

Living with Autism and Asperger's Syndrome

People who are affected by Autism or Asperger's Syndrome have been telling Bradford LINK what needs to be done to make their lives easier. We held a meeting in Saltaire for people with the conditions and their parents and carers. Professionals working for agencies or services that support them also attended.



Autism and Asperger's Syndrome are also known as Autism Spectrum Conditions (ASC). People with these conditions often have difficulty with social communication, and making sense of people's thoughts, feelings and actions. It is often referred to as a 'hidden disability'.

Many people at the meeting told us that they have to keep fighting to get the support and help they need, from being diagnosed with a condition to living with it.

Getting diagnosed

Many parents or carers said they had to fight to get someone diagnosed with Autism and Asperger's Syndrome.

We were told that some doctors do not recognise the conditions. It was also suggested that there is nowhere for adults to go to get diagnosed in Bradford. The nearest place is in Sheffield.



Once a person has been diagnosed, living with Autism and Asperger's Syndrome is the next hurdle for many who are affected.

Being supported for life!

These are conditions people have for life. So they need to be supported for life. We were told that many people are in danger of slipping through the net as they get older. We heard that there needs to be more support in place for teenagers entering adulthood. Many people said they want more advice on how to deal with

issues like relationships, sexuality and practical things like housing and employment. Some people also said they wanted more support for College and University students with the condition

Being assessed 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 does not properly take into account the person's condition. Firstly, they might not show any obvious symptoms. It can often be a 'hidden disability'. Also, when a person who is affected is questioned to find out how the condition affects their life, they may have a different understanding of what is being asked of them. This can make the process very difficult for everyone involved. Some people said they felt they had to convince service providers etc, that they have a disability. Many also said the disability allowance is often geared towards people with physical disabilities. There was a general feeling that too many people fall through the net. They might not be seen to have either a learning disability or a mental health condition but do have great difficulty living independently.

Misunderstandings

Almost everyone at the meeting talked about how the conditions are often misunderstood. Not just among the public, but also professionals who work with people with Autism and Asperger's Syndrome such as GPs, nurses and psychologists. Workplace environments often do not adapt for people with the conditions. Everyone with the

condition should be treated as an individual. It can affect people in different ways. Someone might appear to be unaffected but still need support.

What needs to change?

- There should be more **funding** for services for people with Autism and Asperger's Syndrome in the Bradford district.
- Agencies and services that support people with the conditions need to **get better at talking to each other**.
- Service providers need to find more ways to **stop people falling through the net**.
- The process of **assessing a person** for benefits or access to social care services needs an **overhaul**.
- Professionals working with people with Autism or Asperger's Syndrome need **more training** on the conditions.
- There is a general need to **raise awareness** in society.

What happens next?

The Department of Health recently promised to make many changes to the way health and social care services are delivered for people with the condition. It has pledged to provide more **training** to the people caring for people

with the condition including GPs, doctors and nurses. It wants to **raise awareness** of the condition to help dispel any myths or misconceptions. The Department of Health promises to **make getting a diagnosis easier**. It also wants to help adults with autism get **access to services** they need to help them **live more independently** in the community.

Based on what people told us at our recent meeting, Bradford LINK will be handing a report to the people who decide what services should be available to those with Autism or Asperger's Syndrome.

Many people who attended said they want to **take action** to make change happen. They are forming a work group that will meet regularly and find ways to make this happen this.

The group's next meeting
Monday 19th April 2010
10am-12pm
Victoria Hall, Saltaire,
BD18 3JS

Andrew's Story



He knew he had difficulties but didn't know why. Working was

Andrew Smith was diagnosed with Asperger's Syndrome 2 years ago. Before diagnosis Andrew told us he felt very depressed.

difficult as he was often put in a large busy office where he was confused and felt people didn't understand him. This made him feel anxious paranoid and depressed.

Andrew had a long battle to get doctors to listen to him. His GP eventually referred him to a Psychiatrist for depression. Andrew gave the consultant a written account of how he felt at the time and how he lived day to day. He was then referred to a specialist service in Sheffield who confirmed that he has Asperger's Syndrome and supported him to understand his condition.

Since then life has got much better for Andrew. He has started college and gets the support he needs to work towards his GCSEs. He still struggles to live on his own. Andrew says because he has no structure at home, he can't always cope. Andrew is learning new ways of dealing with his condition like finding patterns to follow when he is in different situations. Andrew gave the example that when he is in a 'posh house' his pattern is that he must not swear.

Although Andrew can explain how Asperger's Syndrome affects him, he doesn't always have the skills to cope with it. He said "Just because I can read a car manual, doesn't mean I know how to fix a car". Andrew says his diagnosis has given him a second chance and with the right support he can now work towards getting a job he really enjoys.

To find out more about Bradford LINK's work on Autism and Asperger's Syndrome please call Becky Mears on 01535 665258 or email becky@bradfordlink.org.uk

Mental Health Day Services

Bradford LINK is asking people across the community about their experiences using mental health day services.



A Mental Health Day service is somewhere people of working age with mental health conditions can go during the day and get involved in meaningful activities both in the place where the service happens and out in the wider community.

Bradford Council is looking to improve the mental health day services it provides for people over the age of 18 and under the age of 65 in the District and it asked Bradford LINK to help find ways of doing that.



Our research officer, Daniel Park has been out in the different communities, gathering information from as many people as possible. He is now in the process of putting all that information into a report which will be given to Bradford Metropolitan District Council.

If you would like to know more about Daniel's work email Daniel@bradfordlink.org.uk or call: 01535 665258.

Mental Health Work Group

The first meeting of the new Bradford LINK mental health group took place on 25th March. This group will take the work of the Bradford & Airedale Mental Health Forum and make sure everyone interested in mental health has somewhere to find out what is happening in the district and to make their views known.

At the first meeting, members of the group talked about what important things they want the group to work on. They decided

- To look at how people with mental health problems access GPs and other primary care services.
- To make sure these people **understand any new plans** the NHS introduces that affects them.
- To make sure people with mental health problems **have their say** when health services are changing.
- To look at how well mental health services serve all **the different communities in Bradford** and make sure **everyone gets the same standard of care**.

The next meeting is on

Monday May 10th

2:30pm

Victoria Hall

Keighley

BD21 3JN

To find out more email mentalhealth@bradfordlink.org.uk

Speaking Out Together

Bradford LINK is helping to create an **Advocacy Network** in the district.



Advocacy means speaking out on behalf of another person about important issues that affect their everyday lives. For example, in Bradford there are agencies like People First and Choice Advocacy that represent people with learning disabilities.

Jae Hargan has been working with Bradford LINK to help get the network up and running. So far we have been told the Advocacy Network should

- Raise awareness about what advocacy is and how advocacy agencies can help vulnerable people.
- Raise awareness of how people can use advocacy agencies and get someone to speak out for them.
- Make the agencies in the Bradford district stronger by getting them to work together.
- Make sure the standards at these agencies are kept high by providing training when needed.

If you would like to know more or want to get involved call Becky Mears on 01535 665258 or email becky@bradfordlink.org.uk



Your Care Your Choice

Bradford Alliance on Community Care (BACC) has been asking different community groups for their views on **Personalisation**.



Personalisation means giving people more choice and control over their care. Care plans are designed to meet the individual needs of the user. For some it could mean managing their own health and social care budget and deciding what services the money is spent on.

BACC asked some small groups from different communities to talk about Personalisation. The people who came to the events were told more about what it is and how it could affect them. They were asked whether they think it is a good idea and for their views about making it work well in Bradford.

BACC will be producing a report for Bradford LINK. The report will be given to people in the district who decide how personalisation will work here.

BACC will also be holding a big event about Personalisation.

Wednesday April 28th
10am-1pm
Light lunch included
Carlisle Business Centre
Carlisle Road
Bradford BD8 8BD

To book a place call 01274 481590
or email
Admin@bacc.uk.com

Working with Foundation Trusts

Bradford LINK has a new group focusing on NHS foundation trusts.



Foundation trusts are NHS organisations which are independent of the rest of the NHS. In Bradford we have one foundation trust which is Bradford Teaching Hospitals. Two trusts expect to become foundation trusts quite soon. They are Airedale Hospital and Bradford District Care Trust.

The foundation trust work group will ensure that foundation trusts in the Bradford district are accountable to all their service users, carers and public, not just the people who are members. This group has met three times. Find out more about what the group has done in the summer edition of Connect.

If you would like to join in with the work this group is doing you can call Mike Quiggin at Bradford Resource Centre on 01274 779003 or email mike@brc-net.org.uk

Or you can call Melvyn Newton at Bradford LINK on 01535 665258 or email melvyn@bradfordlink.org.uk

Dignity Champions making waves in Bradford

Congratulations to all the Dignity Champions in Bradford who have been working hard to promote the Dignity in Care Campaign.



With over 100 members, the Dignity Champions Network is now one of the biggest in the country. It is made up of people from all walks of life from councillors and health or social care professionals, to volunteers and people who use services in the area. The network will meet regularly to find ways for people to work together to make sure everyone in the district is treated with **dignity and respect**.

Next Dignity Champions Network Meeting
Wednesday April 28th 2010
2pm-4pm
East Riddlesden Hall, Nr Keighley

To find out more or book a place please call 01535 665258 or email info@bradfordlink.org.uk

Counting the cost of Dementia

A report by the Alzheimer's Research Trust claims not enough research is being done around Dementia.

The Trust asked the University of Oxford to look at how much the condition costs society. It found the impact it has on society and the UK economy is higher than ever. But, not enough money is being invested in research into Dementia.

According to the report, called *Dementia 2010*, 822,000 people are affected by the condition. It costs the UK £23 billion a year to care for these people, which is almost double the money it costs to care for people with cancer and almost 3 times more than it costs to care for those with heart disease. Despite this, there is less money available to carry out research into Dementia to find better ways of looking after the people who have it.

The report also claims only 31 percent of people with Dementia are registered on GP lists. It blames a lack of training and confidence in diagnosing dementia.

Rebecca Wood, chief executive of the Alzheimer's Research Trust, said: "The true impact of dementia has been ignored for too long. The UK's dementia crisis is worse than we feared. This report shows that dementia is the greatest medical challenge of the 21st century."

Choose your GP

People are being asked what they think of plans to let everyone choose which GP surgery they visit.



At the moment, we all have to register with GP's within a certain distance from where we live. The Department of Health is thinking about letting people choose between whichever surgery they like. It might be that you want to visit a doctor that is closer to the place where you work. It might be that you have moved house but do not want to change your doctor.

However, some people are worried about the idea. They think it could mean 'good' surgeries get lots of people registering and become overcrowded. It could see people being turned away from the surgery they want.

There are many different options for change, including choices about what should happen to those people who need out of hours care, but live too far away.

To have your say and find out more information visit

www.gpchoice.dh.gov.uk

Have your Say!

Bradford LINK wants to know what you think about the work we are doing. Phone us!
Email us! Or visiting our Facebook Page –
www.facebook.com/BardfordLINK.org



Bradford LINK takes to the airwaves



Bradford LINK is launching a series of radio programmes on Bradford Community Broadcasting (BCB). We will be on air every four weeks. A panel of people will be invited to take part in each show so we can have a full discussion on the issues that affect you.

Our first show is on **Wednesday April 14th at 6pm**. Tune in on **106.6FM**. You will also be able to download the show from our website. www.bradfordlink.org.uk

If you'd like to know more or find out about ways you can get involved with the programmes, call our communications officer Bethan Davies on 01535 665258 or email bethan@bradfordlink.org.uk

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Bradford LINK is now on Facebook and Twitter! You can find out more about the work we are doing and tell us your views on health or social care services in the district.



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