

BRIGHTON & HOVE CITY COUNCIL

**SCRUTINY PANEL ON SERVICES FOR ADULTS WITH AUTISTIC SPECTRUM
CONDITIONS**

2.00pm 15 OCTOBER 2010

COUNCIL CHAMBER, HOVE TOWN HALL

MINUTES

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

PART ONE

24. PROCEDURAL BUSINESS

24a Declaration of Substitutes

25.1 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's 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 set 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.

- 30.11 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 NHSB&H 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 'passported' 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

Signed

Chair

Dated this

day of