# Autism Care Pathway in Bromley 18+

A report by Healthwatch Bromley



January 2020



## "Autism Forward are an amazing charity. I still use their service to help my son gain employment."

Local family

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## Introduction

#### Who we are and what we do

Healthwatch Bromley is the independent champion for people using local health and social care services. We listen to what people like about services and what could be improved. We share their views with those with the power to make change happen. People can also speak to us to find information about health and social care services available locally.

Our sole purpose is to help make care better for people by:

- Providing information and advice to the public about accessing health and social care services and choice in relation to those services.
- Obtaining the views of people about their needs for, and experience of, local health and social care services and make those views known to those involved in the commissioning and scrutiny of care services
- Making reports and recommendations about how those services could or should be improved
- Promoting and supporting the involvement of people in the monitoring, commissioning and provision of local health and social care services.
- Making the views and experiences of people known to Healthwatch England and helping it to carry out its role as national champion
- Making recommendations to Healthwatch England to advise the Care Quality Commission to carry out special reviews or investigations into areas of concern

Healthwatch Bromley carried out a research project in the London Borough of Bromley considering adults 18+ years who live in the Borough and who have a diagnosis under the Autistic Spectrum Condition (ASC). The aim of this project was to: hear the experiences of people with this condition; gain a greater understanding that would help to improve local health and social care services; review the local strategies; and inform an Autism Care Pathway for Bromley.

The Autism Act 2009 is a piece of disability legislation in England which requires the provision of a governmental strategy for improving the services to individuals living with ASD. The NHS, alongside local authorities, is responsible for implementing strategies in different areas such as training, identification and diagnosis, planning, employment and criminal justice.

In March 2010, the Department of Health published the first Autism strategy for England. The strategy "Fulfilling and rewarding lives: the strategy for adults with Autism in England", focused on five core activities:

- To increase professionals' awareness and understanding of Autism
- To develop a clear and consistent pathway for diagnosis in every area
- To improve access to services and to provide support for individuals to be able to live independently within the community
- To provide help and support into employment
- To enable local partners to plan and develop services that would meet identified needs and priorities.

In December 2010, the Department of Health and Social Care published guidance to enable local authorities and the NHS to develop their own adult Autism strategy. The guidance focused on the following key areas (House of Commons overview, 2020):

- Provision of training services for staff
- Assessment of needs for services, identification, and diagnosis of Autism
- Planning and provision of services in relation to ageing (children to adults)
- Local planning and leadership in relation to the provision of services for adults.

The Department of Health and Social Care and the Department of Education are currently undertaking a review of the adult strategy. The new document was intended to be published by the end of 2019. The current strategy is still in effect; however, the Government has committed to extend the strategy to cover children, young adults, and adults with Autism.

## Acknowledgements

We would like to extend our sincere thanks to all the families and individuals across Bromley who took the time out to complete the online survey and openly share their views and experiences of accessing services. Without them, this project would not have been successful. We would also like to acknowledge the advice and support we received from individuals, organisations and services across Bromley who work with the Autism community, in particular Carol Ellis, Lisa Lamb, Rob Morgan, Tracey Crockford, Isaac Lee and Helen Dyer.

## What is Autism?

Autism is a spectrum disorder that describes a group of neurodevelopmental disorders. It is a lifelong disability that affects the individual's brain. Therefore, people with ASC often demonstrate restricted, repetitive and stereotyped interest or patterns of behaviour. This means that individuals with Autism may behave and act in a different way to other people. As every individual is unique, people affected by this condition will present with a wide spectrum of needs, in that some may require everyday support, and others, little or no support.

### What Causes Autism?

ASC is recognised in individuals around the world, regardless of factors such as race, culture, or socioeconomic background. Currently, the cause of Autism is unknown; however, some possible contributing risk factors might include:

- Genetic mutations
- A family member with Autism
- Various genetic disorders
- Pregnancy in older age
- Low birth weight
- Viral infections
- Metabolic imbalances
- Exposure to some heavy metals and/or environmental toxins
- Foetal exposure to the medications valproic acid or thalidomide.

The National Institute of Neurological Disorders and Stroke (NINDS considers that genetic and environmental factors might influence whether an individual develops Autism.

### Treatment Approach

Although there is no 'cure' for Autism disorder, various therapies and alternative treatment can help to manage the condition. Treatment results will vary, as some people on the spectrum may respond well, while others might not.

Treatment therapies typically include: speech; physical; behavioural; play and occupational therapy.

### National Level

Numerous diagnostic descriptions have been used to name Autism, such us: Autism Spectrum Condition (ASC), Autism Spectrum Disorder (ASD), classic Autism, Asperger syndrome, Kanner Autism, Pervasive Developmental Disorder (PDD) and Pathological Demand Avoidance (PAD). For the purpose of this report, Autism will be referred to as Autism Spectrum Condition.

The National Autistic Society (2019), suggests that ASC currently affects approximately 700,000 people in the United Kingdom (1-100). Autism is a part of the daily life of approximately 2.8millon of people if family and carers are included. The research shows that the level of awareness about Autism Spectrum Condition in the UK is satisfactory. Approximately 99% of research participants have heard about the disorder; however, understanding and knowledge of ASC is limited (YouGov, 2015).

This condition imposes a high cost on the wider UK economy. Annual treatment costs are estimated at around £32 billion and the average lifetime support of an individual on the spectrum costs £1.5 million (Beyond Autism, 2020).

Although the spectrum disorder will vary for every individual, some people affected may require daily care and others may be partially or fully independent. Furthermore, the research shows that 85% of those on the autistic spectrum (autistic society) do not work full time (Beyond Autism, 2020).

## NHS Long Term Plan

The NHS has a crucial role to play in helping people with a Learning Disability, Autism or both, to lead longer, happier and healthier lives. Under the NHS Long Term Plan, in which thousands of people across the country were engaged, a strategy has been drawn up, to:

- Improve community-based support so that people can lead lives of their choosing in homes not hospitals; further reducing reliance on specialist hospitals and strengthening focus on children and young people.
- Develop a clearer and more widespread focus on the needs of autistic people and their families, starting with autistic children with the most complex needs
- Make sure that all NHS commissioned services **provide good quality health**, **care and treatment to people with a learning disability and to autistic people and their families.** NHS staff will be supported to make the changes needed (i.e. reasonable adjustments) to make sure people with a learning disability and autistic people get equal access to, experience of and outcomes from care and treatment.
- **Reduce health inequalities** by: improving uptake of annual health checks; reducing over-medication through the 'Stopping The Over-Medication of children and young People with a learning disability, Autism or both' (STOMP) and 'Supporting Treatment and Appropriate Medication in Paediatrics' (STAMP)

programmes; and taking action to prevent avoidable deaths through the 'Learning from Deaths' Reviews (LeDeR)

- Continue to champion the insight and strengths of people with lived experience, and their families, in all of our work and become a model employer of people with a learning disability and of those with Autism.
- Ensure that the whole NHS has an **awareness of the needs of people with a learning disability and those with Autism**, working together to improve the way it cares, supports, listens to, works with and improves the health and wellbeing of them and their families.

## Methodology

Healthwatch Bromley, working in partnership with the London Borough of Bromley Commission lead for Autism, developed a small but detailed survey to gain a greater understanding of the Autism care pathway in Bromley.

The aim of this research survey was to:

- 1. Understand the Autism Care Pathway for adults 18+.
- 2. Gather information about the experience of people who live with Autism and / or their family's experience.
- 3. Explore the experience of those on the spectrum and their families (family and patients' experiences) when accessing Health and Social Care services in the borough.

The Autism care pathway services in Bromley are divided into specific areas:

- 1. Diagnosis and Assessment
- 2. General Support and Advice
- 3. Counselling
- 4. Employment
- 5. Social Support Centres
- 6. Residential
- 7. In-patient Units
- 8. Ad Hoc Leisure Activities

These groups respond to patients' needs and provide ongoing support to adults with ASC. Healthwatch Bromley used an online survey that was available in hard copy (Appendix).

## The Survey

Healthwatch Bromley collected 40 survey responses that helped to identify and acknowledge accessibility of services and also identify any gaps.

The online survey was available for two months from November 2019 to January 2020.

The survey contains five sections, with questions regarding:

- a) Diagnosis
- b) Support and needs of the participant
- c) Participant experience
- d) Use of services
- e) Information about the participant

The survey was sent out to the key stakeholder providers to promote and encourage the service user groups to complete the survey. Both online and a hard copy version were available, with a freepost address.

#### Key stakeholders engaged

- 1. Bromley Well
- 2. Bromley Mencap
- 3. Advocacy for All
- 4. Choice Support
- 5. CASPA (Children on the Autistic Spectrum Parent's Association)
- 6. Early Intervention and Family Support
- 7. Kings College Hospital NHS Foundation Trust
- 8. Bromley Third Sector Enterprise
- 9. London Borough of Bromley
- 10. Public Health Bromley
- 11. Sanctuary Supported Living
- 12. Bromley Clincal Commissioning Group

## Strengths and Limitations

Healthwatch Bromley's research project has both strengths and limitations. This project aimed to gather information about local services within the borough and focused on the patient's experience of those who live with the Autism Spectrum Condition (ASC) and their families. The research was not an evaluation of the Health and Social Care services; however, it provided a general overview of the available support and the need for further improvements.

Seventy percent of the respondents were parents or carers who generously gave their time and to share their experiences with Healthwatch Bromley. This report does not, therefore, represent the whole ASC population of the borough. The research allowed us to gather information about the services and also, highlighted the difficulties that individuals with Autism and their families have experienced when accessing available support services.

## Report layout

The report looks at each survey section and question in turn. The findings are given in an executive summary at the start of each section. This is followed by charts and data for each question and example quotes where appropriate.

## **Executive Summary**

Autism (ASC) is a lifelong developmental disability that affects how a person communicates with, and relates to, other people, and how they experience the world around them (NAS, 2018b). No two people with ASC are the same; however, autistic people share common difficulties in three areas: social interaction; social communication; and imagination (Lai et al., 2014).

The NHS Long Term Plan on Autism and learning disabilities identified key clinical priorities for improvement of services over the next ten years, with a focus on developing services at both national and local level.

ASC is high on the agenda across Bromley, with a drive towards the development of an Autism and Learning Disability strategy for Bromley, in line with the Autism Act 2009. Local authorities and NHS services have a statutory duty to ensure that services are in place to meet the needs of individuals and their families living with ASC.

With an awareness of the national context of ASC and the London Borough of Bromley's local priority to review and update the Autism and Learning Disability strategy, we aimed to explore services accessibility across care pathways and impact further. We wanted to explore the perspectives and experiences of adults with Autism, and their families, of accessing help and support from local health and social care services and whether the individual living with Autism and their families were getting the right help and support. The method and approach adopted involved quantitative and qualitative data captured through the use of online and hard copy surveys. A total of 40 people completed the survey, of which 12 were completed by people with Autism and 28 by carers/family members.

1. Over half reported receiving the ASC diagnosis, by health care professionals, within the first year of seeking a diagnosis, while a significant number waited more than one year, and some up to four years. One third stated they had been misdiagnosed before receiving their formal diagnosis. There were mixed

experiences once a formal diagnosis had been received. In some cases, it enabled easier access to services and support. Despite this, some experienced lack of involvement in their care and treatment and varying levels of stigma, discrimination and neglect across health, social care, and educational settings. This highlights the need for greater training, awareness and understanding of Autism across health, social care, and educational service pathways, particularly in mental health services, schools, and colleges.

- 2. Over half reported a lack of support and assessment for their care needs. Increased access to employment opportunities and social activities were highlighted as key areas requiring improvement. Some had recognised the benefits of receiving support services through the direct payments schemes but reported these services were often outside the borough boundaries. Another area that required particular attention and improvement was some families' experience of long waiting times to access support services. Some also mentioned the need for carer and advocacy support.
- 3. There were significant levels of unmet needs for those who failed to receive an assessment of their care needs. This resulted in parents feeling that they were living without any adequate support from the borough and that their adult children with Autism were fully dependent on them for support. Concerns were also raised about the mental wellbeing of elderly carers and the long-term impact of isolation on both the individual and their families. Some also expressed frustration about the lack of reasonable adjustments in primary care services and some felt that professionals failed to understand, listen to, or respect their needs. This suggested that there was a particularly poor understanding of ASC across care pathways including acute mental health care settings. The lack of services was also identified as a gap in service provision for young people with ASC. Support with travel and carer support, alongside poor communication in providing information and signposting, were also highlighted as areas some families found difficulty in accessing.
- 4. Overall, around one third responded to the question on accessing a range of the health, community, and social care services. They reported a mix of positive and negative experiences. For some, the services they had accessed had been beneficial supportive and helpful, whereas, for others, it had left them feeling misunderstood, disempowered, and isolated, with a lack of appropriate support.

## Summary of Findings

#### Diagnosis

• The majority of people were diagnosed by NHS services (63%), at some stage in their childhood (before the age of 18).

• Around half of people (48%) were diagnosed within the first year of beginning the process, while a significant number (37%) waited longer - over four years in some cases.

#### Support

- Two thirds of people (64%) indicated they had not been assessed for care needs and the vast majority (77%) said they did not receive help.
- When asked about additional support, many regarded social opportunity as important as clinical health or care needs.
- Levels of support available during a mental health crisis were questioned by many. Some also worried about hospital detention within mental health settings.
- People needed a broad range of support to live independently 7 of the 8 categories identified such as employment polled more than 10%.
- Families said their children were dependent on them, with accounts of little or no support, following transition from CYP (Children and Young People services) to adult services.
- Direct payments were popular, allowing people to access services across other boroughs, but the services were not available locally.

#### Communication and Involvement

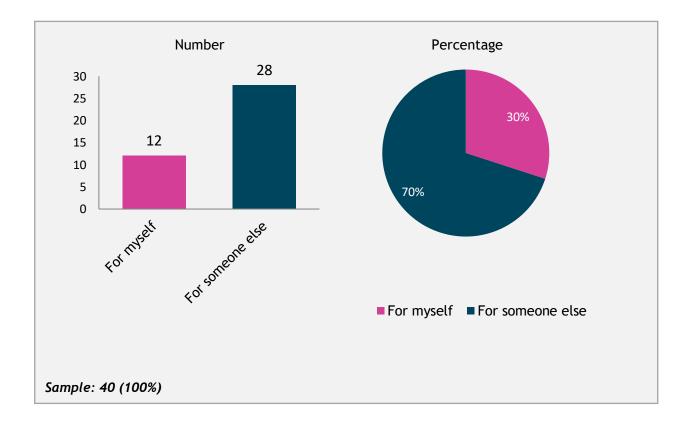
- Communication was a leading issue 59% of people (who did not receive support for care needs) did not know whom to contact to receive help.
- 69% of people indicated they were 'not respected or listened to' and expressed frustration that adjustments, such as language and tone, were overlooked.
- Stigma and potential discrimination were demonstrated to occur within schools, and health and social care services. 31% of people cited issues with poor staff attitude.

#### Training and Awareness

• A range of the above themes could be attributed, in large part, to training and general awareness - within services, institutions and the wider community.

#### Survey Response

We received 40 survey responses in total. This included 12 completed by people with Autism, and a further 28 by carers/family members.



## Section 1- Diagnosis

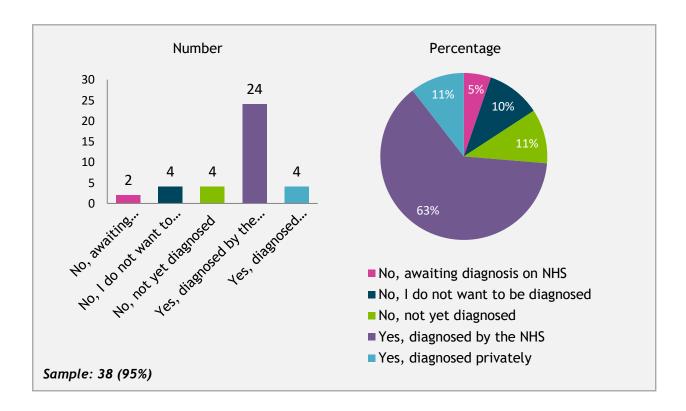
The majority of people were diagnosed by NHS services at some stage in their childhood (before the age of 18).

Referrals were initiated by a wide range of health and care professionals - examples included a learning disabilities specialist, educational psychologist and a midwife.

Around half of people were diagnosed within the first year, while a significant number said they had waited longer - over four years in some cases. One family, whose child was self-harming, took on debt to secure a private diagnosis.

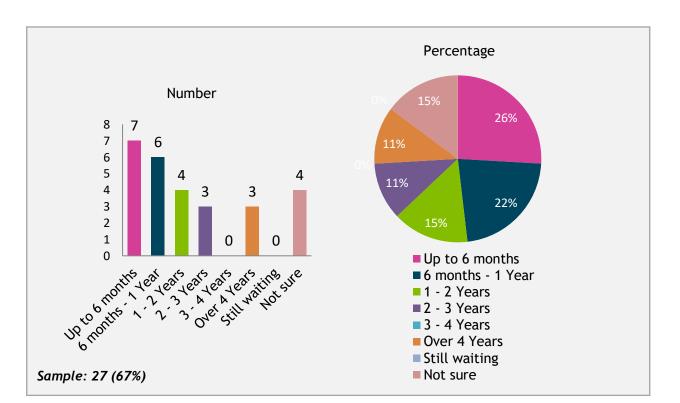
We heard that diagnosis brought the positives of enhanced service access and support but, equally, people sometimes experienced the negatives of stigma and neglect - at health and social care services and institutions such as schools and colleges.

#### 2. Do you, or the person you care for, have a diagnosis of Autism



Around three quarters of people (74%) have a diagnosis. The majority (63% total) were diagnosed by the NHS, while 11% chose private options, in some cases to expedite waiting times. 10% of people prefer not to be diagnosed.

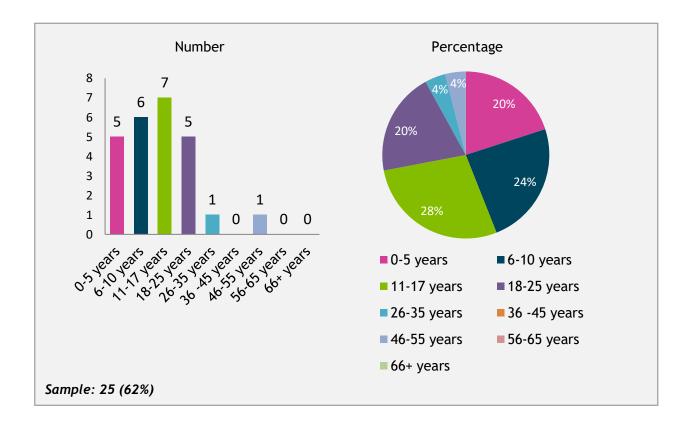
3. If you, or the person you care for, have already been diagnosed with Autism, how long did you have to wait for an Autism (ASD) diagnosis from the first of contact with a health professional?



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Around a quarter of people (26%) were diagnosed within six months of their first contact with a health professional, while an additional 22% were also diagnosed within the first year.

37% of people have been waiting for more than a year, with some (11% total) waiting over 4 years.



#### 4. How old were you, or the person with Autism, when the diagnosis was made?

The majority of people (72%) were diagnosed in childhood (0-17 years), while 20% were diagnosed as young adults (18-25). Just 8% of people received a diagnosis after the age of 25.

The survey did not take into account that there be many people within the community who remain undiagnosed. It is widely accepted that this would be the case particularly within older sections of the community.

#### 5. Please tell us about your diagnosis experience.

We asked people to share their general experience of diagnosis.

#### **Selected Comments**

#### Positives

"His Autism was missed at his three year check but picked up by a midwife at his brother's six week check up!"

"My son's diagnosis was fairly quick and straightforward. He was assessed by the Phoenix Centre and given a diagnosis."

"Still on waiting list for NHS diagnosis, so went to Lorna Wing and were seen within 2 months."

#### Negatives

"Diagnosis went fine, did the usual tests. But the support of my school (X) and the place where I took my A' Levels X were appalling. insisted I wouldn't be able to take my English Language A' Level because I was autistic and 'far too ambitious' to realise my dreams. With a diagnosis should come opportunities, not stigma. Also from other students who thought people with Autism were retarded and spastics."

"Our experience at Bromley Wellbeing was appalling. We were told that as our son could talk and make eye contact he was unlikely to meet the threshold for an Autism diagnosis. After over a year of providing supporting documents from school and private health professionals, we still made little headway."

"Very poor, the path to diagnosis was very confused as I wasn't supported by any services and once diagnosed the available services to me were limited."

"We felt we had no choice but to take out debt and see someone privately because our child was self-harming and the wait on the NHS was 18 months minimum."

#### 6. Were you misdiagnosed before the Autism diagnosis?



Over a third of people (37%) indicated they might have been misdiagnosed, prior to the official Autism diagnosis.

#### Selected Comments

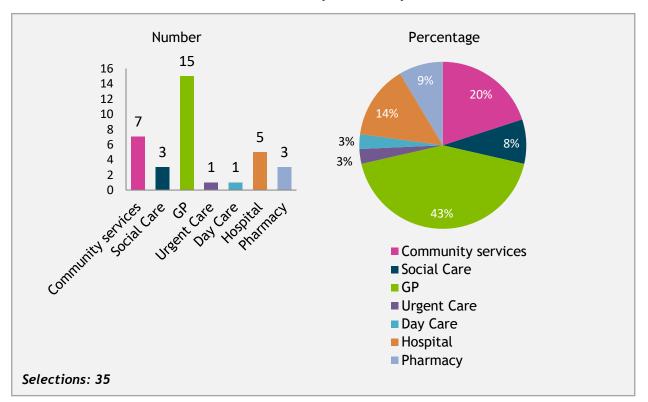
#### General

"Daughter first attended a speech and language provision at primary, then for learning difficulties before we asked for an Autism assessment."

"I'm not sure anyone diagnosed anything. I had mild to moderate learning disabilities/difficulties. I had OCD (Obsessive Compulsive Disorder) and was having help for that."

#### Negatives

"Not diagnosed. Anxiety blamed on chromosome disorder."

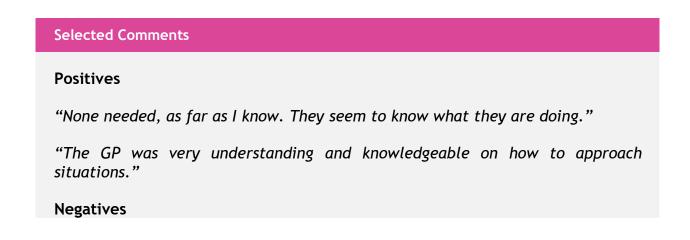


#### 7. Please tell us more about the Bromley services you have used.

43% of people had accessed their local GP services, while a fifth (20%) had used community-based services such as CAMHS (Child and Adolescent Mental Health Services) and Bertha James Day Centre. Day or Urgent Care had not been widely used.

## 8. Please tell us, from the services you have used, if any reasonable adjustments were made in order to help you?

Around two thirds of people said that no 'reasonable adjustments' were made by services; however, it was not clear whether support was requested, or required, in the majority of responses.

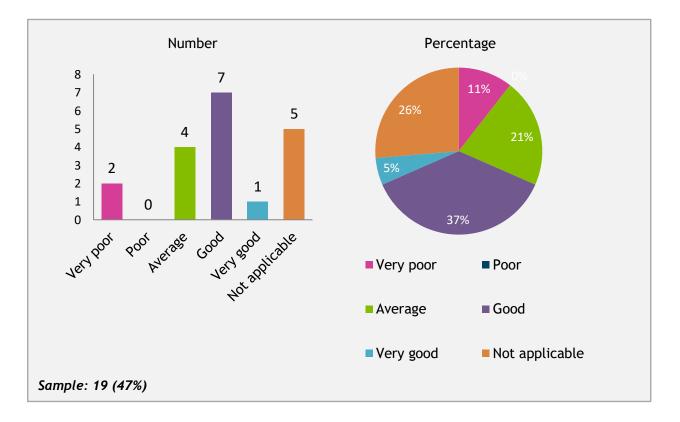


"GP practice X were awful. I described my difficulties and troubles - they told me 'have you ever thought of it being your fault all these things happening to you'. I don't trust GPs anymore as a result. But the CAHMS service who diagnosed me were lovely and understanding."

"Our GP surgery has to be repeatedly reminded that our daughter is autistic and has a learning disability, despite us having written a letter to them to keep on file."

"The GP was great. He's retired now and current one doesn't know me at all. I'm not offered an annual health check or anything like that. Hospital was kind and helpful but didn't really understand I needed advocacy. If my mother hadn't been there, I would have not told the anesthetist that I have osteoporosis which he said was important. There should be a person allocated for advocacy at each hospital. Social Services have not helped much at all. They keep doing assessments but nothing comes of them."

#### 9. Please rate your experience of this service?



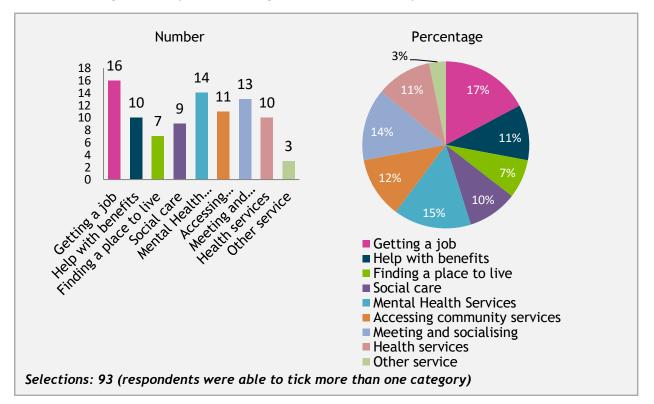
It is notable that relatively few people rated services as very good or very poor. 58% said that services are either good or average, with CAMHS and Phoenix Centre widely slotted into these 'middle' categories.

## Section 2 - Your Needs

Responses suggest people need a broad range of support to live independently, as part of the community, with employment, mental health services and socialising the top categories identified. Also desirable are assistance with independent living and greater general support (including for carers). Support in finding accommodation is considered least important.

There is evidence that many people's care needs have not been assessed, and where support is lacking, it is not always clear whom to contact for help. As a result, families often go unsupported, with some parents commenting that their children are 'entirely dependent' on them.

Although negative comments were made in respect to some schools and GP practices, others received positive feedback, as did Bromley Mencap and other local services.



10. Please tell us what type of support or help you, or the person you care for needs, to live independently and to be part of a community

With most categories polling 10% or more, it is clear that people need a broad range of support to live independently, as part of the community.

At 17%, support in getting a job was considered marginally most important, followed by mental health services (15%) and socialising (14%). At 7%, support in finding accommodation was considered least important. This may indicate that those who completed the survey are already in secure and stable accommodation. In many cases, carers completed the survey.

#### 10a. Please tell us about other help and support you need

When asked what other help and support was needed, people said they would like greater choice, particularly on groups and activities.

Difficulties with travel were also mentioned.

#### Selected Comments

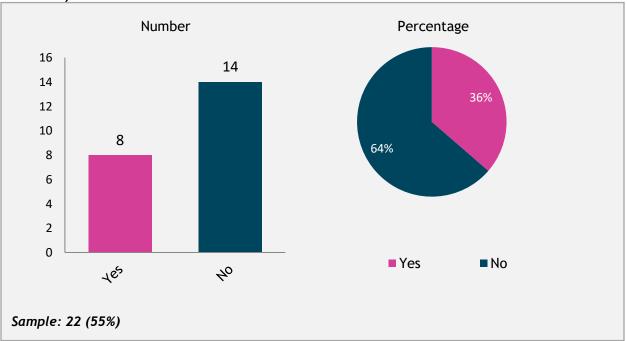
#### General

"A group for 18 to 25 year olds with Aspergers. All the groups I have looked at are for more severe ends of the spectrum there is nothing at all for young adults with Aspergers. I would love more than anything for a group in Bromley."

"Day Activities that are not designed to meet the lowest need learning disability as these are not appropriate for those with Autism."

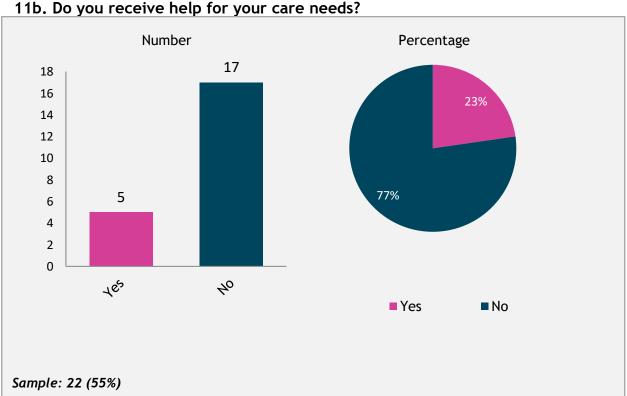
"They are not able to travel independently on unknown routes, or other than by bus. They are isolated and feel lonely, but do not want to feel different and so will not accept help from community services because they do not want to be seen as needing them. They do not socialise with their peers unless heavily encouraged and supported by us, parents. They need our support to attend any health appointments."

"This is about my son aged 50. He is very withdrawn and rarely sees anyone outside the close family. He needs help to meet people and to socialise."

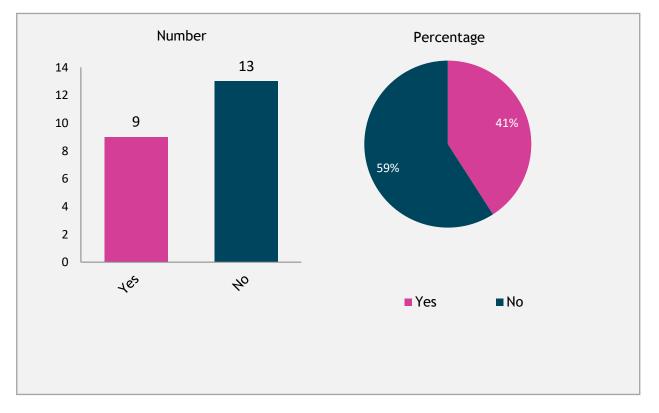


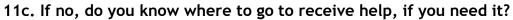
11a. Have you been assessed for your care needs? (for the person living with Autism)

Around two thirds of people (64%) indicate they have not been assessed for care needs. While front-line staff (such as social workers) are able to recommend assessments, this is not always supported by management, or systems as a whole.

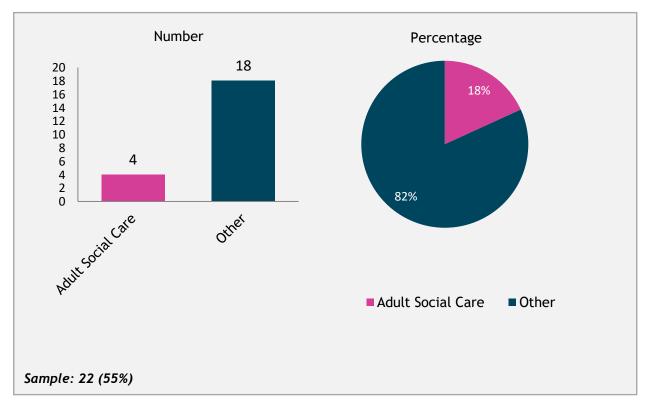


The vast majority of people (77%) said they/the person living with Autism did not receive help for care needs.





12. If you do receive help with your care needs, which organisation provides that help?



Adult Social Care accounted for 18% of responses, with Bromley Mencap, Choice Support (Beckenham) and Autism Forward also mentioned.

#### 13. What services do you get help and support from at the moment?

Bromley Mencap is a popular service, with others citing GPs and schools for general support. One person said 'services outside of the borough provide appropriate day activities for those adults with high functioning Autism - there's nothing in borough' so local availability is an issue.

One parent said 'everyone passes us to someone else because he doesn't quite fit - meanwhile my child is suicidal'.

## 14. Please tell us what type of support services in Health and Social Care you think are missing to better support you?

When asked 'what services do you think are missing', people cited employment support, information and signposting, social and sports activities, independent living opportunities and general support - including for carers. One person recalled 'barriers' when trying to access support, while another said 'poor administration causes delays'.

People also said there should be better support for people in mental health crisis better staff training generally; joined up working between health and social care; and someone 'in the surgery' to coordinate health and care support.

#### Selected Comments

#### General

"Our experience has not been a positive one. The staff are all amazing and caring but there didn't seem to be anyone who was trained to deal with a young adult with Aspergers who was in mental health crisis. We were told by a few professionals that the NHS did not have the resources or trained staff to support our son and they apologised for the NHS letting him down!"

#### Negatives

"There are barriers to everything, I cannot even get help from Bromley Well because I have been told he isn't under social care (who won't accept him), they can only assist with a CV, he needs much more help."

"Better record keeping so that we don't have to start all over again from scratch each time we book, confirm and attend an appointment." 15. Are there any other services, apart from Health and Social Care, you would like to have to meet your needs or the needs of the person for whom you care, in Bromley?

Families would like greater levels of support and cited training and awareness as a clear problem. There is also anxiety about the long-term consequences of isolation, with some families worried about wellbeing and mental health.

#### **Selected Comments**

#### Negatives

"Any support would have been nice, rather than keep being turned away, there is a total lack of support for ASD (Autistic Spectrum Disorder), ADHD (Attention Deficit Hyperactivity Disorder) and related conditions and people are ignorant to the severe issues it causes."

"More support for people with Asperger's and more education needed to teach students and teachers not to stigmatise or bully people with Autism. I was bullied by both teachers and students, the teachers thought I wouldn't get anywhere with my life because of me being autistic."

"More support for the family, especially during times of mental health crisis. It is really difficult to find out what is out there to help once young people reach adulthood which is why we feel the need to have to pay privately to try and get the help and support needed for our son. Both my husband and I have had to cut down our working hours to support our son as well as paying out to get him the help and care he needs."

"Too little too late. We are trying to combat years of specialist isolation and separation from the majority of their peers. They have no local friends or connections since they did not attend our local schools. They are now fearful of engaging in anything that is seen as 'different' or for people with disabilities ironically, like them, but equally, have no way of knowing how to engage with peers who are in jobs or at university. We are so, so worried about their mental wellbeing."

## Section 3 - Your Experience of Services

The lack of local opportunities was highlighted by many, with some people trained for jobs that are difficult to secure in the borough, and others having to travel out of borough to access support groups and activities. Direct Payments were seen as a good way to increase choice, particularly on out-of-borough provision.

When asked specifically about difficulties, information and advice was a prominent issue, along with levels of support post-transition. User involvement was also a continuing issue - with varied accounts of people not being involved in their own treatment and care (such as being ignored or use of inappropriate language or tone).

Some parents were also concerned about sectioning/detainment to mental health hospitals, as they felt there is not adequate training and awareness of Aspergers or Autism.

16. Please tell us about the type of support that has been helpful and worked well for you, or the person you care for when you have used Health and Social Care Services?

People offered a range of examples of support that had worked, and been helpful - this included adult education, GPs and social activities.

Some families have benefited from direct payments - enabling greater choice, such as access to services out of borough. Others said that when in transition from children and young people to adult services, there was little or no support available.

#### Selected Comments

#### Positives

"Occasional professionals (such as opticians) who just 'get it' and are relaxed and communicate well."

"Direct payment assessment means we can go out of borough to meet our son's needs."

#### Negatives

"When our son was under 16 the services were amazing. We had help and support from specialised teams and social services. Unfortunately, our experience now he is a young adult is more negative and we feel that we are left to cope on our own as a family."

"Have had serious difficulty in securing appropriate support."

17. What difficulties, if any, have you, or the person you care for, experienced when using Health and Social Care Services in Bromley?

When asked specifically about difficulties, information and advice is a prominent issue - many people do not know whom to contact, or which services are available locally. One person recounted frequent 'communication breakdowns'.

Other issues included training, waiting lists and a lack of advocacy support.

#### Selected Comments

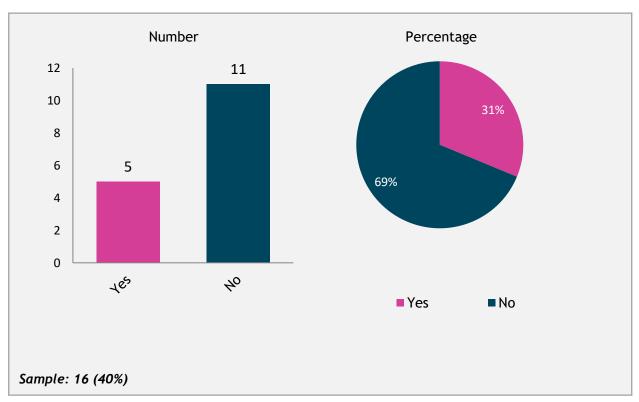
#### Negatives

"GPs aren't understanding of Autism at all."

"No-one cares, he came out of school and as soon as he went to college, he ceased to exist, he has been going downhill ever since and we are now in crisis. I have tried to get help and no one will help us."

"People who talk to us instead of our young adult when at appointments for them."

"We have never tried to contact Health and Social care and do not know how to contact the right people."



## 18. Did you feel respected and listened to when you used Health and Social Care Services?

69% of people indicated they were 'not respected or listened to' by health and social care services.

#### General

"It's a mix, but we have learnt to expect the worst. Sorry."

"You feel you are listened to at the time but no-one follows it through or does anything."

#### Negatives

"Although this isn't anyone's fault directly it's just that the resources and experience to deal with Autism for young adults just isn't available."

"I feel processed and misunderstood. Staff are uncaring and looking for ways to discharge you without resolving issues."

"Just got told by my GP have you ever thought it was your fault everyone being mean and bullying you because you are different. People with Autism are let down and not given the motivation we so desperately need."

## 19. Please tell us what improvements need to be made in Health and Social Care Services for people with Autism?

Families raised the serious issue of sectioning and placement in secure mental health hospitals. Although acknowledged as necessary, some families regret the oftendetrimental impact, and say this could be minimised if staff were more knowledgeable about Aspergers and Autism.

Practical suggestions for general improvement included greater peer support, plus environmental adjustments such as lighting and noise.

#### **Selected Comments**

"Perhaps a committee of people with Autism who have first - hand experience helping to educate others."

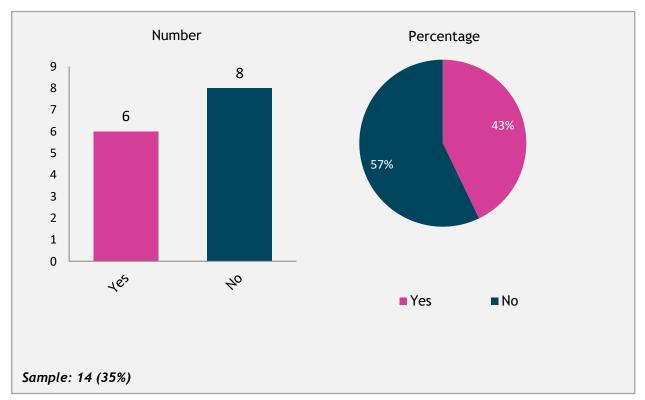
"Reasonable adjustments, such as lighting and noise - quiet hours are helpful."

"More training for staff to be better equipped and be able to offer support to a young person and their families during mental health crisis. Sectioning a young person I understand needs to happen at times but putting a young person with ASD in a mental health hospital is not the answer. For our son going to somewhere he's never been before with people he doesn't know and all the sensory overload that would be happening would only make the crisis worse not better. It took a long time to make the mental health emergency team understand this and their lack of awareness and understanding of ASD was shocking. With one member of this team stating, what is this Aspergers you are talking about! As you can imagine this did not fill us with confidence in their care and support of our son's needs."

"Understanding that ASD/Autism can mean that someone has a number of different issues and it's time a wider service exists that is inclusive and can help our young people live independently without jumping through barriers."

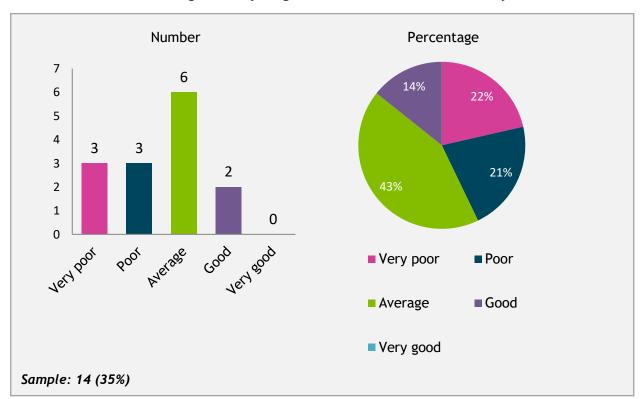
"More understanding, more open mindedness, much more sympathy and understanding of personal struggles."

"More community placements and skilled care management staff ensuring autistic individuals who present with challenging behaviour are not passed over to mental health and sent to hospitals."



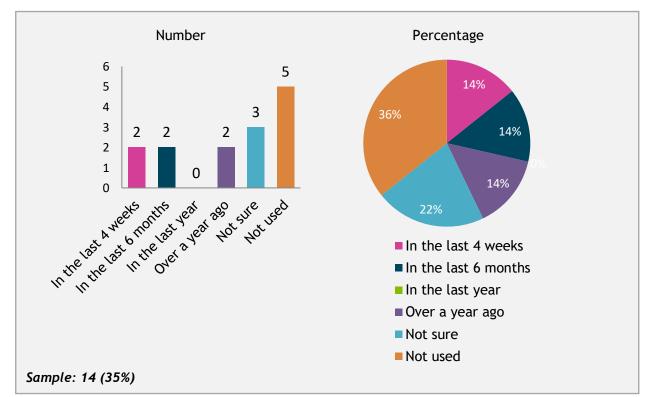
#### 20. Have you used any Social Care Services in the last 2 years?

6 people had used social care services in the last 2 years. The Adult Learning Disability team and service at Widmore Road received mentions.



#### 21. What overall rating would you give the Social Care Services you have used?

It is notable that only 14% of people rated social care services as good.



#### 22. When did you last use Social Care Services?

Responses on last use were varied.

#### Positives

"The Adult Learning Disability Psychology Team were excellent in helping with my son's anxieties."

#### Negatives

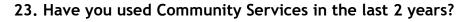
"I felt that we were not listened to."

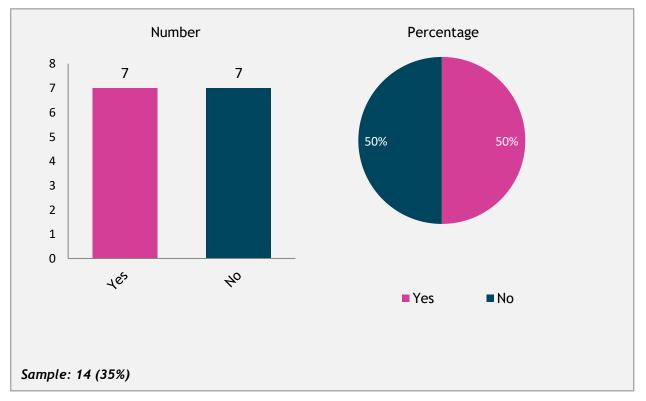
"It's random and ineffective."

"More attention paid to management's reputation than safety of the individual."

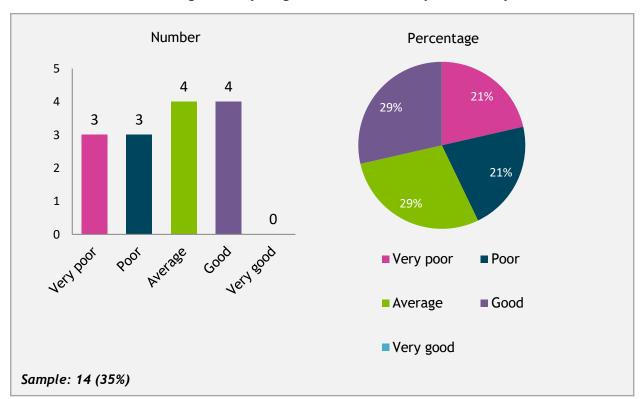
"Overstretched, unaccommodating and basically not interested (with the exception of Psychology)."

"Unsympathetic and uncaring."



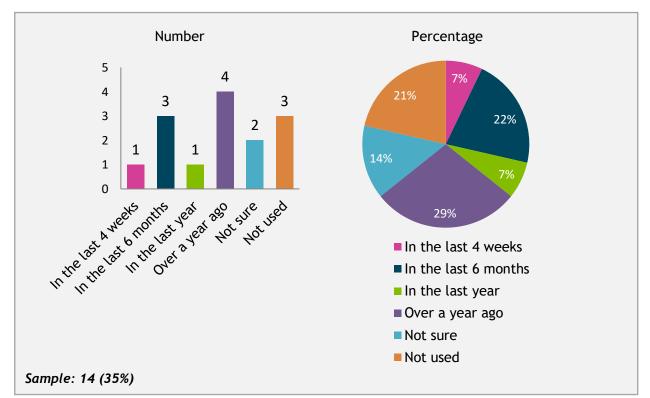


7 people had used community services in the last 2 years. Bromley Mencap and Choice Support were mentioned.



#### 24. What overall rating would you give the Community Services you have used?

Ratings are mixed, however nobody considered services as 'very good'.



#### 25. When did you last use Community Services?

Around a third of people (36%) had used services recently.

#### **Selected Comments**

#### General

"They try very hard to get young people ready for work but the opportunities for work experience locally, in areas that would engage those with Autism, is very limited."

"Lovely people, just not the resources and skills available for people with ASD."

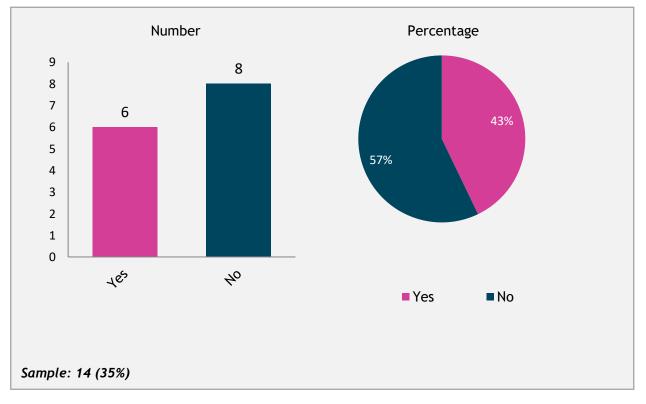
#### Positives

"They understand me."

"Bromley Mencap are always helpful and ready to listen."

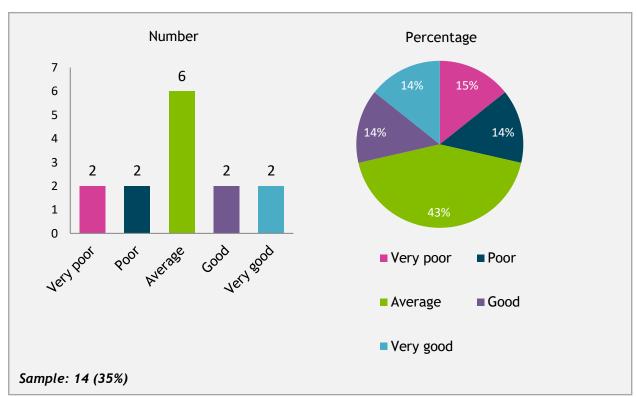
#### Negatives

"Was advised that can't give what my son needs."



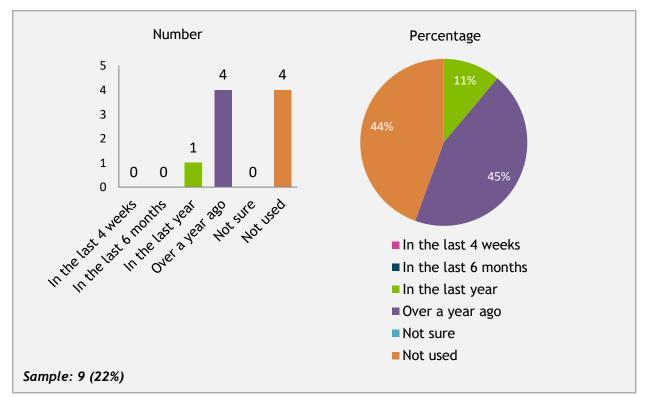
#### 26. Have you used Mental Health Services in the last 2 years?

6 people had used mental health services in the last 2 years. The ALD Psychology Team received a mention.



### 27. What overall rating would you give the Mental Health Service you have used?

Almost half of people (43%) consider services to be 'average'.



### 28. When did you last use Mental Health Services?

The majority of people used the service over a year ago.

**Selected Comments** 

#### General

"Psychiatrist good, but no follow up, medication will not resolve his issues."

#### Positives

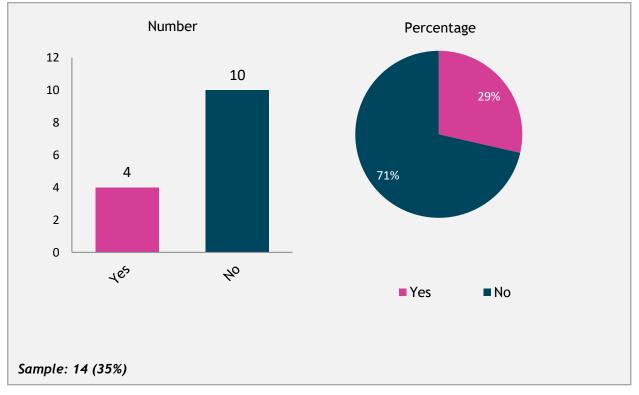
"The psychiatrist was very good with my son."

#### Negatives

"Daunting."

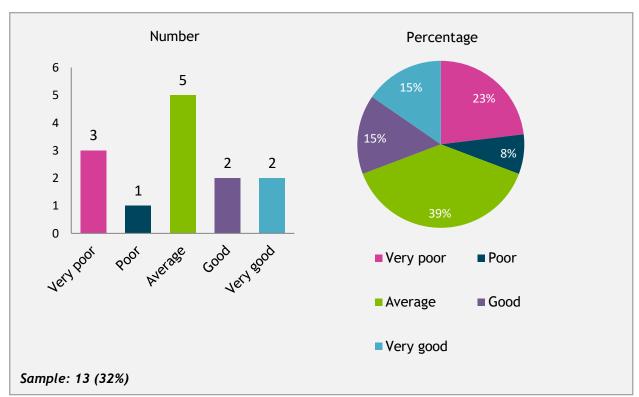
"Devastating, most uncaring, unsympathetic doctor ever."

"I felt anxious the last time and felt they saw me in a negative light."



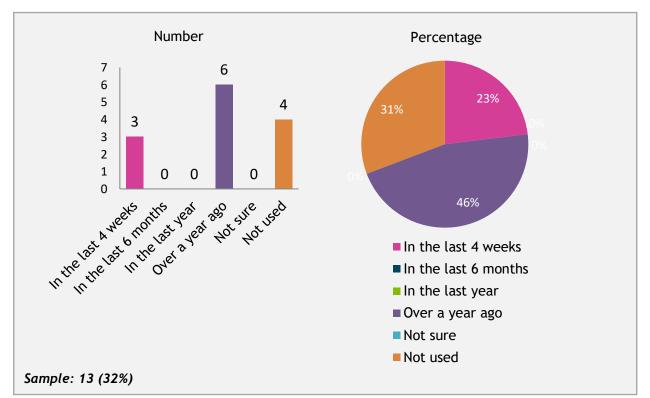
#### 29. Have you used Employment Support Services in the last 2 years?

4 people had used employment support services in the last 2 years, with Autism Forward, Bromley Mencap, Choice Support and Community Links cited.



## 30. What overall rating would you give the Employment Support Services?

Just 30% of people gave ratings of 'good' or 'very good'.



31. When did you last use Employment Support Services?

3 people had used the service recently, with the remainder over a year ago.

#### Positives

"Amazing support for my son and us as a family."

"Autism Forward - amazing charity - still using their service to help my son gain employment."

#### Negatives

"There are minimal opportunities to put what they learn into practice within a reasonable area. They offered my son the opportunity to go to Covent Garden to work in an office when he is not an independent traveller!!!

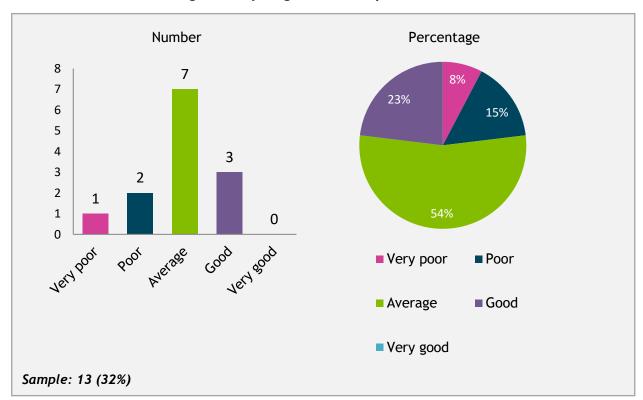
"They are helpful but employment prospects are few and far between."

"Community Links volunteering. I got a volunteer position through them we tried to, but they would only offer CV help and job search, many in my son's situation require a job curve and support at work, but he cannot receive this as he isn't under social care."



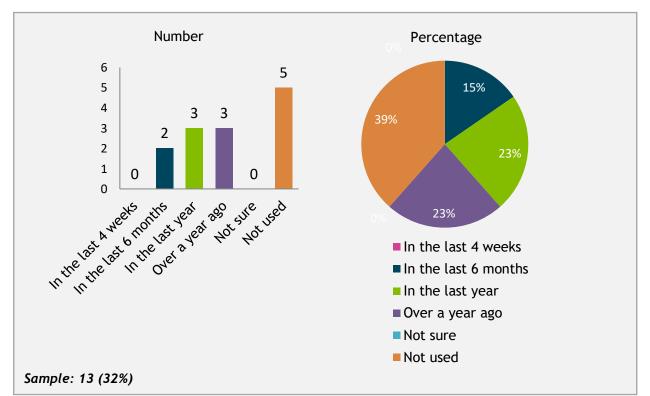
#### 32. Have you used Hospital Services in the last 2 years?

6 people had used hospital services in the last 2 years.



## 33. What overall rating would you give the Hospital Services?

Over half of people (54%) considered services to be 'average'.



## 34. When did you last use Hospital Services?

5 people had used services recently, with 3 having used them over a year ago.

**Selected Comments** 

#### General

"It just depends who you get. Some staff are nice and others are not."

## Positives

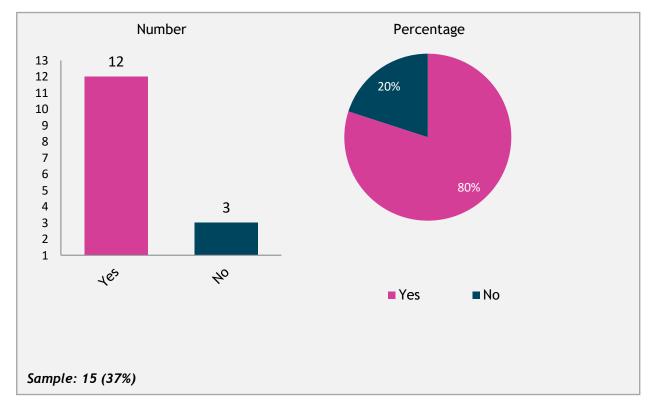
"It was sinus related, the doctor was very friendly and reassuring."

## Negatives

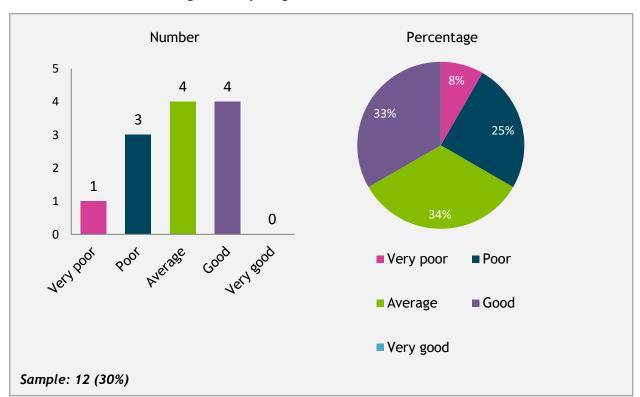
"I got misdiagnosed ended up having an ambulance which wasn't needed and strong injection of antibiotics which I didn't need. It has given me a real phobia of hospitals."

"Princess Royal. No reasonable adjustments made on the day despite meeting the week before the operation to discuss the reasonable adjustments - failure to implement them caused serious issues."



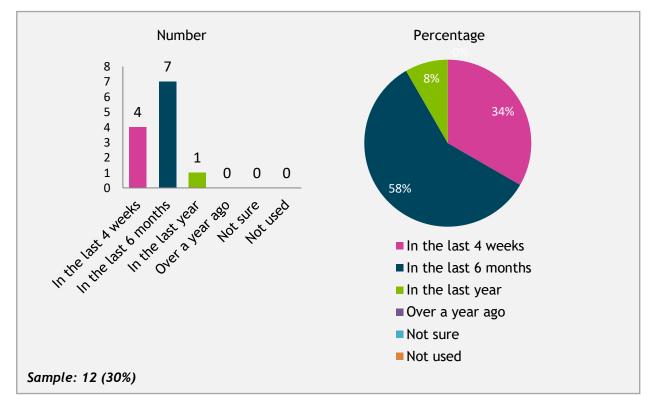


12 people have used GP services in the last 2 years, with several practices cited.



## 36. What overall rating would you give GP Services?

It is notable that just 33% of people considered services to be 'good'.



## 37. When did you last use GP Services?

The vast majority of people had used services recently.

### Selected Comments

#### General

"Doctor was nice but didn't really have much time to make allowances for my Autism."

#### Positives

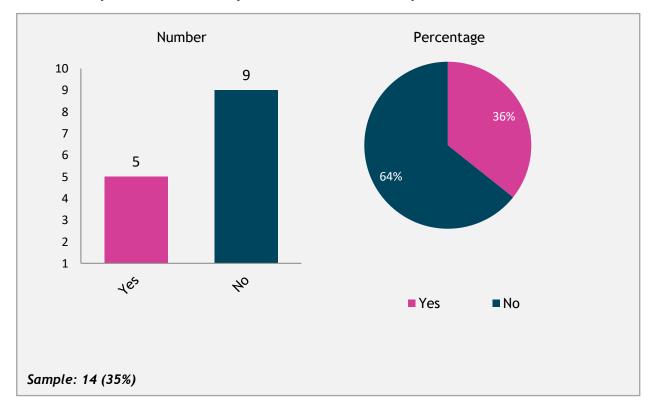
"The practice nurse was happy for me to join my adult son for the appointment Beckenham GP Services - they know of my Aspergers."

"Our GP is usually very supportive to us as a family."

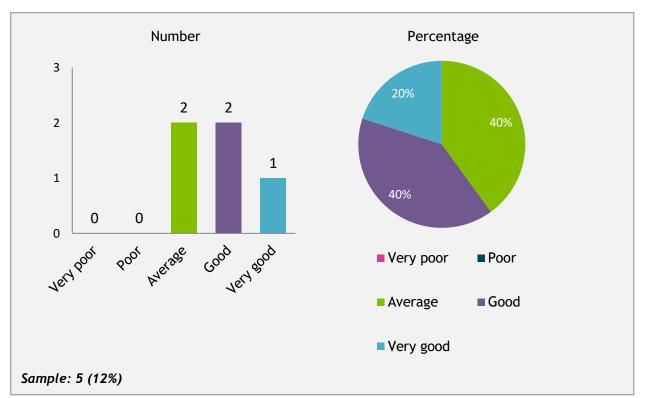
#### Negatives

"Didn't have a record of the Learning Disability or Autism, spoke to us instead of them, didn't adjust their language to accommodate."

"No follow up, no help, asked for a referral back for my son a couple of months ago, we haven't even had a letter acknowledging this."

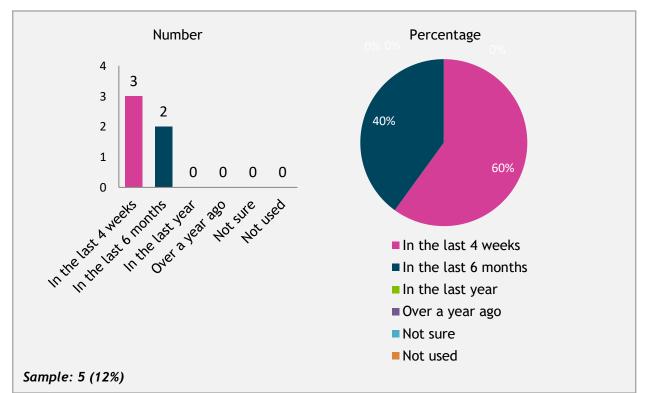


## 38. Have you used Pharmacy Services in the last 2 years?



## 39. What overall rating would you give Pharmacy Service?

The majority of people were satisfied with services overall, with 60% rated 'good' or 'very good'.



40. When did you last use Pharmacy Services?

All had used services recently.

Selected Comments

#### Positives

"So far as I know my son found them very helpful. Very good."

#### Negatives

"I am aware no adjustments were made."

## 41-43. Day Care Services

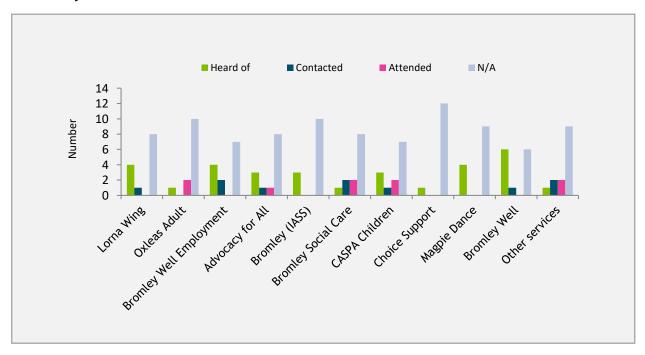
Just one person mentioned a day care service - Bertha James Day Centre, used over a year ago, with a rating of 'very good'.

Section 4 - Services

There was awareness of all services on the list - half of which had been attended.

#### 44-45. Which of these local services have you used?

Of the services listed, Bromley Well appeared to be the most familiar. However, Bromley Mencap was not listed in this survey question, but many people named this service under 'other'. NB. Bromley Mencap deliver services under the umbrella of Bromley Well.



#### **Selected Comments**

#### General

"Bromley Mencap - used the buddying service which was pretty good albeit time limited."

#### Positives

"Bromley Mencap gave me good advice and help on benefits and on social activities."

# Section 5 - Living in Bromley

In this section we asked for views on the borough itself.

#### 46a. How do you get around or travel to Bromley?

The majority of people preferred using the bus to get around. A significant number also used a car or walked. As mentioned earlier in the report, many people had limited ability to travel, with reliance on family and carers.

#### 46b. How do you find it living in Bromley?

It was interesting that the majority of people said life in Bromley was 'average' or 'okay', with one finding it 'depressing' and another 'frustrating'.

#### 46c. What do you like or value about living in Bromley?

People valued living close to family, friends and their support network - related to this was a good level of familiarity with surroundings. On the environment, green spaces, lack of crowds and existence of places to visit or shop locally were all appreciated. Transport links were also welcomed.

## Suggestions for improvements to care pathway

Based on the evidence outlined in this report, we offer some practical suggestions.

- To improve and increase awareness of the assessment and diagnostic service pathways and access to carer support services.
- To give better access and information on local support service provision.
- To provide a level of continuity of support services for young people with ASC when transitioning into adulthood.
- To have more locally diverse and better levels of access to direct payment services and community /social base and employment support services.
- To provide Autism awareness training across universal health and social care services and educational settings in Bromley to fully meet the needs of individuals and families living with ASC and promote equality of access more Autism friendly service across pathway of care.
- The survey returned only a small number of respondents. To ensure greater feedback about the Autism pathway going forward it is important to embed feedback mechanisms at various stages in the diagnosis pathway and ongoing support provision. Partners to jointly review and agree mechanisms, implementation, and monitoring.

#### Based on the findings...

#### Social Opportunity

There is evidence that lack of choice within Bromley limits people's opportunities to integrate, for example, to socialise, find employment, and live fuller lives. We heard that some people travel out of borough to access social groups, while others, having obtained job skills and training locally, cannot find employment near where they live.

**Suggestion**: Enhance links with local community groups and employers, to better enable local people to socialise, and work in Bromley.

## **User Involvement**

We heard accounts of stigma, and perhaps discriminatory attitude, at schools, colleges, GPs and social care services. We were also told that people are not being involved in their own treatment and care - for example a GP talking to the parents, or using language the patient does not understand.

**Suggestion:** Encourage staff to undertake training on Aspergers and Autism to increase levels of awareness. In addition, better enable patients and carers to feed back on their experience - to highlight and tackle issues.

## Parents and Carers

It is clear that much of the care burden falls on families, and some report that their loved ones are 'entirely dependent' on them. In one case, we heard that parents had to reduce working hours to take on significant care role and additionally impacted the family finances.

**Suggestion**: As many of these parents may be entitled to assessments and support, increase levels of information and awareness around benefits and entitlements (such as Direct Payments).

## Communication

We found that additional care needs are often not supported, and the majority of those requiring help do not know whom to contact, to secure assistance - resulting in deteriorating physical and mental health.

**Suggestion:** Make information about services, support groups and hubs more widely available - online or in the community. For example, council staff joining a Facebook or WhatsApp group.

## Wider Themes...

While there are no 'quick fixes' for waiting times and levels of staffing, we urge that:

- People in a mental health crisis are properly supported. At the very least, we expect staff to give information and signposting advice that may help (nobody should be left unassisted).
- While on waiting lists for diagnosis some stated to be 18 months we expect parents and patients to be supported in the interim, as much as possible. Frequent and regular communication can do much to alleviate anxiety, and also to discover and support needs.

#### BeyondAutism - "Stats and facts" (2020)

https://www.beyondAutism.org.uk/about-Autism/stats-and-facts/ [Accessed 11.02.2020]

#### Buzzgolife - "Life with AJ-Part 1" (2020)

https://buzzgolife.com/2014/06/05/Autism-life-with-aj-part-1/ [Accessed 11.02.2020]

House of Commons - "Autism - overview of policy and services" (2020) https://researchbriefings.files.parliament.uk/documents/CBP-7172/CBP-7172.pdf [Accessed 11.01.2020]

#### Kings Fund - "Health Management and Policy Alert" (2019)

https://kingsfund.blogs.com/health\_management/2019/09/the-Autism-act-10-years-on-areport-from-the-all-party-parliamentary-group-on-Autism-on-understandin.html [Accessed 11.02.2020]

#### National Autistic Society - "Autism" (2018)

Available at: https://www.Autism.org.uk/about/what-is/asd.aspx [Accessed: 11.02.2020]

#### National Autistic society "The Autism Act: 10 Years On" (2019)

https://www.Autism.org.uk/get-involved/media-centre/news/2019-01-17-Autism-act-10years-on.aspx [Accessed 11.02.2020]

#### NICE - "Autism Spectrum Disorder overview" (2019)

https://pathways.nice.org.uk/pathways/Autism-spectrum-disorder [Accessed 11.02.2020]

#### YouGov - "More people in the UK are aware of Autism (2015)

Available at:https://yougov.co.uk/topics/politics/articles-reports/2015/04/13/more-peopleuk-are-aware-Autism [Accessed: 11.02.2020]

# Glossary of Terms

ADHD ALD ASC CAMHS	Attention Deficit Hyperactivity Disorder Adrenoleukodystrophy Autistic Spectrum Condition Child and Adolescent Mental Health Services
CYP	Children and Young People
LD	Learning Disability
MH	Mental Health
OCD	Obsessive Compulsive Disorder

# **Distribution and Comment**

This report is available to the general public and is shared with our statutory and community partners. Accessible formats are available.

If you have any comments on this report or wish to share your views and experiences, please contact us.

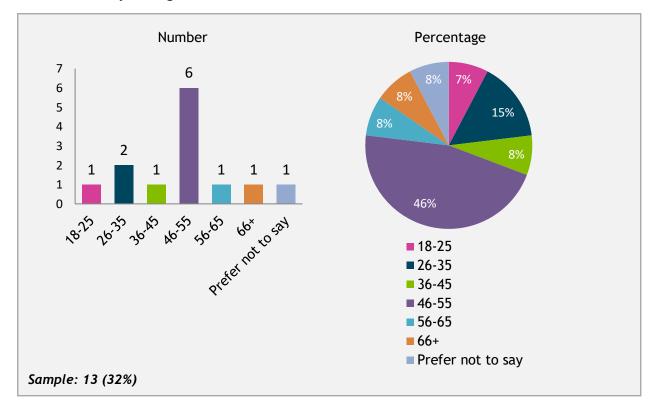
Healthwatch Bromley Community House South Street Bromley BR1 1RH

Telephone:020 388 60752Email:info@healthwatchbromley.co.ukWebsite:www.healthwatchbromley.co.uk

# Section 6 - More About You

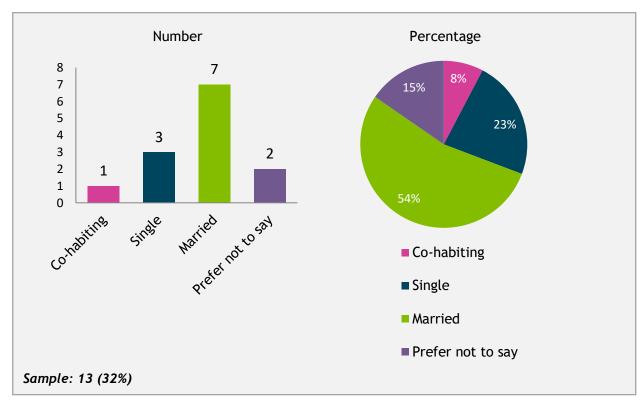
Demographics are stated as follows.

#### 47. What is your age?



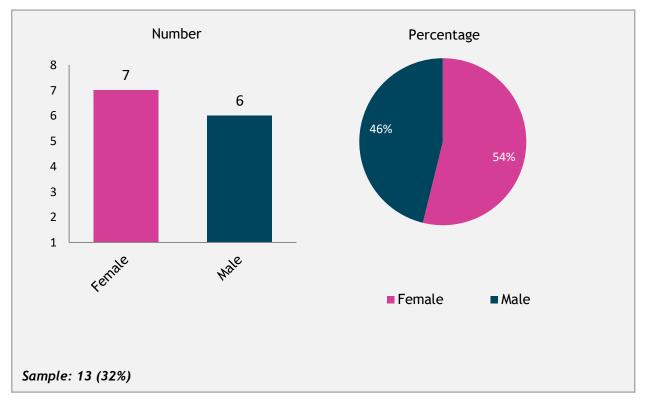
Almost half of people (46%) are aged 46-55.

## 48. What is your marital status?



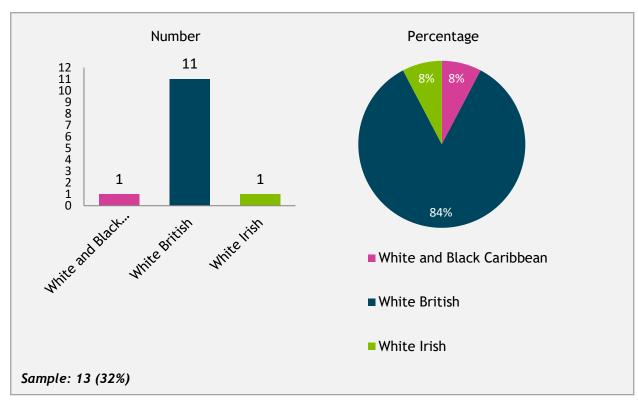
Just over half of people (54%) are married.

49. With which gender do you most identify?



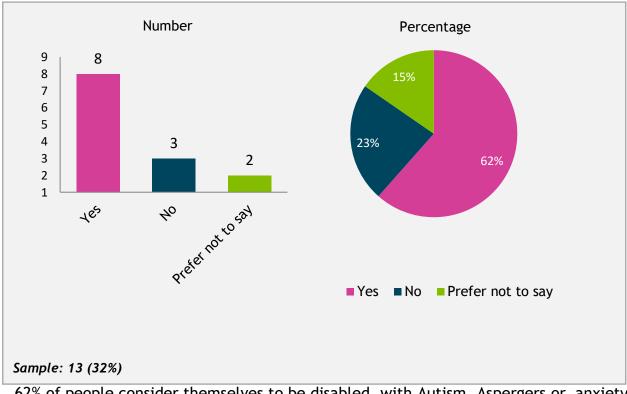
Gender is almost evenly balanced.

## 50. Which ethnic group do you belong to?

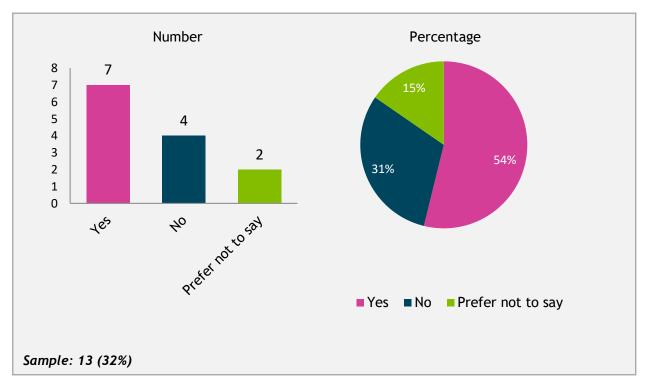


The vast majority of people (84%) are White British.

## 51. Do you consider yourself to be disabled?

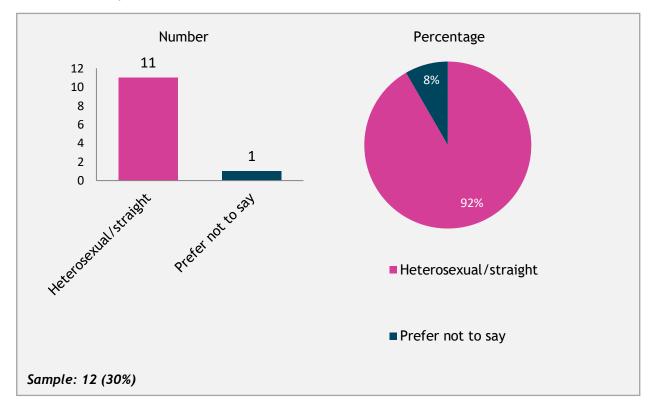


62% of people consider themselves to be disabled, with Autism, Aspergers or anxiety cited.



52. Do you consider yourself to have a long-term condition or health and social care need?

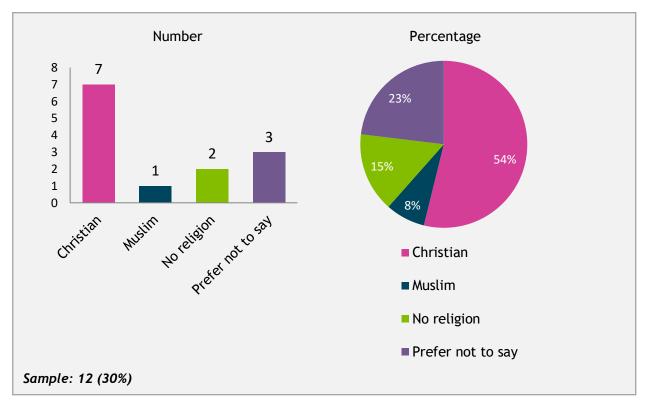
Of those specifying a long-term condition, most cited Autism, anxiety or depression.



53. What is your sexual orientation?

The vast majority of people (92%) identify as heterosexual.

## 54. What is your religion?



Just over half of people (54%) are Christian.

# Autism Survey in Bromley

#### Who we are:

Healthwatch Bromley is the independent champion for people using local health and social care services. We listen to the views of local people about their needs and experiences of local health and social care services and make those views known to improve or change the provision of local health and social care services.

## What is the purpose of this survey?

Healthwatch Bromley is conducting a survey with adults (18+) who have a diagnosis of Autistic

Spectrum Condition (ASC), or their Carers, who live in the London Borough of Bromley. The purpose of the survey is to gain an understanding of your views and experiences to help improve the health and care services in Bromley for people with Autism.

Please complete this survey if you are on the Autistic Spectrum or care for someone who is. If you are not able to complete the form, please ask the person who cares for you to complete it or contact Healthwatch Bromley on 0203 886 0752.

By completing this Survey, you consent to have your information anonymously used in a report, which will be published on Healthwatch Bromley website.

Thank you for your help

1. Are you completing this survey for yourself if you have Autism or for someone you care for who has Autism?

□ For myself

 $\Box$  On behalf of someone for whom I provide care

#### Section 1 - Diagnosis

In this section we ask you about whether you've been diagnosed and, if so, some questions about your diagnosis.

## 2. Do you, or the person you care for, have a diagnosis of Autism?

 $\Box$  Yes, diagnosed by the NHS

□ No, not yet diagnosed --> Please go to section 2

□ No, awaiting diagnosis on NHS --> Please go to section 2

□ No, I do not want to be diagnosed --> Please go to section 2

 $\Box$  Yes, diagnosed privately.

Please state who/which organisation diagnosed you:

3. If you, or the person you care for, have already been diagnosed with Autism, how long did you have to wait for an Autism (ASC) diagnosis from the first of contact with a health professional?

 $\Box$  Up to 6 months

□ Over 6 month - up to 1 year

 $\Box$  Over 1 year - up to 2 years

□ Over 2 years - up to 3 years

- □ Over 3 years up to 4 years
- □ Over 4 years
- □ I am still waiting
- □ Not sure
- $\Box$  Not used

4. How old were you, or the person with Autism, when the diagnosis was made?

- $\Box$  0-5 years
- $\Box$  6-10 years
- □ 11-17 years
- □ 18-25 years
- □ 26-35 years
- □ 36 -45 years
- □ 46-55 years
- □ 56-65 years
- $\Box$  66+ years

## 5. Please tell us about your diagnosis experience.

If appropriate, you may want to mention your experience with your G.P., hospital, Day Care, Social Care, community services (this might include, for example, Bromley Well, voluntary sector services, etc.) or other organisations.

## 6. Were you misdiagnosed before the Autism diagnosis?

(Examples of misdiagnosis might include ADHD; Obsessive-Compulsive Disorder; Post Traumatic Stress Disorder, Learning Difficulties, Anxiety, Oppositional Defiance Disorder etc.)

🗆 No

 $\Box$  Yes, please specify:

# 7. Please tell us more about the Bromley services you have accessed by ticking the services you have used.

 $\Box$  Community services (this might include, for example, Bromley Well, voluntary sector services, etc.)

 $\Box$  Social Care

 $\Box$  GP

Urgent Care

□ Day Care

□ Hospital

□ Pharmacy

# 8. Please tell us from the services you have used, if any reasonable adjustments were made in order to help you?

#### For example:

Community services (this might include Bromley Well, voluntary sector services, etc.) /

Social Care / GP / Urgent Care / Day Care / Hospital / Pharmacy, etc.

9. Please rate your experience of this service below and tell us the name of the Autism Service Diagnosis service you have used.

□ Very poor

□ Poor

□ Average

 $\Box$  Good

□ Very good

□ Not applicable

Please give the name of the Autism Service Diagnosis service:

## Section 2 - Your Needs

This section is about your needs and what might help you.

10. Please tell us what type of support or help you, or the person you care for needs, to live independently and to be part of a community

□ Getting a job

□ Help with benefits

□ Finding a place to live (Accommodation)

□ Social care

□ Mental Health Services

 $\hfill\square$  Accessing community services, local charitable support services this might

include, for example, Bromley Well.

□ Meeting and socialising with other people

□ Health services

□ Other service

Please tell us about other help and support you need:

### 11. Asking about your care needs.

	Yes	No
Have you assessed for your needs?	$\bigcirc$	$\bigcirc$
Do you receive help your care needs?	$\bigcirc$	$\bigcirc$
If No, do you where to go to help if you need	$\bigcirc$	$\bigcirc$
Please tell us below:		

12. If you do receive help with your care needs, which organisation provides that help?

□ Adult Social Care

 $\Box$  Other, if you receive help from another organisation, please give the name:

13. What services do you get help and support from at the moment?

14. Please tell us what type of support services in Health and Social Care you think is missing to better support you?

15. Are there any other services, apart from Health and Social Care, you would like to have to meet your needs or the needs of the person for whom you care, in Bromley?

Section 3 - Your Experience of Services

In this section, please answer the following questions about when you, or the person you care for, have used Health and Social Care Services?

16. Please tell us about the type of support that has been helpful and worked well for you, or the person you care for when you have used <u>Health and Social Care</u> <u>Services</u>?

17. What difficulties, if any, have you, or the person you care for, experienced when using <u>Health and Social Care Services</u> in Bromley?

18. Did you feel respected and listened to when you used <u>Health and Social Care</u> <u>Services</u>?

🗆 Yes

 $\Box$  No

Please share your experience:

19. Please tell us what improvements need to be made in <u>Health and Social Care</u> <u>Services</u> for people with Autism? 20. Have you used any Social Care Services in the last 2 years?

□ Yes

 $\Box$  No  $\rightarrow$  Please go to question 23

If yes, please give the name of the service(s) and what reasonable adjustments were made to ensure you felt safe and listened to during your visit:

21. What overall rating would you give the Social Care Services you have used?

- $\Box$  Very poor
- 🗆 Poor
- $\Box$  Average
- $\Box$  Good
- $\Box$  Very good

## 22. When did you last use Social Care Services?

- $\Box$  In the last 4 weeks
- $\Box$  In the last 6 months
- $\Box$  In the last year
- $\Box$  Over a year ago
- $\Box$  Not sure
- $\Box$  Not used

Please tell us about your experience of this service in the box below:

## 23. Have you used <u>Community Services</u> in the last 2 years?

This might include, Bromley Well; Voluntary Sector Services, etc.

 $\Box$  Yes

 $\Box$  No  $\rightarrow$  Please go to question 26

If yes, please give the name of the service(s) and what reasonable adjustments were made to ensure you felt safe and listened to during your visit:

24. What overall rating would you give the <u>Community Services</u> you have used?

□ Very poor

🗆 Poor

 $\Box$  Average

 $\Box$  Good

 $\Box$  Very good

## 25. When did you last use Community Services?

 $\Box$  In the last 4 weeks

 $\Box$  In the last 6 months

 $\hfill\square$  In the last year

 $\Box$  Over a year ago

 $\Box$  Not sure

 $\Box$  Not used

Please tell us about your experience of this service in the box below:

## 26. Have you used <u>Mental Health Services</u> in the last 2 years?

□ Yes

 $\Box$  No  $\rightarrow$  Please go to question 29

If yes, please give the name of the service(s) and what reasonable adjustments were made to ensure you felt safe and listened to during your visit:

27. What overall rating would you give the <u>Mental Health Service</u> you have used?

 $\Box$  Very poor

□ Poor

 $\Box$  Average

 $\Box$  Good

 $\Box$  Very good

28. When did you last use Mental Health Services?

 $\Box$  In the last 4 weeks

 $\Box$  In the last 6 months

 $\hfill\square$  In the last year

 $\Box$  Over a year ago

 $\Box$  Not sure

 $\Box$  Not used

Please tell us about your experience of this service in the box below:

29. Have you used Employment Support Services in the last 2 years?

This might include, Bromley Well, Charity Services, etc.

□ Yes

 $\Box$  No  $\rightarrow$  Please go to question 32

If yes, please give the name of the service(s) and what reasonable adjustments were made to ensure you felt safe and listened to during your visit:

## 30. What overall rating would you give the Employment Support Services you used?

□ Very poor

□ Poor

 $\Box$  Average

 $\Box$  Good

 $\Box$  Very good

31. When did you last use Employment Support Service?

 $\Box$  In the last 4 weeks

 $\Box$  In the last 6 months

 $\Box$  In the last year

 $\Box$  Over a year ago

 $\Box$  Not sure

 $\Box$  Not used

Please tell us about your experience of this service in the box below:

32. Have you used <u>Hospital Services</u> in the last 2 years?

□ Yes

 $\Box$  No  $\rightarrow$  Please go to question 35

If yes, please give the name of the service(s) and what reasonable adjustments were made to ensure you felt safe and listened to during your visit:

33. What overall rating would you give the <u>Hospital Services</u>?

- $\Box$  Very poor
- □ Poor
- $\Box$  Average
- $\Box$  Good
- □ Very good

34. When did you last use Hospital Services?

- $\Box$  In the last 4 weeks
- $\Box$  In the last 6 months
- $\Box$  In the last year
- $\Box$  Over a year ago
- $\Box$  Not sure
- $\Box$  Not used

Please tell us about your experience of this service in the box below:

35. Have you used GP Services in the last 2 years?

□ Yes

 $\Box$  No  $\rightarrow$  Please go to question 38

If yes, please give the name of the service(s) and what reasonable adjustments were made to ensure you felt safe and listened to during your visit:

36. What overall rating would you give <u>GP Services</u>?

 $\Box$  Very poor

□ Poor

□ Average

 $\Box$  Good

 $\Box$  Very good

## 37. When did you last use GP Services?

- $\Box$  In the last 4 weeks
- $\Box$  In the last 6 months
- $\hfill\square$  In the last year
- $\Box$  Over a year ago
- $\Box$  Not sure

 $\Box$  Not used

Please tell us about your experience of this service in the box below:

## 38. Have you used Pharmacy Services in the last 2 years?

🗆 Yes

 $\Box$  No  $\rightarrow$  Please go to question 41

If yes, please give the name of the service(s) and what reasonable adjustments were made to ensure you felt safe and listened to during your visit:

39. What overall rating would you give Pharmacy Service?

- $\Box$  Very poor
- Poor
- $\Box$  Average
- □ Good
- $\Box$  Very good

## 40. When did you last use Pharmacy Services?

- $\Box$  In the last 4 weeks
- $\Box$  In the last 6 months
- $\hfill\square$  In the last year
- $\Box$  Over a year ago
- $\Box$  Not sure
- $\Box$  Not used

Please tell us about your experience of this service in the box below:

## 41. Have you used any <u>Day Care Services</u> in the last 2 years?

 $\Box$  Yes

## $\Box$ No $\rightarrow$ Please go to question 44

If yes, please give the name of the service(s) and what reasonable adjustments were made to ensure you felt safe and listened to during your visit:

## 42. What overall rating would you give <u>Day Care Service</u>?

- $\Box$  Very poor
- □ Poor
- □ Average
- $\Box$  Good
- □ Very good

## 43. When did you last use <u>Day Care Services</u>?

- $\Box$  In the last 4 weeks
- $\Box$  In the last 6 months
- $\hfill\square$  In the last year
- $\Box$  Over a year ago
- $\Box$  Not sure
- $\Box$  Not used

Please tell us about your experience of this service in the box below:

## 44. Section 4 - Which of these local services have you used?

	Heard of	Contacted	Attended	N/A
Lorna Wing Centre for Autism				
Oxleas Adult Autism Assessment service (Bexley, Bromley, Greenwich)				
Bromley Well- Employment and Education Services				
Advocacy for All				
Information, advice and support service – Bromley (IASS)				
Bromley Social Care Services				
CASPA 'Children on the Autistic Spectrum Parent's Association				
Choice Support Social Club (Beckenham)				
Magpie Dance				
Bromley Well services				
Other charity/community services				
Other (please specify)				

## 45. How well did the support you accessed meet your needs?

	Very good	Good	poor	Poor	Very Poor	N/A
Lorna Wing Centre for Autism	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Oxleas Adult Autism Assessment service (Bexley, Bromley, Greenwich)	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Bromley Well - Education and Employment services	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Advocacy for All	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Information, advice and support service (IASS)	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Bromley Social Care Services	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
CASPA 'Children on the Autistic Spectrum Parent's Association	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Choice Support Social Club (Beckenham)	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Magpie Dance	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Gateway Clubs	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$
Other services	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$	$\bigcirc$

Please tell us what importance and value has the services you used given to you.

## Section 5 - Living in Bromley

## 46. Please tell us about living in Bromley

<ol> <li>How do you get around</li> </ol>	
or travel to Bromley?	
2. How do you find it living in Bromley?	
3. What do you like or	
value about living in	1
Bromley?	

## MONITORING INFORMATION

Your answers will remain confidential. You do not have to answer all these questions if you do not wish to but answering will help us to ensure that all are treated equally and that we are gathering the views of all communities and population groups within the Borough.

If you are a carer completing this form, please give us your monitoring information below.

47. What is your age?

□ 18-25

□ 26-35

- □ 36-45
- □ 46-55
- □ 56-65
- □ 66+
- $\Box$  Prefer not to say

## 48. To what is your marital status?

- $\Box$  Married
- □ Single
- $\Box$  Widowed
- $\Box$  Divorced
- $\Box$  Co-habiting
- □ Civil Partnership
- $\Box$  Prefer not to say

49. To which gender identity do you most identify?

- 🗆 Male
- $\Box$  Female
- □ Transgender male
- □ Transgender female
- □ Gender variant/Non-conforming
- $\Box$  Prefer not to say
- $\Box$  Other, please specify

## 50. Which ethnic group do you belong to?

These categories are based on the Census 2011 categories and recommended by the Commission for Racial Equality.

- □ White English, Welsh, Scottish, Northern Irish, British
- $\Box$  White Irish
- □ White Gypsy or Traveller
- □ White Other backgrounds
- □ Asian British, Asian English, Asian Scottish, Asian Welsh
- $\Box$  Asian Indian
- 🗆 Asian Pakistani
- □ Asian Bangladeshi
- $\hfill\square$  Asian Chinese
- □ Asian Other backgrounds
- □ Black British, Black English, Mixed
- □ Black Scottish, Black Welsh
- □ Black African
- □ Black British
- □ Black Caribbean
- □ Black Other backgrounds
- □ Mixed/Multiple White and Black Caribbean
- □ Mixed/Multiple White and Black African
- □ Mixed/Multiple White and Asian
- □ Mixed/Multiple White and Chinese
- □ Mixed/Multiple Other backgrounds
- 🗆 Arab
- $\Box$  Not known
- $\Box$  Prefer not to say

 $\Box$  Any other ethnicity not listed above, please specify:

#### 51. Disability:

The Equality Act 2010 defines a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

#### Do you consider yourself to be disabled?

□ Yes

 $\Box$  No

 $\Box$  Prefer not to say

If yes, please if you wish:

# 52. Do you consider yourself to have a long-term condition or health and social care need?

 $\Box$  Yes

□ No

 $\Box$  Prefer not to say

If yes, please if you wish:

#### 53. What is your sexual orientation?

□ Heterosexual/straight

□ Gay man/homosexual

□ Gay woman/lesbian

□ Transgender/gender re-assignment

🗆 Bisexual

 $\Box$  Prefer not to say

 $\Box$  Other, please specify

54. What is your religion?
Christian
Muslim
Buddhist
Jewish
Hindu
Sikh
No religion
Prefer not to say
Other, please specify:

# Thank you very much for completing this survey.

Your feedback is valuable to us and a report from the findings of this survey will published on the Healthwatch Bromley website in a near future.

Please return completed forms by post to:

Freepost RTHC\_JCSH-ERTE Healthwatch Bromley Community House South Street Bromley BR1 1RH "Our experience has not been a positive one.

The staff are all amazing and caring but there didn't seem to be anyone who was trained to deal with a young adult with Aspergers who was in mental health crisis.

We were told by a few professionals that the NHS did not have the resources or trained staff to support our son and apologised for the NHS letting him down!"

Local family

