

## Warrington

# Joint Strategic Needs Assessment (JSNA)

## Autism Chapter 2014/15

March 2015

**Version control**

Version	Description of amendments	Date of amendment
3.0	Final Draft includes comments from various staff	13/02/2015
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The Joint Strategic Needs Assessment (JSNA) considers a wide range of factors that affect the health and wellbeing of the people of Warrington. The objective of the JSNA is to involve partner organisations, such as the local NHS, local authorities, Police, Fire and third sector organisations in order to provide a top level, holistic view of current and future need within the borough. The JSNA is used to agree key priorities to improve the health and wellbeing of all our communities at the same time as reducing health inequalities

## EXECUTIVE SUMMARY

### Introduction

The aim of this JSNA chapter is to describe the existing knowledge of people with autism and the services that are currently in place in Warrington Borough Council (WBC) to support them. It examines the issue of autism in Warrington for both children and young people (CYP) and adults, and includes all conditions within the autistic spectrum.

### What is autism?

Autism Spectrum Disorder (ASD) is a lifelong condition that typically starts to develop during childhood. ASD is a condition that affects social interaction, social communication and social imagination (this is also referred to as the 'triad of impairments') (The National Autistic Society, 2014).

Autism is a 'spectrum' condition; this means that although all people with autism share certain difficulties, the extent of these difficulties will affect each individual differently. Some people with a diagnosis of autism will be able to live an independent life with little support, whilst for other people autism may be one of multiple disabilities that will require specialist support (The National Autistic Society, 2014).

Asperger's Syndrome is a form of autism; people with Asperger's syndrome often have average or above average intelligence (IQ of 80 or above). They have fewer problems with speech, but may have problems processing and understanding language (The National Autistic Society, 2014).

**Figure 1: Autism as a spectrum disorder**

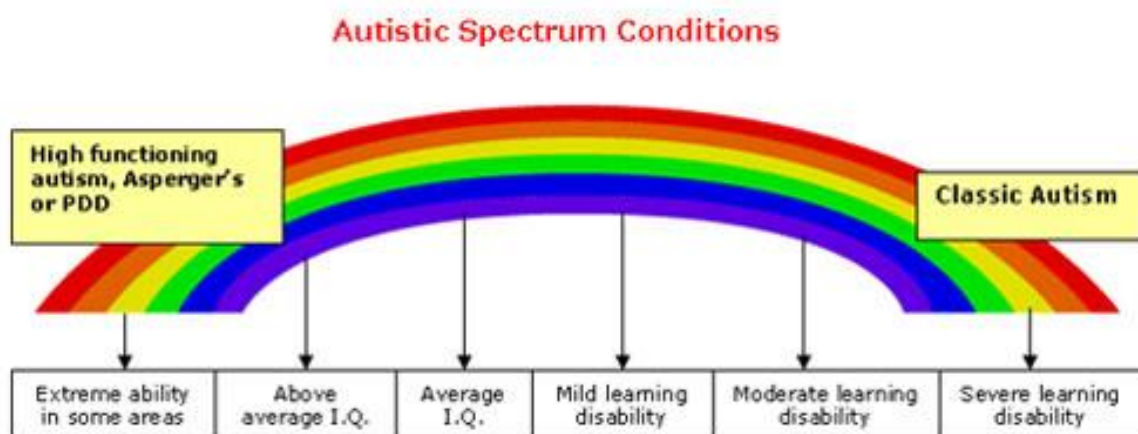


Image Source: myaspergerschild.com

For the purposes of this JSNA chapter, the term autism will encompass Autistic Spectrum Disorder (ASD), Autistic Spectrum Condition (ASC), autistic spectrum

difference and neuro diversity, high functioning autism, Pervasive Development Disorder and Asperger's Syndrome.

In the United Kingdom it is estimated that 1% of the population have autism (Baird et al, 2006), this equates to approximately 700,000 people nationally (The National Autistic Society, 2014). Numerous studies have found that autism is more prevalent in males than females (The National Autistic Society, 2014). Data presented by the Health and Social Care Information Centre (HSCIC, 2009) estimate that the prevalence of autism in males is 1.8% compared to 0.2% in females.

Around a third of people with a learning disability (IQ less than 70) may also have autism (The National Autistic Society, 2014).

Deciding to seek a diagnosis of autism for either themselves or for a child is a personal decision. A parent may feel that having a diagnosis for their child brings a sense of relief as it helps to explain the problems a child may have been experiencing, and a formal diagnosis can also help to gain access to appropriate educational support and services. Some parents choose not to receive a formal diagnosis if autism is suspected as they do not want their child to think of themselves having a disability (The National Autistic Society, 2014).

There are many reasons as to whether an adult chooses to receive a formal diagnosis of autism if they suspect that they have the condition. Receiving a formal diagnosis as an adult can have a number of benefits, for example being able to access specific autism services, being able to claim financial support more easily and being able to understand the condition in greater detail (The National Autistic Society, 2014).

### **Key Findings, Issues and Gaps**

- The chapter has highlighted that there is under-diagnosis of adults with autism in Warrington, therefore it is possible that health and social care professionals/services may not be meeting the needs of adults with autism. This could lead to the increased risk of these services first coming into contact with autistic adults when they reach crisis point and they require intensive support from health and social care.
- The number of 5 Borough Partnership NHS Foundation Trust (5BP) non-learning disability assessments that are commissioned by Warrington Council/Warrington CCG appear to be low when compared to the number of appropriate referrals made via GPs to the referral pathway.
- At present it is unknown how many people with autism are in employment in Warrington. Increasing employment opportunities for people with autism is a strategic objective within the Warrington Autism Strategy for Adults.

- Post-diagnosis support to patients and their families/carers has been identified as an issue within both children's and non-learning disability diagnosis pathways. Once the diagnosis of autism has been made, parents, carers and the person diagnosed with autism have requested additional support from the diagnosis teams as they were unsure who to contact for further support and advice.
- 89% of children who have autism who are of primary and secondary school age attended schools within Warrington, whilst for post-16, this dropped substantially to 48%.
- The lack of autism awareness training for frontline staff has been highlighted as an issue by Warrington Council through the autism self-assessment tool and is being addressed through the Warrington Autism Strategy for Adults.

### **Recommendations for Commissioning**

- It is recommended that Warrington Clinical Commissioning Group (CCG) work in partnership with Warrington Borough Council to create an autism register which will help to ensure that services can be adequately planned/funded to ensure that any individual diagnosed with autism can access the support they require.
- It is recommended that specific projects are developed to help adults with autism into employment.
- It is recommended that employment status information about adults with autism should be collected to establish a baseline position to monitor progress of the autism strategy.
- It is recommended that a post-diagnosis pathway is developed between the Complex Case Panel and Warrington CCG/Warrington Borough Council.
- It is recommended that the local authority, in conjunction with Green Lane and Fox Wood (specialist schools) explore opportunities for additional post-16 education provision which can address the needs of young people with autism.
- It is recommended that the Warrington autism awareness training programme is implemented as soon as practicable.
- It is recommended that commissioners and partners use data gathered about people with autism as the basis for planning services.

### **1) WHO IS AT RISK AND WHY?**

The causes of autism remain unknown, although ongoing research is offering some insight into the probable reasons as to why some people develop this lifelong condition. Many experts believe that the pattern of behaviour from which autism is

diagnosed may not result from a single cause. There is strong evidence to suggest that autism can be caused by a variety of physical factors, all of which affect brain development. There is evidence to suggest that genetic factors are responsible for some forms of autism. Scientists have been attempting for some years to identify which genes might be implicated in autism (The National Autistic Society, 2014).

**National Picture:** In the United Kingdom it is estimated that 1% of the population have autism (Baird et al, 2006), this equates to approximately 700,000 people nationally (The National Autistic Society, 2014).

**Gender:** Numerous studies have found that autism is more prevalent in males than females (The National Autistic Society, 2014). Data presented by the Health and Social Care Information Centre (HSCIC, 2009) estimate that the prevalence of autism in males is 1.8% and 0.2% in females. Research conducted by The National Autistic Society found that it was much more difficult for females to gain a diagnosis of autism and they were much more likely to be misdiagnosed. The research also found that only one fifth of females with Asperger's Syndrome were diagnosed by the time that they were eleven years old; whilst for males over half had been diagnosed by this age (Bancroft et al 2013 cited in Liverpool Health Observatory 2013). Some research has suggested that there is under-diagnosis in females because autism is seen as a male condition (Liverpool Health Observatory, 2013). Also, further research has suggested that girls are better at masking the symptoms of autism to 'fit in' with their peer groups (The National Autistic Society, 2014).

**Existing Learning Disabilities:** Around a third of people with a learning disability (IQ less than 70) may also have autism (The National Autistic Society, 2014).

Some associations have been found between age, ethnicity and autism (Emerson and Baines, 2010 cited in Liverpool Health Observatory 2013).

**Age:** Due to the reduced life expectancy of people with learning disabilities, learning disabilities are significantly more prevalent in younger adult age groups. As a result, areas with younger demographic profiles would be expected to have increased numbers of adults with learning disabilities and autism (Liverpool Health Observatory, 2013).

**Ethnicity:** Severe learning disabilities are more common among Pakistani and Bangladeshi children. As a result, areas with higher proportions of young Pakistani and Bangladeshi adults would be expected to have an increased number of adults with learning disabilities and autism (Liverpool Health Observatory, 2013).

**Misdiagnosis:** Sometimes, adults with autism have been misdiagnosed with mental health problems such as schizophrenia. This may mean they have received inappropriate treatment or services (National Autistic Society, 2014).

## National Policy

The 2009 Autism Act was written in response to increasing evidence that adults with autism were being prevented from leading a fulfilling life due to exclusion (both socially and economically). The 2009 Autism Act stated that a national autism strategy must be written by 2010 (Autism Act 2009).

In response to the declaration made with the 2009 Autism Act, the national autism strategy '*Fulfilling and Rewarding Lives*' (HM Government, 2010) was written. The aim of this strategy was to "*unlock aspiration and make a reality of genuine equality and opportunity for all*" (HM Government, 2010). The strategy highlighted the need for raising awareness and understanding of autism through training key frontline staff that may come into contact with people who have autism. Each local area should have a clear diagnosis/referral pathway that health professionals are aware of. People with autism should be able to access relevant services or support that they may need, and be given the opportunity to be in employment. Through partnership, local areas should develop services that reflect local need. At the heart of the strategy was the following vision: "*All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.*" (HM Government, 2010).

To ensure that local areas were implementing the vision and aims of the strategy, an annual self-assessment process was introduced in 2013.

The 2010 strategy was then updated in 2014 with '*Think autism: Fulfilling and rewarding lives, the strategy for adults with autism in England – an update*'. The update had been published for three reasons: updates are a requirement of the 2009 Autism Act; progress had been made since the previous strategy; and widespread reforms of services have taken place since the 2010 strategy was written. The 2014 strategy still has the same vision as the 2010 strategy, but the focus of the 2014 strategy lies with fifteen priority challenges (HM Government, 2014).

A statutory guidance consultation ran between 7<sup>th</sup> November and 19<sup>th</sup> December 2014. The aim of the consultation was to seek views on proposed new statutory guidance to local authorities and NHS organisations, and to support the implementation of the new 2014 autism strategy. The consultation looked at issues including: staff training; identification and diagnosis of autism in adults and the planning of services; preventative support; and safeguarding and employment for adults with autism (Department of Health, 2014).

The strategies above relate only to adults with autism. For CYP with autism, there are radical new provisions in the Children and Families Act 2014 for special educational needs (SEN) and disabilities support, and for the health and social care support that young people with SEN receive (Children and Families Act, 2014). The

Act came into force in September 2014 and aims to transform the system for children and young people with SEN and disabilities (SEND) by placing families at the centre of decision making. It sets out requirements that education, health and care services should work together to provide coordinated support across all areas of a child or young person's life.

The Act will replace SEN statements with Education, Health and Care (EHC) plans, and the system will run from birth to 25, rather than ending when a young person leaves education (The National Autistic Society, 2014).

**National Institute for Health and Care Excellence (NICE) Guidelines:** Based on the findings and recommendations from the 2010 National Strategy, NICE has developed three Clinical Guidelines in relation to the recognition, referral, diagnosis and management of people with autism. These are discussed in further detail in section 5.

## **2) THE LEVEL OF NEED IN THE LOCAL POPULATION**

### **Estimated Prevalence**

As stated in section 1, the estimated prevalence of autism in the population is 1%; 1.8% in males and 0.2% in females. There is no way of knowing the actual number of people in Warrington with autism, because many are undiagnosed. The best estimate that can be made is to apply these prevalence's to the Warrington male and female population estimates (2013 mid-year population estimates sourced from the Office of National Statistics); this gives an estimate of **2,038** people (1,831 males and 207 females). When applying the estimated prevalence to broad age groups, there are approximately 500 people with autism aged under 19; 1,216 people aged 20 to 64 and 322 people aged 65 and over.

### **GP Practice records**

The number of people registered with a Warrington GP and been diagnosed with autism was **695** (as at May 2014, when data was extracted from the clinical databases of Warrington GP practices by the North West Commissioning Support Unit (NWCSU) during May 2014). Of these 695, by broad age band, 455 were aged 0 to 19; 235 were aged 20 to 64, and 5 were aged 65 years and over.

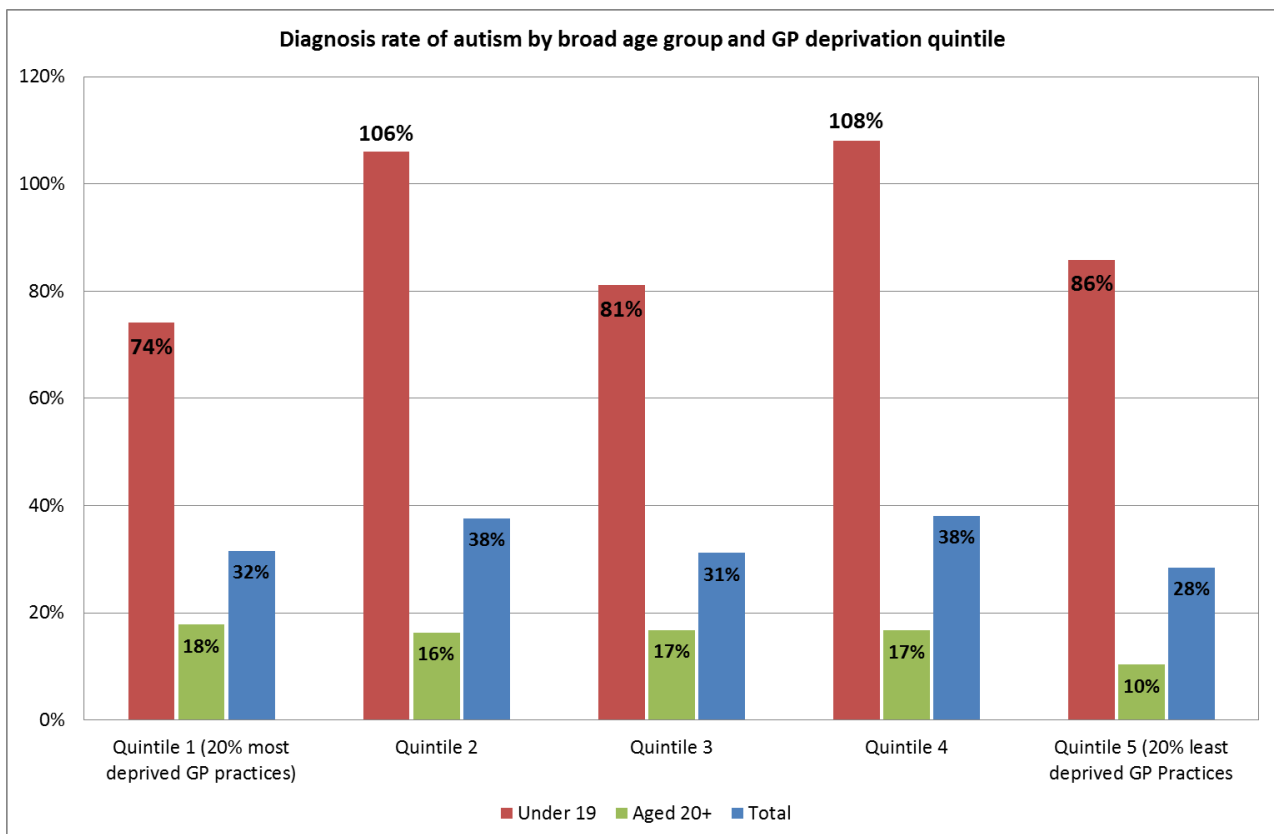
The estimated number of people in Warrington with autism is 2,038, and there are 695 people with a diagnosis, suggesting that approximately only a third (34%) have been diagnosed. However, this estimated under-diagnosis changes with age; 91% of those aged 0 to 19 have received a diagnosis, but only 16% in those aged 20 and over.



Estimates of the number of people with autism were calculated for each GP practice, based on the number of people registered at each practice. This was compared with the number of people at each practice with a diagnosis of autism. The diagnosis rate varied quite widely between GP practices and by the age group of the patient. For example, in those aged under 19, the diagnosis rate ranged from 12% to 138% (GP practices with a percentage above 100 have identified more people with autism than expected in their population). For those aged 20 and over, the diagnosis rate ranged from 4% to 36%.

The following chart presents the diagnosis rate by GP deprivation quintile<sup>1</sup> and broad age band. In each GP deprivation quintile, the diagnosis rate in those aged under 19 was higher than in those aged 20 and over. There was no apparent pattern between diagnosis rate and deprivation.

**Chart 1: Diagnosis rate of autism by broad age group and GP deprivation quintile**



The number of CYP with a diagnosis on their clinical records is 91% of the total estimated number of CYP with autism, suggesting a high level of identification of

<sup>1</sup> Deprivation scores have been assigned to each GP Practice in Warrington based on the deprivation scores (Index of Multiple Deprivation 2010) for each patient postcode. The overall deprivation score for each practice was ranked and then split into five groups (quintiles) where quintile 1 is the most deprived group and quintile 5 is the least deprived group.

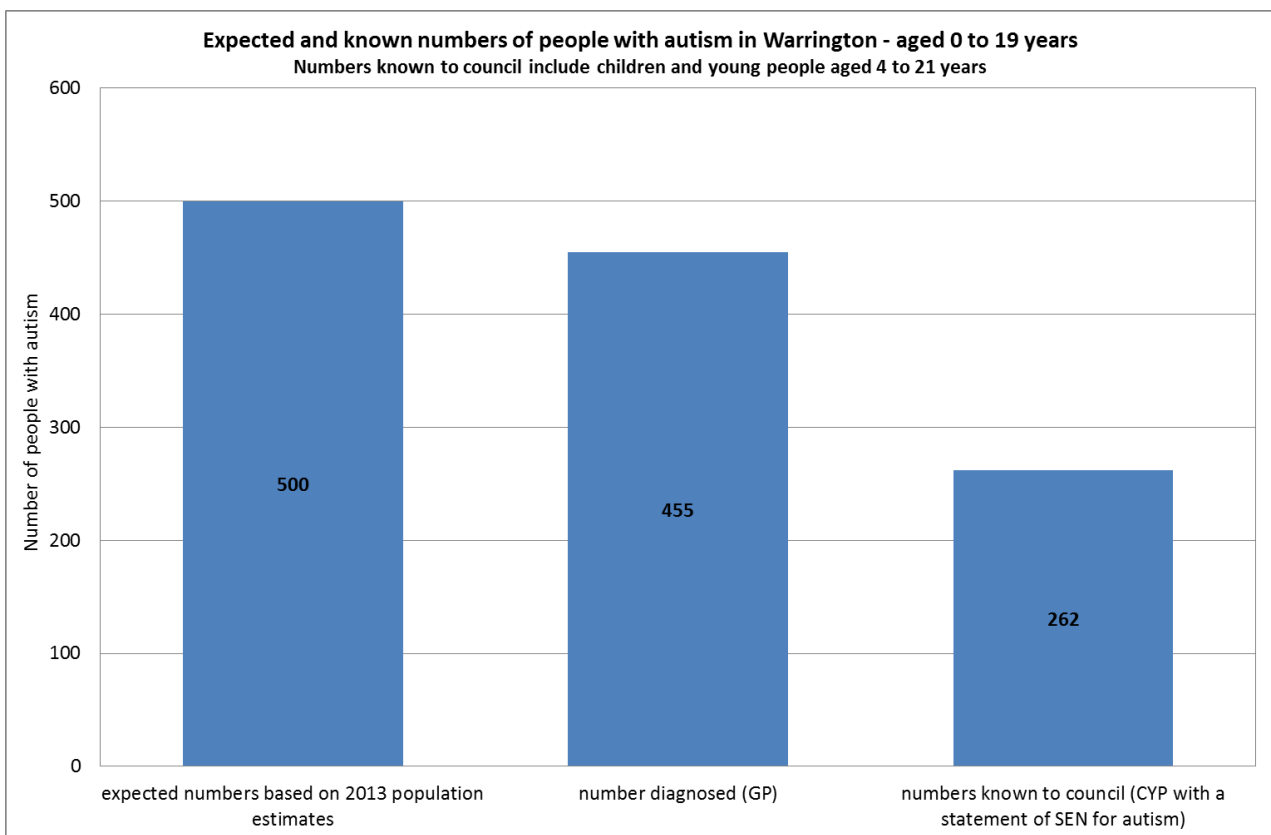
autism in CYP. However, the identification of adults with autism is much lower at 16%. The high diagnosis rate of autism in CYP is likely to be a reflection of increased awareness of autism in health professionals, educational professionals, parents/carers and the existence of the Complex Case Panel.

The low diagnosis rate for adults is possibly the result of a combination of factors that have prevented the diagnosis being made for the patient. The patient may not have received a diagnosis as a child, have chosen not to receive a formal diagnosis, have been misdiagnosed, and/or have developed coping techniques. Under these circumstances, they have therefore not received support from health or social services. Alternatively, autism may not be their primary health condition and it is felt a formal diagnosis will not benefit the patient as they are already receiving their required levels of support.

### Children and young people

The following chart illustrates the number of CYP who are expected to have a diagnosis of autism, the actual number with a diagnosis and the number known to the council because the child or young person has a statement of SEN for autism.

**Chart 2: Expected and known numbers of people with autism in Warrington - aged 0 to 19 years**



## **Children and Young people with autism and a Statement of Special Educational Needs (SEN)**

The following data has been sourced from a WBC report which was written before the Children and Families Act (2014) introduced a range of reforms from September 2014. The analysis is based on the number of CYP who had received a statement of SEN for autism as at January 2014.

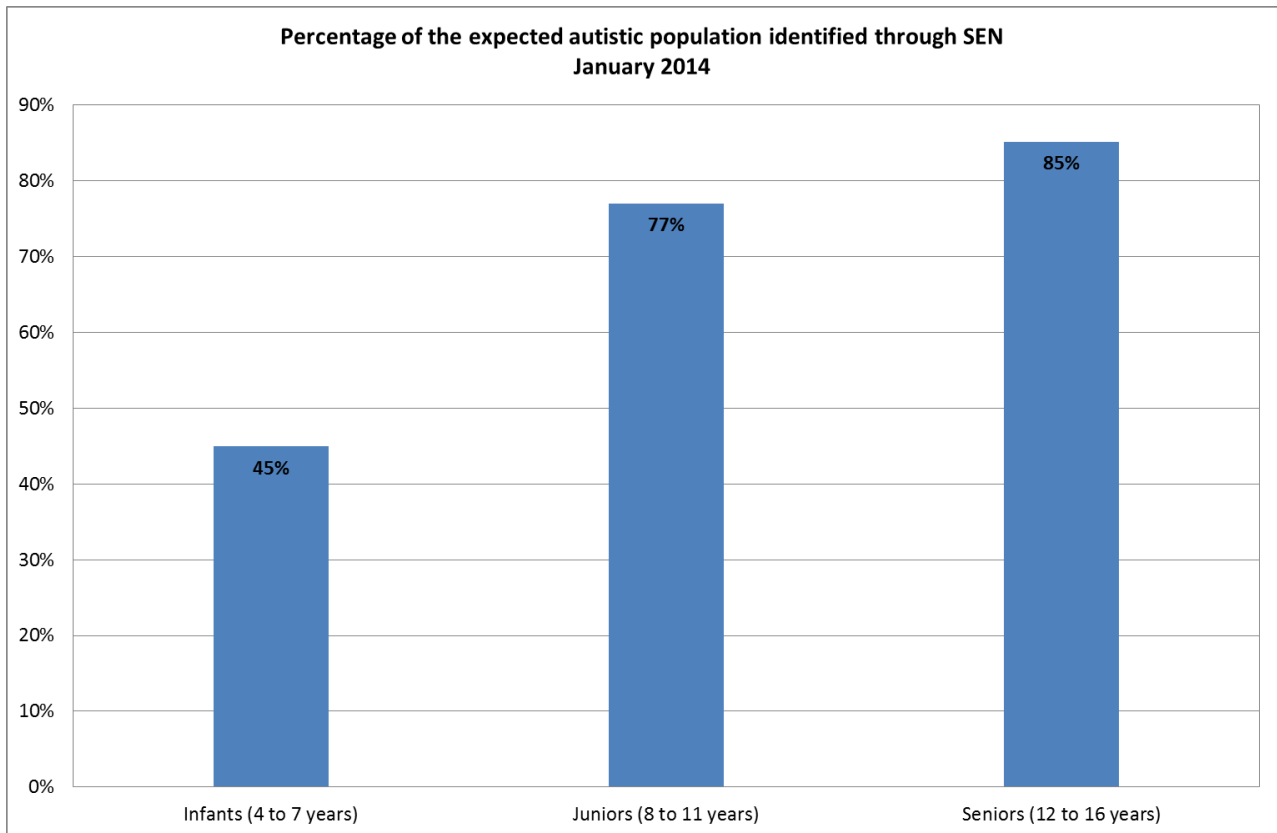
In Warrington 262 children aged 4 to 21 years have a statement of SEN for autism (based on data extracted during January 2014 by Warrington Borough Council). This number appears to be quite low when compared to the number of CYP who have received a diagnosis; however it should be remembered that not all CYP with autism will require a statement of SEN (or an EHC after September 2014). Caution should also be applied to the interpretation of this data because the number of CYP with a statement of SEN presented above only relates to those aged 4 to 21 years who are in education, whilst the expected prevalence and GP data relates to those aged 19 years and under.

Further analysis of the number of CYP with a statement of SEN due to autism has shown that a higher number of diagnoses are made as the age of the child increases. This is to be expected, as the child develops both within the home and school environment, and differences in the way the child interacts with parents/carers, teachers and peers can be identified and processes to receive a formal diagnosis can begin.

0.9% of senior school aged CYP (aged 12 to 16 years) have a statement of SEN due to autism; this equates to 105 students. Within this age group, the estimated number with autism is 123, suggesting that 85% of 12 to 16 year olds expected to have autism have a statement of SEN for autism.

The following chart illustrates the percentage of the expected autistic population identified through receiving a statement of SEN due to autism. The chart shows that as the age group of the child increases, a greater proportion of the expected autistic population have been identified and supported.

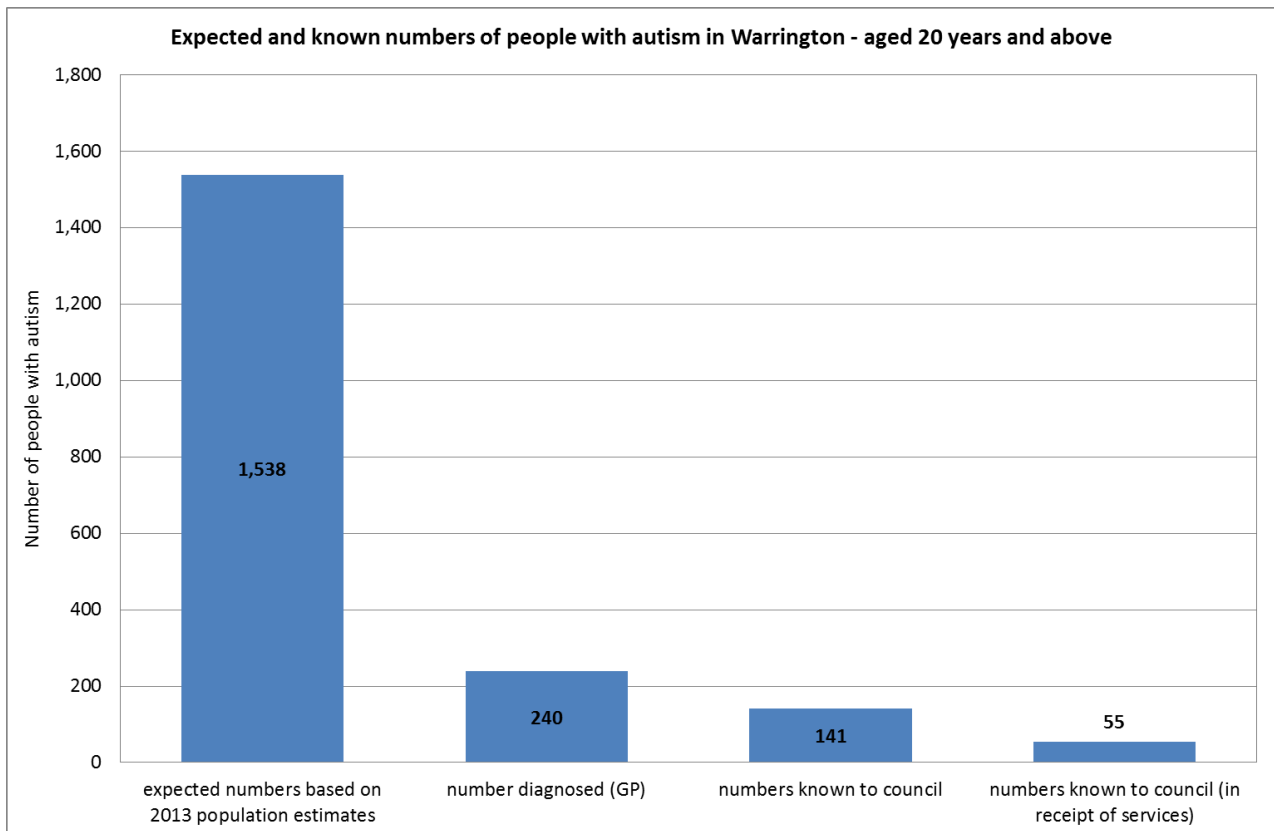
**Chart 3: Percentage of the expected autistic population identified through a statement of SEN due to autism**



This finding is positive as it provides assurance to Warrington Council, education and health professionals that the majority of senior school CYP who are expected to have autism have been identified and are receiving the support they may require. However, the chart emphasises that children of infant age are underdiagnosed; this finding is to be expected. As mentioned previously, it can take time for a child to be identified as possibly having autism and the process of receiving a formal diagnosis can also be lengthy.

## Adults (20 years and above)

**Chart 4: Expected and known numbers of people with autism in Warrington - aged 20 years and above**



Data from CareFirst (the clinical system that records the details of individuals who require council services) has shown that there are 55 adults currently in receipt of services who have a diagnosed condition of autism/Asperger's. A further 86 adults with a diagnosis of autism are currently known to Warrington; however they are not currently receiving services. It is expected that the recorded number of clients with autism will increase over the coming year as social workers now have the option to include any other health conditions to CareFirst (rather than only the primary condition for which the client is receiving services).

Diagnosis of adults with autism is low in Warrington. The estimated number of adults with autism is 1,538. However, only 240 have been diagnosed with autism. (i.e. approximately only 16% of the expected numbers have been identified). At present it is unknown how many GPs have attended autism awareness training or are aware of local adult autism diagnosis pathways. However, as diagnosis rates are so low in the adult population, it is recommended that an audit is conducted to assess the number of GPs trained in autism awareness, and the promotion of the adult autism diagnosis pathways is required.

Over time, it is expected that the diagnosis rate in adults will increase as the children and young people already diagnosed with autism mature into adulthood.

Records held by WBC show that the number of adults with autism who receive services are very low. Not all individuals with autism will require support from social services or meet the threshold where support can be offered. However, it means that WBC is only aware of approximately 4% of the expected number of adults with autism. For WBC to be able to plan services effectively for the future, it will require a more accurate number of individuals who have received a diagnosis of autism.

It is recommended that Warrington Clinical Commissioning Group (CCG) work in partnership with Warrington Borough Council to create an autism register which will help to ensure that services can be adequately planned/funded to ensure that any individual with autism can access the support they require. This recommendation aligns with the expectation made within Think Autism (HM Government, 2014) that local authorities, NHS foundation trusts and health bodies should jointly seek to gather accurate local data about the number of people with autism and their needs. It should ideally include age, gender, ethnicity, employment status, requiring employment support and accommodation status.

### **3) CURRENT SERVICES IN RELATION TO NEED**

#### **Local Referral Pathways for Diagnosis**

##### **Children and young people aged under 18 years (in education)**

In Warrington, one referral pathway is in existence for a child or young person to receive a diagnosis of autism. The referral pathway begins with concerns being raised by the parent/carer, health professional, specialist teachers or educational specialists. Referral forms (ideally completed by all of the above professionals to gain a full picture of the issues facing a child) are completed and sent to the Warrington Community Paediatric Medical Service and are then reviewed by the Complex Case Panel.

The Complex Case Panel is comprised of multi-disciplinary staff, including an educational psychologist, Speech, Language and Communication (SLC) staff, Learning Disability (LD) staff, Consultant Paediatrician, Occupational Therapist and Child and Adolescent Mental Health Services (CAMHS) staff. The panel decide whether an assessment would be appropriate for the child (based on the information provided within the referral forms) and if so, the child is referred on for further assessment. The further assessments are reviewed and a decision is made by the Complex Case Panel as to whether the child is on the autistic spectrum. Health and education professionals ensure that appropriate services and support are in place for that child and that parents are signposted to support services.

## **Adults aged 18 years and above (and 16 and 17 year olds no longer in education)**

There are two adult referral pathways in Warrington that have been jointly commissioned by Warrington Council and Warrington CCG. Both of the referral pathways are led by 5 Boroughs Partnership NHS Foundation Trust (5BP).

The first referral pathway will only assess adults that have already received a learning disability diagnosis. Within this contract there are no limitations for the number of autism assessments that can take place. However, few assessments are conducted through this pathway by 5BP as the focus of care and support for these clients tends to be based on the pre-existing learning disabilities. For some clients, the diagnosis of autism will not alter the services and support a client already receives, therefore the client and/or carer may not request an official diagnosis of autism.

The second referral pathway is for adults who do not have a previously identified learning disability. Through this referral pathway, an assessment can only be made if the patient, their GP, or another professional with specialist knowledge of autism, complete the referral paperwork. If the referral is appropriate, the patient will receive a comprehensive assessment, and a diagnosis will be made (if applicable). A very high proportion (approximately 80%) of referrals received from Warrington GPs has led to a diagnosis of autism. Between April and September 2014, 5BP had received 28 appropriate referrals to their service.

Warrington CCG/Warrington council have commissioned a block contract of 24 assessments to be conducted during 2014/15 (12 assessments were commissioned during 2013/14).

However, given that there were already 28 appropriate referrals in the first 6 months of 2014/15, and given the likely number of underdiagnosed adults, it may be beneficial to increase the annual number of assessments from 24.

## **Post-diagnosis**

Post-diagnosis has been identified as an issue within both children's and non-learning disability diagnosis pathways. Once the diagnosis of autism has been made, parents, carers and the person diagnosed with autism have requested additional support from the diagnosis teams as they were unsure of who to contact for further support and advice.

A draft post-diagnosis pathway is currently being developed between 5BP non-learning disability team and Warrington CCG/Warrington Council. It is recommended that a post-diagnosis pathway is also developed between the Complex Case Panel and Warrington CCG/Warrington Council.

## Local Strategy

Warrington Borough Council completed a self-assessment tool which was developed by Public Health England and the Learning Disabilities Observatory in October 2013. The self-assessment tool enables Local Authorities and relevant partners to assess the services and support they were able to provide to children and adults with autism. The self-assessment tool identified that Warrington had put into place many of the recommendations that had been made in Fulfilling and Rewarding Lives (HM Government, 2010). These include:

- A joint commissioner/senior manager who is responsible for adults with autism has been named.
- Transition processes are in place from Children's social services to Adult social services. The transition process also includes an employment focus.
- A local diagnostic pathway has been established.
- A diagnosis of autism automatically triggers the offer of a Community Care Assessment.
- A single identifiable contact point has been established where people with autism, whether or not in receipt of statutory services can get information signposting autism-friendly entry points for a wide range of local services.
- People with autism can still access support if they do not meet Fair Access Criteria (FACS) or are not eligible for statutory services.
- The Criminal Justice System (CJS) are engaged as a key partner when planning for adults with autism.

However, the self-assessment report highlighted actions that had not been implemented locally.

- Staff training (specialist training for front line staff and general awareness for remaining staff groups).
- Reasonable adjustments have not been made to everyday frontline services.
- Recognising the needs of older people with autism.

In response to these actions that have not been met locally, the Warrington Autism Strategy for Adults has been developed.

The Warrington Autism Strategy for Adults 2014-17 (Warrington Borough Council, 2014a) was developed jointly with Warrington CCG and led by the Joint Learning Disability and Autism Partnership Board. It is envisaged that this strategy will evolve to incorporate the needs of autistic children and young people. The strategy was published in December 2014. The framework of the strategy is taken from Fulfilling and Rewarding Lives (HM Government, 2010) and includes recommendations made in Think Autism (HM Government, 2014). Locally, the strategic goals are to:

- Improve the ways in which we identify the needs of adults with autism.



- Incorporate those identified needs, more effectively, into local service planning and commissioning, so that adults with autism and their carers are better able to make relevant choices about their lives.

The strategic objectives are to:

1. Increase awareness and understanding of autism among frontline professionals.
2. Develop a clear, consistent pathway for diagnosis in every area, which is followed by the offer of a personalised needs assessment.
3. Improve access to the services and support which adults with autism may need to live independently within the community.
4. Help adults with autism into work.
5. Enable local partners to plan and develop relevant services for adults with autism to meet identified needs and priorities.

### **Services offered in Warrington for Children and Young People**

The Children's Family Act (2014) stated that by September 2014, all Local Authorities should publish information about local provision that is available to children and young people who have special educational needs or a disability; this is known as the 'local offer'. The 'local offer' must include information about education, health and care provision; other educational provision; other training provision; travel arrangements and preparation for independent living (this includes finding employment, finding somewhere to live and participating in society).

The 'local offer' in Warrington is available at the following website: <http://warrington.fsd.org.uk/kb5/warrington/fsd/localoffer.page>

There are very few services in Warrington that are specifically for children and young people with autism. The services that are available are aimed at all children and young people with any learning difficulty or disability. The services available will make reasonable adjustments to allow children with autism to participate in activities. However, support and information is available from the Warrington branch of the National Autistic Society and Warrington Asperger's Society (WASPS).

### **Education Provision**

The following information has been sourced from the Warrington 'Assessment of Educational Needs of Children with Autism' (Warrington Borough Council, 2014b).

In Warrington, there is a range of education provision to meet the needs of pupils with autism including mainstream, designated and specialist educational provision.

As of January 2014, the majority of 4 to 21 year olds with a statement of SEN for autism (82%) attended a school within the local authority area.

The National Autistic Society's report 'Make school sense' found that nationally, 21% of children with autism attended a school located outside of their local authority area (National Autistic Society, 2006 cited in Warrington Borough Council, 2014b). This was attributed to a lack of appropriate educational provision in borough to meet the needs of children with autism.

At 18%, Warrington is just below the national average, suggesting that there is adequate education provision in the borough to meet the current needs of autistic children and young people. 89% of children of primary and secondary school age attended in borough provision, post 16 this dropped substantially to 48%. The drop in the percentage of post 16 CYP with autism attending an educational establishment in Warrington may be due to a number of possibilities which requires further investigation to understand the educational need in the local population.

In order to understand if those young people could be better provided for in the local authority area, it is recommended that the local authority, in conjunction with Green Lane and Fox Wood (specialist schools) and Future Tech Studio (state school for all abilities for children and young people aged 14 to 19 years) explore opportunities for additional post 16 provision which can address the needs of young people with autism. (Warrington Borough Council, 2014b).

In Warrington there are also four mainstream schools (two primary and two secondary<sup>2</sup>) that have designated provision for children and young people with autism. Designated provision is an area within a mainstream school which acts as a base for the pupils but they can also access the main part of the school.

### **Transition from children's services to adult services**

The transitional process of moving from services that offer support for young people with autism to adult services or stopping receiving any support can be a very difficult and unsettling time for young people with autism. Consultation (which was led by Speak Up) with young people who have autism found that very often, there was a large reduction in terms of formal support provided.

### **Services offered in Warrington for Adults**

As with children and young people, there are very few services specifically aimed at adults with autism; rather, services are available for adults with any learning difficulty

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<sup>2</sup> Dallam Community Primary, Woolston Community Primary, St Gregory's Catholic High School and Bridgewater High School.

or disability, and adjustments are made for those who also have autism. The only support specifically relating to autism is mainly via the Warrington branch of the National Autistic Society or WASPS.

The Community Connector service was set up as a pilot project in 2012 in response to the eligibility criteria being made more stringent, and therefore more difficult for people to receive Fair Access to Care Services (FACS) support from the council. The Community Connector service signposted people to community services that could offer them support, advice or give the opportunity to socialise. However, this service ended during the summer of 2014 as long-term funding could not be secured.

The 'My Care and Support Directory' is an online directory of social care and support services, clubs, groups, community and voluntary organisations for people in the Warrington area. The aim of this webpage is to signpost people to relevant services or support. (<http://www.warrington.gov.uk/mycareandsupportdirectory>).

## **Employment support**

**Adult supported employment service:** Supported employment can provide a helpful way in to work for people with learning disabilities. It can promote confidence, a sense of self-worth, can enable people with disabilities to achieve sustainable long-term employment, and can give the opportunity for businesses to employ valuable workers.

The adult supported employment service supports people aged 18 to 65, who have a learning disability and who are Warrington residents to help them to make vocational choices through voluntary work, work tasters and work experience. They provide close and on-going support within the workplace to the individual and the employers (Warrington Borough Council, 2014c).

Warrington Disability Partnership also offers tailored employment support and advice through their qualified advisors.

## **Housing**

The current Warrington housing strategy (Warrington Borough Council, 2008) includes an action to provide thirteen affordable housing units for rent for people with a learning disability. These were completed in 2011/12. In addition, two of the 32 older persons bungalows constructed by the council in 2011/12 were leased to Adult Social Care for occupation by tenants with learning difficulties/autism who require a live in carer.

## **Criminal justice system**

The Criminal Justice System (CJS) are engaged with Warrington council when planning for adults with autism. Representatives from the CJS for part of the Joint Learning Disability and Autism Partnership Board. Within the multi-disciplinary Criminal Justice Liaison Team there is a nurse practitioner whose role is to scope demand, and to provide support and advice for people with a learning disability and/or autism. The usual eligibility criteria for the Learning Disability Services have been relaxed in response to the difficulties faced by people on the autistic spectrum who are within the CJS.

Autism alert cards were introduced in Warrington during 2011 and are used by the CJS. The National Autistic Society's Autism Alert Card has been developed in consultation with adults with autism and their parents. The card can be carried by a person with autism and used in situations where they may find communication difficult. The card tells people about the condition and asks them to show respect and tolerance. It comprises a wallet, which contains an information leaflet and a credit card style card where people can write emergency contact details (Warrington Borough Council, 2011).

## **Training**

Levels of training vary a great deal from organisation to organisation, from virtually no staff trained at all, to some staff trained to a small degree, to many staff trained to a high degree. 5BP already have a comprehensive training pathway in place for most staff, this training includes:

- The 5BP hosted Learning Disability Training Alliance provides a two day Autism workshop.
- The British Psychological Society (BPS) provide a half day free training which is funded through the Department of Health.
- E-learning module for awareness level training (this training is mandatory for all front line 5PB staff).
- Specialist practitioners will complete specialist training, for example, post graduate certificates; degrees; Masters Degrees; Continued Professional Development (CPD) short courses.

The lack of autism awareness training for frontline staff (not including 5BP staff) has been highlighted as an issue by Warrington Council through the autism self-assessment tool and is being addressed through the Warrington Autism Strategy. At present an autism training programme is being developed by Warrington Council and will be based on the recommendations made by Skills for Care with Skills for Health and the National Autistic Society (Skills for Care, 2014). The training programme will offer three levels of autism training:

- *Basic awareness:* The basic knowledge and skills required for all non-specialist staff whose day-to-day roles may bring them into contact with those who have autism. This training will be offered to all social care and health services, and includes non-care and non-clinical workers such as administrators, receptionists, drivers and catering staff.
- *Intermediate knowledge and skills:* This will build on the basic awareness and is aimed at staff who have frequent or intensive contact with people with autism, and those members of staff who may spend little time but have a high impact on the outcomes for people with autism.
- *Specialist development:* Skills for specialist workers or workers in specialist services.

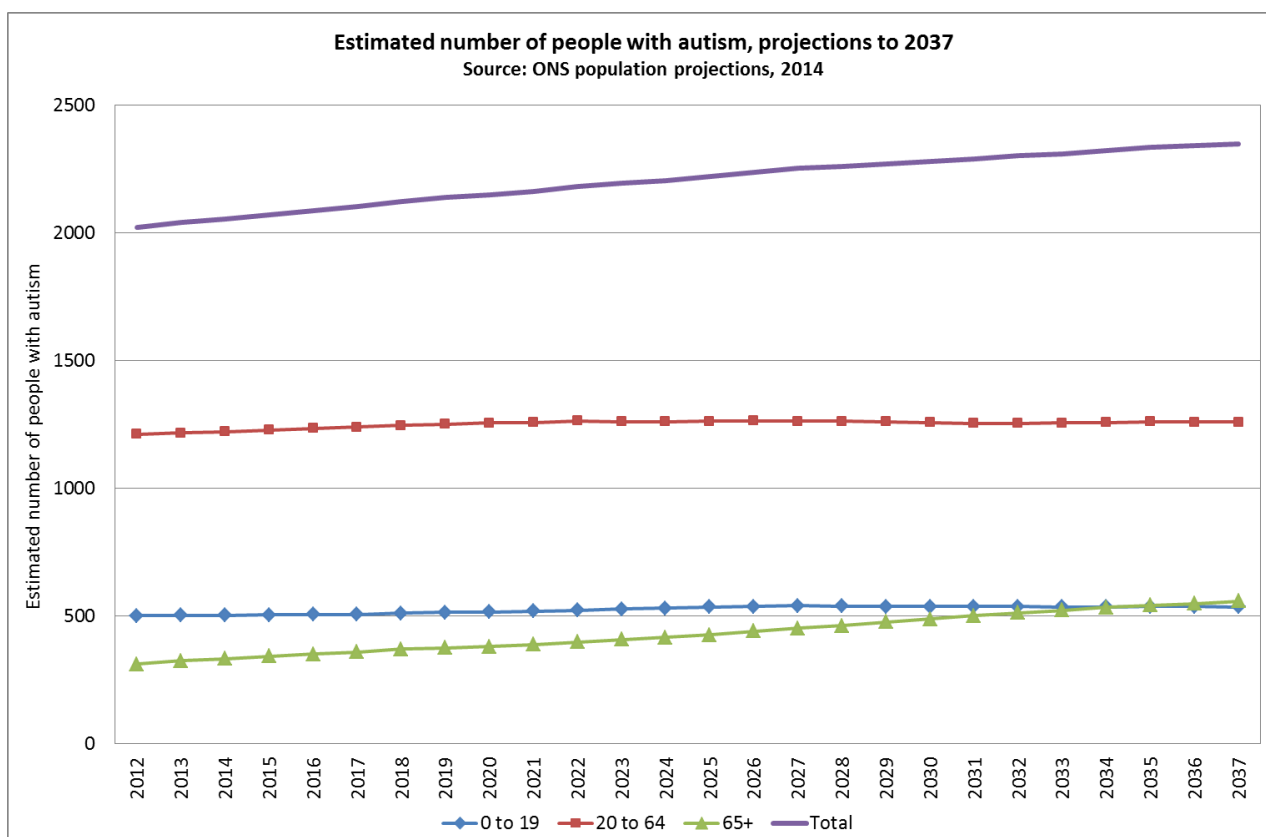
At present it is not known how many GPs have received autism training.

#### **4) PROJECTED SERVICE USE AND OUTCOMES**

The following analysis and chart has been based on population projections supplied by the Office of National Statistics (ONS) and assumes that the estimated prevalence of autism will remain at 1%. By 2037, it is estimated that the projected number of people with autism in Warrington will increase by 15% to 2,348 (based on estimated numbers in 2013).

Percentage changes by broad age bands suggest a 7% increase for children and young people aged 19 and under; a 4% increase for adults aged 20 to 64; and a 72% increase for older people aged 65 years and above. The large increase for those aged 65 and above is a reflection of the expected increase in the ageing population of Warrington.

**Chart 5: Estimated number of people with autism, projections to 2037**



It is also expected that the number of adults with autism that the council are aware of will increase with time. At present, data suggests that a low proportion of adults with autism have been diagnosed. However, the diagnosis rate in children is substantially higher, and this diagnosis will be carried through to adulthood resulting in health and social care professionals being aware of more people with autism. The establishment of the 5BP diagnosis pathways for adults will also identify adults with autism who were not diagnosed a child; this will lead to a small increase in the number of adults with autism being identified.

## **5) EVIDENCE OF WHAT WORKS**

The National Institute for Health and Care Excellence (NICE) has published one quality standard and three clinical guidelines on autism.

**Quality statement on autism QS51** (January 2014): this quality statement provides eight statements about support and services that should be offered in each local area (NICE, 2014).

**Autism: recognition, referral and diagnosis of children and young people on the autism spectrum - Clinical Guideline 128** (2011): This guideline covers the

recognition, referral and diagnosis of autism in children and young people from birth up to 19 years.

***Autism – management of autism in children and young people – Clinical Guideline 170*** (2013): This guideline covers children and young people with autism (across the full range of intellectual ability) from birth until their 19th birthday, and their parents and carers. It should be used alongside *Autism: recognition, referral and diagnosis of children and young people on the autism spectrum* (NICE clinical guideline 128) and *Autism: recognition, referral, diagnosis and management of adults on the autism spectrum* (NICE clinical guideline 142).

***Autism: recognition, referral, diagnosis and management of adults on the autism spectrum – Clinical guideline 142*** (2012): This guideline covers the care provided by primary, community, secondary, tertiary and other health and social care professionals who have direct contact with, and make decisions concerning the care of, adults with autism.

The use of autism registers in local areas has been recommended in *Think Autism* (HM Government, 2014) to enable local services to plan appropriate levels of support and care, and to provide assurance that they are aware of those with autism. There are few examples of autism registers in the UK, two of which are:

- The Haringey branch of the National Autistic Society collect information about all children with a diagnosis of autism (with parent/carer consent) and their diagnosis will be shared with the Council's Children's Services (Haringey Autism, 2014).
- The London Borough of Bexley's Autism Strategy has as one of its priorities for the next three years, to establish a pathway where all agencies inform a central register when alerted to a diagnosis of autism and the action plan states that it will develop and implement proposals to establish an autism register (London Borough of Bexley, 2013).

The evidence available on registers is mainly from research studies from outside the UK. Denmark has a nationwide autism register which has been used in a number of studies; registers are also used in Sweden and Norway. Western Australia has an autism register, which it says is the first of its kind in Australia. The Register has collected information on newly diagnosed cases of Autism Spectrum Disorders in Western Australia since 1999 (Western Australian Register, 2014).

The data presented in section 2 highlights that there appears to be under diagnosis of adults with autism in Warrington. The main risk of being undiagnosed with autism spectrum disorder as an adult is that a health professional could misdiagnose symptoms as a different disorder, such as schizophrenia or ADHD. This has serious repercussions in that the patient could be given the wrong medication or even institutionalised.

The Swedish study (Eriksson et al, 2013) states that “*Symptoms in the ASD panorama sometimes overlap with symptoms of mood disorders, anxiety disorders, psychotic disorders, attention deficit hyperactivity disorder (ADHD), or personality disorders, and this may cause diagnostic confusion*”. The Royal College of Psychiatrists report ‘Good practice in the management of autism (including Asperger syndrome) in adults’ (2014), states that “*Autism is particularly prevalent in the population presenting to adult mental healthcare services, where it may be misdiagnosed or its presence obscured by comorbid psychiatric disorder*” (Royal College of Psychiatrists, 2014).

## **6) (TARGET) POPULATION/SERVICE USER VIEWS**

In developing the Warrington Autism Strategy for Adults, local consultation exercises have taken place with stakeholders, including people with autism and their families, to explore what the local issues are. Questionnaires were developed, enabling people with autism and friends/family to share their experiences of using services and to provide information on how services can be improved in the future within Warrington.

Information obtained from the consultation has helped inform the development of the strategy. Although the response rate to the questionnaire was low, the results give some indication of potential needs within the Warrington area.

- **Improving Independence:** The majority of respondents (93%) do not live alone, with 80% living with their parents. However, the majority of respondents felt that their accommodation met their needs.
- **Harassment and hate crime:** Half of the respondents said that they had been harassed or bullied since the age of 18 and 23% had been a victim of crime.
- **Transition from children’s services to adult services:** Less than half (45%) of respondents stated that they had a transition and the majority of respondents reported that they did not receive any support during the transition process.
- **Employment:** Over half (58%) are not in employment, and of those who are, 60% worked part time.
- **Receiving Support:** In accessing support from Warrington Borough Council, 45% of respondents reported problems in seeking support and 44% did not receive any support from the council.

(Warrington Borough Council, 2014a)



## **7) UNMET NEEDS AND SERVICE GAPS**

- The chapter has highlighted that there is under-diagnosis of adults with autism in Warrington, therefore it is possible that health and social care professionals/services may not be meeting the needs of adults with autism. This could lead to the increased risk of these services first coming into contact with autistic adults when they reach crisis point and they require intensive support from health and social care.
- The number of 5 Borough Partnership NHS Foundation Trust (5BP) non-learning disability assessments that are commissioned by Warrington Council/Warrington CCG appear to be low when compared to the number of appropriate referrals made via GPs to the referral pathway.
- At present it is unknown how many people with autism are in employment in Warrington. Increasing employment opportunities for people with autism is a strategic objective within the Warrington Autism Strategy for Adults.
- Post-diagnosis support to patients and their families/carers has been identified as an issue within both children's and non-learning disability diagnosis pathways. Once the diagnosis of autism has been made, parents, carers and the person diagnosed with autism have requested additional support from the diagnosis teams as they were unsure who to contact for further support and advice.
- 89% of children who have autism who are of primary and secondary school age attended schools within Warrington, whilst for post-16, this dropped substantially to 48%.
- The lack of autism awareness training for frontline staff has been highlighted as an issue by Warrington Council through the autism self-assessment tool and is being addressed through the Warrington Autism Strategy for Adults.

## **8) RECOMMENDATIONS FOR COMMISSIONING**

- It is recommended that Warrington Clinical Commissioning Group (CCG) work in partnership with Warrington Borough Council to create an autism register which will help to ensure that services can be adequately planned/funded to ensure that any individual diagnosed with autism can access the support they require.
- It is recommended that specific projects are developed to help adults with autism into employment.
- It is recommended that employment status information about adults with autism should be collected to establish a baseline position to monitor progress of the autism strategy.
- It is recommended that a post-diagnosis pathway is developed between the Complex Case Panel and Warrington CCG/Warrington Borough Council.

- It is recommended that the local authority, in conjunction with Green Lane and Fox Wood (specialist schools) explore opportunities for additional post-16 education provision which can address the needs of young people with autism.
- It is recommended that the Warrington autism awareness training programme is implemented as soon as practicable.
- It is recommended that commissioners and partners use data gathered about people with autism as the basis for planning services.

## **9) RECOMMENDATIONS FOR NEEDS ASSESSMENT WORK**

It is recommended that a needs assessment is conducted once the autism register has been established.

### **Key Contacts**

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