





FINAL DRAFT

City & Hackney
All Age Autism Strategy

2020-2025



Views from autistic residents

"As an autistic adult living and working in the City & Hackney area, I am pleased that autism awareness has been raised and this is certainly useful for everyone, including those on the autistic spectrum and all other members of the public. More work needs to be done and the efforts being made are going in the right direction"

"All autistic people should be considered as everyone else when we go out"

"There needs to be more awareness of what autism is"

"Services should be knowledgeable about autism in all the ways it can present"

"We need an appreciation and understanding that autism often co-exists with and manifests in multiple other disabilities and conditions including mental health issues, physical disabilities or addiction issues"

Contents

- 1. Foreword
- 2. A word from one of our Co-Chairs
- 3. Co-Production and Consultation
- 4. Terminology
- 5. Introduction
- 6. Coronavirus Pandemic
- 7. Local Guidance
- 8. National Guidance
- 9. Preventing Crisis and Managing Independence
- 10. Health, Social Care and Wellbeing
- 11. Planning and Leadership
- 12. Education, Training, Employment and Skills
- 13. Criminal Justice
- 14. Wider Community and Private Sector
- 15. Strategy Action Plan How will we ensure this is delivered?
- 16. Final word

Hackney & City Partner Organisations involved in developing this Strategy:

Appendix A

1. Foreword

This strategy sets out a challenging vision with a clear action plan for making City and Hackney more accessible for autistic people of all ages, and their carers, who live and work in City and Hackney.

The aim of this strategy is to ensure that by understanding the needs of autistic people and their carers, and accepting autistic people for who they are, we can design, shape and transform services. By working with partners, providers and our communities, we can develop and design services that will achieve improved outcomes.

The strategy sets out expectations for public sector organisations and their partners in the City and Hackney to ensure that services are more accessible to autistic people.

Our vision is to have an Autism Friendly City and Hackney.

"We believe that autistic people living and working in the City of London and the London Borough of Hackney should be able to live fulfilling and rewarding lives within a society that accepts and understands them."

2. A word from one of our Co-Chairs



Simon Galczynski

Director of Adult Services and co-chair of Autism Alliance Board Autism touches the lives of many people in both City and Hackney and can affect all aspects of life, from education to healthcare to employment and social lives.

This strategy covers the whole life-course, including children, young people, adults and families, and carers. Making City & Hackney autism friendly, in which autistic people can live fulfilling and rewarding lives, is an important priority for us. We recognise that increasing awareness and acceptance of autism in the wider community and increasing knowledge and understanding is the key to succeeding in this.

In developing this strategy we engaged with, and heard the views of, autistic residents, families, carers and partners from across City & Hackney and we want this to continue as the strategy is delivered. The strategy is challenging but aims to make the City and Hackney a better place to live for autistic people. Delivery of the strategy will require that we work in partnership for and with our communities to ensure we achieve our positive ambitions.

3. Co-Production and Consultation

City and Hackney have a genuine commitment to co-production, and while we don't always get it right, our co-production journey has been led by the work we have done together on the Autism Alliance Board over the last few years.

When we talk about co-production, we mean that we see people who use services or who support people who use services as equal partners and as an asset, with skills. It helps break down the barriers between people who use services and professionals and builds on people's existing capabilities. Co-production is a way of working where all stakeholders including service users and service providers, work together to decide or create services which works for all.

From the early days 2 co-chairs were appointed to the Autism Alliance Board, the Director of Adult Social Care for London Borough of Hackney and an autistic resident. Agendas are set in consultation between the chairs, meetings are co-chaired and the Board see this as the "norm".

Various recent work groups, set up to work on aspects of the strategy have also all been co-chaired between an officer and an autistic resident or a parent/carer.

This writing of this report has been supported by an editorial group made up of autistic residents and is a genuine collaboration and co-produced report.

The Autism Alliance Board has also sought to, wherever possible, consult with the wider community, stakeholders, partners and agencies. We have done this by promoting wide membership of the Autism Alliance Board, holding seminars and workshops and, as discussed below, produced a questionnaire aimed at getting wider views from residents.

Public questionnaire

A questionnaire was created with questions designed by commissioners, the diagnostic team and autistic residents. It was published in early April 2019 and promoted and distributed through our partners. The questionnaire was open for 12 weeks and we had 106 responses. We have used information gained from this questionnaire to feed into this strategy, to ensure the voices of all the autistic residents and their carers that took the time to complete the questionnaire have been heard.

Drop-in engagement events

In July 2019, we held a series of drop-in events in both City and Hackney where we displayed an accessible version of the draft strategy and people could vote on recommendations and make other suggestions and share ideas. Approximately 30 people came along and the feedback from these events has been used to shape this strategy and will also be used in our work going forward where relevant.

4. Terminology

For consistency with the National Strategy and associated guidance, recent research into terminology, and in line with an aim to de-medicalise autism, the terms 'autism community', 'autism' and 'autistic' will be used in this strategy.

These terms are taken to cover various descriptions of autism, diagnosed or otherwise, and include Autistic Spectrum Disorder (ASD), Asperger's Syndrome, Autistic Spectrum Condition (ASC) and neuro-divergence.

- Autistic person refers to children, young people and adults, pre or post autism diagnosis, and encompasses the breadth, complexity and diversity of autism across a wide spectrum of ability
- We recognise that every person has a preference on how they identify (e.g. autistic person or person with autism). For this strategy, identify-first descriptions (e.g. 'autistic' or 'autistic resident' rather than 'resident with autism') will be used as per the agreed Autism Alliance Board Terms of Reference
- Parent (s) and Families includes biological, birth, foster and adoptive parent (s) and families
- Carer someone who's looking after a partner, friend or family member who's not able to manage by themselves
- Child as defined by the Children and Families Act as being up to 16yrs old and of compulsory school age. However, in other areas of law, 'child' is a person under the age of 18
- Young person aged between 16-25 years old
- Adult any person over the age of 18 years old
- Older person aged 65 and over
- City and Hackney This term is used throughout this strategy and encompasses the London Borough of Hackney, City of London Corporation and City and Hackney Clinical Commissioning Group (CCG)
- Assessment of need This term covers a range of assessments including Care Act needs assessment for adults and Education, Health and Care needs assessment for children and young people
- Schools where Schools are referenced this is inclusive of independent Schools

5. Introduction

Many autistic people and their families are socially and economically excluded, and services are currently unable to meet the range of needs. This strategy sets out a local response and explores the development of local services to ensure a better understanding, improved outcomes and quality of life for autistic adults, children and young people, their families and carers.

Autism is a lifelong developmental disability that affects how people perceive the world and interact with others.

Autistic people see, hear and feel the world differently to other people. If you are autistic, you are autistic for life; autism is not an illness or disease and cannot be 'cured'. Often people feel being autistic is a fundamental aspect of their identity.

Autism is a spectrum condition. All autistic people share certain difficulties but being autistic will affect them in different ways. Some autistic people also have learning disabilities, mental health issues or other conditions, meaning people need different levels of support. All people on the autism spectrum learn and develop. With the right sort of support, all can be helped to live a more fulfilling life of their own choosing.

The characteristics of autism vary from one person to another but in order for a diagnosis to be made, a person will usually be assessed as:

- having had persistent difficulties with social communication and social interaction
- and restricted and repetitive patterns of behaviours, activities or interests since early childhood,
- to the extent that these "limit and impair everyday functioning,".

National Autistic Society (2016).

Everyone should be informed, supported and equipped to ensure that all autistic people living or working in City and Hackney are able to live fulfilling and rewarding lives within a society that accepts and understands.

Processes for diagnosis should be clear and appropriate support available when needed; mainstream public service functions will treat everyone fairly, whilst identifying and responding to diverse needs and improved education and employment opportunities will help everyone contribute to society.

This strategy has been co-produced, and we have worked with, heard and listened to many autistic residents and their families and carers over the development of this document.

There are a number of themes that stand out as a priority for residents and we have tried to embed them into the strategy. For the avoidance of doubt, and to be clear

that we have heard and want to act upon these main themes, we have spelt them out clearly here:

Mental Health

Autistic people are more prone to have mental illnesses, and current mental health services don't feel accessible to the majority of autistic residents. There is a feeling that more education and experience is needed within the services and also a recognition that in primary care, services need to better understand the relationship between mental health and Autism in order to identify and treat mental health issues of Autistic residents.

Accessibility

It is clear that autistic people do not find services and organisations easy to access in terms of both the sensory environment and the methods of communication available. This strategy focused on ensuring organisations are accessible to autistic people, have a range of communication methods (including email) and can access quality training.

Autistic Hub

In all our consultations one proposal that kept being raised by everyone was to establish a community "Hub", a place or places where people who are autistic or who care for autistic people can meet, socialise, learn, get peer support and build up a library of knowledge and guidance. The hub could evolve from the expert by experience group, taking in support from other organisations.

Girls and Women

We heard very clearly as part of our consultation that autistic girls and women have a different experience to boys and men and that this needs to be acknowledged, understood and people need to be educated to understand the differences. Girls and women are better at masking symptoms and better at adapting their behaviours and as a result there is probably an under diagnosis of girls and women. Services need to be better tailored to meet these needs once diagnosed. The strategy attempts to address this need.

Children and young people

We recognise that there are some key priorities identified for autistic children and young people and their families/carers. There is a focus within the Children and Young People system to provide an ongoing offer of integrated support pre and post diagnosis that children, young people and parents/carers understand and can access when needed.

6. Coronavirus Pandemic

It is recognised that this strategy has been developed and agreed by The Autism Alliance Board prior to the Coronavirus Pandemic in March 2020. The recommendations within the Strategy are still relevant but there is an acknowledgment that some of the priorities and ways in which actions are delivered may change or be impacted.

It is also recognised that the coronavirus pandemic has had a particular impact on the autistic community, especially in relation to mental health needs and social isolation. As we work towards coronavirus recovery, particular actions may be identified in these areas and prioritised within the action plan for this strategy.

7. Local Guidance

Autism Alliance Board

The London Borough of Hackney set up an Autism Alliance Board in May 2016 and set out the principle that the work of this Board will be co-produced with residents that are autistic and people who care for them. In 2018 the Autism Alliance Board agreed to include the City of London Corporation to its membership.

The Autism Alliance Board and its work groups have led on the writing of this strategy and maintained the principles of co-production and each section of this document has been worked on, agreed and co-written by autistic people.

The strategy has been designed to mirror the same areas of life that the National Strategy covers, whilst making it relevant for City and Hackney.

Local Strategies and Plans

This strategy also compliments and should be read alongside a number of other local strategies and plans for City and Hackney, including;

- The draft Learning Disability Strategy
- The draft Mental Health Joint Strategy
- The developing Ageing Well Strategy
- The forthcoming strategy for Safeguarding Adults (2020-2025)
- The Local Strategic Delivery Plan for the City and Hackney System Responding to the NHS Long Term Plan
- The draft Integrated Emotional Health and Wellbeing Strategy for Children and Young People
- The Joint Health and Wellbeing Strategy
- The Special Educational Needs and Disability (SEND) Strategies

Public Health Autism Needs Assessment

In 2019 the City and Hackney joint Public Health team put together an Autism Needs Assessment which highlights areas of need relating to autism for children and adults in both local authorities. This assessment looks at research, data, specific needs and co-existing conditions and current available services as well as makes recommendations for future provision. The findings of this needs assessment has been used to inform this strategy.

2018 Self Assessment

In September 2018 we received a joint letter from The Association of Directors of Adult Social Services (ADASS) and The Department of Health and Social Care (DHSC) advising of the fifth autism self-assessment framework.

The submitted self assessment required sign off by the local Programme Board - in the case of City and Hackney this was the Autism Alliance Board. There is also a requirement that consultations of each question are undertaken with autistic residents.

We divided the self-assessment questions into "themes" that matched the remit of the work groups that the Board has created. The groups answered these questions and then the Autism Alliance Board carried out an exercise with groups reviewing the full submission. There were a few changes and points of accuracy but the group agreed to the sign off of the return.

One member stated "I feel last time the completion of the form was managed, I think this time the process was managed but the completion was co-produced and reflects more accurately the local position," Members of the Board agreed with this statement.

The Board also agreed that this process had been very helpful in guiding the writing of the local strategy as it helps state the current position and also guide our future plans. So, for example, where an area scores RED our strategy will support us working towards becoming GREEN.

As in previous years the information submitted is collated and analysed by Public Health England. The Cross Government Autism Strategy dates from 2010 (updated in 2014) and followed the Autism Act of 2009. It has a focus on adults and children transitioning to adulthood, who don't have a learning disability. The strategy is being reviewed during 2019 and the responses to the self-assessment exercise will also help with that process.

8. National Guidance

This autism strategy will be influenced by national and local policy and research, with particular reference to the following:

- Fulfilling and rewarding lives: The strategy for adults with autism in England (March 2010)
- Think Autism (2014)
- Care Act 2014
- NHS Long-Term Plan 2019 (and easy read version)
- Equality Act 2010
- Children and Families Act 2014
- 'Joint Commissioning autism services' guidance (Draft July 2019)
- The Westminster Commission on Autism report; A Spectrum of Obstacles (2016)
- Centre for Research in Autism and Education (CRAE) study on GPs' confidence in caring for their patients on the autism spectrum (2017)

Appendix A gives further information on these policy and research documents and where they're relevant to this strategy.

9. Preventing Crisis and Managing Independence

Think Autism (2014) Priority Challenges for action

"I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low level support."

"I want to know that my family can get help and support when they need it."

Our vision

Autistic people will know where to go for support and information. There will be access to services and support which focuses on early identification, early intervention, crisis prevention and promotes greater independence as well as more long term support for those that need it.

This will include support after diagnosis, peer support groups and better access to support for managing money and benefits, maintaining home and tenancies as well as homelessness services. We want autistic individuals to be empowered and for each autistic individual to experience feelings of competence, inclusion, content and joy of life.

We want to ensure the wellbeing of parents and/or carers of autistic people of all ages is maintained and that their needs are also taken into account. This includes improved long term planning and timely interventions to avoid crisis situations when carers cannot provide support.

Observations by autistic residents and carers

- Organisations and services aren't particularly autistic friendly
- Advice and information about accessible services is incomplete and not readily available
- Some people feel isolated and would like more opportunities to meet up and share experiences and frustrations
- Low level interpersonal/preventative support opportunities are not readily available
- There is little support after diagnosis, would like more post-diagnostic quidance given
- It would be helpful if there was a more extensive and better resourced autism (diagnostic) support service for adults
- Being a carer can be draining and lonely as you cannot get out much

KEY ACTIVITIES	WE	WILL
Information	1	Develop an autism page on the Hackney Council and City of London's websites which are developed with Experts by Experience
	2	Improve and promote the digital information available by service providers including; - on Hackney iCare for autistics and their families and carers - on the City of London Adult Social Care pages - on the Local Offer for Hackney for children and young people - on the Local Offer for City of London for children and young people
General support for autistic people	3	Work with existing groups, including the experts by experience group, to empower individuals to set up an autistic led "Hub"
	4	Explore piloting the use of Assistive Technology such as mobile apps to support autistic people to live as independently as possible
	5	Work with autistic women to identify specific support they may require
Support for parents and carers (including autistic carers)	6	Ensure carers of autistic people are offered carers assessments and relevant advice on support including peer support which will help carers to understand what support they need to be able to continue their caring roles
	7	Ensure there are suitable and adequate respite opportunities for carers of autistic people
	8	Ensure the City Carers' Strategy is implemented and the new adult carers outreach service in Hackney is accessible to autistic people and carers of autistic people, including the training and awareness of their staff and volunteers

	9	Work with parents of girls and women to help them understand the unique presentation and how they can support
	10	Address the waiting times for Early Bird service
Money Management	11	Work with money management services (including debt management) to ensure staff are trained and understand autism and support those services who wish to apply for an accreditation
	12	Work with organisations, such as the local Citizens Advice, to support autistic people in filling out benefit forms (e.g. Personal Independence Payments and Disability Living Allowance)
	13	Work with gambling awareness services to ensure staff are trained and understand autism and support those services who wish to apply for an accreditation
Housing and Homelessnes s	14	Work with Housing Needs team to ensure reasonable adjustments are taken into account when allocating housing for autistic people
	15	Work with Homeless and Rough Sleeper services to increase awareness of autism through training which is co-facilitated by autistic trainers
	16	Develop a pathway for referrals of homeless clients into autistic assessment services
Cultural Diversity	17	Support the creation and development of culturally diverse peer support groups, to improve information and educational sharing as well as greater understanding and specific support to different community groups and encourage awareness, appreciation and understanding of autism within different communities
Awareness in a crisis	18	Promote the use and recognition of the communication card across City and Hackney and collect voluntary feedback from people that have used the cards to inform any improvements

		(The communication card has been developed with autistic residents and is designed to be used in the community to help inform others on how to best support and communicate with a person)
	19	Work with Accident & Emergency services to promote the Hospital Passport and to help increase awareness of autistic 'meltdowns/shutdowns'
		(A hospital passport is designed to give hospital staff helpful information that isn't only about illness and health. The passport might include a range of things e.g. likes and dislikes, the amount of physical contact you're ok with, favourite foods and drinks, interests.)
	20	Work with Mental Health services, including crisis services, to ensure staff are trained and services are more accessible to autistic residents

CASE STUDIES OF WORK ALREADY HAPPENING:

- Both London Borough of Hackney and City of London have Local Offer websites that offer information about a range of autism specific groups and support for parents and carers and opportunities for young people with SEND including autistic young people
- Support for carers is available in City and Hackney, and a new local carers strategy and service is being developed, which includes the needs of carers of autistic people
- There are peer groups which have been set up by autistic residents
- Engage Hackney can support autistic residents with housing related difficulties (e.g. managing tenancies and reporting repairs)
- A 'communication card' has been co-developed for use in the community;



10. Health, Social Care and Wellbeing

Think Autism (2014) Priority Challenges for action

"I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process."

"I want staff in health and social care services to understand that I have autism and how this affects me."

"I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies."

"I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging."

Our vision

There will be clear routes to access and pathways through diagnostic, assessment and therapeutic services for autistic people of all ages:

Diagnostic services

We know that across England, the majority of newly diagnosed autistic people are children. Early years settings and schools have a responsibility to identify additional needs and refer on to relevant Health agencies. In City and Hackney we have established diagnostic pathways in the Child and Adolescent Mental Health Service (CAMHS) and the Adult Autism Service which will continue to support people across all ages with diagnosis.

Post diagnostic support

There should be a clear pathway post diagnosis onto an assessment of need for autistic people. Agencies will work together to avoid diagnosis overshadowing commonly co-occurring conditions like ADHD, dyspraxia, epilepsy and mental health needs so that these aren't missed and support required for issues such as nutrition can be identified.

Better access to mainstream health and social care including appropriate environmental adjustments

We want to ensure autistic people are better able to access mainstream health and preventative services as appropriate, including those who have additional needs such as a learning disability or mental health. This will include access to Occupational Therapists, Speech and Language Therapists, GPs, Dentists, Mental

Health teams and Improving Access to Psychological Therapy (IAPT). We also want to ensure that an autism diagnosis doesn't overshadow any other health needs which a person may have.

Mental Health

Mental illness can be more common for autistic people than in the general population and is often overlooked. It is also more common for autistic people to think about suicide, and die by suicide, than the general population. We will work with Board members, mental health professionals/clinicians, providers, schools and commissioners to ensure the "I statements" previously worked on by autistic residents be embedded in the way services are delivered in order to be more accessible to autistic residents. This includes mental health crisis services and preventative services, to ensure that professionals and vounteers understand the increased risk of autistic residents thinking about suicide and to be trained to understand how to communicate and support autistic people in a mental health crisis.

We want all mental health services to recognise, understand and be trained to support autistics who have mental illnesses in City and Hackney.

Preparing for Adulthood

Preparing for the future is when children and young people think about what they want to do when they are older. It is important for everyone to think about this and make a plan. Some autistic children and young people need additional support in school or college to aid learning. This support is described in an Educational, Health and Care Plan which says what support a child or young person who has special educational needs requires. We want every young autistic person to have a clear pathway for transition from being a child to being an adult which is developed at the right time for the person and includes access to a range of suitable timely support.

Transforming Care

Under the Transforming Care agenda, we will continue to improve the quality of care and quality of life for people with a learning disability and/or are autistic, with a particular focus under this strategy on those without a learning disability. We will also continue to reduce inappropriate hospital admissions and length of stay by enhancing community capacity.

Older adults

The autism strategy is not just for autistic children and young adults, it also recognises that it's important that services think about specific support required for older autistic people. In July 2013, the National Autistic Society (NAS) published a policy report 'Getting on? Growing Older With Autism' which identifies that there is likely to be a significant number of undiagnosed older autistic people because autism was not included in psychiatric classification systems until 1980 and aspergers was only established in these systems in 1994. Part of our vision is to ensure that we do

what we can to identify autistic older people and better understand what support is needed.

Observations by autistic residents and carers

- Post diagnosis support is insufficient
- The Hackney Adult Autism (diagnostic) Service is a good point of contact and they are very helpful
- More promotion is needed on services available
- Doctors, nurses and health visitors need more training to understand autistic people better
- Adapted mental health support is important
- Parents want to have a picture of what will be available for children as they
 move to adulthood in terms of housing, supported employment or other
 activities, day centres, leisure activities, social care, etc.
- Specific support and advice for girls and women is missing
- Occupational Therapist (OT) and Speech and Language Therapist (SALT) support is good but limited due to them being stretched
- Some parent information sessions have a long waiting list
- There is a gap for autistic people with a mild learning disability that do not meet the eligibility for the Integrated Learning Disability Service.
- There is some good access to GPs in Hackney but there are still some issues
- There is an identified lack of accessibility within the Health Visiting service and antenatal clinic for autistic parents
- The post diagnostic support group is very helpful
- Personal budgets are not easily accessible for autistic people

KEY ACTIVITIES	WE	WE WILL	
Post Diagnosis Support	21	Work with diagnostic services and other autistic support groups to support people who are diagnosed as an autistic in adulthood by offering guides, peer support and information and advice, and in particular advice on how to deal with your new diagnosis and share this with friends and family	
	22	Develop a clear pathway post diagnosis onto an assessment of need for autistic adults, for all levels of need and support	
	23	Revise training to ensure it includes information on the risks of a diagnosis overshadowing commonly co-occurring conditions like ADHD, dyspraxia, epilepsy and mental health	

	24	Ensure timely and accurate diagnoses and Co-produce specific post diagnostic support for girls and women
Universal Health Promotion services	25	Ensure that universal health promotion and preventative services are accessible to autistic people. This will include smoking cessation, weight management, exercise opportunities, substance misuse and vaccination services
	26	Ensure greater take up of health checks for autistic people in line with the NHS Long-Term Plan
		(An NHS health check is offered to those aged between 40 and 74 designed to spot early signs of stroke, kidney disease, heart disease, type 2 diabetes or dementia.)
	27	Ensure GP and other health professionals know where to signpost and refer autistic people to access peer support, community-based services and specialist support
Coexisting conditions	28	Address significant health inequalities identified by the needs assessment (e.g. epilepsy, weight management for children and young people)
Health and Social Care staff	29	Increase the autism awareness and acceptance of staff across health and social care including commissioners, GPs, nurses, mental health professionals, dentists, social workers and allied professionals
	30	Work with health, schools and social care providers including GPs to make reasonable adjustments for autistic people (using the recommendations made by the Experts by Experience group)
	31	Work with health, schools, social care and other staff working with autistic people to develop a functional approach to communication, interaction and participation
	32	Promote the use of the <u>Autistic Spectrum Disorders Toolkit</u> by the The Royal College of General Practitioners (RCGP)
	33	Review the impact of the social worker for autism and the ongoing offer including where it sits within Social Care
	34	Explore options for specialist services for autistic people and how this links with the Integrated Learning Disabilities Service

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	35	Explore options to improve access to a multidisciplinary team for autistic adults (including OTs, SALT and Psychiatrists)
	36	Make sure all new health and social care service specifications include a requirement for reasonable adjustments to be implemented for autistic residents
	37	Promote development of autism friendly dentists and opticians
New Parents	38	Explore how autistic new parents (antenatal and postnatal) are supported and what they need
Personalised care and support	39	Review personal budget and direct payment offer for autistic people including personal budgets for children and young people
	40	Explore the 'Hospital Passport' and other communication methods to ensure care is given in the right way for the person
		(A hospital passport is designed to give hospital staff helpful information that isn't only about illness and health. The passport might include a range of things e.g. likes and dislikes, the amount of physical contact you're ok with, favourite foods and drinks, interests.)
Mental Health	41	Ensure Mental Health services staff are trained and supported in working with autistic clients
	42	Work with Mental Health commissioners and services to develop more accessible mental health services for autistic residents, including mental health admission wards, using "I statements" already agreed by the Autism Alliance Board
	43	To improve the uptake and accessibility of Mental Health IAPT services (Improving Access to Psychological Therapies) for autistic residents, including for those aged 18-25
	44	Encourage Mental Health services to audit themselves against best practice resources such as the Green Light Toolkit
Children and Young People including	45	Work across Education, Health and Local Authorities (including Social Care) to improve their support for children

	1	
Preparing for Adulthood		and young people with learning disabilities, autism or both in line with the NHS Long Term Plan
	46	Develop information and support for children, young people and their parents about transferring from children's services to adult services, particularly in relation to health and social care
	47	Review the youth service offer for autistic children and young people
	48	Develop packages to support autistic children and their families throughout the diagnostic process in line with the NHS Long Term Plan
Transformin g Care	49	Continue to address the Transforming Care Agenda through the Transforming Care Partnership. This will be addressed as part of the Learning Disabilities strategy
	50	Ensure that autistic people without a learning disability are identified and included on the transforming care risk register and that lessons are learnt from this cohort
	51	Strengthen our approach to Care and Treatment Reviews and interventions for people with a learning disability and/or are autistic (including children and young people)
Older people	52	Promote autism awareness and acceptance specifically at services that work with older adults (including home care providers, residential care homes and voluntary services). This will include offering co-facilitated training to care staff
	53	Increase the number of older adults seeking a diagnostic assessments and offer post diagnostic support tailored to this group
Cultural diversity	54	Ensure an understanding of where health messages and support groups are promoted and advertised, using diverse community venues (E.g. most Orthodox Jewish children do not attend state schools)

CASE STUDIES OF WORK ALREADY HAPPENING:

- There is an Adults Autism Service within East London Foundation Trust (ELFT) which offers diagnosis, brief interventions and advice to adults living in City and Hackney who have not had a previous diagnosis of Autism. People diagnosed through this service can access time-limited post diagnostic interventions/support including the post-diagnostic course, monthly peer support group, reasonable adjustments for work or education and Occupational Therapy (OT) assessments.
- There is a dedicated Social Worker for autistic adults for those that require a care act assessment.
- Transitions clinics are held by CAMHS Disability with the Integrated Learning Disability Service (ILDS) for autistic children and young people with a learning disability.
- Hackney Ark is a centre for children and young people with disabilities and additional needs. The centre brings together health, education and social care services to provide an integrated multi-disciplinary response to the needs of disabled children and their families.
- Multi-disciplinary workshops are available through Hackney Ark, specialist CAMHS, children's speech and language therapy and occupational therapy drop-ins.

11. Planning and Leadership

Think Autism (2014) Priority Challenges for action

"I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others."

"I want autism to be included in local strategic needs assessments so that person centred local health, care and support services, based on good information about local needs, is available for people with autism."

Our vision

There will be clear leadership and governance in place to develop, monitor and evaluate actions within this and future strategies to achieve change and the overall vision of the Board.

To be meaningful, we know involvement and participation must have the confidence of autistic residents and carers to make a real difference. We regard autistic residents and carers as equal partners in the journey to making City and Hackney more autism friendly and we will continue to work together with residents and carers throughout the delivery of the aims in this strategy. We will always seek a new involvement and do our best to ensure that we are representative of a cross section of the population and breadth of local needs.

New guidance, evidence and national strategies are produced regularly and we will commit to ensuring that the Autism Alliance stays up to date and that this strategy is flexible to adapt to meet new challenges as they arise.

Children and young people

There is an identified need for greater involvement of children and young people, their families and the relevant professionals within children's services to develop the action plan that will deliver this strategy. The Children, Young People, Maternity and Families workstream is establishing a 'system influencers' engagement project which will support this and link in with the Autism Alliance Board.

Observations by autistic residents and carers

- Support and service provision needs to be driven by autistic people
- All senior leaders including those on the Autism Alliance Board should have autism training delivered by an autistic person
- Using examples such as the autism questionnaire is a good first step, but the emphasis must always be on working to include autistic residents and carers as a default, rather than as a bolt-on

KEY ACTIVITIES	WE	WILL
Leadership	55	We will continue to hold the Autism Alliance Board, with two co-chairs, one of which must be autistic. The Board will lead on the delivery of the Autism Strategy and monitor the progress of its implementation, requiring an annual action plan to move forward on the key activities with clear targets set
	56	Further develop partnership working, with an ongoing dialogue between social workers, health professionals, criminal justice services, education, training, employment, leaders and staff working with autistic people
	57	Continue to have a named commissioning lead for Hackney and the City
	58	Continue to work towards meeting the NICE 'Autism Quality Standard' (The quality standard covers health and social care services for autistic adults, young people and children. It includes assessment and diagnosis as well as care and support and describes high-quality care in priority areas for improvement.)
Coproduction	59	Continue to support the Expert by Experience group and support any plans to help the group become self funding and independent
	60	Continue to seek a new involvement to include those in identified underrepresented groups (e.g. autistic girls and women and those with a learning disability)
Data	61	Work with GPs to record the number of autistic patients on their records as part of The NHS Long-Term Plan objectives
	62	Promote greater consistency and accurate recording of autistic diagnosis on Adult Social Care case management systems
Accountability	63	Co-produce an action plan for each year using objectives in this strategy
	64	Produce a communication plan to promote the strategy and ongoing progress
	65	Produce an annual report for the Autism Alliance Board to

		inform progress made on the strategy objectives
	66	Regularly evaluate the effectiveness of the strategy by getting feedback from autistic people and their families and carers to identify if they are feeling included and heard
Autism Training Plan	67	Make autism training, co-facilitated by an autistic trainer, available for all members of The Autism Alliance Board
	68	Build on the success of the existing autism training plan and ensure this is published each year, informed by the local needs assessment and strategy. Training will be designed and co-facilitated by autistic people where possible
Cultural Diversity	69	Establish a voluntary register of residents involved in the coproduction of the autism strategy and work streams to enable us to identify under-represented groups (this will inform action number 54 above)

CASE STUDIES OF WORK ALREADY HAPPENING:

- We have adopted a set of principles for engaging and consulting autistic residents which has been developed by users and carers.
- We currently have an Autism Alliance Board which is leading on this strategy. Board membership includes autistic residents and carers, City and Hackney Local Authorities, City and Hackney CCG, NHS Trust, Special Educational Needs and Disability, Adult Social Care, Education, Department for Work and Pensions and Criminal justice services.
- The Autism Alliance Board is co-chaired and co-produced.
- We have an established 'experts by experience' work group which has helped to coproduce this strategy alongside other work in relation to autism.
- Public Health have undertaken a local needs assessment which has been used to inform this strategy.
- The Workforce Development Unit produces an Autism Training Plan annually with targeted training developed where need is identified. This training is often designed and delivered with autistic people.

12. Education, Training, Employment and Skills

Think Autism (2014) Priority Challenges for action

"I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism."

"I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible."

"I want support to get a job and support from my employer to help me keep it."

"I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies."

Our vision

Education

In City and Hackney we believe that all children, regardless of any disability or additional need, should have the best possible experience within education and children's services from the earliest years thorough to college and beyond. Education has a key role to play in the skills developed for living independently, entering into and remaining in employment and leading a socially inclusive life. All educational settings have a duty to be inclusive and follow a range of statutory guidance including the Equality Act 2010, the Children and Families Act 2014, SEND Code of Practice: 0-25 years and careers guidance and access for education and training providers.

Early Years settings, Schools and Colleges will work with health services to ensure autistic young people are identified early and accurately and supported to achieve the best possible outcomes. This will include making personalised reasonable adjustments and using best endeavours to remove barriers to learning and take differences into account, including for example, adjusting exams, homework and written assignments to allow differing recording and flexible means of demonstrating understanding as well as opportunities for social interaction in school for autistic children and young people.

We aspire to ensure a range of provision including mainstream, resourced provision and special schools which have the capacity to meet current and future needs.

Early Years

We recognise that good preparation for adulthood starts at the earliest point in a child's life and brings together parents/carers, education, health and social care staff.

In City and Hackney agencies will work closely together around early intervention and support services for young children who may be autistic. Early years settings have to have SEND policies and a qualified SENCO. Those staff are supported locally by an Area SENCO and specialist teams to ensure that the settings have the knowledge and confidence to meet the needs of a variety of children. Where children may require additional support the settings can apply for Disability Inclusion and/or Early Years Inclusion funding to support them in this. Where families prefer to keep their children at home before they go to school, Hackney Portage team provide support at home.

Schools

All schools are required to follow the SEND Code of Practice: 0-25 years and the Disability Act 2010. City and Hackney expect all schools to provide a warm welcome to all children, young people and families regardless of any additional need they may have. The SEND Code of Practice: 0-25 years details guidance of how schools assess, plan for, deliver and review any additional support required for children and young people. Most children and young people will have their needs met in a mainstream setting. Schools are provided with additional funding to meet need and a range of mainstream and specialist provision is available. For children and young people with additional needs, schools and colleges receive funding so that they can put additional support in place. Some children and young people will require a greater level of support and in these cases may need an Education, Health and Care Plan to support access to education or training.

Preparing for Adulthood

Good preparation for adulthood starts early. It brings together parents/carers, education, health and social care staff. In City and Hackney our vision is to develop clear pathways for transition from children to adult services with meaningful employment as a key outcome alongside independent living, participating in society and being as healthy as possible. We want to ensure autistic young people have equal access to career related activities and that different careers and education opportunities are explored, developing interests and ambitions as outlined in the latest statutory guidance and associated toolkit.

Skills

Autistic people will have access to appropriate vocational, life and practical skills training, which will include meaningful work experience in schools and sixth forms. There will be a range of volunteering opportunities for autistic people, including those with learning disabilities.

Employment or Occupation

Autistic people will be aware of the employment and volunteering opportunities available to them in the City and Hackney. Autistic people will have access to appropriate adapted work opportunities e.g. supported internships, access to work, traineeships, apprenticeships and will be supported effectively by a range of local organisations including the local Supported Employment provision and Job Centres.

Local employers will know how to make personalised reasonable adjustments for autistic adults to ensure that differences are taken into account. Employers will be supported to recognise the positive aspects of autism which are often overlooked and encourage organisations to reflect on the strengths and benefits of employing autistic people.

Support services will be available to support autistic people with significant learning disabilities into employment or occupation.

Training

Training will be available for a range of services that provide support for or come into contact with autistic people, including;

- Health and Social Care staff
- Schools, Colleges and Universities
- Job Centre staff
- Criminal Justice services
- Housing services
- Private, Voluntary and Independent Organisations
- Carers

Training is already designed and delivered with autistic people and/or their carers where possible. We want to continue this and ultimately for all training to be co-designed and co-facilitated by autistic people who are paid for their time.

Observations by autistic residents and carers

- The current transition to adulthood process isn't joined up there needs to be
 a clear picture of what is available for children and young people as they
 prepare for adulthood it feels like a cliff edge after exams
- All information needs to be accessible and given to autistic people and their parents/carers so they don't have to go searching for what is available
- Organisations and schools should work in partnership to help support our young people to gain skills into employment or supported employment
- Job searches can be difficult because of our differences (e.g. language barriers)
- Employment support is patchy
- There is a lack of 6th form progression provision for autistic young people

KEY ACTIVITIES	WE	WILL
Education	70	Continue to support Early Years Providers, Schools and Colleges, Health professionals and parent/carers to work closely together to identify social communication difficulties early and make provision, which is evidence based and reviewed regularly
	71	Continue to research and share best practice and guidance for Early Years Providers, Schools and Colleges around reasonable adjustments for pupils
	72	Continue to support Early Years Providers, Schools and Colleges to work with pupils and parents/carers to ensure reasonable adjustments and best endeavours are used in a personalised way (e.g. sensory room, safe haven room available)
	73	Continue to encourage Early Years Providers, Schools and Colleges to regularly review and adapt reasonable adjustments as appropriate using recommendations made by autistic people
Preparing for Adulthood	74	Continue to support/train Careers Advisors in Schools and Colleges to improve career advice offered for autistic people, including those with learning disabilities. This will be based on the latest statutory guidance and associated toolkit e.g. SENCo forum session on careers advice and work experience
	75	Continue to support Schools and Colleges to use the preparing for adulthood toolkit and the SEND code of practice to think about becoming an adult from the earliest opportunity. Meaningful employment will be a key outcome in transition to adulthood plans for autistic young people
	76	Provide better information about a range of pathways through further and higher education, training, apprenticeships, vocational opportunities and employment. Encourage setting to become members of The Careers Collaborative run by Hackney Learning Trust which will promote careers, work

		experience and other opportunities for children and young people with additional needs, including autistic young people
	77	Develop a clear personalised employment support offer for young people to include placements, mentors, apprenticeships, summer work placements, university and advice and support for autistic young people with and without a learning disability
Skills	78	Ensure appropriate vocational and practical skills training is available for autistic people with or without learning disabilities
	79	Support people to access training such as employment skills/interview skills which are meaningful for them
	80	Support people to access volunteering and vocational activities
Employment or Occupation	81	Research and share best practice and guidance for employers around reasonable adjustments for employees
	82	Showcase examples of where autistic people have been employed, and the benefits seen by employers
	83	Support local Job Centres to promote their "Calm and Quiet" sessions for autistic people and/or people with learning disabilities/difficulties
	84	Support local Job Centres to work with employers and charity organisations to become Disability Confident to create more job opportunities appropriate to autistic people
	85	Work with employers to offer alternative ways of recruitment (e.g. work trials, ring fenced temporary positions, aptitude tests)
	86	Promote supported internship opportunities in the NHS targeted at people with a learning disability and/or autism - at least half of these will be converted to paid employment

	87	Ensure there is clear accessible information about the range of services available to support people into employment (including Supported Employment)
	88	Review employment support services in line with NICE guidance
Training	89	Provide/commission, enable and support a wide spectrum of ongoing training and awareness-raising opportunities targeting the specific needs of the intended audience to cover all education, social care, health and public services staff as well as the public and statutory services e.g. police/probation/job centre/advocacy. This should include support for non English-speaking communities and parents/carers
	90	Develop more autistic trainers and design training with autistic people and/or their carers
	91	Monitor the uptake of training and report this to Integrated Commissioning and Health and Wellbeing Boards within the Planned Care detailed reviews

CASE STUDIES OF WORK ALREADY HAPPENING:

- The Local Offer has detailed information and advice on preparing for adulthood, including a section on preparing for work.
- We currently have a multi-agency autism training plan which includes delivering training to Adult Social Care, Housing Services, East London Foundation Trust (ELFT), Homerton Hospital, City of London Police, Metropolitan Police, Jobcentre Plus, Carers, GPs as well as Private, Voluntary and Independent organisations. Autistic trainers are commissioned to deliver some courses.
- There are a range of supported employment services such as Hackney Works Supported Employment.
- The Garden is an autism specific school. There is also provision within other schools. Some offer link programmes to assist with transition to education and training providers. The Garden has a café for work skills development.
- There are a range of supported internships on offer aimed at or available to young autistic people.
- Hackney Council have a commitment to employing autistic people and has different routes into this (including apprenticeships, flexible selection processes and work experience etc).
- Local bespoke training from children's speech and language therapy (SALT) is available across education settings.

13. Criminal Justice

Think Autism (2014) Priority Challenges for action

"I want to be safe in my community and free from the risk of discrimination, hate crime and abuse."

"If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services."

Our vision

The <u>National Autistic Society</u> has lots of useful information on why autistic people are more likely to be victims or witnesses of crime but also includes information and examples for why autistic people may commit an offence or come under police suspicion.

Our vision for Hackney and the City of London is that all parts of the local criminal justice system have an awareness of autism, consider autism and make reasonable adjustments where possible.

Police, Community support officers and probation services will be autism aware; understanding that behaving differently can mean being autistic and not suspicious as well as increasing skills to work with people with communication difficulties.

Observations by autistic residents and carers

- Often the processes for arrest, custody and victims aren't clear to autistic people which causes anxiety
- Hate crime is often not reported due to the environment of police stations or difficulties in reporting over the phone
- The communication card has been useful
- Training for criminal justice services needs to be more than autism awareness and needs to detail specifics around crime and autism

KEY ACTIVITIES	WE WILL	
Accessibility	92	Encourage Criminal Justice Services to use the <u>guidance</u> available from the National Autistic Society to make reasonable adjustments where appropriate; e.g. appointment/interview length, environment, communication differences and arrest process

	93	Ensure that the processes for arrest, custody and victims are explained in an accessible way for autistic people - building on the good example of the poster identified in Stoke Newington Station
	94	Review the methods for reporting of crime (e.g. hate crime, mate crime) locally and identify any reasonable adjustments which can be made
	95	Support the City of London Police in the roll out of their Pegasus card
	96	Review the appropriate adult contract to ensure it is inline with autism guidance (An appropriate adult 's role is to ensure that the suspect is treated in a fair and just manner and is able to participate effectively)
Training	97	Review the local training offered to the Criminal Justice Services to ensure it includes specific information about the issues and barriers experienced by autistic people. Where possible, ensure training is designed and delivered with autistic people
	98	Identify key stakeholders for criminal justice autism training and deliver training, including Courts, Family Courts, Probation and Youth Offending
	99	Ensure that the Health and Social Care pathway and local support offer for autistic people is clear to the Criminal Justice Services and that they are aware of how to make a referral

CASE STUDIES OF WORK ALREADY HAPPENING:

- Training is available to a range of staff in the criminal justice system. Currently this training is accessed by the local police and some probation staff.
- There is a commissioned appropriate adult service which supports clients to exercise their rights under the Police and Criminal Evidence Act and to provide a safeguard to vulnerable adults and juveniles in police custody in situations where a preferred appropriate adult (e.g. a parent, carer, spouse etc.) is either not available or not appropriate. This service is available for autistic people in custody suites and nominated 'places of safety' and all of these staff have received autism awareness training.
- The Autism Alliance Board has some engagement with criminal justice services with the police attending meetings.
- City of London Police have launched a service to make it easier for people with disability or illness to contact the force. Pegasus is targeted specifically at

people who live and/ or work in the Square Mile who find it difficult to communicate when calling police or speaking face-to-face with a police officer.



• Childrens SALT are employed directly by the Youth Justice Teams to deliver training and support to children, young people and the workforce at the point of identified need.

14. Wider Community and Private Sector

Think Autism (2014) Priority Challenges for action

"I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism."

"I want to be seen as me and for my gender, sexual orientation and race to be taken into account"

"I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible."

Our vision

We want City and Hackney to be an autistic friendly place to live and work. All adults working for the community will have an **awareness and appreciation** of autism and know how to make reasonable adjustments to help people live a meaningful life.

Autistic people will be able to access services in the local communities (e.g. shops, hairdressers, places of worship, transport, leisure centres, cinemas etc.) without barriers.

Community activities will be accessible and available for autistic people with and without learning disabilities.

Observations by autistic residents and carers

- Lots of support services seem designed for non-autistic people, going to noisy and busy places
- More information is needed on services, public spaces and businesses in the community (e.g. noise levels, lighting)
- Better public understanding of the breadth of the condition would help
- Maps/layouts, facilities, visual guides or social stories are really helpful in advance. e.g. for an event knowing whether it's dark/bright, loud/quiet, formal/relaxed or for a service then understanding how it works (e.g. is there a wait, what is the average wait, is there a waiting area, if so what is it like, do I have to sit still and quietly or can I move around).

KEY ACTIVITIES	WE WILL	
Neighbourho ods	100	Explore opportunities for piloting a 'creating acceptance in my neighbourhood' approach with one estate
Accessible Services	101	Work with local organisations to increase awareness of autism to support services to become more accessible for autistic people. e.g. encourage autistic friendly sessions of mainstream voluntary services, including faith groups, art and therapy groups, advice and information, etc.
	102	Make co-facilitated autism awareness training available to public facing City & Hackney Council staff
	103	Encourage facilities and events in the community to make reasonable adjustments to their services e.g. libraries, museums, exhibitions, sports centres and other leisure services to promote autistic friendly sessions. This includes those with learning disabilities
	104	Use resources such as the National Autistic Society's campaign toolkit to support local businesses and organisations to become more accessible
	105	Encourage local organisations and businesses to apply for an accreditation (for example, the Autism Friendly Award) (The Autism Friendly Award is an accreditation offered by The National Autistic Society which champions premises who commit to making sure their business is more accessible to autistic people and their families)
	106	Use the City's Business Healthy network to promote best practice to businesses and employers for autistic service users and employees (Business Healthy is a network of employers in the City of London)
Information	107	Highlight the local businesses and services that achieve an autism accreditation on the council's autism webpage to promote knowledge of those more accessible organisations and services

	108	Explore mapping local businesses in terms of lighting, noise levels etc. to identify and advertise quiet and autistic accessible places
Transport	109	Work with Transport for London to promote their "Please offer me a seat' packs and to offer training to transport staff on autism awareness
	110	Raise awareness of the autism communication card with Transport for London staff
	111	Support the roll out of the revised Blue Badge scheme as it is announced by the Central Government which will support people with hidden disabilities, including autism, to help remove the barriers many face to travel
	112	Review local Freedom Pass offer
Cultural Diversity	113	Promote an inclusive, community based offer encouraging existing services which support diverse groups to make reasonable adjustments, by following the guidance in The National Autistic Society's Autism Accreditation

CASE STUDIES OF WORK ALREADY HAPPENING

- Age UK City of London have expressed an interest in signing up to the Autism Friendly Award.
- Hackney picturehouse has autism screenings.
- The HIT Squad and Short Breaks team at Hackney Ark work with community leisure providers to train staff and promote autism friendly activities.

15. Strategy Action Plan - How will we ensure this is delivered?

The recommendations in this strategy will be put into an action plan which will include information on priority, time frames and who will be leading on each recommendation with clear targets set.

This action plan will be monitored by the Autism Alliance Board and partner Local Authorities who will be responsible for reporting on progress at each Alliance Board meeting.

16. Final word

We would like to thank all autistic residents, families, carers and professionals for their time and commitment in attending the Autism Alliance Board and all its work groups, which has resulted in us being able to present the first City and Hackney Autism Strategy.

We expect the Board to maintain oversight of the action plan included in the strategy, to lead the work which will drive us towards our vision:

"We believe that everyone with autistic spectrum conditions living and working in the City and London Borough of Hackney should be able to live fulfilling and rewarding lives within a society that accepts and understands them."

For more information on City & Hackney Autism Strategy and services available please contact userengagement@hackney.gov.uk

Hackney & City Partner Organisations involved in developing this Strategy:

- London Borough of Hackney
- City of London Corporation
- City and Hackney NHS CCG
- Hackney & City Health Watch
- Hackney Works
- Hackney Learning Trust
- Hackney HIP
- City and Hackney Child and Adolescent Mental Health Services
- East London Foundation Trust Mental Health Services
- Integrated Learning Disability Service
- East London Foundation Trust Adult Autism Service
- Metropolitan Police
- City Police
- Community Rehabilitation Company
- Department for Work and Pensions (Finsbury Park, Hackney and Hoxton Jobcentreplus
- Hackney Branch of National Autism Society
- Koach Parenting

Appendix A

National Guidance relevant to this Strategy

National Autism Strategy - Fulfilling and rewarding lives: The strategy for adults with autism in England (March 2010);

This has five main areas for development:

- Increasing awareness and understanding of autism
- Developing pathways for diagnosis and personalised needs assessment
- Improving access to support services in the local community
- Helping autistic people into work
- Enabling local partners to plan and develop appropriate services

The refreshed national strategy, Think Autism (2014);

This maintains a similar focus for development, with three new key proposals:

- to enable people with autism to really be included as part of the community.
 This means looking beyond statutory services at how we build communities
 that are more aware of and accessible to the needs of people with autism,
 bringing together champions for change.
- to promote innovative local ideas, services or projects which can help people in their communities through new models of care, particularly for "lower level" support for those not meeting eligibility criteria for statutory support. This includes models which will support early intervention or crisis prevention or which support people to gain and grow their independence, or to find employment.
- to focus on how advice and information on services can be joined up better for people.

Think Autism (2014)

The refreshed Think Autism national strategy reinforces **15 priority challenges for action** which have been identified by autistic people, carers and professionals and can be summarised under three key themes:

- An equal part of my local community
- The right support at the right time during my lifetime
- Developing my skills and independence and working to the best of my ability

To measure the success of the strategy's intentions, we will use these outcome/" I" statements as one way of demonstrating the difference made to the lives of people in City and Hackney. These priorities are referenced in this strategy under each relevant heading as appropriate.

Care Act 2014

The Care Act aims to put people and their carers in control of their care and support; Including:

- A national minimum eligibility threshold for care
- The right to a personal budget for people and their carers who meet eligibility criteria
- New rights for carers, including a right to an assessment and support if they are eligible
- A duty for councils to consider the physical, mental and emotional wellbeing of people needing care, and to provide preventative services
- National Institute for Clinical Excellence (NICE) Guidelines;
 - o Autism: Recognition, Referral and Diagnosis of Children and Young People on the Autism Spectrum CG128 (2011)
 - o Autism: The Management and Support of Children on the Autism Spectrum CG120 (2013)
 - Autism: Recognition, Referral and Diagnosis of Adults on the Autism Spectrum CG142 (2012)
 - o Quality Standard
 - o Autism QS51 (2014)

NHS Long-Term Plan - 2019

In 2019 the National Health Service (NHS) produced their Long-Term Plan which sets out intentions to address pressures faced and accelerate the redesign of patient care in order to future-proof the NHS for the next 10 years. The plan refers to autism in the following identified priorities:

 "We will pilot the introduction of a specific health check for people with autism, and if successful, extend it more widely,"

- "The whole NHS will improve its understanding of the needs of people with learning disabilities and autism, and work together to improve their health and wellbeing,"
- "By 2023/24, a 'digital flag' in the patient record will ensure staff know a patient has a learning disability or autism,'
- "We will work with the Department for Education and local authorities to improve their awareness of, and support for, children and young people with learning disabilities, autism or both,"
- "Over the next three years, autism diagnosis will be included alongside work with children and young people's mental health services to test and implement the most effective ways to reduce waiting times for specialist services,"
- "Children, young people and adults with a learning disability, autism or both, with the most complex needs, have the same rights to live fulfilling lives.
 Where possible, people with a learning disability, autism or both will be enabled to have a personal health budget (PHBs)"
- "Supported internship opportunities targeted at people with a learning disability and/or autism will increase by 2023/24, with at least half converted to paid employment over the first five years of the Long-Term Plan,"

NHS England have produced an <u>easy read version of the Long-Term Plan</u> which has been developed with people with lived experience of learning disabilities, autism or both.

Equality Act 2010

The Equality Act 2010 and subsequent <u>guidance documents</u> are in place to ensure people with protected characteristics aren't discriminated against; this includes in employment, school and in the wider community.

Children and Families Act 2014

The Children and Families Act 2014 aims for children and young people with special educational needs to:

- get education, health care and social care services working together
- tell children, young people and their parents what they need to know about their disability or special educational needs
- make sure children, young people and families know what help they can get when a child or young person has special educational needs or a disability
- make sure that different organisations work together to help children and young people with special educational needs
- give children and young people and their parents more say about the help they get

- set up one overall assessment to look at what special help a child or young person needs with their education, and their health and social care needs, all at the same time
- give a child or young person just one plan for meeting their education, health and social care needs, which can run from birth to age 25 if councils agree that a young person needs more time to get ready for adulthood
- make sure children, young people and their parents can choose some help they need
- provide ways to help sort things out if a child or young person or their parent needs to appeal about the help they get

SEND Code of Practice (2014)

The Special Educational Needs and Disability (SEND) Code of Practice gives statutory guidance to services supporting those with SEND aged 0-25.

'Joint Commissioning autism services' guidance (Draft July 2019)

Skills for Care, National Autistic Society and the National Development Team for Inclusion, on behalf of the Department of Health and Social Care, are developing guidance about commissioning services for autistic people. A draft was published in July 2019.

The guidance will support the commissioning workforce in health and social care to improve the way they commission services and support for autistic people. Although the document is in draft form, we have embedded the 4 themes of the document into the strategy. The four themes are: Things to measure; Things to do; who to engage and resources to use.

Research:

The Westminster Commission on Autism report; A Spectrum of Obstacles (2016)

This report summarises the findings from an inquiry into access to healthcare for autistic people and makes 6 recommendations;

- Care Quality Commission (CQC) should make sure that health professionals are doing a good job for autistic people
- Doctors should make a note on the computer for autistic patients
- All autistic people should be offered to go to their doctor every year to have a health check
- All health professionals should have autism training
- The Government should make some money available which should be used to help autistic people understand what will happen at the doctor or hospital
- NHS England should have an Autism Champion to lead on making changes for autistic people

Centre for Research in Autism and Education (CRAE) study on GPs' confidence in caring for their patients on the autism spectrum (2017)

This online self-report study aims to understand GPs' perceived self-efficacy in identifying and managing their patients on the autism spectrum and concludes that 'there is an urgent need for improved local specialist service provision alongside clearer referral pathways for diagnosis to improve both GPs' confidence in caring for their autistic patients and the healthcare experiences of autistic patients and their families.'