
Adult Autism Strategy and Action Plan 2019-2022

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1 Introduction

- 1.1 Autism is a lifelong development disorder that affects the way that a person communicates with and relates to others, and makes sense of the world around them. There are around 700,000 people on the autism spectrum in the UK – more than 1 in 100¹ which would mean that approximately 1,585 residents in West Berkshire have autism. Some West Berkshire residents will require support from Health and Social Care as a result of their diagnosis but most will manage independently.
- 1.2 Autism is a spectrum condition which can present differently in each individual. This may be attributed to co-morbid conditions such as learning disabilities or mental health diagnoses. The spectrum of autism covers individuals who need low level support with communication or activities of daily living to individuals who need a lifetime of high level specialist support. Autism is not a learning disability or a mental health condition, however autistic people have a higher rate of mental health issues.
- 1.3 Some strategies which have been proven to aid Autistic people include:
 - Attention to the individual's sensory profile;
 - Clear communication and expectations;
 - Routine;
 - Adjustments to sound and lighting;
 - Visual cues.
- 1.4 This strategy sets out the actions and activities that the Autism Partnership Board (APB) have taken so far and the six strategic priorities for future work to support autistic people in West Berkshire.

2 National Strategic Guidance

- 2.1 The Autism Act 2009 aimed to improve the provision of relevant services and a wider appreciation and understanding of the condition as a whole. The Secretary of State for Health (now the Secretary for Health and Social Care) was charged with overseeing the progress of the Autism Strategy.
- 2.2 West Berkshire Council's response to the Autism Act 2009 was to provide strategic leadership in the form of the Autism Partnership Board (APB), chaired by the Adult Social Care Head of Service. Its purpose is to provide strategic leadership and user and family engagement in the planning and developing of services.
- 2.3 Membership of the APB includes autistic adults, parent carers, NHS providers and commissioners, WBC Children's and Adult Social Care and voluntary sector representation from the National Autistic Society (NAS), NAS West Berkshire and Job Centre Plus.
- 2.4 England's first Adult Autism Strategy, *Fulfilling and Rewarding Lives*, was published in 2010 and was updated in April 2014 along with statutory guidance published in November 2014. This guidance outlined nine areas of focus to be addressed:

¹ The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al (2012). *Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey*. Leeds: NHS Information Centre for Health and Social Care

- 1 Training of staff who provide services to autistic adults in both voluntary and statutory services;
- 2 Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services;
- 3 Planning in relation to the provision of services for autistic people as they move from being children to adults;
- 4 Local planning and leadership in relation to the provision of services for autistic adults;
- 5 Preventative support and safeguarding in line with the Care Act;
- 6 Reasonable adjustments for everyone that requires them;
- 7 Supporting people with complex needs, whose behaviour may challenge or who may lack capacity;
- 8 Employment for autistic adults;
- 9 Working with the criminal justice system.

2.5 The West Berkshire Autism Partnership Board have recognised that, in common with other boards across the country, they want to do more to support the implementation the national autism strategy at a local level. This point was acknowledged within the *Think Autism Strategy Government refresh* (2018)ⁱ that stated 'In some areas, it was agreed with stakeholders that progress was not as quick as envisaged, and that there was scope to streamline the set of actions and commitments and to re-confirm ownership of specific actions to focus on those that would best realise the objectives of the Strategy'.

2.6 In the same report, the government have produced a revised governance model which has grouped 19 strategic objectives into five domains:

- 1 Measuring, understanding and reporting the needs of autistic people;
- 2 Workforce development;
- 3 Health, care and wellbeing;
- 4 Specific support;
- 5 Participation in the local community.

2.7 The delivery of these strategic objectives will be the responsibility of five task and finish groups, who are overseen by an executive group. The five domains have aided us in developing our autism survey from which we devised our strategic vision and priorities.

3 **Scope**

3.1 West Berkshire's Adult Autism Strategy is aimed at those over the age of 18 and looks to reflect the national strategy while recognising local variations where appropriate. The Strategy aims to ensure that appropriate advice and support is available post diagnosis which will be something to develop in coordination with partner agencies. The Strategy also seeks to have an impact on local services and businesses to help and advise them how to be more autism friendly with particular reference to the lived experience of autistic adults such as lighting and noise as well as their employment practices. The Strategy aims to support all autistic adults, including those who do not meet adult social care eligibility criteria.

3.2 This Strategy has been developed based on feedback from autistic adults and in partnership with a range of organisations including:

- West Berkshire Council
- West Berkshire National Autistic Society
- Berkshire Healthcare Foundation Trust
- Autistic Adult representatives
- Watermill Theatre

4 Vision

4.1 Locally West Berkshire Council has a Vision document entitled *Building On Our Strengths 2019- 2023*: The main aims are identified as follows:

- Ensuring our vulnerable children and adults achieve better outcomes;
- Supporting everyone to reach their full potential;
- Supporting businesses to start, develop and thrive in West Berkshire;
- Developing local infrastructure, including housing, to support and grow the local economy;
- Maintaining a green district;
- Ensuring sustainable services through innovation and partnerships.

4.2 This Autism Strategy will provide a strategic direction and approach in order to realise the above vision and enable the Board to have the potential to check and affect change where possible in order to improve the lives of autistic adults. What will be delivered within each priority is outlined below.

5 Priorities - introduction

5.1 The APB previously developed an autism strategy survey for autistic adults (aged 18 and over) to find out about different aspects of their lives including; school life, finding a job, living arrangements, using local services and other experiences.

5.2 The survey was open between 11 September 2017-10 December 2017 and 99 local residents responded. As a result of the survey, six priority areas were identified which are described below.

6 Priorities

6.1 ***Priority 1: Autistic adults have access to information, advice and guidance***

6.1.1 Why is this important?

Getting access to the right information, advice and guidance is essential so that autistic adults and their families are able to find and access services that can support them. Information available about local support needs to be easily accessible to autistic people as this will support their independence and wider community engagement.

6.1.2 What is the picture in West Berkshire?

Autistic adults require information and support on how to live with autism after their diagnosis and understand what it means. The results from the autism strategy survey found that half of respondents found it hard to find the information they required. Many respondents thought it would be helpful to have information in one place. Almost three-quarters of respondents found information from the internet and half from parents or carers.

6.1.3 This will be achieved by:

- Developing an autism directory/booklet that gives information about autism and lists local services for autistic people - this will be updated annually;
- Continuing to update and maintain relevant information on the West Berkshire Directory;
- Setting up an autism page on the West Berkshire Council Website and work with board members to ensure its kept up to date;
- Working with the local autism diagnostic service to ensure everyone who receives a diagnosis has more information about existing groups/services pre or post diagnosis;
- Raising awareness of the Autism Alert Card;
- Identifying with the support of board members to identify a single identifiable contact point where autistic adults (whether or not in receipt of a statutory services) can get information, signposting and autism-friendly entry points for a wide range of local services.

6.2 ***Priority 2: Autistic adults have had supportive education and training opportunities***

6.2.1 Why is this important?

According to the National Autistic Society some autistic children, teenagers and young people will need additional help and support in education. Fewer than one in four school leavers stay in further or higher education. Of those young people with a special educational need that take A levels or equivalent, 77% go on to higher education employment or training. Many young people with special educational needs including autism experience higher levels of bullying and exclusion while at school.

6.2.2 What is the picture in West Berkshire?

The results from the Autism Strategy Survey showed that some autistic adults felt there was a lack of autism training and awareness among teachers, which could lead them to feeling unsupported. The APB will look to develop links with local colleges in order to develop our understanding of this.

6.2.3 This will be achieved by:

- Mapping what autism awareness training is given to teachers and school staff in West Berkshire;
- Inviting a schools/college representative to sit on the Autism Partnership Board.

6.3 ***Priority 3: Autistic adults are able to find employment or volunteering opportunities and are supported to remain employed.***

6.3.1 Why is this important?

According to the National Autistic Society², not all autistic people are able to work, but, with understanding from their employer and colleagues, and reasonable adjustments to the interview process and workplace, many autistic people can be a real asset to businesses. They found that only 16% of autistic adults are in full-time paid employment, and this figure has remained static since 2007. They also report that over three quarters (77%) of autistic adults who are unemployed say they want to work and 40% have never worked.

Overall, 80% of non-disabled people are in work, but only 47% of disabled people are in work and only 32% of autistic adults are in work. Having paid employment has a range of benefits for the individual in terms of increased independence and confidence. It also benefits wider society as the out-of-work benefits payments could be saved.

There needs to be more done to help support autistic adults to find and stay in work. In addition, employers need information about how to employ and support an autistic person.

6.3.2 What is the picture in West Berkshire?

Our survey found that many autistic adults are not currently working or volunteering and it was felt that their autism could create barriers for them when seeking employment. Typical barriers included; feeling anxious, lacking confidence, experiencing sensory overload, communication difficulties, not managing social interactions, travel to and from work and overall difficulties with the recruitment process.

Some respondents reported that keeping a job had its challenges due to lack of flexible working, employers not understanding their autism, time keeping, not feeling a part of the team and lack of training opportunities.

6.3.3 This will be achieved by:

- Developing employment and structured activities for autistic adults by working with local organisations. We will be looking to the DWP (Department of Work and Pensions) to take a lead in this area;
- Increasing awareness of autism to employers and working with relevant organisations such as Job Centre Plus;
- Development of a hints and tips sheet to be sent to local employers;
- Conducting a survey at West Berkshire Council to learn about the experiences of its autistic employees in order to find out whether the workplace is meeting their specific needs adequately. By conducting such a survey within West Berks we should have examples of what a good employer should do and provide examples of it to share.

6.4 ***Priority 4: Enabling and encouraging Autism Friendly environments***

6.4.1 Why is this important?

Autistic adults experience sensory overload which means that excess noise, flashing lights, background music and beeping noises can make things unbearable. In

² <https://www.autism.org.uk/get-involved/media-centre/news/2016-10-27-employment-gap.aspx> (accessed 11/02/2019)

addition, autistic adults need clear unambiguous communication as they can sometimes find it difficult to understand what other people say.

6.4.2 What is the picture in West Berkshire?

The results from our survey found that less than 20 respondents thought the following services and facilities were autism friendly; community activities, council offices, places of worship, public transport, shops and sports and leisure facilities. Over 30 people thought the following places were autism friendly; museums, theatres and cinemas, and parks and open spaces. Autistic adults gave reasons for why facilities are not autism friendly and most reasons involved issues with sensory processing. For example, many respondents felt that noise from other people, loud music, bright florescent lights and too many visuals, made it hard to access certain facilities along with crowds and queuing.

A lack of awareness among staff was also mentioned, which meant they often felt unsupported or found it difficult for how to ask for help. Almost one in four people that answered our survey said there was things that could be done to make facilities and services more autism friendly. Suggestions included; autism awareness training which would benefit staff and organisations, having a member of staff with greater knowledge of autism to provide support and making this person visible to the autistic person (eg by wearing a badge). Clear signage would help (visuals), along with autism friendly events. Toning down lighting and turning down the volume of music could also make places more autism friendly.

6.4.3 This will be achieved by:

- Raising awareness of initiatives undertaken elsewhere and encouraging them locally;
- Finding good practice about autism friendly shopping experiences (e.g. slower checkouts, dim lights, no music) and present to Newbury Bid at a themed Autism Partnership Board;
- Encouraging organisations to make autism friendly adjustments to the physical environment and practice, provide autism friendly specific sessions/days where possible. Ask board members to look to their own examples of best practice and take a lead locally in realising this priority.

6.5 ***Priority 5: Increase awareness and understanding of autism***

6.5.1 Why is this important?

It will help if more people understand what autism is so that they can understand people they work or come into contact with.

6.5.2 What is the picture in West Berkshire?

There is a general lack of knowledge and awareness of autism, which has an impact on autistic adults in employment as employers in many organisations are often unaware of the characteristics of autism. As mentioned above, if staff had autism awareness training, this would help to create autism friendly environments which would help autistic adults to participate more fully in day-to-day activities, such as shopping and visiting the cinema.

6.5.3 This will be achieved by:

- Developing a range of information stands about autism and coordinate where they will be displayed with the engagement and support of board members;
- Supporting autism training in our different organisations as that enables delegates to understand autistic behaviours and how to deal effectively with them;
- The board promoting an annual event to celebrate national autism day;
- Ensuring local residents, professionals, and employers have access to autism awareness training to learn more about autism.

6.6 ***Priority 6: Autistic adults are given support to understand themselves***

6.6.1 Why is this important?

Autism can affect a person psychologically and physically. Someone with a diagnosis of autism needs help and support to enable a greater sense of self awareness, an understanding their behaviours and how they interact with others. We need to enable autistic adults to learn, understand and accept themselves, and their experiences to help them to realise that what they experience might be different from someone else. This insight might help them to feel more confident and aware of their personal strengths, helping them to lead fulfilling lives.

6.6.2 What is the picture in West Berkshire?

The Autism Survey showed that 49% of our survey respondents were able to find all the information they needed on their diagnosis. They often had to do extensive research themselves to find out how to live with autism post diagnosis and understand what it means for them. Information and support were sought from the internet, family, friends, professionals, and support groups.

6.6.3 This will be achieved by:

- Working in partnership with the West Berkshire libraries service to develop and promote a list of books about autism;
- Working in partnership with our local autism diagnostic service to provide information and support to people pre-autism diagnosis.

7 **Monitoring arrangements**

The APB will meet every three months and they will further define:

- Monitoring arrangements;
- Actions to support priorities - the Board owns the action plan (see Appendix), which is a working document and this subject to amendment;
- Measures of success.

8 **Funding**

- 8.1 The APB has access to a non-recurrent Autism Innovation Capital Grant which can be used for any projects that make local areas more autism-friendly. This is capital funding which could be spent things like improving buildings, purchasing books or buying autism friendly technology and equipment.

- 8.2 It will be expected that any funding proposal submitted to the APB is fully costed. Applications for funding will be presented on a completed funding form so that proposals for the use of the grant can be submitted in advance of a board meeting and it will include the above criteria.
- 8.3 Application forms to apply for the Autism Innovation Capital Grant are available at: ccenquiries@westberks.gov.uk
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Appendix – Action Plan

Priority	Action	Owner	Measure
PRIORITY 1: Autistic adults have access to information, advice and guidance	Develop an autism service directory/booklet that gives information about autism and lists local services for autistic people	Public Health	Devon booklet has been adapted, with West Berkshire Services included and all links and information checked and corrected
		Autism Partnership Board	Booklet has been printed and made available at a minimum of 2 events
		Autism Partnership Board	Booklet has been widely promoted
	Set up an autism web page on West Berkshire Council Website	Adult Social Care	Website set up, friendly url promoted,
	Work with the local autism diagnostic service to ensure everyone who receives a diagnosis has more information about existing groups/services post diagnosis	Berkshire Healthcare Foundation Trust and Autism Partnership Board	Number of people diagnosed with Autism, Number of people on waiting list receiving autism service directory
	Raise awareness of the Autism Alert Card	Autism Partnership Board	Information about the autism alert card on Website, in directory and on stands/leaflet
	Identify a single identifiable contact point where autistic adults (whether or not in receipt of a statutory services) can get information, signposting and autism-friendly entry points for a wide range of local services	Adult Social Care	
PRIORITY 2: Autistic adults have had supportive education and training opportunities	Map what autism awareness training is given to teachers and school staff in West Berkshire	Public Health and Autism Partnership Board	Schools survey has been developed, any training needs have been identified and recommendations sent to Service Manager
	Invite a schools representative to sit on the autism partnership board	Autism Partnership Board	Representative is a member of the autism partnership board
PRIORITY 3: Autistic adults are able to find employment or volunteering opportunities and are supported to remain employed.	Developing employment and structured activities for autistic adults by working with local organisations	Autism Partnership Board	Themed Autism Partnership Board held to develop ideas and sharing good practice from elsewhere
	Increase awareness of autism to employers and work with relevant	Autism Partnership Board	Twice year training, course and banner or leaflet developed

Priority	Action	Owner	Measure
	organisations such as Job Centre Plus		
	Development of a hints and tips sheet to be sent to local employers	Autism Partnership Board	Leaflet designed and printed, list of employers identified, leaflet sent to local employers
	Conduct survey at West Berkshire Council to learn about the experiences of its autistic employees in order to find out whether the workplace is meeting their specific needs adequately	Adult Social Care and Public Health	Questions designed, permission sought from HR, sign off from adult social care SMT, questionnaire circulated to staff, interviews conducted with staff members
PRIORITY 4: Enabling and encouraging Autism Friendly environments	Raising awareness of initiatives undertaken elsewhere and encouraging them locally: Find good practice about slower lanes / quieter hours, changing lighting, turning down volume of music etc. and present to Newbury Bid at a themed Autism Partnership Board	Autism Partnership Board	At least 5 examples of good practice identified, Newbury BID invited to a themed board in 2019/20
	Encourage organisations to make autism friendly adjustments to the physical environment and practice, provide autism friendly specific sessions/days where possible	Autism Partnership Board	Promote the National Autistic Society's "Autism Hour" to different shops in West Berkshire and encourage sign up, letter developed and sent (October 2019)
PRIORITY 5: Increase awareness and understanding of autism	Develop a range of information stands/roll up banners and coordinate where they will be displayed	Autism Partnership Board	At least 2 stands designed and printed, list of locations identified, feedback on stands obtained
	Support autism training that enables delegates to understand autistic behaviours and how to deal effectively with them	Autism Pride	Twice yearly course held
	Hold an annual event to celebrate national autism day (2 nd April each year)	Autism Partnership Board	At least 1 event per year
	Ensure local residents, professionals, and employers have	Autism Partnership Board	At least 2 training events per year

Priority	Action	Owner	Measure
	access to autism awareness training to learn more about autism		
PRIORITY 6: Autistic adults are given support to understand themselves	Work in partnership with the West Berkshire libraries service to develop and promote a list of books about autism	Public Health and Autism Partnership Board	Autism booklist developed and published, number of autism books loaned 6 monthly figures
	Work in partnership with our local autism diagnostic service to provide information and support to people pre-autism diagnosis	Autism Pride, BHFT and Autism Partnership Board	Twice yearly course for people waiting for an autism diagnosis, number of autism service directories given to people on waiting list

Progress on the Action Plan will be checked at every other board meeting. A number of the initiatives noted above have now started and the board's role will be monitoring progress and considering how a response to the 6 priorities might need to develop over the 3 years of the strategy.

ⁱ Autism Refresh Available at:
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/696667/think-autism-strategy-governance-refresh.pdf <accessed 30/10/2018>