

Buckinghamshire Autism Strategy

2023 to 2027



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Autism and terminology

Being autistic does not mean you have an illness or disease. It means your brain works in a different way from other people. It's something you're born with or first appears when you're very young. If you're autistic, you're autistic your whole life. Autism is not a medical condition with treatments or a "cure".

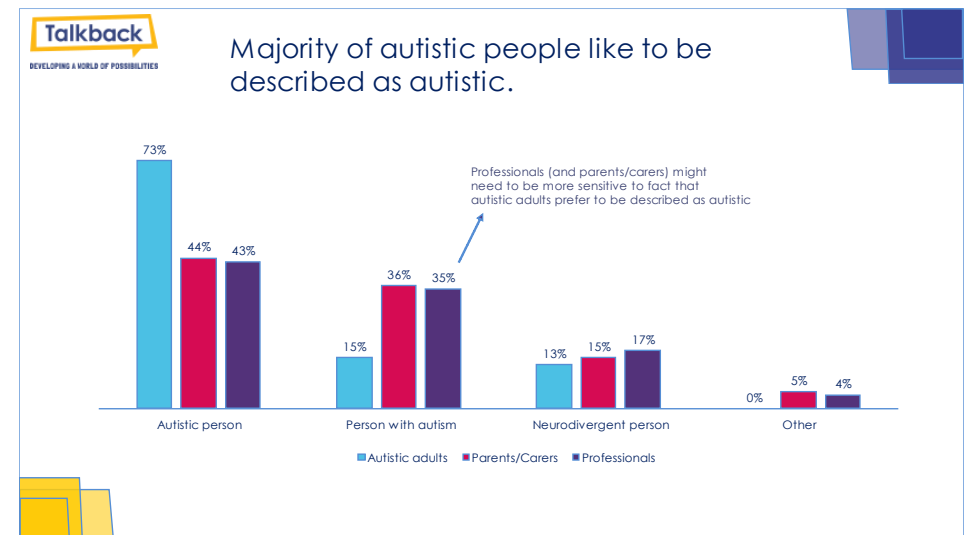
Autism is a developmental condition which affects how people process information, perceive the world around them and make sense of their place in it. Autism also impacts how people communicate, relate to, and interact with others. It affects each person in different ways.

We do know that Autistic people are much more likely to have co-occurring conditions too. In fact, recent World Health Organisation (WHO) studies have demonstrated that around 7 in 10 autistic people also meet the diagnostic criteria for other psychiatric disorders and that around half of all young autistic people have a learning disability.

We recognise that people prefer different ways of saying that they have a diagnosis of autism. For example, Autistic person, person with autism, neurodiverse and neurodivergent.

When we reached out to the community, we asked how they like to be referred to when discussing their autism and 75% of people prefer identity-first language over the other options.

We understand that we won't get it right for everyone all the time and that people's preference may change over time. For the purposes of this document, we will refer to people with a diagnosis of autism as "autistic people".



Developing the right approach for Buckinghamshire

Historically, autism has been identified within Health and Social Care as a medical condition linked to either a Learning Disability or a Mental Health condition. This means the approach to offering care and support has been similar to Learning Disability or Mental Health. However, as research and understanding of Autism gets better and is thought of in its own right, it is now thought of a Neurodivergence instead of a condition.

The old views on Autism have left many autistic people to feel excluded or unable to engage with the community that is often built around care and support. When we received this feedback, we knew we had to take a different approach; one that is understanding, inclusive and representative of Autism in Buckinghamshire.

This meant Buckinghamshire Council approached this work specifically putting Autism at the core of the conversation and crucially understanding how Autism is different from the historic model. This approach has led us to gather the most information ever collected in Buckinghamshire on Autism and has involved the feedback of more people with lived experience than ever.

Although we recognise that Buckinghamshire Council still has much to do to better involve and support autistic people, we are committed to coproduction.

This strategy has been developed alongside Autistic people, their families and support networks enabling autistic people to have an equal say through our development of this strategy and into our future action planning and service developments.

We aim to develop a culture based on:

- Shared understanding
- Relationship and trust building
- Empowerment

When developing this strategy, we have used the expertise of our Health and Social Care professionals, provider partners and our residents, engaging and communicating with all those who have an interest so their views can be heard and incorporated into our strategy.

Our coproduction has included, but is not limited to:

- Finding out how people want to participate and using a wide range of ways to include people
- Proactively seeking out a range of interested people with valuable input including the public, autistic community, and professionals
- Establish relationships with the community and making cross-organisational links to support the strategy
- To test all our work with open, public consultation

Stakeholder Scoping Meetings

In March 2022 we hosted our first scoping meeting that brought together more than 20 specialisms from across Buckinghamshire Council, Buckinghamshire Healthcare Trust (BHT), Voluntary Sector organisations, Children and Adolescent Mental Health Service (CAMHS), GPs, Hertfordshire Partnership Foundation Trust (HPFT) and Schools.

The meeting asked people to tell the Council how they would like to see the All-Age Autism Strategy be developed and whether there were any key themes or thoughts that must be included. The suggestions made during the meeting were collated and informed our initial plan for developing our priority areas. This was a critical exercise for us to undertake, and ensured we were open, listening and aligned to the views of others from the very beginning of the process.

In May 2022 Buckinghamshire Council hosted a second meeting where we outlined what we'd done based on feedback we received so far. The meeting was also an opportunity for our Engagement Partner, Talkback to show everyone how they would work with Buckinghamshire residents to make sure as many voices are heard as possible.

Talkback discussed how they'd meet with people, carry out surveys, visit support services and produce a report about what Autism looks like in Buckinghamshire. Talkback leading on this piece of work would be critical for us to develop a broad, inclusive understanding of the needs our autistic residents, their families and the professionals supporting them.

Whilst Talkback developed their report alongside Buckinghamshire residents, the Council ran a wide range of smaller, specific workshops across adults', children's, health, mental health, education, disabilities, and provider services. We invited autistic people, experts, and practitioners to

take part and share their skills, knowledge, and experience to ensure that each priority area had an equal involvement, representation, and scope for development. These workshops helped us to identify our gaps and challenges, and, how we'd tackle these to improve outcomes for Autistic people.

TalkBack engagement and consultation project

In 2022, Buckinghamshire Council commissioned Talkback, to work in partnership, writing a report that would gain feedback from local organisations, parent / carers, and autistic people in the county. The report would outline the scale of our Autistic population, where they use support or care services, how often, and what they think about them. All of this previously untapped information would inform the new local Autism Strategy for Buckinghamshire.

An online quantitative survey was carried out in June 2022. This survey was formatted for different groups of people to participate – autistic adults, parents of autistic children and professionals who work with autistic people. For people who couldn't use the internet, questionnaires were created and mailed out via a network of contacts in various organisations and services working with autistic people in Buckinghamshire. In addition to all this, links to Talkback surveys were 'advertised' via social media.

Youth Engagement

In December 2022 and January 2023, the Your Views Survey was shared to gather the views of autistic children and young people (CYP) across Buckinghamshire. These surveys were designed in collaboration with Specialist Teachers and other Special Educational Needs and Youth Participation colleagues.

Three versions of the Your Views Survey were created:

- A Plain Text version for fluent readers who need very little support
- A Text and Pictures version for young people who benefit from some visual support and who might need some support from an adult

- A Picture Exchange Communication System (PECS) version for young people who are likely to require full support from an adult who can interpret the questions on their behalf

Autistic people in the LGBT+ community

Throughout the engagement activities, we heard that there is little information known about the number of people in Buckinghamshire who identify as autistic and are part of the LGBT+ community and / or don't identify with the gender that they were assigned at birth.

Buckinghamshire Council are motivated to open the discussion in this area and will look to include system partners and autistic people to identify the support needs of this group of people, if it is felt that it is needed.

Introducing our Vision

Autistic people in Buckinghamshire have told us that they want to live as independently as possible and to have the same opportunities and experiences as everyone else. That autistic people should be able to use the services they need when they need them. And that they should work with us to change our policies, approach, and services.

This is our vision too.

The next four years implementing the strategy will mark a significant change in approach to supporting autistic people. Our support and services have previously been siloed rather than, as here, brought together as an all-age plan for lifelong support.

This strategy also marks the first time that autistic and neurodiverse people will be the sole focus of a Council strategy.

It builds on and aligns with national and local guidance (Think Autism, The National Strategy for Autistic Children, Young People and Adults, and Integrated Care System (ICS) Learning Disabilities and / or Autism 3 Year Plan).

This is an outcomes-driven strategy that spells out what we will achieve together.

Autistic people's needs are diverse. Many autistic people in Buckinghamshire live independent lives, but others may require care and support to help them face additional challenges in their lives. People experience a wide range of support needs both in the amount and nature of support needed.

This diversity is directly reflected in our strategy. There are five key areas where we plan to improve in Buckinghamshire: Awareness and understanding of autism, reducing health and social care inequalities, meeting the needs of autistic and young people, supporting employment and meaningful activities, increasing independence and community provision.

This work will be driven by joint action across health, social care, and education together with autistic people. We are committed to doing things differently, creatively, and collaboratively to deliver great value services.



Buckinghamshire Autism Outcomes



Autistic people will feel more welcome, listened too and understood by our staff and in the wider community



Health and social care inequalities will be reduced, wait times for an assessment will go down



Autistic children and young people will be better supported with their needs so they get the best start in life



More autistic people will be supported into employment and meaningful activities



More autistic adults will maintain their independence and remain in the community



Improving awareness and understanding of autism

What partners say

- There is a profound lack of awareness and understanding in our services and schools and in the wider community
- Most staff in services are considered by autistic people and their families / carers to have no understanding or acceptance of autism and autistic people
- Our services know they need to improve
- Poor awareness and understanding has direct impacts on accessibility, early identification, and effective diagnosis, the take up and experience of services, entrenches health and social care inequalities and can lead to bullying and exclusion

Our approach

- We will ensure that that campaigns and training are coproduced and developed with autistic people
- We will ensure consistency between training offers
- We will make it easier to find factual autism related information
- We will work in partnership with the public, schools, local organisations, and the voluntary sector to create training opportunities

Our ambition – we'll make sure...

- Autistic people feel more welcome, listened to and understood by our staff in the council and across Buckinghamshire
- The understanding and acceptance of autism are improved
- Our staff understand how autism can affect people differently, including the difference in how autistic women and girls present, and to help change people's behaviour towards autistic people and their families
- Autistic people can access our spaces and services, just like everyone else

Areas of focus – what we need to do...

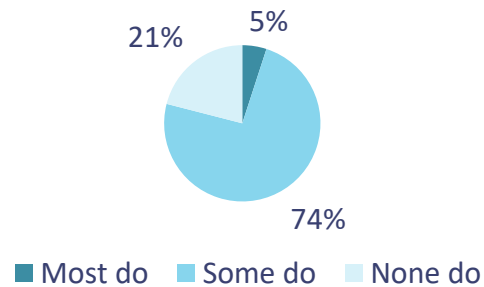
- Improve our own awareness and understanding – we will focus on this first
- Autistic people training all frontline police officers and staff in autism awareness
- Youth Offending Service offer 1:1 support to autistic people, or people suspected of being autistic, on probation and post-release
- Autism awareness training for parents of teenagers as well as younger children
- Review the Special Educational Needs and Disabilities (SEND) Local Offer website and other online directories to be more accessible for autistic people and their families and support network



What you told us about improving awareness and understanding

- Most parents and carers, and autistic adults we spoke to believed that the majority of those working in services did not understand or accept autistic people
- Only 9% of parents and carers think people understand and accept autistic people
- While most autistic people think some people do understand them, 1 in 5 believe that nobody understands them

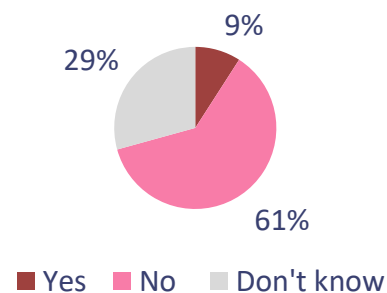
Percentage of autistic adults who feel understood and accepted



*“There is a real level of ignorance, particularly in professional services that should have a better understanding”
(Parent / carer)*

“On the whole I think there is still an extreme lack of understanding around Autism, especially in woman and adults” (Autistic adult)

Percentage of parents / carers who feel that autism is understood and accepted



*“What makes a person really understand is having someone with Autism in their lives they care about”
(Autistic adult)*



Tackling health and care inequalities

What partners say

- Autistic people face significant health inequalities, having poorer physical health outcomes and a lower life expectancy than the general population
- Autistic people face significant barriers accessing health services and as a result more autistic people have serious co-existing health and mental health conditions
- Wait times for both children's and adult diagnostic services are unacceptably long, and a significant minority feel the need to seek a private assessment
- Receiving a timely autism diagnosis is still vital in getting the right support and helping autistic people and those supporting them to better understand their needs. Many adults have received a diagnosis late in life and girls and women are still less likely to receive a timely diagnosis
- The assessment process is confusing for many
- There is an absence of support before and after diagnosis and there is a lack of collaboration between professionals in the system
- Autistic people find it harder to gain and maintain their own housing offers including independent tenancies and landlord relationships
- Community amenities and wraparound services (linked to health, social care and education) do not understand autistic needs and as a result staff training and the environment are frequently not suitable

Our approach

- We will work alongside diagnostic services to identify areas of strength and develop more capacity
- We will share best practice models of diagnosis across the Berkshire West, Oxfordshire, and Buckinghamshire Integrated Care Board (BOB ICB) to drive improvement
- We will use people's experiences of the assessment and diagnostic process to improve the experience of service users
- We will encourage services and support to use a needs-based approach, reducing dependency of formal diagnosis to access services



Tackling health and care inequalities

Our ambition – we'll make sure...

- We will reduce the health and care inequalities autistic people face and show that autistic people are living healthier lives
- We reduce waiting times for high quality autism assessments, improve our diagnostic pathways and the support that autistic people need
- Physical and emotional wellbeing is promoted through prevention and community services – reducing reliance on health services
- We review current and future housing needs to ensure Buckinghamshire has more appropriate housing and housing related support
- Getting a diagnosis will better link with our education offer, support services and health offer
- Accessing services and support is not always dependent on receiving a diagnosis

Areas of focus – what we need to do...

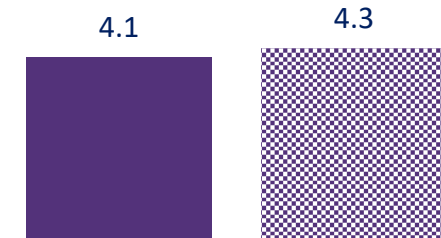
- Invest in our assessment and diagnostic services
- Hospitals collect information to better deliver services
- Health organisations working together across Berkshire West, Oxfordshire, and Buckinghamshire to develop different approaches to diagnosis
- Education takes a needs-led approach, moving away from the assessment model – this will mean it is less critical to receive a diagnosis to get support
- Working with health organisations to fund services with a best practice, needs led and earliest intervention approach



What you told us about health and care inequalities

- Most people – 40% of autistic adults and 67% of parents and carers – thought it was not easy to navigate the diagnosis and assessment pathway
- Around one quarter of assessment and diagnosis is gained outside of the NHS offer because it is too difficult to get timely diagnosis
- Even people working alongside professionals to assess and diagnose autism believe there is much to improve. Most health and social care professionals rated the diagnosis pathway as below average

Average rating of the diagnosis process by professionals (0-10)



■ All ▨ Know a lot about process

“Less form filling, more in person meetings, more thought put in to the emotional toll the process has on the person and their family - in our meetings with the paediatrician they spoke about my child as if they were invisible and couldn’t hear or understand”

“Have greater collaboration between health, education, CAMHS, social care so that families are heard, supported and have a clear and consistent pathway of support, with everyone working towards the same plan”



Developing a needs-based approach – so that autistic children and young people get the best start in life

What partners say

- It is difficult to find and access support for autistic people's needs
- There is not enough support offered before a diagnosis or indeed after one
- Support should not just be based on a diagnosis or being in receipt of an Education Health and Care Plan) but regularly parents are told that specific support is unavailable without one
- Support needs to be provided earlier and in particular in education settings
- Transitional pathways from children to adults' services (health, education, and social care) are not well understood and autistic people and their carers do not feel properly prepared for their adult lives

Our approach

- We will offer support based on needs not on diagnosis
- We will encourage schools to make their support offer clear, so that people know what to expect from them
- We will promote good practice in education settings enabling them to make adaptations and reasonable adjustments to practice and environment
- We will work in partnership with council colleagues to enhance the Preparation for Adulthood Pathway and Toolkit



Developing a needs-based approach – so that autistic children and young people get the best start in life

Our ambition – we'll make sure...

- Autistic people can get education support with or without a diagnosis
- Education and school staff are trained to understand autism and how to better support needs (including differences in behaviour and environmental need)
- Fewer autistic people experience Emotionally Based School Avoidance (EBSA) – difficulty attending school due to emotional reasons
- Autistic people and their families feel prepared for adulthood –whether this means they get a job, go into further education, or look for other opportunities

Areas of focus – what we need to do...

- Change how autistic children access education support (needs rather than diagnosis led)
- Start Autism Standards Training for all schools across Buckinghamshire – outlining best practice support for autistic young people
- Publish a new Therapies Strategy – to meet the needs of children and young people who need speech and language, communication and occupational therapy
- Making changes to physical environments to meet the needs of autistic people
- Create a new, accessible Preparation for Adulthood Toolkit - to support families and professionals as autistic children and young people become adults



What you told us about Support Services and Schools

- Support for adults is regularly frustrating for autistic people and their family and carers
- Staff are not well equipped to support autistic people
- School support is based on the availability of funding and that funding is not always appropriately used
- Parents and autistic children often feel discouraged from getting a diagnosis or EHCP

He has had intermittent support workers over the more recent years he no sooner gets used to one than they leave or the organisation makes changes and everything goes up in the air again”

*“It (full time PA for daughter at xxxxxx) worked up to the end of GCSEs, then they started withdrawing support and she had a total breakdown ... she got A*s in her GCSEs but Ds in her A levels”*

“Usually we have to find a PA who is willing to learn about Autism and we have to guide them. This can be hugely hit and miss and putting in a PA who doesn’t really understand Autism can do more harm than good. For people who need a high level of input at home to prevent admission into hospital or care settings, it’s pretty impossible”

“I feel sorry for teachers, They receive no specific autism training, they don’t know how to support people”



Developing better support for employment and meaningful activities

What partners say

- Autistic people have a tremendous potential to contribute to the local employment market and wider economy when offered the right opportunities and given a fair chance to demonstrate their skills
- Only 17% of autistic adults in Bucks have ever received support to find work or training opportunities and the adults that had received advice often were led into inappropriate career pathways
- Unemployment is linked to lowered self-esteem and poorer mental health. Financially, more autistic people are also reliant on benefits leading to fewer life and social opportunities

Our approach

- We will provide help to make training and work choices (that last for longer)
- We will improve training for those offering career advice so that fewer people follow unsuitable job pathways
- We will encourage 'Good fit' jobs that fit with people's interests and that they can excel at
- We will help employers understand reasonable adjustments and how to achieve better employer relationships with autistic people
- We will improve our Preparing for Adulthood pathway so that work and training is a normal discussion and is properly planned for

Our ambition – we'll make sure...

- Autistic people have more opportunities to work in areas where their skills are a 'good fit'
- Autistic people understand work, training, and volunteering opportunities – so they can make decisions about their future
- People offering advice and support have more awareness and understanding of reasonable adjustments and employer responsibilities
- More employers understand what autistic people can do and provide work or volunteering opportunities

Areas of focus – what we need to do...

- We will work with employment and training support to improve the quality and amount of support offered by:
 - Improving our Preparing for Adulthood offer
 - Launching the Reasonable Adjustments Toolkit for our staff and health colleagues – which promotes and sets good practice
- Work with the local Job Centres to share opportunities and have more Disability Confident employers
- Encourage local businesses to attend autism related events and training to enhance their skills



What you told us about employment and meaningful activities

- Only 17% of autistic adults in Bucks have ever received support to find work or training opportunities and the adults that had received advice often were led into inappropriate career pathways, often requiring high levels of interpersonal skills. These kinds of experiences drain the confidence of autistic people and mean that withdrawal from the training and job market is common
- Through conversation with autistic people, their families and professionals in workshops hosted by the council, we learned that autistic people often find it particularly challenging to find and maintain meaningful employment

“Think outside the box, many people with autism have skills and knowledge that could be used in the workplace” (A parent)

“I was good at my job; it was certain aspects of it that I couldn’t handle, such as when the job went wrong and certain social aspects I held it for three and a half years”

- Employment or training opportunities offered are often a ‘bad fit’ and don’t utilise the unique talents or interest of autistic people
- We heard that autistic people would like and need more support to find the right opportunities, including support to manage their jobs, education or volunteering



Ensuring more autistic adults maintain their independence

What partners say

- Autism is never 'cured' – there is a lifelong need
- Autistic people can 'fall off a cliff' or go from 'hero to zero' at any time and need support to help them regain their mental health and confidence throughout their life, before they reach crisis point
- There is a gap in the provision of practical social support for autistic adults
- Lack of lifetime support is a particular issue for those without learning disabilities – those with learning disabilities are supported
- Autistic people find it harder to gain and maintain their own housing offers including independent tenancies and landlord relationships

Our approach

- To support autistic people across the life course to maintain their independence

Our ambition – we'll make sure...

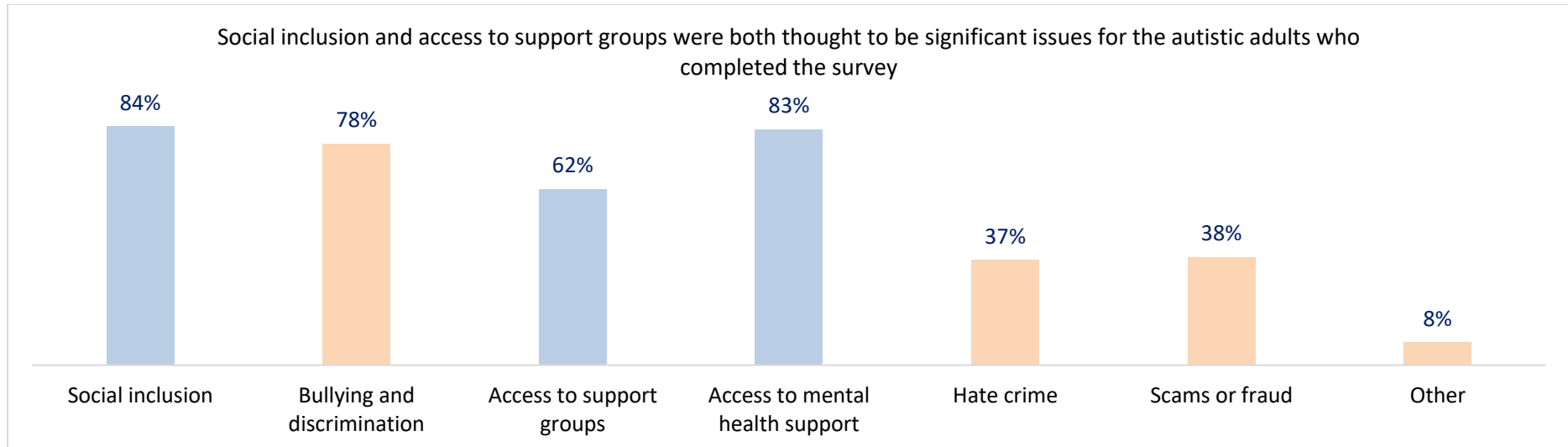
- We work with autistic people and stakeholders to address gaps in our current support

Areas of focus – what we need to do...

- Address the social support gap for autistic adults – autistic adults who do not have associated care needs have told us about difficulties accessing social support services
- Evaluate support for autistic people with and without social care support – including online and / or in-person 'drop ins'
- Work with health partners to deliver reasonable adjustments across services and settings
- Look at how to improve specialist housing



What you told us about accessing services



- Accessing health, social care and education services is linked to a broad range of interdependencies. Being able to engage with public transport, leisure, housing and mental health all contribute to an individual's health and wellbeing

"Social inclusion and access to support groups would reduce the bullying, discrimination and hate crimes and therefore reduce the need for mental health support"

- Autistic people tell us that this is a significant barrier for them

"For community support, think of parents. What happens if parents can't cope? Who will support their autistic sons and daughters?"

Delivering our priorities

In Buckinghamshire, we want the Autism Strategy to drive improvements in support and services for autistic people. There will be a large number of autistic people, organisations, and Council services taking ownership over actions to ensure we make consistent progress towards delivering improvements.

To make sure that our various work streams are contributing to the delivery of appropriate support at the right time Buckinghamshire will create an Autism Steering Group.

The Autism Steering group will:

- Be chaired by a Head of Service from Integrated Commissioning
- Establish working groups to filter insight and development areas into this steering group
- Be attended by reps from each of the working groups, autistic people, and relevant Buckinghamshire Council colleagues
- Report to our various governance boards for senior leadership oversight
- Be responsible for ongoing oversight and monitoring of the strategy action plan

The Autism Steering Group will also lead co-ordination of the strategy delivery, developing a comprehensive action and implementation plan including our measures of success. These plans will be overseen by a task and finish sub-group which can focus on areas of specialism or delivery to ensure work priorities are progressed.

This approach will ensure that partners across all areas receive the same support and guidance to deliver their outcomes. Partners will be held accountable by the Autism Steering Group whilst carrying out their duty and desire to improve the lives of autistic people and their families and carers.

This strategy and the action / implementation plans will be live documents. This means that as circumstances and needs of autistic people change, we can respond accordingly and continue to develop a Buckinghamshire offer.

All actions and the associated progress against each priority area will be formally reported to and monitored by:

- Adults and Health Board
- Adults Integrated Care Board
- SEND Integrated Care Board



Enabling our strategy: Improving communication and engagement with Autistic people, their families, and support networks

What partners say

- We know that autistic people have not always felt that they have been listened to and that they don't know the best way to get their views across to the Council
- Sometimes autistic people and parent / carers don't feel that they are involved in decision-making when it comes to health and social care changes
- Parents of autistic children told us that they can sometimes find the process of engaging with professionals very challenging

Our approach

- We will work with autistic people, their families, and carers so they have an active input into Autism support in Buckinghamshire
- We will provide opportunities and forums for people with lived experience to voice their opinions and shape their own support
- We will gather and share best practice and lessons learnt with services to further enhance support and service delivery

Our ambition – we'll make sure...

- Autistic people and those with lived experience feel listened to and valued
- The experience of autistic residents in Buckinghamshire are reflected in our support and services
- A range of communication channels will be in place throughout education, social care and health
- People in Buckinghamshire know how to engage with us and can do so regularly – not just when we ask

Areas of focus – what we need to do...

- Launch a SEND Coproduction Charter
- Introduce Autism and Learning Disability Forums that are facilitated by our quality standards team
- Run regular awareness and training events such as Shout Out for SEND and Access All Areas
- Use information gathered from autistic people and their carers to improve the way that we work – autistic people will be involved when we are making changes to services



Enabling our strategy: Making the right decisions about services and support using local data and insights

What partners say

- Collecting and using information about autistic people is inconsistent throughout education, health and social care
- Data isn't regularly shared across organisations as it is collected and stored in different ways, making it hard to make comparisons or build population and need trends
- The lack of good data analysis means services are sometimes developed without meaningful insight into who it is we are supporting

Our approach

- We will collaborate with partner organisations to improve data collection and understand the needs of the community
- Develop a clear data set to understand current needs and use data to predict possible future service needs
- Build a shared data repository with partners to support a clear understanding of information relevant to autistic people
- Use the data we collect to analyse what we do, improve practice and develop new support and services

Our ambition – we'll make sure...

- The council clearly understands who our population is in detail
- We use this information effectively so that we can understand need and proactively change services, reducing future delays in diagnosis, support or services
- Shared information leads to better support and outcomes throughout autistic peoples' life

Areas of focus – what we need to do...

- Work with our services and support to define what data we collect and how it will be used
- We will identify which key partners hold information that can add to a better understanding of our population and their needs
- Build a pool of information that can be shared to improve development of services

More information

Contact us:

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Key Documents

Talkback Community Engagement Report 2022

Stakeholder Mapping 2022

Your Views Children and Young People Engagement Summary 2023

National Autism Strategy 2021-2026

South East Regional Autism Strategy 2021-2026

Integrated Care System (ICS) Learning Disabilities and / or Autism 3 Year Plan (2021-2024)

2022 Local Area Send Inspection – Written Statement of Action

Buckinghamshire Council Equality, Diversity, and Inclusion Plan Need