

## Bradford LINK Autism & Asperger event

---

Bradford Link hosted an event at Victoria Hall in Saltaire to give the people of Bradford District an opportunity to come together to look at the issues people with autistic spectrum conditions (ASC) have accessing health & social care services in the district. ASC includes people with Autism and Asperger Syndrome.

This event took place on Thursday 4<sup>th</sup> March; the day after the department of health launched its strategy for improving the lives of adults with autism in England. The meeting was attended by almost 50 people who have an interest in ASC. This number included: people with an autistic spectrum condition (ASC), parents, carers and professionals working for statutory and voluntary agencies or services that support people with ASC.

The meeting was run in an Open Space style. This means that the people who attended set the agenda on the day. The topics people wanted to look at included: diagnosis; support for adults with ASC; developing a specialist support service for ASC in Bradford; and ASC being recognised as a disability and thus having access to services. Bradford LINK support staff also had individual discussions with people with an ASC who found it difficult to take part in group discussions and their opinions are considered in this report too.

Each discussion group suggested a number of recommended actions from their discussions. It was decided that Bradford LINK would facilitate a work group to meet regularly to look at the recommended actions and how these could be put in place in Bradford. These actions are listed at the end of this report.

As Bradford LINK is involved in adult services this event and report is mostly about issues and difficulties facing adults but is also concerned with the transition from children to adult services. The concerns that were raised fit under the following themes.

### Main Concerns raised

#### a) Diagnosis

People are experiencing many difficulties in getting a diagnosis of ASC. Individuals report that some doctors still don't recognise the condition in adults and many parents, carers or relatives have to push to get someone diagnosed.

There is still a lack of understanding and awareness of the condition, particularly among ethnic minority communities. People discussed that:

- There should be more training for professionals who work with anyone with an ASC (GPs, teachers, nurses, psychologists) particularly for GPs who are usually the first contact for people seeking a diagnosis
- There needs to be better communication between services
- When making a diagnosis, doctors should observe the person for longer than they currently do. Families and carers should be encouraged to keep a diary to help with diagnosis.
- There are few experts in ASC in Bradford. Adults have to go to Sheffield to get a diagnosis or pay for a private diagnosis. There is a feeling that private diagnoses are not viewed favourably when it comes to ensuring the individual then gets the support that they need from health & social care.

## **b) Supporting people for life**

Once a person has been diagnosed with an ASC, getting support so that they can live an independent life is the next hurdle for many who are affected.

People felt that Autism Spectrum Condition is a condition people have for life, so they need support for life!

It was discussed that people with Asperger's or high functioning autism often do not meet the criteria for help from mental health services or learning disability services so end up with no support or inappropriate support.

Services need to work harder and work together to stop people with ASC falling in to the gap between services. They need to continue to support them and their parents as they move into adulthood. People said that:

- There is a need for a specialist ASC service that links and supports up the various agencies working with people with an ASC.
- There needs to be a whole of life service for a whole of life condition.
- There needs to be a clear pathway from diagnosis to support services.
- There needs to be a clear pathway to help for families and inter-agency cooperation
- There needs to be more training for health & social care staff who may be working with people with ASC.
- Mental health providers need to recognise Asperger Syndrome  
Commissioners need to secure funding specifically for ASC services
- they wanted more support for College and University students with a condition, both in and out of University

### **c) Assessment for disability benefits or access to social care services.**

Many of the people who attended thought the process of being assessed for benefits and services is very complicated does not take into account the person's condition. People are often left without access to the few services there are because of the difficulty of getting through the assessment process. One man told us of how his daughter just gave up because she found the process so distressing.

A major difficulty with the process is that the people carrying out assessments don't have enough training in ASC. This means that:

- Asperger syndrome or high functioning autism is often not recognised as a disability because if an individual can function well on some levels in the assessment process then they might not be considered 'disabled' and entitled to benefits. These people do require support with their daily lives. ASC can be a hidden disability
- The questions that are asked when establishing if someone is entitled to benefits or social care services do not take into account the person's condition. Someone with ASC may misunderstand the questions and this will impact on the answers that they give.
- People don't know what they have to do to CONVINCE those assessing them that they do have a disability

Further difficulties included:

- Too many people fall through the net of whether they have a learning disability or a mental health issue and so get no services.
- Disability living allowance forms are loaded towards physical disabilities with not enough consideration given to the difficulties someone with an ASC experiences.
- There are still misunderstandings and assumptions about the condition and a tendency to try to fit people into services that are not appropriate for them– everyone with the condition is different and should not be treated the same.
- Workplace environments are often not adapted for people with the condition.

More training and awareness is needed so that ASC is better understood and individuals with ASC better provided for.

## **Common concerns from all the group discussions**

More funding and more services are needed.

More communication and co-operation is needed between different agencies

There should be more training for professionals who work with people with ASC, particularly GPs, to make being diagnosed an easier process.

People with the conditions often fall between mental health and learning disability and so get no services.

The process of being assessed for disability benefits or social care services needs an overhaul. A person with an ASC will not respond in the same way as someone with a physical disability, learning disability, or mental health condition.

There is a general need to raise awareness of Autism and Asperger's Syndrome in society.

## **Follow up from this event**

This report will be sent to the people who attended the event on the 4<sup>th</sup> March and any others who have contacted Bradford LINK and expressed an interest in ASC.

A number of people at the event signed up to be part of an ASC work group which Bradford LINK can facilitate initially. The people who signed up include: individuals with an ASC; parents/carers; people working for voluntary sector organisations supporting individuals with an ASC; a representative from a statutory organisation and a representative from higher education.

It was decided at the event on 4<sup>th</sup> March that the first work for this group is to look at the recommended actions from the event and prioritise them. See Appendix A for the recommended actions from each work group

## **Appendix A: Recommendations from each discussion group**

### **Group A: Diagnosis**

- Early diagnosis (school age)
- More training for professionals at all levels – prioritise professionals who have contact with people (special educational needs teachers, doctors, teachers, psychologists, mental health nurses, CAMHS, social workers)
- Diagnostic Observation should be done over a longer period of time
- Family/carer to keep a diary to record all the events, which can help to sustain the case for diagnosis.
- More co-ordination between professionals (for children is now a legal obligation, see Every Child Matters)

### **Group B Specialist health and social care services for autism in Bradford**

Bradford needs:

- A special, linked up, educational, health and social care service for ASC that supports other agencies (e.g. Mental Health, Relate, DWP, Connexions etc)
- Training in ASC for health & social care professionals in all services
- A whole of life service for a whole of life disorder

### **Group C Access to services (Should people with ASC have to go through confusing means testing processes in order to be able to access services?)**

- Rachael to send Fran Horror's report on Development of Autism services at BDCT to Bradford LINK so that we can send it on through networks
- Bradford LINK to let everyone know when Bradford Council's Social Care Improvement Committee meets to scrutinise move of Learning Disability Services from Care Trust to council (section 75)

### **Group D Support for adults: diagnosis and help**

Bradford needs:

- A formal diagnostic pathway
- University support-in and out of university
- To improve the situation where people with possible AS are not meeting criteria for MH or social services support
- To improve GPs knowledge about ASC
- A diagnostic service for adults in Bradford
- To make it possible for people to be able to choose the service provider which is best for them.

**Group E When is a disability, not a disability?** (*Why is ASC is often not recognised and understood, meaning people don't get the services they need?*)

Bradford needs:

- A clear route through diagnosis, plus post diagnosis support
- More awareness and training for people working with individuals with ASC
- Professionals, in particular those carrying out social care needs assessments, have to have enough knowledge of ASC to be able to identify underlying problems that might not be initially apparent.
- Ownership of ASC by either mental health or learning disabilities to stop people falling between the services and so not getting the support that they need.
- Support to be adaptable to individuals needs: not everyone with ASC has the same needs.