

## Vulnerable Groups

### Adults with Autism

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#### Introduction

According to [The National Autistic Society](#), Autism spectrum disorder (ASD) is a lifelong developmental disability that affects how a person communicates and relates to other people. It also affects how they make sense of the world around them. Autism is a spectrum condition which means that people with ASD are affected in different ways but most have the following difficulties; social understanding and social behaviour, social communication, rigidity of thinking and difficulties with social imagination. People with ASD may experience sensory problems, such as been over or under sensitive to sounds, tastes, smells, lights or colours. Living independently is achievable for some people with autism but not for others. Some people with autism might also have a learning disability.

Asperger's Syndrome is a form of autism which is often accompanied with average or above average intelligence but with a lack of social skills that often prevents them being able to access the community and join in with activities. As such, it is a "hidden disability". Asperger's affects how a person makes sense of the world, processes information and reacts to other people. People with Asperger's find it more difficult to communicate and interact with others which can lead to high levels of anxiety and confusion. They may also have learning difficulties such as dyslexia, dyspraxia or attention deficit hyperactivity disorder (ADHD).

#### What do we know?

[Around 1 in 100 \(1%\) people in England will have autism.](#) As the total estimated population of West Berkshire in 2015 was 156,020, it can be estimated that around 1,560 people in West Berkshire will be somewhere on the autistic spectrum.

The Projecting Adult Needs and Services Information System (PANSI) uses Office for National Statistics population projections and estimates of the number of adults with an autistic spectrum disorder to project how many people aged 18 to 64 will have an autistic spectrum disorder between 2012 to 2020. Around 940 adults in West Berkshire are estimated to have an Autistic Spectrum Disorder with this figure estimated to rise to around 970 by 2020.]

**Table 1: People aged 18-64 predicted to have autistic spectrum disorders, by age and gender, projected to 2030**

Autistic spectrum disorders - all people	2014	2015	2020	2025	2030

## West Berkshire Council Joint Strategic Needs Assessment

People aged 18-24 predicted to have autistic spectrum disorders	107	107	101	101	114
People aged 25-34 predicted to have autistic spectrum disorders	174	172	179	179	170
People aged 35-44 predicted to have autistic spectrum disorders	217	215	203	205	211
People aged 45-54 predicted to have autistic spectrum disorders	246	246	237	217	211
People aged 55-64 predicted to have autistic spectrum disorders	190	194	218	231	225
Total population aged 18-64 predicted to have autistic spectrum disorders	934	934	937	932	932

[Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007](#)

**Table 2: Males aged 18-64 predicted to have autistic spectrum disorders, by age, projected to 2020**

Autistic spectrum disorders by gender	2014	2015	2020	2025	2030
	Males aged 18-24 predicted to have autistic spectrum disorders	97	97	92	92
Males aged 25-34 predicted to have autistic spectrum disorders	157	155	162	162	155
Males aged 35-44 predicted to have autistic spectrum disorders	194	193	182	184	191
Males aged 45-54 predicted to have autistic spectrum disorders	221	221	212	194	189
Males aged 55-64 predicted to have autistic spectrum disorders	171	175	196	207	202
Total males aged 18-64 predicted to have autistic spectrum disorders	841	841	844	839	841

[Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007](#)

**Table 3: Females aged 18-64 predicted to have autistic spectrum disorders, by age, projected to 2020**

<b>Autistic spectrum disorders by gender</b>	<b>2014</b>	<b>2015</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>
Females aged 18-24 predicted to have autistic spectrum disorders	10	10	9	9	10
Females aged 25-34 predicted to have autistic spectrum disorders	18	18	17	17	16
Females aged 35-44 predicted to have autistic spectrum disorders	23	22	21	21	21
Females aged 45-54 predicted to have autistic spectrum disorders	24	25	24	23	22
Females aged 55-64 predicted to have autistic spectrum disorders	19	20	22	24	23
<b>Total females aged 18-64 predicted to have autistic spectrum disorders</b>	<b>94</b>	<b>94</b>	<b>93</b>	<b>93</b>	<b>91</b>

[Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007](#)

The data appears to indicate that in West Berkshire, more males than females are predicted to have Autistic Spectrum Disorder.

**Autism and aging:** Autism was only recognised as a range of medical conditions in the late 1960s and as a consequence, many older people will be undiagnosed with autism. In addition, the condition can be overshadowed by other co-occurring conditions such as a mental health problem, learning disability or attention deficit hyperactivity disorder.

In 2013, the National Autistic Society reported on the challenges facing older people with autism in the UK. They reported that many older people have to wait too long for a diagnosis; the implication being that for some people being diagnosed with autism later in life is seen as positive or can be hard for people to accept and come to terms with missed opportunities because of undiagnosed autism.

They also report that some people with autism have difficulty knowing if they have a health condition and how to let a medical professional aware. In addition, many people with autism find GP surgeries and hospitals stressful because of the noise and lights, which may have an impact on whether they attend medical appointments.

Some people with autism rely on people they know for support, and as they get older the support they rely on might not be there. Parents and siblings worry about what will happen to their relative with autism when they are no longer around.

Local older people's services don't always understand autism and some autism services struggle to support older people.

In West Berkshire, an estimated 264 people aged 65 and over have autistic spectrum disorders.

**Table 4: People aged 65 and over predicted to have autistic spectrum disorders, by age and gender, projected to 2030**

<b>Autistic spectrum disorders by gender</b>	<b>2014</b>	<b>2015</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>
People aged 65-74 predicted to have autistic spectrum disorders	151	155	167	173	195
People aged 75 and over predicted to have autistic spectrum disorders	105	109	133	168	194
<b>Total population aged 65 and over predicted to have autistic spectrum disorders</b>	<b>256</b>	<b>264</b>	<b>300</b>	<b>341</b>	<b>389</b>

Source: [Projecting Older People Population Information System \(2014\)](#)

<b>Autistic spectrum disorders by gender</b>	<b>2014</b>	<b>2015</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>
Males aged 65-74 predicted to have autistic spectrum disorders	135	139	149	155	175
Males aged 75 and over predicted to have autistic spectrum disorders	92	95	117	148	171
<b>Total males aged 65 and over predicted to have autistic spectrum disorders</b>	<b>227</b>	<b>234</b>	<b>266</b>	<b>302</b>	<b>346</b>

Source: [Projecting Older People Population Information System \(2014\)](#)

<b>Autistic spectrum disorders by gender</b>	<b>2014</b>	<b>2015</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>
Females aged 65-74 predicted to have autistic spectrum disorders	16	16	18	18	20
Females aged 75 and over predicted to have autistic spectrum disorders	13	14	16	20	23
<b>Total female population aged 65 and over predicted to have autistic spectrum disorders</b>	<b>29</b>	<b>30</b>	<b>34</b>	<b>38</b>	<b>44</b>

Source: [Projecting Older People Population Information System \(2014\)](#)

### What is the data telling us?

There is little data on the actual numbers of adults with autism, and less data on their needs. It is difficult, therefore, to understand the level of need and commission appropriate local services.

Due to this, many adults with autism are failing to get the support they need. The National Autistic Society conducted research with over 1,000 adults with autism finding out their experiences of assessing support. Over one third (36%) needed help with washing and dressing, around two thirds (63%) needed help preparing a meal, about three quarters (73%) needed help doing housework, 68% needed help with shopping, a larger percentage (83%) needed help paying a bill or dealing with letters and 77% needed help managing money. Interestingly, this report did not mention any emotional support. The respondents reported that this help was not available from their local authority. The level of support required varies from individual to individual. The National Autistic Society also found that people with autism wanted help with social skills, employment support and social groups.

It was highlighted in the government's [national autism strategy \(2010\)](#) that people with autism are socially and economically excluded; not many people with autism are

in employment, many still live at home, rather than independently and many have unmet needs which means their health outcomes are worse than the general population.

The National Autistic Society said that one of the key issues for many adults with autism is that they could 'fall through the gaps', because autism is not a learning disability or a mental health problem, they do not easily fit into a mental health or learning disability services. If someone's autism is not recognised and diagnosed in childhood, adults with Asperger Syndrome and High Functioning Autism in particular can struggle to receive the support they need to lead fulfilling and rewarding lives.

This means that some people with autism are only seen by services when their needs are more acute or if they also have a co-occurring condition such as a learning disability which has been identified in childhood or a mental health problem. However if an adult with autism does not receive the support they need for this condition they are more likely to develop a mental health problem. Low level support at the right time could prevent this arising.

In addition, The National Autistic Society also highlighted gaps between the types of support people with ASD wanted and what services they actually received. Social skills support, employment support and social groups were the top three areas of need. Low level support such as these can make a huge difference and avoid people with ASD falling into crisis situations where they need more intense support.

Whilst West Berkshire Council has an Autism Development worker that supports families and carers by providing; advice, signposting, training and joint working, for children with autism, there is no equivalent post for a worker focusing on adults with autism. The National Autistic Society identified that low level services can help to prevent the development of more complex needs over time.

**The Care Act 2014:** The Care Act was introduced by the government in April 2014 and outlined a range of changes to be implemented by Local Authorities. A new single national eligibility criteria was introduced for all local authorities which means that a person will be entitled to have their needs met if they meet certain criteria. In addition, a new duty means that people could be able to access preventative services and provided with information and advice about local support and resources are available to them. The Care Act gives local authorities a duty to carry out a needs assessment in order to determine whether an adult has needs for care and support (such as practical assistance at home or in the community). Not everyone who has a needs assessment will then be entitled to receive support from the council, but the only way to find out is to have a needs assessment.

If an individual requests an assessment to determine if they are eligible for support, they should receive one regardless of where they are on the autistic disorder spectrum. Assessors must be able to carry out assessments of particular conditions, which means they should be trained in autism. If they lack sufficient experience of autism, they are required to consult someone who does have experience.

### **Recommendations for consideration**

- Gather local information about the prevalence, range of need and age profiles of adults with autism. Partner agencies may also help identify people with autism.
- Gather information about the specific needs of (i) older adults with autism, (ii) adults with autism who may also have mental health problems or (iii) adults with autism who do/do not have a learning disability. Ensure there is early identification of the needs of adults with autism.
- Develop a commissioning plan around support for adults with autism, which reflects local assessment of need.
- Include more people with autism in the Autism Partnership board so they can be involved in planning.
- Have more information about local support and services for people with autism and their families or carers of people with autism e.g. support groups and respite care or short breaks.
- Ensure people with autism know where to find out about services available to them including advocacy services.
- Plan for transition, when a young people with autism are transitioning from children's services into adult services. Councils need to find out what support young people need before they turn 18 in order to help them lead independent lives.
- To improve access to employment opportunities for adults with autism. This could be by setting up schemes to help people with autism get a job e.g. through apprenticeship, signposting to Access to Work interview. Representatives from Jobcentre Plus and employers could be invited to join the Autism Partnership Board to assist with this.
- To undertake further assessment of the housing needs of adults with autism including options for supported housing.

## **Other services and partner organisations**

### **Diagnosis**

There is an established autism assessment and diagnosis pathway for autism commissioned by Berkshire Clinical Commissioning Groups (CCGs) and is provided through Berkshire NHS Foundation Trust. Dr Trevor Powell is a clinical psychologist employed by Berkshire Healthcare NHS Foundation Trust and carries out diagnostic assessments for adults across Berkshire. In 2014, he received 240 referrals, of which around 45% get a full diagnosis of autism and around 45% get diagnosed with having some of the traits and were on the spectrum. Around 10% of referrals do not have traits or a diagnosis of autism. Currently waiting times for a diagnostic test are running at about 12 months. There are around 100 people waiting for an assessment across Berkshire. The diagnosis pathway is currently being reviewed by BHFT and Berkshire local authorities.

### [NAS West Berkshire](#)

The National Autistic Society offer post diagnosis support in partnership with Dr Trevor Powell for people with autism of any age.

### [Autism Berkshire](#)

Autism Berkshire (Previously Berkshire Autistic Society) runs “Being me” and “Social Eyes” courses for people recently diagnosed with being on the autism spectrum to help them understand their diagnosis.

### **Community Mental Health Team**

Although there are currently two mental health carer support groups, they are not autism specific. A new group is going to be set up.

### [Carers UK Reading & West Berkshire Carers Hub](#)

Offer general support for all carers rather than specialise support.

### **Autism Partnership Board**

The council host a multi-agency Autism Partnership Board that meet on a quarterly basis. This group is committed to work together to help support people with autism and aspersers and their families.

### **National and local strategies**

The National Autistic Society (2009), A better future: consultation response from The National Autistic Society

[Department of Health \(2014\), 'Think Autism': an update to the government adult autism strategy](#)

[Department of Health \(2010\) 'Fulfilling and rewarding lives': The strategy for adults with autism in England](#)

[NICE Clinical Guidelines CG142 \(2012\) Autism: recognition, referral, diagnosis and management of adults on the autism spectrum](#)

[Equality Act \(2010\)](#)

[Care and Support Bill \(2010\)](#)

[NICE Clinical Guidelines CG170 \(2013\) Autism - management of autism in children and young people](#)

[HMG Autism Act 2009](#)

[Emerson and Baines \(2010\) Health Inequalities & People](#)

### **Other chapters you might be interested in**

## West Berkshire Council Joint Strategic Needs Assessment

Child & Adolescent Mental Health  
Mental Health  
Mental Health in Old Age  
Adults with a Learning Disability

If you have any questions about this chapter, please contact Public Health and Wellbeing Team on [publichealthandwellbeing@westberks.gov.uk](mailto:publichealthandwellbeing@westberks.gov.uk) or 01635 503437