An autism-friendly Croydon

Croydon's Autism Strategy 2021-24

A partnership strategy

Our partnership includes:



Clinical Commissioning Group

South London and Maudsley





Croydon Everything we do is about valuing and supporting children with additional needs and adults with a learning disability, their families, and carers.



Introduction

We are very pleased to introduce Croydon's first autism strategy, which we hope and expect will begin to make life easier for our thousands of autistic residents and their families, and increase awareness and understanding of autism across the whole of our population.

We are especially pleased to be working together as a partnership of organisations, committing to collaborating to help our autistic community. We can do much more together, and this shows how ambitious we are to do more, and do better. We are very hopeful that other organisations and individuals will join us in signing up as partners as we take this work forward.

Our Autism Partnership board, which meets bi-monthly, brings together partner organisations from across Croydon, along with autistic people, their families and carers. They have led the work on this strategy, and first and foremost, we have considered the views of autistic people at every stage. As well as a wide-ranging public consultation, council staff and councillors attended large numbers of meetings, including with parents groups and autistic residents. In total over 500 people were consulted before this document was produced; and the strategy itself was written by an autistic Croydon resident, with support from other local autistic people and their families.

This is the start of a journey, though, not the end. We recognise that having a strategy means very little until we deliver on it. A detailed action plan will follow this, and will clearly show who is responsible for delivering the strategy, and how and when updates will be provided.

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Of course, there were limitations to what we could do. Restrictions placed on meeting in person, due to Covid-19, made it very difficult to properly gauge the views of autistic people with greater support needs. We will seek to listen to and work with this group before we finalise the action plan, to make sure that their views are clearly and fairly represented too.

We hope that you will read this document; join us in learning more about autism, and autistic people; and help us to make Croydon a better place for our talented and diverse autistic community to live, and to thrive.

Our vision

"Our vision is that Croydon will be a place where autistic people feel welcomed, understood and supported to live happy and productive lives."

To make this happen, we need to think about every part of a person's life and dreams, and what will make them possible. We also need to think about rights and responsibilities — what support autistic people and their families should be able to receive, and which organisations should provide this support.

What is autism, and how can we help autistic people

Autism is a lifelong neurological disability that affects how a person communicates, processes and interacts with the world. Put simply, the autistic brain is wired differently from other people's brains. Many autistic people have difficulty processing sensory information, and can be very sensitive to lights, noises, smells and textures. Some autistic people are non-speaking or nonverbal, and may use alternate methods of communicating with people. Autistic people are also much more likely to have other medical conditions than most people, and those who have can regularly face multiple barriers to being accepted, and functioning from day to day. There is no cure or treatment for autism.

Every autistic person is completely unique, and experiences the world in different ways. In fact, individual autistic people's ability to cope and interact with others can vary hugely from day-to-day. Some autistic people are able to "mask", which means that they can appear to fit in or manage better, but it is very difficult and tiring to do this and is linked to a greater risk of severe mental health problems. For many autistic people, having a clear routine helps them feel more in control of their life and reduces their anxiety.

One shared experience is that day-to-day life is harder than it is for people who are not autistic. Society is mainly made up of people who aren't autistic, and

isn't designed with autistic people in mind, which can make many parts of life more difficult for them. There is also a general lack of understanding about what autism is and how it might affect a person.

There are lots of simple, mainly cost-free things which the public, employers and people working and interacting with autistic people can do, which will help the majority of autistic people::

- Don't make loud or unexpected noises
- Don't use bright or harsh artificial lighting
- Explain things in simple, clear terms without being patronising
- Maintain a routine and try to avoid changing this unnecessarily
- Ensure signposts and instructions are clear and obvious in public places, such as hospitals, schools and colleges or railway stations
- Don't force autistic people to do things they don't want to do because "everyone else is doing it" — everyone else probably isn't autistic
- Avoid unnecessary physical contact if you don't know someone well some autistic people do not like to be touched at all, or they may need their personal space to feel safe
- Undertake autism awareness and understanding training, and check regularly that your knowledge is still up to date
- Treat all autistic people with respect, listen to their needs and views, and follow their lead when helping them
- Don't make assumptions and wherever possible, ask the autistic person whether, and how, they would like your support

Many organisations, including most of the partners in this strategy such as the NHS and local councils, also have legal responsibilities or duties to recognise the needs that autistic people may have, and to provide certain types of support to autistic people. Some responsibilities relate to everyone, but also require organisations to consider if autistic people need to be supported differently due to their autism. Others are specific requirements to support autistic people. A list of some of these duties will be produced alongside the action plan. You can find out more about autism here from the <u>Autism Alliance / National Autistic Society / Ambitious about Autism</u>.

About this strategy

In Croydon, we want everyone to live a happy and productive life. For our estimated 8-11,000 autistic residents¹ and their families this is often harder, but we can all help to change this.

This strategy document was created by speaking to autistic people and their families in Croydon through a survey to find out what our residents want and need, and is split into priority areas, and recommendations of what can be done to improve how we support autistic people in these areas.

We developed our list of priority areas by creating an initial list based on the <u>national Autism Strategy</u>. This was shared with the local Croydon community for comments for around seven weeks, and was discussed in lots of meetings, including the APB. In total, over 500 people provided input into this consultation, and we added new priorities which were suggested to us during the process.

Each section focuses on one priority area raised by our residents, and ends with recommendations about what can be done to better support autistic people. You can see a summary of these recommendations on page 7.

Through this process, we can help people understand autism better, and they can help us create an inclusive community in Croydon, and beyond. We want businesses, professionals and the public to learn about simple changes they can make that will help autistic people, and will benefit other people too. By understanding more about autism, we can make Croydon a better, more inclusive and empathetic place to live for everyone, but especially for our autistic residents.

We want to thank all the people who contributed to this strategy. Special thanks go to everyone who completed our online survey or provided feedback, particularly autistic residents themselves. Thanks also to our Autism Working Party, which is made up of autistic residents, families and carers, who provided lots of guidance and support. Finally, enormous thanks to all of the staff and pupils at Bensham Manor School for telling us all about their hopes and wishes for the future. We hope that they will come true.

 $^{^1}$ Based on likely % of autistic people within the population, according to latest studies, and current Croydon population figures

Who we are

The Autism Partnership Board (APB) was set up to improve the lives of autistic people in Croydon. The members of the board include autistic residents, family members and carers, and people who work to support them, such as staff from as staff from schools and colleges, council staff, health professionals and many more. You can find out more about the APB in Appendix 4, right at the end of the document.

The APB has helped to develop this strategy. They will also help to create an Action Plan afterwards, and make sure that over the next three years we do what the strategy and action plan says — or if our plans change, explain why that has happened too.

We are very grateful to all of the organisations who have agreed to be named partners in this strategy. You can see who they are on the front page of this documeny. We know that no person or organisation on their own can make all of the changes that are needed to help our autistic residents.

If you represent another organisation and would like to join us in this work, please use the contact details at the end of the document. We would be delighted to add more organisations to our partnership.

Executive Summary of recommendations

These are some of the most important commitments which we will make to help our autistic residents.

- We will raise awareness and understanding of autism throughout Croydon, via a broad training and awareness programme
- We will ensure that autistic people are aware of their basic rights, and that public organisations are aware of their duties and responsibilities
- We will improve the pathways for children and adults seeking an autism diagnosis, from first contact through to support after diagnosis
- We will aim to provide support as early as possible to avoid autistic people going into crisis or burnout, particularly when supporting their mental health and wellbeing
- We will recognise that many autistic people without Learning
 Disabilities, who do not normally receive services, can still frequently
 struggle and require support to stay on track
- We will recognise that many autistic people have multiple diagnoses, and work to tailor services to meet these needs
- We will also recognise that many autistic people face multiple barriers to success, and work to understand and overcome these barriers with them
- We will make the most of our Active Lives and localities work and use the expertise we already have locally to deliver key parts of this strategy
- We will seek to involve autistic people and their families in all major decisions we take relating to autistic people
- We will seek to make buildings and public spaces as autism-friendly as possible
- We will produce a detailed Action Plan, which shows who is in charge of making each of these actions happen, and by when
- We will provide updates on our progress annually, and revise the strategy every three years, or earlier if there are significant changes

Our stories

Every autistic person has their own story to tell. Here are just a small number of stories from our autism community in Croydon, out of the hundreds of people who have told us what autism means to them and their family.

David's story

David is autistic, and in his late forties. He lives independently, and is very keen to be able to find paid employment. He has been trying to do this for most of his adult life but unfortunately has not been successful. David applies for jobs regularly, but does not get invited for interviews.

David has accessed support programmes aimed at helping autistic adults into work a number of times. However, these have provided short work experience placements which haven't led to paid work, or the offer of work has been completely inappropriate for David. For example, he was offered irregular shift work in a very busy retail environment, but the employer did not offer the reasonable adjustments that might have made this possible for him to do.

David has lots of experience of volunteering and work placements in an office environment. However, when he applies for permanent jobs, he finds that employers don't tend to value his volunteering work, and that they are looking for people who have already had paid jobs instead. As a result David rarely gets an interview and has not managed to find paid work.

David is talented and wants to work, and so through this strategy we need to work with employers to understand the benefits of hiring autistic people, and the reasonable adjustments they might need to succeed at their job.

Julian's story

Julian is autistic and has a moderate learning disability. He attended a local special school and left a few years ago, with some qualifications at entry levels, and a couple of GCSEs in creative subjects. After taking part in the transition programme from school to college, he was able to spend three years at college, developing his Maths and English skills, and studying Catering and Public Services.

Julian has been able to use his skills and qualifications to the full. Now in his mid-twenties, he has two paid jobs — working in catering at a local football club, and as a youth worker for disabled children, using his own experiences to help other people.

It is important to share the successes of people like Julian, and think about what services and support worked which helped him flourish.

Joanne's story

Joanne lives with a flatmate, in council accommodation in the borough. She struggled a lot at school, and only started to do better once she was transferred to a special school which understood her needs better. Having moved out of the area for a while, Joanne attended college and gained a number of practical qualifications, in areas such as Food Hygiene and Safety.

Like David, Joanne would like to find a job, but has really struggled with this. She volunteers a day a week in a local charity shop, but is looking for part-time work with consistent hours, and this is very hard to find. In the meantime, Joanne would like to be able to access more training opportunities, which she has found much harder to do as an adult than when she was younger. Her preferred way of doing this is accessing short residential courses so that she can focus fully on what she's doing and not be distracted by day-to-day life.

We need to think carefully about what support would help Joanne, and also perhaps younger people who could end up in a similar position, to make sure that employers understand what autistic people can do, but that in return they may need flexibility such as part-time working or fixed hours each week.

Laura and Andrew's story

Laura is Andrew's mother; Andrew is autistic and Laura isn't. Andrew has a learning disability and is mainly non-verbal, though he can talk. His needs are considered fairly complex and although he was at a local special school for a while, his behaviour meant that they were unable to safely meet his needs, and those of other pupils around him. He has also caused injuries to members of his family, and his parents have often worried for his younger sister's safety.

The family spent a lot of time and money challenging various decisions and in the end it was agreed that Andrew would attend a residential school some distance away from where he lives. With a quiet environment and 2:1 support he has thrived, and has calmed down so much that he has begun to speak more often and has almost no episodes of concern with his behaviour.

We need to think about what is on offer locally for young people like Andrew, because although this was a good outcome, it has come at a high financial cost. If we were able to support people such as Andrew locally it would be better for them and their families, as well as saving important resources.

Our priority areas

The follow priorities were agreed on after a lot of discussion and consultation with autistic people, their families, and people who work with them.

There are three core areas of the strategy:

- Increasing public awareness and understanding of autism
- Increasing the understanding and knowledge of the workforce
- Engagement and co-production with autistic people.

These are further divided into specific issues that autistic people, their families and carers have highlighted as important to them, which are summarised below.

Improving the support we offer

- Early support and intervention
- Education and training
- Health
 - Diagnosis and support
 - o Mental health
 - o Other health conditions
- Housing
- Social care and getting older
- Work

Improving our community

- Community and social activities
- Improving our information and data
- Raising awareness and understanding of autism
- Safe public spaces and autism-friendly environments

Improving equality

- Supporting BAME autistic residents
- Co-production listening to the autistic voice
- Supporting autistic people without Learning Difficulties
- Supporting parents and carers
- Supporting women and girls who are autistic
- Supporting LGBTQ+ autistic people

Early support and intervention

PRIORITY 1: AUTISTIC CHILDREN AND THEIR FAMILIES SHOULD BE SUPPORTED SO THAT THEIR NEEDS ARE UNDERSTOOD AND MET AS EARLY AS POSSIBLE



The right support early in someone's life can make a huge difference to their development as they get older.

Young autistic children should have their needs identified as early as possible, and be given the most appropriate health and educational support to meet these needs.

You said:

"The assessment time is too long. That's (key time for) early intervention lost."

"More support for early years staff and health visitors please"

- Improve the autism diagnosis pathway for children, following a recent review
- Continue and expand our delivery of the Autism Education Trust training programme
- Look at early interventions across health organisations to prevent greater support needs later in childhood
- Provide clear information online about what support is available at what stage

PRIORITY 2: AUTISTIC RESIDENTS SHOULD BE ABLE TO ATTEND SUITABLE EDUCATION OR TRAINING, IN AN ENVIRONMENT THAT IS APPROPRIATE FOR THEM



All autistic children and young adults under 18, or under 25 with an Education, Health and Care Plan have the right to an appropriate education or training placement. Autistic people and their families should have a say what this placement looks like. Placements should focus on developing skills, knowledge and independence.

You said:

"Teach (all pupils) understanding of autism from an early age"

"Schools should celebrate Autism Awareness Week"

"Ensure schools are inclusive and have sufficient SEND training."

- Work with all of our schools to improve staff and pupils' understanding of autism
- Look to expand our Autism Education Trust training programme, with the aim of training primary, secondary school and college staff in autism awareness and understanding
- Continue the development of our special schools to better cater for autistic pupils locally
- Seek to develop Supported Internships and other work-related training courses in Croydon

Health

PRIORITY 3: AUTISTIC RESIDENTS SHOULD BE ABLE TO ACCESS HEALTH SERVICES WHICH MEET THEIR NEEDS AND CAN ADAPT TO SUPPORT THEM



We want all autistic people to be able to access the support and treatment that they need in a way that works for them. We also want practitioners to think about their wellbeing more generally to avoid crises, and avoid the need for emergency medical support.

You said:

"Many people with ASD... might feel they can't go to a GP or will feel nervous about going"

"I sometimes have to wait ages at the hospital"

- Work to make clinical settings, particularly Croydon's Emergency Department and doctors' surgeries, more autism-friendly
- Train more staff in autism awareness and understanding
- Work to improve our data about autistic patients so that we can treat each person in the most appropriate way for them – including a digital "flag" for autistic patients
- Consult autistic people when we commission and develop health services
- Wait for the outcome of a national pilot on a health check for autistic patients, and consider doing this locally

Health – Diagnosis and Support

PRIORITY 3a: AUTISTIC RESIDENTS SHOULD BE ABLE TO QUICKLY ACCESS DIAGNOSTIC SERVICES, WITH CLEAR INFORMATION ABOUT THE PROCESS AND SUPPORT AVAILABLE AFTERWARDS



When an individual or their family thinks they may be autistic, they should be able to quickly understand what their options are, and what to do next.

There needs to be a full and clear "diagnostic pathway" that explains the process of being diagnosed as both a child and adult, and includes information about accessing support and services after diagnosis.

You said:

"(Either provide) Early diagnosis (or) provide official support without diagnosis"

"Shorter waiting times for diagnosis"

- Improve the diagnostic pathway for children (see early years section above)
- Introduce a multi-borough adult diagnostic pathway, working with Lambeth and Lewisham, to offer a better service
- Review the changes to both the children and adult pathways to make sure that they are working well
- Set clear targets in our action plan for diagnosis times, with a view to making the process quicker

PRIORITY 3b: AUTISTIC RESIDENTS SHOULD BE ABLE TO ACCESS MENTAL HEALTH SUPPORT TAILORED TO THEIR NEEDS, INCLUDING EARLY SUPPORT TO PREVENT CRISIS



Autistic people are more than three times as likely to have mental health problems than people who aren't autistic.

Mental health services should take into account the particular needs of autistic people, and look at what early support is available to avoid greater problems or even crises later on.

You said:

"I would like to see mental health services (be) more accessible"

"There should be autism champions in mental health teams"

- Support mental health professionals to improve their understanding and awareness of autism
- Consider what early support for autistic people particularly those without learning disabilities – might reduce the need for crisis support later
- Think about how the buildings which house mental health services can be as friendly and accessible as possible for autistic service users
- Consider how the use of technology could make mental health services more accessible for some autistic people

Health — Other Related Health Conditions

PRIORITY 3c: AUTISTIC RESIDENTS SHOULD BE ABLE TO ACCESS SUPPORT WHICH ALSO MEETS THEIR OTHER MEDICAL NEEDS



Many autistic people also have other conditions or medical needs. For example, autistic people are more likely to be dyslexic or dyscalculic, or have ADHD, epilepsy or a number of other diagnoses than people who aren't autistic.

The best support for any individual needs to take into account all of their requirements: a one-size-fits-all approach won't work for autistic people any more than it does for anyone else.

You said:

"ASD is not the cause of all problems (even when you have) the diagnosis"

"Nothing seems to be available to support (someone) with Autism, Epilepsy, ADD (and more)".

- Train staff to understand not just about autistic people, but also autistic people with additional conditions
- Look to understand more about commonly co-occurring diagnoses amongst our autism community, so that we can support them better
- Listen carefully to autistic people and their families, to understand what their conditions mean for them in practice

Housing and Accommodation

PRIORITY 4: AUTISTIC RESIDENTS SHOULD BE ABLE TO LIVE IN SUITABLE ACCOMMODATION



A stable and calm home environment is very important for autistic people, and for their families and carers. Autistic people should have the same level of choice about where they live as everyone else does. Some people will want to live on their own; some people with friends, family or partners. But everyone should have a say in where they live and who they live with.

You said:

"There (is little) supported accommodation to support adults with autism if they don't have a learning disability"

"More and better housing opportunities please"

"I don't want to live with my parents forever."

- Work with housing providers to offer autism awareness and understanding training for their staff
- Look at our offer of Supported Housing and Supported Living accommodation locally to see if it is meeting the needs of autistic residents
- Work with autistic people as we commission housing services for autistic people
- Consider the wishes of autistic people when making any housing placement, including for homeless autistic people

PRIORITY 5: AUTISTIC RESIDENTS SHOULD BE ABLE TO ACCESS APPROPRIATE SOCIAL CARE, AND UNDERSTAND HOW THEY WILL BE SUPPORTED AS THEY GET OLDER



We need to ensure that social care and support can meet autistic people's needs, and that autistic people understand how they will be cared for in their later years.

You said:

"(Think more about) needs that relate to people ageing with autism, particularly...support networks (which) become less accessible as parents (get older)."

"More support and training for social care workers"

- Seek to understand how many older autistic residents we have locally, and what their needs are likely to be
- Include autism as a specific category when commissioning care services locally
- Review our offer of specialist care support for autistic people with the highest level of need
- Ensure commissioners work with autistic people and their families to understand more about how to make our care services as inclusive as possible for autistic people
- Consider the possible impact of likely under-diagnosis amongst older autistic people

PRIORITY 6: AUTISTIC RESIDENTS SHOULD BE ENABLED TO WORK OR VOLUNTEER IF POSSIBLE, AND TO BE UNDERSTOOD AND SUPPORTED IN THEIR WORKPLACE



Only 16% of autistic adults in the UK are in full-time jobs, and over twothirds are not in work at all. However, the vast majority want to work. Autistic adults should be supported in gaining skills and training, and accessing appropriate jobs.

You said:

"Support into meaningful employment – opportunities to do more skilled work and not just shelf-filling or cleaning!"

"Access to work opportunities after school"

"It is hard for people with autism to get voluntary or paid work"

- Offer autism awareness and understanding training to local employers
- Support employers to create Autism Champions in the workplace, and develop an Autism Pledge and self-assessment
- Provide and promote case studies of autistic people who have successfully transitioned into work, and share these widely
- Review our offer of job-related training for autistic adults, including Inclusive Apprenticeships
- Work with autistic adults to develop the training which they want and need

Community and Social Activities

PRIORITY 7: AUTISTIC RESIDENTS SHOULD HAVE ACCESS TO APPROPRIATE COMMUNITY AND SOCIAL ACTIVITIES, WHETHER OR NOT THESE ARE WITH OTHER AUTISTIC PEOPLE



It is hugely important that people feel like they are part of their community, and are able to take part in activities they enjoy. There should be a clear programme of activities for at autistic residents, but also better understanding of autism across Croydon so autistic people can be supported to access any community activity

You said:

"There are not enough clubs available for the autistic community within Croydon"

"I'm an adult with autism and I've no idea what's available to me."

- Provide a directory of services which will include community and social activities for autistic people, to make sure people are aware of everything on offer
- Seek to make as many other community groups and activities as possible – particularly those funded by our organisations – mindful and inclusive of our autistic residents.
- Promote the excellent work done in this area by our community and voluntary sector as widely as possible
- Consider how to use technology in a way which promotes community, particularly during the Covid-19 pandemic

Improving Our Information and Data

PRIORITY 8: WE WILL IMPROVE HOW WE COLLECT, SHARE AND USE DATA TO UNDERSTAND MORE ABOUT OUR AUTISTIC RESIDENTS



We don't know very much about Croydon's autistic residents due to incomplete data. Nationally, information about autistic people is often wrongly placed together with mental health or learning disabilities. We have little information about autistic residents who are not accessing Croydon services. By knowing more about the autistic people who live here, we can better understand and support them.

You said:

"Information should be centralised so there's equality of access."

- Consider how we can share and use data better within, and across our organisations while being compliant with data protection laws
- Expand the membership of our Autism Data Group, reporting to the Autism Partnership Board, to monitor this
- Use our improved data to commission more effective services
- Ensure a flag in NHS data when patients are diagnosed or declare that they are autistic see health section above
- Keep all residents informed about what we're using data for and why

Raising Awareness and Understanding of Autism

PRIORITY 9: WE WANT EVERYONE IN CROYDON, ESPECIALLY THOSE WHO COME INTO REGULAR CONTACT WITH AUTISTIC PEOPLE, TO UNDERSTAND AUTISM BETTER



To really make Croydon more autism-friendly, we need as many people in our community as possible to understand more about what autism is, and how their actions might affect autistic residents. Basic information and training should be available for all residents, and businesses, so that more people are aware of, and understand, our autistic community.

You said:

"Consider more community awareness promotions"

"Train people to understand autism, not just be aware of it"

- Encourage our schools to speak with pupils about what autism is, not just undertake training for staff
- Provide information and / or web links on our website about autism, and autism in Croydon
- Offer autism awareness and understanding training to residents and businesses
- Publicise the launch of our strategy widely, including on our websites
- Encourage organisations to appoint Autism Champions
- Look to create an autism homepage on the Croydon Council website

Safe Public Spaces and Autism-Friendly Environments

PRIORITY 10: AUTISTIC RESIDENTS SHOULD BE ABLE TO ACCESS SAFE PUBLIC SPACES, AND BUILDINGS WHICH TAKE ACCOUNT OF THEIR NEEDS



Being out in noisy, busy public places can sometimes be very challenging for autistic people, and they made need safe, quiet spaces where they can get away from crowds when they need to.

There are also simple changes which can be made to the layout of public areas and buildings, which can help make it easier for autistic people to feel comfortable.

You said:

"More places to go, more accessibility, safe spaces"

"Croydon is so loud. Can there be somewhere we can escape to calm down?"

- Ask our community if they can provide safe, quiet spaces where autistic people can go if they need a break
- Provide basic guidance on ways to improve buildings, layouts, etc, so that they are more helpful for autistic people
- Think about the buildings and sites which our own organisations operate, and what more we can do to make them autism-friendly, as well as others like supermarkets and public transport hubs
- Lead by example think more about what else our own organisations can do to be more inclusive for autistic staff and visitors

Supporting BAME Autistic Residents

PRIORITY 11: AUTISTIC RESIDENTS FROM BAME COMMUNITIES SHOULD NOT HAVE TO FACE ANY ADDITIONAL BARRIERS IN RELATION TO ANY OF THESE PRIORITIES



We know from our survey, and many other discussions, that autistic people from our BAME communities can face multiple barriers to accessing the support that they and their families need. It is vital that we identify issues that make accessing support more difficult, and work to support every BAME autistic resident in achieving their goals.

You said:

"Being BAME and with two disabled children I get disempowered at every request"

"Why are the needs of black boys not addressed earlier?"

- Be open about recognising that autistic people from BAME backgrounds face additional challenges that we need to meet
- Listen specifically to BAME residents who are autistic, or their families and carers, to understand more about any additional barriers which they face, and what needs to be done
- Lobby for more research on autism in BAME communities
- Seek to ensure that our workforces are representative of the communities which we serve, including both autistic and BAME voices
- Tackle both direct and indirect discrimination

Co-production – Listening to Autistic Voices

PRIORITY 12: AUTISTIC RESIDENTS SHOULD BE CONSULTED ABOUT, AND WHEREVER POSSIBLE CO-PRODUCE, SERVICES FOR AUTISTIC PEOPLE



Autistic people, and their families, are best placed to understand what they need and want from public services. All local services for autistic people should be developed or reviewed with consultation from autistic people — this is called co-production, and will help to ensure that services are fit-for-purpose and autism-friendly.

You said:

"This is very important."

"(Yes), as long as consultation is with a wide demographic."

- Use our Autism Working Party meetings as a way for commissioners to discuss planned changes to services with autistic residents and their families
- Look to co-produce services with autistic residents wherever possible
- Look at our sub-contracts, and ensure that our contractors are being inclusive and supportive of autistic residents
- Regularly review the effectiveness of our services, with our service users, including autistic residents
- Seek to make mainstream services as inclusive and autism-friendly as possible

Supporting Autistic People Without Learning Disabilities

PRIORITY 13: AUTISTIC RESIDENTS WITHOUT LEARNING DISABILITIES SHOULD HAVE THEIR NEEDS CONSIDERED AND MET, EVEN IF THEY ARE NOT ACCESSING AUTISM SERVICES.



Around 30% of autistic people also have learning disabilities. The majority do not and there is less support available for them, both in Croydon and across the country. We need to review what will make life easier for this group of autistic residents, many of whom will be living independently, or not currently be accessing autism related services.

You said:

"People only pay attention to (those) with a visible need."

"People (often) don't recognise the difficulties of high functioning folk and...judge them to be dismissive, rude or shy"

- Think about all autistic people when creating our directory of services, and not only list services which are just for autistic people
- Seek to be inclusive first think about how we can make most services accessible to autistic people, rather than creating a separate pathway
- Aim to create a borough where autistic people do not feel marginalised or uncomfortable
- Look to build an online community for autistic residents
- Use our data improvements to enable bids for external funding to support the priorities in the strategy

Supporting Parents and Carers

PRIORITY 14: PARENTS AND CARERS OF AUTISTIC RESIDENTS SHOULD BE SUPPORTED WITH THEIR OWN HEALTH AND WELLBEING



Parents and carers have told us, both through our survey and wider conversations, that they need more support with their own health and wellbeing.

We need to recognise the significant contribution made by parents and carers, but also understand more about what will help them to look after their children, and look after themselves.

You said:

"Speak to parents and carers regularly, not just as a one-off."

"There is very little support for parents during the (diagnostic process)".

"It is vital that families of those with autism are supported."

- Be as clear as possible about processes and support available, particularly in the Early Years and Primary phases when the majority of diagnosis takes place.
- Provide access to groups, online and face to face, for parents to meet and discuss autism and parenting
- Signpost people to national support if we are unable to provide it locally

Supporting Autistic Women and Girls

PRIORITY 15: THE NEEDS OF AUTISTIC WOMEN AND GIRLS SHOULD BE CONSIDERED SPECIFICALLY, GIVEN THAT THEY CAN OFTEN BE VERY DIFFERENT TO THOSE OF AUTISTIC MEN



Until recently, research focused on men and boys, meaning we know less about autism in women and girls. This means that autism remains under-diagnosed in women and girls. Autism services must to be gender-inclusive and knowledgeable of different autistic presentations.

You said:

"We need different early interventions for girls."

"What provision is there for higher attaining girls?"

"Autism is often diagnosed late in girls...and the support is geared more to boys and men."

"Professionals often have a limited view of autism (in this respect)."

- Speak to autistic women and their families, to understand better how their needs may be different from autistic men
- Use this information to think about what changes may need to be made to our services or information available
- Consider whether our autism training accurately reflects what we know about autistic women
- Use our improving knowledge of autistic women and girls to ensure more accurate diagnosis
- Revise our local projections about the number of autistic female residents, based on new national data

Supporting LGBTQ+ Autistic Residents

PRIORITY 16: WE WILL SEEK TO UNDERSTAND MORE ABOUT THE NEEDS OF LGBTQ+ AUTISTIC PEOPLE, AND OPENLY RECOGNISE THE ADDITIONAL CHALLENGES THAT THEY FACE



We know that autistic people are more likely to be LGBTQ+ than people who aren't autistic. We need to think about how we support autistic LGBTQ+ individuals, and ensure that they feel accepted and supported.

You said:

This was not initially included as a category in our survey, but has been added as a result of a number of conversations, and an increasing research base.

- Recognise that autistic people are more likely to identify as homosexual, bi- or pan-sexual, asexual, and/or trans or non-binary, and that this may bring additional support and service needs
- Work with organisations and individuals supporting the LGBTQ+ communities to ensure that there is recognition and understanding amongst both groups of the crossover
- Seek to challenge possible infantilisation of autistic people the perception that autistic people, especially those with LD, may not be aware of their sexuality or gender when this is not the case
- Be as open as possible about discussing LGBTQ+ issues affecting autistic people

Developing awareness and understanding of autism – a core thread running through the strategy

A significant number of the recommendations above relate to improving public awareness and understanding of autism, or expanding training programmes to support staff working with autistic people. It is important to consider this as one programme of work, rather than trying to devise separate training for each one of the priorities.

One of the first actions from this strategy will be to work on a training and awareness-raising programme, to build confidence and understanding of what autism is, and removing any concerns or myths about autistic people. We will also consider a stronger presence online, including a focal point for this awareness training. Ideally, all training will be developed and delivered by or with autistic people. We will seek to use the expertise of organisations locally who already offer training or support, as well as working with our autistic community to think about the content and delivery of any training that we offer.

To do this, we will work across our organisations and with the Autism Partnership Board. We will almost certainly seek input from other partners, such as our local voluntary, community and charitable sector. We will also continue to work with our autistic residents and their families to make sure that they are involved.

Our first step will be to evaluate what we already do, and what impact it has. Currently, we deliver Autism Education Trust training to Early Years / Nursery staff across Croydon, and the Council's Autism Service has often delivered training across a variety of settings.

What will happen next?

Now that we have agreed this strategy, we must work to make it happen. It is important that there are clear targets in place to deliver our priorities, and that we know which organisation and which people are in charge of each one.

To do this, over the next few weeks we will develop a more detailed plan, which will explain how we intend to do what we have set out in the strategy.

The Action Plan will have SMART targets – these make it easier for us to tell what will be done, when it will be done by, and who is in charge of making it happen.

The Autism Partnership Board, and the Autism Working Party, will look in more detail at all of the targets, and keep checking to make sure that this work is happening.

To help with the strategy, we have spoken a lot with different groups of people about what autistic people need. We will keep listening to autistic people and their families in the future, so that as things change, we understand if the things our autistic residents need or want have changed as well. We will also make sure that people can give us their view on what we have got right, and what we haven't.

We will keep people updated on how we are getting on with our work, too. We will publish the action plan online when it's ready, and provide annual updates on what has changed as a result of this work.

At the time this is being written, we are expecting a new national strategy about autism to be published by the government. We're not sure exactly when this will be ready but it is expected soon. The last one is called Think Autism, and is from 2014.

If there are major changes nationally or locally, particularly if they affect what we can or must do for autistic people, we may update Croydon's strategy straight away. Otherwise we expect to update it before the strategy's end date, in 2024.

How you can get involved

We would love for you to join us to make this vision a reality, and we need as many people as possible to help.

If you're an autistic person, or a parent or carer, you could consider joining one of our working groups, where your views will help to determine what services for autistic people look like. Or you can get in touch with us, and we can contact you with updates, or invite you to future consultation sessions we may run.

If you're a professional working with autistic people – have you undertaken autism awareness and understanding training? Have your staff or colleagues done this? And does your department or organisation have an Autism Champion, helping others to learn more about autistic people and what they can offer? Please get in touch if you'd like to hear or do more.

If you're running or working for a business locally – are your premises as autism-friendly as they could be? Are your staff autism-aware? Do you have an Autism Champion who could help and advise other staff if they have queries or concerns? Could you offer anywhere as a safe space for autistic people in the community to drop in if they need one? Again, please get in touch with us if you can help.

And whatever your interest – if you're a member of the Croydon community who just wants to know more, we'd be delighted to hear from you as we develop this work.

For more information, please contact:

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Contributors to this strategy

A huge number of people contributed to this document, and it was also taken to large numbers of meetings as it was being worked on, to ensure that as many people as possible had the chance to provide feedback.

We had 222 responses to our public consultation. In addition to this:

181 pupils from Bensham Manor School told us about their hopes for the future.

Individual meetings took place with at least 20 different organisations.

The Autism Inclusion Lead, and / or the Borough Autism Champion, attended the following groups and meetings, among others, to talk about the strategy:

- The Autism Partnership Board
- The Autism Working Party thanks to all members of this group, mainly autistic residents and parents / carers, who provided significant help and input into this document
- Croydon Health and Wellbeing Board
- GP Collaborative
- Health and Social Care Scrutiny Sub-Committee
- Croydon Health Services Mental Health, Autism and LD Board
- SEND Forum and SEND Strategic Board (schools and education meetings)
- Croydon Clinical Health Leads meeting
- Safeguarding Children Board

Links to useful information and relevant documents

There is a huge range of information about autism available online and elsewhere. There is also quite a lot of disinformation — you cannot cure autism, and nor do vaccines cause autism, but these are common myths shared online. Below, we have provided a list of starting points to understand more about autism. This isn't a recommendation for any of the organisations listed – however, these are generally considered to be reputable organisations providing accurate information.

<u>The National Autistic Society</u> is the UK's largest autism-specific organisation, providing information and services, and lobbying for resources for autistic people.

<u>Ambitious about Autism</u> is a national organisation focusing on Children and Young People with autism. They also provide information and services, and lobby government.

<u>The Autism Alliance</u> is a group of organisations who work with autistic people, mostly covering individual regions of the UK, or smaller areas like counties.

The <u>APPGA</u> is a parliamentary group – made up of MPs and representatives from the autism sector – who promote autism in government.

<u>The National Autism Strategy</u> – Think Autism – is now seven years old but is due to be updated at some point in 2021.

<u>The Autism Education Trust</u> provides a national training programme for education staff. We deliver this in Croydon to staff in the Early Years phase.

<u>Autistica</u> is the largest organisation in the UK dedicated to research about autism.

<u>CRAE</u> carries out research on autism in education, and publishes lots of interesting research and articles.

The NHS has an information page about autism, diagnosis, support and more.

<u>The Council for Disabled Children</u> isn't specifically an autism organisation, but it does provide lots of useful resources and information

Glossary of terms used in this strategy

Autism: Autism is a lifelong neurological disability that affects the way a person communicates and interacts with people and the world around them. There are many terms that fall under the autism umbrella — Autism Spectrum Condition, Asperger's Syndrome, Pathological Demand Avoidance — but for simplicity we have simply used autism throughout.

Autism Champion: Someone with a strong interest and understanding of autism, who promotes autism understanding and acceptance either within their organisation or community.

Autistic: an autistic person is a person with autism. The majority of people prefer autistic over person with autism [link to Lorcan Kelly's study], but it is always best to use personal preference.

Action Plan: An action plan, which will follow on from this strategy, contains more detailed information and targets which will show how we will make these actions happen.

BAME: People from black and minority ethnic backgrounds.

Co-Production: People from a certain community – in this case, autistic people and their families – working with professionals to make sure that services reflect the needs and desires of that community.

Learning Disability: A Learning Disability affects the way a person understands information, and how they communicate. This means it can be harder for them to understand new or complex information, learn new skills, or cope and live independently.

LGBTQ+: Lesbian, Gay, Bisexual, Trans, Queer and more.

National Strategy: Think Autism is the government's National Autism Strategy. It is due to be revised, probably some time in 2021.

SMART targets: SMART is an acronym – where each letter stands for a word. SMART means Specific, Measureable, Achievable, Realistic and Time-Bound. If a target is all of these things it should be clear what needs to be done, by when, and that you will know when it has been completed.

About the Autism Partnership Board and its work

The Autism Partnership Board is a regularly meeting group Croydon which specifically looks at autism, and how to support autistic people. The meeting is chaired by the Borough Autism Lead (currently Cllr Jerry Fitzpatrick), co-chaired by a member of the public from the autism community (currently Nicky Selwyn), and supported by Croydon Council staff. Invitation to the meeting is by invitation, to ensure the number of people attending is manageable and meetings aren't overly long.

The group is made up of autistic residents, or parents and carers of autistic people, as well as a number of groups and organisations which include:

Croydon Council (officers, and politicians from both the council and the opposition)

Croydon Health Services

South London and Maudsley (SLaM)

South West London Clinical Commissioning Group (CCG)

Croydon College

Croydon Mencap

MIND in Croydon

Inaspectrum

The Autism Service

JobCentre Plus

Met Police

Parents in Partnership