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"We want our Autistic residents to feel supported and empowered to live their lives as independently as possible."

Bernie Flaherty
Executive Director of Adult
Social Care and Health,
Westminster City Council and
the Royal Borough of Kensington
and Chelsea

# **FOREWORD**



It gives me great pleasure to introduce this Autism Strategy. I am delighted that so much attention has been paid, listening to and incorporating the wishes, needs and ambitions of our autistic community in Westminster. Residents asked for this strategy, and their involvement is key to its voice and aspirations. I'm convinced that by setting out and being transparent on our roadmap we can more easily deliver the goals and targets set by residents. You will hear their stories clearly in this document, and it is by hearing people's stories that we create change - through awareness and understanding.

There are many practical issues and goals set out in the strategy and I welcome this systematic and methodical way of setting out what we need to achieve, and how we will know we have succeeded. Ambition and aspirations need to be underpinned by rigour and explanation, this strategy aims to do that.

Strategy and planning is vital, but so is attitude, and mindset, and it is those things we must really look to as well. I am struck by the emphasis on working together, whatever our roles and positions. Not just the importance of co-production with our autistic residents in Westminster, but also all departments of the two councils with other public and voluntary agencies co-ordinating and integrating responses. This strategy gives a blueprint for effective collaboration in this way, to break down barriers and overcome challenges. Education and awareness is key and I look forward to seeing real and inspiring changes in the near future. This strategy I believe enables that.

### **Cllr Tim Mitchell**

Councillor for St. James's Ward, Cabinet Member for Adult Social Care and Public Health, Deputy Leader, Westminster City Council



Autism is under-diagnosed and under-managed nationally. This joint Autism Strategy serves to help address these issues across Kensington and Chelsea and Westminster. The document sets out the context, the need and the challenges of diagnosis and the lack of vocal representation for a large portion of our residents. Some of the statistics before you are eye-opening and have reaffirmed our determination and commitment to tackling the issues faced by our autistic residents, in partnership with them.

This strategy has the voice and experience of over 200 autistic residents and those who care for and support them woven within it. No better perspectives could have been called upon to explain and analyse current needs than from those who experience autism-related challenges daily. It is these perspectives that have really brought the strategy to life.

Our boroughs have committed to becoming a more welcoming and hospitable environment for our autistic residents, and this strategy sets out the framework for how we will deliver the actions to really make this happen over the coming years.

I am immensely thankful for the residents who took the time to shape this strategy. It is written by them, for them and has opened the eyes of our respective councils to the opportunities and improvements we can make.

We have an incredibly exciting journey ahead of us, working in partnership to deliver on the actions in this strategy, and I look forward to seeing how we get on.

### Cllr Cem Kemahli

Lead Member for Adult Social Care and Public Health, Royal Borough of Kensington and Chelsea



I'm very proud to introduce this Autism Strategy, which sets out our goals, ambitions and creative vision for how we can support and enhance the lives of autistic people in our boroughs.

I have always been passionate that the writing and implementation of the strategy should be led by the diverse, lived experience of people in the autistic community. It should not only be a structure and framework to which we can work and hold ourselves to account, but also be imaginative, inventive and inspiring. I hope the voice and aspirations of residents is loud and clear in this document.

The strategy sets the tone and ambition of what we want to achieve working alongside residents, their families, carers and friends. Above all, we can't be prescriptive - we should be adaptive, flexible and responsive to individual lives and experiences, and to changing situations.

We have structured the document so that it is easy to read and sets out in a clear way what residents tell us works well, where we need to focus more attention and how we'll be able to measure when we have achieved success in those areas. These benchmarks will be important for us to be successful in our ambitious aims to improve every aspect of the lives of autistic people.

Autism is often said to be a 'hidden disability' – I hope this strategy shows that, together, we are bringing awareness of the diverse and distinctive richness of the autistic community into clear view.

### Bernie Flaherty

Executive Director of Adult Social Care and Health, Westminster City Council and the Royal Borough of Kensington and Chelsea



This strategy is the culmination of the outstanding contribution by the autistic community, in Westminster and the Royal Borough of Kensington and Chelsea who passionately champion the forward momentum needed to do better and be better.

The strategy aims to clearly outline the mission, vision for where we want to be in the future, and the values that will guide our actions. I see in this strategy a reflection of the beautiful individuality of the autistic community and the variety and breadth of input that recognises that autism services and support must reflect difference and cannot be generic. The respect for autonomy, choice and control over their own lives and influencing their community is evident.

The impact of a good strategic plan is the respectful disappearance of the barriers in our current society and our local communities.

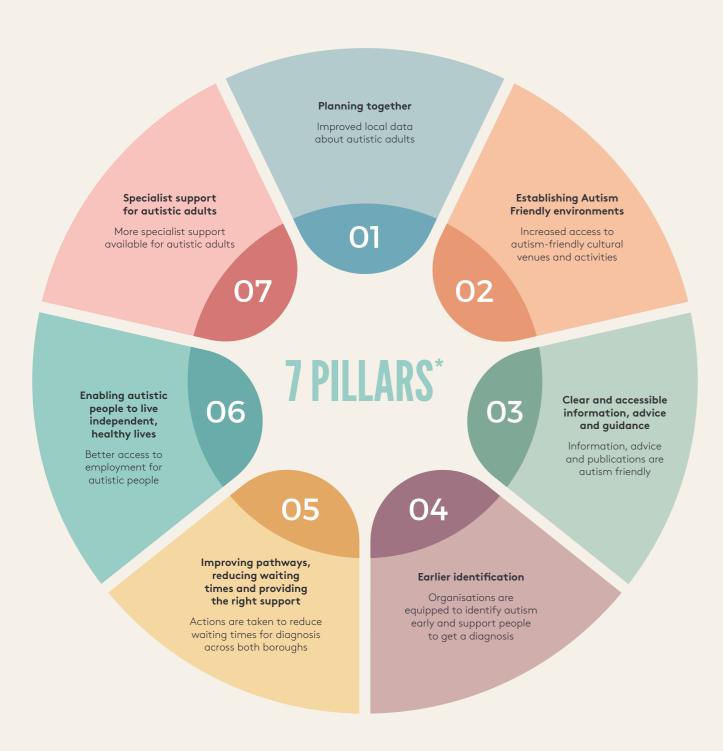
We must not underestimate the importance of this document as the roadmap that defines the future of autism services in our boroughs, providing a welcome guide to measure against our collective development and improvement for the autistic community.

### Helen Fleetwood Centre for ADHD and Autism Support, Adult Services Manager



# **KEY ACTIONS**

Changing Lives: Adults Autism Strategy 2021-2024



<sup>\*</sup>These are the 7 pillars from the biborough All Age Autism Strategy, 2020

# INTRODUCTION

This strategy is the second phase of our 'All Age Autism Strategy, 2020'. The first phase is our 'All Age Strategy' and this, the 'Changing Lives: Adults Autism Strategy 2021-2024' is the second. Both strategies have the same pillars, but this one focuses on actions impacting adults across the two boroughs. We are committed to reflecting on the importance of a whole-life approach to autism and addressing the issues and challenges faced by our autistic residents.

This strategy focuses on autistic adults, with some references to young people in transition. The purpose of the strategy is to ensure that all autistic adults, their carers, partners, families and allies are supported to live a full, safe, happy and healthy life in the boroughs of Royal Borough of Kensington and Chelsea and Westminster.

This strategy has been co-produced with over 200 autistic people, their families and carers as well as the people and leading organisations that support them professionally. It identifies the strategic challenges faced and some of the potential solutions and ongoing improvement plans to make our boroughs a welcoming place for autistic people and those who care for them.

### **Local Plans and Strategies**

- The Big Plan 2018-2020
- Council Plan, Royal Borough of Kensington and Chelsea
- City for All, Westminster City Council
- Royal Borough of Kensington and Chelsea Cultural Strategy 2020
- The Royal Borough of Kensington and Chelsea, Charter for Public Participation
- Active Westminster Strategy
- SEND Strategy 2021-2024

### **Regional and National Plans and Acts**

- Fulfilling and Rewarding Lives: the strategy for adults with autism in England (2010)
- The Autism Act 2009 and ensuing statutory guidance including the 2021 updated guidance and plans including the new national autism strategy 2021
- The Children and Families Act 2014 (Part 3) and associated Code of Practice
- The Care Act 2014 and associated regulations
- National disability strategy 2021
- NICE Guidelines (2016)
- NHS Long Term Plan (2019)
- The Sustainability and Transformation Plan
- Liberty Protection Safeguards
- Mental Health Act Changes planned
- The national strategy for autistic children, young people and adults 2021-2026<sup>1</sup>

In line with the Government guidance, the implementation of the strategy will be overseen by the Health and Wellbeing Board and the Autism Partnership Group and operationally monitored and managed by the Adult Social Care leads for Autism.



**Seth Mills**Biborough Head of Learning
Disability, Autism Lead



Rachel Dickinson
Biborough Service User Engagement and
Policy Manager, Autism Strategy Lead

# **ABOUT AUTISM**

### What is Autism?

Autism is a lifelong condition that affects how people perceive the world and interact with others. Very often, autistic people see, hear and feel the world in a different way. The social model of disability emphasises that autism is not an illness or disease and cannot be 'cured'. Indeed, the idea of a cure is deeply resented by many autistic people. With the right support and accommodations, all can live a fulfilling life of their own choosing. Many autistic people experience sensory-processing difficulties e.g. becoming overwhelmed by their environment, avoiding or not noticing certain sensations, or seeking out certain sensations.

It can also have an impact on their experience of and relationship to food, which can lead to health problems and/or misdiagnosis of an eating disorder. Autism is known as a spectrum condition, both because of the range of issues that affect children and adults, and the way that these present in different people.

### **Terminology**

This strategy uses the term "autistic person" or "autistic adult". This is in line with the National Autistic Society guidance around terminology which says: 'The most important thing to remember is that many autistic people see their autism as a fundamental part of who they are, so it is important to use positive language'. This is often known as 'identity first' language meaning that the term 'autistic person' is used instead of 'person with autism'. The people involved in the design of this strategy also stated this was their preference.

### Why we need a strategy

The Autism Act 2009 expects health and social care to have a local autism strategy that is co-produced with residents. With additional guidance around the implementation of the Autism Act 2009 and some of the challenges posed by the COVID-19 pandemic, our residents have told us we need to work strategically to improve the lives of autistic adults across the two boroughs.

Many local authorities have launched similar strategies to help their organisation and their local community stay focused on this important agenda. It is important to recognise that some autistic people will need very little or no support in their day to day lives, some people will require lots of support and some autistic people require round the clock care. We have tried to consider the needs of people across this spectrum when developing this strategy and have spoken with over 200 autistic people and their families in the planning of this strategy.

The National Autistic
Society Says – Autism is
a lifelong development
disability which affects
how people communicate
and interact with the world.
One in 100 people are on
the autism spectrum and
there are around 700,000
autistic adults and children
in the UK.<sup>2</sup>

### NATIONAL THEMES

The National strategy for autistic children, young people and adults: 2021 to 2026 works on 6 key themes.

Each of these themes are highlighted within this plan.



1.

Improving understanding and acceptance of autism within society



2

Improving autistic children and young people's access to education and supporting positive transitions into adulthood



3

Supporting more autistic people into employment



4.

Tackling health inequalities for autistic people



b

Building the right support in the community and supporting people in inpatient care



b

Improving support within the criminal justice and youth justice systems



## **AUTISM AND DIVERSITY**

### LGBTQ+

Recent research by the University of Cambridge suggests that autistic individuals are less likely to identify as heterosexual and are more likely to identify with a diverse range of sexual orientations than non-autistic individuals.<sup>3</sup>

Further research also suggests that gender identity is also more varied among autistic adults than the wider adult population with autism three to six times as common in people who do not identify as their assigned sex.<sup>4</sup> With these statistics in mind, it is important to ensure that all services supporting autistic adults are fully aware and are sensitive to the individual needs of all residents they support, including using appropriate pronouns and terminology.

### Autism in women and girls

It is acknowledged nationally that there is under-diagnosis of autism in women and girls, and that statistically autism is more prevalent in men and boys; but many of the women (both autistic people and professionals working with autistic adults) felt greater acknowledgment and understanding of the challenges faced by autistic women is required. Many women involved in the design of this strategy shared their stories of misdiagnosis and the damaging psychological impact later in life of masking their autism. (See Sophie's story over the page).

### CASE STUDY

### **AutAngel**

AutAngel is a Community Interest Company run by and for autistic people. We run a number of online peer support groups, including two groups for autistic adults who are also part of the LGBTQ+ community. The groups provide a safe online space for Queer Autistic adults to support one another. We can be contacted at info@autangel.org.uk about group membership.

We also have our website which has a calendar of nationwide events of interest to autistic people. We are constantly updating our resources page with useful information.

www.autangel.org.uk

### CASE STUDY

### Riley's story

"I am a lawyer working in a law firm. I am also in a long-term relationship. I am a parent to a happy, intelligent child with many friends. I am a friend and colleague. I am a mental health advocate, and I have won and been shortlisted for national awards. I am non-binary. What most people do not know is that I am autistic. I didn't know myself until a few years ago.

It makes a lot of sense, though. I have always struggled but I have also had incredible support. My Dad who would always sort things out when needed. A boss who accepted me for who I am, who promoted my strengths, who encouraged me and made me feel in control at all times. A very good friend. A therapist to discuss difficult topics with. It is tricky during times when it feels as if there is no support.

Without support, living in a world not made for, nor very accepting of, autistic people can be extremely hard. In those times I think of myself as a roly poly figure - I always come up straight, again. It may not be easy, it may be a really tough time, it may take clenched teeth, but ultimately, I always end up upright, things improve, and support may pop out of an unexpected corner.

During those times I tell myself that challenges usually have a silver lining. It may not be obvious at first, but ultimately these challenges are almost always a catalyst for an exciting new period, for something to learn, something interesting to explore, to investigate, to research, to get excited about, something positive, a new obsession. Being autistic in a neurotypical world is not easy by any means, but I wouldn't want to be any different."

# MENOPAUSE AND AUTISM

Sophie, an autistic woman, wanted to share her experience of accessing treatment for menopausal symptoms from her GP.

"I had classic menopausal symptoms; such as mind fog, unstable emotions, hot flushes and not feeling 'like myself anymore', problems I have been struggling with my whole life. When my existing coping strategies (mindfulness for example) became repetitively overwhelmed, I knew that this was not just a problem in my head.

The initial consultation with my GP wasn't that helpful because the focus was on the symptoms rather than cause. I came away with prescriptions for antipsychotics for the presenting anxiety, but I did get referred to the specialist gynaecology team (about five years ago) who did hormone testing to confirm I was menopausal, and I was given HRT. After a shaky start, I felt a dramatic improvement in my mood. Much more able to cope, and even when a meltdown felt imminent, it wasn't completely overwhelming.

The doctors at my GP's surgery were matter of fact and did not patronise, or pander to, my erratic behaviour. I think this was important as it made me accountable in my own treatment plan. It was a case of "we can offer you this, but you have to do that" type of exchange.

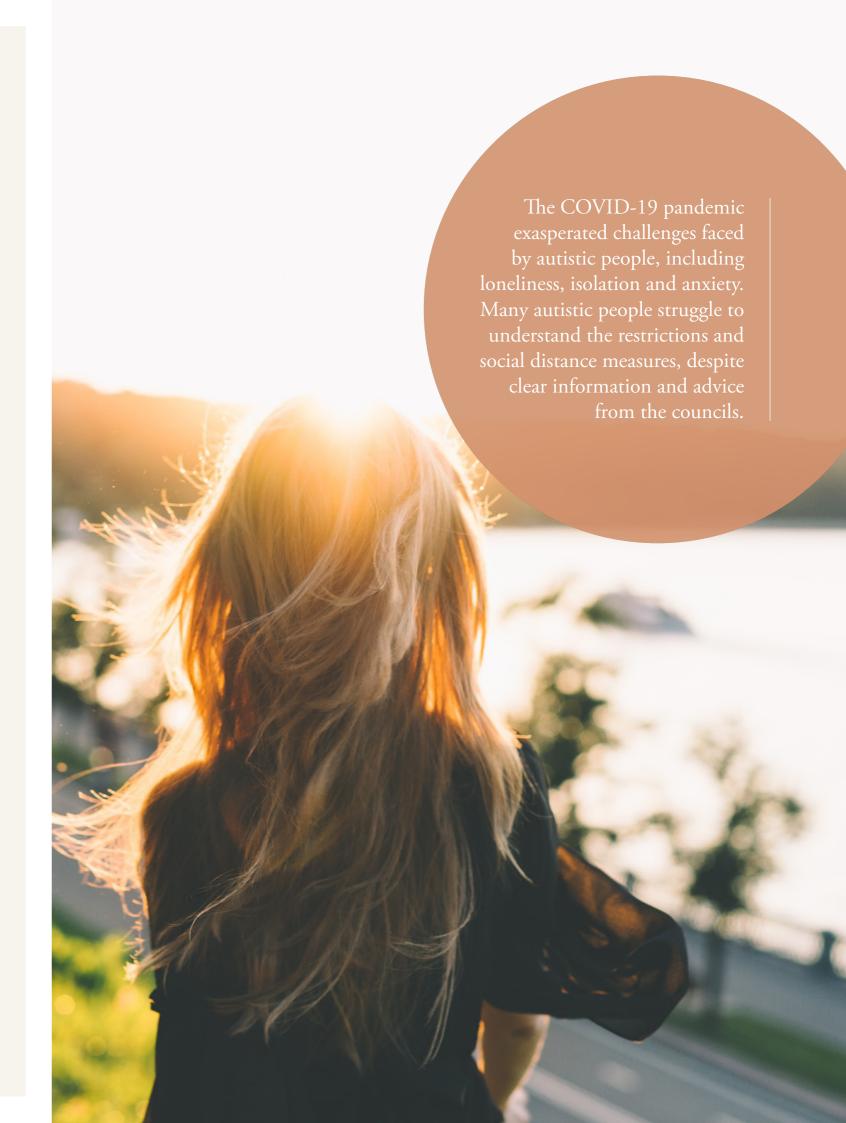
What I did have to do was articulate what I actually needed, rather than going into victim 'no one can help or understand me' mode.

The extraordinary kindness and empathy of the GP's reception staff was key in my being able to approach the surgery without feeling that horrible gripping shame, which can so easily turn into rage. They used gentle humour and empathy and told me to come in, even just for a chat with one of them if I was feeling overwhelmed. Knowing I had that resource there, that someone had my back, made me feel more in control and able to make my own decisions. It broke that paralysis of fear-based responses where I felt utterly helpless and not even a participant in my own issues.

Instead of reaching for alcohol (which I admit was a problem) I truly felt heard and seen. And that I mattered. I did go into the surgery a couple of times and felt immediately reassured.

I'm not sure if these gentle skills can be quantified, but they need to be recognised for sure! I am extremely thankful to all the team at my GP's surgery."

"What I did have to do was articulate what I actually needed, rather than going into victim 'no one can help or understand me' mode."



# **STATISTICS**

It is nationally recognised that statistics and data about autistic adults is very difficult to capture and nationally there is a limited amount of accurate data relating to autistic people. This strategy recognises this and aims to go some way to improve local data collection.

### **National statistics**

- There are 700,000 people on the autism spectrum in the UK. That's more than 1 in 100 people. Autism is part of daily life for 2.8 million people<sup>5</sup>
- 21.7% of autistic adults in the UK are in any form of paid employment<sup>6</sup>
- Autism is 3 times more prevalent in boys than girls<sup>7</sup>
- 79% of autistic people have had a mental health problem within their lifetime<sup>8</sup>
- Autism can co-occur with a learning disability but at least half of the people on the autistic spectrum do not have a learning disability<sup>9</sup>
- Studies in the prison population show 20-50% prevalence of Attention Deficit Hyperactivity Disorder and autism in prison<sup>10</sup>
- 79% of autistic people say they feel socially isolated<sup>11</sup>
- Up to 66% of autistic adults have contemplated suicide in their lifetime, compared to 17% of the general population<sup>12</sup>

### **Local statistics**

We know that locally we do not have the best access to data about autistic people. However, the data below sets out what we do know, based on the 1.1% population estimate.

- There are approximately 4,500 autistic people living in the biborough (2800 in Westminster and 1700 in The Royal Borough of Kensington and Chelsea)
- There are approximately 26,500 autistic people living in North West London.

700,000

people on the autism spectrum in the UK

70% of autistic people say they feel socially isolated

4,500
autistic people living in the biborough

26,500
autistic people living in North West London

Graphs to illustrate the number of people predicted to have autistic spectrum disorders, by age, projected to 2040<sup>13</sup>



2,095

Total population aged
18-64 predicted to
have autistic spectrum
disorders by 2040

### Royal Borough of Kensington and Chelsea



Total population aged 18-64 predicted to have autistic spectrum disorders by 2040



## **FEEDBACK**

The biborough All Age Autism Strategy, 2020 states: autistic adults told us that there is a significant gap in adult provision, and a need for specialist, ongoing psycho-education and practical support.

This adults strategy aims to address this gap by working with autistic adults and their families with the key pillars from the All Age Autism Strategy, 2020. (These priorities have been created and designed by the autistic people that have helped to write this strategy).

- Planning together real improvement through involving autistic people, their families, providers and practitioners in the development of our strategic approach and service delivery.
- Establishing autism-friendly environments

   supporting staff and the wider community to
   understand autism and the needs of autistic people
   and their families, and that our physical locations

are accessible.

- Clear and accessible information, advice and guidance supporting autistic people, families and professionals by providing effective resources, advice and signposting.
- **Earlier identification** identifying autism as early as possible in children, young people and adults.
- Improving pathways, reducing waiting times and providing the right support - providing a high-quality health service which responds quickly to people's needs.
- Enabling autistic people to live independent, healthy lives - providing effective support for autistic people to enable them to fulfil their potential in all educational settings (whether early years, school, college or at home).
- Specialist support for autistic adults working across employment, housing, health, education and social care to support autistic people to live full independent lives.

### CASE STUDY Royal Albert Hall

The Royal Albert Hall has offered relaxed performances in its main auditorium for a number of years, including Relaxed Proms as part of the BBC Proms, Relaxed Christmas Carol concerts and Relaxed family film screenings. Adjustments made for these performances include extra resources such as a Booking Guide and Visual Story, designated chill-out spaces, symbolbased signage, a Mobiloo (mobile accessible toilet with adult-sized changing bench and hoist) and British Sign Language (BSL) interpretation.

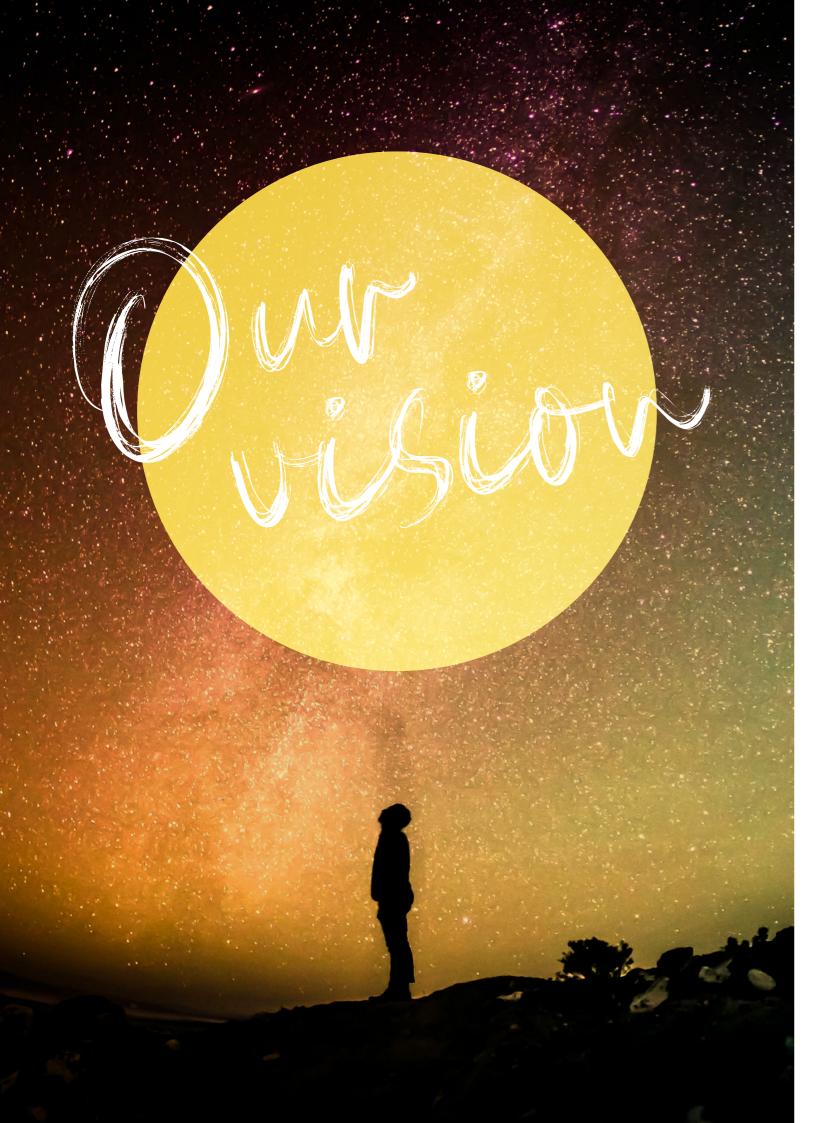
These events have proved very popular and we have received lots of positive feedback:

"A wonderful experience that I'd love to attend again. Relaxed performances give our family the opportunities just like other families, but everyone who attends has patience and understanding."

"Great SEN (Special Educational Needs) provision, and helpful staff - thank you for the chill out area! A life-saver."

In order to create a specific offer for autistic adults, we will develop a pilot of autism-friendly Film Screenings for adults in the Hall's state of the art performance space, the Elgar Room. Working with the Centre for ADHD and Autism Support (CASS) and other groups over the next year, we will listen to feedback from our target audience about how these events could be designed to best suit them.

We will aim to have an established series of events widely available from 2023, which will offer a cultural and social experience for Autistic adults in a relaxed environment.



# **OUR VISION**

Our vision is for all autistic people in Kensington and Chelsea and Westminster to be able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it. They can depend on mainstream services to treat them fairly as individuals, helping them make the most of their talents in an accessible physical environment.

Our ambition is that autistic people in Westminster and Kensington and Chelsea can expect to play an equal part in the local community, get the right support at the right time throughout their lives and develop their skills and independence and work to the best of their abilities.

We believe that by working with residents, and professionals, focusing on these priorities we can deliver our vision to create a welcoming, understanding environment for autistic people and their families; in turn, reducing stigma, increasing awareness and providing the right support at the right time.

### Making it Happen - Our Strategy

The remainder of the strategy is centred around 7 of the key priorities from the all age strategy and aims to answer 4 key questions:

- What works well? This is what the residents and professionals involved in designing this strategy told us was working well to support autistic people across both boroughs.
- What do we need to focus on? This is from the feedback across both boroughs when we asked what is not working so well, or what do we need this strategy to work on and improve.
- **How do we achieve this?** This is ideas, suggestions and plans to support improvement across different sectors to improve the lives of autistic adults across both boroughs.
- How will we know we have achieved it? This is based on our shared recognition of the importance of measuring and monitoring important agendas.

Each pillar of this strategy is aligned to The National Strategy for autistic children, young people and adults: 2021 to 2026, and to the priorities and overarching outcomes of the Autism Partnership.

"Autistic people have lots of skills and ideas. We see the world in a different way and may feel things differently. Include us in your projects and you will learn lots!"

### Planning together

This pillar is about real improvement through involving autistic people, their families, providers and practitioners in the development of our strategic approach and service delivery.



### Leadership

### What works well?

• The new 'Autism Partnership' was set up in 2021, with defined working groups, actions and activities across both councils and our partners. The group is co-chaired by an autistic person and will oversee the activity as a result of the all age strategy and this strategy. Many of the autistic adults designing this strategy are interested in being part of the partnership to support improvements in both boroughs.

### What do we need to focus on?

- Linking in with other groups and seeking feedback from autistic residents and responding to suggestions.
- Finalising a defined workplan to oversee the actions of the strategies.
- Remaining up to date with best practice. Identifying more autistic people to be part of improvement planning and feedback.

### How do we achieve this?

- Working in collaboration with key stakeholders including children's services, housing, communications, culture, health and other departments of the partnership.
- The final work plan will have several working groups focusing on each pillar of this strategy and All Age Autism Strategy, 2020.
- The overarching outcome of each is included under each of the pillars in this strategy.

### How will we know we have achieved it?

- Regular review of the achievements, membership, successes and challenges of the Partnership against the pillars of the two strategies.
- Improved partnership working to support autistic adults.
- Better data available and consistent feedback from autistic adults.

### **Meaningful Engagement**

### What works well?

- There are lots of examples of engagement, coproduction and codesign events across both councils and health partners, including the work of the Local Account Group, citizens panel, regeneration, and planning consultations and Central North West London NHS Foundation Trust (CNWL NHS FT) new Adult Expert by Experience Reference Group. Both council plans have been designed with engaging residents at the heart.
- Public Health Community Champions Programme.
- This strategy has been designed with the input of 200 autistic residents and their families, who feel it is fundamental that autism in adults is recognised in its own right to support better planning and design of services.
- The Royal Borough of Kensington and Chelsea Council has a Community Engagement Network where professionals can learn from each other and share examples of community engagement programmes.

Nationally, 24% of autistic adults and 26% of family members think public understanding has improved since the introduction of the 2009 Autism Act. 16

#### What do we need to focus on?

- Opening and promoting established groups to autistic adults and encouraging the establishment of more peer led organisations focusing on autism in both boroughs, and existing peer-led organisations focusing on how they can be more accessible to autistic people.
- For the Central Northwest London NHS Foundation Trust autism group: the focus will be; increasing membership, setting group objectives and supporting services to understand gaps in provision and codesign solutions. The current focus is on communication and codelivery of training to health staff, aimed at the recovery colleges.
- Leading by example and encouraging partner organisations to tailor consultations, engagement, and campaigns to be accessible for autistic residents.
- Sharing the feedback to learning from both positive and negative stories.

### How do we achieve this?

- Creating a respectful, patient listening space for autistic adults who may feel they have been dismissed and overlooked in the past.
- Making reasonable adjustments to make the engagement experience welcoming and meaningful for the autistic residents. This may include consideration at events for autistic attendees, including providing quiet rooms/tents/environments where people can feel safe and take a rest from the activities.
- Encouraging autistic adults to be active participants, while
  respecting that not all autistic people are able to fully express
  their needs and share their experiences, and it may take a little
  longer to build rapport and creative means of engagement may
  need to be used.

### How will we know we have achieved it?

- Increased representation of autistic residents in consultation and engagement activity. With autistic representatives on established groups and programmes (Local Account Group and Community Champions).
- Evidence of provision for autistic people at events across both boroughs.
- Across both councils and health partners; there are autism specific focus and engagement groups, these groups may be smaller or 1:1 and use non-traditional methods to ensure that the voice of autistic people is captured.
- Central North West London NHS Foundation Trust (CNWL NHS FT) training is rolled out to all local mental health teams.
- Ensuring that autism is listed as a characteristic on all surveys and consultations produced to allow improved data collection.
- Continued sharing of best practice around engagement, with an emphasis on autism.



#### CASE STUDY

### Pursuing Independent Paths (PiP)

Pursuing Independent Paths (PIP) a local charity empowering adults with a learning disability or autism to achieve their ambitions. We are here to support adults with a learning disability or autism to gain skills and opportunities to find and use their voice and to live a life of their choice. We approach our work with energy and creativity and believe we can achieve anything we set our minds to. Most importantly, we are proud of who we are.

We achieve all this by delivering a person-centred programme of learning that increases skills for our students independence, health and wellbeing, participation in the community and future prospects. Our sessions focus on independent living skills, employment and training and creative and performing arts, and range from numeracy, money management and literacy, to art, music and drama, to communication, cooking, and self-advocacy.

Our students choose the sessions that best suit them, their skills, their interests, and ultimately their goals and ambitions in life.

### **Individual Planning**

### What works well?

 When there are individual assessments, reasonable adjustments are made, to make the process more comfortable for autistic people.

#### What do we need to focus on?

- Ensuring that adjustments are considered in advance of an initial/first meeting.
- Appreciating that first meetings with professionals can be very stressful and uncomfortable for autistic adults.
- Asking meaningful questions about individual needs and being mindful of their communication requirements when doing so.

### How do we achieve this?

- Training for front line staff on the needs of autistic people and the types of adjustments that can be made.
- In Westminster, encouraging the use of the WelcoMe app for first, and all visits to minimise distress and discomfort when meeting with services.

### How will we know we have achieved it?

- Positive feedback is gathered from autistic people following their initial and ongoing assessments. This includes homelessness, support with benefits, adult social care and health appointments.
- Increased uptake of the WelcoMe app across Westminster residents. (See page 31 for more information)

### Advice for professionals

See page 62 for some practical tips for professionals when meeting an autistic person.

his part of the strategy supports the National Strategy priority: to improve understanding and acceptance of autism within society.

This pillar will be monitored by the Autism Partnership group overall leadership programme.

**Reminder:** In line with 'Planning together' this strategy was developed and designed with 200 autistic people and their families. The design, themes and layouts were created by their hardwork and commitment to the project!



### CASE STUDY Fruitful

Fruitful is a key part of PiP's employment programme. Students join Fruitful to gain employability skills, work experience and to test out working in a hospitality industry. They also gain employment support in small groups and 1:1, updating their CVs, practising interviews and going on workplace visits.

By learning how to run a juice stall, students learn employability skills such as:

- Customer service
- Working in a team
- Managing time
- Working to deadlines
- Food hygiene
- Health and safety
- Money management
- Marketing
- Social media

Once our Fruitful Trainees have gained confidence in making juices and practiced working together as a team, Fruitful then pops up at local markets and businesses to sell juices, smoothies and our awesome student-designed Fruitful merchandise.

After adding this great training and work experience opportunity to their CV, Fruitful trainees might go on to get paid employment in the hospitality industry or use their new skills to progress towards achieving their ambitions in other industries too.

# MOUSETRAP THEATRE PROJECTS

Mousetrap Theatre Projects is a charity dedicated to enriching the lives of children and young adults through theatre, especially those who are socially and financially disadvantaged or are neuro-diverse. Their mission is to create better access to theatre for all young people, regardless of circumstance, and they work in a variety of settings using drama as a tool to build essential life skills.

### **Relaxed performances**

Mousetrap ran the first relaxed performance in London's West End (Shrek the Musical in 2012) and has hosted 8 West End relaxed performances since then. These are available to young people up to the age of 25 (and their parents and/or carers) with autism, learning disabilities or other sensory and communication needs who would benefit from a more relaxed environment. Tickets are heavily subsidised and offered at only £5-£10 per young person and £6 to £20 per adult.

To find out more, visit <a href="https://www.mousetrap.org.uk/relaxed">www.mousetrap.org.uk/relaxed</a>

To sign up for the mailing list visit <a href="https://www.mousetrap.org.uk/email-signup">www.mousetrap.org.uk/email-signup</a>

### **Drama Skills for Employability**

Mousetrap works with neuro-diverse students at FE Colleges who are studying Employment Preparation and Supported Internships. Expert drama practitioners use creative techniques to help students gain the confidence, communication and teamwork skills needed for the work-place. In 8 sessions, students work on their interview technique, body language and vocal skills, and explore how to evaluate their talents and advocate for their needs. The project includes a West End theatre trip, an inspirational workplace visit and a showcase, which brings all the colleges together to share their successes.

To find out more, contact jo@mousetrap.org.uk

### Theatregoing Clubs

For seasoned theatre-lovers or those who just want to give it a try, Mousetrap runs 2 unique theatre clubs, with tickets to some of London's most exciting shows for just £7 a ticket. Go Live is for young people aged 15-24, is free to join and has at least 2 outings a month to see amazing London theatre for as little as £7 a ticket, usually with a Q and A with people from the cast or creative team.

Find out more, visit

www.mousetrap.org.uk/golive

People aged 24-29 can sign up to Go Live Grads for just £10 a year, and see shows for just £15 a ticket.

Find out more, visit

www.mousetrap.org.uk/go-live-grads

To join the club, visit

 $\underline{www.mousetrap.org.uk/golive application}$ 

### Interested in a career in theatre but not a performer?

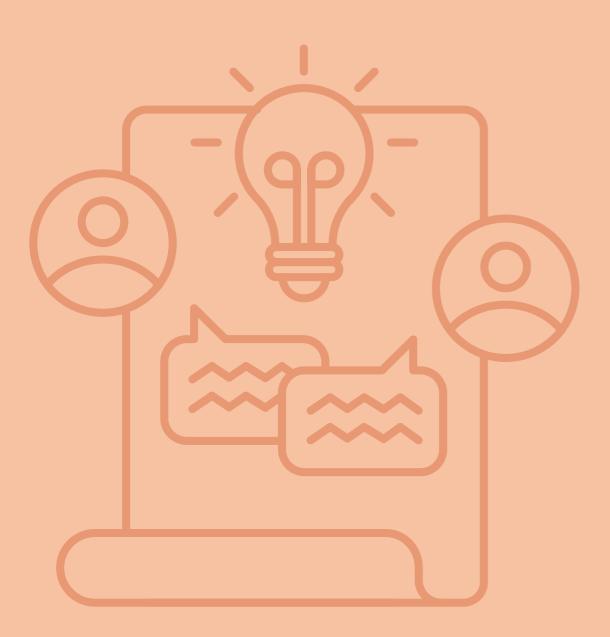
Mousetrap runs an annual Youth Leadership in the Arts Conference in the spring, which is open to anyone aged 15 to 24 who is considering an off-stage career in theatre. There are workshops and discussions led by industry experts and it's a great chance to find out what it means to work in the theatre, in a very supportive and friendly environment.

To find out more, visit <a href="https://www.mousetrap.org.uk/">www.mousetrap.org.uk/</a> youth-leadership-in-the-arts-conference



# Establishing Autism Friendly environments

Supporting staff and the wider community to understand autism and the needs of autistic people and their families, and that our physical locations are accessible.



### Leadership

#### What works well?

• Our residents have said that organisations based in the boroughs are starting to change the way they view autism and the support for autistic people, but are at the beginning of their journey.

### What do we need to focus on?

- Lead by example to raise awareness of the needs of autistic people.
- Making a variety of training opportunities and awareness sessions available across our communities.
- Making sure autistic people feel accepted, safe and valued in our communities.
- Taking a leadership role in our communities to encourage local businesses to create opportunities for autistic adults.
- Providing networking and learning to support local businesses to employ autistic people.

### How do we achieve this?

- Bringing together lots of different community organisations, individuals and statutory bodies to create an understanding community for autistic people and their families.
- Promoting local awareness sessions and encouraging businesses and organisations to be autism aware and autism friendly.

### How will we know we have achieved it?

 Organisations, businesses and community services will develop their own autism strategies, learning from the examples included within this strategy and the National Strategy.

### **Autism-friendly Communities**

### What works well?

- There are autism-friendly services, quiet hours in supermarkets, shops, and local businesses across both boroughs, usually near supported accommodation services.
- Pursuing Independent Paths (see case studies on pages 22 & 23)
  have developed an initiative called Fruitful which aims to teach
  people to make smoothies and healthy products and earn an
  income. They have recently had a pop up at Paddington Station.
- Leisure centres across both boroughs are welcoming and understanding of the needs and experiences of autistic people, including day opportunities for people with learning disabilities and autism friendly/quiet hours.
- Positive examples of autism-friendly activities in museums, galleries and entertainment venues across the two boroughs including relaxed performances in cinemas and theatres, music concerts and ballet performances.



### CASE STUDY English National

### English Nation

The English National Opera (ENO) works closely with children and young people with autism and their families focusing on engaging people with arts and health. Recently, the ENO has started to expand this offer to work with adults to improve health and wellbeing. Through this strategy the ENO hopes to be able to work more with autistic adults with a love of music and performative arts.

### What do we need to focus on?

- Rolling this out more widely and consistently across both boroughs.
- Promoting new opportunities like PIP and Fruitful in different fields, including customer service, retail, admin, entertainment and more.
- Making sure that all leisure centres are participating in these initiatives and actively encouraging autistic people to attend.
- Ensuring that these events are widely publicised, with consistent availability and publicity, including the promotion of subsidised/ free activities.
- Increased training for the staff working the events to understand autism and be able to respond to challenges autistic attendees might have.
- Ensuring that events for autistic people, are not just for autistic children and their families. Events and groups for autistic adults should be promoted and prioritised.

### How do we achieve this?

- Encouraging businesses to put on 'autism hours', have 'autism champions' and promote 'autism awards.'
- Working with organisations to understand what knowledge of autism they have and supporting them to fill in any gaps and make necessary adjustments to create autism-friendly environments.
- Supporting the use of Fruitful and other enterprises supporting autistic people.
- Encouraging museums and cultural venues to host autism-friendly activities, not just aimed at children but adults as well. <a href="www.officiallondontheatre.com/access/relaxed">www.officiallondontheatre.com/access/relaxed</a>
- Promoting autism awareness training to arts and cultural venues.

### How will we know we have achieved it?

- Increase in supermarkets across Kensington and Chelsea and Westminster offering autism-friendly shopping times that are widely publicised.
- A 'call to action' around autism in the community, meaning increased communications and networking with local businesses, and more autism champions in local businesses.
- More activities and events aimed at autistic adults in museums, theatres and cultural venues across both boroughs, that are well attended, well publicised and staffed by people who have had awareness training.
- Museum activity focused on autistic people will be captured and more easily accessed, including through the use of webtools like: <u>www.autisminmuseums.com</u>



### CASE STUDY Manga Club 'Xpress

This is a weekly meeting place for young people (11-20 years), who are interested in watching Anime films, drawing Manga/cartoon characters and taking part in the role-playing game, Dungeons and Dragons. The biborough Autism Advisory Team are aware that these activities reflect the interests of many of the young people they work with in schools and colleges.

The setting provides a safe, low arousal, autism-friendly environment in the brand new premises of the Westbourne Park Family Centre.
Siblings and friends are also welcome. There is a team of volunteers made up of supportive adults and young people who have received initial training in understanding autism, and a member of the biborough Inclusion Service's autism team has given advice in the setting up of the Club.

### Each week they offer:

- An introduction to a Dungeons and Dragons role playing game.
- Opportunities to watch Anime [initially Studio Ghibli films] with other young enthusiasts.
- A chance to draw and share Manga or cartoon characters.
- Time to dress up 'Cosplay style'.
- A separate area for parents to meet – with the possibility of a facilitated discussion if this proves popular.

### **Tools and Technology**

#### What works well?

- Westminster Council have introduced the 'WelcoMe' App at Westminster City Hall as a way to make autistic people, and people with disabilities, experience the council in a more welcoming and friendly way. (See case study on page 31).
- There have been reviews undertaken of facilities, including police stations and dental surgeries, that have highlighted how these important community environments could be more autism friendly.
- The local police are doing more to help autistic people, in particular autistic women, feel safer in the two boroughs, but there is still a long way to go.
- The Metropolitan Police, in partnership with the British Transport
  Police and the City of London Police have created an 'Autism Alert
  Card' that informs officers of additional needs for autistic people
  if they are to be arrested. It is focused on better communication
  and a reduction in stressful interactions with police officers. It
  encourages the police to make reasonable adjustments when an
  autistic person is in their custody.

### What do we need to focus on?

- Encouraging more businesses to sign up to the 'WelcoMe' app and make reasonable adjustments for autistic people and people with additional needs.
- Reviewing health settings including GP surgeries and hospitals which are not always autism-friendly and additional needs are not always considered in a consistent way.
- Some of the young people, particularly the young women that
  developed this strategy felt that more education and training
  was required to help them keep safe, especially when their
  autism challenges their ability to understand predatory or unsafe
  behaviours when socialising in the city.
- Making social workers, GPs and other key staff in the community aware of the Autism Alert Cards scheme, with access to the cards and actively encouraging autistic people to carry them.



#### CASE STUDY

### London Transport Museum

The London Transport Museum, in Covent Garden, is a fun environment with lots of simulators and interactives. They recognise the potential for sensory overload, so have a programme of early and late openings for school children and families with SEND, which are accessed by many people with autism

These provide quieter environments with soundscapes switched off. Additional activities, such as costumed interpreters and sensory bags, are also available.

The Museum Depot in Acton is a museum store with public access at particular moments in the year. It's generally a quieter environment without interactive exhibitions. It is a great place to visit if you have a specialist interest in particular vehicles or transport topics. They are continually seeking opportunities to improve the visitor experience, particularly to ensure that those with autism can have a rich and engaging day out. The Museum is keen to collaborate and consult with us, and to consult with our autistic service users.

#### How do we achieve this?

- Publicising the WelcoMe app and encouraging innovation and creativity to allow similar apps like this to help autistic people living in our boroughs.
- Services across both boroughs are encouraged to enlist the help of autism specific organisations to undertake reviews of their buildings and services to make them autism friendly.
- Increasing public awareness of autism.
- Many bars across the two boroughs are signed up to the 'Ask for Angela' initiative led by the Safersounds partnership with the Metropolitan Police and Mayor of London to reduce sexual violence and vulnerability in licensed venues across London.
- All venues that support 'Ask for Angela' have been given 'Welfare and Vulnerability Engagement' Training (WAVE) delivered by the Metropolitain Police licensing officers and Safer Sounds to give staff the ability to help customers who may be in a situation that makes them vulnerable or unsafe.

#### How will we know we have achieved it?

- Apps like WelcoMe are used in all services by people across the council when meeting with autistic people.
   Westminster aim to have the app rolled out to 10 sites in the first year of this strategy.
- Other organisations across both boroughs, supporting autistic people use the WelcoMe app, and other apps like it.
- Services and businesses welcome challenge and assessment by autistic people to improve the way they deliver services to autistic people.
- All licensed premises in both boroughs to sign up to the 'Ask for Angela' initiative <u>www.met.police.uk/</u> <u>AskforAngela</u>
- Greater promotion of the police's 'Autism Alert Card' scheme. With stores of the cards available to give to people regularly.
- All autistic adults across both boroughs given the opportunity to carry the Autism Alert Cards.

"Focusing on keeping autistic people safe, particularly women, and people who identify as LGBTQ+ is crucial to making sure that our communities are 'friendly' for autistic people."

Chira
Autistic Royal Borough of Kensington
and Chelsea resident

AQ10<sup>14</sup> autism screening is in place at Charing Cross police station to identify autistic traits displayed by people detained at this site. The purpose of the tool is to allow additional support and reasonable adjustments to be made when a person is in custody.

### Advice for professionals

This part of the strategy supports the National Strategy priority: Improving understanding and acceptance of autism within society, and; Improving support within the criminal justice and youth justice systems

The working group of the autism partnership board will focus on the overarching outcome of improving organisational policies to be more autism friendly, and improving local environments for autistic residents

In line with the updated Autism statutory guidance to consider autism in the field of criminal justice, thi strategy has been developed with the support of the Metropolitan Police.

### **WELCOME APP**

Westminster City Council are excited to become the first council in London to introduce the WelcoMe App into their venues, a unique web-based tool to support people with accessibility needs.

The WelcoMe App enables visitors to plan ahead by advising venues, prior to their arrival, of any specific requirements or accommodations that they require. This removes the stress and anxiety often felt by those with additional needs when visiting new locations, whilst supporting our staff to offer excellent customer service.

WelcoMe was launched in 2017 and is now in place in over 70 venues across the UK including locations such as the Scottish Parliament, Edinburgh Airport, and the RNIB Headquarters in London.

The app is very intuitive and easy to use and works as a 'meet and greet' tool. Visitors install the WelcoMe App onto their phone and access the venue that is listed on the main site. The user provides details of their visit (date/time), their disability/condition and what support they would like on arrival or during their visit.

Visitors can then notify staff on arrival and where requested, be met at the door by a member of staff who can assist them. This has proven to reduce the stress and anxiety that many disabled users feel when visiting new venues.

In January 2021, Westminster Council's Corporate Property department identified the WelcoMe App as a useful tool that could support our disabled visitors when accessing our buildings. Working with members of the Disabled staff network (ABLE network), the App was piloted at City Hall, and following positive feedback will be rolled out to other operational buildings.

We have developed a marketing and communications plan that aims to reach residents and businesses in Westminster. Internal communications and support are also planned to ensure staff have the confidence to use the app and support visitors.

www.wel-co.me/visitors







# Clear and accessible information, advice and guidance

Supporting autistic people, families and professionals by providing effective resources, advice and signposting.



### **Publications**

#### What works well?

- Residents involved in this strategy gave positive feedback around the COVID-19 information and clear one way systems.
   This was because the information was explicit, straight forward and clear.
- Many recent strategies and plans produced by both boroughs have involved residents and are produced in an accessible, user friendly way.
- Councils are committed to making their websites as user friendly as possible and are doing extensive work to become more accessible to all disabilities.<sup>15</sup>

#### What do we need to focus on?

- Ensuring that consistent efforts are made to make all council published information, advice and guidance as autism-friendly as possible with support from autistic residents.
- Making sure alternative versions of documents are available, this includes different languages including British Sign Language (BSL), easy read and audio described versions.
- Ensuring that terminology is accurate in all published documents. In particular, making sure that references are accurate and in line with current practice (e.g. not referring to out of date phrases and terminology).
- Writing in clear, plain English with no jargon or unexplained acronyms.

### How do we achieve this?

- Consistent, clear and agreed use of up to date language in all documentation relating to autistic adults.
- Not using out of date language, including 'low functioning', 'high functioning' or person 'with autism' and staying up to date as these preferences change.
- Referring to reputable sources like: <u>How to talk about autism</u> when writing about or speaking to autistic people.

### How will we know we have achieved it?

- All documents produced by the councils' will be available in an autism-friendly format, with a variety of different formats available.
- All terminology used is up to date, accurate and in keeping with the recognised standards.
- Ongoing feedback is collected from autistic people about the information displayed on the councils' webpages including temporary campaigns, launches and events.



### Case STUDY Come & Create Band

Come and Create Band is a fortnightly music club at Wigmore Hall for autistic young people aged 15–19. The group explores and creates new music together alongside professional musicians. Each session finishes with an informal sharing for parents and carers, and the chance to spend time together as a group. Recently, the band have released a track called 'Sea Sounds'.

The programme was created in 2017 through consultation and collaboration with our partner Turtle Key Arts; a specific need was identified for autistic young people, aged over 15, as other arts activities were oversubscribed.

### Wigmore Hall's commitment to autistic people includes:

- a plan to offer training and workshops for staff, including music leader and front-of-house. This training will support their commitment to becoming a sector leading, 'autism-friendly' venue.
- a 'Come and Create' music programme, including a summer project, open to young people aged 15+ with a hope for this to develop into a fully youth-led
- a concert series, 'Imagine', that will be produced with and for young people aged 16-25, in partnership with a range of different arts organisations. The concerts will be informal, with movement in and out of the Hall, plus designated quiet zones.

### **Personalised Communication**

### What works well?

- There have been stories of positive interactions and communication. 1:1 with staff from across the council and the health services.
- Many of our autistic residents prefer confirmation of appointments and plans in writing (by email or letter) and will avoid telephone contact where possible.

### What do we need to focus on?

- Ensuring all staff working in front facing roles are upskilled and feel confident to work with autistic adults.
- Enabling residents to express their communication preferences when interacting with council services with flexible communication methods made available and respected consistently.
- This should include, telephone, letter, email and other more flexible means where possible.

### How do we achieve this?

- Focusing on training for front line staff, including the potential use of the 'Oliver McGowan Training' (<a href="www.olivermcgowan.org">www.olivermcgowan.org</a>) currently being considered by Central Government.
- Working closely with other agencies and partners to ensure their communications are accessible to autistic people, including the police, local voluntary organisations, and all other agencies that may provide information, advice and guidance to autistic adults and their families.

### How will we know we have achieved it?

- All staff across both councils undertake autism awareness training, that is kept up to date, with additional indepth training provided to those working with more complex autism cases.
- Promoting other sources, and where appropriate different levels of autism training, including the training for professionals in North West London funded by North West London Clinical Commissioning Group (NWLCCG) and provided by Centre for ADHD and Autism Support (CAAS).

"I would like to see local businesses proudly stating they are autismfriendly or autism aware, it would make me feel welcome in my community."

Recognising that autism is a spectrum and what works for one does not work for all, however some basic principles, from the Home Office are<sup>17</sup>:

#### Do:

- Use simple colours
- Write in plain English
- Use simple sentences and bullet points
- Make buttons descriptive

### Do not:

- Use bright, contrasting colours
- Use figures of speech or idioms
- Create a wall of text
- Make buttons vague and unpredictable
- Build complex and cluttered layouts

### Advice for professionals

This part of the strategy supports the National Strategy priority: Improving understanding and acceptance of autism within society.

The working group of the autism partnership board will focus on the overarching outcome of improving offline and online communication for autistic people and providing clear and accessible guidance for all autistic people in the two boroughs.

# Designing for users on the autistic spectrum



| Do                                    | Don't   |
|---------------------------------------|---|
| use simple colours                    | use bright contrasting colours                    |
| write in plain English Do this.       | use figures of speech and idioms                  |
| use simple sentences and bullets      | create a wall of text                             |
| make buttons descriptive Attach files | make buttons vague and unpredictable  Click here! |
| build simple and consistent layouts   | build complex and cluttered layouts               |

# SUPPORTED INTERNSHIP JOURNEY



Planet Organic is the UK's first Soil Association certified organic and natural food health store, and we are now the largest, with 12 stores across London. We are at the forefront of the trend towards healthier eating and sustainable retail and are the UK's first zero food waste food retailer.

At Planet Organic, we strive to be more than just a shop. We want to do more for our customers, neighbourhoods, employees, suppliers and the planet than simply buying and selling products. We believe in promoting health in our communities through organic, natural and sustainable products, and acting sustainably and ethically as

We care deeply about the communities we are a part of. Our goal is to promote health within our communities and to be ethical in our treatment of both people and the planet. Being part of a community also means being part of conversations, listening and using the views of those we serve to improve what we do.

Our supported internships help young people aged 16 to 24 with complex learning difficulties or disabilities to find work. Launched in November 2019, the scheme is available to SEND (special educational needs and disability) candidates from local schools. To deliver this, we have collaborated with a biborough council group from Westminster City Council and Kensington and Chelsea Council.

Study programmes include on-the-job training with expert coaches responsible for supporting both interns and their managers. As well as the experience they gain with employers, programmes can also give interns the opportunity to take courses to develop other relevant skills, such as effective communication or understanding money.

The scheme has allowed Planet Organic to strengthen ties with local communities to our stores and increased the capabilities of our managers and team leaders through developing new ways to train and manage people with diverse needs and abilities.

The enthusiasm that the interns have brought to our stores, particularly after what has been a really testing period for all of our staff over the last eighteen months, has been really uplifting for everyone connected with us. We are proud to be supporting these young people to gain the skills they need to find fulfilling roles.

Our supported internships have been the first step in our objective of making Planet Organic a Disability Confident organisation, a process we formally began this year. Whilst this fits well with our mission as an ethical and community-focussed retailer, we also see a huge commercial benefit to being able to attract and accommodate workers with different needs as it is a pool of talent too often ignored by other employers.



"Our mission to create a truly inclusive culture at Planet Organic, including becoming more autism-friendly and accessible."

James Marsh Learning & Development Manager, Planet Organic We know we have a long way to travel on our journey to be truly inclusive, but we feel confident that we are making strides in the right direction. An example of this has been the story of a young man called Arthur, who came to us as part of the supported internship scheme and who has gone on to secure a paid role with us on our Retail Academy apprenticeship programme.

Arthur's experience has taught us a great deal. After completing his ten-week placement, during which his Store Manager had encouraged him to apply for a job with us as he was impressed with Arthur's attitude and his ability with customers. Arthur applied for a number of vacancies but was unsuccessful, with hiring managers perhaps favouring those with previous experience and who wouldn't need the same level of training and support. Undeterred, Arthur contacted Planet Organic again to apply for our apprenticeship programme and attended one of our assessment centres held in our store in Tottenham Court Road, whilst it was closed due to the pandemic.

Arthur used this opportunity to show everyone on the day why he was such a great fit for us and was offered a role very quickly. We have been in close contact with our training provider for our Retail Academy, HIT, the ESFA and with Westminster City Council to ensure that we provide the right support for him to learn and develop through his apprenticeship year. We now understand that we need to look at our existing recruitment processes to understand how we can adapt them to ensure that we don't overlook candidates like Arthur again.

We are confident that the partners we are working with on becoming Disability Confident, as well as the work we are doing on diversity, equity and inclusion with specialist consultancy The EW Group, including being a part of their Inclusive Culture Pledge for a second year in 2021, will help us review and reimagine policies and processes to ensure they do not disadvantage different minority groups. We have always known we would need support to do this, and so we have been so grateful to the different stakeholders who have helped us so far, including some of the borough councils in London, who have taken time to share their expertise in a number of different ways.

As we affirmed in our pledge statement this year, we aspire to demonstrate kindness and understanding in everything we do, to emphasise the importance of standing opposed to any form of discrimination wherever we encounter it, and to create a culture that celebrates the broadest range of skills, experience and backgrounds and gives them a space in which to thrive. This is why making our brand more autism-friendly makes sense for us and why we hope to continue to learn and progress in this area.

### James Marsh

Learning & Development Manager, Planet Organic



CASE STUDY

### Arthur's story

I am one of the interns who finished the Westminster Supported Internship Programme. Following my internship, I am starting a new job as a team member at Planet Organic in Tottenham Court Road. I feel a little worried, but very excited.

I am glad I did this programme because it helped me develop new skills and improve my communication.

When I was on my work placement at Planet Organic at Torrington Place, I learnt what good teamwork is, I learnt about manual handling, I learnt how to operate a till and how to serve customers in a nice way.

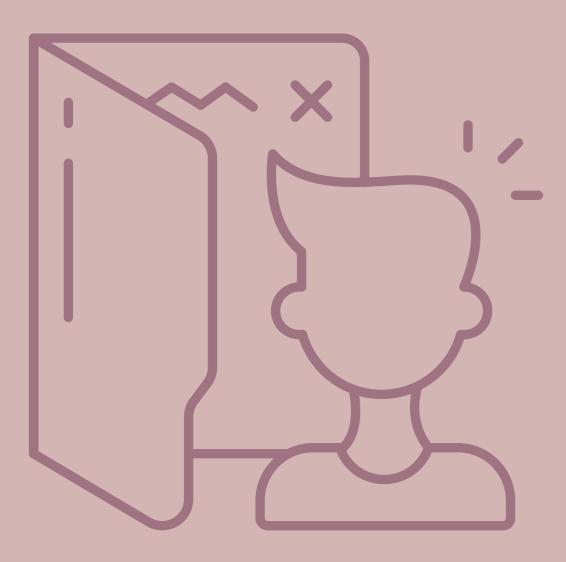
My manager, Andrew, and my job coach Emma were really happy with my work and they asked me to apply for an apprenticeship with Planet Organic. I did it and I got it!

"Arthur has really worked out well! He is looking to be hired and if there is an opening, I can recommend him. He really has fit in well with the team here. If you need any more information - please let me know!" Andrew, Store Manager, Planet Organic

"Arthur has been a pleasure to have as part of the team at Planet Organic and his enthusiasm, his willingness to learn and his skills and attitude with our customers have been incredibly impressive. I hope he enjoys continuing his development with us as part of our Retail Academy apprenticeship programme." James, HR Manager, Planet Organic

### **Earlier identification**

Identifying autism as early as possible in children, young people and adults.



### **Systems**

#### What works well?

- All Age Autism Strategy, 2020 forward plan emphasises the importance of identifying autism in children and early years settings, and as a key to ensuring lifelong support.
- There is work across London to review pathways, systems and mechanisms of good practice for supporting autistic people and their families.

### What do we need to focus on?

- Ensuring that adults without co-occurring learning disabilities or mental health needs, receive high quality, person-centered care and support.
- Services caring for young people transitioning to adult services and ensuring they are set up to support young adults in a way that provides specialist support to meet their needs.
- Improving pre-referral support.
- Ensuring that social care providers, higher and further education providers, healthcare workers and GPs are aware of the signs of autism in adults (who may not yet have their diagnosis, or who may have resisted the diagnosis) and that when they identify this, are able to signpost to appropriate diagnostic and support services.

### How do we achieve this?

- Working with professionals, service providers, community organisations and residents to ensure there is an up to date, clear referral and diagnostic pathway for autistic adults.
- Ensuring that this pathway, and the pathway for children and young people transitioning to adult services is clear and communicated early.
- The pathway for children and young people into adult services should also be clear and communicated early.
- Improving the pathway to get a diagnosis.
- Promoting training offers throughout the borough and other providers to ensure staff from all care services are aware of the signs of autism and know where to make referrals sensitively for appropriate support.
- Focusing on identification in women and girls (where this is widely under reported and undetected) who are nationally commonly misdiagnosed with mental health needs and personality disorders.

### CASE STUDY

### Supported Internship

Westminster City Council Supported Internship Programme was brought to life in September 2019 when it opened its door to a group of young individuals (16-24) with learning disabilities who had embarked on the journey to obtaining paid, sustainable employment.

The programme is run by two closely collaborating teams: the educational part is overseen by City of Westminster College (Maida Vale Campus) and the employment part is run by Westminster Employment SEND Team.

During an academic year, the interns were scheduled to complete 3 different work placements, each one lasting 8-10 weeks. A typical week was divided into one day at college (Mondays) and four days in work placement (Tuesday to Friday). When at college, the interns worked towards obtaining their Pearson's BTEC in Work Skills qualification and when in a work placement, the interns learnt about specific job tasks and how to perform them to a satisfactory standard. The programme partnered up with organisations such as Planet Organic, Veolia, National Portrait Gallery, 5 stores, Elior, Everyone Active/Westminster Active, and many Westminster City Council services as placement hosts.

The supported internship for the first cohort was extended until Apr 2021 due to the global pandemic (COVID-19) and various lockdowns. However, despite all these hurdles, the programme pushed ahead and welcomed a new cohort of interns in September 2020 as well. Thankfully, both groups successfully completed it and at the beginning of September 2021 a third cohort embarked on their employment journey.

### How will we know we have achieved it?

- There is a clear pathway for autistic adults that is regularly reviewed in line with this strategy and the All Age Autism Strategy, 2020.
- There are clear pathways post diagnosis that focus on lifelong support for autistic adults.
- There is an improved experience for young people transitioning to adult support, not just in adult social care but also through health, housing and other adult focused services with young adults providing regular feedback on these services.
- Increased focus and attention to autism, by Social Care, education and healthcare providers. With a call to action across the system that visibly promotes positive conversations about autism.
- Increase in autistic women accessing support services.

22% autistic people aged 16 to 64 are in employment (against 52% disabled and 81% non disabled)

### **Partnerships**

### What works well?

 There is work across London to review pathways, systems and mechanisms of good practice for supporting autistic people and their families.

### What do we need to focus on?

 Working more closely with other boroughs through the London Association of Directors of Adult Social Care (ADASS) and Association of Directors of Childrens Services (ADCS) programmes.

### How do we achieve this?

- Working with London ADASS and ADCS, and utilising the London ADASS bulletin for sharing news, events and examples of good practice.
- Working with London ADASS to implement this strategy and the All Age Autism Strategy, 2020 in line with National guidance.

### How will we know we have achieved it?

• Creative ideas and initiatives develop that bring together professionals from the NHS and other local authorities.

### Advice for professionals

This part of the strategy supports the National Strategy priority: Tackling health inequalities for autistic people, and; Building the right support in the community and supporting people in inpatient care.

The working group of the autism partnership board will focus on the overarching outcome of improving the whole systems ability to identify signs of autism and offering appropriate support at all ages.

## CHARLOTTE'S STORY

I was prevented from getting a diagnosis of autism as a child, so I really struggled throughout my childhood with my autism and my other neurological conditions.

I moved to London in 2020 and sought out a diagnosis immediately of autism, and I was referred to Westminster for my diagnosis. The waiting time was very short and I felt well supported by the clinic throughout my waiting time.

My psychologist was kind and understanding, and was up to date on the latest autism research and understood how autism presented in girls too. She was extremely considerate and I was extremely supported all the way through.

I was diagnosed within two weeks of my initial assessment, and was also able to attend a post-diagnostic session a week after my diagnosis to discuss any concerns or questions I had with the psychologist.

Since my diagnosis, I have been able to get the accommodations I need to succeed at university, and was also able to find work as an autism support worker. It has also allowed me to understand myself better, and to be more kind to myself for not meeting people's neurotypical standards set by society.

The post-diagnostic support sessions later on in the year also helped me develop coping skills and I am a lot more confident now in social situations. The clinic was also able to refer me to mental health services, and give me resources to help with my mental health that were specifically for autistic people.

I am now in my second year of university at King's College London doing history and political economy and I am planning on attending Cambridge for my masters and my doctorate in the future. Getting diagnosed with autism, as well as Attention Deficit Hyperactivity Disorder (ADHD), dyslexia and dyspraxia, is one of the best things I have ever done and it is never too late to seek out help.

The adult autism strategy is important as it recognises people like me need help and gives us the tools to succeed in my life. A strategy that is heavily contributed to by autistic individuals is important as it gives us a say in our own help, empowers autistic voices and gives us self-autonomy. It gives autistic adults the chance to succeed, not only autistic children.

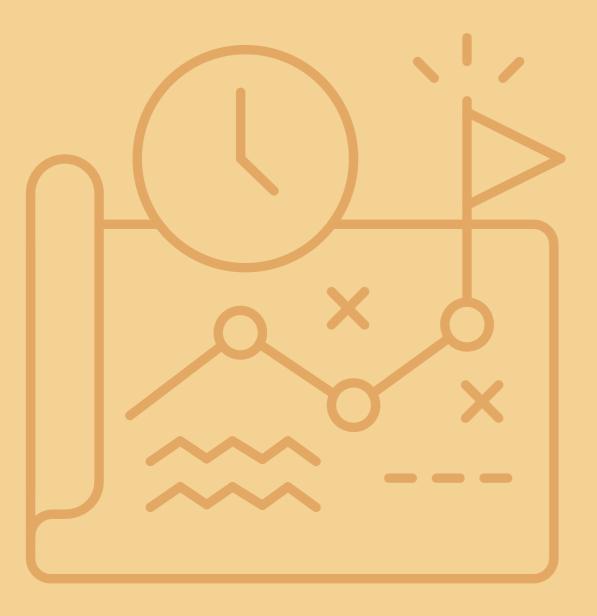


positive experience just like

Charlotte!

# Improving pathways, reducing waiting times and providing the right support

Providing a high-quality health service which responds quickly to people's needs. Nationally, waiting lists for autism assessments are extremely high (anywhere from 1 to 3 years).



### Reducing waiting times

### What works well?

 There is a dedicated adults assessment service in both boroughs provided by Central London Community Healthcare NHS Trust (CNWL) and funded by North West London Clinical Commissioning Group (NWLCCG).

### What do we need to focus on?

- Reducing waiting times for assessment and support services.
- Ensuring that referrals for diagnosis are appropriate.
- Working to bring down the waiting times in line with National Institute of Clinical Excellence (NICE) guidance.

### How do we achieve this?

- Central London Community Healthcare (CLCH), Northwest London Clinical Commissioning Group (NWLCCG), Central and North West London NHS Foundation Trust (CNWL), both councils and the voluntary sector will be working through pilots and plans to reduce waiting times throughout the life of this strategy.
- New models of support are being tested to try and reduce the
  waiting times with people receiving support while they await
  an assessment and once they have had the outcome of their
  assessment. Both councils, working with the North West London
  Clinical Commissioning Group will support efforts to reduce
  waiting times locally.

### How will we know we have achieved it?

- Waiting times reduced (currently between 1 and 3 years).
- Services available post-diagnosis.
- Referrals made to the assessment service are appropriate, accurate and timely.
- Individual residents feel supported through their diagnosis journey, and are clear about the challenges faced nationally with waiting times.

### **Crisis Prevention**

### What works well?

- For adults, we have established a dynamic support register (DSR) for people who are autistic where there is a risk of placement breakdown or admission to hospital to manage and prevent crisis. This list is multi-agency and autistic people must provide their consent to be included on the list.
- North West London Clinical Commissioning Group have made autism a priority and acknowledge that autistic adults need to get the right support at the right time.

### What do we need to focus on?

- Ensuring that the register is kept up to date and the correct people are included within it.
- Providing adequate access to local respite provision for autistic residents, and where relevant carers, to prevent crisis and breakdown of relationships.



### CASE STUDY

### Royal Borough of Kensington and Chelsea Food Growing Project

The Royal Borough of Kensington and Chelsea's Food Growing Project offers allotment style raised beds to residents without gardens wishing to cultivate fruit, vegetables, and herbs. The council's two community gardeners provide advice and support and manage the borough wide scheme of over 65 community kitchen garden sites - with over 700 residents engaged and signed-up as plot holders.

Additionally, support and bespoke gardening workshops are delivered to adult mental health providers including Hestia Royal Borough of Kensington and Chelsea Integrated Mental Health Service at the Grove Resource Centre, NHS Grenfell Recovery Service and St Charles Centre for Health and Wellbeing Mental Health Unit. Workshops about cultivating food are devised and delivered by the community gardeners with support from respective staff. These practical sessions also explore associated topics such as climate change, sustainability, creating habitats for pollinators and the non-chemical control of pests and diseases. The growing project is accessible and open to autistic residents living in the Royal Borough of Kensington and Chelsea. Feedback from service users and staff has indicated the positive benefits that these sessions have on the wellbeing of clients. A volunteering programme for residents and groups is also offered around food growing.

### How do we achieve this?

- The register is a newly implemented support to help keep autistic people and their family safe and avoid hospital admission. The register will be kept under review and shaped as required.
- Ensure there is provision in both boroughs for planned and emergency respite/short breaks to prevent crisis and strain on families.
- Improving the pathways in adult mental health inpatient settings for autistic people.
- Keeping in regular contact with people on the waiting list for an autism assessment and using creative technological means to do this. Not just telephone/letter, but exploring opportunities to use video conferencing.
- Central North West London NHS Foundation Trust (CNWL) have created two posts to embed autism-friendly practices in inpatient mental health settings, and have developed an autistic peer support worker role to provide positive role modelling.

How will we know we have achieved it?

- All parties involved in supporting autistic adults are aware of admissions to hospital and are able to support discharge to prevent unnecessary readmission.
- Increased use of respite provision for autistic adults.
- Autistic people supported in inpatient settings feel their needs are met and they do not fall through the net any longer.
- More autistic people are encouraged to provide and receive peer support.

Environments

What works well?

- Autism-friendly design and accessibility has been considered in recent builds across both boroughs.
- Central North West London NHS Foundation Trust (CNWL) are developing autism-friendly inpatient environments across Child and Adolescent Mental Health Services (CAMHS) and adult services.

What do we need to focus on?

- Hospitals and health settings including GP practices, clinics and therapeutic services as they can be challenging for autistic adults to access and navigate.
- Listening to autistic people about the challenges they face with accessing health settings.
- Working to codesign solutions.
- Supporting autistic people who need admitting as inpatients in the most suitable environment to meet their needs and involving them in decision making as much as possible.

How do we achieve this?

- Making health settings friendlier places for autistic people, including:
  - Clear and consistent signage
  - Use of a side room and a calm waiting area

1 in 10 people are neurodivergent, meaning that the brain functions, learns and processes information differently (Embracing Complexity Coalition, 2019)

- Offering to collect people from the waiting area
- Keeping patients informed if a clinician is running late
- Fast tracking people who present at A & E
- Longer appointments and flexible appointments to allow people to travel at quieter times
- Familiarisation appointments for wards and departments.
- Development of sensory environments such as rooms and gardens.
- Sensory kits are being trialled in wards.
- Teams will be receiving sensory integration training to increase their understanding of the impact of the environment on the people being cared for.

How will we know we have achieved it?

- A project by North West London Clinical Commissioning Group (NWLCCG) will be implemented to improve GP services for autistic patients focused on raising awareness of the needs of autistic adults and recommending reasonable adjustments.
- Evidence of increased understanding by staff, and positive feedback from autistic people accessing inpatient services across CAMHs and adult services.

**Practical Support** 

What works well?

- The feedback about the support groups for people awaiting diagnosis and post-diagnosis is very positive. Autistic people have fed back that they provide an opportunity for people to meet others going through similar experiences.
- There is already a drop-in advice clinic, post diagnosis support/ brief psychological therapy for those diagnosed, social groups (6 sessions, every 2 weeks) where people can meet other autistic adults and share experiences.
- The autism specialists at Central North West London NHS
   Foundation Trust (CNWL) have also been joining with Care Act
   Assessments to work in a more joined up way.
- Both boroughs are serviced by the Centre for ADHD and Autism Support. This is a North West London service providing dedicated, individual support for autistic adults in both boroughs.

What do we need to focus on?

- More support provided to people awaiting diagnosis.
- Increased peer support offers for people awaiting diagnosis and post-diagnosis.
- Community organisations providing support for people awaiting diagnosis and post-diagnosis.
- Better information provided about delays, and regular updates on case progression.
- Making contact with more autistic people, as this is a newly commissioned service.
- Developing tailored support for individuals and families.
- Making connections with existing providers and organisations across both boroughs.



CASE STUDY

Royal Collection Trust

Royal Collection Trust (RCT) manages the opening of the official residences of the Queen. In Westminster these sites are The Queen's Gallery, the Royal Mews and the State Rooms of Buckingham Palace. All front of house staff receive disability confidence training and Buckingham Palace was recognised as an autism-friendly venue by the National Autistic Society in 2019.

Royal Collection Trust aims to help as many people as possible to access and enjoy the art, architecture and history of the official residences of Her Majesty The Queen. Our community programme, for those who might not normally engage with our sites and stories, focuses on groups with different needs, who may experience barriers to engagement. We seek to adapt our offer to suit the interests of groups whenever possible, and work with smaller group sizes to ensure a quality experience. Our community sessions are free of charge and subject to availability.

### How do we achieve this?

- Central North West London NHS Foundation Trust (CNWL) aim
  to reinstate psychology led groups for clients on the waiting list.
  This aimed at reducing the people on the waiting list who would
  benefit from support elsewhere and encourage people to have the
  right support at the right time.
- Central North West London NHS Foundation Trust (CNWL) ran a
  pilot satellite assessment clinic with one of the London universities
  from April 2021. This means that instead of waiting years, people
  are seen within 6 months, with many receiving a diagnostic
  outcome within 2 to 3 sessions (versus 4 to 6 sessions). There
  is more satisfaction with the assessment process: clients not
  receiving a diagnosis are more accepting and understanding of
  the outcome, and those with a positive diagnosis can access help
  in a timely manner.
- The service will look to provide pre and post-diagnostic support, including:
  - Practical support with communication and executive functioning task (like making phone calls, planning and organising time)
  - Support with paying bills, form filling and applications
  - Joint working with clinicians to ensure people receive follow up support and signposting
  - Group sessions which offers the opportunity to have peer support and shared learning.

### How will we know we have achieved it?

- More support is available pre and post-diagnosis.
- Learning from the Central London Community Healthcare Trust pilot can be translated into services for autism across both boroughs.
- More examples of creative working across different organisations.
- Autistic adults within the two boroughs access support from Centre for ADHD and Autism Support Adult service and provide positive experience testimony.
- Autistic adults work with Northwest London Clinical Commissioning Group to review and monitor the services provided by Centre for ADHD and Autism Support.



### In Deep

In Deep is a registered charity that works with older people and children and young adults with SEND, including autism, and supporting their families. We run free music therapy sessions for young adults up to the age of 25, both face to face and online. We support parents through carers groups and providing manicures and pedicures.

For over 50s with a learning disability, we have a befriending scheme where trained volunteers either have a weekly phone call or meet up with a person. We also have a over 50s choir with professional conductor. We also provide meals where you can meet other people. For more information please check out our website at <a href="https://www.in-deep.org.uk">www.in-deep.org.uk</a> or email

emma.chapman@in-deep.org.uk

Emma Chapman MBE General Secretary to In Deep

### Advice for professionals

This part of the strategy supports the National Strategy priority: Improving autistic children and young people's access to education and supporting positive transitions into adulthood, and;

Tackling health inequalities for autistic people, and;

Building the right support in the community and supporting people in inpatient care

The working group of the Autism Partnership Group will focus on the overarching outcome of improving the whole systems ability to identify and assess signs of autism and offer appropriate support including pre-referral support and support while undergoing diagnosis.

# **INCLUSIVE DANCE**

Step Change Studios was created by Rashmi Becker MBE, a Westminster resident who wanted to provide an inclusive dance company that supports disabled people.

### **Step Change Studios**

Rashmi is guardian to her older brother who has autism, and she has professional experience in the social care, arts, and sports sector. This personal and professional experience has given her a deep understanding of the benefits of dance and movement on mental health and wellbeing. Dance can have a positive impact on challenging behaviour, anxiety, communication, social interaction, and most importantly, it can bring great joy to people.

Step Change Studios provide dance in a range of settings including health and social care, education, sports, arts, and different community settings. Their work is pan-disability, supporting all ages and abilities. As well as regular classes, Step Change Studios have collaborated on a range of creative initiatives in Westminster.

### **Dance Westminster**

In partnership with Westminster City Council, Rashmi created 'Dance Westminster' an inclusive community dance competition. The first Dance Westminster in 2020 was a huge success, generating national media coverage and over 100 participants. In 2021, Dance Westminster was presented as a film, which was screened at the Odeon Leicester Square. The competition winners for both years were young adults with autism. When Kelvin, the 2021 winner auditioned, it was the first time his college knew he could dance! Recognising the value of dance, Westminster City Council and Everyone Active is now supporting a weekly dance class for disabled people led by Step Change Studios.

Alongside her community work, Rashmi also produces professional dance work with disabled and non-disabled dancers. With support from Arts Council England, she has created a project called 'Conversations with Carers' which gives voice to the lived experience of carers. This work includes a solo performance by a dancer who has autism.



Whether it's enabling people to dance for the first time, or providing a platform for new talent, Rashmi sees Step Change Studios as playing an important role in promoting diversity and inclusion in the arts.

Over the years, Rashmi has seen the positive influence of her efforts, with more organisations and professionals recognising the importance of inclusive practice and the value that the arts bring to quality of life, for all ages and abilities. Central to this, has been working collaboratively with like-minded individuals and organisations that are committed to representing the diversity of our community.

### www.stepchangestudios.com



# Enabling autistic people to live independent, healthy lives

Providing effective support for autistic people to enable them to fulfil their potential in all educational settings, whether early years, school, college or at home.



#### What works well?

 We have a dedicated Adult Employment service that provides support for autistic adults to fulfil their goals around employment, working with local businesses, apprenticeships and training schemes to empower autistic adults and adults with a learning disability to achieve their goals.

### What do we need to focus on?

- Ensuring this service is well publicised and autistic people and their families know this service caters for them.
- Promoting more employment opportunities across the two boroughs and creating more workplaces that are autism-friendly with reasonable adjustments for workers.
- Encouraging all businesses in Kensington and Chelsea and Westminster to be open to working with people who are neurodiverse.

### How do we achieve this?

- Working with communications and media teams to promote this service and target publicity around autism.
- Working with local businesses to promote the benefits of working with autistic people and supporting working adults who may be caring for an autistic person.
- Working with local voluntary and community organisations to encourage more opportunities for autistic people and ensuring that support is available and accessible to autistic adults.
- We would like to work more with organisations like Auticon who focus on the positive skills, behaviours and qualities held by some of our autistic residents. <a href="https://www.auticon.co.uk">www.auticon.co.uk</a>

### Some cognitive strengths tend to be more prevalent in the autism community including:

- enhanced logical and analytical abilities
- sustained attention and concentration
- impartial and honest communication
- an affinity for attending to detail, spotting errors and enhanced accuracy enhanced retention of information (long-term memory).

### How will we know we have achieved it?

- Increased numbers of autistic people supported by the service.
- Employment data reflects an increase in employment for autistic people in both boroughs.
- More businesses in the two boroughs are connected with autism services and openly advertise, market and share their autism awareness status.

### CASE STUDY

# Faisa's story Resident of the Royal Borough of Kensington and Chelsea

"The supported internship helped me improve my skills and efficiency and helped me get used to the workplace in a friendly way.

In my work experiences, I learnt all about being good to the environment and customer service in Planet Organic.

In the National portrait Gallery I learned about GDPR and consequences of giving out personal data, and admin skills. At City Hall I learnt where different departments are and how to complete a room booking spreadsheet.

My placement has created an opportunity in the department to do an inclusive apprenticeship. So far I have learnt lots, including prioritising room booking, doing multi bookings, continuing the room booking spreadsheet, communicating with people over the phone, describing where the rooms are when people come for their booking, mentoring others on how to use the room booking spreadsheet.

On Fridays I do college work with support from Westminster Adult Employment Service (WAES) and have learnt different things about the council and about rules and rights. I feel happy in my team and I have got to know my team better."

### **Community Activities**

### What works well?

- There are some brilliant activities for adults with autism across the two boroughs that promote independence and health living.
- Some of our services run autism-friendly dedicated support.

#### What do we need to focus on?

- Some of these services at the moment do not go beyond age 25, some go to 30 (Turtle Key Arts).
- Encouraging services for over 25-30 year olds.
- Making sure that people do not just find out about these services when they are in crisis.
- Addressing the concerns raised by the autistic community about isolation and loneliness as a result of their condition. We would like to focus on encouraging the set up of peer support services where autistic people can learn from other autistic adults with support and safeguards in place.
- Autism must be recognised as a lifelong condition that does not go away or improve. Through coproduction, commissioning and market management, we will encourage more autism specific groups and support services.
- Ideally services that are drop-in and can be accessed at any point.

### How do we achieve this?

- As part of this strategy our Public Health team will commit to investing £50,000 into improving universal services and tailoring the support offered to autistic adults throughout the two boroughs.
- Manage the market across the two boroughs to encourage more adult focused activity for autistic adults that is well promoted, well attended and achieves positive outcomes.
- Being creative about the services, groups and networks available to autistic adults. This includes work with arts organisations, promoting social activities and working to provide a range of autism-friendly groups and activities.
- Commissioning and review of contracts, taking consideration of the autism Joint Strategic Needs Assessment (JSNA) that will be developed and better local intelligence and data.
- Investment in greater access for autistic residents to universal services for promotion of healthy living, active lifestyles and more.



### Safe Haven Basketball

Safe Haven Basketball was founded in 2016 by a Westminster resident, who returned from New York with her autistic daughter. Having seen first hand how much her daughter and others had enjoyed and benefitted from playing basketball in New York, she was determined that her daughter and others should have the same opportunities in London.

It's an inclusive basketball club, targeted at young people aged 14 to 25, offering weekly coaching to players of all levels of ability. They believe that autism need not be a barrier to participation and enjoyment of sport. The focus is on fitness, fun and friendship, alongside developing players' skills.

To join, get in touch by email at emmacolverd@safehavenbasketball.co.uk, or turn up at a session in Little Venice Sports Centre. It's on any Monday during term time between 5.00pm and 6.00pm. New members are always welcome, and the first session is free so you can try it and see if it is something you enjoy.

For more information, go to <a href="https://www.facebook.com/safehavenbasketball/">www.facebook.com/safehavenbasketball/</a>, or <a href="https://www.safehavenbasketball.co.uk">www.safehavenbasketball.co.uk</a>

### How will we know we have achieved it?

- Monitoring how the investment through Public Health is spent.
- Evidence of new/additional groups and leisure activities for autistic adults.
- Working with local universities, and other organisations to make sure people are directed and signposted to autism specific services for adults, to help them manage and maintain a healthy, happy life.
- There will be a number of autism-friendly groups, exercises and activities aimed at encouraging autistic adults to socialise and get involved!
- Evidence of support services created that are specifically targeted towards autism.
- Evidence of increased autistic people accessing universal services with a positive experience.

"You are an adult a lot longer than you are a child, and it's important to look at autism from an adults perspective."

Helen Fleetwood
Centre for ADHD and Autism Support

### **Housing and Homelessness**

### What works well?

- The Rough Sleeping Team in Westminster have been working to better support autistic people. This is significant, particularly as Westminster has the highest concentration of rough sleepers in the UK
- The Rough Sleeping Team worked with Resources for Autism, Homeless Link, St Mungos and the National Autistic Society to develop the 'Autism and Homelessness toolkit'.
- In the Royal Borough of Kensington and Chelsea all senior managers in housing have received autism awareness training.

### What do we need to focus on?

- Broadening this out across all areas of housing and across the council. Taking the learning from this activity and rolling it out to other council services.
- There are pockets of positive work targeted at supporting autistic people, but these need to be better joined up.
- Ensuring all managers, and front line workers attend autism awareness training, to ensure that activities across housing and support, provided by the housing department, is autismfriendly and takes into consideration the needs and wishes of autistic adults.
- Autistic people generally have worse health outcomes than non autistic people.

### How do we achieve this?

- The success of the programmes led by the rough sleeping team, was the bitesize training, changes to assessments and setting up an advice clinic for professionals to seek advice around autism.
- Learning from the programme, look to change contracts to reflect support available for autistic adults.
- Maintain the autism support around tenancy sustainment issues.
- Rolling out autism awareness sessions across both councils, targeting resident facing and other planning roles.
- Through our public health service we will develop annual health checks for people with an ASD diagnosis.

### How will we know we have achieved it?

- The work of the housing and rough sleeping teams will spread across the council departments and beyond, to improve the way autistic people are supported with their housing needs and other needs too.
- Monitoring 12 months after the service is set up to ensure people are accessing this offer.

### **Outside Spaces**

### What works well?

- Across the Royal Borough of Kensington and Chelsea there is the food growing project offering allotment-style raised beds to allow residents to grow fruit, vegetables and herbs.
- There are gardening workshops delivered to support mental health services at the Grove, NHS Grenfell Recovery Service and St Charles Centre.

### What do we need to focus on?

Ensuring that these services are opened up to autistic adults.
 Gardening is an activity many of the autistic adults are involved with. The development of this strategy really valued and helped them to relax and manage their own wellbeing.

### How do we achieve this?

 Working with organisations across both Westminster and Royal Borough of Kensington and Chelsea to promote growing and gardening opportunities for autistic adults.

### How will we know we have achieved it?

 More autistic adults are able to access growing and gardening programmes across the two boroughs.



#### CASE STUDY

### The Cartoon Museum

The Cartoon Museum is expanding its offer to provide an inclusive environment accessible to autistic people. The museum is working on a number of initiatives to use cartoons and comic art to tackle issues around health and wellbeing. The museum is on a journey aiming to become an inclusive hub for cartooning and art, providing exciting new programmes and resources, focusing on improving health and wellbeing through art.

### Advice for professionals

This part of the strategy supports the National Strategy priority: Improving understanding and acceptance of autism within society, and;

Supporting more autistic people into employment, and;

Tackling health inequalities for autistic people.

The working group of the autism partnership board will focus on the overarching outcome of improving the local environment for all autistic residents, improving access to health facilities and supporting local employers.

# **EQUAL PEOPLE**

Equal People Mencap offer one to one community, independent living and personal care and support. and support. Alongside this, they also offer a weekly programme of community and online based healthy living, social activities, training sessions and drop-in sessions.



Support is person-centred and directed by the individual, using accessible tools and information to support each individual to participate in, and contribute to, their local and wider community as much as they wish. The charity offers one to one and group digital training to support individuals to stay connected with their family, friends, professionals and health services and has supported a group of individuals with autism to design and complete surveys for the NHS.

### Fazad's story\*

When joining Equal People Mencap, Fazad was a quiet and shy young man, but with support he has progressed tremendously into being very sociable and independent. Fazad enjoys many of the groups run by Equal People, including cricket, theatre, zumba and many more. These groups have enabled him to be more confident, make friends and learn about inclusivity.

After living with family all his life, Fazad recently moved into his own flat. This was an exciting but difficult time for Fazad and his family, but with the right support, he has settled well into his new home and is enjoying having his own space!

### Annie's story\*

Annie is a lovely young lady who attends Equal People Mencap. She has autism and a learning disability. Annie joins in with the cooking sessions which she really enjoys. Unfortunately, Annie felt isolated during lockdown as she and her parents had to 'shield' meaning they did not leave the house very much.



Equal People Mencap have been running a wide variety of online activities to combat social isolation, to keep fit and to be creative. Annie participated in many online zoom sessions like zumba and our super quiz. She has been supported by her mum to log on to Zoom and take part. They both struggled at first, but now Annie and her mum have both become more confident with the computer.

The Zoom sessions run frequently, and Annie no longer feels overwhelmed by the computer. Annie engages really well in all of her groups and it is a good opportunity to see her friends and take part in the activities. The groups have increased Annie's confidence and helped her to learn new skills.

### Kasem's story\*

Kasem is part of the 'Equal People - Let's get Digital' project and he has received a tablet from us to be part of the project. Kasem has learning disabilites and autism. His friends say he is easy to talk too and fun to be around!

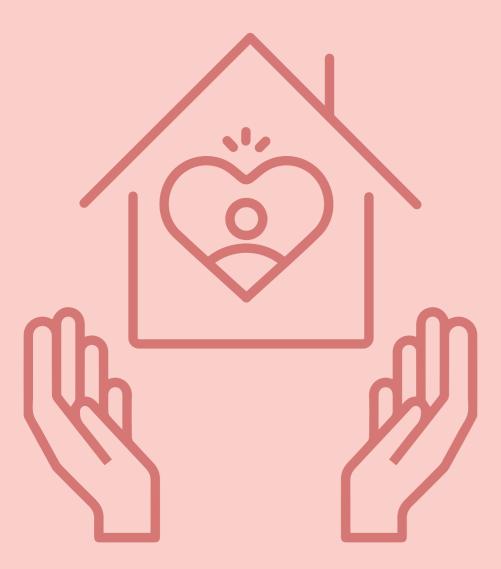
He comes to Equal People with a support worker or when he is able, he travels independently. Kasem is very eager to learn and tackle tasks thrown his way. He had used a tablet before and was able to use it to complete the 'Learn my Way' training. He has used the tablet to join in with the bingo group, and online social group. Kasem has worked with Equal People to help people understand online abuse and how to report it.



<sup>\*</sup>Names have been changed to protect identities

# Specialist support for autistic adults

Working across employment, housing, health, education and social care to support autistic people to live full independent lives.



### Information and Assessments

### What works well?

 Social workers and practitioners are starting to better understand autism and cater to the needs of autistic residents when conducting assessments.

### What do we need to focus on?

- All assessments, particularly those under the Homelessness Act and the Care Act, should be assessed in an autism-friendly way .
- All other assessments by the council and the Clinical Commissioning Group must take a persons autism into account and make reasonable adjustments to ensure that all parties get the very best out of the assessment.
- Improved data collection across health and social care, including updating the way we record autism diagnoses on our systems to help information professionals on an individual and strategic level.
- Working to identify the autistic community, including those who
  are hard to reach or disengaged from services including people
  who are; homeless, sex workers, financially independent, LGBTQ+,
  high level employed, hearing and sight impaired, living with eating
  disorders, and more.

### How do we achieve this?

- The Government are currently testing the Oliver McGowan training, and both councils and the Clinical Commissioning Group will be closely monitoring the developments in this area to ensure that staff receive the most up to date training available.
- Training and awareness must be regularly made available for new staff in all departments.
- Improving data and systems capturing information about people and their needs.

### How will we know we have achieved it?

- Autistic people feel that their autism is considered even when their autism is not the focus of the assessment.
- Autism is accurately recorded on case management systems as a primary support reason.
- Health case management (System 1) health data will have an 'autism flag' on all records relating to autistic people.
- All staff will receive autism awareness training, with additional training in place for those requiring a more indepth understanding of autism.
- We will develop an Autism Joint Strategic Needs
   Assessment (JSNA) to help inform all of the work on the
   back of this strategy.
- Coproduced menu of reasonable adjustment options is available for people undergoing assessments.

### Ambitious about Autism

Many of the residents included within this strategy talked about isolation and loneliness, and some talked about anxiety when meeting new people face to face.

Ambitious about autism is the UK's largest online autism community! A safe space, which provides an invaluable source of peer support. It has an online discussion forum that members can use to post questions, provide information and share experiences with those who have first-hand experience or a deep connection with autism.

Visit the website at:

www.ambitiousaboutautism.org.

uk/talk-about-autism

# VEOLIA SUPPORTED INTERNSHIP

Veolia group is the global leader in optimised resource management. With over 179,000 employees worldwide, the group designs and provides water, waste and energy management solutions that contribute to the sustainable development of communities and industries.

Through its three complementary business activities, Veolia helps to develop access to resources, preserve available resources, and to replenish them.

Veolia's Westminster City Council contract set out a new inclusion strategy in 2017. As part of this strategy, the 'Road to work' programme was established with an initial focus of supporting homeless and long term unemployed locals into work through Veolia.

Phase two of this strategy was then mobilised in 2019 which aimed to support Westminster's local disabled community. This involved creating a partnership with Westminster's Special Educational Needs and Disabilities (SEND) programme to help bring Autistic adults into work placements. Since establishing the work placement Veolia has provided two placement opportunities for autistic adults working in communications and admin. One of these two placements was made a permanent employee working in Veolia's administration team.

### **Supported Internship Scheme**

Since April 2021, Ahmed Mitten has been working with the Veolia team and has been gaining experience in business administration, data mapping and communications. His keen eye for design and enthusiasm for technology has even helped create our newsletter! The placement has been such a success that Ahmed has been offered a permanent position at Veolia and is looking forward to the next stage of his career.

"I have gained plenty of experience working at Veolia, for example, I began familiarising myself with its contracts and its policies and had even learned to utilise the tools and websites needed to support the company"

Ahmed Mitten, Veolia Supported Intern

### The futur

Currently, Veolia's placement programme is operating on a very local level. Once established Veolia would like to roll this scheme out on a national scale with all their partnered local authorities to help drive down unemployment rates amongst autistic adults.



"I have gained plenty of experience working at Veolia, for example, I began familiarising myself with its contracts and its policies and had even learned to utilise the tools and websites needed to support the company"



### Mental Health and Wellbeing

### What works well?

- The Improving Access to Psychological Therapies (IAPT) service is staffed by people who are specifically trained to provide therapeutic services for autistic adults experiencing anxiety and emotional distress.
- There are mental health specific universal services across both boroughs that work to prevent people entering crisis.

### What do we need to focus on?

- Making sure autistic people are aware of this service and are using it appropriately.
- These services do not specialise in support and crisis prevention for autistic adults.

#### How do we achieve this?

- Identify the number of autistic people accessing the service and develop a plan to improve access to psychological therapies for autistic people.
- As part of this strategy £50,000 will be invested from public health into universal services to support autistic adults across Westminster and Royal Borough of Kensington and Chelsea.

### How will we know we have achieved it?

- Increase in autistic people accessing the IAPT services with positive experiences.
- Autistic resdients support the implementation and monitoring of these services to check that they are providing the right support for autistic adults.

### **Specialist Support**

### What works well?

- Centre for ADHD and Autism Support provide free one to one support and information sessions for autistic adults without a learning disability. This support helps with form filling, benefits applications and support with goal setting, future planning and breaking down steps to help individuals achieve their goals.
- Centre for ADHD and Autism Support provide a parents, peer support group, that meet monthly for any parent across North West London with an adult child diagnosed with autism.
- Centre for ADHD and Autism Support provide a 'Thinking about adulthood' workshop (14-19 year olds) to prepare them for what happens when they become adults.
- The rough sleeping team in Westminster have done a lot of work on specialist support, toolkits and training for working with autistic people.

Many autistic people found some of the changes of the pandemic suited them better, including increased virtual spaces, less societal pressure and avoidance of anxiety inducing activities such as public transport.

### What do we need to focus on?

- Promoting and expanding groups like the ones organised by Centre for ADHD and Autism Support to ensure that parents and residents are aware of the support available.
- Ensuring professionals supporting autistic people understand the services provided by Centre for ADHD and Autism Support and make appropriate referrals for the right support.
- Building on existing relationships with Centre for ADHD and Autism Support to ensure that referrals are appropriate.
- Expanding these considerations to all people working for the councils and other statutory services to provide practical advice about how best to work with autistic people.

### How do we achieve this?

- Close monitoring of attendance and consideration for additional sessions.
- Including organisations like Centre for ADHD and Autism Support
  in the work that comes out of this strategy and the All Age
  Autism Strategy, 2020, and learning from specialist organisations
  to ensure that support provided specifically for autistic adults
  is current, up to date and meeting the needs of autistic people
  across the boroughs.
- Greater understanding of some of the practical advice outlined in the toolkit and working to apply it to other key areas.

### How will we know we have achieved it?

- Autistic adults across both boroughs are familiar with the work Centre for ADHD and Autism Support do and are able to access support services when they need them to prevent crisis/people only seeking support at at time of crisis.
- Autistic adults feedback positive experiences and interactions with services like Centre for ADHD and Autism Support.
- Parents of autistic adult children feel supported and well informed.
- More council, health and other services are autismfriendly with staff understanding the ways to better engage with autistic people.

### **Peer Support**

### What works well?

- Peer support/trainers being recruited to develop training with the recovery colleges.
- There are some brilliant activities for autistic adults across the two boroughs that promote independence and healthy living.
- The rough sleeping team have been awarded £3.3 million over 2.5 years through a 'Changing Futures' grant to work with people with severe multiple disadvantage who face challenges around homelessness, substance misuse, criminal justice interactions, domestic abuse and mental health needs.



#### CASE STUDY

### Disney Theatrical Relaxed Performances

Relaxed Performances are specially adapted to be accessible to a wide range of audiences such as those with autism, those with a learning disability or anyone with a sensory sensitivity. Extra trained staff are on hand and there are dedicated quiet areas inside the theatre should anyone need to leave their seat.

A visual story is provided ahead of the performance to assist guests in planning their theatre visit and and help them to know what to expect when they arrive. All venue staff and the show company take part in autism awareness training.

On the day, the theatre foyer and bars area are designated quiet and activity areas during the performance and guest can move around the theatre as they wish.

Slight adjustments to the performance to make some sound and lighting effects less surprising, but the show is the same magical experience as always!

Cast members give a welcome to the audience before the show begins. Tickets are priced at reduced rates.

Disney Theatrical Productions run a relaxed performance at each of the West End shows once a year and at every venue the show visits when on tour

www.thelionking.co.uk/access

www.frozenthemusical.co.uk/access

### What do we need to focus on?

- Co-development of the peer trainer role by the Central North West London NHS Foundation Trust's 'Expert by Experience' group.
- Some of these services at the moment do not go beyond the age of 25.
- Ensuring that the services are connected to one another, there is a lot of silo working in this, not being connected. Creating opportunities for networking and development is key to this.
- Ensuring that this support meets the needs of people who may have a variety of complex needs.

#### How do we achieve this?

- Development of a training programme for mental health staff that recognises the needs of autistic people when carrying out an assessment or when waiting for one.
- Manage the market across the two boroughs to encourage more adult focused activity for autistic adults based on 'planning together'.
- As a result of this strategy, the council will aim to set up an
  autism network of providers from across the community including
  traditional support services, culture and the arts to come together
  and share programmes and activities they are planning or are
  underway. This will ensure that autistic residents are able to
  access any gaps in support available can be closed.
- This is a new programme that aims to support people with the help of clinical psychologists, peer mentors and co-ordinators to provide a multi agency support offer.

### How will we know we have achieved it?

- Autistic people feel supported and represented throughout the Mental Health trust.
- Evidence of new/additional groups and leisure activities for autistic adults that are suggested, designed and supported by autistic people in the community.
- Autism, and supporting autistic people, is viewed as a community responsibility with arts, culture, theatre, horticulture, leisure, employment, and housing all coming together to ensure autism is well understood, supported and celebrated.



#### CASE STUDY

### Roshana's story\*

Roshana joined Key Club because she had no friends and no means of connecting with her peers. She was too shy to speak in front of the members when she arrived. Gradually she built up confidence in a smaller team and started to offer ideas. Initially these were via a member of staff, but then direct communication evolved. Roshana then stated she would like to direct the scene and the group willingly agreed. She was very interested in the photography of the drama and worked closely with the director of photography, being the camera person on many of the shoots. By the end of the year everyone was calling Roshana the 'assistant director', she was offering ideas in front of the whole club, and visibly enjoying herself. Roshana belongs to a group who enjoy her company. She is no longer isolated and alone.

\*Name has been changed to protect identities

### Advice for professionals

This part of the strategy supports the National Strategy priority: Building the right support in the community and supporting people in inpatient care.

The working group of the autism partnership board will focus on the overarching outcome of developing and supporting existing specialist services for autistic adults.

# TURTLE KEY ARTS THE KEY CLUB

Key Club is a monthly arts club for people from 16 to 30 years old with autism. They manage to connect with and help an extraordinary and diverse group of vulnerable young people.

The club responds to the individuals and nurtures them in different ways. For some, Key Club is their only activity "it is the only hobby I have, I didn't want to come out before".

Key Club gives the members a reason to leave their house, something to look forward to, a place where they belong. One should never underestimate the impact for an autistic person of arriving in a space when you are welcomed and accepted, where your ideas are valued, and you can be yourself.

For other young people the Key Club has enabled transition. They have started the club because they are in limbo, attended for a year whilst reviewing their options and left when they have started college or work. This particular journey has only been possible because Turtle Key Arts were able to take younger participants in the newly formed afternoon key club.

'It (Key Club Sharing) was the first time X has spoken in public. We are in no doubt that this helped him to interview with confidence and get the job!' (Key Club parent).

'Y now feels comfortable with his decision to take up his place at college. Thank you for everything you offered Y over the last academic year' (Key Club parent).

Transition has also happened over a longer time scale. Members have attended regularly for 5 or 6 years, gradually improved their communication skills, grown in confidence, and formed friendships. They have then begun to make other connections, take part time jobs, and left Key Club after 7 or 8 years.

'During his time at Key Club, Z has become an independent traveller, learnt to speak with more volume and communicate within a team' (Key Club parent'). Z is now in full time employment.

Key Club has influenced the lives of its members beyond the Key Club sessions. Some are now friends and in contact on social media. Various members have met for lunch, gone to the cinema, attended each others birthday parties, and joined sports clubs together. Three long standing members made a short film together last summer.

www.turtlekeyarts.org.uk



# HELPFUL RESOURCES

### Tips from the toolkit for supporting and working with autistic people:

### Adapt how you build relationships

 Consider moving from long sessions to multiple short sessions where possible. Hold appointment slots at a regular time and at regular intervals can sometimes be the most helpful.

### Be consistent

 Where possible, see the person at the same time and place and discuss changes to their routine as far in advance as possible.

### Slow down

• Allow people to process what you are asking or telling them.

### Reduce choice and minimise demands

 Be very clear with communication and limit the amount of options offered at once.

### Make communication clear and use images where appropriate

 Ask one clear question at a time and give the person time to answer.

### Make instructions as clear and minimal as possible

• Provide images to explain what you are saying.

### Break down information into bite-sized chunks

- Email records of communication to people so they can go back and refer to them at a later date.
- Use clear, concise and unambiguous language. Avoid using idioms, irony, metaphors and words with double meanings (for example, it's raining cats and dogs out there).
- Be aware of sensory sensitivity and take steps to make the person more comfortable.
- Be aware of things outside of your conversation that may make them uncomfortable. Simple steps like offering to move somewhere quiet or away from bright lights.

### Use strength-based approaches

- Focus on their skills and what an individual can do, not what they cannot.
- Get to know them a little, understand their interests, likes and dislikes and use this to support open conversation about more challenging issues.



We would like to thank everyone who has given up their time and contributed to this strategy. Especially the autistic adults and their families who have shared their own personal experiences of living with autism. Your ideas, stories and solutions have made this strategy possible!

### Links to websites mentioned throughout this document

www.autangel.org.uk www.autism.org.uk www.auticon.co.uk www.rct.uk www.thelionking.co.uk/access www.frozenthemusical.co.uk/ access www.turtlekeyarts.org.uk www.ambitiousaboutautism.org.uk www.safehavenbasketball.co.uk www.stepchangestudios.com www.in-deep.org.uk www.planetorganic.com www.olivermcgowan.org www.wel-co.me/visitors www.met.police.uk/AskforAngela www.autisminmuseums.com

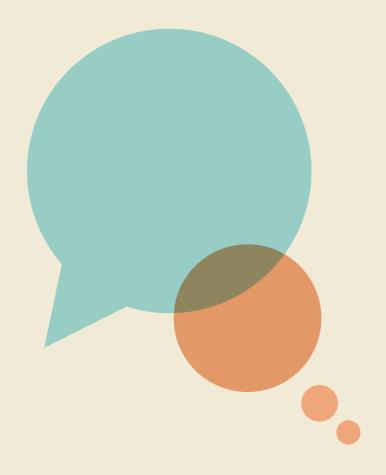
www.officiallondontheatre.com/

www.mousetrap.org.uk/relaxed

access/relaxed

### **Endnotes**

- https://www.gov.uk/government/publications/national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026#our-roadmap-for-the-next-5-years
- 2 https://www.autism.org.uk/advice-and-guidance/what-is-autism
- 6 Autistic individuals are more likely to be LGBTQ+ | University of Cambridge
- Warrier V. et al. Nat. Commun. 11, 3959 (2020) PubMed
- 5 The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al (2012). Estimating the prevalence of autism spectrum conditions in adults: extending the 2007 Adult Psychiatric Morbidity Survey. Leeds: NHS Information Centre for Health and Social Care
- 6 Office for National Statistics (2021). Outcomes for disabled people in the UK: 2020
- 7 The NHS, Mental Health of Children and Young People in England, (2017)
- 8 Lever & Geurts, 2016
- 9 MacKay et al, 2017
- 10 Prison Reform Trust No One Knows, 2018
- 11 National Autistic Society 2016
- 12 Suicidal Ideation and plans or attempts in adults with Autism (Cassidy et.al. 2014)
- 13 Data from Poppi and Pansi
- 14 AQ10 is a tool designed to help identify when a person may require a specialist autism diagnostic assessment. It is an evidence based clinical tool in the referral pathway to support the decision to undertake additional diagnostic assessment. NICE guidance states that it aims to improve access and engagement with interventions and services and improve the experience of care and support for people with autism.
- 15 Their accessibility statements can be found here: Accessibility | Westminster City Council Accessibility Statement | Royal Borough of Kensington and Chelsea (rbkc.gov.uk)
- 16 The National Strategy for autistic children, young people and adults: 2021-2026, 21st July 2021
- 17 autistic-spectrum.png (1590×2328) (blog.gov.uk)





The City of Westminster Tel: +44 (0)2076416000 Email: adultsocialcare@westminster.gov.uk www.westminster.gov.uk



The Royal Borough of Kensington and Chelsea Tel: +44 (0) 20 7361 3000 Email: SocialServiceLine@rbkc.gov.uk www.rbkc.gov.uk