

DRAFT CALDERDALE ADULT AUTISM STRATEGY 2015-2018

Introduction

The first Calderdale Autism Strategy was produced in 2012. This is the second local strategy covering the next three years. The Autism Strategy Group consists of people with Aspergers and family members and staff from Adult Social Care, the Clinical Commissioning Group, South West Yorkshire Trust, Health, Education, Job Centre Plus and Criminal Justice sector, NAS, voluntary organisations and providers. The group meets quarterly to oversee the implementation of the strategy and action plan.

Prevalence

1,597 adults (18+) are estimated to have Autism Spectrum Conditions in Calderdale according to www.pansi.org.uk (projecting adults needs and service information system) and www.poppi.org.uk (projecting older people population information system). This is approximately 1% of the adult population.

Of these it is estimated that 1,278 are male and 319 are female.

55% of people with Autism are believed to have a learning disability which is 799 people.

10% of the population of Calderdale are from Black Minority Ethnic communities so it is estimated that there are around 160 BME adults with Autism Spectrum Conditions.

Of the 1,597 adults with ASC, approximately 300 are known to services.

There are 390 children and young people in Calderdale diagnosed with ASC; 328 boys and 62 girls.

Autism Awareness Training

AIM - To provide Autism Awareness Training to staff in Social Care and specialist training for social workers to adapt community care assessments

PROGRESS - Autism Awareness Training is available to staff and specialist training is planned for early 2016

RATING - Amber

The Autism Act (2009) placed a statutory duty on Adult Social Care to provide autism awareness training and specialist training to social workers. Calderdale Adult Social Care has provided autism awareness training for several years and we are holding specialist training for social workers in early 2016.

The NAS, in partnership with the British Association of Social Workers, has put together a step-by-step guide to help social care staff prepare for and deliver

assessments for adults with ASC: <http://www.autism.org.uk/working-with/social-care.aspx>

Reasonable Adjustments

AIM - to make services aware of the need to make adjustments for people with ASC

PROGRESS - a sub group of the Autism Strategy Group and people from the Aspergers Groups are meeting to produce a leaflet and a poster to promote the need for reasonable adjustments to services

RATING - Amber

The National Autism Strategy states that services should make reasonable adjustments so that people with ASC can access them. A group of people from the Aspergers Group and the Autism Strategy Group are producing promotional literature to give to a wide range of organisations to encourage them to do this.

Reasonable adjustments can be around clear communication, reducing sensory stimulus such as noise and bright lights, or providing a quiet space for people.

National Autism Self Assessments

AIM - to achieve good results in the national autism self assessments

PROGRESS - our results so far have been quite good but there are a few areas where we scored red

RATING - Amber

All local authorities are required to complete a national self assessment on Autism every year. They are asked to score themselves on a wide range of areas using a traffic light system (red for poor, amber for okay and green for good).

There have been three self assessments so far and Calderdale have scored mostly ambers and greens each time. There are a small number of red areas that we need to address, such as support for older people with autism and reasonable adjustments, which we are now working on.

Think Autism - Priority Challenges for Action

The National Autism Strategy, Think Autism, lists 15 priority challenges for action that it is focussing on. We consulted the Aspergers Group on which of the 15 were most important to them. 12 people responded and here is a summary of their responses:

- 8 people agreed with the statement: *"I want to be safe in my community and free from the risk of discrimination, hate crime and abuse"*
- 7 people agreed with the statement: *"I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism."*

- 7 people agreed with the statement: *"I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic procedure."*
- 7 people agreed with the statement: *"I want autism to be included in local strategic needs assessments so that person centred local health, care and support services, based on good information about local needs, is available for people with autism."*
- 7 people agreed with the statement: *"I want support to get a job and support from my employer to help me keep it."*
- 6 people agreed with the statement: *"I want staff in health and social care services to understand that I have autism and how this affects me."*
- 6 people agreed with the statement: *"I want to know that my family can get help and support when they need it."*
- 5 people agreed with the statement: *"I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism."*
- 5 people agreed with the statement: *"I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies."*
- 5 people agreed with the statement: *"I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging."*
- 5 people agreed with the statement: *"If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services."*
- 4 people agreed with the statement: *"I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others."*
- 4 people agreed with the statement: *"I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low level support."*
- 4 people agreed with the statement: *"I want to be seen as me and for my gender, sexual orientation and race to be taken into account."*
- 4 people agreed with the statement: *"I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible."*
- 1 person added two more statements of their own: *"Keep things consistent and if things need to change plenty of communication in advance and being kept informed."* and *"Keeping me informed of progress even if there is no definite news. No news at all causes me uncertainty."*

Diagnosis

AIM - To provide an easy to access diagnostic assessment within six months

PROGRESS - The assessment is usually easy to access depending on the GP but there is currently a long waiting list

RATING - Amber

The majority of children with ASC are identified in school now, although some are still missed and girls are more likely to be missed than boys.

However this was not the case in the past so many adults are only now being diagnosed with ASC. The more obvious someone's difficulties, the more likely they are to be diagnosed.

Adults seeking a diagnosis have to get special funding through their GP and in Calderdale, until recently, they were then referred to the Sheffield Asperger Service for diagnostic assessment. In 2014 South West Yorkshire Trust Autism Service were commissioned to carry out diagnostic assessments. These can be carried out in Halifax which is more convenient.

31 people have been offered diagnostic assessments from SWYT in the first block contract and 27 people attended with 6 being diagnosed with ASC. (Two people were diagnosed with a social communication disorder and one with possible ADHD.) This represents a diagnostic rate of 22.2%.

The gender of the people assessed was 15 male, 11 female and 1 transgender. 5 men and 1 woman received a diagnosis. The age range was 21 to 48 years. 1 person was Asian British, 1 person was White Irish and the rest were White British.

Getting a diagnosis as an adult can be a relief after years of feeling different or not fitting in, but it can also bring up feelings of anger or sadness at not being diagnosed earlier and having to struggle unnecessarily. Post diagnostic support is helpful for people at this stage to talk through their feelings and be signposted to additional support. The Aspergers Peer Support Groups are a useful source of pre and post diagnostic support. Specialist counselling is available privately.

Social Care Assessment

AIM - To provide a social care assessment to people with ASC who need one, and for the process to be clear and easily accessible.

PROGRESS - A new specialist social worker has just been appointed for the Autism Pathway

RATING - Amber

People who are diagnosed as adults are entitled to a social care assessment although not everyone will want or need one. If someone's level of need is assessed as being eligible for social care support, they could get a personal budget for support or a personal assistant.

Until a few years ago, people with ASC requesting an assessment would struggle if they didn't have a learning disability or mental health need, as they didn't fit into either team. Since the Autism Act in 2009, this should no longer happen.

A specialist social worker post was commissioned from the Community Mental Health Team in 2014. This was provided by two part-time social workers, and later a part-time social worker and a part-time Community Psychiatric Nurse from January 2014 to March 2015. They assessed and supported 17 people during this time.

A wide range of support was given around social isolation, family relationships, depression and anxiety, employment, benefits and liaison with other services. Having someone to liaise with other services can be very useful for some people with ASC as social anxiety and communication difficulties can make this difficult for people.

In April 2015 SWYT Autism Service were commissioned to provide social work support. They have now recruited a specialist social worker for one year. Then we will seek further funding.

NAS Development Project

AIM - to raise awareness of ASC and develop services for adults with ASC

PROGRESS - Completed (see below)

RATING - Green

This was commissioned in December 2013 and ran until October 2015. There have had two development workers in that time who have brought a wide variety of skills to the project. As a result there is now a website www.thecalderdaleautismnetwork.co.uk, a directory of services that people with ASC can access, a regular newsletter edited by someone with ASC and a Sukoon group for BME females with ASC and mental health needs and their carers. Two Autism Information Days have been held at Calderdale College and support for students with ASC has been explored. Also two Family Information Days have taken place around accessing Adult Social Care.

Whilst this project was commissioned from the National Autistic Society, links will be maintained with the local Calderdale NAS Branch.

AREAS OF SUPPORT

Education

AIM - for young people with ASC to get the support they need in education

PROGRESS - specialist support is available in schools, college and higher education

RATING - Green

The Specialist Inclusion Service's ASD Team provide support to 289 children and young people in mainstream schools. There are also 97 children and young people in special schools and 4 children taught at home, making a total of 390.

Children who are academically able and/or well behaved are more likely to get missed. Some children can hold it together at school and then struggle when they get home which can lead to staff believing it could be a parenting issue as they don't exhibit any unusual behaviours at school. Some children with undiagnosed ASC may have severe behavioural problems and get excluded from school.

Calderdale College have seen an increase in the number of students with ASC and there are approximately 90 students now. They have a team of support staff who support them with their courses and with wider issues, such as getting a bus pass or emotional needs. They have recently set up a Quiet Room for students with ASC and others who need some time out to relax at lunchtimes.

We have held annual Autism Information Days at Calderdale College which helps to raise awareness amongst students, staff and the public.

Universities offer student support or mentors to students with ASC and other conditions. Awareness of ASC on learning and student life has increased over recent years and support has increased. The support mainly focuses on academic studies and some students can struggle with the social side of university life. Students with ASC are more likely to drop out of university. Some universities now offer summer schemes for students with ASC to attend before they start their courses, these cover getting to know the campus and local area, eg banks, supermarkets, local transport.

Transition

AIM - for young people to have a smooth transition to adult services

PROGRESS - young people and their parents often find this a difficult time as it involves big changes

RATING - Amber

There is a transitions social worker and a co-ordinator as part of the CLDT who support young people accessing adult services when they are coming up to 18. The ASD Team who support children and young people in mainstream school sit on the Autism Strategy Group, as do Calderdale College who have students from 16.

The transition from full-time education can be difficult for some people with ASC. Once the routine and structure of school, college or university life ends, they can struggle with the uncertainty of looking for work, and their lack of social life can become more apparent, as it is harder to maintain when they're not seeing their peers regularly. Extra-curricular activities eg. sport, music, dance, scouts, air cadets, can be very helpful as they can continue after school or college has ended and can provide a routine and social life. They could also lead to some voluntary or paid work through becoming a leader or teacher. Leaving home and living independently can be difficult for young people with ASC as they can be particularly vulnerable and safe accommodation is essential.

Autism and learning disability

AIM - to provide a specialist service for adults with Autism and a learning disability

PROGRESS - this is an ongoing service and continues to be provided

RATING - Green

People with ASC and a learning disability are able to access a wide variety of services through the Community Learning Disability Team. There is a range of day services, respite and supported living homes available. People can also access personal budgets. It is estimated that one third of adults with a learning disability also have autism although older adults may not have been diagnosed with autism, just a learning disability. As there are around 750 people known to the CLDT, that would mean that approximately 250 have Autism.

Autism and mental health

AIM - to provide a specialist service for adults with ASC and mental health needs

PROGRESS - this is an ongoing service and continues to be provided

RATING - Green

Around 50 people with ASC and mental health needs are supported by the Community Mental Health Team. The CMHT's main work is with people with severe and enduring mental health needs. People who access CMHT can also access services at Hope Street Resource Centre such as occupational therapy, the Refresh Cafe and the Recovery College [link]

Peer Support

AIM - for people with ASC to meet and share experiences and coping strategies.

PROGRESS - We have had peer support groups for 4 years which have expanded into 3 groups with occasional talks and workshops.

RATING - Green

Calderdale Aspergers Group is a monthly peer support group for adults diagnosed or seeking diagnosis. It started in November 2011 and over 100 people have attended since then. There are now 3 groups; 2 in Halifax and an evening group in Hebden Bridge. There is also a peer support group for partners of adults with Aspergers that meets monthly. The main Friday group is co-facilitated by a member with Aspergers.

Occasional guest speakers have included a nutritional therapist, a life coach and the author of a book about living with undiagnosed autism. Occasional outings have included canal boat trips, pub lunches, bowling, walking and museums. Occasional workshops have included social skills, emotional awareness, anxiety management and anger management.

There is also a social, mutual support and action group Upper Valley Autistic Adults.

Benefits

AIM - for people with ASC to get support to access the right benefits

PROGRESS - generic support is available from the Citizens Advice Bureau and Healthy Minds have a welfare rights service for people with mental health needs

RATING - Amber

Accessing the benefits system can be stressful for people with ASC, as it can be for other people. They can find dealing with bureaucracy even more difficult than others. There is support available from the Citizens Advice Bureau and Healthy Minds.

The NAS have a free welfare rights service which offers advice and information on benefits entitlement, completing claim forms and how to appeal. Advice is given via email or telephone appointment. Tel. 0808 800 4104 or email

welfare.rights@nas.org.uk or website www.autism.org.uk/benefits

Employment

AIM - for people with ASC to get support to find and maintain employment

PROGRESS - The DWP funded a specialist employment support service for 12 months and we are now funding another 12 months with money from the Department of Health.

RATING - Green

Only 15% of people with autism are in full time employment, despite the fact that 79% of people with autism on out of work benefits want to work.

It can be more difficult for people with ASC to get a job as they may not do well at interviews if they lack social skills. If someone declares their ASC as a disability on the application form, reasonable adjustments should be made at interview. If it is a practical job, this could take the form of a work trial so the person can show they can complete the tasks required even if they are not very good at talking about themselves in interview.

Some people with ASC may struggle with the social aspects of work such as getting along with their colleagues, and may prefer to work alone. If their workmates don't have much awareness of their condition, they could misinterpret their behaviour. Misunderstandings can arise with communication which can lead to disciplinary action or even dismissal. Specialist support is useful to prevent this. Specialist Autism Services and the Disability Employment Advisers at Job Centre Plus are experienced in providing this support. Specialist Autism Services and the DEAs are very knowledgeable about ASC and other related conditions and are members of the Autism Strategy Group.

The DWP funded specialist employment workshops for people with ASC across West Yorkshire from November 2013 to November 2014. This was very successful. 13 people were supported in Calderdale; 2 gained full-time paid employment, 1 gained full-time temporary paid employment, 6 gained voluntary work and 8 had

work experience or work trials. We are now able to fund this project for another year thanks to funding from the Department of Health.

The NAS website has information for employers on interviewing and supporting people with ASC in the workplace:

<http://www.autism.org.uk/working-with/support-for-employers/employers/factsheets.aspx>

Housing

AIM - for people with ASC to be able to access suitable housing if needed

PROGRESS - a range of supported accommodation is available to people with ASC and additional needs (a learning disability or mental health need). People without additional needs can find it harder to find suitable housing.

RATING - Amber

Appropriate housing can be difficult to find to meet the needs of people with Autism, especially if noise is an issue. Noise from neighbours or traffic can be very difficult. Noise that most people would find irritating can be unbearable. Privacy can also be an issue, and sharing living space can be a problem. People with ASC can be particularly vulnerable and accommodation in safe areas is important.

There are local housing agencies that provide good support to their tenants, eg. Pennine, Smart Move and Horton Housing.

The Welsh Assembly Government produced a very useful guide for housing providers, which includes the impact of ASC on housing and how it can be misunderstood as antisocial behaviour:

http://www.asdinfoales.co.uk/resource/e_110324asdhousingen.pdf

Criminal Justice

AIM - for staff working in the Criminal Justice Sector to be able to recognise ASC, which may be undiagnosed, and make reasonable adjustments

PROGRESS - Police in West Yorkshire and the Calderdale Youth Offending Team have done some autism awareness training. We have had difficulty engaging with the Probation Service.

RATING - Amber

As ASC can be a hidden disability it is important for people working in the criminal justice sector to have an awareness of ASC. It is particularly important in this sector as if behaviour is misinterpreted it can have serious consequences.

The National Autistic Society produced a useful guide for criminal justice professionals <http://www.autism.org.uk/working-with/criminal-justice/a-guide.aspx> and have other resources on their website.

SUPPORT FOR DIFFERENT GROUPS OF PEOPLE

Families

AIM - for families and carers of people with ASC to get support if needed

PROGRESS - support is available from a range of voluntary and statutory services

RATING - Green

Families of people with Autism may need support at times, depending on the needs of their family member. There are a number of local sources of support.

There is a local branch of the National Autistic Society in Calderdale that is run by volunteers. They hold monthly coffee mornings, training and do fund-raising.

Contact: 07798 617448 or calderdale@nas.org.uk

Calderdale Parents and Carers is a voluntary organisation that supports parents and carers of children and young people aged 0-25 with disabilities or additional needs, including ASC. Contact: 01422 343090 or info@cpandc.org.uk

Calderdale Carers is a voluntary organisation that supports all carers of children and adults. They provide information and advice, carers support groups, training and activities. Contact: 01422 369101 or enquiries@calderdale-carers.co.uk

Making Space is a mental health charity which provides support to carers of people with mental health needs, including ASC. Contact:

Marilynn.Ingram@makingspace.co.uk or Theresa.Rawson@makingspace.co.uk

Families who are providing caring can have a Carers Assessment through Calderdale Council which can lead to a Carers Personal Budget for funding to meet their well-being needs as a carer. Contact: Gateway to Care on 01422 393000 or Gatewaytocare@Calderdale.gov.uk

The National Autistic Society website has a section for family members including parents, grandparents, siblings and partners:

<http://www.autism.org.uk/living-with-autism/parents-relatives-and-carers.aspx>

Different Together is a new website for partners of adults with ASC: www.different-together.co.uk

Women

AIM - to recognise ASC in women with their different presentations and needs

PROGRESS - about one third of people attending the Aspergers Groups are female, but the diagnosis rate is lower and awareness needs raising

RATING - Amber

ASC can be harder to spot in women as the diagnostic assessments are based on original research which was done on males. ASC is believed to be more common in males at a rate of 1:4. The rate of girls:boys with ASC in Calderdale is approximately

1:5 although the rate of women:men in the Aspergers Groups is roughly 1:2. This may be because women are more likely to attend a support group.

Four women from the Aspergers Group attended the NAS Women and Girls Conference in Leeds in 2013 and two women attended the Women and Autism conference in Sheffield in 2014. The learning from the events was shared with the rest of the group.

It is believed that girls are better at copying others and fitting in socially so they are less likely to be identified at school. Transition to high school can be a difficult time and adolescents with ASC may present with school phobia, eating disorders or anxiety. If their ASC isn't recognised, they can sometimes be misdiagnosed with mental health conditions such as personality disorders.

Useful resources for women with ASC include Rudy Simone's website: www.help4aspergers.com which includes a list of female traits. Rudy Simone wrote the book "Aspergirls" (2010).

Black and Minority Ethnic Communities

AIM - for people from BME communities to recognise ASC and access support
PROGRESS - we have recently set up a Sukoon wellbeing group for people with ASC and mental health needs and their carers
RATING - Amber

16% of children and young people with ASC are from BME communities, compared to 12% of all children. A lower proportion of BME adults access services, although exact figures are not currently available. There appears to be a lack of awareness of ASC and a reluctance to access services amongst BME communities. Although this may change as the children and young people with ASC become adults.

A Sukoon wellbeing group has recently been set up for people with ASC and mental health needs and their carers. The group meets monthly at Queens Road Neighbourhood Centre. Sessions include head, neck and shoulder massages, and talks on dealing with anxiety and dementia.

Healthy Minds are running a Roshani project working with the local Asian community to raise awareness and tackle stigma around mental health.

<http://www.healthymindscalderdale.co.uk>

Making Space mental health carers support service have a bilingual carers support worker who can provide emotional support to carers of people with mental health needs including ASC.

Lesbian, Gay, Bisexual and Transgender

AIM - for LGBT people with ASC to receive support and understanding

PROGRESS - the Aspergers Groups are open to all including LGBT people, generic LGBT support groups are available

RATING - Amber

It is believed that there is a higher percentage of people with ASC who are LGBT and asexual. This could support Simon Baron-Cohen's theory of Autism being the extreme male brain for some groups eg. female-to-male transgender. Gender Dysphoria, where significant distress is experienced due to a mismatch between your biological sex and your gender identity, is said to be more common in people with ASC and research is being done to find out why this could be. People with ASC may be asexual due to sensory issues of finding it difficult to be physically close to other people.

Older people

AIM - to raise awareness of the needs of older people with ASC

PROGRESS - need to promote Autism Awareness training to older people's services

RATING - Red

Older people (65+) are the least likely to have a diagnosis of ASC. If someone has lived the majority of their lives alone, having to go into a care home or have care workers coming into their home in old age can be distressing. If their ASC isn't recognised their behaviour may be seen as difficult.

The Welsh Assembly Government produced a guide for people working with older adults which is useful:

http://www.asdinfo.wales.co.uk/resource/en_110127asdolderadultsen.pdf

The National Autistic Society have an Autism and Ageing Advice Service which provides advice on benefits, community care issues and housing for people with Autism aged 40 plus and their relatives, carers and representatives. Contact: advice40plus@nas.org.uk or 0808 800 4104 (Monday - Friday, 10am - 4pm)

SUMMARY + CONCLUSION