

BRIGHTON & HOVE CITY COUNCIL

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

2.00pm 15 DECEMBER 2010

BRIGHTHELM CENTRE - NORTH ROAD

MINUTES

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

PART ONE

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.

55.5 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 childrens' 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.

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

Signed

Chair

Dated this

day of