

Overview & Scrutiny Commission

Title:	Scrutiny Panel on services for children with autism
Date:	9 July 2013
Time:	12.30pm
Venue	Committee Room 1, Brighton Town Hall
Members:	Councillors: Jarrett Pissaridou Wealls Rosie Moore, co-opted member
Contact:	Julia Riches Scrutiny Officer Tel: 01273 290451 Julia.riches@brighton-hove.gov.uk

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1. Procedural Business

No substitutes are allowed on Scrutiny Panels. Are their any declarations of interest? Any declaration of party whip? Any reason to exclude press and public?

2. Chair's Communications

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A background paper taken from the National Autistic Society is attached for background information.

3. National pathway

Vicky Slonims, Consultant Speech and Language Therapist, Newcomen Centre, St Thomas' Hospital, London

4. Local pathway - CAHMS

Brenda Davis, Consultant Clinical Psychologist and Lead for Psychology for Brighton & Hove CAMHS, Sussex Partnership NHS Trust

5. Local pathways - Seaside View Child Development Centre

Dr Katharine Anderson, Consultant Community Paediatrician, Seaside View Child Development Centre

6. Special Educational Needs provision in Brighton & Hove

Regan Delf, Head of Special Educational Needs (SEN), Brighton & Hove City Council

7. Date of next meeting

Tuesday 17 September 2.00-5.00pm Thursday 19 September 10.00-12.30pm The City Council actively welcomes members of the public and the press to attend its meetings and holds as many of its meetings as possible in public. Provision is also made on the agendas for public questions to committees and details of how questions can be raised can be found on the website and/or on agendas for the meetings.

Agendas and minutes are published on the council's website <u>www.brighton-hove.gov.uk</u>. Agendas are available to view five working days prior to the meeting date.

Meeting papers can be provided, on request, in large print, in Braille, on audio tape or on disc, or translated into any other language as requested.

For further details and general enquiries about this meeting contact Julia Riches, (01273 290451 – email Julia.riches@brighton-hove.gov.uk) or email scrutiny@brighton-hove.gov.uk

Date of Publication 2 July 2013

To consider the following Procedural Business:-

A. Declaration of Substitutes

Where a Member of the Committee is unable to attend a meeting for whatever reason, a substitute Member (who is not a Cabinet Member) may attend and speak and vote in their place for that meeting. Substitutes are not allowed on Scrutiny Select Committees or Scrutiny Panels.

B. Declarations of Interest

- (1) To seek declarations of any personal or personal & prejudicial interests under Part 2 of the Code of Conduct for Members in relation to matters on the Agenda. Members who do declare such interests are required to clearly describe the nature of the interest.
- (2) A Member of the Overview and Scrutiny Committee, an Overview and Scrutiny Committee or a Select Committee has a prejudical interest in any business at meeting of that Committee where –

(a) that business relates to a decision made (whether implemented or not) or action taken by the Executive or another of the Council's committees, sub-committees, joint committees or joint sub-committees; and

(b) at the time the decision was made or action was taken the Member was

(i) a Member of the Executive or that committee, subcommittee, joint committee or joint sub-committee and

(ii) was present when the decision was made or action taken.

- (3) If the interest is a prejudicial interest, the Code requires the Member concerned:-
 - (a) to leave the room or chamber where the meeting takes place while the item in respect of which the declaration is made is under consideration. [There are three exceptions to this rule which are set out at paragraph (4) below].
 - (b) not to exercise executive functions in relation to that business and

- (c) not to seek improperly to influence a decision about that business.
- (4) The circumstances in which a Member who has declared a prejudicial interest is permitted to remain while the item in respect of which the interest has been declared is under consideration are:-
 - (a) for the purpose of making representations, answering questions or giving evidence relating to the item, provided that the public are also allowed to attend the meeting for the same purpose, whether under a statutory right or otherwise, BUT the Member must leave immediately after he/she has made the representations, answered the questions, or given the evidence,
 - (b) if the Member has obtained a dispensation from the Standards Committee, or
 - (c) if the Member is the Leader or a Cabinet Member and has been required to attend before an Overview and Scrutiny Committee or Sub-Committee to answer questions.

C. Declaration of Party Whip

To seek declarations of the existence and nature of any party whip in relation to any matter on the Agenda as set out at paragraph 8 of the Overview and Scrutiny Ways of Working.

D. Exclusion of Press and Public

To consider whether, in view of the nature of the business to be transacted, or the nature of the proceedings, the press and public should be excluded from the meeting when any of the following items are under consideration.

NOTE: Any item appearing in Part 2 of the Agenda states in its heading the category under which the information disclosed in the report is confidential and therefore not available to the public.

A list and description of the exempt categories is available for public inspection at Brighton and Hove Town Halls.

TAKEN FROM THE NATIONAL AUTISTIC SOCIETY WEBSITE

http://www.autism.org.uk/about-autism/autism-and-asperger-syndromean-introduction/what-is-autism.aspx

"Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.

It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying <u>learning disabilities</u> and need a lifetime of specialist support. People with autism may also experience <u>over- or under-sensitivity</u> to sounds, touch, tastes, smells, light or colours.

<u>Asperger syndrome</u> is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.

How do people with autism see the world?

People with autism have said that the world, to them, is a mass of people, places and events which they struggle to make sense of, and which can cause them considerable anxiety.

In particular, understanding and relating to other people, and taking part in everyday family and <u>social</u> <u>life</u> may be harder for them. Other people appear to know, intuitively, how to communicate and interact with each other, and some people with autism may wonder why they are 'different'.

About autism

Autism is a lifelong developmental disability. It is part of the autism spectrum and is sometimes referred to as an autism spectrum disorder, or an ASD. The word 'spectrum' is used because, while all people with autism share three main areas of difficulty, their condition will affect them in very different ways. Some are able to live relatively 'everyday' lives; others will require a lifetime of specialist support.

The three main areas of difficulty which all people with autism share are sometimes known as the 'triad of impairments'. They are:

- difficulty with social communication
- difficulty with social interaction
- difficulty with social imagination.

These are described in more detail on page 3.

It can be hard to create awareness of autism as people with the condition do not 'look' disabled: parents of children with autism often say that other people simply think their child is naughty; while adults find that they are misunderstood.

All people with autism can benefit from a timely <u>diagnosis</u> and access to appropriate <u>services and</u> <u>support</u>.

Asperger syndrome

There is a form of autism called Asperger syndrome. Our website has more information about <u>Asperger</u> <u>syndrome</u>, or you can order a leaflet <u>from our online shop</u>.

Three main areas of difficulty

The characteristics of autism vary from one person to another but are generally divided into three main groups. These are:

- difficulty with social communication
- difficulty with social interaction
- difficulty with social imagination.

Difficulty with social communication

For people with autistic spectrum disorders, 'body language' can appear just as foreign as if people were speaking ancient Greek.

People with autism have difficulties with both verbal and non-verbal language. Many have a very literal understanding of language, and think people always mean exactly what they say. They can find it difficult to use or understand:

- facial expressions or tone of voice
- jokes and sarcasm
- common phrases and sayings; an example might be the phrase 'It's cool', which people often say when they think that something is good, but strictly speaking, means that it's a bit cold.

Some people with autism may not speak, or have fairly limited speech. They will usually understand what other people say to them, but prefer to use alternative means of communication themselves, such as sign language or <u>visual symbols</u>.

Others will have good language skills, but they may still find it hard to understand the give-and-take nature of conversations, perhaps repeating what the other person has just said (this is known as echolalia) or talking at length about their own <u>interests</u>.

It helps if other people speak in a clear, consistent way and give people with autism time to process what has been said to them.

Difficulty with social interaction

Socialising doesn't come naturally - we have to learn it.

People with autism often have difficulty recognising or understanding other people's emotions and feelings, and expressing their own, which can make it more difficult for them to fit in socially. They may:

- not understand the unwritten social rules which most of us pick up without thinking: they may stand too close to another person for example, or start an inappropriate subject of conversation
- appear to be insensitive because they have not recognised how someone else is feeling
- prefer to spend time alone rather than seeking out the company of other people
- not seek comfort from other people
- appear to behave 'strangely' or inappropriately, as it is not always easy for them to express feelings, emotions or needs.

Difficulties with social interaction can mean that people with autism find it hard to form friendships: some may want to interact with other people and make friends, but may be unsure how to go about this.

Difficulty with social imagination

We have trouble working out what other people know. We have more difficulty guessing what other people are thinking.

Social imagination allows us to understand and predict other people's behaviour, make sense of abstract ideas, and to imagine situations outside our immediate daily routine. Difficulties with social imagination mean that people with autism find it hard to:

- understand and interpret other people's thoughts, feelings and actions
- predict what will happen next, or what could happen next
- understand the concept of danger, for example that running on to a busy road poses a threat to them
- engage in imaginative <u>play and activities</u>: children with autism may enjoy some imaginative play but prefer to act out the same scenes each time
- prepare for change and plan for the future
- cope in new or unfamiliar situations.

Difficulties with social imagination should not be confused with a lack of imagination. Many people with autism are very creative and may be, for example, accomplished artists, musicians or writers.

Characteristics of autism

The characteristics of autism vary from one person to another but as well as the **three main areas of difficulty**, people with autism may have:

- love of routines
- sensory sensitivity
- special interests
- learning disabilities.

Love of routines

One young person with autism attended a day service. He would be dropped off by taxi, walk up to the door of the day service, knock on it and be let in. One day, the door opened before he could knock and a person came out. Rather than go in through the open door, he returned to the taxi and began the routine again.

The world can seem a very unpredictable and confusing place to people with autism, who often prefer to have a fixed daily <u>routine</u> so that they know what is going to happen every day. This routine can extend to always wanting to travel the same way to and from school or work, or eat exactly the same food for breakfast.

Rules can also be important: it may be difficult for a person with autism to take a different approach to something once they have been taught the 'right' way to do it. People with autism may not be comfortable with the idea of change, but can cope well if they are prepared for it in advance.

Sensory sensitivity

Rowan loves art but he hates wearing a shirt to protect his clothing - the feeling of the fabric against his skin causes him distress. We have agreed with his school that he can wear a loose-fitting apron instead.

People with autism may experience some form of <u>sensory sensitivity</u>. This can occur in one or more of the five senses - sight, sound, smell, touch and taste. A person's senses are either intensified (hypersensitive) or under-sensitive (hypo-sensitive).

For example, a person with autism may find certain background sounds, which other people ignore or block out, unbearably loud or distracting. This can cause anxiety or even physical pain.

People who are hypo-sensitive may not feel pain or extremes of temperature. Some may rock, spin or flap their hands to stimulate sensation, to help with balance and posture or to deal with stress.

People with sensory sensitivity may also find it harder to use their body awareness system. This system tells us where our bodies are, so for those with reduced body awareness, it can be harder to navigate rooms avoiding obstructions, stand at an appropriate distance from other people and carry out 'fine motor' tasks such as tying shoelaces.

Special interests

My art activity has enabled me to become a part of society. When there is something that a person with autism does well, it should be encouraged and cultivated.

Many people with autism have intense special interests, often from a fairly young age. These can change over time or be lifelong, and can be anything from art or music, to trains or computers. Some people with autism may eventually be able to work or study in related areas. For others, it will remain a hobby.

A special interest may sometimes be unusual. One person with autism loved collecting rubbish, for example; with encouragement, this was channelled into an interest in recycling and the environment.

Learning disabilities

I have a helper who sits with me and if I'm stuck on a word she helps me. It makes a big difference.

People with autism may have <u>learning disabilities</u>, which can affect all aspects of someone's life, from studying in school, to learning how to wash themselves or make a meal. As with autism, people can have different 'degrees' of learning disability, so some will be able to live fairly independently - although they may need a degree of support to achieve this - while others may require lifelong, specialist support. However, all people with autism can, and do, learn and develop with the right sort of support.

Other conditions are sometimes associated with autism. These may include <u>attention deficit</u> <u>hyperactivity disorder</u> (ADHD), or learning difficulties such as <u>dyslexia</u> and <u>dyspraxia</u>.

Who is affected by autism?

Autism is much more common than most people think. There are <u>over half a million people in the UK</u> with autism - that's around 1 in 100 people.

People from all nationalities and cultural, religious and social backgrounds can have autism, although it appears to affect <u>more men than women</u>. It is a lifelong condition: children with autism grow up to become adults with autism.

Causes and cures

What causes autism?

The exact <u>cause of autism</u> is still being investigated. However, research suggests that a combination of factors - genetic and environmental - may account for changes in brain development.

Autism is not caused by a person's upbringing, their social circumstances and is not the fault of the individual with the condition.

Is there a cure?

At present, there is no '<u>cure</u>' for autism. However, there is a range of interventions - methods of enabling learning and development - which people may find to be helpful. Many of these are detailed at: <u>www.autism.org.uk/approaches</u>

Diagnosis

A <u>diagnosis</u> is the formal identification of autism, usually by a health professional such as a paediatrician or a psychiatrist. Having a diagnosis is helpful for two reasons:

- it helps people with autism (and their families) to understand why they may experience certain difficulties and what they can do about them
- it allows people to access services and support.

People's GPs can refer them to a specialist who is able to make a diagnosis. Many people are diagnosed as children; their parents and carers can ask GPs for a referral.

You can find more information about diagnosis and how to get one here.

Different names for autism

Some professionals may refer to autism by a different name, such as autism or autistic spectrum disorder (ASD), classic autism or Kanner autism, pervasive developmental disorder (PDD) or high-functioning autism (HFA)."¹

¹ <u>http://www.autism.org.uk/about-autism/autism-and-asperger-syndrome-an-introduction/what-is-autism.aspx</u>