Autism Rapid Health Needs Assessment Gateshead 2016

Updated: July 2018

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Executive Summary

Introduction

Autism spectrum disorder (ASD) is a lifelong condition characterised by a 'triad' of impairments: social interaction, communication and the presence of repetitive behaviours. 'Spectrum' describes the large variations in severity and presentation, various IQ levels and general functioning.

One percent of the adult population in England has an ASD. Autism is more prevalent in men, 1.8% compared to 0.2% of women.

Gateshead population

Applying national population prevalence rates to Gateshead's population projections, 1,227 adults (18-64) may have ASD and 361 over 65's. With more people living longer, it is expected that the number of those with autism aged 65 and over will increase by 35% (127 individuals) by 2035, while the number for those under 65 will remain stable. 438 (January 2018) school-aged pupils (Years 1-11) have autism. This has increased significantly from 228 (Years 1-11) in 2012, following both regional and national trends.

Risk factors

Onset for all ASD conditions is before 3 years of age. Additionally, the aetiology is unknown. Misconceptions and false perceptions surrounding the condition are common, making it more difficult for people with ASD to access the right support. These negative connotations and perceptions can lead to isolation, loneliness, abuse and bullying.

Inequalities

The association between low socio-economic profile (SEP) and child disability is particularly strong for children with learning disabilities, especially children with *less* severe learning disabilities. More than 50 percent of the people who have an ASD condition also have an intellectual disability. Children with learning disabilities will experience a lower quality of life due to inequalities in access to support and services.

Morbidity and Mortality

Those with ASD are at greater risk of health problems and premature death than those without ASD. A Danish study by Mouridsen et al (2008) showed standard mortality rates for people with ASD are twice as high as the general population. Those with both epilepsy and autism have an 800% higher rate or mortality than those with autism alone. In Gateshead, this rate would calculate to 103 school aged children with both autism and epilepsy.

National reports, strategies and recommendations

'Fulfilling and rewarding lives' outlines the government's strategy for adults with autism in England, the first national strategy for adults with autism in England. This strategy followed on from the Autism Act, written to address the great disparity in services and care for adults with autism.

'Fulfilling and rewarding lives', the updated autism strategy was published, 'Think Autism: an update to the government adult autism strategy'. This strategy outlines three new, additional proposals:

1. *Autism Aware Communities* - Think Autism community awareness projects will be established in local communities and there will be pledges/awards for local organisations to work towards

2. *Autism Innovation Fund* - funding for projects that promote innovative local services and projects, particularly for lower-level preventative support

3. *Better data collection and more joined up advice and information* services - including a new way of social care staff recording someone's condition as autism, and a commitment to make it easier for people with autism to find information online about how their local authorities are performing.

Children and Young People
There is a greater prevalence of ASD for children aged 0-18 in more deprived areas of Gateshead. Exactly half (178) of all children with ASD are in the 30% most deprived areas and 75% or 2 out of every 3 children with ASD in Gateshead live in one of the 40% most deprived areas.

Adults & Older People
The particular needs of older people are considered in Gateshead's autism strategy, focusing on the themes of independent living and support. The National Autistic Society found that people with autism are 'often disregarded at both national and local level'. Despite the passing of the Autism Act in 2009, making it a legal requirement for all people diagnosed with autism to have their needs assessed by local services, 71% of over 45s who responded to a national survey did not have their needs assessed. In Gateshead, few services focus specifically on the needs of adults with autism.

Referrals to the ASD diagnostic service at NTW has increased over the period from 2010 – 2016, from 2 to 61.

There is an estimated 1,200 working aged adults in Gateshead with autism, 350 at retirement age and this is due to increase by 1/3 by 2030.

Oral Health
There are no dental practices in the Gateshead area which provide specialist services for individuals with autism. However, these patients are referred to the Community Dental Services (previous: salaried dental services), which has the skills required to assist patients with autism.

Learning Disabilities (IQ < 70)

There is a high prevalence of autism for those who have a learning disability. When planning service provision this high prevalence ought to be considered.

The exact number of those in Gateshead who have a learning disability *and* ASD is unknown, although 136 children with autism attend a SEN school in Gateshead.

Mental Health

Mental health issues appear to be more prevalent in people with intellectual disabilities than in the general population; a large number of those with autism also have a learning disability. Many symptoms of mental illness are wrongly regarded as challenging behaviour and so do not receive appropriate treatment. Mental health problems such as depression tend to be under-diagnosed in people with autism. People with autism may experience depression/anxiety, Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (ACD) or Schizophrenia. One third of adults with autism experience severe Mental Health issues due to lack of support.

Gypsy, Roma and Travellers

Children of Gypsies and Travellers experience a higher burden of illness and disease, with challenges in accessing sustained healthcare, contemporary advice and information. Consequently, early identification of special educational needs (SEN) often is lacking, resulting in diagnosis and interventions not occurring until school age, which can be less effective.

A health visitor and the Traveller Education Service regularly visit the site, identifying children in education and ensuring children are registered with a GP, however no specific autism services are provided for these communities.

Lesbian, Gay, Bisexual, Transgender (LGBT)

People with autism and those who identify as LGBT are often faced with discrimination and bullying. It has been shown that there is a higher percentage of people within the LGBT community who are on the ASD spectrum, the reasons for this are not well understood.

Young LGBT people who are diagnosed with autism are at a higher risk for compromised sexual health. There are no specific services in Gateshead for people who identify as LGBT and have ASD.

Advocates & Carers

Parents who care for their adult children with autism are mostly concerned with who will care for their children after they are no longer able to provide this care.

Parents, carers and people with autism are represented on the Gateshead Autism Steering Group and feedback relevant information to its members. Advocates have mixed knowledge and experience. Support is provided for people with autism as part of their personal care and support plan, enabling them to access everyday services. Carers and those with autism

also have means of participating with planning of services through 'Your Voice Counts' in Gateshead.

Black and Minority Ethnic communities
Approximately 3.7% or 7,500 people in Gateshead are from a BME group. This does not include the orthodox Jewish community, with over 3,000 people who state their religion as Jewish (including non-orthodox Jewish population).

Participants in a focus group study by the National Autistic Society, reported delays in diagnosis, which makes it challenging to access services. Some parents in the study found that schools tended to 'label their child with a behavioural issue', assuming 'black boys are badly behaved' or bad parenting was to blame, rather than sending the child for an autism assessment. Language issues can also delay diagnosis, as schools may believe the child's delayed development is 'due to them speaking another language as their first', rather than a delay due to autism.

Some communities are less aware than others of autism and understanding its affect on their child's development, although they may recognise something is 'different', they often misdiagnose the cause. Parents may try physical discipline or prayer to solve their behavioural issues.

Families found the condition isolating. Some lacked confidence when speaking with professionals and felt patronised at times, while others found it 'difficult to relate to professionals from a different ethnic background'.

Homelessness & Housing
There has been little research in the area of homelessness and autism; however, there is evidence that homelessness is considerably more common among people with autism than the general population. The housing needs of people with Autism are referred to in Gateshead's Universal Housing Strategy. Gateshead Council has a housing portal which allows for the council to understand specific housing needs of the community, a single point of contact. A more coordinated housing approach is being used to increase the supply of specialist and adapted homes, incorporating the specific needs of those with autism.

Employment
Interviews from a focus group suggest employment as a significant challenge for those with autism, including poverty, resulting in homelessness. GATES or Gateshead Access to Employment Services provided employment to 28 people with disabilities, in 2013 (including autism).

Offenders, including prison population
'Autistic people are more likely to be victims and witnesses of crime than offenders' (National Autistic Society, 2016); however, there are a significant number of prisoners who have autism. In 2011, NICE guidance was published for those in the prison system with autism. The Prison Reform Trust claims many of those in contact with the criminal justice system

have autism, including children; the system is particularly poor at supporting their needs and recognising those with autism.

Training has occurred and is ongoing within the Northumbria Probation Trust around autism, with one-off events for Offender Managers as well. Gateshead is hoping to have briefing sessions for Judges and barristers as well. Continuing discussions with the Criminal Justice System are occurring in terms of training around autism.

Gateshead Self-assessment
Prior to the most recent Autism consultation, in October 2013, Gateshead completed the Autism Self-assessment, a new requirement under the 'Think Autism' strategy. This self-assessment highlights areas where improvements can be made and where services are already meeting national requirements.

Consultation
A consultation took place from 23rd October 2014 – 19th December 2014 for all stakeholders in the Gateshead area to help shape the working priorities of the Autism Steering Group and Working groups.

Gateshead Autism Steering group developed an All Age Autism Strategy, with action areas for carers and partners dealing with autism, which they identified as being important and enabling, in order for them to live fulfilling lives.

The following services were created in response to consultation:

Autism Service Directory

An autism service directory was created, providing 'clearer information about the services and support' that is available in the area.

Autism Information Hub (Gateshead (AIH), 2016)

The Hub provides resources about autism and face-to-face monthly signposting and information services with trained autism specialists. Resources include books on diagnosis, sensory differences, anxiety, sleep and social skills. Many of the staff in the library are trained Autism Supporters. The library also provides a quiet space.

Autism Support Services

Set up following consultation with parents and families of children with autism, Autism Support Services supports people in the referral for diagnosis process, early stages of diagnosis, outreach support, home education support, sibling support, group support, online support, appeals and tribunals, behaviour challenges, information on autism and liaising with schools and professionals.

Recommendations

- Audit of services available for those with ASD who are 18+

- Research into the local homeless community and rough sleepers

- Gypsy Roma Traveller groups: better understanding of engagement with autistic children within these communities

- Autism Supporters: so far there has been no uptake of use of this service at the Council, however it is a new service. Increase awareness of this service to the local community and professionals.

- 2 of 3 children who are diagnosed with ASD living in the most deprived areas of Gateshead
    – Diagnostic bias?
    – Social Worker involvement?
    – Behavioural issues at school more likely to lead to ASD diagnosis if poor?
    – Stigma of diagnosis?
    – More research needed in this area to find out why autism seems to be linked with deprivation, in children.

- Dental practices within the Gateshead area ought to provide specialist services for individuals with autism through the provision of training for General Dentists.

1. Purpose of Health Needs Assessment

'A community of interest is a group of people who may come from any gender, background or geographical area who have something in common. Their link can be an interest or a health issue and they may share some of the same concerns' (Gateshead, 2016). People with autism have been identified as a community of interest in Gateshead's Joint Strategic Needs Assessment. This document provides an overview of autism in Gateshead. This autism needs assessment aims to provide quality evidence to inform Gateshead's Autism Strategy.

A health needs assessment (HNA) is a systematic method for reviewing the health issues facing a population, leading to agreed priorities and resource allocation that will improve health and reduce inequalities

Why undertake HNA?

- HNA is a recommended public health tool to provide evidence about a population on which to plan services and address health inequalities

- HNA provides an opportunity to engage with specific populations and enable them to contribute to targeted service planning and resource allocation

- HNA provides an opportunity for cross-sectoral partnership working and developing creative and effective interventions

Benefits:

- Strengthened community involvement in decision making

- Improved team and partnership working

- Professional development of skills and experience

- Improved communication with other agencies and the public

- Better use of resources

Challenges:

- Working across professional boundaries that prevent information sharing

- Developing a shared language between sectors

- Obtaining commitment from 'the top'

- Accessing relevant data

- Accessing the target population

- Maintaining team impetus and commitment

- Translating findings into effective action

Health needs can be:

- Perceptions and expectations of the relevant population (felt and expressed needs)

- Perception of professionals providing services

- Perceptions of managers of commissioner/provider organisations, based on available data about the size and severity of health issues for a population, and inequalities compared with other populations (normative needs)

- Priorities of the organisations commissioning and managing services for the profiled population, linked to national, regional or local priorities (corporate needs)

- HNA should involve balancing these differing needs and using the results to improve health and health services

HNA may also involve the assessment of health inequalities between or within a population. Health inequalities are defined as 'disparities in health between population groups that are systematically associated with socioeconomic and cultural factors', such as educational status, social class, ethnicity, place of residence, income.

2. Introduction

Autism spectrum disorder (ASD) is a lifelong condition characterised by the following three impairments: social interaction, communication and the presence of repetitive behaviours. 'Spectrum' describes the large variations in severity and presentation, various IQ levels and general functioning. For the purposes of this health needs assessment, Asperger's Syndrome and high functioning autism will be included (National Autistic Society, 2013). According to ICD 10, an autistic disorder 'is the abnormal or impaired development in social interaction and communication coupled with a restricted repertoire of activity and interest. Manifestations of the disorder vary depending on the developmental level and chronological age of the individual' (World Health Organisation, 1993).

One percent of the adult population in England has an ASD, according to a survey from 2007 (HSCIC, 2007). Autism is more prevalent in men, 1.8% compared to 0.2% of women (Gateshead, 2016). Of the estimated 1.2 million people with learning disabilities (one in 50) in the UK, 20-33% also has an autistic spectrum disorder (ASD). In other estimates, 55%

of children (10-14) with an ASD also have a learning disability, which may require lifelong specialist support (Emerson et al, 2012; Gateshead, 2016).

3. Aim & Objectives

The aim of the autism health needs assessment is to understand the needs of those with autism in the Gateshead population, including high-risk groups, and establish whether the content and configuration of existing services meet this demand. It aims to inform the planning and development of autism health and social care provision across Gateshead, by understanding the population, epidemiology, current services and future need. In addition, in understanding the needs of those with autism in Gateshead, the following questions will be answered:

- How many people in Gateshead currently have ASD?

- What preventative factors could reduce demand for services and reduce need for primary and secondary care interventions?

- What is the impact on physical co-morbidities for people with autism?

Objectives for this HNA include:

- A summary of the national and local policy and strategic background;

- An estimation of current incidence and prevalence of autism in Gateshead;

- A forecast of numbers affected, future population projections for Gateshead and what this may mean in terms of the needs of local people and demand for services;

- An assessment of impact of autism on individuals, families, carers and communities;

- An assessment of the impact on physical co-morbidities for people with autism;

- Identification of current autism services available to people in Gateshead, assess whether they meet current demand and highlight any gaps or overprovision now and in the future;

- A summary of evidence and guidance;

- Recommendations for next steps in the response to current needs in Gateshead.

4. Inclusion and Exclusion

The autism health needs assessment will include all ages, including the needs of high priority groups where information is available, as detailed below:

- Children & young people

- Adults & Older people

- Learning disabilities

- Mental health issues

- Gypsy Roma Traveller

- LGBT

- Carers

- BME

- Homelessness & Housing

- Employment

- Offenders including prison population

5. Background

Autism is a spectrum condition, meaning the condition affects different people in different ways, however they may share 'certain areas of difficulty'; some may need specialist care due to learning disabilities and others may live independently (Gateshead, 2016). 'Over or under sensitivity to sounds, touch, tastes, smells, light or colours' may also be experienced by those with autism (Gateshead, 2016). Those with Asperger Syndrome may experience difficulties understanding and processing language, however, they may have fewer issues with speech and average or above average intelligence (Gateshead, 2016).

All people on the autism spectrum share the 'triad of impairments', which include difficulty with social communication, social interaction and social imagination (Foundation for people with Learning Disabilities, 2012).

6. Gateshead population

Figure 1: Mid-year population estimates 2005-2015

| All Ages	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
Gateshead	192,900	193,600	194,900	196,100	197,500	198,700	200,300	200,200	200,000	200,500	201,000

Applying national population prevalence rates to Gateshead's population projections, 1,227 adults (18-64) may have ASD and 361 over 65's (PANSI and POPPI, 2014). With more people living longer, it is expected that the number of those with autism aged 65 and over will increase by 35% (127 individuals) by 2035, while the number for those under 65 will remain stable (Gateshead, 2016). 438 school-aged pupils (Jan 2018) (Years 1-11) have autism. This has increased significantly from 228 (Years 1-11) in 2012, following both regional and national trends. 365 under 0-18's have a diagnosis of Autism in Gateshead.

Some with ASD overcome difficulties finding employment and live a fulfilling life without the support of services, while others may find employment and independence difficult, despite being intellectually able, so will need support from services (Gateshead, 2016).

Figure 2: Mid-year population estimates 2005 – 2015 (Age 0-24)

Age 0-24	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
Gateshead	56,800	56,800	57,200	57,100	57,100	57,100	57,400	57,000	56,500	56,700	57,200
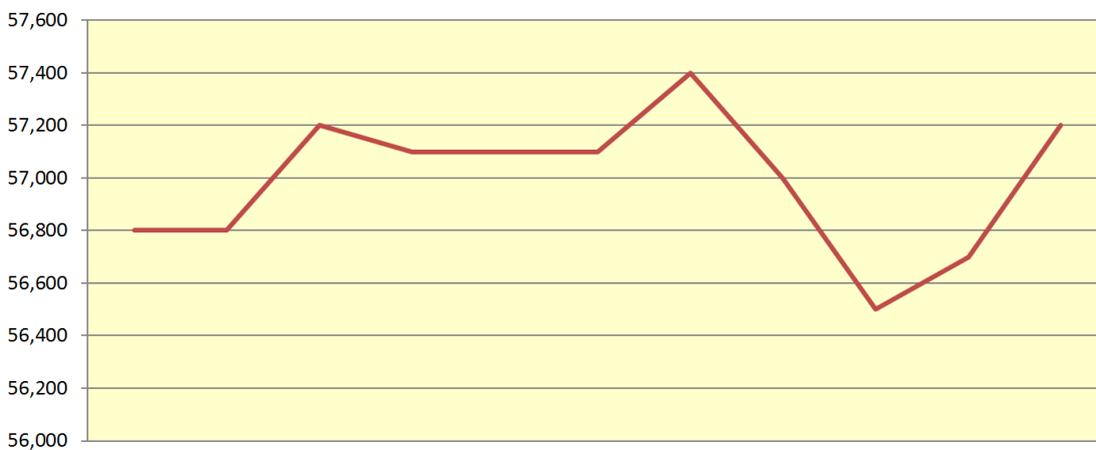
7. Risk factors

Onset for all ASD conditions is before 3 years of age (Foundation for people with Learning Disabilities, 2012). Additionally, the aetiology is unknown, although there are some instances where there may be a genetic link (Foundation for people with learning disabilities, 2012).

With 1 in 100 people in England diagnosed with autism, misconceptions and false perceptions surrounding the condition are common, making it more difficult for people with ASD to access the right support (Gateshead, 2016). These negative connotations and perceptions can lead to isolation, loneliness, abuse and bullying (Gateshead, 2016).

- Autism affects both children and adults

- Can be a 'hidden disability'

- According to the Gateshead JSNA (2016), 70% of adults with ASD say 'they are not getting the help they need from social services'.

- Seventy percent of adults with ASD said 'that with more support they would feel less isolated' (Gateshead, 2016).

- Lacking in adequate support, 1 in 3 experiences mental health issues (Gateshead, 2016).

- 15% are in full-time employment (Gateshead, 2016)

- 10% receive employment support, while 53% say they would like support in gaining employment (Gateshead, 2016).

8. Public Health & Inequalities

The UK Faculty of Public Health defines Public Health as 'the science and art of promoting and protecting health and well-being, preventing ill-health and prolonging life through the organised efforts of society', which includes protecting the health and well-being of people with autism (Faculty of Public Health, 2010). Factors such as income, housing, workplace, access to healthcare, education, public planning and relationships all affect the health and well-being of an individual (Local Government Association, 2010). Altering these environmental conditions through policy, strategy and public services may increase one's health outcomes and overall quality of life.

Source: Local Government Association, 2010

The UK government is committed to reducing health inequalities within the population. It is a statutory requirement under the Public Sector Equality Duty of the Equality Act 2010 for health and social care agencies to address inequalities (Equality and Human Rights Commission, 2010).

The association between low socio-economic profile (SEP) and child disability is particularly strong for children with learning disabilities, especially children with *less* severe learning disabilities. More than 50 percent of the people who have an ASD condition also have an intellectual disability (Brugha et al, 2012). For those with both autism and learning disabilities, this is of great concern. Children with these conditions are more likely to become poor, remain poor and experience longer spells of poverty and less likely to escape poverty (PHE, 2015). Children with learning disabilities will experience a lower quality of life due to inequalities in access to support and services (WHO Europe, 2010).

Figure 3: Gateshead IMD Ranking

Gateshead is ranked 73rd out of 326 local authorities where 1 is the most deprived (rank of average score – overall IMD).

	IMD 2004	IMD 2007	IMD 2010	IMD 2015
Gateshead	26	52	43	73
Newcastle	20	37	40	53
North Tyneside	80	102	113	130
South Tyneside	27	38	52	32
Sunderland	22	35	44	37

A rank of 1 represents the highest level of deprivation in England

Due to improved diagnostic methods, widening criteria, increased awareness and less stigmatisation, autism diagnosis amongst children has seen a steady increase since the 1960's (Brugha, 2012). Despite this, a study by researchers at Newcastle University, published in 2010, highlights the inequalities that remain in diagnostic services for children with ASD after the creation of a standardised diagnostic assessment tool in 2003, as there are many areas across the country that continue to see delays in their referral service and diagnosis (Palmer et al, 2010). The tool has 'considerable resource implications' for the assessment teams which could be why significant delays still occur (Palmer et al, 2010). The study concludes that 'providers should continue to improve services in order to deliver timely and comprehensive assessments for children with ASD' (Palmer et al, 2010).

Following the publication of this study, updated NICE guidance on ASD was published in January 2014. The following are eight NICE statements, which aim to reduce inequalities and improve quality of outcomes for those with ASD (NICE, 2014).

Statement 1: People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.

Statement 2: People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.

Statement 3: People with autism have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team.

Statement 4: People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.

Statement 5: People with autism have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address the core features of autism.

Statement 6: People with autism are not prescribed medication to address the core features of autism.

Statement 7: People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.

Statement 8: People with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

Additionally, an appraisal of the literature by Emerson et al (2011) 'suggests higher rates of mortality and morbidity among people with ASD.

9. Morbidity and Mortality

Those with ASD are at greater risk of health problems and premature death than those without ASD. A Danish study by Mouridsen et al (2008) showed standard mortality rates for people with ASD are twice as high as the general population. In particular, the study found women with ASD are at greater risk (Mouridsen et al., 2008). 26 individuals died in the study, nearly double the expected rates predicted of 13.5 deaths. Additionally, epilepsy either caused or contributed to 12 or 46% of these deaths, while infectious disease and 'unnatural' deaths, such as suffocation or drowning were the other causes of death (Mouridsen et al, 2008).

Communication difficulties, including poor social communication, may make it more difficult for people with ASD to access timely and adequate medical attention than the general population or be more susceptible to accidental death, while insensitivity to cold or pain may further exacerbate the issue (Mouridsen et al, 2008).

A study by Pickett et al (2011) shows a high risk of mortality for those with both autism and epilepsy, a co-morbidity of autism, 30% of those with ASD also have epilepsy (University of Washington, 2010). Those with both epilepsy and autism have an 800% higher rate or mortality than those with autism alone (Pickett et al, 2011). In Gateshead, this rate would calculate to 103 school aged children with both autism and epilepsy.

10. National reports, strategies and recommendations

In 2007, the **Mental Capacity Act 2005** came into force, empowering and protecting people who may not be able to make decisions on their own. This Act helps to protect the health and well-being of vulnerable people.

The Government paper, '**Fulfilling and rewarding lives**' outlines the government's strategy for adults with autism in England, the first national strategy for adults with autism in England (Department of Health, 2011). This strategy followed on from the **Autism Act**, which was signed into legislation in 2009, demonstrating the government's new commitment in supporting adults with autism, transforming the care and support provided previously. This Act was written to address the great disparity in services and care for adults with autism, as many remain unemployed, have worse health outcomes, and lack independence (Department of Health, 2011).

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

(Department of Health, 2011). Although most adults with autism do live high quality, fulfilling, rewarding lives, which are well supported, there are still some who are 'socially and economically excluded', in many cases, public services have failed them (Department of Health, 2011). Their voice often goes unheard.

'Fulfilling and rewarding lives' addresses the following areas (Department of Health, 2011):

- Increasing awareness and understanding of autism

- Developing a clear, consistent pathway for diagnosis of autism

- Improving access for adults with autism to the services and support they need to live independently within the community

- Helping adults with autism into work

- Enabling local partners to develop relevant services for adults with autism to meet identified needs and priorities

Following on from the 2010 autism strategy, 'Fulfilling and rewarding lives', the updated autism strategy was published, '**Think Autism: an update to the government adult autism strategy**' (The National Autistic Society, 2014). This strategy outlines three new, additional proposals:

4. *Autism Aware Communities* - Think Autism community awareness projects will be established in local communities and there will be pledges/awards for local organisations to work towards

5. *Autism Innovation Fund* - funding for projects that promote innovative local services and projects, particularly for lower-level preventative support

6. *Better data collection and more joined up advice and information* services - including a new way of social care staff recording someone's condition as autism, and a commitment to make it easier for people with autism to find information online about how their local authorities are performing.

Other developments in 'Think Autism' include (The National Autistic Society, 2014):

- local authorities need to report on data about people with autism for the first time

- the Royal College of GPs has made autism a priority for training and awareness over the next three years

- autism awareness training will be made available to all mainstream healthcare professionals

- new autism training will hopefully be rolled out to all Disability Employment Advisors at Jobcentres

- the Government has committed to reviewing the autism strategy again within the next five years.

Subsequent to the updated autism strategy, the government wrote '**Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy**' (Department of Health, March 2015). This document outlines what the local authorities CCGs and NHS bodies ought to do and must do concerning the provision and planning of autism services under the 'Think Autism' strategy.

Gateshead Council has aligned its Autism strategy with national policy. The following ten key priorities have been set from the Transforming Care Autism Task and Finish group. Feedback from two conferences held to raise the profile of Autism as part of the Transforming Care agenda in September 2016 and April 2017 provide information from autistic people, family, carers, and professionals regarding gaps in services.

A life course approach should be taken to supporting autistic people.

1. "Nothing about us without us' - Autistic People represented at Local and Regional Transforming Care groups.

2. Training - Co commissioned by Health and Social Care, which is co delivered and co designed by Autistic People, to be delivered to Health, Education, Social Care, Criminal Justice System, Community and Voluntary sector staff.

3. Appropriately resourced Diagnostic and post Diagnostic follow up and support services across the region.

4. Ongoing access to low level preventative services.

5. 24/7 Access to Specialist community support for Autistic people.

6. Housing and Accommodation with Autism specific support and Multi-Disciplinary specialist input.

7. To ensure that autistic people have their voice heard carers should be involved where appropriate, and advocacy support readily available for individuals who need it.

8. Closer Health and Social Care integration.

9. Reduce current inequalities for Autistic People (Annual Health, Register, Education Healthcare Plans).

10. Paid employment for Autistic people linking to TC project work e.g IT service directory, self-help guides etc.

11. Children and Young People

- 34% of children with ASD say that being picked on is the worst thing about being at school (Reid, 2011).

- 63% of children with ASD 'are not in the kind of school their parents believe would best support them' (Reid, 2011).

- 17% of children with ASD have been suspended from school and almost half of these have been suspended three or more times, while 4% of these have been expelled from one or more schools (Reid, 2011).

Young people with autism are particularly vulnerable to abuse and violence. The National Autistic Society developed guidance, *the protection of children and young people with autism from violence and abuse* (National Autistic Society, 2007), for professionals on how to reduce the risk of abuse and violence and counsel those who have suffered from abuse and violence. People with autism have difficulties understanding social situations and communication; therefore, professionals must learn the best means of clearly communicating with individuals and learn to recognise signs of abuse (National Autistic Society, 2007).

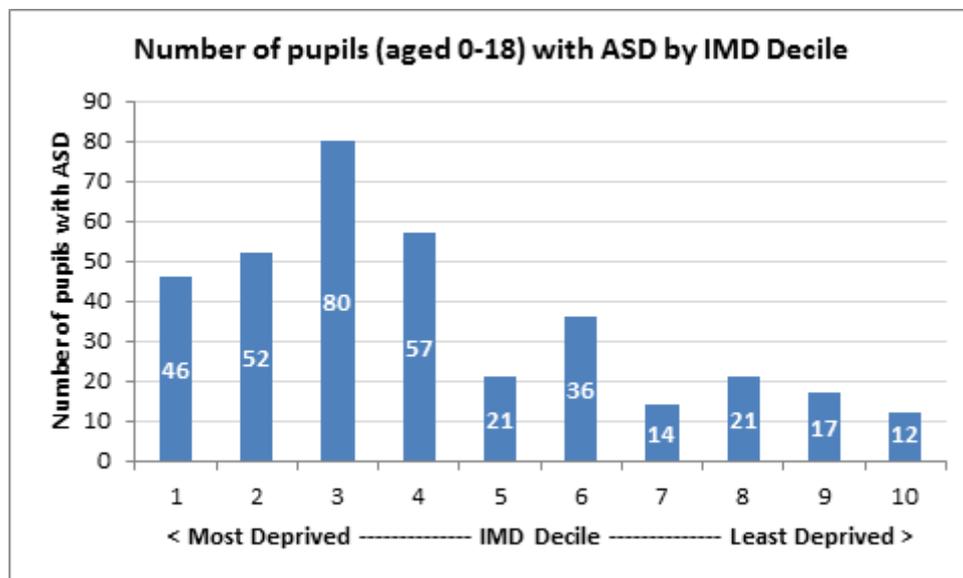*Figure 4: Number of pupils (aged 0-18) with ASD by IMD Decile*

Figure 4 shows a greater prevalence of ASD for children aged 0-18 in more deprived areas of Gateshead. Approximately half of all children with ASD are in the 30% most deprived areas and 75% or 2 out of every 3 children with ASD in Gateshead live in one of the 40% most deprived areas.

The number of pupils with autism diagnosis in Gateshead has steadily risen since 2015, from 293 in 2015 to 379 pupils in 2017. 108 of these students, in 2017, were in mainstream primary schools, while 115 in mainstream secondary schools.

The Gateshead Autism Steering Group developed an all age autism strategy, in which the transition team are represented on the group. The transition process for children with autism from Children's Social Services to Adult Social Services has been highlighted as a key area in the government's autism strategy (Department of Health, 2011). This is an automatic process in Gateshead in Year 9, as Children's Social Services passes the young person's details on to a transition team (PHE, October 2013). This team works with the child until the age of 16 when the team will work together with the young person, their family and Children's Social Services to develop a plan for their move into Adult Social Services (PHE, October 2013). In some instances due to the individual's level of need, an individual with autism may not meet the Fair Access to Care criteria (PHE, October 2013).

12. Adults & Older People

The particular needs of older people are considered in Gateshead's autism strategy, focusing on the themes of independent living and support. Autism does not only affect children but children with ASD grow into adults and now the first generation of people who were diagnosed with autism are entering their 60's and 70's.

After a campaign to highlight the challenges that adults with autism face, the National Autistic Society found that people with autism are 'often disregarded at both national and local level' (National Autistic Society, 2012). Despite the passing of the Autism Act in 2009, making it a legal requirement for all people diagnosed with autism to have their needs assessed by local services, '71% of over 45s who responded to our survey haven't had their needs assessed' (National Autistic Society, 2012). This may be the reason why more than half of those over 45+ 'said they don't have enough support to meet their needs' (National Autistic Society, 2012).

For those over the age of 45 who feel they do not have enough support (National Autistic Society, 2012):

- 62% said with more support, I would be less isolated

- 61% said with more support, my general health would improve

- 51% said with more support, I would be more independent.

- 46% of over-45s and 45% of over-55s rely on their family to some extent for financial support

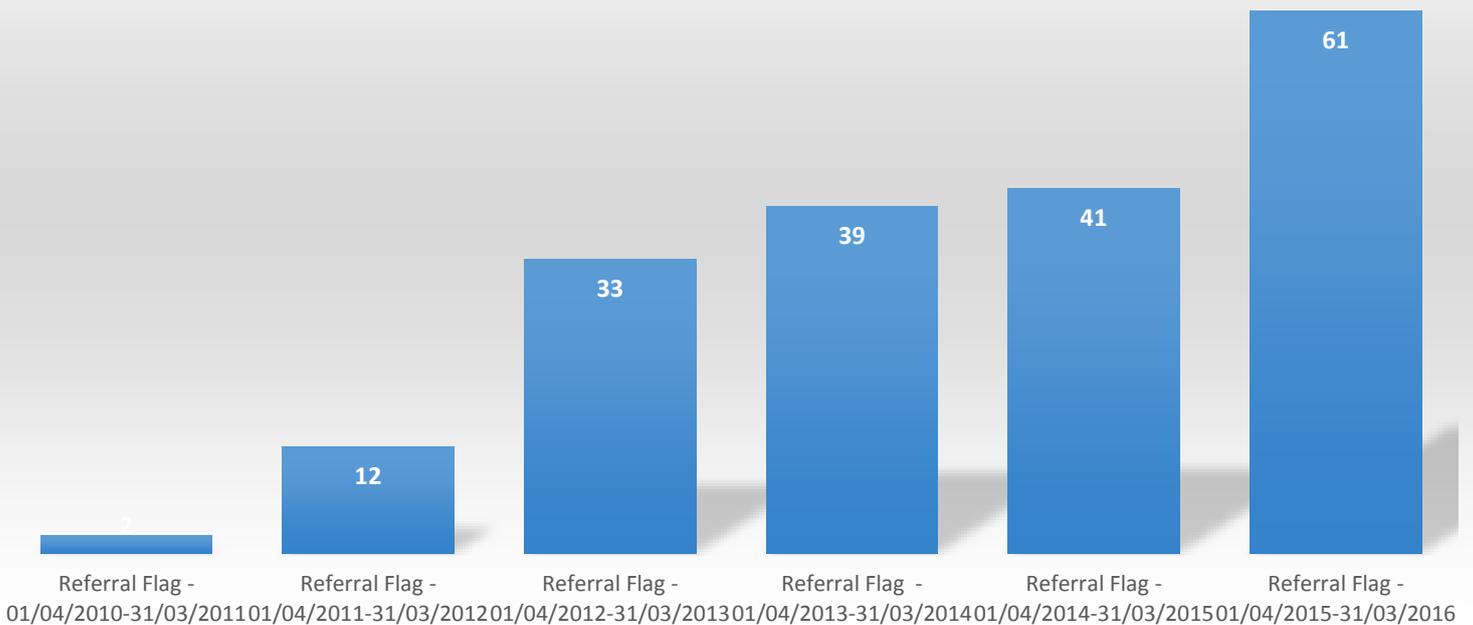- 21% of over-45s and 24% of over-55s rely a lot on their family

- 25% of over-45s and 21% of over-55s rely occasionally on their family.

Most of their peers will have moved on to independence after 18 years of age, while many adults with autism are never able to gain this independence (National Autistic Society, 2012). This may be due to the lack of local authority support. Social isolation experienced by older people with autism is an area requiring more investigation and attention (National Autistic Society, 2012).

A study of the literature by Mukaetova-Ladinska et al (2011) suggest the urgent need for research into ageing for people with ASD. With a growing care crisis, this is an important matter, additionally, 'the prospect of understanding brain ageing in this population may bring potential rewards beyond immediate clinical need given the precedent of Down syndrome' (Mukaetova-Ladinska et al, 2011).

In Gateshead, few services specifically focus on the needs of adults with autism. Just over 10% of the services listed in the Autism Gateshead Service Directory are directed towards adults and children, while the other 90% are specifically for children or young people (Gateshead council (Service Directory), 2016). The numbers used to count adults with autism are based on national census data, with projections based on the Gateshead population.

Adult ASD Referrals to service Gateshead CCG only 2010-2016

Referral Flag - 01/04/2010-31/03/2011	Referral Flag - 01/04/2011-31/03/2012	Referral Flag - 01/04/2012-31/03/2013	Referral Flag - 01/04/2013-31/03/2014	Referral Flag - 01/04/2014-31/03/2015	Referral Flag - 01/04/2015-31/03/2016
2	12	33	39	41	61

13. Oral Health

Individuals with autism may find going to the dentist a distressing experience, as this may trigger anxiety related to their senses (National Autistic Society, Jan 2016). Sensations in the mouth of cold and pain, along with the noise of the equipment may be a problem. Additionally the tastes and smells could cause distress (National Autistic Society, Jan 2016). The entering of their personal space by a dentist may also cause anxiety for an autistic person (National Autistic Society, Jan 2016).

The manifestations below are relevant for children with classic autism, in relation to Oral Health (University of Washington, 2010):

- Bruxism (20-25%)

- Non-nutritive chewing

- Tongue thrusting

- Self-injury (picking at gingiva, biting lips) creating ulcerations

- Erosion (many parents report regurgitation, medical consult may be indicated)

- Caries-similar to general population, however some children receive sweet foods as behavioural rewards (suggest sugar-free substitutes)

- Poor oral hygiene since home care measures are exceedingly difficult for many children/parents

- Many children have very limited dietary preferences (exclusively pureed foods, no fruits/vegetables, etc.)

There are no dental practices in the Gateshead area which provide specialist services for individuals with autism (NHS England, 2016). However, these patients are referred to the Community Dental Services (previous: salaried dental services), which has the skills required to assist patients with autism (NHS England, 2016). There is no data collected on these patients.

14. Learning Disabilities

Brugha et al (2012) demonstrate the high prevalence of autism amongst those who have a learning disability, with no significant difference between those who live in care housing and those in private accommodation. When planning service provision this high prevalence ought to be considered. Additionally, the higher rate of autism amongst those with a learning disability means the overall prevalence of ASD in England is 1.1 per cent compared with most published estimates of 1.0 per cent (Brugha et al, 2012).

Predicted verbal IQ was collected, combined with severity of learning disability to assess any differences in autism prevalence (Brugha et al, 2012).

Figure 1: Prevalence of autism among men and women by predicted verbal IQ/learning disability severity (Brugha et al, 2012).

Predicted verbal IQ/severity of learning disability (LD)
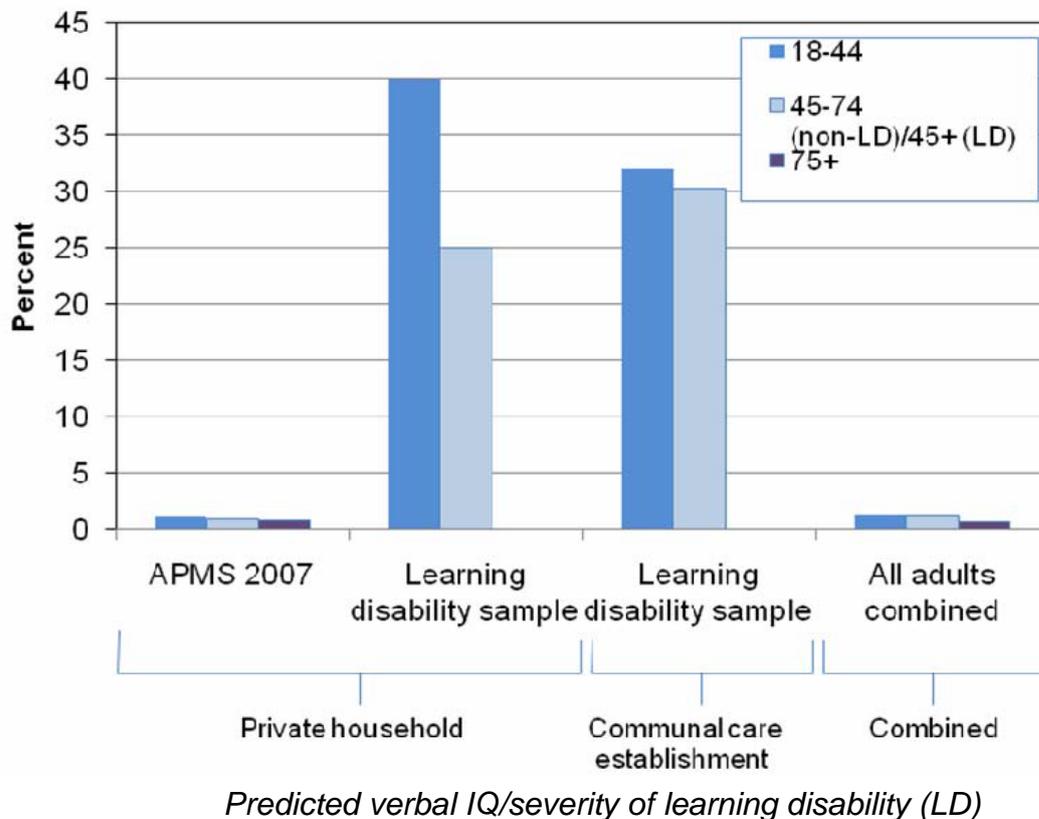
According to Figure 1, a gradient in prevalence exists, with highest among those with the most severe intellectual ability (Brugha et al, 2012).

The exact number of those in Gateshead who have a learning disability *and* ASD is unknown, although 136 children with autism attend a SEN school in Gateshead.

Most handling of people with complex needs is dealt with through separate service providers, resulting in many people falling through the gaps. Therefore, integrated services are the best way to help those with complex needs, meeting the specific needs of individuals (Turning point, 2016).

15. Mental Health

Mental health issues appear to be more prevalent in people with intellectual disabilities than in the general population (Buckles et al, 2013); a large number of those with autism also have a learning disability. Many symptoms of mental illness are wrongly regarded as challenging behaviour and so do not receive appropriate treatment. Mental health problems such as depression tend to be under-diagnosed in people with autism. People with autism

may experience depression/anxiety, Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (ACD) or Schizophrenia (University of Washington, 2010).

The prevalence rate for diagnosable psychiatric disorders is 36% for children and young people, while those of the same age without a learning disability experience an 8% prevalence rate (Improving Health and Lives, 2011).

The following identify the mental health outcomes experienced by those who have learning disabilities (and autism):

- People with LD demonstrate the complete spectrum of mental health diagnoses (FPLD, 2016)

- Dementia prevalence is higher in adults who have LD

- Schizophrenia rates are three times higher for people with learning disabilities than the wider population (FPLD, 2016)

- 10-15% of people with LD display challenging behaviour (FPLD, 2016)

16. Gypsy, Roma and Travellers

For Gypsy, Roma and Traveller families, evidence suggest these groups often remain excluded from 'mainstream services and opportunities, particularly health and education services' (Riches, 2007). Riches (2007) argues that 'an 'open door' policy for access to services is not enough', as the individual must still know the system before accessing that system or institution.

Children of Gypsies and Travellers experience a higher burden of illness and disease, with challenges in accessing sustained healthcare, contemporary advice and information (Riches, 2007). Consequently, early identification of special educational needs (SEN) often is lacking, resulting in diagnosis and interventions not occurring until school age, which can be less effective (Riches, 2007). This can result in stress for parents trying to cope without clear support services and networks, which is why outreach services are important (Riches, 2007).

Often without a named GP, screening for autism is extremely difficult for gypsies and travellers, with inability to access routine check-ups (Bingham, 2010). Literacy difficulties are also a barrier to accessing health screening, many feeling 'ashamed to admit that they do not understand' (Bingham, 2010).

The number of caravans in Gateshead fluctuates at the socially rented caravan site, Oakwell Park, in Felling (Gateshead JSNA, 2016). Therefore, the number of Travellers in the area is difficult to track. The numbers have changed every six months from 34 in July 2012 to 20, 40, 34, 25, 27 and then 27 again in July 2015 (Gateshead JSNA, 2016). 'During this time

there were no private caravans or unauthorised sites officially recorded, however, the caravan count has been criticised in the past for its inability to provide an accurate picture of unauthorised camping (perhaps due to its 'at a point in time' approach' (Gateshead JSNA, 2016).

Additionally, there is a private residential caravan site at Bewick Main, hosting Traveller families (Gateshead JSNA, 2016).

Number of caravans rented at Oakwell Park
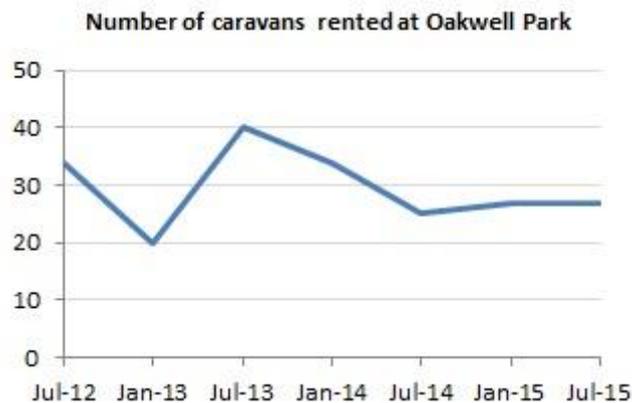
Source: Gateshead JSNA, 2016

There are no specific engagement services for these communities, in terms of autism specific services. However, a health visitor and the Traveller Education Service regularly visit the site, identifying children in education and ensuring children are registered with a GP (Gateshead JSNA, 2016).

17. Lesbian, Gay, Bisexual, Transgender (LGBT)

Public Health England has a role in taking forward initiatives that can help tackle stigma and discrimination. People with autism and those who identify as LGBT are often faced with discrimination and bullying. It has been shown that there is a higher percentage of people within the LGBT community who are on the ASD spectrum, the reasons for this are not well understood (Schalkwyk et al, 2015).

Young LGBT people who are diagnosed with intellectual disabilities and autism 'are at a heightened risk for compromised sexual health' (McClelland et al, 2012). Participants in a focus group study (McClelland et al, 2012) 'reported multiple limitations on their autonomy that resulted in having sex in places where they did not feel comfortable and were unlikely to practice safer sex'. McClelland et al. (2012) argue that limiting a young person's autonomy, who has an intellectual disability and/or autism may lead to negative sexual health outcomes.

There are no specific services in Gateshead for people who identify as LGBT and have ASD.

18. Advocates & Carers

Parents who care for their adult children with autism are mostly concerned with who will care for their children after they are no longer able to provide this care (National Autistic Society, 2012).

- 96% of parents worried about their son's or daughter's future when they are no longer able to support them.

- 35% have made some plans for what will happen if they are no longer able to support their son or daughter.

- 65% have not made any plans for what will happen if they are no longer able to support their son or daughter

- 48%of carers aged 50+ have not made plans for when they are no longer able to care for their adult children

Therefore, work needs to be done in the area of supporting siblings who are carers for their autistic siblings after the parents have passed away or physically are unable to take care of their adult children (National Autistic Society, 2012). More attention needs to be given to parents caring for their autistic children who are ageing and may need assistance in planning for future care.

Engagement

Parents, carers and people with autism are represented on the Gateshead Autism Steering Group and feedback relevant information to its members (PHE, October 2013). Additionally, parents, carers and people with autism have been involved in consultation events, gathering evidence for a previous autism health needs exercise. Engagement with this group of people is also a work stream in the Autism Steering Group (PHE, October 2013).

Training

Advocates have mixed knowledge and experience; however, most paid advocates possess the national advocacy qualification and have extensive training in working with people with a learning disability (PHE, October 2013). Some have also undertaken specific training in advocating for people with autism, sourcing this from providers with specialist knowledge, such as the National Autistic Society, psychology and speech and language therapy (PHE, October 2013).

Volunteer advocates are trained and supervised by volunteer co-ordinators, all having varying degrees of training or qualifications (PHE, October 2013). Some have previously been employed in roles such as social workers, psychiatric nurses and support workers (PHE, October 2013).

Reasonable adjustments

Support is provided for people with autism as part of their personal care and support plan, enabling them to access everyday services (PHE, October 2013). Membership of the Autism Steering Group includes libraries, leisure, economic development, housing and a work stream looking at Independent Living (PHE, October 2013).

Carers and those with autism also have means of participating with planning of services through 'Your Voice Counts' in Gateshead (PHE, October 2013).

Those with autism who are not eligible under Fair Access Criteria for statutory services for support can find support through the National Autistic Society's resource centre in Newcastle. Support, training and information is given at this centre for those affected by autism (PHE, 2013).

19. Black and Minority Ethnic communities

- Approximately 3.7% or 7,500 people in Gateshead are from a BME group (Gateshead Council (2), 2016). This does not include the orthodox Jewish community, with over 3,000 people who state their religion as Jewish (including non-orthodox Jewish population).

- Over 400 aged 0-4 and 1,200 aged 5-17 (Gateshead Council (2), 2016).

- Significant increases in residents of Chinese (+690) and African (+695) origin, and 2% of households do not contain anyone who considers English to be their main language, which can have service implications in certain communities (Gateshead Council (2), 2016).

- Bridges ward has the largest number of people from Black or Minority Ethnic groups at 1,281, followed by Saltwell with 1,030 (Gateshead Council (2), 2016).

- The Asian ethnic group has increased the most since 2001, with the largest increase in Bridges at +464 (over half Chinese).

White	Mixed	Asian	Black	Other
192,742 (96%)	1,558 (0.8%)	3,738 (1.9%)	1,081 (0.5%)	1,095 (0.5%)

Challenges in diagnosis

Participants in a focus group study by the National Autistic Society, reported delays in diagnosis, which makes it challenging to access services (Slade, 2014). Some parents in the study found that schools tended to 'label their child with a behavioural issue', assuming 'black boys are badly behaved' or bad parenting was to blame, rather than sending the child

for an autism assessment (Slade, 2014). Even after diagnosis, parents often found themselves trying to convince the school that 'autism was the cause of behaviour' (Slade, 2014). One parent said,

"The barriers that BME families can experience are misdiagnosis or no diagnosis. My son was originally diagnosed with emotional and behavioural difficulties, but after much persistence on my behalf was eventually diagnosed as autistic on the Asperger spectrum."
– Parent

Language issues can also delay diagnosis, as schools may believe the child's delayed development is 'due to them speaking another language as their first', rather than a delay due to autism (Slade, 2014).

Low awareness of autism and child development

Some communities are less aware than others of autism and understanding its affect on their child's development, although they may recognise something is 'different', they often misdiagnose the cause (Slade, 2014). Parents may try physical discipline or prayer to solve their behavioural issues (Slade, 2014).

Shame and blame were also key themes in this study, as parents faced 'hostile and judgemental attitudes' within their close communities, often blaming the parents for their child's bad behaviour (Slade, 2014). This shame and blame culture results in parents choosing to 'hide away their children' to avoid shame and embarrassment, staying away from social places and events, deepening their own social isolation (Slade, 2014). Parents felt that there are few BME high profile role models with autism, and associating it as a 'white-only condition', not expecting it within their own community (Slade, 2014).

Barriers to support

Families found the condition isolating, as women are not allowed to leave the family home in the evenings, in some communities or not speak with 'men beyond the family', which created barriers for accessing evening support groups and services (Slade, 2014).

Furthermore, parents found information and services difficult to access, not clear and containing jargon, especially for those who could not read English (Slade, 2014). Additionally, interpreters sometimes gave misinterpretations due to 'their own cultural assumptions' or giving partial translations (Slade, 2014).

Some lacked confidence when speaking with professionals and felt patronised at times, while others found it 'difficult to relate to professionals from a different ethnic background' (Slade, 2014). One parent stated that 'white families meet white professionals and seem to be on personal terms. We are made to feel like outsiders' (Slade, 2014). And some participants wanted to see more professionals from the BME communities represented, 'however, others argued that professionals from BME communities are not necessarily

supportive and understanding' (Slade, 2014). Overall, parents wanted professionals who listened to their concerns and understood autism (Slade, 2014).

Recommendations from the study:

Local authorities and Clinical Commissioning Groups (CCGs) should:

- consult families from BME communities about their specific needs when commissioning autism services

- ensure that the needs of BME communities are included in the autism chapter of the Health and Wellbeing Board's Joint Strategic Needs Assessment

- record the number of diagnoses of autism in people from BME communities and whether people from BME communities are using local autism services

- raise awareness and understanding of autism in local BME communities, where needed

- ensure service providers' information on autism and their services is readily available in appropriate languages and is promoted to BME communities

- commission services that are accessible for local BME communities, including in appropriate locations and at appropriate times

- commission peer support forums for parents and carers from local BME communities and, where appropriate, tailored support services

- provide advocacy, translation and interpretation services for families from BME communities who require support during and following an autism diagnosis.

20. Homelessness & Housing

There has been little research in the area of homelessness and autism; however, there is 'compelling evidence that homelessness is considerably more common among people with autism than the general population' (Campbell, 2015). In 2011, the National Autistic Society in Wales found 12 percent of their adults with autism were homeless during their lifetime (Campbell, 2015). Additionally, a study by Pritchard in 2010 found 65% of rough sleepers in Devon had ASD, although the study only surveyed 14 rough sleepers (Campbell, 2015). However, finding accurate assessments and risk factors for homeless people with ASD is difficult (Campbell, 2015).

A recent study by Campbell (2015) (sponsored by Shelter) presented qualitative case studies of homeless with ASD. The interviews found 'a lack of awareness of housing and related services amongst people with ASD', while a few described positive experiences with

services (Campbell, 2015). Bad practice was also highlighted, including people not being believed about having ASD, unhelpful staff, inefficient communication and offers of unsuitable accommodation' (Campbell, 2015).

The study made the following recommendations for housing professionals:

- We recommend tailored training for housing staff which includes the identification of ASD risk factors (for example, the worker flags up traits of ASD but does not give a diagnosis).

- Within Housing Options, staff awareness of ASD is particularly important in light of local authorities' new powers to discharge homelessness duties for 'failure to cooperate'.

- As well as through training, awareness can be raised via housing policy and guidance, including the Homelessness Code of Guidance.

- We also recommend that the National Autism Alert card is recognised at housing services.

- Due to the sensory issues that people with ASD face, service users should be offered a quiet and private room for their housing interview.

- There is a need for improvements in communication, possibly through altering the current means of communicating.

- To ensure that people access the support and help they are entitled to, we recommend that people with ASD who present as homeless have access to an advocate who, if necessary, can communicate on the person's behalf.

- When people with ASD are housed by the local authority, we recommend that they are followed up in their tenancy six months later.

- We recommend that there is closer collaboration between ASD charities, housing organisations and statutory sectors such as Supporting People and GPs.

- A lack of support, particularly among those with higher-functioning ASD, was a common theme of the research.

- Individuals with ASD would benefit from increased support in building up a range of skills and resources, such as independent life skills; tenancy management; social interaction skills; and increased resilience in coping with difficult situations.

- The thematic analysis highlighted how individuals with ASD felt they were not aware of the range of services available to them. One of our key recommendations is the

need to raise awareness of services for individuals with ASD by better publicising what support is already available and how individuals with ASD can best access it.

- We have identified the need for a homelessness prevention leaflet to be developed in collaboration with people who have ASD, to assist people on the spectrum who find themselves homeless or in inappropriate housing.

The housing needs of people with Autism are referred to in Gateshead's Universal Housing Strategy (PHE, 2013). Gateshead Council has a housing portal which allows for the council to understand specific housing needs of the community, a single point of contact (PHE, 2013). A more coordinated housing approach is being used to increase the supply of specialist and adapted homes, while also informing people when this is available (PHE, 2013). This approach incorporates the specific needs of those with autism (PHE, 2013). Additionally, a quiet room is available in the Council building for those with ASD who many need a friendly space to wait.

21. Employment

Interviews suggest employment as a 'significant challenge' for those with autism, including poverty, resulting in homelessness (Campbell, 2015).

GATES or Gateshead Access to Employment Services provided employment to 28 people with disabilities, in 2013 (including autism) (PHE, 2013). 12 others commenced an employment programme with GATES in 2013. Placements are located within the Council, social enterprises, and private companies in order to develop work related competencies for those seeking employment (PHE, 2013). The transition team also focuses on education and employment for the young people leaving children's' services and moving into adult services (PHE, 2013).

22. Offenders, including prison population

Due to the nature of autism, people with ASD may exhibit 'odd' behaviour, which draws unwanted attention, and affects social interactions (National Autistic Society, 2016). However, many autistic people have a 'hidden disability' and do not display 'odd' behaviour (National Autistic Society, 2016). 'Autistic people are more likely to be victims and witnesses of crime than offenders' (National Autistic Society, 2016).

When autistic people do commit a crime, there may be several reasons (National Autistic Society, 2016):

- Social naivety: befriending criminals unknowingly and becoming accomplices to crimes through lack of understanding of other's motives.

- Difficulty with change or unexpected events: anxiety and distress due to changes in schedules or routines, such as a train delay, may cause the person to act aggressively.

- Misunderstanding of social cues: some behaviour may be interpreted as a sexual advance, such as standing too close to someone or pronged eye contact.

- Rigid adherence to rules: becoming annoyed when someone else breaks the rules. For example, an autistic man was known to kick cars that were parked illegally.

- Not understanding the implications of their behaviour: may repeatedly offend if not offered the correct support and intervention.

In 2011, NICE guidance was published for those in the prison system with autism. The Prison Reform Trust claims many of those in contact with the criminal justice system have autism, including children; the system is particularly poor at supporting their needs and recognising those with autism (Talbot, 2011). The NICE guidance acts to support those in the system and those working with them (Talbot, 2011).

A recent article in the BMJ suggests that 'autism is underdiagnosed in prisoners' and calls for 'more investment…assessment in forensic settings' (Ashworth, June 2016). Ashworth (2016) claims that prisoners often go undiagnosed due to the lack of resources and training amongst prison employees, and prisoners often do not receive adequate assessment and care as a result.

Training has occurred and is ongoing within the Northumbria Probation Trust around autism, with one-off events for Offender Managers as well (PHE, 2013). Gateshead is hoping to have briefing sessions for Judges and barristers as well (PHE, 2013). Continuing discussions with the Criminal Justice System are occurring in terms of training around autism.

23. Gateshead Self-assessment

Prior to the most recent Autism consultation, in October 2013, Gateshead completed the Autism Self-assessment, a new requirement under the 'Think Autism' strategy. This self-assessment highlights areas where improvements can be made and where services are already meeting national requirements (PHE, October 2013). The following outlines this assessment:

Commissioning

Commissioning priorities reflect the local needs of people with autism, including the four priority areas of work: early intervention/prevention, diagnosis, independent living and support.

The Commissioning Plan identifies the following as areas of improvement:

- More autism data is required to inform commissioning priorities and models of work, including performance data, financial data and obtaining views from user groups.

- The need to explore the potential to develop more local, cost effective services.

- Identify the future needs of all young people, including those returning to Gateshead from Out of Borough residential schools and colleges.

Currently, Gateshead uses the Council's Care First System, Daslne database, Autism Needs Assessment, Schools database, assessment and diagnostic service, GP register's and Gateshead Network for Disabled Children for collecting local data on autism.

A representative from the North East Commissioning Support Unit and a lead GP for autism are both engaged in the planning and implementation of the local autism strategy.

Training

Assessment and Support Planning training in Autism for social workers and assessment officers was carried out in 2012 from 'Positive about Autism'.

Autism awareness training is available through e-learning, national websites, social care staff within Gateshead Council, and Gateshead council has developed an accredited training course 'Solving the Autism Puzzle'. Level 2 and 3 qualifications are available to social care staff. The Autism Steering Group will ensure further development occurs in these areas.

Diagnosis

Through the work of the Autism Steering Group, diagnosis and data on diagnosis has been made a key area of work. Diagnosis is a key theme of the Autism Steering Group. A diagnosis sub group, led by the diagnostic service engages with GPs regarding diagnosis. A local diagnostic pathway was put into place in April of 2012. The average referral time is 12 weeks. The Diagnostic sub group of the Autism Steering Group works to positively influence and reduce the waiting time for the service.

In 2012, 39 people completed the diagnostic pathway, including 28 males and 11 females (19 – 64). The local CCG commissioned NTW to deliver the assessment and diagnostic service. The pathway is a 'specialist autism specific service', which is an interim service with a plan over time for "straight forward" diagnosis to be carried out by mainstream services with specialist awareness.

A diagnosis leads to the individual being informed that they are eligible to apply for a Community Care Assessment. A follow up session facilitates an opportunity to support this process.

Follow-up

Everyone is offered a follow up sessions, addressing four areas: how do you feel following diagnosis, what is your understanding of autism, what are your current difficulties and signposting individuals to appropriate services. The Adult Social Care Direct Service signposts people to appropriate services. Gateshead Council has an Adult Social Care Direct team who passes on details to the relevant team within Adult Social Care. The team manager allocates an assessment worker to visit the person in his or her own home and carry out the assessment.

24. Consultation

Gateshead is committed to supporting all people with autism (Gateshead, 2016):

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

A consultation took place from 23rd October 2014 – 19th December 2014 for all stakeholders in the Gateshead area to help shape the working priorities of the Autism Steering Group and Working groups (Gateshead Council, 2014).

- 120 people attended a consultation event

- 30 completed a survey

- Used the National Autistic Society Report (2013), including their consultation from 43 individuals with autism and 49 professionals

Recommendations from this consultation include the following (Gateshead Council, 2014):

- Provide good information and advice at a time when people need it in either written or web form.

- A clear route for diagnosis for all people.

- A place to go that offers people with autism and their families a broad range of interventions, including supporting people to access their local communities.

- Support and breaks for Carers.

- Making services and the general community "autism friendly" and general awareness raising about the condition. To include training for all staff who have front line contact with customers in retail outlets, on public transport, cafes and medical centres.

- Role of Steering and Working Groups around influencing external Partners, organisations, employers and services to raise awareness and increase understanding.

- People indicated they would like to be in work. There is a need to work with potential employers and businesses so they are not afraid to employ and support people with autism.

- Ensure flexible housing opportunities to support people to either live independently alone or with others.

25. Response to Consultation

Interventions ought to be applied in a universally proportionate way, providing greater levels of intervention to those at higher risk, reducing health and social inequalities. Gateshead Autism Steering group developed an All Age Autism Strategy, with action areas for carers and partners dealing with autism, which they identified as being important and enabling, in order for them to live fulfilling lives (Gateshead, 2016).

The strategy has been developed in line with the Gateshead CCG and the Adult Social Care Commissioning Intentions. The five action areas of the strategy are (Gateshead, 2016):

1. Increasing awareness and understanding of autism

2. Developing clear, consistent pathways for the diagnosis of autism

3. Improving access for adults with autism to services and support

4. Helping adults with autism into work

5. Enabling local partners to develop relevant services

The strategy is structured around four key priority areas in order to promote awareness and understanding:

1. Awareness, Understanding and Early Identification

2. Independent Living and Support

3. Diagnosis

4. Commissioning

Investment needs to shift towards prevention and early diagnosis, making sure services are effective and meeting the needs of people with autism.

The following services were created in response to consultation:

Autism Service Directory

An autism service directory was created, providing 'clearer information about the services and support' that is available in the area (Gateshead council (Service Directory), 2016). This directory contains brief summaries of all services in the region that are available for those with autism and their carers, along with contact details for the services. The directory is comprehensive, up-to-date and provides accurate contact information.

Autism Information Hub (Gateshead (AIH), 2016)

Gateshead created an Autism Information Hub, located in the Gateshead Central Library, with a smaller but similar service at Pelaw Library. This Hub is a significant service created in response to the consultation in 2013/2014. The Hub provides resources about autism and face-to-face monthly signposting and information services with trained autism specialists. Resources include books on diagnosis, sensory differences, anxiety, sleep and social skills. Many of the staff in the library are trained Autism Supporters. The library also provides a quiet space.

Additionally, 'a guide for parents wishing to claim Disability Living Allowance for their autistic child' has been written and produced by one of the parents who attends the monthly session (Gateshead (AIH), 2016).

An evaluation of the autism Hub was recently completed. On average, there were between 4 and 10 visitors attending the monthly drop-in sessions, held on the third Monday every month between 9.30am–11.30am. The drop-in sessions, with the highest number of visitors were September 2017 (10) and December 2017 (8).

Visitors to the hub drop-in sessions are most often family members of those with autism. However, recently an increasing number of adults pre and post diagnosis visit the hub. Most queries have been in relation to social opportunities, employment and training opportunities, diagnosis, health, benefits, the EHC Plan assessment process or concerns about education. Representatives from organisations and services visit to find out more information in order to signpost parents and also to share resources and materials about the services they provide.

Feedback received informally by practitioners, volunteers and library staff from visitors to the drop-in sessions has been extremely positive, with 100% of the feedback from visitors recommending the Hub.

Comments received from the Hub drop-in visitor evaluation forms, include the following:

> *"Thank you from the bottom of my heart. You have given me hope. You listened and you reassured me that my child's difficulties are not a product of my imagination and I am now armed to get us some help."*

> *"I would definitely recommend this service. Amazing support. Helped me so much A really good service which needs more to shout about it."*

> *"I was really nervous about coming here today but everyone has made me feel so welcome."*

> *"Very well organised and lots of information available on various topics."*

> *"Very useful. Good to see resources available for future use."*

Autism Support Services

Set up following consultation with parents and families of children with autism, Autism Support Services supports people in the referral for diagnosis process, early stages of diagnosis, outreach support, home education support, sibling support, group support, online support, appeals and tribunals, behaviour challenges, information on autism and liaising with schools and professionals (Our Gateshead, 2014). Additionally, they provide 'awareness training'. The service recommends starting a special playgroup for those with autism (Our Gateshead, 2014).

26. Additional Local and Regional Services

Northumberland, Tyne and Wear NHS Trust (NTW)

Northumberland, Tyne and Wear NHS Trust provides a Complex Neurodevelopmental Disorder Service (CNDS) for Children and Young People, which works with several agencies in providing 'second opinions about children and young people who may have ASD and other complex mental health neurodevelopmental problems' (NTW, 2016). The service accepts referrals locally, regionally and nationally (NTW, 2016).

Adult Autism Diagnostic Service

One of the few services for adults with autism in the area, the Adult Autism Diagnostic Service 'considers referral for assessment for possible autism' by anyone over 18 'who thinks they may have autism' or any carer, GP, or educator (Gateshead (AIH), 2016). This service is run by Northumberland, Tyne and Wear (NTW) Mental Health Trust. The service

only collects data on the total numbers of referrals form Gateshead for all presentations, not just ASD but it does have a care pathway in place for those who present with ASD.

FACETS

Facets is a specialist play scheme specifically for children in need (social care) with autism *and* a learning disability or challenging behaviour (aged 5-17) (Gateshead (AIH), 2016). FACETS is delivered exclusively for children referred to the group by Social Workers in Gateshead. 25 children attend 2 or 3 days per week over 10 weeks of the year (during school holidays).

Quiet Room

The Gateshead Civic Centre provides an autism-friendly space, quiet and private, allowing people with ASD a place 'to take time out to be away from people' (Gateshead (AIH), 2016). The space is filled with relaxing colours and images which create a calm environment for people with autism but also can be used for older people or more vulnerable people (Gateshead (AIH), 2016). The quiet room was completed and opened for use at the end of 2015. The Council plans to collect data on the usage of this room beginning September 2016. Initial data was unavailable at the time or writing this report.

Autism Parenting Programmes

A free training programme for parents of children with ASD who are aged 4 – 11. This is a service provided through the Council.

Autism Supporters

Trained autism workers which support people with ASD who visit the Civic Centre. They arrange practical support during their visit. As this is a new programme, no one has used this service yet.

Gateshead Autism Group (GAG)

This charity group provides information, advocacy and advice for anyone with autism, as well as carers and family, along with practical support, if required. The group operates out of Low Fell, run by 14 volunteers from the Education, Health and Social Care sectors. The group holds quarterly meetings and runs a monthly arts and craft club for children, located in Low Fell.

Many of their service users contact GAG with specific needs, thus the service tailors their service for individual needs, using a wide range of knowledge, skills and resources within the team of volunteers.

Over the past 5 years GAG has run two conferences, attended by over 250 people, and has assisted 80 individuals. GAG has also been in contact or responded to enquires from over

400 people, including professionals. GAG developed an accredited level 2 training with NCFE and delivered this training to 50 Council staff, which has helped in funding the charity. Additionally, they have developed 3 more courses to be accredited by NCFE.

NEAS Parent Support Group

This group is for parents and their children with ASD which meets fortnightly at Heworth Grange School. This is a one hour meeting which runs during term time. The group has been in session for two years and has 10 regular attendees that are mostly parents and one grandparent. On average five children attend the group, ranging in age from 5 to 18.

Autism Friendly Cinema Screenings

Autism friendly screenings are shown on Sunday mornings throughout the month, in a sensory friendly environment, with adjustments made to reduce over-stimulation.

Autism North East

A not for profit organisation which offers assessments and intervention services for both families and professionals in the North East. Referrals are made from both families and professionals. There is however, a significant cost assessment, diagnosis, feedback and post-diagnostic liaison, ranging from £950 - £1,800. The service was unable to provide a figure on how many people from Gateshead use this service.

Daslne

This is a research database for children with ASD living in the North East. It gives an accurate number of children with ASD and provides information on topics which may affect those with autism. It is run by Newcastle University.

Spectrum – theatre group

This theatre group based at Northern Stage in Newcastle is for adults with ASD.

Toby Henderson Trust

Independent charity based in Northumberland that supports autistic children and their carers. It focuses on 2-7 year olds to improve long-term quality of life, while offering advice and information.

27. Recommendations

- Audit of services available for those with ASD who are 18+

- Research into the local homeless community and rough sleepers

- Gypsy Roma Traveller groups: better understanding of engagement with autistic children within these communities

- Autism Supporters: so far there has been no uptake of use of this service at the Council, however it is a new service. Increase awareness of this service to the local community and professionals.

- 2 of 3 children who are diagnosed with ASD living in the most deprived areas of Gateshead
    – Diagnostic bias?
    – Social Worker involvement?
    – Behavioural issues at school more likely to lead to ASD diagnosis if poor?
    – Stigma of diagnosis?
    – More research needed in this area to find out why autism seems to be linked with deprivation, in children.

- Dental practices within the Gateshead area ought to provide specialist services for individuals with autism through the provision of training for General Dentists.

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