

Brighton and Hove Adult Autism Strategy

Introduction

“This work represents a meaningful paradigm, culture and power shift, incorporating the social model of disability and progressive thinking around autism and neurodiversity. This strategy flips the narrative from outdated, pathological and deficit-based theories of autism towards up to date, forward thinking about autism as a natural and valuable form of diversity. Priority is being given to the strengths and lived experience of autistic people and to the view that autistic people are not broken, nor need 'fixing', but are the experts - the experts of our lives and of our own experience. This emphasis on Autistic voice, on listening to autistic people and prioritising our views and expertise, offers true participation rather than tokenism and respects the rally call of the autistic and disability rights movements --"Nothing about us, without us."

Central to this cultural shift within the strategy is recognition of the research of leading autistic academics and their up to date and evidence based work with autistic people. This includes monotropism, the autistic language hypothesis and double empathy. Milton's work on double empathy underpins the work we will be doing in re-setting the narrative for autistic people. This theory highlights that autistic people do not lack empathy or emotions - a core belief in old, deficit-based thinking about autism. Milton flips the narrative and argues instead that autistic people experience the world and express emotions differently to non-autistic people. This difference makes it difficult for non-autistic people to understand and to empathise with, autistic people, and vice-versa - so, it's a two-way street. These differences of experience lead to an empathy divide and communication breakdown between autistic and non-autistic people. As autistic people are in the minority, we are blamed for this communication breakdown and our ways of being are stigmatised and suppressed. The value of incorporating progressive theories about autism from autistic thinkers into our strategy is that they reframe the relationship between autistic and non-autistic communities, and enable innovate opportunities to tackle inequalities, build on autistic strengths and achieve positive outcomes. Double empathy and the marginalisation of autistic perspectives and experiences mean that it has been especially important that autistic people are at the forefront of decision making about our lives.

There is often a lack of understanding of invisible disabilities and accessibility needs, which can be experienced as oppressive by neurodivergent people. Changing the lens on autism, will hopefully change understanding, culture and practices, and thus, the outcomes for autistic people, many of whom have previously been unheard and unseen. It's exciting that through this work there is a commitment towards systemic change and 'doing things differently,' to improve the lives of autistic people. I am passionate that the Brighton and Hove Adult Autism Strategy will promote a neurodiversity-affirming culture and practice approach that amplifies autistic voice, recognises autistic culture and celebrates autistic strengths .”

Alice Conroy, Autistic Co-Chair of Brighton and Hove Autism Partnership Board

“I'm immensely proud to live in a city with an active and engaged Autism Partnership Board that we can work in partnership with. Over the next 5 years, whether feeling safe and empowered when out and about in their communities, or accessing mental and physical health support from the NHS for themselves or their carers, the Autism Strategy is the start of a new era for autistic people living in Brighton & Hove, and should serve as a national benchmark of how to create and deliver a strategy in close collaboration with the people who need it most.

We believe that the autistic population in Brighton and Hove is likely to be significantly higher than national averages due to our reputation as a city that celebrates diversity. We have long needed a coherent strategy to guide services for the many thousands of autistic people in the city. Our understanding of the needs, motivations and differences of autistic people and between the autistic and non-autistic population has accelerated in recent years. We need to respond to new evidence and understanding, and co-design and co-produce an equitable service according to the vital lived experience of our local autistic and otherwise neurodivergent populations. The Autism Strategy before you is the result of a careful partnership and consultation between local communities, voluntary sector organisations, the NHS and Brighton and Hove City Council.”

**Councillor Tristram Burden, Chair of Adult Social Care and Public Health Sub-Committee,
Brighton and Hove City Council**

What is Autism?

Autism is a natural part of human diversity. Autistic people tend to communicate and experience the world in a different way to non-autistic people. Historically, autism has been considered a 'disorder' seen in terms of deficits in social interaction and communication. However, this has been challenged by many autistic people and researchers who have argued for a neuro-affirmative approach that recognises autism as a different neurological style that is marginalised and stigmatised within a predominately non-autistic world (Leadbitter *et al.*, 2021; Walker, 2021).

From a neuro-affirmative approach, autistic researchers have argued that the way autistic people experience the world is characterised by monotropism (Lawson, 2011; Murray, 2021). The theory of monotropism argues that autistic brains are pulled more strongly to a narrower attentional focus compared to non-autistic people. This can mean that autistic people can have more intense experiences, miss things outside of their current area of attention and find it hard to shift their attention from one thing from another. Non-autistic people generally have polytropic brains where they can spread their attention amongst multiple things in a less intense way. The theory of monotropism validates the experience of autistic people without pathologizing their differences.

Strong passionate interests

Autistic people tend to have strong passions and their interests pull them in very strongly over time. All humans have things they are passionate about but what is generally different for autistic people is the intensity of their interests. It is important not to have stereotypical assumptions about what autistic people may be interested in.

Autistic inertia

Autistic inertia describes the tendency of autistic brains to resist changing states, stopping, starting or changing direction. This can make starting new tasks, being interrupted and changing plans challenging, however can also be associated with hyperfocus – the ability to intensely focus for long periods of time.

Sensory differences

Everyone has eight sensory systems. The commonly known – sight, hearing, smell, touch and taste – give information outside our bodies. However, there are also three internal sensing systems – vestibular (co-ordinating movement with balance), proprioception (awareness of movement of the body) and interoception (awareness of our internal state including emotions, temperature, pain hunger and thirst). Every autistic person is different however, many are hypersensitive to external senses and hyposensitive to internal senses. It is much easier for autistic people to process one channel at a time and sensory over load can lead to exhaustion, meltdown or shutdown.

Stimming

Many autistic people will engage in stimming (or self-stimulatory behaviour) and this can be repetitive movements and/or sounds such as hand flapping, rocking or twirling. Stimming can be for enjoyment, to express happiness, or to increase or reduce sensory input (Charlton *et al.*, 2021). Acceptance of stimming can enable autistic people to communicate and support sensory and emotional regulation.

Autistic people argue that it's damaging to discourage stimming and leads to them being less tuned into their bodies and needs. Interventions aimed at reducing stimming – such as applied behaviour analysis (ABA) – have been associated with long term negative mental health outcomes such as increased post traumatic stress symptoms (Kupferstein, 2018; Anderson, 2022). Interventions to support autistic people whose stimming may cause harm to themselves or others need to be person-centred, trauma-informed and neuro-affirmative.

Social differences

Autistic researchers have argued that social differences in autistic communication are linked to sensory differences and monotropism (Murray, 2018). The social norms of non-autistic communication include eye contact, small talk and indirect communication, for example, not saying directly what you mean. Being unable to process multiple channels of sensory input at one time can make processing the combination of speech, body language and eye contact involved in non-autistic communication very challenging. Some autistic people without a learning disability may not use speech some or all of the time and will benefit from alternative communication methods.

These differences can lead to the perception that autistic people struggle with social communication. However, research suggests that non-autistic people struggle to understand the communication of autistic people (Sheppard, 2015; Edley *et al.*, 2016). This has led to the theory of double empathy – that generally autistic people communicate most effectively with other autistic people, and non-autistic people communicate most effectively with other non-autistic people (Milton, 2012). However, when autistic people communicate with non-autistic people they experience communication breakdown due to their different ways of experiencing the world.

Masking

Masking is when autistic people will consciously or unconsciously hide autistic characteristics or behaviours in order to fit in with a non-autistic world. This may include: mimicking the behaviour of non-autistic people, hiding stimming or autistic passions, or developing complex social scripts in order to manage non-autistic communication. Masking can be physically and mentally exhausting and research has suggested that masking has a negative impact on mental health (Cook *et al.*, 2021) and can lead to an increase in suicidal behaviours (Cassidy *et al.*, 2020). High masking also increases the likelihood of later diagnosis.

Autistic Burnout

The cumulative impact of masking, sensory overload and living in a world that is not adapted for autistic people can lead to autistic burnout (Raymaker *et al.*, 2020).

As one autistic person in Raymaker and colleagues' (2020:p137) research said: "Autistic burnout is a state of physical and mental fatigue, heightened stress, and diminished capacity to manage life skills, sensory input, and/or social interactions, which comes from years of being severely overtaxed by the strain of trying to live up to demands that are out of sync with our needs."

Many autistic people reported experiencing gaslighting or dismissal when they discussed their experiences of autistic burnout and reported that this exacerbates the negative impacts and led to feelings of social isolation (Raymaker *et al.*, 2020).

Autistic people said that autistic burnout recovery is supported through:

- acceptance,
- learning how to recognise the signs of autistic burnout,
- reduced external pressures and sensory rest,
- learning how to set healthy boundaries,
- inclusive adjustments being made to support or work,
- unmasking and being able to authentically live their lives as an autistic person (Mantzas *et al.*, 2022).

Autistic people tell us that recovery from autistic burnout is often a prolonged and staged process.

PDA

PDA is commonly referred to as Pathological Demand Avoidance but a more neuro-affirmative reframing is 'pervasive drive for autonomy' (PDA Society, 2022). People with a PDA profile generally experience a fight, flight or freeze response as a result of demands (which are anything they perceive as a threat to their autonomy). This could include self care tasks such as bathing or doing laundry, social expectations or being told what to do by others, for instance at work, home or school.

People with a PDA profile may want to do something but not be able to because their internal response to a perceived loss of autonomy is so intense. They may respond by avoiding demands and expectations, having intense emotional responses or using strategies to remain in control of a situation. People with a PDA profile are also often innovative and independent thinkers and highly empathetic and intuitive.

Co-occurring Experiences

Autistic people often experience other forms of neurodivergence such as ADHD (Attention Deficit Hyperactivity Disorder), dyslexia, dyspraxia, epilepsy and OCD (Obsessive Compulsive Disorder). Many autistic people also experience gastrointestinal issues, sleep issues and Ehlers-Danlos syndrome or other forms of hypermobility.

Language

The language we use when we talk about people is very important and it communicates dignity and respect.

Autistic people do not all have the same preferences for what words should be used when talking about them. It is best practice to ask someone what language they want to be used when referring to them. However, this guidance is currently considered best practice when talking about autistic communities as a whole.

Use	Do not use	Why?
Autistic people	People with autism	Not everyone agrees but increasingly autistic people do not like 'person-first' language. This is because they see autism as part of who they are and not separate from their personhood.
Autism	ASD or Autism Spectrum Disorder or suffering from autism	Autism Spectrum Disorder is still an official diagnosis, however, disorder and 'suffering' are considered negative and medicalised language. A neurodiverse approach equally values all types of brains.
Autistic people with a learning disability or autistic people without a learning disability	High or low functioning Asperger's syndrome	Some individuals may find terms such as 'high functioning' or 'Asperger's syndrome' as meaningful ways to refer to themselves and this choice should be respected. However, terminology such as 'high-functioning' is generally believed to be unhelpful and disrespectful by autistic people. Describing someone as 'high-functioning' can minimise the areas where someone may mask or need support (Autistic Self Advocacy Network, 2021). Aspergers' is no longer given as a diagnosis and has associations with Nazi genocide (Czech, 2018).
A neurodivergent individual	A neurodiverse individual	The neurodiversity movement promotes equally valuing all human minds and neurotypes. This contrasts with the medical model which has historically considered autism as a 'disorder'. You cannot be a neurodiverse individual because it's not possible to be 'a diverse individual'. Neurodivergent means having a mind that functions in ways which diverges significantly from dominant societal standards of 'normal'. Forms of neurodivergence include lifelong neurotypes such as autism, ADHD as well as acquired such as complex post traumatic stress disorder.

Data

It is very challenging to find data that represents autistic people due to the challenges in accessing diagnosis. The UK government estimates that 1.1% of the population are autistic (Brugha *et al.*, 2012). Using this statistic, we can estimate that there may be the following number of autistic people within Brighton and Hove.

Year	Office of National Statistics resident population estimated figures Brighton and Hove				Estimated population of autistic people calculated at 1.1% of resident population			
	2020	2025	2030	2035	2020	2025	2030	2035
Total Population	295,337	302,584	311,516	319,400	3,250	3,330	3,430	3,510
Total Population - Children and Young People	51,940	52,682	52,347	52,550	570	580	580	580
Total Population – Adults	243,397	249,902	259,169	266,850	2,680	2,750	2,850	2,940

However, many consider the 1.1% statistic used by national government to be too low. For example, English primary care data suggests that 3% of children aged 10-17 have an autism diagnosis without a learning disability (O’Niens *et al.*, 2023). Older people much less likely to have a formal diagnosis and more than 90% of autistic people over the age of 50 may be undiagnosed (O’Neins *et al.*, 2023).

There is the perception amongst local autistic people that there is likely to be significantly larger autistic community in Brighton and Hove. Research suggests that autistic people are significantly more likely to be LGBTQ+ (Weir *et al.*, 2021) and many people may move to Brighton and Hove due to its reputation as a city that celebrates gender and sexual diversity. This is reflected in the equality data for the autistic people who responded to our consultation survey (see Appendix 1).

Three in depth needs assessment are planned to take place between 2023-2026. These will explore the health and wellbeing, and ideally gather clearer data, of the following communities:

- Special Educational Needs and Disabilities (SEND), neurodiversity, and learning disabilities (children and young people aged 0-25)
- Neurodiversity and learning disabilities (adults aged 18 and over)
- Young people transitioning between children’s and adults’ services (aged 16-25)

Who is this strategy for?

This strategy is aimed at improving the lives of autistic adults without a learning disability, their unpaid carers and members of their support network. This is so we do not duplicate the work of the Adult Learning Disability Strategy and the Special Educational Needs and Disability Strategy which focuses on the needs of children and young people.

Government guidance says that local areas need to plan how to improve services for autistic people (Department of Health, 2015). However, we hope that many of the outcomes in this strategy will have a positive impact on all neurodivergent people.

Who is leading on this strategy?

This strategy has been developed by Brighton and Hove Autism Partnership Board.

The Autism Partnership Board is a group including:

- autistic adults,
- unpaid carers of autistic people and members of their support network,
- representatives from Brighton and Hove City Council, Sussex Police and the NHS and,
- community and voluntary organisations such as Assert, Amaze, the Parents and Carers Council, Mascot, and the Carers Centre.

The Autism Partnership Board will work together to improve the lives of autistic people, unpaid carers and members of their support network in Brighton and Hove.

How did we make this strategy?

The Autism Partnership Board have developed this strategy through an approach of partnership and collaboration. This is defined as:

- Citizens and staff working together to identify issues and find shared solutions,
- Recognising, valuing and promoting the knowledge, skills and expertise of autistic people, their unpaid carers and members of their support network,
- Board members sharing decision making wherever possible. Being honest and open when shared decision making is not possible,
- Valuing and respecting all members,
- Everyone having the same opportunity to take part in an activity in a way that suits them best.

The Autism Partnership Board agreed the topics that we wanted to find out about as part of exploring the experiences of autistic people, their unpaid carers and members of their support network. The Partnership Board agreed the questions that we would ask.

Online Consultation

An online consultation survey was held on the Brighton and Hove City Council website for 4 weeks in May and June 2023. The survey was shared by local partner organisations and media.

213 people completed the online survey

- 63.4% were autistic
- 29.1% were an unpaid carer or a family member of an autistic person
- 27.2% were professionals
- 1.9% were none of the above

These numbers do not add up to 100% as some people were in multiple categories. For example, autistic professionals or autistic unpaid carers. If the person answering the survey said they were an unpaid carer or a family member of an autistic person, they were asked additional questions about their experience.

The survey included a mixture of multiple-choice questions and questions where people could write about their views and experiences. People who answered the survey could choose which sections they wanted to answer.

What percentage of people who answered the survey completed each section?

- 1. Mental health 93.4%
- 2. Diagnosis and Support from the Neurodevelopmental service 81.2%
- 3. Physical health 74.2%
- 4. Feeling part of the community 69%
- 5. Jobs and volunteering 66.7%
- 6. Parenting and relationships 63.8%
- 7. Social care 62.9%
- 8. Housing 61.9%
- 9. Feeling safe, police and the justice system 59.2%

Intersectionality

The Autism Partnership Board agreed that we needed to recognise intersectionality.

Intersectionality is a concept for understanding how aspects of a person's identities combine to create different and multiple discrimination and privilege. An intersectional perspective means we need to think about how autistic people may have different experiences depending on other parts of their identity. For example, their age, gender, race and ethnicity.

We worked with different local community groups and organisations to understand the experiences of the diverse local community of autistic people, their unpaid carers and members of their support network.

Culturally and Racially Diverse Communities (black and racially minoritized communities)

Trust for Developing Communities completed a report based on interviews with culturally and racially diverse autistic people and their family members.

Experiences included:

- Significant difficulties accessing an autism diagnosis and the view that there was a racial or ethnic element to the reluctance of others to accept the diagnosis.
- The view that there was little cultural consideration in support groups and services, and this meant that participants were less likely to access support.
- The difficulty of accessing information and advice about autism, support, and services, particularly if English was not someone's first language.

For more information please see the full report [here](#).

Disabled people who are also autistic

Possability People completed a report based on a focus group with autistic people who identify as disabled and have physical or mental health needs.

Experiences included:

- Significant difficulties accessing medical appointments due to a lack of understanding of reasonable adjustments or environments that cause sensory distress.
- Significant difficulties accessing services for healthy eating and exercise due to the lack of understanding of reasonable adjustments and sensory needs.
- Significant difficulties access mental health services due to the lack of reasonable adjustments and poor understanding of autism.

For more information please see the report [here](#).

Autistic People who may not be able to complete the online survey

Assert completed a report based on interviews, focus groups and their experience of working with autistic people without a learning disability. Assert also supported autistic people who could not access the online survey to share their views and experiences.

Experiences included:

- Significant struggles accessing mental health services, a lack of willingness to make adaptations and being told that their services don't work with autistic people. Autistic adults reported when seeking support for mental health conditions (including but not limited to: anxiety; depression; eating disorders; substance and alcohol misuse; self-harm; suicidal ideation and plans; psychosis; paranoia and personality disorders) that they are often advised that these conditions are an expected result of being autistic, and/or that because they are autistic they cannot be supported by mental health services.
- Due to the difficulties of accessing adapted and appropriate mental health support, many autistic people are admitted to mental health hospitals when this could have been prevented by earlier intervention and support.
- Assert need to decline around 14% of their referrals as they are from professionals seeking specialist mental health support for autistic people experiencing significant crisis. Assert staff are not qualified mental health specialists and the organisation does not provide specialist mental health advice or services.

For more information please see the full report [here](#).

Parents and/or unpaid carers of autistic people

The Parent Carers' Council (PaCC), Amaze and The Hangleton & Knoll Project (HKP) completed a report based on focus groups and interviews with parent carers of autistic people.

Experiences included:

- The significant challenge of navigating services, long waiting lists and the difficulty accessing information and advice having a significant impact on the wellbeing of parent carers.
- The significant need for professionals in services such as social care, the police and the NHS to have better knowledge and skills in working with autistic people.
- Autistic young people struggling to access affordable, accessible housing leading to them living with families for longer and relationships breaking down.

For more information please see the report [here](#).

LGBTQ+ Autistic People

We worked with the Ledward Centre LGBTQ+ Neurodiversity group and The Clare Project to better understand the needs of LGBTQ+ autistic people.

Experiences included:

- Trans autistic people said they were often hesitant about seeking a formal autism diagnosis as they were concerned that this would impact on their ability to access gender-affirming healthcare.
- Trans autistic people experienced a higher prevalence of mental health issues and suicidal ideation. They did not experience mental health services as being trans inclusive and this impacted their ability to access support.
- Trans autistic people said that they felt that they were taken less seriously by medical professionals.

Autistic parents

Focus groups were held to explore the experience of autistic people who are also parents.

Experiences included:

- Support services for parents rarely made reasonable adjustments so it was harder for autistic parents to access support, information and advice in relation to parenting.
- Many parents were hesitant to disclose their autism to Childrens' Services because they were concerned about potential discrimination.
- Autistic parents are more likely to have autistic children. However, they felt that professionals did not respect that this meant that they had insight and understanding into the neurodivergent needs of their children.

Autistic women and/or autistic people assigned female at birth

Focus groups were held to explore the experiences of autistic women and/or autistic people assigned female at birth.

Experiences included:

- The perception that autistic women may be more likely to be perceived as ‘difficult’ or ‘challenging’ and have a poorer experience of services as a result. Autistic women and/or autistic people assigned female at birth felt that it was much harder to get taken seriously by health professionals who reportedly held outdated assumptions around autism and gender.
- Autistic women and/or autistic people assigned female at birth were more likely to understand themselves as autistic later in life and many were initially misdiagnosed with mental health conditions such as personality disorders.
- A lack of understanding of how the experiences of menopause and perimenopause may be different for autistic people and how it may make autistic characteristics more apparent.

Equality Impact Assessment

An equality impact assessment has been completed for this strategy. This explores a more detailed analysis of how we can reduce discrimination experienced by the diverse community of autistic people, their unpaid carers and members of their support network. The equality impact assessment can be found [here](#) and the equality data for the autistic people who completed the consultation can be found in Appendix 1.

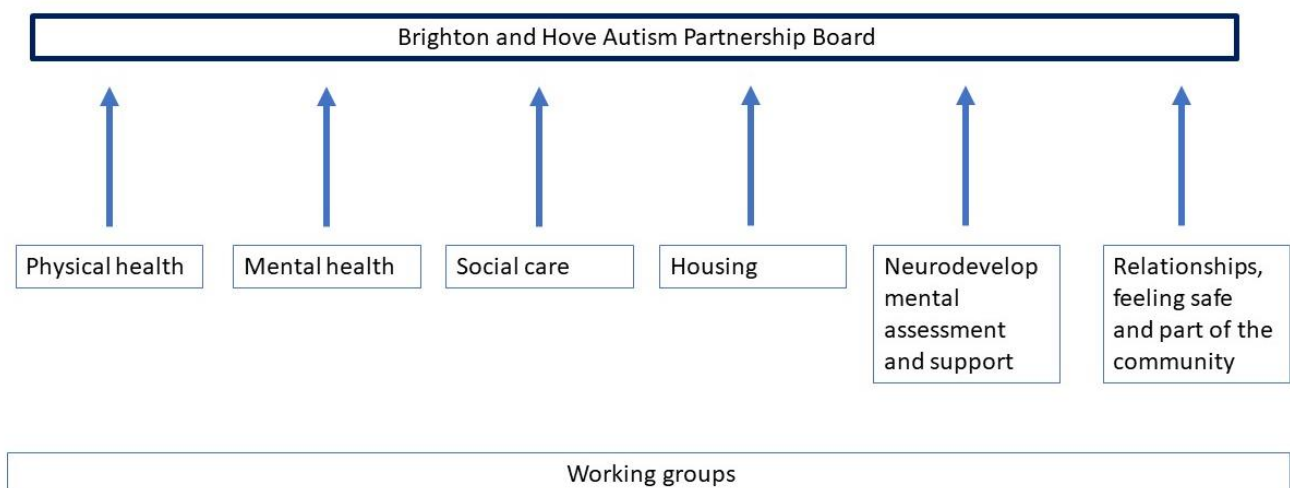
Working groups

Based on this consultation and engagement work, six key themes were agreed:

- Physical health
- Mental health
- Neurodevelopmental assessment and support
- Housing
- Social Care
- Relationships, feeling safe and part of the community

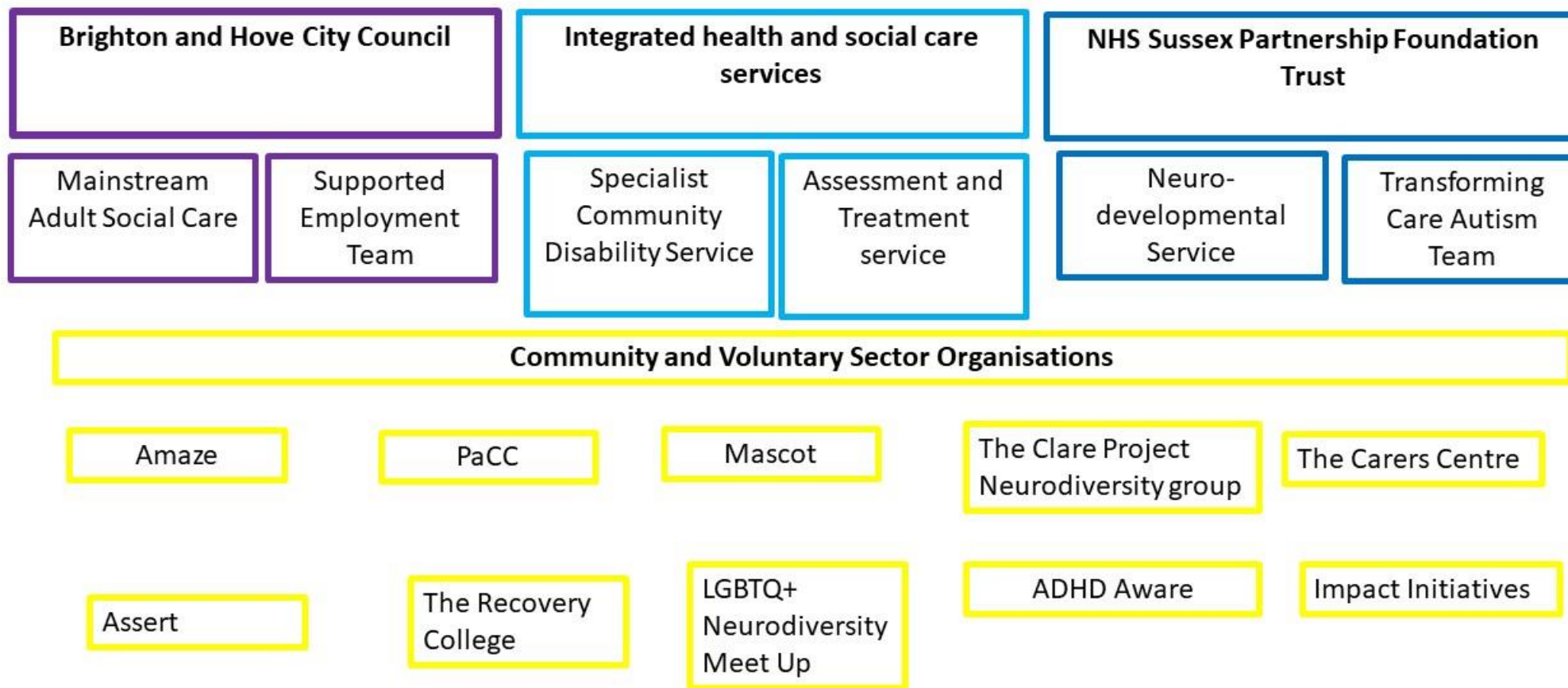
Multiple working groups were held for each key theme in July, August and September 2023. These groups were attended by autistic people, unpaid carers and family members and professionals from statutory and community organisations. In every working group the majority of attendees were autistic. Working groups developed outcomes and actions for each key theme based on the consultation and engagement feedback. These outcomes and actions were then shared with key local decision makers and commissioners to ensure that they were achievable over the five years of the strategy.

Working groups for each key theme will continue over the timeline of the strategy and will prioritise and monitor outcomes and actions. Progress will be reported back to the Autism Partnership Board.



The Local Context

Here is a picture of current services that support autistic (and otherwise neurodivergent) adults and their unpaid carers in Brighton and Hove.



Mainstream Adult Social Care is part of Brighton and Hove City Council. Adult social care staff complete assessments with adults and unpaid carers who may have eligible needs under the Care Act 2014, Autistic adults may be eligible for care and support. Depending on an individual's personal situation this could include:

- information and advice
- equipment or adaptations to help at home
- devices to call for help and keep people safe
- help from a carer
- help to get out and about
- support to move to more suitable accommodation

Adult social care staff also lead safeguarding enquiries for adults at risk of and/or experiencing abuse or neglect in accordance with the Care Act 2014.

The **Supported Employment Team** provide advice or support to autistic people to help them find or maintain work.

The **Specialist Community Disability Service** is an integrated team of social workers and clinical professionals such as psychologists, nurses, speech and language therapists and physiotherapists. The Specialist Community Disability service work with adults with a learning disability. They do not work with autistic adults without a learning disability.

The **Assessment and Treatment Service** provides support and treatment to adults with severe mental health issues. This is an integrated team including social workers, psychiatrists, mental health nurses and occupational therapists. The Assessment and Treatment service completes Care Act assessments and leads safeguarding enquiries for individuals under their service.

The **Neuro-developmental service** provides diagnostic assessments of autism, ADHD and Tourette's Syndrome.

The **Transforming Care Autism Team** supports autistic people either at high risk of admission to a mental health/specialist hospital, or who are ready for discharge from hospital and need support. They are a small team including clinical psychologists, occupational therapists, speech and language therapists and therapy assistants. The Transforming Care Autism Team only work with individuals who have a Lead Practitioner with the Assessment and Treatment service.

There are a range of local community and voluntary sector organisations that work with autistic people and their unpaid carers.

Amaze is a charity that gives information, advice and support to families of children and young people with special educational needs and disabilities (SEND). Amaze supports families including young people with SEND up to the age of 25.

PaCC is the parent carer forum for Brighton & Hove, representing parent carers of children and young people with SEND age 0-25. They work in coproduction with services to improve the outcomes for families in the City.

Mascot is a parent led peer to peer support network for families who have an autistic child/children or young person in Brighton and Hove.

The Clare Project Neurodivergent drop-in is a monthly space where people who are autistic/neurodivergent and also trans, nonbinary, intersex, gender-variant or gender-questioning can come along to connect with each other, chat and find out more about local support services.

The Carers Centre provides emotional support, information, guidance and advocacy to a wide range of carers in Brighton and Hove. This includes a monthly support group for unpaid carers of people with a learning disability and/or autistic people.

Assert is a small, charitable organisation offering support to autistic adults (whether they have a diagnosis or not) across Brighton and Hove and the surrounding area. Assert offers support, including: benefits advice and support; short-term goal-oriented support sessions; in-person short courses; 1:1 short courses; signposting; social groups and activities - including a group for the parents; partners and carers of autistic adults. Assert staff are not qualified mental health specialists and the organisation does not provide specialist mental health advice or services.

The Recovery College offers free educational courses designed and delivered by people with lived experience of mental health challenges, together with clinical staff and other professionals. This includes an 'understanding autism' course delivered in partnership with staff from the local neurodevelopmental service.

The LGBTQ+ Neurodiversity Meet Up is a peer led meet up group for LGBTQ+ people who identify as neurodivergent or are questioning whether they are neurodivergent.

ADHD Aware is a charity based in Brighton that offers peer support groups for adults with ADHD, their partners and parents of children and young people with ADHD.

Impact Initiatives provided 1-1 issue based advocacy for autistic adults. They also facilitate a monthly self advocacy group for autistic adults connected to the Autism Partnership Board.

What are the links to other strategies and initiatives?

The **Sussex Learning Disability and Autism Strategy 2021-24** is based on achieving the following three objectives:

1. Close the gap in physical and mental health outcomes for people with a learning disability, autism, or both.
2. Secure equitable access to early intervention and prevention services across the local NHS.
3. Use the talent, knowledge, and skills of experts by experience to design better services.

LeDeR is a service improvement programme for people with a learning disability and autistic people led by NHS Sussex.

LeDeR works to:

- improve care for people with a learning disability and autistic people
- reduce health inequalities for people with a learning disability and autistic people
- prevent people with a learning disability and autistic people from early deaths

A Sussex wide programme is in place to deliver an integrated strategy to **improve the neurodevelopmental pathway** for local people including approaches to assessment, diagnosis and support for children, young people and adults who may be autistic, have ADHD and/or Tourette's Syndrome. The outcomes and actions of the Brighton and Hove Autism Strategy complement and are aligned to the goals of this ongoing Sussex wide Neurodevelopmental review.

Autistic people have been identified as a priority group in the National Suicide Prevention strategy (Department of Health and Social Care, 2023) and this is reflected in **Brighton and Hove Suicide Prevention Action Plan**.

There are many potential links between the outcomes and actions of the **Brighton and Hove SEND strategy** and the **Brighton and Hove Adult Learning Disability Strategy**, particularly in areas such as accessible transport, improving interactions with the police and improving the transition between childrens' and adult services. The Autism Partnership Board will seek opportunities to work with the SEND and Learning Disability Partnership boards in order to maximise impact.

Feedback from the survey consultation regarding jobs and volunteering will inform the development of the new **City Employment and Skills Recovery Plan**.

The **Accessible City Strategy** has been developed to put accessibility at the heart of how Brighton and Hove City Council designs and delivers services. In line with the Accessible City strategy, we use the language of 'inclusive adjustments' within this strategy to reflect the council's commitment to go above and beyond minimum expectations of legal compliance with the Equality Act 2010.

The Health and Care Act 2022 introduced a requirement that service providers, regulated by the Care Quality Commission, must ensure their staff receive learning disability and autism training appropriate to their role. The **Oliver McGowan Mandatory Training on Learning Disability and Autism** is the standardised training that was developed for this purpose.

The **National Autism Strategy 2021-26** and the **NHS long term plan** support many of the outcomes and actions outlined in this strategy including: developing annual health checks for autistic people, ensuring all local healthcare providers are making reasonable adjustments for autistic people and increasing community support to ensure that less autistic people are admitted to hospital.



Values

The Autism Strategy should be based on these values:

- **Believe autistic people and the people who support them**
- Nothing about me without me – led by autistic people.
- Destigmatise autism
- Using a neuro-affirmative approach that recognises and celebrates autistic culture, communication and values.
- Using a trauma informed and intersectional approach that recognises and accounts for the impact of minority stress that autistic people experience.
- Recognise the needs of unpaid carers and family members and actively engage with them to understand the experience of the autistic person with their permission.
- Making inclusive adjustments that reflect five core autistic needs: Sensory needs, Predictability, Acceptance, Communication and Empathy.



Outcomes that are relevant for all areas

My needs will be met when:

- I am listened and believed as an autistic person.
- Services are flexibly adapted and commissioned to meet my needs instead of labelling me 'too complex' to work with
- When things go wrong, I know how to complain, I am taken seriously, and my concerns will be used to improve services.
- Services make adaptations to my needs and explore why I am struggling to engage before stopping working with me.
- I do not experience trauma caused by services.
- If I am supported by an unpaid carer or family member, services consider their needs and wellbeing.

Relationships, feeling safe and part of the community

What did people say their experiences were in this area?



There is a large autistic community in Brighton and Hove. This a real strength that we can celebrate as a city but there is a lot of work we need to do.



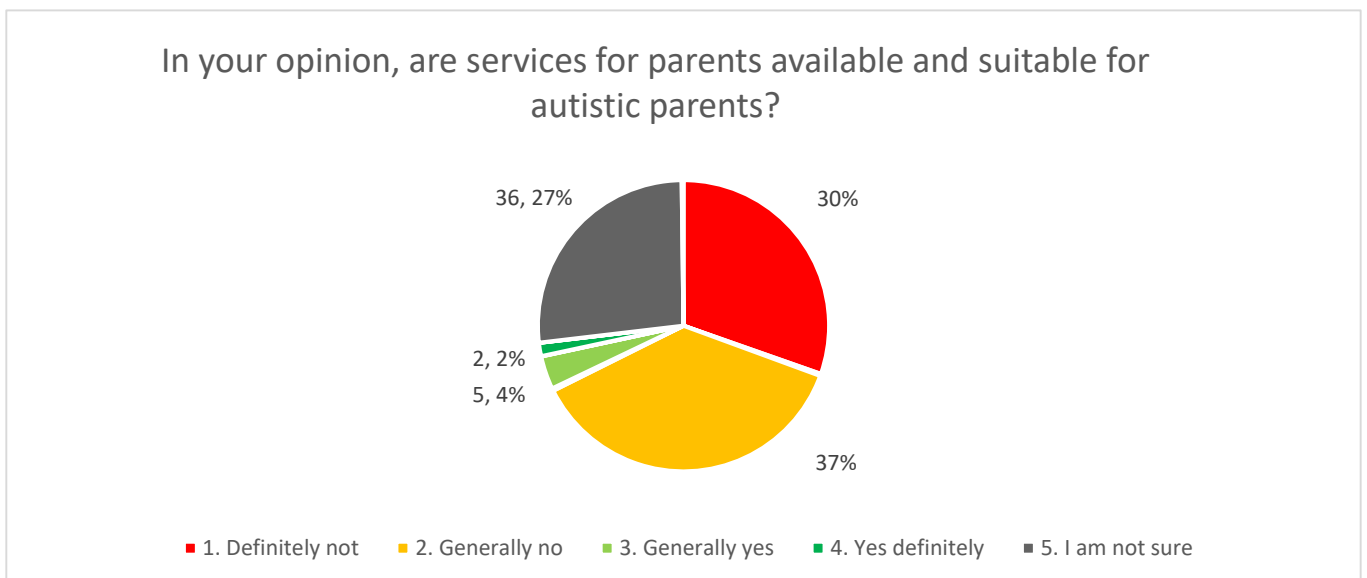
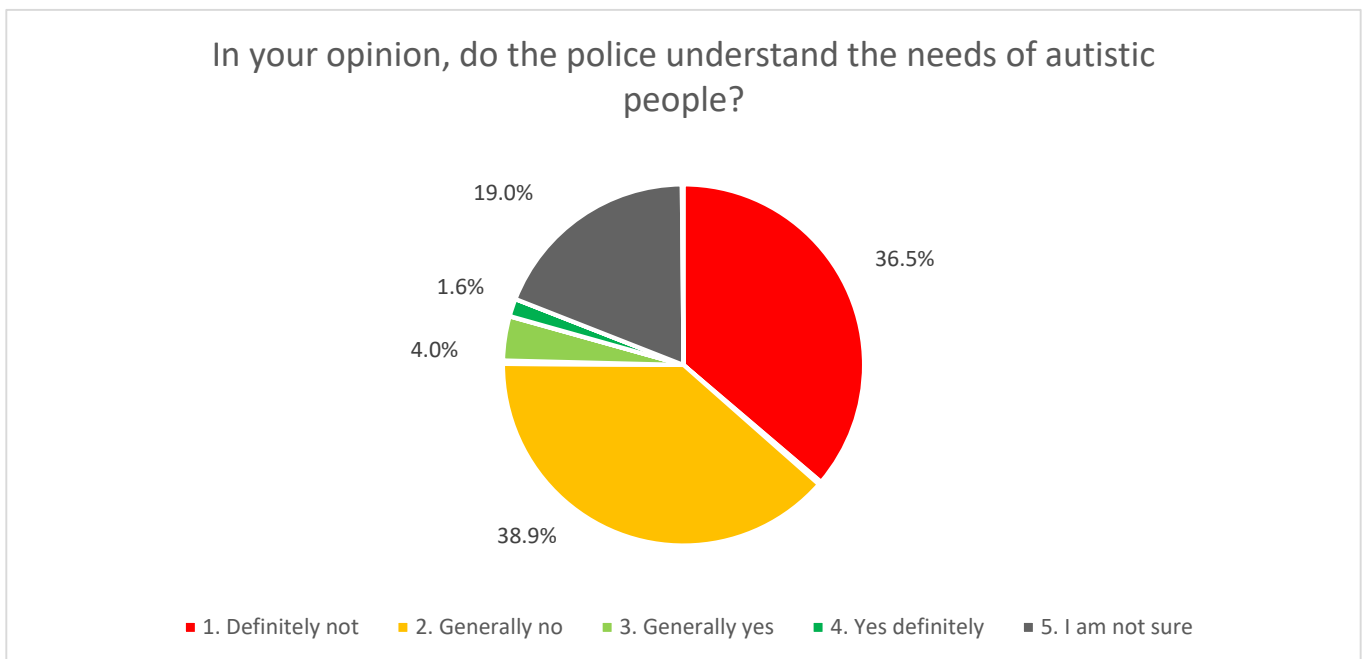
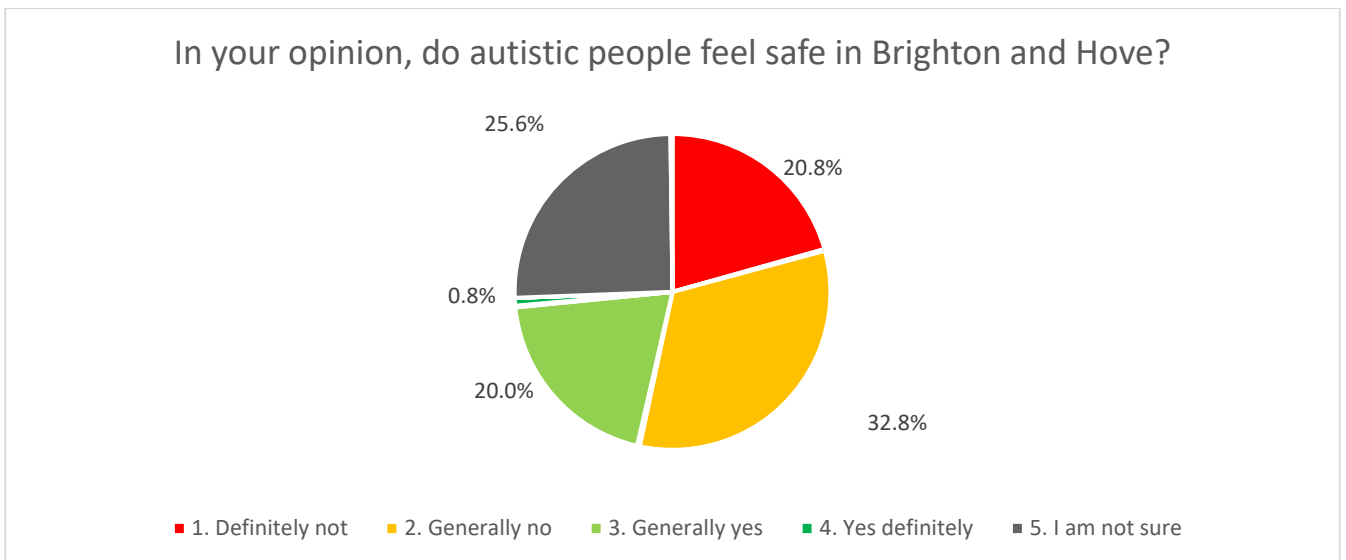
Unfortunately, many autistic people reported experiences of harassment from other members of the public and reported negative experiences of the police. Autistic people reported that the police had limited understanding of their communication differences, sensory needs, and the experience of meltdown and shutdown. They reported that stimming could be perceived as anti-social, violent or disruptive and could lead to arrest or restraint.

Autistic people can be more vulnerable to abuse (Person *et al.*, 2022) and survey respondents wanted more support around identifying and leaving unhealthy relationships and friendships.



Many autistic people felt socially isolated. The Office for National Statistics (2022) says that only 29% of autistic people are in paid employment. Many autistic people told us that the cost-of-living crisis was having a significant impact on their wellbeing and ability to access community activities leading to further isolation. Brighton and Hove can also be very overwhelming to the senses with bright lights, noise and is particularly busy in the summer.

This is what we were told as part of the online consultation survey:





Outcomes - Relationships, feeling safe and part of the community

My needs will be met when:

- I know that when I interact with the police, they will make inclusive adjustments and understand my needs as an autistic person.
- I am not socially isolated, I have support to have healthy relationships and know how to recognise and leave unhealthy relationships and friendships if I want to.
- I can access support with the cost of living.
- I can access shops and services in the city centre and in my neighbourhood. I know where I can go when I am feeling overwhelmed.



Housing

What did people say their experiences were in this area?

Autistic people want and need safe, stable living environments that meet their sensory needs. Unstable and inaccessible housing can have particularly detrimental impacts on autistic people due to sensory sensitivities and autistic needs for consistency, stability, and predictability (NDTI, 2020). A safe and stable home is key in enabling autistic people to decompress from overwhelming sensory environments.

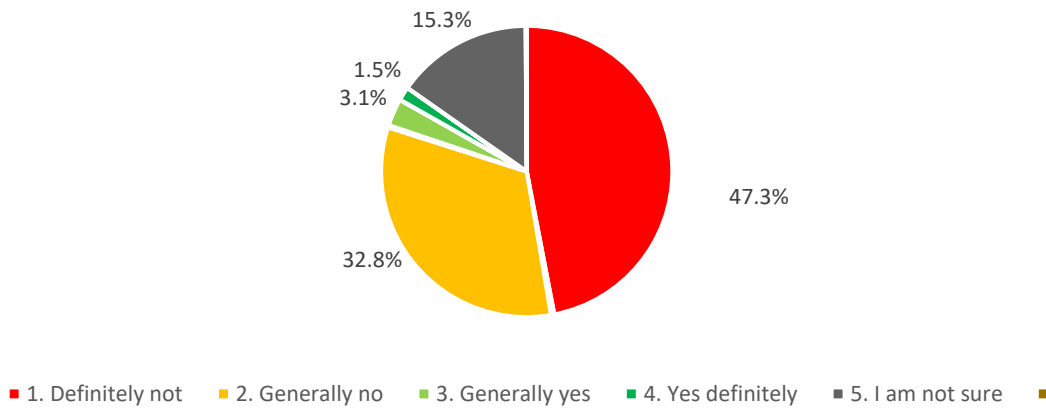


Housing in Brighton and Hove is very expensive. National policies around housing benefit are based on people under the age of 35 sharing with others. This is often not accessible for autistic people who need their own space.

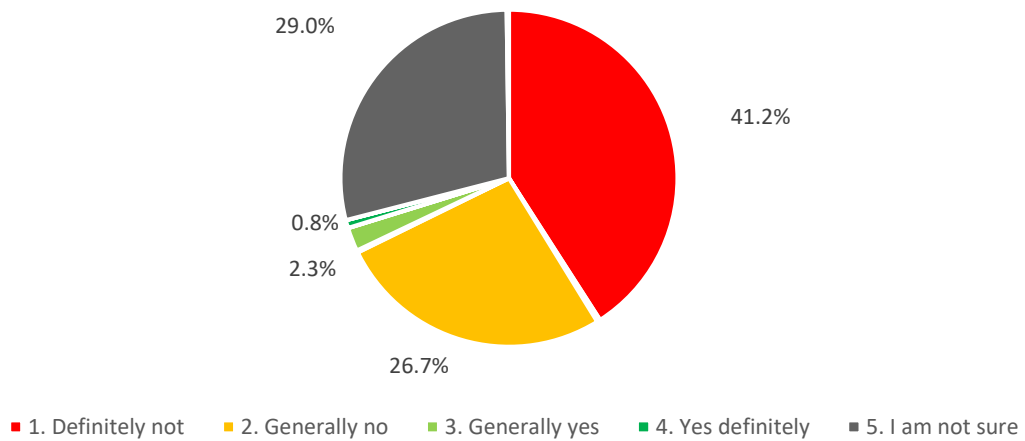
This means that young autistic people are likely to stay living with family or guardians for longer. Relationships can often break down and the autistic person can need to move out of the local area and away from their support networks or become homeless. Research suggests that autistic people are more likely to be homeless and this is made worse by barriers to services (Stone, Cameron and Dowling, 2023). Autistic people said that their sensory needs were not taken into account when trying to find a home and emergency, temporary and supported accommodation was often not accessible. Autistic people found it particularly difficult when there was conflict with neighbours and landlords and this led to a significant impact on their wellbeing.

This is what we were told as part of the online consultation survey:

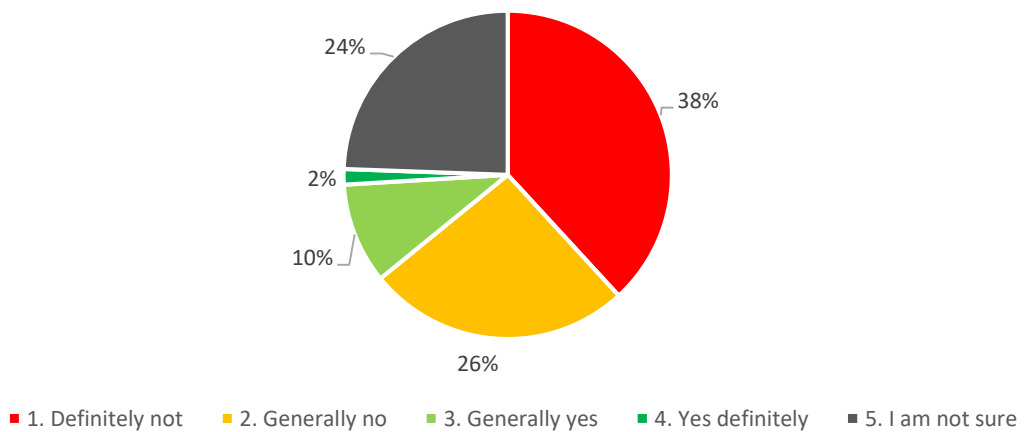
In your opinion, can autistic people in Brighton and Hove access suitable and available housing that meets their needs?



In your opinion, do council housing staff understand autism and the needs of autistic people?



In your opinion, is information about housing easily understood and accessible to autistic people?





Outcomes – Housing

My needs will be met when:

- I have clear and accessible information about housing.
- Inclusive adjustments are made to enable me to access support around my housing.
- I can access safe housing that meets my sensory needs, whether it is private or council housing.
- I am less likely to become homeless. If I am homeless, I can access support from staff that understand my needs.



Mental health

What did people say their experiences were in this area?

Mental health was seen as the most important area by those people who completed the consultation survey. Autistic people reported that they were often told by NHS talking therapies and secondary mental health services that they were 'too complex to work with' or that their service does not work with autistic people. As a result, many autistic people were not able to access support with their mental health. Autistic adults without a learning disability are 9 times more likely to die by suicide (Autistica, 2021) and almost 80% of autistic adults experience mental health conditions (Autistica, 2019). Autistic people have been identified as a priority group in the National Suicide Prevention strategy (Department of Health and Social Care, 2023) and this is reflected in Brighton and Hove Suicide Prevention Action Plan.



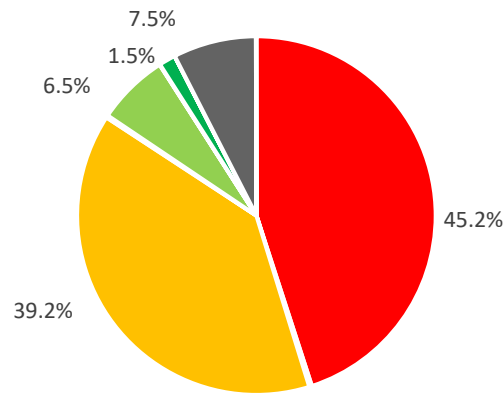
Autistic people who were supported by mental health services said that there was a lack of understanding and inflexibility around inclusive adjustments. Mental health interventions that were not adjusted for autistic people were experienced as ineffective or harmful.



There were significant issues with accessing crisis services. These included needing to be able to use the phone to access support, different clinicians, the inaccessibility of Accident and Emergency and risk assessments not taking into account how autistic people may present differently when in crisis. It is particularly important to consider how to reduce barriers for mental health services for trans autistic people. Autistic women and/or people assigned female at birth are likely to be misdiagnosed with mental health conditions, such as personality disorders (McCrossin, 2022), and report that treatments for misdiagnosed conditions can be harmful and can be the cause of further mental health issues.

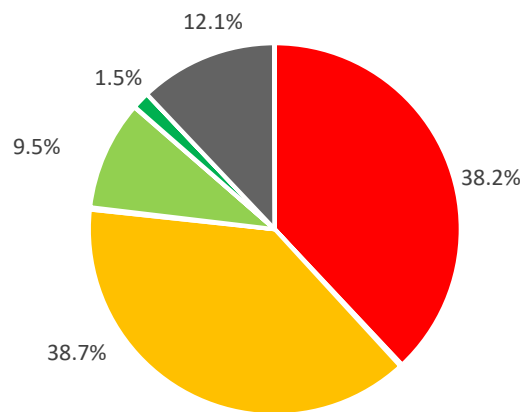
This is what we were told as part of the online consultation survey:

In your opinion, are mental health services suitable and available for autistic people?



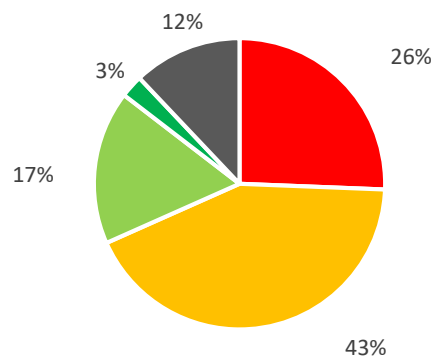
1. Definitely not 2. Generally no 3. Generally yes 4. Yes definitely 5. I am not sure

Is support accessible for autistic people when they are having a mental health crisis?



1. Definitely not 2. Generally no 3. Generally yes 4. Yes definitely 5. I am not sure

In your opinion, do staff who work for mental health services understand autism and the needs of autistic people?



1. Definitely not 2. Generally no 3. Generally yes 4. Yes definitely 5. I am not sure



Outcomes – Mental health

My needs will be met when:

- I can access support for my mental health, and I am not prevented from accessing mental health support due to my autism.
- I can access clear, accessible, and up to date information about where to go for help with my mental health.
- I know that professionals, especially my GP, understand my mental health needs and how these might present differently as an autistic person.
- I can access different models of mental health support that are adapted to meet my needs as an autistic person and prevent me from experiencing a mental health crisis. As a result, fewer autistic people are admitted to mental health hospitals.

Physical health

What did people say their experiences were in this area?



Some autistic people said they were supported well by their doctor, but experiences were very inconsistent particularly in relation to GP surgeries making inclusive adjustments. Clinical environments can be very inaccessible due to short appointments, bright lights, noisy waiting rooms and not knowing how long you may need to wait for an appointment. The local accident and emergency department and inpatient environments were perceived to be hostile and extremely inaccessible.



There are other significant barriers to autistic people accessing physical health services. These include: having to make appointments over the phone or through inaccessible online forms, and the difficulty of getting appointments when your supporter is available. Accessing healthcare in these circumstances can be very stressful. Autistic people said that when they communicated frustration at inclusive adjustments not being made, they were perceived as being 'difficult' and trust and communication can break down.



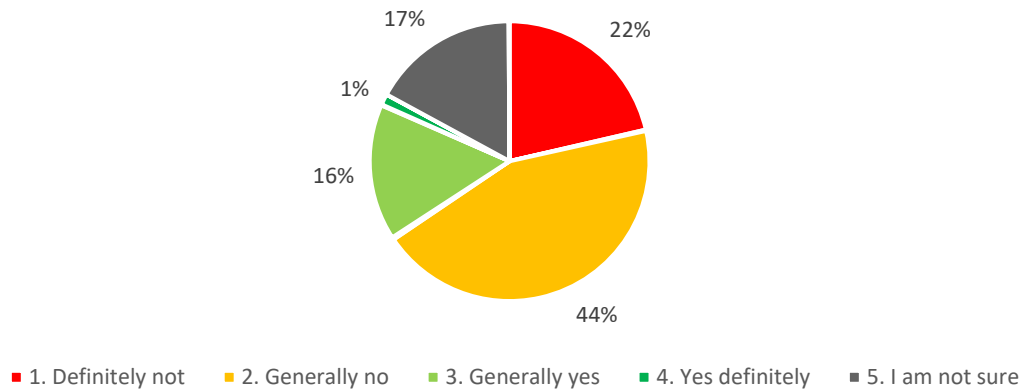
If autistic people were able to access an appointment, they reported it can often be very difficult to be listened to and believed by health staff. This was especially true for women and/or people assigned female at birth, trans people and those from Black and racially minoritised communities. Autistic people said that there was a lack of understanding of how being autistic, masking and differences in interoception might impact your experience of physical health, tests and interventions. There was a limited understanding of how autistic people experience autistic burnout, pain, medication and hormonal changes including menopause.



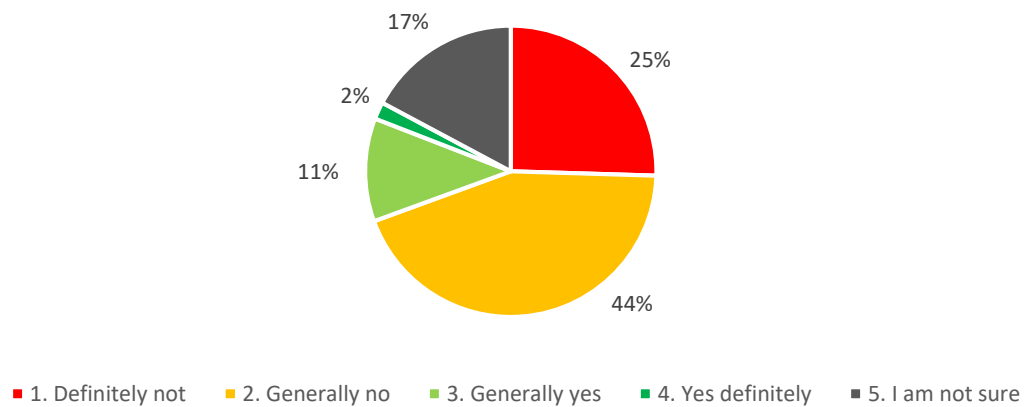
Due to these negative experiences many autistic people said that they did not feel comfortable seeking medical help when they really needed it.

This is what we were told as part of the online consultation survey:

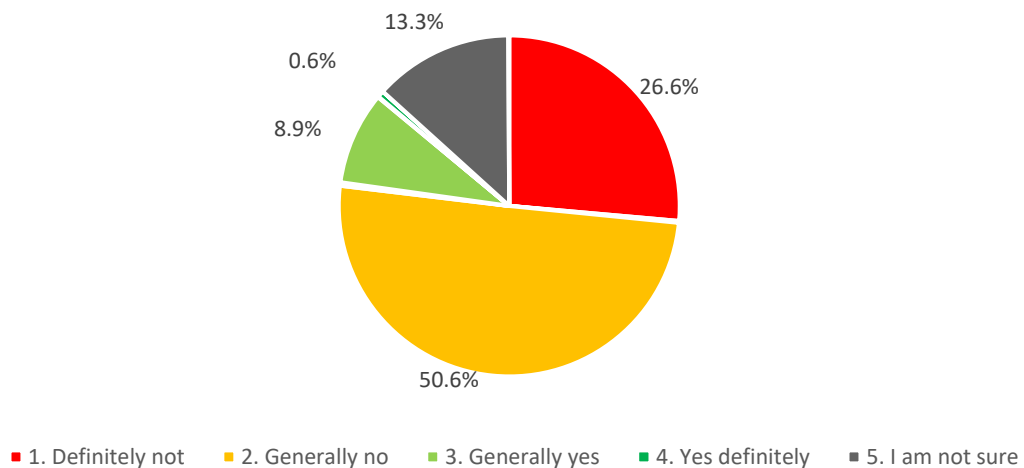
In your opinion, do staff at your local doctor's or GP surgery understand what autistic people need to use their service?



In your opinion, do staff at the hospital or specialist clinics understand what autistic people need to use their service?



In your opinion, are autistic people easily able to get the help they need from physical health services and staff?





Outcomes – Physical health

My needs will be met when:

- I can access the healthcare support I need, and inclusive adjustments will be proactively offered and noted on my file where necessary.
- I can access an annual health check that aims to reduce the known health inequalities that I may experience as an autistic person.
- I can access clinical environments and waiting rooms without significant sensory distress.
- My health professionals understand how neurodivergence may be associated with particular health conditions, may impact how I experience my body and my ability to report symptoms, and can make adaptations to health advice based on my situation and personal circumstances.
- I can access a dentist who is sensitive to my needs as a neurodivergent person.



Social care

What did people say their experiences were in this area?

Autistic people report that getting a social care assessment was very difficult and not accessible for autistic people. There were some good experiences of individual social workers, but overall autistic people felt that autism was poorly understood. Lots of dangerous and outdated assumptions were made about the needs of people who present as very reflective, highly verbal and can mask their support needs. Older people were less likely to have a diagnosis and more likely to have support through mainstream service providers who were not always able to understand their needs.



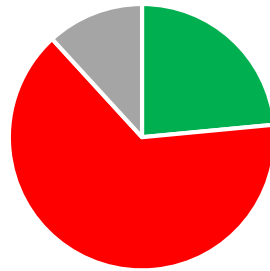
There were very unclear pathways to support, and services were experienced as working in isolation which created delays and barriers to accessing support. There are currently no specialist service providers locally for autistic people without a learning disability and the lack of support available puts significant pressure on unpaid carers and/or family members.



Parents and carers who are also autistic said that staff in Childrens' Services have a poor understanding of autism. Autistic parents regularly experience 'parent-blame' and assessments and support plans do not reflect neurodivergent strengths and parenting styles nor consider inclusive adjustments. Negative perceptions of autistic parenting and negative experiences of services mean that parents and carers often do not tell services that they are autistic and may not seek out diagnosis or support because of fears of discrimination.

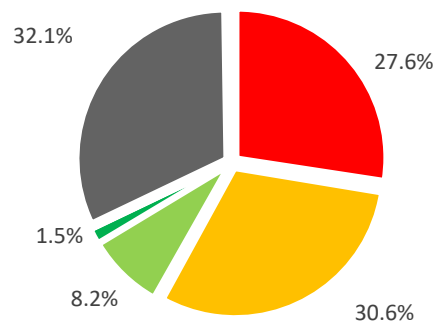
This is what we were told as part of the online consultation survey:

Have you had a carers assessment? (answered by respondents who identified as an unpaid carer or family member)



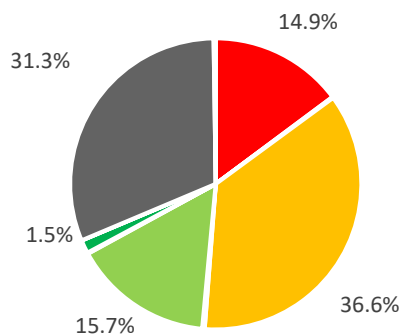
■ yes ■ no ■ I don't know

In your opinion, can autistic people and their unpaid carers easily get a social care assessment when they need one?



■ 1. Definitely not ■ 2. Generally no ■ 3. Generally yes ■ 4. Yes definitely ■ 5. I am not sure

In your opinion, do assessment staff – like social workers – understand autism and the needs of autistic people and their unpaid carers?



■ 1. Definitely not ■ 2. Generally no ■ 3. Generally yes ■ 4. Yes definitely ■ 5. I am not sure ■



Outcomes – Social care

My needs will be met when:

- I can access clear, accessible and up to date information about social care.
- I can co-produce a social care assessment with the inclusive adjustments I need to participate.
- Social care assessment staff have the knowledge and skills to make inclusive adjustments to their service, understand autistic culture, communication and values, and co-produce an assessment with me that well reflects the breadth of my needs.
- Social care support providers have the knowledge and skills to support me as an autistic person and I can access specialist support if I need to.
- Social care support promotes stability and reduces the risk of me experiencing a crisis and/or autistic burnout.
- If I do experience a crisis and/or autistic burnout there will be appropriate and accessible services to support my wellbeing and recovery.
- I know that Childrens' services will take a neuro-affirmative and strengths based approach to working with autistic parents and carers.

Neurodevelopmental assessment and support

What did people say their experiences were in this area?



There were significant barriers in the first steps of accessing a diagnosis and autistic people said many GPs were dismissive and discouraged them from seeking a diagnosis. This was particularly the experience of women and/or people assigned female at birth, trans people, and people from culturally and ethnically diverse communities.

Most autistic people had very positive feedback about the staff at the local Neurodevelopmental service. However, long waiting lists for assessment were very challenging and had a significant impact on wellbeing. Not all autistic people want to seek an autism diagnosis, particularly trans people who are concerned it will impact on their ability to access gender-affirming healthcare. However, for many, understanding themselves as autistic and was crucial in terms of their identity, self-esteem, sense of community, understanding of life history and ability to access appropriate services. Many in the autistic community have also argued that access to diagnosis is key in reducing the rates of autistic people who die by suicide (INSAR, 2021). Many respondents said there was significant potential in peer support and sharing experiences and learning from other autistic people.

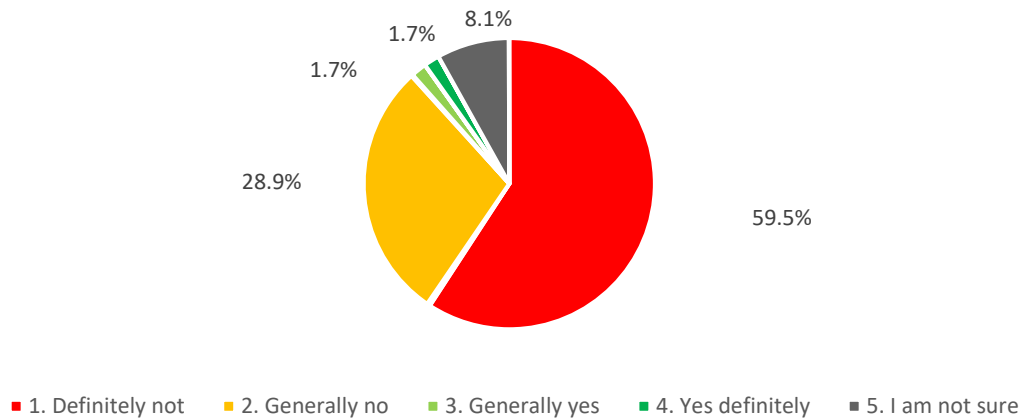


Services were seen as working in isolation. Autistic people, unpaid carers and staff wanted services to work in more integrated and multi-disciplinary ways. It was argued that health and social working together would help people have a more holistic understanding of their needs and better access support.

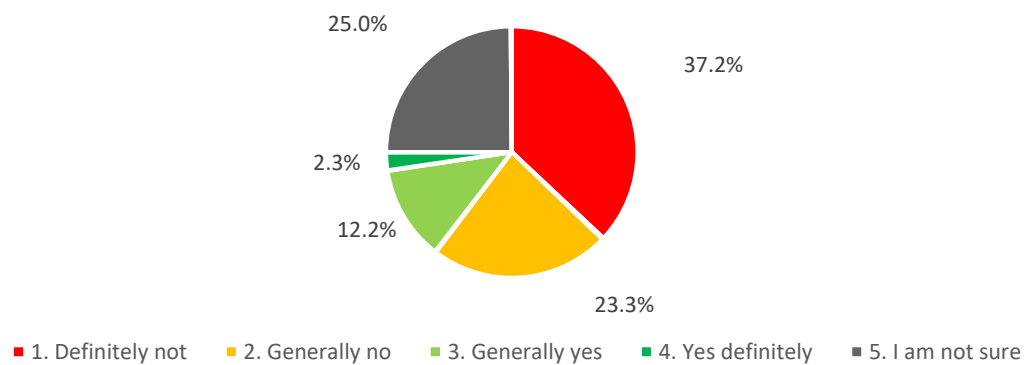


This is what we were told as part of the online consultation survey:

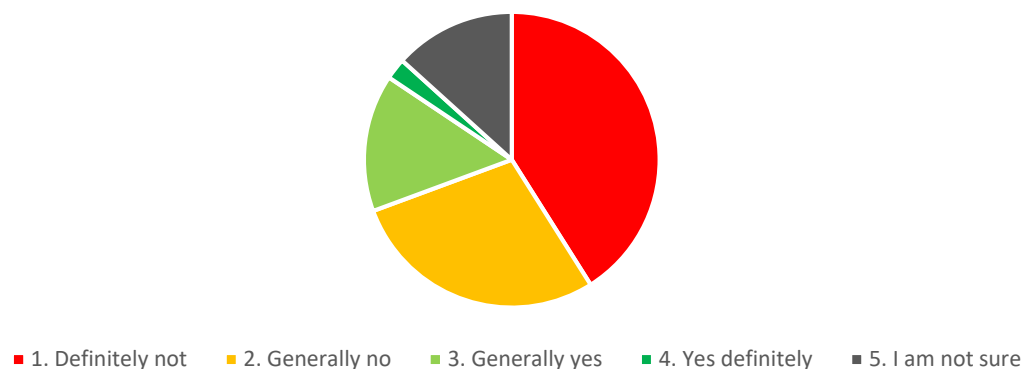
In your opinion, do autistic people and their unpaid carers get the support they need whilst on the waiting list for an autism diagnosis?



In your opinion, do autistic people and their unpaid carers get the support they need from the Neurodevelopmental service after an autism diagnosis?



In your opinion, do autistic people and their unpaid carers have the support they need to understand the different stages of an autism diagnosis?





Outcomes - Neurodevelopmental assessment and support

My needs will be met when:

- I know where I can go to meet people who can understand my experience and support me to explore my autistic identity.
- I have access to clear information and advice about support available to me as an autistic person or an unpaid carer.
- I can access a timely assessment of my neurodevelopmental needs and strengths.
- If I have an unpaid carer or family member, they know how they can access support for themselves.
- I can access services based on my need whether I have an NHS, private or self-diagnosis.

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Appendix 1

Equality data of autistic people who answered the consultation

135 autistic people completed the equality data at the end of the consultation and some chose not to answer some of the questions.

Age group		
	Frequency	Percent
18 to 24	5	3.8
25 to 54	105	80.8
55 or older	20	15.4
Total	130	100.0

What gender are you?		
	Frequency	Percent
Female	72	57.1
Male	22	17.5
Non-Binary	27	21.4
Other, please give details below	5	4.0
Total	126	100.0

Do you identify as the sex you were assigned at birth? For people who are transgender, the sex they were assigned at birth is not the same as their own sense of their gender.		
	Frequency	Percent
Yes	92	76.0
No	29	24.0
Total	121	100.0

How would you describe your ethnic origin?		
	Frequency	Percent
Any other Asian background	1	0.8
Black or Black British: Caribbean	1	0.8
Mixed: Asian and White	1	0.8
Mixed: Black African and White	1	0.8
Mixed: Black Caribbean and White	4	3.4
Any other mixed background	2	1.7
White: English / Welsh / Scottish / Northern Irish / British	94	79.7
White: Gypsy or Irish Traveller	1	0.8
Any other White background	9	7.6
Any other ethnic group	4	3.4
Total	118	100.0

"BME"		
	Frequency	Valid Percent
White UK/British	94	79.7
BME	24	20.3
Total	118	100.0

Which of the following best describes your sexual orientation?		
	Frequency	Valid Percent
Bisexual	26	24.1
Gay	10	9.3
Heterosexual/'Straight'	41	38.0
Lesbian	13	12.0
Other (please give detail below)	18	16.7
Total	108	100.0

LGB+		
	Frequency	Percent
Heterosexual/'Straight	41	38.0
LGB+	67	62.0
Total	108	100.0

What is your religion or belief?		
	Frequency	Valid Percent
I have no particular religion	64	54.2
Buddhist	5	4.2
Christian	13	11.0
Jewish	4	3.4
Pagan	4	3.4
Sikh	1	0.8
Agnostic	8	6.8
Atheist	10	8.5
Other religion	4	3.4
Other philosophical belief	5	4.2
Total	118	100.0

Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last at least 12 months?

	Frequency	Percent
Yes a little	58	44.3
Yes a lot	62	47.3
No	11	8.4
Total	131	100.0

Are you a carer? a carer provides unpaid support to family or friends who are ill, frail, disabled, or have mental health or substance misuse problems.

	Frequency	Percent
Yes	32	25.4
No	94	74.6
Total	126	100.0

Connection to armed forces

	Frequency	Valid Percent
Yes	1	0.9
No	111	99.1
Total	112	100.0