Topic Summaries

Autism

The following list of facts and statistics about Autism, and how it can affect children, adults and their families have been published by the National Autistic Society\(^1\). The term 'autism' is used in the list to describe all diagnoses on the autism spectrum including classic autism, Asperger syndrome and high-functioning autism:

- Autism can be a serious, lifelong and disabling condition. Without the right support, it can have a profound - sometimes devastating - effect on individuals and 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 one in 100. If you include their families, autism touches the lives of over two million people every day. Autism doesn't just affect children. Children with autism grow up to be adults with autism.
- Autism is a hidden disability - 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.
- Over 40% of children with autism have been bullied at school.
- Over 50% of children with autism are not in the kind of school their parents believe would best support them.
- One in five children with autism has been excluded from school, many more than once.
- Nearly two-thirds of adults with autism in England do not have enough support to meet their needs.
- At least one in three adults with autism experience 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.

A national prevalence for autism of about one in 100 suggests that we could expect around 837 children and young people in the county to have a diagnosis of autism. In 2013 there were 370 children with Special Educational Needs (SEN) whose primary need was autism, equivalent to 20.5% of the statemented population. It was the most common primary need among statemented children. Of those children with a current statement, the statement had been in effect for an average of six years\(^2\).

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\(^2\) Figures produced by NYCC Children and Young People’s Service.
In addition to those with a statement, in 2013 there were 189 children at SAP (School Action Plus) with a primary need of ASD, equivalent to 5.9% of the population at SAP (compared to 4.0% observed nationally) and was the 6th most common primary need among children at SAP in North Yorkshire. The number of children at SAP has risen sharply in North Yorkshire. This represents a trend for rising numbers of children with ASD at SAP.\textsuperscript{3}

Placements for children with statements for autism have changed from a larger proportion in special school in 2004 (46.6%) to a larger proportion in mainstream schools in 2010 (48.6%)\textsuperscript{4}.

Based on predicated adult population changes there is a small increase in the number of people aged 18-64 predicated to have autistic spectrum disorders in North Yorkshire. The predicted increase is from 3,587 (3,231 male, 356 female) in 2011 to 3,733 (3,379 male, 354 female) in 2030, a 4% increase. The highest percentage increase, 10.8%, is forecast in Selby and the lowest, a 3.9% decrease, is in Hambleton.\textsuperscript{5} The relative small numbers involved compared with the overall population sizes suggest not too much significance should be attached to the variations across the county. The overall prevalence might also be a slightly low estimate. The forecasts use a prevalence rate for ASD of 1.0% of the adult population in England (men 1.8%, women 0.2%), based on studies published in 2007. A new study suggests the rates may be nearer 1.1 % (men 2%, women 0.3%)\textsuperscript{6}.

The predicated small increase in the number of adults with autistic spectrum disorders in the county is also challenged by data produced by North Yorkshire’s Children and Young People’s Service which indicates an overall increase in statements for pupils with autism leading to an eventual comparable increase in the number of adults with autism.

\textsuperscript{3} Figures produced by NYCC Children and Young People’s Service.
\textsuperscript{4} Figures produced by NYCC Children and Young People’s Service.
\textsuperscript{5} Projecting Adult Needs and Service Information. Available at www.pansi.org.uk. Accessed 12/06/2012.
Evidence Base

The work on the North Yorkshire Children and Young People Strategy has been guided by the National Institute for Health and Clinical Excellence (NICE) guidance Recognition, referral and diagnosis of children and young people on the autism spectrum\(^7\). Other important publications include:

- The Autism Act 2010\(^8\).
- National Autistic Society publications\(^10\).

The Autism Education Trust\(^11\) publishes best practice regarding education of young people with autism.

NICE guidelines on the recognition, referral, diagnosis and management of adults with autism have been published in 2012. NICE are also currently considering proposed autism quality standards for adults and young people.

Services, interventions and programmes

- Service Level Agreements with Special Schools, Enhanced Mainstream Schools.
- ASCOSS—Autism Spectrum Condition Outreach Support Service for children and young people (centrally retained and commissioned elements).
- Three adult support groups provided by the National Autistic Society in Selby, Thirsk and Scarborough.
- Personalised Support packages for young people in transitions.
- Service Level Agreement with Health Providers specialist support services.

North Yorkshire Health and Adult Services provides and commissions a variety of services including respite, domiciliary day and supported employment services which are not specialists but accommodate people with autism. Two in-house services in Scarborough are accredited with the National Autistic Society. Advanced planning is in place to accredit the autism outreach team, enhanced mainstream schools and all learning disability services provided by North Yorkshire Health and Adult Services.

An Autism Steering Group comprising Adult Services, NAS and representatives from the North Yorkshire CCGs is drafting an adult services strategy for people with autism. A number of Engagement events throughout North Yorkshire delivered by the National Autistic Society. A strategy for meeting the needs of children and young people with autism has now been published and is available at northyorks.gov.uk/SEND. A joint health and

education implementation plan is in the process of being developed and will be published alongside the strategy. This, together with the SEND Strategy, the overarching local authority strategy for children with Special Educational Needs and Disability, will determine future shape of services.

**Unmet Need**

**Children**

Support for parents, carers, family and siblings e.g. at time of crisis, weekends and school holidays is limited. Specialist teachers are employed on Teachers’ Pay and Conditions and work term-time only. Children and young people frequently do not meet the criteria for ‘short breaks’, particularly those with a diagnosis of Asperger syndrome. Links with CAMHS, Disabled Children’s Services and Children Social Care need developing further. Universal services require additional support and training to enhance their knowledge and understanding of autism.

**Early intervention with families and young people.**

Early intervention is available for parents of recently diagnosed children and young people through parent training workshops such as Cygnet. Early intervention for families, particularly those in crisis is an issue due to lack of clarity re which agency provides support. The remains a necessity to increase the knowledge and understanding of universal, services in relation to autism.

- Support in pre-diagnosis and ‘no diagnosis’ cases. Support for children and young people of school age is offered by primary Enhanced Mainstream Schools and ASCOSS for Communication and Interaction and secondary Schools for Autism.
- Children with special issues e.g.: dietary issue, sexuality, mental health, continence. There is a clear need for specialist health input to address these areas. However, the LA includes input on key issues as part of Conferences, where possible. The strategy implementation plan includes workforce development opportunities in the areas of sexuality and mental health.
- A number of young people with autism not requiring specialist interventions are supported from general provisions from children social care (e.g. short breaks). The training needs of the staff in generic services will be identified and suitable training provided, as appropriate.

**Adults**

- Pathway for adult diagnosis is being reviewed by the Autism Strategy Group which will consider the feasibility of a local pathway for diagnosis and early support.
- Consideration is being given to enhance the support to follow up families post diagnosis for both children & adults.
- To facilitate lifestyle changes and adjustments as well as to access appropriate services. This could be provided in a number of ways depending on individual circumstances and severity.
• Specialist advice and signposting for adults not meeting Fair Access to Care (FAC) criteria and their families. Information on management of the condition and other services suitable for people with autism.

• General service provision needs to be reviewed in terms of suitability for people for autism. Awareness training will be required to ensure non-specialist services are able to adjust to the needs of people with autism.

• Specialist training for assessment staff within health and adult social to ensure they have the appropriate skills to undertake assessments.

Please note these are current needs identified as work in developing a local strategic document progresses; this will be updated.

Local Resources and Partnership Groups

Strategy for meeting the needs of children and young people with autism in North Yorkshire.

Adult Autism Self Assessment February 2012.

North Yorkshire PACT.

A Parent Forum for parents and carers of children with disabilities and special educational needs in North Yorkshire which although not specific to autism, does include autism. There is also strong partnership with the National Autistic Society locally, regionally and nationally and local voluntary groups, e.g. Flying High, Shortbreak Providers.

Transition Steering Group.

A Transition Steering Group co-ordinates the joint working between the children and adult services from the three key agencies (North Yorkshire Children and Young People Services, Health and Adult Services and North Yorkshire and York PCT) around transition and autism.

A specific Autism Strategic Group has been established and a Development Officer (Autism Strategy) has been appointed to co-ordinate a North Yorkshire strategy for adults; the post is also supported by an Autism Strategy Officer with specific responsibility for supporting Health and Adult Services staff undertaking assessments of adults with autism.

SEND 16-18 Group

A multi agency group responsible for the implementation of the 16-18 element of the North Yorkshire Children and Young People Services SEND Strategy.

Local Integrated Transition Planning and Review Groups. Three groups have been set up where all professionals involved in transition co-ordinate the assessment and review work of individual young people, including those with autism.

Other JSNA Themes

• Learning Disabilities.

• Carers.
Districts

• All.

Age Groups

• Adults.
• Children.

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