

FOCUS ON:

AUTISM IN ADULTS

January 2018

This assessment considers the needs of adults with autism in Camden

- 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

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AUTISM NEEDS ASSESSMENT SUMMARY

JANUARY 2018

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

- Prevalence estimates suggest that there are 1071 adults with autism without an LD living in Camden in 2017.
- Statutory services are only able to identify a small proportion of the estimated population of people with autism in Camden.
- The estimated number people with autism (both with and without an LD) in Camden is estimated to rise from 2,060 individuals in 2017 to 2,301 individuals in 2025.
- There was a 96% increase in the average number of referrals to the Adult Autism Diagnostic Consultation Service (AADCS) between 2013/14 16/17.
- Many of the people accessing AADCS have a mental health condition too

Service provision and good practice

- The Camden All Age Autism Plan 2016 - 2021 sets out a vision and action plan for how to meet the needs of people with autism.
- The Camden Autism Partnership Board is a new forum for services and experts by experience to work together and address the local needs of people with autism. They are currently developing the priority areas to focus on over the coming years.
- There are a number of specialist and non-specialist services Camden providing a range of different kinds of support and care to adults with autism and their families.
- Specialist services include the AADCS and a number of services in the Voluntary and Community Sector.

SUMMARY OF UNMET NEEDS AND RECOMMENDATIONS

This assessment has identified a number of needs which are currently not being fully met, including:

- There is a lack of understanding of the numbers of people with autism living in Camden 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 Camden 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

- There is a lack of understanding of autism, and there needs to be more awareness raising for the general population and training for those who might work with people with autism.
- People with autism 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 the Adult Autism Diagnostic and Consultation Service, Adult Social Care, Occupational Therapy, Speech and Language Therapy, leading to long waiting times 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 are few preventative services to reduce the likelihood of escalation of mental health conditions for people with autism
- 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.
- People with autism would like support around housing and training and employment.

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

Camden recently published 'Camden's plan for people with autism 2016-2021' Camden's Autism Partnership Board has commenced work to meet some of these needs and others are addressed in the recommendations section.

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

[3] Think Autism - 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

SUMMARY OF DUTIES UNDER THE STATUTORY GUIDANCE

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

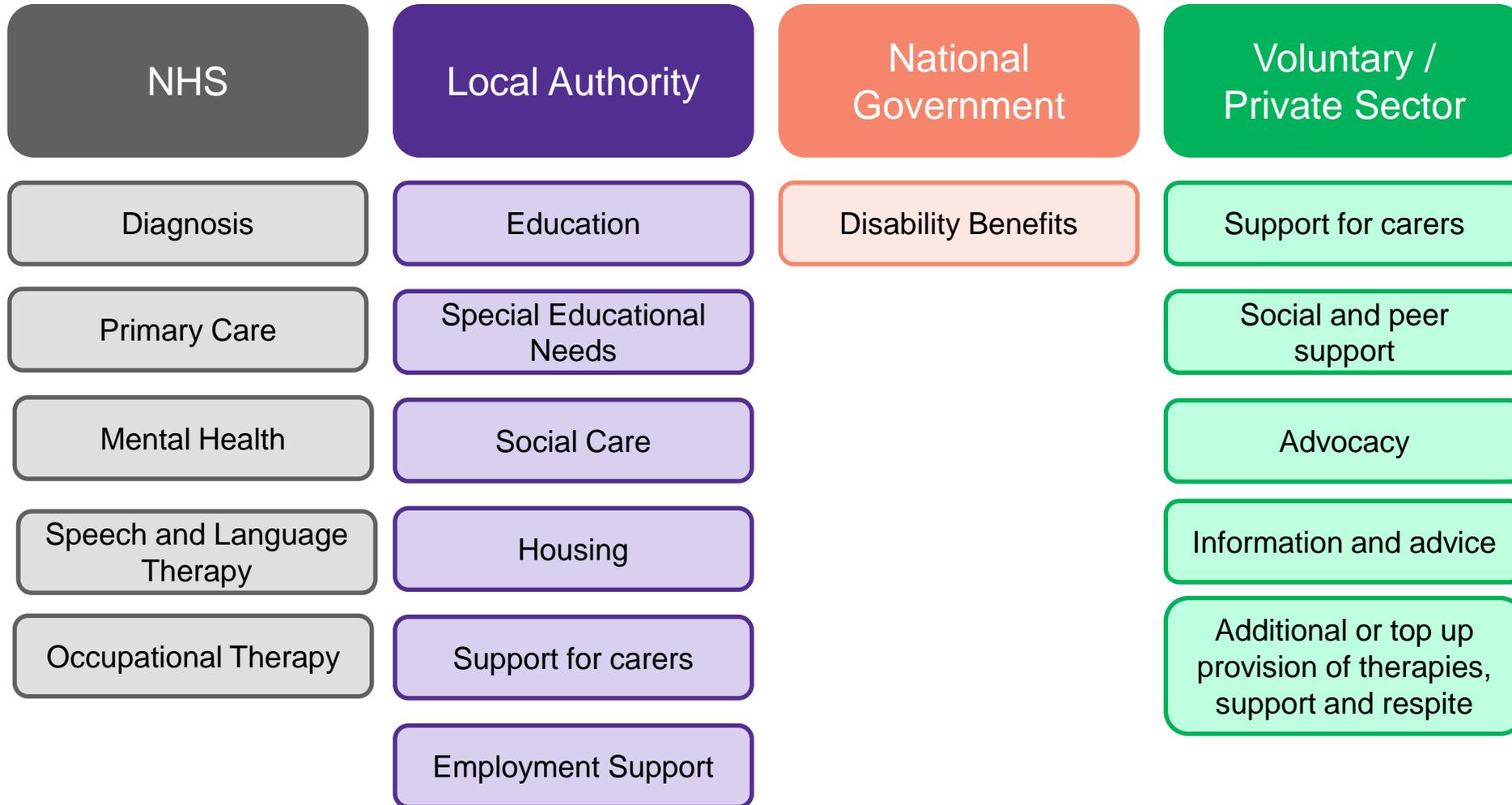
... **Should** work together to put in place a locally agreed joint plan to ensure high-quality care and support services for all people with challenging behaviour, including autism

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

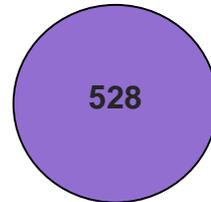
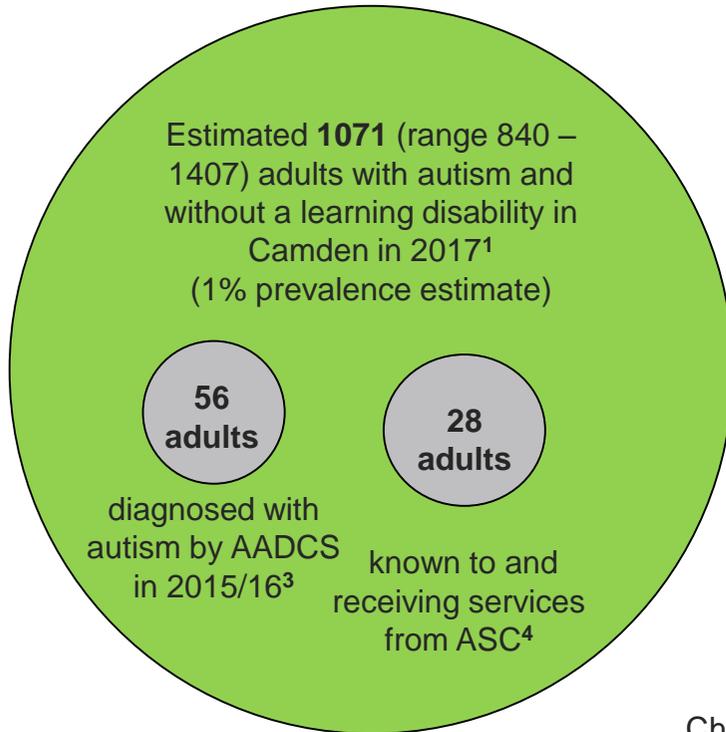
[3] 4 times: NICE Guidance <https://www.nice.org.uk/guidance/qs51/resources/support-for-commissioning-for-autism-253717885>, 9 times: British Psychiatric Survey

[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

[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

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

THE LOCAL PICTURE: PREVALENCE



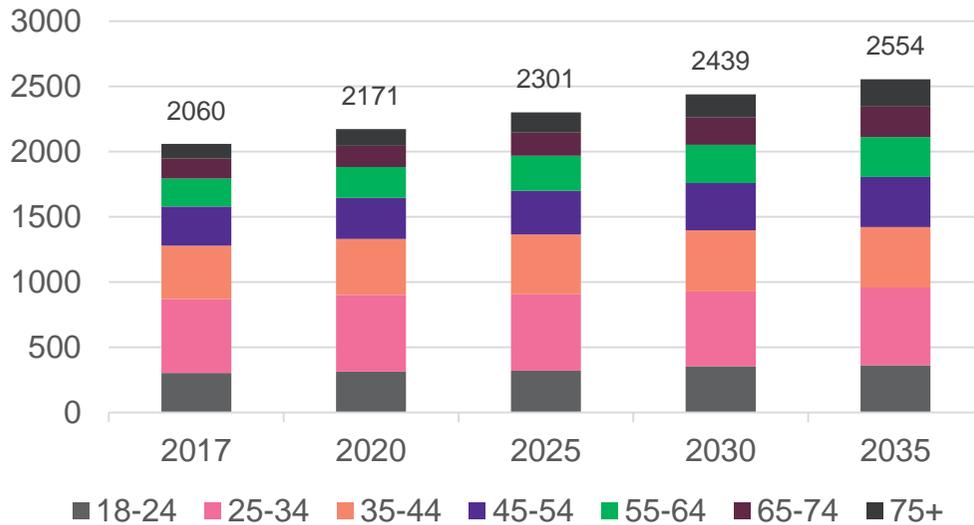
Children and young people with autism*
known to SEND²

- There is limited local data on the numbers of people with autism without a learning disability (LD) in Camden. This lack of local data is not unique to Camden.
- Prevalence estimates suggest that there are 1071 adults with autism without an LD living in Camden in 2017.
- Statutory services are only able to identify a small proportion of the estimated population of people with autism in Camden: 56 receiving a diagnosis from Adult Autism Diagnostic Consultation Service (AADCS) and 28 people known to Adult Social Care (ASC). 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 very few records of adults with autism without an LD accessing services.
- 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. Number of children and young people known to children's services with autism, 2011/12-2014/15.
3. Camden and Islington Community Mental Health and Primary Care Division, 2017.
4. Camden Adult Social Care, August 2017

THE LOCAL PICTURE: FUTURE NEED

Estimated population with autism in Camden from 2017 to 2025

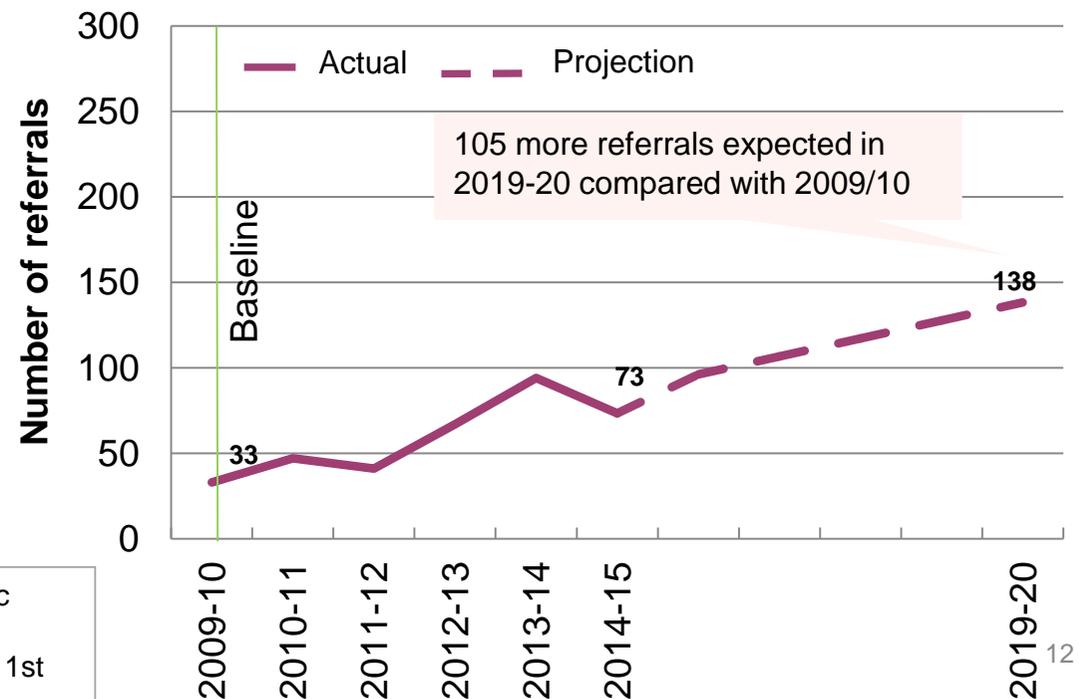


Estimated number of referrals for autism, in children aged 5-18, 2019-20

- The number of referrals has more than doubled since the baseline from 33 in 2009/10 to an estimated ~73* in 2014/15.
- The number of referrals is projected to almost double in 5 years from 73 in 2014/15 to **138** in 2019/20 (+105 referrals on 2009/10), assuming that there is no change in the trend in referrals.
- An increase in children and young people with diagnosed autism will mean that in future years there will be an increased demand on transition and adult services.

- PANSI and POPPI calculated autism prevalence estimates based on the Adult Psychiatric Morbidity Survey in 2007. However, these include people with LD.
- Using these rates, the estimated number of people with autism (both with and without an LD) in Camden is estimated to rise from 2,060 individuals in 2017 to 2,301 individuals in 2025.
- The greatest percentage increase is expected to be in those age 75+, increasing 38% between 2017 and 2025

Actual number and estimated projection of children aged 5-18 years old referred for autism, Camden, 2009-10 to 2019-20



Note: Projection estimates (2019-20) calculated by the Camden and Islington Public Health (2015)

* Number of referrals for 2014-15 has been estimated for the entire period between 1st April 2014 to 31st of March 2015 based on earlier referral trend.

Source: Kentish Town Health Centre - MOSAIC CAMHS & SCAS (2015)

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>

DIAGNOSTIC SERVICES

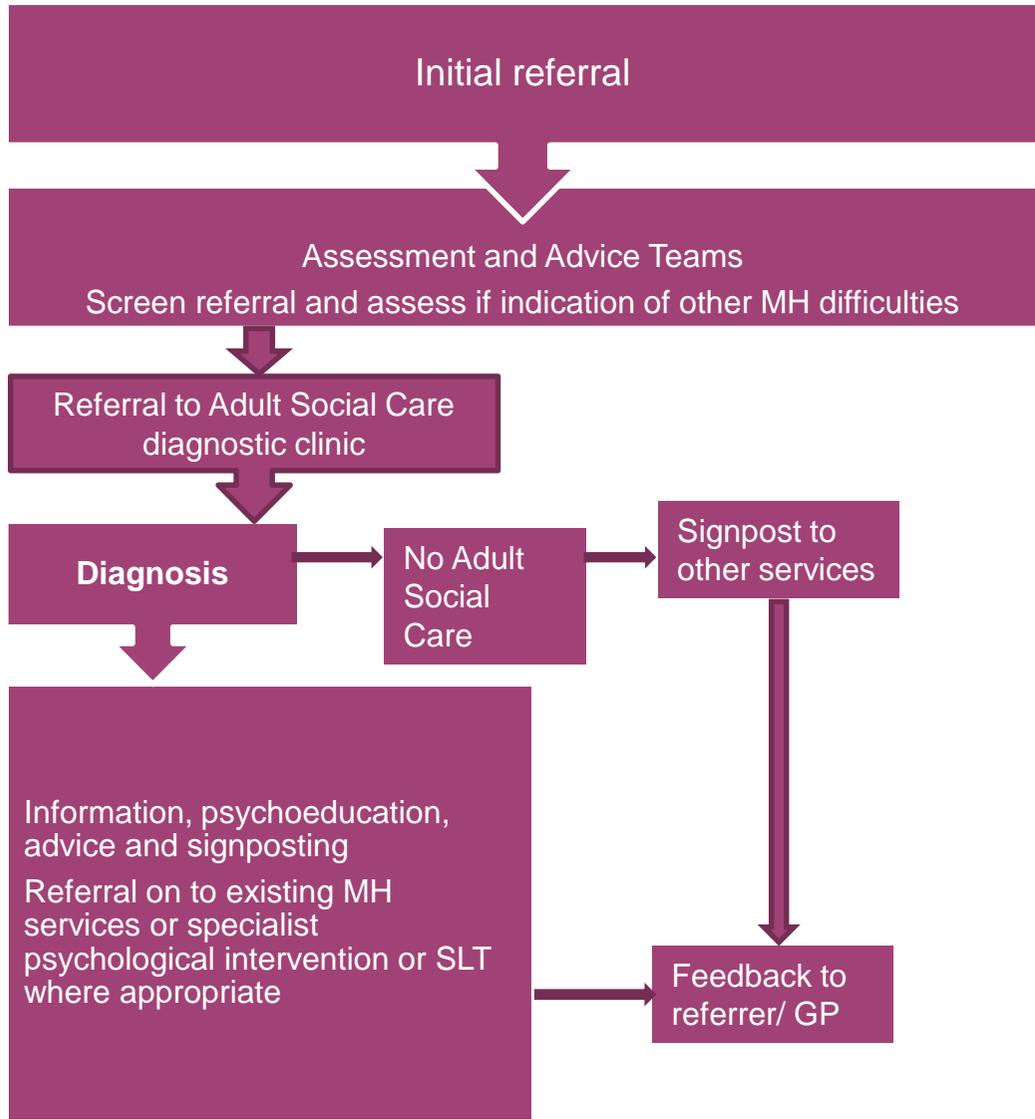
There are two different diagnostic pathways for people with and without a learning disability (see next slide).

Camden & Islington Adult Autism Diagnostic and Consultation Service

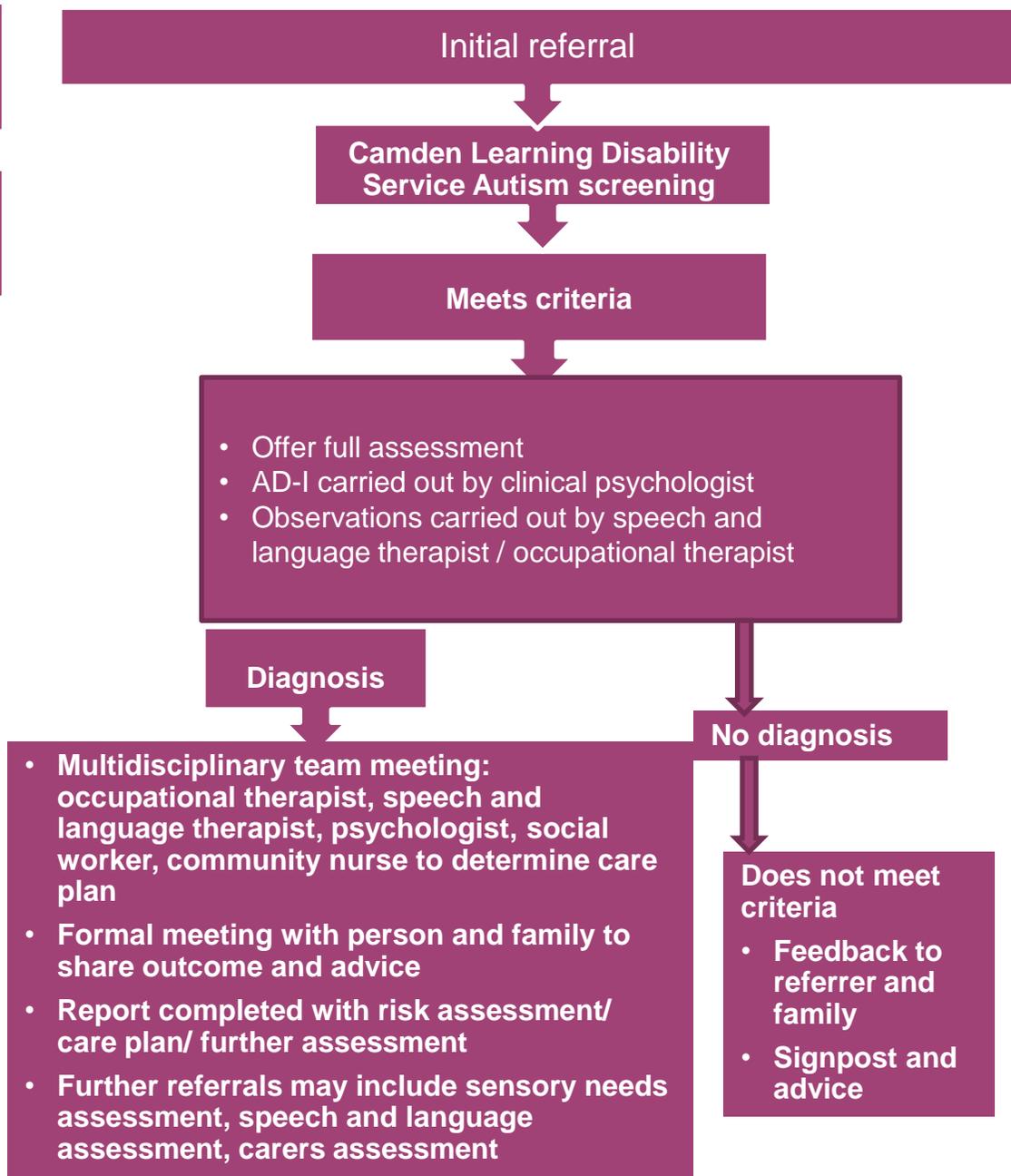
- People who don't have a global learning disability are referred to the Camden & Islington Adult Autism Diagnostic and Consultation Service (AADCS) for assessment. This service has been available since 2013.
- AADCS operates one day a week providing thorough diagnostic assessments and consultations to residents of Camden and Islington. The team consists of a Consultant Psychiatrists (2 x 0.1wte), Clinical psychologists (2 x 0.2wte) 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 ASD assessment, it did not prove to be effective at screening out patients who would not need to be seen and is no longer in use.
- The diagnostic service offers at least one follow-up appointment after a detailed assessment has been completed. Service users are aware that they can return if need be, but 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 and to Speech and Language Therapy in Mental Health.
- A service review is currently being undertaken by commissioners.

LOCAL DIAGNOSTIC SERVICES

ADULTS WITHOUT LD

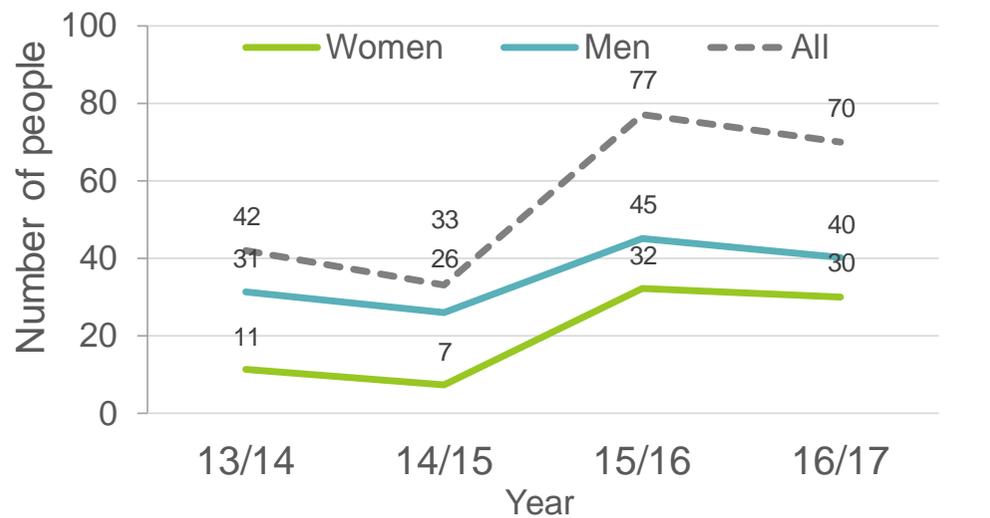


ADULTS WITH LD



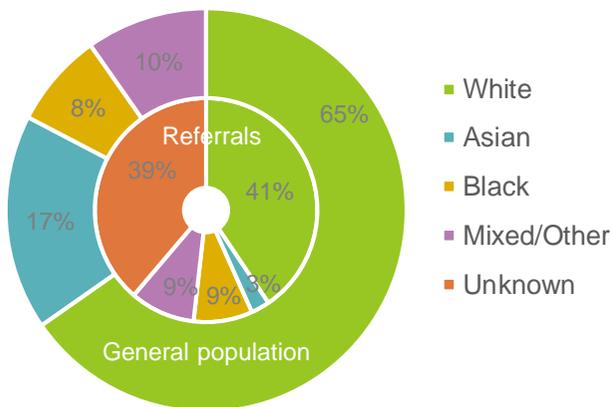
THE LOCAL PICTURE: ADULT AUTISM AND DIAGNOSTIC CONSULTATION SERVICE (AADCS)

Camden and Islington referrals to AADCS (16+) by sex, April 2013 to March 2017



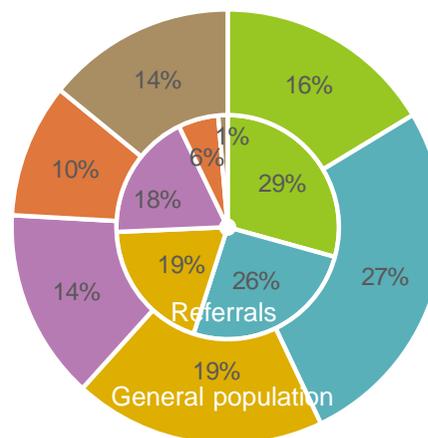
- Referrals to the AADCS increased from an average of 38 in 2013/14-14/15 to 74 in 2015/16-16/17 a rise of 96%
- Men account for about 65 per cent of all referrals (142 out of 222) between 2013/14 and 2016/17. It is being increasingly recognised that autism in women is under-diagnosed, and services need to investigate how to improve access for women.

Referrals to AADCS (16+) by ethnicity, April 2013 to March 2017



Referrals from the Asian population (16+) were significantly less than expected based on the Asian profile in Camden and Islington (4% vs 17%). About 90 people referred (39% of the total referred) didn't have a recorded ethnicity.

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



Compared to the overall general population in Camden there is a larger than expected number of 16-24 year olds referred (29% vs 16%), and people aged 45-54 years old (18% vs 14%). There is a less than expected number of people aged 55-64 years old (10% vs 6%).

- Older people (65+) referred are underrepresented; 1% of referrals for older people (65+) compared with 14% of older residents (65+) in the general population.

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

THE LOCAL PICTURE: ADULT AUTISM AND DIAGNOSTIC CONSULTATION SERVICE

People seen at the AADCS and diagnostic rates for people living in Camden and Islington in 2015/16*

Camden and Islington	2015/16
Autism diagnosis rate	56%
Average waiting times	18 months

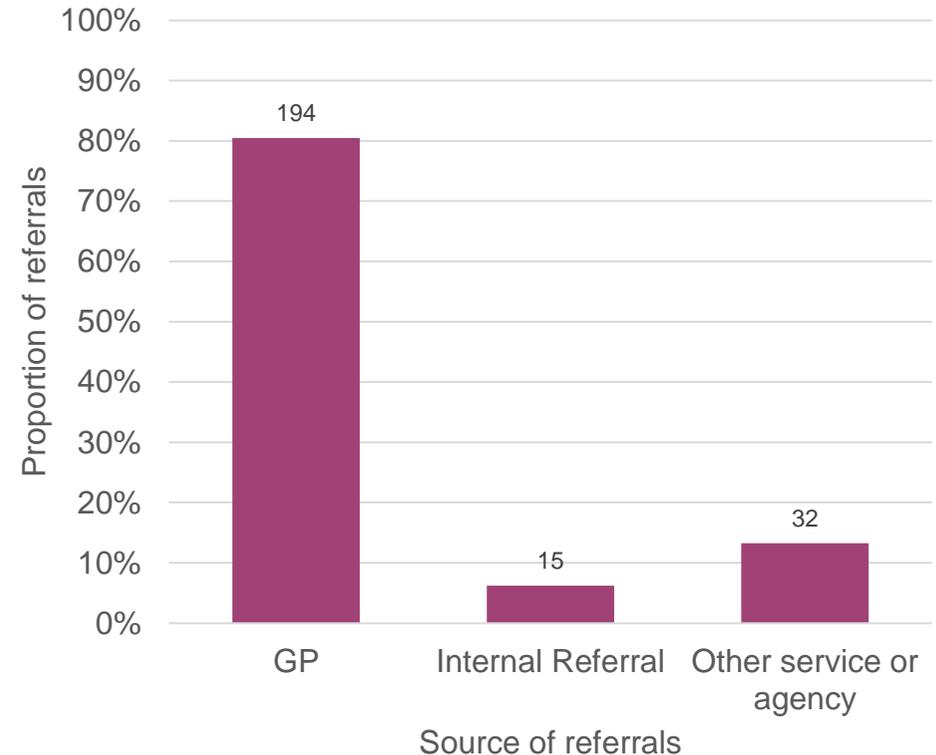
* We do not have this information by borough

- 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 seen 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, Camden population, 2013-17



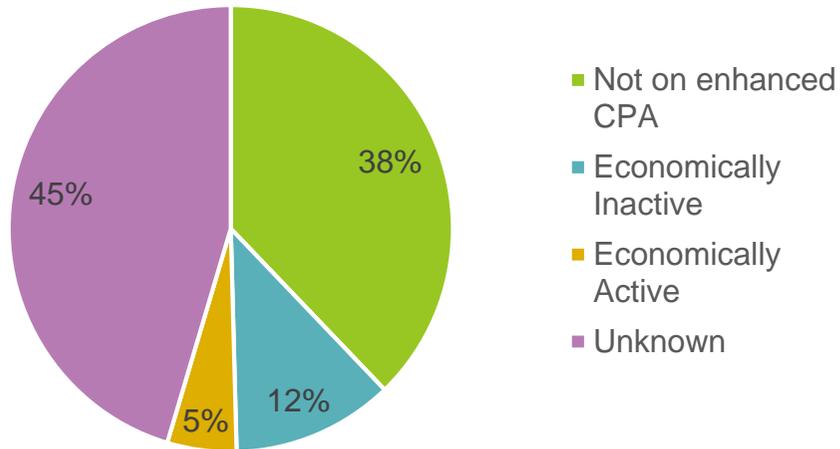
The majority of people (80%) were referred to AADCS by their GP. Other sources of referral included internal referrals to adult mental health inpatient services, social services and self-referrals.

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

THE LOCAL PICTURE: ADULT AUTISM AND DIAGNOSTIC CONSULTATION SERVICE

Economic activity

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



- AADCS only 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, overall employment status was not known for 83% of people seen by the service, either because they were not on an enhanced CPA or the data had not been recorded.
- 5% (12) of people accessing the service were economically active and on an enhanced CPA.
- 12% (28) of people accessing the service were economically inactive and on an enhanced CPA. Of this group, 68% (19 people) were long term sick or disabled.
- The long term sick or disabled proportion of patients with autism is larger than that in the general Camden and Islington population.

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

TRANSITIONS

- The process of transition has been developed in recent years in response to the “cliff edge” faced by many children and young people 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 young person 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
- 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 autism
 - Voluntary work placements in setting where autism is understood and accommodated [1]

THE LOCAL PICTURE: TRANSITIONS

- Camden is developing positive Preparing for Adulthood and Transitioning Services with a view to ensuring that young people with disabilities, including those with autism, transition safely and smoothly into adulthood, and that the support they receive enables them to achieve their aspirations.
- This means that holistic transition planning will start at age 14 and be better co-ordinated so that:
 - parents/young people are empowered to make informed choices and enabled to have their views heard
 - support plans are co-produced and tailored to suit individual needs
 - services are cohesive, emphasise continuity of care and are aligned towards achieving articulated outcomes
 - opportunities exist beyond education, which enable young people to be as independent or inter-dependent as they can be and remain in Camden.
- In order to achieve this, Camden commissioned a review of the services available across children and adults teams and have developed a holistic pathway into adulthood for young people with disabilities aged 14 to 25. As part of this, Camden has aligned and improved social work practice and intend to further align SEN support and local health care provision so that the local offer is more clearly defined and more aligned to the resilient families' way of working which promotes a bespoke and flexible approach to help build resilience and improve outcomes.
- Adults and children's services are in one "Supporting People" directorate in the council, including a 0-25 Disability Service & a multi-disciplinary Preparing for Adulthood team leading person-centred transitions for 14-25s. Transition is automatic – triggered by being in receipt of services – but can also be requested.
- A holistic transition assessment takes place at 14, reviewed at 16 and 18. Education Health Care Plans (EHCP) consider future adult social care need.
- The adult LD service is engaged with children's counterparts and aware of cases coming up, however, for those without comorbid LD and/ or mental health conditions, it is not clear which team leads after transition.
- The local Self-Assessment Framework (SAF) validation group felt transition works well in theory, but in practice people can be waiting at 17 for assessment, EHCP and realistic options.
- Local parents/carers feel support for them is not always considered, and there is insufficient consideration of housing needs.
- Consultation with carers and adults with autism have highlighted the restricted options for diagnosis, support and access to education and employment opportunities for young 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. For someone with autism but not a learning disability, it is difficult to get access to specialist health care in the absence of a secondary mental health condition or significant behavioural deterioration.

- **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

[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 a diagnosis of autism.
- All health providers are bound by the Equalities Act.
- Acute services are contractually required to make reasonable adjustments, including for those with communication difficulties, and provide to commissioners a plan detailing how they will deliver their Equality Act duties.
- 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 make reasonable adjustments for people with autism.
- At present we do not have local data on access to Mental Health services.
- iCope and substance misuse services do not record autism diagnoses.
- SHP, a local substance misuse service, is currently working in partnership with Achievability to pilot a support group inclusive to people with autism: REFUND - **R**ecovery **E**ducation **F**or **U**ndiagnosed **N**euro **D**ivergence. They recognised that this group may turn to substances as a comfort and set up this group in response. To date two courses have been run across Camden and Islington.
- The local SAF validation group felt that health services make adjustments for those with learning/other disabilities, but not for hidden conditions like autism.

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

- The AADCS offers one follow-up appointment which includes psychoeducation.
- Service users are aware that they can return if need be, but 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.
- 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, and clinicians at AADSC report difficulties in referring people with autism to an occupational therapist with the appropriate expertise.
- OTs attached to either learning disability or mental health teams are not able to work with people who are not allocated to their respective team.

THE LOCAL PICTURE: THERAPEUTIC NEEDS

Speech and language therapy (SLT)

- Clinicians at AADSC can make referrals to specialise SLT, however, people with autism without an LD or mental health condition report difficulties accessing these services.

Speech and language therapy for those aged 13 - 25

- Westminster Kingsway buy in SLT from Camden and Islington NHS Foundation Trust, and so potentially any student that attends this provision with ASD can access SLT if they require it and the service feels that they can meet their needs. In addition the SLT team does a lot of training with the staff team about ASD, adapting the environment etc.
- Camden Summer University commission Whittington Health to provide a course for young people with high functioning ASD for one week in the summer to make a film. The age range is 13-19, but 20 year olds have attended in the past. Usually 10 young people attend.
- Occasionally the Camden SLT service for Children and Young people from Whittington Health see 18 year olds, usually following a referral from CAMHS teams. These are often exceptions and related to particular concerns around accurate diagnosis, safeguarding, etc.
- Camden SEN may contact SLT for an EHCP review/assessment. This service is spot-purchased.
- No one else currently is commissioning SLT for 18-25 year olds, but if there is interest the SLT service can set up service level agreements.

Speech and language therapy for adults

- Camden and Islington NHS 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 are 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 ASC without learning disabilities but with a mental health need.
- The focus is on social learning tasks for everyday communication within work and social situations, which improves social interaction.
- They run 2 or 3 times a year, once weekly 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 20 people (11 males and 9 females) from Camden 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 (2015) 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 (2015) 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.

THE LOCAL PICTURE: SOCIAL CARE

- There is not a specific team in Adult Social care for those with autism without a learning disability.
- The pathway to access a care assessment and support for people with autism without LD is through referral to Adult Social Care, which responds quickly on receipt of a referral. However, referral numbers are very low.
- The SAF reported that as of March 2016:
 - 109 adults with autism met the Adult Social Care (ASC) criteria. 13 of these did not have an LD.
 - However, this is likely to be under-reported as autism is a non-mandatory field in the adult social care reporting system and not routinely recorded.
- In August 2017, 28 people with autism without an LD were recorded on ASC systems as receiving services. This may reflect an improvement in recognition and recording of autism diagnosis or may reflect an increase in demand.
- An apparent disconnect has been identified between the diagnostic service and referrals to social care. AADCS explains that patients are entitled to a care needs assessment and refers, but ASC records suggest these are not received. This is being investigated.
- For the referrals received by ASC, screening is completed to identify whether to fully needs assess or to signpost and offer information/advice.
- The local SAF validation group highlighted the barriers to accessing services. Camden council recognises this and is committed to establishing clear links between services and compliance with statutory requirements
- Camden council recognises there are gaps in post-diagnostic support for adults with ASC, and there is a need to ensure better ongoing support is available. Options are being considered for providing a specialist support function for this group of adults.

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) to supported 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

[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: EMPLOYMENT

- Locally, people with autism have reported a lack of opportunities for employment-related support that would make a substantial difference to their lives. Camden's most recent self-assessment framework (SAF) process revealed gaps around support for people with autism to find or stay in work. People with autism highlighted the importance of work in preventing poor mental/physical health or crisis, and in contributing to fulfilling/rewarding lives.
- Services available include:

The Autism Project
A charity providing opportunities for Londoners with autism to transition from school/college towards and into employment. The Autism Project (TAP) is a full-time, two-year, employability programme for young people on the autistic spectrum, aged 18-25. Includes supported internships, counselling, and support to find work.

Project Search
Based at GOSH - takes on 5 people to learn key admin skills, leading to possible permanent role at GOSH

The Leighton Project
Three year further education facility teaching independent life skills to bridge the gap between adolescence to adulthood. A two year course in 'Personal Development' and a third year course in 'Employability.'

Westminster Kingsway College
Further education college for young people with profound and multiple learning disabilities and autism. Focuses on health, employment, independent living and community inclusion and the learning is underpinned by specialist support.

The Camden Society Job brokerage.
Drop-in sessions, offer training, work placements, and support to find and keep a job.

Camden Ability

- Camden and Job Centre Plus jointly commissioned Camden Ability to support people with physical & learning disabilities into work. The project is delivered in partnership by Business Disability Forum and Cross River Partnership and has a dual focus in terms of providing one to one employment support to residents with physical and learning disabilities as well as building a network of businesses to make them more confident in employing people with disabilities.
- The project started in October 2015 and support will continue until December 2017.
- To date, 18 employers have joined the Camden Ability network and have been given access to training sessions (including making adaptations in the work place and neurodiversity) as well as the offer of free consultancy support.
- To date (August 2017), 52 candidates with physical and learning disabilities have been provided with employability training through the project.
- In Quarter 1 17/18 8% of candidates supported were 'neurodiverse'.

- While some of these services provide training, there is little information on what training is available for adults with autism without a learning disability.

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)
 - Supporting People funding can provide extra support to enable people to maintain an independent tenancy
 - 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

- A recent consultation with people with autism has highlighted the importance of support to find/maintain appropriate housing.
- At present, the council does not record a diagnosis of autism and is unable to report on the number of people with autism receiving housing support.
- Housing services are committed to collaborating to develop and allocate appropriate accommodation, and to repatriate people with autism who would like to return to Camden.
- Under Camden's Allocations Scheme people with autism do not get additional priority, but it is recognised as a medical condition and it may attract an award of health and housing points, dependent on the severity of the autism i.e. behaviour that challenges. There are occasions where the team may recommend properties with window restrictors, no balconies and a green play area close by (not specifically a garden). Other adaptations may also be made if required.
- If a housing team becomes aware of a particular need they will make reasonable adjustments and tailor the service where appropriate to suit the customer's needs. Teams seek information on autism when they require it, liaising regularly with Camden Learning Disabilities Service, and will signpost tenants to relevant services. Easy read documents are used with current and prospective tenants where these are available.
- Housing teams do not have a policy of specially training staff members in autism and standalone autism training has not been rolled out to ward housing team staff. All Council staff complete mandatory "equality and diversity" e-learning and managers have also attended learning disability awareness training. Staff can access "introduction to autism" courses, although this is not specifically tailored to housing staff.

Future developments

- In Camden's All Age Autism Strategy there is a commitment to give new placement options within Camden, and to repatriate people who live out of Borough who would like to return to Camden. This will include the development of suitable accommodation options, particularly for those with more complex needs.
- An adult social care accommodation strategy is in development, which specifically identifies/addresses autism. It estimates numbers of people with autism who need specific accommodation, covers a range of housing types and helps stakeholders work jointly to identify/progress development opportunities/funding.

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

- Local people who do not need formal care and support depend on local universal services and community/ voluntary sector provision in order to live well, and people are signposted to universal services if they are not eligible for statutory services.
- People need clear information at the right time and in the right format so that they can choose what is right to meet their health and wellbeing needs; however this information can be difficult to find and is not currently brought together in one place.
- The local SAF validation group highlighted that signposting is only effective if social (care) workers are equipped with detailed local information.
- General council services are accessed via Contact Camden, who seek to make adjustments for all customers. Guidance/support and information is provided in accessible formats. The Council website includes accessibility tools/adaptations (e.g. BrowseAloud software; EasyRead pages).
- Autism awareness training is available but has not been rolled out to Contact Camden staff. This would improve effectiveness and consistency of adjustments, including for face-to-face appointments.
- People with autism have highlighted the need to ensure that relevant Council policies and procedures are extended to contractors.
- Local people with autism have reported that adjustments are made for those with learning/other disabilities, but not for hidden conditions like autism.
- Members of the Asperger London Area Group (ALAG) have indicated the need to develop an autism-aware society, utilising tools such as the Autism Charter, in order to remove barriers to inclusion and wellbeing for people with autism. These barriers include: confusing public services and transport, people's attitudes and assumptions, and a lack of quiet space from over-stimulating light and noise.
- ALAG has highlighted the importance of developing universal services that accept neuro-diversity and understand the needs and aspirations of people with autism and how to support them.

THE LOCAL PICTURE: STAFF TRAINING

- A key strategy in improving access to services is to train staff in autism awareness and how to make reasonable adjustments.
- Autism training is open to the whole Camden workforce, including all Camden Council staff, social care, health, schools, the voluntary and community sector, and other partners agencies. All staff groups are included, from frontline workers to specialist practitioners.
- Currently the majority of attendance is from children's teams and education settings, with some attendance from social care settings and adults' teams.
- Since September 2010 courses have been run by Camden's Training and Development Service (TDS) in line with annual identified needs. The Integrated Early Years Service (IEYS) has its own training arrangements.
- However, the local SAF validation group felt that low-level awareness training is insufficient to change understanding and attitudes: regular contact with adults with autism is required or a national awareness raising campaign
- The Autism Development Group has designed a tiered system of training. There are four different levels that build one on the other, from basic awareness (such as "introduction to adult autism") to specialist (such as "advanced skills in working with autistic spectrum conditions").
- Camden and Islington Mental Health NHS Foundation Trust also provides 2 training days, one introductory, one advanced, for Health and Social Services staff working with autistic adults. The course runs once or twice a year and is also open to third sector staff, though trust staff are prioritised

Future developments

- Camden's all-age Autism Plan commits to re-developing the training programme, with increased delivery by people with autism and families, to improve staff awareness and education about autism. Three levels are proposed:
 - Level 1 - where staff are given basic autism awareness training
 - Level 2 - which provides training in practical knowledge and techniques; and
 - Level 3 - for staff like lead practitioners for autism, Special Educational Needs Coordinators, inclusion managers, and adult social workers.
- The Autism Plan also commits to developing targeted sessions for GPs and primary care practitioners, and working with local employers to offer autism awareness training to their staff.

SOCIAL SUPPORT

- Alongside need for mainstream 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

- Those who are not eligible for social care services will be signposted towards information via a variety of means, including local Council and NHS websites, and the Voluntary and Community Sector (VCS). Similar signposting will also be undertaken on diagnosis and a leaflet has been created to give to people following diagnosis outlining local support.
- There is a range of online information, however, people with autism have reported that it is not all in one place and difficult to navigate. The local SAF validation group felt information should be in one place, and that a website was the best platform for this, but highlighted that not everyone uses the internet.
- Contact Camden, the local offer websites (camdencarechoices.camden.gov.uk & localoffer.camden.gov.uk) and camden.clickstart.org.uk are general contact points. cindex.camden.gov.uk is an online information directory that includes a range of services catering specifically or making reasonable adjustments for people with autism, e.g. cinemas, peer support, travel training, colleges, outreach, employment, carer support.
- During consultation on the all-age Autism Plan, people with autism reported that more opportunities for peer/low-level psychological support would make a big difference. Camden recognises there are gaps in low-level/peer/family support, and is committed to enhancing the local offer.
- In addition, adults with autism told us that it is vitally important to their wellbeing to have the opportunity to develop good relationships with friends and family and to pursue meaningful things to do (such as employment, recreation and hobbies). This requires appropriate support and development opportunities to be available, such as peer groups for sharing coping strategies and learning and practising social skills to overcome the challenges of conversation and relationship building.

THE LOCAL PICTURE: SOCIAL SUPPORT

Service	Offer	Contact
Asperger London Area Group (ALAG)	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.	www.alag.org.uk
Au Struck- Social group for adults in North London	The group is open to people who have Asperger Syndrome or High Functioning Autism. They meet weekly in Islington. The aim of the group is 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.	www.resourcesforautism.org.uk
National Autistic Society	National Autistic Society provides information for individuals and friends/families of individuals who have received a diagnosis of an autism spectrum condition.	www.autism.org.uk
Resources for Autism	Resources for autism 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. As of July 2017 42 Camden adults were accessing this service.	www.resourcesforautism.org.uk
Outward ASD Outreach Service	Supports adults with autism spectrum conditions and Asperger's Syndrome to be more independent and to better manage anxiety. Includes support to access community services and independent travel training.	

- People with autism are able to self-refer to these services, and can contact them by telephone, online or by attending the groups.

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>

SYSTEMIC NEEDS - PREVENTION

- Although the symptoms and deficits of autism may be life-long, appropriate support can make the condition easier to live with.
- We 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]

People with autism have told us that preventative support can be difficult to access, especially for people who don't meet social care thresholds.

[1] *I 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

[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]
- 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;
 - Training of the majority of frontline police officers in autism awareness;
 - Offering fixed activity routines 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
 - 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
- There is a national Registered Intermediaries (RI) Scheme for vulnerable victims and witnesses in criminal cases. RIs are communication specialists who assist victims and witnesses, including autistic adults, to communicate their answers more effectively during police interview and when giving evidence at trial. There is currently no registered scheme for defendants. RIs are provided via the National Crime Agency’s matching service.

[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: 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,

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 ASD in 2016/17
- In Camden and Islington 18 adults (7 Camden; 11 Islington) were identified as having suspected ASD 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 an average of 25% of families headed by a single parent 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: THE NEEDS OF FAMILY CARERS

- It is routine when assessing people (including those with autism) to identify carers and offer carer’s assessments.
- The Adult Autism Diagnostic and Consultation Service seek to identify carers and refer for assessment, although most individuals they assess do not have carers.
- A third to a half of carer’s assessments are completed by Camden Carers Service on the Council’s behalf, the majority of which are self-referrals.
- Identification and support of carers of people with autism no longer depends on the eligibility of the person cared for.
- The Carers Service provide information and advice to carers via telephone and hard copy.
- Individuals in the local SAF validation group had not been offered carers assessments, but may not have met the definition of a carer. They felt practical support (e.g. a back-up person), not just information, would make a critical difference to the lives of carers.

Camden Carer’s Centre

Provide support to all carers who live, work or study in Camden or who support a person who lives in Camden. They offer a wide range of support including carers assessments, breaks and activities, one to one support and advice, counselling, health checks, workshops, groups, training. As of July 2017 they supported 132 carers for people with autism, across a range of ages:

Age	0-15	16-18	19-25	26-35	36-45	46-55	56-65	66-75
Number of people	51	18	24	14	4	7	2	1

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.

Co-production in Camden

- Camden's most recent self-assessment framework process revealed gaps in co-production of services with people with autism and their carers - it was highlighted that a new relationship is needed between people with autism and services, whereby a co-production approach is taken to the review, development and delivery of services that listen, act in people's best interests and are held to account.
- The Autism Partnership Board will facilitate the development of this new relationship, and is looking to develop its approach to coproduction.

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>

CAMDEN PLAN FOR PEOPLE WITH AUTISM 2016 - 2021

In 2016 Camden launched its All Age Autism Plan. This plan was based on local understanding of needs using the self-assessment framework, needs assessments and engagement with people with autism and their family/ carers.

It sets out a vision for Camden:

Camden is a place where people with autism can be an equal part of their local community, access the right support at the right time throughout their lifetimes and develop their skills and independence and work to the best of their ability

By 2021, people with autism and their carers will

- achieve better health outcomes
- be included and economically active
- live in accommodation that meets their needs
- benefit from the personalisation agenda in education, health and social care, and access personal budgets
- no longer be managed inappropriately in the criminal justice system
- be satisfied with local services, as will their families
- be actively involved in planning the services that affect their lives

CAMDEN PLAN FOR PEOPLE WITH AUTISM 2016 - 2021

Top Priorities for the Autism Plan:

- Establish an Autism Partnership Board to take forward the autism plan and develop a detailed action plan
- Develop capacity within existing local secondary school provision with the possibility of developing more autism spectrum disorder resource bases so that families have more local options.
- Ensure that All Together Better programme meets the needs of children and young people with autism
- Continue the implementation of an integrated Preparing for Adulthood Team
- Review the adults with autism pathway to ensure that adults can get the right help at the right time.
- Address the waiting times for diagnostic services
- Consider the option of providing specialist support function for adults.
- Assist universal services to be more accessible to people with autism.
- Review and promote an autism training programme across the partnership
- Implement Transforming Care in Camden in line with national guidance
- Ensure liaison and diversion schemes divert people to appropriate health and social care services
- Implement plans in relation to housing and employment
- Continue to review, develop and deliver services for people with autism with co-production at its heart.
- Improve local data collection, reporting and use to support needs identification, service planning and commissioning, and tracking of outcomes.
- Include an in depth chapter on autism in the local Joint Strategic Needs Assessment

Camden Autism Partnership Board (APB)

- The aim of the Partnership Board 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 APB had its first meeting in September 2017, and will meet 3 times a year. It will be supported by a service user led group who will report into the board. 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.
- The APB is currently developing an action plan, and the recommendations from this needs assessment will contribute to that.

As part of the development of the Autism Strategy, a focus group of 5 people with autism was held. Below is a summary of the key issues identified.

What helps you to live a full and rewarding life?	What gets in the way?	What needs to change?
<ul style="list-style-type: none"> • good relationships • recreation and hobbies (things to do) • safe predictable surroundings • employment and education • being understood and accepted 	<ul style="list-style-type: none"> • prejudice and lack of awareness • unpredictability of the world • difficulties with conversations and relationships • sensory overload • additional health problems 	<ul style="list-style-type: none"> • Support following diagnosis – e.g. to find and keep a job, socially, coping strategies, and peer/ self-support • Develop a disability aware society • New relationship between neurodiverse people and services: services listen, act in our best interests and are held to account.

AUDIT – AUTISM STRATEGY STATUTORY REQUIREMENTS

Below is a RAG rating that displays how Camden is meeting the Adult Autism Strategy requirements. These can be aligned to the recommendations, which are indicated in the third column below.

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	Partially met, although training needs to be rolled out
... 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	Not in scope
... 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)	Partially met, in progress but not complete
... Must 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
... Must provide access to advocacy provision where the person would have a significant difficulty in understanding the assessment and care management process (Care Act)	Partially met, in progress but not complete
... 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	Partially met, in progress but not complete

AUDIT – AUTISM STRATEGY RECOMMENDATIONS

Local authorities..

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

Met

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

Met

... **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

Not met

... **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

Partially met

NHS bodies...

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

Met

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

Met

... **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

Under review

... **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

Met

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

Work under Transforming Care is in progress

Both...

... **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

Under Review

... **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

Work under Transforming Care is in progress

FULL RECOMMENDATIONS – THEME 1

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

Recommendations	Benefits	Responsibility
Establish consistent recording of autism diagnosis by all of Adult Social Care, Housing, mental health services, GPs and other secondary care providers.	Awareness of diagnosis facilitates better care and improves data available to understand local need	GPs Adult Social Care Housing Services Mental Health Service Providers Substance Misuse Services
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.	Awareness of diagnosis facilitates better care and improves data available to understand local need	Data sub-group of Autism Partnership Board GPs Adult Social Care Housing Services Mental Health Service Providers Substance Misuse Services

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 Needs and Adult Social Care assessors and Police) and wider groups	Understanding of the current scale of gaps in knowledge Ensure training is well targeted and accessible	Autism Partnership Board
Provide 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.	Improved awareness among non-specialists Better and more responsive care Prevention of escalation	Adult Social Care GPs
Develop an autism awareness raising campaign	Improved autism awareness of the public and service providers Better understanding of autism so that reasonable adjustments can be made for people with autism	Autism Partnership Board Service providers
Health services (including mental health) and GPs are able to offer reasonably adjusted care to people with autism	Better quality of care Prevention of escalation of mental health issues	Commissioning and providers 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.	Source of expert advice to other practitioners Meeting NICE recommendations Improved access to and navigation through mainstream services	Autism Partnership Board Transforming Care Programme

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	All eligible adults receive a Care Act assessment	CCG Adult Social Care
Ensure that there is a team within Adult Social Care who are able to support people with autism without an LD	Meeting Care Act obligations Improved ability to meet needs of adults with autism but no LD	Adult Social Care
Ensure clear pathways and protocols for transition planning, including the early involvement of Adult Social Care	Better transition planning Improved information to inform Adult Social Care planning	Adult Social Care Children's Services
Review the adult autism diagnostic service offer to improve capacity and meet demand	With the aim of reducing waiting times and improving access	Adult Social Care CCG
Increase focus on participation in volunteering and employment for those with autism	Improved outcomes for people with autism Meeting Autism Act statutory guidance	Autism Partnership Board Employment Services
Improve support for people with housing needs to ensure they are able to live in and maintain appropriate accommodation	Housing needs understood and addressed for people with autism	Adult Social Care Housing

FULL RECOMMENDATIONS – THEME 4

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

Recommendations	Benefits	Responsibility
<p>Explore more opportunities to obtain feedback from people with autism and their family carers, outside the Autism Partnership Board</p>	<p>Reach greater numbers Improve two way communication</p>	<p>Autism Partnership Board All service providers</p>
<p>Support the development of social activities for autistic adults, which might include social skills classes, peer support and / or support to access mainstream social or interest-based groups</p> <p>Support the development of a central information point for people with autism, as well as coordinated offer of social activities, which might include social skills classes, peer support, low level psychological support and / or support to access mainstream social or interest-based groups</p>	<p>Meeting need for low intensity, social and preventative support</p>	<p>Autism Partnership Board All service providers</p>
<p>Use surveys and other methodologies to better understand needs and concerns (the Oxfordshire Aspergers JSNA contains a description of a sample methodology)</p>	<p>Wider opportunities to inform co-design of services Improved data for planning</p>	<p>Autism Partnership Board and other relevant engagement groups</p>

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About Camden's JSNA

[Open Data Camden](#) brings together information held across the organisations into one accessible place. It provides access to evidence, intelligence and data on the current and anticipated needs of Camden's population and is designed to be used by a broad range of audiences including practitioners, researchers, commissioners, policy makers, Councillors, students and the general public.

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