

BRIGHTON & HOVE CITY COUNCIL

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

10.00am 24 SEPTEMBER 2010

COUNCIL CHAMBER, HOVE TOWN HALL

MINUTES

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

PART ONE

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 a 'service user governor' 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's, 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 eg 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 Aspergers 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's, 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

Signed

Chair

Dated this

day of