

Bury Council

Market Position Statement: Adult Autism Strategy 2014



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1. What is a Market Position Statement?

A Market Position Statement is a document written by Bury Council, mainly for providers of care services, which will help them to:

- Make decisions about whether and how to invest and deliver services in Bury;
- React to opportunities that arise as a result of the introduction of Personal Budgets.

The main aim of this Market Position Statement is to raise awareness, increase access to universal services and to support and challenge stereotypes and perceptions. We will also work with people with autism, carers, partners and service providers to plan, commission and provide services in Bury where there is a need.

Bury Adult Care Services also want to make sure that people have more choice and control over the services they use and that these services offer high quality care and good outcomes.

The Adult Autism Market Position Statement must also have a major focus on raising awareness of autism across all agencies and partners. Therefore, it would be appropriate for providers to look at what they could do differently and how they could make reasonable adjustments to ensure adults with autism could access their services. They could also ensure that all staff have an adequate understanding and awareness of autism.

Please note that all data is correct at date of publication (October 2013).

2. Who is this document for?

This document is aimed at existing and future providers of services. This does not necessarily mean providing specialist autism services, this means that providers need to understand the needs of people with autism, be autism aware and train their staff appropriately in order that adults with autism are able to access services or use their budgets to access support or services.

It gives information on the current social care market alongside a vision for a diverse and active future for services.

Providers of services for people with autism can learn about the support which is purchased by both Bury Council and adults with autism themselves. This Market Position Statement also includes information on how services might respond to the personalisation of adult social care.

Voluntary and community organisations can learn about future opportunities in which to develop new activities and services for people with autism, whilst ensuring that current services are accessible to this audience.

People interested in local business development and social enterprise can read about new opportunities. You can also use this document as an opportunity to tell us what would attract you into the social care market. Social care providers and organisations not currently active in Bury could find opportunities to use their strengths and skills to benefit local people and develop their business. This also includes Community and 3rd sector organisations and citizens of Bury where they wish to consider developing community links based on an asset approach.

3. What is happening nationally?

In 2010, The Department of Health published a National Autism Strategy entitled "Fulfilling and Rewarding Lives: The Strategy for Adults with Autism in England (2010) which was followed by 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:

- Increasing awareness and understanding of autism among frontline professionals.
- Developing a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment.
- Improving access to the services and support which adults with autism need to live independently within the community.
- Helping adults with autism into work.
- Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities.

Traditionally, autism has not been identified as an individual service area. People with autism who are eligible for care services have usually been identified as having either a learning disability or mental health problem. However, this has now begun to change following the production of the National Autism Strategy.

On top of this, Adult social care is radically changing. Nationally there are a number of important messages to consider about how services are being transformed and how funding for them is changing.

Key considerations:

The government is committed to ensuring that personal budgets are available to everyone that receives ongoing funded social care by 2014.

More people, usually those with low or moderate needs, will also be funding their own care needs in the future.

The aim is to give people with disabilities the same opportunities and responsibilities, aspirations and life chances as other people. This is about making sure people with disabilities are involved in, and are in control of, decisions made about their lives; with greater access to housing, health, education, employment, leisure and transport opportunities and to participation in family and community life.

There is a key shift from caring to enabling and developing independence.

4. What is happening in Bury?

In 2012, Bury Council and the Clinical Commissioning Group in Bury developed the *Bury Adult Autism Strategy 2013-2016*. This strategy builds on the national autism strategy "Fulfilling and Rewarding Lives" to set out the local position in Bury. The strategy provides some useful background information to this Market Position Statement. The strategy can be found at <http://www.bury.gov.uk/index.aspx?articleid=8315>)

4.1 Data on people with autism

At the present time, it is not mandatory for any statutory service to record the numbers of people with autism. Currently, the only local data available to us is that gathered via GP registers, anecdotal data collected in Education by the Additional Needs Team, information on children who have a Statement of Educational Needs or Learners with Learning Difficulty/Disability and the numbers of adults with autism receiving a personal budget. However this data is not robust and cannot be used to accurately predict the numbers of adults with autism in Bury. However, this issue is being addressed, from April 2014 the Department of Health are requiring the mandatory recording of diagnosed autism for health and adult social care.

With the absence of any robust data, prevalence rates have been used widely to estimate numbers of people with autism. In recent years, we have seen a reported increase in the number of individuals with autism; research estimates suggests 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 accurate 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. Further information on people with autism can be found by accessing the local strategy (following the link above).

** 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)*

4.2 The pathway for adults with autism

There is currently no specific pathway into services for adult with autism in Bury. For Adult Social Care, any person with autism would be referred to the Vulnerable Adults Team and follow their pathway.

In the past, adults in Bury who required an assessment and diagnosis of autism could only access via a commissioned service based in Sheffield. However, Bury Clinical Commissioning Group have recently developed an interim local diagnostic service based in Bury which covers the North East Sector of Greater Manchester. The development of a more comprehensive multi-disciplinary service is currently in progress and will be up and running by March 2014. The focus of the service initially will be assessment, diagnosis and referral on to the appropriate services in an integrated manner. This diagnostic pathway will include post diagnostic support, signposting and referral as well as an automatic trigger for a Community Care Assessment.

4.3 Universal services

The term 'universal services' refers to information or a service which is available to everyone. There is no criteria or assessment to determine whether a person can access the service or not.

Examples of these universal services include community services such as social groups, information and advice services, help lines, brokerage and advocacy services, public health services and community meals.

4.4 Services available for adults with autism with an assessed need:

Personal Budgets

Bury Adult Care Services offer personal budgets to people who are eligible for Adult Care Services. The aim is to give people choice and control over the support that is right for them. To receive a personal budget a person has to be assessed by Adult Care Services as needing support to help them live independently and also be eligible for services under the Fair Access to Care Services criteria.

It is important, however, to ensure that all universal services and other support services make reasonable adjustments to ensure that adults with autism who hold a personal budget are able to access and purchase these services for their support.

Adult Care Services:

Although there are no specific specialist services, adults with autism who are eligible for care services may have access to traditional commissioned services, such as:

- Respite and short break services for carers
- Supported Living Services
- Domiciliary Care
- Intermediate Care
- Equipment
- Day Care
- Adult Placement

5. Finance and funding

The majority of the actions will be achieved by greater partnership working and investigating new models of delivery. This is particularly true in the case of awareness raising, social activity and information. We will work with the Greater Manchester Autism Consortium to look at best practice and share resources across the area. There is no specific budget or allocation of funding attached to the Adult Autism Strategy. However, we will invest in specialist training for those staff that need a detailed knowledge of autism. Funding has been allocated by the Clinical Commissioning Group for a local diagnosis pathway in Bury.

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 it is not possible, at present, to give an indicative spend on this client group.

6. What support do Bury adults with autism want?

In 2012, a consultation was undertaken with people with autism, carers of people with autism and professionals who work with people with autism by Bury Council and NHS Bury to inform the *Bury Adult Autism Strategy 2013-2016*.

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

- Lack of a clear local diagnosis assessment pathway and post-diagnosis support
- Lack of understanding of autism among frontline staff and those who undertake assessments within health and social care

- A shortage of preventative support services such as housing related support. For instance, people have highlighted a lack of understanding of autism during the allocation of appropriate housing. People also reported a lack of employment support services and volunteering opportunities, 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 and the general public
- Lack of facilitators to allow access to social opportunity

7. What does all of this mean to potential providers of services to people with autism?

These changes mean that there are opportunities for organisations to provide services for people with personal budgets and for individuals funding their own care needs, both in autism/learning disability services and in other areas of adult social care.

Based on the feedback from the Adult Autism Strategy consultation, people with autism and their carers in Bury are keen to access services and become a part of the community but are isolated due to the lack of understanding and awareness amongst services. Therefore, there are many opportunities to provide services for people with autism that may be of developmental interest to providers of services for people with autism. These opportunities could include working in partnership with an organisation already providing a service to expand their current remit.

Whilst we are keen to see innovative services developed for adults with autism within Bury, it is essential that they are:

- Flexible;
- Local;
- Affordable;
- Encourage peer support and friendship to decrease social isolation;
- Encourage independence and education/employment.
- Be fully autism aware to enable ease of access.

Types of support could include:

Autism Awareness

Throughout the consultation it was clear that there is a general lack of autism awareness across services. Therefore, an important consideration for all services is to ensure that staff at all levels are trained and fully autism aware to ensure that services are accessible to adults with autism.

Community activities, day services, social activity and low level support – you may want to consider providing recreational, social and leisure opportunities in the local community. You may also wish to consider supporting people with autism to attend existing clubs or activities in their local area or enabling them to access mainstream activity such as cinema, bowling, night clubs etc.

Employment, education, voluntary work and training – you may want to consider providing support and opportunities for people with autism to engage in employment, education, volunteering and training. In the consultation, it was stated that support to find employment had been very difficult or difficult. The main issues raised were the lack of appropriately trained support staff to help people with autism gain and maintain employment and the lack of understanding of employers. Also that job placements and placement suggestions are often unsuitable.

Advocacy, support planning and brokerage – some people with personal budgets may need support to make decisions and choices regarding their package of care. You may wish to offer services to help people set up and maintain their support plan or provide different types of advocacy support.

Personal support/personal assistants – in addition to the above point, some people with autism may wish to have personal support to enable them to gain more independence, rather than receiving traditional care on a day to day basis. This may be via paid employees such as personal assistants or befrienders or others who could facilitate social interaction and support.

During the consultation for the Bury Adult Autism Strategy, this was one which raised many issues for the respondents. People were passionate about wanting to develop a social life but were unsure how to do so. People are worried about meeting other people and how other people will react to them. Many respondents said they were 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. People stated they needed support to have a social life away from their parents and this is not available.

Respite – some people with autism or their carers may wish to take breaks away, stay in a hotel, stay with another family, or have assistants to stay in their home rather than go to traditional residential respite placements.

Managing a budget – you may wish to consider setting up a service to support people with autism and their carers to manage their personal budget.

Back office services – people that choose to have a personal budget may wish to employ a personal assistant to help them manage their support package and finances. This means they may need support recruiting, employing and training people as personal assistants, or help with job descriptions, payroll and criminal record bureau checks.

Housing. A 2011 Mencap national survey showed that most people with a learning disability want to live independently – either by themselves (43%) or sharing a home with friends (30%). Although there will always be a need for residential care, many people with learning disabilities would like to be able to live in their own homes, with greater independence, and have the opportunity to better integrate with their local community. Providers may wish to consider delivering services which meet these needs in Bury.

Specialist support. There are a variety of opportunities for providers to deliver specialist services. In Bury there are currently limited services for people on the autistic spectrum.

8. Quality

Bury Council has a Quality Assurance team that assess providers against the standards set by the Care Quality Commission and the Council's own Quality Assurance framework.

To support providers through the process, we have aligned the Council's Quality Assurance framework with the standards that have been set by the Care Quality Commission. This has streamlined the requirements placed on providers and enables them to focus on delivering quality services to customers.

We expect the highest standards of service for our customers and are supporting providers of services to work towards our standards.

9. Safeguarding

Bury Council has a strong commitment to keeping adults safe. This is achieved through positive and collaborative multi-agency working. Providers delivering services within the Borough will be expected to commit to this and will benefit from the support offered through our dedicated Safeguarding Adults Team.

10. Facilitating the market

In Bury, Personal Budgets have transformed the way services are commissioned and delivered and people are now in control of the support they wish to access. To support this transformation, the Council wishes to encourage innovation and the development of best practice in service delivery.

Further consideration is being given to how Bury Council can offer support to third sector organisations and private business which will enable the development of sustainable enterprises. This support could range from working with individuals to develop micro-enterprises from an initial concept, to supporting an existing organisation develop and adapt their business model to offer the range of services our customers want.

The Council has developed an online Care Directory for suppliers to advertise the services they offer, and importantly, for customers to have access to information on the types of services that are available in the market.

We actively encourage providers to submit their details onto our Care Directory; however, it is clearly up to the customer to decide whether or not they would choose to use such services. Details of the directory can be found by visiting our website using the following link: <http://www.bury.gov.uk/index.aspx?articleid=1621>

Who can I contact for more information?

We want to talk to all current and potential service providers to help you identify opportunities and provide innovative services.

For general information about the Market Position Statement, please contact:

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