

## **ADULT SERVICES SCRUTINY COMMITTEE**

**TUESDAY 8 MARCH 2011**

### **Minute of the Meeting on 27 April 2010**

#### **SERVICES FOR ADULTS ON THE AUTISTIC SPECTRUM**

(Agenda No. 8)

Ms Fenella Trevillion (Head of Joint Commissioning, NHS Oxfordshire), Mr Martin Mellors (Service Development Manager – Mental Health, NHS Oxfordshire) and Ms Ann Nursey (Assistant Head of Adult Social Care - Learning Disabilities) attended for this item in order to update the Committee and to answer Member's questions. The Cabinet Member for Adult Services also attended for this item.

A report was before the Committee (AS8) which covered a definition of autism, the national and local contexts, prevalence levels, an outline of the needs analysis, costs to the system, emerging trends/information, potential service models and issues for discussion.

Two young people with Asperger's Syndrome, Ms Lindsay Smith and Mr Paul Isaacs also attended for this item in order to describe the issues they faced and what would help them and people on the autistic spectrum in future.

They were accompanied by Ms Kathy Erangey, the parent of an eighteen year old son with Asperger's Syndrome, who was also assisting Oxfordshire County Council and NHS Oxfordshire with the work they were doing on Asperger's Syndrome specific service development as both a Consultant and an expert by qualification and experience.

Ms Smith began the discussion by making the following points:

- support was needed at college. It would be helpful if there was a room where students with Asperger's Syndrome could go if they wanted to be on their own for a while. Socialising was hard work;
- it would be helpful to have someone to talk to once a week, for example, about going to college or finding a job.

Mr Isaacs then made the following points:

- diagnostic services for people with Asperger's Syndrome needed to be improved. He had been to Charter House in Thame (Thame Adult Community Mental Health Team) for an assessment and on requesting his notes had discovered that he had been misdiagnosed with schizotypal personality disorder and psychosis and also as having Asperger's traits

- with a complex personality. He would not be able to tell a future employer that he had Asperger's traits with "a complex personality" as it was a bizarre and meaning less diagnosis;
- he had finally managed to obtain a Statement of Special Educational Needs from a specialist in Asperger's Syndrome at Littlemore Hospital;
  - too many people with Asperger's Syndrome were being misdiagnosed and wrongly labelled, which was upsetting for both the person concerned and for their family;
  - a cluster of symptoms created this complex syndrome: dyspraxia (includes clumsiness and co-ordination/motor difficulties), social emotional agnosia (eg "blindness" to body language, facial expressions and the intentions of the individual) and alexithymia (eg. understanding of one's own feelings), as well as being on the autistic spectrum (eg restricted social capabilities);
  - coping at work was very difficult for many people with this condition. Pre-diagnosis he had experienced a nervous breakdown as a result of finding work difficult but had not been sure what was wrong with him. Many people with Asperger's Syndrome found it difficult to find work and not being able to obtain benefits or work support were also common problems. The Benefits Service was not clued up as how to assist people with Asperger's Syndrome;
  - he had started an Asperger's social group in Thame at The Well (a cafe). It would be helpful if the Council could provide funding for this group. It met once a month which meant that only £576 per year was needed;
  - social groups for people with Asperger's Syndrome were very important because they enabled people to come together to help each other and learn how to relate to other people. People with autistic spectrum disorders often had very strong interests and it was good to enable them to share them, relax and be free from the anxieties of mixing with the "outside world". There should be more social groups for people with Asperger's Syndrome. This would also help to raise awareness of the condition. Specialists (eg. Psychiatrists) could be invited to the group in order to learn more about the condition which would raise awareness and increase correct diagnosis;
  - people with the condition should be provided with Disability Living Allowance (DLA) as soon as the condition was diagnosed. He had been to Oxfordshire Welfare Rights for assistance with claiming DLA. DLA was useful in that it helped people to have a better life and was also recognition that the person receiving it had a disability;
  - Job Centre Staff needed to be more understanding towards people with Asperger's Syndrome who were on Job Seekers' Allowance. For example, they might need to rephrase some of the questions that they were asking that people with this condition found hard to answer. There was a need for mutual understanding on both sides.

Ms Smith then made the following comments:

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- she found it useful going to social groups for people with Asperger's Syndrome as you could "be yourself" and relax, without other people thinking that you were weird or being judged harshly or having to make a conscious effort to fit in and be "normal";
- everyone she knew with Asperger's Syndrome either did not have a job or struggled with this;
- people with the condition had many interests and needed support to enable them to develop themselves. It was hard for them to work it out for themselves and they often needed prompting.

Ms Erangey stated that as the parent of an eighteen year-old son with Asperger's Syndrome she concurred with the points made by Ms Smith and Mr Isaacs, and then made the following points:

- there was a huge need for understanding of the needs of people with Asperger's Syndrome - particularly in terms of support at college, with employment and socially;
- people with the condition often found it hard to fit into social groups because they thought differently and did not have the innate social instinct that most people were born with;
- not all people with Asperger's Syndrome wanted to have a social group especially for people with this condition. They also wanted to socialise with people without the condition but would need support to do so initially, which could then be gradually withdrawn.

The Committee then asked Mr Isaacs and Ms Smith a number of questions, a selection of which, together with their responses, is given below:

- **[To Mr Isaacs] Did you manage to amend your medical records?**

Yes.

- **Should there be more training (eg focus groups) for employers to explain autistic spectrum conditions?**

Yes.

- **Would you want formal or informal social services intervention or would you prefer to set up your own groups for people with Asperger's Syndrome?**

Ms Smith stated that it was nice when people with Asperger's Syndrome could start these groups on their own because it helped to reduce feelings of alienation, as people with Asperger's Syndrome knew that it had been started by people "like them". However, they did need to be provided with funding as a lack of funding deterred people from starting up groups.

Ms Erangey commented that not everyone with Asperger's Syndrome was capable of setting up their own group and therefore a range of services was needed. For example, a considerable number of people on the autistic spectrum had difficulties with organisation.

- **Do you have one special person to go to other than your parents if you have problems or are too many people involved?**

Mr Isaacs stated that he relied a lot on his parents - probably more so than someone who was not on the autistic spectrum - and that his parents were worried that he would not be able to lead an independent life due to his condition. In his view there needed to be more help and more people involved and there was no such thing as too much support. Support to parents was also important.

Ms Smith stated that she relied heavily on her mother and that it was sometimes difficult to assert her independence as a result. She added that she sometimes did want to speak to someone that was not her mother, but as she found communication difficult she had not managed to speak to anyone else.

Ms Erangey stated that there needed to be a bespoke service available that people with Asperger's syndrome could ring to speak to someone about their worries.

- **Would it be helpful for people to be invited to speak to the Asperger's Groups, for example, to provide benefits and careers advice?**

Yes.

- **[to Ms Smith] At Oxford University some colleges had set up a buddying system for people on the autistic spectrum on a voluntary basis, whereby people not on the autistic spectrum provided support. Would this be helpful and do you already have any experience of this?**

A buddying system would be helpful and she did not have any experience of this.

- **[to Ms Smith] If you did ask for support at college did they try to meet your needs?**

Ms Smith stated that she had found it too hard to ask for support at college until she was desperate for help. Her mother had helped her to ask but

she had not received much support. Ms Smith further stated that she had to leave college due to a lack of support and that a buddying system would have helped.

- **Would you relate to an office situation? What about volunteering? How would you prefer to ease yourselves into employment?**

Mr Isaacs stated that he was currently volunteering at Autism Resource Base (Thame) and that he was at an advantage in that he could relate to the children and their behaviour. Staff at the base had told him that his involvement had been of benefit to the children.

In terms of employment Mr Isaacs stated that staff did not have to be experts in autistic spectrum conditions, but did need to have a basic understanding of what a person with such a condition could and could not instinctively do. For example, many people with Asperger's Syndrome took things literally and misinterpreted instructions. He added that having a mentor would be helpful possibly for the first six months. This support could then be gradually reduced when the individual had settled into work and felt more comfortable.

Ms Smith stated that she had done a lot of voluntary work and it was a good way to gain skills and confidence as "you weren't expected to be perfect". However, in her experience, it seemed to hardly ever lead to paid employment even if the volunteer was very good and had been volunteering for a long time. Finding paid work afterwards was problematic.

Mr Isaacs stated that many people with autistic spectrum conditions were loyal, reliable and hard working. In his view, it was less likely that they would get involved with office politics and gossip.

The officers present then spoke to the Committee.

Ms Trevillion stated that as Head of Joint Commissioning (NHS Oxfordshire) she was the lead for mental health and was therefore the lead budget manager for the pooled budget for mental health. Therefore she was speaking on behalf of the single arrangements which brought both pots of money together. She added that Ms Nursey (Assistant Head of Adult Social Care – Learning Disabilities) was the lead for learning disabilities and the lead budget manager for the pooled budget for learning disabilities.

Ms Trevillion then made the following points:

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- service development for adults on the autistic spectrum was being led by mental health because at least 50% of people with autism did not have a learning disability;
- however, people with Asperger's syndrome had a higher incidence of mental health problems than the general population. People with Asperger's Syndrome had a great deal of insight and therefore negatively responded to the appalling experiences they may have had. Unfortunately, misdiagnosis was prevalent;
- however, in recent years the Government had begun to issue specific guidance in relation to people with autism. In March 2010 the Strategy for Adults with Autism in England was published as required by the Autism Act 2009; and by 31<sup>st</sup> December 2010 statutory guidance for Local Authorities and the NHS on the implementation of its Autism Strategy was to have been published;
- better services for people on the autistic spectrum was a cross party issue and was not likely to be discontinued after the elections
- Ms Erangey had led on the six focus groups in Oxfordshire for adults with Asperger's syndrome/High Functioning autism across the county, which had identified key themes including diagnosis, employment, housing and health. Many people with these conditions felt isolated and unrecognised;
- on a positive note Goldman Sachs provided a good case study for the successful recruitment and retention of people with Asperger's Syndrome. A number of senior managers at the company had sons or daughters with the condition. They had set up a workstation for this group of employees (who all happened to excel at IT) in a small part of the office to provide them with a calmer, less distracting environment in which to work. Training was carried out on an individual basis or in small groups. Other employees were then asked to email them to avoid distracting discussions. The outcome for this group of employees and the organisation was very positive and they were so hard working that they had to be reminded to go home;
- many of the issues which had been raised at today's meeting would be covered in the commissioning strategy that was being developed.

Ms Nursey stated that although adults with Asperger's Syndrome who did not also have a learning disability did not meet the eligibility criteria for services from the learning disability teams there was a great deal of expertise in supporting people with autism in those teams. She added that some people with the condition were supported by both the mental health and learning disability teams and that expertise had been drawn from both teams.

Mr Mellors added that many of the issues experienced by people with Asperger's Syndrome related to how they interacted with the world, which was something that they needed help with.

The Committee then asked the officers present a number of questions, a selection of which, together with their responses, is given below:

- **What would be done to improve training, diagnosis and support?**

Mr Mellors stated that plans were being developed. He had spoken to Ms Erangey regarding the needs analysis which she had been working on and people had been identified who needed help now. Actual or virtual teams also needed to be set up who were trained in recognising symptoms and providing appropriate support. The development of these services would then attract people that needed the services.

Ms Erangey stated that she was organising a conference on autism to be held in June which aimed to reach a wider range of people. Mr Isaacs and Ms Smith had both spoken at events and had been very well received. However, it was notable that not many GPs attended these events.

- **What was happening with regard to the transition from children's to adult services?**

Transition processes were not perfect but a number of systems were in place. There were clear processes for identifying young people when they reached the age of fourteen who might require services (eg. The Transition Panel) and officers tried to direct people to the "best fit" team.

- **Did officers speak to the District Councils regarding appropriate housing?**

Officers were currently looking at an appropriate housing strategy.

Following the question and answer session the Committee then **AGREED**:

- to thank Ms Smith and Mr Isaacs for sharing their moving and informative personal experiences and suggestions, which will help to shape responsive services for people with Asperger's Syndrome;
- to thank Ms Erangey and officers for their contribution; and
- to keep this service area under review, including considering a report on the outline commissioning strategy (or the draft Strategy if it is ready) at its September meeting.

Councillor Dr Peter Skolar undertook to draw the attention of the Oxfordshire Joint Health Overview and Scrutiny Committee to the lack of diagnosis of Asperger's Syndrome by many GPs and the need for more training and awareness raising to be provided to them.

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