

Living with autism in Sunderland

**An assessment of the health, care and wellbeing
needs of people living in Sunderland with autistic
spectrum conditions**

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Author: Andrew Billett

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Glossary of terms

AIM – Autism in Mind, a community interest company (CIC) based in Sunderland

CAMHS – Child and Adolescent Mental Health Service

CCG – Clinical Commissioning Group, an NHS body which, among other responsibilities, purchases some health care services for the population of Sunderland

CG – clinical guidelines

DLA – Disability Living Allowance

EHCP – Education, Health and Care Plan

FME – forensic medical examiner, typically a General Practitioner, providing a specialised health care service within the criminal justice system

GATES – Gateshead Access to Employment Service

GP – General Practitioner

IQ – intelligence quota

NHS – National Health Service

NICE – National Institute for Health and Care Excellence

PIP – Personal Independence Payments

QOF – Quality and Outcomes Framework

SEN – special educational needs

SENCO – special educational needs coordinator, a role taken on by a specialist teacher within a primary or secondary school

SEND – special educational needs and disabilities

1. Executive summary

The 2010 national autism strategy “Fulfilling and Rewarding Lives”, and the progress report “Think Autism”, published in 2014, set out a vision of a society that is more understanding of people with autistic spectrum conditions. Health, care and public-facing services are adapted to make them more accessible to people with autism and they can live independently, reach their full potential and make a positive contribution to society. We have a long way to go before this vision is realised in England, but some progress has been made.

This section of Sunderland Partnership’s Joint Strategic Needs Assessment looks at the population of people living in Sunderland with autistic spectrum conditions and their experiences. It looks at provision within education, health and care services, the opportunities for employment, services that make autistic people feel safe in public places and adaptations to recognise the needs of people with autism in the criminal justice system. Finally it looks at the opportunities for people with autism to access their community – doing routine activities that most of us take for granted – shopping, sport, visiting the theatre or the cinema or attending sporting events.

It finds that:

- 1.1. autism diagnosis services for young people are being reviewed to make sure that they meet recommended National Institute for Health and Care Excellence (NICE) guidelines
- 1.2. referrals into autism diagnosis services among adults are growing, but most people accessing the service are under 35 years of age
- 1.3. there are around 10 young people and adults with severe learning disabilities and/or an autistic spectrum condition that are cared for in inpatient mental health settings whose care is reviewed regularly by a multi-disciplinary team. The aim is to reduce this number over time.
- 1.4. there is a wide choice of educational provision for children and young people with autism in Sunderland but that parents and carers of children with autism cannot always find the information that they want about these services
- 1.5. demand for specialist education provision for children with autism is growing, but there is uncertainty as to whether this growth will continue
- 1.6. employment opportunities for people with autistic spectrum conditions are limited. There is currently no way of tracking training and employment outcomes for people with autism
- 1.7. autism awareness training is not widespread but there are some local examples of good practice.

- 1.8. health and care services often make adjustments to meet the needs of people with learning disabilities, but these adaptations need to be widened to account for the needs of people with autism who have a regular or high IQ
- 1.9. GP Practices are not currently required to identify a list of service users with autistic spectrum conditions as part of the national Quality and Outcomes Framework (QOF) scheme. Identifying service users with autistic spectrum conditions in primary care would help hospital services mark their electronic service user records with a flag identifying them as having additional needs.
- 1.10. there is a Safe Places scheme which helps to ensure that people with a learning disability and/or an autistic spectrum condition can feel safe when in local public places such as shopping centres
- 1.11. Northumbria Constabulary have made adaptations to custody procedures to take account of the needs of suspects with a mental health condition or a learning disability. Autism awareness training among health care staff within custody suites would help to ensure that people with an autistic spectrum condition also have their needs recognised.
- 1.12. There are a number of examples where local leisure services have made adjustments to facilitate access by people with an autistic spectrum condition and their family, friends or carers. There are now occasional “relaxed” performances of films or plays where people with autism can feel comfortable.

It recommends that:

- 1.13. data on aggregate numbers diagnosed with autistic spectrum conditions is collected annually from GP practices by single year of age up to 24 years of age, by 10 year age band thereafter and by gender. This will help to plan special education services.
- 1.14. work to align the autism diagnosis pathway for children and young people with NICE guidelines is reported on in a future edition of the Sunderland Joint Strategic Needs Assessment
- 1.15. any barriers to accessing diagnosis services for people over 35 years of age should be investigated. The prevalence of diagnosed autism recorded in primary care among this age group is very low
- 1.16. there should be work undertaken locally to understand the benefits of a of a ‘step-down’ or post-diagnosis autism service and describe what a local service might look like

- 1.17. progress continues to be monitored towards achieving the following objectives of the Transforming Care programme:
 - reduced reliance on inpatient services (closing hospital services and strengthening support in the community)
 - improved quality of life for people in inpatient and community settings
 - improved quality of care for people in inpatient and community settings
- 1.18. parents, carers, education commissioners, teachers, lecturers, special educational needs coordinators and health and care professionals with an interest in educational provision for people with autism come together for a half day workshop to discuss issues raised during engagement around this needs assessment
- 1.19. autism model employers are identified – that is employers that have successfully employed people with autistic spectrum conditions. With their consent, their experiences can be used to promote the benefits of employing people with autism to other local employers.
- 1.20. there is consideration as to whether the Connexions database could be used to monitor training and education outcomes for young people with autistic spectrum conditions aged 16 to 24 years of age.
- 1.21. wider adoption of autism awareness training among health and social care staff is discussed at the Board of the Sunderland CARE Academy.
- 1.22. strategic level champions for autism awareness training among local health and care organisations are identified
- 1.23. the alert flag in operation at City Hospitals Sunderland for service users with a learning disability is extended to service users with an autistic spectrum condition
- 1.24. autism awareness training sessions should be introduced as part of refresher training among hospital staff groups
- 1.25. the list of long-term conditions for which prevalence is reported annually within the national Quality and Outcomes Framework (QOF) is extended to include autistic spectrum conditions
- 1.26. recording of autistic spectrum conditions and making reasonable adjustments to care processes within primary care is discussed at a Time In Time Out development session for Sunderland GP Practice staff. This session should be addressed by a person with an autistic spectrum condition.
- 1.27. the Safe Places scheme continues to be widely publicised

- 1.28. healthcare staff working in Northumbria Police custody suites undertake autism awareness training as part of their continuing professional development.
- 1.29. The “Local Offer” web page, within Sunderland City Councils website, which identifies autism-friendly leisure services, is widely publicised. This will raise awareness of the increasing opportunities for sport and social networking accessible to children and young people with autistic spectrum conditions.

2. Introduction

Autism is a spectrum of lifelong developmental conditions that affect how a person communicates with, and relates to, other people. These conditions are commonly described in relation to a ‘triad of impairments’. These are difficulties with:

- Social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice)
- Social interaction (e.g. problems in recognising and understanding other people’s feelings and managing their own)
- Social imagination (e.g. problems in understanding and predicting other people’s intentions and behaviour and imagining situations outside their own routine)

People with autism may also experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. Autism is known as a spectrum condition, both because of the range of difficulties that affect people with autism, and the way that these present in different people. It is estimated that around 50% of people with conditions on the autistic spectrum will also have a learning disability¹ and some will exhibit behaviour that many describe as challenging².

In 2009, the *Autism Act 2009* received Royal Assent and in the following year the UK Government published a national autism strategy *Fulfilling and Rewarding Lives*. Together these two documents set out the Government’s commitment to meeting the needs of adults in England with autistic spectrum conditions by improving the provision of relevant services to such adults by:

- Local authorities
- NHS bodies
- NHS Foundation Trusts

The subsequent update report, *Think Autism* (2014), recognised that, for people with autism to really be included as part of the community, there was a need to look beyond statutory services at how we build communities that are more aware of and accessible to the needs of people with autism.

This needs assessment describes the population in Sunderland with autistic spectrum conditions. It identifies key services that support them through the life course, from child to young person and into adulthood. It looks at how these services

¹ Emerson E, Baines S (2010) “The Estimated Prevalence of Autism among Adults with Learning Disabilities in England”, *Improving Health and Lives*, available at http://www.improvinghealthandlives.org.uk/uploads/doc/vid_8731_IHAL2010-05Autism.pdf (last accessed 30th October 2015)

² McTiernan A, Leader G, Healy O and Mannion A (2011) “Analysis of risk factors and early predictors of challenging behaviour for children with autism spectrum disorder”, *Research in Autism Spectrum Disorders* 5 (2011) 1215–1222, available at [http://www.nuigalway.ie/ican/content/McTiernan%20\(2011\).pdf](http://www.nuigalway.ie/ican/content/McTiernan%20(2011).pdf) (last accessed 30th October 2015)

meet their needs and focuses on five issues highlighted in the Fulfilling and Rewarding Lives strategy:

- Increasing awareness and understanding of autism
- Developing a clear and 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

Work to research this report has been undertaken with the support and co-operation of the Sunderland Autism Partnership Board. To inform this report, there have been two engagement meetings, in March and July 2015, attended by stakeholders, including people with autism, representatives of voluntary sector organisations, health and care professionals and service commissioners. There was discussion at the meetings about the experiences of people living in Sunderland with autistic spectrum conditions and particular issues that they have faced when accessing services that support them to grow within a family unit or live independently as an adult.

3. Background

3.1. National context

The publication of the 2010 national strategy, *Fulfilling and Rewarding Lives*, was followed in 2014 by an update report, *Think Autism*. This revisited and reframed the goals set out in the original autism strategy via a large engagement exercise with people with autistic spectrum conditions, their families, carers and advocates, service providers and service commissioners. Key themes were:

- Building communities that are more accepting and understanding of people with autism. Developing opportunities where people with autism can access their community e.g. visiting the cinema or attending sporting events.
- Developing structures where people with autism can have a say about local strategies and public services which affect their lives
- Enabling people with autism to access adult social care and/or low level interpersonal services such as buddying and peer support groups. These services can prevent people going into crisis situations.
- Improving access to mainstream public services through reasonable adjustments and autism awareness training for staff.
- Improving community safety and eliminating discrimination, hate crime and abuse.

- Looking beyond pre-conceptions of people with autism. This may prevent people from accessing support that they need, for example, in relation to their sexuality or which is right for their cultural or religious background.
- A timely diagnosis with relevant information and support throughout the process.
- Including autism in local strategic needs assessments
- Improving access to health and care services through reasonable adjustments, but also through enhanced autism awareness training
- Developing support services for carers
- Developing services that support people with autism through big life changes such as transition from school into adult life, aging and bereavement
- Providing support for people with autism who have additional needs, such as a mental health problem, a learning disability or challenging behaviour
- Increasing awareness of autism within the criminal justice system, for the benefit of victims, witnesses and suspects.
- Developing opportunities for people with autism to enhance their skills and be as independent as possible
- Providing support for people with autism to get a job and helping them to keep it

3.2. Local context

The Local Autism Working Group, formed in Sunderland after the publication of the 2010 national strategy, has now become the Sunderland Autism Partnership Board. It comprises a range of stakeholders including:

- people with autistic spectrum conditions living in Sunderland
- representatives of voluntary sector organisations with a membership including people with autism or their families or carers
- senior managers from local public agencies that commission health and care services
- senior managers from organisations that provide services which support people with autism.

The group has convened a number of task and finish group to progress specific actions – Awareness and Training, Employment, Joint Strategic Needs Assessment, Quick Wins and Health. The group also completes an annual self-assessment requested by the Department of Health, which asks questions around the themes highlighted in the *Think Autism* report noted above.

4. Population profile

4.1. Predicted population and numbers with a diagnosis recorded in primary care

Best estimates of the prevalence of autism in the UK (Baird, 2006³ for children and Brugha, 2012⁴ for adults) suggest that 1.1% of the population of Sunderland, or 3,000 people based on 2013 population estimates, may have a condition on the autistic spectrum.

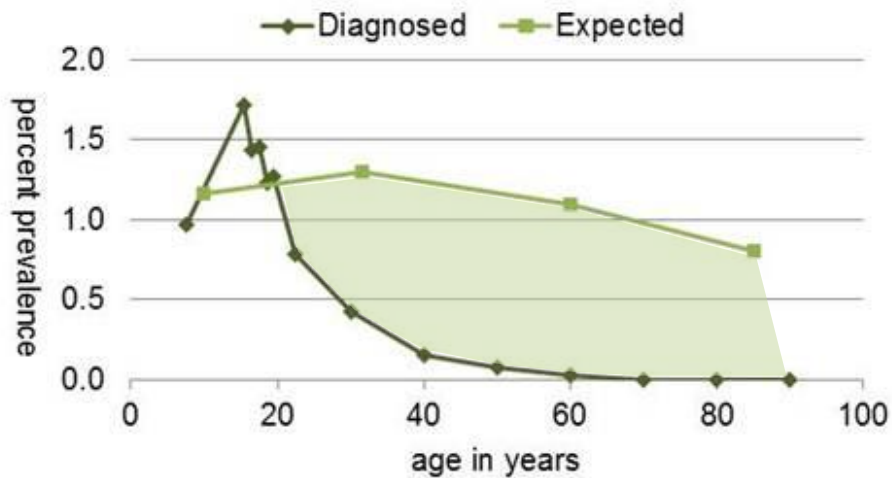
A count of records of diagnosis within primary care in Sunderland, taken in March 2012, showed that 900 people, or 0.3% of the population, had a diagnosis of autism. The proportion of GP Practice populations diagnosed with the condition varied from 0.1% to 1.2% which suggests that there is variation in the effectiveness of case finding between GP Practices or in assigning the appropriate clinical code to a record once a diagnosis has been established. The count was undertaken again in March 2015 and this showed that the number of diagnoses had increased to 1,200 or 0.4% of the population. In March 2014, among 16-24 year olds (the transition period between children's and adult services) there were 290 people diagnosed in 2012 (0.8% of the population 16-24) and 350 people diagnosed in 2014 (1.0%). The figures suggest that there are 1,800 people in Sunderland who have an autistic spectrum condition but remain undiagnosed, and thus are not receiving the most appropriate support from health and social care services.

Calculation of prevalence by age band shows that there is a large gap between diagnosed and expected prevalence among adults over 20 years of age (the area shaded green in the graph below). But among young adults 16-19 years, a target population for diagnosis services, the number diagnosed with autism in Sunderland is now above the number we would expect given the size of the population.

³ Baird G et al (2006) "Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP).", *Lancet*, 2006 Jul 15;368(9531):210-5 abstract available at <http://www.ncbi.nlm.nih.gov/pubmed/16844490> (last accessed 17th August 2014)

⁴ Brugha, T., Cooper, S. A., McManus, S., et al. (2012) "Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey." The Health and Social Care Information Centre, Leeds available at <http://www.hscic.gov.uk/pubs/autism11> (last accessed 17th September 2014)

Prevalence of diagnosed autism and Asperger syndrome by age within primary care in Sunderland, March 2014



Data source: Diagnosed - North of England Commissioning Support.
Expected - research papers by Baird (2006) and Brugha (2012)

Expected prevalence of autism and Asperger syndrome

Percent prevalence	1.16	1.3	1.1	0.8
Age band (years)	9-10	18-44	45-74	75+
Mid point (years)	10	31.5	60	85
Source	Baird 2006	Brugha 2012	Brugha 2012	Brugha 2012

Prevalence of diagnosed autism and Asperger syndrome, March 2014

Observations	447	56	48	49	42	48	165	150	54	30	9	0	0	0
Percent prevalence	1.0	1.7	1.4	1.5	1.2	1.3	0.8	0.4	0.2	0.1	0.0	0.0	0.0	0.0
Age band (years)	0-14	15	16	17	18	19	20-24	25-34	35-44	45-54	55-64	65-74	75-84	85+
Mid point (years)	7.5	15.5	16.5	17.5	18.5	19.5	22.5	30	40	50	60	70	80	90
Source	North of England Commissioning Support Unit													

Recommendation: Request that this data collection is carried out by Sunderland Clinical Commissioning Group in March 2016 (at financial year end) and annually thereafter. Request that numbers with a diagnosis are provided for single year age groups from 0 to 24 years and share these statistics with commissioners within the Local Educational Authority and Clinical Commissioning Group, to assist planning of specialist education and health services. Also request that the numbers are split by gender to understand differences in diagnosed prevalence between males and females.

4.2. Numbers identified with a special educational need where the primary need is autism

Department for Education statistics also suggest a high prevalence of autism among children and young people in Sunderland. The figures show the number of children and young people attending Sunderland schools with a special educational need

where the primary need is autistic spectrum conditions. The average prevalence is 1.7% compared to the expected prevalence of 1.2%.

Children with Special Educational Needs in Sunderland schools with an autistic spectrum condition as a primary need in 2015

School type	children with SEN primary need ASC	total pupils on school roll at 31st January 2015	% with SEN primary need ASC
Primary	249	23791	1.0
Secondary	201	15652	1.3
Special schools	249	670	37.2
Totals	699	40113	1.7

Source: 2015 Department for Education Statistical First Release "Special Educational Needs in England, January 2015"

<https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2015>

4.3. Numbers of adults accessing social care

People accessing adult social care packages commissioned by Sunderland City Council with autism or Asperger's Syndrome by age group and gender, 31st March 2015

Age group	total with packages of care		diagnosed population 2014	% of diagnosed with packages of care	expected population 2014	% of expected with packages of care
	female	male				
18 to 24		41	255	16	345	12
25 to 34		31	150	21	494	6
35 to 44		24	54	44	468	5
45 to 54		10	30	33	459	2
55 to 64		<6	<10	*	395	*
65 to 74		<6	<6	*	302	*
Total	24	89	113	23		
Percent	21	79				

Source: Sunderland City Council

There are currently (at March 2015) 113 adults 18 years and over living in Sunderland, with autism listed as a health condition, in receipt of packages of adult social care. It is noted above how the prevalence of diagnosed autism falls with age, probably due to the fact that dedicated autism diagnosis services have only emerged in recent years. Thus while the proportion of adults diagnosed with autism, who are receiving packages of social care rises with age as a proportion of diagnosed autism,

it falls with age when expressed as a proportion of the expected population with autism.

Brugha⁵ found that prevalence of autistic spectrum disorders among adults responding to a survey was 1.8% among males and 0.2% among females. This suggests a 9:1 ratio of males to females with autism in the general population. The ratio of males to females among people with autistic spectrum conditions in receipt of adult social care packages in Sunderland is currently 4:1.

People resident in Sunderland accessing adult social care packages have a primary reason for support and a health condition listed separately on their electronic service user records. “Autistic spectrum conditions” is not one of the “primary reason for support” classifications. Of the 113 people accessing adult social care packages in Sunderland, with autistic spectrum conditions listed as a health condition, the breakdown by primary reason for support is: 104 with a learning disability, 8 with a physical disability and 1 with a mental health condition. This suggests that there are between 0 and 9 people with high functioning autism accessing social care packages. The 9 people with autism, who have a physical disability or a mental health condition recorded as their primary reason for support, may or may not also have a learning disability.

5. Autism diagnosis services

Pathways are different for the diagnosis of autism among children and young people (under 18 years of age) and adults (18 years and over). Among children and young people, in Sunderland, autism can currently be diagnosed by a paediatrician within City Hospitals Sunderland NHS Trust or by a consultant psychologist within the Child and Adolescent Mental Health Service (CAMHS) which is part of Northumberland, Tyne and Wear NHS Foundation Trust. Adults are diagnosed within the Adult Autism Spectrum Disorder service delivered by Northumberland, Tyne and Wear NHS Foundation Trust, which is a specialist mental health Trust.

Sunderland Clinical Commissioning Group, City Hospitals Sunderland NHS Foundation Trust, Northumberland Tyne and Wear NHS Foundation Trust and Sunderland City Council are currently working together to align the children’s diagnosis pathway with NICE guidelines [CG128] “Autism in Under 19s: recognition, referral and diagnosis”⁶. The aim is to design a single diagnosis pathway.

⁵ Brugha, T. (2009). Autism spectrum disorders in adults living in households throughout England: report from the Adult Psychiatric Morbidity Survey 2007. The NHS Information Centre for Health and Social Care. Available from: www.ic.nhs.uk/statistics-and-data-collections/mental-health/mental-health-surveys (last accessed 29th October 2015)

⁶ National Institute for Health and Care Excellence (NICE) (2011) “Autism in Under 19s: recognition, referral and diagnosis” available at <https://www.nice.org.uk/guidance/cg128/> (last accessed 30th October 2015)

The Adult Autism Spectrum Disorder Service delivered by Northumberland, Tyne and Wear NHS Trust was established in 2010. The Sunderland team has experienced increasing demand for its services in recent years. In 2013/14 it received 44 referrals of which 37 received a diagnosis of an autistic spectrum disorder. In 2014/15 referrals increased to 60 with 55 receiving a diagnosis. Of these 60 referrals, 45 were male and 15 female. The multi-disciplinary team includes a clinical specialist, a speech and language therapist and is led by two consultant clinical psychologists. The service is currently recruiting to two further full time clinical specialist posts. The team has had an open referral policy since 2012, so adults can self-refer into the service. A recent development has been to provide a follow-up appointment for all people who receive a diagnosis of an autistic spectrum condition at a time determined by the needs of individual service users.

Recommendation: report on work to align the autism diagnosis pathway for children and young people with NICE guidelines in a future edition of this Sunderland Joint Strategic Needs Assessment chapter

Recommendation: investigate any barriers to accessing diagnosis services for people over 35 years of age among whom the prevalence of diagnosed autism recorded in primary care is very low (see section 3.1)

6. Low level crisis prevention services

A theme of comments made at engagement events attended by a range of stakeholders (people with autism and providers and commissioners of services accessed by people with autism) has been that there is a lack of services available to people diagnosed with autism, after the diagnosis care episode. People receiving a diagnosis of an autistic spectrum condition are offered a follow-up appointment with the diagnosis service at a time chosen by the service user. In some cases, diagnosis may lead to assessment for a package of care. In these cases, where a client is considered eligible for a package of care, a personal budget can be spent on support for tasks such as completing housing or welfare benefit claims, processing Council Tax or utility bills or being supported to access opportunities for social contact. But many people are left unsupported and in many cases this support may not be needed on an ongoing basis, but at difficult times when they need help to avert a crisis situation. The requirement may be a need to access a psychological therapy, otherwise referred to as “talking therapy” offered by an “Improving Access to Psychological Therapies” (IAPT) team. Why is this important? If there are people with autism that can’t access appropriate support services, this will increase the risk of them experiencing social isolation, which will in turn increase the burden on

health, mental health and care services in future as social isolation leads to poorer wellbeing, mental and physical health⁷.

An example of service provision elsewhere which has been designed to meet needs for follow-on care is the Bristol Autism Spectrum Service which was highlighted in the 2014 national report *Think Autism*. For four days a week the service offers a diagnosis service in a clinical setting, where service users are assessed for a diagnosis of an autistic spectrum condition. For one day a week, however, the service moves to a non-clinical setting in Bristol city centre. A team of one psychologist, two social workers, one occupational therapist and one administration worker provide a range of services for people who have previously been given a diagnosis of an autistic spectrum disorder.

The work often comprises a second phase assessment, with a wider scope than the assessment for an autism diagnosis. It considers the individual's housing situation, eligibility for benefits and a triage against Fair Access to Care Services (FACS) criteria. The assessment will involve action planning including signposting to other services such as housing support. The service is clear that this process does not involve care management or care co-ordination.

Other workers, such as mental health workers delivering psychological interventions, hold sessions at the venue during the day and also receive support and training from autism specialists to inform their practice and make their services more accessible to people with autism.

A recently published progress report on the 2014 Think Autism updated autism strategy⁸ identifies that third sector or voluntary organisations have an important role to play in supporting people with autism to meet their needs for social contact and friendship, and to avert crisis situations.

⁷ Windle K, Francis J and Coomber C (2011) "Preventing loneliness and social isolation: interventions and outcomes" p2, Social Care Institute for Excellence available at <http://www.scie.org.uk/publications/briefings/files/briefing39.pdf> (last accessed 7th January 2016)

⁸ Department of Health (2016) "Progress Report on *Think Autism*: the updated strategy for adults with autism in England" p48, available at <https://www.gov.uk/government/publications/progress-report-on-strategy-for-adults-with-autism> (last accessed 20th January 2016)

4.1 Preventative support can do much to give people with autism confidence and reduce their levels of anxiety, allow them independence and avoid crisis situations linked to events in their lives. Such support can be more cost-effective in relation to more expensive interventions should a crisis develop.

Care and support

4.2 Many people with autism do not meet the criteria for social care support. However, from April 2015 section 2 of the Care Act placed a duty on local authorities to provide or arrange preventative services for people within their communities. In discharging their duties on prevention, local authorities should, in particular, ensure that they are considering the needs of their local adult population who have autism, including those who do not meet the eligibility threshold for care and support.

4.3 Preventative support can be provided in many different ways. Many adults with autism find it difficult to make friends. User-led and voluntary support groups help adults with autism build relationships with peers, friends, partners and colleagues and also support independent living and being part of the community. Such provision should form part of a comprehensive range of preventative support and should be accessible and provide choice – for example, by ensuring there are a number of support options across a geographical area. Preventative support and advocacy are also important themes in the Care Act statutory guidance.

Extract taken from “Progress Report on *Think Autism*: the updated strategy for adults with autism in England”, Department of Health, 2014

Recommendation: *There should be work undertaken locally to understand the benefits of a of a ‘step-down’ or post-diagnosis autism service and describe what a local service might look like.*

7. Advocacy services

During engagement to inform this needs assessment the view that has been expressed is that there is an absence of local advocacy services that have the skills and knowledge to provide an effective service for people with autism. Two advocacy services exist serving the Sunderland population, with distinct roles.

The North East NHS Independent Complaints Advocacy service is based in Sunderland. It provides its advocacy service to people with a range of disabilities, mental health conditions, learning disabilities or autistic spectrum conditions, specifically in relation to NHS complaints. It has the capacity to record clients with an autistic spectrum condition but doesn’t currently monitor this because it is not

required to as part of statutory contract monitoring. It is currently in the process of asking commissioners if it can include this as a dimension of its contract monitoring. Autism and learning disability awareness training is part of the curriculum of the Advocacy qualification that all advocates employed by the organisation have, or are working towards. The organisation, however, does not currently deliver autism awareness training as part of continuing professional development of advocacy staff.

The second organisation that delivers an advocacy service within Sunderland is the Voiceability Consortium, comprising Total Voice Sunderland and Mental Health Matters. Total Voice Sunderland provides advocacy in six areas:

- i) Mental Health Act advocacy
- ii) Mental Capacity Act advocacy
- iii) Deprivation of Liberty Safeguarding advocacy
- iv) New Care Act advocacy
- v) General professional advocacy
- vi) Litigation friend advocacy – dealing with court of protection issues

All advocates working for the organisation have, or are working towards, a professional advocacy qualification. Studies are largely work- or case-focused and so autism may or may not be covered in their professional training depending on individuals' case mix. Staff note that, while many clients may have an autistic spectrum condition, this is not always captured as a primary or secondary need, simply because other issues take precedence. Autism, however, is one of the categories of primary or secondary need that can be recorded for all clients. Continuing professional development doesn't currently include autism awareness training.

At recent engagement events which discussed the experiences of people living in Sunderland with an autistic spectrum condition, the following issues were raised in relation to advocacy:

- Suitably trained advocates could effectively support parents and adults with autism

Recommendation: *Advocates working within organisations providing an advocacy service should undertake autism awareness training as part of their continuing professional development*

Recommendation: *Commissioners and providers of advocacy services should work together to record the number of clients that access these services who have an autistic spectrum condition. Aggregate numbers should be returned to commissioners as part of regular performance management reports.*

8. Welfare benefits advice

Following diagnosis with an autistic spectrum condition, people often seek help to understand if they are eligible for welfare benefits. These benefits can support them to make any adjustments required to live independently, to access opportunities for social networking and to access employment. The following organisations offer support in Sunderland.

Sunderland Welfare Rights Service

Sunderland Welfare Rights Service provides free, confidential, independent, advice services through a range of access channels.

Sunderland Welfare Rights Service provides help to Sunderland residents to:

- Receive their correct benefits entitlements
- Effectively assert their rights
- Receive assistance with benefits and other support before starting work and while working
- Challenge benefit decisions, including tax credits
- Appeal at tribunals with welfare rights staff representation to dispute a decision about benefits made by the Department for Work and Pensions or a decision about tax credits made by HM Revenue and Customs
- Deal with employment disputes, for example, minimum wage or refusal to grant leave. They also advise anyone who thinks they are disabled and who may need their contract adjusting. Advice can also be provided about employment rights following dismissal. The service also represents employees at Employment Tribunals
- Deal with debt problems
- The service offers advice over the telephone so that they can provide an answer to enquiries straightaway. However, some issues are more complex than others and an appointment would need to be arranged at one of the locations/surgeries that operate across the city.

Sunderland City Council also funds two local advice providers, Shiney Advice and Resource Project (ShARP) and Sunderland West Advice Project. These services are free of charge and can be accessed Monday to Friday, close to where people live. The services offer advice and assistance on all welfare benefits, Personal Independent Payments (PIP), debt and prevention of homelessness.

Advisors within these services can also put people in touch with a range of specialists, including council services such as Sunderland Welfare Rights Service, should a query be more complex.

The providers will signpost people onto a number of other services across the city that can offer advice, information and support depending on the circumstances and needs of the customer. These include:

- Family Support – Family Wise and Children’s Centres
- Local Welfare provision for specialist health support – MIND, North East Council for Addictions (NECA), Counted4, AgeUK, Wearside in Need, Connexions
- Education and training skills – Sunderland North Community Business Centre (SNCBC) support people into work, Jobcentre Plus
- Referrals are also made into appropriate agencies to support with
 - financial/budgeting skills
 - safeguarding concerns
 - Food bank referrals

Autism in Mind

Autism-in-Mind (AIM) supports anyone who is living with autism in Sunderland. AIM is run solely by volunteers, all of whom are living with, or support people who live with autism and other special needs. AIM has no paid employees. It offers online and telephone support to parents and carers.

The organisation can provide and advocate for parents, carers and adults with autism. All of the advocates live with autism themselves and have good understanding and knowledge of autism, essential when communicating with the professionals and services providers who may come into their lives following a diagnosis of autism.

They can offer support to adults with Asperger’s syndrome and high functioning autism who are undergoing benefits assessments and reassessments. They advocate for adults in the work-related activity group and adults taking part in work programmes.

They support parents when they are dealing with Personal Independence Payment (PIP) applications and Disability Living Allowance (DLA) forms and offer support at DLA tribunals.

The National Autistic Society

The National Autistic Society offers advice and information on all aspects of benefit entitlement.

Structural changes to welfare benefits

At the current time there is also a separate, ongoing programme of welfare reform, up to and beyond 2020, affecting a range of individual benefit and or tax credits and the people receiving them. The changes are predominantly aimed at people of working age and, given the number of changes, these will impact on people in different ways.

At recent engagement events the following issues were raised in relation to welfare benefits advice:

- A lack of knowledge and understanding of autism among staff within welfare benefits advice services is creating a barrier to access for some adults with an autistic spectrum condition.

Recommendation: *Sunderland Welfare Rights Service staff, and staff in organisations that they refer into, should undertake autism awareness training as part of continuing professional development.*

Recommendation: *Autism In Mind has recently become a Community Interest Company (CIC). It should consider what services it is able to provide that will develop the CIC into a sustainable organisation.*

9. Care of people with autism with additional needs

In May 2011 a BBC television Panorama report revealed criminal abuse at the Winterbourne View hospital which provided care for adults with learning disabilities or autism. In response to this, the Department of Health published a report “Transforming Care”⁹. The report responded to the abuse at Winterbourne View, but addressed more widely the care and support experienced by all children, young people and adults with learning disabilities or autism who also have mental health conditions or behave in ways that are often described as challenging. The report sets out a programme of action to transform care services for this group of people. It recognises that these people can be, and have a right to be, given the support and care they need in a community-based setting, near to family and friends. Many are currently cared for in hospital inpatient settings, and these may be located outside their area of usual residence.

In Sunderland, at any one time, there are approximately 10 young people and adults with learning disabilities or autism who also have mental health conditions or behave in ways that are often described as challenging, who are cared for in inpatient settings¹⁰. These people may be cared for within or outside Sunderland. Sunderland Clinical Commissioning Group work with Northumberland, Tyne and Wear NHS Foundation (mental health) Trust and social care teams within Sunderland City Council to put in place care packages for these people. Jointly, these organisations have put in place processes to ensure that the care of people currently in inpatient mental health settings is reviewed regularly by a multi-disciplinary team including a senior commissioning manager, a consultant psychiatrist, an independent expert by

⁹ Department of Health (2012) “Transforming care: A national response to Winterbourne View Hospital: Department of Health Review Final Report”, available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf (last accessed 30th October 2015)

¹⁰ Data source: Sunderland Clinical Commissioning Group

experience, an independent clinician and other key individuals involved with the care of the service user whose case management is being reviewed. A similar team meet to review cases for people who are at risk of future inpatient admission e.g. those newly diagnosed or who are in a community care setting but have experienced crisis episodes. A key feature of the resultant care plans is that, if an inpatient care setting is considered appropriate, a planned discharge date is set and the steps needed to prepare the service user for discharge are detailed. The national improvement plan is set out in the report “Building the right support”¹¹. The aim is that, in three years’ time, no area will need capacity for more than 10-15 inpatients per million population in clinical commissioning group (CCG) commissioned beds (such as assessment and treatment units), and 20-25 inpatients per million population in NHS England-commissioned beds (such as low-, medium- or high-secure services). This equates to 3-5 CCG commissioned beds in Sunderland.

Recommendation: continue to monitor progress in Sunderland towards achieving the following objectives of the Transforming Care programme:

- *Reduced reliance on inpatient services (closing hospital services and strengthening support in the community)*
- *Improved quality of life for people in inpatient and community settings*
- *Improved quality of care for people in inpatient and community settings*

10. Educational provision

Depending on the severity of the autistic condition, the individual characteristics of a young person and the choice of the young person and parents or carers, the educational needs of children and young people in Sunderland may be met through supported provision within mainstream education or within a special primary or secondary school. In the state-funded sector, Columbia Grange in Washington is a specialist primary school for children with autism and, in 2015, has 92 pupils on its roll, with a further 11 on a waiting list for a place. Some pupils have a severe learning disability or profound and multiple learning disabilities in addition to autism. In contrast, some pupils may have a normal to high intelligence quota (IQ) but find social communication and interaction very challenging. A group of pupils, who may be from either group, may also exhibit challenging behaviour. The school also has an Autism Outreach Team which supports pupils diagnosed with autistic spectrum conditions in mainstream schools across Sunderland and the team currently has around 1,200 pupils on its register.

¹¹ Houlden A (2015) “Building the right support: A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition”, Local Government Association & Association of Directors of Adult Social Services & NHS England, available at <https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf> (last accessed 30th October 2015)

At secondary and sixth form level, there are two state-funded special schools in Sunderland attended by students with autistic spectrum conditions, among pupils with other special needs. The Barbara Priestman Academy is in Barnes ward and is for students with an autistic spectrum condition or complex learning disabilities. It currently has around 120 pupils on its roll. The Portland Academy is in Doxford ward and is for pupils with a severe learning disability or profound and multiple learning disabilities. A growing number of its pupils also have an autistic spectrum condition. It has a school roll of around 150 pupils. Together, these two schools form the Ascent Trust. Biddick Academy has a specialist unit supporting around 10 pupils with autistic spectrum conditions to access education within the main school.

In the independent sector Thornhill Park School in Southwick ward is a special day school for students with autism and Asperger's syndrome. It is run by the North East Autism Society and there are currently around 65 students on the roll from 9 to 19 years of age.

With the passing of the Children and Families Act in 2014, the system changed, by which the needs of children and young people with special educational needs and disabilities (SEND) are assessed. Where, previously, a pupil with a special need was given a Statement of Special Educational Need, they will now receive special education needs (SEN) support within their school or college, or an Education, Health and Care Plan (EHCP) will be put together where a child or young person needs more support than is available through SEN support. These provisions now apply from 0 to 25 years of age.

It is estimated from research¹² that 1.2% of children have an autistic spectrum condition and Department for Education statistics show that, currently in 2015 in Sunderland, 1.7% of all pupils in state-funded primary, secondary and special education have a special educational need where the primary need is an autistic spectrum condition (see section 3.2 above). There have been growing numbers of pupils identified in recent years with an autistic spectrum condition. This may be due to a growing awareness of autism among education, health and care professionals, but also among parents and carers. The development of autism diagnosis services within the city in recent years may have contributed to the growth in numbers. This is leading to increased pressure on special educational provision and the buildings at Columbia Grange school are currently being enlarged to accommodate more pupils.

From 16 years onwards, there are opportunities to continue studying at the Barbara Priestman and Portland Academies and Thornhill Park School. Students with autistic

¹² Baird G et al (2006) "Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP).", *Lancet*, 2006 Jul 15;368(9531):210-5 abstract available at <http://www.ncbi.nlm.nih.gov/pubmed/16844490> (last accessed 17th August 2014)

spectrum conditions can also access supported learning opportunities at Sunderland College, South Tyneside College and Newcastle College.

During two engagement events held in March and July 2015 to consider the experiences of people living with autism in Sunderland the following points were raised in relation to educational provision:

- planning and support is needed for all transitions e.g. moving to a new classroom at school or moving from primary school to secondary school, especially where there is no statement
- more structured support for people with autism is required within schools
- schools need to promote and share information about the Education, Health and Care Plan (EHCP) process to parents
- schools need to be inclusive of children with autism and improve communication between the school, the family and the person with autism throughout school life
- there should be wider accessibility to advocates to support parents with autism
- Special Educational Needs Coordinators (SENCOs) in schools do not always understand that autism presents differently in different people.
- colleges no longer provide support with transport
- colleges and universities should have a support officer with autism training – *Sunderland College have Learning Support Advisers, South Tyneside College has a department specifically for people with autism and Newcastle College provides Interface Support for students with autistic spectrum conditions and other additional needs*
- young people identified with conditions on the autistic spectrum should be tracked over time to ensure that their needs are being met at all times e.g. through annual review of Education Health and Care Plans – *Connexions track education and employment destinations for all pupils and college students in Sunderland but the autism flag within their database is not well used*

Recommendation: *Parents, carers, education commissioners, teachers, lecturers, Special Educational Needs Coordinators with an interest in educational provision for people with autism, health professionals and care professionals come together for a half day workshop. At the workshop, share information about initiatives to address the above issues and consider solutions where there are gaps in provision.*

11. Employment

Employment opportunities for people with autism are limited. Employment statistics are collated for people diagnosed with a learning disability living in England who

receive adult social care packages, of whom 20%-30% will have autism¹³, but are not currently collated for people diagnosed with an autistic spectrum condition. In 2014/15 6% of working age adults with learning disabilities was reported to be in paid or self-employment¹⁴. Of those in employment, 70% work for less than 16 hours per week¹⁵. Recording employment statistics for people diagnosed with an autistic spectrum condition would allow the effectiveness of initiatives to improve employment opportunities to be monitored.

Because of concern about a lack of employment opportunities for people with learning disabilities and autism, the Sunderland Learning Disability Partnership Board and the Sunderland Autism Partnership Board have convened an Employment Subgroup to identify and liaise with providers of employment opportunities, bring together information about local supported employment initiatives and raise awareness of the shortage of opportunities. A report produced by the subgroup¹⁶ makes some recommendations, including the following:

- Information about pathways into paid employment should be stored in a single, easily accessible place, such as a public-facing website
- There should be more support for Community Interest Companies and micro enterprises
- There should be more support for supported Internships – Gateshead Access to Employment Service (GATES) is an example of a supported employment service elsewhere in the North East of England. It has been developed by Gateshead Council and is located on the Team Valley Trading Estate

Examples of supported employment opportunities available for people with autism living in Sunderland are:

- Autism Works software testing employ people with autism. Autism Works is a subsidiary of Education and Services for People with Autism (ESPA).
- Beckwiths community interest company, runs a range of cafes and snack bars across Sunderland. The company employs people with a learning disability or autism.

¹³ Emerson E, Baines S (2010) "The Estimated Prevalence of Autism among Adults with Learning Disabilities in England", Improving Health and Lives, available at http://www.improvinghealthandlives.org.uk/uploads/doc/vid_8731_IHAL2010-05Autism.pdf (last accessed 11th November 2015)

¹⁴ Health and Social Care Information Centre (2015) "Measures from the Adult Social Care Outcomes Framework (ASCOF), England", HSCIC, Leeds available at <http://www.hscic.gov.uk/catalogue/PUB18657/meas-from-asc-of-eng-time-sers-anx.xlsx> (last accessed 4th Dec 2015)

¹⁵ Hatton C, Emerson E et al (2014) "People with Learning Disabilities in England 2013", Public Health England available at https://www.improvinghealthandlives.org.uk/securefiles/151101_1551//People%20with%20learning%20disabilities%20in%20England%202013.pdf (last accessed 30th October 2015)

¹⁶ Sunderland Learning Disability Partnership Board, Learning Disabilities Employment Subgroup (2014) "Employment Report – Learning Disabilities and Autism", Sunderland City Council

- North East Autism Society's supported employment programme offers work experience placements with local employers.
- Project Choice, an education and employment initiative based at Gateshead College, but who work with local employers including City Hospitals Sunderland to identify work experience placements. Project Choice provides 12 month supported internships with support to find employment at the end of the internship.
- Shaw Trust who provide the Work Choice programme, delivered from an office in central Sunderland. The Work Choice programme provides support to search for employment opportunities, training and coaching.

Connexions provides a specialist further education and careers advice service for young people 13-19 years of age delivered by professionally qualified Personal/Careers Advisers. It is not a statutory service so individual schools may choose to purchase careers advice from Connexions or provide it themselves. As an example, Connexions currently has an officer that provides an education and careers advice service at Portland Academy special school.

Jobcentre Plus has offices in Sunderland city centre, Houghton le Spring, Southwick and Washington. Staff at these centres offer advice and support to people seeking employment and electronic information points provide information about local job vacancies which can be searched by location of, and/or type of employment. Previously, up to 2015, each Jobcentre Plus office had a disability employment adviser, but since 2015 there has been a change to the way in which this aspect of the service is delivered. Now "work coaches" support clients with and without a disability. The advantage of this model of delivery is that it provides continuity in the relationship between work coach and client. The service still has a small number of specialist disability employment advisers and three work psychologists at regional level in the North East, but these officers typically support, advise and train work coaches who are working one-to-one with people with a range of disabilities.

The following are examples of reasonable adjustments to the way in which Jobcentre Plus delivers its service which, it is hoped, improve the experience of people accessing the service who have an autistic spectrum condition. In November 2015, 20 work coaches from across the North East region attended a one-day autism awareness training course delivered by Autism Alliance UK which included a presentation from a person with autism, recounting their experiences navigating the Jobcentre Plus system and accessing employment. The service recognises that autism awareness training is an important aspect of continuing professional development for its staff and the need for additional courses will be reviewed on an ongoing basis. A second adjustment is the provision, in all Jobcentre Plus offices, of a private meeting space for clients who find it difficult to contend with peripheral noise and activity in an open plan office environment. Clients requiring use of this

space need to advise the service in advance so the private meeting space can be booked and its use guaranteed.

As an example of service provision elsewhere, Gateshead Council's Adult Social Care, Provider Services deliver Gateshead Access to Employment Service (GATES). GATES is a Supported Employment service which is open to those who are entitled to a package of care provided by, or funded by the local authority, reducing the need for services. This makes GATES cost neutral or 'spend to save' provision. The service offers support to people with a disability who require long term supervision or support to obtain employment. It also liaises with employers to identify suitable vacancies, assist them implementing equal opportunities policies and provide tailored employment training and support packages including on-the job training.

Since opening in September 2013, GATES has supported 28 people with complex learning disabilities, physical disability, autism or mental health conditions, into paid, permanent work, raising the proportion of people with a learning disability in employment (Adult Social Care Framework indicator 1e) from 5.8% to 7.7%¹⁷. This is 1.7% above the national average of 6.0%. GATES also maintains the employment of a further 53 individuals who require long term support and supervision.

The following issues were raised in relation to training and education at engagement events held to inform this needs assessment:

- More supported internships are required as although Project Choice provides training opportunities for people with high functioning Asperger syndrome (post 18), places are limited.
- Mainstream employers lack understanding of autism and don't recognise the skills and qualities that a person with autism may have to offer. Autism 'model employers' (employers that have successfully employed people with autism) could have a role here.
- Build links to employers in order to develop employment opportunities for people with autism
- Job Centres should provide support into employment and be more inclusive, e.g. speak to people in a quiet environment as open plan offices can cause sensory problems for some people with autism. Sunderland People First have organised test visits to organisations such as Sunderland Council Customer Contact Centres in the past, involving people with learning disabilities and autism. A visit to Sunderland's Jobcentre Plus would be beneficial.

¹⁷ Health and Social Care Information Centre (2015) "Measures from the Adult Social Care Outcomes Framework (ASCOF), England", HSCIC, Leeds available at <http://www.hscic.gov.uk/catalogue/PUB18657/meas-from-asc-of-eng-time-sers-anx.xlsx> (last accessed 4th Dec 2015)

- It was felt that advisers at Connexions did not have any specialist understanding which could help them to support people on the autistic spectrum.
- Better pre-employment support (during application and interview stages) could improve levels of employment among people with autism.
- Post-employment support is not available e.g. support for people with special needs, including autism, who have to change job e.g. due to redundancy.

Recommendation: *identify autism model employers – that is employers that have successfully employed people with autistic spectrum conditions. With their consent, use their experiences to promote the benefits of employing people with autism to other local employers.*

Recommendation: *employment rates among people with autistic spectrum conditions are not routinely monitored. Investigate whether the Connexions database could be used to monitor training and education outcomes for young people with autistic spectrum conditions aged 16 to 24 years of age.*

Recommendation: *Locally, monitor employment rate of people with autism of working age (16-64 years) who receive social care packages, via employment status that is recorded at the annual review.*

12. Autism awareness and training

A major theme of the 2010 national autism strategy and the subsequent update “Think Autism” was building communities that are more accepting and understanding of people with autism. Linked to this ambition is improving access to mainstream public services through a greater awareness of the needs of people with autistic spectrum conditions. Autism awareness may be raised through media campaigns, similar to the ongoing campaign to encourage people to become Dementia Friends. However, improved access to public services is more likely to be achieved through widespread adoption of regular autism awareness sessions as part of initial training or continuing professional development for health and care staff. These sessions will have a common element discussing the needs of people with autistic spectrum conditions, but will consider appropriate adaptations to care processes in specific environments such as home care, dentistry or hospital nursing.

A census of autism awareness sessions within local health and care training courses revealed that they are not widespread. The census included pharmacy, social work, nursing and health care courses at further education institutions in Sunderland and Newcastle and was undertaken between July and September 2015. The exception was the social work degree course at Sunderland University. As part of the *Working With Adults* module, followed by all students, the North East Autism Society deliver a two hour autism awareness session which is co-delivered by people with autistic

spectrum conditions. The health and social care foundation degree course at Sunderland College includes an autism case study analysis, focusing on personalised care planning, as one of its examined assessments.

Similarly, as part of induction or continuing professional development, regular autism awareness refresher courses or e-learning modules for health and care professionals are not universal but there are examples of good practice. The adult social work team at Sunderland City Council run autism awareness sessions for staff. The Autism Outreach Team at Columbia Grange school run autism awareness sessions, separately, for teachers and parents or carers of autistic children. At Sunderland Care and Support, a team led by two Learning Disability Registered Nurses (RNLDs) delivers autism awareness training to staff who support service users with autistic spectrum conditions. Sunderland Clinical Commissioning Group HQ staff have had autism awareness training.

Wider provision of autism awareness training sessions for health and care staff, co-delivered by people with autism spectrum conditions, would also contribute towards the goal of creating more paid employment opportunities for people with autism.

Recommendation: identify and publicise local providers of autism awareness training. Identify standards of good practice for this training

Recommendation: discuss wider adoption of autism awareness training among health and social care staff at the Board of the Sunderland CARE Academy.

Recommendation: identify strategic-level champions for autism awareness training among local health and care organisations

13. Improving access to mainstream public services through reasonable adjustments

The Equality Act 2010 includes provisions that require organisations such as employers, shops and all public services to make “reasonable adjustments” to remove barriers to access by people with a disability. The Improving Health and Lives learning disability website¹⁸ has drawn together examples of reasonable adjustments made by healthcare providers which can equally improve access for people with autism. Examples are:

- A Care Passport¹⁹, in use at City Hospitals Sunderland, including things hospital staff must know about a person, things that are important to them, a

¹⁸ Improving Health and Lives (2014) “Reasonable Adjustments Database” available at <https://www.improvinghealthandlives.org.uk/adjustments/> (last accessed 4th November 2015)

¹⁹ City Hospitals Sunderland NHS Foundation Trust (2015) “Supporting you with your hospital visit. Acute Liaison Service for People with Learning Disabilities”

list of what a person likes and dislikes and any reasonable adjustments that they require

- Provision of eye tests using pictures rather than the traditional Snellen Chart involving letter recognition²⁰

The Acute Liaison Nurse at City Hospitals Sunderland NHS Foundation Trust contacts Sunderland GP Practices annually and practice managers provide her with a list of people on their practice list that have a learning disability diagnosis. This allows the hospital to update its internal patient administration system and flag up service users with a learning disability booked for planned inpatient admissions or outpatient appointments in advance of them arriving. Depending on the needs of the service user, it may be appropriate, for example, to allocate a double time outpatient appointment, or access patient information in an easy read format. This system is effective because the Quality and Outcomes Framework²¹ requires all GP Practices to identify a list of service users with a diagnosis of a learning disability. Currently there is no such requirement to identify a list of service users with autistic spectrum conditions. Thus, even if the Acute Liaison Nurse at City Hospitals Sunderland requested a list of service users with an autistic spectrum condition, it is likely that the clinical records of many service users with autism would not have the correct clinical code to allow them to be identified. While not perfect, extension of the alert flag system to include people with an autistic spectrum condition would be an improvement on current practice.

Through provision of an Acute Liaison Nurse service at City Hospitals, adjustments to hospital care can be made more effectively where a person with an autistic spectrum disorder also has a learning disability. However, those who don't have a learning disability and those with high functioning autism may, currently, slip through the net.

Recommendation: extend the alert flag in operation at City Hospitals Sunderland to service users with an autistic spectrum condition

Recommendation: introduce autism awareness training sessions as part of refresher training among hospital staff groups

Recommendation: discuss autism, and specifically identifying people with autism within their primary care record, at a future Time In Time Out session, organised by Sunderland Clinical Commissioning Group and attended by Sunderland GP Practice staff. The session should be addressed by a local service user who has an autistic spectrum condition.

²⁰ SeeAbility (2015) "The eye test explained" available at https://www.seeability.org/uploads/files/PDFs_Books_non_Easy_Read/Eye_test_explained.pdf (last accessed 4th November 2014)

²¹ Health and Social Care Information Centre (2015) "Quality and Outcomes Framework" available at <http://www.hscic.gov.uk/qof> (last accessed 4th November 2015)

Recommendation: ask the National Institute for Health and Care Excellence Quality and Outcomes Framework Indicator Advisory Committee²² that autistic spectrum conditions are considered for inclusion in the list of long-term conditions for which prevalence is published annually for GP Practice, CCG and national populations.

Case study: Improving patient experience for people with autism and learning disabilities through reasonable adjustments to care, City Hospitals Sunderland Surgical Day Case Unit



The Surgical Day Case Unit is located at entrance 9 of Sunderland Royal Hospital. It is a consultant led service and includes the specialities of Gynaecology, Urology, General surgery, Chronic pain management, Orthopaedic, Head and Neck, Ear nose and Throat (ENT), Oral and Facial. Surgery is performed under local and general anaesthetic.

The team receive referrals via the Patient Liaison Nurse or direct referrals from health professionals. Before the procedure is due to take place, the team gather information about patients' needs from a variety of sources including the patient, family members and patient liaison nurse. This care planning approach team allows the team to address individual patient needs. Team leader: "The more information we have the better the patient's experience"

²² The work of this group is summarised at <https://www.nice.org.uk/standards-and-indicators/how-we-develop-qof> (last accessed 8th January 2016)

The Surgical Day Case Unit team provide a wide range of reasonable adjustments for patients with learning disabilities or autism. This includes arranging pre-visits, making changes to the environment and coordinating multiple procedures to avoid repeat visits. The team have provided examples of individualised support which has enabled patients who find accessing hospital difficult, to undergo procedures.

The team are proactive in reviewing communication and information. They are currently developing an accessible guide around the 'Patients Journey' and utilise accessible hospital passport guides. The service provides clear information relating to the procedure, information about eating and drinking, medication and what patients can expect after the procedure.

The service is keen to listen to / receive feedback from patients and families. The service is part of the 'Friends & Family test' and 'How did we do' leaflets are given to patients after appointments.

14. Community safety and the criminal justice system

Two distinct issues affect people with autistic spectrum conditions in relation to community safety. Firstly there is the issue of making public places like town centres safe places for people with a learning disability, an autistic spectrum condition, a physical disability or a sensory impairment. The second issue is adapting processes in the criminal justice system so that people with additional needs such as those with an autistic spectrum condition have their needs recognised.

14.1. Safety in public places

Results from the Crime Survey for England and Wales²³ suggest that there are 62,000 disability motivated hate crimes every year. There is a large gap between this and the 1,985 disability hate crimes reported to the police and recorded by the Home Office in 2013/14²⁴. A local initiative, called the "Sunderland Safe Places scheme", aims to make public places such as shopping centres and town centres safer places for people with a learning disability, an autistic spectrum condition, a physical disability or a sensory impairment. The scheme identifies shops, leisure services and public services who have staff trained to support a member of the public who has additional needs and who is being harassed or abused. The scheme is called the Sunderland Safe Places scheme and Safe Places are identified by displaying a sticker in their window or on their door.

²³ Home Office, Office for National Statistics and Ministry of Justice (2013) "An Overview of Hate Crime in England and Wales", available at www.gov.uk/government/statistics/an-overview-of-hate-crime-in-england-and-wales (last accessed 5th November 2015)

²⁴ Home Office (2014) "Hate crimes, England and Wales 2013 to 2014" available at <https://www.gov.uk/government/statistics/hate-crimes-england-and-wales-2013-to-2014> (last accessed 5th November 2015)



Staff at Safe Places have followed a training course that is co-delivered by people with a learning disability. The course covers the procedure that staff should follow when a member of the public comes in with a concern about their safety. It also highlights ways in which staff should communicate e.g. using simple language, giving the member of the public time to explain what has happened, and finding a quiet and safe place where they can wait for a friend, carer or family member to come and assist them. Sunderland People First, a voluntary sector organisation that advocates for people with learning disabilities, has produced a 10-minute video which describes the scheme and can be viewed on YouTube at <https://www.youtube.com/watch?v=kG5uTbuR8SI>.

Recommendation: *the Safe Places scheme continues to be widely publicised*

14.2. Criminal justice system

In 2009 the Lord Bradley report²⁵ recognised that there were many people within the criminal justice system with mental health conditions or learning disabilities. It acknowledged that public protection remained the priority, but that prison might not always be the right environment for these people. Custody can exacerbate mental ill health, heighten vulnerability and increase the risk of self-harm and suicide. Many of the people to which the report refers will have an autistic spectrum condition.

²⁵ Bradley, Rt Hon Lord (2009) "Lord Bradley's review of people with mental health problems or learning disabilities in the criminal justice system", Department of Health, available at http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/PublicationsandStatistics/Publications/PublicationsPolicyAndGuidance/DH_098694 (last accessed 11th November 2015)

Following a health needs assessment of Northumbria Police custody suites undertaken in 2012²⁶, a Liaison and Diversion nursing service was commissioned to enhance the existing medical service provided by forensic medical examiners (FMEs). FMEs tend to be General Practitioners (GPs) undertaking the role on a sessional basis while maintaining general practice. The Liaison and Diversion nursing service screens people entering the custody suite for mental health conditions so that, where it is appropriate, they can be referred into mental health services, or referred on to prison health services where they are being remanded. Screening also covers housing issues, debt, social issues such as substance misuse, acquired brain injury and veteran status.

As a further refinement of this service model, a modified version of the risk assessment tool currently in use (the new version is referred to as the Newcastle Risk Assessment Tool) was introduced into custody suites across Northumbria Constabulary in 2015. The tool includes questions that increase the likelihood of identifying people with a learning disability, so that appropriate healthcare staff can be brought in to support the person in custody. As around half of people with an autistic spectrum disorder do not have a learning disability it is possible that the needs of these people will remain unidentified. However, Liaison and Diversion nursing staff employed within custody suites across the Northumbria Constabulary area all undergo autism awareness training as part of statutory training updates. Also, where these nursing staff observe a communication difficulty, they complete a communication form, which is shared with the magistrate, the solicitor, the Crown Prosecution Service, the Probation Service, contracted staff that manage prison cells and the Prison Service if the person is remanded. Autism awareness training among healthcare staff that are present 24/7 within Northumbria Constabulary's custody suites could further reduce the risk of people slipping through the risk assessment safety net.

Recommendation: ensure that the Safe Places scheme continues to be widely publicised. Member organisations should be encouraged to host refresher staff training courses every few years to ensure that new staff are appropriately trained and existing staff do not lose their skills.

Recommendation: healthcare staff within Northumbria Constabulary's custody suites undertake autism awareness training as part of their continuing professional development.

²⁶ Brooker C, Sirdfield C et al (2012) "Northumbria Police Custody: Health Needs Assessment", University of Lincoln available at http://eprints.lincoln.ac.uk/6270/1/Northumbria_Police_Custody_HNA.pdf (last accessed 8th November 2015)

15. Developing opportunities where people with autism can access their community

In other sections of this report there has been discussion of developing awareness of autistic spectrum conditions, and making reasonable adjustments to the provision of services. If changes are made in these areas it is hoped that, over time, there will become an increasing array of opportunities – shopping, cinemas, theatres, sports centres and sports arenas to name just a few – where people with autism can participate in activities and leisure pursuits that most people take for granted.

In Sunderland there are a number of examples where adaptations to local public-facing services are making it increasingly possible for people with autistic spectrum conditions to take part in leisure activities:

Sunderland Empire Theatre has a Creative Learning Team which works in partnership with North East Autism Society and other groups. The theatre is happy for people with additional needs such as a learning disability or an autistic spectrum condition to visit the theatre with friends, family or carers for an orientation visit prior to attending a performance, usually during the day when building is quiet. On occasions, the theatre

has organised “relaxed” performances, where the audience are free to move around and walk out of the auditorium if they need to. A community outreach programme of autism-friendly events and activities were held recently when the theatre presented “The Curious Incident of the Dog in the Night-time” in which the main character is a child with Asperger’s syndrome. All front-of-house staff have taken part in autism awareness training delivered by the North East Autism Society. This is part of a wider initiative to enable access to the Theatre by all sections within the community.

Sunderland Empire cinema has been piloting autism friendly performances of films once a month on a Sunday to assess uptake. In these screenings members of the



Children explore the Empire theatre as part of the *Get Curious* learning project

audience can move around the auditorium or walk outside and come back in if they need to. The cinema will be deciding on a policy for these showings in January 2016.

Sunderland AFC football club have introduced a family zone open on match days where there is an area away from the noise of the crowd that young people can access throughout matches. The area offers fun play activities and is an area where young people can relax if they get anxious due to noise and activity in the crowd.. There is also a sensory room where supporters, young or old, who are affected by the noise of the crowd can watch the match from inside, behind a glass window.

Sunderland City Council have brought together information about sports clubs and municipal sports facilities in Sunderland that have adapted provision for children and young people (0-24 years of age) with additional needs. This information can be found on the Council's "Local Offer" web page (go to <http://sunderland.fsd.org.uk/kb5/sunderland/fis/home.page>) and entries include contact details for provider clubs and organisations and information about specific adaptations. Activities can be searched by key word, age group and locality to identify, for example, all activities suitable for 16-19 year olds with autism in Washington. There remains a gap in the provision of information about adapted provision of opportunities to undertake sport and leisure activities for adults.

16. Gap analysis

Gaps are identified under the headings used in the main report:

16.1. Population profile

There is a need for an annual collection of aggregate numbers of people with a diagnosis of autism or Asperger's syndrome in their medical records from all 51 GP Practices in Sunderland. The collection should break down the total numbers diagnosed by gender and single year age band between 0 and 24 years and 10 year age band thereafter. This data will help education commissioners to plan local school provision. It will also help health service managers and commissioners consider the cumulative effect of autism diagnosis services on population prevalence.

Including a requirement for General Practices to be able to identify a register of service users diagnosed with autistic spectrum conditions within the Quality and Outcomes Framework would improve the quality of prevalence data. The Quality and Outcomes Framework is a national service specification reviewed each year by the National Institute for Health and Care Excellence (NICE) along with representatives of general practice professional bodies.

16.2. Autism diagnosis services

There is ongoing work between Sunderland Clinical Commissioning Group and City Hospitals Sunderland to bring the autism diagnosis pathway in line with NICE guidance. Completion of this work will produce a single consistent diagnosis pathway.

Prevalence of autistic spectrum conditions in general practice records is very low among adults 35 years of age and over. Similarly the number of people recorded as having autism in receipt of a package of social care aged 35 and over is very low. There is a need to study barriers to accessing the adult autism diagnosis service among this age group.

16.3. Care of people with autism with additional needs

The Transforming Care programme aims to reduce the number of people with severe learning disabilities and/or autism and who may have challenging behaviour who are cared for in inpatient mental health care settings. The number of Sunderland residents in these settings should be regularly monitored to assess the efficacy of the programme. Measures should also be monitored which assess the quality of life, and the quality of care for these people in both inpatient and community settings.

16.4. Educational provision

Engagement with a range of stakeholders to inform this needs assessment raised a wide range of questions regarding educational provision of children and young people with autistic spectrum conditions. These questions have been noted in the body of this report. It has not been within the scope of this needs assessment to answer all of these questions and so it is recommended that stakeholders – parents, carers, education commissioners, teachers, lecturers and special educational needs coordinators – come together for a half day workshop to discuss these issues.

16.5. Employment

Employment rates among adults with a learning disability are low. Employment rates among people with an autistic spectrum condition are reported to be low, but there is currently no means of recording training and employment status for these people. Investigate whether the Connexions database could be used to monitor training and education outcomes for young people with autistic spectrum conditions aged 16 to 24 years of age.

There are few supported employment opportunities for people with learning disabilities and/or autism. Identify autism model employers – that is employers that have successfully employed people with autistic spectrum conditions. With their consent, use their experiences to promote the benefits of employing people with autism to other local employers.

Understand how the Gateshead Employment Support project has evaluated. Has it increased the employment rate among people with autistic spectrum conditions and has it realised net cost savings, if increased employment has reduced reliance on care services?

16.6. Autism awareness and training

Autism awareness training is not common among local health and care staff, or on courses that train health and care staff within local further education establishments. Discuss wider adoption of autism awareness training among health and social care students and staff at the Board of the Sunderland CARE Academy.

Identify strategic-level champions for autism awareness training among local health and care organisations

16.7. Improving access to mainstream public services through reasonable adjustments

The acute liaison nurse at City Hospitals Sunderland, annually, collects a list of all service users registered with Sunderland GPs who have a diagnosis of a learning disability and updates their hospital care record with a learning disability flag. This scheme should be extended to service users with an autistic spectrum condition who should have a separate autism flag on their record.

Autism awareness training sessions should be introduced as part of refresher training among hospital staff groups.

16.8. Community safety and the criminal justice system

A “Safe Places” scheme provides locations in public places that have trained staff where a child, young person or adult with additional needs who is being harassed or abused can ask for help. The Sunderland Safe Places scheme should be widely publicised and member organisations should be encouraged to host refresher staff training courses every few years to ensure that new staff are appropriately trained and existing staff do not lose their skills.

Procedures in police custody suites have been modified since 2009 to include use of a risk assessment tool which aims to identify suspects with a mental health condition or a learning disability and provide appropriate support. Autism is not specifically addressed by the risk assessment tool.

Specialist mental health liaison and diversion nursing staff undertake statutory autism awareness training as part of their continuing professional development. Health care staff within custody suites should also undertake this training.

16.9. Developing opportunities where people with autism can access their community

There are an increasing number of autism-friendly leisure services in Sunderland. The Local Offer website brings together information about opportunities accessible to people with autistic spectrum conditions aged 0-24 years of age. A gap remains in the provision of information about adapted provision of opportunities to undertake sport and leisure activities for adults.

17. Conclusions

The publication of the national autism strategy “Fulfilling and Rewarding Lives” in 2010 outlined a vision of a society that is more understanding of people with autistic spectrum conditions and where health, care and public-facing services are adapted to make it easier for people with autistic spectrum conditions to access them. This vision was reinforced in 2011 with the publication of NICE guidelines for autism diagnosis services. And yet, with the change in government in 2010, and the changes in the structure of health services in 2013²⁷, this drive for change appears to have lost some of its initial momentum.

There has been a rise in the number of people with a diagnosis of autism identified in their medical records in recent years. But there are still very few people over the age of 35 years who have a recorded diagnosis and so may not be receiving the services that could support them to live independently. Around half of people with an autistic spectrum condition also have a learning disability and there are many examples of adjustments to health and care services which make them more accessible to people with learning disabilities. But the needs of people with autism who have a regular or high IQ will not be addressed by these adaptations and they may fall through this ‘safety net’.

The relatively recent development of autism diagnosis services will increase the number of people with a diagnosis on their medical records. This, in turn, will increase the number of people that can access appropriate services which can support them to live independently. It appears, however, that there are still significant barriers for adults 35 years and over to gain a diagnosis, reflected in very low prevalence among this age group.

If the recommendations within this needs assessment are adopted, the rate of change towards a society in which people with an autistic spectrum condition are recognised and their needs are met will be accelerated.

²⁷ Under the provisions of the 2012 Health and Social Care Act, Primary Care Trusts were dissolved. Responsibilities for commissioning local health services were placed with Clinical Commissioning Groups and the responsibility for public health was placed with Local Authorities.

18. Next steps

The Sunderland Joint Strategic Needs Assessment is an evolving statement of the health, care and wellbeing needs of the population of Sunderland. This chapter will be refreshed in future years. Between now and then, the Sunderland Autism Partnership Board and its subgroups will continue to gather evidence so that future editions of this chapter on autism will represent a more comprehensive coverage of the broad range of issues affecting people living with autism in Sunderland.

Sunderland City Council, February 2016

Annex A

Issues raised during discussions on the draft text with members of the Sunderland Autism Partnership Board Joint Strategic Needs Assessment Task and Finish Group

During discussions with the task and finish group, a number of gaps in the draft text were identified. The issues raised are set out below and against each, there is a commentary to demonstrate how these have been addressed in this final text.

- i) There should be some local scoping undertaken to understand the benefits of a 'step-down' or post-diagnosis autism service and describe what a local service might look like (such services exist in some other Local Authority areas in England, the Bristol service is described within the chapter, but the existing NICE guidance and quality standard do not explicitly recommend such a service). This could be a piece of work that a task and finish subgroup of the Sunderland Autism Partnership Board could be tasked with.

Response - a new recommendation has been included, that some scoping work should be undertaken locally to describe what such a service might look like (p18)

- ii) The chapter should include a description of adjustments made to the local psychological (talking) therapy service such that it is appropriate for and accessible to people with autism.

No response was received to requests for information asking what reasonable adjustments are made to the Improving Access to Psychological Therapies service delivered by Northumberland Tyne and Wear NHS Foundation Trust to meet the needs of service users with autism. A response will be requested and included in a future update of this Joint Strategic Needs Assessment chapter.

- iii) The numbers accessing adult social care with a diagnosis of autism should be broken down to show the number with a dual diagnosis of autism and a learning disability and the number with just a diagnosis of autism. A breakdown of current data will be sourced as a means of evidencing how many people with autism as a sole diagnosis actually access care services.

Response – breakdown now provided, along with an explanation of how autism is recorded in the social care service user record

- iv) There should be an acknowledgement in the chapter that if there are people with autism that can't access appropriate support services, this will increase the risk of them experiencing social isolation, which will in turn increase the burden on health, mental health and care services in future as social isolation leads to poorer physical and mental health.

Response – this is acknowledged on p16 along with a link to an evidence briefing from the Social Care Institute for Excellence (SCIE) which sets out the evidence that links social isolation to poor mental health and wellbeing

- v) GP Practices should be able to identify a list of service users among their practice population that have a diagnosis of autism. This will help in the future to understand and measure health inequalities experienced by people with autism e.g. reduced life expectancy. Numbers of people diagnosed with autism is not currently collected at a national level within the Quality Outcomes Framework (QOF) and there should be local pressure, into national processes which modify and review QOF, to include autism. The Clinical Commissioning Group committee that sets the agendas for the monthly Time In Time Out (TITO) sessions for GP Practice staff should include autism as an agenda item for a future TITO session. This session should be addressed by a person with autism.

Response – two additional recommendations have been included (p31). The first recommends that reasonable adjustments to primary care processes and the recording of autism diagnoses in primary care should be discussed at a future Time In Time Out development session attended by GP Practice staff. This meeting should be addressed by a person with an autistic spectrum condition. The second recommends that the National Institute for Health and Care Excellence QOF Indicator Advisory Committee is asked that autistic spectrum conditions are considered for inclusion in the list of long-term conditions for which prevalence is published annually for GP Practice, CCG and national populations.

- vi) The day case unit within City Hospitals Sunderland makes adjustments to its services which accommodate people with autism, and this work has been independently assessed and praised by Sunderland People First. There are also several GP Practices within Sunderland that make adjustments to services to accommodate the needs of people with autism whose work has been acknowledged positively by Sunderland People First. Sunderland People First is gathering information about these initiatives which will be the basis of one or two short case studies within the Chapter highlighting good practice.

Information on these initiatives was not available within the timescale for producing this report, but case studies will be included in a future edition of the report.

- vii) Speech and Language Therapists and Occupational Therapists within Northumberland, Tyne and Wear NHS Foundation Trust's Community Learning Disability Service provide services that could also be of benefit to people with autism but who don't have a learning disability. A request should be made to the Learning Disability Community Treatment team service manager in Sunderland, to ask for a professional view on whether these services would be of benefit to people with autism alone e.g. to address "sensory integration" which is a challenge for people with autism. The request should also ask whether the current service pathway provides access to these services, if appropriate, for people with autism but who don't have a learning disability.

A response was received from the service which indicated that speech and language therapy and occupation therapy services could be of benefit to people with autism but who don't have a learning disability. However, because the service pathway specifies that these services are primarily provided for people with a learning disability, referrals into the service for people with autism but without a learning disability would have to come via a GP. A service user has noted that they were unable to access the service following referral from their GP. Access to these services by people with autism but without a learning disability will be reported on in a future update of this Joint Strategic Needs Assessment chapter.

- viii) The use of the term "autism champions" to refer to employers that have successfully employed people with autism is not helpful because it creates confusion with an existing initiative to identify "autism champions" within different settings within the community. It is better to refer to these employers as "model employers".

Response - references to "autism champions" have been amended. They are now referred to as "model employers".

- ix) The chapter should include a section on adjustments made to Disability Employment Advice service within local Jobcentre Plus, Sunderland to accommodate the needs of people with autism. The section should also include adjustments made to the benefit eligibility assessment process to accommodate the needs of people with autism. Sunderland Job Centre Plus will be contacted to ask for information on these topics.

Response – two paragraphs describing the service provided by Jobcentre Plus, the model of service delivery for clients with a disability or additional needs and reasonable adjustments to the service made to respond to the needs of people with autistic spectrum conditions have now been included (p27). Information on reasonable adjustments made to the benefit eligibility assessment process will be gathered and included in a future update to the Joint Strategic Needs Assessment chapter.