually call us to handle it. No big deal." Pardon me if I prefer that officers not use their pepper spray as an assessment tool. Take your time and be ready to "change gears" when you think you have a subject with special needs.

An officer must always do what they must to protect themselves or others. By having a thorough knowledge of what you're up against, your actions will have a better chance of a successful outcome for both you and your subject with autism. When responding to calls involving subjects with autism, 4 out of 5 times you'll be handling a subject in crisis who is scared and/or lost, not a criminal. Questions regarding the use of pain compliance techniques, control devices like OC Spray, Electronic Control Devices, and impact weapons on special needs subjects should be discussed with your department experts on the use of force and the individual weapon systems involved.

28. **Support and constantly monitor breathing.** Because they are often hypotonic, they often have difficulty breathing under stress. Also, their chest muscles may be weak and have difficulty

supporting even their own weight, in some positions. Position your handcuffed subject on their side in the lateral recumbent (low-level foetal) position, meaning slightly bent at the waist and knees. If it's safe, sit them up.

Consider transporting them in the lateral recumbent position in an ambulance. Every cop knows about positional asphyxia. Consider all your subjects with developmental disabilities to be at risk.

29. **Adrenaline stays up.** Whether for organic or behavioural reasons (and I've been told by experts that it's one, the other, or both) persons with autism need lots of extra time to cool down. It's just like any other person in crisis.

    As public safety professionals, the academic evidence is against us. What we do next at the scene of a person in crisis, or potential crisis, will usually determine if the situation is resolved peacefully or not — not the subject.

The good news is, as a parent of a child with autism, and someone who's worked and trained with street cops for most of my professional life, I know that cops are very good at sizing up these situations. Give them the tools and they'll know what to do with them! If the pros can provide police, corrections, and healthcare security officers with the necessary tools to recognize and communicate with subjects likely to have ASD, then the situation will have a fighting chance to resolve peacefully.

A police and corrections officers' ability to influence the lives of others is enormous. Your proper handling and reporting of persons with ASD could have the power to determine their destiny for the better — just as the improper handling will have the equal ability to injure them — even ruin their lives and your career. That, officers, is a tremendous responsibility. It is a responsibility as great as the responsibility for the proper execution of force, perhaps even lethal force. The power of a single police encounter has the ability to change a life forever. At no time is this more the case, then when dealing with persons in crisis, whether they have autism or not.

Special thanks to Lt. Dave Nickels with the Appleton, WI Police Department and a TASER Senior Master Instructor.

About the author: Senior Officer Joel Lashley is a Crisis Management and Defensive Tactics Instructor, who has worked as a public safety professional for over 25 years, including 18 years of service in the healthcare setting. Joel leads the training program for hospital, clinical, and social outreach staff in clinical violence management, at Children's Hospital of Wisconsin in Milwaukee, the only level-one paediatric trauma centre in the region, serving critically injured and ill patients throughout the mid-west. Joel is a trainer, program developer, and consultant on forensic patients, behavioural restraint, and special needs clients and subjects. He has trained nursing, clinical, social work, psychiatric, education, law enforcement and other public safety professionals, in the management of clients in crisis and those with cognitive disabilities. He has consulted to healthcare systems, school districts, police departments, and crisis management companies. He is a certified instructor for Interventions for Patients with Challenging Behaviours®, Principles of Subject Control (POSC®), and Tactical Communications (Verbal Judo®). Joel has developed models for the management of forensic patients or 'patient prisoners' in the clinical setting. He also co-developed a program for managing the challenging behaviours of children, adolescents, and adults with autism and other cognitive disabilities for police officers, corrections officers, and healthcare providers. The fact that his son has autism has made him concerned about how this segment of our population is managed in the educational, medical, and law enforcement arenas. Future articles deal with this and other issues facing our medical and mental health facilities, as we search for ways to best protect, serve, and when necessary, maintain the safe custody of these special populations.

APPENDIX 5: Sources of help (details)

Web-Based services

Autism West Midlands, phone number 0121 450 7582, website www.autismwestmidlands.org.uk. Amongst the website resources are downloadable information and advice guides, each designed to be useful for a particular professional dealing with people with autism, or for anyone dealing with a particular issue concerning autism. As at late August 2012 there were 23 of these, namely:

01: Explaining autism to the person with autism;
02: Explaining autism to other people;
03: Developing play and social skills;
04: Fun & leisure activities for children with autism;
05: Sibling issues and autism;
06: Helping children & young people with autism to learn;
07: Choosing a school for a child with autism;
08: Education strategies for assisting a child with autism;
09: Autism and challenging behaviour;
10: Communication and autism;
11: Sensory issues and autism;
12: Understanding & managing change and transition;
13: Personal independence payments;
14: Welfare reform and universal credit;
15: Access to work;

plus eight unnumbered guides designed for the criminal justice sector:

Autism and the police;
Acceptable behaviour contracts;
Intermediaries – a voice for vulnerable witnesses;
Police: dealing with suspects who have autism;
Police: dealing with victims and witnesses with autism;
Probation: dealing with offenders with autism;
Legal professionals: clients with autism; and
A&E staff: dealing with patients with autism.

The **National Autistic Society** website www.autism.org.uk gives access to information and advice on a range of matters including possible housing solutions; benefit entitlements; diagnosing complex needs; living with autism; leisure & environment; communicating & interacting; employment; the criminal justice system, and several other topics. It also gives access to a document called 'Autism: a guide for criminal justice professionals' prepared by the National Autistic

Society but also approved by the Association of Chief Police Officers. Our witness from the Crown Prosecution Service (CPS) has supplied a copy of this to every judge, and to every prosecutor it employs.

The National Autistic Society (NAS) employment service, Prospects, is a specialist service supporting people who have autism into mainstream jobs. Prospects provide student support, work preparation programmes, job-finding support and employment support for people with autism. They also help employers with the recruitment, training and retention of staff with autism. The NAS evaluates that between 1995 and 2003, 67% of the clients they supported found work, and that 70% of the pilot scheme's beneficiaries from 1995-97 were still in employment in 2003.

Many commercial websites offer autism-related advice, information and services. Two dissimilar examples we list at random from a long list of choices are Living Autism and Fairway Training. We have not tested their services so do not imply anything about their competence or service quality.

Living Autism, telephone number 01138 150 210, website address www.livingautism.co.uk acts as a network, matching supply and demand. It invites individuals seeking autism accommodation or therapy services to register with them and set out the services they need. It also invites organisations to register with it if they can supply autism-related services. The aim is to introduce the individuals to the organisations that may be able to meet their needs.

Fairway Training Healthcare, telephone 0845 450 3971, gives half-day training courses on a wide range of topics including for individuals and families living with autism. Its web address is http://www.fairwaystraininghealthcare.co.uk

Voluntary & Third Sector

Birmingham Voluntary Services Council (BVSC) kindly provided the following list of third sector organisations that have autism as their main focus. BVSC has over 1,000 other organisations on its database, and it may be that some of them could offer some autism support even though it may not be their prime role. BVSC's web address is http://www.bvsc.org/

Some of these organisations can provide support services directly, while others can assist autistic people to access other services.

organisation name	**organisation contact**
Autism Support Group, Solihull	http://www.solihullsassi.co.uk/
Autism Centre for Education and Research (ACER)	http://www.birmingham.ac.uk/research/activity/education/acer/index.aspx
Parent support group asperger syndrome (Adults)	mike@theirstory.org.uk
Spectrum Support Group - Sheldon	www.spectrumsupportgroup.org.uk

Birmingham Autistic Club	http://birminghamautism.org.uk/
Project Aspie	http://www.projectaspie.com/
Sutton Coldfield Autism Support Group	http://www.autismsuttoncoldfield.co.uk/
The National Autistic Society	http://www.autism.org.uk/
autism alliance	http://www.autism-alliance.org.uk/shell/home.shtml
Ambitious about Autism	http://www.ambitiousaboutautism.org.uk/page/index.cfm
Research Autism	http://www.researchautism.net/pages/welcome/home.ikml
The Disabilities Trust	http://www.disabilities-trust.org.uk/
B-Autistic	B-autistic.org.uk
Barnardo's Harris House	harris.house@barnardos.org.uk
Norman Laud Association	www.normanlaud.org.uk
Resources For Autism (West Midlands)	http://www.resourcesforautism.org.uk/
The Together Trust	www.togethertrust.org.uk

APPENDIX 6: List of Witnesses

We are very grateful to the following witnesses, without whose evidence we could not have completed the inquiry.

* indicates the 16 witnesses who attended formal member-led evidence-gathering events on 22 August and/or on 3 September 2012. Many of them, and the other listed witnesses, gave additional evidence by email, in telephone discussions, or in meetings with the inquiry's lead officer.

Young man with early-diagnosed high-functioning autism:
M. E.

Parents of autistic adults:
Nigel Archer*
B. E.* with Judy Morgan*
F. M.

Autism West Midlands:
Nigel Archer, Criminal Justice System Development Lead*
Jonathan Shephard, Chief Executive

Crown Prosecution Service:
Rosemary Thompson, CPS West Midlands Regional Lead on Hate Crime, Mental Health, Disability & Elder Abuse, and CPS Lead Tutor, Mental Health*

West Midlands Police:
Sue Southern, Superintendent*; &
Fiona Washington, Equalities, Disabilities & Human Rights Manager*.

Her Majesty's Prison, Birmingham:
Steve Williams, Deputy Director.

Children, Young People & Families Directorate:
Chris Atkinson, Assistant Director, Children with Special Needs*,
Narinder Saggu, Commissioning & Development Manager*,
Lesley Baker, Head of Communications & Autism* &
Martin Fleet, Adviser, Connexions*

Joint Commissioning:
Jon Tomlinson, Director of Joint Commissioning*
Rob Devlin, Strategic Rehabilitation & Reablement Lead*
Daniella Gilligan-King, Commissioning Officer*

Birmingham & Solihull Mental Health Foundation Trust:

Dr Amanda Skeate, Consultant Psychologist, Clinical Lead for Early Detection & Intervention Team & Youth Support Services*

Dr Anne Jasper, Consultant Psychiatrist*

Birmingham Autism Partnership Board:

Dr Ashok Roy, Consultant Psychiatrist & BAPB Chair, with Jon Tomlinson, Rob Devlin and Emma FitzGibbons, Commissioning Officer

Adults & Communities Directorate Workforce Development

Ariela Reed, Lead Practitioner, Mental Health

Bethan Welch, Lead Practitioner, Learning Disabilities

Birmingham Community Healthcare Trust - Learning Disabilities Service

Dr Steve Hinder, Consultant Psychiatrist

Dr Farooq Ahmad, Forensic Consultant

Birmingham City Council - Public Health

Dr Iris Fermin, Head of Information and Intelligence