

**City of York**

# **Needs Assessment for All Age Autism**

**December 2016**

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## Ronnie's Story

As a child I was never invited to birthday parties. I wasn't even aware that this was a 'thing' until I had children of my own. I was the child who felt somehow different, who found social situations confusing and who would stim and make strange noises. The signs were there but were dismissed by family as something I would grow out of and by teachers as eccentricities. I was of a generation where the autism spectrum was still in the early days of being fully understood and all but the severest of cases were overlooked or, in some cases, misdiagnosed. I managed to get through childhood and early adulthood with a mixture of copying my peers and the fact that I was completely unaware that not everybody experienced the world in the way that I do.

By chance, I found myself reading about autism in my early 40's and quickly realised that many of the signs applied to me, both as a child and now. Not only the main signs of autism but also many of the common co-morbid conditions. Throughout my life I'd baffled doctors with my constant stomach problems and severe vertigo and light sensitivity. I'd had decades of tests, medications and even psychiatric counselling but nothing seemed to help and nobody could find a root cause. How obvious it now seemed, researching autism and finding all the pieces suddenly fitting together.

After a couple of years of researching autism on a daily basis I finally decided to visit my GP. My doctor looked through my medical history in light of my findings and agreed that it warranted investigation. At the time there were no facilities locally for adult assessments and I was placed on a waiting list in West Yorkshire. I remained on the waiting list for a couple of years before the opening of an autism assessment centre for adults at The Tuke Centre in York, part of The Retreat. I arranged myself to transfer the referral and funding. From there the process was very quick including the approval of funding. The staff at The Tuke Centre were excellent and after a series of appointments and tests with both myself and a family member, a diagnosis of Autism Spectrum Disorder was confirmed. I had just turned 45 and it really feels that it was then that my life truly began. The sense of relief was enormous. A huge weight was lifted off my shoulders and I really had a sense of who I was. Everything finally made sense and I was slowly able to forgive myself for a lifetime of my own perceived failings. Yes, I had been happily married for many years with happy, successful children but I had always struggled with everyday life when others didn't seem to. Social situations, theory of mind, sensory differences and many other challenges were all something I'd just lived with without explanation. Now I knew that I was autistic. For me this revelation was huge and certainly nothing to be embarrassed or ashamed about. I've discovered many times that autism only seems to be seen as this terrible condition that can be a devastating diagnosis by neurotypicals, usually parents or peers. For myself, as an autistic person, it is no such thing. It is rather the lack of understanding from others that is the real cause of problems. I am not neurotypical and so I see, feel, hear and experience everything differently in a world that is not built for me. However, armed with my diagnosis and this knowledge I can accept and understand these differences.

Since my diagnosis the world has opened up for me. I am now doing things I wouldn't have even considered attempting before I was diagnosed. I know my limitations but I also now know my strengths. It would be so easy to be bitter about my late diagnosis. Would I rather I'd been diagnosed as a child? Of course. I spent a lot of time wondering what my life would have been like with that knowledge. However, I will be forever grateful for my diagnosis, no matter how late in life it came. I finally know who I am. Autism is part and parcel of who I am. I am autistic but I wouldn't change a thing even if it were possible. I'm a Mac in a PC world. I'm wired a little differently with a different operating system but I can still reach the same goals when allowed to do things the way that I'm designed to.

## Definitions

ADHD	Attention deficit hyperactivity disorder (ADHD) is a group of behavioural symptoms that include inattentiveness, hyperactivity and impulsiveness.
ASCEND	Autism Spectrum Condition Enhancing And Nurturing Development is a course for adults with children who have recently received a diagnosis.
ASD	Autism Spectrum Disorder
CAAT	The Customer Access and Assessment Team ( CAAT ) is the first point of contact for any adult with social care enquiries for new customers who reside in the City Of York Area.
CAMHS	Stands for Child and Adolescent Mental Health Service
CDC	Child Development Centre
City of York Council	is the local authority in York which manages social care and other Public Services.
Clinical Commissioning Group (CCG)	is a group of doctors and other health professionals who decide what local health services to spend money on.
CYP	Children and Young People
Diagnosis	is when the symptoms or problems you are having are recognised as being caused by a known illness or condition.
EHCP	An Education, Health and Care (EHC) Plan is for children and young people aged up to 25 who need more support than is available through special educational needs support. EHC plans identify educational, health and social needs and set out the additional support to meet those needs.
ERP	is an enhanced resource provision within a mainstream school for young people with autism
ESC	Early Support Coordinator works in the Early Support is a programme designed to deliver better coordinated service for parents/carers of disabled children aged 0-5, as soon as the child is identified as needing additional support.
GP	General Practitioner (doctor)
IQ	intelligence quotient - an intelligence test score that is obtained by dividing mental age by chronological age and multiplying by 100: a score of 100 therefore indicates a performance at exactly the normal level for that age group

LAC	Looked After Children – a child is ‘looked after’ if they are in the care of the local authority for more than 24 hours.
LTT	Long Term Team (adults) is one of the Local Authority’s adult social care teams.
PA	Personal Assistant
Personal budget	is an agreed amount of money that is allocated to a person by the local council (and other funding streams) following an assessment of their care and support needs
Portage	is a home visiting education service for pre-school children with disabilities and/or additional needs. The aim of Portage is to help parents help children develop and learn.
Priorities	are the things that you must do first because they are the most important.
Public Services	are services provided for local people by the council. This includes things like buses, bin collection and traffic wardens.
SAF	Self Assessment Framework – is primarily for adults and is a return by Local Authorities for Central Government to identify progress in the implementation of Think Autism (2014)
SALT	Speech and Language Therapy
SEND	Special Educational Needs and Disabilities
SEYT	Specialist Early Years Teachers
Transition	a word used to describe when something changes, like when a child grows up into an adult.
Autism	Includes those with a diagnosis of autism, Asperger’s syndrome, ASC/ASD

## Summary

Between 1% and 1.5% of the population are estimated to have autism. About 206,000 people live in York which means there are over 2,000 people living in York with autism, either diagnosed or undiagnosed. Autism is a lifelong condition which can be diagnosed at different points in a person's life depending on how it is affecting their daily lives.

### The local picture in York – demographic information:

- ⇒ **Diagnosis for children** - the diagnosis service for children in York is not currently performing well. As at September 2016 there was a waiting list of 107 children with an average waiting time of 35 weeks from referral to first appointment. Once the diagnostic process has been completed only 50% will have a positive diagnosis which is low in comparison to surrounding CCG areas.
- ⇒ **Diagnosis for adults** - there is a diagnosis service for adults with autism York but this service does not assess those with complex learning disabilities and autism. The service in York started in January 2016 and has a limited budget. From August 2016 it started to hold a waiting list. Of those who have been assessed there is a 96% positive diagnosis for autism.
- ⇒ **Education** – there are currently 250 students (including year 14) in York who have a diagnosis of autism which is a 70% increase in autism diagnosis for students in York schools. 65% of those 250 students are supported in mainstream settings compared to 35% in more specialised settings.
- ⇒ **Student female / male diagnosis** – Although male student diagnosis remains higher than female diagnosis, it is to be noted that from 2012-16 there was a 63% increase in male diagnosis but a 115% increase in female diagnosis. This trend is likely to continue.
- ⇒ **Adults known to social care** – collation of data for the SAF has become more robust and there is a significant increase from 23 to 38 adults who are known to social care who have autism but no learning disability from 2014 to 2016.

### The local picture in York – services available

- ⇒ **Post diagnostic support** – post diagnostic support is limited and further work is being undertaken with regards to the pathway for support.
- ⇒ **Education** – the support provided is dependent on the needs of the individual student.
- ⇒ **Adults with a learning disability and autism** – if support is required it will be through the Community Learning Disability Team which is a multi-disciplinary and multi-agency team.
- ⇒ **Adults with autism and no learning disability** – if an individual requires support and is in agreement to an assessment this will be delivered through the adult social care teams.

- ⇒ **Parent / carers of someone with autism** – if someone wishes to receive support in their role as a carer, an assessment of need can be undertaken and ongoing support or a carers grant are available, where appropriate.
- ⇒ **Voluntary sector / local support groups** – there is a vibrant voluntary sector in York and a few proactive groups have been started at a grass roots level.

### Projected Service Use in York:

- ⇒ **Education** – if the trend of increased diagnosis continues there could be an increase of approximately 97 students with an autism diagnosis in schools by 2021.
- ⇒ **Adult population** – as the increase in diagnosis continues in childhood this means there will be an increased population of adults with autism who have a formal diagnosis. This will need to be recognised and adjustments made in higher education and into work environment. As the general population live longer into old age so too with adults with autism.

### Residents in York views:

- ⇒ An all age autism joint strategic needs assessment survey was undertaken which was responded to by 39 people, there was also a focus group and information from the Inclusive Communities survey (152 responses) were also reviewed. Key points were with regards:-
  - waiting times for an assessment although there were no issues with the process of the actual diagnosis;
  - over 40% of those who responded have not been able to access mental health services when they needed them;
  - more easily accessible and available information and advice;
  - parent training courses at different times in a persons life; and
  - more employment support.

## **Key issues / Gaps**

- Robustness and consistency of data collection and recording of people with a diagnosis of autism.
- Disparity in prevalence as between males and females, arising from inbuilt bias in diagnostic tests
- Some adults with high functioning autism continue to be excluded from accessing health and social care services because they do not fit the perceived remit of learning disability or mental health services.
- There may be some gaps in training / knowledge amongst frontline staff in the Local Authority and Health Services with regard to how to work effectively and efficiently with people with autism.

## Introduction

Autism is defined as:

“a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all autistic people share certain difficulties, their condition will affect them in different ways. Some autistic people are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People on the autism spectrum may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.”<sup>1</sup>

Asperger syndrome is a condition on the autistic spectrum most commonly used to describe people with autism with average to above-average intellectual ability. Therefore individuals with Asperger syndrome generally will not be classified as having a learning disability. In the UK adults with Asperger syndrome are often excluded from accessing statutory health and social care services because they do not fit the perceived remit of having learning disability or need for mental health services.

The term autism in this needs assessment includes those with Asperger syndrome.

It is currently estimated that approximately 1% of the population has autism with the prevalence rate being higher in men than it is in women (1.8% versus 0.2%)<sup>2</sup>. Current thinking, however, is beginning to question this perceived gender split and querying whether there is a potential under diagnosis of autism in females. **The Adult Psychiatric Morbidity Survey (2014)**<sup>3</sup> states “It has been suggested that assessments for autism may draw more on how the condition manifests in men, and this may lead to under identification of autism in women (Trubanova et al. 2014)”

The gender split is being researched more and a summary of current theories can be found in a National Autistic Society (NAS) article, **Gender and Autism**<sup>4</sup>

It is estimated that 60-70% of people who have autism will also have a learning disability.<sup>5</sup>

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<sup>1</sup> National Autistic Society, website definition, March 2016, <http://www.autism.org.uk/about/what-is/asd.aspx>

<sup>2</sup> NHS Information Centre, *Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey*, 2012

<sup>3</sup> *Adult Psychiatric Morbidity Survey of Mental Health and Wellbeing*, England 2014, NHS Digital

<sup>4</sup> How does autism present differently in women and girls, NAS article, November 2016, <http://www.autism.org.uk/about/what-is/gender.aspx>

<sup>5</sup> NHS Information Centre, *Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey*, 2012

There are estimated to be 388 children<sup>6</sup> (0-18) and 1,635<sup>7</sup> adults (18+) with autism in York, either diagnosed or undiagnosed.

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<sup>6</sup> Estimate based on 2012 ONS census 0-17 population, York, assumed 1% prevalence.

<sup>7</sup> Projecting Adult Needs and Service Information website (18-65) and Projecting Older People Population Information System website (65+), February 2016

## The bigger picture – national policy

**The Autism Act (2009)** identifies the collective commitment to improve the lives of all people with autism and their families. It was the first legislation which focussed on autism and ensured the government made a commitment to improving service provision and support for those with autism. The Act made two key provisions; that the Government produce an adult autism strategy by 1 April 2010, and that the Secretary of State for Health issue statutory guidance for local authorities and local health bodies on supporting the needs of adults with autism by 31 December 2010.

It is important to note that all adults with autism are now formally recognised as having a disability by the Autism Act (2009). This is a slightly stronger position than that of the Guidance published in 2006 to accompany the Disability Discrimination Act which makes it clear that the definition of disability can cover people with all forms of autism, including Aspergers Syndrome. This is especially relevant given the difficulties people with autism report in accessing mainstream services in Health and Social Care. It gives added weight to the legal duties on the NHS bodies and local authorities, for example to ensure access to diagnosis, assessment, information and advice.

In 2010 **Fulfilling and rewarding lives. The strategy for adults with autism in England**<sup>8</sup> was published with the key aim of improving the lives of people with autism and their families. Following on from this the first year delivery plan was published in April 2010, **Towards fulfilling and rewarding lives: the first-year delivery plan**<sup>9</sup> This set out the governance structure and the actions, with timescales and responsibilities, to be taken in the first year to support the implementation of the adult autism strategy.

In December 2010, the Department of Health published **Implementing Fulfilling and rewarding lives: Statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy**<sup>10</sup> This provided guidance to local authorities, NHS bodies and NHS Trusts on the following key areas; training of staff who provide services to adults with autism, identification and diagnosis of autism in adults, leading to assessment of needs for relevant services, planning in relation to the provision of services to people with autism as they move from being children to adults; and local planning and leadership in relation to the provision of services for adults with autism.

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<sup>8</sup> "Fulfilling and rewarding lives" *The strategy for adults with autism in England*, Department of Health, 2010

<sup>9</sup> *Towards "Fulfilling and rewarding lives" The first year delivery plan for adults with autism in England*, Department of Health 2010

<sup>10</sup> *Implementing Fulfilling and rewarding lives: statutory guidance for local authorities and NHS organisations to support implementation of the autism strategy*, Department of Health, 2010

**Children and Families Act (2014)** amends existing legislation and services for children and young people, and provides a new special educational needs and disability support system, covering education, health and social care.

In January 2015, the Government published a new **Special Educational needs and disability code of practice**<sup>11</sup> for children and young people between 0 – 25 which provides statutory guidance for organisations which work and support children and young people who have special educational needs or disabilities.

**The Care Act (2014)** builds on recent reviews and reforms, replacing numerous previous laws, to provide a coherent approach to adult social care in England. It states clearly that all staff who undertake autism assessments must have appropriate training.

In 2014 **Think Autism strategy**<sup>12</sup> was published. This builds on rather than replaces the themes in *Fulfilling and Rewarding Lives* (2010). *Think Autism* sets out fifteen priority challenges for action from the perspective of people with autism and carers. There are three new key proposals in the *Think Autism* strategy (building communities that are more aware of and accessible to the needs of people with autism, which have autism champions for change; promoting innovative local ideas, services or projects which can help people in their communities through new models of care, and focusing on how advice and information on services can be joined up better for people.) which are in addition to the existing duties of the 2010 strategy.

In 2015 The Government published a new statutory guidance, which replaced the existing statutory guidance. **Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy**<sup>13</sup>. This guidance tells local authorities, NHS bodies and NHS Foundation Trusts what actions should be taken to meet the needs of people with autism living in their area. The guidance was revised to take account of responses to a related consultation<sup>14</sup>. It also takes into account progress made since the 2010 guidance, and recent legislation including the *Health and Social Care Act 2012*, the *Care Act 2014* and the *Children and Families Act 2014* which provided new duties for people with autism.

In March 2015 the Government published the consultation paper, **No voice unheard, no right ignored** which was for people with learning disabilities, autism and mental health conditions. The consultation examined how people's rights and

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<sup>11</sup> *Special educational needs and disability code of practice: 0 to 25 years; Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities*, Department of Education, 2015

<sup>12</sup> *Think Autism Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update*, Department of Health 2014

<sup>13</sup> *Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy*, Department of Health 2015

<sup>14</sup> *The Government response to the consultation on revised statutory guidance to implement the Strategy for Adults with Autism in England*, Department of Health, March 2015

choices can be strengthened. The Government provided a response to this consultation in November 2015. **Government response to No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions.**<sup>15</sup> The Government set a series of proposals grouped into three implementation phases, early actions that seek to sustain momentum generated, chiefly through the use of existing powers and building on work currently underway, further changes, including proposed legislative changes that cannot be achieved via existing powers (and which relate principally to the Mental Health Act 1983), and, a third phase, which explores more radical solutions to longer-term issues, as well as ongoing monitoring and review, and a commitment that the Government will intervene further, including through legislation if necessary, if the improvements sought continue not to be realised in practice.

In 2016 the **Progress report on Think Autism: the updated strategy for adults with autism in England**<sup>16</sup> was published. This report details what has been achieved since the publication of *Think Autism*. It also sets 31 new actions to continue to help local areas implement the autism strategy and focuses on education, employment, the criminal justice system and better data reporting.

In 2011 the Winterbourne View Hospital scandal occurred when a BBC Panorama programme revealed widespread abuse by staff of people with learning disabilities. . The Department of Health undertook a review and In response to this **Transforming care: A national response to Winterbourne View Hospital**<sup>17</sup> was published which committed to producing a report 2 years later setting out the progress that had been made to ensure what happened at Winterbourne View is not repeated.

The subsequent report, **Winterbourne View: Transforming Care Two Years On**<sup>18</sup>, set out what had been achieved but recognised that there was still progress to be made. The national plan, **Building the Right Support**<sup>19</sup>, 2015, has been developed jointly by NHS England, the LGA and ADASS, and is the next key milestone in the cross-system Transforming Care programme. This programme includes those with more severe autism who are in residential care.

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<sup>15</sup> *Government response to No voice unheard, no right ignored – a consultation for people with learning disabilities, autism and mental health conditions*, Department of Health, November 2015

<sup>16</sup> *Progress report on Think Autism: the updated strategy for adults with autism in England*, Department of Health, 2016

<sup>17</sup> *Transforming care: A national response to Winterbourne View Hospital*, Department of Health Review, 2012

<sup>18</sup> *Winterbourne View: Transforming Care Two Years On*, Department of Health Review, 2015

<sup>19</sup> *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*, NHS England, the LGA and ADASS, 2015

## NICE guidance

The National Institute for Health and Clinical Excellence (NICE) has published the following clinical guidelines on autism:

- *Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum;*<sup>20</sup>
- *Autism: The management and support of children and young people on the autism spectrum);*<sup>21</sup>
- *Autism: recognition, referral, diagnosis and management of adults on the autism spectrum.*<sup>22</sup>

The NICE guidance states that the local services (including health, mental health, learning disability, education and social care services) for children and young people with autism, should be coordinated by a local autism multi-agency strategy group and that the coordination of care should be provided through local specialist community-based multidisciplinary teams ('local autism teams') which should include professionals from health, mental health, learning disability, education and social care services. A recent self-assessment exercise to map progress locally and nationally with delivery of the adult autism strategy showed that structures are in place in many areas, including the creation of diagnostic leads.

NICE has also published a Quality Standard (QS51, January 2014) to help inform the commissioning of autism services for children, young people and adults, focusing on the key areas for improving the quality of existing services.

NICE guidelines describe best practice to help reduce variations in service provision for people with autism, but they are not mandatory. However, the Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality.

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<sup>20</sup> *Autism spectrum disorder in under 19s: recognition, referral and diagnosis*, Clinical guideline [CG128] Published date: September 2011

<sup>21</sup> *Autism spectrum disorder in under 19s: support and management* Clinical guideline [CG170] Published date: August 2013

<sup>22</sup> *Autism spectrum disorder in adults: diagnosis and management* Clinical guideline [CG142] Published date: June 2012, updated: August 2016

## The local picture – demographic information

### Diagnosis for children

In York there is a diagnostic service for children and a separate service for adults. The service for children is delivered by the National Health Service. The assessment is undertaken by York Hospital for those aged 0-5 and at Lime Trees for those aged 5-18.

#### Under five years old diagnostic process

Children under the age of five are referred into the paediatric service in York for assessment.

- ✓ The child is seen by a paediatrician, and also by a specialist speech and language therapist, and sometimes other therapists (for example occupational therapists).
- ✓ Clinical observation and information gathering takes place. As young children often have a rapidly changing presentation and develop different skills at different rates, the timing of the process is not fixed.
- ✓ Once sufficient information has been gathered, and the child's overall developmental profile considered, the child is discussed at the multi-agency autism forum (convened in conjunction with CAMHS) and a decision as to whether the child meets the ICD 10 criteria<sup>23</sup> for a diagnosis of autism is reached.
- ✓ Sometimes a further period of observation or further assessments are recommended as a result of discussion at the autism forum, and the child is then taken back for further discussion at the autism forum once these are completed.

#### Five to 18 years old diagnostic process

Children aged 5 to 18 are assessed by trained staff (including Clinical Psychologists and Clinical Nurse Specialists) at Limetrees Clinic in York. All children and young people referred have an initial screening by a trained health worker, this includes gathering information from school and parents. Following screening if indicated the family are offered a full assessment for Autism Spectrum Disorder by the multi-disciplinary team. . This will include an autism specific diagnostic interview with the parents and an Autism Diagnostic Observation Schedule (ADOS) with the child. Where needed an observation of the child/young person will be completed in school. A multi-disciplinary discussion then takes place in order to determine whether the

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<sup>23</sup> <http://www.autism.org.uk/about/diagnosis/criteria-changes.aspx>

child/young person meets the ICD-10 criteria for a diagnosis of an Autism Spectrum Disorder.

At the moment the whole pathway from 0-18 is being reviewed in order to make the process meet the standards set out in NICE Guidance 128 for the referral, assessment and diagnosis of children and young people with suspected autism. In particular in the pathway for 5-18 year olds this would include a reduction in waiting times and the inclusion of Speech and Language Therapy in the diagnostic process. To make the pathway fully compliant a number of developments are being undertaken.

#### Diagnosis data for children (5-18 years old)

Referrals for autism are increasing in York. As at September 2016 there was a waiting list of 107 children with an average waiting time of 35 weeks from referral to the first appointment.

	Numbers of individuals (5-18 year old)		Weeks		
	Total no. referrals	Waiting list – <b>NOT</b> had apt by end of reporting period	<u>Average</u> wait time from referral to 1 <sup>st</sup> Apt.	<u>Longest</u> wait time to 1 <sup>st</sup> Apt.	<u>Average</u> wait time from 1 <sup>st</sup> Apt to diagnosis
<b>April 2014 to March 2015</b>	88	31	22	26	18
<b>April 2015 to March 2016</b>	130	66	16	39	17
<b>April 2016 to Sept. 2016</b>	70	107	35	51	15
<b>HALF YEAR</b>					

Professionals working in this area are sensitive to the emotional impact of the diagnostic process as it can be complex and challenging for families and individuals. The assessment process and the confirmation of diagnosis through a multi disciplinary panel can take up to 15 weeks or longer in some cases. This means currently individuals and their families / carers can wait for up to a year from referral to diagnosis.

	No. completed diagnosis process (age 5-18)	Outcome		Percentage (%) Positive autism diagnosis
		Yes	No	
<b>April 2014 to March 2015</b>	89	49	40	55%
<b>April 2015 to</b>	89	54	35	61%

<b>March 2016</b>				
<b>April 2016 to Sept. 2016 HALF YEAR</b>	22	11	11	50%

From April 2016 to September 2016 there were 22 assessments with a conversion rate of 50%. This is low in comparison to other surrounding areas where there is a conversion rate of about 75-80% which is the expected level if inappropriate referrals are screened out at an early stage.

<b>CCG Area</b>	<b>Percentage (%) Positive autism diagnosis April 2016 – September 2016 (age 5-18)</b>
HaRD (Harrogate & Rural District)	77%
HRW (Hambleton, Richmondshire & Whitby)	78%
SR (Scarborough & Ryedale)	75%
VoY (Vale of York)	54%

The low conversion rate in York needs to be explored as there may be a number of contributing factors.

If there is no diagnosis of Autism Spectrum Disorder then the multi-disciplinary team will consider if further assessment or intervention is necessary

## **Diagnosis for adults**

### Diagnosis process for adults with autism

The adult service is commissioned and delivered by the Tuke Centre at the Retreat in York. The service assesses for autism and ADHD, but does not assess those with complex learning disabilities.

This is a new local diagnosis and assessment service which started in January 2016. The service has a limited budget and as of August 2016 started to hold a waiting list. Up to that date there was a 96% conversion rate from referral to a positive diagnosis. This is to be expected in an adult diagnostic service.

Data from the Tuke Centre for the period January to September 2016 for the whole of the Vale of York CCG area shows:

- 47 screenings for ASD
- 41 assessments for ASD
- 57 waiting for screening or assessment
- 7 discharged without screening or assessment

It has not been possible to disaggregate the screenings and assessments for those people referred from the City of York.

These figures are significantly higher than for other North Yorkshire CCG areas, but the commensurately larger population will explain the disparity in figures.

Recording for adults receiving a diagnosis up to the new service starting in January 2016 wasn't recorded specifically for York. Historic data in the Vale of York in 2014 indicates an average of 2 to 3 referrals a month for autism and ADHD.<sup>24</sup> The conversion rate of these referrals is unknown.

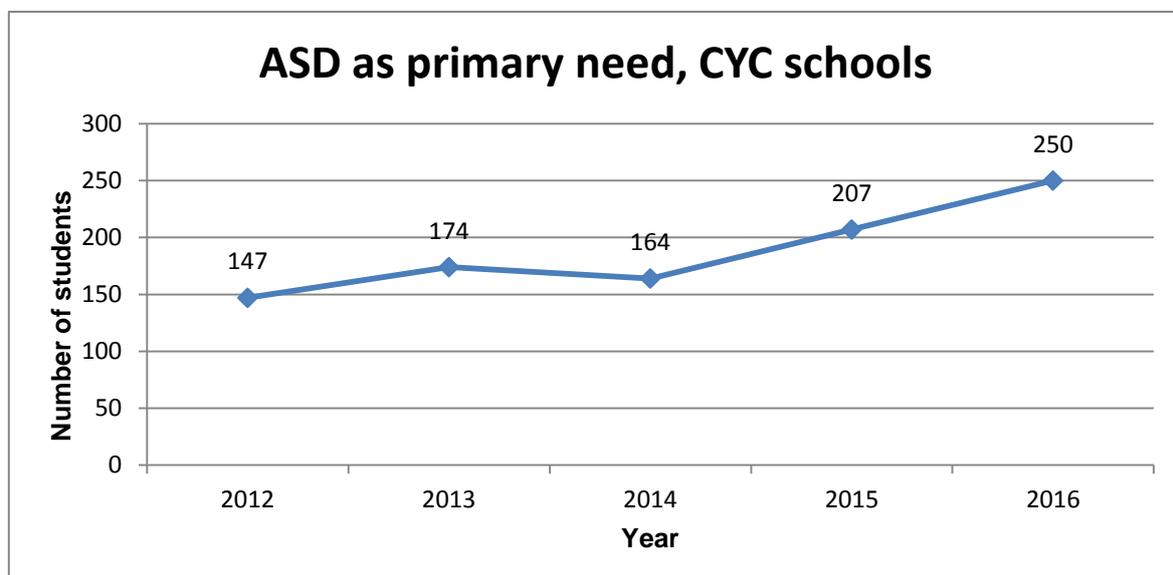
#### Diagnosis process for adults with autism and a learning disability

For adults who have a learning disability and are known to mental health services, the assessment will be undertaken by the adults' service. The small number not known to services would need to be referred by their GP to a specialist out of area service.

#### **Education and autism (age three to 19 years)**

Within the general school population there has been a growth from 0.62% students diagnosed with autism in 2012 to 1% of students being diagnosed with autism in 2016 (1.1% in primary and 0.8% in secondary)<sup>25</sup>.

There are currently 250 students (including year 14) in York schools who have a diagnosis of autism. In addition to these 250 there are also 6 students who are currently not attending school who have autism. In January 2012 there were 147 students (including year 14) in York schools with autism - a 70% increase in autism diagnosis for students in York schools from 2012 to 2016.

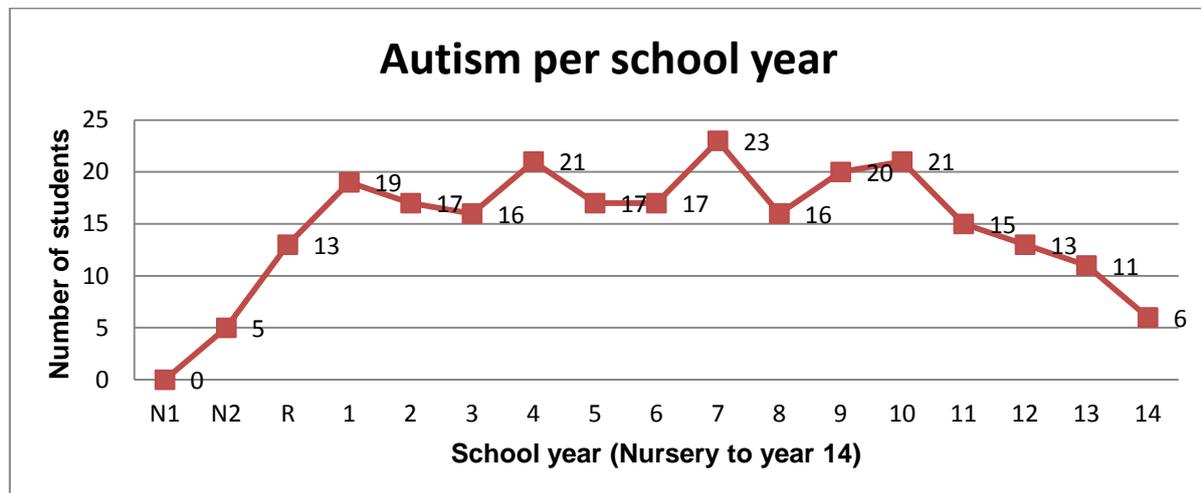


<sup>24</sup> Attention deficit hyperactivity disorder

<sup>25</sup> School Census, January 2016

There are more students with autism being supported in mainstream schools (65%) as compared to those in more specialised settings (35%).

Diagnosis before age five will continue to remain low because of the difficulties giving a firm diagnosis in this age group. Autism diagnosis rises from age five when children enter formal education where there are over ten students a year with autism, peaking at 23 in year 7.



### Student female / male diagnosis

As detailed above, from 2012 there has been a 0.4% growth in students with autism in the general school population to 1% in 2016. The diagnosis for male students remains far higher than for female students with a 63% increase in diagnosis from 2012 to 2016. However, in that same period there has been a 115% increase in female diagnosis. Anecdotal evidence suggests that the increase in female diagnosis will continue as a trend.

Year	Male	% Male	Female	% Female	Total
2012	127	86%	20	14%	147
2013	146	84%	28	16%	174
2014	140	85%	24	15%	164
2015	175	85%	32	15%	207
2016	207	83%	43	17%	250

If autism were compared to other disabilities, for example, learning disabilities, where the gender split is approximately 60/40 (male/female)<sup>26</sup> the disparity in diagnosis further demonstrates that female presentation and diagnosis is an area which needs to be explored.

### Adults and autism - Self Assessment Framework, 2016

The purpose of the self-assessment is to enable local strategy groups to review their progress and to assist in future planning with partners including people with autism and their families. The self-assessment is primarily for adults and sets out and expands on the priorities set out in **Think Autism** (2014) and updated in the **Progress Report on Think Autism: the updated strategy for adults with autism in England** (2016). The process is the key means of identifying progress in the implementation of the strategy at a local level.

The process has just been completed and returned to the Department of Health for York. This will be analysed and published in early 2017. Results from the 2014 Self Assessment Framework (SAF) are available online.<sup>27</sup>

From 2014 to the 2016 SAF some of the questions changed to enable more meaningful data analysis. Where there is comparable data progress can be evidenced. Transitions data is much more robust across all children services with a diagnosis being included whereas previously this was mainly for children with autism and a learning disability. Therefore the figures have increased substantially from 26 in 2014 to 71 children aged 15-18 years in 2015-2016.

### Adult Social Care – Care & Support

As part of the SAF return the following data was submitted with regards to adult social care.

1	What is the number of adults assessed as being eligible for adults social care services who have a diagnosis of autism and in receipt of a personal budget?	87
2	What is the number of those in question 1, who have a diagnosis of autism but not a learning disability	38
3	What is the number of those in question 1, who have a diagnosis of autism AND a learning disability	49

<sup>26</sup> *People with Learning Disabilities in England 2010, Services and Support*, E Emerson, C Hatton, J Robertson, H Roberts, S Baines & G Glover, Improving Health and Lives : Learning Disabilities Observatory and DH, 2010

<sup>27</sup> <http://www.improvinghealthandlives.org.uk/projects/autsaf2014results>

The questions with regards to autism and adult social care have been modified but where it is comparable it shows there has been an increase of those with diagnosis of autism but no learning disability from 23 to 38 which is a significant increase.

## The local picture – services available

### Post Diagnostic support

#### Post diagnostic support for parent / carers of children 0-18 years old

For the parents of children / young people who have received a diagnosis there is a course called ASCEND (Autism Spectrum Condition Enhancing and Nurturing Development). The programme aims to share theoretical and practical strategies with parents and carers of children on the autism spectrum and to give opportunity for parents to meet with and gain support from each other as well as from the course facilitators. This is currently managed by CAMHS and co-delivered with the Specialist Teaching Team for Autism.

#### Post diagnostic support for adults who have received a recent diagnosis

When an adult is diagnosed they are offered either 2 one to one follow up sessions or 5 group sessions to help to understand the diagnosis.

As autism is not a medical condition, once the diagnostic process has been undertaken and a diagnosis of autism has been given support from Health is limited and this is the reason further work on joint pathways is being undertaken.

### Education (Early years to 19)

Early Support is a way of working that aims to improve the delivery of services for disabled children, young people and their families. It enables services to coordinate their activity better and provide families with a single point of contact and continuity through key working. It ensures that service delivery is child, young person and family-centred. It focuses on enabling services and practitioners to work in partnership with children, young people and their families.

Portage is a home visiting education service for pre-school children with disabilities and special educational needs. Visits are made on a weekly or fortnightly basis. It helps parents and carers to support their child's learning by breaking skills down into small steps. The service is available to families who have a child under five years old with difficulties or delays in more than one area of development. The service was expanded in 2004 to also include children at risk of developmental difficulties through low birth weight and/or premature birth or those who are 'looked after' (LAC) by the local authority.

Educational Psychologists for Early Years, alongside the Specialist Early Years Teachers (SEN) and Portage Home Visitors, play a major role in supporting transitions to nursery or school and provides advice toward statutory assessment when required. They also provide advice on children's development to practitioners, staff and parents/carers through direct casework, training and consultation

The Specialist Early Years Teachers (SEN) provide support and advice for children from 2-5 years with additional needs. They have expertise and training in child development, early learning and teaching children with additional needs. They work directly with pre-school children as well as providing information and advice to others: parents and carers, staff in early years settings, medical practitioners and therapists in the community and at the Child Development Centre (CDC), York Hospital and any other professionals involved with a child

The post of Early Support Coordinator (ESC) within the Specialist Early Years Specialist Teachers (EYST) was developed in 2007 as part of the original Early Support Programme for young disabled children age 0-5 years and their families. The Early Support Key Worker Coordinator (ESC) works closely support services and practitioners from education, health and children's social care, and particularly the health and disabilities team.

City of York Council also has a Specialist Teaching Team for Autism. This team consists of two specialist teachers and two specialist teaching assistants who work in mainstream nurseries, schools and York College with children, young people, teachers and support staff in these settings. A referral to the team is usually made by clinicians, after a diagnosis has been made at the Autism Forum. Specialist Teacher's (SPT) make an initial assessment and then make recommendations for each child or young person using a variety of methods including school observation, parent consultation, discussion with school staff, attending reviews etc. Their involvement will vary according to the needs of the child or young person. A specialist teaching assistant may then visit to support the setting implement the advice, for example to establish a social communication group, write a Social Story or set up an individual structured teaching activity. The team will assess and review progress of each child to make sure children are benefiting from the team's interventions. Specialist teachers are involved in contributing to My Support Plans (MSP) and Education Health Care Plans (EHCP)

In York there are two Enhanced Resourced Provisions (ERPs) at secondary school; these are Joseph Rowntree and Fulford School. These both support ten students with a diagnosis of autism in the mainstream school. The nature of the support depends up the individual needs of each student. Inclusion is a priority and the students spend most of their time in mainstream lessons with their peers. To enable this to happen there is liaison between Subject Teachers, Form Tutors, Directors of Learning, the Senior Leadership Team and Student Support. Additional help and support is given with communication, social interaction and organisational skills and personal development lessons are planned to meet the individual needs of each student in the context of a busy secondary school environment.

Small Step Transition programmes are designed for students moving from Year 6 to Year 7, from KS3 to KS4 and then finally from Year 11 to post-16 provision. The ERPs work closely with families and many other agencies (EPS, Lime Trees, SALT, Occupational Therapists, Social Services etc.) to provide a holistic approach giving each student the opportunity to thrive and succeed.

In addition to this there is a new Enhanced Resourced Provision (ERP) for primary aged pupils opening at Haxby Road School at Easter 2017 which will offer specialist provision for up to 8 children. There is also an inclusion class at Hob Moor Oaks offering specialist provision to children who can access some mainstream learning.

Hob Moor Oaks Special school is federated with Hob Moor Primary and offers specialist autism provision, as does Applefields Secondary special school, for those pupils who have autism and significant special needs.

St. Paul's Nursery School is also classed and funded by the Local Authority (LA) as an Enhanced Resource Centre (ERC), offering 12 additional part-time places for children with a range of special needs and disabilities (SEN), including social communication difficulties/autism.

### **Further/Higher Education and options Post 16**

Young people with autism can study further at York College and Askham Bryan College. Support is available, including mentoring, for young people with an EHCP. Both York University and York St John University offer a range of support to students with autism according to their needs.

There are a number of alternative Post 16 options for young people with autism; including apprenticeships, supported internships and personalised packages.

### **14-25 year olds with autism, the Transitions Team**

The Transitions team is a multi-agency co-located team that works primarily with young people with a learning disability who are aged 14-25. The team is comprised of social care from the children's health and disability team and adult social workers from the Adult Learning Disability Team. Connexions advisors are also part of the team as are independent travel trainers. Young people with Autism can make a referral via adult or children's social care or via your school or college. We work with local education and social care providers to be as creative as possible in order for young people to reach their goal and achieve their full potential.

### **Adults with a Learning Disability and autism**

If an individual has a learning disability and autism, and requires support, this will be delivered through The Community Learning Disability Team. This is a multi-disciplinary and multi-agency team that includes a range of professionals (including Consultant Psychiatrist, Community Learning Disability Nurse, Social Worker, Physiotherapist, Occupational Therapist, Speech and Language Therapist, Clinical Psychologist and Administrative support). It acts as the gate-keeper to services for adults with a learning disability and / or autism living in the community.

Services in the community range from day activities, hydrotherapy, supported living opportunities to short breaks if the individual still lives at home with their parents /

carers. There are different referral routes for the health and social care parts of the team.

### Adults with complex autism

An Autism Hub was opened in October 2016 which provides support for adults with more complex autism. The Autism Hub provides a safe, predictable, comfortable and autism friendly environment for people to spend time accessing support. Individuals receive training and life skills development and increased confidence leading to an improved quality of life.

“An individual’s special interests are nurtured and used as the base for learning and skills can be built around these that can be used in different situations. For example; one person who comes to The Hub has a special interest in The X-Factor. We are supporting him to ‘be a judge’, he watches clips of the show and decides who he is going to vote to stay in or vote out of the show. We then spend time with him looking at how the decision he has made might make the contestant feel, exploring empathy and consequence.

This gentleman recently had his annual review and the feedback we received at that review was amazing. His support team told of how attending The Hub had actually ‘changed his life’. He now has reason to get out of bed in a morning and has more meaningful conversations when at home, talking about the things he has done whilst at The Hub. He has also started doing more things for the person he lives with such as setting the table for tea for both of them rather than just for himself and buying his housemate a birthday card. These are things which he wouldn’t have thought about doing previously.”

The Autism Hub, November 2016

### Adults with autism and no learning disability

If an individual, who has autism and no learning disability, requires support and is in agreement to an assessment, this is delivered through the adult social care teams.

Customers who are transitioning from children’s services who have a diagnosis and have an IQ of over 70 are routed either through the Long Term Team (Adults) or Mental Health Team depending on their main presenting need.

Customers who are not known to the children’s team and are not known to adult social care already come via CAAT (Customer Access and Assessment Team) for an assessment.

The Long Term (Adults) Team (LTT) currently supports a number of customers who have had an assessment of their needs and require assistance with maintaining their personal care or home environment, maintaining their nutritional needs, and / or family and personal relationships. The Long Term Team can also assist customers

in accessing work, education, volunteering or training opportunities and give advice as to options within the wider community for recreational opportunities. The team work alongside individuals to meet their identified outcomes whether this is via a commissioned service, a direct payment to employ a PA or support to access voluntary services.

### Parents / carers of someone with autism

City of York Council's Carers Support Workers work alongside York Carers Centre to provide ongoing support to carers of adults with Autism who wish to receive support in their role as a carer. York Carers Centre also work with parent carers and also support parents of young people with autism.

An assessment of needs is carried out and ongoing support or carers grants are available, where appropriate, to sustain this caring role.

### Employment

There is no robust data with regards to employment and autism. Research undertaken by the National Autistic Society, in 2009,<sup>28</sup> indicated that the number of people with autism in employment is very low, indicating that just 15% of adults with autism in the UK are in full-time paid work. The research also found that many of those not in work were also excluded from the benefits system with one third currently without a job or benefits.

Sustainable employment is still difficult to achieve with no evidence that the findings from 2009 have improved. The Department for Work and Pensions have recently published **Improving Lives, the work, health and disability green paper**<sup>29</sup>, which highlights the inequalities faced by those with disabilities, for example, 52% of disabled people are not in employment and 54% of those people will experience mental health conditions.

### Criminal Justice System

Recording autism as a condition is not required by the criminal justice system (CJS) which means there is no reliable data and therefore there has been only limited analysis regarding prevalence of individuals within the CJS. An individual with autism may enter the CJS as a victim, witness or as a suspect/offender.

It is unclear how many adults with autism are within the CJS but limited research studies indicate that they are over represented within the whole system, both as victim and perpetrator.

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<sup>28</sup> *Don't write me off, make the system fair for people with autism*, National Autistic Society, 2009

<sup>29</sup> *Improving Lives, the Work, Health and Disability, Green Paper*, Department for Work and Pensions, October 2016

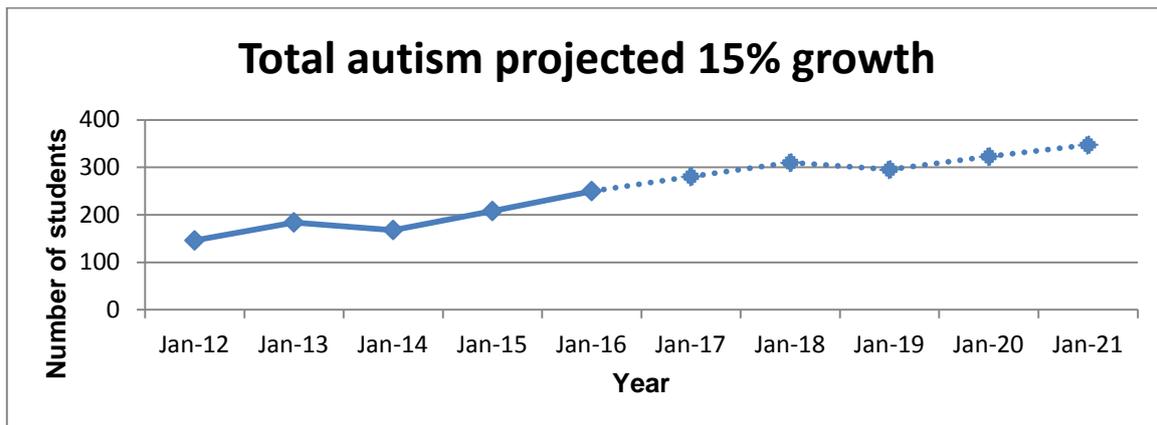
**Voluntary sector / local support groups**

York has a vibrant voluntary sector and proactive groups which have started at grass roots level. A comprehensive mapping of opportunities and groups needs to be undertaken and information made accessible and kept up to date.

## Projected service use

### Education (Early years to 19)

From 2012 to 2016 there has been a 70% increase of students diagnosed with autism. If this trend is averaged out over this period it means an approximate 15% increase year on year during this period. If this is projected forward this would mean that there would be 347<sup>30</sup> students with a diagnosis of autism by 2021 in both mainstream and specialist school settings, a growth of approximately 97 students which is a 39% overall growth in students with autism.



It must be noted that this also means that approximately 66 students will become adults and this may impact on adult services depending on presenting need.

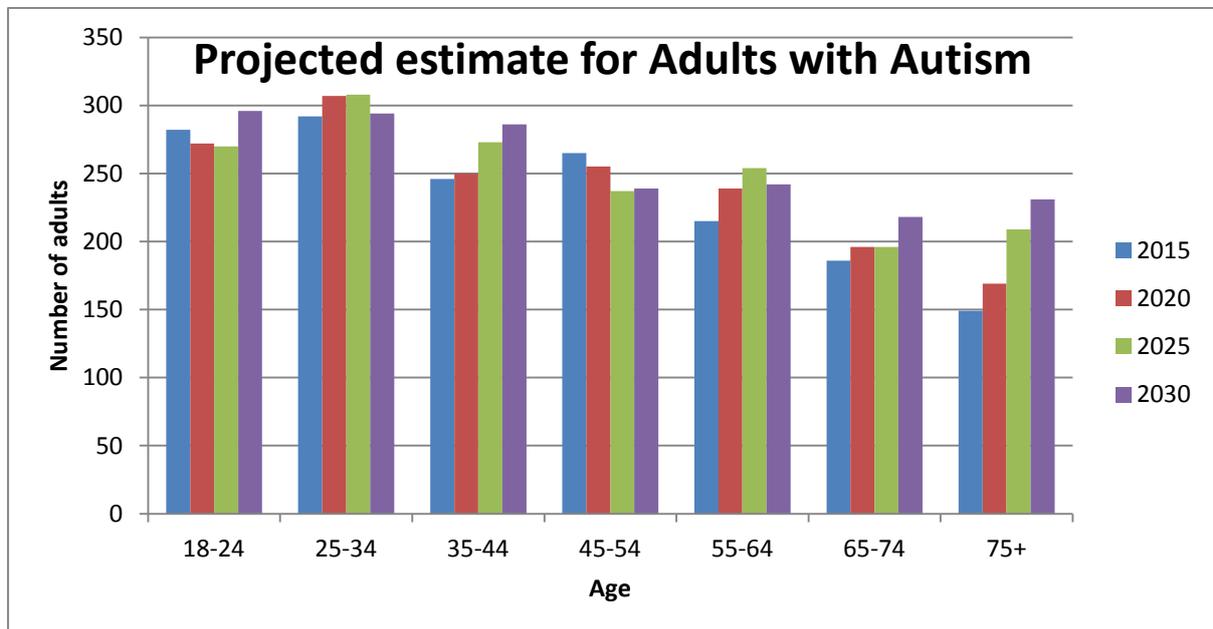
**To note** – due to the long waiting times for an assessment (at September 2016 there was a waiting list of 107), taking into account current conversion rates of 50% this would mean that the actual figures in 2017 could potentially be low but the projection should still be accurate as assessments are completed.

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<sup>30</sup> Based on current yearly intake minus students leaving school (total 66 estimated school leavers)

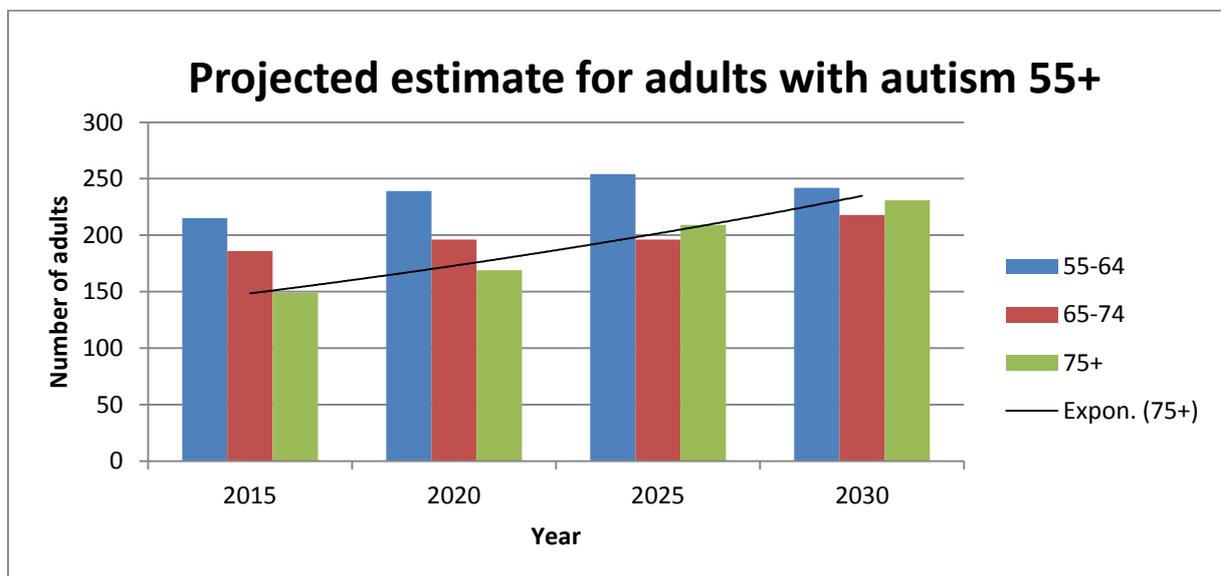
### Adult population (18+)

General population estimates<sup>31</sup> show an increase in line with overall population. Data is projected using a 1% growth assumption.



POPPI/PANSI data, November 2016

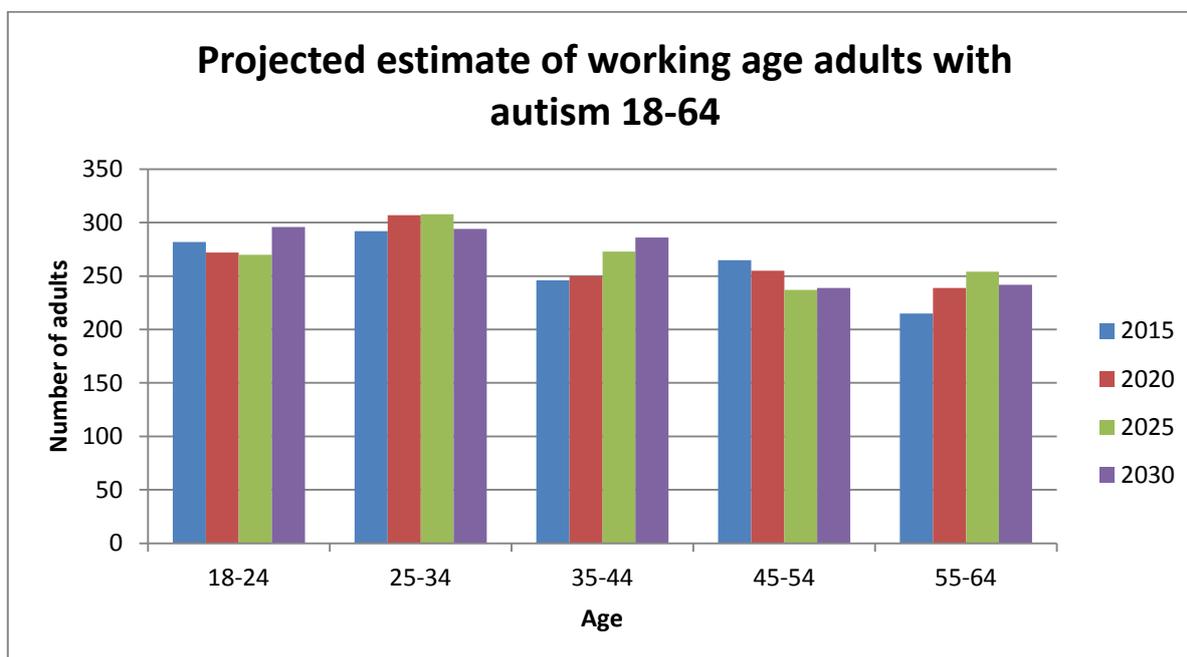
As with the general population, people are living longer into old age. This means that the autism population is also aging.



POPPI/PANSI data, November 2016

<sup>31</sup> Projecting Older People Population Information (POPPI) and Projecting Adult Needs Service Information (PANSI)

Projections indicate, working age adults with autism will also increase, especially amongst the 18-24 year olds. If the trend of increased diagnosis in childhood continues this will increase the number of working age adults with autism.



*POPPI/PANSI data, November 2016*

## Residents Views

Residents views with regards to living in York with autism or supporting someone with autism are very important.

In March 2016 an engagement event took place in relation to writing the first All Age Autism Strategy for York. Over 100 people attended and the themes discussed at this event have been the bedrock of the Strategy and the work which has unfolded from it.

- ⇒ Diagnostic support
- ⇒ Inclusive communities
- ⇒ Transitions
- ⇒ Training / education
- ⇒ Employment
- ⇒ Parent / Carer support

Views from residents were also sought through a survey which was available on line, by post or by email.

Invitations were also sent out for people to participate in a focus group. This group had representation of an adult with autism, parent/carers and professionals who work both with people with autism and their families.

The All Age Autism Strategy Sub-Group 'Inclusive Communities' has also recently undertaken a survey with regards to inclusive venues and feedback from this is also incorporated.

### All Age Autism Joint Strategic Needs Assessment Survey

This survey was undertaken during November and closed on 16<sup>th</sup> December 2016. In total there were 39 responses from individuals with autism, parent/carers and professionals.

Questions and key points were:

- Diagnosis
  - There were no issues with the diagnostic process.
  - The waiting time for an assessment was too long

*"Parents repeatedly report frustration with the wait for an assessment."*

*"The waiting times were quite lengthy, however once the diagnostic process started the diagnosis was pretty quick."*

- Local groups and information

- Just under 50% of those who responded were not confident that they could find information regarding local groups.
- Of those that responded. Over 60% said there was not a local group which would fit their needs.

*“There are a few groups but I think we need a wider range and maybe one for girls, or groups around specific interests eg cookery group, computer group eg coding, train interest. Also need a support to access groups by someone other than parents eg a befriender to take some young people to a group.”*

*“Sometimes there are suitable groups but not always.”*

*“I have attended one of these groups and did not find people who were interested in the same things as me.”*

- Mental Health
  - Over 40% of those that responded have not been able to get support from Mental Health services when they needed it.
  - Of those that have accessed Mental Health services over 60% considered the support helpful.
- Other areas of importance (Inclusive communities, support through change, training/education, employment, parent/carer support and access to support / information.
  - The majority of respondents considered all these areas of high importance.
- What information would you find useful – themes in these responses were:
  - Information,
  - Practical strategies for managing behaviours,
  - More links with employment

*“It would be useful to have a service that has the skills and knowledge to work with adults with a dual diagnosis – ie autism and complex health needs as going to two different services that can’t communicate with each other and often provide conflicting information is helpful.”*

*“I would like to know what is available when the young person turns 18 and he is legally an adult if has not been able to access education due to his condition. I have not been able to find out what the next step to get help for him.”*

*“Comprehensive list of autism services in one leaflet or website that covers mental health support to autism friendly public places likes shops.”*

*“The mistake most people make when dealing with autistics is they “sign post” us rather than “taking us” or “helping us”. This distinction is crucial. There is*

*often information but no one to help or to guide us through it or help us in our lives.”*

- Other comments – themes in these responses were:
  - Information
  - Parent training courses at different levels
  - Mental health support to be improved
  - More employment support

*“We need more Parent training courses at different levels eg pre- 5, school age and teenage to meet the needs of families with CYP with autism. faster referral routes so CYP are not waiting for long periods of time for assessments, ongoing awareness training for communities, the public to enable CYP with autism to feel welcome in their communities. More accessible mental health services with quick easy access, and more training for professionals in mental health and autism, so early intervention can be offered.”*

*“There is a need for a 'drop in' service where people can go for low level advice/ support to help them through a mini 'crisis/ change. There are some people on the Autism Spectrum who currently use the Mainstay drop in for this.”*

*“An information pack with all the above info after diagnosis would be most useful instead of learning as you go on in a hotchpotch manner”*

### Focus Group

A Focus Group took place in January 2017 and included representation of an adult with autism, parent/carers and professionals who work both with people with autism and their families/carers.

The discussions involved experiences of services and key points were:

- Peoples experiences of waiting for a diagnosis varied but on the whole waiting for a diagnosis took a long time but the actual diagnostic process was fine.
- There have been poor experiences of Lime trees with individuals having to see multiple staff and having to repeat information previously given.
- There has been little support / advice on the effects / implications of a diagnosis for the individual.
- There has been good experience of York Hospital with staff understanding and adjusting practises for those with autism.
- There have been variable experiences of transition from primary to secondary schools and support within secondary seeming to be dependent on the individual teachers understanding of autism.
- A neurotypical view of a 'good social life' is not always relevant – there should be an acceptance of different lifestyles and different ways / methods of socialising.

Suggestions for a better experience:

- An integrated approach between Health and Social Care.
- Consistency of professionals working with the person / family and where there are changes to be informed in advance. Alongside a robust handover between professionals so the person / family does not have to repeat themselves.
- Consider environments and sensory implications, CYC offices and Lime Trees were given as an example of a poor sensory experience.
- Consistency of procedures and pathways.

Funding for initiatives, broad autism awareness training programmes and support was seen as a barrier. However being creative and trying to do things differently was also seen as a way of making a positive difference.

### Inclusive Communities Survey results

As part of the work the Inclusive Communities sub-group are doing a 'Survey Monkey' was sent out with regards to accessible venues and public places. A 152 people responded to this survey and some really interesting and useful information was gathered. This has been shared with the organisations who have been on the 'Train the Trainer' courses commissioned for public venues / spaces in York.

Key points raised were:

- Staff who are autism aware and are approachable – 89% of respondents said this would be helpful.
- A 'safe' / quiet space
- Clear signage showing exits etc.
- A good / accessible website
- An autism friendly guide which tells individuals what to expect (eg sudden noises, smells etc.)
- Autism friendly openings.

## Unmet need and information gaps

National and international evidence suggests that people with autism can have increased mental health issues, such as anxiety, as opposed to the general population. If timely support and interventions are readily available this would lead to a decrease in longer term mental health issues. The full use of mental health services by people with autism is not well documented.

There are significant issues in recording of information with regards to people with autism and there are significant gaps in robust data and information which is needed to inform future policy and direction.

## Recommendations for consideration

1	Review diagnostic pathways and waiting lists
2	Improve the quality of primary care data including the improvement of recording those with autism.
3	Review uptake of Health and Social Care autism training within York.
4	Review pre and post diagnostic advice, support and information.
5	Ensure Health and Social Services work with people who use their services in a way which looks at peoples strengths and the capacity of the community.
6	Engage with mental health services to work towards timely and appropriate access to services for people with autism.
7	Increase public awareness in the community and work with mainstream services and employers to ensure they are as inclusive as possible.
8	Increase autism awareness across the City.
9	Create a specialist training package for employers, police and others in the criminal justice system.
10	Consult and engage with people with autism, and their families and carers, to understand their particular needs and experiences.
11	Scope information available and gaps and how to make accessible and keep up to date.
12	Ageing well with autism – scope information available on those who are aging with autism.

## Key Challenges

- Achieving the recommendations without any new investment.
- Development of sufficient local expertise for the needs of the population.