

BRIGHTON & HOVE CITY COUNCIL

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

2.00pm 25 NOVEMBER 2010

COMMITTEE ROOM 1, HOVE TOWN HALL

MINUTES

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

PART ONE

43. PROCEDURAL BUSINESS

37A Declaration of Substitutes

37.1 There were none.

37B Declarations of Interest

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

37C Declarations of Party Whip

37.3 There were none.

37D Exclusion of Press and Public

37.4 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.

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

44. CHAIRMAN'S COMMUNICATIONS

38.1 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.

38.2 The Chairman gave some background information, explaining the remit of the scrutiny panel. This was the fourth meeting of the Panel, and the second one intended to hear from people with Autistic Spectrum conditions and their parents and carers. The Chairman said that he was delighted that so many people were able to make it to the meeting and thanked them for giving up their time to take part in what he hoped would be a very valuable and informative session looking at experiences of using the current services for adults with ASC.

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

45. EVIDENCE GATHERING FROM MEMBERS OF THE PUBLIC ETC

46. SPEAKER ONE

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

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

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

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

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

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

41.2 Mr Stephenson was concerned about provision post 19. The transition from their services into adult social care was like 'falling off a cliff' - and their families also 'fall off the cliff'. Often people with autism have a much younger developmental age: they may

be 18 but have the mental age of between 3 and 12 years. The lack of provision puts a huge strain on families like Ms A's. Their case was a damning indictment of the local authority and transition.

- 41.3 Mr Stephenson and Ms Howell had done a lot of research into autism. However, their role disappeared at 19 and there were no specialist teachers available for adults with ASC. The role of a teacher to help children past 19 into their 20s and 30s was essential. It was ridiculous to assume learning finished at 19. Paediatricians also disappeared at the same age. The doctors, teachers and paediatricians who have supported a child all through their life, all disappeared.
- 41.4 There are no learning disability specialists equivalent to the role of paediatricians in the NHS. As a result of losing the professional role in their lives, people with ASC run the risk to be left with carers who are not trained to a post-graduate level in ASC and don't necessarily have the expertise with challenging behaviour.
- 41.5 Ms Howell told the Panel that there was fantastic provision across the spectrum up until the age of 19, with attention paid to individual needs. There were as many autisms as there were people with autism. The fantastic model up to 18/19 should be repeated up until people are 30 and beyond if necessary, although they did recognise that there were some young people with ASC who were able to progress to university at 18/19.

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

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

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

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

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

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

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

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

48. SPEAKER THREE

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

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

By the middle of year 10 at school, Mr B had no GCSEs. He signed up to a course at City College and did a year crash course. His determination pushed him forward and he got his A Levels. At 18, all the support he had had vanished. Mr B went to Oxford University but the University did not know he had Asperger's. When Mr B started at University, there was a huge party in the Halls, the Dean was away and Mr B, who had been used to central control found there was no-one to help and no safe place. It was very stressful but he eventually pulled through to achieve his degree.

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

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

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

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

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

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

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

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

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

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

49. SPEAKER FOUR

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

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

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

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

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

Mr C had hit a hurdle after college. Positions available in animal care were inevitably in rural areas so he needed to learn to drive. This was very difficult. Some days he was ok but on other days when his emotions went over the top, he showed it physically. Mr C had to stop himself driving when he knew he was not mentally strong enough.

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

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

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

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

50. SPEAKER FIVE

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

She saw several doctors at CAMHS but none were helpful. One in particular was very bad. Ms D creates characters as friends, as an interior universe to support her, but the

doctor considered it a handicap and tried to give her drugs to get rid of these friends. A different doctor sent Ms D to a speech and language therapist who was much more understanding and who diagnosed Asperger's. Ms D had joined in with the café project that Lalli Howell had set up and through this met others on the autistic spectrum. When the cafe moved back to a building managed by CAMHS, she hated it.

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

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

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

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

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

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

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

51. SPEAKER SIX

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

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

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

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

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

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

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

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

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

52. SPEAKER SEVEN

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

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

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

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

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

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

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

53. DATE OF NEXT MEETING

- 47.1 The Chairman thanked everyone for taking part in the session and for speaking so openly.
- 47.2 The next panel meeting would be on 15 December 2010 in the afternoon.

The meeting concluded at 4pm

Signed

Chair

Dated this

day of