

Tower Hamlets Autism Strategy for Adults 2017-22



1. TOWER HAMLETS AUTISM STRATEGY FOR ADULTS 2017-22: SUMMARY

1.1 Background

It is estimated that around one per cent of the adult population have Autism Spectrum Disorder (ASD). It is a condition that is characterised by impairments in social interaction, social imagination and communication. Autistic adults can experience difficulties in life, and are more likely to experience problems related to things like health, housing and crime. This strategy sets out how the Council, health services and others will help autistic adults between 2017 and 2022.

1.2 Aims

Our vision locally is the same as the government's vision, which is as follows:
"All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents¹."

1.3 Objectives

The eight objectives we will work on in order to improve things for autistic adults are to:

- 1) Help autistic people to feel like part of their community
- 2) Help autistic people access good quality health and social care services
- 3) Support young people with autism to transition into adulthood
- 4) Raise people's skills and knowledge in relation to autism
- 5) Help autistic people to find and keep work
- 6) Help autistic people to live in good quality housing that meets their needs
- 7) Reduce and improve autistic people's interaction with the criminal justice system
- 8) Help those who care for friends and family with autism

1.4 How we will make this happen

We will set up an Autistic Adults Partnership Board to make sure that this strategy is put into place. We are really keen to make sure this Board includes autistic adults and their carers.

2. INTRODUCTION

2.1 Autistic Spectrum Disorder (ASD) is a lifelong developmental disorder, characterised by impairments in social interaction, social imagination and communication. Autism is a spectrum condition, which includes autism and Asperger's syndrome. Research and feedback indicates that autistic adults can have needs in a range of areas that relate to health, social care, housing,

¹ 2010 Adult Autism Strategy *Fulfilling and Rewarding Lives – Vision statement*

the criminal justice system and social inclusion. This strategy aims to address these needs, setting out how the Council, health services and others will help autistic adults between 2017 and 2022.

2.2 Throughout this strategy, the phrase “autistic adults” or “autistic people” is used in preference to “adults with autism” or “people with autism”. This is in line with feedback from autistic people.

2.3 This strategy is a partnership strategy. It is held by the Council and the Tower Hamlets Clinical Commissioning Group, and has implications for other services, such as the criminal justice system. As such, it sets out the collective vision for autistic adults in the borough.

3. BACKGROUND INFORMATION

3.1 The number of autistic adults

3.1.1 Autism in adults is often under-diagnosed, under-reported and misdiagnosed, largely due to the social and communication difficulties associated with the condition².

3.1.2 Recent estimates suggest that there are around 450,000 adults nationally living with autism. This equates to 1.1% of the population. The rate of autism among men (2.0 per cent) is higher than among women (0.3 per cent). The current evidence suggests that the prevalence of autism in adults who also have learning disabilities is between 7 per cent and 20 per cent.

3.1.3 In 2015 there were thought to be almost 2,300 adults with ASD in Tower Hamlets³. This equates to 0.8% of the population. However, this figure is an estimate and therefore needs to be approached with caution. It is estimated that around half of this group have a learning disability.

3.1.4 Evidence suggests that the number of children and young people diagnosed with autism has grown rapidly in recent years, and according to staff feedback, autism is now one of the three most common long-term conditions affecting children. Inevitably, as this group get older, we can expect the number of adults with autism to increase accordingly. In an environment of restricted public resources, one of the aims of this Strategy is to set out how we can address an increase in demand in a sustainable way. Moreover, early intervention for children and young people with Special Educational

² Tower Hamlets JSNA Factsheet – Adults with Autism Spectrum Disorder (2016) Peter Lamb

³ 2125 adults 18-64, 153 aged 65 or over. Source: Tower Hamlets JSNA Factsheet – Adults with Autism Spectrum Disorder (2016) Peter Lamb

Needs or Disabilities (SEND), many of which will transition into Adult Services, is a priority in the SEND strategy.

3.2 The characteristics of autism spectrum disorder

3.2.1 One of the main characteristics of autism is difficulties with social interaction and communication. Another characteristic of autism relates to restricted and repetitive patterns of behavior, activities or interests. Some people with autism can display challenging behavior. This can include physically aggressive behaviour, but can also include other behaviours that have a negative impact on themselves or others.

3.2.2 It is recognised both nationally and locally that there is work to be done to improve public and professional understanding of autism. People with autism can experience social isolation, stigma or bullying.

3.3 The needs of autistic adults

3.3.1 A spectrum of needs

Autism is a spectrum condition, so whilst all autistic people share certain difficulties, being autistic will affect different people in different ways. For example, it is plausible (though it is not quantifiable) that only a small proportion of autistic adults will meet the eligibility threshold for support from adult social care. Feedback from staff is that high functioning people with autism can be at risk of falling “under the radar” of support services, which can then lead to preventable issues escalating unnecessarily.

3.3.2 Accessing and using care and support

Feedback at a national level suggests that people with autism do not always get the help they need from adult social care, and do not always have a positive experience. Locally, there are systems in place to help identify and support autistic people to get the support they need. There are two main ways that people are identified: Adults may have been diagnosed as children and be in contact with Children’s Social Care, in which case staff will work together to manage the transition to adult social care. Alternatively, the Tower Hamlets Autism Diagnosis and Intervention Service is there to help identify adults with autism who have not yet received a diagnosis. The total number of referrals (including self-referrals) for diagnosis since the start of the project to end of 2015-16 is 221⁴. Once identified, adults with autism are subject to the same eligibility criteria as everyone else in relation to receiving a care package. Despite this, records show that as of March 2016, less than

⁴ Tower Hamlets JSNA Factsheet – Adults with Autism Spectrum Disorder (2016) Peter Lamb

one per cent of the people receiving a care package from adult social care had autism⁵, although there may be issues with the accuracy of this data.

The 2014 Care Act introduced a legal duty on local authorities to provide preventative support in relation to adult social care. A range of services are funded with this in mind, including the post-diagnosis support offered to adults with autism by the Tower Hamlets Autism Diagnosis and Intervention Service. However, there is arguably less tailored preventative support available for adults with a pre-existing autism diagnosis.

3.3.3 Accessing and using health services

As well as having symptoms related to autism, people with the condition also suffer from the same general types of physical and mental health problems as everyone else in the community. However, because of their autism they are at an increased risk of ill health than the general population. For many people with autism, mainstream health services can be hard to access⁶. This can be due to a lack of understanding of autism among staff in those services but there are other contributory factors. Putting in place reasonable adjustments can ensure that adults with autism are able to benefit fully from mainstream health services to live independently and healthily.

The health community need to ensure that GPs, as the gatekeepers to diagnostic services and other referrers, such as mental health teams, have a good understanding of the whole autistic spectrum and the diagnostic pathway that has been developed in Tower Hamlets. This will enable adults with autism to be supported more effectively from the start of their assessment process.

3.3.4 Housing

Housing can play a vital role in supporting autistic people to maintain good health, independence and improve their quality of life.

A survey by the National Autistic Society showed that 49% of adults with autism still live with their parents⁷. This may reflect the fact that many autistic

⁵ The 2015-16 SALT return indicated that there were 15 adult social care users with autism as a reported health condition as of 31.3.16, out of approximately 3,500 adult social care users. It should be noted that there were approaching 3000 clients for whom no health condition was recorded. This may be an accurate reflection of the situation, but it is also possible that there are issues with staff recording this information on Framework-I (the client database used in adult social care)

⁶ Westminster Commission on Autism, Inquiry into Access to Healthcare for Autistic People 2016

⁷ Barnard, J. et al (2001). Ignored or ineligible? The reality for adults with autism spectrum disorders.

people require ongoing support into adulthood due to their needs or that support to help them live independently is limited. Secondly people with autism may also live in accommodation that is unsuitable for them e.g. in terms of environmental factors such as noise and space. Inappropriate housing can reduce their ability to live independently.

There is no supported housing, extra-care sheltered housing, residential care or nursing care provision in the borough that is targeted solely at autistic adults. There is no evidence available which indicates how many people need this now or are likely to need it in future. For this reason, an important first step is to build up a clearer picture of the housing-related support needs of autistic adults now and in future. This can then be used to decide what supported housing models might need to be developed in future.

Locally, the way that we meet the housing needs of autistic people in Tower Hamlets is currently undergoing change. The needs of autistic people living in the community in Tower Hamlets are addressed as part of the 2017-22 Tower Hamlets Housing Strategy. The new local Housing Strategy has specifically recognized the needs of people with learning difficulty and autism and contains a commitment to work to support the development of an Accommodation Plan for People with Learning Disabilities and autism.

3.3.5 Criminal Justice System

It is estimated that a disproportionately high number of prisoners have autism. Some studies suggest that between two and four per cent of offenders have autism⁸. Autistic people are also thought to be more likely to be a victim of crime, with one report suggesting that they are seven times more likely to experience this.

There are already a range of measures in place to help identify and support autistic people who are in contact with the criminal justice system. However feedback suggests there can be issues with these practices. There is also room for improvement in terms of how staff in the criminal justice system understand autism overall, and their knowledge of where to signpost or refer autistic people to in Tower Hamlets.

3.3.6 Employment

Autistic adults are significantly underrepresented in the workforce. Nationally, only 16% of autistic adults in the UK are in full-time paid

⁸ 'A Whistle-Stop Tour of ASD and vulnerability for involvement in criminality' (Richard Mills) September 2013

employment⁹. 32% of autistic adults in the UK are in any kind of paid work, compared to 47% of disabled people and 80% of non-disabled adults¹⁰. Only 10% of autistic adults receive employment support, but 53% say they want it¹¹.

Local employment levels for autistic people are not known¹². An employment support service is available for autistic people in the borough¹³. This support includes supporting autistic people to develop their CVs, support to search and apply for work, confidence-building, job coaching and training. The service also looks to build relationships with potential employers (for example, developing work placements) to expand work opportunities for people with autism. Between November 2015 and November 2016, the employment support service helped four adults with higher functioning autism into employment, helped six more to sustain their existing jobs, and helped three to go into higher education. The service helped 10 adults with lower functioning autism into employment¹⁴.

National and local feedback indicates that autistic people can experience a range of barriers in relation to employment. Recruitment processes can be daunting and difficult to get through and employers may not have a good understanding of how to make reasonable adjustments for autistic employees.

Carers of people with autism can also find it difficult to work. According to 'Ambitious about Autism', only 11% of carers of children with autism work full-time, whilst 70% say that the lack of appropriate care facilities stops them working.

3.4 Autism - National, local policy context

3.4.1 The 2009 Autism Act

⁹ National Autistic Society (2016) *The Autism Employment Gap*

¹⁰ National Autistic Society (2016) *The Autism Employment Gap*

¹¹ Bancroft et al (2012). *The Way We Are: Autism in 2012*. London: The National Autistic Society

¹² Employment levels for people with a mental health or mental health problem who are in contact with social care are recorded, but this does not specify if someone also has autism, and does not include employment rates for people who have autism only. In 2015-16, 4.9% of adults with a learning disability receiving long-term support were in paid employment, equating to 28 people. 4% of adults in contact with secondary mental health services are in paid employment, compared to 5% last year and an average of 7% across England. 93% are living independently, compared to 92% last year and an average of 59% across England.

¹³ The Tower Hamlets Jobs, Enterprise and Training service is commissioned by the Tower Hamlets Autism Diagnostic and Intervention Service to provide this service

¹⁴ Records are not kept as to how many adults with lower functioning autism have been supported into higher education, but the service estimates this to be about 10 people.

The 2009 Autism Act was the first ever disability-specific law in England. The law said that the Government must produce an autism strategy, and must set out what health and social care have to do to put the strategy into place. The government did this in 2010, and more details are set out below.

3.4.2 The national autism strategy

In the UK: The government first published an autism strategy in 2010, called 'Fulfilling and Rewarding Lives', in 2010. Since then:

- An updated autism strategy and a progress report has been published, most recently in 2016¹⁵.
- Government guidance setting out what local authorities and health services must do to meet the needs of people autism, most recently updated in 2015.

The strategy sets out 15 priority challenges for action.

In Tower Hamlets: A self-assessment to assess progress in Tower Hamlets against the national strategy was last completed in October 2016. This self-assessment identified a number of areas of good practice, and a number of areas for improvement. This strategy aims to ensure that we are working in line with the national autism strategy in Tower Hamlets, and to work on those areas identified through the self-assessment as areas for improvement.

3.4.3 The 2014 Care Act

In the UK: The 2014 Care Act introduced a number of legal changes to adult social care. These legal duties apply to all adults, including those with autism, and have largely been welcomed. Amongst other things, they mean that autistic adults and their carers should find it easier to find information and advice related to adult social care and should have access to services that help them stay as well as possible for as long as possible. If an autistic person or their carer has a significant need of care and support (as defined in the Care Act), they should receive this.

In Tower Hamlets: We put in place a programme of work to make changes following the 2014 Care Act. The changes that have been made apply to all adults. However, feedback indicates that we could do more to address the specific needs of adults with autism within the work we do. We also know that we could do more to support young people who are not yet 18 years old. This Strategy includes actions to address these issues.

¹⁵ <https://www.gov.uk/government/publications/progress-report-on-strategy-for-adults-with-autism>

3.4.4 The Transforming Care Programme

In the UK: The 'Transforming Care Programme' seeks to improve services and support for people with a learning disability and/or autism who display behaviours that challenge. One of the main aims of the programme is to replace more in-patient services with community-based services for this group, in the wake of things like the 2011 Winterbourne View scandal¹⁶. There are two main documents that describe the programme in more detail:

- 'Building the Right Support', which is the national plan setting out what needs to change¹⁷, and
- A 'Service Model'¹⁸, which sets out what good health and social care services look like.

Collectively, these documents want things to improve for people with autism who have challenging behaviour, so that there is:

- More choice for people and their families, and more say in their care;
- More care in the community, with personalised support provided by multi-disciplinary health and care teams;
- More innovative services to give people a range of care options, with personal budgets, so that care meets individual needs;
- More intensive, early support for those who need it, so that people can stay in the community, close to home;
- Things in place to make sure that people who need in-patient care only get this for as long as they need it.

In Tower Hamlets: The Tower Hamlets Clinical Commissioning Group – in partnership with others - is leading on the implementation of the Transforming Care Programme in Tower Hamlets, which is overseen by the regional Transforming Care Board. The intention is to continue to develop community-based services to prevent people with challenging behaviour being admitted to in-patient facilities, and to design these services so that they are person-centered in line with the Transforming Care Service Model.

3.4.5 Funding and resources

A number of public services are experiencing a restriction in resources in real terms. The local authority, for example, has been required to save £138 million between 2010 and 2016, and needs to save a further £58 million by 2020. This strategy has been written with an awareness that resources are restricted, and aims to put the resources available to public services to the best possible use.

¹⁶ Winterbourne View was a private hospital. In 2011, a BBC Panorama programme uncovered abuse taking place in the hospital.

¹⁷ <https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf>

¹⁸ <https://www.england.nhs.uk/wp-content/uploads/2015/10/service-model-291015.pdf>

4. CURRENT SUPPORT FOR AUTISTIC ADULTS IN TOWER HAMLETS

- 4.1 Tower Hamlets Autism Diagnosis and Intervention Service was established in May 2014 to diagnose autistic adults. It is part of the East London NHS Foundation Trust (ELFT) and is currently funded through the Better Care Fund¹⁹. The service offers a number of interventions to adults who have recently been diagnosed with autism. These can be psychological interventions, support with speech and language, or interventions from an Occupational Therapist or Social Worker. The service can also help with things like housing, benefits, social communication skills and independent travel training; and can refer people onto other services as appropriate. It should be noted that these interventions are available to adults after they have received a diagnosis: They are not available to adults with a pre-existing diagnosis.

Tower Hamlets Autism Diagnosis and Intervention Service commission the Tower Hamlets Jobs, Enterprise and Training (JET) service to provide employment-related support to people with autism in the borough.

- 4.2 Staff in a range of organisations in Tower Hamlets have been offered support and training in the past in relation to how they work with autistic people. The local authority has previously provided training, which has been targeted at Council staff. The Tower Hamlets Autism Diagnosis and Intervention Service has also provided training to staff at the East London NHS Foundation Trust and externally where requested. The service can also provide support to external professionals in relation to individual cases.

5. OUR AIMS AND OBJECTIVES

The aim of this strategy is to meet the ambition of national autism strategy for autistic adults in Tower Hamlets, so that:

All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents²⁰.

¹⁹ The Better Care Fund is an annual budget jointly held by the local authority and Clinical Commissioning Group.

²⁰ 2010 Adult Autism Strategy *Fulfilling and Rewarding Lives – Vision statement*

We have identified eight objectives in relation to this aim. We think these are the main areas we need to work on in order to improve things for autistic adults, based on research and feedback.

Objective 1: Help autistic to feel like part of their community

Main themes

- Autistic people may not feel like an accepted part of their local community and are more likely to feel socially isolated
- Staff who work for local organisations may not always understand autism, so may not always help people as much as they could.
- Many people with autism will not need specific support from health or social care, but they may still need others to understand how autism affects them
- Health and social care will tailor information for people with autism when we are asked to²¹, but general information provided by public services is not always easy for people with autism to understand.

What we will do

- We will use “World Autism Awareness Week” each year to raise awareness of autism. We will run a public awareness-raising campaign at this time to help combat stigma and discrimination around autism.
- We will encourage organisations to be “autism-friendly”, where quiet spaces with limited sensory distractions will be provided along with clear information. We will look to have these in GP surgeries, Idea Stores and One-Stop Shops to start with.
- We will offer training to staff who work for local organisations on autism. There are more details in Objective 4.
- We will provide good quality, online information and advice on autism that is available for everyone to read and make use of. We will develop this in partnership with those with autism.
- We will try harder to produce information and advice that is clear, useful and easy to understand for people with autism. We will do this with our partners where it is appropriate to do so.

²¹ In line with the NHS England Accessible Information Standard and our Accessible Information Policy

Objective 2: Help people with autism access good quality health and social care services

Main themes

- The Autism Diagnosis and Intervention Service in Tower Hamlets can diagnose autism and can help people following this diagnosis for a limited period of time.
- The Service is funded one year at a time through the Better Care Fund, which can make staff recruitment difficult.
- There may be a number of women and older people who have autism living in Tower Hamlets who have not yet been diagnosed as such.
- The number of people with autism who will need help from health and social care is likely to go up in future.
- Only a small number of people with autism are likely to need ongoing support from adult social care. However, many more may benefit from using the “preventative” services that adult social care funds.
- Social care services sometimes categorise people as having a “learning disability”, “physical disability” or “mental health issue”, and can struggle to know where to place people with autism
- Very few referrals to the Tower Hamlets Autism Diagnosis and Intervention Service come from adult social care at the local authority.

What we will do

- We will encourage more women, older people and people with English as a second language who suspect they have autism to come forward for an assessment. We will do this through awareness raising and training.
- We will support people with autism who have challenging behaviour through our ‘transforming care programme’. This includes offering support to people with challenging behaviour and their carers who are in a crisis²²
- We will aim to fund a Tower Hamlets Diagnosis and Intervention Service on a more longer-term basis
- We will change the role of the Tower Hamlets Diagnosis and Intervention Service so that interventions can be offered to someone with a pre-existing diagnosis of autism, and can be offered to them more than once
- We will offer person-centred social care and choice to those who are eligible for adult social care, including the offer of direct payments so that people can purchase their own care and support
- Through training, we will make sure that staff in *all* social care teams are able to

²² This could mean the provision of specialist challenging behaviour support. One model could be a team of senior support workers supervised by a behavioural psychologist. Respite provision could also be looked at.

support people with autism (not just the Community Learning Disability Service or Community Mental Health Teams)

- We will look into the idea of having 'peer mentors' for people with autism. They will have autism themselves, and can help others by doing things like going with them for appointments.
- We will encourage adults with autism to set up user-led support groups
- We will add information on services for people with autism, including autism-friendly universal services to online service directories, including the Community Catalogue in adult social care
- We will strengthen the links between the Autism Service and the Council so that staff are working more closely together. We want to see more referrals from the Council and other agencies being made to the Autism Service.
- We will identify a health lead to make reasonable adjustments to reduce barriers for autistic people accessing mainstream healthcare services and encourage the use of "annual health checks" with GPs for autistic adults.
- We will modernise day service provision for people with autism who have social care needs, so that services help people to be part of their communities through an increased focus on a more personalised, community focused approach. We will improve the information we record about people with autism in the borough
- We will work towards codesigning and coproducing support services to ensure they are accessible for autistic adults and their carers

Objective 3: Support autistic young people to transition into adulthood

Main themes

- Some young autistic people and their families can feel that there is less support available to autistic adults
- The criteria for being eligible for a support package from adult social care is different to the criteria used in children's social care. This can also result in some people experiencing an end to support once they reach adulthood
- For autistic young people who need ongoing support from adult social care, feedback is that adult social care staff do not always get involved at an early stage

What we will do

- Adult social care in the Council will work with children's social care, in line with The Transition Policy.
- We will work with children's services to ensure appropriate information on the transition pathway is clearly communicated to relevant stakeholders, including parent carers.
- We will work with the Children and Young People ASD Provider Network to strengthen multi-agency planning during the transition period from childhood to adulthood so that young people and their carers are aware of the support they will receive from adult service prior to their 18th birthday.

Objective 4: To raise people's skills and knowledge in relation to autism

Main themes

- Across Tower Hamlets, professionals may not always understand autism. They may not always help people with autism as much as they could, and sometimes may accidentally make things worse.
- Change can be unsettling for people with autism, and they may need particular help and support when going through a big change in their lives.

What we will do

- We will design new online training for professionals on how to work with autistic adults and make reasonable adjustments. We will work closely with autistic adults on this project.
- We will make sure that professionals know that they can contact the Autism Diagnosis and Intervention service for advice on case work
- We will offer training on autism to staff at the Council, Housing Associations, the Police, the Probation Service, and other local organisations
- We will offer training on autism to advocates in adult social care
- We will offer social skills training for adults with autism as part of a preventative offer of support in line with our duties under s2 Care Act 2014.
- We will offer other training to people with autism and their carers where this is needed – for example, training to help deal with challenging behaviour . We will offer this when a person is diagnosed with autism, and when they are going through a big change in their lives (e.g. going from being a child to an adult).

Objective 5: Help autistic people to find and keep work

Main themes

- People with autism are more likely to be out of work
- Some people with autism can find it difficult to get and keep a job
- Employers do not always understand autism, so do not always help people as much as they could.

What we will do

- We will try to make it easier for people with autism to apply for a local job. We will start by looking at how people apply for jobs in the Council and NHS.
- We will offer training to employers in the borough to help them understand what “reasonable adjustments” they can make. There are more details in Objective 4. We will also let employers know where they can go for more information²³.
- We will work to establish more opportunities for work experience for adults with autism in Tower Hamlets. This includes work experience in the Council and NHS.
- We will continue to support services to help people with autism in the borough find and sustain work, and will look at setting targets in relation to this.
- We will ensure Social Impact Bond (SIB) supported employment also works with autistic adults.

²³ For example: National Autistic Society resources or Trade Unions Congress (TUC) resources.

Objective 6: Help autistic people to live in good quality housing that meets their needs

Main themes

- The design of housing in Tower Hamlets will not always meet the needs of autistic people.
- Some people with autism may need to live in supported housing. At the moment, there is no supported housing in Tower Hamlets aimed at people with autism.
- Staff who work for housing associations may not always understand autism, so may not always help people as much as they could.

What we will do

- We will include autism in the Tower Hamlets Housing Strategy. This is to make sure that when new homes are designed and commissioned, the needs of those with autism are taken into account as much as possible. This will include supported housing and extra care sheltered housing (ECSH).
- We will offer training to staff who work for housing associations on autism. There are more details in Objective 4. Our aim is for each local housing office to have at least one member of staff who has received this training.
- We will work with colleagues to carry out the Accommodation Plan for People with Learning Disabilities (PWLD) and autism.

Objective 7: Reduce and improve autistic people's interaction with the criminal justice system

Main themes

- Autistic people are more likely to be offenders
- Autistic people are more likely to be the victim of a crime
- There are things in place to help identify and support people with autism who may have been arrested , witnessed or been the victim of a crime, but there is also room for improvement
- If an autistic person is suspected of a crime and needs an "appropriate adult" with them from social care, we are not always sending someone with the right knowledge of autism

What we will do

- We will develop Autism Alert cards. People with autism will be encouraged to carry these with them. They will set out the kinds of things that professionals need to be aware of when they are dealing with the person with autism.
- We will improve the provision of "appropriate adults" to the police for adults with autism. We will make sure that the police know to contact the Tower Hamlets Autism Diagnosis and Intervention Service if they need an appropriate adult for someone with autism
- We will offer training to staff in the criminal justice system on autism. There are more details in Objective 4.
- We will see if health and social care staff would benefit from being able to talk to a forensic psychologist if they are working with someone with autism who has been accused of or committed an offence, as part of our work on the Transforming Care Programme.

Objective 8: Help those who care for friends and family with autism

Main themes

- It can be difficult for carers to balance caring with work, and a lot of carers do not work
- It can be difficult for carers to manage the challenging behaviour some people have as part of having autism
- Some carers of autistic people can find it hard to have a life of their own

What we will do

- We will give carers and people with autism advice and information about short breaks and respite care in the home.
- We will help employers think about what they can do to support employees who are caring for someone with autism. There are more details in Objective 5
- We will offer carers training on how to deal with challenging behaviour as part of the planned Carer Academy
- We will let carers of people with autism know about Carer Needs Assessments in social care

6. HOW WE WILL MAKE THIS HAPPEN

We will set up an 'Autistic Adults Partnership Board'. This group can be made up of staff, people with autism and their carers. The group can make sure that this strategy is put into place. The group will meet regularly from spring 2017 onwards, and can develop a work plan to set out what specific actions will be worked on each year.

7. HOW WE DEVELOPED THIS STRATEGY

7.1 Research

We carried out research on the needs of autistic adults. We looked at national research and information, and local information. A key document was the "Autism Joint Strategic Needs Assessment", which sets out the needs of autistic adults in Tower Hamlets. This strategy aims to meet the needs identified in research.

7.2 Input from autistic adults and carers

We were keen to have as much input as possible from autistic adults and carers in Tower Hamlets. We advertised a focus group for autistic adults and

carers in December 2016. For people who were unable or preferred not to attend a focus group, we also advertised an online survey. The views and experiences we heard have driven the contents of this strategy. We are now committed to making sure we continue to work in partnership with autistic people and carers to put the strategy into place.

7.3 Input from staff

We talked to staff in a range of settings to get their views on what works well for autistic adults in Tower Hamlets and where things need to improve. We talked to staff in social care, health services, the criminal justice system, employment support and in housing. Their views have informed this strategy, and we are keen to continue to work with a range of staff through the planned Autistic Adults Partnership Board.

8. **OTHER STRATEGIES AND PLANS THAT ARE LINKED TO THIS**

This Strategy has close ties to the following strategies and plans in Tower Hamlets:

- The 2017-18 Tower Hamlets Strategic Plan
- The 2017-20 Health and Wellbeing Strategy
- The 2017 Carer Strategy
- The 2017 Aging Well Strategy
- The 2017 Housing Strategy
- The 2016-19 Children and Families Plan
- The Community Safety Partnership Plan
- The Special Education Needs and Disabilities (SEND) strategy (currently being planned).

When putting this strategy into place, we will work with an awareness of these strategies. This is to make sure that resources are put to the best possible use, and that there is no duplication of resource.

Appendix I: Feedback from autistic people and carers Gathered via an online survey (5 respondents) and focus groups (10 attendees) in December 2016

General

- People support the idea of staff training on autism and feel it is needed.
- Some people find the label “autism” useful. Others do not, and would actively seek to avoid it. As a result, there was a divide in opinion when it came to “Autism Alert” cards: Some people feel strongly that they would be useful. Others feel strongly that they do not want to use them. Those who like the idea of an Autism Alert card would also like to see IT systems “flag” the issue that a person has autism, so that they do not have to repeatedly explain themselves when contacting public services.
- Some autistic people may actively seek to avoid interaction with services (e.g. primary care). This could be due to previous negative experiences. This can cause problems in getting a diagnosis, and getting post-diagnostic support. Have to think through how to get support to these people.
- People would like to see form-filling that is brief and to the point

Health

- People suggested the idea of having annual Health Checks with GPs
- People suggested that autism awareness training be provided to health professionals, but also frontline staff (e.g. GP receptionists)
- People would like to see:
 - o The offer of home visits from GPs or community nurses for autistic people who cannot leave their homes
 - o Forms that are brief and to the point
 - o The offer of GP appointments that are longer than 10 minutes
 - o The offer of GP appointments at quieter times
 - o The offer of seeing a consistent GP
 - o A reduction in waiting times at the GPs
 - o GPs using visual diagrams (e.g. body diagrams, or a picture of the GP) to assist with communication
 - o Visitor parking permits for appointment times

Housing

- People like that they can reapply for housing on medical grounds
- People would like planning to consider:
 - o Access to space (e.g. gardens) for those who are housebound
 - o The risks posed by having an open-plan kitchen and living room (it can be easier for autistic people to access kitchen hazards)
 - o The risks posed by having balconies in high-rises
 - o The risks posed by having locks that are easy to unlock (it can lead to people wandering)
 - o Cluttered pavements that can be difficult to navigate through.

- Would be good for people to “make an effort” with their neighbours in order to get support from their communities.

Crime

- There was mention that the British Transport Police are good – people had good experience of them interacting with people with autism
- People would like to see:
 - o The system providing quiet and calm spaces for autistic people
 - o Criminal justice system staff using communication aids
- People raised the question as to when challenging behaviour becomes criminal behaviour
- People mentioned “mate crime” as an issue facing some autistic people.

Social Care

- A number of people recounted that they had received help whilst children, but that this had ended at the point of reaching adulthood. There was a feeling that resources are stretched and that little is available.
- People would like adult social care to consider:
 - o Providing people with a consistent Social Worker
 - o Staff sending a write-up of meetings after they take place
 - o The autism diagnostic service in Tower Hamlets providing support on a longer-term basis
 - o Providing support to combat social isolation for autistic people
 - o Supporting an occasional informal coffee morning in a safe, quiet space
 - o A drop-in service provided in a less formal way may be useful

Society

- It would be good to work with local shops so that staff are more aware of how to deal with autistic people and challenging behaviour.
- A peer-led group may be useful to establish.

Employment

- People would like to see:
 - o More work placements and employment opportunities for autistic people
 - o More CV preparation and interview training, more mentors
 - o Support for autistic adults on how to manage social situations at work
 - o Application forms that are as brief as possible
 - o Support with using public transport, recognising that people may struggle with employment if the travel there is stressful.
- One person mentioned a service in Camden, whereby employers with specific requirements are linked up with autistic people with specific skill-sets. People liked the idea of focusing on the special interests to autistic adults.