Adults with autism and the criminal justice system



A report from Overview & Scrutiny

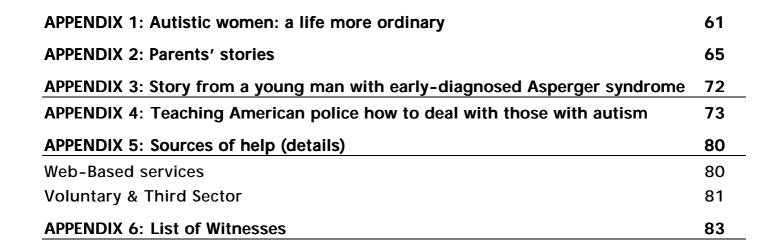




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Preface

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 tho

Report of the Health & Social Care Overview and
Scrutiny Committee, for 4 December 2012 Counci



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:

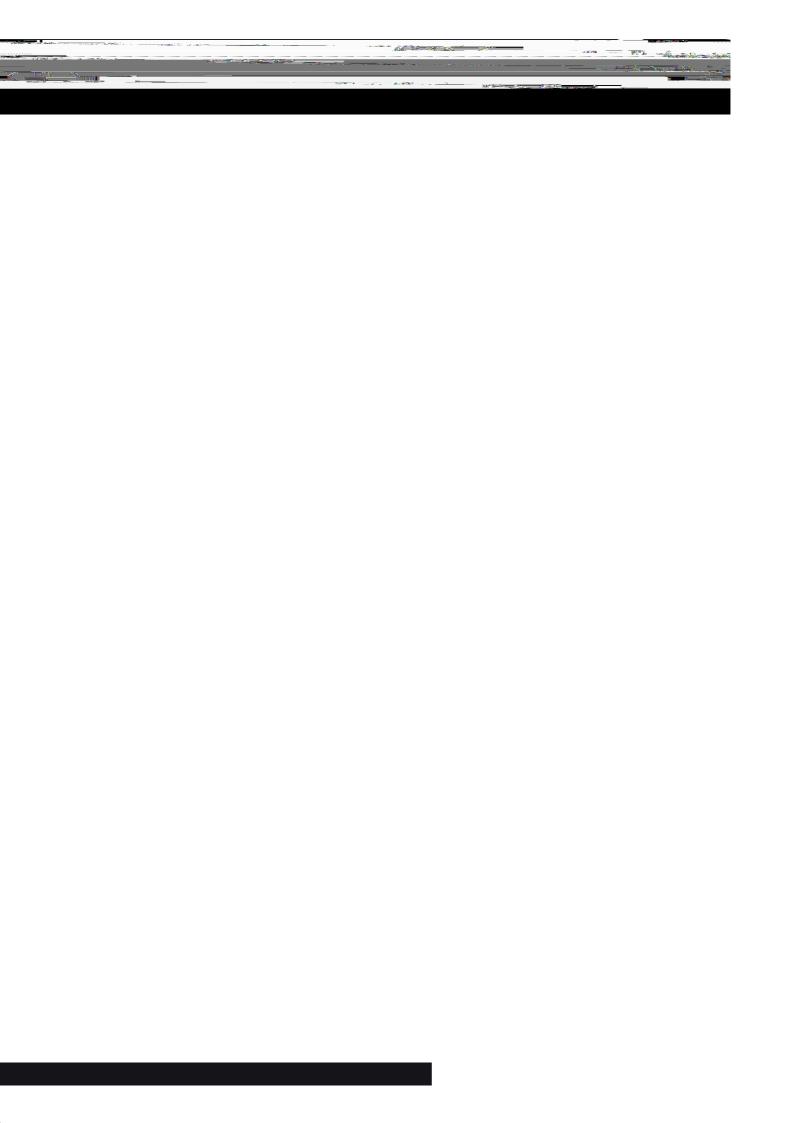
- Apprehended and detained by the police, who are the "front end" of the criminal justice system;
- Encountered by the Crown Prosecution Service, which decides which cases should come to court;
- Seen by the courts themselves;
- In the prisoner population; or
- Referred to the secondary care of the Mental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

Many autistic people and the agencies that serve or interact with them could benefit from a Birmingham-



RO7	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
RO8	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
RO9	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, Police and Crime Panel, supported by a letter from the Cabinet and Cabinet Member for Member for Health & Wellbeing, ask the Health & Wellbeing '7F0Fjt GrF8q-GF newly-appointed **Police** and Commissioner to include in the Police and Crime Plan how and by when the majority of front line police officers will be trained self-trained in autism awareness sufficiently to support them when interacting with autistic people or those whose behaviours appear to be autistic

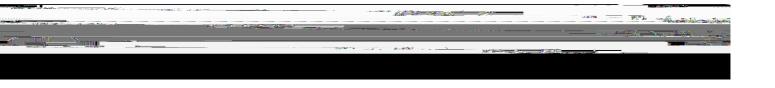


1 Autism and the criminal justice system

1.1 Introduction

1.1.1





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

2 Numbers of people with autism

2.1 National statistics

2.1.1





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 U&P'N%8G,g6%k6j%N8U,QkL&Gj%GS,gkP&G'NLL,pk67/146GN116,gkP&GLN-%,ek'& recommend:

R01: That Joint Commissioning involve Autism West Midtladsnipe UjAis Sistiff Colora Co

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



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

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 conse

- - 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





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





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

'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

- '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



to avoid trouble with the family or community. Criminal behaviours can be conied and

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 m



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



5.9.6



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 h



- - 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.





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 ge"OLE;MO] =90)LH;E3;3W90)LH;E3;3ScR"EH"M2 t c t

psychologists and other specialist staff, and can prescribe drugs that can be very

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.

dangerous and need patients to be tested frequently to ensure the drugs are doing

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

- 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 ad"OW=mo*S R

- 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.

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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. £ym"E";SyE3"M;SnROO1R)LM1ME"H3M2;I Mhe sSrROE""3"31usStR)LEH2;2"SeR"E"OHO1SSMR)OEH

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

8.4 Offenders and 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	URGENT		NON URGENT
INDIVIDUAL			
NUMBER OF PEOPLE			·
PEOPLE			



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 IrF

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 t

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

psOHRVI;SVR);YVE;HNW2SVLR);OZERKISI"R);OHE!ENI;SCOR)!!'(ZZMZSGRR);QECCORST)RE3SIRELISER"Z;SOHST

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

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

- - 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 I

- 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 referend=9oL"HEOL;OH3SfR).LM3SfRLE3;;""S R);1EL2HH;E"LShR)HEOL;OH3M

- - 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 h2W)M"fbela icer

APPENDIX 1:



trips and watches television. But her autism has ca

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 p7¹) 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 a



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 re

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 selfesteem 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 o

Progress in implementing the 2010 Adult Autism Strategy. http://www.nao.org.uk//idoc.ashx?docId=aa73991d-d02



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

<u>Situations for People with Autism Spectrum Disorders</u>. 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 <u>Autism Risk & Safety Managment</u>.)

Mr. Debbaudt's co-presenter, Dr. Stephen Shore, is author of the book, <u>Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome</u>, and co-author of the Dummies series book, <u>Understanding Autism for Dummies</u>. (Also visit <u>www.autismasperger.net</u>.) 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 <u>Center for Disease Control</u> 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

Report of the Health & Social Care Overview an	١d
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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.

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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

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.

it's safe, sit them up.

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.

APPENDIX 5: Sources of help (details)

Web-Based services



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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

<u>Birmingham Community Healthcare Trust - Learning Disabilities Service</u>

Dr Steve Hinder, Consultant Psychiatrist Dr Farooq Ahmad, Forensic Consultant

Birmingham City Council - Public Health

Dr Iris Fermin, Head of Information and Intelligence