

# **Lewisham All-age Autism Strategy for children, young people, and adults.**

**2023-2028**

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## **Foreword by Councillor Paul Bell, Cabinet Member for Health and Adult Social Care**

I am delighted to present the new Lewisham All-age Autism Strategy (2023-2028). This strategy represents the first step of many in Lewisham's journey to become an autism inclusive borough. We are a borough that thrives because of the celebration of our differences and diversity and while we make good progress improving the inclusivity of our communities, there is still a lot more we can do for autistic people living in Lewisham.

Through conversations with our autistic community and their carers we know that our autistic population continues to experience numerous inequalities with mental, physical, economic and social health outcomes being some of the worst. We need to ensure that we do not see autism as something that should be 'fixed.' Rather we will be a borough that improves and creates the conditions for autistic people to feel welcome, safe and able to thrive.

We need to ensure that the priorities in this strategy are implemented as a partnership and that all stakeholders in Lewisham, including the Council, NHS, voluntary, community and private organisations are held accountable for their role in improving the quality of life for our residents. We will do this in equal partnership with our autistic community members by establishing a new Autism Partnership Board.

The development of this strategy would not have been possible without the contributions of all involved across our services and communities. We want to thank everyone who took the time to contribute to this work and share their knowledge and experience. We recognise we have a way to go and want to be mindful this document is a springboard to be built upon.

# **Chapter One: Introduction**

## **Autism: A Lewisham Perspective**

Autism is a form of neurodiversity and describes a broad range of communication and sensory differences that lead to those with the condition experiencing the world in a very different way. Autism affects at least 1% of the population worldwide, although we know that the availability of diagnostic services is variable, and the majority of autistic people are currently undiagnosed.

Autism is often referred to as a spectrum condition because of the range of ways it can impact on people and the differing levels of support they may need at different stages of their lives. Some autistic people will need very little or no support in their everyday lives while others may need high levels of care, such as 24-hour support in residential care. It is also important to remember that autism is often referred to as a 'hidden disability' because the difficulties faced are not always visible to others. In the UK, autism is a recognised disability, although it is important to acknowledge that there are differing opinions on this and not all autistic people see themselves as disabled.

In Lewisham, there are approximately 4,000 people with a formal diagnosis of autism. Approximately half are currently under 18 years of age, and half are adults. Our oldest autistic resident is 91 years old!

In line with Lewisham's diverse ethnic mix, the autistic community has almost equal representation from BAME and White European. However, there are 2.5 times more males with an autistic diagnosis in Lewisham than females. This is a common finding around the United Kingdom and is thought to be related to the differences in presentation between males and females. Females are less likely to fit with the social stereotypes of autism, so their needs are often unrecognised and unmet. In Lewisham, we want to challenge the public perspective and help society to understand the commonly stated....

***'.... If you have met one person with autism, you have met one person with autism....'***

## **Why do we need an Autism Strategy?**

A strategy defines the area of focus to take us from where we are now to where we want to be. A strategy is not a detailed action plan, it is a document that presents our vision for the borough and describes the priority areas that we will work on over the next five years. We will work in partnership with the autistic community, parents, carers, schools, social services and health care settings towards an autism inclusive borough. The overriding aim is to enable Lewisham's autistic community to live happier, healthier and longer lives.

As part of implementing the All-age Autism Strategy, we will form the first Lewisham Autism Partnership Board (LAPB) in 2023. The group will bring together professionals who deliver services and support to work in collaboration with the autistic community towards a common goal. It will be the responsibility of the LAPB to use this strategy to develop detailed action plans for each of the priority areas. The LAPB will be responsible for ensuring there is a robust structure in place for measuring the impact on these actions. Membership of the LAPB will include members of the autistic community, parents & carer forums, the education sector including the SEND partnership, health and social care commissioners, providers, adult and children's social care and partners from the voluntary sectors.

### **Identity first language**

Many autistic people see autism as a fundamental part of their identity but do not feel that it is the only characteristic which defines them. 95% of the autistic community prefer identity first and neuro-inclusive language such as 'autistic person' and 'autistic spectrum condition'. For this reason, we will avoid the use of person-first language such as 'child with autism' and avoid the term 'Autism Spectrum Disorder' in this document.

## **Our approach to this strategy**

The key principles of our approach can be summarised as follows:

- 1) **'Nothing about us without us'** - Autistic people, their families and carers are at the forefront of everything we do. We will ask, we will listen and make decisions together. We will reach out to lesser heard communities and those less able to advocate for themselves. We will ensure co-production in any services we plan.
- 2) **Neuro-affirmative approach** – We will celebrate differences. We will promote the understanding of individual strengths and areas in need of support. We will enable autistic people to advocate for themselves and their families. We will challenge stereotypes, improve public understanding of autism, and work towards autism inclusive schools, workplaces, public spaces and services.
- 3) **Whole system collaboration** – As a newly integrated care system, we would focus more intensively on effective collaboration between health, education, local authorities, voluntary, community and the private sector. We recognise that autistic people can have many different types of needs. For example, we know that 70% of autistic people also have another physical or mental health condition. We know that autistic people have more special educational and social care needs than the general population. For this reason, we will bring together interdependent services to enable the autistic community to be supported holistically.
- 4) **Keeping you informed** - We will ensure that guidance and information services are comprehensive, easy to find, and accessible for all abilities and ages. This is to empower individuals to seek the right support at the right time.
- 5) **Closer to home** – We aim for autistic children, young people and adults to be included and supported within their local communities. By improving the provision of community services, we hope to lessen the need for specialist, residential and hospital-based services.

## **Chapter 2: our roadmap for the next 5 years**

### **How we decided what is important**

Our vision is that Lewisham is a borough in which autistic people can lead fulfilling lives. We will become an autism-inclusive borough, meaning the Lewisham will actively work with autistic residents to remove barriers to a high quality of life.

In 2021, the policy paper “The national strategy for autistic children, young people and adults: 2021-26” was published, setting out the Government’s plans to improve the quality of life for autistic people across the country<sup>1</sup>. Since its publication, we have been working with autistic residents, carers and service professionals in Lewisham to tailor our approach to delivering these aims. By working together, we sought to identify what an autism-inclusive borough would look like for us, and the steps we need to take to achieve this.

In May 2021, Lewisham Council consulted autistic individuals, parents and carers and health professionals to find out what is important to the autistic community in Lewisham. We used the feedback we received and included their insights into the public consultation that took place in May 2022 where we received over 140 responses. From looking at this feedback, we recognised that we did not receive a large number of responses from people under the age of 18 years. To ensure that their insights were considered, we undertook further engagement work during October and November 2022 where we received 70 responses from young people. Based on this feedback we have created the following vision statements. Only when a large proportion of our autistic community feel that these vision statements are a true reflection of their lives, can we say we are autism inclusive-

- I feel safe and welcomed in the community, including public services, schools and in my workplace.
- I have access to reliable information about autism; and have access to diagnostic services.
- I can ask for help whilst I am waiting for an assessment for a diagnosis of autism.
- My family, carers, and I are supported to understand autism and what it means for me
- I can learn in ways that work for me; my teachers understand how to support me.
- I am supported to make my own decisions about my future, my views are taken seriously no matter what sex, gender, ethnicity, sexuality or disability I have.

- I have access to services and therapies based on my needs. The NHS and other service providers understand how to make reasonable adjustments so that I can access their services.
- My family and carer(s) receive the help they need to care for me and for themselves.

## **How we will work towards the vision statements**

We will formally establish a Lewisham Autism Partnership Board (LAPB) that will bring together representatives from adult and children social care health and social commissioners education commisioners and providers, SEND, parents and carers, and the providers of key borough based services.

The responsibility of the Board is to co-produce the action plans that sit under this strategy, ensure that the plans are implemented, and that our objectives are achieved. This will also include setting realistic timescales and ensuring that we are collecting the information we need to monitor the impact these actions are having. The LAPB will establish working groups as necessary to deliver on these plans and will oversee the work of these groups. An initial step towards our co-productive approach would be to work with community organisations to identify a co-chair from the lived experience community and to ensure the voice of autistic people is integral to our partnership development and plans.

A key action for the LAPB is to ensure that temperature checks are taken periodically throughout the lifespan of this strategy, and beyond, as a way to measure its impact. We know that we need to improve on the information that we have available to us, and will use the information we received during 2021/22 as a starting point from which to measure improvement from.

## **Our commitments in the first year**

- We will make sure that, where appropriate, we work collaboratively in establishing any plans and actions with other services and support across Lewisham to ensure that we work as part of a local care system and not in silos. This will include ensuring close links are made with teams working on SEND and learning disabilities.
- We will establish the Lewisham Autism Partnership Board
- We will ensure that we co-produce an action plan that has realistic timescales and that we put a system in place so that we are able to monitor the impact of these actions and share the progress publicly.
- We are committed to improving the information we collect in relation to autism in the



borough. We will ensure that we have processes in place so that services and support across social care, schools, primary care and hospitals are improving the information they collect so that we are able to measure the impact on the strategy action plan.

## **What will change as a result of this strategy**

At the end of the five years, we expect the following changes.

- We will make sure that we have produced reliable information about autism that is easily available in the borough, whether this be leaflets or posters in public places, or online for those who wish to receive information in this way.
- We will have delivered awareness and increased understanding of autism training in the borough for professionals (health and social care, education, potential employers, police), schools and members of the community.
- We will have an improved and less fragmented local offer to support both children and adults for both pre and post diagnosis of autism.
- We will endeavour to increase the number of autistic people who attend their annual physical health checks.
- We will ensure that reasonable adjustments are made for people with autism attending health and care appointments to reduce some of the barriers as to why autistic people do not attend appointments.
- We expect that autistic people will have an improved patient experience when attending health and care appointments.
- We expect to have a reduction in variation of young people's experiences of school for autistic people, especially for those in mainstream schools.
- We will increase employment opportunities for autistic people in Lewisham.

## **Chapter 3: Our Priorities**

### **Priority 1: Improving understanding and acceptance of autism within the community**

Lewisham is committed to supporting the working partnership of autistic people, their families and supporters together with agencies in health, education and social care, reducing inequalities and ensuring that every autistic child, young person and adult across the spectrum of neurodiversity feels listened to, understood, accepted and valued.

We will ensure that autistic people are able to access specialised support, information and advice when they need it by creating a community that provides equality of provision and life chances, supporting independence and championing autonomy. Essential to the nurturing of the autism community will be the ongoing training and autism awareness raising across the whole Lewisham community. Autism awareness training will be offered to a wide range of organisations including schools, businesses and service providers in order to create an autism friendly borough. The process of creating an autism friendly borough will also be achieved through collaboration and joint working with the autism community and by taking account of individual lived experiences and personal perspectives. This will be undertaken with the acknowledgment and understanding that autistic identity is not one thing but multifaceted, encompassing many other aspects of identity that are ever changing and multi-layered, including cultural, ethnic and religious attitudes, values and beliefs of autistic people and the families and communities they are part of.

### **Priority 2: Improving autistic children's and young people's access to education**

We will strive to be ambitious for children and families through recognising the importance of a timely identification of need and post-diagnosis support. We will advocate for clarity of individual profiles of strengths and needs - recognising, accepting and addressing those needs, supporting and promoting meaningful inclusion in nurseries, schools and post-16 provisions. We will ensure all educational practitioners and support and pastoral staff have a good understanding of autism as well as a working knowledge of evidence-based approaches, strategies and adaptations, enabling schools to provide for different needs and ensuring equality of provision for all. We aim to ensure specialised support, training, advice and signposting to all stakeholders involved in the care, education and effective inclusion of autistic children and young people in order to create a community that provides equality of

provision and life chances, supports independence, champions autonomy and promotes acceptance of difference/neurodiversity.

In supporting the educational achievement, social inclusion and emotional health and wellbeing of autistic children and young people, we will ensure they feel safe, valued and empowered, have opportunities and aspirations for their future and feel enabled to make a meaningful contribution to their communities. In working with families, we will also strive to acknowledge, understand and value the views and perspectives of parents and carers. We will also consider family priorities and preferences for intervention and work in partnership with parents to ensure the best outcomes for children and young people.

### **Working with marginalised families.**

In working with and supporting autistic people and their families we will develop our awareness of the different and overlapping ways that families can be marginalised. This means acknowledging that some families may be marginalised due to ethnicity and culture, socioeconomic status, housing inequality, language challenges, physical or mental health needs, or having children in care. We need to understand how this can lead to differences in education, health and the experiences of the criminal justice system, and prioritise recognition and support for the diverse and often overlapping needs of our communities.

### **Priority 3: Improving diagnostic pathways and autism support services**

Nationally, autism diagnostic pathways for adults and children are under pressure due to growing waiting lists. We are working closely with regional and national teams to innovate and find creative solutions to improve autism diagnostic pathways and reduce waiting times.

Whilst accurate and timely diagnosis is important, we equally recognise the need for high quality pre and post diagnostic support services in Lewisham. We will work with community services to increase the availability and accessibility of autism specific information and advice, signposting, psychoeducation and peer support groups.

### **Priority 4: Tackling health and care inequalities for autistic people**

We know that autistic people experience poorer physical and mental health, along with reduced life expectancy compared with non-autistic people. Around 40% of autistic adults also have a learning disability. Most medical conditions are more common in the autistic population including diabetes, hypertension, heart disease and obesity. We know that autistic people are

twice as likely to use emergency departments, three times more likely to be admitted to hospitals, and find it much harder to advocate for themselves within the NHS. We know that one in five inpatients in eating disorder units are autistic, and the help they need to recover is different to non-autistic patients.

Suicide is a leading cause of early mortality amongst autistic people, with studies finding that an autistic person is 9 times more likely to die from suicide than a non-autistic person. Research shows that 14% of autistic children in the UK experiences suicidal thoughts compared with 0.5% of non-autistic children. Evidence is also emerging that the lack of social acceptance, feelings of isolation, and persistent 'masking' or 'social camouflaging' is linked to increased risk of suicide.

For these reasons, it is not surprising that the life expectancy of an autistic person without a learning disability is 16 years less than the general population. If a person is both autistic and learning disabled, their life expectancy is 30 years less.

In Lewisham, we are committed to reducing these health inequalities. We will do this by:

- Reducing barriers and improving access to health care
- Providing accessible information to empower the autistic community to advocate for themselves
- Embedding reasonable adjustments into health care settings
- Improving early identification of autism and diagnostic pathways
- Improving the community support available to autistic people and their families
- Committing to national plans for delivering Oliver McGowan training to health and social care staff in South East London. The training will provide general awareness of what support autistic people may need.
- Moving forward with the NHS National Long Term Plans to improve the health of autistic adults by making sure they receive timely annual health checks.
- Committing to implement learning recommendations from the LeDeR program (Learning from lives and death – People with a learning disability and autistic people).
- Recognising the additional barriers faced by autistic individuals from lower social economic backgrounds
- Ensure commissioned services are culturally appropriate and meet the needs of our diverse community.
- Supporting positive transitions into adulthood

## **Priority 5: Supporting autistic people into employment**

We know that Lewisham has the lowest job density of any local authority area not just in London, but of all local authorities in Great Britain. This is because we have a high number of people who live here but work elsewhere in London. Lewisham Council has established programmes to support residents to gain skills, enter employment and access more high quality apprenticeships, including Lewisham Works and Lewisham Young Futures. The council is committed to offering more jobs, training and education opportunities for people with learning disabilities, including autism. We will work together as a partnership with the Jobs and Skills Programmes, SEND team, partner organisations and Adult Learning Lewisham.

Lewisham SEND services has an established Supported Internship programme for young people aged 16-25 with Educational Health and Care (EHCP) plans, including placements with Better Leisure and various council services including Adult Social Care and Sports, Parks and Leisure among others.

As part of the internships work, Lewisham council have recently been awarded a NDTi grant to develop SEND employment forums to improve Supported Internship provision in Lewisham and focus on pathways to employment for young people with SEND.

Since April 2022, Adult Learning Lewisham has been delivering 'Pathways to Employment', a 12-week programme for adults with learning disabilities and mental ill health.

Through Neighbourhood Community Infrastructure Levy (NCIL), Lewisham Council has provided grant funding to Ignition Brewery to develop their Inclusive Community Enterprise Generator Project for adults with learning disabilities, working with residents to gain skills and identify job and business opportunities, such as Ignition Ice and Lewi Club.

Lewisham Local are delivering the 'Building People, Changing Minds' programme in partnership with Lewisham Speaking Up, a pilot project aimed at placing adults with learning disabilities into voluntary work placements.

## **Priority 6: Reducing mental health admissions and supporting quality inpatient care**

We will achieve the targets set out in the NHS Long Term Plan to reduce the number of autistic people being admitted into inpatient mental health services. We will do so by improving the provision of talking therapies available, support individuals through crisis intervention services, keyworking, Dynamic Support Registers, and improved personalisation of care. We will also improve the suitability and availability of supported housing and social care provision.

Autistic people who require inpatient care will receive reasonable adjustments to feel safe, receive advocacy to ensure their needs are met, and treatment plans that are tailored to their individual needs. We will increase the options available for 'step-down care' to ensure people are discharged back into their communities as soon as they are well enough to leave.

## **Priority 7: Improving support within the criminal and youth justice systems**

The Youth Offending Service (YOS) work with young people aged 10 to 17 years who get into trouble with the police, charged or convicted of a crime. They also work with schools and other local agencies young people may come into contact with. The YOS have embedded the use of "Social Graces", a practical toolkit that can be used to address inequality. It uses particular skills to help us navigate in our social circles and covers aspects of social and personal identity such as race, gender, religion and age that can have an effect on an individual's privilege in society. The service will use communication passport in courts and ensure reasonable adjustments are made. For example, by providing the use of fidget spinners in sessions, relaxation and meditation techniques in group work.

We know that people with autism are over-represented as people that come into contact with the Criminal Justice System, yet studies indicate a rate of offending lower or equivalent to the general population. Most will not have a diagnosis, and many may find the Criminal Justice System complicated. In 2021, HM Inspectorate of Prisons and HM Inspectorate of Probation joined HM Inspectorate of Constabulary and Fire & Rescue Services to conduct a joint review on 'Neurodiversity in the Criminal Justice System'. A significant finding was that there were "low levels of awareness, understanding and confidence in relation to neurodiversity" from professionals within the Police, prison and Probation Service. Whether the reason for contact with the Criminal Justice System is as a victim, witness, defendant or a combination; personalised provision should be championed in order to achieve positive outcomes. The Safer Lewisham Partnership Board will establish how partners across statutory, community and voluntary work with people who have autism. The board will facilitate training opportunities to these agencies and will improve the data collection in order to inform service planning.

## **Priority 8: Improving experiences of caring**

Carers told us that a significant gap in both practical and emotional support left them struggling to look after themselves and those they care for. The focus of this priority area is to improve support for carers and family members. We will do this by focusing on the following objectives:

- **Improve direct support for carers**

Carers highlighted the positive impact of community services to reduce feelings of isolation. We will work to increase the availability for peer support groups, ensure short break and respite services are available to families who need them and improve the range of direct support available for carers, including psychoeducational interventions and coaching.

- **Help to navigate the system**

Carers shared their experiences of complex pathways and said they found identifying and accessing support difficult. We will work towards clear, accessible, up to date information available in our Local Offer, increase the availability of signposting services, and ensure help is available for specific difficulties such as applying for Education Health and Care Plans, Access to Work schemes or navigating the benefits system.

- **Improve the range of short-term respite options**

Local parents identified a lack of affordable short-term respite opportunities for autistic children in the borough. We will work to improve the range, availability and accessibility of activities and groups in the area that promote independence for autistic children and their guardians.

## **APPENDICES**

### **National and local policy and legislation**

The Autism Act 2009 is currently the only disability-specific legislation in England and requires the Government to introduce and keep under review an adult autism strategy<sup>2</sup>. The government has since published:

#### **Fulfilling and Rewarding Lives (2010)**

The statutory guidance entitled “Fulfilling and Rewarding Lives” 2010 aimed to kick start fundamental change in public services to enable adults with autism to live independent lives and find work. This strategy aimed to improve training for groups in contact with autistic people in health and social care but also in job centres, as well as improving the accessibility of public services, buildings and transport. It also aimed to ensure a clear pathway to diagnosis<sup>3</sup>.

#### **Think Autism (2014)**

Think Autism built on the themes of the previous strategy. It also highlights the importance of autism awareness communities and the autism innovation fund to encourage community level support and championing as well as the importance of recording this data and making it easy for people with autism to access this information<sup>4</sup>.

#### **Adult Autism Strategy: Supporting its Use (2015)**

Further local statutory guidance was published in 2015 instructing local authorities and NHS trusts on key areas for development including: training in autism awareness for staff; appointment of an autism lead; developing a clear diagnostic pathway; and adequate assessment of local area needs based on population data. The guidance also highlighted the importance of care needs assessments not being refused based on normal IQ scores, which had previously been an issue. Diagnosis of women is also an important area which literature suggests has been under recognised and should be addressed in training<sup>5</sup>.

#### **National All Age Autism Strategy (2022)**

The latest update to the strategy seeks to extend the scope of the strategy to children and young people for the first time. Accompanying statutory guidance is aimed at supporting the NHS and local authorities in implementing the strategy in areas such as staff training,

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identification and diagnosis, transition planning when people move from children to adult services, employment and criminal justice.

#### Children and Families Act (2014)

Part 3 - Children and Young People in England with SEN or Disabilities (Sections 19 to 83)

Section 19 sets out the matters to which local authorities must have regard in exercising their functions in cases of children and young people with SEN. These include the wishes and feelings of the child, young person and their parents and the importance of the child or young people participating in decision.

Special Educational Needs and Disability Code of Practice (2015) which place duties on LAs, NHS organisations and schools re autistic children and young people.

#### National

- Mental Capacity Act 2005
- Mental Health Act 2007
- Care Act 2014
- No Health Without Mental Health
- NHS Long Term Plan
- Mental Health Forward View
- Advancing Mental Health Equalities Strategy
- Improving Access to Mental Health Services by 2020

#### Local

- Corporate Strategy 2023-27
- Lewisham Health and Wellbeing Strategy 2013/23
- Lewisham SEND strategy
- South London and Maudsley NHS Foundation Trust Autism Strategy