

Bury Adult Autism Strategy

2013 - 2016



Contents and quick read guide

We want to make this strategy easy to read. By explaining below what each of the main sections contains, you can go straight to the part you want.

Main heading	Page	What it contains
Welcome	3	Foreword
Introduction	6	Executive Summary
	7	Definition of Autism
National and Local Context	10	National and Local context
	11	Numbers of people with autism
	14	Risk Factors for People with Autism
What People Have told us	17	What people have told us
	22	Gap analysis
Our priorities	24	Increase awareness and understanding of autism among frontline professionals
	25	Developing a clear and consistent pathway for diagnosis in every area which is followed by a personalised needs assessment
	26	Improving access to the services and support which adults with autism need to live independently within their community
	29	Helping adults with autism into work
	30	Enabling local partners to plan and develop appropriate services for adults with autism to meet their identified needs and priorities
	32	Perceptions
	32	Brief Aims
Monitoring and Leadership	34	Monitoring and Leadership
	34	Resources
	35	Endnotes
	36	Bibliography
	37	Glossary
Appendices (available as separate documents)		Appendix 1A and 1B: Summary of consultation responses from carer, customer and professional surveys Appendix 2: Action Plan



Welcome to the Bury Adult Autism Strategy

Foreword

I am pleased to present Bury's Adult Autism Strategy 2013 - 2016. This strategy sets out a challenging programme of improvement over the next three years as part of our commitment to improve the lives of people with autism, their carers and their families. It details how we are taking forward and delivering on the objectives of the National Autism Strategy at a local level.

Anyone who comes into contact with other people as part of their job or has met more than 100 people in their life will have probably met someone with Autism and didn't even realise it. There are many people with autism in England - 1 out of every 100 people has autism. Although some of us will know someone who is on the autistic spectrum, the condition in many cases it remains a hidden disability. Too many people with autism are still experiencing problems in managing their everyday affairs, finding it difficult to access appropriate services and support and are missing out on the change of quality of life that others enjoy.

It is clear all areas of England face a significant challenge to change this, including Bury. We have started to make progress to improve the lives of people with autism, their carers and their families - but we know there is more we can do. We will take action to generate greater awareness and knowledge about autism and improve access to services and support for those on the autistic spectrum. We will make sure that people, families and carers affected by autism know what services and support are available to them and where to go for information and help.

We believe in working with the people that use our services to improve them and that is why this strategy has been co-produced. Although the Bury Council's Adult Care Services Department have taken a lead on developing this strategy, it is a joint strategy with Health and we have involved our partners from Education, Children's services, people with autism and their carers and professionals who work with people with autism. I would like to take this opportunity to thank them all for their help, involvement and contributions.



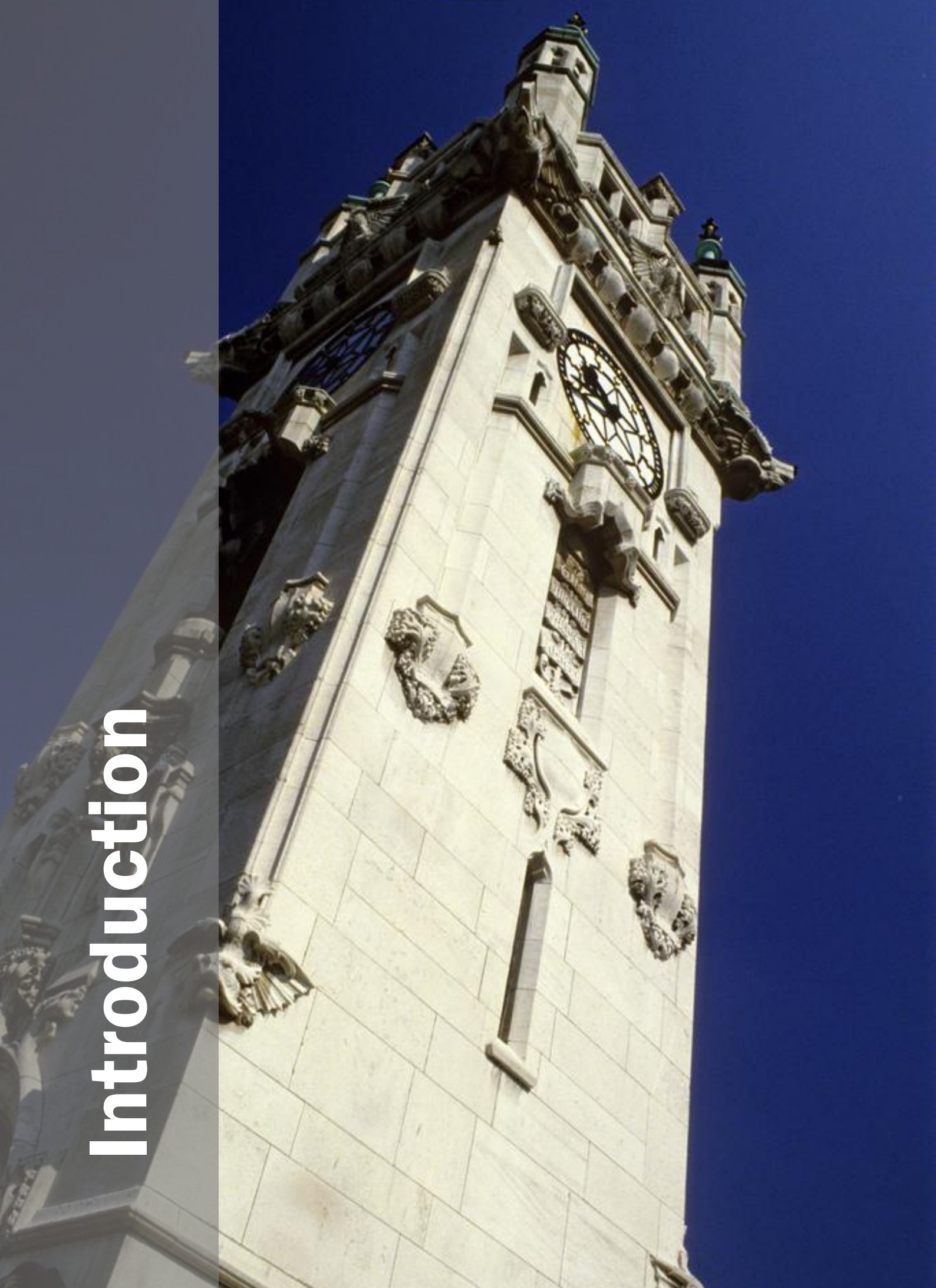
With the positive commitment of all partners in the Council, the NHS, public, private and voluntary sectors, and by working together, we are confident that we will deliver change and have a positive impact on the lives of people with autism and their families in our Borough.

Councillor Rishi Shori

Executive Member, Adult Care and Wellbeing



Introduction



Introduction

Executive Summary

The vision of the National Autism Strategy: Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England (2010) states that:

All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents”

The purpose of this strategy is to provide a basis for partnership working on the provision of services, support and signposting for adults with autism in Bury.

All key strategies being developed in Bury will need to take full account of the principles outlined in this strategy, so that adults with autism can fully access the full range of local servicesⁱ. It is not the intention of this strategy solely to create additional separate services for people with autism, but to enhance current services and supports to people, by ensuring that staff have the necessary skills to support adults with autism in Bury. The strategy aims to ensure that people on the autistic spectrum, are fully understood and their needs are taken into account throughout the assessment, care management, service delivery and review processes.

This strategy aims to raise awareness of autism, promote early identification of their needs, and seek joint responses to improve the outcomes and quality of life for adults with autism and their families in line with the objectives of the National Autism Strategy.



Introduction

This strategy has been developed by Bury Adult Care Services in conjunction with NHS Bury and the Autism Services Development Group. This Group includes members from Adult Care Services, Education, Communication Difficulties staff, Psychology, CAHMS, Additional Needs Team, Youth Services, and Children's Services, Carer representatives, health colleagues and the National Autistic Society.

Bury Adults Autism Strategy sets out the vision for adults with autism who live in Bury. This includes those with Aspergers Syndrome and those who have a dual diagnosis which includes an Autistic Spectrum Disorder. It describes what the Government policies mean for the people of Bury, analyses the needs of people with autism in Bury and uses this information to outline the strategic direction for services across Bury.

Definition of Autism

In this strategy, we will use the term 'autism' as an umbrella term for all autistic spectrum conditions, in line with the National Strategy: Fulfilling and Rewarding Lives. In the strategy, autism is defined as "*a lifelong condition that affects how a person communicates with, and relates to, other people. It also affects how a person makes sense of the world around them.*" (Department of Health 2010).

The three main areas of difficulty, which all people with autism share and are the basis for diagnosis, are referred to as the 'triad of impairments' these are:

- Social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice)
- Social interaction (e.g. problems in recognising and understanding other people's feelings and managing their own)
- Social imagination (e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine).



Autism is known as a spectrum condition, both because of the range of difficulties that affect adults with autism, and the way that these present differently in different people. It is estimated that 50% of those with autism may also have a learning disability (The National Autistic Society 2011). People with high-functioning autism and Asperger Syndrome, are affected by the triad of impairments common to all people with autism described above, but both groups are also likely to be of average or above average intelligence (IQ of more than 70). Many people with autism also have other conditions such as Attention Deficit Hyperactivity Disorder (ADHD), Deficits in Attention and Motor Perception (DAMP), epilepsy, dyslexia and dyspraxia. The broad spectrum of needs means that some people with autism are therefore able to live relatively independent lives; others need crisis intervention from time to time; and others need a lifetime of specialist support.





Part 1

BU

Part 1: National and Local Context

In 2010, The Department of Health published “Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England (2010) and Statutory Guidance (2011)”.

This national strategy and subsequent statutory guidance, sets out to improve access to services and ensure that adults with autism are able to benefit fully from mainstream public services. The strategy focuses on five core areas of activity:

1. Increasing awareness and understanding of autism among frontline professionals.
2. Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment.
3. Improving access to the services and support which adults with autism need 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 to meet identified needs and priorities.

This links with other key policy drivers such as:

- Health and Social Care Bill, July 2012
- Personalisation and self directed support
- A vision for adult social care: Capable communities and active citizens (2010)
- Think Local, Act Personal (2010)
- Decentralisation and Localism Bill (2010)

It is recognised within Bury that improvements could be made, in particular the development of a local diagnostic and care pathway. A consultation has been undertaken with customers, carers and professionals, details are given later in the strategy and in Appendix 1A and 1B. We aim to build on the good work already started in Bury such as:

- Support into employment and help to maintain and cope with work available via Bury Employment Support and Training
- The pilot brokerage service run by the National Autistic Society which ran for two years from August 2009 for people with autism who held a personal budget
- Support offered to carers at Bury Carers Centre



Number of people with an Autism in Bury

In recent years, we have seen a reported increase in the number of individuals with autism and research estimates that autism affects 1 in 100 adults (Brugha et al, 2009). These estimates indicate that prevalence is higher among men (1.8%) than among women (0.2%), and rates change slightly between different age groups (1.1% for age band 16-44, 0.9% for age band 45-74, and 0.8% for people aged 75+). These prevalence rates must be treated with caution as the research is based on a small sample. However, the study has been cited widely and in the absence of more accurate data, and with no local sources of information that record incidence and prevalence of autism, we have chosen these rates to estimate the population of people with autism in Bury.

If we are to take the average prevalence rate of 1% and apply it to the Office of National Statistics Population Estimates for adults living in Bury, it equates to a predicted population of 1,139 adults with autism in 2012.

Currently, the only local data available to us is that gathered via GP registers and data collected in Education by the Additional Needs Team, as shown below.

Number of patients in Bury GP practices diagnosed with Autism

AUTISM under 18 years old

Asperger's syndrome - 74

Autistic disorder - 143

Autism - 45

Childhood autism - 2

Childhood autism - 5

Grand Total - 269

Autism over 18 years old

Asperger's syndrome - 95

Autistic disorder - 44

Autism - 39

Infantile autism - 4

Atypical autism - 4

Autistic child - 1

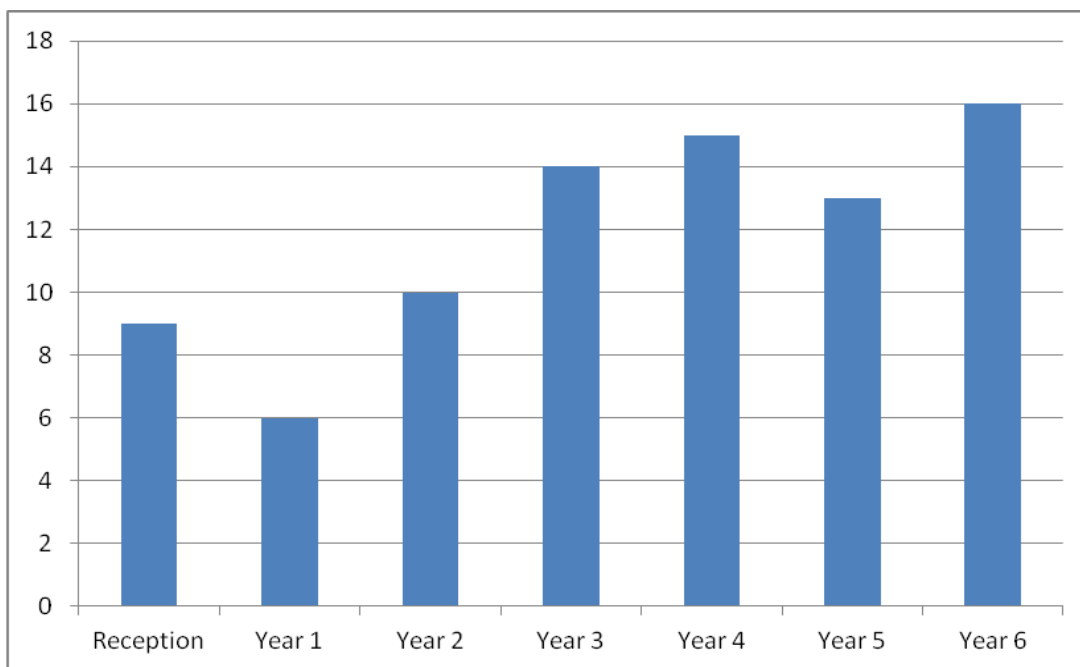
Grand Total - 187



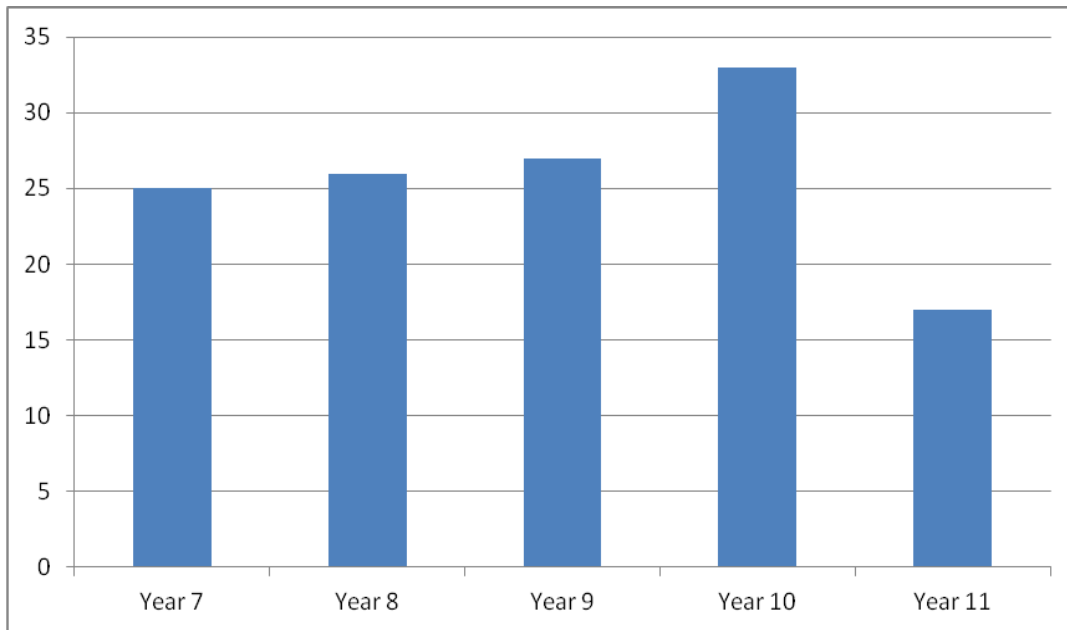
The Additional Needs Team in Learning Division (which includes the Social Communication Difficulties Team) is able to collate figures for the numbers of pupils from between 5 and 18 years for whom support is requested directly from them by schools or colleges. These pupils are either diagnosed with autism or are displaying social communication difficulties similar to autism but are, as yet, undiagnosed. These figures will not include all children and young people with social communication difficulties who are in education in Bury. In July 2012, there were 519 pupils with social communication difficulties known to the Additional Needs Teamⁱⁱ. Of these 267 were undiagnosed and 252 had a diagnosis. This is a similar picture to the GP registers figure. From the Additional Needs Team data, the breakdown of those with a formal diagnosis of autism is:

Number of people confirmed diagnosis in Bury within Nursery education: 2 people

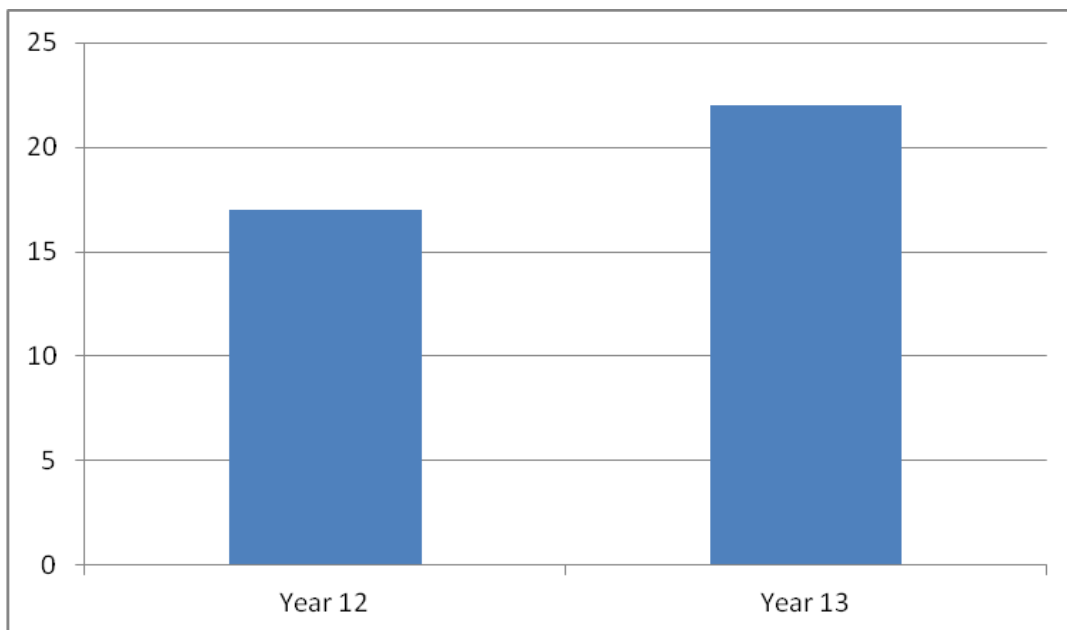
Number of people with confirmed diagnosis in Bury within Primary education: 83 people as shown in the chart below:



Number of people with confirmed diagnosis in Bury within secondary education: 128 people as shown in the chart below:



Number of people with confirmed diagnosis in Bury within further education: 39 people as shown in the chart below:



Based on the figures for those pupils in the latter years of education, there are an average of approximately 24 pupils per year with a diagnosis of autism. Therefore, using these figures to estimate the number of children with social communication difficulties entering adulthood in the next few years, the prevalence rate of 1% of adults have autism is approximately accurate for Bury.

Risk factors for people with Autism

Several pieces of research has been undertaken to examine potentials risk factors for people with autism including the impact of socio-economic factors. Key findings are that:

- Gender: There are predicted to be a higher number of males than females with autism (Brugha et al 2009)
- Age: People with autism in Bury may have different needs according to their age – in particular consideration should be given to those in transition from children’s to adult services and older people with autism as they may be more likely to be undiagnosed or misdiagnosed due to the lack of knowledge on autistic spectrum disorders until recent years (Brugha et al, 2009).
- Learning disabilities: 50% of those with autism may also have learning disabilities (The National Autistic Society 2011).
- Race and ethnicity: The figures in PANSI show that across Bury in 2012, 10,045 people belong to Mixed, Asian/Asian British, Black/Black British, Chinese or another ethnic group. Potentially therefore, there could be around 100 people in Bury from the BME community group with autism (assuming an autism prevalence rate of 1%).
- Level of deprivation: Autism is significantly associated with levels of deprivation. Using the Index of Multiple Deprivation (IMD), researchers (Brugha et al 2009) found that in areas with an IMD score indicative of higher deprivation, the rate of autism was also higher. Therefore, this suggests that the areas of Moorside East, Radcliffe East, Radcliffe West, Unsworth and Besses could potentially have the highest prevalence rates of people with autism in Bury
- Education: People with autism are less likely to have had a higher education (Brugha et al 2009).
- Housing: People with autism are more likely than people without autism to live in accommodation rented from a social landlord (Brugha et al 2009).



- Criminal Justice System: Research nationally shows that people with learning disabilities, learning difficulties and autism experience a number of problems once they enter the criminal justice system. For example, the individual has a lack of understanding of what is required from them and the professionals have a lack of understanding of the needs of the individual (Mason and Murphy 2002; BIBIC 2005).

Mental health needs of people with autism is a risk factor. There is evidence to suggest that there is a relatively high prevalence of mental health problems in children and adults with autism. The NICE guidance recommends that adults with autism have access to psychosocial interventions, psychological therapies and pharmacological interventions (<http://www.nice.org.uk/CG142>).

Challenging behaviour and autism is a risk factor. The recommendations from Winterbourne view relate to adults with autism and learning disabilities; who form 50 per cent of adults addressed via this strategy (<http://www.dh.gov.uk/health/2012/12/final-winterbourne>). Anecdotal feedback from families and carers of adults with autism but no Learning Disability who access Pennine Care psychological therapy services, is that understanding and managing challenging behaviour is one of their biggest problems, and is often the cause of placement breakdown. It can also restrict opportunities for independent living and employment. NICE guidance has a section on challenging behaviour (<http://www.nice.org.uk/CG142>).

Health inequalities are a well known risk factor for adults with learning disabilities: 50% of adults with autism have a learning disability.

Currently specific, reliable data on people with autism is not collected in Bury. This is a similar picture across the UK. Therefore it is difficult to understand the numbers of people with autism in Bury, what their needs are and how they are being met, if these services are appropriate and if there are unmet needs. Adult Care Services are in the process of implementing a new case management system which will enable better recording of data in future. It is also envisaged that autism will be included as a category within the JSNA in future. Transition also needs to be considered as where identification of children and young people with autism statistics are provided, early transition pathway planning would be a link factor between Childrens and Adult Services for future planning and targeting resources.

The current NHS and Local Authority data collection systems do not report on existing expenditure for services for people with autism. This is because the spend information is included within Mental Health and Learning Disability services. Therefore, the breakdown of data should be reviewed to ensure it is fit for purpose.



Part 2



Part 2: What People Have Told Us

Feedback from Carers at Bury Carers Centre who attend the support group for autism have confirmed their agreement with the national evidence, and some of the comments made include:

- “There needs to be an increase in the understanding and awareness of professionals”
- “Eligibility criteria for services is too fixed and without the assessors having the correct training questions are not asked in the right way”
- “Physical environments need to be assessed to ensure they are suitable for the needs of adults with autism”
- “More opportunities for supported employment to be made available”

Bury Adult Care Services undertook a 12 week consultation with stakeholders commencing on 6 March 2012. The consultation was aimed at carers, professionals and customers to collect their views and experiences of services and support for people with autism in Buryⁱⁱⁱ.

It was particularly difficult to specifically target people with autism and their carers as neither Adult Care Services due to the lack of data recorded on people with autism in Bury. Therefore we had to ensure we reached as many people in Bury as possible. Although the strategy is for Adults aged 18+, we did not restrict the consultation to adults with autism or carers of adults with autism as we felt the views of the whole population of Bury would enable the strategy to reflect what is currently available and what is required for the future. Following the consultation, there were 73 professionals, 23 customers and 41 carers who responded to the survey, together with separate results from the consultation event and the drop in sessions (Appendix 1A and 1B).

The feedback from the consultation with people with autism, carers of people with autism and professionals has been grouped into themes, as follows:

Training

Of the 73 professionals across health, social care, private and voluntary sector who responded to the professionals survey, 58.3% had undertaken some form of autism training or awareness raising activities by a variety of providers. Of these, 82.5% felt the training had been either very helpful or helpful.

The comments on the training had common themes. On the whole, people reported that the training they had undertaken had been useful and appropriate. However, the training had been delivered as a one off session and not ongoing or with refresher sessions. Some people commented the training was too basic and should involve the different aspects of autism and behaviour management strategies. It should also involve customers and carers as case studies and real life stories are more powerful than classroom based training. The training should be available to all stakeholders and not just mental health and learning disability teams.

Assessment for social care

78% of customers and 70% of carers who responded to the survey reported that getting access to social care was either difficult or very difficult. The main reason given was that people with high functioning autism do not meet the levels of Critical or Substantial within the Fair Access to Care Services (FACS) eligibility criteria and so are not eligible for services (ie, a diagnosis of autism does not automatically mean that a person would be eligible for social care services).

There is a perceived lack of understanding of autism within social care and the lack of specialist social workers was highlighted as an issue of concern. Customers and carers felt that the communication difficulties of people with autism are not fully understood by those undertaking assessments and therefore questions and discussions are being misinterpreted or misunderstood by the person. This can lead to the assessment not being an accurate reflection of the persons needs.

Other areas highlighted by carers and customers was the lack of trained support workers, befrienders or facilitators. This was particularly apparent in relation to people with autism being able to access mainstream activity, employment and health services.

Housing

The majority of customers had not tried to get support to find housing and 50% of respondents currently live with their family or others. The majority of the people with autism cared for by the respondents of the carers survey, were living with their family or other people (76%). This may be because a high percentage of the cared for people with autism who answered the survey are under the age of 18, but this is only an assumption. Therefore these figures are not accurate enough to use as a guide to reflect the needs of adults with autism living in Bury.



The customers and carers stated, on the whole, that young people with autism would like to move into supported accommodation at some point in the future. However, their perceptions of accessing housing support were negative, they worry about the time it would take to arrange the support and seek suitable housing; the long process and complicated paperwork and the lack of both appropriately trained support workers and appropriate housing options available.

Employment

Of the 17 people with autism who answered this question, only 2 had ever had support to find employment and only one reported they currently had a job. However, many respondents reported they would like to find employment but did not know where to go for support or information

The customer perception is that there is currently no support readily available in mainstream work placements and that employers are still reluctant to take on people with a diagnosis of Autism. They believe that employers have a lack of understanding of autism and therefore do not see the benefits of employing people with autism only potential problems that may arise.

49% of carer respondents stated that support to find employment had been very difficult or difficult. The main perceptions of the services were that there is a lack of appropriately trained support staff to help people with autism gain and maintain employment and the lack of understanding of employers and that placements and placement suggestions are often unsuitable.

Several carers reported that the Job Centre Environment was very challenging for a person with autism, they have little understanding of the communication or sensory difficulties of people with autism and make no reasonable adjustments. However there was praise for Bury Employment Support and Training and ASGMA in Stretford.

Having a social Life

Customer and carer respondents were passionate about the need to develop a social life away from parents. Many respondents said they felt isolated and had no friends or social lives. They stated that the activities they undertook as children were no longer available as adults so the friendships they had built up were lost. The key theme from the respondents was that there are currently little or no appropriate adult social opportunities for people with autism in Bury. People expressed that there should be a range of supported activities such as groups and leisure pursuits but also a greater number of appropriately trained support staff to allow people to access mainstream activity.



Diagnosis

The results show that people who were not diagnosed before primary school age were generally not diagnosed until secondary school or adulthood. However, this was a very small sample so may not be representative of the whole population of Bury.

The main issue for most people with autism and carers was the lack of local diagnostic services for adults living in Bury. If an adult in Bury needs to have an assessment for autism, they must be referred to the diagnostic services in Sheffield. This is very time consuming and stressful for people. People who had undergone the diagnosis assessment reported that it took a long time to get a diagnosis and assessment approved and there was little or no post-diagnostic support for adults in Bury.

The numbers of people currently approved to undergo an assessment for diagnosis of autism in adulthood is low. The reason for this is unclear. The statutory guidance for the national autism strategy states that each area must have a pathway to diagnosis in place. Bury currently has a pathway in place although referring people to Sheffield may not be the best use of resources.

General Health Services

There was a mixed response to this question from the customers. Some respondents stated that although they had access to a GP, they struggled to get them to understand what they were trying to tell them. They also had difficulties with the appointment and queuing systems as there were many delays, lots of people and it is noisy in the waiting rooms. However, other respondents stated that their GP was very supportive and understanding.

Likewise, there was a mixed response to this question from the carers, however carers reported a better experience of accessing health services than customers. Most respondents were happy with their GP but felt they had little or no understanding or awareness of how to make reasonable adjustments for a person with autism. Therefore GPs appointments, waiting rooms and waiting times could be very stressful for people.

Specialist Health Services

Specialist health services are those such as occupational therapy, physiotherapy, cognitive therapy or mental health services. Customer responses to this were very varied; 42% of the respondents said access to specialist services had been easy and also 42% had said access was very difficult.



The main points highlighted were the long waiting periods for access to the services. People stated that they sought specialist services in times of crisis and so the services should be available quickly rather than having to wait for a long period. Another key issue was the lack of understanding of autism within the specialist health services.

The carers survey showed that 60% of respondents reported the person with autism they care for had found it difficult or very difficult to access specialist health services. One of the key areas mentioned was the lack of understanding or awareness of autism within specialist services. Also the waiting times and sensory issues within a hospital setting are very challenging for a person with autism. There are no specialist services or support staff available to assist people at Fairfield Hospital. No reasonable adjustments are made.

Information

On the whole respondents reported that information given is not timely or appropriate or generally lacking. People reported that the lack of understanding of autism by health staff, social workers etc has meant that information has been hard to reach.

The National Autistic Society was quoted several times as being a good source of general information. The carers centre/Bury Carers Group and the Parents Forum are a good source of information and allows for contact with other carers. The Re:d Centre is a good source of information but is only available for children.

Support Services

From the customer survey, 57% of respondents reported that services in Bury are very poor. The main reasons for this were the lack of autism specific services across social care, voluntary organisations and in particular health services. Several respondents reported the Bury Brokerage Project was excellent but had now ended. Some respondents felt that support groups are more for families and carers and do a really good job, but what is needed is facilitators to help with social opportunities. It was also stated that community groups and places of worship need to have more involvement. One respondent stated that *people from ethnic backgrounds don't really understand what autism is, where to get help and what services are available in Bury (especially from the Pakistani community)*. Other suggestions are more support and social groups, employment opportunities, workshops on how to build self esteem, gain confidence, sociability, understand the rational of the ordinary person in the street



A key theme throughout was the lack of understanding of autism by the public and professionals.

There was a varied response to this question from the carers survey. The overall themes were that services for children provided by Hurdles and befriending services are excellent but these do not extend to adulthood. The National Autistic Society were praised for the support they offer to parents and for the information they provide. There was praise for personal budgets which allows the flexibility for appropriate social opportunities and parent participation workers employed by the Together Trust a source of information. There seems to be a lack of autism specific services or awareness of autism within mainstream services.

Gap Analysis

From consultation, the main gaps in service provision highlighted by customers, carers and professionals were:

- Lack of a clear local diagnosis and assessment pathway and post-diagnosis support
- Lack of understanding of autism among frontline staff and those who undertake assessments
- Few preventative support services such as housing related support, employment support and lack of availability or information about these services
- Lack of coordination of low level services such as social groups, peer support, befriending and lack of information about these services
- Lack of accessible and timely information on autism, support and services available
- Absence of robust data collection systems which records numbers of people with autism and the services they use/need
- Lack of understanding and knowledge of autism within BME communities
- Lack of facilitators to allow access to social opportunity



Part 3



Part 3: Our Priorities

Following the consultation, it is clear that we have some clear priorities and also some further information and consultation needs to take place around several areas of work. There are also some areas that need to be developed in the short term. These can be placed under the five headings in the National Autism Strategy as follows:

Increasing awareness and understanding of autism among frontline professionals.

Where are we now?

Bury Council, NHS Bury and Community Services Bury provide Equality and Diversity training to all staff. Local providers deliver awareness training and support sessions to staff and employers to enable the needs of adults with autism to be met.

Bury Council provide two sessions per year of autism awareness training to staff working in Learning Disability services.

The National Strategy aims to *"increase the understanding of autism by improving autism awareness training for all frontline public service staff, in line with the needs of their job, and developing specialist training for staff in health and social care"*. This is reflected in what people have told us and is a consistent theme across all the feedback.

Where we want to be?

We want to ensure that all staff have an awareness of autism and that social workers have an in-depth knowledge and understanding. Work on this has already commenced and is detailed below:

How will we achieve this?

A sub-group of the Autism Services Development Group has been set up to plan and set up the delivery of autism training in Bury. The main focus of this group is:

- Awareness training on autism for all social care staff will be mandatory and offered to all other departments within the Council. This will be delivered via an on-line training package. This awareness training will also be offered to all front line health care staff.
- Specific and in-depth training packages will be commissioned to deliver detailed training for staff who need a detailed and specialist knowledge and understanding of autism and/or work closely with adults with autism and/or their carers. This will also be offered to frontline clinicians.



- Mid-level training will also be developed for those who undertake social care assessments. We are working with the Greater Manchester Autism Consortium in the development of autism training. This will be similar to the specialist training but have less detail. It would be aimed at “front-line” staff, PAs, health staff, social workers etc. The training should be mandatory to all identified staff and then run on a regular basis for new starters/refresher courses. This would include staff from universal services.

- Our aim is to improve equality and diversity training, provide awareness training as part of the induction process for all new Health and Social care staff and determine additional training required for staff and providers of services, in line with the needs of their job.

- Training will be developed involving adults with autism, their families and carers, and autism representative groups in the design of training. There will be a mechanism in place to ensure the required outcome of training has been achieved.

- To work with partners to raise awareness and deliver training effectively to all stakeholders. This could include projects such as “train the trainer” or autism champions to enable ongoing training.

- To work with partners to raise awareness on making “reasonable adjustments”. We will seek to raise awareness of “reasonable adjustment” criteria and how best to approach it with primary care services, secondary care services and community staff.

- The “reasonable adjustment” criteria training should also be extended to include partners such as job centre staff, police and other stakeholders. The requirement and understanding of having to make “reasonable adjustments” for people with autism should be understood by all.

Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment.

Where are we now?

It is recognised that it is often difficult to get a diagnosis of autism within Bury and it can take a significant length of time and often means accessing services outside of the Bury area. The lack of diagnosis for adults with autism can be explained by their needs not being identified at an early age, particularly because the signs of a mild disorder may be difficult to pick up with any certainty.



The national strategy "Fulfilling and Rewarding Lives" says: *Receiving a clinical diagnosis of autism is for many adults, an important step towards leading a fulfilling life. It can not only help them and their families understand their behaviour and responses, but should also help with access to services and support, if they need them. Diagnosis can be a complex and lengthy process with adults often having to battle to get a diagnosis, only to have this challenged when they try and access services.*

Where do we want to be?

In order to improve diagnosis of adults with autism a clear local pathway will be developed which will increase capacity around diagnosis. Information will be provided to adults with autism and their family or carers at the point of diagnosis to help them understand their condition and access support, and we will ensure that a diagnosis is recognised as a reason for a community care assessment, or reassessment. The N.I.C.E. (National Institute for Health and Clinical Excellence) guidance published in July 2012 will be used to help develop a clear and consistent pathway.

How will we achieve this?

We have an identified lead for diagnosis within Bury who we will support to drive this work forward. Bury Primary Care Trust/Clinical Commissioning Groups is committed to identifying a new local pathway for the assessment and diagnosis of adults with autism and their carers. This will include developing the service to include post diagnostic support, sibling screening and re-assessments.

We will also consider how to ensure a community care assessment is triggered on diagnosis of autism.

Improving access to the services and support which adults with autism need to live independently within the community.

Where are we now?

The Bury Coalition for Independent Living (BCIL) has recently been formed to offer signposting and helpline services to disabled people in Bury, including adults with autism. BCIL is made up of a number of disabled organisations and their long term plan is to offer signposting, a helpline, advocacy and brokerage.



In Bury Council we currently work with a disability organisation to undertake disabled access audits for buildings and services, through self directed support more people are devising their support plan and taking up the option of arranging their own services. We recognise the importance of a robust transition process and have a dedicated transition worker.

The National Strategy states that;

“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.”

The National Strategy aims to change this and ensure that adults with autism are able to benefit fully from mainstream public services by;

- *Reiterating the Disability Discrimination Act requirement for services to make reasonable adjustments for adults with autism*
- *Enabling adults with autism to benefit from personalisation of social care, and*
- *Improving transition planning to give people with autism the right start in their adult life.*

Where do we want to be?

We want to ensure that adults with autism are aware of the advice and information available to enable them to make choices about their care and ensuring there is a support system available if they require help to make their choice, and/or arrange services to meet identified needs.

We want to continue to develop universal services and current services to ensure they are more accessible for adults with autism.

Young people with autism should have support in transition as they move into adulthood. They will be informed of their right to a community care assessment and the right of their carer to receive a carer’s assessment. Young people with autism and their parents/carers will be involved in their transition planning and support. They should be given information about self directed support and services to enable them to make informed choices about the way they are supported in adulthood.

A consultation exercise will take place with people with autism and carers of people with autism to identify future housing needs including housing options and any other issues around housing and housing support. This will enable us to come up with some recommendations for future housing needs including any gaps in appropriate support and housing choices. This will be fed into the wider strategic planning on housing for vulnerable people.



Work streams will also look at the development of opportunities for social activity for adults with autism in Bury. We will work with our partners on this to develop current services and set up new services where appropriate. These services need to be sustainable and around developing relationships and skills to promote independence. This could include working with volunteer agencies and the third sector, youth organisations, support and befriending to access mainstream activity and support to maintain friendships that have been built up in childhood.

Progress has already started on this as we have recently supported the development of a Social/Film Club for people with Asperger's Syndrome or high functioning autism who are aged 18 or over, who live in the borough of Bury. This club runs once a month on a Saturday afternoon and has a variety of activity or quiet areas. We are also in the process of developing an Art club via an established project for adults with autism in Bury.

More information is needed on how people with autism fit within the current Fair Access to Care Services (FACS) criteria and how we can signpost people to low level preventative services for those who do not meet FACS criteria but need support, information and advice. We will work with the Greater Manchester Autism Consortium on meeting the needs of those who do not fit the FACS criteria and a "basic core offer" that should be offered to all those with a diagnosis. This would include signposting and access to low level, preventative support and access to information.

Timely, accessible and appropriate information should be provided to adults with autism and their carers. Information should also be accessible. Work with partners will take place on the production of a Bury Post Diagnosis Information Pack via the Autism Services Development Group.

The views of people with autism and carers will be fed into a separate piece of work to look at the future direction of support planning and brokerage in Bury. This should help adults with autism to overcome any barriers they may face when trying to access a personal budget.

How will we achieve this?

- To work with partners to provide more opportunities for social activity
- To work with partners to provide more timely and accessible information
- To work with partners to provide better signposting to universal services



- To understand the current housing choices and housing support and look at what people require in the future. This will be fed into the wider strategic housing for vulnerable people initiative.
- To work with partners to develop current services including services for those who are not eligible for adult care services
- To work with people with autism and carers around the negative perceptions of services in Bury
- To work with partners to ensure they understand how to make reasonable adjustments for people with autism

Helping adults with autism into work.

Where are we now?

Support to help adults with autism into work is currently provided by; Bury Council via Bury Employment Support and Training (Bury EST), Disability Employment Advisors (D.E.A) within the jobcentres, and also through voluntary and private independent sector providers. There is also support via Langdon Trust and Work Choice. Bury is also one of the areas taking part in the Right to Control Pilot.

The National Strategy states that;

The ability to get, and keep, a job and then to progress in work is the best route out of poverty, and a central part of social inclusion. Adults with autism are significantly underrepresented in the labour market. The National Strategy focuses on four aspects to support adults with autism into work;

- Ensuring adults with autism benefit from wider employment initiatives
- Personalising welfare and engaging employers
- Improving existing provision of services based on individual need, rather than “one size fits all” approach
- Developing new approaches that will better support adults with autism



Where do we want to be?

We will work with partners with the aim to improve access into work by identifying the personal needs of the adult with autism and providing the appropriate level of support required. We will examine current services and supports in place and ensure that these meet the needs to support adults with autism into work.

As part of the autism training and awareness raising development, we will endeavour to include employers, Job centre and employment support agencies so they understand the needs of people with autism and how to make reasonable adjustments. Also the benefits of employing people with autism.

More and appropriate information on support services should be available for adults with autism.

How will we achieve this?

- To work with partners to raise their awareness of autism
- To work with partners to provide greater opportunities for employment
- To work with partners on providing more information on support available.

Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.

Where are we now?

We have a senior manager who has a clear commissioning responsibility to develop a plan around services for adults with autism. Adults with autism are able to access personal budgets if they meet the eligibility criteria, and benefit from personalisation of social care. We help them to do this through the provision of an independent advocacy service. Personal budgets for Carers are currently offered in Bury. Carers Personal Budgets are currently being evaluated to ensure the needs of carers are being met appropriately.

The National Strategy states that:

A fundamental goal is that public services better meet the needs of adults with autism. Central Government can set a framework but much of the responsibility for delivery of the strategy sits locally. It is here that partners can come together to develop local services, and extend existing ones, that enable adults with autism to be included in society, reflecting the needs and priorities of the local area.



Each local authority should “develop its own commissioning plan around services for adults with autism that reflects the output of the Joint Strategic Needs Assessment (JSNA) and all other relevant data around prevalence”

Effective local leadership is essential to ensuring the needs of adults with autism are met.

Where do we want to be?

We will develop a commissioning plan which will identify gaps in services and how we will ensure that adults with autism can access and benefit from personalisation of social care to have more choice and control of their lives. We will consider where a separate service offer needs to be considered as part of the commissioning intentions. We will improve our data collection to gather relevant local information and ensure autism is firmly embedded within our JSNA.

We will develop clear leadership and governance procedures which will be communicated so that our processes are transparent to all. We will improve our consultation and engagement processes to encourage all adults with autism and their carers to have a voice.

In order to effectively plan for the future we need to understand our market. Therefore we need do further work to understand what people currently access and any gaps in the market. We also need to develop effective data collection processes for the future.

Endeavour to engage with mental health services to facilitate access to interventions for co-existing mental health problems and/or challenging behaviour.

As part of the pathway, we need to consider how adults with autism can access specialist interventions, as outlined in the NICE guidance, e.g., psychosocial interventions, communication interventions, interventions to understand and manage challenging behaviour, risk assessment and management (including forensic risk). Adults with autism who do not have a Learning Disability are in most cases unable to access the specialist interventions they require because these services are not specifically commissioned, and they are not eligible to access services provided by learning disability or mental health services.

How will we achieve this?

- To better understand what is currently available and any gaps that need addressing for the future



- To work with partners to develop current services and ensuring they are fit for purpose
- To develop robust data collection systems

Perceptions

Customer and Carer Perceptions of Services

The results of the consultation showed that on the whole adults with autism and carers of adults with autism have a very negative perception of services in Bury. People noted that they envisaged it would be difficult to get information, appropriate housing or employment support even if they had never tried to access these services. Work will be undertaken with our customers, carers and other stakeholders to offer more information and advice on services and what is available in order to dispel the negative perceptions they hold.

General Public Perceptions

Autism is a disorder which is generally misunderstood by the general public, therefore people may have negative perceptions of what autism is and how it affects the people who have autism. We will seek to publicise good news stories by people with autism and promote their talents to employers and others in Bury to try to dispel the myths around autism. We can do this by publishing case studies, general awareness raising and including people with autism and their carers in consultations and in the developing and delivering of training.

Brief Aims

In short, the aims of this strategy are to:

- Ensure that people have a better understanding of autism. This includes everyone from frontline staff, Job Centre Plus, receptionists, GPs and social workers.
- Develop a local diagnosis pathway for adults with autism including post diagnostic support, sibling screening and reassessments
- Develop new opportunities for social activity by working with partners
- Ensure information is timely, accessible and relevant
- Develop better access to universal services
- Dispel negative perceptions of services and of autism
- Develop more opportunities for employment, education and volunteering
- Develop robust data collection systems



Part 4



Part 4: Monitoring and Leadership

The Bury Autism Development Group will monitor and track progress within the work streams and the action plan. This is a multi-agency group with carer representation. The progress will also be reported to Adult Care Services Senior Management Team as required.

Fulfilling and rewarding lives: the strategy for adults with autism – evaluating progress (DoH, 2011) set out guidance and a self assessment framework to help support local authorities, NHS organisations and their partners to implement the statutory guidance in their localities. The self assessment is primarily for commissioners as a template to respond to the statutory guidance. However, this helps us check our progress against both the national strategy and other authorities.

In line with national guidance, leads for autism have been identified within health and social care. These are:

- Adult Care Services – Head of Commissioning and Strategy – Strategic Autism Lead
- Adult Care Services – Strategic Strategy and Policy Officer – Autism Policy Lead
- NHS Bury - Health Development Service Redesign Lead – Learning Disabilities and Mental Health – NHS commissioning lead for autism
- Local GP – Lead for diagnosis

Progress will also be reported to the Learning disability partnership board and the Mental Health Steering Group as and when required.

Resources

Although there is no funding attached to the implementation of this strategy, the majority of the actions will be achieved by greater partnership working and investigating new ways of working. This is particularly true in the case of awareness raising, social activity and information. We will work with the Greater Manchester Autism Consortium to develop in-house training programmes via “train the trainer” and Bury is a pilot site for this programme. However, we will invest in specialist training for those staff who need a detailed knowledge of autism. Funding will be sought via the Clinical Commissioning Group for a local diagnosis pathway in Bury.



Endnotes

ⁱThis is not a “stand alone” strategy and needs to link with a number of other developments including:

- Bury Learning Disability Commissioning Strategy
- Joint Commissioning Strategy for Adult Mental Health in Bury
- Workforce development strategy
- Self directed support programme
- Carers strategy
- Market intelligence/market management exercise currently being undertaken in order to develop a wider offer to all vulnerable adults in Bury

ⁱⁱPlease note these figures may not be a true and accurate reflection of the number of young people with a diagnosis of autism. Of the 519, 252 had a diagnosis of autism. The data is produced using one source only (i.e. data held by the Additional Needs Team, Bury).

ⁱⁱⁱThe consultation with people with autism, carers of people with autism and professionals who work with people with autism consisted of:

- An event on 7 March 2012 based on the key themes within the National Strategy. This was attended by over 80 stakeholders including customers, carers and professionals. The aim was to gather experiences, views and suggestions.
- Questionnaires were produced for customers, carers and professionals. People were able to complete these online, by post or via the telephone.
- Seven drop in sessions were held to enable people to talk to someone confidentially and/or get help to complete a questionnaire.

The consultation was advertised widely by post, email, facebook, twitter, on the website, in public buildings, newsletters and via poster.

Bibliography

British Institute for Brain Injured Children (BIBIC) (2005) *Anti-social behaviour orders and young people with learning disabilities*. Critical Social Policy, February 2011, p102-125

Brugha T, McManus S, Meltzer H, Smith J, Scott FJ, Purdon S, Harris J, Bankart J, (2009) *Autistic Spectrum Disorders in adults living in households throughout England, Report from the Adult Psychiatric Morbidity Survey 2007*, Leeds: The health and social care information centre

Communities and Local Government (2010) *Decentralisation and Localism Bill*

Department of Health (2010) *A vision for adult social care: Capable Communities and active citizens*

Department of Health (2010) *Fulfilling and Rewarding Lives: the strategy for adults with autism in England*

Department of Health (2010) *implementing fulfilling and rewarding lives: statutory guidance for local authorities and NHS organisations to support the implementation of the autism strategy*

Department of Health (2010) *Towards full filling and rewarding lives: first year delivery plan for adults with autism in England*

Department of Health (2011) *Fulfilling and rewarding lives: evaluating progress*

Knapp M, Romeo R and Beecham J (2007) *Economic consequences of autism in t he UK*, Foundation for people with learning disabilities

Mason J and Murphy G (2002) *intellectual disability amongst people on probation: prevalence and outcome*, Journal of intellectual disability research, vol46(3), p230-238

National Audit Office (2009) *Supporting people with autism through adulthood*, The stationary office

Social care institute for excellence (2011) *think local, act personal (online)*
www.scie.org.uk/news/mediareleases/2011/270111.asp , 2 May 2011

The National Autistic Society (2011) *About Autism (online)* available at www.autism.org.uk/about-autism.aspx, **12 May 2011**

A national response to Winterbourne View Hospital, DoH, (2012) <http://www.dh.gov.uk/health/2012/12/final-winterbourne>

Glossary

To help you read this strategy, an explanation of the technical words and phrases that you will find used in the strategy are set out below:

Key word	What does it mean?
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autistic Spectrum Disorder
ASGMA	Autistic Society Greater Manchester Area
BME	Black and Minority Ethnic
Bury EST	Bury Employment Support and Training
DAMP	Deficits in Attention and Motor Perception
DEA	Disability Employment Advisors
DoH	Department of Health
FACS	Fair Access to Care Services
GP	General Practitioner
IMD	Index of Multiple Deprivation
IQ	Intelligence Quotient
JSNA	Joint Strategic Needs Assessment
NAS	National Autistic Society
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
PA	Personal Assistant
PANSI	Projecting Adult Needs and Service Information

Version control

Version number	Purpose / change	Author	Date
0.1	Draft for consultation	J.Waite	4.2.13
0.2	Draft for Health Scrutiny Committee	J.waite	21.3.13

Contact us

For further information about the Bury Autism Strategy 2013 – 2016:



Log on to

www.bury.gov.uk



Email us at

strategicplanning@bury.gov.uk



Write to us at

Strategic Planning Team
Bury Council Adult Care Services
1st Floor Castle Buildings
Market Place
Bury
BL9 0LT



Call us on

0161 253 7975