

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

**2.00pm 6 SEPTEMBER 2010**

**COMMITTEE ROOM 1, HOVE TOWN HALL**

**MINUTES**

**Present:** Councillor Harmer-Strange (Chairman)

**Also in attendance:** Councillor Phillips and Watkins

Apologies: Councillor Meadows

**PART ONE**

**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 an 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

Signed

Chair

Dated this

day of