

# Joint commissioning strategy for adults with autism

2015 - 2020



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# A summary of this strategy

A commissioning strategy is a plan which sets out how support and services for people with autism will be developed in the local area. The Joint Commissioning Strategy for Adults with Autism in Bracknell Forest has been refreshed, to listen to the views of people with autism and show what has changed over the last three years.

A consultation started on 1st July and finished on September 30th 2014. As part of the consultation people were asked to comment on how important they believed certain issues were over the next 5 years. These issues were:

- Access to specialist health services
- Social inclusion (Being part of the community)
- Help with finding work and employment
- Help with finding suitable housing
- Support for parents and carers of people with autism
- Being able to access health and / or social care staff
- Having information about what support and services are available

The Government strategy “Fulfilling and Rewarding Lives” listed 7 positive outcomes that would show whether progress has been made to improve support for people with autism. These were:

- Adults with autism achieve better health outcomes.
- Adults with autism are included and economically active.
- Adults with autism are living in accommodation that meets their needs.
- Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets.
- Adults with autism are no longer managed inappropriately in the criminal justice system.
- Adults with autism, their families and carers are satisfied with local services.
- Adults with autism are involved with service planning.

These outcomes will be put into an action plan with the priorities from the consultation. Priorities around information and social inclusion are not covered by the outcomes listed above, but will still be part of the action plan. Results from the consultation show that there is work to do, particularly around Housing.

The Council and the Clinical Commissioning Group, through the work of the Autism Partnership Board, will be looking in detail at the consultation comments and developing the Action Plan by April 2015. This will identify things that could be done under each of the headings above. It will ensure that the comments and information from the public consultation will also form part of the Action Plan.

# Introduction

If you need help to understand the language in this document, there is a “Glossary of terms” on Page 22 to explain what some of the words and terms mean. Words in this document that are explained in the glossary are underlined.

In 2010 the Government wrote a plan for people with autism called “Fulfilling and Rewarding Lives”. In the plan they ask that “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.”<sup>1</sup>

Since that time, there have been changes to health and social care services brought about by new laws. The most important of these laws are the Health and Social Care Act 2012 and the Care Act 2014. These laws have changed the way that health and social care services work together. There has also been an important update to the Government plan for people with autism. The updated plan was written in 2014. It is called the “Think Autism strategy 2014”.

There are other local plans that are important because they help the Council and Clinical Commissioning Group to say what needs to happen to improve the health and wellbeing of local people, including people with autism, based on the particular health problems that are common in Bracknell Forest. One of these plans is called the Health and Wellbeing Strategy. This makes clear what the most important things are that need to be achieved (outcomes) when organisations provide or pay for (commission) services.

The Health and Wellbeing Strategy says that people with autism cannot always access the good quality of support and services that other people do. This might be for a number of reasons, but it is important to make sure that everybody can live the lives they want to. This includes people with autism.

Because of the new laws and plans that have happened over the last few years, the Council needs to update the first “Adult Autism Strategy for Bracknell Forest”, which was written in 2009 when the Autism Act became law.

This new commissioning strategy has been written after consulting with people in Bracknell Forest, to find out what they think the most important priorities are and what needs to be done over the next 5 years.

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<sup>1</sup> “Fulfilling and rewarding lives” The strategy for adults with autism in England (2010) [http://web.archive.org/20130107105354/http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_113405.pdf](http://web.archive.org/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113405.pdf)

## What is a Commissioning Strategy?

A commissioning strategy is a plan which sets out how support and services for people with autism will be developed in the local area. There are a number of ways that help the Council to help understand what is important for people with autism in Bracknell Forest. These are by:

- Talking to people with autism in Bracknell Forest, their families and people important to them, to ask them what they think the highest priorities are and what they think needs to be done over the next 5 years.

Also by:

- Looking at legislation (laws) and national guidance from the Government.
- Looking at the needs of the people in the local area and thinking about how these are likely to change in the future.
- Looking at the support and services that are available in the area at the moment and thinking about how well these are working for people with autism or whether they could be made to work better.
- Looking at what is happening in other areas of the country to see how the services in Bracknell Forest compare.

All of this information has helped the Council and the Clinical Commissioning Group to write this new 5 year Commissioning Strategy and to develop plans to make sure that people with autism living in Bracknell Forest are able to live fulfilling and rewarding lives.



## The National and Local Context

### The first national autism strategy

In 2010 the Government published the first national autism strategy called “Fulfilling and Rewarding Lives”<sup>1</sup>. The five priorities were;

- Increasing awareness and understanding of autism among frontline workers.
- Developing a clear, consistent pathway for diagnosis of autism in every area, which is followed by an offer of a personalised needs assessment.
- Improving access for adults with autism to the services and support they need to live independently within the community.
- Focusing on helping adults with autism into work, by improving access to information, advice and guidance, ensuring adults with autism gain from wider plans to improve opportunities in the workforce, and providing effective support through the benefits system.
- Enabling local partners to plan and develop relevant services for adults with autism to meet identified needs and priorities, learning from what already works and involving adults with autism in developing those services where possible.

Since then, the Government has written more plans and given more guidance to help support adults with autism; details of which can be found on the Department of Health website.<sup>2</sup> The two most important of these are the ‘Think Autism’ strategy which was published in 2014 and The Care Act (2014).

### The 2014 strategy – “Think Autism”

This new strategy sets out important areas or priorities from Fulfilling and Rewarding Lives. But it makes it clear that there should be much more work across the different Government departments, to improve outcomes for people with autism. The new strategy also has 15 priority challenges for action which had been put forward by people with autism. These are grouped under three areas. If the new strategy works, people with autism should be able to say:

- I am an equal part of the local community
- I am able to have the right support at the right time
- I am able to develop my own skills and independence and work to the best of my ability.

These 15 ‘Priority Challenges’ that were the most important to people with autism, or practitioners supporting people with autism, are:-

<sup>2</sup> <https://www.gov.uk/government/news/fulfilling-and-rewarding-lives-the-strategy-for-adults-with-autism-in-england>

## An equal part of my local community

I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.

I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.

I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low level support.

I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism.

I want to be safe in my community and free from the risk of discrimination, hate crime and abuse.

I want to be seen as me and for my gender, sexual orientation and race to be taken into account.

## The right support at the right time during my lifetime

I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.

I want autism to be included in local strategic needs assessments so that person centred local health, care and support services, based on good information about local needs, is available for people with autism.

I want staff in health and social care services to understand that I have autism and how this affects me.

I want to know that my family can get help and support when they need it.

I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.

I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.

If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.

## Developing my skills and independence and working to the best of my ability

I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.

I want support to get a job and support from my employer to help me keep it.

As well as the 15 Priority Challenges, the new strategy also sets out three new key proposals. These are to develop:

## Autism Aware Communities

These were launched in 2014, based on the “dementia friendly communities programme”. This programme says that in dementia friendly communities: people will be aware of and understand more about dementia; people with dementia and their carers will be encouraged to seek help and support; and people with dementia will feel included in their community, be more independent and have more choice and control over their lives. The Prime Minister’s challenge on dementia also includes an ambition to create communities that are working to help people live well with dementia. The Government want to achieve the same outcomes for people with autism.

## Autism Innovation Fund

This will be a total of £1.2 million funding nationally. There were four areas available for funding:

- Advice and information
- Gaining and growing skills for independence
- Early intervention and crisis prevention
- Employment, particularly involving the use of apprenticeships

## Better data collection, and more joined up advice and information services

This includes a new way of social care staff recording if a person has autism as well as a promise to make it easier for people with autism to find information online about how their local council is performing. This should be ready by March 2015.

## The Care Act 2014

The Care Act 2014 is a new law, placing a series of new duties and responsibilities about how care and support for adults is to happen. Many people currently pay for their own care and support but in the future there will be a limit to how much people pay for their care if it is agreed by the Council as an “eligible” need. This limit is called the “cap on care costs” or “cap on care”, which it is expected to become law from 1st April 2016.

The Care Act also gives increased rights for Carers to receive support from Councils. It introduces a duty on them to meet eligible Carers’ support needs. Carers will no longer have to show they provide substantial care and on a regular basis in order to request a Carers assessment.

The Act also makes it important that the Council must think about how they can help keep people well and prevent people’s needs from becoming more serious. This applies to everybody living in the area, not just those who currently receive support from the Council. This should help to improve outcomes for adults with autism.

This means that:

- People who provide services must think about how to make life better for people with autism.
- The Government will have the same rules for everyone about who can get care and support.
- Everyone should have better information and advice about being healthy and preventing ill health.
- People will have more control over their lives and choice over how their needs are met.
- Family carers will get better support.
- Health services and social services must work together so that people can be supported better.



## Review of the last three years

When Bracknell Forest’s first Adult Autism Strategy was agreed, an “action plan” was written which showed what the Council said it was going to do to help raise awareness, improve access to services, and help with other partners to plan and develop services for people with autism. This new strategy gives the Council the opportunity to look at what has happened over the last three years.

The action plan was based on the question of how to build ‘Fulfilling and rewarding lives’. The table below shows the areas that local people with autism wanted the Council, and its partners, through a group called the Autism Partnership Board, to focus on and what has been done in each area.

Below are some key successes delivered by the Autism Partnership Board. The full action plan is available through the Bracknell Forest Council website.

Outcome 1: Increase awareness and understanding of ASD among frontline professionals	
Action	What happened in Bracknell Forest
Public autism awareness	This started with the launch of the Joint Commissioning Strategy and Autism Alert Card as well as a programme of awareness delivered by the Berkshire Autistic Society over the last three years. Additionally, an e-learning module was developed for Council staff but made available to the public after good feedback. Training was matched to worker’s needs and delivered council wide. Specialist training was delivered to the <u>Community Autism Team</u> .
Autism team to identify areas of learning and development needed to provide on-going person centred support to adults with ASD	<u>Community Autism Team</u> have had <u>Spectrum Star</u> training. This is a person-centred, outcome based planning tool which focuses on achieving the greatest independence possible.
Promote awareness of Autism within the <u>Criminal Justice System</u> .	Berkshire Autistic Society has worked with the <u>Criminal Justice System</u> locally to build links and develop training. The <u>Community Autism Team</u> has worked closely with the probation service, the police and the prison service to promote awareness and to achieve the best outcomes for the people the team supports.

Outcome 2: Developing a clear, consistent pathway for diagnosis in every area which is followed by the offer of a personalised needs assessment	
Action	What happened in Bracknell Forest
When someone is diagnosed with autism, the health worker advises the person and/or their carer that they have a right to have their needs assessed by Adult Social Care and Health	A working relationship now exists between the <u>Community Autism Team</u> and the medical Assessment Team so that all people who have been assessed are offered the option of being referred to Social Care when they receive their diagnosis.
Improve access to Psychological therapies involving Mental Health services	People with autism can now be referred directly to Talking Therapies by the <u>Community Autism Team</u> .



Outcome 3: Improving access to services	
Action	What happened in Bracknell Forest
Based on analysis of the persons' needs, appropriate services need to be identified that can match and meet the needs of people with autism locally.	A <u>Floating Support</u> service started in 2012 to try to provide a quicker and responsive support for people with autism. The pilot proved a success and the Floating Support service has remained in place.
All adults with autism and their carers who meet the Social Care <u>eligibility</u> criteria have individual budgets and their carers are offered an assessment.	All people who meet the Social Care <u>eligibility</u> criteria have individual budgets and their carers have been offered an assessment.
Promote the work of the Autism Team in the local community and also to other teams and partner agencies	There is an information leaflet and website publishing details of services available to all people with ASD from the <u>Community Autism Team</u> . BAS (the Berkshire Autistic Society) have also held events raising awareness about Autism which includes the work of the <u>Community Autism Team</u> .
Provide accessible information about support and services available, including for people not eligible for public funded services.	Autism leaflet and updated website, publishing details of services is available to all people with Autism.
Develop advocacy strategy and support services that fit around the needs of people with autism and their carers	People with autism and their carers are supported by Just Advocacy, Pohwer (IMCA), Mencap And Berkshire Autistic Society. There is also a self-advocacy group for people with autism.
Develop <u>social inclusion</u> opportunities and reduce <u>social isolation</u> .	There are a number of social groups in operation and a number of others being developed, in partnership with various agencies.
Provide a supported employment service for adults with autism who need support finding employment.	<u>Breakthrough</u> are now supporting people with autism in supported employment. There are skills workshops being offered – to improve independence and confidence when job seeking and accessing employment opportunities. <u>Breakthrough</u> is working with employers around reasonable adjustments.
Implementation of the Alert Card for people with autism.	This has been fully implemented.
Carry out a housing needs analysis for young people and adults with autism and work with colleagues in housing and other partners to meet local need	Various strategies are in place to meet the needs of individuals with Autism. This includes provision from Registered Social Landlords and properties purchased by the Council with grant money.

Outcome 4: Helping adults with Autism into work	
Action	What happened in Bracknell Forest
Autism training for Breakthrough staff	All staff working for <u>Breakthrough</u> have attending Autism Training and work closely with the <u>Community Autism Team</u> .
Breakthrough to develop employment plan specific to people with ASD	This plan has been developed and is in place.
Delivery of awareness sessions / training to local employers	Offer has been made to various employers within Bracknell. Training has been delivered to the Job Centre, A4E and Maximus.
Work with education providers, e.g. colleges, to identify further education training opportunities and apprenticeships meet and support needs of people ASD	Mentoring scheme delivered at Bracknell & Wokingham College. The aim was to assist students with Autism to manage more effectively whilst at college. Tutors were also in attendance at the training.

Outcome 5 : Enabling local partners to plan and develop appropriate services for adults with autism to meet identified needs and priorities	
Action	What happened in Bracknell Forest
Develop and maintain a database / record of people with autism and look at how to support them on an on-going basis.	A list of people with autism that are supported, including those Approaching Adulthood, is kept by the <u>Community Autism Team</u> . Information from this spread sheet has been used to develop support and services.
Help to support people with autism to set up self help groups.	A Self-Advocacy group is in place supported by Just Advocacy. The Self-Advocacy group was one of only a few groups regionally who were asked to contribute to the National Autistic Society "Push For Action" campaign.
Carers support in place for Carers	Carers are offered Carers Assessments and support from MENCAP or Just Advocacy
Support the function of the Autism Partnership Board: governance, monitoring and supporting delivery of the requirements of the National Autism Strategy in partnership	Fully functioning partnership board in place. The partnership board was fully active within the review of the current strategy.
Carers support in place for Carers	Carers are offered carers assessments from Berkshire Carers Service and the Community Autism Team, in addition support is offered to all carers from Just Advocacy and Mencap.
On-going partnership and engagement work with the Police and Criminal Justice system.	The Community Autism Team continue to work with probation, police and the criminal justice system.

## Needs Analysis

A needs analysis is a way of working out what the needs of a particular group of people are, so that the right support can be planned. This section looks at the needs analysis that was done for this autism strategy.

### Expected Local Need

This section looks at the population as a whole and based on statistics and other information, it can then be worked out how many people there are in the Bracknell Forest area who are likely to have autism.

National research estimates that 1% of the population has autism. PANSI (Projecting Adult Needs and Service Information) and POPPI (Projecting Older People Population Information System) offer numbers to help the Council to try to understand how many people, of various age groups, would be expected to have autism.

	2015	2016	2017	2018	2020	2025	2030
People aged 18-24	93	93	93	91	89	91	101
People aged 25-34	166	166	168	171	173	173	169
People aged 35-44	175	173	171	171	171	178	186
People aged 45-54	182	184	184	184	180	172	171
People aged 55-64	134	136	142	146	156	168	166
Total aged 18-64	749	752	757	763	769	783	792
People aged 65-74	87	93	95	97	101	111	129
People aged 75 and over	66	66	68	70	76	96	114
Total aged 65 and over	153	159	163	167	177	207	243

People aged 18-64 predicted to have autistic spectrum disorders, by age, projected to 2030 (Source: pansi.org.uk) and people aged 65 and over predicted to have autistic spectrum disorders, by age, projected to 2030 (Source: poppi.org.uk)

#### Other key factors:

##### Ethnicity

The number of people with autism is not thought to be higher in any specific ethnic group but the diversity of the population is expected to widen and this will be a factor to take into account when planning culturally sensitive support.

##### Gender

The number of people with autism is higher in males. National research currently shows that 60% of people with autism are male; however this percentage is likely to become lower as diagnosis rates improve for females. For Bracknell Forest this would suggest 541 males and 451 females over 18 years.

##### Religion / Belief

Religious belief is not a factor in terms of the number of people with autism but should be taken into account in ensuring culturally appropriate support.

## Local Need

- There are currently 84 people supported by the Community Autism Team known to have autism.
- Other people in Bracknell Forest with autism could be receiving support from other Adult Social Care Teams but the main reason for needing support could be a physical or mental illness.
- Other people may not yet have been diagnosed as having autism.
- Other people may be eligible for support but not receiving it for various reasons, for example they have chosen not to ask for it.

## Young People Approaching Adulthood

The Community Autism Team supports young people with a single diagnosis of autism when they are approaching adulthood. The main way this happens is through an Approaching Adulthood panel, where young people with autism are likely to need support when they are 18. The Community Autism Team aims to meet people when they are in their final years of school and attend school reviews to make relationships with the young person and their families or carers.

Autism is one of the areas the current Bracknell Forest Council Approaching Adulthood Strategy looks at to help the Council plan for meeting the needs of young adults with autism.

The team also attends the Participation Group where young people who are not in employment or education are discussed.

There are 48 young people between 16 and 18 years already receiving support from Children, Young People and Learning (CYPL) who are known to the Autism Team and who are expected to be eligible for adult social care support when they become 18 years old.



## Consultation

This strategy was developed after a 13 week consultation had taken place for people with autism living in Bracknell Forest, their families and people who support them. The consultation started on 1st July and ran until 30th September 2014. People took part by attending events, responding to questionnaires, taking part in one-to-one interviews and by giving online feedback.

The majority of people who took part in the consultations, (over 85%), were people with autism or their carers.

The Autism Partnership Board also took part.

In terms of the age and backgrounds of the people who took part, the consultation showed:

- There was a fairly even split between genders, with 53% males and 47% females.
- The majority of people who took part were between 18 and 25 years old, with 36 to 45 being the next highest age category.
- 48% of people who answered the question, said they were Christian with 34% saying they had no religion or belief.
- The majority of responses came from people saying they were as “White: English/Welsh/Scottish/Northern Irish/British”.
- 53% of the people who took part felt that they “have a health problem or disability which has lasted, or is expected to last, at least 12 months” and of these people, 68% said that they felt that this limited their day-to-day activities.

The consultation questionnaire asked people about:

- The support that they had used in the last three years,
- What they saw as being the most important priorities and
- What they thought about the priority challenges set out in the Government strategy “Think Autism”.

People who took part in the consultation were asked questions about their experience of using the different services such as Social Care, Housing and Health Services.

People were also asked how **Hard** or how **Easy** they had found it using that particular service and how **Aware** they were of what that service could provide for them.

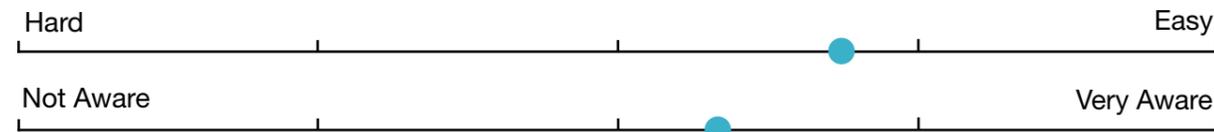
The answers that people gave are shown in the following tables. These are set out on a service by service basis (Social Care, Housing, Employment and Volunteering, Health Services Specialist Health Services and the Voluntary and Community Sector.)

Each table shows a circle which is the average ratings for all of the responses received. The closer the circle is to Easy or Very Aware, the better people felt about the service or support. The closer the circle is to Hard or Not Aware, the worse people felt about the service or support.

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## Social Care

58% of respondents had accessed Social Care support.



**What you said:** The majority of respondents found Social Care both easy to make contact with and were generally very aware of autism. Those who expressed dissatisfaction commented on having difficulty with support in a crisis. Compared against other services, Social Care was the third best in terms of access and awareness ratings.

## Housing

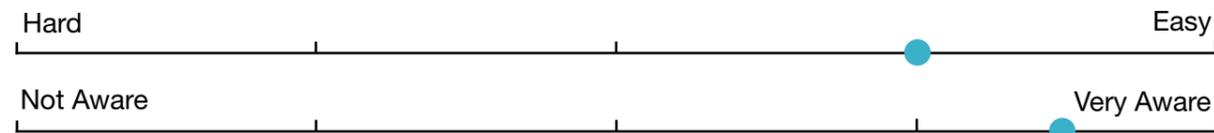
25% of respondents had accessed Housing support.



**What you said:** Of the six areas consulted on, housing scored the worst in terms of access and awareness. A range of problems were highlighted including waiting times for housing and supply of suitable housing to meet the needs of people with autism. These are issues that don't only affect people with autism, but that also affect other people looking for housing too.

## Employment and Volunteering

71% of respondents had accessed Employment and Volunteering support.



**What you said:** Employment support was reported as easy to access and generally very autism aware. It was the second highest rated of all the support types. Positive feedback centred on Breakthrough and praised the efforts of the team in supporting both employment and volunteering opportunities.

## Health Services

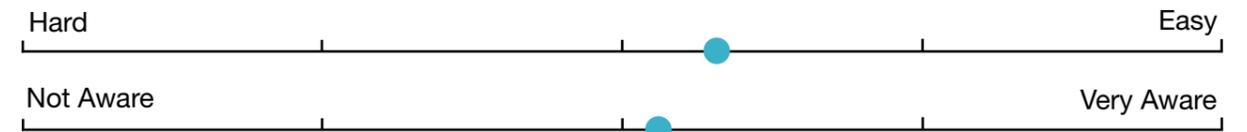
50% of respondents had accessed Health Services support.



**What you said:** Many respondents were happy with their experience of access and awareness in health services. Some people had faced problems with diagnosis and referral, as well as not being able to access the right services. Access and awareness for health services was rated only just below social care.

## Specialist Health Services

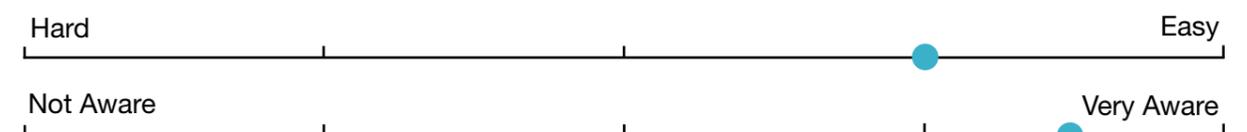
33% of respondents had accessed Specialist Health Services.



**What you said:** The main issues people reported on were about Occupational Therapy and Psychological support not being present or accessible. Access and awareness for specialist health services was rated as being second to the lowest (worst) of the six service areas.

## Voluntary and Community Sector

50% of respondents had accessed Voluntary and Community Sector support.



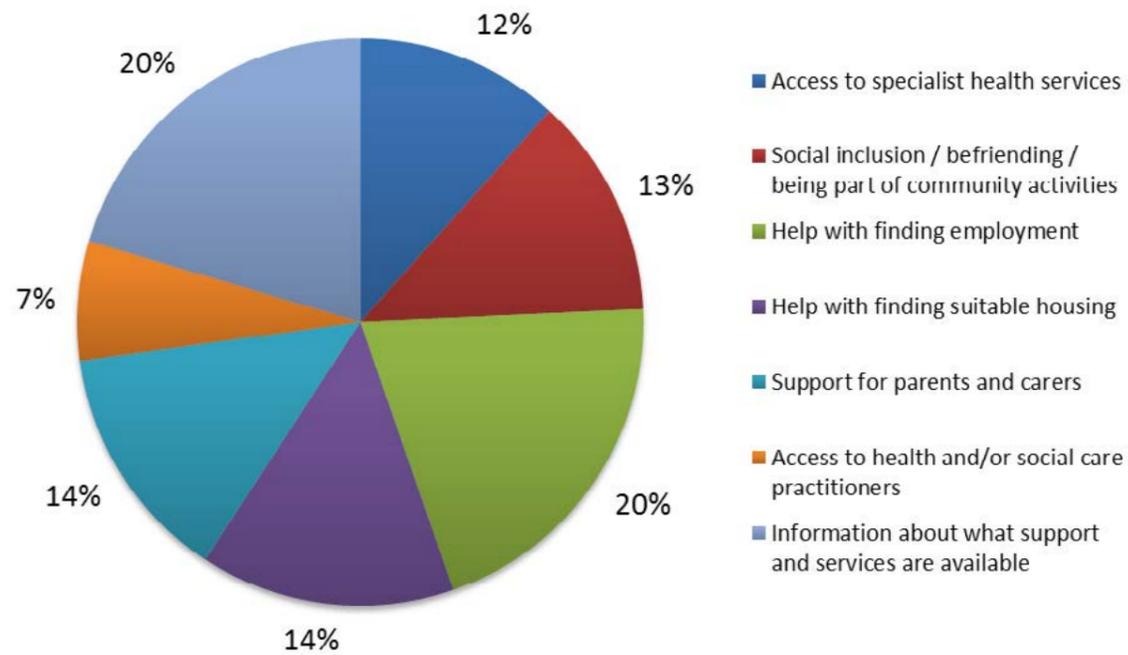
**What you said:** Access and awareness for voluntary and community sector support was rated the highest, with most people having very good experiences. None of the people asked had struggled with, or had issues with, services or support provided. Berkshire Autistic Society, Mencap and JustAdvocacy were all equally praised in the responses to these questions. There was little feedback about more general organisations within the voluntary and community sector.

# Consultation Priorities

The number of adults with autism supported by the Council has doubled in the last year and is expected to continue to rise. It is therefore very important that the Council provides the right support at the right time to make best use of existing resources.

As part of the consultation people were asked to comment on how important they believed certain issues were over the next 5 years. These issues were:

- Access to specialist health services
- Social inclusion (Being part of the community)
- Help with finding work and employment
- Help with finding suitable housing
- Support for parents and carers of people with autism
- Being able to access health and / or social care staff
- Having information about what support and services are available



The responses, shown in the chart above, show that all seven areas put forward are important to people with autism and their families and carers. This is shown in the comments that people wrote.

People were also asked to think about whether they agreed with the 15 Priority Challenges set out in the new Government strategy (“Think Autism”). Those people who responded believed that the highest priorities should be focussed on were:

- Finding employment and
- Accessing information and advice on the services available

# Next Steps

The Government strategy “Fulfilling and Rewarding Lives” listed 7 positive outcomes (National priorities) that would show whether progress has been made to improve support for people with autism. These were:

- Adults with autism achieve better health outcomes.
- Adults with autism are included and economically active.
- Adults with autism are living in accommodation that meets their needs.
- Adults with autism are benefiting from the personalisation agenda in health and social care, and can access personal budgets.
- Adults with autism are no longer managed inappropriately in the criminal justice system.
- Adults with autism, their families and carers are satisfied with local services.
- Adults with autism are involved with service planning.

These outcomes will be achieved through an action plan with the priorities from the consultation. Priorities around information and social inclusion are not covered by the outcomes listed above, but will still be part of the action plan. Results from the consultation show that there is work to do, particularly around Housing.

The Council and the Clinical Commissioning Group have worked through the last two National Self-Assessments to check how well progress is being delivered against the national strategy. This has also helped to set some of the priorities, particularly in areas such as access to specialist health services, such as occupational therapy and psychology support, which were highlighted at the Health and Wellbeing Board after the Self-Assessment in 2013.

The Council and the Clinical Commissioning Group, through the work of the Autism Partnership Board, will be looking in detail at the consultation comments and developing the Action Plan during April 2015. This will identify things that could be done under each of the headings above. It will ensure that the comments and information from the public consultation will also form part of the action plan.

# Glossary of Terms

Words	What the Words Mean
Action Plan	This is a document that shows what the Council, Clinical Commissioning Group and partner organisations, through the Autism Partnership Board, will do to make support and services better for people with autism.
Adaptations	Changes to buildings and equipment to make it easier for people with disabilities to use.
Advocate	Someone to help to get your voice heard. Having help to say what you think and what is important to you.
ASC	Autistic Spectrum Condition, see Autism.
ASD	Autistic Spectrum Disorder, see Autism.
Autism	Autism is used to reflect all autistic spectrum conditions. More information can be found on autism in Annex 1.
Autism Partnership Board	The Bracknell Forest Autism Partnership Board meets every three months and has two chairs, one with autism. The board is there to lead in local planning to support the local implementation of the National Autism Strategy.
BAS	Berkshire Autistic Society
Best Interest Decision	This is when other people decide what is best for you when you cannot make the decision for yourself.
Bracknell Forest Voluntary Action (BFVA)	Please see Involve.
Breakthrough	A service that helps you find and get a job.
Clinical Commissioning Group	Groups of doctors who work together to buy the health services that are needed.
Commissioning Strategy	This is a five year plan about how services need to be changed to make sure people continue to get the support they need in the future.
Community Autism Team	This is a team of social care staff, working for the Council, who can provide support and assessment of needs to people with autism. For more information on the team please see <a href="http://www.bracknell-forest.gov.uk/autismteam">http://www.bracknell-forest.gov.uk/autismteam</a> , call 01344 354466 or e-mail <a href="mailto:autism@bracknell-forest.gov.uk">autism@bracknell-forest.gov.uk</a> .
Complex Needs	Having lots of different problems or problems that are difficult to help people with.
Consultation Period	The time that the Council and Clinical Commissioning Group will be asking questions.
Consulting / Consultation	Asking for people's opinions.
Criminal Justice System	This includes the police, probation, courts and other services who are responsible for the law being upheld.
Diagnosis	Where an expert judges that you have a condition or disorder.
Dyslexia	Difficulty with reading and writing caused by a neurological disorder

Dyspraxia	A disorder of the nervous system which prevents a person from performing tasks or movements when asked to even though they understand the request and are willing to perform the task
Eligible / Eligibility	This is whether someone meets the right criteria to be provided certain types of support.
Ethnicity	Relating to or characteristic of a group of people having racial, religious, linguistic or other traits in common
Floating Support Service	This is support that is provided as part of a Person Centred Plan which is always changing depending on how the person supported uses or needs the service.
Government	The people who make the laws.
GP	Your family doctor.
Hate and Mate Crime	These are things that are against the law. Hate crime is when a person does something wrong because they do not like you. Mate crime is when a friend or someone you know does something wrong.
Health Service	Help you get from services such as doctors, hospitals, dentists and opticians. This is to help you stay healthy and make you feel better when you are ill.
Health and Social Services Outcomes Frameworks	The measures to check that support has made a good difference to someone's life.
Human Rights	Your human rights are <ul style="list-style-type: none"> <li>• the right to life</li> <li>• the right not to be treated badly or punished in a cruel way</li> <li>• the right to freedom</li> <li>• the right to a fair trial in court if the police think you have broken the law</li> <li>• the right to respect for your own private life</li> <li>• people should respect your family life.</li> </ul>
Legislation	Law.
Mentor	Adviser.
MH	Mental Health.
NAS	National Autistic Society
National Health Service	This is the health service that is all over the country.
Needs Analysis	A report which details the needs and extent of a population
Neglect	Not helping people when they need it.
NICE	National Institute for Health and Clinical Excellence
Outcomes	The difference that support makes to someone's life.
Partnership Board	The Government asked every council to set up a Partnership Board. This is to make sure people work together to make the lives of people with autism.
Person Centred Plan	This is a plan to say how you want to live your life. The plan says what your dreams and wishes are as well.
Personal Budget	An amount of money that is given to a person to plan and buy the support they need.
Population	People in a defined area.
Prevalence	Existing or occurring

Principles	The moral or reason for doing something.
Priorities	Things that are important to you.
Recommendations	A suggestion about what is a good and sensible thing to do.
Respite	Time away from a caring.
Responsibilities	Things that you have to do.
Resources	Time or money.
Rights	Things that you should be allowed to do.
Self-Assessment	Using a form to look at what you are doing and making sure that you are doing the right things.
Social Inclusion	The provision of rights to all individuals and groups in society such as employment, housing, social care, education and training etc.
Social Isolation	Social isolation means not having contact with people.
Social Services	Support you get from the council to help you live the life you want.
Spectrum Star	The Spectrum Star is a Person Centred Plan for people with autism which focuses on the following nine areas; 1. Physical health 2. Living skills & Self-Care 3. Well-being & self-esteem 4. Sensory differences 5. Communication 6. Social skills 7. Relationships 8. Socially responsible behaviour 9. Time and activities
Support Plan	This is a plan about what support you want to help you live the life you want.
Tenancies	What you and your landlord agree to do when you are living in a house and pay rent.



# Annex 1 – Autism Explained

## What is Autism?

Autism is the name for a condition which affects how people with the condition deal with other people and how to understand the world around them. The government estimates that around 1 in every 100 people have autism.

If a person has autism, it is for life. People with autism are all different but usually have problems in 3 main areas. These are:

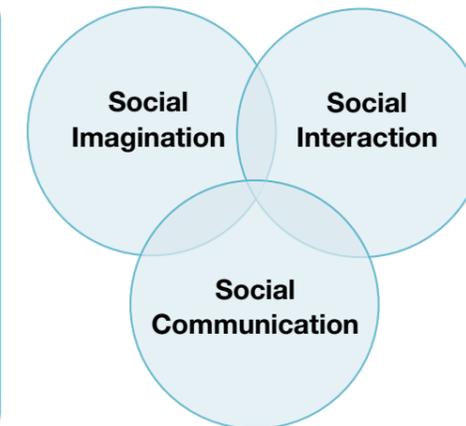
- Talking to other people to say what you need and how you feel
- Meeting new friends and making new friends
- Understanding what other people are thinking

These 3 main areas are sometimes known as the “Triad of Impairments” and the diagram below gives more detail on this.

## The Triad Impairments

People with autism can have difficulty;

- Understanding ideas,
- predicting what other people will do or think,
- with new or unexpected situations or planning for the future,
- thinking outside of their routines,
- understanding other people’s feelings.



People with autism may not;

- be able to understand other people’s feelings,
- understand social rules e.g. they can speak about inappropriate subjects or appear very blunt,
- be able to express / understand their own feelings.

People with autism can have difficulties with verbal and non verbal communication. This could include the following:

- Understanding people’s facial expressions and tone of voice;
- Sarcasm or jokes;
- Taking things people say very literally

Some people with autism cannot communicate verbally, but others who may have good language skills may not understand the social rules associated with conversation. So they might speak for too long or not understand that you need to take turns in a conversation.

Autism is known as a “spectrum condition” which means that the condition affects them differently, so that some people with autism are able to live relatively independent lives but others may need more specialist support through their life.

There is a form of autism called Asperger syndrome. People with Asperger syndrome are often described as having above average intelligence. They may have fewer problems with speech but may still have difficulties understanding language and what people are thinking and saying.

On its own, autism is not a learning disability or a mental health condition, although some people with autism may also have a learning disability or mental health condition.

There are three other areas that may be important to people with autism:

- **Routines and special interests**

**Routines:** People with autism may use routines very carefully and in a regular, particular sequence. This may help them make sense of a world that can otherwise appear to them to be very unpredictable.

**Special Interests:** Some people with autism can develop very deep interests in specialist areas and may be very knowledgeable in these areas. This could be for example bird watching or characters from Television.

- **Sensory sensitivity**

People on the spectrum may experience over sensitivity (sometimes referred to as hypersensitivity) or under sensitivity (hypo-sensitive) in relation to any of the 7 senses; vision, hearing, taste, smell, touch, body awareness and movement awareness.

**Examples of hypersensitivity:** People can find it impossible to block out background noise, deal with bright colours or the seams on their clothing.

**Examples of hypo-sensitivity:** Some people will rock back and forth or poke their eyes in order to create a sensation. Difficulties with body awareness can lead to problems in navigating rooms full of obstacles, such as furniture and people, and with fine motor skills.

- **Mental health – some information from researchers**

Researchers have found evidence that people with autism or Asperger syndrome may be particularly vulnerable to mental health problems such as anxiety and depression, especially in late adolescence and early adult life<sup>3</sup>. Other research<sup>4</sup> with a group of people with Asperger syndrome showed that 65% of the group also had some symptoms of psychiatric disorder.

Because people with autism can struggle to communicate it can mean that it is not until the condition is well developed that it is recognised. This delay in recognition and access to appropriate support can lead to the person with autism feeling aggression or paranoia, or feeling withdrawn so that they refuse to leave a house or room. It may also lead to increased obsessional behaviour and suicidal feelings.

Other researchers have found that the three main issues that are most likely to affect people with autism are:

- Depression
- Anxiety and
- Obsessive compulsive disorder.

**Depression:** About 1 in 15 people with Asperger syndrome experience symptoms<sup>5</sup>

**Anxiety:** Some other research<sup>6</sup> found that 84.1% of people with autism also had at least one anxiety condition such as a phobia, panic disorder, separation anxiety disorder, avoidant disorder, overanxious disorder, obsessive compulsive disorder. Their research showed that this does not necessarily go away as the child grows older. For some people, it is the treatment of their anxiety disorder that leads to a diagnosis of Asperger syndrome.

**Obsessive compulsive disorder (O.C.D.):** Other researchers<sup>7</sup> studied a group of 24 people with autism and discovered that 18% of the group had a diagnosis with O.C.D. This compared to 5% of the control group of people without autism but who had some problems with social contact with other people. Other evidence<sup>8</sup> suggests that people who had O.C.D. continued with this throughout adulthood.

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<sup>3</sup> Tantam and Prestwood 1999

<sup>4</sup> Ghaziuddin et al (1998)

<sup>5</sup> Tantam (1991)

<sup>6</sup> Muris et al (1998)

<sup>7</sup> Szatmari et al (1989)

<sup>8</sup> Thomsen et al (1994)

# Annex 2 – Bracknell Forest Autism Partnership Board

## Terms of Reference

### Aim/Purpose

1. To lead in local planning to support the implementation within Bracknell Forest of local and national strategies and legislation for people with ASD (Autistic Spectrum Disorder).
2. To implement the key principles contained in other related legislation, including the Care Act 2014.
3. To draw up and implement the Action Plan based on public consultation in order to support the Joint Commissioning Strategy for adults with autism (2015-20).
4. To respond to the results of the annual Joint Health and Social Care Autism Self-Assessment exercise and to use evidence from the Self Assessment as part of the process to review, amend or develop services for people with ASD as appropriate.
5. Encourage new and innovative delivery of services for people with ASD which are consistent with the need to give people choice, control, flexibility and independence.
6. Support and advise all stakeholders on the implementation of the Bracknell Forest Joint Commissioning Strategy for adults with autism 2015 – 20.
7. To raise awareness and understanding within the Council and key partners, of issues affecting people with ASD.
8. Maintain links with other departments and services to ensure that there is no duplication of effort and services for all people with ASD and their carers.
9. When required, to form Sub- Groups, with relevant expertise and agreed by the Board, to work on specific time-limited projects.

# Membership

## Autism Partnership Board Members

Organisation / Representative
Chief Officer – Older People and Long Term Conditions (BFC) (Chair)
PA to Chief Officer (BFC) (Secretary to the Chair)
Director / Operations Lead Bracknell and Ascot CCG
Head of Learning Disability Services (BFC)
Joint Commissioning Officer BFC
Berkshire Autistic Society / National Autistic Regional Team
Involve Representative
Bracknell Mencap and Just Advocacy
Individuals with ASD (maximum of 3 people) (One of whom should be Co-Chair)
Carer/s of person with ASD (maximum of 3 people)
Berkshire Healthcare Foundation Trust Psychologist
Autism Team Manager from Bracknell Forest Community Team for People with ASD
Development Manager BFC
Representative from the local community
Representative from appropriate academic or educational institutions

## 1. Membership and Chairing Arrangements

The Partnership Board will have a Co-Chairing arrangement; the Co-Chair being a person with ASD and the Chair a representative from a statutory or third sector organisation.

Members must attend 3 meetings per year.

A minimum of seven members must be present per meeting to ensure effective decision making.

The position of Co-Chair will be for a maximum term of 2 years. At the end of every 2 year period, the existing Co-Chair must either stand down or request to be re-elected for a further term.

Members of the Board will decide by majority vote, either the election of a new Co-Chair, or the re-election of an existing Co-Chair.

An existing Co-Chair can request to stand down from the role at any time by giving notice to the Board. At the next available Partnership Board meeting, voting will take place for a new Co-Chair.

In order to be considered as Co-Chair, any potential candidate is expected to have attended at least 2 Autism Partnership Boards in the preceding 12 months.

## 2. Frequency of Meetings and Approach

Meetings of the Board will take place once every three months.

Additional meetings/working groups will be held if necessary.

The meetings will be for 2 hours and held at Time Square (no costs).

### 3. Co-ordination of Meetings

In consultation with the Co-Chair and the Chair, the Secretary to the Chair will co-ordinate the paperwork and circulate details 2 weeks prior to the scheduled meeting. Dates and venues of meetings will be set annually in advance.

The Joint Commissioning Officer, Development Manager, Autism Team Manager and Head of Learning Disability Services will support the Chair and Board with setting future agenda items/work plans in line with the aims of the local strategy and action plan.

### 4. Deputising for a Member of the Board

Members of the Board can nominate a representative to attend meetings on their behalf if they cannot attend for a specific reason e.g. annual leave

In this situation, the Board member must inform the Chair and provide the name of the representative.

### 5. Decision Making

Only members of the Board have the right to vote.

Therefore:

- Guest visitors/speakers do not have the right to vote
- People who are at the meeting in a supportive capacity do not have the right to vote

### 6. Conflict of Interest

Board members will be asked to declare any areas/information about their work/personal circumstance where they may have a conflict of interest. This does not affect their membership but does keep a record of where it might not be appropriate for the person to be involved in voting or decision-making

An example of this could be seen as an 'interest' that would need to be declared to avoid conflict;

- Any connection with an organisation contracted to provide services by either the CCG or BFC
- Any personal relationships or connections which could benefit from a decision
- Any connection with a financial interest.

### 7. Confidentiality

The work of the Board may involve discussion and decisions about other organisations or funding which are not to be discussed outside of the Board meeting.

The Chair and/or Co-Chair will highlight areas that are confidential in the meeting and these will be documented in the minutes.

### 8. Members with ASD Joining/Leaving the Board.

In order to ensure the Board is representative of the wide range of views and experiences of people with ASD, a mechanism should be in place to ensure that people with ASD have equal opportunity of access to apply to become members of the Board and that a mechanism also exists for existing members to leave the Board after an appropriate time period.

To allow for new people with ASD to join the Board, it is proposed that members should join the Board for a 2 year term, although members may choose to stand down at any time within this time. At the end of every 2 year term, the following should take place:

- If there are new members who have expressed an interest in applying to join the Board.** In these circumstances, the existing members who have served a 2 year term will stand down from the Board.
- If there are no new members who have expressed an interest in applying to join the Board.** In these circumstances, if the existing members wish to remain on the Board and if this is agreed by the majority of the Board through a vote, then they may remain on the Board until such time as new members apply to join.

Any proposed members who wish to join the Autism Partnership Board will first be required to:

- Contact the Bracknell Forest Council Community Team for people with ASD stating their interest, together with a brief explanation of their reasons for wishing to join and how they believe they could participate towards the work of the Partnership Board, as described in this document.
- Attend one Autism Partnership Board meeting as a guest, where they would introduce themselves to the Board and observe the working of the meeting.
- If after the meeting, it is agreed by the Board and the individual wishes to continue, the Bracknell Forest Council Community Team for people with ASD will then formally contact the proposed member, inviting them to join the Board for a 2 year term. The conditions of the Terms of Reference, Membership and Governance laid out in this document will apply for the new Member.

**If you want to talk more about the work described in this strategy please contact:**

Bracknell Forest Council Community Team for People with ASD

Telephone number 01344 354466

Or email us at <https://forms.bracknell-forest.gov.uk/popup.aspx/RenderForm/?F.Name=TTgmpex-38nJ>

Copies of this booklet may be obtained in large print, Braille, on audio cassette or in other languages. To obtain a copy in an alternative format please telephone 01344 352000.

## Nepali

यस प्रचारको सक्षेपं वा सार निचोड चाहिं दिइने छ ठूलो अक्षरमा, ब्रेल वा क्यासेट सून्नको लागी । अरु भाषाको नक्कल पनि हासिल गर्न सकिने छ । कृपया सम्पर्क गनुहोला ०१३४४ ३५२००० ।

## Tagalog

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## Urdu

اس دستاویز کے خلاصے یا مختصر متن جلی حروف، بریل لکھائی یا پھر آڈیو کیسٹ پر ریکارڈ شدہ صورت میں فراہم کئے جا سکتے ہیں۔ دیگر زبانوں میں اس کی کاپی بھی حاصل کی جا سکتی ہے۔ اس کے لیے براہ مہربانی ٹیلیفون نمبر 01344 352000 پر رابطہ کریں۔

## Polish

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## Portuguese

Podemos disponibilizar resumos ou extractos deste documento em impressão grande, em Braille ou em audiocassete. Podem também ser obtidas cópias em outros idiomas. Por favor ligue para o 01344 352000.