



**Brighton & Hove
City Council**

**Report of the Adult Social Care & Housing
Overview and Scrutiny Panel**

Date: March 2011

**Scrutiny Panel on Services for Adults with
Autistic Spectrum Conditions**

VOLUME 2 – MINUTES AND EVIDENCE

Panel Members

**Councillor Steve Harmer-Strange (Chairman)
Councillor Anne Meadows
Councillor Alex Philips
Councillor David Watkins**

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6 September 2010

Professor Jeremy Turk, Professor of Developmental Psychiatry & Consultant Child & Adolescent Psychiatrist, Southwark Child & Adolescent Mental Health Developmental Neuropsychiatry Service, South London & Maudsley Foundation NHS Trust

Diana Bernhardt, Lead Commissioner for Learning Disabilities, Brighton & Hove City Council

Claire Newman, Acting Strategic Commissioner, Substance Misuse and Mental Health Commissioning Team, NHS Brighton & Hove

24 September 2010

Sarah Faulkner, Project Leader, Assert

Speaker 2 - Parent

Speaker 3 - Witness from Health Care

Speaker 4 - Mr B, Service User

Speaker 5 - Mr C, Service User

Speaker 6 - Mr D, Service User

Speaker 7 - Mr E, Parent

Speaker 8 - Adam Lavis, Former Support Worker

Speaker 9 - Ms F, Service User

Speaker 10 - Ms G, Parent

Speaker 11 - Ms H, Parent/child/Service User

Speaker 12 - Mr J, Parent

15 October 2010

Naomi Cox, General Manager, Adult Learning Disability Services, Brighton & Hove City Council

John Rosser, Service Director for Working Age Mental Health Services, Sussex Partnership Foundation Trust (SPFT)

Rebecca Simpson Team Leader in West Recovery Team, Millview Hospital and previously the Clinical Nurse Specialist in high functioning autism and Asperger in West Sussex

Dr Neil Harrison, Consultant Psychiatrist, Assessment Service run by Dr Hugo Critchley

Dr Dawn Howard, Clinical Psychologist, the Neurobehavioural Diagnostic Clinic

Jenny Brickell, Head of Child Development and Disability Service, Brighton & Hove City Council

Lizzie Batten, Amaze

19 November 2010

Dr Becky Jarvis, GP

Professor Hugo Critchley, Neurobehavioural Team, Brighton and Sussex Medical School

Ian Watling, Deputy Service Director, Sussex Partnership Foundation Trust

Guy Montague-Smith, Access Point Operations Manager, Brighton & Hove City Council

Graham Bourne, Head of Revenues and Benefits, Brighton & Hove City Council

James Crane, Service Improvement Manager, Brighton & Hove City Council

Alex Cooter, Youth Offending Service, Brighton & Hove City Council

Miranda Wharam, Children's Disability Social Work Team, Brighton & Hove City Council

Mary Evans, Head of Communities and Equality, Brighton & Hove City Council

25 November 2010

Speaker 1 – Ms A Parent

Speaker 2 – Lalli Howell and Ian Stephenson, Downs View Link College

Speaker 3 – Mr B, Service User

Speaker 4 – Mr C, Service User

Speaker 5 – Ms D, Service User

Speaker 6 – Ms F, Parent

Speaker 7 – Mr G, Carer

15 December 2010

Professor Jeremy Turk (please see above)

Sergeant Peter Castleton, Sussex Police, Strategic and Neighbourhood Policing Support

Jugal Sharma, Lead Commissioner, Housing, Brighton & Hove City Council

Tamsin Peart, Commissioner, Adult Social Care, Brighton & Hove City Council

Diana Bernhardt , Lead Commissioner for Learning Disabilities, Brighton & Hove City Council

Maureen Pasmore, Service Manager, Supported Employment, Brighton & Hove City Council

Sarah Faulkner, Assert

Maxine Thomas, Impact Workability

BRIGHTON & HOVE CITY COUNCIL SCRUTINY PANEL ON SERVICES FOR ADULTS WITH AUTISTIC SPECTRUM CONDITIONS

6 September 2010 Minutes

Present: Councillors Harmer-Strange (Chairman); Phillips and Watkins

Apologies: Councillor Meadows

1. PROCEDURAL BUSINESS

1a Declaration of Substitutes

1.1 There were none

1b Declarations of Interest

1.2 Councillor Harmer-Strange declared a non-prejudicial interest in the remit of the panel as a parent with two children on the autistic spectrum.

1c Declarations of Party Whip

1.3 There were none

1d Exclusion of Press and Public

1.4 In accordance with section 100A(4) of the Local Government Act 1972, it was considered whether the press and public should be excluded from the meeting during the consideration of any items contained in the agenda, having regard to the nature of the business to be transacted and the nature of the proceedings and the likelihood as to whether, if members of the press and public were present, there would be disclosure to them of confidential or exempt information as defined in section 100I (1) of the said Act.

1.5 **RESOLVED** – that the press and public be not excluded from the meeting.

2. CHAIRMAN'S COMMUNICATIONS

2.1 Councillor Steve Harmer-Strange introduced himself as Chairman of the panel and welcomed everyone to the first public scrutiny panel meeting looking at services for adults with Autistic Spectrum Conditions (ASC). Councillor Harmer-Strange introduced the other panel members, Councillors Phillips and Watkins. Apologies had been received from Councillor Meadows.

2.2 The Chairman explained the remit of the panel, established to look at services for adults with Autistic Spectrum Conditions (ASC) in Brighton and Hove. The panel had been established to review services provided

by the council and partner organisations in light of the recent National Autism Strategy, to see which areas were already working well and which could be improved.

- 2.3 The Chairman said that it was known that there were already well established services for children with autism spectrum conditions in the city. The review would focus on services for adults and the transition from children's services to adult services.
- 2.4 There were due to be five public meetings in total. The panel was aware that the subject matter was immense and it might only be possible to scratch the surface of some of the areas that need to be considered but it would at least shed some light as to where there needed to be further research.
- 2.5 The second meeting, on 24 September 2010, would be an open meeting for members of the public who have used ASC services in the city to give their views on the current provision and what they would like to see in future service delivery. The panel would also be inviting service providers, health colleagues and council officers to take part in this meeting and others throughout the process.
- 2.6 Following the five meetings, the panel members would consider the information that they had heard and make recommendations for how the service might be shaped in the future. The panel hoped to have the final report and recommendations by next spring.

3. OVERVIEW OF AUTISTIC SPECTRUM CONDITIONS

- 3.1 The Chairman introduced the first speaker, Professor Jeremy Turk. Jeremy Turk is Professor of Developmental Psychiatry at the Institute of Psychiatry and St. George's, University of London. He is also Honorary Consultant Child & Adolescent Neuropsychiatrist at South London & Maudsley Foundation NHS Trust, where he is Southwark Borough Child & Adolescent Mental Health Learning Disability Lead and Consultant Psychiatrist on their Child & Adolescent Mental Health Neurodevelopmental Service. In addition he runs a National CAMHS Behavioural Phenotype clinic at The Maudsley Hospital, is Consultant Psychiatrist to the National Autistic Society Centre, and is President of the Royal Society of Medicine Intellectual Disability Forum. Professor Turk has longstanding clinical & academic interests in the mental health needs of children and young people with autism, intellectual disability, ADHD & other developmental disorders, and is first author of the standard textbook, *Child & Adolescent Psychiatry: a Developmental Approach*, published by Oxford University Press. He is also co-author of *Developing Mental Health Services for Children and Adolescents with Learning Disabilities: a Toolkit for Clinicians*. He is member of the editorial boards of *Journal of Intellectual Disability Research*, *Journal of Applied Research in Intellectual Disabilities* and

Advances in Mental Health and Learning Disabilities and is Associate Editor of American Journal of Intellectual & Developmental Disabilities.

Professor Turk studied medicine at The Middlesex Hospital Medical School and psychology at University College London before undertaking higher training in paediatrics and then psychiatry prior to becoming Clinical Lecturer in Child & Adolescent Psychiatry at Great Ormond Street Hospital, and the Institute of Child Health. He took up his Senior Lectureship at St. George's in 1993, progressing through Readership to Professor. He commenced his current positions at the Institute of Psychiatry and South London & Maudsley Foundation NHS Trust in September 2009.

3.2 Professor Turk gave a very detailed and comprehensive overview of ASC in order to provide the panel with a baseline for their discussions. (Please see minute book for a copy of the slides). Professor Turk answered questions during and after his presentation.

3.3 In relation to the slide showing the overlap between ASC, ADHD and intellectual disabilities, the panel asked whether it was the case that the presence of one of the conditions made it more likely that another of the conditions would present themselves and whether the individual conditions could be treated by themselves.

Professor Turk said that there were a number of important crossovers between the conditions. If one had an intellectual disability, the risk of also having ASC rose from the general population's level of 1-2% to almost a third. This was also the case for those who had ASC; the risk of having an intellectual disability was much higher. 70% of people with ASC have an IQ below 70; only 5% have an above average IQ. The people within this group had very complex needs which were often unmet. There were similar crossovers in terms of ADHD and ASC.

3.4 In terms of prevalence rates in Brighton and Hove, Professor Turk said that, based on the generally accepted rates, calculations showed that in the city's population of approximately 250 000 residents, assuming 80% adults, in adulthood there should be approximately 6000 adults with a degree of intellectual disability (with 195 000 without).

From this 195 000, there would be approximately 2000 adults with ASC, not all of whom would need help or support, and a similar number of adults with intellectual disabilities and ASC. As many as a third of these people could also have mental health problems of some type.

3.5 Children and young people tended to receive better services, as did adults who also had intellectual disabilities as they were known to service providers. The group who are not being helped at present are adults who do not have an intellectual disability but who do have ASC and possibly a mental health problem as well.

- 3.6** In response to a question about whether people diagnosed with ASC could be ‘compartmentalised’ into recognisable areas, so that treatments and support were most effectively used, members heard that the model used increasingly by Learning Disabilities (LD) was a good one to follow. In this, the acknowledgement that someone had LD was not itself an indication that they needed support, but that having LD would leave a person more vulnerable to requiring support and it was important to recognise what support was needed.

In terms of ASC, the baseline of general awareness and understanding was still very low. There needed to be an acknowledgement that ASC could affect anyone, that there were special educational issues, whether provided within mainstream or specialist provision, and that there were social and welfare aspects. Resources needed to be focused on those most in need and who would benefit most, including the family needs.

In adulthood, if someone has a severe LD and additionally an ASC, they were more likely to have all of their LD and ASC needs recognised as they were already being helped within the LD service. This was not always the case for someone who was not being supported by the LD services. Mental Health professionals might not necessarily have a good understanding of ASC so they might not be able to support both needs.

- 3.7** This was often a major issue at transition from children’s to adults’ services, as families and carers did not know who would be able to help the person with ASC with adult social services. This led to a question about where services for adults with ASC should best lie, whether within services for adults with LD or within adult neurology? There was no easy solution to this question.

There was a follow up comment regarding a scrutiny panel a number of years ago, looking at the Palmeira project, a home for children and young people with severe ASC. The young people would now be in their mid-twenties. The panel hoped that parents who had been involved with the scrutiny panel at that time would come back and tell the current panel about their experiences with transition and the issues that it raised.

The panel member said that he was currently in contact with the parents of a teenage child with ASC. They said that the service that they received from CYPT was excellent but they were very concerned about what would happen at the transition stage. It was vital that the panel looked at transition and how this could be best supported and managed in order to support and reassure parents.

- 3.8** There was a question about early diagnosis and the query about whether the statistics about boys being more prone to ASC was due to the way that they externalised behaviours. Was there a need for more

training within schools and for GPs in order to identify any girls who might have ASC?

Professor Turk said that he would advocate investing in two areas; the first was helping families to feel supported and empowered, particularly as they were approaching transition stage. The second was to provide improved training and awareness for all front line services including health colleagues and local authority workers.

- 3.9** There was a question about the perceived lack of GP awareness and understanding. How would people with ASC be identified if it was not through a GP's diagnosis?

Professor Turk said that colleagues of at Guys Hospital were working on developing screening instruments. There were discussions about whether it was appropriate to screen all toddlers and primary school pupils in order to identify those most at risk so that early intervention steps could be taken, to minimise later issues. This would avoid the problems associated with self referral and would link with Special Educational Needs guidance that a proactive approach should be taken.

- 3.10** The panel asked whether the council should be more proactive in employing people with ASC who were able to work. Professor Turk said that this would be a very positive step. ASC was now legally recognised as a disability and was covered by the relevant legislation; therefore an employer would be expected to have a proportion of staff with ASC, working with the necessary support.

It may well be the case that there were employees in all organisations who had ASC but who had not publicly identified themselves as such. There might be benefits in 'coming out' as having ASC; this would help with identifying problems and solutions that arose later. There were certain types of job role that would suit a person with a particular sort of ASC, for example repetitive tasks. It was about finding the right niche for the person.

- 3.11** There was a follow up question regarding the proportion of people with ASC who did go on to employment of some kind.

Professor Turk said that research had shown that there were a number of factors involved, including the level of intellectual ability and the available support to be able to function and undertake meaningful employment. However it was still the minority of people with ASC who had a meaningful job; this was a missed opportunity in many ways.

- 3.12** Professor Turk was asked whether he was aware of any other local authorities who had good practice in providing services for adults with ASC. Professor Turk was not aware of any at present. He did comment that he was concerned that there was a focus on repeated mapping

exercises without looking further. It would be better to look at what were the quick wins – eg training; interdisciplinary approaches – and at the priorities, in order to move on with the work.

- 3.13** Professor Turk was thanked for his excellent presentation and for his invaluable input.

4. INTRODUCTION AND BRIEF OVERVIEW OF THE CURRENT PICTURE LOCALLY

- 4.1** Diana Bernhardt is Lead Commissioner for Learning Disabilities Brighton and Hove. Ms Bernhardt is based within the local authority as a joint post between the council and with NHS Brighton and Hove. She is responsible for the strategic commissioning of services for people with learning disabilities in Brighton and Hove.

Her roles include identifying and understanding local need through feedback from people who use services and consultation with the wider community; and ensuring local needs are met within resources available through outcome focused commissioning.

- 4.2** Ms Bernhardt gave a presentation on the new National Autism Strategy (NAS) (please see minute book for a copy of the presentation); she commented that this was a long term solution although there were quick wins to be had, as Professor Turk had explained.
- 4.3** Ms Bernhardt began by asking what was different about ASC? She said that there was no single diagnostic test, and there are so many behaviours linked to ASC, it is very difficult to identify a person with ASC and to organise local services in the best ways.

She commented that local authorities nationwide had very different ways of addressing the ASC situation; there was no one prescribed way at present. However, guidance from NICE was expected in June 2011 which may give a pathway for local authorities to follow.

Ms Bernhardt commented that, because there had been so many approaches, there was a lack of evidence about what worked best and what the best ways of investing resources were

The first NAS had been issued last year, which was leading into the guidance currently out for consultation, and the first year's delivery plan, which Claire Newman would discuss.

- 4.4** Locally there were currently two pathways to diagnosis, one through Learning Disabilities and one through Mental Health services. They were both accessed through a GP referral; this may be a barrier if GPs did not understand ASC. It would also require the person's family or carer to initiate the referral.

Ms Bernhardt said that the current system was not perfect and people fell outside of the referral pathways; if someone did not have LD, then it was necessary for them to come through the mental health system to be diagnosed, although ASC is not a mental health condition or an LD in itself. The pathways were being considered in the near future.

- 4.5** Ms Bernhardt showed the figures provided to the National Audit Office based on 2007/8 data indicating the number of people identified as having ASC in Brighton and Hove who were receiving social care services. The LD services had 121 identified individuals; recent projections would put this at approximately 140 people, so there was not a significant rise since 2007/8.

34 people were identified as having ASC and receiving social care services who did not have LD. This was very low and would indicate issues around the referral pathways. In addition it was likely that there would be people receiving services who had not been identified as having ASC. Services were organised around client groups and people with ASC did not neatly fit within the client groups. There was clear under reporting and under recording at present.

- 4.6** In terms of current services, this would be looked at in more detail in the third panel meeting. Anecdotally, the supported employment team have said that they work with people with ASC to support them into work. There are people receiving LD day services and mental health services that have ASC. However the services were structured primarily to deal with LD or mental health issues rather than the ASC.

In terms of advocacy, the council and PCT funded Speakout (for people with LD) and MIND (for mental health problems). Locally, the group ASSERT worked with people with Asperger's syndrome for casework and advocacy. There were also mainstream advocacy groups such as AMAZE for children.

For accommodation, there are residential or supported living services for adults with ASC. LD and mental health services both used Autism Sussex services. In LD accommodation services, there was a young people's scheme which was linked to the Palmeira project; a large number of the residents had ASC. There were people receiving homelessness support services who had ASC but who were not recorded as such, as this was not one of the homelessness's identified client groups. There were a range of information and advice services provided locally that would be accessed by people with ASC.

- 4.7** Ms Bernhardt concluded her presentation by saying that this was only a brief picture of local services. What was needed was a better understanding of what works well locally and what needed to be done to make the processes work more smoothly. In addition, there were training needs for providers and staff; this was all part of the long term view.

5. KEY THEMES FROM THE NATIONAL AUTISM STRATEGY AND DELIVERY PLAN

- 5.1** Ms Bernhardt then handed over to Claire Newman, with questions for both presenters coming after the second presentation.

Ms Newman is Acting Strategic Commissioner, Mental Health and Substance Misuse for NHS Brighton and Hove. Her key duties include being responsible for the strategic commissioning of Mental Health and Substance Misuse services across Brighton & Hove ensuring that a comprehensive range of high quality, responsive and efficient services are commissioned within allocated resources and in line with national and local policy.

Ms Newman has a clinical background predominantly in Substance Misuse, working across a range of third sector, and statutory organisations including the NHS and the Prison Service. She has latterly moved into a commissioning role with the PCT.

- 5.2** Ms Newman's presentation focussed on key aspects of the National Autism Strategy (NAS), the approach to commissioning services for ASC and Asperger's and what can be done in terms of more immediate actions with regard to the first year delivery action plan.

- 5.3** The NAS has issues cutting across services and partners. There were five key themes:

- *Increasing awareness and understanding of autism among frontline professionals*

Ms Newman said that it was clear that staff in health and social care only came into contact with people who had conditions at the extreme ends of the autistic spectrum.

The majority of people who have ASC did not come into contact with specialist services although they would be coming into contact with other frontline services including housing, the DWP, GPs etc. It was likely that their needs were not being acknowledged so it was necessary to train frontline staff according to the needs of their job, with specialist training for staff in health and social care.

The NAS also refers to raising awareness for and through employers, extending the Employability scheme, extending the disability discrimination act to encourage employers to make reasonable adjustments, and raising public awareness.

The national delivery plan alludes to a package of training that can be rolled out across a variety of agencies. This should be produced by the

end of 2010, with a specific focus on employment services and criminal justice services

- *Developing a clear and consistent pathway for diagnosis in every area, which is followed by the offer of personalised needs assessment*

The panel had already heard from Ms Bernhardt about the two main pathways leading to the diagnosis of ASC in adults in Brighton and Hove. To access diagnosis through the mental health pathway is very complex with a number of hurdles, and could take up to 18 months. This was not acceptable and needed to be addressed.

The NAS listed a number of requirements under this theme. Amongst these was a requirement to provide information at the point of diagnosis; Ms Newman felt that this was not currently happening in the city. NICE guidance was due to be issued but it was important to take action as soon as possible, rather than to wait for it to be issued.

The Strategy suggests that a lead professional is identified to assist in championing the work; Ms Newman said that it would be possible to do this quickly.

Ms Newman spoke about the cohort of individuals who had reached adulthood without an ASC diagnosis; it was necessary to work with people who came into contact with those individuals and increase their awareness.

- *Improving access for adults with autism to the services and support they need to live independently within the community*

The NAS was concerned with adults accessing mainstream services, maximising the use of personalisation, supporting travel training etc. A key period was the transition period into adult services. Experience suggested that for people with a LD diagnosis as well as ASC, the transition was more joined up; for those with a mental health issue and ASC, there was more likelihood of falling through the gaps as the services were not as joined up.

- *Helping adults with autism into work*

Ms Newman spoke about the various employment initiatives. These included Valuing People Now, as well as job coaching, which had a very good evidence base behind it.

There was a new scheme called Project Search around internships for people with LD, which may help people with ASC, and a scheme called Work Choice, due to start in October 2010, which was a pan-disability work scheme.

The DWP had made a commitment to double the number of Mental Health Coordinators, helping people back into work. The previous government had made a financial commitment to the Access to Work scheme until 2013/ 14 but it was not known what the current government's proposals were for any of the initiatives.

• *Enabling local partners to develop relevant services for adults with autism to meet identified needs and priorities*

This strand was about all mainstream services acknowledging autism and having it on their service map. There were a number of suggestions and requirements listed.

6. DEVELOPING A LOCAL AUTISM STRATEGY

6.1 Ms Newman then spoke about developing an ASC commissioning strategy for Brighton and Hove. She gave an overview of the commissioning cycle and spoke of some quick wins in the next 12-18 months but this would take a much longer approach in order to ensure that it was the right approach.

6.2 One of the key issues was understanding the needs locally; a comprehensive Joint Strategic Needs Assessment was needed. The Audit Office overview showed that there was a huge issue in terms of knowing the level of need. It would not be enough to focus on those already identified as having ASC and using a service, due to underreporting.

Professor Turk's figures suggested that there should be approximately 6000 people with ASC; current data showed approximately 200 people using services.

6.3 There were some financial realities with regard to business planning and budgeting: increasing services for ASC may well mean decommissioning or reducing other services. This message would be taken to the PCT and partner groups.

6.4 Ms Newman spoke about the timeline for developing a commissioning strategy. One of the key messages was that this was a multi agency partnership approach. Ms Newman was planning to establish a local governance structure, an Adult Autism Strategy Programme Board, working with partners including the criminal justice system. There was a Mental Health Court Diversion scheme in place which could have a significant impact in identifying people with ASC within the criminal justice system.

Ms Newman also committed to the priority target of increasing awareness of autism among frontline professionals. This could be done quickly; she gave more information about this.

Ms Newman's second priority area was looking at the diagnostic pathway process. As heard, the mental health pathway seemed to take an unacceptably long time before diagnosis and to see what could be done to minimise this. There were also plans to work with providers to improve the information given to patients and their families.

- 6.5** Ms Bernhardt and Ms Newman answered questions from the panel. There were concerns about the low figures being recorded as having ASC and using services. The panel asked for details about the numbers of children going through the transition process each year; should it not be the case that the figures should be higher year on year? Are people being filtered out of the system somehow or are the numbers elsewhere? It was a concern that it was only now that adults with ASC were being recognised as a need for the city.

Ms Bernhardt said that it was very important to recognise that the level of resources for adults was very different than those given for children's services and the legislation for each group was different. This led to two different systems being set up; there was however room for improvement and better communication between the two systems.

There was no desire to treat the two groups differently but it was due to the framework given and the level of resources in comparison.

In terms of identifying people with ASC, the Audit Office figures included people under 18 as well; they were not high numbers. The figures reported to the Audit Office were that there were 229 people with LD and ASC (this included children and young people) and 255 without LD and ASC.

The city needed to get better at identifying/ recording people with ASC. A Children's Disability Joint Strategic Needs Assessment (JSNA) was underway, as was a Learning Disabilities JSNA and there were plans to carry out some needs mapping around ASC.

From a social care perspective, when children went through the transition phase, they were assessed as to whether they meet the eligibility criteria.

Denise D'Souza, Acting Director of Adult Social Care, spoke in order to put the figures in some context. There were about 780 people who received LD services; the figure of 229 with ASC was a proportion of that. The total number of children with LD who came through transition each year was between 15-18; this was for all LD including ASC.

Ms Newman said that, for her, the issue was the mental health pathway. ASC was not a mental health diagnosis, but there was not an

appropriate service for those who came through the mental health pathway unless you had a concurrent mental health diagnosis.

Ms D'Souza said that her concern was for those people who had not been diagnosed as children; they might not be picked up but would be vulnerable adults, possibly with inappropriate behaviours or subject to abuse. This might lead to criminal justice involvement.

6.6 The panel asked Professor Turk whether a diagnosis in an individual changed throughout their life. He said that you tended to be who you were and that diagnosis did not often change. In terms of figures being lower than expected, this might be because families had given up asking for help and no longer presented for help. Professor Turk would recommend the re-orientation of resources if possible.

6.7 The panel asked how the council worked with third sector organisations such as ASSERT and what support were the groups given? Ms Bernhardt said that the council did not fund ASSERT, they received charitable funding. Ms Bernhardt and Ms Newman had recently met with ASSERT and were going to have follow up meetings to understand their issues. They wanted to work more closely with ASSERT and had committed to try and see what could be done to address the issues. Future arrangements would need to be considered in light of the local pathway.

6.8 The panel asked about training for professionals. What plans were there within the strategy to address training needs for professionals across the board?

Ms Newman said that the DoH would be issuing a toolkit in the year. In the meantime the Steering Group, which would include a number of frontline service representatives, would work to carry out a training need analysis, including cost and resource implications. The suggestion was that staff would be given appropriate training according to their level of need and the service that they were working in.

The Chairman said that this meeting was being recorded so that Professor Turk's presentation as well as the others could be used as training resources in the future.

7. DATE OF NEXT MEETING

7.1 The Chairman thanked all of the speakers for their presentations and involvement in raising awareness and thanked the panel too.

7.2 The next meeting would be on 24 September 2010 at 10am in Hove Town Hall.

The meeting concluded at 4.15pm

24 September 2010 Minutes

Present: Councillors Harmer-Strange (Chairman); Meadows, Phillips and Watkins

8. PROCEDURAL BUSINESS

8a Declaration of Substitutes

8.1 There were none

8b Declarations of Interest

8.2 Councillor Harmer-Strange declared a non-prejudicial interest in the remit of the panel as a parent with two children on the autistic spectrum.

8c Declarations of Party Whip

8.3 There were none

8d Exclusion of Press and Public

8.4 In accordance with section 100A(4) of the Local Government Act 1972, it was considered whether the press and public should be excluded from the meeting during the consideration of any items contained in the agenda, having regard to the nature of the business to be transacted and the nature of the proceedings and the likelihood as to whether, if members of the press and public were present, there would be disclosure to them of confidential or exempt information as defined in section 100I (1) of the said Act.

8.5 **RESOLVED** – that the press and public be not excluded from the meeting.

9. MINUTES OF PREVIOUS MEETING

9.1 These were agreed.

10. CHAIRMAN'S COMMUNICATIONS

10.1 The Chairman welcomed everyone to the meeting and introduced the panel members.

The Chairman advised people that the meeting was being recorded for use as a training resource although it was not being broadcast live. He said that the panel had tried to contact as many attendees as possible to check that they were happy to be recorded but asked that people did

not wish to be recorded, please let the panel know so that it could be removed afterwards.

10.2 The Chairman said that he was delighted that so many people were able to make it to the meeting and thanked them for giving up their time to take part in what he hoped would be a very valuable and informative session looking at experiences of using the current services for adults with ASC.

10.3 The Chairman gave some background information, explaining the remit of the scrutiny panel. He said that this meeting was intended for the panel to hear from residents about their experiences of the services for adults in Brighton and Hove. The panel were hoping to hear about positive as well as negative experiences in order to see what was working well and what ought to be reviewed

**11. EVIDENCE GATHERING FROM MEMBERS OF THE PUBLIC –
SPEAKER 1, SARAH FAULKNER FROM ASSERT**

11.1 Ms Faulkner is the Project Leader for ASSERT, which supports adults with high functioning ASC and Asperger's Syndrome in Brighton & Hove. She is the only paid employee.

11.2 ASSERT was set up to give low level support, but there has been such a high demand for services, they are now overwhelmed with many individuals in extreme crisis. If someone's ASC needs are ignored, then it can lead to mental health problems and more need for support and services.

They have 250 clients on their books and rising - with 50 of those in crisis and needing regular support. They provide free/ low cost support.

11.3 Their funding comes from philanthropy. ASSERT did not receive any funding from the council or health service. They had asked the council twice, and been refused. Most recently, they had been told to wait for the outcome of the autism strategy's introduction.

ASSERT does not have the time to carry out fundraising as well as caring/ supporting its clients. If they did receive statutory funding, they would prefer that it was not attached to a service user; most of ASSERT's users were not known to social services and so would not receive funding.

ASSERT desperately needs more resources and more staff; there is a huge need for their services but no funding to provide the services. ASSERT has had to close its books twice recently due to overwhelming demand for its services and they were growing increasingly worried about people's wellbeing. ASSERT was often the first point of contact for people with ASC.

ASSERT used to be able to offer day trips etc but their funding was now focussed on keeping people alive. It was almost impossible to obtain funding but the demand was increasing greatly

- 11.4** When ASSERT refers people to the council, eg via Access Point, the client is often referred back to ASSERT as the council does not have services available. The person is left to manage their own lives, often moving further and further into crisis and this is when they present to ASSERT again. At least 80% of ASSERT's clients do not have a social worker. It was very hard to get a diagnosis as an adult.

ASSERT might see a parent with their child. The child may have received an informal diagnosis, but it was often quite woolly and might not even be written down. Parents and children were often not given coping skills or information.

- 11.5** Ms Faulkner said that there were a number of issues around communication for people with ASC:
- people needed clear information
 - you shouldn't give too many options as this became overwhelming, try and limit options to three at most
 - ask simple questions with one element at a time
 - give prompts and reminders to attend appointments
 - the worker might need to tease out important information from the client.

Ms Faulkner gave the example of a man who had come to ASSERT for help with university applications. At the end of an hour's appointment, he mentioned in passing his appalling living conditions. He had not known that it was important to mention it.

- 11.6** Ms Faulkner said that some education colleagues were helpful in supporting adults with ASC. Some were very keen to help, but there were not enough staff in universities and there were often delays in arranging for assessments for the student. These delays could mean the student would drop out of university rather than cope with the situations they were put in. For example, people with ASC would not be able to give presentations nor do group work, so alternative assessments needed to be found if the placement was to be successful.

Jane Frost from ASSERT said that her son was at Manchester and had been fortunate in having all of the support mechanisms in place before he started. In addition, the educational establishment needed to be willing to change; this was not always the case.

12. SPEAKER 2 - MR A, PARENT

- 12.1** Mr A moved to the UK 3 years ago. He had a son, now 20, who had Asperger's Syndrome. He was very frustrated with the UK's system and had suggestions for how it could be changed.

He was very shocked that he had had to wait four months for a school place for his son when they moved to Brighton. He had told the council that it was very important that his son had a school place for consistency.

- 12.2** He had had not help from the council; ASSERT had not been able to help either, perhaps because they were overwhelmed? Mr A had had someone from the council promise to come and visit about twenty times. They never came and he lost heart

- 12.3** In Germany, a person with ASC had an officially appointed professional link person, between the system and the person. It was always the same person – it was vital to have the consistency. The client and support worker met up perhaps once a week

In the UK, it seemed as though charities were staffed by volunteers, who were willing to help but who often changed and who did not have the necessary knowledge of ASC to provide meaningful intervention.

- 12.4** Mr A said that the UK system was also frustrating as there was one system until a child was 16; there did not seem to be anything between 16 and 18. His son was 17 when they moved and so they were told to wait until he reached 18 for help.

13. SPEAKER 3 - WITNESS FROM HEALTH CARE

- 13.1** The witness from Health Care was someone who worked with young people aged 14- 25, supporting them with emotional and psychological issues. The service received a lot of referrals for young people with Asperger's Syndrome.

The witness would back up what ASSERT had said; there was a desperate lack of services, and some people were completely isolated. The clients often had a dual diagnosis of a mental health problem as well as ASC. The witness felt that the mental health was often a later development, due to the stresses and anxieties of dealing with the ASC.

- 13.2** The witness agreed that it was vital to have a consistent link person, eg in providing help to get to appointments. A number of the young people that they worked with had help from Connexions; Connexions may have worked with that young person for a long time and built up a relationship. The plans to cut the service would have severe impacts on those young people. All of the referrals for young people with Asperger's had come from Connexions.

- 13.3** There was a huge training need for frontline workers including Housing Benefit/ Housing etc to be able to identify ASC symptoms in people who had not yet been diagnosed. This included doctors, who must come across a number of people who had ASC

Difficulties arose in categorising ASC. People with high functioning ASC fell outside Learning Disability Services and Mental Health services, so it was difficult to place them. Young people often did not want the stigma of being publically identified as having ASC or a 'mental health' condition. It would be useful for there to be a joint medical/ social work assessment; this could be coordinated by the mentor that had been suggested previously.

There was a vast burden for families who have to struggle on without adequate support.

The witness was unable to think of any aspects of the current service that worked well.

14. SPEAKER 4 - MR B, SERVICE USER

- 14.1** Mr B is 59 and has high functioning autism. He receives some support from MENCAP, 4 hours a week plus 3 hours a month, via social services. They help him with shopping, banking etc – he cannot cope with multitasking. MENCAP has to arrange their rota in advance; this is hard when he has to deal with ad hoc problems.

- 14.2** Mr B has lived with his parents his whole life. He now lives in a retirement flat with his mother, the rent is manageable between them but he worries about what will happen when she passes away and he loses his carer's allowance.

- 14.3** When he was a child, he had to pretend he was 'all right' at school. He was not diagnosed until he was an adult. He had approached his GP for help with mental health issues and was referred to Millview. The psychologist there suggested that he had Asperger's; he was nearly 50 when he was diagnosed. He was referred onto Dr Critchley; there was a year between referral and the appointment.

Mr B has attended some social groups but he's not keen on shared activities due to poor coordination and he cannot always cope with evening meetings so social groups are not always suitable.

15. SPEAKER 5 - MR C, SERVICE USER

- 15.1** Mr C received his ASC diagnosis yesterday; it had taken nearly three years from start to finish. He had been bounced around SPFT, and had seriously considered resigning his position as on the board as he was not receiving any services. He had had special intervention from the

Assistant Chief Executive, but even then it took a further one and a half years to have a diagnosis. It was lucky he was resilient.

- 15.2** After his three and half hour diagnostic session yesterday, he was given fact sheets for advice. They referred him to ASPIRE, ASSERT and Autism Sussex. There was nothing on offer within the council or health services. He had gone full circle and ended up with the same people. As a citizen, it angered him that these groups were not receiving the funding that the statutory agencies do.
- 15.3** He had had help from ASSERT, they explained the NHS system and fully listened to all of his problems. They acted as advocates and visited clinics for him. They have been fantastic.

He received weekly mentoring sessions from ASPIRE for a year; this is all that is allocated. ASPIRE had nearly stopped this year because their funding was due to end.

In an ideal world, he would like a prescription for a 'kindly uncle/ aunt' figure to turn to for his whole life.

- 15.4** He suggested that the panel speak formally to SPFT; when he raised the issue of ASC care at the Joint Commissioning Board and as a Governor, he was told that services were 'excellent'. He knows that this is not the case; the executives do not know what's going on in front line services yet they are the ones giving the answers. How is scrutiny going to tackle this?
- 15.5** He would be willing to come back to the panel as a witness at a later stage.

16. SPEAKER 6 - MR D, SERVICE USER

- 16.1** Mr D is a service user. He had been diagnosed this year. Mr D also has a physical disability and is in a wheelchair.
- 16.2** Mr D explained that ASSERT had phoned the crisis team last week as he had been close to suicide. ASSERT asked the team to contact Mr D urgently. It took over a week for them to phone him and they then said that they would be carrying out a home visit in the next two weeks. He would not be here if it was not for ASSERT.
- 16.3** Due to his physical problems, Mr D regularly has to go to hospital for lengthy stays. He needs to be in a side room as this minimises stress but his Asperger's is not listed on his records and so it does not always happen. He only gets good service if the nurses know about his Asperger's. Last time he was in hospital he was put in a middle cubicle and could only cope by turning his back on everyone and rocking in his wheelchair for a couple of days.

- 16.4** ASSERT are the only people to help him. Mr D feels that the council and health are stonewalling him. He feels there is a sign on his files 'do not help Mr D'.

In terms of his physical disability, Mr D lives in an unadapted ground floor flat. He has been waiting for adaptations for 7 years but is refused as the council 'needs more evidence'. Regarding his mental health, Mr D was recently on the phone to someone from Mental Health. The person on the phone accused him of flirting and decided that he would not get any services. Mr D said that he feels more relaxed communicating with a barrier in place, so he can relax on the phone.

He received a care package from social services but this was stopped earlier this year. He has been applying for a review but has been unsuccessful so far. Social services do not see the mental health impact; he cannot carry out housework due to traumatic memories. He is then threatened with eviction by the council for not keeping his property in a good state.

17. SPEAKER 7 - MR E, PARENT

- 17.1** Mr E is the parent of a 13 year old daughter with high functioning ASC. She will be progressing into adult services in due course.

- 17.2** Mr E's daughter was diagnosed at pre-school and the family felt then that the council was focussing on ASC. Since then, services have deteriorated. It is getting harder for children, even with a statement, to receive good quality services. Mr E is concerned about people over 18 who have not been diagnosed.

The council has to pay for children who have been diagnosed with ASC; fewer diagnoses mean lower costs. If children with ASC are not supported, this is likely to escalate into adults with mental health problems. Investing in children and young people at an early stage gives them more of a chance of getting through adulthood successfully.

- 17.3** In terms of further schooling, if his daughter stays at the same school for sixth form, she will keep her statement. If she changes school, the statement will go too. It is discrimination. Mr E is an articulate parent and can fight for his daughter; other parents may not be able to do so.

- 17.4** Connexions is very important; if the service is cut, the council will still need to provide those services. Mr E would support the key worker system suggested by others. You need to be able to understand the signals and non-verbal cues that the person with ASC will show.

18. SPEAKER 8 - ADAM LAVIS, FORMER SUPPORT WORKER

- 18.1** Mr Lavis used to be a support worker, working in children's, adults and education system in Brighton and Hove. He now works for Animal Monday media company. They are making a film for the council to raise awareness about ASC, especially about more challenging young people. This will link with Thumbs Up (<http://www.brightpart.org/thumbsup.php>) , to educate staff about autism and Asperger, helping to break down barriers and fears of the unknown.
- 18.2** Mr Lavis thinks that the council has done some things well in terms of supporting people who have ASC. Problems have arisen when the service is outsourced. In the private sector, there can be a high staff turnover, which compounds the problems for the service user. The best care provision is provided by a stable team of people
- 18.3** A lot of buildings used for support have been closed down, for example, the Palmeira project. Many of the young people from the Palmeira project had a very hard time at transition; there were just not enough services available for them. The children's and the adult's services are two separate entities. The service user would tend only get help when they reached crisis point.
- 18.4** Mr Lavis felt that it was often the case in transition that the young person's needs were not put first. They may have 40+ people in and out of their lives. There is an army of people - families, carers, friends- doing the hardest work. Parents often do not feel empowered to voice their concerns although they are often the professional in terms of caring for that young person.
- 18.5** There is a huge educational need for the public. People with ASC often try and fit in with our world, where can we 'meet' them in their world?

19. SPEAKER 9 - MS F, SERVICE USER

- 19.1** Ms F had been diagnosed with Asperger's 4 years ago, as an adult. Her diagnosis had happened purely through ASSERT's intervention and she would like to publically thank them.

How do we reach out to the undiagnosed? There are signs that she was struggling as a child. Teachers have a lot of time with young people; it could be a good way in. Could health service proactively contact schools and ask teachers if they had noticed any children who might have ASC?

- 19.2** Ms F has a job and a mortgage. Previously she was very withdrawn. It would have been helpful to have someone explain to her how to act in social situations. A link person would have been helpful but the world needs to let her be herself too. It is necessary for society to try to meet people with Asperger's Syndrome (AS) half way.

The burden for people with AS to try to understand neuro typical (NT) behaviour and fit in is too high. If society was more aware of ASC generally and accepted quirks associated with this it would give people with AS a much better quality of life as they would be allowed to be themselves more.

- 19.3** Social situations and groups were very difficult for Ms F. Having social situations based around activities in very small groups or in pairs would have made it easier for Ms F to be sociable, for example groups for people who like board games, puzzles or quizzes.

Ms F reached crisis point and had counselling. This did not help as she felt it too stressful to talk about her feelings and emotions. In her view, and based on conversations that she has had with others with AS, Ms F believes that discussions around problem solving would be more helpful. Many people with AS do not have the same level of emotions as NTs therefore asking them to try to find these emotions when we are in a stressful situation just adds to the stress and confusion.

20. SPEAKER 10 - MS G, PARENT

- 20.1** Ms G is mother to a 30 year old son who had been diagnosed 5 years ago. They had had to pay privately for his diagnosis. Ms G became aware of ASC through an article about ASSERT in the Argus.

- 20.2** Ms G thought that having a diagnosis would help. It has made it better for the parents as they can understand their son better, but it has not helped him. He cannot cope with having the diagnosis and the family have not received any help.

- 20.3** The neuro-behavioural clinic has recommended counselling for her son, but he only gets medication instead. He has been on medication for 5 years although two psychologists have said that he should not be on medication on a long-term basis. The family should have the opportunity to try therapy too; they cannot give up the medication without an alternative source of therapy. They are concerned about the effect that using medication long-term will have on their son's health. The family has complained to the PCT and is waiting for a response.

Her son has not had an assessment from the council; he only deals with the mental health team at the health service. The team want to discharge him although there has been no change in his situation in five years.

- 20.4** Her son has a huge fear of other people and cannot even see his sister any more. ASSERT have been great, the parents attend but her son cannot leave the house to go there. The family cannot get past the first hurdle before he can tackle other parts of his life.

20.5 Her son wanted to try living independently; the council was unable to help so they have rented a private flat for him. This is another worry as it could come to an end at any point.

20.6 Ms G had a carer's assessment from the council but it didn't make any difference, there was no practical help, what was the point?

21. SPEAKER 11 - MS H, PARENT/ CHILD/ SERVICE USER

21.1 Ms H is the 'middle person' in an autistic family, there is bi-polar disorder and autism from parentage and in the external family, her sister Z has high functioning Asperger, one of her children has been diagnosed with ASC and Ms H is trying to have her other child diagnosed too as well as being in the middle of having her own diagnosis.

She is trying to speak for everyone including herself. She is there for everybody else but no one is there for her. She is in the middle of a year of anxiety waiting for her own diagnosis

21.2 Ms H has been a carer from a young age, helping to look after her sister Z and teaching her coping mechanisms that Ms H had found worked for herself. Her mother tries to support and help Z but they argue a lot. This does not help Z's condition and she becomes more withdrawn.

Z was given council accommodation but did not have any choice about where she was given. She was put in a very unsuitable property, with neighbours having parties all night around her. The noise and stress probably made her head explode. She is no longer there. ASSERT are trying to help find alternative accommodation but wherever she lives she will need support and guidance.

Z left school at 16. There was nothing for her after 16. Until then, her problems were being managed but since she left school, behavioural problems have escalated. She had blossomed at school and was now going backwards. Z is managing to hold down a part time job, this helps her organise her time and interact with people.

21.3 Ms H came through ASSERT via her daughter who has high functioning autism. Ms H found Amaze; they helped with her daughter, the ASC support service in Portslade offers monthly parent support sessions. They supported her daughter through nursery into school. Social Services are talking about cutting her daughter's support as she is managing well.

Ms H is trying to have her son assessed; she has seen signs of ASC in his behaviour and shown this to health visitors but they have not taken it further. She thinks that there should be improved training for health visitors, they focus on encouraging skills such as trying to promote

children drinking water, eating fruit and drinking out of a cup- all the simple things that an autistic child finds impossible and upsetting when pushed to do.

If you don't give people the support and advice that they need, they just get lost in the system.

21.4 Ms H suggested that teachers should be encouraged to read <http://www.amazon.co.uk/Things-Every-Child-Autism-Wishes/dp/1932565302> by Ellen Notbohm. It is a brilliant resource and would help build confidence in children which would make a huge difference.

22. SPEAKER 12- MR J, PARENT

22.1 Mr J is the parent of a 33 year old daughter with ASC. She is also deaf, has no speech, and behavioural problems.

22.2 Schooling finished at 19 for his daughter, the only help that they as parents were offered was 2 days per week training & 2 weeks respite care a year. They found it too hard to cope with her needs so they pushed and pushed for help, eventually getting her a place in a residential home. Nothing was available in Brighton so it was out of county. Mr J was very pleased to say that his daughter was moved back to Brighton this week.

22.3 There needs to be planning for people through the school system as to what they need.

You don't get any help unless you push and push.

23. CHAIRMAN'S COMMENTS AND DATE OF NEXT MEETING

23.1 The Chairman thanked everyone for taking part in the session and for speaking so openly. He said that it may well be the case that there would be another meeting like this arranged in order to give more people the opportunity to talk. Details would be circulated as soon as possible.

23.2 The next panel meeting would be on 15 October 2010 in the afternoon.

The meeting concluded at 12.30pm

15 October 2010 Minutes

Present: Councillors Harmer-Strange (Chairman); Meadows, Phillips and Watkins

24. PROCEDURAL BUSINESS

24a Declaration of Substitutes

24.1 There were none

24b Declarations of Interest

24.2 Councillor Harmer-Strange declared a non-prejudicial interest in the remit of the panel as a parent with two children on the autistic spectrum.

24c Declarations of Party Whip

24.3 There were none

24d Exclusion of Press and Public

24.4 In accordance with section 100A(4) of the Local Government Act 1972, it was considered whether the press and public should be excluded from the meeting during the consideration of any items contained in the agenda, having regard to the nature of the business to be transacted and the nature of the proceedings and the likelihood as to whether, if members of the press and public were present, there would be disclosure to them of confidential or exempt information as defined in section 100I (1) of the said Act.

24.5 RESOLVED – that the press and public be not excluded from the meeting.

25. MINUTES OF THE PREVIOUS MEETING

25.1 These were agreed.

26. CHAIRMAN'S INTRODUCTION

26.1 The Chairman welcomed everyone to the meeting and introduced the panel members.

The Chairman advised people that the meeting was being recorded for use as a training resource although it was not being broadcast live

26.2 Councillor Harmer-Strange explained that the theme of this meeting had changed as one of the planned speakers was unable to make the panel meeting. The session was originally intended to discuss

improving diagnosis for adults with ASC; it had been decided to postpone that discussion until the meeting on 19 November.

The Chairman said that this meeting would instead focus on looking at care assessments and transition. The panel would hear from officers from the council and from the health sector on both of these topics.

27. CARE ASSESSMENTS

27.1 Naomi Cox General Manager of Adult Learning Disability Services gave the panel a presentation about the eligibility criteria for adult social care services (see minute book for copy). Ms Cox said that she also had a role in coordinating the Asperger's Stakeholder group and gave some more information about the group. One of the priorities for the group was supporting the development of a local diagnostic service as this had not been available in the city, although it now is.

The panel asked questions of Ms Cox:

27.2 There had been a concern raised previously around the assessment process. Some carers had said that actions that had been included in an action plan were not being followed up. Who was responsible for ensuring that the actions were carried out, particularly the lower level preventative actions? Ms Cox said that there were dedicated Carers' care managers who work with individual family carers who would be responsible for carrying out the assessment and for following up any action that arose from the assessment. In terms of low level prevention services, it is important to make sure that people received the right help at the right time; low level intervention could really help this. There is potential to further develop low level prevention services in the city which would assist those people who did not meet the eligibility criteria for help from the local authority.

27.3 Members asked what the procedure was for taking action to help people with ASC with neighbour disputes.

Ms Cox said that it was important that the Housing Officer was made aware that the tenant had ASC so that they could take action quickly. Some staff from housing had taken the Asperger's basic awareness course but this was not compulsory.

27.4 Members asked about the needs assessment - could someone else refer a third party for assessment if the person in question was unable to present themselves for assessments. Ms Cox said that requests for assessments came through from many sources including the person themselves, families, GP's, housing officers, health visitors etc.

It was important that the person in question was agreeable to having their needs assessed. Members then asked whether there was enough knowledge and expertise in the community to recognise ASC and

recommend assessments where necessary. Ms Cox said that there was still more that could be done. Training courses were open to housing and social care staff but more could be done to raise awareness; she noted that the training was currently voluntary.

- 27.5** Members asked for clarification of the levels of eligibility for help in comparison with those levels used for assessing Disabled Living Allowance. Ms Cox said that the council had decided on its own local eligibility criteria; it had determined to help those in critical and substantial need. For those that did not qualify for help, assistance was given in the form of providing information and advice. This was based on national guidance – Fair Access to Care.

In the putting people first/ Personalisation agenda, there was a lot of emphasis on preventative work to stop escalation of problems. Currently, if people have not been identified as having ASC, there was a chance that service providers could miss them.

- 27.6** Members asked whether the council used the knowledge of its staff with ASC to widen its knowledge. Ms Cox said that this did not happen currently. There was an ambition for the council to employ more people with disabilities including learning disabilities. It would be helpful to use the experiences of staff with ASC to improve services and support.

- 27.7** Members asked whether the police were involved with the Asperger stakeholder group or whether there were plans to include them. Ms Cox said that the group would welcome the police's involvement. Ms Cox said that ASSERT had recently done some training with the police force so they were open to training and skilling up their work force.

- 27.8** Members asked about sensory services and occupational therapy services being labelled as preventative; for people on the spectrum they tended to be life long problems so was it correct to call the services preventative? Ms Cox said that the help and support from those teams could be on a long term basis although it may be that equipment was being loaned.

- 27.9** Members asked whether adults would have to contribute financially to their support services. Ms Cox said that for all adults receiving a service from Adult Social Care there was a fairer charging policy, taking income and outgoings into account and assessing whether they could make a financial contribution. This differed from Children's Services where no charge was made.

- 27.10** Members commented that people were often signposted to ASSERT and ASPIRE, who were doing a tremendous job with little if any resource from the council. It was hoped that intelligent commissioning could recognise the value of the services particularly in providing low level support and help them accordingly. Ms Cox agreed with the comments but clarified that the decision was not hers to make.

27.11 A member of the audience asked for clarification as to why people who had diagnosed with ASC were not automatically within the two highest eligibility bands for help as there would be a severe impact on their lives. Ms Cox said that the decision was based on a person's needs rather than the diagnosis. The assessment would look at the whole person and their needs.

27.12 Ms Cox was thanked for her presentation and information.

28. DIAGNOSTIC SERVICES IN BRIGHTON AND HOVE

28.1 The panel heard from:

- John Rosser, Service Director for Working Age Mental Health Services for Sussex Partnership Foundation Trust (SPFT);
- Rebecca Simpson Team Leader in West Recovery Team, Millview Hospital and previously the Clinical Nurse Specialist in high functioning autism and Asperger's in West Sussex;
- Dr Neil Harrison, Consultant Psychiatrist in the Assessment Service run by Dr Hugo Critchley, and
- Dr Dawn Howard, Clinical Psychologist working in the Neurobehavioural Diagnostic Clinic

28.2 Mr Rosser said that his span of responsibility included adults of working age with severe and enduring Mental Health problems. They are commissioned to provide services for Autistic Spectrum Conditions with co-existing Mental Health conditions. Mr Rosser commented that the Sussex Partnership Foundation Trust (SPFT) covered three localities, and that the services varied across the counties depending on local need and consequently what service was commissioned.

Dr Harrison said that he worked for the assessment service that had been sent up by Professor Hugo Critchley together with Dr Dawn Howard, and another colleague Anne Walker, a Speech and Language Therapist, three years ago. It focuses on adults between 18 and 60 and is principally diagnostic. If someone wants to be assessed, they first need to be referred to the Community Mental Health Team (CMHT) and then referred on by them to the diagnostic service. This is because any recommendations that are made are referred back to the CMHT for implementation. In addition, people that they see often have multiple Mental Health needs, so the CMHT coordinates the services. It can be often difficult for the CMHT to put the recommendations into place due to their training. Additionally, different services are provided in different areas so the diagnostic team has to be aware of that.

The service is currently funded to provide a one day a week diagnostic clinic. Within that time, they are carrying out detailed assessments, identifying needs and making recommendations back to the CMHTs. The team consists of two consultant psychiatrists, a speech and

language therapist, and a psychologist. They are trying to get trainee psychiatrists to enable them to expand the service, as there is a backlog of assessments at the moment. They are not able to see everyone who comes through immediately. They would also like to be able to offer more training to secondary mental health teams such as CMHTs, to improve their knowledge of ASC and to provide psychological therapies within the clinic.

In terms of numbers and demand for services, current estimates indicate rates of about one percent of the population having ASC. Not everyone with ASC wants or needs to see the diagnostic service so they would potentially expect to see up to one in four hundred people.

As mentioned, there are some training and awareness issues and needs. There is a growing awareness of ASC and Asperger's, but it may not have been picked up by the GP or psychiatrist especially if the practitioner was trained a long time ago and had limited knowledge of ASC. For the Trust, one of the priorities is to educate services to improve their awareness so that they can pick up on the signs of ASC more quickly and refer people on for diagnosis.

28.3 Ms Simpson spoke about the system in West Sussex. When she was employed there she was linked to the diagnostic clinic and would screen/ triage all referrals for Asperger's and high-functioning autism. She would meet the person and their family in their home, as that was a more comfortable environment. She would arrange for the most complex cases to come to the monthly diagnostic clinic. For more straightforward cases she would work with people to understand their diagnosis, work with care coordinators for the best care, deal with probation services, transition services etc.

28.4 Members asked questions from the four officers:
Members asked where GPs stood both in terms of training and expertise and within the triage system.

Dr Harrison said that, in terms of diagnosis, ultimately this would ideally be based within psychiatric services as these were best placed to deal with complex and dual diagnoses. However GP s clearly had close relationships with their patients. Different GP s would have different training needs, but it was crucial for GP s to be able to identify signs of Asperger's and other ASCs. Current training aims were focussed on secondary care but with plans to move this into primary care when resources allow.

28.5 The panel asked whether clinical information was ever shared amongst medical professionals; they heard this was routinely shared where practitioners were involved with specific individuals. Secondary mental health services operate a Care Program Approach (CPA) which is a case management system whereby a single care coordinator works

with a service user to develop a plan of care with input from a range of practitioners/agencies. The CPA is then shared with those who are involved. The clinical diagnosis would automatically be sent to the person's GP.

- 28.6** The panel asked about the potential numbers of people who had ASC who were not being diagnosed, particularly those who did not have a co-existing mental health problem. The panel heard that a large number of people came to the attention of Mental Health services before they had a diagnosis of ASC.

The team at Millview would also deal with people who had such complex needs due to ASC that they needed support services. It was often the case that people who had been supported by their parents and who had not had a formal diagnosis who would present to services in crisis, if their support was affected.

- 28.7** The panel asked whether many people on the spectrum were reliant on drugs to manage their condition. They heard that the diagnostic clinic saw people with a number of co-morbidities eg ADHD. Drugs were not effective for ASC or Asperger's itself but they could have a positive effect on other commonly associated conditions such as anxiety and depression.

The clinic had carried out an audit of the types of recommendations that they had made; they tended to be recommending social care assessments, occupational therapy input, help with daily living, help with employment etc.

Mr Rosser said that he wanted to emphasise the role of the care coordinator; where it worked effectively, it could really support the role of the diagnostic and other specialist assessment services and develop an integrated plan of care. This would make a real difference to peoples' lives. The answers often came about through multi-agency working, particularly in terms of advocacy.

- 28.8** The panel asked how services locally compared to other authorities in terms of early diagnosis? They heard that the work of Professor Critchley and his team was laudable, providing a national standard level service locally. The work of Assert and Aspire as well as other third sector groups was commended; the diagnostic clinic could not have been developed as quickly without them. A lot of people that were seen in the clinic were employed or wanted a job. Assert and Aspire were key in supporting people in their aims. Brighton and Hove was very lucky to have vocational specialists in each Recovery team, they worked to train people in ASC and support people back into work.

- 28.9** The panel asked about the working relationship between SPFT and the council. Mr Rosser said that that he had regular meetings with Denise D'Souza and Jane Simmons to review the Section 75 arrangements

and service provision, but there was always room for improvement. Individually the council and the health service operate different systems and standards. In an integrated service where the system worked at its best, it could work extraordinarily well at keeping the service user at the centre of the service, addressing a variety of needs at the same time within a single plan with contributions from a variety of agencies and mainstream services and opportunities.

- 28.10** Panels asked about the waiting list for assessment as a number of people had raised concerns that it could take up to eighteen months for assessment. They heard that it was still too long and that the team was looking at different ways of carrying out high quality assessments to speed this up. Professor Critchley and Dr Harrison are both university employees who donated one day a week to the diagnostic clinic; on other days they work at the university researching the basis of emotional disorders and teaching medical students. The clinic was looking to incorporate training within the clinic, taking on trainee psychiatrists, speech therapists and psychologists for a year so they could learn how to carry out assessments under supervision. The team had been successful in reducing the waiting times for ADHD assessments so they knew that it could be achieved by changing the way that they operated.

Ms Simpson said that when she worked in West Sussex, with dedicated professionals she was able to see people in four weeks and refer the more complex cases on to the clinic to be seen in twelve weeks. However it should be noted that they saw people once only whilst in the Brighton and Hove clinic provides a follow-up service where they see people more often. Dr Harrison said that his team was considering whether they could take on a person to carry out visits quite rapidly and triage them if necessary; this could speed up the process.

It was important to note the different demographics between Brighton and Hove and West Sussex. In particular, the two big universities in Brighton and Hove which both refer considerable numbers of students to the diagnostic clinic. This was not the case in West Sussex.

- 28.11** Discussing employing more staff, Dr Harrison commented that recruitment for Psychiatric Trainees had been problematic on a national level in the past where few students chose to specialise in psychiatry. However both he and Mr Rosser commented that it was becoming much easier to recruit top consultants in general psychiatry locally, perhaps as a result of the close local ties between the Mental Health Trust and the new (6 year old) local Brighton & Sussex Medical School (BSMS). Continued support of national level specialist services locally may also help to recruit more students leaving BSMS into psychiatry.

28.12 The panel asked about the role of the crisis team. Mr Rosser offered to provide the panel with data about the numbers of users who had ASC. They heard that the team had a very specific set of criteria, to help people who otherwise would be admitted to hospital. This had been proven to be a successful model of working. It was recognised that there were also other needs, and they were looking to develop a rapid response unscheduled care service, to avoid people escalating to the crisis stage. SPFT and NHS Brighton and Hove were developing a plan where a small pool of resources was going to be used to start a pilot scheme. It was about restructuring services to address urgent needs as it was accepted that the current system did not suit everyone's needs.

28.13 Mr Rosser, Ms Simpson, Dr Harrison and Dr Howard were all thanked for their time and their input into the panel's work.

28.14 Claire Newman, Acting Strategic Commissioning Manager, Substance Misuse, NHS Brighton and Hove, updated the panel on progress against the national autism act. She said that the Joint Strategic Needs Assessment (JSNA) was being in hand and that a programme board/steering group was being put together. The key challenge for the group would be resourcing any service development.

28.15 The panel asked where ASC was in the priority list for service provision. Ms Newman said that they were trying to work with Mental Health colleagues on the Better By Design programme to best meet the needs of a range of people. They were working to get an assessment and treatment hub and cohorts of specialist workers. This would use a community case management model and look to align resources more appropriately.

The team was looking at the West Sussex model to see if would work in Brighton and Hove. It was also important to recognise the third sector agencies involved and formalise working arrangements with them. The panel commented that this approach tied in with the information provided in the dual diagnosis scrutiny review; they were pleased to see this.

The panel requested that the paper on the new model be circulated. Ms Newman agreed to this. She commented that she was unsure whether there would still be a training toolkit provided nationally but that she would keep the panel updated on this.

29. TRANSITION FROM CHILDREN'S TO ADULT SERVICES

29.1 The Chairman introduced the item on transition, commenting that many parents had said that there was a feeling of 'falling off a cliff' when their child reached transition stage. Children's services were seen as 'gold plated' but this all changed when it came to adult services. There was a lot of parental anxiety.

29.2 Jenny Brickell, Head of Child Development and Disability Service for Brighton and Hove City Council, spoke about the transition process. There is a joint transition team between Children's services and adult services.

The team was established in 2003 and now consisted of three members of staff across children's and adults' services, working with Connexions. They would like to expand this if resourcing allowed. In terms of accessing the transition team, in Year 9, there was a duty to carry out assessments for pupils with special educational needs to see if they would need adult social care support when they became an adult. This was part of the regular annual review process. If someone was deemed to need adult social care support, a transition plan would be drawn up. During the assessment process, one worker would undertake the assessment on behalf of both children's and adult's services, working with the young person and their family to plan their transition needs.

The team tracks the needs of young people from 14 years plus, and meets regularly with Adult Social Care so that Adult Social Care will be aware of what resources will be needed in the future.

A transitions protocol booklet was sent to all families who would be facing transition. The team also tried to send the booklet out to as many places as possible to raise awareness.

The transitions team currently focussed on working with the young people at Downs View Link College who had severe disabilities. If resourcing allowed, they would like to expand this to be able to work with a wider range of young people.

29.3 Members queried whether a young person could be overlooked by the transition team.

Ms Brickell explained that young people with severe disabilities would not be missed but it was possible that some young people who did not have a statement of special educational needs or who were not classified as a disabled person may slip through.

There was an autistic outreach support group that worked in mainstream schools to support pupils as well as Family Support Workers. All schools had a Special Educational Needs Coordinator (SENCO) who should have an understanding of ASC.

29.4 Members asked whether any consideration had been given to what might happen if the Connexions service was closed as the transition process relied on them for assistance.

Ms Brickell said that the Connexions worker had been funded until the end of the financial year; it was not known what would happen after

this. Ms Brickell's team partly funded an Amaze worker to help provide young people with information and to help prepare them for adulthood, so this would help to bridge any potential gap. The team also funded a publication 'Through The Maze' which included information about all aspects of the young person's life.

http://www.amazebrighton.org.uk/editorial.asp?page_id=106

- 29.5** Members asked about continued education and lifelong learning opportunities. Ms Brickell said that young people with a statement had routes to continued education and to St Johns College locally. There was special provision for young people with ASC.

The transition forum had a number of priority areas that they were focussing on; one of these was to work with Maureen Pasmore from Supported Employment in order to draw up a training programme in order to widen opportunities for young people throughout their lives.

- 29.6** The panel thanked Ms Brickell for her contribution.

30. AMAZE

- 30.1** Lizzie Batten from Amaze spoke from a parents and carers' perspective. Ms Batten was one of the founders of Amaze, a Brighton based charity established twelve years ago. It offers information, advice and support to parents of disabled children and children with special educational needs (SEN). Amaze has fifteen part time staff. Ms Batten specialised in managing the benefits work at Amaze, in particular supporting families to claim Disability Living Allowance and other 'passport' benefits. Ms Batten has personal experience of being a parent of a young adult with ASC.

- 30.2** Inevitably having worked alongside families for some twelve years, as children grow into teenagers, Amaze is spending an increasing proportion of its time on transition work. Amaze has a dedicated Transition worker, Sue Winter. The post is part time, so resources are very stretched. Amaze's transition work is grounded in the principles of Person Centred Planning (PCP). Amaze has run training for schools in PCP. Amaze continues to support parents so that at transition meetings, everyone involved in supporting disabled young people to think about life after school, put that young person's aspirations at the centre of plans for their own futures. However Amaze is only able to directly support a very limited number of parents at reviews. Funding for this worker is at risk.

Ms Batten reported that it was especially important that specialist resources, effort and good will is available to young people with ASC, who may well be unable to begin to imagine doing something new or being somewhere they don't already know well. Some young people with complex needs may not have the language to explain how they feel

or say what they think. For any young person with ASC, being able to make an informed choice means being supported to practice and have a go at potential options and this can only happen meaningfully over a long timescale in a planned way. It is even more important for young people with ASC that they get to practice being involved in decision making and learn about how to make informed decisions.

- 30.3** Ms Batten explained how young people with ASC need specific teaching and lots of opportunities to practice social skills that other young people pick up effortlessly. She described how young people with autism really struggle to compromise, negotiate and see things from another's perspective. They find it much harder than other teenagers to think flexibly and problem solve when things don't go as planned and they are more likely to misread risky situations and other people's intentions. They are more at risk of bullying and abuse and less likely to report this.

Ms Batten reported that specialist provision like Downs View Link College works hard at encouraging the most vulnerable young people in the city to take steps towards thinking for themselves, making choices, learning about risk and keeping safe. These young people have the capacity to learn more but small achievements are hard won and most continue to need specialist support throughout their adult lives. She hoped in the future the city would demonstrate a commitment to extended specialist ASC provision post 19. Ms Batten reported that for most teenagers with ASC, this task falls to their parents.

Amaze has had limited funding to run the Triple P Positive Parenting Programme (PPP) for parents of teenagers, so had only been able to offer this to a limited number of parents. However it was noticeable that most parents signing up for PPP have children on the autistic spectrum. Feedback indicated that parents using PPP strategies were more confident about their own skills. They felt they had more 'tools' to handle tricky situations and that over time they were increasingly able to offer their teenager opportunities to practice being more independent out in the community. This was because at home they had been practicing things like compromise, thinking through consequences of what they said or did and explicitly teaching how to plan risk reducing strategies for things like parties and trips. Amaze believed secure funding, so that it was possible to maintain the post of Transition worker at Amaze and so that all parents of teenagers with ASC had the chance to take part in PPP would send a clear message to parents that Brighton and Hove recognised the extra demands and complexities of parenting a teenager on the autistic spectrum.

- 30.4** Ms Batten reported that families who have at least one child with ASC are more likely than other families to have another child with special needs. That child might also have ASC but might have other diagnoses. In addition, it was not unusual for Amaze to work with

parents who might also present as on the autistic spectrum, and while some of these may have a diagnosis others did not. Ms Batten wondered whether more consideration could be given to parents that might appear angry, overly critical and hard to engage. She explained that it's very hard as a parent to accept that you need extra support to bring up a child, even when they have additional needs. It's all the harder for parents who may experience the world from a uniquely different perspective and one that other organisations might not share.

Services needed to be more autism aware in general, not just in their approach to working with children and young people but in their communication with parents. On occasions when parents disclosed that they thought they were autistic, Amaze encouraged them to consider whether it would be helpful to seek clarity about this and where a parent thought it would be useful, to take steps to request an assessment.

Supporting families on the helpline, to claim Disability Living Allowance or to access the right support for their child at school meant that Amaze often worked alongside parents of a child without a diagnosis. In any of these situations where a parent thought that the child had ASC, Amaze would signpost the parent to the appropriate diagnostic services, eg Seaside View at Brighton General Hospital, or for older children to CAMHS. Amaze remained concerned that too many parents report a history of raising concerns that their child is on the autistic spectrum and that these are dismissed for several years, often until a child is struggling socially at school before getting an assessment.

30.5 From approximately 1500 young people with a statement or disabilities, Compass database Amaze works with 363 children aged between zero to twenty who had a primary diagnosis of Autistic Spectrum Condition. This was the second most common category after learning disabilities. This could be broken down as follows:

Under 5 years old – 30 children (these would be children who were severely autistic and so diagnosed early)

5-10 years old – 80 children

11-15 years old – 140 children

16-20 years old – 113 children

The increase in figures between 5-10 and 11-15 year olds is an indicator of later diagnosis in children, maybe those who have not accessed assessment until they were 7 or 8.

Ms Batten said that Amaze thought they had details of about 50% of the young people in the city with ASC, meaning that there might be approximately 240 young people aged 14 to 20 who would be within or reaching transition. She reiterated that it is important that appropriate resources are in place to support these young people throughout transition.

- 30.6** Amaze works closely with the Connexions service and was very concerned to hear that it was under threat. As planning is so key to successful transitions to further education, supported living and adult placements Ms Batten expressed concern that the quality of transition plans was so variable across the city. Many were incomplete and as such an inaccurate reflection of a young person's strengths, interests and support needs.

Parents are unaware of the significance of good transition plans so without specialist key workers supporting families, she wondered who was providing the information and support that young people with ASC and their families need to secure the help they need in the future.

- 30.7** Members asked about Amaze's funding. Ms Batten said that some came from the council through the Aiming High programme and some came from education, other funding comes from the PCT, from other grant giving organisations and from fundraising. Presently no funding streams are secure.

31. DATE OF NEXT MEETING

- 31.1** The Chairman thanked everyone for taking part in the session and for speaking so openly

- 31.2** The next panel meeting would be on 19 November 2010 in the afternoon.

The meeting concluded at 5.00pm

19 November 2010 Minutes

Present: Councillors Harmer-Strange (Chairman); Meadows and Phillips

Apologies: Councillor Watkins

PART ONE

32. PROCEDURAL BUSINESS

32a Declaration of Substitutes

32.1 There were none

32b Declarations of Interest

32.2 Councillor Harmer-Strange declared a non-prejudicial interest in the remit of the panel as a parent with two children on the autistic spectrum.

32c Declarations of Party Whip

32.3 There were none

32d Exclusion of Press and Public

32.4 In accordance with section 100A(4) of the Local Government Act 1972, it was considered whether the press and public should be excluded from the meeting during contained in the agenda, having regard to the nature of the business to be transacted and the nature of the proceedings and the likelihood as to whether, if members of the press and public were present, there would be disclosure to them of confidential or exempt information as defined in section 100I (1) of the said Act.

32.5 RESOLVED – that the press and public be not excluded from the meeting.

33. MINUTES OF THE PREVIOUS MEETING

33.1 These were agreed.

34. CHAIRMAN'S INTRODUCTION

34.1 The Chairman of the panel welcomed everyone to the panel meeting. He introduced the other panel members and advised everyone that the meeting was being recorded for use as a training resource but it was not being broadcast live.

Councillor Harmer-Strange reminded people that there was also a meeting arranged for the following week for members of the public, people with Autistic Spectrum Conditions, parents and carers to speak

to the panel about their experiences and said that he hoped that some of the audience would be able to join them.

- 34.2** The Chairman said that there was a very packed meeting planned, looking at improving diagnosis and pathways to care; awareness of Autistic Spectrum Conditions for frontline workers, and at adapting services to enable people with Autistic Spectrum Conditions to access them.

35. IMPROVING DIAGNOSIS AND PATHWAYS - DR BECKY JARVIS

- 35.1** Dr Jarvis has been a fulltime GP since 1995; she works at the St Peter's Centre which has the fulltime equivalent staffing of 5 GPs. They have 11,500 patients. Of their patients aged under 18, 1.2% have a diagnosis of autism, and 0.3% a diagnosis of Asperger's Syndrome. In their patients aged over 18, 0.2% have a diagnosis of Asperger's Syndrome and 0.1% have a diagnosis of autism.

These figures are much higher than expected, and might reflect the GPs' own personal experiences of Autistic Spectrum Conditions.

Dr Jarvis also looks at general Mental Health services in the city as part of her practice based commissioning work. GPs were surveyed in summer 2010 and were asked whether there were any gaps in the Mental Health services being provided. Several GPs said that they did not think that an adequate service was provided for people with ASC currently.

- 35.2** Dr Jarvis had been thinking about how services for people with ASC had changed over the last fifteen years.

There were a number of positives. There was a greater public and professional awareness of ASC for children and young people. There was a higher chance that a young person would receive a diagnosis through primary care or through educational services. Once a diagnosis was made, parents received a support package which, although not ideal, had improved consistently over time. Parents might be able to get help with benefits, help within schools etc. There was more multi agency working.

The other major positive change was the introduction of a local diagnostic service; this had been introduced in the last few years. Prior to this, people had to be referred out of area for assessment.

- 35.3** Dr Jarvis also commented on the negative aspects of the current services for adults with ASC. There was a general lack of awareness in the general public; this was mirrored by primary care practitioners. Dr Jarvis was unaware of any training for GPs on how to diagnose ASC in adults or how to manage it. GPs had limited knowledge about Aspire

and Assert, usually acquired through patient feedback and limited knowledge of Professor Critchley's service or how it operated.

- 35.4** There were three groups of people who came to Dr Jarvis as adults: patients who were discharged from CAMHS without any support being offered after the age of 18; patients who self-diagnosed or who had a private diagnosis; and parents of adult children who had not received a diagnosis previously. Dr Jarvis gave the example of the parent of a 33-year old man that she saw yesterday who had not received a diagnosis although he displayed many of the signs of ASC.

When Dr Jarvis sees a patient who seems to have ASC, she can refer them on to Aspire or Assert. She can also refer into Mental Health services, but sometimes people have already been to those services and received an incorrect diagnosis or medication so they may be reluctant to go back. Patients are also unhappy with the Mental Health label.

There seems to be little support for carers and little help with claiming benefits

After someone receives an assessment there is often a long delay before they are seen by Professor Critchley's specialist team due to the demands on the service. He will complete a thorough and comprehensive assessment, and make recommendations for services to be put into place. However the diagnostic team might make recommendations that the Recovery Team does not have the facility to provide in terms of long term support. It is hard for primary care to fill this gap.

- 35.5** In terms of improvements that could be made, Dr Jarvis suggested: more training in primary care; easy access to resources for patients and practitioners; developing a primary care CPN service may help as they may be able to have Autism champions in the service, helping with the initial assessments.

In terms of information for GPs, it would be helpful to know what interventions were most helpful, eg does Cognitive Behavioural Therapy have a positive impact. It would be helpful to know about support for carers too.

- 35.6** Dr Jarvis answered questions from the panel.

The panel asked how GPs accessed training; how could it be put into place for single GP practices?

Dr Jarvis said that training could be approached in a number of ways; not one size would fit all practices. All GPs had to undertake training as part of their ongoing appraisal and revalidation. In Brighton, there was a GP update course held twice a year; one of these sessions would reach a large number of GPs. Training could be held in evening

sessions; all members of a particular practice could attend a half-day training session as part of the protected learning scheme— in this instance the PCT would pay for locum cover.

If a primary care Mental Health service was established, with CPNs in the surgery, they could hold lunchtime training meetings.

On a larger scale, it was possible to incentivize training; in primary care there is a voluntary enhanced services scheme, where GPs can provide an enhanced level of care to their patients, and get paid for the extra time taken. This would take a big shift in approach and may not necessarily be appropriate for patients with ASC.

- 35.7** Members asked what happened to young people when they came to the end of their time with CAMHS; was further support provided? Dr Jarvis said that if the young person had Learning Disabilities as well as ASC, they were likely to receive a good service from the Adult Learning Disabilities Services as their way of working was similar to that of CAMHS. However generally there was no set referral system from CAMHS to the Recovery or Access Teams or to Adult Mental Health Services and no system for a direct referral to the diagnostic clinic.

Dr Jarvis's experience was that there did not seem to be any one person or team providing ongoing holistic support. There were pockets of excellent practice but the services were not coordinated.

When asked who would be the best group to coordinate services, Dr Jarvis said that it could be anybody including GPs, the PCT, the Council, Mental Health services etc. One of the key things for any of these teams would be to agree what a care package should look like for that particular person.

It was important for the services to acknowledge that there would be a period of transition for the young person. Dr Jarvis was aware that it might not be appropriate to refer a person on to Adult Mental Health services but it was difficult to know where else the support might sit.

- 35.8** In terms of diagnosis, Dr Jarvis said that she did not feel qualified to make a diagnosis. She would not feel comfortable labelling someone as having ASC until this had been confirmed by someone properly qualified. It was very important to get it right, particularly as ASC could overlap with other conditions. Dr Jarvis did not think that many GPs would be comfortable diagnosing ASC.

Dr Jarvis said that she would refer a young person for assessment to the Seaside View Centre at Brighton General Hospital. There was a two month waiting time. Sometimes the young person was diagnosed in one visit; on other occasions they may need repeat appointments.

For adults, there was a two to three month waiting list for the first assessment to be carried out, after which the person might be referred on to be seen by Dr Critchley. Last time Dr Jarvis had referred someone on, there had been a nine month waiting list to be seen at the diagnostic clinic.

- 35.9** Panel members asked for more information about what resources could help with diagnosing and supporting someone with ASC. Dr Jarvis said that she felt that it was linked to the need for training. She felt that there might be excellent resources in the city but GPs were unaware of what was available in Brighton and Hove other than Aspire and Assert.

Dr Jarvis explained that GPs used a resource called a 'Map of Medicine' when making a diagnosis and looking for guidelines, which provides local information about resources. This could be updated to include standard information about resources for ASC in the city. This would help to provide a standard city-wide response from GPs.

- 35.10** The panel asked Dr Jarvis how she envisaged the role of an 'Autism Champion' developing. If there was a Primary Care Mental Health service, there would be people within the surgeries who could refer onto secondary services, building close links with the appropriate services. This would bridge the gap between primary and secondary care. More widely there could be champions within each surgery, such as was currently in place for Infection Control champions etc, but this would be more resource-intensive.

- 35.11** Finally, Dr Jarvis said that the one thing, other than training, that could make a difference for people with ASC would be a holistic support package with multi-agency working.

- 35.12** The panel thanked Dr Jarvis for her input.

36. PROFESSOR HUGO CRITCHLEY, NEUROBEHAVIOURAL CLINIC

- 36.1** Professor Hugo Critchley introduced himself to the Panel; he is an academic based at the university's Neuro-behavioural medical school. He has a background in neuroscience, working at various premises including the Maudesley hospital. Professor Critchley moved to Brighton and had the opportunity in 2007 to establish a Brighton and Hove clinical and diagnostic service through the Sussex Partnership Foundation Trust (SPFT). This is primarily focussed on ASC but also including other neuro-developmental conditions that overlap with autism. The remit was to help meet a priority need to diagnose Asperger's Syndrome as a hidden disability, which had not been well diagnosed or supported previously.
- 36.2** The clinic covers Brighton, Hove and East Sussex. It has received 380 referrals, of which 210 were specifically diagnosed with ASC. The clinic

operates one day a week and is multi-disciplinary. It sees adults who do not have Learning Disabilities, who may or may not have been through CAMHS as young people. There is a waiting list of about nine months.

The clinic tries to diagnose ASC and co-morbidities, and to come up with recommendations from the evaluations, referring these back to the original referral team, whether this is the Recovery or Access teams. In the clinic they have tried to build up their knowledge about local services so that they can tailor their recommendations appropriately. They rely a lot on voluntary sector groups such as Assert, to implement recommendations and support the clients.

- 36.3** Professor Critchley said that what was missing in the service was a fast track path to diagnosis. A strategic decision was taken at the start of the process to route the pathway to the clinic through Mental Health, due to the secondary mental health conditions are often present, and that need priority management through Mental Health services.

The service was set up purely as a diagnostic service rather than as an ongoing support service for people with ASC. Due to its limited resources, the diagnostic team cannot take responsibility for following up the recommendations made; these are given back to the referring Mental Health teams.

- 36.4** Professor Critchley addressed questions from the panel. In response to a question about the level of contact that the clinic had with GPs in terms of referrals, the panel heard that GPs were asked to refer via the Recovery or Access teams, rather than directly to the clinic. They try to offer a limited follow-up service for clients, to find out whether recommendations have been taken up.

Professor Critchley said that he thought it would be very beneficial to have someone to coordinate and navigate the different referral systems for users including Health Care, educational providers, occupational health etc. They all had different ways of working and different priorities and it would be useful for there to be a guide.

- 36.5** The panel asked whether the clinic had enough in terms of resources to meet the demand. Professor Critchley said that in comparison to other similar provision, the service in Brighton and Hove was doing quite well, although the nine month waiting list was unsatisfactory. He would ultimately like to see a triage system such as that in place in West Sussex. This would allow people to respond earlier to referrals.

- 36.6** Professor Critchley said that the clinic had some contact with CAMHS as children became adults, although there was less contact with regard to young people with ASC in comparison to the level of contact had for young people with ADHD, which was also seen in the clinic. There was

a co-morbidity between ADHD and ASC, with a third of people having both conditions.

- 36.7** The panel asked Professor Critchley for his view on the level of support available for adults with ASC. He said that it was often the case that a diagnosis could help in terms of being able to access advocacy etc. However there seemed to be a lack of provision for more ongoing support needs such as counselling, and it did not seem that Adult Mental Health services were structured in a way that helped support people who were vulnerable to escalating mental health issues without support.

Many people did not have any long-term management or support; Mental Health services are reactive to crises rather than proactive. Often the only support is through voluntary sector groups.

If long-term management was in place, it would make a difference in terms of occupational and educational needs being met. This would only take low level support and would help improve the quality of life for many people with ASC. The clinic saw a number of people who have dropped out of school or college, due to lack of support. It was important to have student support in place in schools and universities.

- 36.8** Professor Critchley said he thought the Brighton and Hove clinic was the only clinic nationally to have a dedicated Speech and Language therapist as part of the assessment process. This was important in picking up communication problems, part of the triad of impairments. The Speech and Language therapist could make the necessary recommendations in terms of communication problems.

The panel asked whether there were enough resources to see the communication recommendations put into place after they had been made. They heard that there was differing provision in East Sussex and in Brighton & Hove. More resources would be beneficial; there was a lot of work that needed to be done in terms of the responses to all recommendations.

37. IAN WATLING, SUSSEX PARTNERSHIP FOUNDATION TRUST

- 37.1** Ian Watling, Deputy Service Director from Sussex Partnership Foundation Trust (SPFT) introduced himself to the panel. Mr Watling manages Adult Mental Health services in Brighton and Hove, in particular the community services. They have a number of clients with a diagnosis of ASC. The service is currently organised to try and provide a smooth pathway. The services are in the process of being redesigned.

37.2 In general, if someone in Brighton and Hove experiences a mental health problem, they would go to their GP and be referred onto Access Services. Access Services are divided into teams across the

city. Their role is to work with the person to assess the nature of their problems and to see whether short-term or long-term intervention would be beneficial. Short-term intervention might be appropriate for conditions such as anxiety and depression whilst long-term intervention would be appropriate for longer term, more enduring mental health problems. When people require longer-term intervention, they are moved to the one of the three Recovery teams in the city; these were formerly known as Community Mental Health Teams. Some of the people referred on have higher levels of risk.

The Recovery Team also operates a homeless team and manages five recovery support houses in the city.

- 37.3** Brighton and Hove is fortunate in having a pathway for ASC; this is not the case across other parts of Sussex. There is the diagnostic clinic at Buckingham Road, run by Professor Critchley, where people are assessed.

The pathway should work in a way that a person is referred into Access Services, referred to the diagnostic clinic for a diagnosis and referred back to the Recovery Team after diagnosis. This might not work if, for example, the Access Point does not pick up the ASC or misdiagnoses it as another condition.

- 37.4** Mr Watling said that there were about 25 new referrals to Recovery per year; this is rising. This may be because of improved awareness about ASC. Between 2007-2010, there were approximately 52 people with ASC on the SPFT's caseload.

- 37.5** The issues that the partnership faces include:
- a lack of awareness of ASC at the screening stage;
 - going into recovery with a mis-diagnosis can lead to the wrong treatment or lead to delays;
 - the Recovery team being unable to fulfil the recommendations made by the diagnostic clinic, maybe if they relate to Adult Social Care services and the person is ineligible for that service
 - limited number and high costs of specialist services (although they can provide excellent outcomes)

- 37.6** There is great informal enthusiasm amongst the Recovery staff but the lack of formal services can be a problem and the relatively low number of people being seen with ASC means that skills might not develop very quickly.

- 37.7** SPFT is looking to improve the level of training in the Recovery teams. They have identified a worker in each of the three Recovery teams who will be the identified lead worker for ASC.

The West Recovery Team (which covers Hove) is the one that is most likely to lead on this work, as they have a caseload of 35 people with ASC, due to the services available in Hove for people with ASC.

To summarise, this means that there is a growing awareness of ASC, a growing caseload, more staff showing an interest in the condition, and a real opportunity to shape services for the future.

37.8 Mr Watling said that it had not proved possible to easily find a list of people who have had a diagnosis of ASC. This may be indicative of the low priority that ASC had been given in the past and some of the issues that need to be addressed by all of us. We all need to improve our data collection. SPFT has an initiative starting this year to better improve the way in which they record diagnosis.

37.9 Some workers had found it a challenge over the past few years to deal with some of the difficult behaviours that some people with ASC displayed, eg violent behaviour. However a lot had been learnt over the years and it was felt that things were improving.

Mr Watling said that SPFT needed to improve its relationship with the third sector. One way that this could be taken forward could be for the identified lead officer mentioned previously to carry out training with the third sector and to then share this learning with their colleagues.

37.10 Mr Watling explained that SPFT services were currently being reorganised with more of a focus around care management and assessment and treatment. They will have assessment/ treatment centres in the city, enabling them to reorganise staff in a way that will be able to provide more treatment for people with ASC and other conditions.

When Mr Watling undertook this work, it highlighted the fact that there appeared to have been four admissions of people with ASC to acute inpatient services in the last month. This is very concerning; people with ASC do not cope with change easily, and the nature of acute services means that there are often changes of staff, which would be very distressing. The new service model needs to include much more continuity.

37.11 Mr Watling answered questions from the panel. The panel asked how people were referred to SPFT. Mr Watling said that it seemed that most people came through from Access Services. There were Liaison services at the hospital, and SPFT were looking to improve this. This may prove to be a new pathway.

37.12 What was the general trend with regard to acute admissions? Mr Watling said that over the last year, about 20 people had been admitted into acute admissions, so the last month's intake had been

exceptionally high. He will be looking at these admissions in greater detail to find out what happened.

- 37.13** The panel asked about crisis management, and the time taken for the crisis team to respond. Members of the public had told the panel previously that they had been on the verge of suicide before they received help from the crisis team.

Mr Watling said that there were often unrealistic expectations about the role of the crisis team; they are not there to support anyone in a mental health crisis. They are tasked to provide support only for people who would otherwise be admitted as an inpatient. There are many people who have a crisis who are not likely to be admitted, so they would not be eligible for help from the team.

However, one of the big pieces of work that is taking place in conjunction with the PCT is to look at the emergency and urgent referrals from GPs. SPFT and the PCT are looking at how the service can be improved to provide more of an urgent response for people.

- 37.14** The panel asked whether SPFT received any referrals from the prison service. The SPFT has the potential to take those referrals although the data was not currently known. The Secure and Forensic services are linked closely to the prison.

- 37.15** The panel asked how the recommendations from the diagnostic clinic were met and why they might not always be met. Mr Watling said that they needed to do more to understand the various components of the work.

Some of the problems could be due to the Fair Access to Care regulations- not all patients would be eligible for funding under the regulations. However when the SPFT begins to think more creatively, it might be that they no longer need to purchase the services from the council and will rely less on Adult Social Care.

- 37.16** Mr Watling was asked what would be the most useful thing that could be done as a result of the panel. He said that it would be helpful for the council to remind SPFT that they were there to provide services for everyone in the city, and to act in an inclusive way. People have different ways of experiencing crisis, and it is useful for SPFT to remember that.

Mr Watling said that the fact that the panel had been convened and the questions that had been asked had encouraged SPFT to review how they provide services for adults with ASC and to begin to reshape some of their practices.

- 37.17** The panel asked Mr Watling for his view of the transition process. He said that the process had been designed so that it worked well but that tended to cause difficulties for some individuals. For example, the way

in which the CAMHS service is organised is very different to the way in which adult Mental Health services is organised; the CAMHS approach is a lot more involved. This can mean that young people moving from CAMHS to the adult service can feel a sense of loss; this is exacerbated for young people with ASC who cannot manage change.

Work is underway to help design a better transition pathway from CAMHS, maybe to include a worker from CAMHS becoming involved with the adult services for up to a year to make the pathway smoother and offer continuity. However it needed to be remembered that CAMHS also included all aspects of the young person's life including education etc, which did not happen in adult provision.

The panel asked whether there was any legal reason that there had to be a separate children's and adult's service, as there was such a difference in service provision between the two. Mr Watling said that he was not aware that there had to be two different systems but that there was an issue about capacity and demand.

There was an ever increasing demand for adult Mental Health services, and SPFT needed to be more responsive to both short-term and long-term needs. SPFT was assigning Care Coordinators to people with higher levels of needs as a key worker, to provide a level of continuity and help them to access the right level of treatment and support.

37.18 Mr Watling was thanked for his time and for the information that he had provided.

38. AWARENESS OF AUTISTIC SPECTRUM CONDITIONS FOR FRONTLINE SERVICES - GUY MONTAGUE-SMITH, ACCESS POINT

38.1 Guy Montague- Smith, Manager of Access Point, Brighton & Hove City Council introduced himself and the service. Access Point is the main point of referral for all Adult Social Care enquiries and referrals. It has two main functions, one to provide advice, information and signposting and the other part is determining eligibility for services using the Fair Access to Care criteria. This is usually done over the telephone, although there is also an online form and some assessments are carried out over email.

The team operates from Monday to Friday all day. They have just started an outreach service, connected with local voluntary groups and carrying out face to face assessments. This has helped people who have communication issues and cannot communicate over the phone.

The service is very busy. They have approximately 2,500 contacts per month, of which two thirds are seeking advice and information, and one third are seeking assessments. At present, about 94% of cases are completed by Access Point.

The team acts as a safe haven for safeguarding adult alerts. These are triaged to the most appropriate team for investigations. The team can also set up basic services such as Meals on Wheels, minor adaptations or home help. They provide guidance with self-directed support.

- 38.2** The team has a number of areas that it is working on. These include increasing their knowledge of Autistic Spectrum Conditions and Learning Disabilities, including a rapid response team to help people with ASC.

Most of the services that Access Point deals with are geared up for people with physical disabilities; this is probably one of the main stumbling blocks for people with ASC. The teams that Access Point refers on to might not have much knowledge about ASC and what is needed, and might not recognise the issues.

The team does not cover Mental Health services as these fall outside of Adult Social Care and are provided by SPFT.

- 38.9** Mr Montague-Smith responded to questions from the panel.

Would someone approaching Access Point need a diagnosis before receiving support?

Mr Montague-Smith said that people do not need a diagnosis to get help from Access Point but he does feel that services that they have are not currently geared up to help people with ASC. They talk to Assert for assistance now if it's needed but they would prefer to have a specialist within the team, particularly to help with safeguarding queries in relation to people with Learning Disabilities.

- 38.10** The team needs to improve its knowledge of ASC in terms of safeguarding. They have a very high level of referrals – 278 in the last quarter- with half being Mental Health related issues. The Support and Intervention team that deals with a large number of safeguarding issues is more used to dealing with physical issues, so training is needed to raise awareness of the issues.

Most members of the Access Point team have had some element of Autistic Spectrum Conditions training through the Learning and Development team although it has not been possible to release everyone for training at once. The training has also been offered to the other assessment teams. The training was developed by the Aspergers' Stakeholder Group and is provided for the council by Southdown Housing.

- 38.11** The team model that Access Point uses is very resource efficient, it is very effective in reducing waiting lists and referrals to the main

assessment teams, allowing specialists to deal with specialist provision.

38.12 Mr Montague-Smith was thanked for his input and the information provided.

39. GRAHAM BOURNE, REVENUES AND BENEFITS

39.1 Graham Bourne is the Head of Revenues and Benefits for Brighton & Hove City Council, incorporating Council Tax and Housing Benefit administration. Mr Bourne said that he has a particular interest in this subject as he has a son on the autistic spectrum.

39.2 Mr Bourne was asked to speak to the panel as his service deals with a large percentage of the adult population in Brighton and Hove. Mr Bourne explained that there were 125,000 domestic properties registered for Council Tax in the city; a fifth of those were in receipt of Council Tax Benefit and/ or Housing Benefit. His service is a high contact service for a lot of residents of Brighton and Hove. They deal with a very wide range of customers and aim to provide an inclusive accessible service. Staff are trained in customer service and mental health awareness, giving them the tools to understand customers and decide the best way to communicate with them.

39.3 In terms of seeing customers on the autistic spectrum, it is more likely that the team will see people with high-functioning autism, as they can have more of an ability to function without support. However within that group people still have different levels of coping and managing. It is essential that staff can adapt themselves to find the best way of communicating with an individual on a one-to-one level.

Mr Bourne said that he tended to be the point of reference for customers with ASC due to his personal knowledge. He has intervened in a handful of cases where he felt it necessary, mainly in terms of communication. Some people interpret rules in a very black and white way and questions needed to be asked in a way that cause the least distress.

39.4 Mr Bourne said that there was a small sub-team – the Housing Benefit and Homeless Prevention Team – whose role it was to try and support people who have fallen through the net in terms of housing and benefits, trying to fill the gaps between Benefits, Housing and Adult Social Care. They link to third sector groups and link in to other services to try and help the person in a holistic way. It worked well because of the shared customer-focussed approach of all of the partners involved, who engage well with the Revenues and Benefits team.

Mr Bourne said that Brighton and Hove had a very high rate of people claiming Housing Benefit in relation to its size so it was worth resourcing the team in order to prevent problems further down the line. The team has a lot of knowledge and experience of homeless prevention work and has had extensive Mental Health and related training. This model has been highly praised by the Department of Communities and Local Government as a model of homeless prevention. It is highly effective in preventing extra costs escalating in other areas by supporting the person now.

39.5 Mr Bourne answered questions from the panel. He was asked about the impact of the forthcoming national welfare reforms on people with ASC.

Mr Bourne said that any change is difficult for people with ASC. The welfare reforms will change things for a lot of people, both in terms of the level of benefits paid and on how the system was administered. It is vital to make sure that people do not fall through the net purely when the system was altered. He was not sure how many people with ASC claimed benefits, so he could not say how many people would be affected.

39.6 Mr Bourne was asked whether there was any one recommendation that he would like to see. He said that his only comment would be that it might be possible for some people to have been diagnosed with ASC earlier which may have made a difference to their lives.

39.7 Mr Bourne was thanked for his input and the information that he provided. The panel was pleased to hear that the team was doing so well in supporting people with a wide range of different conditions and requirements.

40. JAMES CRANE, HOUSING OPTIONS

40.1 James Crane, Service Improvement Manager for Housing Options including homelessness services, spoke to the panel. Since 2004, Housing Options has aimed to deliver its housing options in a more specialised way; in 2008 it received funding for a Learning Disabilities Housing Options post, whose role includes helping people with housing options including people with ASC.

40.2 Since 2008, the Learning Disabilities Housing Options officer has received twenty referrals for people with ASC; these were divided into 17 males and 3 females, with an age range between 18 and 49. People were referred by the Community Learning Disabilities service; Mental Health services; Millview; Assert and the Supported living Service.

The service would try to engage the person to talk about their housing need; the primary focus is to try and avoid homelessness. There is an integrated support pathway; this has 700 bedspaces for people with a range of vulnerabilities including low level mental health needs or

substance misuse. There are also the Mental Health beds funded by SPFT.

40.3 The project worker works closely with Assert and with the Asperger stakeholder group. They feel that due to poor self reporting skills, people with ASC are often getting a poor service.

40.4 One of the particular problems in housing is the waiting list for diagnosis, particularly if someone has high-functioning ASC. If someone is able to work and manage their lives it can be hard to see how they whether they might be assessed as 'in priority need' if they are homeless.

It would not be reasonable to keep someone in temporary accommodation for twelve months whilst waiting for a formal diagnosis and so they have to use the available information from GPs in order to make their decision about whether someone should be accepted as priority homeless or not. It would be useful if the waiting lists could be reduced in order to help address this problem.

40.5 Thinking about the supported accommodation pathway, there is no one particular project that deals with specifically with people with ASC. The one most likely to be used would be accommodation provided by Carr Gomm, for people with either Learning Disabilities or Mental Health issues.

40.6 Mr Crane said that there was a lot of confusion about the definition of 'priority need' throughout housing. Having a particular condition in itself was not necessarily an indication of someone being in priority need, it depended on how they managed their condition and how this was affected by their accommodation.

40.7 People with ASC tend to be unable to describe how their condition affects their daily life -one customer was quoted as saying 'I don't know what you mean when you ask how this affects my daily life, it is my daily life'. This can make it very hard for Housing Options staff to make a decision about someone's housing need or whether they are eligible for help.

40.8 If someone was on the Joint Housing Register, and they lived in at home or in supported housing, it was likely that they would be given Band C banding due to their medical needs. The Housing Options Officer said that it seemed hard to get a higher banding than this. Most council allocated accommodation tends to go to people in Bands A and B so it was difficult to access housing.

Council accommodation on housing estates was not always suitable for people with ASC, particularly in terms of noise etc and could increase problems. It was often the case that private rented accommodation or specialist accommodation was more appropriate.

- 40.9** In terms of accessibility, the team had developed visual guides to go alongside council leaflets about housing options, tenancy agreements etc.
- 40.10** Members asked Mr Crane what type of property tended to be offered by the council as they had heard about problems that tenants with ASC had had in council accommodation. Mr Crane said that they were restricted by what was available although they tried to make suitable matches. The Allocations team was unable to discriminate of possible future problems that someone may cause if they were not currently causing a problem, but had to be ready to offer support in those situations.
- 40.11** It was possible to offer floating support services to help someone deal with neighbour problems rather than moving someone to live in supported accommodation. Floating support services were provided by Southdown Housing and Brighton Housing Trust. Support services worked successfully in keeping someone in their tenancy; problems tended to occur if the support worker changed or if other care services had been withdrawn without the council's knowledge. This could mean that issues could escalate outside of the council's control.
- 40.12** Mr Crane was asked whether it was possible to increase the levels of people with Asperger's syndrome being identified as he had referred to them having poor selfreporting skills. He said that officers currently asked clients if they had physical or mental health problems but were less likely to ask if someone had a learning disability.
- Mr Crane suggested that the team could start asking this and recording the responses.
- 40.13** Mr Crane was asked how the Medical Advisor carried out the banding. He said that there was an in-house Medical Officer in Homemove who managed a lot of the banding, but the council could also access external experts if needed. The Medical Advisor recommends the banding based on medical need.
- 40.14** The panel heard that the Homemove eligibility criteria was decided by the council's administration and could be reviewed and amended at any time should the administration choose to do so.
- 40.15** Mr Crane was thanked for his contribution to the panel.

41. ALEX COOTER, YOUTH OFFENDING TEAM AND MIRANDA WHARAM, CHILDREN'S DISABILITY SOCIAL WORK TEAM

- 41.1** Alex Cooter, Practice Manager at Brighton and Hove's Youth Offending Service (YOS) and Miranda Wharam, Manager, Integrated Child

Development and Disability Service, introduced themselves to the panel.

- 41.2** Ms Cooter explained that the YOS is a multi-disciplinary team, covering a wide range of services in order to provide a holistic response to offending. All new casework includes a comprehensive assessment of the young person including their family, living arrangements, vulnerability etc.

The team works across different tiers. They currently have 48 cases open to them at a preventative level, where the young person might not have a criminal response, but will have some services provided for the whole family by the YOS; there are 128 cases open on court orders, either leading to community orders or custodial sentences.

- 41.3** It has proved very hard to get data about how many of the young people have ASC. Of the 128 on court orders, at least three have had diagnoses before they came to the attention of YOS. Ms Cooter estimated that, over a year, the YOS would have five or six new cases where the young person had already had a diagnosis.

The three young men that Ms Cooter mentioned previously all have Asperger's and ADHD. All have significant substance misuse and family difficulties. Two are at risk of homelessness, one is in custody following a violent offence, committed two days after he left school having received a year of intensive support and tuition. Ms Cooter pointed out that the transition stage for this young person began at sixteen, as he left education then.

The young people who come to the attention of the YOS are lucky in that they have access to a wide range of experts who will work with them to address their behaviour and to support them into change. Transition into the adult world is difficult for all of their clients.

- 41.4** Ms Cooter said that in her experience, most of the young people with ASC do not want to have that label attached to them and do not want to work with specialist services. Fortunately the court orders quite often determine that the young person will work with the YOS and receive those services.
- 41.5** Ms Cooter said that there were examples of good practice of police and custodial staff responding well to young people with ASC. This had markedly improved over the five years that Ms Cooter had been involved. A young person does carry an Autism Alert card; there was anecdotal evidence that this has led to child-centred, sensitive approaches from the police.

There is much better partnership working and multi-agency approaches although there is still plenty that can be improved.

The YOS had started to notice recently that they had clients in common with the Children's Disability Social Work team, particularly in terms of clients with Learning disabilities. This was a relatively new phenomenon.

- 41.6** Ms Wharam then spoke to the panel. She manages the Integrated Child Development and Disability Service. It is an integrated service, with social care elements, and medical/ educational aspects. CAMHS is based within their service. They have about 190 staff overall in a wide range of specialisms.
- 41.7** Members asked whether Ms Cooter and Ms Wharam had noticed a gender split in ASC. Ms Cooter said that most of the YOS's clients were young men (about 70%) though she could not say what percentage of these had ASC. Ms Wharam said that at least 80% of the young people with ASC seen by her service were male.
- 41.8** Ms Wharam said that one of the major issues has been the police's understanding of ASC. Ms Wharam said that they had been unsuccessful so far in trying to liaise with police to raise awareness and had had quite a negative response. It is key for the police to be aware of the issues and how to approach the young person to avoid the situation escalating. The child protection police had a good understanding of ASC and had done a lot of work regarding safeguarding and appropriate adult representation. This was not necessarily the case for uniformed police officers.
- 41.9** Ms Cooter said that she believed that the police and the YOS had learned a lot from each other over the years that they had spent working more closely together. She suggested that all police officers should spend some time in the YOS as part of their training and post-qualification so that they could come to know young people better, learn ways of dealing with challenging behaviour and realise that they did not have to approach them with fear.

Jane Frost from Assert added that they had tried to arrange ASC awareness for the police. They had provided two sessions and then the police had stopped it. The Chairman said that this would be taken up at a later meeting where the police were due to attend.

Ian Stephenson from Downsview School commented that a lot of young people with ASC also had epilepsy. This was a very complicated situation and police needed to be aware of this.

- 41.10** Ms Cooter and Ms Wharam were thanked for their information and contributions.

42. ADAPTING SERVICES TO ENABLE PEOPLE WITH ASC TO ACCESS THEM - MARY EVANS, COMMUNITIES AND EQUALITIES

42.1 Ms Evans introduced herself and her work to the panel. She is the Commissioner with responsibility for involvement and inclusion and for links with the voluntary sector. Ms Evans was attending the panel to talk about making reasonable adjustments and best practice.

42.2 Ms Evans said that the local authority had a responsibility to undertake reasonable adjustments through equalities legislation; this was embedded in the council's policy.

There was an overarching principle of effective communication to ensure that the adjustments are the right ones for people with differing needs. As the panel had heard, there can be an issue with self-reporting or identifying as having ASC, which is a potential issue for the council.

The council needed to ensure that it was making reasonable adjustments in terms of customer service. The panel had heard examples of good practice from Graham Bourne how Revenues and Benefits was using different forms of communication, raising frontline staffs' awareness of issues in order to treat people as individuals etc.

Another area was housing; the council needed to look at whether we made enough adjustments in housing management? Ms Evans did not have any answers at present though she did share some housing management guidance with the panel, eg looking at soundproofing/ bedroom numbers.

Training was another area that needed to be considered. Ms Evans was aware that the council's Learning and Development team had had awareness training themselves and were working to cascade this to colleagues in the council. They were also working to ensure that corporate training was accessible to colleagues with ASC.

42.3 Ms Evans was had the most concern about employment, particularly with the welfare reforms as this was likely to become more of a pressing issue. Issues included the job advert, the application process, and the interview process and then providing employee support and appropriate training.

The council had been working on its employment practices over a number of years and had some good practice in some of the areas above, for example in interviews the council aimed to avoid multiple questions, avoiding hypothetical questions etc. This had been influenced by feedback from the Disabled Workers' Forum who had a number of members both now and in the past who had ASC. There was an ongoing issue with the application process and the length of the application form; this was being explored further.

Ms Evans said that she would be interested to hear what Jobcentre+'s approach would be in terms of supporting people into employment.

- 42.4** Ms Evans also wanted to comment on transition; how could they help the commissioning strategy build in some wrap-around support models? This could have a strong role for the voluntary sector, recognising the good work done in supporting adults and their families and include the good practice already built up. Any intelligent commissioning should include statutory and third sector agencies in a joint working approach.
- 42.5** Ms Evans said that the police were working with the Community Safety Team to deal with disabled hate crime; they were working well to support victims of crime.

42.6 Ms Evans was thanked for her input to the panel.

The meeting concluded at 5.00pm

25 November 2010 Minutes

Present: Councillors Harmer-Strange (Chairman); Meadows. Phillips and Watkins

43. PROCEDURAL BUSINESS

43A Declaration of Substitutes

43.1 There were none.

43B Declarations of Interest

43.2 Councillor Harmer- Strange declared a non-prejudicial interest in the remit of the panel as a parent with two children on the autistic spectrum.

43C Declarations of Party Whip

43.3 There were none.

43D Exclusion of Press and Public

43.4 In accordance with section 100A(4) of the Local Government Act 1972, it was considered whether the press and public should be excluded from the meeting during the consideration of any items contained in the agenda, having regard to the nature of the business to be transacted and the nature of the proceedings and the likelihood as to whether, if members of the press and public were present, there would be disclosure to them of confidential or exempt information as defined in section 100I (1) of the said Act.

43.5 RESOLVED – that the press and public be not excluded from the meeting.

44. CHAIRMAN'S COMMUNICATIONS

44.1 The Chairman, Councillor Steve Harmer-Strange, welcomed everyone to the meeting and introduced the panel members. The Chairman advised people that the meeting was being recorded for use as a training resource although it was not being broadcast live.

44.2 The Chairman gave some background information, explaining the remit of the scrutiny panel. This was the fourth meeting of the Panel, and the second one intended to hear from people with Autistic Spectrum conditions and their parents and carers. The Chairman said that he was delighted that so many people were able to make it to the meeting and thanked them for giving up their time to take part in what he hoped

would be a very valuable and informative session looking at experiences of using the current services for adults with ASC.

44.3 Those who wished to speak were asked to come up to the table and identify themselves.

45. EVIDENCE GATHERING FROM MEMBERS OF THE PUBLIC ETC

46. SPEAKER ONE – MS A, PARENT

46.1 Ms A had a son who is on the severe end of the spectrum with very complex needs. He will be 18 in February 2011. Ms A had grave concerns about the lack of progression through transition. Her son had had an annual review aged 14 when the family were asked what provision they needed and agreed that a full-time placement was an option. Ms A felt confident at that meeting that, since there was 4 years to go, the plans would be in place and the provision made available. Nothing happened and there was nothing put in place at all. So far, her son had only been offered one place, and that was inappropriate. They had found one place out of the county, but the current policy was only to place people in Brighton & Hove – but how can that policy work if there is no provision available?

46.2 Her son was currently in a children's shared care package which had worked well and Children's Services had agreed that he can stay there until an adult placement is found.

46.3 The Chairman thanked Ms A and Panel members asked questions.

46.4 In response to questions Ms A told the Panel that someone from Adult Social Care had been at the meeting when her son was 14 years old, and had said they would secure funding for the adult placement that afternoon. The family have a transition worker and they are meeting each month now to discuss progress. Everyone has the best intentions, but the service isn't there. The latest information is that there may be a placement next summer at the very earliest. The transition worker is still looking but some of the placements are not appropriate because of her son's complex needs.

47. SPEAKER TWO - LALLI HOWELL AND IAN STEPHENSON, DOWNS VIEW LINK COLLEGE

47.1 Ms Howell said that 47% of the pupils at Down's View Link College were on the Autistic Spectrum. Mr Stephenson had been at Down's View for fourteen years and Ms Howell used to run the Autistic Spectrum Conditions Outreach service for the council; between the two of them they had a vast amount of experience and knowledge.

- 47.2** Mr Stephenson was concerned about provision post 19. The transition from their services into adult social care was like ‘falling off a cliff’ - and their families also ‘fall off the cliff’. Often people with autism have a much younger developmental age: they may be 18 but have the mental age of between 3 and 12 years. The lack of provision puts a huge strain on families like Ms A’s. Their case was a damning indictment of the local authority and transition.
- 47.3** Mr Stephenson and Ms Howell had done a lot of research into autism. However, their role disappeared at 19 and there were no specialist teachers available for adults with ASC. The role of a teacher to help children past 19 into their 20s and 30s was essential. It was ridiculous to assume learning finished at 19. Paediatricians also disappeared at the same age. The doctors, teachers and paediatricians who have supported a child all through their life, all disappeared.
- 47.4** There are no learning disability specialists equivalent to the role of paediatricians in the NHS. As a result of losing the professional role in their lives, people with ASC run the risk to be left with carers who are not trained to a post-graduate level in ASC and don’t necessarily have the expertise with challenging behaviour.
- 47.5** Ms Howell told the Panel that there was fantastic provision across the spectrum up until the age of 19, with attention paid to individual needs. There were as many autisms as there were people with autism. The fantastic model up to 18/ 19 should be repeated up until people are 30 and beyond if necessary, although they did recognise that there were some young people with ASC who were able to progress to university at 18/19.

Sometimes situations break down and young people with ASC end up in police cells. There should be an emergency team that can help and who have specialist knowledge.

- 47.6** The Chairman thanked Ms Howell and Mr Stephenson and the Panel asked questions.

In response to questions, Ms Howell told the Panel that education continuing on past 19 would help children as their mental age progressed. It would help facilitate moving out from home, learning life skills etc. There was a need to work with families. Whilst further education was not for everyone, if a child had severe learning difficulties then they would need continued support.

Mr Stevenson gave the example about assumptions made by non-professionals in the field, that often people think of being unable to look someone in the eyes as a sign of autism but many people with autism will look into your eyes. Carers need to know that some general assumptions made could be misleading

Transition was not really the correct word: it was continuing care and continuing structured education. It was also the case that there was often nothing to transition to.

47.7 Ms Howell told the Panel that for children, there was professional understanding to facilitate choices. The ability to make choices was very difficult for people on the spectrum. In term of continued education, rather than a traditional 6th form college, what would be helpful would be teams of people to support those with ASC not only with issues such as housing, but also to provide an educational establishment with support for employment. Mr Stephenson made the point that if education lasted longer, young people could stay at home longer which would ultimately save money. The ideal was a cradle to grave provision. Sometimes choice for people with ASC meant staying in and then their world gets smaller and smaller.

47.8 Ms Howell said they have anecdotal reports from students who have left and there were many different outcomes. Drawing on the example of the TEACCH programme, continuing care and staff training were required. Attention should also be paid to the fact that recruiting young people as carers would also provide a peer group for young people on the spectrum. Mr Stephenson made the point that overall, the UK was doing well for young people in comparison with other European countries.

The Chairman thanked Ms Howell and Mr Stevenson for their insightful comments.

48. SPEAKER THREE – MR B, SERVICE USER

48.1 Mr B was diagnosed with Asperger when he was 4 years old. A specialist in London diagnosed him as on the autistic spectrum. This early diagnosis was both a curse and a blessing.

He has been shipped around different schools. His primary education was ok, but later mainstream schools did not work for him; he had difficulty with social skills. He was very good at maths and computing and found those lessons too easy. Due to having problems socially, Mr B went to a school in Hampshire when he was 11 years old. This was specifically for children with Asperger but Mr B described it as like an open prison. There was an emphasis on life skills over formal education and no GCSEs so Mr B's education went downhill. He tried to explain that this was not right but no-one listened. At 13 he was molested; it took two years before he could tell the staff. The result was he was immediately expelled. As a consequence, Mr B felt he could not trust people particularly those in positions of responsibility.

By the middle of year 10 at school, Mr B had no GCSEs. He signed up to a course at City College and did a year crash course. His determination pushed him forward and he got his A Levels. At 18, all

the support he had had vanished. Mr B went to Oxford University but the University did not know he had Asperger. When Mr B started at University, there was a huge party in the Halls, the Dean was away and Mr B, who had been used to central control found there was no-one to help and no safe place. It was very stressful but he eventually pulled through to achieve his degree.

Mr B got a job as a data entry clerk in a bank but when he told his supervisor he had Asperger he was sacked the following day. As he had been a temporary worker, this was not illegal.

Assert had been brilliant. He was very stressed and they helped him to get incapacity benefit, although Mr B felt was an insult to be classified as incapacitated.

Mr B now works full time at a company in Watford which meant moving house. The first house-share didn't work and he ended up in a psychiatric hospital for 3 days. Now Mr B lives out of that catchment area so does not have the same support. The transfer between health authorities was taking a while. It is difficult when his support workers change as it takes time to build a relationship with new people.

In the past, people had gone by the book, for example, thinking people with ASC did not have any empathy, but many people do have empathy, they just do not know how to show it. At the school in Hampshire, they did not know how to handle Mr B's maths and computing ability.

Since Mr B left Oxford University, things are better now at Magdalene College because of Mr B – they have learnt from Mr B and it was good to have helped the next generation.

Today, Mr B finds it difficult to know how to live his life. He does not want pity, nor to be treated like a child.

- 48.2** In response to questions from the Panel, Mr B confirmed that he had been supported between the ages of 8 and 11 years old in mainstream education, but one term at school in Eastbourne had been a disaster with the teacher not understanding Mr B's mathematic ability. He had got to college and university on his own initiative which had been exhausting. There was a disability officer at Oxford University and in the second term Mr B had a support worker. Unfortunately, despite having a child with Asperger herself, she did not really understand and made serious allegations against Mr B because of misunderstandings.

Mr B's employer was accommodating and his manager is sympathetic. He now lives in a quiet flat with a co-worker so that is ok. Following a question about how he sees his future, Mr B told the panel he was quite ambitious and would like to run his own company one day.

- 48.3** In response to a question on what the local authority could do to help, Mr B said counselling would help. He can get emotionally down and it would help to talk to someone who knows him well. Mr B still finds it a struggle to deal with things such as cooking and cleaning the house.

The Panel thanked Mr B for coming to talk to them and praised his articulate and detailed submission.

49. SPEAKER FOUR – MR C, SERVICE USER

- 49.1** Mr C was diagnosed with a mild form of autism at 5 years old. Mr C said that after hearing Mr B speak, he felt that he was one of the lucky ones. He had 1-2-1 help through primary school up until senior school which had really helped. He had very low confidence all the time and always looked for the negatives in things. The 1-2-1 had worked very well and when it stopped when he got older, it was very hard. There were some very good helpers who had helped him socialise with other children, as it was mentally very hard to make friends with other children. When that help went, Mr C became more and more isolated. People look at Mr C and think that there was nothing wrong, but that is untrue: it is a lifelong mental condition.

When Mr C was leaving school, he told them what he wanted to do and the response was 'you can't'. He was very annoyed about that. At senior school, Mr C had found it hard to cope. There were lots of people but he could not tell the teacher and didn't want to make a fuss. His parents had to give him support, not the school. Mrs C said they had had problems with Connexions.

Mr C went to Plumpton College to study land based studies with animal management. He had great support and excelled there, making fantastic progress. Mr C had felt comfortable well and was able to excel. He got the award for top student.

- 49.2** Mr C's mother, Mrs C, said that the transition had been hard. Connexions at that time did not have any real idea about autism. It is very important that professionals have understanding. Mr C had lots of support at school and then support for one term at college. He hit a crisis and then there was no one there to help. The Autistic Spectrum Condition Support Services had stepped in to help. Mr C eventually found out about Assert and they were great.

Recently Mr C had another crisis and only the National Autistic Society had helped; Mr C is high functioning so he does not have a social worker. Mr C pointed out that he didn't like the term 'high functioning'.

Mr C had hit a hurdle after college. Positions available in animal care were inevitably in rural areas so he needed to learn to drive. This was very difficult. Some days he was ok but on other days when his

emotions went over the top, he showed it physically. Mr C had to stop himself driving when he knew he was not mentally strong enough.

It was a problem that people can't see that someone had autism – people want proof of autism. The only benefit available is Incapacity Benefit (which Mr C does not like) and to get this you need to see a GP. The GP at the Jobcentre had asked Mr C what autism was and if he was going to get better.

Mr C is now giving talks and advice to parents and teachers on what autism is like. This is unpaid but is something Mr Smith would like to continue.

Mr C asked why someone with Autistic Spectrum Conditions had not been sitting on this Scrutiny Panel?

The Panel thanked Mr C for his excellent and informative talk and wished him well with the advice talks.

50. SPEAKER FIVE – MS D, SERVICE USER

50.1 Ms D went through mainstream education and was bullied both in primary school and secondary school. In secondary school she ended up in the care of the Child & Adolescent Mental Health Services (CAHMS).

She saw several doctors at CAMHS but none were helpful. One in particular was very bad. Ms D creates characters as friends, as an interior universe to support her, but the doctor considered it a handicap and tried to give her drugs to get rid of these friends. A different doctor sent Ms D to a speech and language therapist who was much more understanding and who diagnosed Asperger's. Ms D had joined in with the café project that Lalli Howell had set up and through this met others on the autistic spectrum. When the cafe moved back to a building managed by CAMHS, she hated it.

Ms D went to Brighton and Hove Sixth Form College (BHASVIC) and the support she received was incredible. Special classes were organised and teachers were provided to support her. The two years Ms D spent there were the best in her education. She became more confident and assertive and can now stand up for others with ASC.

She has now left BHASVIC and is volunteering in a museum but BHASVIC are still supporting her. They gave her advice about joining the student demonstration. Ms D was also involved in the Twitter campaign to free Garry McKinnon. The peer mentoring at BHASVIC was fantastic. It had been organised by Ms D's tutor and it had worked very well.

- 50.2** Ms D's mother, Mrs E, told the Panel that at 18, Ms D had been abandoned by CAHMS. CAMHS said that they would organise aftercare but they did not do so. They did not refer her on to anybody or give her any information about support services. Ms D had to rely on teachers and it was very hard to get the support. Mrs E would like to see a system where there was someone who could help with things like taking Ms D to appointments.

When CAMHS support ended, Adult Social Care carried out some telephone interviews and had decided they weren't needed. There had been six telephone calls and Adult Social Care decided Ms D was coping, even though she had said she was stressed. Ms D explained that Adult Mental Health had rung during an afternoon when she was feeling calm. At other times, such as prior to exams, she was very stressed.

Mrs E said that as Ms D was not statemented, there were no annual reviews. She had had Independent Education Plans at school that were reviewed each year but not since then.

Ms D tried to limit her medications and bring herself back by using her characters – she would like to turn them into a novel one day.

The Panel thanked Ms D and Mrs E for their clear and very helpful contribution to the Panel's enquiry.

51. SPEAKER SIX – MS F, PARENT

- 51.1** Ms F had attended the meeting with her 29 year old son who has Asperger's Syndrome. She had brought him so that he could hear other peoples' stories but he had left as he hadn't wanted to think about his past and he had found some of the stories too traumatic.

They had both wanted to attend to show their support for Assert.

Having failed in mainstream education his family paid for a private Educational Psychologist assessment but the school ignored what the assessment said. He is quiet and so was not seen as a priority by the school; some teachers thought he was lazy. He had an awful educational experience and has not got any qualifications.

Eventually he was diagnosed at 18 through Millview, due to accessing mental health services for depression. He was suicidal in his teenage years.

Ms F approached CAMHS twice for help, once when her son was five and then again at fifteen. The first time, CAMHS said that they thought it was a family issue, rather than a problem that her son had. Later when the psychiatrist said that there was no point in diagnosing and giving the label of Asperger Syndrome as there was no cure. At the

same time she was told that they needed a diagnosis for signposting purposes.

Her son had lived independently for six years. He understands that he can achieve things, but later than other people without AS. He is very adept at IT etc but is not comfortable in social situations. Her son thinks in a very linear fashion.

His accommodation options are limited and further limited by the need to be somewhere he would feel safe and secure?

Her son has had some benefit problems; he was receiving DLA but this has been stopped for administrative technical reasons so he was currently not receiving anything. He was trying to get Income Support as this is needed in order to claim Housing Benefit.

Ms F commented that we try and fit people on the spectrum into our world, when we can learn so much from them.

52. SPEAKER SEVEN – MR G, CARER

52.1 Mr G was attending the meeting on behalf of his niece, Ms H. she is in her 50s and Mr G and his wife have acted *in loco parentis* for nearly 40 years.

When his niece was young, very little was known about Autistic Spectrum Conditions and Asperger's Syndrome. Mr and Mrs G came to know about it when they saw a television programme about autism. Ms H was officially diagnosed at 40 but the family suspected that she had ASC when she was 25.

Mr and Mrs G suggested that Ms H went to the Jobcentre to ask for help. Via the Jobcentre, she was referred to Castleham Industries which provides jobs for people with disabilities. She has worked there for twenty years.

The council has decided to stop funding Castleham from the end of March 2011. There is a need for employment for adults with disabilities including ASC in the city and working gives them dignity, they often cannot fit into regular jobs. Could the council reconsider their decision about Castleham?

Ms H has had help from the National Autistic Society, from Sussex Asperger's Group and from Assert.

She has a lack of confidence as she cannot achieve what other people who are not on the spectrum have achieved. However she is now helping other people with ASC to move forward.

Ms H is very artistic and has set up a website to promote her art via help that Assert gave her.

53. DATE OF NEXT MEETING

53.1 The Chairman thanked everyone for taking part in the session and for speaking so openly.

53.2 The next panel meeting would be on 15 December 2010 in the afternoon.

The meeting concluded at 4pm

15 December 2010 Minutes

Present: Councillors Harmer-Strange (Chairman); Meadows, Phillips and Watkins

54. PROCEDURAL BUSINESS

54A Declaration of Substitutes

54.1 There were none.

54B Declarations of Interest

54.2 Councillor Harmer- Strange declared a non-prejudicial interest in the remit of the panel as a parent with two children on the autistic spectrum.

54C Declarations of Party Whip

54.3 There were none.

54D Exclusion of Press and Public

54.4 In accordance with section 100A(4) of the Local Government Act 1972, it was considered whether the press and public should be excluded from the meeting during the consideration of any items contained in the agenda, having regard to the nature of the business to be transacted and the nature of the proceedings and the likelihood as to whether, if members of the press and public were present, there would be disclosure to them of confidential or exempt information as defined in section 100I (1) of the said Act.

54.5 **RESOLVED** – that the press and public be not excluded from the meeting.

55. CHAIRMAN'S COMMUNICATIONS

55.1 The Chairman, Councillor Steve Harmer-Strange, welcomed everyone to the meeting and introduced the panel members. The Chairman advised people that the meeting was being recorded for use as a training resource although it was not being broadcast live.

55.2 The Chairman gave some background information, explaining the remit of the scrutiny panel. This was the final meeting of the Panel. He explained that, after the Christmas break, the panel members would consider the information that they had heard and make recommendations for how the service might be shaped in the future. It was hoped that they would have the final report and recommendations by next spring.

56. PROFESSOR JEREMY TURK, CONSULTANT CHILD & ADOLESCENT PSYCHIATRIST

- 56.1** Professor Jeremy Turk from the South London and Maudesley Hospital returned to speak to the panel. Professor Turk introduced himself and thanked the panel for asking him to return to speak to them.

He said that he had previously given the panel a comprehensive overview of ASC and was now attending in order to talk about services for adults. He was worried about the lack of services that were provided for adults with ASC; there was a chasm between the quality and availability of children's' and adults' provision.

- 56.2** Professor Turk began by summarising a number of the points that he had made to the panel at his first session.

ASC was not an illness or a mental health problem, it was a lifelong developmental disability. It cannot be cured. Someone's needs could vary at stages through people's lives. Services needed to be sensitive to this and to the varying spectrum of autistic conditions. They needed to base services around a person's individual needs, their dignity and pride.

The primary issue for Professor Turk was diagnosis. This tended to happen during a person's childhood or adolescence; diagnostic services were focussed there at the expense of providing more in adult services. Traditionally help had also been focussed in children's' services although it was now recognised that it was a lifelong condition.

Once a diagnosis had been given, it was important to confirm whether the person needed or wanted any support services; having a diagnosis did not automatically mean that you needed treatment. Having ASC was an entirely valid lifestyle.

Services needed to be based on the evidence available. There were some groups in America who offered 'cures' for autism; Autistic Spectrum Conditions cannot be cured and this was not an appropriate line to follow.

- 56.3** The panel asked Professor Turk for his views on what support could best be offered to adults with ASC. He said that the first thing to consider was whether the person wanted or needed support. It might not be necessary to provide services for everyone with ASC as some people might not want or need the support. The service provider would have to consider which people they would target.

If someone did want services, it was important to have an individualised person-centred approach to providing the care package rather than an impersonal package. Professor Turk also said that

lifelong learning was important as was advocacy; it was helpful to use information provided by national organisations such as the National Autistic Society, who ran a local network of services. In addition there were local self-help groups that could help to support a person with ASC.

- 56.4** The panel asked Professor Turk for his views on transition. They said that there had been a commonly expressed fear amongst parents that things would become worse at the transition stage. Was it possible to provide a seamless, transition-free service?

Professor Turk said that during his career, he had seen a move away from medical services being provided as lifelong services towards more age-appropriate services, divided into children and adult services. However ASC like many other conditions did not respect these boundaries. Professor Turk would therefore support the argument for more life-long services. He pointed out that there were a number of transition phases for young people; these included the move from pre-school to primary school and from primary to secondary school. These could each have their own stresses and anxieties for the young person involved. It was prudent to try and minimise transitions as far as possible for young people with ASC.

- 56.5** Members asked about 'labelling'. They understood that some people were happy to be known as having ASC whilst others were not.

Professor Turk said that a label was only as useful as the benefits that it accrued for each individual. If the label was distressing the person then there was little merit in using it. The professional needed to consider to what extent they believed that the person had ASC, and how much benefit there would be in making that a public diagnosis for that individual. Would hiding the diagnosis prevent the person from accessing autism-friendly services? People tended to be positive to being labelled if there was a positive outcome for them. There also needed to be sensitivity to peoples' perceptions of themselves and in how autism fitted in with this.

- 56.5** Professor Turk was thanked for his time and contribution to the panel.

57. SERGEANT PETER CASTLETON , SUSSEX POLICE, STRATEGIC AND NEIGHBOURHOOD POLICING SUPPORT

- 57.1** Sergeant Peter Castleton Police Sergeant spoke to the panel. He explained that he specialised in Community Safety; this included strategic responsibility for dealing with hate crime and anti-social behaviour. Sergeant Castleton clarified that he was speaking on behalf of the police service but not other criminal justice colleagues.

57.2 Sergeant Castleton said that the police would become involved in a crisis situation, either when someone was the victim of a crime or if someone thought that another person was acting inappropriately. He noted that Professor Turk had said earlier that even he could not always spot ASC in someone so it was understandably much harder for a frontline police officer or members of the general public to make that judgement call, particularly in a stressful or heated environment. He equated police officers to GPs in terms of having to know a little bit about a great many things, but were unable to specialise in many areas.

Currently all existing frontline officers in Sussex received regular six-month training. This included some element of ASC awareness, both in terms of someone being an offender or being a victim. Officers were taught to communicate with people clearly and directly; that there may not be any visible signs of ASC; to avoid physical contact and to try and keep the person in a safe place. They were taught that someone's behaviour might not be deliberately aggressive or antagonistic; it was often hard to judge in the middle of a stressed situation.

The aim was for all officers to have a general awareness of ASC; sessions were 40 minutes long. Training was provided by an in-house Learning and Development team based on information from the National Autistic Society.

Sergeant Castleton said that his work in hate crime had shown him that the biggest area for improvement was that of disability hate crime. It was the least recognised or reported. The police force had recognised this needed to be improved and was working to improve its awareness, including the training courses mentioned above. The force has a Disability Champion, a Senior Officer at Force level, Neil Honour.

Sergeant Castleton said that some people were unable to form safe relationships. There was some history of people preying on people with various disabilities, befriending and abusing them in Brighton and Hove or encouraging them to carry out criminal behaviour. The police service was at the front end of picking this up.

57.3 Sergeant Castleton said that if someone with ASC was in custody, they would need to have an appropriate adult with an understanding of ASC with them, rather than a duty social worker. However this presupposed that the person knew and had disclosed that they had ASC or that the police had recognised it. Police officers were encouraged to check for Autism Awareness Cards if they felt that this was appropriate but as the panel had previously heard, this was reliant on the person being willing to be labelled as having ASC.

Heather Wildsmith from the National Autistic Society said that some forces actively handed out Autism Awareness cards. Sergeant Castleton said that Neil Honour was exploring this at a local level on

behalf of the force. The Chairman added that West Sussex Fire and Rescue also handed out the cards.

57.4 Members asked whether it was possible for the police force to promote themselves as an employment option for people with ASC. Sergeant Castleton said that they did encourage people with disabilities to apply for positions; in terms of ASC it would depend where someone was on the spectrum. He was not aware personally of any staff who had ASC, but it was likely that the police did employ some people on the spectrum in various roles.

57.5 Members asked how the police force could check whether training was being implemented; Sergeant Castleton said that it was down to robust supervision. Officers also learnt through experience. They would also encourage people to make complaints if they felt that police officers were acting incorrectly. The police would not necessarily know which police officers needed more training or supervision unless they have feedback from customers.

57.6 With regards to training, Members suggested that police lay visitors should be included in the training programme as they could be speaking with people with ASC who were in the prison cells; this suggestion was welcomed by Sergeant Castleton. Ms Wildsmith commented that training was available showing how a police visit was experienced from the perspective of someone with ASC.

It was agreed that there could be specialist training for specialist investigators and custody suite staff. This could potentially be provided by Assert or another local organisation. Assert and Sergeant Castleton agreed to meet at a later date to discuss issues regarding training.

57.7 Sergeant Castleton was thanked for his contribution to the panel.

58. JUGAL SHARMA, LEAD COMMISSIONER, HOUSING

58.1 Jugal Sharma, Lead Commissioner for Housing, spoke to the panel about housing demand in the city.

58.2 Mr Sharma explained the housing profile of the city; it is different to most London boroughs in its make up and demand for accommodation.

In Brighton and Hove most accommodation is in the private rented sector; there is a high amount of parental eviction but most homelessness demand comes from the private rented sector; most homelessness is within young men aged 16-25, often with dual drug/alcohol problems. Within that, there are a large number of young men with additional mental health priorities. Homelessness demand peaks in winter months. Changes over demand in the last few years include a high level of young single women; there are rising rates of low levels of

depression. There are a large number of hostels in the city, and a comprehensive specialist rough sleepers' team.

The key difference in demand for accommodation is that there are a disproportionate amount of people with special needs applying in Brighton and Hove; the expected level is 16% of applicants but the actual figure is closer to 20%.

Approximately 3500 people approach the council for help every year; this has been fairly steady for the last decade. There is an acceptance rate of about 1000 people per year; of these, 70% are likely to be young single men with a dual diagnosis.

58.3 There are diminishing vacancies in public rented stock. Most social housing stock is now in bedsits and sheltered, shared accommodation. Social housing accommodation tends to only become available in one part of the city. The council does not want to rehouse vulnerable people in deprived areas. It is working with private rented landlords to lease accommodation for up to ten years to minimise change and disruption to the person. This sustainable longterm leasing allows the council time to work with the person to address any issues or needs that they have. Resources also allow for everybody in temporary accommodation to have approximately one hour of support per week.

58.4 Members asked how the forthcoming changes in Housing Benefit legislation were likely to affect people with ASC. Mr Sharma said that people with any form of recognised need would be excluded from the Housing Benefit single room rate. There was concern about what would happen for people who did not have a diagnosis.

58.5 Councillors said that a more formal link ought to be recognised between the dual diagnosis scrutiny panel and the current work being undertaken on autism as it was becoming more apparent that autism was an underlying factor in many of the cases. This was noted.

58.6 Mr Sharma was thanked for his contribution to the panel.

59. TAMSIN PEART, COMMISSIONER, ADULT SOCIAL CARE

59.1 Tamsin Peart, Carer's Commissioner, spoke about services for carers of adults.

59.2 Ms Peart said that the central resource was a Carer's Centre in Brighton, which was a citywide service available for any carer and offered a variety of resources including advice, information, casework and support groups. These included a transitions project for 16-25 year old carers to support them moving into adulthood. The Centre works to bring services out to the community and takes part in community engagement work. Carers were able to call in or telephone the centre for help.

The Crossroads project offered paid and trained relief care in the home in order to offer respite. Other support services were available through the Buddhist Centre and PATCHED for carers of substance misusers.

The council offered a free emergency back up scheme for carers; any carer could register. If the carer was suddenly unavailable, the council could provide emergency cover. The carers and the council would jointly develop an emergency plan which is held by Carelink so that it can be accessed at any time.

Work was underway to develop a Carer's Card, similar to the compass card offered by Amaze, which will offer discounts and incentives to carers themselves. This was due to be launched in April 2011.

- 59.3** Some carers are funded to manage their own support. Some carers have had Carer's Needs Assessments, arranged through Access Point. The assessment is designed to think about the needs of the person being cared for, how the carer is affected by their caring responsibilities, what is needed to support the carer etc.

23, 000 people had identified themselves as carers in the 2001 census. The Carer's Centre has details of over 2000 carers in the city. There were a great many more who were not known to the Carer's Centre or the council. The Carer's Centre were trying to raise awareness of their service and encourage people to come to them.

- 59.4** Members asked how many carers were carers for people with ASC. Ms Peart said that Autistic Spectrum Conditions were not currently listed as a category on Carefirst. Diana Bernhardt said that it had recently been agreed that it would be added on to Carefirst as a subcategory of mental health. Ms Bernhardt was not sure when this was due to happen. It was also important that housing colleagues use the category when it was introduced in order to build up a comprehensive picture of needs.

- 59.5** Ms Peart was asked how services for carers could be improved. Ms Peart said that carers could be helped by raising awareness of their role in the cared for person's life, respecting their role and to be seen as partners in care. For example, health professionals should consider the carer as an expert care partner who can work with them to meet the needs of the person that they care for.

- 59.6** Ms Peart was thanked for her contribution to the panel.

60. DIANA BERNHARDT , LEAD COMMISSIONER FOR LEARNING DISABILITIES

- 60.1** Diana Bernhardt, Lead Commissioner for Learning Disabilities spoke to the panel.

60.2 The National Autism Strategy estimates that about 50% of people with ASC will also have some type of learning disability and so it had been agreed that Ms Bernhardt is jointly leading on implementing the strategy along with Claire Newman from the PCT, to develop a local response. Ms Bernhardt, Ms Newman and colleagues were considering what the local vision should be, and what the city wants the service to look like.

Ms Bernhardt said that the team was still waiting for statutory guidance from central government and for a training toolkit that had been promised. The local strategy should emerge in the summertime.

60.3 A Joint Strategic Needs Assessment is being carried out to look at what services are available locally and who provides them; it will also look at best practice, the evidence and the local market for providing services. There are some services for adults with ASC in the city at present but there are not very many. It should be noted that Autism Sussex had recently opened a resource centre in the city.

One of the key challenges will be developing the market. In terms of developing the strategy, this would be carried out in the context of the new vision for adult social care. With the new vision and the move to personalisation, it will be necessary to commission services differently. It is necessary to think about the local response and local services, what is good practice in other areas, how can services be provided on a personalised basis etc? In future provision, personalisation will be an option; service providers need to think about a personalised response to each person. One service would not be suitable for everyone so it was necessary to have a variety of service provision.

All of this was reliant on resourcing and funding; there was no budget that had been marked as 'for Autistic Spectrum Conditions'. This added an extra challenge to the whole process.

Transition was also an issue; the processes needed to be and could be managed more smoothly and more effectively. Services tried to plan ahead and share information as much as possible but there was more that could be improved.

60.4 It needed to be remembered that there were a great many people who had a diagnosis of ASC who had been very successful with their lives. Conversely, some people might become 'stuck' on the pathway once they had a diagnosis. People needed to be provided with opportunities for development and life-chances.

Ms Bernhardt would be setting up a stakeholder group to try and reflect all of the demands that would be put on the service.

- 60.5** Another challenge was to decide how the local authority can help those adults who do not meet the eligibility criteria for services? There are different eligibility criteria for children and adult services. Because of this some children who receive support will not be eligible for adult social care services. However, it is important that we assess the whole needs of the person as for some people it is the combination of their needs that put them at risk and therefore would make them eligible for support.
- 60.6** Ms Bernhardt commented that it needs to be recognised that the aims of the strategy are long term and would take time to implement. For example, we should reflect that the Learning Disability White Paper was first introduced in 2001; 10 years later while there had been progress locally and nationally we still had a long way to go. It was likely to be the same case with autism; it would take a long time for all of the elements of the strategy to be incorporated and for everyone to be aware of ASC.
- 60.7** Ms Bernhardt was thanked for her contribution to the panel and for her help in implementing the strategy.

61. MAUREEN PASMORE , SERVICE MANAGER, SUPPORTED EMPLOYMENT

- 61.1** Maureen Pasmore, Supported Employment Manager, Brighton and Hove City Council, spoke to the panel.

The service is there for both employers and employees. They try to match people to jobs, to offer interview practice and training in order to get a job. They offer help to support people at risk of losing their job if they are unable to manage.

For employers, they can help in suggesting reasonable adjustments and in recognising what is not reasonable, assist with procedural and disciplinary issues etc.

- 61.2** One of Ms Pasmore's main concerns was the area of benefits. She had noticed that a lot of people, including people at the higher end of the spectrum who also had high support needs regarding work were being turned down for Employment Support Allowance. They were being assessed as ready for work on Jobseekers' Allowance. This was a particular concern for people with mental health needs.
- 61.3** Another area of concern was that of how people were categorised. She worked with people with mental health needs, learning disabilities, physical disabilities and other needs, but there was no agreement of where ASC sat; it was currently logged under 'other'. In introducing their new Work Choice programme The Department of Work and Pensions did not have a way of categorising someone who is on the spectrum and they did not have an 'other' category. This meant that Ms

Pasmore's service could not register people under the correct category.

- 61.4** Ms Pasmore's team could support people with and without a formal diagnosis of ASC. Some people prefer to have a diagnosis and they are happy to share this with their employers in order to agree 'reasonable adjustments' in the workplace. In Ms Pasmore's experience it was hard to get a diagnosis as an adult.
- 61.5** Brighton and Hove has a significant service industry with a focus on customer service. This can be hard for people who have trouble communicating or engaging with others. Previously there were jobs in the back offices/ warehouses of shops etc that were better placed for people who were less confident in communicating with others but customer service jobs are much more prevalent.
- 61.6** Problems for people with ASC can occur in a number of areas; the systematic nature of recruitment including the application forms; the emphasis on customer service; a lack of services to support people who have issues in the workplace. There is often a lack of awareness of the importance of employment for people with ASC.
- 61.7** Ms Pasmore was thanked for her contribution to the panel.

62. SARAH FAULKNER, ASSERT

- 62.1** Sarah Faulkner, Project Leader, Assert, gave some information about what is like for people with Asperger's Syndrome in employment.
- 62.2** Ms Faulkner said that most people with ASC want to work and have skills that can be used. She provided the panel with a number of practical tips that would be useful for any employer to bear in mind.

These included:

- Problems occur for people with ASC in unstructured time when there is not a set task; this can lead to them losing their jobs for example an argument during a coffee break.
- In recruitment you need to find the right job for the person. The person with Asperger's Syndrome might not be able to identify their own skills set.
- Common abilities include: reliability, motivation, technical ability, accuracy, attention to detail, memory, logical approach, concentration, ability to carry out set procedures.
- Not everyone with ASC works in computers; people have a wide range of abilities

- Avoid jobs with social skills, a need to make quick decisions or multi tasking.
- It helps to be shown if there is a right and a wrong way of doing things so the person can learn the right way of doing something, rather than a job with a grey area.
- Job adverts should be very clear about what the requirements are. Adverts tended to give standard requirements that are not always necessary and may put people off, eg '*excellent communication skills*' or '*be a team player*'
- Someone with Asperger syndrome may have difficulties with 'selling themselves' in an interview, dealing with open questions or hypothetical situations. Such individuals would usually benefit from specific and clear questions. They would also benefit from being allowed extra time for processing the question and planning their response. My plea to employers - please do not assume that a candidate with an ASC will automatically know how much to say, how much is enough or when to stop! This would all be in line with reasonable adjustments.
- There is the issue of disclosure, do you tell people you have ASC or not? If you disclose your condition, the job would provide reasonable adjustments, but the person may face prejudice.
- In the workplace, reasonable adjustments can be simple and low cost, eg offering flexible working hours; allowing the person time for health appointments/ support groups; providing written or visual instructions as well as verbal instructions; providing a work place buddy to check in with and explain the unwritten rules of the workplace. The buddy can check their understanding and provide a social link.
- Do not expect the person to attend social events and respect and understand the decision.
- Be clear and direct about the reason for tasks, the quality needed and the time frame. Check the person understands as they may be too embarrassed to ask for clarification.
- It can be helpful to tell immediate colleagues about someone's condition either face to face or by email. If they are too anxious, perhaps the manager can tell colleagues on the person's behalf. This will help colleagues understand particular behaviours or coping mechanisms
- Some people with Asperger's Syndrome may need guidance from their supervisor about appropriate/ safe topics of conversation in public, to avoid personal topics and concentrate on shared interests and neutral topics.

- Feedback should be honest and constructive so that they can alter their work if necessary. Positive feedback is also important due to low self-esteem.

If the employer takes the simple steps above, they are likely to have a reliable, hard working and dedicated member of staff working for them.

63. MAXINE THOMAS, IMPACT WORKABILITY

- 63.1** Maxine Thomas from Impact Workability Services spoke to the panel. Their project is based in West Sussex. They are funded by West Sussex County Council to provide specialist service. They can only become involved with people with ASC if they have a dual diagnosis too; this can mean that people with ASC fall between the gaps in service provision and support.

Ms Thomas supported everything that had been said regarding employing people with ASC. She gave examples of two people with ASC who the project had helped into work, and how this had been sustained.

- 63.2** Ms Thomas said that she had spoken to Disability Employment Advisors from the Department of Work and Pensions. They had said that there was no support for people with ASC. They would support the introduction of support for people with ASC that was not time limited and was not dependent on benefits being received.

64. CLOSING COMMENTS

- 64.1** The Chairman thanked everyone for contributing to the panel. He said that the report resulting from the scrutiny panel would be completed in spring 2011.

The meeting concluded at 4.30pm

**Emails received from parents/ carers
(These have been anonymised)**

Dear

I will be attending the meeting on the 15th December.

Although I have made my points at previous meeting I feel these cannot be reiterated enough. So if you could again include the points that we :-

1. Desperately need therapies rather than drugs.
2. Housing is a huge problem and careful consideration needs to be made for this as the needs a someone with an ASD is very different, to lets say, people with drug and drink abuse problems and quite often these just get lumped together. We need specialist housing officers to help adults with aspergers.
3. Joined up support across the board i.e. welfare, housing, mental health and work.
4. Lastly and at the moment the most important we need help now with the changes to the benefits system. We must be assured that the DWP staff who carry out the new assessments are experienced with ASDs and we need help from welfare officers to support us through these changes as most carers of adults with ASDs are already losing sleep regarding these changes.

Yours sincerely

From:
Sent: Sunday, November 07, 2010 3:11 PM
To: scrutiny@brighton-hove.gov.uk
Subject: Fw: Meeting re Autistic Services

I wish to add that I know training days are held but I don't think a general overview is the answer for some parents but that more specific issues could be addressed eg. temper outbursts, eating habits, OCD, interaction etc.

I have a few points which might be raised at your meeting as I don't have any answers!

Is there any respite available for families such as Day care at home or at a Centre. Obviously the children would have to get to know their helpers really well.

Parents in the situation (such as with my grandchildren, neither are now attending school due to their acute anxieties) can get to breaking point, but where do they go for relief or help.

I would like to learn how to handle my grandchildren better, maybe spend a day at a Boarding school or special school, particularly learning how to deal with outbursts. This would be useful for parents as well.

Insensitivity when dealing with parents is another issue, all parents would like their children to not be on the Autistic spectrum and to attend social occasions and school.

They do not want to feel "bad parents" when they are doing such a difficult job and trying to hold families together.

Schooling.. I know the current trend is to join in mainstream be it in a special unit but some children may benefit from a small group say 6, away from a main school. This way they could still socialise, learn and interact with others

It is difficult to sort out from their behaviour what is autistic behaviour and what is just being crafty when they don't want to do something. A training day on autism would not help, I know these are already run by the Authority,

Hopefully this meeting will address more specific issues.

Thank you

Hi

I came to the meeting a couple of weeks ago but did not have time to speak so said I would send an e-mail with my views.

I am a parent with of a 13 year old child with Asperger's Syndrome.

I don't think adult autism strategies can be looked at in isolation. There needs to be a combined strategy starting from when diagnosis is made as a child and there then needs to be support and continuation of this support right through from childhood to adulthood. I think there needs to be a person or team allocated to a child (or adult) on diagnosis whose remit is to provide information and support to both the child and the parents, and help them access what they are entitled to. This could provide the consistency autistic people need and allow adults with autism to access the services more easily through someone they know and trust. An extension of the connexions service could form the basis of such a service. I, as a parent, am terrified that the current connexions service is being removed.

We also need to make sure that the support provided at childhood is right and there are a lot of problems re SEN provision in schools and not enough support. If more help was provided in childhood, autistic people would be more able to cope as adults and put less pressure on these services. Currently parents have to fight for all the support their child needs - if an autistic child has a parent who will not or cannot do this, they will not have the support they need and will then be a bigger "drain" on adult services. It would help if the SEN code were compulsory so parents would know what support they could expect and ask for - and schools should be answerable to someone if they don't follow it.

Questions were asked about how we could better identify people with ASC. Teachers should have training in identifying ASC in the children they teach. When my child was pre-school he was playing with another child whose parent was a teacher in a private school. He had recently had training in identifying children with Autistic Spectrum conditions. He said to my son's Nan (who my son was staying with at the time) that he thought he had Asperger's. Unfortunately, however, my son went all through infants and junior school with me being told that he would "grow out of it". It is very difficult to get a diagnosis for your child if the school do not support you so I did not feel that I could take things any further. When he started secondary school everything fell apart and he really began to struggle. It was at this point, thanks to a good form tutor, that I was supported in getting him assessed. I did this privately as by this time I wanted to get this done quickly as he would not get any support at school until he was diagnosed and he was already 12 - time was of the essence. He was diagnosed with Aspergers and ADHD shortly afterwards. If his previous teachers were trained as this private school teacher was, my son's needs could have been identified earlier and he could have been helped earlier.

I hope this feedback helps. I would be grateful if you have a further meeting if you could let me know when it is. I am happy to provide further information about any of the above if that would be helpful. Kind regards.

Hi

Thought I should forward this email to you, as I responded to an email sent to me about improving services from pharmacies to parents with disabled children. As you can see the services are clearly outlined that they offer, in my email I tried to explain how I struggle to sort things like this for kids with autism and for myself but as you can see there is no basic understanding of Autism and how it affects an individual, let alone a family! The clearer labelling is not about the size of the print but clearer instructions on the exact dosage to take and how often! As this is the information that 'gets lost' between the doctors surgery and picking it up from the chemist and also remembering to sort repeat prescriptions, as one minute i remember and the next it's gone or there's something that has distracted me or am having to sort something else out to do with home or the kids, the cat maybe etc....

Which sounds futile to someone else but is a big deal to me as organising my day doesn't always come natural.

I hope this evidence may help towards one of the meetings- Katie and I will hopefully make it to the meeting on the 10th of December, lets hope for good results all round! Take care.

Kind Regards

----- Forwarded message -----

From: **(Brighton & Hove City PCT)** <

Date: 14 October 2010 11:58

Subject: RE: Help for patients with disabled children getting prescriptions.

To:

Dear

Many (though not all) community pharmacies have prescription delivery services set up and you should be able to arrange such a service by speaking to the pharmacy manager.

There is also a scheme called Repeat Dispensing (or batch prescribing) which is suitable for patients whose medication is unlikely to change in the foreseeable future. Under this scheme, the GP can issue several repeat prescriptions, which can then be dispensed (and delivered, if necessary) by the pharmacy of your choice. Although there is no automatic reminder, the prescriptions are there and available at the pharmacy for when you need them. Your pharmacy should be able to give you further details of this, and if you feel this system would suit you, you would then need to discuss setting it up with your GP.

In terms of clearer labelling, there are certainly all sorts of aids available such as large print etc., if you discuss your needs with your pharmacy, they should be able to help.

Many pharmacies also offer a free medicines check up service – this means sitting down with you in a private consulting room and going through your medicines with you, explaining how and when to use them and listening to any concerns you may have about them.

I hope this helps.

Please feel free to contact me if there is any further information you need

Regards

From: [mailto:
Sent: 08 October 2010 20:25
To: Medicines Management (Brighton & Hove City PCT)
Subject: Help for patients with disabled children getting prescriptions.

Dear Sir/Madam,

I wish that there was a service for help with delivering prescriptions to our home as it's not always possible to get the kids and or myself to the pharmacy, due to the fact both my children have Autism and are not always compliant to your wishes!
Also an automatic reminder system would be good to ask you if you require more of you're regular repeat medication or your childrens and all you have to say is yes or no and it gets dispensed for you.

I am also (along with others inc. the council) trying to help get more support for adults, parents and children with autism - clearer labelling on medication and instructions on how to use it correctly would be great from the pharماسist as this kind of information can get lost or forgotten between the time of leaving the doctors room to the pharماسist.

Thankyou for your time.

Regards

dear sir/madam,

Unfortunately due to work commitments i am unable to attend the meeting to-morrow (friday 24th september) however i understand i can express my views here!

My name is Mrs B and i have a son who is 25years old and on the autistic spectrum, it would take to much time to go over the history of problems and difficulties we have had to obtain for M what he has needed during his life. To sum up i would say we have never recieved any support and help until now!! and that support and help has been a lifeline. It has assisted us in all aspects with him, it has offered the most profound assistance, which has enabled him to: gain support and understanding in an educational setting on a one to one hands on way!! creating awareness of his needs with tutors and teachers has been so important to his development and attendance; personal assistance with other disability services to enhance and help his independence.

The service that has provided this is the charity ASSERT, it is a 'frontline' hands on approach offering a supportive, active and developmental service for its users. I have found it difficult to go through the doctor and referral service to get him an assessment with an autistic specialist, we have been on a waiting list for nearly 3 years!! A doctor is not free to go with him to a college interview or sit and discuss his issues around independent living etc. however ASSERT offers this service and it is priceless.

A service that is personable, interactive and does not loose touch with its service users is very important!! practical and emotional support for young people with autism is essential for their well being and their integration in society. This hidden disability affects us all, and i know that without the service that ASSERT has offered to us and continues to offer under very over stretched circumstances, he and myself as parent could be in a very different space, which was less productive for him.

The education to other services of the autistic condition is also essential, in areas of education (further and university), employment and housing etc... is imperative if people who are living with autism are to have an equal chance in life.

please pass this on to the members at the meeting.

best wishes

Hello

I am responding to the invitation to the meeting on 24th September regarding support for autistic adults.

Unfortunately I can not attend this meeting however, I would like my view known that as a parent of an autistic teenager I believe there is no support to be had.

Whenever I have asked for help or tried to seek help I have always been told that because my son went through mainstream school there is no help for him. Whenever I have tried to get either support help or advice I have always been stonewalled with no help offered or passed from department to department until you get so frustrated you give up altogether! My son is currently attending college and the lack of advance provision for this major transition for him was appalling I had to go to the college myself and sort his timetable and demand information about special support and ensure they were in contact with my son so he knew where to go for support and help. I fear for my son going to university as it is not made clear where to go for help and support while studying and for any financial assistance that may be available for him. The lack of clear information is disgraceful and no central office to refer to really just leaves parents at a total loss as to where they are supposed to go to find the help and support so desperately needed to help parents guide thier autistic children to cope into an outside world.

I am responding to an email from Amaze concerning adult support for people on the autism spectrum.

I can not attend the meeting but would like it known that I feel not enough information is given out regarding finding help and support for young adults, whether they are going into employment and trying to start an independent life or going into further information. My son is high functioning but still needs a lot of help and support. Currently he is in College studying for his A levels to go to university. There has been little support on services and support available in regards to study aids or any financial assistance he may be entitled to. It is my belief there is a register of disabled people within records so why is the relevant information not passed out as the child gets older. The only time I have ever discovered any help is when I have been informed by other people who have recieved help and thought it might be helpful to gain some assistance for my son. Why is there no central body within the council that holds all the information that young disabled adults may need from independent living to further education? one place where parents can go directly to without being passed from department to department when trying to get information.

Hi there

I received information on the meeting by email, unfortunately, I am unable to attend as I work at a school so it's impossible to get time off during term time.

I would like to put forward the problem that I have regarding my autistic son.

My son has high functioning Autism, he is very intelligent, but would not cope in mainstream school, mainly because he has problems dealing with other people.

I am a single parent without family that live close by and during the holidays, particularly the summer holidays I find it difficult at times.

I looked everywhere for a suitable place for him to attend a play scheme for a couple of weeks and found one that ran in Worthing that I thought would be appropriate, supporting children with special needs including autism. My son lasted one day, he was quiet and withdrawn when he came back and sat on my lap in silence for an hour, so I couldn't let him go again.

The problem is that my child, and I imagine other children would be similar who are in his position is, he doesn't fit in anywhere, not in a play scheme for children with disabilities and not in a play scheme for children without special needs.

I need a break in the holiday and his older brother needs a break too, but my son has autism, he doesn't really want to socialize with other children he finds it too hard to deal with, he manages at school but this is because there are well trained people there who understand autism. I am coming to terms with the fact that I am on my own with my son's autism, he is 9 I feel I have had no support all these years and I can not see it getting any easier in the future. I have been on the waiting list from the Carers Centre at least all this year but nothing.

It seems unfair that I have a child with disabilities and there is no support out there for him or me. My social worker has said they will pay for any support I want, but what support is there?! None as far as I can see.

Thank you for taking the time to read my letter.

Regards

Hi

This is real basic information that might be helpful to pass on to health professionals and nursery teachers etc.....

Hope all is going well.

Regards

.

----- Forwarded message -----

From: <

Date: 26 October 2010 12:42

Subject: Identifying and Understanding Autism Symptoms

To:

Are you unsure how to identify or understand Autism symptoms?

Autism, which is actually part of Autism Spectrum Disorders (ASD) isn't always apparent immediately in a person. Symptoms can usually be identified in a child when they are less than 3 years old, but not always.

Some of the main symptoms of autism are impaired social, emotional and communication skills. These are often manifested in very specific ways. For example, individuals might have certain repetitive behaviours and have a great deal of difficulty changing their routine. Learning, focusing, paying attention and other tasks can be difficult for individuals with autism and quite often they do these things in a way that is very different from other people. As noted, these symptoms begin most often by the age of 3 and usually last throughout a person's life. There is no known cure to autism at this time.

One of the main issues for people with autism is extreme difficulty with social interaction. When children are little - even in infancy - they usually enjoy interaction with the world around them. The marked lack of this type of interaction is quite evident in children with autism. The usual smiles, finger grabbing, babbling and imitating words of the people around them is absent in toddlers with autism, which is a sign that the child should have medical attention.

Thank you again for your time.

Occupational Therapist

My Autism Network, LLC

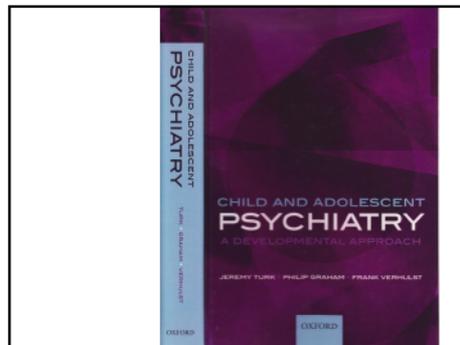
<http://MyAutismNetwork.com>

Presentations to the Panel

6 September 2010 - Professor Jeremy Turk



Autism Spectrum Conditions Across The Lifespan
Jeremy Turk
Academic Child & Adolescent Mental Health,
St. George's & Institute of Psychiatry, University of London
&
Child & Adolescent Mental Health Neurodevelopmental Service,
Southwark and National & Specialist Services
South London & Maudsley Foundation Mental Health NHS Trust



Developing Mental Health Services for Children and Adolescents with Learning Disabilities: a Toolkit for Clinicians
Sarah Bernard & Jeremy Turk
March 2009
Royal College of Psychiatrists Publications, London



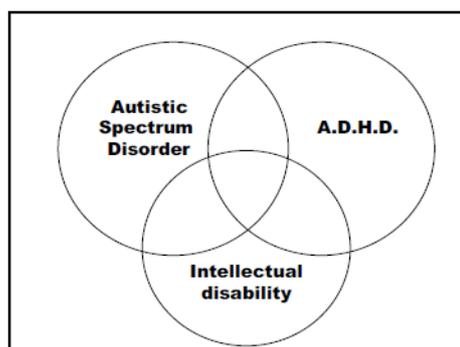
Autism Spectrum Conditions:

- are developmental disabilities
- are not psychiatric disorders
- But they predispose individuals to mental health problems for a variety of biological, psychological, educational and social reasons



What are developmental disabilities?

- Early onset
- Long-term
- Frequently multiple
- Interferences in normally fluent skill acquisitions
- Necessary for maximisation of potential and quality of life
- Producing adverse physical & psychological functional consequences
- & multiple social adversities & social disadvantage







Intellectual Disability

- Mild 50 – 70
- Moderate 35 – 50
- Severe 20 – 35
- Profound < 20

Learning Difficulties

- Moderate 50 – 70
- Severe < 50





ASD Core Diagnostic Criteria:

- Impairments in reciprocal social interaction
- Impairments in language & communication
 - Receptive & expressive
 - Verbal & non-verbal
- Repetitive & stereotypic behaviours & interests
 - Gross motor
 - Abnormal sensory experiences
 - Abnormal obsessional interests
 - Insistence on routine & sameness
- Lack of imaginary & symbolic skills





Additional diagnostic criteria:

- Onset before 3 years of age
- Other non-specific problems
 - Phobias
 - Sleep & eating disorders
 - Tantrums & aggression
 - Psychiatric disorders
 - Depression
 - Anxiety states
 - Paranoia
 - Obsessive-compulsive disorder
 - Catatonia





Prevalence: how common?

- Kanner 1943: 3-5/10,000
- Fombonne: 10-20/10,000
- NAS: 1/200





Gender Ratio

- Autism: m:f = 2:1
- Autistic Spectrum: m:f = 5:1
- Asperger: m:f = 9:1





Attention Deficit-Hyperactivity Disorders

- Overactivity
- Inattentiveness
- Restlessness
- Fidgetiness
- Impulsiveness
- Distractibility
- All-pervasive





ID, ASC & ADHD

- are spectra of developmental disabilities
- are not psychiatric disorders
- predispose the individual & family to a range of psychiatric, psychological, educational & social adversities



Individuals with ID, ASC or ADHD are individuals at risk





Families who have a member with ID, ASC or ADHD are families at risk





...at risk of:

- Biological, psychological, educational and social adversity
- Misunderstandings regarding:
 - aetiology
 - nature and profile of special needs
 - nature and suitability of appropriate interventions
 - psychological, educational and social needs of individual and family





Prevalence: how common?

- Intellectual Disability
 - Mild: 2-3%
 - Moderate-to-profound: 0.5%
- ADHD/HKD:
 - DSM: 3-5%
 - ICD: 0.5-1%
 - Prendergast et al.: differences in rates due to diagnostic systems, not regional prevalence variations
- Autistic Spectrum Disorders 0.5%





Autism is Highly Genetic

- MZ/DZ twin studies
- Sibling risks
- Family prevalences (Jorde et al)
- Parental features (Piven et al)
- Broader phenotype within families
- Adoption studies
- Discrete genetic aetiologies
- N.B. Roumania
- N.B. Epilepsy





Autistic Spectrum Disorder may be a presenting feature of:

- fragile X syndrome
- untreated phenylketonuria
- neurofibromatosis
- tuberous sclerosis
- Williams syndrome
- Angelman syndrome
- Turner syndrome
- Cohen syndrome
- XYY syndrome

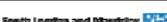




Autistic Spectrum Disorder may be a presenting feature of:

- Congenital Rubella
 - With severe/profound intellectual disability & sensory impairments
- Fetal Alcohol Syndrome
- ? Profound neglect at critical early phase in neurodevelopment





FETAL ALCOHOL SYNDROME (Alcohol Related Neurodevelopmental Disorder)

- most common major toxin to which fetus is exposed
- MLD, pre & post-natal growth deficiency
- IQ in MLD/borderline range
- Fine motor & visuospatial problems, tremulousness
- Executive function, numeracy & abstraction problems
- Expressive & receptive language difficulties
- Irritability in infancy, hyperactivity in childhood
- Problems perceiving social cues
- Very unstable family environments





Association Between Intellectual Disability & Autism

- 70% of children with ASD have a non verbal IQ below 70
- 50% of children with ASD have a non verbal IQ below 50
- Only 5% of children with ASD have an IQ above 100 (high functioning autism)
- Degree of intellectual disability related to likelihood of having ASD & severity of autistic features
- Up to 50% of individuals with severe learning difficulties have an autistic spectrum disorder





Clinical Types

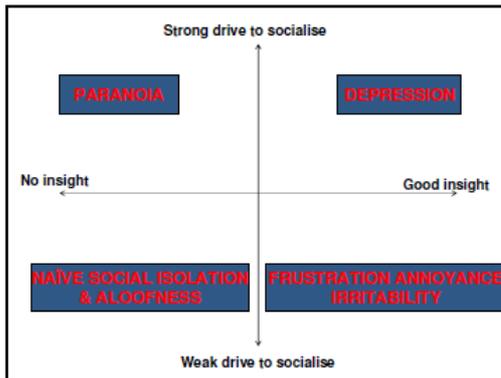
- Aloof
- Passive
- Active but odd
- Overpedantic & pseudomature
- Relates well, but only to one person





Important Dimensions

- Degree of insight
- Drive to socialise



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Psychological Impairments

- General intellectual disability (common)
- Uneven cognitive profile & V/P discrepancy
- Alexithymia
- Lack of theory of mind
- Executive function deficits
- Poor central coherence
 - ↓ drive towards meaning, piecemeal processing
 - "proof reader" rather than "big picture" people
 - → world perceived in fragmented & often incomprehensible & scary way

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Asperger Syndrome

- Usually
 - At least average general intellectual ability
 - "Normal" early language development
 - Marked gross & fine motor coordination problems
 - Marked social interaction difficulties
 - Restricted, stereotyped & often unusual repertoire of interests & activities
 - Mostly male
 - Problems usually persist in to adult life

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Asperger Syndrome

- Is not:
 - "A mild form of autism"
- Is:
 - "An often severe form of autistic spectrum disorder, yet one that is frequently associated with average or even above average general intelligence"

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"We are dealing with a spectrum of disorders...the reasonable way forward would be to retain an umbrella diagnosis for "autistic spectrum disorders" and to specify according to:

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- Severity & nature of defining features
- General level of intellectual functioning
- Unusual or specific clinical traits
- Associated medical conditions
 - causative, consequential, complicating, coincidental
- Associated specific developmental difficulties
- Associated social issues
- Possible aetiologies
- Management intervention & support implications





What Sort Of Autism Is It?

- **Fragile X Syndrome**
 - Friendly & sociable (albeit shy & socially anxious) personality in presence of certain autistic-like features
- **Tuberous Sclerosis**
 - Stubborn, oppositional, defiant with frequent overactivity & inattentiveness
- **Smith-Magenis Syndrome**
 - Frequent ASD using semi-structured assessments yet rarely diagnosed as such (+ ↓sleep, SIB, ADHD)
- **Angelman Syndrome**
 - High rates of predominantly aloof & passive ASD
- **Turner Syndrome**
 - Social anxiety, shyness & attentional problems
 - Ring Variant associated with severe intellectual disability & autistic features





Helping with autistic features

- **Early diagnosis**
- **The right educational setting & input**
 - advocacy role of clinician
- **Social & language skills groups**
- **Cognitive-behavioural approaches**
 - social functioning
 - perspective & turn taking
 - anger management
 - emotion recognition
 - obsessions & rituals
- **Speech & language therapy**
 - social use of language
 - semantic & pragmatic aspects
- **Occupational Therapy**





Common Misdiagnoses in Adolescence & Adulthood

- **Eccentricity**
- **Lazy, good-for-nothing...**
- **Personality disorder**
- **Chronic drug-resistant simple schizophrenia**
- **Selective mutism**
- **Abuse & neglect**





Medication

- **Selective serotonin reuptake inhibitors**
 - Depression, anxiety, OCD, social phobia
- **Atypical antipsychotics**
 - Psychosis, agitation, aggression
- **Tricyclic antidepressants**
 - Depression, OCD
- **Anticonvulsants**
 - Epilepsy, cyclical mood & behaviour disorders
- **Psychostimulants**
 - ADHD
- **Clonidine, Melatonin**





Clinical Hints

- **Literal thinking & understanding**
- **One-sidedness**
- **Lack of empathy & understanding**
- **Friendship & social difficulties**
- **Problems with meaning & use of language**
- **Obsessional preoccupations/behaviours**
- **Lack of imaginary play**





Developmental hurdles

- **Individuation & separation**
- **Restructuring of family relationships**
- **Need for carers to recognise stress associated with maturation & transition**
- **Need to recognise stress to carers & siblings associated with maturation & transition**
- **Need for support with struggle over autonomy versus continuing dependence**
- **Letting go**





Promoting emotional wellbeing

- Graded, planned, coordinated & successful separations
- Supported risk taking
- Encouraging mature & self-preservatory problem-solving
- Facilitating a growing sense of control over potential or experienced trauma
- Supporting & reality-orientating dreams
- Nurturing resilience





Autism During Adolescence

- May improve
- May get worse
- May herald epilepsy
- May herald depression & anxiety relating to increased awareness of disabilities & limited life opportunities
- > Consistency, common sense & not to much emotion
- > Simple rules, agreed by all, repeated frequently & regularly





Developmental Issues

- Oversociability or undersociability
- Expressive speech outstripping understanding of language
- Persisting inattentiveness & impulsiveness despite slowing down
- Problems with processing sequences of information
- Appearing more able than you are
- Accentuation of social & communication issues
- ↑ obsessiveness, repetitiveness & rigidity





Natural desires

- Being part of a group
- Succeeding
- Friendship, company, love, romance, sex.....? children
- Meaningful work
- A home
- Fulfilling leisure life
- Enough money to get by
- Driving





Diagnostic Tools

- Autism Diagnostic Interview
- Autism Diagnostic Observation Schedule
- Diagnostic Instrument for Social & Communication Disorders
- Developmental, Dimensional & Diagnostic Interview
- Social & Communication Questionnaire





Screening Instruments

- Checklist for Autism in Toddlers
 - Protodeclarative pointing
 - Gaze monitoring
 - Pretend play
- Autism Screening Questionnaire
- Childhood Asperger Screening Test
- Asperger Syndrome & High Functioning Autism Diagnostic Interview
- Childhood Behavior Check List
- SDQ
- Conners





Social, Linguistic, Ritualistic, Imaginary & Attentional Deficits may be:

- consistent with developmental level
- indicative of a specific developmental delay
- part of a "general" genetic predisposition
- specific to particular condition





Autistic Features

- May improve, deteriorate or remain static
- Longitudinal twin studies show increasing concordance for autistic features over time
- Suggests that autistic spectrum disorders should be conceptualised as long term developmental disabilities rather like intellectual disability, instead of as illnesses to be "cured"
- ↑ risk epilepsy
- ↑ risk depression & anxiety relating to ↑ awareness of disabilities & limited life opportunities





Positive Prognostic Features

- Level of intellectual functioning
- Presence of social awareness
- Presence of meaningful language
- Presence of attentional skills
- Warm, nurturing & structured family environment
- Developmentally appropriate, focussed & structured schooling
- Progress to date





Cerebral Palsy

- Psychiatric disorder in 40%
- No gender predominance for boys
- Hemiplegia:
 - 25% conduct/emotional disorder
 - 10% hyperkinetic disorder
 - 3% autistic disorder
- Best predictor = low IQ
- Disorders manifest identically to those of psychosocial origin





Mental Health Problems in Children & Young People with Autism Spectrum Disorders

- Are common
- Are frequently severe, multiple & challenging
- Often manifest in different ways from usual e.g. aggression, self-injury, chaotic disruptive & destructive hyperactivity, repetitive stereotypic behaviours, obsessions, passive resistance
- Create substantial morbidity for family
- Have substantial economic cost
- Are treatable





Conclusions

- People with Autism Spectrum Conditions can have intellectual disability and/or ADHD.
- The same biological, psychological, educational & social interventions can be of use.
- ASC, ADHD & intellectual disability in the same person can have same or different causes.
- These causes can influence how ASC, ID & ADHD present & how interventions & supports should be formulated.


Brighton & Hove
City Council


Brighton and Hove

The national strategy and what this means locally

Scrutiny Panel on Services for Adults with Autism Spectrum Disorders.

6th September 2010

- Diana Bernhardt Lead Commissioner for Learning Disabilities
- Claire Newman Acting Strategic Commissioner for Substance Misuse Mental Health




Brighton & Hove
City Council


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The national strategy and what this means locally

Introduction and Overview

- No single diagnostic process for autism
- Variation of approach and services across the country
- Lack of evidence of what works
- First Autism strategy 2009



The national strategy and what this means locally

Current pathways to services

•Locally there are 2 pathways to diagnosis:

- Learning Disability
- Mental Health

•Initial Access though GP referral



The national strategy and what this means locally

Current Picture of local need

*Extract below from Supporting people with autism through adulthood
– The National Audit Office 2010*

Adults

With a learning disability	Number	121
	Estimate/known /don't know	Estimate
	Proportion of local population base	0.06%
Without a learning disability	Number	34
	Estimate/known /don't know	Estimate
	Proportion of local population base	0.02%



Current services

- People access a range of services;
- Supported employment and DWP
- Day services and advocacy
- Residential care and support accommodation e.g. Sussex Autistic Society, learning disability services, homeless and mental health services, secure and forensic
- Information and advice

More accurate picture through the development of the strategy.



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Commissioning Adult, Adolescent, and Children's Services in Brighton and Hove

Claire Newman
Acting Strategic Commissioner: Mental Health and Substance Misuse
NHS Brighton and Hove



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Children's and Adolescent Mental Health Services in Brighton and Hove

The Vision:
'All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.'

5 Key Themes:
The strategy focuses on five core areas of activity over the next 3 years



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Increasing awareness and understanding of autism among frontline professionals

- Improving autism awareness training for all frontline public service staff, in line with the needs of their job
- Developing specialist training for staff in health and social care
- Raising awareness among and through employers
- Raising public awareness



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Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of personalised needs assessment

- Building on increased awareness to increase referrals
- Increasing capacity around diagnosis
- Linking diagnosis to a rigorous assessment of individual need
- Reviewing eligibility criteria for social care
- Providing relevant information to adults with autism and their family or carers *at the point of diagnosis*



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Improving access for adults with autism to the services and support they need to live independently within our community

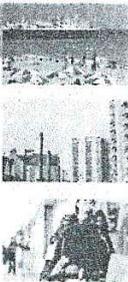
- Ensuring that adults with autism can access the services and support they need
- Enabling adults with autism to benefit from personalisation of social care
- Supporting travel training
- Ensuring transition planning gives people with autism the right start in their adult life



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Helping adults with autism into work

- Ensuring adults with autism benefit from wider employment initiatives
- Personalising welfare and work support
- Reforming existing provision
- Developing new approaches that will better support adults with autism



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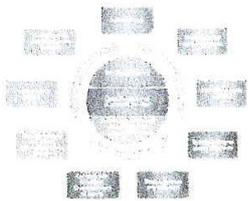
Enabling local partners to develop relevant services for adults with autism to meet identified needs and priorities

- Putting the needs of adults with autism on the map in every area
- Identifying and promoting service models that are proven to make a positive difference for adults with autism
- Enabling adults with autism and their families to have greater choice and control over where and how they live
- Reforming Housing Benefit



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Developing an ASD Commissioning Strategy for Brighton and Hove




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Commissioning Strategy Timeline

Commissioning Activity	Timescales
Establish steering group	30.10.10
TOR - membership, accountability, responsibility	
PID - scope of strategy etc	
Joint strategic needs assessment	31.12.10
Service review and gap analysis	31.12.10
Review evidence base, needs assessment, national strategy/guidance and gap analysis - prioritisation process	31.12.10
Strategic planning:	30.04.11
Commissioning intentions and plan/strategy	
Pathway development	
Service development - business case/planning process	
Resource identification	
Delivery planning:	2011 - onwards
Pathway service re-design	
Service development/procurement	



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Priority Areas and Actions (1)

Establish local governance structure:

- Establish local Adult Autism Strategy Programme Board
- Agree membership, TOR etc
- Oversee development of commissioning PID

Increasing awareness and understanding of autism among frontline professionals:

- Work with current mainstream service providers
 - TNA
- Develop training programme (utilising DH toolkits)



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Priority Areas and Actions (2)

Diagnostic Pathway/Process:

- Review current referral and diagnostic pathways
- Implement streamlined pathway
- Providers to develop literature/information for patients/carers
- Ensure providers undertaking:
 - Carer's assessment
 - Adult social care assessments



15 October 2010 – Naomi Cox



Presentation to Scrutiny October 15th 2010 Autistic Spectrum Conditions

Naomi Cox
General Manager Learning Disability Services

Fair Access to Care Criteria

- Adults on the Autistic Spectrum are entitled to request and assessment of their needs if they believe they maybe in need of social care services.
- In Brighton and Hove our eligibility criteria for social care services is set at 'Critical' or 'Substantial' . This criteria is set out in public leaflet circulated and is based on National Guidance.
- The assessment involves the person and where appropriate their family carer. A persons needs and risks will be discussed.
- The impact of needs not being met will be looked at and this will be considered against the likelihood of risk occurring.
- If a person has critical or substantial needs they will be supported to develop a 'support plan' to meet their needs. They may have to pay a financial contribution. *(for support plan)*

Fair Access to Care Criteria

- If you do not have critical or substantial needs you will be given information and advice.
- If needs were assessed as 'moderate' with a high risk that they may deteriorate within 12 weeks and the person has no other means of support help may be given by Adult Social Care Services.
- Occupational Therapy and Sensory Services may be available to people on the 'moderate' and 'low' eligibility bands as preventative services.

Assessment Pathways

- Adults who have not previously used social care services would use the Access Point to request an assessment.
- Adults on the autistic spectrum who also have a learning disability will receive an assessment from the Community Learning Disability Team.
- Adults on the autistic spectrum who also have mental health needs would be assessed by SPFT Mental Health Teams.
- Adults who are on the autistic spectrum whose predominant need relates to a physical disability would be assessed by the Support and Intervention Team.

Further Information

- The Aspergers Stakeholders Group meets regularly to improve pathways, share information and have specifically worked to support the development of a local diagnosis service. Membership includes: Assert , Aspire, Autism Sussex, NAS Regional Rep, Housing Options, Access Point, Diagnostic Clinic (Hugo Critchley).
- Adult Social Care are working to improve the experience of people with ASC who make contact with Access Point by providing training for Access Point staff and the Access Point Manager has joined the Aspergers Stakeholders Group.
- People who do not meet eligibility criteria - sign posting / prevention services – currently there are only two small voluntary sector organisations specifically working with people with Aspergers Syndrome in the city – Assert & Aspire.

Further Information

- Housing related issues – people with ASC need to have support to access appropriate housing – The Housing Options Officer (Learning Disability) provides advice to people with ASC. Low level support from staff who have had training in ASC will enable people to maintain their tenancies.
- Training – Autism Modules and Aspergers Basic Awareness.
- Employment Support and Benefit advice.
- Hate Crime – the Cross Government Hate Crime Report and local initiatives to support people to report hate crime - Hate Incidents Team Partnership Community Safety Team.

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Autism Spectrum Conditions: Services For Adults

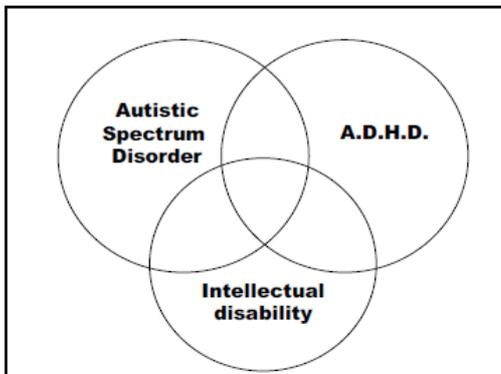
Jeremy Turk

Academic Child & Adolescent Mental Health,
St. George's & Institute of Psychiatry, University of London
&
Child & Adolescent Mental Health Neurodevelopmental Service,
Southwark and National & Specialist Services
South London & Maudsley Foundation Mental Health NHS Trust

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Autism Spectrum Conditions:

- are developmental disabilities
- are not psychiatric disorders
- But they predispose individuals to mental health problems for a variety of biological, psychological, educational and social reasons



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ASD Core Diagnostic Criteria:

- Impairments in reciprocal social interaction
- Impairments in language & communication
 - Receptive & expressive
 - Verbal & non-verbal
- Repetitive & stereotypic behaviours & interests
 - Gross motor
 - Abnormal sensory experiences
 - Abnormal obsessional interests
 - Insistence on routine & sameness
- Lack of imaginary & symbolic skills

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Additional diagnostic criteria:

- Onset before 3 years of age
- Other non-specific problems
 - Phobias
 - Sleep & eating disorders
 - Tantrums & aggression
 - Psychiatric disorders
 - Depression
 - Anxiety states
 - Paranoia
 - Obsessive-compulsive disorder
 - Catatonia

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Prevalence: how common?

- Kanner 1943: 3-5/10,000
- Fombonne: 10-20/10,000
- NAS: 1/200







FETAL ALCOHOL SYNDROME
(Alcohol Related Neurodevelopmental Disorder)

- most common major toxin to which fetus is exposed
- MLD, pre & post-natal growth deficiency
- IQ in MLD/borderline range
- Fine motor & visuospatial problems, tremulousness
- Executive function, numeracy & abstraction problems
- Expressive & receptive language difficulties
- Irritability in infancy, hyperactivity in childhood
- Problems perceiving social cues
- Very unstable family environments





Clinical Types

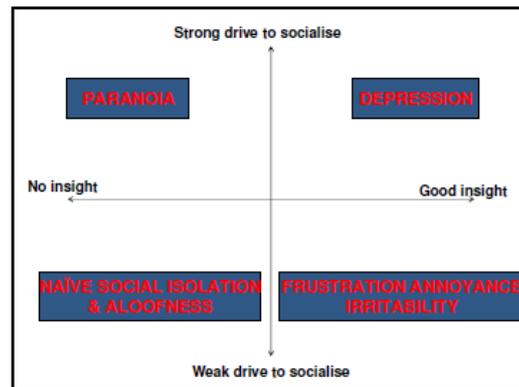
- Aloof
- Passive
- Active but odd
- Overpedantic & pseudomature
- Relates well, but only to one person





Important Dimensions

- Degree of insight
- Drive to socialise







Asperger Syndrome

- Usually
 - At least average general intellectual ability
 - "Normal" early language development
 - Marked gross & fine motor coordination problems
 - Marked social interaction difficulties
 - Restricted, stereotyped & often unusual repertoire of interests & activities
 - Mostly male
 - Problems usually persist in to adult life





Asperger Syndrome

- Is not:
 - "A mild form of autism"
- Is:
 - "An often severe form of autistic spectrum disorder, yet one that is frequently associated with average or even above average general intelligence"





Helping with autistic features

- **Early diagnosis**
- **The right educational setting & input**
 - advocacy role of clinician
- **Social & language skills groups**
- **Cognitive-behavioural approaches**
 - social functioning
 - perspective & turn taking
 - anger management
 - emotion recognition
 - obsessions & rituals
- **Speech & language therapy**
 - social use of language
 - semantic & pragmatic aspects
- **Occupational Therapy**





Common Misdiagnoses in Adolescence & Adulthood

- **Eccentricity**
- **Lazy, good-for-nothing...**
- **Personality disorder**
- **Chronic drug-resistant simple schizophrenia**
- **Selective mutism**
- **Abuse & neglect**





Medication

- **Selective serotonin reuptake inhibitors**
 - Depression, anxiety, OCD, social phobia
- **Atypical antipsychotics**
 - Psychosis, agitation, aggression
- **Tricyclic antidepressants**
 - Depression, OCD
- **Anticonvulsants**
 - Epilepsy, cyclical mood & behaviour disorders
- **Psychostimulants**
 - ADHD
- **Clonidine, Melatonin**





Developmental hurdles

- **Individuation & separation**
- **Restructuring of family relationships**
- **Need for carers to recognise stress associated with maturation & transition**
- **Need to recognise stress to carers & siblings associated with maturation & transition**
- **Need for support with struggle over autonomy versus continuing dependence**
- **Letting go**





Promoting emotional wellbeing

- **Graded, planned, coordinated & successful separations**
- **Supported risk taking**
- **Encouraging mature & self-preservatory problem-solving**
- **Facilitating a growing sense of control over potential or experienced trauma**
- **Supporting & reality-orientating dreams**
- **Nurturing resilience**





Autism During Adolescence

- **May improve**
- **May get worse**
- **May herald epilepsy**
- **May herald depression & anxiety relating to increased awareness of disabilities & limited life opportunities**
 - > Consistency, common sense & not to much emotion
 - > Simple rules, agreed by all, repeated frequently & regularly





Developmental Issues

- Oversociability or undersociability
- Expressive speech outstripping understanding of language
- Persisting inattentiveness & impulsiveness despite slowing down
- Problems with processing sequences of information
- Appearing more able than you are
- Accentuation of social & communication issues
- ↑ obsessiveness, repetitiveness & rigidity





Natural desires

- Being part of a group
- Succeeding
- Friendship, company, love, romance, sex.....? children
- Meaningful work
- A home
- Fulfilling leisure life
- Enough money to get by
- Driving





Autistic Features

- May improve, deteriorate or remain static
- Longitudinal twin studies show increasing concordance for autistic features over time
- Suggests that autistic spectrum disorders should be conceptualised as long term developmental disabilities rather like intellectual disability, instead of as illnesses to be "cured"
- ↑ risk epilepsy
- ↑ risk depression & anxiety relating to ↑ awareness of disabilities & limited life opportunities





Positive Prognostic Features

- Level of intellectual functioning
- Presence of social awareness
- Presence of meaningful language
- Presence of attentional skills
- Warm, nurturing & structured family environment
- Developmentally appropriate, focussed & structured schooling
- Progress to date





Mental Health Needs

- Diagnostic
- Therapeutic
 - Medication
 - Psychological therapies
 - Rehabilitation & Recovery
- Consultation & liaison
- Long term follow-up





Other essential services

- Education – life long learning
- Social support
- Attention to co-existing learning disability
- Social and legal advocacy
- National Autistic Society
 - Nationally
 - Locally
- Literature
- Friendship
- Identity