

SECTION 3: ADULTS WITH AUTISM

Introduction

This is the first time detailed information about autism has been included in the Darlington Single Needs Assessment.

The Autism Act 2009 and the subsequent national strategy “Fulfilling and rewarding lives: The strategy for adults with autism in England”, place a range of obligations on the NHS, local authorities and other statutory agencies to meet the needs of people with autism.

The National Autistic Society describes autism as:

“A lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them”

It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have an accompanying learning disability and need particular support. People with autism may also experience over or under sensitivity to sounds, touch, tastes, smells, light or colours.

Asperger’s syndrome is a form of autism. People with Asperger’s syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.

The National Autistic Society also describes some of the impacts of autism and they include:

- Autism is a serious, lifelong and disabling condition. Without the right support, it can have a profound, sometimes devastating effect on individuals and their families.
- Autism is much more common than many people think. There are over half a million people in the UK with autism, that's around 1 in 100. If you include their families, autism touches the lives of over two million people every day. Using these figures there are approximately 1,000 people in Darlington on the autism spectrum.
- Autism doesn't just affect children. Children with autism grow up to be adults with autism.
- Autism is a hidden impairment; you can't always tell if someone has it.
- While autism is incurable, the right support at the right time can make an enormous difference to people’s lives.
- Nearly two-thirds of adults with autism in England maintain that they do not have enough support to meet their needs.
- At least one in three adults with autism also experience severe mental health difficulties due to a lack of support.
- Only 15% of adults with autism in the UK are in full-time paid employment.
- 51% of adults with autism in the UK have spent time with neither a job, nor access to benefits, 10% of those having been in this position for a decade or more
- 61% of those out of work say they want to work
- 79% of those on Incapacity Benefit say they want to work

On 17 December 2010 the Government published statutory guidance for local councils and local NHS bodies setting out what they have to do to ensure they meet the needs of adults with autism. The guidance is structured around four key themes.

- *Better Training:* Training to staff who provide services and support to adult's with autism. General autism awareness training should be available for everyone working in health and social care and key staff such as GP's and those responsible for conducting community care assessments should have specialist training. The guidance also says that people with autism and their carers should play a part in delivering this training
- *Diagnosis:* Central to the Governments vision for improving services and support is an improved diagnostic service. The guidance reaffirms the view that a community care assessment cannot be denied on the grounds of IQ alone. The guidance is clear that anyone with a diagnosis of autism is entitled to a community care assessment and their carers, a carer's assessment. Each area should have a clear route through which an individual can receive a diagnosis and access a community care assessment
- *Transition to adult services:* There is clear evidence that the transition from being supported as a child to being supported as an adult is a complex time for young people with autism and their families. The guidance seeks to make sure that the whole transition process works better for people with autism. The guidance also sets out that NHS bodies should make sure that there are agreements in place in each area for the transition of clinical mental health care for adults with autism who receive support from Child and Adolescent Mental Health services
- *Local Planning and leadership.* Each area is required to develop a local plan in relation to the provision of services and support to people with autism. The guidance also identifies two key actions:
 - Each Local Authority should allocate responsibility to a named joint commissioner/senior manager to lead commissioning of services and support locally
 - Commissioning should be based on accurate population figures and as such local authorities must improve the data they collect on autism.

In March 2015 the Government published further statutory guidance for Local Authorities and NHS organisations to support the continued implementation of the Adult Autism Strategy.

The Guidance reinforces the two key priorities of:

- A person having access to a clear pathway to diagnosis and that pathway is aligned with care and support assessments and there is post diagnostic support available if people do not meet the social care support criteria.
- Commissioning decisions need to be based on knowledge and awareness of autism, the needs of the local population and informed by people with autism and their families.

The overall vision of the strategy remains as “All adults with autism are able to live fulfilling and rewarding lives with a society that accepts and understand 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 to make the most of their talents”

The guidance is broken down into nine broad themes:

- Training of staff who provide services and support to adults with autism
- Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services and support
- Planning in relation to the provision of services for people with autism as they move from being children to adults
- Local planning and leadership in relation to the provision of services for adults with autism
- Preventative support and safeguarding in line with the Care Act 2014
- Reasonable adjustments and equality
- Supporting people with complex needs, whose behaviour may challenge or who may lack capacity
- Employment for adults with autism
- Working with the criminal justice system

What are the levels of need?

At present it is difficult to determine the actual levels of people with autism living in Darlington. Projecting Adult Need and Service Information (PANSI) predicts the potential need in Darlington. This is shown in the following graphs.

The following figures show a gradual reduction in the number of people with autism living in Darlington, however detailed work needs to be undertaken to establish and understand the actual need in Darlington.

Fig 41:

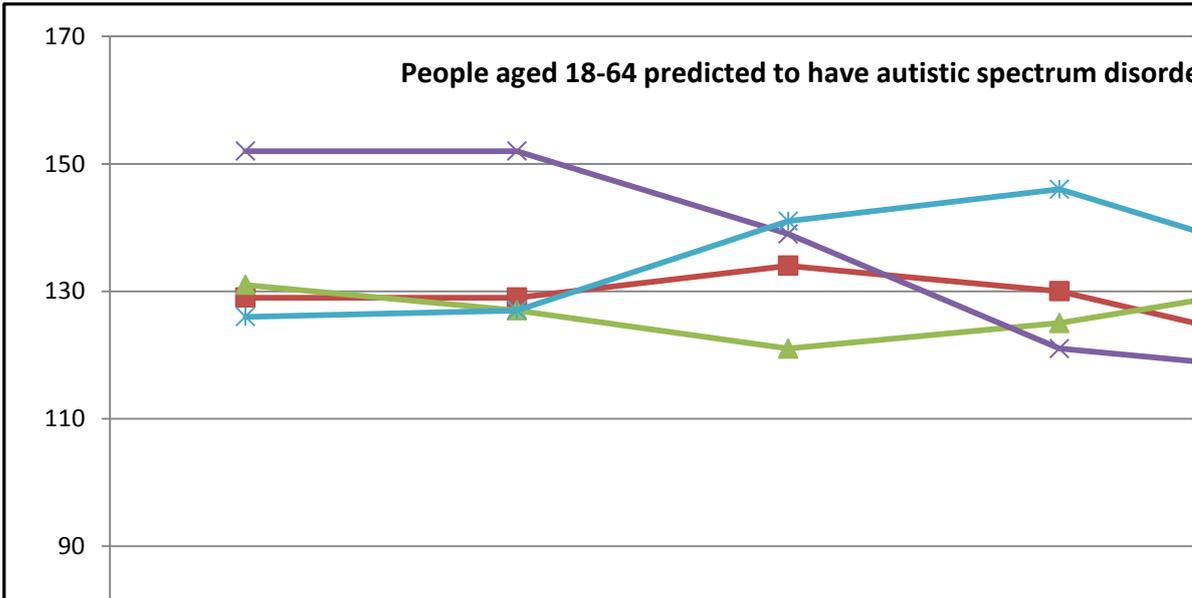


Fig 42:

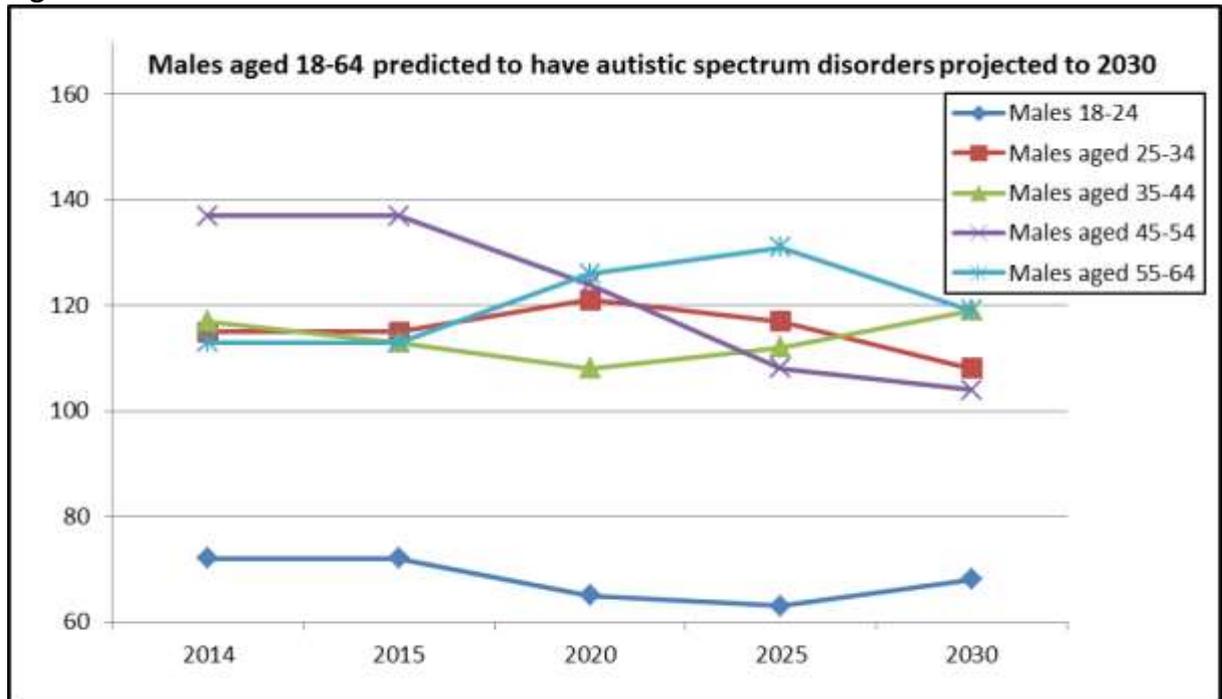
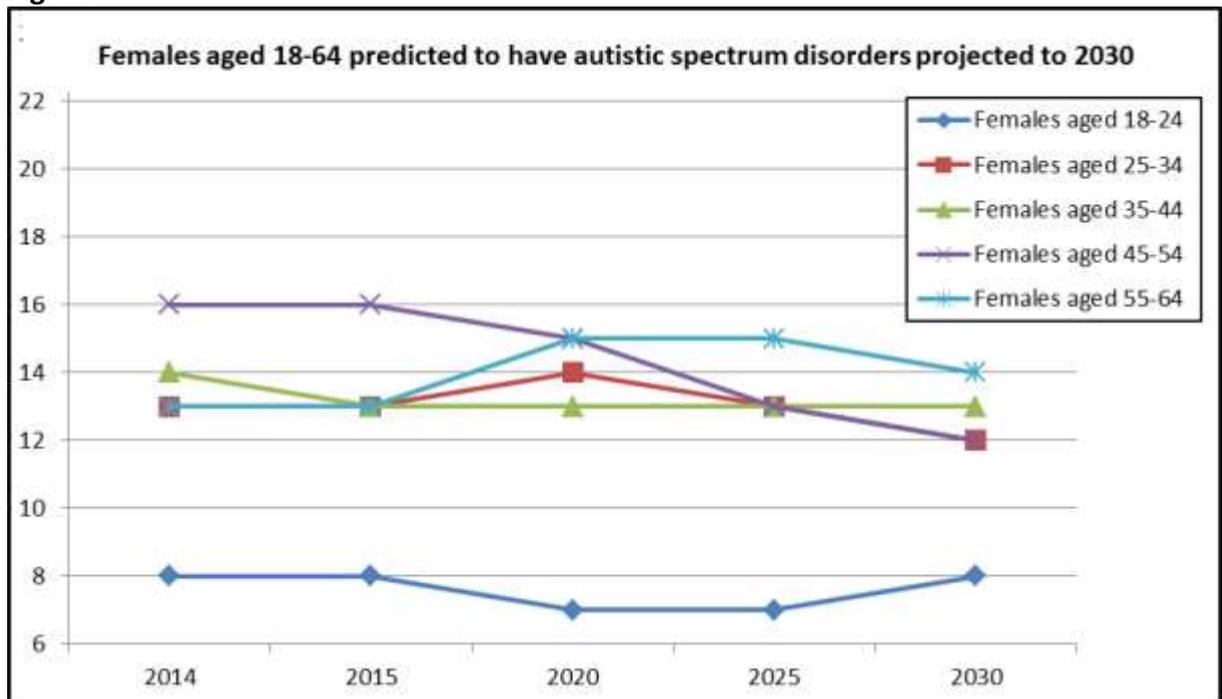


Fig 43:



Which groups are most vulnerable?

The latest prevalence studies of autism indicate that 1.1% of the population in the United Kingdom may have autism. However there are a number of groups who may be at greater risk

People with a learning disability – Research findings on the proportion of people with autism who also have a learning disability vary considerably as they are often affected by the method of case finding and sample size. However recent research published by the NHS Information Centre supports a prevalence rate of around a third of people with a learning disability also have autism.

Gender- Research indicates that five times as many males as females are diagnosed with autism. However there is some evidence that autism is under diagnosed in females, however the prevalence is higher in males than females.

Ethnicity – There is very little research into the impact of autism on individuals from black and minority ethnic communities. Given this it's likely that different communities will not be aware of autism, their rights and what support is available and the support that is available may not be able to meet need.

What are people telling us?

People with autism and their supporters in Darlington have identified the following issues/areas for support:-

- Access to and support in paid employment
- Support accessing benefits
- Using personal budgets
- Getting a diagnosis of autism
- Getting the right support
- The public should know more about autism
- People with autism need the right information

Nationally these are the issues that have been identified.

- Adults with autism often also have other co occurring conditions such as a learning disability or a mental health problem and the impact of autism can be lost by focusing on the other condition.
- Many older people are undiagnosed as autism was not formally recognised as a range of conditions until the late 1960's.
- People with autism and their supporters identify the potential to fall between learning disability and mental health services as a real risk.
- Access to and support in paid employment.
- People with autism are at high risk of social isolation and exclusion. The characteristics of having autism mean that developing friendships and social networks can be difficult and stressful.
- The National Autistic Society report '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's syndrome, 83% of individuals with Asperger's syndrome surveyed felt strongly that many of the problems they faced were as a direct result of others not understanding them.
- 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 adults.
- The incidence of disability hate crime against people 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.

What are the issues?

- Data on children, young people and adults with autism in Darlington is incomplete. Work is underway to ensure the data needed to effectively plan is captured and understood.
- Better engagement is needed with people with autism and their carers and supporters. Attempts so far have not been successful. The Council needs to understand how to do this better.
- Not enough staff trained in understanding autism and how it impacts on individuals.
- The impact of autism on older people is still not clear.
- Support available for people with autism who do not meet the eligibility criteria for social care is not set out in a way that people can use effectively.
- Work needs to continue in helping the wider community understand autism and how it impacts and an understanding of what reasonable adjustments services can make to accommodate people with autism.
- The needs of people with autism should be reflected in council and National Health Service plans, e.g. housing plans, public health plans.
- The support that people need to access paid work needs to be available.
- More information is needed about people with autism and their involvement in the criminal justice system.

Significant changes from last year

This is the first inclusion in detail of adults with autism in the Strategic Needs Assessment. Future Strategic Needs Assessments will include specific products to assist professionals and commissioners.