

## FOCUS ON:

# AUTISM IN ADULTS

NOVEMBER 2017

This assessment considers the needs of adults with autism in Islington:

- Across the autistic spectrum, focusing on those without a Learning Disability
- The needs of people who may not have a diagnosis or currently be accessing any services

Page numbers	Chapter
3 – 4	1 – Summary and Recommendations
5 – 10	2 – Background and Context
11 – 13	3 – Prevalence
14 – 19	4 – Needs and assets Each section presents national evidence followed by local service information and data
20 – 21	
22 – 24	
25 – 26	
27 – 28	
29 – 30	
31 – 32	
33 – 35	
36 – 37	
38	
39 – 40	
41 – 42	
43 – 44	
45 - 48	
49 – 34	5 – Recommendations and audit against the adult autism strategy requirements

# AUTISM NEEDS ASSESSMENT SUMMARY

NOVEMBER 2017

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'. 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 can learn and develop and with the right support be helped to live a fulfilling life of their own choosing.

This needs assessment focusses on the needs of adults with autism without a learning disability.

## Facts and figures

- The estimated number of adults with autism without a learning disability (LD) living in Islington is 1020. However, only a very small number are recorded as accessing services.
- The demand for diagnostic services increased by 49% between 2014/15 and 2015/16. As a result of this the waiting time for assessment is around 18 months (this is based on data from 2016/17).
- Men account for about 70 per cent of all referrals to Adult Autism Diagnostic Consultation Service (AADCS) (145 out 209) between 2013 and 2017.
- Asian ethnic groups referred for diagnosis are underrepresented at AADCS compared to the overall ethnic Asian profile in Islington (3% vs 10%).
- Under 34s account for the highest proportion of referrals to AADCS (48%).
- Many of the people accessing AADCS have a co-morbid mental health condition.
- The Islington Autism Project have identified that people with autism need support around social inclusion, housing and employment.

## Service provision and good practice

- There are a few specialist services in Islington providing support and care to adults with autism and their families.
- Within non-specialist services there is a lack of awareness of the needs of people with autism which creates barriers for this cohort.
- Specialist services include the short-term Islington Autism Project. It is a 1 year project from September 2016-September 2017, with a 6 month extension to complete community development work until March 2018.
- There are a few services in the local Voluntary and Community Sector, which include the Aspergers London Area Group, Resources for Autism and the National Autistic Society.
- Islington is working well with service users and family carers to understand local need and improve services.
- The Autism Partnership Board is a useful forum for services and experts by experience to work together and address the local needs of people with autism. They have set up a number of subgroups who are leading on the delivery of a local action plan for meeting the needs of people with autism.

## SUMMARY OF UNMET NEEDS AND RECOMMENDATIONS

This assessment has identified a number of needs which are currently not being fully met. These are presented below with the corresponding recommendation.

- There is a **lack of understanding of the numbers** of people with autism living in Islington and what services they are accessing. There is a need for all services across social services, NHS and VCS to record an autism diagnosis in order to improve our understanding of who in Islington has autism, what their needs are and how they can be met.

### Recommendation 1: Improve data collection and understanding of compliance with clinical good practice

- People with autism may find it hard to access many **mainstream services**, and staff are often ill-equipped to identify autism and make reasonable adjustments.
- There is a **lack of capacity and/ or specialism** in some services including Adult Social Care, Occupational Therapy, Speech and Language Therapy, diagnostic services, leading to long waiting lists and / or services being unable to offer the support needed.

### Recommendation 2: Improve the capability and responsiveness of services so that people with autism receive services which are able to adapt to meet their needs

- There is a **lack of transition pathway** for young people to move to adult services, which results in people losing the support that they need and an escalation in difficulties.
- **Females are under-represented** in those accessing diagnostic services compared to the general population.
- There are **few preventative** services that are available to people with autism . This means that people with autism are at increased risk of an escalation of physical or mental health conditions, increasing demand on services which could be prevented.
- There is a **lack of co-ordination and support across pathways**, and people with autism and their families can find it very difficult to navigate a support system populated by so many different agencies

### Recommendation 3: Review service provision with the aim of improving the ability to meet the needs of those with autism.

### Recommendation 4: Support engagement and collaboration with service users and their families

Work is already underway to meet some of these needs and others are addressed in the recommendations section. The recommendations will be owned and addressed by the Autism Partnership Board.

## DEFINITION OF AUTISM

- 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'
- 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 can learn and develop and with the right support be helped to live a 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,
  - 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".
- In this needs assessment, the term "autism" is used to refer to all parts of the spectrum. The phrase "people with autism" is also used, although we recognise that this will not be everyone's preferred terminology.

## POLICY CONTEXT

- **The Autism Act (2009)** established the requirement for the Government to produce a strategy for meeting the needs of adults in England with autism spectrum conditions by improving the provision of relevant services by local authorities, NHS bodies and NHS foundation trusts [1].
- The first autism strategy – ***Fulfilling and Rewarding Lives*** – was produced in 2010 [2]
- This was updated in 2014 and published as ***Think Autism*** [3]
- There are duties on local authorities and NHS bodies to act under the **statutory guidance** produced by the Government to accompany each strategy [4]

[1] Autism Act 2009 - <http://www.legislation.gov.uk/ukpga/2009/15/section/1>

[2] Fulfilling and rewarding lives -

[http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_113369](http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_113369)

[3] Think Autism - [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/299866/Autism\\_Strategy.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strategy.pdf)

[4] Statutory Guidance - [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/422338/autism-guidance.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf)

## SUMMARY OF DUTIES UNDER THE STATUTORY GUIDANCE

The Adult Autism Strategy outlined a number of duties for Local Authorities and the NHS. This needs assessment will look at how Islington is meeting these duties.

### Local authorities

... **Must** ensure that any person carrying out a needs assessment under the Care Act 2014 has the skills, knowledge and competence to carry out the assessment

... **Must** ensure that the duties under the Children and Families Act (2014) are applied where relevant to children and young people with autism and their families

... **Must** identify and develop resources that will prevent or delay the development of care and support needs of adults with autism and their carers (Care Act)

... **Must** identify the local care and support needs of people with autism and gaps in service provision (Care Act)

... **Must** provide access to advocacy provision where the person would have a significant difficulty in understanding the assessment and care management process (Care Act)

... **Must** ensure that the assessment and care planning process for adult needs for care and support considers participation in employment as a key outcome, if appropriate

... **Should** ensure that there is a meaningful local autism partnership arrangement that brings together different stakeholders locally, including the CCG, and people with autism

... **Should** allocate responsibility to a named joint commissioner / senior manager for commissioning services (autism lead)

... **Should** bring partners together, for example through Health and Wellbeing Boards, to ensure information sharing protocols are in place and that all necessary information for service planning is available

## SUMMARY OF DUTIES UNDER THE STATUTORY GUIDANCE

### NHS bodies

... **Should** ensure they are involved in the development of local workforce planning, and GPs and primary care practitioners are engaged in the training agenda in relation to autism

... **Should** provide access to an autism diagnostic and treatment pathway including those who do not have a learning disability

... **Should** designate a health lead responsible for developing, maintaining and promoting a diagnostic and treatment pathway

... **Should** ensure that in commissioning health services for persons in prison and other forms of detention prisoners are able to access autism diagnosis in a timely way

... **Should** ensure that Liaison and Diversion services have in place a clear process to communicate the needs of an offender with autism to the relevant prison or probation provider

... **Should** work in partnership so there is a substantial reduction in reliance on inpatient care for people with autism

### LAs and NHS bodies jointly

... **Should** ensure the existence of a clear trigger from diagnostic to local authority adult services to notify individuals of their entitlement to an assessment of needs

... **Should** work together to put in place a locally agreed joint plan to ensure high-quality care and support services for all people with challenging behaviour, including autism

## THE NEEDS OF PEOPLE WITH AUTISM – NATIONAL ASSESSMENT

The NAS research report *I Exist* (2008) surveyed 1400 adults with autism (with and without learning disabilities) and their families. They found that adults with autism are often isolated, unable to access support and are dependent on their families [1]. The report states that:

- 63% of adults with autism do not have enough support to meet their needs
- 92% of parents are either very worried or quite worried about their son or daughter's future when they are no longer able to support them
- 60% of parents say that a lack of support has resulted in their son or daughter having higher support needs in the longer term
- 61% of adults with autism rely on their parents financially
- 40% live with their parents
- 33% have experienced severe mental health difficulties because of a lack of support
- Only 15% are in full time employment
- 66% are not working at all (including voluntary employment)
- 67% of Local Authorities do not know how many adults with autism are in their area
- 65% of Local Authorities do not know how many adults with autism they support”

## OVERVIEW OF KEY ORGANISATIONS AND SERVICES



The above diagram features an overview of key services in meeting the needs of adults with autism and their families and carers. It is based on the duties set out within statutory guidance and national strategies. This needs assessment will look at the local provision of these services.

## NATIONAL PICTURE: PREVALENCE

- Autism is believed to affect approximately **1 in 100** people in the UK
  - Leo Kanner’s original conception of the condition in the 1940s emphasised its rarity, and it was estimated to affect only 2-4 per 10,000 of the population [1]
  - Since then, our understanding of autism has developed, with changes to diagnostic criteria and the incorporation of other parts of the spectrum, including that described by Hans Asperger in the 1940s.
  - The definition of autism has broadened and diagnosis rates have increased significantly, with some estimates of population prevalence as high as 1.5% [2]
  - There is disagreement about the cause of this increase; whilst it could be explained solely through changes to diagnostic criteria and improved awareness and detection, some have suggested that actual prevalence may also have increased in this period.
- It is estimated that autism is between 4 and 9 times more common in men than women [3]:
  - However, there is increasing recognition that women are often misdiagnosed or missed due to different presentation and stereotypes about autism [4]
- Autism affects **all ethnic and socio-economic groups**
- It is estimated that around half of people with autism have a **learning disability** (IQ below 70), and around half do not:
  - A review undertaken in 2010 found substantial differences in estimates of the prevalence of LD between different studies among people with autism, and settled on a lower estimate of 40% and a higher estimate of 67% for its modeling [5]
- The most **common co-morbidities** for people with autism are mental health conditions; although different studies have calculated different figures, up to 70% of people with autism also meet the diagnostic criteria for at least one other mental health condition [6]

[1] Wing, L., Potter, D (2002) The Epidemiology of autistic spectrum disorders: is the prevalence rising? *Developmental Disorders Research Reviews* 8:3 pp51–161

[2] Baron-Cohen et al. (2009) Prevalence of autism-spectrum conditions: UK school-based population study. *British Journal of Psychiatry*, 194 (6) pp 500-509

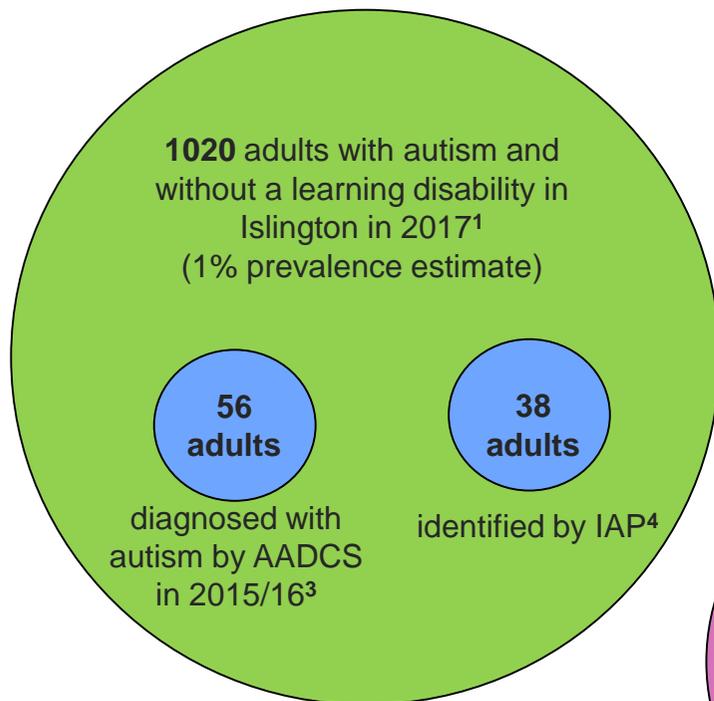
[3] 4 times: NICE Guidance <https://www.nice.org.uk/guidance/qs51/resources/support-for-commissioning-for-autism-253717885>, 9 times: British Psychiatric Survey

[4] Statutory Guidance to support the implementation of the adult autism strategy - [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/422338/autism-guidance.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf)

[5] Emerson, E., Baines, S (2010) *The estimated prevalence of autism among adults with learning disabilities in England*. Improving Health and Lives [http://www.improvinghealthandlives.org.uk/uploads/doc/vid\\_8731\\_IHAL2010-05Autism.pdf](http://www.improvinghealthandlives.org.uk/uploads/doc/vid_8731_IHAL2010-05Autism.pdf)

[6] <https://www.nice.org.uk/guidance/cg128/chapter/introduction> - mainly anxiety, ADHD and oppositional defiant disorder

## THE LOCAL PICTURE: PREVALENCE



- There is no local data on the numbers of people with autism without a learning disability (LD) in Islington. This lack of data is not unique to Islington.
- Prevalence estimates suggest that there are 1020 adults with autism without an LD living in Islington in 2017.
- Statutory services are only able to identify a small proportion of the estimated population of people with autism in Islington: 56 receiving a diagnosis from AADCS and 38 people accessing the Islington Autism Project (IAP). The rest may be:
  - Undiagnosed .
  - Diagnosed and accessing services, but their diagnosis not known by the service.
  - Known to services (including their diagnosis) but not recorded in a way which can be reported.

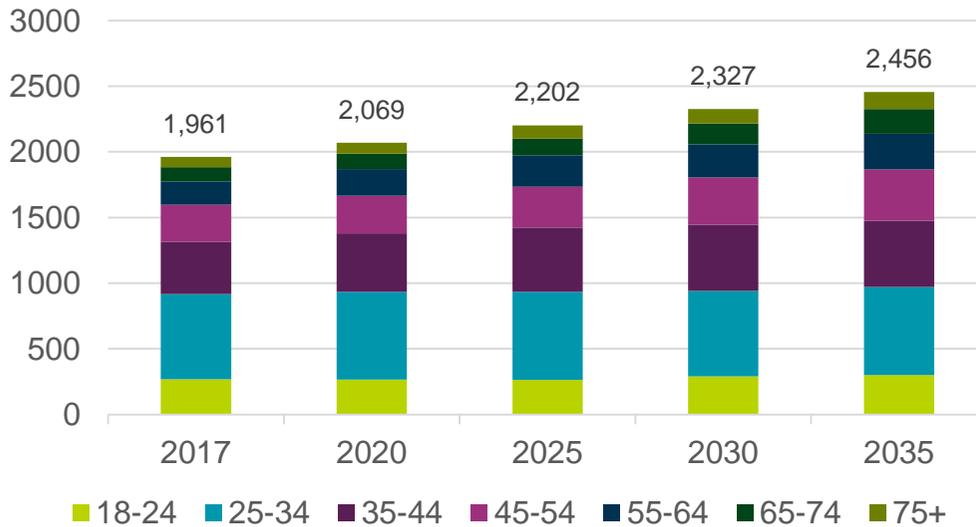
- Given the spectrum nature of autism, the needs of this group will vary considerably. We cannot tell how many of those not known to services might benefit from them.
- Within the local authority, there are no records of adults with autism without a LD accessing services. This reflects the fact that processes for recording diagnoses of autism are better developed in LD than in Mental Health, Physical Disabilities and Older People teams. Although there are no records outside LD services, it is likely that some adults with autism do receive services for social care, but it is not possible to identify why.
- Children's services do have recording systems in place for autism, and in 2017, there were 528 children with autism known as having Special Educational Needs and Disability (SEND).

1. PANSI and POPPI calculated autism prevalence estimates based on the Adult Psychiatric Morbidity Survey in 2007. Using modelling of autism prevalence that suggests that between 40% and 67% of people with autism have an LD [1], we used a mid point of 52% of the PANSI and POPPI estimates to estimate the number of people with autism and without a learning disability.
2. Children's services, 2017
3. Camden and Islington Community Mental Health and Primary Care Division, 2017.
4. Islington Autism Project, September 2016 – July 2017

[1] Emerson, E., Baines, S (2010) *The estimated prevalence of autism among adults with learning disabilities in England*. Improving Health and Lives [http://www.improvinghealthandlives.org.uk/uploads/doc/vid\\_8731\\_IHAL2010-05Autism.pdf](http://www.improvinghealthandlives.org.uk/uploads/doc/vid_8731_IHAL2010-05Autism.pdf)

## THE LOCAL PICTURE: FUTURE NEED

### Estimated population with autism in Islington from 2017 to 2025



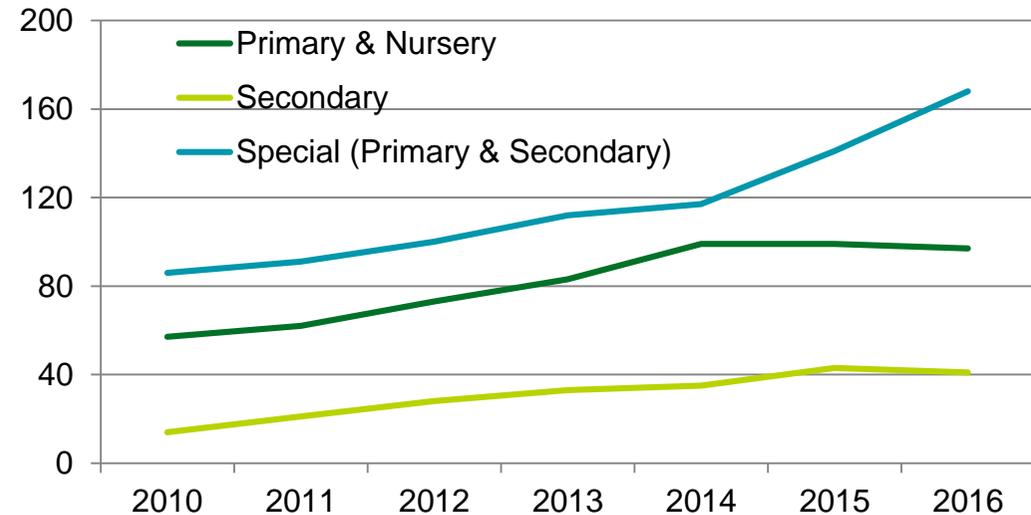
### Estimated population with autism, age 14-17 2017-2025



- The number of young people (14-17 years old) diagnosed with autism only (with no learning disability) is projected to increase from 102 in 2017 to 130 in 2025 (30% increase).
- About 10% of these were expected to be of a high need and it is likely that this group will transition into adult social care.

- PANSI and POPPI calculated autism prevalence estimates based on the Adult Psychiatric Morbidity Survey in 2007. These include people with LD.
- Using these rates, the estimated number people with autism (both with and without an LD) in Islington is estimated to rise from 1,961 individuals in 2017 to 2,202 individuals in 2025.
- The greatest percentage increase will be in those age 65-74, increasing 73% between 2017 and 2025

### Number of pupils with autism by level of education in Islington, 2010-2016



- There has been a substantial increase in the number of pupils with statements or Education and Health Care (EHC) plans for autism from 157 pupils in 2010 to 306 pupils in 2016 (95% increase).
- An increase in children and young people with autism will mean that in future years there will be an increased demand on transition and adult services.

**Source:** Children's services (2017) – estimated population, age 14-17, with autism was calculated by the Camden and Islington Public Health department

## DIAGNOSIS

- As awareness of autism has increased, so have rates of diagnosis. There is also some evidence that diagnostic substitution has taken place, with people previously given diagnoses of Learning Disabilities now being recognised as having autism[1].
- However, there are still significant numbers of people with autism but without a diagnosis:
  - Baron-Cohen found only 2 of 3 children with autism in primary schools had received a diagnosis [2]
  - Diagnosis rates are believed to be particularly low for some parts of the population, including women, adults and older people, and people from BME groups
- Diagnosis is important for a number of reasons:
  - It may facilitate access to benefits, specialist services and support, or adapted mainstream services
  - Especially for those diagnosed in later life, it can be a relief and provide an explanation for challenges and difficulties they have faced, as well as providing a framework for understanding triggers which can help inform adjustments to make every day living more comfortable
  - Lack of diagnosis can contribute to a range of conditions including anxiety, depression and prolonged stress due to lack of explanation of symptoms, and behaviour not being understood by others
- Statutory guidance based on the Autism Act states that CCGs should commission a local diagnostic pathway, and should work closely with the local authority to provide post-diagnostic support
- Nationally, there are long waits to receive diagnosis
  - In a recent report, 69% of parents said they had waited more than a year to get a diagnosis for their child after first raising concerns, and 16% had waited more than three years [3]
  - In 2015 the National Autistic Society reported average waits of two years for adults [4]
  - Neighbouring boroughs have waits of up to a year in their locally commissioned pathways for adults

[1] Polyak, A., Kubina, R.M., Girirajan, S. (2015) Comorbidity of intellectual disability confounds ascertainment of autism: implications for genetic diagnosis. *American Journal of Medical Genetics B Neuropsychiatric Genetics*. 168(7):600-8

[2] Baron-Cohen et al. (2009) Prevalence of autism-spectrum conditions: UK school-based population study. *British Journal of Psychiatry*, 194 (6) pp 500-509

[3] School Report (2016) NAS <http://www.autism.org.uk/get-involved/media-centre/news/2016-09-02-school-report-2016.aspx>

[4] <http://www.autism.org.uk/~media/nas/documents/get-involved/autism%20diagnosis%20campaign%20briefing.ashx>

## THE LOCAL PICTURE: DIAGNOSIS

There are two different diagnostic pathways for people with and without a learning disability (see next slide).

### **Camden & Islington Adult Autism Diagnostic and Consultation Service**

- People who don't have a global learning disability are referred to the Camden & Islington Adult Autism Diagnostic and Consultation Service (AADCS) for assessment. This service has been available since 2013.
- AADCS operates one day a week providing thorough diagnostic assessments and consultations to residents of Camden and Islington. The team consists of a Consultant Psychiatrist (2 x 0.1 wte), Clinical psychologists (2 x 0.2 wte) and an administrator (1 x 0.5 wte).
- The service was originally commissioned to deliver 80 assessments per year across both Camden and Islington, which is 6.7 referrals per month. However, the service currently has capacity to deliver 5 assessments a month (60 referrals a year) across Camden and Islington due to loss of funding for a care coordinator as they were unable to recruit to the role.
- Referrals from mental health professionals are immediately triaged and processed by the AADCS. Referrals from GP's or other professionals are triaged and assessed by the Assessment and Advice Team to ensure that immediate mental health needs are addressed and treated. If indicated and appropriate, the AADCS will place the service user on the waiting list.
- Service users who are currently in-patients are immediately placed on the waiting list. Staff liaise with in-patient staff to ascertain if the service user is currently well enough to undergo an assessment and if so, they are seen as soon as possible.
- A screening process at referral was piloted, however, due to the complex presentation of patients seeking an assessment it did not prove to be effective at screening out patients and is no longer in use.
- The diagnostic service offers one follow-up appointment after a detailed assessment has been completed. The service does not have the capacity to offer further substantial adjustment interventions.
- A service review is currently being undertaken by commissioners.

ADULTS WITHOUT LD

Initial referral

Assessment and Advice Teams

Screen referral and assess if indication of other MH difficulties

Referral to ASC diagnostic clinic

No ASC

Signpost to other services

Diagnosis

Information, psychoeducation, advice and signposting

Referral on to existing MH or specialist psychological intervention where appropriate

Feedback to referrer/ GP and service user

ADULTS WITH LD

Initial referral

CLDS Autism screening

Meets criteria

Discussion and Psychology and make referral

- Offer full assessment
- AD-I carried out by clinical psychologist
- Observations carried out by SLT/OT

Diagnosis

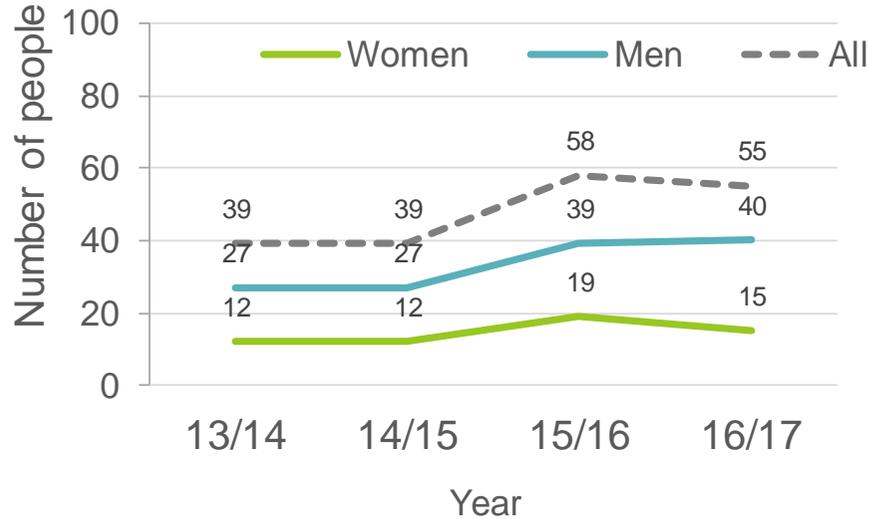
- MDT meeting: OT SLT, Psychology, Social Worker, Community Nurse to determine care plan
- Formal meeting with person and family to share outcome and advice
- Report completed with risk assessment/ care plan/ further assessment
- Further referrals may include sensory needs assessment, speech and language assessment, carers assessment

No diagnosis

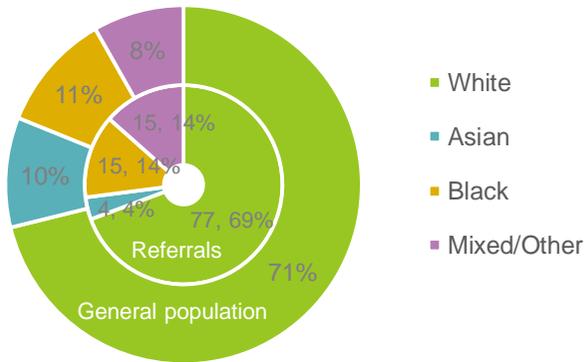
- Does not meet criteria
- Feedback to referrer and service user
  - Signpost and advice

# THE LOCAL PICTURE: ADULT AUTISM AND DIAGNOSTIC CONSULTATION SERVICE

## Referrals to AADCS (16+) by sex, 2013/14 to 2016/17



## Referrals to AADCS (16+) by ethnicity, 2013/14 to 2016/17

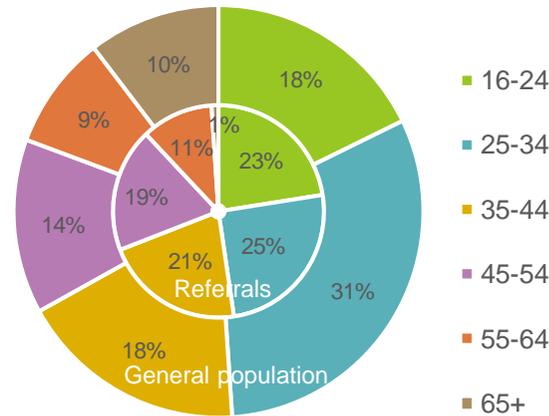


People (16+) from the Asian population had significantly lower referrals when compared to the overall ethnic Asian profile Islington (4% vs 10%).

Source: Camden and Islington Community Mental Health and Primary Care Division (2017)

- Men account for about 70 per cent of all referrals (133 out of 191) between 2013/14 and 2016/17. It is being increasingly recognised that autism in women is under-diagnosed, and services need to investigate how to improve access for women.
- There was a 49% increase in the number of referrals to AADCS 2014/15 and 2015/16.
- In 2016/2017 the service received an average 4.6 referrals per month, which is higher than the commissioned service capacity.

## Referrals to AADCS (16+) by age compared to the general population, April 2013 to March 2017



- 48% of those referred are aged 34 years or younger.
- Compared to the overall general population in Islington there is a larger than expected number of 16-24 year olds referred (23% vs 18%), but less than expected number of 25-34 year olds (25% vs 31%).

- Older people (65+) referred are underrepresented; 1% of referrals for older people (65+) compared with 10% of older residents (65+).

Note: 80 people referred (42% of total referred) didn't have a recorded ethnicity and were excluded from this analysis.

## THE LOCAL PICTURE: ADULT AUTISM AND DIAGNOSTIC CONSULTATION SERVICE

Snapshot of AADCS people seen and diagnostic rates for people living in Camden and Islington in 2015/16\*

Camden and Islington	2015/16
Number of referrals	126
Number assessed	71
Autism diagnosis rate	56%
Average waiting times	18 months

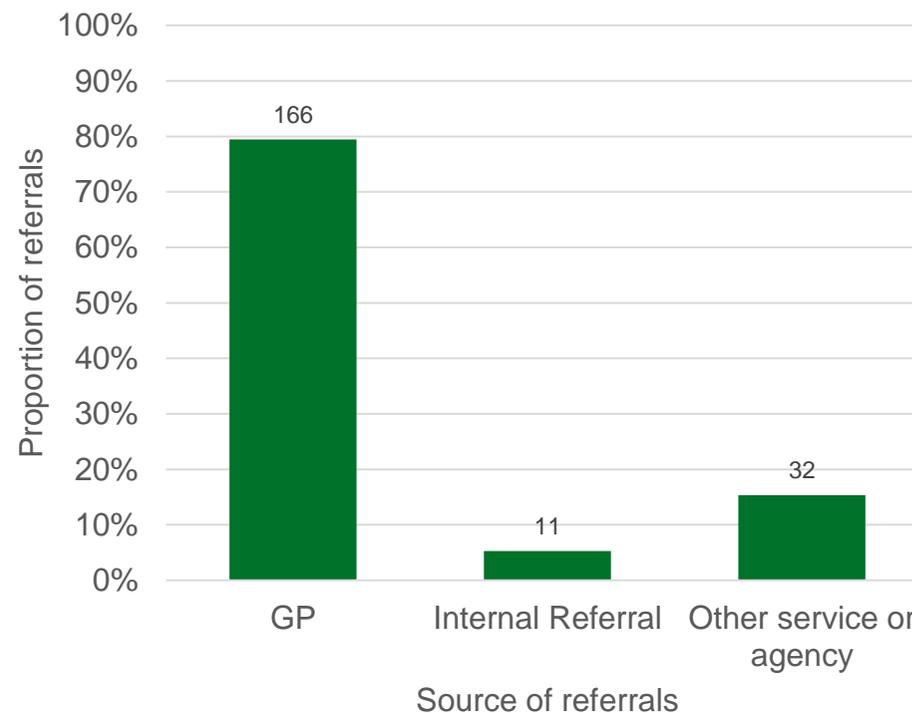
\* We do not have this information by borough

- Due to higher than commissioned demand for the service, an 18 month waiting list for the service was reported in 15/16 which remained in 16/17.
- In 2015/16 71 out of 126 referrals were seen due to the higher than commissioned demand for the service. The diagnostic rate was 56%.

### Co-morbidities

- In a report from October 2015 AADCS identified 70% of people diagnosed with autism as having a co-morbid diagnosis or additional needs but not a formal diagnosis. These additional diagnoses include:
  - ADHD (40%)
  - Depression (40%)
  - Anxiety including OCD (30%)
  - Personality disorder (10%)
  - Mild learning disability (10%)
  - Dyslexia or Dyspraxia (10%)
  - Psychosis (10%)
- 60% of service users were referred on to mental health services for treatment of co-morbid mental health problems. These included iCope, Psychotherapy Service, Personality Disorder Service, Speech and Language Team, ADHD Service, the Lifespan Service at the Tavistock, or other services such as Remploy and Social Services.

Number and proportion of referrals per referral source, Islington population, 2013-17

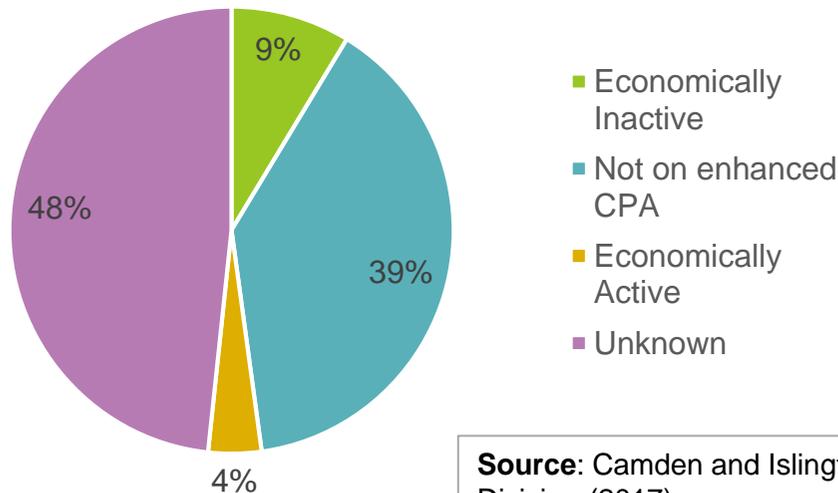


The vast majority of people (79%) were referred to AADCS by their GP. Other sources of referral included adult mental health inpatient services, social services and self-referrals.

## THE LOCAL PICTURE: ADULT AUTISM AND DIAGNOSTIC CONSULTATION SERVICE

### Economic activity

#### Economic activity of patients accessing AADCS, Islington, 2013/14 to 2016/17



**Source:** Camden and Islington Community Mental Health and Primary Care Division (2017)

- AADCS were only able to record the economic activity of those who are on the Care Programme Approach (CPA), which is for those who have a severe mental illness (SMI). Therefore unknown accounted for about 87% of the economic activity data.
- 9% of people accessing the service were on CPA and known to be economically inactive. Of this group, 80% were long term sick or disabled, the equivalent of 15 people.
- Despite the proportion of unknown economic activity, the long term sick or disabled proportion of patients with autism is larger than that in the general Islington population.

### What local people think

- In their review of services (see slide 44) for people with autism, Healthwatch spoke to 35 people about the diagnostic pathway and processes. Their feedback included:
  - The process of receiving a diagnosis took too long, with little communication about the expected wait time.
  - Some people feel like the process of getting diagnosis is a 'battle'. Some people think that this is due to funding arrangements.
  - There is a lack of information and support during diagnosis.
  - However, not everyone reported difficulties.

## TRANSITIONS

- The process of transition has been developed in recent years in response to the “cliff edge” faced by many children in the past moving from the support received while in education to adulthood, since they no longer get services.
  - It should ensure continuity of services, as well as co-ordination between a young person’s health, education and care needs, which should all be considered during the transition planning phase
- Transition planning should be a multi-agency process, and should include consideration of benefits, further education, higher education, employment, health issues, transport, housing, leisure opportunities, social care services, direct payments and individual budgets
- Not every child with autism is automatically eligible for a transition plan. However, their care needs should be assessed by the local authority if there is a chance they will meet the national eligibility criteria for care:
  - Their needs arise from or are related to a physical or mental impairment or illness AND
  - This makes them unable to achieve two or more specified outcomes (including maintaining personal hygiene, managing toileting, maintaining relationships to prevent loneliness, accessing and maintaining employment, keeping the home clean and safe etc) AND
  - As a result of being unable to meet these outcomes, there is likely to be a significant impact on the adult’s wellbeing
- Transition planning is crucial to the prevention of escalating needs.
- All young people with autism, regardless of their eligibility for a formal transition plan, are likely to benefit from planning around key aspects of life as an adult, including:
  - Help with facing and planning for adult life
  - Specialist and ongoing employment support
  - Peer support and opportunities to spend time with others with the same diagnosis
  - Voluntary work placements in setting where autism was understood and accommodated [1]

## THE LOCAL PICTURE: TRANSITIONS

- The remit of the current transition team does not include young people with autism who do not have a learning disability.
- Assessment of young people with a diagnosis of autism but not a global learning disability is at the request of parents/others.
- Education Health and Care Plans (EHCPs) are in place for some young people with autism without an LD, but there is no input from adult social care / health teams. However, not all young people with autism without an LD have an EHCP, and this is likely to increase as the eligibility for EHC's diminishes.
- The Islington Autism Project (IAP) have been offering some support to this group (see slides 46-47). As of July 2017 the project team were case managing 6 young people in order to carry out assessments and transition planning. This is unsustainable because IAP is a short-term resource.
- IAP have identified a significant number of individuals who have struggled with transition to adulthood. The project team have found:
  - high levels of unemployment and limited expectations for the future
  - high levels of social isolation and risky use of the internet
  - lack of support in colleges
  - admissions to acute mental health services, suicidal ideations and suicide attempts
- In July 2017 the Autism Partnership Board discussed what would help young people and their families during transition. Key areas that were identified:

### Schools / education

Higher expectations around employment potential, whilst recognising people need support to prepare for work and maintain it

More effective use of apprenticeship schemes

Strengthening employment in EHCPs - currently these are very education-focussed

Education for schools and parents about autism – including educating children

### Transitions

A transitions service for people with autism  
Timely transitions assessments by experienced and qualified staff

A clear and transparent transition pathway with responsibilities and timeframes

YP and their families should know what to expect from this pathway

### Prevention

Supporting families and young people at the right time (preventative)

Understanding amongst commissioners of how the needs of young people can be met, thinking about prevention and early intervention

### Local Offer

Better communication and joint-working between all agencies

Access to advocacy for young people

Better use of community services

Ensuring people know what services are out there

Improved eligibility criteria for services to stop people falling through the gaps

Better use of peer support

### Clinical needs

Better understanding of people's sensory needs – requires an enhanced OT service that can also work in mainstream schools and with adults

Health input from adults services to sign off / support EHCPs

### Adult Services

Availability of formal support, where appropriate, post 18. Without this, there's nowhere to transition to, there isn't anybody to receive the transition plan

Improved engagement and understanding amongst adult social care and health

Adult assessment tools that are appropriate for people with autism

## HEALTH NEEDS

- People with autism have the same health needs as other people in the population, but are also at higher risk for some conditions, as well as often requiring reasonable adjustments to enable them to access health services
- **Physical health** – people with autism have higher rates of many physical health conditions than the general population, including epilepsy, diabetes, stroke, respiratory conditions and heart disease. Autistic adults die on average 16 years earlier than the population average, and 30 years earlier for those with autism and a learning disability[1].
- **Mental health** – as many as 70% of people with autism also meet the diagnostic criteria for at least one other (often unrecognised) mental and behavioural disorder, and 40% for at least two. Most commonly these are anxiety, attention deficit hyperactivity disorder (ADHD) and oppositional defiant disorder (ODD) [2]. Other studies have found high rates of anxiety and depression, especially during late adolescence and early adulthood [3], suicidal thoughts [7] and suicide [1].
- NICE recommends that for adults with autism and a mental health condition, the NICE guidelines for treating the mental health condition be followed, with modifications to make them more effective and accessible to people with autism. Similarly, Research Autism finds strong evidence for the effectiveness of adapted CBT [4].
- **Accessing health services** – people with autism may struggle to access health services for a number of reasons, including:
  - Limited communication, or difficulties explaining health needs when put on the spot
  - Not being taken seriously / symptoms being dismissed as “autistic behaviours” rather than signs of co-morbid conditions [1]
  - Difficulties being in health care settings, due to sensory overload (e.g. Bright, electronic lights, noisy equipment etc)
- The Westminster Autism Commission recommended autism awareness training for health professionals, annual health checks and routine recording of autism by GPs to improve the health of people with autism [6]
- **Co-ordination of health services** – because people with autism often have multiple health professionals involved in their care it is recommended that each person should have a care co-ordinator or case manager to co-ordinate care across different professions [5]

[1] Cusak, J et al (2015) *Personal Tragedies, public crisis: the urgent need for a national response to early death in autism*. London: Autistica

<https://www.autistica.org.uk/wp-content/uploads/2016/03/Personal-tragedies-public-crisis.pdf>

[2] Simonoff E, et al. (2008) Psychiatric disorders in children with autism spectrum disorders: prevalence, co-morbidity and associated factors. *Journal of the American Academy of Child and Adolescent Psychiatry* 47: 921–9.

[3] Tantum, D., Prestwood, S. (1999) *A mind of one's own: a guide to the special difficulties and needs of the more able person with autism*

[4] <http://researchautism.net/autism-interventions/our-evaluations-interventions/15/cognitive-behavioural-therapy-and-autism>

[5] <http://www.nhs.uk/Conditions/Autistic-spectrum-disorder/Pages/Treatment.aspx> . It should be noted that NICE does not recommend this model for children, and calls for further research into its effectiveness, but does recommend it for adults in its Guideline on Diagnosis and Management of autism in Adults -

<https://www.nice.org.uk/Guidance/CG142>

[6] [https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011\\_ncg-autism-report-july-2016.pdf](https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011_ncg-autism-report-july-2016.pdf)

[7] Cassidy, S. et al (2014) Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome. *The Lancet Psychiatry* 1:2, 142-147

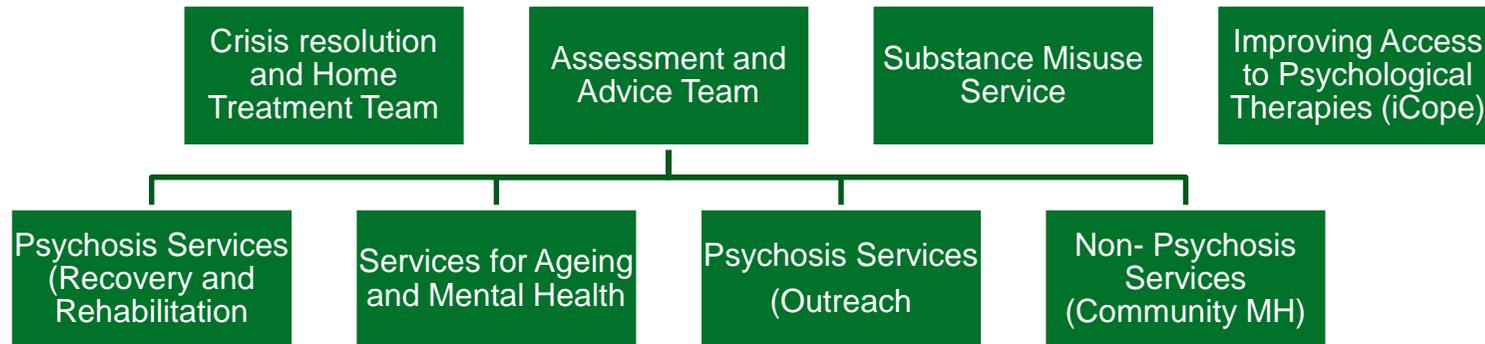
## THE LOCAL PICTURE: HEALTH NEEDS

- Despite the recognition that people with autism have higher rates of physical health conditions than the general population in national studies and reports, we do not have local data on these health needs.
- Currently GP practices do not routinely record (code) a diagnosis of autism.
- We do not have any local data which looks at hospital admissions for people with autism.
- There are no adapted health services in Islington for people with autism, however, all services are required to make reasonable adjustments.
- Healthwatch identified a number of challenges for people with autism and their families/ carers accessing health services during their engagement in 2016 (see slide 44). These included:
  - Difficulties accessing services.
  - Services are not flexible enough to meet the needs of people with autism. People report that appointments are difficult to make and not long enough.
  - Waiting areas are not autism friendly.
  - There is lack of understanding of autism amongst staff and communication needs are not met.
  
  - People with ASC and their families/ carers would like:
    - Services to be more prepared for appointments.
    - Services to make reasonable adjustments and support people with autism to access services.
    - Autism friendly waiting areas.
    - Appointments times to be flexible with longer slots.
    - Professionals to adapt their communication style to meet the needs of people with autism.

## THE LOCAL PICTURE: MENTAL HEALTH SERVICES

- Mental Health Services are available for those with a comorbid mental health condition, such as obsessive compulsive disorder, attention deficit hyperactivity disorder, psychosis, anxiety or depression.
- Improving Access to Psychological Therapies (IAPT) service and other local secondary mental health services should make reasonable adjustments for people with autism, however, people with autism have reported that accessing these services is difficult.
- At present we do not have local data on access to MH services.
- iCope and substance misuse services do not record autism diagnoses.

### Camden and Islington Mental Health Foundation Trust Services: Overview of services provided



## THERAPEUTIC NEEDS

- People with autism often experience difficulties and delays in development and everyday functioning which can be alleviated through the use of therapies.
- For children, early provision of suitable therapies is believed to make a big difference in ability to communicate, learn and be independent.
- In England, the NHS provides two therapies to children (and some adults) – Occupational Therapy (OT) and Speech and Language Therapy (SLT). A range of agencies, including schools, therapists, voluntary sector and private sector providers may deliver other interventions, including Applied Behavioural Analysis (ABA), vision therapy and social skills classes.
- NICE guidelines recommend only psychosocial interventions such as social skills classes for treatment of the core symptoms of autism in children, and emphasise that all children with autism are individuals and their care should be individually tailored [2]; it is likely this is because the range of interventions offered under the banner of OT, ABA or SLT is too great to be able to generalise about effectiveness [3].
- A survey of American parents of children with autism asked which therapies worked best for their child, and found these four therapies were the most commonly mentioned [1]:
  - Occupational therapy by 39% of respondents
  - Speech and language therapy by 27% of respondents
  - ABA by 15% of respondents
  - Social skills classes by 8% of respondents

[1] <https://www.autismspeaks.org/blog/2012/09/25/top-8-autism-therapies-%E2%80%93-reported-parents>

[2] <https://www.nice.org.uk/guidance/cg170>

[3] <http://researchautism.net/autism-interventions/our-evaluations-interventions>

## THE LOCAL PICTURE: THERAPEUTIC NEEDS

- AADCS offers at least one follow-up appointment which includes psychoeducation. The service does not have the capacity to offer substantial adjustment interventions.
- If appropriate, the service will refer people on to the Lifespan Service who offer psychotherapy. However, this is only open to people who are under the care of a community mental health team, and a recent change in eligibility criteria mean that very few people can access this service.

### **Occupational Therapy**

- When an adult with autism and without LD is assessed as having eligible occupational therapy needs, adults are referred to reasonably adjusted services. However, people with autism without an LD or mental health condition report difficulties accessing these services.
- OTs attached to either learning disability or mental health teams aren't able to work with people who aren't allocated to their respective team.
- However occupational therapists (OTs) in Adult Social Care teams are specialists in equipment and adaptations relating to physical disabilities and mobility problems, and not in other difficulties – such as wider life-skills as a result of the individual's autism. This can present challenges in accessing the relevant expertise for this group of clients. Clinicians at AADSC service report difficulties in referring people with autism to an occupational therapist with the appropriate expertise.
- There is a need for specialist OT sensory integration Assessments that no other Team (aside from LD) are commissioned to carry out.

### **Speech and language therapy (SLT)**

- Clinicians at AADSC can make referrals to mainstream speech and language therapy services who make reasonable adjustments for people with autism. However, people with autism without an LD or mental health condition report difficulties accessing these services.
- Camden and Islington Mental Health Foundation Trust offer individual SLT service to adults with autism and a mental health diagnosis who are current users of C&I MH Foundation Trust, i.e. they're either:
  - Care coordinated in the community by one of the local MH teams
  - an inpatient on a psychiatric ward
  - attending a Recovery Centre
- If they don't meet the above criteria they are not offered individual SLT.

### **Social Communication Group**

- A social communication group is available to those with a diagnosis of autism without learning disabilities with underlying mental health conditions.
- The focus is on social learning tasks for everyday communication within work and social situations, which improves social interaction.
- Groups run 2 or 3 times a year, meeting once a week for 5-6 weeks at Goodinge Health Centre.
- Referrals are considered on a case-by-case basis, but generally are available to individuals who are not currently receiving a service from the MH Trust, but have a MH problem or are vulnerable to developing MH difficulties.
- From 1/1/16 – 1/1/17 9 people from Islington were referred to the group.
- Many adults are not eligible for this group but still need something similar.

## SOCIAL CARE

- Social care for adults is generally divided into four strands:
  - Physical disabilities
  - Learning disabilities
  - Mental health
  - Older people
- Nationally this has meant there is a gap in service provision for adults with autism who may have substantial care needs but who do not fall into one of these. The Care Act (2014) requires Councils to meet the needs of people who have eligible needs but may not fall into one of these groups.
- Under statutory guidance accompanying the national autism strategy (2014) local authorities cannot refuse a care assessment for adults with autism on the basis of IQ (i.e. that they don't have a learning disability) – this aims to break down the traditional silos described above
- The statutory guidance also sets out the level of specialist knowledge and skills around autism which assessors ought to have, including:
  - how autism may present across lifespan and levels of ability, and are defined and diagnosed, and the relevant pathways and screening tools
  - the common difficulties faced by individuals on the spectrum and their families/carers, including social and economic hardship
  - the impact of autism on personal, social, educational and occupational functioning, and interaction with the social and physical environment
  - current good practice guidelines (e.g. NICE Quality Standard 11) and local diagnostic and care pathways
  - current good practice guidance with respect to an individual with autism's capacity to assess risk [1].
- For those who do not meet eligibility thresholds, there should be advice and signposting to other sources of support and guidance
- Additionally, the Care Act places new responsibilities on councils around prevention and wellbeing which apply not only to those eligible for services but also to those for whom the development of eligible needs could be prevented.

[1] <http://network.autism.org.uk/knowledge/policy-guidance/what-does-care-act-mean-people-autism-spectrum>

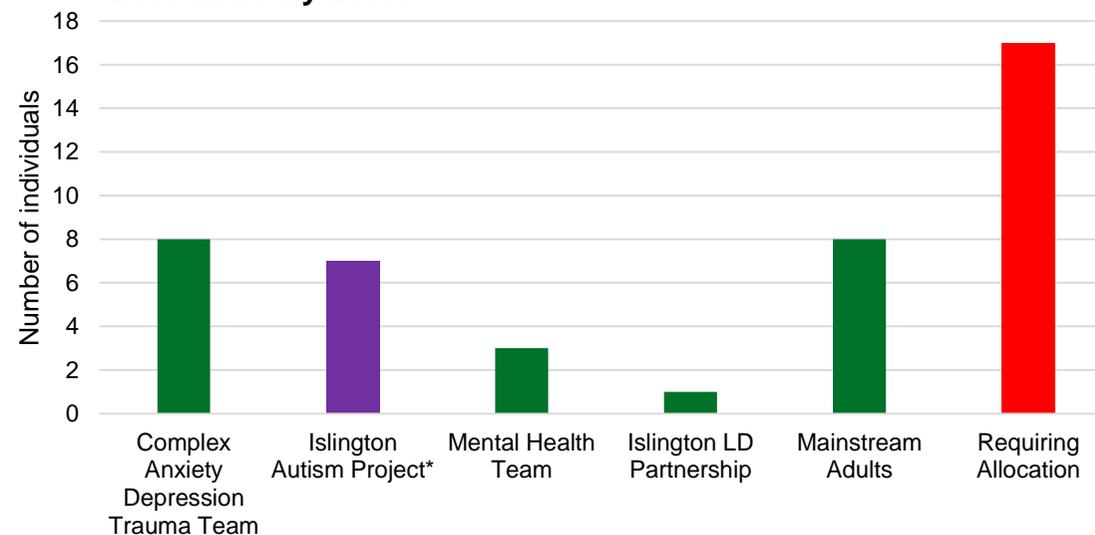
## THE LOCAL PICTURE: SOCIAL CARE

- Adults with autism are eligible for an assessment for mainstream adult social care services. However, there is not a specific team within adult social care that works with people with autism without a learning disability, and access to social care services is a challenge for this group.
- There are concerns that social care assessments do not adequately capture the needs of people with autism. A common issue in assessments has been an underestimation of people’s social and communication needs. This means that people are often deemed ineligible for services, despite having needs to be addressed.
- Of the 38 individuals known to IAP, a large number of people are awaiting allocation to a team.
- **20** require a social care assessment and **18** need support planning.
- Referrals ‘bounce’ around teams due to:
  - Inappropriate referrals to learning disability or mental health teams
  - Individuals are identified as a low priority for assessment and are put on waiting lists. However in some cases this delay in assessment has resulted in escalation of needs to the point of crisis.
- IAP also have observed that:
  - The skillset in mainstream adults service is focussed on older people and/or people with a physical disability.
  - Social care assessments underestimate people’s social and communication needs, which results in people not being eligible for services
  - There is no access to a transition team for people without a learning disability
  - There is a lack of access to support for individuals and carers to understand pathways
- IAP have recommended that social care assessments are improved by allowing more time (conducted over more than one sitting) to get an understanding of an individual’s needs. They also need to consider social and communication difficulties.

### Adult Social Care data collection

- For those who receive adult social care services, records are incomplete.
- Autism is not recorded within adult social care systems, and therefore it is not possible to identify those with autism without an LD who are accessing services.
- As part of the SAF in March 2016, 172 people were identified in Housing and Adult Social Care, however, all of these people also had a learning disability.
- A solution to this is currently being investigated by the Housing and Adult Social Care data manager as part of the APB data sub-group work.

**Team allocations for those accessing IAP between September 2016 and July 2017.**



## TRAINING AND EMPLOYMENT

- Depending on the needs and abilities of individuals, a wide range of **training** could be appropriate; this could range from the development of life skills to support; independence (as recommended by NICE); apprenticeships or higher education.
  - Tailoring to both the needs and the existing strengths of the individual is essential to delivering successful outcomes in terms of both increased independence and employment.
  - Genuinely tailored opportunities may require additional investment e.g. to set up a work experience placement in a setting in which the person with autism is comfortable rather than with existing partners, but should be more effective in the long term
- People with autism are substantially disadvantaged in the **employment** market:
  - Only 16% of adults with autism are in full time paid employment, 16% are in part time work [1]
  - 77% of unemployed people with autism want to work, and 40% of those who work part time want to increase their hours [1]
  - 26% of graduates with autism are unemployed, the highest percentage for any disability group [2]
  - People with autism face a number of barriers to employment, including:
    - Lack of understanding of autism by employers, and lack of knowledge to make reasonable adjustments
    - Difficulties handling sensory and social aspects of the work environment
    - Workplace bullying and discrimination
    - Difficulties managing change in the workplace, and the need for additional support through change [5]
- NICE guidelines recommend supported employment programmes for those without significant learning disabilities who are struggling to obtain or maintain employment
  - Work Choice and Access to Work are national services to help disabled people to work
  - A number of methodologies, including Individual Placement Support, Prospects and ProjectSEARCH have been evaluated and found to be effective and cost effective [3] [4] [6] for people with autism
  - A specialist agency – [Specialisterne](#) – has been successful placing people with Asperger’s in IT companies

[1] National Autistic Society (2016) *Too much information: the autism employment gap* - <http://www.autism.org.uk/get-involved/tmi/advice.aspx>

[2] Data from AGCAS Disability Task Group, in <https://www.theguardian.com/tmi/2016/jun/24/breaking-down-the-barriers-to-employment-for-autistic-people>

[3] Mavranouzouli, I., et al (2014). The cost-effectiveness of supported employment for adults with autism in the United Kingdom. *Autism*, 18(8), 975–984.

[4] Schall, CM et al (2015) Employment interventions for individuals with ASD. *Journal of Autism and Developmental Disorders* 45:3990-4001

[5] [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/210683/rrep846.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/210683/rrep846.pdf)

[6] Mawhood, L, Howlin, P (1999) The outcome of a supported employment service for high ability adults with autism or Asperger’s Syndrome. *Autism* 3:229-54

AND Howlin, P. et al (2005) An 8 year follow up of a specialist supported employment service. *Autism* 9:533-49

## THE LOCAL PICTURE: TRAINING AND EMPLOYMENT

- Asperger's London Area Group Members report a need for support in dealing with reasonable adjustments at work.

**The Autism Partnership Board has an employment sub-group who have set out an action plan for 2017/18. Their objectives include:**

- Build a knowledge base about people with autism in Islington and establish a baseline
- Improve the pathways from education to employment
- Increase the number of people with autism in good jobs (London Living Wage, right support, development, etc) which suit them
- Change the culture and systems so that it is "normal" and easy for Islington residents with autism to be in employment.

The subgroup has been mapping the training and employment offer for people with autism in Islington. There are a number of services which people can access for training and employment support, however, the numbers of people accessing these services identified as having autism are very low.

### Universal services

**Job Centre Plus** coaches have all received training on hidden disabilities, including autism. Additionally Disability Employment Advisors provide support and information to the work coaches. The Employer Advisors work with employers to promote Disability Confident and show employers the benefits that employing people with a range of disabilities can give.

**iWork (Islington Council)** works with individuals who have been out of work for six months or more. iWork coaches help people to develop the skills and confidence they need to find and keep a job. They also help people to find training, volunteering, apprenticeship or other additional support such as debt or benefits advice. Islington Council is also supporting local businesses, through the London Workplace Charter, to become healthier workplaces to support people to stay in work.

**IPS**  
Employment specialists based in GP surgeries or community clinics supporting people with a long term health condition and/ or disability to find employment. It is based upon 'Individual Placement and Support' (IPS) principles which include time unlimited support to both the employee and employer, rapid job search tailored to the individuals preferences, and integration with the patients clinical treatment where possible.

### Services for people with LD/ Autism

**Scope** works with individuals with a disability. They offer 121 support through the recruitment process and group-based training sessions..

#### Project Search

City & Islington College are running a Project Search with Great Ormond Street Hospital for people aged 18 – 25. It is a full time academic year long programme which consists of 3 10 week internships at the hospital. Participants have support of a job coach.

**Community Access Project** offers a time limited 1-1 support service for people with LD to reach specific outcomes. They have worked with some clients who were referred by the Islington Autism Project who have autism but not an LD.

**Hillside Clubhouse** is a partner in Camden and Islington's Mental Health Working flagship with Remploy and Twining Enterprise. They support people with a mental health problem to prepare for, find, and stay in employment.

**National Autistic Society** train employers and provide support to employees

## HOUSING

- Across all parts of the autism spectrum, accessing suitable housing can be a challenge:
  - For those with substantial complex needs, residential care or supported accommodation may be designed to meet the needs of those with severe learning disabilities or physical health problems but not specifically for people with autism
  - Those with an intermediate level of need may not qualify for (enough) funding to make independent living possible, and family carers may end up shouldering a significant burden of care throughout a lifetime
  - For those with less significant needs, the general shortage of affordable housing can create a barrier to independence and leaving the family home, even where the person has the skills and confidence to do so
- In 2012, 38% of adults with autism lived with their parents – and of these half would have liked to live in their own home (either supported or independently) [1]
- Whilst many parents and other family members may be happy to provide care within the family home on a long term basis, there is often significant concern about what will happen when they are no longer able to do so (and some may not be willing or able)
  - “If anything were to happen to my husband, well, within days I wouldn’t be eating or I would be eating wildly inappropriately... Within weeks I would no longer be washing or leaving the house or communicating at all with the outside world, and I’d know something was very wrong, I just wouldn’t know what to do to make it any better... Even if I get no worse than I am at the moment, I’m not going to be able to cope, so that would mean not even supported living, but residential care, and that’s a dreadful prospect” [2]
- Housing and associated support can be paid for in a number of ways:
  - Housing benefit can cover the cost of rent, often from a social landlord
  - Adult Social Care can pay for the care and support needed to function in a residential setting (which could be a family home, an independent tenancy or a residential care home)
  - For those with the most complex needs, accommodation and care costs are met from Continuing Health Care funds (the provision of support either in a family home or in a care home)

[1] Bancroft K, Batten A, Lambert S, Madders T (2013) *The way we are: autism in 2012*. The National Autistic Society. London

[2] Getting On? Growing Older with Autism (2013) National Autistic Society <http://www.autism.org.uk/get-involved/campaign/campaign-archive-to-be-actioned/getting-on-growing-older-with-autism-campaign.aspx>

## THE LOCAL PICTURE: HOUSING

- There is a lack of information about the housing situation of adults with autism in Islington. At present, autism is not recorded on housing systems, and so if people with autism have a need it is not always identified, unless they let housing know directly.
- It is likely that there are a significant number of people with autism living in social housing.
- The needs of people with autism are not currently considered in Islington's housing strategy.
- Housing can offer reasonable adjustments and support if they are aware of support needs.
- If Housing Operations identify support needs at any time during a tenancy they make support referrals to various organisations, including children and adult social care, drug and alcohol and mental health services
- Of the 38 people in contact with IAP, 20 had difficulties related to their housing. These included:
  - Sensory issues: Due to sensitivities to noise some people with autism can find living in noisy environments difficult. The Anti-social Behaviour (ASB) team have clear indicators for noise and ASB (e.g. noise recorders that quantify noise), however, someone with autism may be particularly sensitive and find that they cannot cope with noise that is below this threshold.
  - Activities of daily living: some people need support to cook, eat, wash, manage bills, or attend appointments.

### **Ongoing work to address the needs of people with autism:**

- Housing teams are looking into how they can identify and record autism to enable them to develop their offer.
- Housing operations and repairs are currently setting up some training on autism awareness for staff so that they are better able to identify support needs and know what to do if needs are identified.

## MAINSTREAM SERVICES

- Whilst specialist services are important, much of the time people with autism are likely to be accessing mainstream services, and these can be made more accessible and autism friendly.
- Mainstream services include most NHS health services, most Council services, as well as a range of services offered by the private sector (e.g. leisure and shopping)
- For statutory services, at a minimum, the National Autism Strategy requires that all staff in health or care roles should have autism awareness training and should know how to make reasonable adjustments [1]
- For non-statutory services, there is no requirement to ensure staff are trained but autism awareness training is available from a number of providers and could be incorporated into standard equalities and diversity training.
- The National Autistic Society has developed an “Autism friendly” accreditation for mainstream services and has published guidelines on how to meet it, which include actions in the following five areas [2]:
  - customer information
  - staff and volunteer understanding
  - physical environment
  - customer experience
  - promoting understanding

## THE LOCAL PICTURE: MAINSTREAM SERVICES

### Islington Council Services

- Islington Council is committed to ensuring that its services are universally accessible to all groups in the community.
- People with autism who don't have a learning disability make contact with the Council through the central access team. The access team have had training in autism awareness and are able to signpost people with information from the Council's local offer website. The access team are also currently able to refer people with a primary need of autism to IAP for more specialist information and signposting (although this is a short-term service)
- Islington has an accessible information policy and has recently updated its website to make information more accessible.
- Resident impact assessments are completed for any proposed changes to services or when new services are introduced. This ensures the implementation of any reasonable adjustments necessary to ensure equality of opportunity and compliance with the Equality Act 2010.

## THE LOCAL PICTURE: AUTISM AWARENESS TRAINING

- A key strategy in improving access to services is to train staff in autism awareness and how to make reasonable adjustments.
- Islington has coproduced an e-learning training on autism awareness. However, it is not accessible to all sectors outside of the local authority, and does not cover reasonable adjustments. The Islington Autism Project are working with the Learning and Development Team to update this.
- The SAF reports that 10 autism awareness courses took place over 2015/16 and reached 222 learners.
- Although not all primary and secondary healthcare providers receive specific autism training, the Camden and Islington Foundation Trust held 2 autism training courses in 2016 and have further courses planned throughout 2017. The courses are open to all trust staff, Camden and Islington council staff and VCS organisations working in both boroughs.
- In 2017 Islington Council provided a number of courses, delivered by the National Autistic Society. These included:
  - Supporting people on the autism spectrum through social care assessments (for teams carrying out social care assessments): 1 session, 12 delegates attended
  - Supporting people on the autism spectrum – the spell framework (for anyone who wants to understand autism and strategies to support people): 2 sessions, 52 delegates attended
  - Understanding the autistic spectrum framework (for anyone who wants to understand autism and strategies to support people): 2 sessions, 44 delegates attended
  - For all sessions except one (which we do not have data for), the attendees were from Housing and Adult Social Care. Of 47 people, 36% were residential care workers; 30% were social workers; 11% were case managers; 9% were senior practitioners.

## SOCIAL SUPPORT

- Alongside needs for more traditional services, people with autism can benefit from a range of social support services.
- In the NICE guidance for adults with autism, the only recommended treatments for core symptoms are psychosocial interventions [1], for example:
  - Group-based or individual learning sessions focused on improving social interaction
  - Autism-tailored anger-management
  - Anti-victimisation interventions based on teaching decision-making and problem-solving skills
  - Employment support programmes
  - Social support, facilitated group leisure activities and peer support
- NICE guidance also suggests:
  - “Where there are gaps in availability of psychosocial support, CCGs may need to work together with the local authority to commission additional interventions... Some individually tailored psychosocial support may be needed to help people with autism to develop their social, communication and life skills”
- In 2008, the National Autistic Society’s survey found that “The biggest gap between the types of support people want and what they actually receive is in the area of social support”
  - Such support could include befriending, social programmes, social skills and life skills training
  - 82% of respondents said that with more support they would be less isolated

[1] <https://www.nice.org.uk/Guidance/CG142>

[2] / *Exist* (2008) National Autistic Society

## THE LOCAL PICTURE: SOCIAL SUPPORT

- Residents can search the online Islington directory of services to find out about local support. Searching for ‘autism’ and adults comes up with 25 results, however, many of these are for people with learning disabilities. Services include day opportunities, residential services, peer support groups and services provided by the VCS.
- Case reviews have led IAP to believe there is a limited specialist and reasonably adjusted community offer. This significantly impacts on people’s ability to self-manage and leads to an escalation of difficulties experienced.
- IAP have mapped the local offer for people with autism. In partnership with the AADST, they have developed a signposting leaflet to give to people following diagnosis. The services that they signpost people to include:

Service	Offer	Contact
<b>Asperger London Area Group (ALAG)</b>	A monthly support group for high-functioning adults with Asperger's syndrome living in the Greater London area. The group meets on the first Tuesday of every month in Islington.	<a href="http://www.alag.org.uk">www.alag.org.uk</a>
<b>Au Struck- Social group for adults in North London</b>	A weekly group, which aims to improve confidence and practice social situations that members may find difficult. Every other week the group go out on a trip in the London area. The group is open to people who have Asperger Syndrome or High Functioning Autism.	<a href="http://www.resourcesforautism.org.uk">www.resourcesforautism.org.uk</a>
<b>National Autistic Society</b>	Provide information for individuals and friends/families of individuals who have received a diagnosis of an autism spectrum condition.	<a href="http://www.autism.org.uk">www.autism.org.uk</a>
<b>Resources for Autism</b>	Offers practical support for children and adults with an autism spectrum condition. Their work with adults includes running social groups, art groups and one-to-one support through the befriending service.	<a href="http://www.resourcesforautism.org.uk">www.resourcesforautism.org.uk</a>

- People with autism are able to self-refer to these services, and can contact them by telephone, online or by attending the groups.
- Following their recent engagement activity, Healthwatch made a recommendation for a single point of contact for support and signposting for people with autism.
- IAP have also made a recommendation to set up an Autism Hub: A place where isolated people can make contact with others and begin to build relationships, get information and advice and seek support in crisis. Because of the nature of autism, people want to know where it is, what it looks like and know they will be understood by those inside.
- Through the Autism Partnership Board, IAP are developing this proposal. A key feature is that it will be user-led.

## PREVENTION

- Although the symptoms and deficits of autism may be life-long, appropriate support can make the condition easier to live with.
- We already know that people with autism are at significantly greater risk of serious mental health conditions than the population as a whole.
- Statutory guidance gives the following rationale for preventative support [2]:
  - Lack of early help can lead to spiraling mental health crises with families left to pick up the pieces of expensive and inappropriate hospital inpatient admissions or even contact with the criminal justice system
  - Preventive support can help people with autism better manage stressful events (bereavement, marriage, divorce, workplace conflict) which may have a more significant effect on them than they would on others
  - Prevention is a duty built into section 2 of the Care Act – including for those who do not (currently) meet the eligibility threshold for care and support
- NICE guidance suggests that investment in services for people with autism can lead to reductions in GP appointments, fewer emergency admissions and less use of mental health crisis services
- Research by the National Autistic Society suggests that high rates of mental illness among people with autism may be caused, in part, by a lack of preventive support [1]:
  - 67% of respondents experienced anxiety as a result of lack of support
  - 33% of respondents experienced serious mental health problems due to lack of support
  - NAS also states that “Our survey data demonstrates clear demand from autistic adults for what could be described as “preventive services” such as employment support or help with social skills – those services that are low level and less intensive in nature, but which can help prevent the development of more complex needs over time” [4]

**IAP have identified that preventative support is often unavailable, especially for people who don't meet social care thresholds.**

[1] *Exist* (2008) National Autistic Society

[2] Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/422338/autism-guidance.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/422338/autism-guidance.pdf)

[3] NICE support for commissioning for autism (2014). <https://www.nice.org.uk/guidance/qs51/resources/support-for-commissioning-for-autism-253717885>

[4] NAS guidance on implementing the autism strategy - <http://www.autism.org.uk/autismstrategyguide>

## THE CRIMINAL JUSTICE SYSTEM

- There is a lack of research on the prevalence of autism among people in the criminal justice system, especially in the UK, but what exists suggests that people with autism are overrepresented:
  - American research in the 1990s suggested that people with autism were seven times more likely to have contact with the Criminal Justice System than the general population, while another study found prevalence in the incarcerated population of up to 4.4% [1]
  - In 1998 it was estimated that 2% (i.e. twice the estimated national prevalence) of people in secure Psychiatric establishments had autism [2]
- The National Autistic Society has produced guidance for interacting with people with autism for police and those working in the Court system [3], and there is also specialist advice available for barristers [4]
- Under the national autism strategy, local authorities have a responsibility to assess the needs of their residents in prison and ensure support is in place for them [5]
- A review by Birmingham City Council identified the following as the most important factors to reduce the number of people with autism who enter in the criminal justice system [6]:
  - Early diagnosis of autism which gives access to support services;
  - Training of the majority of frontline police officers in autism awareness;
  - Offering fixed activity routines (wherever possible, paid employment) to people with autism that could fill much of their day, that they will feel safe doing, which would minimise the risk of other people exploiting their vulnerabilities;
  - Enabling them to know where and how to obtain advice and support services when needed, particularly around the various transitions in their lives;
  - To develop a social care advice, guidance and coaching pathway to which courts could divert autistic offenders as an alternative to giving them criminal convictions.
- One English prison – YOI Feltham – has been accredited as “autism friendly” by NAS

[1] Curry, K., Posluszny, M. and Draska, S. (1993) *Training Criminal Justice Personnel to Recognize Offenders with Disabilities*. Washington, DC: Office of Special Education and Rehabilitative Services News AND Fazio, RL et al (2012) An Estimate of the Prevalence of Autism-Spectrum Disorders in an Incarcerated Population. *Open Access Journal of Forensic Psychology* 2012:69-80

[2] Hare JL (1998) *A Preliminary Study of People with Autistic Conditions in three Special Hospitals in England*. London: National Autistic Society

[3] <http://www.autism.org.uk/cjs>

[4] <http://www.theadvocatesgateway.org/images/toolkits/3-planning-to-question-someone-with-an-autism-spectrum-disorder-including-asperger-syndrome-2016.pdf>

[5] <http://www.autism.org.uk/about/strategy/practical-guidance.aspx> - Criminal Justice section

[6] Birmingham CC Overview and Scrutiny (2012) Adults with Autism in the Criminal Justice System

## THE LOCAL PICTURE: CRIMINAL JUSTICE SYSTEM

### Liaison and Diversion Services

- Liaison and Diversion (L&D) services are intended to improve health and justice outcomes for adults and children who come into contact with the youth and criminal justice systems where a range of complex needs are identified as factors in their offending behaviour.
- NHS England, DH, MoJ and YJB agreed a standard service specification and ten trial schemes (wave 1) were initially selected nationally to operate the model, from April 2014. From April 2015, 13 more sites were selected and became the second wave of services funded to operate under the new specification (wave 2). L&D service providers focus on identification, screening and assessment of individuals, advice, referral, short-term interventions, data-collection, monitoring and safeguarding.
- Camden and Islington are part of wave 2, which consists of three clusters and involves three NHS Trusts (Central and North West London NHS Foundation Trust, Barnet, Enfield and Haringey Mental Health NHS Trust and West London Mental Health NHS Trust) and a voluntary sector organisation, Together for Mental Wellbeing.

### Aims:

- Improved access to healthcare and support services for vulnerable individuals and a reduction in health inequalities
- Diversion of individuals, where appropriate, out of the youth and criminal justice systems into health, social care or other supportive services
- To deliver efficiencies within the youth and criminal justice systems
- To reduce re-offending or escalation of offending behaviours

### The service provision includes:

- **Identification:** Criminal justice agencies working at the Police and Courts stages of the pathway are trained to recognise possible signs of vulnerability in people when they first meet them. They then alert their local L&D service about the person.
- **Screening:** Once someone is identified as having a potential vulnerability, the L&D practitioner can go through screening questions to identify the need, level of risk and urgency presented. It also helps determine whether further assessment is required.
- **Assessment:** Using approved screening and assessment tools an L&D practitioner will undertake a more detailed assessment of the person's vulnerability. This provides more information on a person's needs and also whether they should be referred on for treatment or further support.
- **Referral:** The L&D practitioner may refer someone to appropriate mainstream health and social care services or other relevant interventions and support services that can help. A person is also supported to attend their first appointment with any new services and the outcomes of referrals are recorded. L&D services will also provide a route to treatment for people whose offending behaviour is linked to their illness or vulnerability.
- Across wave 1 & 2 sites in London 129 adults were identified with suspected autism in 2016/17
- In Camden and Islington 18 adults (7 Camden; 11 Islington) were identified as having suspected autism and 14 had another suspected social or communication difficulty in 2016/17. Of those screened, 27 engaged with L&D for an assessment.
- Their ages ranged from 18 to 65 and the majority were male. 48% were White and 52% were from BME groups or not stated.

## THE NEEDS OF FAMILY CARERS

- The majority of care for children and adults with autism is provided by family carers [1].
- Family carers often receive little or no support for their caring responsibilities:
  - In 2008, NAS found that 76% of carers were not receiving any support from their Local Authority [2]
  - In the same study 68% had not received a carers' assessment [2]
  - In 2001 the APPG on Autism calculated that the benefits received by family carers were insufficient to cover the costs incurred in caring for a child with significant needs due to autism [3]
- A recent review found strong evidence that short term support programmes, including NAS EarlyBird can improve parental wellbeing [6]
- 92% of parents are either very worried or quite worried about their son or daughter's future when they are no longer able to support them [2]
- Under the Care Act, carers have a statutory right to receive an assessment of their needs, and eligibility is determined at a national level:
  - Carers are eligible if there is (likely to be) a significant impact on their wellbeing as a result of caring for another person. This may facilitate access to a range of support including:
    - Access to respite – either through day opportunities or overnight
    - Support to maintain good health and wellbeing
    - Training, advice and support to feel confident providing care
    - Access to adaptations, equipment or IT to aid caring
  - Carers' allowance is paid at a rate of £62.10 for carers who meet further criteria
  - Support should include support to remain in work if that is what the carer wants
- There is also evidence to suggest that caring for someone with autism places strain on families and can increase the likelihood of family breakdown [3]:
  - In 2004 one (small) study found 31% of families with a child with autism are headed by a single parent [4] compared with 25% of families nationally [5]

[1] Barnard, J, Harvey, V, Potter, D and Prior, A (2001) *Ignored or Ineligible? The Reality for Adults with Autistic Spectrum Disorder* NAS, London

[2] *I Exist* (2008) National Autistic Society

[3] The Impact of Autism (2001) All Party Parliamentary Group on Autism =

<http://www.appga.org.uk/sitecore/content/Microsites/APPGA/Home/Resources/Past-Reports.aspx>

[4] Bromley et al (2004) Mothers supporting children with autistic spectrum disorders. *Autism* 8:409

[5] ONS - <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/families/bulletins/familiesandhouseholds/2015-01-28>

[6] National Autism Project (2017) *The Autism Dividend* - <http://nationalautismproject.org.uk/the-report>

## THE LOCAL PICTURE: FAMILY CARERS

- When a care assessment for a person with autism is carried out, practitioners are automatically prompted to offer any carer involved a carers assessment.
- Carers can request their own care assessment through the central access team and information about this is available on the Islington website.

### Services available to support carers:

Service	Description and numbers of people accessing the service
<b>Young Carer's Project</b>	This project supports young people (under 18) who provide care to another family member due to illness or disability. At present, there are very low numbers of cases where autism is the care need, and these are where sibling care is being provided.
<b>Centre 404</b>	Provide information, advice, one to one support, family activities or groups. In 2016/17, 438 people accessed the service caring for someone with diagnosis of autism. 367 were under 18 and 71 were over 18. Some of these people may have also had an LD.
<b>Islington Carers Hub</b>	<p>Age UK Islington took over the delivery of Islington Carers Hub in October 2015. The Carers Hub offers:</p> <ul style="list-style-type: none"> <li>• Face to face case work (including form filling, housing, training, transport, breaks fund and grants)</li> <li>• Young adult carers service, for carers aged 18 – 25.</li> <li>• Support groups</li> <li>• Flexible breaks fund</li> <li>• Carers pathway meetings, giving carers that opportunity contribute to develop service development</li> <li>• Carers Assessments</li> <li>• Support GP practices to identify and support carers</li> </ul> <p>In 2015/16 they were supporting 14 carers who cared for someone with autism (with and without an LD). In 2016/17 they supported 13 carers who cared someone with autism (with and without an LD). For those supporting someone with autism the demographic breakdown has remained stable with 73% of cared for clients with autism recorded as female and the highest number were in their 70s and 80s (55%).</p>

## INVOLVEMENT IN SERVICE PROVISION AND DECISION MAKING

- The National Strategy is very clear about the importance of actively involving people with autism in the design and development of services.

### What is being done locally?

- In Islington, people with autism are involved in the development of strategy, action plans and service development.
  - The Islington Autism Partnership Board is co-chaired by a person with autism, referred to as an expert by experience.
  - Other experts by experience attend the board and its sub-groups along with several family carers. The experience and knowledge they bring to meetings is highly valued and helps to shape discussions about service user needs and how those needs can be met.
  - In 2016 Healthwatch Islington completed a large scale piece of engagement work around autism; asking local residents with autism and their family carers to share their experiences of living in the borough. This has been used to shape autism work going forward. (see next slide)

## THE LOCAL PICTURE: FINDINGS FROM HEALTHWATCH ISLINGTON

Throughout the Autumn of 2016 Healthwatch Islington spoke with Islington residents with autism (both with and without LD) and their families. They spoke to 15 people with autism, 33 carers, 7 family members, and 5 healthcare professionals. They used a range of techniques, such as focus groups, interviews, surveys, online and at meetings.

### Findings

- **Accessibility of health and care services** (45 people spoke about this)

Respondents found getting appointments difficult, waiting rooms were not autism friendly and sometimes health professionals did not understand their needs. More could be done to make health and care services accessible. It was also felt that the experience of accessing autism specific services was inconsistent, varying widely between individual service users.

- **Diagnosis pathways and processes** (35 people spoke about this)

Many respondents spoke about the assessment and diagnosis of autism. The process was felt to be complex and lengthy, with more information and support needed. The point was also made that it was even harder to get an autism diagnosis as an adult.

- **Awareness of autism amongst health and care staff** (26 people spoke about this)

In general it was felt that there was a lack of awareness of autism and how to meet the needs of people with autism and that more training was needed on this.

- **Availability of autism-specific services and information**

A number of respondents called for more easily accessible and comprehensive information about autism-specific services. Several parents talked about the need for training on meeting the needs of their child.

### What would help?

- Services could do more to prepare for appointments, ensuring that they are at an appropriate time and length, they understand the person's needs, and send reminders.
- A separate, quiet, waiting area.
- Using symbols or text to communicate
- Continuity and routine is important for people with autism

### Healthwatch's Recommendations (and Islington Council's response):

- Reasonable adjustments from all health and social care providers. These include appropriate appointment times and locations, longer appointments and suitable waiting areas. Commissioning leads will work with colleagues in primary care to explore a programme of work to support access to primary care services for people with autism. We must ensure that primary care services are accessible to everyone, including staff training and awareness, the physical environment.
- A more integrated approach to care from autism specific services. There needs to be more information on what services are available and the pathways need to be clearer. A central information point or contact person would be helpful. IAP have been investigating this and have made recommendations to develop an Autism Hub.
- Better autism awareness amongst health and care professionals. A training programme is being developed.

## SYSTEMIC NEEDS – CO-ORDINATION

NICE guidance for adults is very clear about the need for co-ordination in the care of people with autism, because of the large number of services likely to be involved. It recommends the following local structures [1]:

- An **autism strategy group** should be responsible for developing, managing and evaluating local care pathways, including appointing a lead professional for the local autism care pathway (or potentially two, one for adults and one for children) to support the integrated delivery of services across all care settings
- An **autism team for children** should be established to provide a single point of referral for diagnosis and post-diagnostic support, including a care co-ordinator for every child or young person with a diagnosis, to include at a minimum (but not limited to) [2]:
  - Paediatrician and / or child and adolescent psychiatrist
  - Speech and language therapists
  - Clinical and / or educational psychologists
- An **autism team for adults** should be established, including a care co-ordinator for every adult with a diagnosis, to include [1]:
  - Clinical psychologists
  - Nurses
  - Occupational Therapists
  - Psychiatrists
  - Social workers
  - Speech and language therapists
  - Support staff (e.g. for housing, education, employment, financial advice etc)

[1] <https://www.nice.org.uk/Guidance/CG142>

[2] <https://www.nice.org.uk/guidance/cg170/chapter/1-Recommendations#general-principles-of-care>

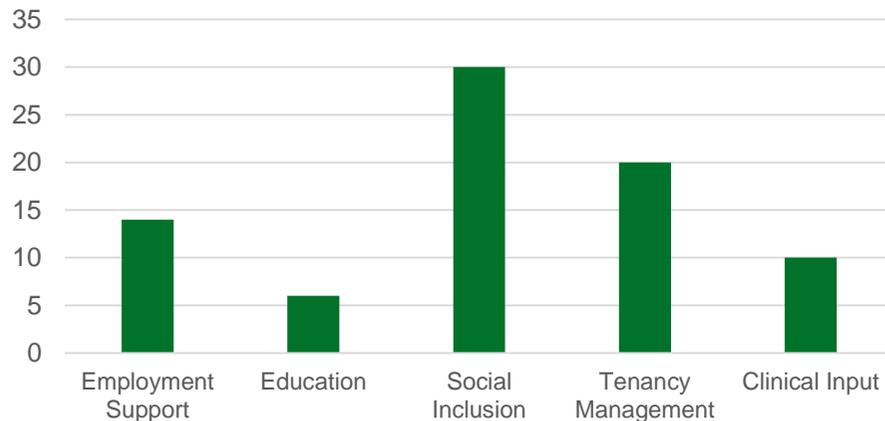
## THE LOCAL PICTURE: ISLINGTON AUTISM PROJECT

The Islington Autism Project was a 1 year project from September 2016-September 2017 which has a 6 month extension to complete community development work until March 2018. IAP had a specific remit around adults with autism who don't have a global learning disability. The team consists of one senior practitioner and one support worker.

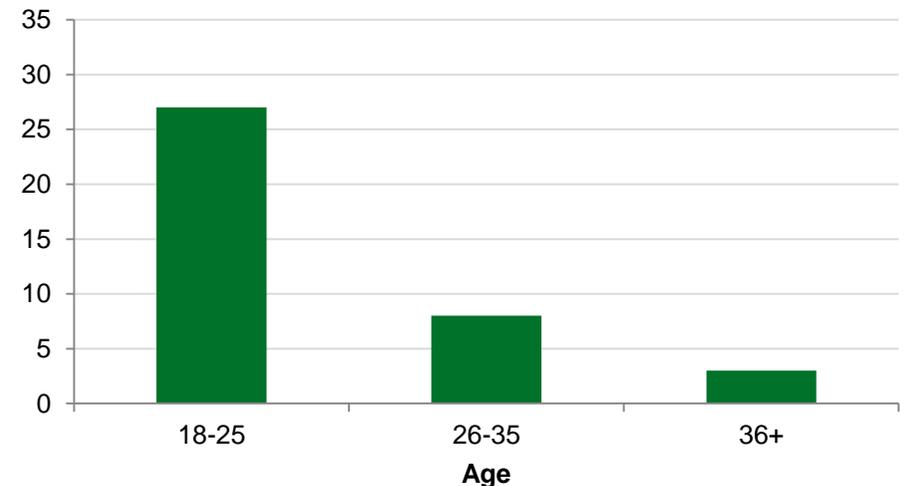
The initial IAP objectives (these have been amended as the project progressed) were to:

- Ensure pathways to social care assessment are clear and staff are equipped to appropriately assess and care manage people with autism
- Develop an understanding of the needs of people with autism in Islington and where the gaps are in meeting these
- Map the local offer for people with autism in order to identify and start addressing some of the gaps in provision
- Raise awareness of autism locally and work to ensure reasonable adjustments are made across Council and public services
- Support work streams of the Autism Partnership Board; including staff training, employment and housing
- From September 2016 until July 2017 the service identified and worked with 38 people. The team worked with social care services and AADSC to identify these people who needed their support. 30 people had a primary diagnosis of autism and were accessing Social Care Services. 8 had a primary mental health diagnosis. They were accessing a range of services, across the system, including mental health and learning disabilities, and only 9 had an agreed care package. 79% were male; 16% female and 5% transgender. The majority were aged 18 – 25.
- The key areas of need identified were around social inclusion, housing and employment and education. Some people had multiple needs.

**Unmet needs of people with autism identified by IAP, September 2016- July 2017**



**Age of people accessing IAP, September 2016- July 2017**



## THE LOCAL PICTURE: ISLINGTON AUTISM PROJECT- CHALLENGES

Key challenges the IAP project team encountered:

- There is limited buy-in from management and front line staff in mainstream adult social care teams to take responsibility for people with autism, citing capacity issues, lack of multi-disciplinary (MDT) support and not feeling suitably trained
- There is a lack of MDT support and specialist / reasonably adjusted clinical input available, despite the complexities of the client group
- There is a limited community offer to signpost to
- There is a lack of effective transition support
- There is a lack of pathway on the adult social care systems for people with autism – what is required is an accurate recording of diagnosis, adjusted resource allocation tool (RAS) and a respite calculator
- There is a lack of pathway for agreement and funding of care packages

### Recommendations made by IAP in July 2017

1. Extend the project team to March 2018 and agree the focus of their work for this 6-month period; including how this work will be embedded in business as usual in the long-term [this has been agreed]
2. Improve the local offer to people with autism. [An Autism Hub proposal is now being developed by IAP through the APB.]
3. A clear steer from senior management regarding which team has social care responsibility for this cohort; including assessment, support planning and funding (this is likely to lead to an ongoing training requirement)
4. Consider the availability of specialist / reasonably adjusted clinical input as part of discussions for an NCL-wide diagnostic service
5. Consider a transition pathway for young people with autism as part of discussions to remodel the transitions team
6. Request changes to LAS (adult social care recording system) to create a pathway for people with autism

## THE LOCAL PICTURE: AUTISM PARTNERSHIP BOARD

- The aim of the Autism Partnership Board (APB) is to work together with other organisations to improve the lives, health and wellbeing of people with an autistic spectrum condition. It also aims to give people on the spectrum a voice and empower them to make positive changes to enable increased choice and control. The meetings are co—chaired by a service user with autism, and people with ASC and their family/ carers are invited to the meetings.
- The board meet bi-monthly. Attendees include; officers from the local authority (both from children’s and adults services), the CCG, health colleagues, experts by experience, family carers, local advocacy / user groups, education colleagues, representatives from the criminal justice system and local providers.
- There are currently 3 subgroups:
  - Reasonable adjustments & raising awareness
  - Training
  - Employment
  - The Board is looking to establish a fourth subgroup to focus on pathways and information.
- The Autism Partnership Board is responsible for taking forward the recommendations of this needs assessment. The recommendations are outlined below, along with an audit on how Islington is delivering the Adult Autism Strategy recommendations.

## AUDIT – AUTISM STRATEGY STATUTORY REQUIREMENTS

We have looked at how Islington is meeting the Adult Autism Strategy requirements using a RAG rating system. These can be aligned to the recommendations, which are indicated in the third column below.

Local authorities..

... <b>Must</b> ensure that any person carrying out a needs assessment under the Care Act 2014 has the skills, knowledge and competence to carry out the assessment	Partially met, although training needs to be rolled out	R2
... <b>Must</b> ensure that the duties under the Children and Families Act (2014) are applied where relevant to children and young people with autism and their families	Not known as not in scope of this needs assessment	
... <b>Must</b> identify and develop resources that will prevent or delay the development of care and support needs of adults with autism and their carers (Care Act)	Not met	R3
... <b>Must</b> identify the local care and support needs of people with autism and gaps in service provision (Care Act)	Partially met, in progress but not complete	All
... <b>Must</b> provide access to advocacy provision where the person would have a significant difficulty in understanding the assessment and care management process (Care Act)	Met	R3
... <b>Must</b> ensure that the assessment and care planning process for adult needs for care and support considers participation in employment as a key outcome, if appropriate	Partially met	R3

# AUDIT – AUTISM STRATEGY RECOMMENDATIONS

Local authorities..

... <b>Should</b> ensure that there is a meaningful local autism partnership arrangement that brings together different stakeholders locally, including the CCG, and people with autism	Met	R4
... <b>Should</b> allocate responsibility to a named joint commissioner / senior manager for commissioning services (autism lead)	Met	
... <b>Should</b> bring partners together, for example through Health and Wellbeing Boards, to ensure information sharing protocols are in place and that all necessary information for service planning is available	Partially met, in progress through data sub-group of APB	R1
... <b>Should</b> ensure they are involved in the development of local workforce planning, and GPs and primary care practitioners are engaged in the training agenda in relation to autism	Not met	R2
... <b>Should</b> provide access to an autism diagnostic and treatment pathway including those who do not have a learning disability	Partially met, need to address the long waiting times	R2,3

NHS bodies...

... <b>Should</b> designate a health lead responsible for developing, maintaining and promoting a diagnostic and treatment pathway	Not met	R2,3
... <b>Should</b> ensure that in commissioning health services for persons in prison and other forms of detention prisoners are able to access autism diagnosis in a timely way	Not known	R3
... <b>Should</b> ensure that Liaison and Diversion services have in place a clear process to communicate the needs of an offender with autism to the relevant prison or probation provider	Met	
... <b>Should</b> work in partnership so there is a substantial reduction in reliance on inpatient care for people with autism	Work is in progress	

Both...

... <b>Should</b> ensure the existence of a clear trigger from diagnostic to local authority adult services to notify individuals of their entitlement to an assessment of needs	Partially met, needs to be more systematic	R2
... <b>Should</b> work together to put in place a locally agreed joint plan to ensure high-quality care and support services for all people with challenging behaviour, including autism	Work is in progress	R2,3

## FULL RECOMMENDATIONS – THEME 1

### 1. Improve data collection and understanding of compliance with clinical good practice

Recommendations	Benefits	Responsibility
<p>Establish consistent recording of autism diagnosis by all of Adult Social Care, Housing, mental health services, GPs and other secondary care providers.</p>	<p>Awareness of diagnosis facilitates better care and improves data available to understand local need</p>	<p>Data sub-group of Autism Partnership Board GPs Adult Social Care Housing Services Mental Health Service Providers Substance Misuse Services</p>
<p>Improve the way that data is accessed and collated to ensure that all relevant stakeholders are able to get a better understanding of who has autism, and what their needs are.</p>	<p>Awareness of diagnosis facilitates better care and improves data available to understand local need</p>	<p>Data sub-group of Autism Partnership Board GPs Adult Social Care Housing Services Mental Health Service Providers Substance Misuse Services</p>

## FULL RECOMMENDATIONS – THEME 2

2. Improve the capability and responsiveness of services so that people with autism receive services which are able to adapt to meet their needs

Recommendations	Benefits	Responsibility
Undertake a training needs assessment for key service providers (to include GPs, MH staff, Housing and Adult Social Care and Police) and wider groups	<ul style="list-style-type: none"> <li>• Understanding of the current scale of gaps in knowledge</li> <li>• Ensure training is well targeted and accessible</li> </ul>	Workforce Development Subgroup of Autism Partnership Board Learning and Development Teams
Deliver targeted and accessible basic autism training based on findings of the training needs assessment. Ensure this is promoted widely to those who may not previously have accessed training.	<ul style="list-style-type: none"> <li>• Improved awareness among non-specialists</li> <li>• Better and more responsive care</li> <li>• Prevention of escalation</li> </ul>	Commissioning
Ensure those undertaking needs assessment have adequate training.	<ul style="list-style-type: none"> <li>• Better and more responsive care</li> <li>• Prevention of escalation</li> </ul>	Commissioning
Health services (including mental health) and GPs should offer reasonably adjusted care to people with autism	<ul style="list-style-type: none"> <li>• Recognising known higher rates of mental illness</li> <li>• Better quality of care</li> <li>• Prevention of escalation of mental health issues</li> </ul>	Mental Health Commissioning and providers, including VCS GPs
Explore opportunities to develop a service for adults with autism, including transition, to provide expert advice and support, reflecting the NICE recommendations i.e. facilitating a multi-disciplinary care co-ordination approach.	<ul style="list-style-type: none"> <li>• Source of expert advice to other practitioners</li> <li>• Meeting NICE recommendations</li> <li>• Improved access to and navigation through mainstream services</li> </ul>	Pathways subgroups of Autism Partnership Board Adult Social Care

## FULL RECOMMENDATIONS – THEME 3

### 3. Review service provision with the aim of improving the ability to meet the needs of those with autism.

Recommendations	Benefits	Responsibility
Ensure that adults who receive a diagnosis are aware of their entitlement to an assessment of their care needs, and that a user friendly pathway exists for them to access this assessment	<ul style="list-style-type: none"> <li>All eligible adults receive a Care Act assessment</li> </ul>	Pathways subgroup of Autism Partnership Board CCG Adult Social Care
Ensure that there is a team within Adult Social Care who are trained and competent to support people with autism without an LD	<ul style="list-style-type: none"> <li>Meeting Care Act obligations</li> <li>Improved ability to meet needs of adults with autism but no LD</li> </ul>	Adult Social Care
Ensure clear pathways and protocols for transition planning, including the early involvement of Adult Social Care	<ul style="list-style-type: none"> <li>Better transition planning</li> <li>Improved information to inform Children's and Adult Social Care planning</li> </ul>	Pathways subgroup of Autism Partnership Board Adult Social Care Children's Services
Ensure that there is a designated a health lead responsible for developing, maintaining and promoting a diagnostic and treatment pathway	<ul style="list-style-type: none"> <li>Meeting the Autism Strategy recommendations</li> <li>Improved access to diagnostic and treatment pathway</li> </ul>	CCG Adult Social Care
Review the adult autism diagnostic service offer to improve capacity and meet demand	<ul style="list-style-type: none"> <li>With the aim of reducing waiting times and improving access</li> </ul>	Commissioning
Increase focus on participation in training, volunteering and employment for those with autism.	<ul style="list-style-type: none"> <li>Meeting Autism Act statutory guidance</li> </ul>	Employment subgroup of Autism Partnership Board
Increase understanding of housing needs and how to support people to obtain and maintain suitable housing.	<ul style="list-style-type: none"> <li>Housing needs understood and addressed for people with autism</li> </ul>	Autism Partnership Board Adult Social Care Housing

## FULL RECOMMENDATIONS – THEME 4

### 4. Support engagement and collaboration with service users and their families

Recommendations	Benefits	Responsibility
<p>Support the development of an Autism Hub, which will provide a central information point for people with autism, as well as links to social activities, which might include social skills classes, peer support and / or support to access mainstream social or interest-based groups</p>	<ul style="list-style-type: none"> <li>• Meeting need for low intensity, social and preventative support</li> <li>• Proactive approach to prevention of further physical or mental health needs</li> <li>• Source of information/ sign posting for professionals</li> </ul>	<p>Autism Partnership Board Islington Autism Project VCS</p>
<p>Explore more opportunities to obtain feedback from people with autism and their family carers, outside the Autism Partnership Board to improve support and services and understand the needs of people with autism</p>	<ul style="list-style-type: none"> <li>• Reach greater numbers</li> <li>• Improve two way communication</li> </ul>	<p>Autism Partnership Board Service providers</p>
<p>Use surveys and other methodologies to better understand needs and concerns (the Oxfordshire Asperger's JSNA contains a description of a sample methodology)</p>	<ul style="list-style-type: none"> <li>• Wider opportunities to inform co-design of services</li> <li>• Improved data for planning</li> </ul>	<p>Autism Partnership Board and other relevant engagement groups</p>

## FURTHER INFORMATION

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### About Islington's Autism Need Assessment

This Autism Need Assessment was produced by Chloe Gay, Public Health Strategist, Ester Romeri, Public Health Intelligence and Information Analyst, and Lawrence Vandervoort Public Health Intelligence and Information Officer, and approved for publication by Sarah Addiman Consultant in Public Health in November 2017.