



Fulfilling and rewarding lives in the Bradford district

Joint commissioning strategy
for adults with autism (including Asperger syndrome)

City of Bradford MDC

www.bradford.gov.uk

NHS

Bradford and Airedale

Foreword

Too many people with autism miss out on the opportunities and quality of life that other people take for granted. The key statement of the *National Autism Strategy* is about “making faster progress in the future to improve the lives of people with autism and their families.” This is something which is at the heart of adult health and social care across the district.

Our vision is for people with autism to experience improvements in the services they receive to enable them to live fulfilling and rewarding lives and have choice and control over the services and support they receive.

Fulfilling and rewarding lives in the Bradford district is the joint strategy of Bradford Council and NHS Bradford and Airedale and will help to achieve the vision by setting out the changes which need to happen to enable people with autism to have access to health and social care services.

However, for this vision to be truly achieved, supporting people with autism and their families must be recognised as everybody's business and not solely the responsibility of those working in health and social care. The publication of a local autism strategy is an important step to deliver that vision.

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Section 1 – Executive summary

Autism is a condition that affects an estimated 1% of the population, causing sometimes severe difficulties and anxiety when trying to making sense of what other people say and do. The difficulties can be described as a 'triad of impairment': social interaction, social communication and social imagination. This can in turn cause stress and difficulties in coping for parents and other carers. Approximately half of people with autism have intellectual abilities at or above average, sometimes with unusually high specific abilities. For the other half, autism is additional to a learning disability.

Historically, autism has not been well understood and services have often failed to meet needs. People with autism have suffered consequences such as social exclusion, lack of educational and employment opportunities, and poor mental health. People with autism, their families and other carers tell us that there is poor awareness and many gaps in support, leading to social isolation, low incomes and poor well-being. What people say would improve matters includes support to understand the social world and be involved; a greater say in health and social care services; and practical support.

The *Autism Act 2009* was the start of an attempt to improve public policy and practice, and achieve better outcomes for people with autism. This strategy argues that the current direction of all health and social care policy creates opportunities for people with autism and carers, who have never fitted into traditional patterns of provision. Personalisation means better access to information, advice and assessment; individual control over funding; and commissioners working to shape diverse local markets. There is policy emphasis on integration of health and social care, wider partnership working to promote employment and social inclusion, developing a skilled and aware workforce – all of which are vital for people with autism.

The emphasis of this strategy is therefore to enable people with autism to have access to health and social care services, removing the obstacles that have prevented this in the past. The strategy presents five commissioning priorities:

- 1 Increasing awareness and understanding of autism among frontline professionals.
- 2 Developing a clear, consistent pathway for diagnosis in every area; to offer information, advice and assessment, including carers' assessment.
- 3 Improving access to services and support to live independently within the community.
- 4 Helping adults with autism into work.
- 5 Enabling local partners to plan and develop appropriate services for adults with autism.

The strategy will have its own action plan, which will be monitored and tracked to ensure we make progress against these priorities and achieve improved life chances, well-being and support for people with autism and their carers.



Section 2 – Introduction

Purpose

This strategy sets out the vision and commissioning priorities in addressing the needs of adults with an autistic spectrum condition, their carers and families. The overall aim of the strategy is to improve the lives of people by transforming the way local services support adults with autism. All adults with autism should be able to live fulfilling and rewarding lives in a society that accepts and understands them.

This is the first commissioning strategy for people with an autistic spectrum condition in the Bradford district. It takes into account the individual and complex nature of autism and sets out commissioning priorities across health and social care.

Scope and definitions

For the purposes of this strategy, what is meant by people on the autistic spectrum is described in section three. It is an important part of this strategy to raise awareness of a condition that is not well understood, therefore there is a specific section which discusses autism and the “autistic spectrum”. To avoid any repetition of statement the strategy will use the term “ASC” to refer to these individuals with an Autistic Spectrum Condition unless citing quotations where the term “ASD” (Autistic Spectrum Disorder) is sometimes used.

This strategy is written to identify and meet the needs of adults aged 18 - 65. However, we recognise that drawing lines based on age does not reflect people's real lives, and that transitions from childhood and children's services are a very important part of improving people's lives with autism. People aged over 65 with needs arising predominantly from ASC are within the scope of this strategy.

It is estimated that approximately 50% of people with autism have a learning disability. Therefore the scope of this strategy overlaps with the work of the district's “Changing Lives” programme for people with learning disabilities. In general, people with both ASC and learning disability fall within the remit of learning disability services, but this strategy does include reference to needs related to ASC.

It is known that there are links between autism and prevalence of other conditions, including some specific learning difficulties and epilepsy¹. This strategy takes account of these factors in looking at the needs of people with ASC.

Our commissioning approach

This is a joint commissioning strategy between the local NHS and Bradford Council, addressing needs for health, social care and support. Arising directly from ASC, people with autism experience difficulties with social life, and we believe they wish health, social care and a wide range of agencies to work closely together to understand and respond to these difficulties.

We see the commissioning role as 'place-shaping', working creatively with citizens, community groups and service providers to improve the experience of living with autism in the Bradford district – *the creative use of powers and influence to promote the general well-being of a community and its citizens*². We will ensure that people have real, increasing choice and control over how to use individual accounts for social care and individual health budgets; including people who self-fund for social care. This includes good information and support, assuring quality of services and the safeguarding of vulnerable people.

¹ <http://www.autism.org.uk/about-autism/related-conditions.aspx>

² *Lyons Inquiry Into Local Government: Place-shaping, a shared ambition for the future of local government.* Sir Michael Lyons, 2007.

We will ensure that services are effective and efficient, making the best use of the totality of our resource and providing value for money. Commissioning decisions will be based on evidence about the needs of the local population, as described in the *Joint strategic needs assessment*. We will commission for good health and well-being, investing in prevention and enhancing independence and reduce health inequalities.

Carers of people with autism

Carers of people with autism have some experiences in common with carers of other vulnerable people, for example worry about the condition, there might be lack of sleep and impact on the ability to go out to work or for relaxation. However, caring for a person with autism has particular challenges. For example, the difficulties that people have in forming social relationships have a severe impact on the ability for a young person to achieve independence, relate to people other than family members, or be left alone. Bradford district's updated carers' strategy *Caring matters, think carer*, will be published in 2011, and includes important developments for all carers. This strategy for people with ASC and carers will address the particular specific needs often linked to ASC.

Making sure we take action

We will write an action plan to show how we will implement the strategy. This will build on the commissioning priorities in this strategy and identify who will be responsible for delivering the strategy. We will develop ways of measuring and showing that this strategy is making a difference, and review progress against the action plan.



Section 3 – About autism and Asperger syndrome

What is autism?

“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 social life 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'.”

National Autistic Society - www.autism.org.uk

Autism is a lifelong developmental disability and is often referred to as an Autism Spectrum Disorder (ASD) or Autism Spectrum Condition (ASC). The word spectrum is used because, while all people who are on the spectrum will share three main areas of difficulty (the triad of impairment), their condition will affect them in very different ways. Some people on the spectrum are able to live relatively independently whilst others will require a lifetime of specialist support.

Triad of impairment

The three main areas of difficulty which all people with autism share are:

Difficulty with social interaction

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.

- It may be difficult for them to fit in socially as they may, for example, appear insensitive or start an 'inappropriate' subject of conversation.
- Difficulty understanding unwritten social rules which most people will pick up without realising, for example they may stand too close to another person.
- Difficulty expressing feelings, emotions, or needs, which can mean their behaviour, is seen as strange or inappropriate. They may for example prefer to be alone or deal with anxiety by engaging in repetitive behaviour.

Difficulty with social communication

People with autism may have difficulty with both verbal and non-verbal language. Many may have a very literal understanding of language and can think people always mean what they say.

They can find it difficult to use and understand:

- verbal and non-verbal communication - although many people with autism have good language skills, some may not speak or may have limited speech. While they may usually understand what people say to them, some may prefer to use alternative means of communication themselves, such as sign language or visual communication symbols.
- literal understanding of language, and difficulty using or understanding abstract language, jokes or sarcasm.
- non-verbal communication such as facial expressions or tone of voice.

Difficulty with social imagination

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, for example difficulties in accepting a change in routine or unexpected occurrences. This is important and something people need to be aware of as it can cause acute anxiety and 'meltdown' from someone with autism which others find difficult to understand.

People may often display:

- ritualistic behaviour
- a love of routine and rules
- intense interest in a particular subject
- sensory sensitivity (for example, to noise, light and texture)

What is Asperger syndrome?

Asperger syndrome (Aspergers) is a form of autism and is often described as a 'hidden disability'. While there are similarities with autism, people with Aspergers have fewer problems speaking and are often of average or above average intelligence. They do not usually have the accompanying learning disabilities associated with autism, but they may have specific learning difficulties. These may include dyslexia, dyspraxia or other conditions such as attention deficit hyperactivity disorder (ADHD) and epilepsy.

How many people have autism?

The numbers of people with autism in the general population are not well understood, but it is estimated that ASC affects one per cent of the adult population in England³. The National Autism Strategy states that the government is funding further research into this. The Projecting Adult Needs and Information System (PANIS) uses this estimate to locally project that numbers in the 18-64 age group within the Bradford district are 3,164 people in 2010, rising to 3,492 in 2020 and to 3,799 in 2030. The rate among males (1.8%) is higher than the rate for women (0.2%), which fits the profile found in childhood population studies.

The National Autistic Society states that *"estimates of the proportion of people with autistic spectrum disorders (ASD) who have a learning disability, (IQ less than 70) vary considerably, and it is not possible to give an accurate figure. Some very able people with ASD may never come to the attention of services as having special needs, because they have learned strategies to overcome any difficulties with communication and social interaction and found fulfilling employment that suits their particular talents. Other people with ASD may be able intellectually, but have need of support from services, because the degree of impairment they have of social interaction hampers their chances of employment and achieving independence."*

During 2009/10, the local NHS purchased fourteen assessments from Sheffield Care Trust for the diagnosis of autism/Aspergers in adults. People with ASC have, however, reported difficulty in accessing the diagnostic pathway.

Children with autism in the Bradford district

The Bradford district disabled children and young people needs analysis 2010 has identified that there are 3,773 children and young people (aged 0-19) in the category of "known ASC and challenging behaviour". This represents 2.9% of the 131,000 children and young people in that age group, and 42% of children with disabilities. However, many of these children will show challenging behaviour for reasons not

³ <http://www.autism.org.uk/about-autism/some-facts-and-statistics.aspx>

related to autism, and it is important not to stereotype children with autism in terms of challenging behaviour.

The analysis indicates that approximately 300 schoolchildren have a statement of special educational needs related to ASC⁴. This indicates a minimum average of perhaps 25 young people each year approaching transition to adulthood with a significant level of need related to autism.

Autism and learning disability

The estimated prevalence of autism among adults with learning disabilities in England 2010 identified four key factors that could indicate an increased prevalence of residents with learning disabilities and autism:

- **The age profile of the adult population** – due to a reduced life expectancy of people with learning disabilities, learning disabilities are significantly more prevalent in young adult age groups.
- **The ethnic composition of the adult population** – severe learning disabilities are more common among Pakistani and Bangladeshi children. As a result, areas with higher proportions of young Pakistani and Bangladeshi adults would be expected to have an increased number of adults with learning disabilities and autism.
- **The socio-economic profile of the adult population** – learning disabilities are more common in poorer households and less severe learning disabilities are also more common in poorer communities.
- **Patterns of 'migration'** of people with learning disabilities and people with learning disabilities and autism.

Demographic data for Bradford district supports prevalence of at least three of the four factors identified in the study which may suggest that Bradford district has a higher number of adults with learning disabilities and therefore more people with a learning disability and autism.

⁴ http://bradford.limehouse.co.uk/portal/children_and_young_people/bradford_district_childrens_needs_analysis_november_2010?tab=files. Figures from executive summary, p5; and demographics chapter, tables 15 and 16.



Section 4 – What do people with an ASC (and their parents and carers) tell us?

Nationally, there have been very few major surveys or consultations completed which have asked people with an ASC and their families what they need in the form of specialist services and support.

The Department of Health recently held a national consultation on the *Fulfilling and rewarding lives* guidance. However, the biggest piece of national research into the support needs of people with autism was conducted by the National Autistic Society in 2008.

I Exist

In February 2008 the National Autistic Society (NAS) launched the *I Exist* campaign which included a survey of over 1,400 adults with autism and parents/carers, as well as in-depth interviews with adults with autism and surveys of primary care trusts and local authorities. Of those surveyed the NAS found that:

- 63% of adults with autism do not receive enough support to meet their needs;
- 67% have experienced anxiety because of a lack of support;
- over 60% of people who feel that they do not have enough support to meet their needs believe that with more support their general health would improve;
- 33% of adults with autism have experienced severe mental health problems because of lack of support;
- 60% of parents say that a lack of support has led to higher support needs in the long run;
- only 15% of adults with autism have a full time, paid job;
- 66% are not working at all (including in voluntary employment);
- over 60% rely on their family for financial support;
- 82% of parents and carers say that their son or daughter needs some level of daily support to live independently;
- the top three supports that parents and carers believe their son or daughter would benefit from are social skills training (60%), social groups (56%) and befriending (49%);
- 75% do not have any friends or find it hard or very hard to make friends;
- 72% would like to spend more time in the company of other people.

Parents and carers felt that the main barriers to accessing support for the person they care for are:

- funding
- lack of understanding about autism
- lack of understanding of their needs
- lack of clarity concerning who should provide the support

Adults with autism told the NAS that the support they would need to live independently would be (in order of priority):

- help to deal with letters
- help to manage money and pay bills
- help to do housework and laundry
- help to shop
- help to prepare meals
- help with personal care

In addition to this adults with autism told the NAS that they would like to receive support with:

- social skills training
- social groups
- employment support
- befriending
- counselling
- daily living support

Bradford district disabled children and young people needs analysis 2010

As part of the *Bradford district disabled children and young people needs analysis*, parents were asked to rate their child's abilities across a range of behaviour and abilities. The abilities where parents identified that their child needed most help are:

- social abilities, which includes: relating to others, understanding others, overcoming sadness and anxiety, and expressing needs/being understood;
- personal care abilities which includes: personal safety, washing/bathing/showering, toileting, eating or drinking, night supervision, and managing sleep routines;
- mental health abilities including: managing anger, aggression, destructive behaviour, self injury, and phobias or aversions;
- physical abilities including: balancing, reaching for things/combing hair, picking things up/holding a pencil, and outdoor/public mobility.

Common messages from adults with autism

I don't need support all of the time, but when I do need it, I need to know that someone is able to respond quickly and understands my needs.

Diagnosis should also include support to understand that what the diagnosis is and what it means.

If someone is going to work with me they need to be able to take the time to understand my needs and the small changes they could make which could support me better.

Common messages from carers and families of adults with autism

Professionals working with, and assessing the needs of, adults with autism should listen to, and involve, parents and carers as we have a valuable contribution to make in identifying need and appropriate support.

Getting transitional planning right is key in supporting the move into adulthood. It should not focus solely on further education.

Supported housing that is appropriate for adults with autism is very limited and more needs to be developed.

Bradford LINK autism and Aspergers event

Locally Bradford LINK hosted a consultation event in March 2010 which aimed to identify the main issues that people with autism faced.

The main concerns raised are:

- 1 **Diagnosis** – people experience many difficulties in getting a diagnosis. Some people report that doctors still don't recognise the condition in adults. There is a lack of understanding and awareness of the condition particularly within ethnic minority communities. People highlighted that there should be more training for professionals who work with anyone with autism or Aspergers, particularly GPs who are usually the first point of contact for people seeking a diagnosis.
- 2 **Supporting people for life** – autism is a condition people have for life, so they need support for life. People with Aspergers 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.
- 3 **Assessment for disability benefits or access to social care services** – many of those consulted felt that the process of being assessed for benefits and services is very complicated and does not take into account the person's condition. A major difficulty with the process is that people carrying out assessments don't have enough training or experience with autism. Training and awareness is needed so that ASC is better understood and individuals with ASC are better supported.





Section 5 – The bigger picture - national policy context

This section provides a brief overview of some of the national policies which will influence and support this strategy. Although there was a change of government in 2010 there is much continuity in policy, with a strong emphasis on:

- personalisation and choice
- understanding real outcomes for people
- the importance of prevention and early intervention
- services which are high quality and promote safety and dignity
- shaping the care market to meet diverse needs
- the skills of the workforce.

There are key themes which link strongly to the messages we hear from people with autism and carers. People need good information; staff who are trained and aware to understand their needs; services which respond to individual need; and a joined-up approach between health, social care and other support.

The 2006 White Paper, *Our health, our care, our say: a new direction for community services* set a direction of travel for commissioning services that are more responsive to individuals, with a focus on achieving better outcomes for people and carers. It confirmed that the government wants to build on the success of the *In Control* pilot projects which offer individual care budgets rather than traditional packages of care. It envisages an expanded role for social enterprise and the voluntary sector, the need to keep the whole population healthy and offer early support to prevent conditions deteriorating, and the importance of integrated services to support people with long-term conditions

Putting people first (2007) developed the policy of personalisation, with continuing emphasis on how important information is to promote access to services and choice. Challenging targets followed for local authorities to ensure people are offered direct payments and other forms of individual account.

The *Disability Discrimination Act* is especially relevant given the difficulties people with autism report in accessing mainstream services in health and social care. It gives added weight to the legal duties on the NHS bodies and local authorities, for example to ensure access to diagnosis, assessment, information and advice.

The new government has set its direction of travel during 2010, with the White Paper *Equity and excellence: liberating the NHS* (July 2010); and *A vision for social care: capable communities and active citizens* (November 2010). There is an even stronger emphasis on personalisation and localism, and strengthening the role of GPs as commissioners. The proposed seven principles for social care include prevention, people, and pluralism; for people with autism and carers this means, for example, providing early support to prevent complex needs developing; training staff to understand the condition and its effects; and ensuring that diverse, specialist services are available to meet individual needs. It will be important for GPs to understand the needs of local people with autism, in the dual role as clinicians and commissioners.

Turning to specific policy relevant to ASC, the *Autism Act* (2009) identifies the collective commitment to improve the lives of people with autism and their families. It makes provision for publication of a national autism strategy and the development of guidance in particular about:

- the provision of relevant services for the purpose of diagnosing autistic spectrum conditions in adults;
- the assessment of the needs of adults with such conditions for relevant services;
- planning in relation to the provision of relevant services to persons with autistic spectrum conditions as they move from being children to adults;
- other planning in relation to the provision of relevant services to adults with autistic spectrum conditions;
- the training of staff who provide relevant services to adults with such conditions;
- local arrangements for leadership in relation to the provision of relevant services to adults with such conditions.

Fulfilling and rewarding lives: the strategy for adults with autism in England was published in March 2010 with the key aim of improving the lives of people with autism and their families. Following on from this the first year delivery plan was published in April 2010 setting out the governance structure and the key actions, timescales and responsibilities which will be taken in the first year to support the implementation of *Fulfilling and rewarding lives*. The new government has consulted and published guidance for implementing *Fulfilling and rewarding lives*, indicating that it continues to be seen as an important policy.

Key actions and areas for progress are identified as:

- increasing awareness and understanding of autism among frontline professionals;
- developing a clear, consistent pathway for diagnosis in every area;
- improving access for adults with autism to the services and support they need;
- helping adults with autism into work;
- enabling local partners to plan and develop appropriate services for adults with autism including:
 - the identification of a lead commissioner for autism, and
 - the development of a Local Autism Partnership Board.



Section 6 – What is on offer in the district

Transition from children's to adult services

Local authorities are expected to follow the statutory guidance around transition planning in relation to their social services responsibilities for children and young people set out in the *Special educational needs code of practice*. A *Young person with disabilities multi-agency protocol and pathway* has been developed to support the transition to adulthood. These duties apply to young people with autism.

Bradford Metropolitan District Council – adult and community services

The council is responsible for assessment of adults with community care needs, and for assessment of carers. This includes the information and access arrangements which form the 'gateway' to further care and support. This includes individual accounts⁵ for adult social care needs. People with autism have expressed some concerns that the current arrangements for assessment do not work well for people with autism, and that the assessment used to calculate individual accounts does not do justice to people's needs.

Following assessment, there is currently little on offer in the district for people who have autism and do not have a learning disability. However, there is scope for personalisation to enable people with autism to have more individual support which does not rely on fitting into traditional services.

Bradford District Care Trust

New Ridge Centre offers day care provision to adults with a learning disability that may incorporate autistic spectrum condition or challenging behaviour. Activities provided include the Vocational Training Unit. The training unit offers development opportunities for individual progression into supported employment where identified. Other activities are designed to promote healthy living, exercise and social communication skills within a highly structured environment.

Waddiloves Health Centre is an NHS multi-disciplinary diagnostic service for adults with learning disabilities but also includes professionals who have experience of supporting people who are on the autistic spectrum. The team involves clinical psychology, psychiatry, speech and language therapy, occupational therapy, physiotherapy, dietician. Referral must be via a GP or other health professional.

In addition to this the Bradford District Care Trust provides services to support adults with mental health needs including day service provision. Although these services do not represent specialist ASC provision, some of the adults accessing them will have an ASC.

Community, voluntary and private sector

Advocacy Support via *Bradford and Airedale Mental Health Advocacy Group and Choice Advocacy* provides user-led mental health and learning disabilities advocacy to service users across the district. This support is not autism specific.

ASPECT is a support group for families/carers across Bradford and Airedale supporting an adult with Asperger syndrome that may include mental illness.

AWARE is a support group run by parents for families with children and young adults on the autistic spectrum. The group covers Airedale, Wharfedale and Craven areas.

⁵ "Individual accounts" is the term used by the Council to describe the individual allocation of a sum of money, or budget, to meet assessed care needs.

Carlton Supported Living provides independent and shared supported living flats and houses specifically for people with an ASC.

Learning Solutions offers a range of services to develop sensory processing abilities for children and adults with an ASC.

Sibs supports those with a sibling who has special needs, a disability or a chronic illness. The group runs workshops and conferences on sibling issues and offers support to siblings, parents and professionals over the phone.

Specialist Autism Services (previously known as SACAR) is a service that specifically supports people with an ASC. SAS provides support in accessing education and training opportunities as well as delivering a wide range of creative and social skill based workshop. SAS delivers provision at their base and through outreach.

The Old Gables is a private residential unit that supports people with an ASC and associated conditions including learning difficulties, mental health needs, complex behaviours and physical difficulties.

Wrose Adventurers was formed to provide a base where young people and young adults diagnosed with autism or Asperger syndrome can meet and enjoy each other's company. The emphasis is on building social skills through the medium of play and recreation. The age range is between 11 and 25. The older members are being encouraged to take a lead in the general running of the sessions.

Personalisation

Personalisation runs across both health and social care with the aim of giving people choice and control over the services they receive. Individual accounts (IAs) for social care are now a reality and are offered following an assessment where eligible needs are identified. Individual health budgets (IHBs) are being piloted in a few areas, and are likely to become a reality in the Bradford district as they are made national policy.

Both IAs and IHBs have the potential to fund the provision of choice and support that may not be available through traditional services. Indeed, their use is not limited to health and social care services, but they can be used for any provision that will help achieve good results for the goals identified in the individual assessment. IAs can be used to employ personal assistants, rather than leaving it to a care agency to decide which staff to send to the home. Many people with an ASC find it can take longer to build up trust with a carer or support worker; familiarity and routine are important, so employing a personal assistant may be a good idea.

The Social Care Institute for Excellence (SCIE) has published a briefing paper on the potential benefits of personalisation for people with autism, and the opportunity to use social care monies that have until now been tied up in traditional 'blocks' of service. It emphasises the importance of staff training and other measures to ensure people with autism can access assessment and individual accounts in the first place⁶.

⁶ <http://www.scie.org.uk/publications/ataglance/ataglance21.pdf>



Section 7 – Opportunities and challenges

Money

Although ground-breaking in its commitment to meeting the needs of adults with autism through the provision of relevant services, the *Autism Act 2009* does not identify specific investment to support this. Local authorities and NHS partners are expected meet the needs of adults with autism through existing budgets.

The outcome of the comprehensive spending review and subsequent savings within the public sector mean that there will be reduced public sector budgets at a time when people with autism should expect to benefit from legislation and policy directives to address the historic problems of lack of access and support. Therefore, the emphasis must be on using the opportunities to make existing health and social care provision more accessible and better able to meet the needs of people with autism – especially individual accounts and personal health budgets

Commissioning and market development

The council, as the lead commissioner for autism has a key role to play in developing and shaping the market to ensure that appropriate services are available locally to meet the needs of people with autism and their families. It is essential that partnerships are developed with existing and potential providers to ensure that the right services are in place, providing good quality provision which meets identified needs and improves the outcomes for adults with autism.

Transition

Transition between children and adult services can be a very difficult time for people with autism. Whilst in education a package of support should be developed to support the young person within secondary and further education. The support available to adults with autism can be very different to that available within education and other young people's services.

Careful planning is needed to ensure that transition from young people's services through to adult services is as successful as possible. In order to achieve this, children and young people's services, education, and adult services must ensure that strong partnership working is in place to make sure that young people with autism and their families get the support they need to manage this period of change.

Ensuring adults with autism are able to access individual accounts and benefit from the personalisation of social care

Personalisation provides the opportunity to tailor support to meet the diverse range of needs which people with autism may identify. This will require a creative approach when brokering support to ensure that support is tailored to individual need. The district carers' strategy, *Caring matters – think carer*, seeks to ensure that carers can benefit from the same opportunities. In both cases, improved well-being may be achieved by services not traditionally seen as health and social care. The option of 'pooling' personal budgets into group budgets is an opportunity to support and develop services for groups of people with autism.



Section 8 – The Way Forward

Fulfilling and rewarding lives identifies five key areas for improvement which have been identified throughout this strategy and will form the basis of the key priorities on which a three year action plan will be based.

New funding for commissioning activity to support the strategy is unlikely given the current financial position within the public sector. This means that a greater focus will be placed on ensuring existing services are fit for purpose and utilising funding through personalised budgets.

The priorities:

- 1 Increasing awareness and understanding of autism among frontline professionals.
- 2 Developing a clear, consistent pathway for diagnosis in every area; to offer information, advice and assessment, including carers' assessment.
- 3 Improving access to services and support to live independently within the community.
- 4 Helping adults with autism into work.
- 5 Enabling local partners to plan and develop appropriate services for adults with autism.

Governance and Implementation

An Autism Partnership Board has been established to oversee the development of the strategy. On publication the Partnership Board will assume responsibility for the implementation of the key priorities identified within the strategy.

An action plan will be developed detailing the actions needed to deliver the key priorities, timescales for delivery, and the identification of those responsible for making it happen.



Priority 1: Increasing awareness and understanding of autism among frontline professionals

The National Audit Office report (2009) found that “eighty per cent of GPs feel they need additional guidance and training to manage patients with autism more effectively”.

Whilst most professionals will know something about autism, they may not understand how autism affects people. It is essential that all frontline professionals, including receptionists and customer service staff, have a basic awareness and understanding of autism if they are to communicate effectively with adults with an ASC.

Health and social care professionals who are in regular contact with adults with autism need specialist training to enable them to effectively support and respond to their individual, and sometimes complex, needs. Increasing awareness and understanding of autism is only the starting point and should be viewed alongside the other priorities.

Actions:

- Development of an autism awareness e-learning module.
- All frontline staff to have access to, and use, this e-learning.
- Specialist training is available for health and social care professionals who regularly come into contact with adults who have autism.
- Participation in training and awareness is actively promoted and encouraged by senior managers, commissioners and GP consortia, across all health and social care provision and more widely across all agencies and sectors.
- Specialist training is an essential part of the training given to staff carrying out community care assessments, including carers' assessments.

Priority 2: Developing a clear, consistent pathway for diagnosis in every area; to offer information, advice and assessment, including carers' assessment

"Diagnosis - in our case it took 46 years. I had tried and tried to get a diagnosis because we suspected autism – no one would listen. One psychiatrist even said to me 'How could a diagnosis help? It wouldn't alter your situation.'"

Fulfilling and rewarding lives (2010) p34

For an adult trying to get a diagnosis for autism, it may mean that their life to date has been very difficult, not fitting in, unable to understand many social situations and not quite understanding why they may feel 'different' to other people. A diagnosis of autism may be the first step to people understanding themselves and being able to get the support they may need to have access to the same opportunities as other people.

Unfortunately many adults have problems accessing the diagnosis so a clear and consistent pathway which is accessible to people who may have autism is essential. The diagnostic pathway should be seen as the beginning of the support process and not as an assessment to access support.

Note: Community care assessment and carers' assessment should be triggered by diagnosis, but diagnosis is NOT essential prior to the offer of an assessment - it is a statutory duty if a person appears to be in need of community care services, or if a carer is providing regular and substantial care

Actions:

- A lead professional to develop the diagnostic pathway is identified.
- The views and experiences of adults with autism and their carers/families are considered when developing the diagnostic pathway.
- A diagnostic pathway is developed which is clear and consistent .
- Access to the diagnostic assessment takes into account the needs and barriers which adults with autism often experience, such as location and travel arrangements.
- GPs and other health and social care professionals are aware of the diagnostic pathway and know how to make a referral.
- A diagnosis of autism will trigger the offer of a community care assessment – a referral should be made on diagnosis unless rejected by the individual.
- A diagnosis of autism will trigger the offer of a carers' assessment (where applicable).
- Information will be available (pre-assessment) to the adult and their carer (if appropriate) detailing the diagnostic pathway and what to expect.
- Information and advice will be available (post-assessment) about autism, local and national resources, available support and what will happen next.
- For people diagnosed and supported as children, we will get transition to adult services right for people with autism.
- A diagnosis of autism or Aspergers (in childhood or as an adult) should be accepted by health and social care services across the district.

Priority 3: Improving access for adults to the services and support they need to live independently within the community

“Equality of access is a fundamental principle of UK public services. But it is clear that, too often, adults with autism are not currently able to access the services or support they need.”

Fulfilling and rewarding lives (2010) p41

Many adults who have autism can, with the access to the right support, live independently. For other people; a lifetime of support may be required. Often small adjustments to the way professionals engage with adults with an ASC or to the immediate environment can determine if support is accessible to someone with autism or not.

Some people with autism may be very sensitive to light or noise; they may have difficulties with communication or in interpreting particular documents, letters or forms.

Many adults with autism tell us that social situations can be difficult for them and as a result, they feel socially isolated.

Fulfilling and rewarding lives makes clear that autism should be included within the *Equality Discrimination Act (EDA) (2010)* requiring that services make reasonable adjustments for adults with autism.

Actions:

- The views and experiences of adults with autism and their carers/families are considered when planning and developing services.
- Adults with autism will have choice and control over the support they need and are offered personalised options, and information to help them make decisions.
- Services will make reasonable adjustments as stipulated within the *Equality Discrimination Act (EDA) 2010* when engaging with, or providing services to, adults with autism.
- Increase in the take up of personalised budgets for adults with autism which will meet individual support needs.
- The use of 'group' personalised budgets will be explored to enable adults with autism to engage in 'autism friendly' group activities.
- There will be a wider choice of supported housing which meets the support needs of adults with autism.
- Buddying and mentoring schemes should be developed to support and enable adults with autism to engage in social activities.
- Advocacy support will be available for adults with autism.
- Children and Adult services will work together when planning the transition from children's to adult services for young adults with autism.
- Transitional planning will be clear and consistent and will involve the individual and their carer.

Priority 4: Helping adults with autism into work

“Only 15% of adults with autism have a full time, paid job.”

I Exist, National Autistic Society, Feb 2008

It has long been recognised that employment is one of the biggest factors in determining a person's quality of life. Employment is the best route out of poverty, and promotes social inclusion and mental and emotional wellbeing.

Research has shown that many adults with autism are either dependant on benefits or rely on family for financial support.

Employment should be an aspiration for the majority of adults with an ASC, but support is needed make this aspiration a reality.

Some people will need little more than support in accessing employment opportunities and ensuring that employers make reasonable adjustments (as defined in the EDA) while others will need intensive support to develop the skills needed for employment.

Actions:

- Adults with autism will be supported in achieving their full potential and making a positive contribution to society through access to education, training and employment.
- Local employment strategies for vulnerable people (that is, mental health, learning disabilities) will include adults with autism and will recognise the skills and talents that they can offer the workplace.
- Local employment strategies will include the support needed for some adults with autism to maintain employment and ensure employers make reasonable adjustments (EDA) for adults with autism.
- Access to and maintenance within education will be a key component in transitional planning for young adults.
- Local leads to work in partnership with Disability Employment Advisors (DEAs) to ensure that adults with autism get the support they need.

Priority 5: Enabling local partners to plan and develop appropriate services for adults with autism

“It is essential that the views of adults with autism and their carers are sought and taken into account in the development and delivery of services locally.”

Fulfilling and rewarding lives (2010) p62

The *Autism Act (2009)* put a duty on the Secretary of State for Health to introduce a strategy for improving outcomes for adults with autism. The key statement of the *Fulfilling and rewarding lives strategy* is about *“making faster progress in the future to improve the lives of people with autism and their families.”* The Act also puts a duty on the Secretary of State for Health to introduce statutory guidance for local authorities and local health bodies to accompany this strategy.

Whilst the framework for change has been provided by central government, the responsibility for delivering those changes sits locally within the Bradford district.

If the key statement is to be realised local partners across health, social care and within the community and voluntary sector will need to work together.

Actions:

- Adults with autism and their families will be involved in all aspects of the development and delivery of the local autism strategy.
- Local autism leads, planners and commissioners will foster an understanding that meeting the needs of adults with autism is everyone's business.
- An action plan is developed to deliver the priorities within this strategy.
- All partners will work together to ensure that accurate data is available confirming prevalence.
- All partners will work together to identify service priorities for adults with autism through the Joint Strategic Needs Assessment (JSNA). ([Click here to see the report](#))
- Statutory guidance to accompany *Fulfilling and rewarding lives* will be owned and implemented locally.
- The Autism Partnership Board will ensure that local health and social care services are able to meet the support needs of adults with autism and their families.
- The local Autism Partnership Board will continue to meet to ensure that the lives of adults with autism and their families are improved.



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