

JSNA: Autism

Introduction

A number of recent legislative and policy developments have highlighted the gaps in services for people with Autism. The Autism Act 2009 and the National Strategy for Autism 'Fulfilling and rewarding lives: The strategy for adults with autism in England' place new obligations on NHS and local authorities to meet the needs of all people with autism. Bolton is currently in the process of developing its local Autism Strategy which is expected to be launched in April 2013.

The National Audit Office (NAO) suggests that if an area's services identified and appropriately supported just 4% of those with high functioning (HF) autism to live more independently or retain employment, they would become cost-neutral across public spending as a whole over time, as well as improving the mental health and wellbeing of this group of individuals. Furthermore, improving identification could lead to additional savings over time suggesting that identification and support for 6% of people with (HF) autism could save £38 million a year, and 8% could save £67 million per year in England¹.

We recognise that there are a number of terms that individuals and groups prefer to use including autistic spectrum disorder, autistic spectrum condition and autistic spectrum difference. The JSNA will use the term 'autism' as an umbrella term for all such conditions, including Asperger syndrome. This is in line with the approach to terminology adopted by key autism representative organisations, including National Autistic Society (NAS).

Implications for commissioning

As knowledge about autism increases and more people are being diagnosed younger, there is a growing demand for young people with autism and learning disabilities requiring specialist provision in the way of respite (for themselves and their carers), day time support and supported accommodation services.

There is also a growing demand for adults with Asperger's Syndrome requesting a Community Care Assessment under the NHS and Community Care Act 1990, as well as a growing request for Carer's Assessments. The impact of this will be the need for a skilled work force in terms of assessment and care management, as well as a development in the market to ensure that there are support providers with the specialist skills and knowledge to appropriately support adults with Asperger's Syndrome through Direct Payments or managed accounts.

¹ National Audit Office (2009), *Supporting People through Adulthood*, NAO.

There is a need for early review of progress with the revised care pathway for people with Asperger's and High Functioning Autism to check it is able to meet demand and provide the support required.

Who's at risk and why?

What is autism?

Autism is classified as a developmental disability in the International Classification of Diseases and Health Related Problems (ICD-10) diagnostic manual in the same class as Intellectual Disabilities or Attention Deficit Hyperactivity Disorder, complex lifelong conditions involving "pervasive developmental disorder". Autism involves difficulty in three areas, known as the "triad of impairments"²:

1. Difficulties with social communication: language acquisition delay, and difficulty understanding and using speech, writing, body language, mood, gesture, and personal space (e.g. language, gestures, facial expressions and tone of voice);
2. Difficulties with social interaction: problems acquiring and using social skills which can result in isolation, difficulty processing emotional information, difficulty initiating social contact and adhering to social rules and thus difficulty sustaining relationships (e.g. recognising and understanding other people's feelings and managing their own);
3. Difficulties with social imagination: being unable to correctly distinguish the real from imaginary, finding it difficult to be reflexive, to inhibit behaviour, and to exhibit repetitive behaviours and obsessional interests (e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine).

It is also common for people with autism to have unusually high or low sensitivity in one or more of their senses. People with autism often prefer routines and find changes to their routine difficult to manage.

Everyone with autism experiences difficulties across these three areas, albeit the severity and presentation of difficulties can vary significantly and so an 'Autistic Spectrum' is talked of. The word spectrum is used because some people with autism are able to live relatively 'unsupported' lives and others need a lifetime of specialist support. While some people with autism may have limited language skills, others have good language skills but have difficulty understanding. The medical model of autism³:

² Wing, L. and J. Gould (1979) 'Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification' in *Journal of Autism and Developmental Disorders* 9(1):11-29.

³ Adapted from ICD-10, Diagnostic Statistical Manual IV and the National Autistic Society website.

Type	Description
Autistic Disorder ⁴	Autistic Disorder is considered to be at the severe end of the Autistic Spectrum. It is characterised by the presence of the “triad of impairments.” Onset is before the age of three years. The presentation of the disorder is different across individuals depending on their developmental level and chronological age.
Asperger Syndrome (AS)	Asperger Syndrome is also characterised by the presence of the triad of impairments, however there is no delay in the development of language and IQ is in the average to above average range (IQ ≥ 70). Difficulties in motor skills and coordination are often present.
Pervasive Developmental Disorder ⁵	This diagnosis is given if the criteria for another autistic disorder is not met (i.e. one of the triad of impairments may not be present or it is difficult to determine whether onset was before age 3).
High Functioning Autism (HFA)	High Functioning Autism is not currently recognised by either the ICD-10 or the DSM IV, but is nevertheless referred to in the literature. Those with High Functioning Autism also present with the triad of impairments and language delay in childhood, but are found to have IQ levels in the normal range (IQ ≥ 70). Adults with HFA present similarly to those with Asperger’s Syndrome.

Different areas of difficulty experienced by people with autism can lead to varying associated support needs including speech and language therapy, environmental adjustments, monitoring and mentoring, life skills coaching, employment support, and supported living. The impact of autism on the health, economic and social wellbeing of the individual, their family and wider society varies according to a range of factors including age, level of cognition and ability to live independently⁶.

⁴ Also known as Classic Autism or Kanner’s Autism

⁵ Not Otherwise Specified (also referred to as “Atypical Autism”)

⁶ Knapp, M. et al (2007) *The Economic Consequences of Autism in the UK*, Foundation for People with Learning Disabilities.

Autism is a developmental disability that cannot be cured; although early and appropriate intervention can help people fulfil their potential and lead relatively independent lives.

Autism is not a learning disability, but sometimes a person may be on the autistic spectrum and have a learning disability. Around a third of people with autism also have a learning disability, which is sometimes known as 'low-functioning' autism, while the remainder do not have a learning disability so have 'high-functioning' autism, which includes Asperger Syndrome. Generally, those with an IQ of 70 or above are considered to have higher functioning autism or Asperger Syndrome, yet many still experience significant difficulty with social interaction, communication and behaviour. There is often confusion between Asperger Syndrome and high functioning autism as adults with both present very similarly, although it has been suggested that those with high functioning autism have a delay in language not seen in those with Asperger Syndrome, while those with Asperger Syndrome are more likely to have motor difficulties.

Risk factors

Most researchers believe that autism has a variety of causes. It is well established that there is a genetic component to autism but it is unclear how environmental factors may interact with these.

Some studies have been undertaken to determine whether or not exposure before or after birth to drugs, infections or heavy metals are possible risk factors for developing autism. Insufficient evidence makes firm conclusions impossible. It's likely that perinatal complications are a consequence rather than a cause of autism. A small number of cases have reported that viral infections may have played a role. There is no epidemiological evidence of a link between autism and MMR vaccination. Limited data has suggested physiological abnormalities affecting the gastro-intestinal tract, sulphation processes and immune system as a cause. No proper controlled studies have been undertaken however. Current evidence suggests many people with autism may have larger, heavier brains with cellular abnormalities in a number of regions⁷.

Autistic spectrum conditions have an early onset in childhood initially identified through developmental disabilities and difficulty in acquiring skills. In some cases it may not be identified until later in life or may be masked by other co-existing conditions such as a learning disability.

Men are more at risk of developing autism than women. For Asperger Syndrome/High functioning autism DSM-IV-TR gives the ratio of males to females as approximately 4-5:1.

⁷ Medical Research Council (2001) *MRC Review of Autism Research Epidemiology and Causes*, MRC.

For Autistic Disorder it is 4:1. An NHS Information Centre Study⁸ found prevalence of 1.8% in men and 0.2% in females. It has been suggested that men's symptoms of autism are more frequently found on the spectrum than women's, who are more likely to internalise their symptoms. This raises the possibility that autism may be under-diagnosed in women.

There is little national research on the difference in prevalence and experience of autism between ethnic groups. However, research in America suggests that identification and diagnosis of autism in some ethnic groups may be delayed for various reasons, for example, differing cultural interpretations of some developmental issues which may signal possible autism, such as avoidance of eye-contact or hyper-active behaviour. Potential stigma surrounding disability, a reluctance to 'label' a child, and around the potential causes of the condition can be influenced by cultural beliefs which could not only play a role in preventing early diagnosis but also in treatment choice and once a diagnosis is made other issues may impact access to support services.

Autism can occur with other conditions. For instance other conditions that can occur at a higher rate in people with autism than the general population include learning disabilities, epilepsy, ADHD and mental health problems.

It has been estimated that 7.5% of adults with a learning disability living in private households may also have autism. The figure is likely to be much higher amongst adults with learning disability living in communal or institutional setting. A recent systematic review by the Department of Health's Learning Disability Observatory found that up to 33% of adults with a learning disability also had autism⁹.

Autism is not a psychiatric disorder but can predispose people to mental health problems for a variety of biological, psychological, educational and social reasons. Mental health problems in people with autism are relatively common and may be severe. Mental health issues manifest in many different ways, for example, aggression, chaotic hyperactivity, obsessions or passivity, and can have a substantial impact on the health and wellbeing of family and carers¹⁰. Research by the National Autistic Society suggests that nearly two thirds of adults with autism do not have enough support to meet their needs, and one in three adults with autism are experiencing severe mental health difficulties due to lack of support¹¹.

⁸ NHS Information Centre (2009) *Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007*, NHS IC.

⁹ Emerson, E. and S. Baines (2010) *The Estimated Prevalence of Autism among Adults with Learning Disabilities in England*, Department of Health.

¹⁰ Turk, J. (2010) *Autism Spectrum Conditions across the Lifespan*, St. Georges University of London, Kings College London and South London, and Maudsley NHS Trust.

¹¹ Rosenblatt, M. (2008) *I Exist: the message from adults with autism in England*, The National Autistic Society.

The difficulties outlined above with social interaction, social communication and social imagination can result in people with autism perceiving the world in a fragmented and often incomprehensible and scary way. In this sense there may be an increased risk of depression and anxiety over time relating to an increased awareness of disabilities and potential difficulties in life opportunities. Anxiety can affect a person physically, through: excessive thirst; stomach upsets, heart palpitations, muscle aches, headaches, dizziness or tremors, or psychologically through: loss of patience, difficulty concentrating, expecting the worst, sleep deprivation, depression, and obsession. This can lead to a cycle of behaviour which is difficult to break, particularly for a person for whom understanding emotions can be difficult¹².

Impact of autism

Adults with autism face many challenges in life. Often they also have other co-occurring conditions such as learning disabilities or mental health problems. Those who have higher functioning autism or Asperger Syndrome feel they have a 'hidden' condition which is not easily recognised or understood by professionals or the public.

Many older people will be undiagnosed because autism only became formally recognised as a range of conditions in the late 1960s. The condition can also be masked by other co-occurring conditions such as a mental health problem, learning disability or attention deficit hyperactivity disorder¹³.

One of the key issues for adults with autism is that they risk falling into the gap between services for people with learning disability and mental health conditions. Autism is a developmental disorder and not a mental health problem. If they are not identified and diagnosed in childhood, adults with Asperger Syndrome and High Functioning Autism in particular can struggle to receive the support they need to lead fulfilling and rewarding lives. They are more likely to receive support if they also have a co-occurring condition such as a learning disability which has been identified in childhood or a mental health problem. However if an adult with autism does not receive the support they need for this condition they are more likely to develop a mental health problem. Low level support at the right time could prevent this arising.

Many adults with autism cite employment as the single biggest issue or barrier facing them¹⁴. A particular area where adults with autism have highlighted the need for increased

¹² National Autistic Society (2013)

<http://www.autism.org.uk/>

¹³ Turk, J. (2010) *Autism Spectrum Conditions across the Lifespan*, St. Georges University of London, Kings College London and South London, and Maudsley NHS Trust.

¹⁴ Barnard, J. et al (2001) *Ignored or Ineligible: the Reality for Adults with Autistic Spectrum Disorders*, The National Autistic Society.

awareness is among employment and benefits advisers. The number of people with autism in full-time employment is very low with research estimating that 6% of all people with autism are in full-time employment, and 12% of those with Asperger Syndrome or high functioning autism. At the lower functioning end of the spectrum this falls to an estimated 2% rate of employment.¹⁰ The low numbers of adults with autism in employment not only leads to wasted potential, social exclusion and lack of personal fulfilment but also puts pressure on families supporting these adults and on Local Authorities¹⁵. Research Autism suggests that regular employment can bring positive psychological and social benefits to adults with autism and can increase self-esteem and social integration.

A large proportion of the cost of supporting people with autism is accounted for by lost employment. This significantly impacts not only on the people with autism, but also on wider society, and on the UK economy¹⁶. This means that many adults with autism are dependent on benefits, and this under-representation also indicates that UK employers are not benefiting from the skills and talents adults with autism can offer in the workplace¹⁷.

People with autism are at high risk of social isolation and exclusion. The characteristics associated with autism mean that developing friendships and social networks can be very difficult and stressful. As a result, anxiety increases and individuals often either exclude themselves or find themselves excluded, and so have little contact with the outside world. People with Asperger Syndrome in particular often have at least general intellectual ability, but have marked motor coordination problems and social interaction difficulties which can lead to restricted interests and activities¹⁸.

The NAS report¹⁹ 'Think Differently - Act Positively: public perceptions of autism' looks at public attitudes to autism based on a survey of over 2,000 adults from across the UK. The report shows that there are societal misconceptions about the exact characteristics of autism, and there are many negative reactions to the typical behaviour commonly associated with autism. For example, negativity could be exhibited through rudeness, impatience, lack of compassion, or problems at school, work, and at home which have a damaging impact on people affected by autism and their experience of discrimination, intolerance, and isolation. In a 2007 report on the needs of those with Asperger Syndrome,

¹⁵ Department of Health (2010) *Fulfilling and rewarding lives: The strategy for adults with autism in England*, Department of Health.

¹⁶ Knapp, M. et al (2007) *The Economic Consequences of Autism in the UK*, Foundation for People with Learning Disabilities.

¹⁷ Department of Health (2010) *Fulfilling and rewarding lives: The strategy for adults with autism in England*, Department of Health.

¹⁸ Turk, J. (2010) *Autism Spectrum Conditions across the Lifespan*, St. Georges University of London, Kings College London and South London, and Maudsley NHS Trust.

¹⁹ Simons, L. (2007) *Think Differently, Act Positively – Public Perceptions of Autism*, National Autistic Society.

83% of individuals with Asperger Syndrome surveyed felt strongly that many of the problems they faced were as a direct result of others not understanding them²⁰.

People with autism are at high risk of bullying or harassment; over half of adults with autism who were surveyed by the National Autistic Society in 2008 reporting that they had been bullied or harassed as adults²¹.

Characteristics of autism such as the inability to understand social norms, increased likelihood of being socially misunderstood, obsessive interests, apparent lack of empathy, communication difficulties, and literal interpretation of language could all theoretically put people with autism at higher risk of becoming a victim of crime or offending themselves. It is said that people with autism are less likely to become offenders or victims if their needs are identified early and they are properly supported. It is social isolation that increases vulnerability and may lead to people being exploited and either being led to commit crime themselves or becoming a victim of crime. Autism could also render someone highly vulnerable if they come into contact with the criminal justice system²². For example, in the criminal justice system, police officers, probation services and courts may all be unaware of communication challenges – leading to overly heavy-handed responses to incidents²³.

The incidence of disability hate crime against persons with autism may well be severely under-reported due to their communication difficulties and failure to understand what is and what isn't the social norm. Those that do enter the system as victims are often deemed as not being a credible witness, leading to failures to prosecute.

The level of need in the population

The National Autistic Society uses a prevalence rate of 1 in 100 (1%) people to estimate the number of people with a condition somewhere along the autistic spectrum. The rate among men (1.8%) was higher than that among women (0.2%). Using these prevalence rates, as at 2012, there were an estimated 1,653 adults aged 18 -64 years with autism in Bolton with the following demographic profile. These are taken from the Institute of Public Care's PANSI tool; PANSI does not provide any data on the prevalence of autism in the 65+ population.

²⁰ Beardon, L. and G. Edmonds (2007) *ASPECT consultancy report: a national report on the needs of adults with Asperger Syndrome*, Sheffield Hallam University.

²¹ Rosenblatt, M. (2008) *I Exist: the message from adults with autism in England*, The National Autistic Society.

²² Dein, K. and M. Woodbury-Smith (2010) 'Asperger syndrome and criminal behaviour' in *Advances in Psychiatric Treatment* 16:44-46.

²³ Department of Health (2010) *Fulfilling and rewarding lives: The strategy for adults with autism in England*, Department of Health.

Age Group	Males	Females	Total
18-24 years	227	24	251
25-34 years	326	36	361
35-44 years	328	37	365
45-54 years	333	39	372
55-64 years	274	31	305
Total 18-64 years	1487	167	1653

A more recent study published by the Health and Social Care Information Centre in 2012 combined the existing data with a new study of the prevalence of autism among adults with learning disabilities living in private households and communal care establishments. Based on this study the overall prevalence of autism was 1.1% and was higher in men (2.0%) than women (0.3%). This revised prevalence rate has not yet been incorporated into the PANSI tool but is actually closer to the alternative estimates provided by Planning4care, which also includes those aged 14-17 and 65+ years. Unlike PANSI, the Planning4care estimate is also based on population data adjusted for the 2011 Census which is likely to account for some of the difference in estimated numbers.

Total numbers of people estimated with autism, by age in Bolton 2011 (from Planning4care):

- Aged 14-17 = 170;
- Aged 18-64 = 1,950;
- Aged 65+ = 460;
- *Total = 2,580.*

A recent study by the Department of Health's Learning Disabilities Observatory carried out a systematic review to estimate the prevalence of autism amongst adults with Learning Disabilities²⁴. The review led to the conclusion that the prevalence of autism amongst adults with learning disabilities was likely to lie somewhere between 20% and 33%. In 2012 the estimated number of adults aged 18 and over with a learning disability thought to be living in Bolton was 4,962. Of these at least 992 (20%), and at most 1,638 (33%), are likely to have autism. The most recent study²⁵ indicated that the prevalence of autism increased with greater severity of learning disability/lower verbal IQ. Also, sex differences are less marked in adults with learning disabilities compared with the rest of the general population.

²⁴ Emerson, E. and S. Baines (2010) *The Estimated Prevalence of Autism among Adults with Learning Disabilities in England*, Department of Health.

²⁵ Emerson, E. and S. Baines (2010) *The Estimated Prevalence of Autism among Adults with Learning Disabilities in England*, Department of Health.

It has also been estimated that around half of people with autism fall into the category of 'High Functioning Autism' – i.e. they actually have an IQ > 70; indeed many have well above average IQ²⁶. Planning4care estimates that in 2011 there were 1,090 adults aged 18 and over with Asperger Syndrome/High Functioning Autism in Bolton.

It is clear that the estimated prevalence rates for adults with autism can only be a very approximate guide to the actual numbers of people living with this condition in Bolton. However, there are currently no local sources of information on the number of adults with autism, even for those with a diagnosis.

Some information is available from the School Census on the number of pupils with a special education need related to autism. A snapshot of information taken in January 2012 indicated the below numbers of pupils aged 14-16 years (Years 9-11) in Bolton with a primary or secondary special education need of autism. This indicates an average of 30-35 pupils in each year group where autism is diagnosed. For almost half (48%) of these pupils, autism was their only need. Other common needs identified included moderate learning difficulty (22%), severe learning difficulty (9%), behaviour, emotional and social difficulties (11%), and speech, language and communication difficulties (7%). School age children stated as having a Special Educational Need for autism may require ongoing support from Adult Social Care as they become older:

- Pupils with primary SEN of autism:
 - School Action Plus* 21;
 - Statement** 57;
- Pupils with secondary SEN of autism:
 - School Action Plus 4;
 - Statement 20;
- Total 102.

**School Action Plus is the level of intervention for a child where the school requires external support (e.g. from an educational psychologist or speech and language therapist) to meet the needs of the child.*

***A statement is the level of intervention where a child's needs require that the local authority sets out the support required and the local authority is required by law to ensure this support is then provided.*

Current services in relation to need

People with autism require access to a range of services including specialised health and care services to meet individual needs, as well as universal services accessed by the population in

²⁶ Baird, G. et al (2006) 'Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP)' in *The Lancet*, 368:210-215.

general. As there is currently no statutory requirement for services to record or code a diagnosis of autism on their databases, the number of people recorded as known to services is likely to be much lower than the expected prevalence.

Diagnosis

The National Autism Strategy states that identification of possible autism is the first step to effective support. Many adults with autism seek a formal clinical diagnosis that they can refer to when trying to access services, including welfare benefits. Diagnosis is particularly important for adults whose condition has not previously been recognised, as their life to date may have been greatly affected by a sense of not fitting in, of not understanding the way they respond to situations, or why social settings may be difficult. Diagnosis is equally important for families and carers and those who are already receiving support for a learning disability or mental ill-health as a diagnosis of autism can change the treatment and support received. Previous low awareness of autism means that adults with Asperger Syndrome or High Functioning Autism are less likely to have been identified in childhood.

In Bolton, requests for diagnosis of autism have been considered by the Individual Case Request Panel. From 1st April 2010 to 30th November 2012 the panel considered 19 requests for assessment and assessment/treatment for adult Asperger's and/or autistic spectrum disorder. Of these, only a small number of people requesting a formal diagnosis were approved for assessment by providers out-of-area because extenuating circumstances are required for funding approval.

As the existing arrangements are recognised as inadequate, a care pathway for people with Asperger Syndrome is being developed by a multiagency group with the commissioners. Greater Manchester West Mental Health NHS Foundation Trust (GMW) will be developing, within resources available, a specific diagnosis service for those who are suspected to have Asperger Syndrome. Short-term post diagnostic support may be offered to those people given an Autistic Spectrum Condition diagnosis via this arrangement. Longer term care-coordination of support for the small number of individuals with Asperger's and highly complex needs meeting the required criteria will be also available. This service will be operational during 2013/14. The activity levels have been set with commissioners and will be jointly reviewed as the service becomes operational. To date this pilot has not been advertised publicly and as such the true demand for this service may be repressed.

The development of this service will be enhanced by the provision of basic awareness training to staff around autism during 2013/14, and enhanced training to staff identified as requiring a greater knowledge.

Mental health

Where the primary diagnosis is mental illness the full range of mental health services from GMW are accessible for people with autism alongside any other client group.

The Community Mental Health Team aims to enable service users accepted by the service to live as safely and independently in the community as possible, and to promote recovery, social inclusion, and optimum quality of life. The experienced teams operate under Care Programme Approach (CPA) and work closely with service users and carers in the process of assessment, care planning, providing professional support and, where eligible, in commissioning adult social care services. When appropriate, GMW works closely with district disability services and specialist agencies such as the National Autistic Society. Where required, services are adapted to meet the individual needs of patients with autism.

Historically GMW was not commissioned to provide a service to people with the primary diagnosis of autism, however GMW does manage a small number of people who attract this primary diagnosis. This is due to such patients receiving a statutory assessment, for example, as vulnerable adults or following, for instance, a Mental Health Act assessment when psychiatric admission has been indicated to address high risk behaviour or to treat deterioration in a secondary mental health issue.

GMW hosts a Consultant Psychiatrist for Learning Disability in Bolton, commissioned by the CCG who offers a service to people whose primary diagnosis may be autism but with concurrent mental health problems and learning disability.

The total number of active cases for Bolton adults where autism was the primary diagnosis managed by GMW between 01/12/2007 and 30/11/2012 was 95. Those that were active between 01/12/2011 and 30/11/2012 (total of 56) were using the following services:

- Employment Support = 2;
- Criminal Justice = 1;
- Crisis Resolution = 3;
- Forensic = 1;
- Learning Disability = 34;
- Low Secure = 1;
- Adult Functional = 13
- Personality Disorders = 1.

There were 52 cases active between 01/12/2011 and 01/12/2012 where at least one of the autism ICD-10 codes were noted as a concurrent diagnosis. These were split between the following services:

- Employment Support = 1;
- Crisis Resolution = 1;

- Early Intervention = 2;
- Learning Disability = 36;
- Low Secure = 1;
- Adult Functional = 9;
- Personality Disorders = 1;
- Psychology Secondary = 1.

Social Care

In Bolton, Social Care is currently provided to those with substantial or critical needs under the Department of Health's Fair Access to Care Services (FACs) guidelines. It is not currently possible to identify the number of people with autism using social care services but improvements are underway to enable this in the near future. The types of services accessed by people with autism with social care needs include:

- Day care;
- Adult Placement;
- Supported Housing;
- Residential Care;
- Direct Payments;
- Home care;
- Respite.

The Specialist Care Commissioning Strategy 2011-2014 indicates a shifting culture to one of individual choice and responsibility, as well as an increase in service user choice over what and how services are delivered.

Bolton has a specialist autism in-house day service which currently supports adults with autism and learning disabilities. The day service is currently undergoing accreditation from the National Autistic Society.

Staff at the learning disability respite services are also trained to support people with autism.

Primary care service

As a universal service, primary care is accessed by people with autism in the same way as the general population. GPs do not routinely record data related to autism, and it would be difficult to improve this situation given the relatively low priority of the condition and the lack of a disease register.

Primary care services do, however, have a legal responsibility to take account of the special needs of people with learning disabilities and reduce the health inequalities they face. One practical step GP practices in England take to better support people with learning disabilities is to offer them annual health checks. Since 2009, GPs have received extra money for

providing these health checks. In Bolton, data for approximately 850 people with a learning disability that have been offered a health check indicates that 27 people had autism. Based on prevalence estimates it is likely this is a considerable under-estimate and highlights the inadequacies of local data and/or diagnosis among people with learning disabilities currently.

Secondary health care services

Although numbers are very small there is some data relating to hospital admissions for adults in Bolton where autism is recorded as a primary or secondary diagnosis.

Between April 2006 and March 2012 there were 22 hospital admissions where autism was recorded as the primary diagnosis. Over three quarters of these admissions were emergency admissions. No further information is available on the reasons for these admissions.

Over the same time period there were 149 hospital admissions where autism was recorded as a secondary diagnosis. Almost 1 in 5 (19%) of these admissions were for dental caries on a non-emergency basis. It is generally recognised that people with autism tend to have poorer oral hygiene resulting in tooth decay and gum disease²⁷. Reasons for poorer dental health are said to be a preference for soft, sweetened food (sameness), bruxism, poor tongue coordination increasing the amount of time food stays in the mouth before swallowing, suboptimal manual dexterity causing difficulties with brushing and flossing, adverse effects of psychoactive drugs, and being less likely to access dental health services. The number of hospital admissions in Bolton indicates there may be an unmet need for dental services for people with autism locally.

Housing

Some people with autism are able to live independently without external support; others live semi-independently and receive a level of outside support with certain tasks, known as supported living. People with autism may also live with others, for example with families or in a shared house, while some people needing 24-hour support may alternatively live in a residential or group home.

In the absence of primary data the Foundation for People with Learning Disabilities estimated accommodation arrangements for adults with autism based on national research and official statistics and suggests that 79% of adults with High Functioning Autism live with

²⁷ Autism Help (2013)
www.autismhelp.info/

parents or family, 5% in supported housing and 16% in residential care²⁸. Estimations from the National Autistic Society suggest that nationally 40% of adults with autism live at home with their parent, which is a significantly lower figure and is the more widely accepted estimation²⁹.

Research by the Transition Information Network concluded that with the right support and planning through the transition stage, more adults with autism would be able to live independently. However, their research found that currently 70% of parents feel that their son or daughter would be unable to live independently without support³⁰.

When people apply to go on the Housing Register in Bolton only limited information is collected about disabilities. There are plans, however, to improve this and as a result more detailed information about the housing needs of people with autism locally will be available.

Bolton currently commissions a specialist supported housing service to support 12 people with autism, learning disabilities, and complex needs disabilities. The contract will come to an end at the end of March 2014, and there will be an option to extend this for a further two years. Floating Support and Sustainable Tenancy services also exist to help vulnerable people, including those with autism, to secure and maintain a tenancy.

Education

Children's Services hold the funding to support additional educational needs up to the age of 25. There is no specific funding for autism after age 25, only Community Learning which any learner can have for a maximum of 16 weeks once a year. Community Learning is employment focused.

Bolton College provides entry level courses for those aged 16-25 years for learners with additional education needs. In 2012/13 approximately two thirds of students (160 people) on these courses had autism. The support is customised to meet the needs of individuals and there is a focus on preparing people for work, working with local employers to provide appropriate opportunities, and independent living skills. Community learning opportunities at the college are mainly accessed by the over 25s and concentrate on integration within the community, volunteering, and work skills as appropriate.

If a university student has a diagnosis of autism they can apply for Disabled Students' Allowance (DSA).

²⁸ Knapp, M. et al (2007) *The Economic Consequences of Autism in the UK*, Foundation for People with Learning Disabilities.

²⁹ Research Autism: Improving the Quality of Life (2010) *Adolescence to Adulthood with Autism in the UK*, News Release Date: 14 October 2010.

³⁰ Transition Information Network (2013)
<http://www.transitioninfonetwork.org.uk>

Employment support

The Connexions service works closely with specialist and mainstream schools in Bolton. Further Education establishments and employment providers (e.g. Boltonwise, Powerwave) offer class-based and real work-based opportunities to prepare young people aged 16-19 years with autism in Bolton for the world of work.

Adults with autism are supported by Jobcentre Plus and the Work Programme through local contracts with I2I, Avanta, BoltonWise and the Council's The Work Shop service. There is some specialist support for people with learning disabilities and mental health problems, but in the main the focus has been to ensure local employment support providers and employers are aware of autism and for them to consider what changes they can make to help sustain people in employment.

Voluntary sector

The National Autistic Society manages the Family Services Development Project in Greater Manchester. This was set up in 1993 and is funded by the Greater Manchester Autism Consortium, which is made up of the ten Greater Manchester local authorities including Bolton. The Project aims to be a point of contact for anyone in Greater Manchester needing information about autism and related issues. It provides information to parents, people with autism, and professionals as well as directing people to the relevant statutory services and voluntary agencies in their own area. Enquiries can be made by telephone, email or by letter. An individualised response is provided to each enquiry. Over the last five years 63 enquiries from adults in Bolton have been dealt with by this project with numbers increasing significantly in 2011 and 2012.

Locally in Bolton, Time2 communities has recently been successful in securing funding from the European Social Fund for a twelve month period to facilitate a local Asperger support group for individuals on the spectrum and their carers, until the groups have become constituted.

Support for carers

Carers' needs should be considered separately to those of the person with autism. Carers of someone with autism in Bolton can access a local carer support group as well as a Greater Manchester wide support group provided by the National Autistic Society. They can also access more general carer support provided by Bolton Carers Support, and they can request a carers assessment if they are identified as the main carer and provide care and support to a person with autism.

Criminal Justice

People with autism are thought to be at higher risk of coming into contact with the criminal justice system due to their inability to understand social norms. Some limited studies have indicated that up to 7% of the prison population may be on the autistic spectrum.

There is currently no information locally on the number of people who are perpetrators or victims of crime with autism; although with growing awareness of these issues there is some interest in considering trying to estimate this in future. The low level of diagnosis among adults, however, will make this a challenge.

Bolton's Disability Hate Crime initiative 'I'm not Laughing' was launched in summer 2012. This aims to encourage greater awareness and reporting of crimes targeted at people with disabilities. Members of Bolton's Community Safety Team have been to speak to members of the Asperger's support group informing them of the 'I'm Not Laughing' campaign and sharing useful contact numbers.

Autism awareness training

A key element of Bolton's local Autism strategy is to improve awareness of autism among frontline staff. Bolton Council and PCT have agreed a joint training plan to deliver awareness training across health and social care. This has provided training to a range of staff in social care through a combination of classroom based and/or e-learning. GMW will be delivering more advanced training for staff who have been identified as needing a greater knowledge of Asperger's as they maybe completing assessments and co-producing care packages with people with autism.

To date, awareness training has been delivered to some staff teams across health and social care, some staff at Bolton at Home, Bolton Lads and Girls Club, Bolton Community College, and staff who have shown a particular interest in autism from other front line services. A service user with Asperger Syndrome has been facilitating this training with a member of staff from the Council's training department. The key objectives of the training are:

- Demonstrate an understanding of Autistic Spectrum Disorder, how it affects the way people experience their environment and how this in turn influences their behaviour;
- Focus on the difficulties, including hypersensitivities, rather than the problems that service users may present;
- Describe the 'triad of impairments' that are associated with ASD;
- Identify ways of supporting people with ASD to participate more fully in the 'non-autistic world';
- Relate the course content to their work practice.

Projected service use and outcomes

As indicated previously there are two alternative estimates of the number of people with autism in Bolton, from PANSI and Planning4care. As each uses slightly different assumptions and population projection data the estimated number of people with autism in Bolton varies. The increases predicted are based upon population growth rather than increasing prevalence.

Based on the PANSI model there is expected to be a 1.9% increase in the total number of people with autism aged 18-64 years in Bolton over the next 5 years (from 1,653 to 1,684) and a 4.1% increase by 2020 (1,721). Based on the Planning4care model there is expected to be a 2.9% increase in the number of people with autism aged 18 and over the next 5 years (from 2,440 to 2,510) and a 6.2% increase by 2020 (2,600).

It is difficult to estimate how many adults with autism are likely to require Adult Social Care in the future because data is not routinely collected on the numbers that are known to services. There is data though on the number of adults with learning disabilities known to Adult Social Care: 650 in 2011/12 and up to 33% (215) of these are likely to also have autism. Projections have been based upon this cohort identified through national research³¹ which is consistent with the eligibility criteria used in Bolton. Based on these estimates, there will be an increase of 6-14% in the number of adults with a learning disability and autism eligible for social care over the next 5 years, and an increase of 10.7-26% by 2020. This will mean an increase in Bolton from an estimate of 215 eligible users at present to between 238 and 271 in 2020.

Evidence of what works

Diagnosis

Guidance dictates that there must be a clear pathway to diagnosis and an appointed person in the Local Authority developing diagnostic services. All adults receiving a diagnosis of autism should be offered a community care assessment, regardless of where they are on the spectrum, and that all carers should be informed of their right to a carer's assessment³².

Autism awareness training

Health and social care are sectors where staff come into contact with adults with autism most frequently, and can be highly influential in determining the kind of support adults with

³¹ Emerson, E. and C. Hatton (2011) *Estimating future need for social care among adults with learning disabilities in England*, Department of Health.

³² Department of Health (2010) *Fulfilling and rewarding lives: The strategy for adults with autism in England*, Department of Health.

autism receive, both through needs assessment processes and in terms of the actual care and treatment prescribed or provided. For these sectors the need for awareness training is great, not only to improve knowledge but to change behaviour of staff³³.

Commissioning

The NAO surveyed 150 local authorities and their NHS partners between September 2008 and February 2009 and 1,000 GPs to assess service provision for adults with autism, including: health, social care, education, benefits and employment support³⁴. The report concluded that the organisations who support people with autism need better awareness of the number of people with autism, so that services can be planned, delivered and monitored appropriately to meet the needs of this group.

Prevention

Government guidance to local authorities emphasises the need to focus on early support rather than crisis management, placing greater emphasis on prevention, however, while most areas commission generic preventative services, this rarely includes specialist autism provision³⁵.

Personalisation

Health and social care provision is placing emphasis on personalisation to help people with autism access more appropriate services, for example, through individual budgets or direct payments. Direct payments were introduced to provide more flexibility for those assessed as needing services. A person receiving direct payments can arrange their own services instead of receiving the services directly from the local authority with the aim of providing a person with more freedom and control over the community care services that they receive, and ultimately greater independence.

Mental health

The National Autistic Society recommends using tools such as keeping diaries, talking about anxiety, using relaxation techniques and getting support from other people with autism, for example through support groups, to help people become aware of what is making them anxious and to help them manage their anxiety.

³³ Department of Health (2010) *Fulfilling and rewarding lives: The strategy for adults with autism in England*, Department of Health.

³⁴ National Audit Office (2009) *Supporting people through adulthood*, The Stationery Office.

³⁵ Department of Health (2003) *Fair Access to Care Services – Guidance on Eligibility Criteria for Adult Social Care*, Department of Health.

Delays in diagnosis can both impact on the family and give a higher chance of misdiagnosis with a mental health problem³⁶. This can cause expensive and inappropriate mental health interventions.

Cognitive Behavioural Therapy and Applied Behavioural Analysis are two interventions that have shown positive effects for adults with autism. Cognitive Behavioural Therapy can be used to improve social skills as well as treat co-morbid common mental health problems such as depression in people with autism, providing it is adapted to the cognitive style of people with the condition³⁷.

Employment

People with autism have difficulties with communication, social interaction and social imagination which can make finding jobs and retaining jobs problematic, particularly due to a propensity for other people to be unaware or misunderstand autism due to its 'hidden' nature. Support to overcome these barriers includes Disability Employment Advisors who are often the key contact through local job centres for people with autism with regards to training, employment issues, legal frameworks and overcoming general difficulties when job seeking. In addition to this, the Department of Work and Pensions (DWP) has an Access to Work programme aiming to help disabled people overcome work-related obstacles and to meet additional costs resulting from disability such as reasonable adjustments in the workplace, which is a legal requirement for all employers.

Housing

The National Autism Strategy states that:

- The needs of adults with autism should be taken into account in local housing planning, design and allocation, in line with local priorities;
- Support should be available for adults with autism who want to, or have to, live independently – both on an on-going basis and during the transition period into a new home;
- Adults with autism and their carers should be given help to understand the options available to them, including the financial help they may be entitled to.

The Disability Discrimination Act already requires local authorities to take account of the needs of disabled adults, including those with autism, when considering housing provision. For example, considering proximity of the home to sources of support, or recognising the individual sensitivities of the adult, such as hypersensitivity to harsh lighting. Additionally, local authorities are required to look at housing design and make reasonable adjustments to

³⁶ National Autistic Society (2009) *Statistics: How many people have autistic spectrum disorders*, The National Autistic Society.

³⁷ Attwood, T. (2007) *The Complete Guide to Asperger's Syndrome*, Jessica Kingsley Publishers.

choice based lettings. However, for most adults with autism the support programme is as important for living independently as the housing itself, for example assistance with personal care and safety, managing money, or help with decision making. The government's Independent Living Strategy aims to achieve this and to give disabled people who need support, choice and control over support delivery where wanted.

Social inclusion

Services and support dedicated to adults with autism can play a pivotal role in enabling effective use of mainstream services, and can help adults with autism to live more fulfilling lives in society. Similarly, many user-led and voluntary support groups help adults with autism build friendships, share experiences and live independently. These play an important role in enabling adults with autism to develop a social life, build relationships meet others with autism without worrying about how they will be judged or viewed. Support groups can also provide an important setting for training in life skills and social skills, for example in cooking, dealing with money and bills and relationship advice.

People with autism can respond to their environment in both negative and positive ways which may change over time. This may include showing a variety of emotions in different situations, having relationships with others, or the ability to focus in detail, particularly on a single activity which is of interest to them, which can often develop a high level of skill in that area and lead to sustainable employment. Those unable to live this more independent lifestyle want support to cope in social situations and learn social skills.

Advocacy

Advocacy is a process of supporting and enabling people to express their views, to access information and services, to find out about options and make decisions, and to secure their rights. The nature of autism particularly the propensity for an impaired ability to communicate means that many people with autism need help to express their needs and promote their rights. This may be needed at any time in the life-course, for example during the transition from child to adult services, or when seeking housing or employment. Advocacy services are seen as extremely important for people with a autism.

NICE Guidance

NICE guidance on Autism: Recognition, referral, diagnosis and management of adults on the autism spectrum was published in June 2012.

In conclusion, the key interventions for adults with autism are social support such as employment and education support, housing, social groups/social skills training which are likely to reduce isolation and access to early accurate diagnosis. Improvement of social support systems are likely to reduce the likelihood of a person experiencing common mental

health problems, however, appropriate intervention for those experiencing mental health problems is also vital for this vulnerable group. There is a need to support people with autism to be as autonomous as possible. The evidence also indicates that the needs of carers and family need to be considered and appropriately addressed due to the nature of autism and the impact this can have on family and carers' health and wellbeing.

Further key sources for information on effective interventions and evidence-based policy are highlighted on Bolton's Health Matters [by clicking here](#).

Community views and priorities

Since April 2011, a number of listening and consultation events have taken place in Bolton, inviting adults with autism, their families, and the general public to explore the key themes from the national strategy and to talk about living with autism in Bolton. Below is a summary of the key issues and concerns raised.

Improving autism awareness

Lack of information and understanding of the condition led some people to feel isolated, alone, bullied and harassed.

Actual or perceived bullying, harassment and hate crime were major issues for many of the people consulted with.

These negative experiences had occurred in childhood as well as in adulthood; in schools, in the work place, in the town centre, and in people's localities where they live.

All the aforementioned have resulted in some people feeling anxious and scared of being in the community as well as in their own homes.

Perceived positive impacts of raising awareness

People felt that raising awareness of autism would better prepare people to accept difference, be more supportive and understanding, as well as helping reduce the negative stigmas people felt were often associated with autism.

More awareness raising events, information workshops and support groups which provide emotional support for people in similar situations, and easier access into health and well-being centres, could help to increase understanding and reduce isolation.

Target groups for autism awareness raising included professional staff in health and social care including GPs and social workers, the police and probation, staff in Job Centre Plus and the employment sector in general, as well as staff in all mainstream services such as libraries and leisure centres.

Possible consequences of not raising awareness of autism:

- Continued lack of awareness and understanding;
- Continued negative stigmatisation of people with autism;
- Continued perceived and actual bullying, harassment and hate crime.

Getting a diagnosis of autism

A major theme for adults who may be on the autistic spectrum and their families.

Some adults had been diagnosed in adult life but had found it hard to attain this diagnosis.

For some people having a diagnosis of autism helped them better understand themselves as individuals and their own characteristics.

For other people, attaining a diagnosis validated their issues and allowed them additional resources, and/or support under the Disability Discrimination Act 1995.

This included employers, Colleges, and Universities making reasonable adjustments for people with autism.

The negative impacts of autism on people's lives

People indicated the significant impact autism has on their day to day life.

Some of these impacts includes difficulty socialising with others, severe depression and anxiety, irregular sleep patterns, increased anxiety when in the company of strangers, misreading people and situations, difficulty appreciating other people's perspective, being easily misled or being made a fool of.

Priorities for individuals

Getting a diagnosis, receiving good support.

Gaining employment.

Going to places where they felt safe such, as a support group.

Managing their own anxiety and stress and gaining more confidence.

Concerns for carers and families

Some carers and families of people with autism feared what would happen once their children left the structure of school.

They worried whether they would be able to get the right support access Further and Higher Education, whether they would be able to get a job and get the right support in the

workplace to be able to sustain their job, and whether the benefit system would give people the means necessary to live independently.

The type of accommodation on offer and where the accommodation is situated was also an issue for carers, fearing that living in certain ‘hotspots’ known for anti-social behaviour would only exacerbate the difficulties their siblings faced.

A further major cause of concern was how their siblings would cope if they as carers were no longer there. It was recognised that many carers spend a great deal of time in an informal caring capacity, spending hours on the end of the phone or with the person offering verbal and low level support and encouragement.

However, it was acknowledged that without this hidden support, their siblings are likely to require much greater and more formal means of support to survive the everyday challenges of life.

Ways to alleviate their concerns

Parents and carers felt that autism awareness raising was an absolute necessity across all walks of life.

They felt the need was particularly great with health and social care professionals, the police and probation, employers and employment agencies, within further education establishments, staff within the benefits agencies, and with housing officers.

Carers were also happy that the Government has started to recognize the difficulties faced by people with autism, in particular Asperger’s syndrome and are putting things in place to start to improve the issues.

Equality impact assessments

No recent local equality impact assessments have been carried out that we are aware of. If you are aware of any such work locally please let us know at [Bolton Health Matters](#)

Unmet needs and service gaps

A number of key priorities were highlighted in Bolton’s 2010-11 Autism Self-Assessment as follows:

- To identify appropriate preventative services for adults with Asperger Syndrome who may acquire associated mental ill health through anxiety, depression, drug and alcohol related abuse;
- To work with external agencies in targeted and mainstream services to ensure that staff teams have basic autism awareness training as a minimum requirement;

- To develop pathways of support that allow people with autism who are on the cusp of the criminal justice system or who are already within the CJS, improved support mechanisms;
- We need to improve how we engage with people on the spectrum so a wider representation of views can be fed into future commissioning plans;
- Surveys are not yet planned in to take place on a regular basis;
- To have a list of readily available advocates who can demonstrate awareness and expertise in this area;
- There is also a gap in support for adults following diagnosis. To have identified a pathway of support for adults post diagnosis assessed to be high functioning;
- To have agreed the roll out and level of training required across the social care and health workforce. To have identified the cost of training and agree who will deliver the training to such a wide audience.

More recent analysis has indicated the following issues in Bolton:

- Gaps in provision have been identified at all stages of the care pathway however these are hoped to be rectified by the introduction of a new assessment, diagnostic and after post support service being commissioned by the PCT in April 2013. There is, however, a risk that the capacity of the new diagnosis service will be insufficient given the level of unmet demand;
- A particular gap occurs when children with autism go through transition from child to adult services. This is a time when service delivery changes and is organised in a different way. Parents' perceptions of this are that support from the health service is lessened in comparison to the input they previously received from children's services when covered by a paediatrician. Higher thresholds in eligibility criteria also make it harder for them to access support from Adult Social Care. This creates additional stress for the individual and their carer increasing the risk of them both developing mental health problems;
- The challenges faced by adults with autism are often compounded by the lack of awareness and understanding by the public and frontline workers of autism and the adjustments that they could make for example, to the workplace, living environment, educational and leisure settings, to enable them to lead more fulfilling lives;
- There is a risk of falling between services and not having your needs met if you have autism but do not have a learning disability or a mental health problem. This is a particular risk for people with Asperger Syndrome who are not diagnosed until adulthood and for whom there is no distinct care pathway;
- In general, primary care has insufficient knowledge and skills to identify autism or to be able to offer support once diagnosed;
- There is insufficient post diagnostic support both immediately and in the long term if an individual does not meet the Adult Social Care eligibility criteria;
- The Statutory sector relies on the third sector to provide support to people awaiting diagnosis and post diagnosis for Asperger Syndrome but do not give any statutory funding to these services;

- The transition to independent housing options for people living with their parents need to be planned for when they are ready to make this move and well in advance of when the carer is no longer able to fulfil this role;
- Insufficient transition planning for people with Asperger's or High Functioning Autism going to university. They will need support at university if they are to stay the course;
- There are insufficient leisure and social and physical activities for people with autism to become involved with once they are over 18 years;
- There is insufficient access to respite care/breaks for the carers of adults with autism. This is particularly the case for people with Asperger Syndrome who are less likely to meet eligibility criteria for adult social care.

Recent national research³⁸ has highlighted the following:

- Mental health services are not always good at working with people with autism;
- Make sure that people with autism and mental health problems get good advocacy support;
- Identify people with autism and mental health problems in health records so that reasonable adjustments can be made e.g. appointment times, locations, easy read letters etc.
- Information about health services should be available in easy read and accessible formats.;
- Staff need training and other support to work with people with autism and mental health problems;
- Every step of the mental health care pathway needs to be adjusted so that people with autism can receive equal treatment. This starts with supporting people to have a good life, maintain their wellbeing and exercise choice and control. Health checks at the GP surgery should include mental health state, and adjustments should be made to appointment times, duration and interventions with the doctor, staff offering psychological therapies and others. Information about medication and other treatments should be provided in accessible formats and referral to inpatient services and other specialists will need to take account of how autistic people cope in unfamiliar environments. Highly specialist teams and services that assess and treat people with complex needs must also assist mainstream services to respond well in their turn, and discharge planning needs to accommodate the distinctive support needs of autistic and learning disabled people.

Based on the evidence the priority outcomes highlighted in our local Autism strategy are as follows:

1. Local organisations and services have a better awareness and understanding of autism

³⁸ National Development Team for Inclusion (2012) *Reasonably Adjusted? Mental Health Services for People with Autism and People with Learning Disabilities*, National Development Team for Inclusion.

The more people know about autism, the more support can be targeted more promptly and effectively, with the possibility of better outcomes for individuals, carers and their families. A multi-agency training plan will be rolled out across services and agree which staff will be trained and at what level; ranging from basic awareness raising to secondary training for professionals requiring more in-depth knowledge. Health and social care commissioners will ensure that good autism awareness training is built into the services they purchase.

2. A clear and consistent diagnostic pathway exists for adults with autism

A diagnosis can help explain to the individual and their family what had previously been unknown or misunderstood. It also avoids the problem of misdiagnosis and helps people access relevant services and benefits. Health and social care professionals working with people with autism need to know how to make a referral for a diagnosis. Staff involved in diagnosis and assessment will not only receiving training about autism, but also have an in-depth understanding of how the care pathway works.

3. All adults diagnosed with autism are offered a community care assessment along with information and advice about services

Following diagnosis, people need good, prompt information about autism and where to get support. Clear and appropriate information about local services for people with autism needs to be made available. People with autism can find assessments perplexing. Assessing the social care needs of someone with autism should be done by a professional with sufficient training and experience, and reasonable adjustments may need to be made to ensure the assessment is as productive as possible.

4. Transitional support is improved for young people with autism as they move into adulthood

Through school, young people with autism and their families will usually have had access to support that helps them achieve and be included. Without effective transition planning, this support could disappear once people with autism reach adulthood, leaving them isolated at this critical point. Organisations and services need to work collaboratively to ensure that young people with autism are given the right start in their adult life.

5. Adults with autism in Bolton are included and economically active

The ability to get and keep, a job and then to progress in work is a central part of social inclusion. We know that adults with autism are significantly underrepresented in the labour market and we are committed to doing more to help adults with autism into work. This will include new developing approaches that will better support

adults with autism and making sure that they benefit from wider employment initiatives.

6. Local planning and leadership is in place in relation to the provision of services for adults with autism

Through the Joint Strategic Needs Assessment (JSNA), there will be enhanced data available around adults and young people with autism in Bolton, leading to a better understanding of need. There will be local options for people with autism about where to live, how to spend their time and by whom they are supported. Specialist services are available for those who need them, offering structure routine and continuity. Mainstream services will be competent to support people with autism, with trained staff, low arousal areas and flexible processes.

Recommendations for further needs assessment work

There is currently very little local data on the number of adults with autism accessing specific services. Although the low levels of diagnosis among adults do make this challenging there are examples of good practice from other areas where services (e.g. social care, housing, health) are recording and sharing data about people with autism. This will help partners understand the scale of need for particular services currently, to consider service costs and to improve commissioning and monitoring of services.

Although it is unlikely that GPs will record information on autism routinely there have been audits of a sample of GP records in other areas and this suggests a potential way forward to confirm the prevalence of autism locally in the future.

The Bolton Health Survey will be repeated in 2013 and it is recommended that questions are included to provide a local estimate of prevalence based on self-identification of autism.

Although there has been some good consultation with people with autism and carers locally it is recommended that additional consultation focused specifically on the themes in the Autism Strategy and on the delivery of specific services locally would be beneficial.

We have insufficient evidence as of yet how Self Directed Support impacts on the demand and type of services required.

Key contacts

Mark Fraser, Commissioning Manager – Adults with Disabilities, Bolton Council

Autism Implementation Group

Autism Steering Group