

Needs Assessment: Adults and Children with Autism

Public Health
Haringey Council
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- Chapter 1 – Summary and Recommendations

Summary of service provision and good practice



- There are a large number of specialist and non-specialist services in Haringey providing a range of different kinds of support and care to children and adults with autism and their families.
- In the course of preparing this needs assessment, some services have been identified as particularly effective, or as valuable local resources:
 - Primary and secondary education services, especially the special schools and the autism team which supports teachers in mainstream schools
 - The voluntary and community sector, including a strong network of parents and carers providing advice and support to one another, as well as advocacy, and organisations such as Markfield, Kith and Kids and HAIL.
 - Ambitious about Autism's Ambitious College, based at the College of Haringey, Enfield and North East London's Tottenham Green campus
 - The specialist dentist at Tynemouth Road
- For adults with a Global Learning Disability as well as autism, the Learning Disabilities Partnership provides a good range of specialist health and care services
- In addition, in the face of substantial reductions in funding to local government, adult social care teams are working to reconfigure services to ensure everyone who has eligible needs receives support (including those without a Global Learning Disability), and to work with service users and their families to co-design new ways of delivering services.

Summary of unmet needs



- This assessment has identified a number of needs which are currently not being fully met, including:
 - People with autism find it hard to access many **mainstream services**, and staff are often ill-equipped to identify autism and make reasonable adjustments.
 - This is particularly true for **mental health** services; the needs assessment shows people with autism have higher levels of mental ill-health than the general population but mainstream mental health services are often not accessible or adapted to their needs
 - There is a **lack of capacity** in some services including Occupational Therapy for children, diagnosis for adults and social housing, leading to long waiting lists and / or services offering fewer or less frequent sessions than are needed
 - There are few, if any, **preventative** services to reduce the likelihood of escalation of mental health conditions and challenging behaviour
 - People with autism in Haringey do not have opportunities to **inform service decisions**
 - There does not seem to be enough focus on **employment** or **social support** when considering the needs of adults with autism
 - There is a lack of understanding of the needs of people with autism in the **Criminal Justice System**, and how these could be met
 - There is a **lack of co-ordination** between different services, and people with autism and their families can find it very difficult to navigate a support system populated by so many different agencies
 - **Concerns have been raised by parents** about the capacity of Speech and Language Therapy services, and about the closure of day centres
 - Finally, it has been hard to complete a full needs assessment due to **lack of data** from key services; there is a need for better records to be kept in order to improve our understanding of who in Haringey has autism, what their needs are and how we can best meet them.
- Work is already underway to meet some of these needs and others are addressed in the recommendations section.

Summary of recommendations



Strategic Recommendation

In order to meet the needs of children and adults with autism in Haringey, there needs to be a shared understanding of what we are trying to achieve and how we will work collaboratively to achieve it.

Therefore, the over-arching recommendation from the needs assessment is for Haringey to establish this shared understanding, as a foundation for future work. Work to achieve this is likely to include:

- Establishment of commitment from key organisations to working to improve services for people with autism
- Identification of an autism lead (named joint commissioner or senior manager) as per NICE guidelines
- Development of an autism strategy for the borough, to include a shared vision
- Development of partnership governance arrangements which can oversee progress on the strategy once agreed (including a decision on whether there should be a single arrangement or separate ones for children and adults)

Key themes

1. Improve data collection and understanding of compliance with clinical good practice
2. Support engagement and collaboration with service users and their families
3. Increase the likelihood that people with autism receive services which understand and are able to adapt to their needs
4. Make changes to services with the aim of improving their quality and ability to meet the needs of people with autism

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, mental health services and GPs	Awareness of diagnosis facilitates better care and improves data available (e.g. on autism in older people)	GPs Adult Social Care Barnet Enfield and Haringey MHT CAMHS Providers
Undertake an audit to establish gaps in compliance with NICE guidance	Ensure compliance with relevant guidance	CCG Providers

Full recommendations – theme 2



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

Recommendations	Benefits	Responsibility
Explore engagement routes outside the Autism Partnership Board	Reach greater numbers Improve two way communication	Autism Partnership Board
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	Meeting need for low intensity, social and preventative support	Voluntary & Community sector (local and specialist providers)
Consider how best to build the skills of parents of teenagers with behaviour and / or mental health issues	Reduced risk of escalation of issues Children able to remain at home Improved parental wellbeing	CCG - Children's Commissioning
Consider ways to provide ongoing support to parents to implement therapeutic approaches at home	Improved outcomes for children from therapies Improved parental wellbeing	CCG - Children's Commissioning
Use surveys and other methodologies to better understand needs and concerns (the Oxfordshire Aspergers JSNA contains a description of a sample methodology)	Wider opportunities to inform service design Improved data for planning	Autism Partnership Board and other relevant engagement groups

Full recommendations – theme 3



3. Increase the likelihood that people with autism receive services which understand and are able to adapt to 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)	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	Improved awareness among non-specialists Better and more responsive care Prevention of escalation	Co-commissioned through the Autism Partnership Board
Ensure mental health services and GPs are able to offer reasonably adjusted care to people with autism	Recognising known higher rates of mental illness Better quality of care Prevention of escalation of mental health issues	Mental Health Commissioning and providers GPs
Higher training for autism experts or ambassadors in key teams	Source of expert advice within teams, which can be shared outside formal CPD settings	Autism Partnership Board
Explore opportunities to create a virtual “ autism team ” for adults, at a minimum to provide expert advice and support, but ideally reflecting the NICE recommendations i.e. facilitating a multi-disciplinary care co-ordination approach. Aspects of this could be developed within the Transforming Care Programme multi-agency hub being developed across the North Central London partnership	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 4



4. Make changes to services with the aim of improving their quality and ability to meet the needs of people 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 – Vulnerable Adults Adult Social Care
Ensure the new Adult Social Care generic adults’ service (planned for April 2018) is responsive to the needs of adults with autism	Meeting Care Act obligations Improved ability to meet needs of adults with autism but no GLD	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	14+ working group
Explore scope for co-commissioning a local adult diagnostic service	With the aim of reducing cost and/or waiting times and providing a local service (meeting NICE recommendations)	CCG – Vulnerable Adults
Give consideration to the needs of people with autism in the Criminal Justice System (including through Liaison and Diversion service and prison health services)	Meeting Autism Act recommendation	Community Safety Partnership
Increase focus on participation in volunteering and employment as an outcome for adults supported by Adult Social Care	Meeting Autism Act statutory guidance	Adult Social Care

Prevention pyramids – supporting healthy, fulfilling lives



Haringey's Public Health team has been developing a number of “**prevention pyramids**” to map the range of influences on particular health conditions, and identify opportunities for **policy makers, communities and services** to support healthy, fulfilling lives. This includes opportunities to prevent the escalation or deterioration of conditions after they are identified.

The autism prevention pyramids have been developed alongside the needs assessment, and provide a different perspective from which to answer the question of how well we are currently meeting the needs of people with autism in Haringey. While the needs assessment is mainly focused on service provision, the pyramids encourage us to look more broadly, and to consider the role of communities and policy in contributing to positive outcomes for people with autism.

The next two slides show the two pyramids; one showing **the current suite** of interventions available in Haringey to support children and adults with autism, and the second mapping a wider range of **possible interventions**.

Considering the two pyramids, the main questions which arise are:

- How can we ensure that existing services can be better **adapted** to the needs of people with autism?
- Is there more we could be doing to build **capacity in the community** to support people with autism, or to make their lives easier?
- What **role** do statutory services play in preventing the escalation of need?
- Is there scope to do more to **prevent escalation** up the pyramid?

These should also be considered by officers, Councillors and residents when considering how best to meet the needs of people with autism in Haringey.

NB the “as is” pyramid identifies existing services but does not make a judgement as to whether these are effectively meeting needs, or have sufficient capacity to meet demand.

Prevention pyramid – existing interventions

For children with autism

For adults with autism

For adults and children

Tertiary prevention
reducing impact of health and care needs and promoting quality of life

Approximately 100 people

Transforming Care Programme

Disability benefits

Secondary mental health services

Secondary prevention
early detection followed by appropriate intervention or health promotion

Approximately 800 people

Autism Act and Strategy

Learning Disabilities Partnership

Mainstream adults services e.g. Housing, JCP, Benefits

Employment support

FE Colleges

Therapies (NHS)

Primary mental health services

Social clubs (Markfield, HAIL)

Post-diagnosis support for parents

National SEND Policies

Autism youth club (Muswell Hillbillies)

Mainstream and special schools

Diagnostic pathways

Transitions planning

Primary prevention
promoting health and preventing ill-health

Approximately 1,800 people

Support for carers

National Autistic Society local network

Tynemouth Rd specialist dentist

Population health (policy)

Community health

Individual health

Prevention pyramid – scope for further development

For children with autism

For adults with autism

For adults and children

Tertiary prevention
reducing impact of health and care needs and promoting quality of life

Approximately 100 people

Transforming Care Programme

Disability benefits

Secondary mental health services

Approximately 800 people

Secondary prevention
early detection followed by appropriate intervention or health promotion

Autism Act and Strategy

Opportunities to influence service decisions

Learning Disabilities Partnership

Mainstream adults services e.g. Housing, JCP, Benefits

Employment support

FE Colleges

Peer support for adults with autism

Therapies (NHS)

Primary mental health services

National SEND Policies

Social clubs

Post-diagnosis support for parents

Youth clubs

Mainstream and special schools

Diagnostic pathways

Transitions planning

Primary prevention
promoting health and preventing ill-health

VCS facilitated networks

Approximately 1,800 people

Peer support for carers

Adapted mainstream service provision

Autism friendly leisure activities

Autism aware communities

Population health (policy)

Community health

Individual health

- Chapter 2 – Background and Context

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.

Scope of this needs assessment



This assessment considers the needs of people with autism in Haringey:

- Children, adults and older people
- Across the autistic spectrum, including those without a Learning Disability
- The needs of people who may not have a diagnosis or currently be accessing any services

A wide range of needs are considered, and gaps in service provision to meet these needs identified. These needs are:

1. Diagnosis
2. Therapeutic needs
3. Health needs
4. Education
5. Transitions
6. Social care
7. Training and employment
8. Housing
9. Mainstream services
10. Social support
11. Involvement in service planning and provision
12. The needs of carers
13. Systemic needs: co-ordination, early intervention, prevention

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

- Chapter 3 – Prevalence

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 between different studies, 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 psychiatric disorder [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/gs51/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

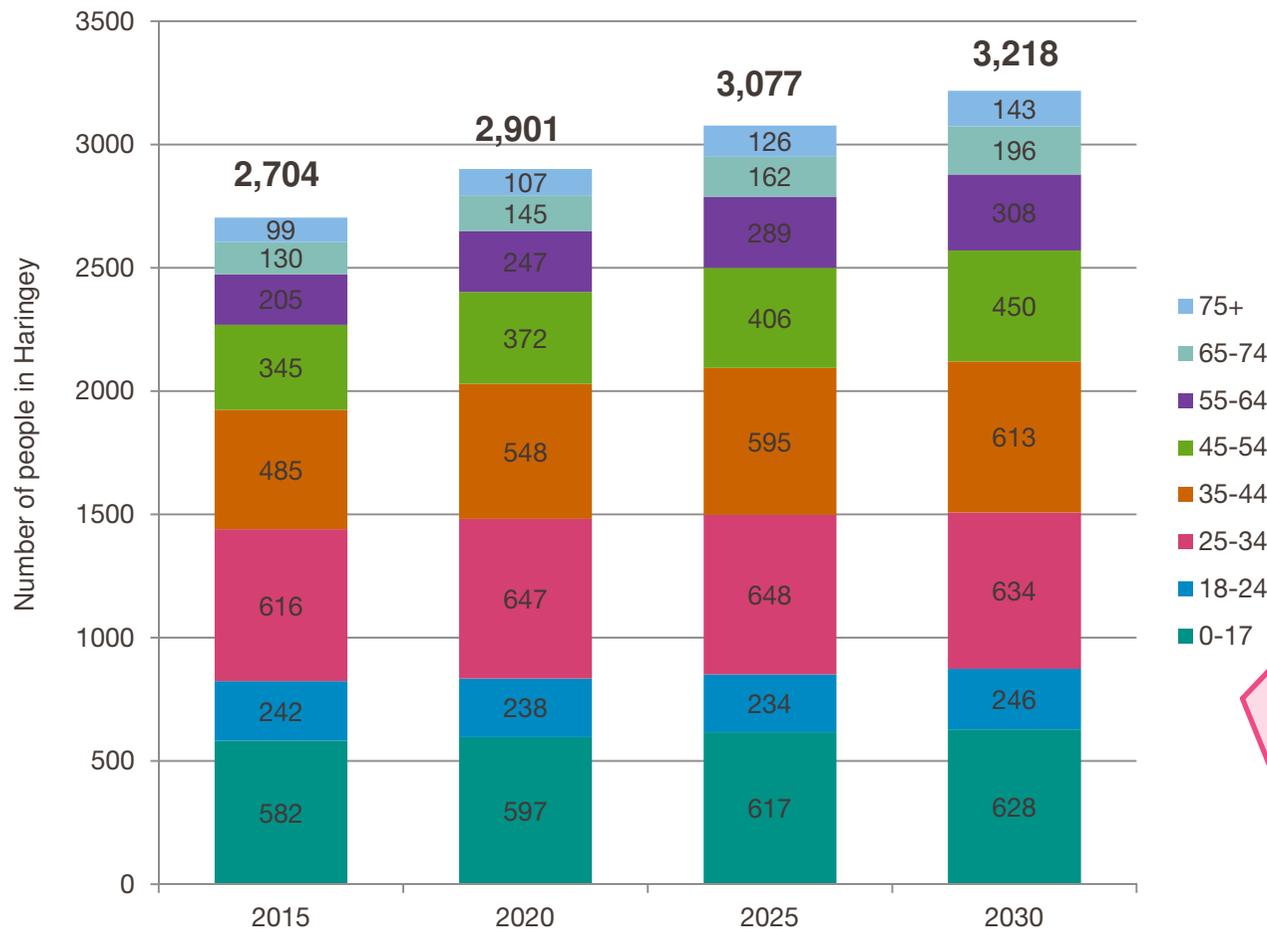
http://www.improvinghealthandlives.org.uk/uploads/doc/vid_8731_IHAL2010-05Autism.pdf

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

Local picture – estimated prevalence



Estimated numbers of children and adults with autism in Haringey

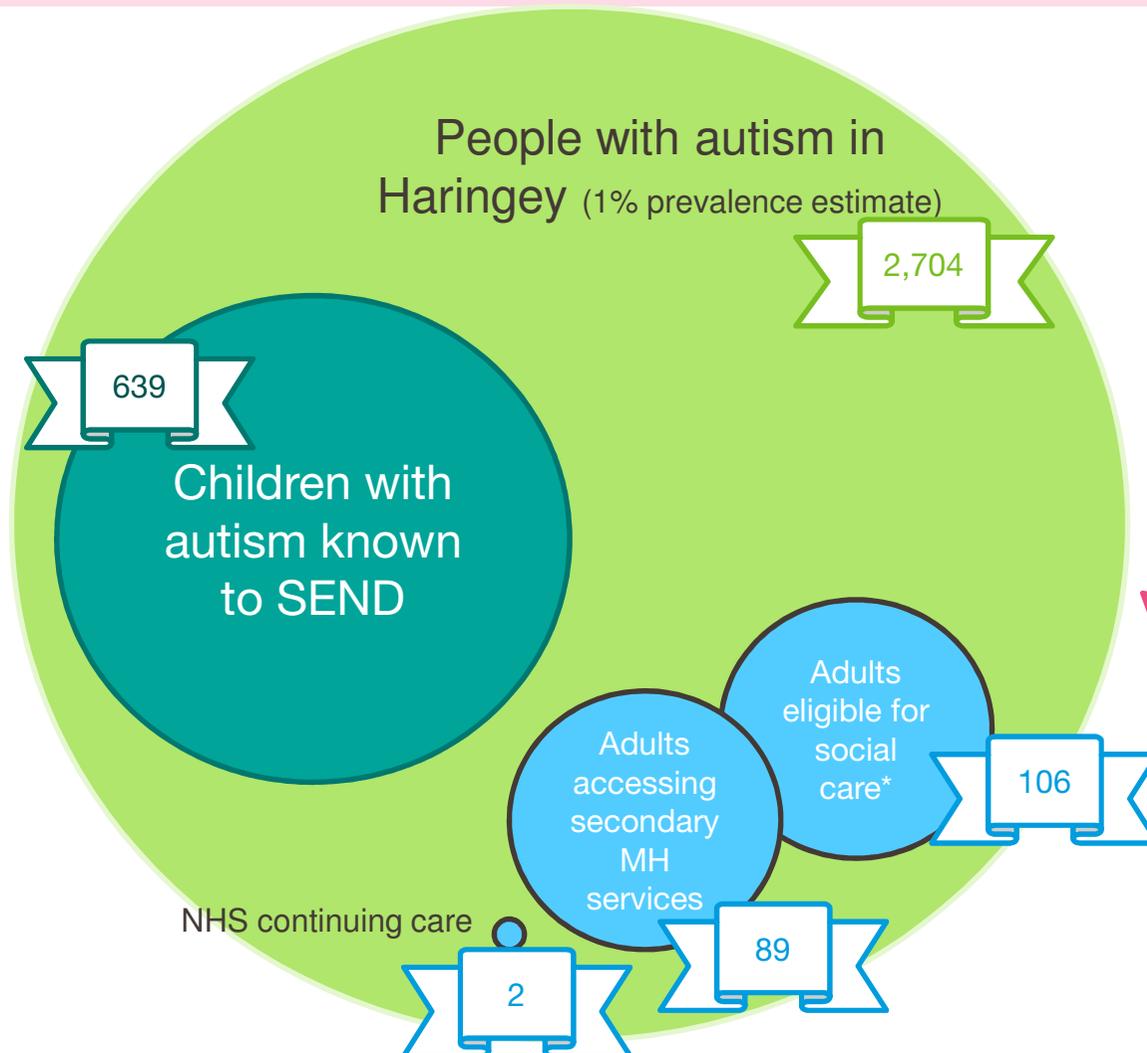


These estimates were calculated by applying a 1% autism prevalence level to Office for National Statistics population projections for Haringey.

The actual numbers could be higher or lower than these. While not accurate, they give an indication of the likely size of the population with autism.

These estimates also assume that prevalence is stable over time (i.e. that the rate of autism in the population has not been increasing in recent years)

Local picture – people known to services



Statutory services are only able to identify a small proportion of the estimated population of people with autism in Haringey. 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

It should be noted that, 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.

Data from PANSI (2015 estimate), POPPI (2015 estimate), Haringey Special Educational Needs and Disabilities database (September 2016), BEH Mental Health Trust (October 2016) and ASC Mosaic database (October 2016)

•Of these, 104 are in Learning Disabilities, 1 in Older People and 1 in Physical Disabilities. This reflects the fact that processes for recording diagnoses of autism are better developed in LD than in Mental Health, Physical Disabilities and Older People teams, and is likely to be an underestimate of the number of adults with autism accessing social care services.

Only 2 adults are flagged as receiving NHS Continuing Care due to autism; others with autism are supported via this funding, but their autism diagnosis is not recorded in a way that enables us to identify or count them.

Local picture – estimates of future need (1)



- The current numbers of children with autism in schools [1] are higher than predicted by a 1% prevalence rate – approximately 13 in 1,000 instead of 10 in 1,000:

	2015/16
1% prevalence estimate (5-17)	412
Total population (5-17)	41,237
Current SEND population (School years 1-13)	539

- As some children will be diagnosed some way through their time in school, it is likely therefore that prevalence is somewhat higher than this level.
- This figure is higher than found by Baird et al (2006) (prevalence rate in South East London children aged 9 and 10 of 11.6 per 1,000) [2] but lower than that found by Baron-Cohen et al (2009) (15.7 in children aged between 5 and 9) [3]

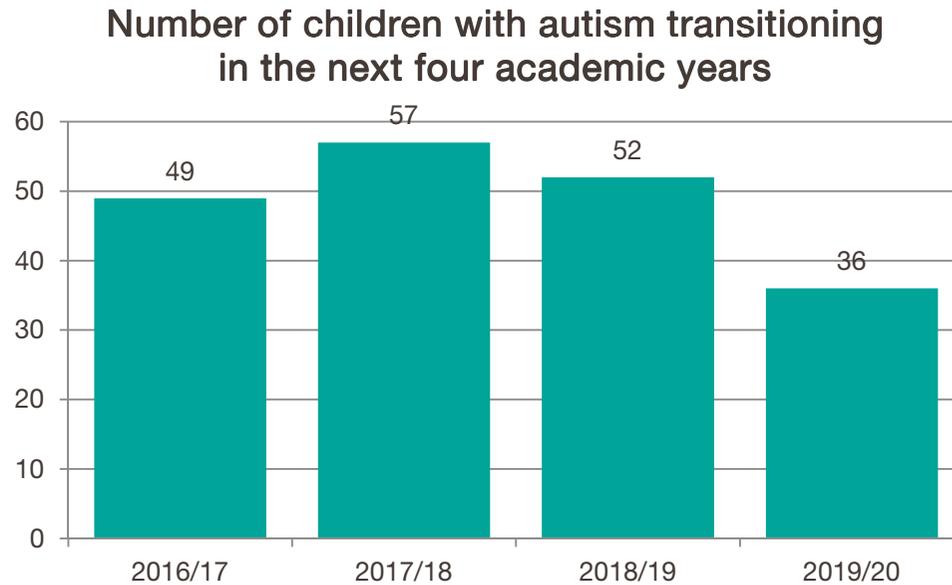
[1] Based on Haringey SEND database summer 2016 covering school years 1 to 13

[2] Baird et al. (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames. *The Lancet* 368 (9531) pp. 210-215

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

Local picture – estimates of future need (2)

- Data from Haringey's SEND database gives an indication of the number of children with autism likely to begin the transition process (Year 9) towards adult services in coming years:



Numbers are small, and therefore subject to variation year on year, but suggest a need to plan for approximately 50 young people with autism entering adulthood each year in Haringey

- The SEND database does not provide details of the level of need of these young people, but by the end of secondary school approximately 6% are recorded as have a diagnosed learning disability (IQ<70) and another 6% as having Social, Emotional and Mental Health needs in addition to their autism. These figures appear low given what we know from national studies of children with autism and suggest there is scope to improve recording of secondary conditions by schools.
- The 2016 Autism SAF identified 3 young people with autism transitioning from education into Adult Social Care services last year. A further 3 transitioned to NHS continuing healthcare, and the rest (6 young people) transitioned to further education. This cohort (at 12 young people) was smaller than those we are expecting to transition in coming years.

Local picture – estimates of future need (3)

- Information from schools gives us an indication of the number of young people with autism entering adulthood each year
- However, we have very limited information, beyond the PANSI estimates based on 1% population prevalence, about the numbers and characteristics of those who are already adults, and therefore what needs this group may have in future.
- A simple projection based on current numbers of users of statutory services and using population growth estimates gives the following level of demand for services.
- In the absence of complete data on the numbers of people with autism receiving NHS Continuing Health Care, it is not possible to estimate how demand for this level of support is likely to grow.

Projections of service use based on estimates of population growth 2015-2030



As they are based on current levels of service use, these may underestimate true demand or need, due to difficulties obtaining diagnosis or accessing existing services, and the absence of specialist services for some autistic people

The local picture – gaps in the data



There are a number of significant gaps in the data which make it impossible to present a comprehensive picture of the autistic population in Haringey and their needs.

These gaps include:

- **Reliable figures** for the number of adults with autism in Haringey
- Haringey-specific data on the numbers of people in different **parts of the autism spectrum** e.g. how many people also have a learning disability or display behaviour that challenges
- Haringey-specific data in a number of **areas of need** including housing, employment and the Criminal Justice System
- A full understanding of the **quality, effectiveness** and **cost** of services available for people with autism in Haringey

Reasons for these gaps include:

- Some people with autism, especially adults, are **undiagnosed** and are therefore not identifiable as having autism
- Some adults, even those with a diagnosis, may **not be eligible for or using any statutory services**
- Statutory services (including Council and NHS services) often do not **keep records** of which people using their services have autism
- There have been issues in **accessing data** held in different parts of the system
- The data available is not always **up to date** or **complete**

- Chapter 4 – Needs

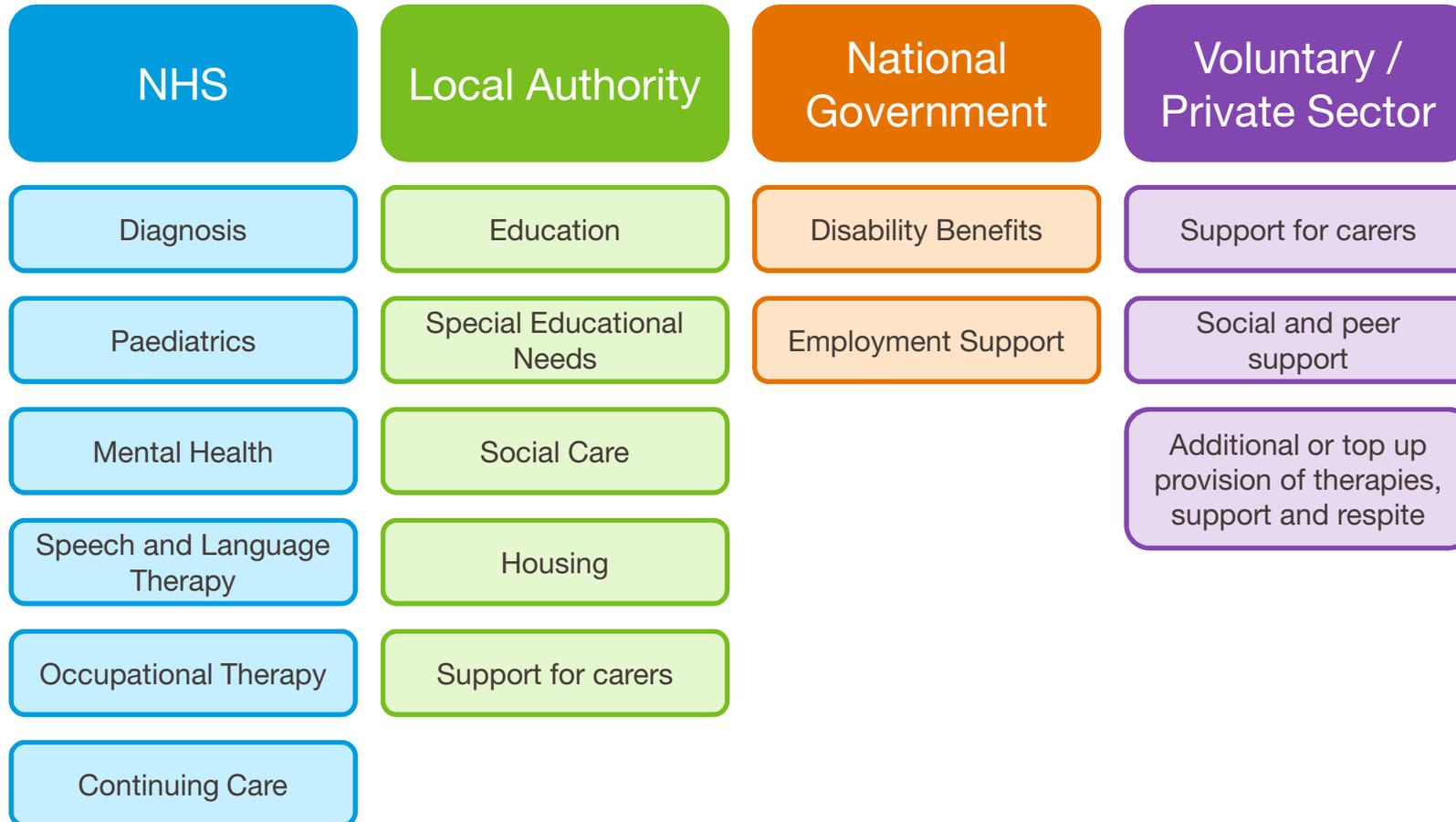
The needs of people with autism – national assessment



The NAS research report *I Exist* (2008) 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"

Summary of organisations and services



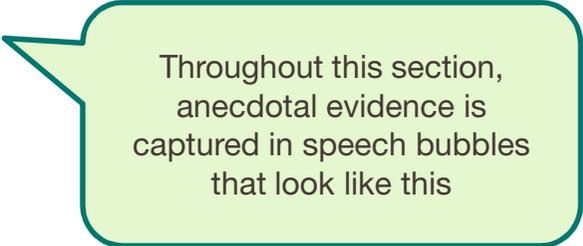
Structure of needs assessment

The rest of the slides in this section are structured as follows:

1. First, a slide setting out what is known **in general, nationally and sometimes internationally**, about the needs of people with autism
2. Secondly, a summary of the services in place **locally in Haringey** to meet those needs, and where available, some commentary on the extent to which these effectively meet needs or adhere to best practice or national guidelines

The needs covered are:

1. Diagnosis
2. Therapeutic needs
3. Health needs
4. Education
5. Transitions
6. Social care
7. Training and employment
8. Housing
9. Mainstream services
10. Social support
11. The criminal justice system
12. Involvement in service planning and provision
13. The needs of carers
14. Systemic needs: co-ordination, early intervention, prevention



Throughout this section,
anecdotal evidence is
captured in speech bubbles
that look like this

Diagnosis



- As awareness of autism has increased, so have rates of diagnosis. There is 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, 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
 - Late 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 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>

Diagnosis – the local picture

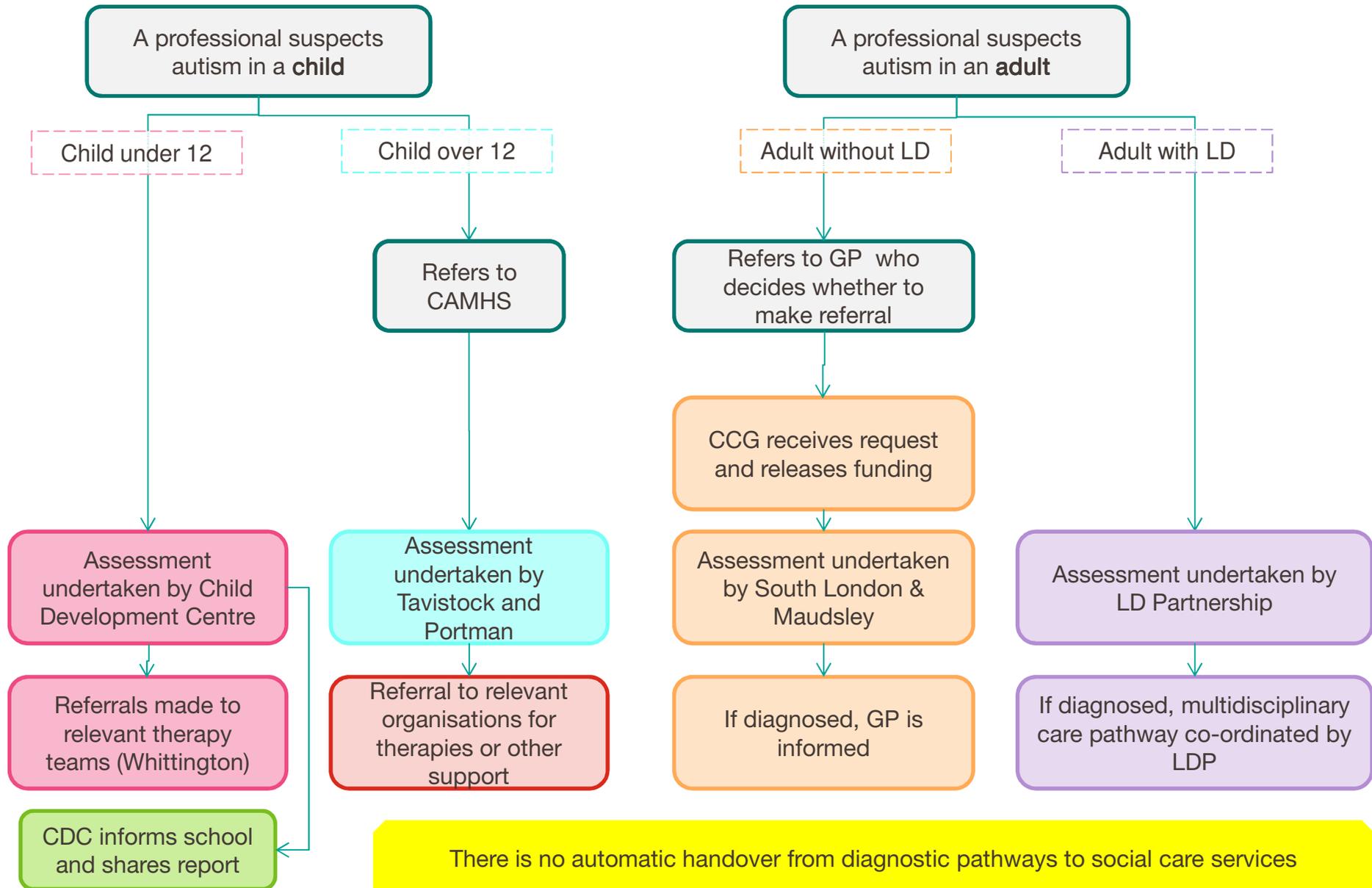


- There are a number of different diagnostic pathways for autism in Haringey (see next slide):

	Provider	Number of referrals p.a.	Average waiting time
Children under 12	Whittington Health	~220	49 weeks
Young people over 12	Previous service: Great Ormond St New service: Tavistock & Portman	~42 N/A new contract	No data N/A new contract
Adults with Learning Disabilities	Haringey LD Partnership	No data	No data
All other adults	South London & Maudsley	~16	29 weeks

- Waiting time is defined as the period between the diagnostic service receiving the referral and when the clinic first sees the person, or the person withdraws from the list. NICE guidelines are for a waiting time of no more than three months.
- There are a number of concerns about current diagnostic arrangements:
 - Waiting times are too long (and can be up to 18 months for adults)
 - Delays in diagnosis can prevent people from accessing services; for example, a social worker was unable to undertake a full assessment for over 18 months because of delays in diagnosis, limiting the level of support that could be provided
 - While the families of children receiving a diagnosis have access to a number of forms of support – including EarlyBird, drop in sessions at the Child Development Centre and FABLE (a behaviour support programme) – this support, alongside statutory provision e.g. education and therapies, is not felt to be well co-ordinated
 - The service at SLAM, whilst believed to be high quality, is not local, and travel to a distant and unfamiliar area may be a barrier to diagnosis for some adults with autism
 - Each request for adult diagnosis required CCG approval before it can be undertaken by SLAM, and there are instances of funding not being approved (including for people who subsequently received a diagnosis)
 - There is no link between SLAM and LB Haringey’s Adult Social Care Team; in 2015/16 there were no referrals for care assessment following a diagnosis of autism
 - Some health professionals still have limited understanding of autism, and can discourage people from seeking diagnosis

Haringey's diagnostic pathways (overview)



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>

Therapeutic needs – the local picture

- Following an autism diagnosis and assessment, children are generally offered time-limited OT and SLT. Those under 5 years old may also be invited to join a social skills group
- Commissioners are confident that there is sufficient provision of NHS **SLT** services:
 - There is a 12-16 week wait for Speech and Language Therapy for Under 5s
 - In October 2016, 231 children in mainstream schools were receiving SLT support – mainly delivered by teachers with support and input from SLT professionals
 - All children in special schools have access to SLT if required, usually delivered in group settings with teachers and teaching assistants
- There are disagreements between commissioners and parents about whether levels of **SLT** support are sufficient:
 - Some parents of both verbally able and non-verbal children feel that SLT services and session frequencies are insufficient to meet their needs.
 - Some parents are supplementing NHS therapies with support from private providers, which may cost £60 per hour / £700 per month depending on their intensity, and believe this has led to significant improvements for their children
 - The CCG plans to review SLT provision for children in 2017
- There are difficulties filling **OT** posts (reflecting national shortages), although the Whittington is working to improve the situation, with support from commissioners. Limited resources tend to be focused on those with physical disabilities. There is a need for more OT support for children with autism and sensory or behavioural needs.
- There is a focus on using Therapists to help teachers, teaching assistants and parents to implement therapies in order to embed approaches across the child's environments
 - Whilst it makes sense to develop skills in the adults that children spend most time with, there will always be a need for highly skilled professionals, not only to develop an action plan, but to monitor progress, adapt strategies and provide support to tweak and tailor interventions
- There are also a range of resources available in the voluntary sector. HAIL Hub provides sensory assessments, training on sensory support and support to test out different communication systems, while Markfield offers training on sensory needs and a Stepping Stones course which uses play to improve communication skills

“Early Bird and other training is excellent, but parents would benefit from more support actually putting training into practice at home”
– Parent of a child with autism

“It is hard to persevere when you see your child repeatedly failing... We need professionals who know how to adapt strategies and who are more emotionally detached” – Parent of a child with autism

Health needs



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

[1] Cusak, J et al (2015) *Personal Tragedies, public crisis: the urgent need for a national response to early death in autism*. London: Autistica
<https://www.autistica.org.uk/wp-content/uploads/2016/03/Personal-tragedies-public-crisis.pdf>

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

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

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

[5] <http://www.nhs.uk/Conditions/Autistic-spectrum-disorder/Pages/Treatment.aspx> . It should be noted that NICE does not recommend this model for children, and calls for further research into its effectiveness, but does recommend it for adults in its Guideline on Diagnosis and Management of autism in Adults - <https://www.nice.org.uk/Guidance/CG142>

[6] https://westminsterautismcommission.files.wordpress.com/2016/03/ar1011_ncg-autism-report-july-2016.pdf

[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

Health needs – the local picture (primary care)



- An audit request was agreed with one GP practice to better understand recording of autism by GP practices
 - Unfortunately, the practice could not find capacity to conduct the audit, so we do not have an indication of how autism diagnoses are recorded by local GPs or what reasonable adjustments (if any) are being put in place by GP practices
- At present there are no specialist GP services for people with autism; informal networks and recommendations are used by parents and carers to find GPs who are knowledgeable and supportive of people with autism
- Continuing Professional Development courses covering autism are available to GPs via the Royal College of General Practitioners, however uptake in Haringey is unknown [1]

[1] <http://www.rcgp.org.uk/learning/online-learning.aspx>

Health needs – the local picture (specialist and secondary care)



- There are a number of specialist health services available to **children** with autism in Haringey:
 - Specialist dentist service at Tynemouth Road
 - LD CAMHS team for children with LD and mental health conditions, including children with autism who meet these criteria, with a focus on managing very challenging behaviour
 - Counselling service for teenagers and young people with disabilities at Open Door (50% of those accessing this service have autism)
 - Therapeutic services provided by the NHS generally appear well adapted to the needs of children with autism
- However, there seems to be a lack of co-ordination between different health services, with no one professional responsible for overseeing the progress a child is making, or ensuring they receive the services they need. The Haringey system is education-led, making it harder to ensure NHS services are accessible if needed. In other areas NHS employees – community paediatricians, therapists or school nurses – play a more active role in this.
- Access to health services for autistic **adults** in Haringey is variable:
 - For those with a learning disability, a range of adapted services are available via the Learning Disability Partnership, including mental health services (psychology and psychiatry), Occupational Therapy, Physiotherapy and Speech and Language Therapy. The LDP also employs specialist LD nurses who can support people to navigate and access health services effectively
 - However, for those without a Learning Disability there are no specially adapted services, either for physical or mental health
 - There are particular concerns about the inaccessibility of mental health services, given known high rates of mental ill health among people with autism. Autism training for mental health professionals appears patchy and is often not detailed, specific or practical enough to make a real difference to how services are delivered
 - There are anecdotal examples of health professionals adapting the provision of health services to the needs of a person with autism e.g. Bringing diagnostic tools to their home, or providing a general anaesthetic for a scan, but no systemic or co-ordinated approach to improving the accessibility of health services
- As with children, there is a lack of co-ordination across health services for adults without learning disabilities. The NICE recommendation on the provision of care co-ordinators has not been implemented in Haringey

“My son’s mental and physical health has been damaged because there is a wide-spread lack of understanding of the needs of young adults with normal IQ” – Parent of a young adult with Asperger’s Syndrome

“Some people with autism can’t access therapies or health services until their challenging behaviour is under control – it can be chicken and egg” – Parent of an adult with autism

“Mental health services seem particularly insensitive to the needs of people with autism” – Parent of an adult with autism

- Because of the spectrum nature of autism, the educational needs of children with autism vary widely. Although approximately half will not have a low IQ (under 70), many of these will still require additional support in order to meet their educational potential, due to sensory, social or attention difficulties.
- A range of educational settings are required to meet the needs of all children with autism:
 - Nationally, the majority of children with autism attend mainstream schools (70%)
 - Others may attend specialist units within mainstream schools, specialist autism schools or schools for children with a range of disabilities
 - A small number will have needs that can only be met through term time or full time residential school placements
- Alongside educational difficulties, children with autism face a number of challenges in education:
 - 27% of children with autism have been formally excluded from school, compared with 4% of children without autism – most commonly due to physical assault against a pupil or teacher [2]
 - NAS expressed concern that one third of children with autism have been “informally excluded” from school on at least one occasion – asked not to attend but no formal record is kept. This has no basis in law and should not be happening [1]
 - Anecdotally, there is also evidence that young people with autism who attend university are at higher risk of dropping out without specialist support [3]. Some universities, including Cambridge and Birmingham City, have developed programmes to improve the experience of young people with autism and reduce drop-out.
- Nationally, 74% of parents of autistic children say it has not been easy to get the educational support their children need, and many have needed to use legal challenge. The most commonly missing areas of support were [1]:
 - SLT (33%), Mental Health (26%), leisure opportunities (26%) (receive but need more)
 - Befriending (70%), short breaks (64%), daily living skills (62%), OT (57%) (want but don't receive)

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

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

[3] <http://network.autism.org.uk/good-practice/evidence-base/widening-access-higher-education-autistic-students>

Education – the local picture



- 38% of children on the SEND register in Haringey have a primary or secondary need of autism
- 63% of children with autism in Haringey attend mainstream schools (with or without specialist units) (vs. 70% nationally)
 - Most other children attend one of the special schools in Haringey (24%) – which have all been judged Good (The Vale, Riverside) or Outstanding (The Brook) by Ofsted, or special schools outside the borough (9%)
 - A small number are educated at home, attend private schools or attend FE colleges
 - Teachers in mainstream schools are supported to work with children with autism by an “autism team”
- Given national estimates that around 50% of children with autism will have a learning disability, a surprisingly small number are recorded as having one in the SEND database (4-6% in Secondary years, and fewer in Primary)
 - It is not clear why this might be. It may be that learning disabilities are not always recorded if a primary diagnosis of autism has already been made. Alternatively, it may be harder to diagnose autism in cases of profound learning disabilities (although it does not appear we have a significant level of under-diagnosis). Under-recording may be an issue if it makes it harder for children transitioning to access adult LD services.
- Children with autism are disproportionately likely to be excluded from school in Haringey; however, rates appear much better than the national picture, with 8 fixed term exclusions of secondary age children with autism in 2014/15, and the local authority challenges unofficial exclusions whenever they are made aware of them. Nevertheless, parents of children with autism make up the largest group using Haringey’s SEND independent advice service (run by Markfield), and frequently raise concerns about both formal exclusions and feeling under pressure to voluntarily withdraw their child from school.
- There are plans to open new 4-19 school for children with autism, offering 104 places with separate units for those working above (16 places) and below (88 places) age-related expectations (the Grove)
 - Currently there is no specialist state provision in the borough for children with high functioning autism
- Some parents are concerned that there is a lack of attention given to children placed in schools out of the borough, including when it comes to transitions

“The autism team in Education were really great, they transformed the situation and made all the difference for the transfer to Secondary school” – Parent of a young adult with Asperger’s

“While he was out of borough, no one from Haringey attended his annual reviews for years. No one knew if his placement was still appropriate” – Parent of a young adult with autism

- The process of transition has been developed in recent years in response to the “cliff edge” faced by many children in the past moving from the support received while in education to adult services.
 - It should ensure continuity of services, as well as co-ordination between a young person’s health, education and care needs, which should all be considered during the transition planning phase
- Transition planning should be a multi-agency process, and should include consideration of benefits, further education, higher education, employment, health issues, transport, housing, leisure opportunities, social care services, direct payments and individual budgets
- Not every child with autism is automatically eligible for a transition plan. However, their care needs should be assessed by the local authority if there is a chance they will meet the national eligibility criteria for care:
 - Their needs arise from or are related to a physical or mental impairment or illness AND
 - This makes them unable to achieve two or more specified outcomes (including maintaining personal hygiene, managing toileting, maintaining relationships to prevent loneliness, accessing and maintaining employment, keeping the home clean and safe etc) AND
 - As a result of being unable to meet these outcomes, there is likely to be a significant impact on the adult’s wellbeing
- All young people with autism, regardless of their eligibility for a formal transition plan, are likely to benefit from planning around key aspects of life as an adult, including:
 - Help with facing and planning for adult life
 - Specialist and ongoing employment support
 - Peer support and opportunities to spend time with others with the same diagnosis
 - Voluntary work placements in setting where autism was understood and accommodated [1]

[1] Beresford, B., Moran, N., Sloper, P., Cusworth, L., Mitchell, W., Spiers, G., Weston, K. and Beecham, J. (2013) *Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions*, Working Paper, no: DH 2525, Social Policy Research Unit, University of York, York.

<http://php.york.ac.uk/inst/spru/research/summs/transitionsASC.php>

Transitions – the local picture

- In Haringey, all children who have a statement of special educational needs or an Education, Health and Care plan receive a transition plan as part of their annual review when they reach the end of school.
- The transition process is led by the young person's school with input from other professionals as required
- Although the transition process is supposed to begin in Year 9 (age 14), it can be difficult to engage adult NHS or council services until the young person turns 18
- In many cases, young people will not be judged likely to be eligible for adult social or health care services, and therefore will not be referred for assessment by these teams. In these cases they will receive transition planning and support for education only
- There are very limited staff resources in the transitions team which sits in Adult Social Care; only two social workers cover transitions for all children with special educational needs (over 100 leaving school every year)
- In the 2015/16 school year, only 3 young people with autism transitioned to Adult Social Care (3 more transitioned to NHS continuing health care, and 6 to further education)

“Staff need to be well informed about transition options and sympathetic, and we need access to independent advocates to make sure nothing is missed” – Parent of a young adult with autism

“We were denied a transition assessment for social care, despite the serious concerns of our experienced SENCO, until my son suffered a serious breakdown in his mental health and was finally deemed eligible for assessment ” – Parent of a young adult with Asperger's

“There are a lot of issues with the transition process. There need to be improvements in staff expertise, the engagement of parents in the preparation of documentation and the quality of the documentation – as it can have such a big impact on what care is received” – Parent of a young adult with autism

“There needs to be more transparency in the criteria determining whether a young person is educable and therefore if education will be funded” – Parent of a young adult with autism

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.

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

Social care – the local picture



- In Haringey, as nationally, there are currently no Council social care services or funding for adults with care needs who do not meet LD, PD or MH criteria, including many adults with autism
 - However, work is currently being done to improve skills in the Integrated Access Team to identify eligible needs in people with autism, and to explore the possibility of moving resources to provide more preventive support, as mandated by the Care Act
 - Changes to the structure of services are planned which will create a generic adults' service, for all without LD or MH conditions
- For those who do receive Council social care, records of autism diagnosis are incomplete.
 - Following a push to improve recording in the LD service, numbers increased from 42 (2014) to 104 (2016) (representing 14% of the total LD cohort); however, there is still under-diagnosis and under-recording, as the lead for diagnosis in the LDP estimates that 30% of the LD cohort also has autism.
 - There appears to be little or no recording by other teams; only one diagnosis is recoded from each of the Older People or Physical Disabilities teams, and none in Mental Health
- Social care is provided in the form of direct services, or funding to purchase services, and there is a move away from the Council providing services towards the development of a market of provision offering choice and variety to those who require care, and a focus on meeting outcomes rather than just providing opportunities.
 - Personal budgets and direct payments can be used to purchase a range of support including support at home / accommodation in supported living and leisure activities. The median cost of packages is just over £31,000 p.a.
 - The Roundway currently offers day opportunities to adults with autism and LD but services are being redesigned; there are some social groups at HAIL and Markfield which mainly cater for those with Asperger's Syndrome but are not explicitly autism services.
 - Work is underway to co-design new day opportunities with LD service users and carers
- In addition to Council funded social care, two adults with a primary diagnosis autism are currently receiving full time residential hospital care under NHS "Continuing Care" funding (and tens more are likely to be, but are categorised under a primary need of LD or MH, which means we cannot tell whether they also have autism)

"My son's care co-ordinator didn't know anything about autism or Asperger's" – Parent of a young adult with Asperger's accessing support from the Mental Health team

"When people are known to be receiving care due to having Learning Disabilities, home- or day-care providers may not realise they also have autism. They may not be trained and there may be issues as they don't understand or can't deal with the behaviours" – Voluntary Sector Organisation

"We are worried about the loss of day services – we fear our son will receive fewer hours, leaving us to pick up more of his care" – Parent of a young adult with autism

"The dynamic purchasing system requires care providers to bid based on a one page summary of needs, which may not be complete or accurate. It was originally meant for purchasing stationery... Very worrying" – Parent of a young adult with autism

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

Training and employment – the local picture



- In addition to mainstream colleges and vocational **training**, Haringey hosts a number of specialist providers:
 - One of Ambitious College’s two campuses is co-located with College of Haringey, Enfield and North East London in Tottenham, offering a curriculum based around Independent Living and Housing; Employment; Friends, Relationships and Community; and Good Health specifically for young adults with complex autism
 - John Dewey Independent College (Area 51) supports young adults with severe learning disabilities and complex needs to become more independent and pursue routes to employment and volunteering
 - Just outside the borough boundary in Southgate (but open to Haringey residents) is DALO, which offers a range of social and training opportunities to young adults with disabilities
- Under the care act, social workers are required to support adults into **employment**:
 - At present, 3% of adults supported by the Learning Disabilities team are in employment, against a local target of 5%
- There is one specialist employment advice and support service for people with autism in Haringey, based at the HAIL autism hub in Tottenham
- There are also a number of more generic national services available:
 - Work Choice – provision of support to find, get and keep a job for people with disabilities (although the national evaluation found it was less effective for some groups of disabled people, including those with autism) [1]. This is accessed via Disability Employment Advisors in Job Centres.
 - Access to Work –provision of support to those already in employment or self employed with disabilities or health issues. Support includes autism training for employers, advice on suitable reasonable adjustments and regular visits from a Support Worker

“With the right support I’m confident my son could hold down a job – but most of the support seems to be with getting a job, and he’d need it on the job as well” – Parent of a young adult with Asperger’s

“It feels like people with autism are made to jump through more hoops in Haringey to avoid benefit sanctions than they are in other parts of London... Lots of people are sent repeatedly on the same schemes which don’t help them and leave them feeling demoralised and confused.” – VCS organisation

[1] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/210683/rrep846.pdf

- 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>

Housing – the local picture



- There is a lack of information about the housing situation of adults with autism in Haringey.
- For adults in receipt of Adult Social Care services (all with Learning Disabilities), 58 are funded for accommodation-based support:
 - 48 receive residential care or supported living and a further 10 receive home-based care in a private property
 - However, this is only a count of those recorded as having autism; lack of recording means this is very likely to be an underestimate
- It is likely that a significant number of the adults with autism in Haringey are social housing tenants, but no data is collected on autism diagnoses by social landlords or Homes for Haringey
- Under Haringey’s allocations policy (currently under review) there is scope to prioritise people for social housing with autism under welfare grounds (if they are considered extremely vulnerable and temporary accommodation would not be suitable (as would be the case for most adults with autism), but it is not clear how often this is done.
- Under the Transforming Care programme there are attempts to reduce the number of hospital beds used to care for adults with autism combined with behaviour that challenges or serious mental health conditions by 50% to provide more choice, and personalised community-based care
- However, this is made more difficult by a lack of suitable community-based provision. Unlike some neighbouring boroughs (e.g. Enfield, Islington), Haringey does not have any autism-specific supported housing schemes.
- Assessments for eligibility for supported living or residential care are usually made by Adults’ Services, but eligibility for Supporting People funding is assessed by a team within the Housing department.

“The lack of sufficient autism-specific supported housing provision in Haringey means people are often placed in unsuitable accommodation, leading to repeated breakdown of placements” –
Provider of supported living services

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

[1] National Strategy Good Practice Guides – Training. NAS. From <http://www.autism.org.uk/autismstrategyguide>

[2] Autism Friendly Guidelines. NAS – downloaded from <http://www.autism.org.uk/professionals/autism-friendly-award/how-to-apply.aspx>

Mainstream services – the local picture



- The 2016 Self Assessment (SAF) concluded that we cannot be confident that at least 50% of those carrying out statutory assessments (for adults) have received autism training, let alone all health and social care staff
- Primary and secondary health providers do not offer autism specific training as a matter of routine – only to those working in autism specialist areas
- The availability of specialist autism training for Council staff has reduced since the 2014 SAF, although staff in the Learning Disabilities service have recently received advanced autism training
- There have been some standalone initiatives to improve staff awareness of autism but these are fragmented and not always sustained:
 - A pilot was run in 2014 with 10 providers of housing-related support to train staff to identify possible signs of autism and make reasonable adjustments
 - Recently, Haringey’s Increasing Access to Psychological Therapies (IAPT) service has undertaken autism awareness training, and also delivered training to the National Autistic Society’s helpline staff to improve their awareness of how IAPT can support their clients
- There is local interest in making volunteering services more tailored to people with autism, to provide more opportunities to contribute and develop skills and confidence.
- No organisations in Haringey have been accredited as “autism friendly”
- Some parents feel that even among SENCOs there is a lack of training and awareness about autism

“The mainstream nursery my child attended struggled to understand my child’s needs and make reasonable adjustments. I had to demand the SENCO receive autism training, which did eventually improve the situation” – Parent of a child with autism

Social support



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

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

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

Social support – the local picture



- Adults with autism who receive a personal budget can choose to spend this on social activities, including day services and social groups. Others can choose to spend their DLA / PIP or own funds to access such services.
- The autism team runs a youth group for secondary school age children with autism called “Muswell Hillbillies”
- There are a number of existing social groups for adults with autism:
 - The HAIL Hub has a gaming night attended by 4-8 adults each week
 - The HAIL Hub also has a computer group which is mainly attended by young adults with autism
 - Markfield has a Monday night social group for young adults with higher functioning autism
 - Markfield also runs social and arts sessions for young adults with Learning Disabilities who may also have autism
- However, in spite of the NICE guidance, there are no autism-specific psychosocial support interventions commissioned by statutory services in Haringey
- In addition, Markfield and HAIL have social support drop in services for the carers of people with autism

“Social support and peer support are really important – having somewhere you don’t feel like the odd one out, especially as most will have been at mainstream schools” – Parent of a young adult with Asperger’s

The criminal justice system



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

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

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

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

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

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

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

The criminal justice system – the local picture



- There is no information currently available about people with autism in Haringey and their interactions with the criminal justice system (CJS)
- Where adults with autism are known to statutory services e.g. Learning Disabilities, they are likely to continue to be supported if they enter the CJS
- However, for those without a diagnosis or without existing service support, there is no provision for specialist support

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.
- There are good examples (see best practice section) of how this has been done elsewhere.
- In Haringey there are currently no structures for involving people with autism in the development of strategy, action plans or service development
 - The Autism Partnership Board has a stated commitment to including people with autism in their work, but has not yet done so
 - There is no established process e.g. surveys or focus groups for gathering service user feedback on autism services in Haringey
 - In 2014 local voluntary organisations developed a survey for service users, carers and care staff focused on Learning Disability services in the borough [1]. Something similar could be a useful way to gain a more comprehensive picture of local needs and concerns.

The needs of family carers



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

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

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

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

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

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

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

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

Family carers – the local picture



- All carers (including those of children with autism) can apply to join the Haringey carers' register and ask to be assessed for support under the national guidelines.
 - Benefits of being on the register include free entrance to council leisure services when caring
- The local branch of the National Autistic Society sends a regular email newsletter to over 500 local people with information on activities and other items of interest to children or adults with autism and their families. This is produced by parent volunteers. They also produce a free information pack on how to navigate local and national services which is distributed by the Child Development Centre to parents following a diagnosis of autism.
- For carers of **children** with autism:
 - 208 received LA-funded respite breaks at an average cost per year of £2,128
 - A one-off post-diagnostic support group is offered by the Child Development Centre alongside more regular drop in sessions; work is currently underway to review post-diagnostic support for this group
 - Markfield also runs a weekly support group for parents caring for a young adult in transition
- For carers of **adults** with autism:
 - For those with LD, there is a Carers' Forum offering peer support and links to Council officers
 - Markfield provides a range of support for carers including benefits surgeries and an SEND advice line

“The respite system needs to be flexible enough to enable us to use the same respite carer now he is an adult that he used as a child... Continuity is so important to him” – Parent of a young adult with autism

“There can be delays to getting a carers' assessment if you need to find alternative care for your son while being assessed” – Parent of a young adult with autism

“My son's college has recently stopped providing sessions during school holidays, leaving us to pick up his care for those extra weeks each year” – Parent of a young adult with autism

“Like lots of parents I have given up work – not so much because my child needs full time care, he is in school during the day, but because navigating the system and fighting for access to services takes so much time and energy” – Parent of a child with autism

“The best thing anyone could do for me as a carer would be to ensure my child had access to the support and services he needs... My wellbeing is better when I know he is having his needs met” – Parent of a young adult with autism

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)

At present, neither of these operational teams exist fully in Haringey (the Whittington CDC has an autism team but not a care co-ordinator model), and the Autism Partnership Board is not currently able to fulfill all the roles of the recommended autism strategy group.

[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 – Early Intervention



- Early diagnosis and support for children with autism is believed to be important in determining long term outcomes.
- Effective early intervention is likely to deliver benefits not only to the person with autism and their family, but to the wider system, in the form of reduced demand on services:
 - For example, a child who has received a prompt diagnosis and suitable early support may be able to successfully attend a mainstream school, where without this their behaviour might have led to permanent exclusion and the need for expensive specialist alternative provision
 - Similarly, the development of communication, personal care and other independent living skills could enable an autistic adult to live independently or undertake paid work who otherwise would not have been capable of doing so
- A large review into early interventions published in 2008 found that [1]:
 - There was a shortage of good quality studies to assess the impact of early intervention, but that the evidence suggested that the core symptoms of autism were malleable at early ages
 - The age when interventions began was an important determinant of their success, with interventions beginning before the age of four years being particularly beneficial
 - For a range of different interventions, intensive (20+ hours per week) focused support with young children was found to improve outcomes (communication, development, behaviour and possibly also IQ)
 - A further review in 2014 [2] also found good evidence in support of the effectiveness of behavioural interventions, but emphasised the importance of parent skills training and positive behaviour support to delivering outcomes
 - Another well-publicised study found that supporting parents to implement behavioural strategies with their autistic children led to significantly improved outcomes even six years later [3]

Some early intervention is offered in Haringey, through NHS therapies and at special schools. At present it is not possible to tell whether this is sufficient to deliver all potential long term gains

[1] Rogers, S., Vismara, L.(2008) Evidence Based Comprehensive treatments for Autism.*Journal of Clinical Child and Adolescent Psychology*. 37(1): 8–38. - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2943764/>

[2] Tonge, BJ et al (2014) A review of evidence-based early intervention for behavioural problems in children with autism spectrum disorder: the core components of effective programs, child-focused interventions and comprehensive treatment models. *Curr Opin Psychiatry*. 27(2):158-65

[3] Pickles, A. Et al (2016) Parent-mediated social communication therapy for young children with autism (PACT): long-term follow-up of a randomised controlled trial. *The Lancet* 388: 2501–09 [http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(16\)31229-6.pdf](http://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(16)31229-6.pdf)

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

There is scope to make a convincing business case for preventive support but at present in Haringey it is rarely available, especially for those who don't meet social care thresholds

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

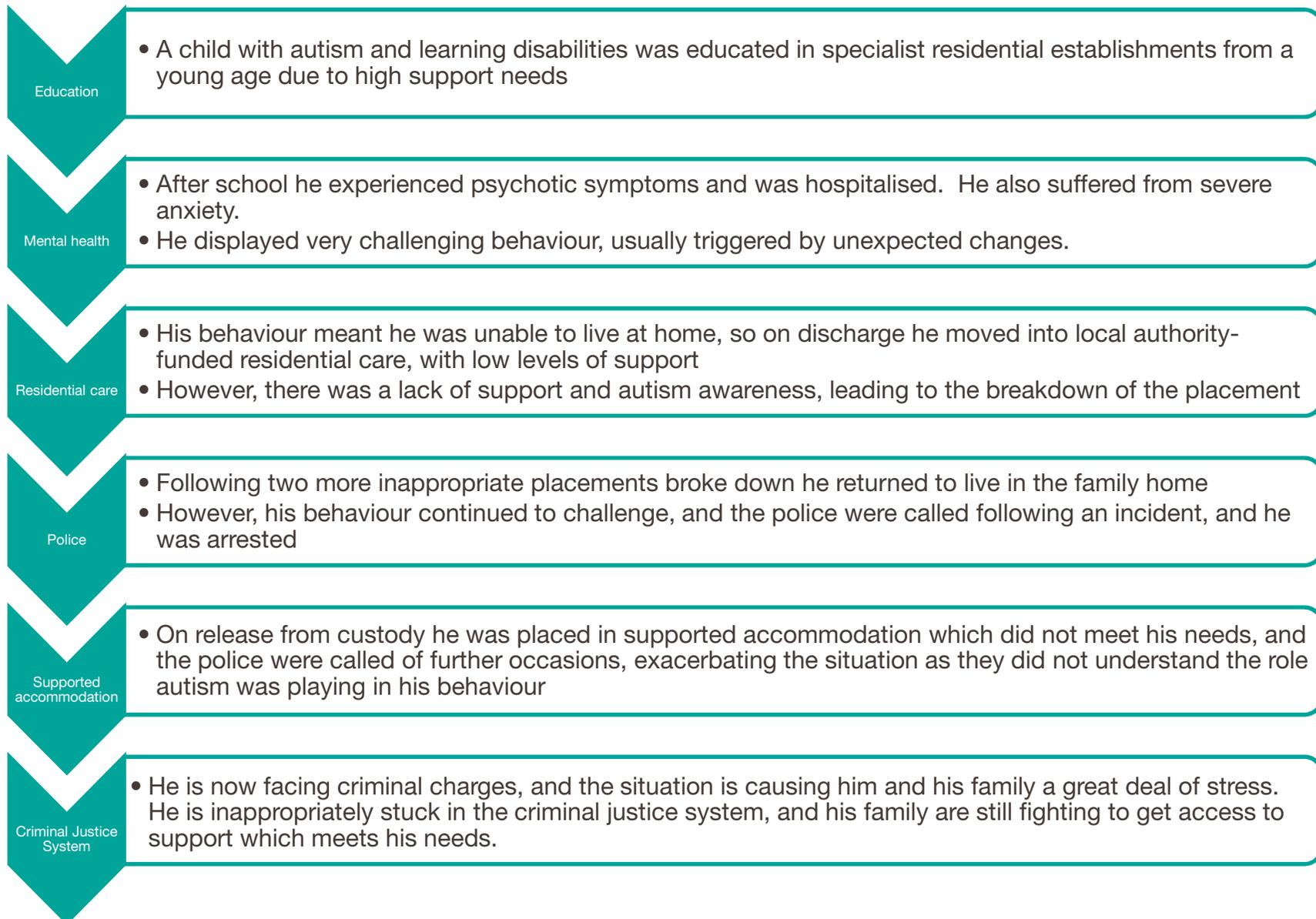
[2] Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy

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/gs51/resources/support-for-commissioning-for-autism-253717885>

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

Case study – lack of suitable and preventative services



Audit – Autism Strategy statutory requirements



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	Unlikely given low levels of autism awareness training
... 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 known
... 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, especially not for those without LD
... 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)	In progress through commissioning
... 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	Records kept but not yet seen as a key outcome

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	Not met
	... Should allocate responsibility to a named joint commissioner / senior manager for commissioning services (autism lead)	Not 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	Not met
	... Should provide access to an autism diagnostic and treatment pathway including those who do not have a learning disability	Met
NHS bodies...	... 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	Not known
	... 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	Not known
	... 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	Not met
	... 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	Not known

- Chapter 5 – Good Practice

Good practice examples - Children



LB Camden MOSAIC team

In Camden, children with disabilities are supported by an integrated team called MOSAIC, comprising Paediatricians, Occupational and Speech & Language Therapists, Family Therapists, Psychiatrists and Psychologists, Physiotherapists and Social Workers. They are co-located and provide assessment, diagnosis and interventions. Strengths of the model include scope for therapists to work in home settings to help parents embed strategies, and a single point of co-ordination for all treatment and interventions for a child.

[Personal communication]

Good practice examples - Adults



Hertfordshire CC

Asperger's team within Adult Social Care to plug the gap of those who don't meet mental health or learning disability criteria. They also manage transition planning for this group. The team consists of a team manager, 3 social workers, an employment officer, an expert by experience and 2 community care officers

[LGA case study]

LB Richmond

Using Better Care Fund, commissioned Resources for Autism to provide two fortnightly drop in groups (one for younger adults, one for all), each of 10-15 people, to reach those who don't meet social care eligibility criteria. They provide a social space but also more formal learning opportunities e.g. Anxiety management, dealing with conflict etc. Activities are chosen by the participants. They feel it has reduced demand on primary care and social care

[LGA case study]

LB Islington

Islington has recently begun a pilot creating two new roles (a social worker and a support worker) within Adult Social Care to support the service to work with those with autism but no learning disability. Instead of holding a caseload, these staff members will identify gaps and issues in the pathway, and deliver training and process improvements to embed effective support for this group, which has traditionally not been able to access social care services.

[Personal communication]

Good practice examples - Engagement



LB Richmond

LB Richmond has developed a range of ways to reach people with autism and engage them in the work of the Autism Partnership Board. These include taking items for discussion out to places where groups of people with autism already meet (for example, day services and social groups), publishing agendas and minutes in an accessible format online and giving people the chance to contribute to decision making via email instead of through attendance at meetings.

[Personal communication]

LB Enfield

Enfield has commissioned a user-led organisation called One-to-One to deliver a peer support network for people who self-identify as having Asperger's.

[Personal communication]

- Chapter 6 – Appendices

Appendix 1 – Full data



Estimated prevalence of autism in Haringey

	2014	2015	2020	2025	2030
People aged 18-24 predicted to have ASC	242	242	238	234	246
People aged 25-34 predicted to have ASC	605	616	647	648	634
People aged 35-44 predicted to have ASC	470	485	548	595	613
People aged 45-54 predicted to have ASC	337	345	372	406	450
People aged 55-64 predicted to have ASC	199	205	247	289	308
People aged 65-74 predicted to have ASC	126	130	145	162	196
People aged 75+ predicted to have ASC	97	99	107	126	143
Total Population aged 18+ predicted to have ASC	2,076	2,122	2,304	2,460	2,590

Appendix 1 – Full data

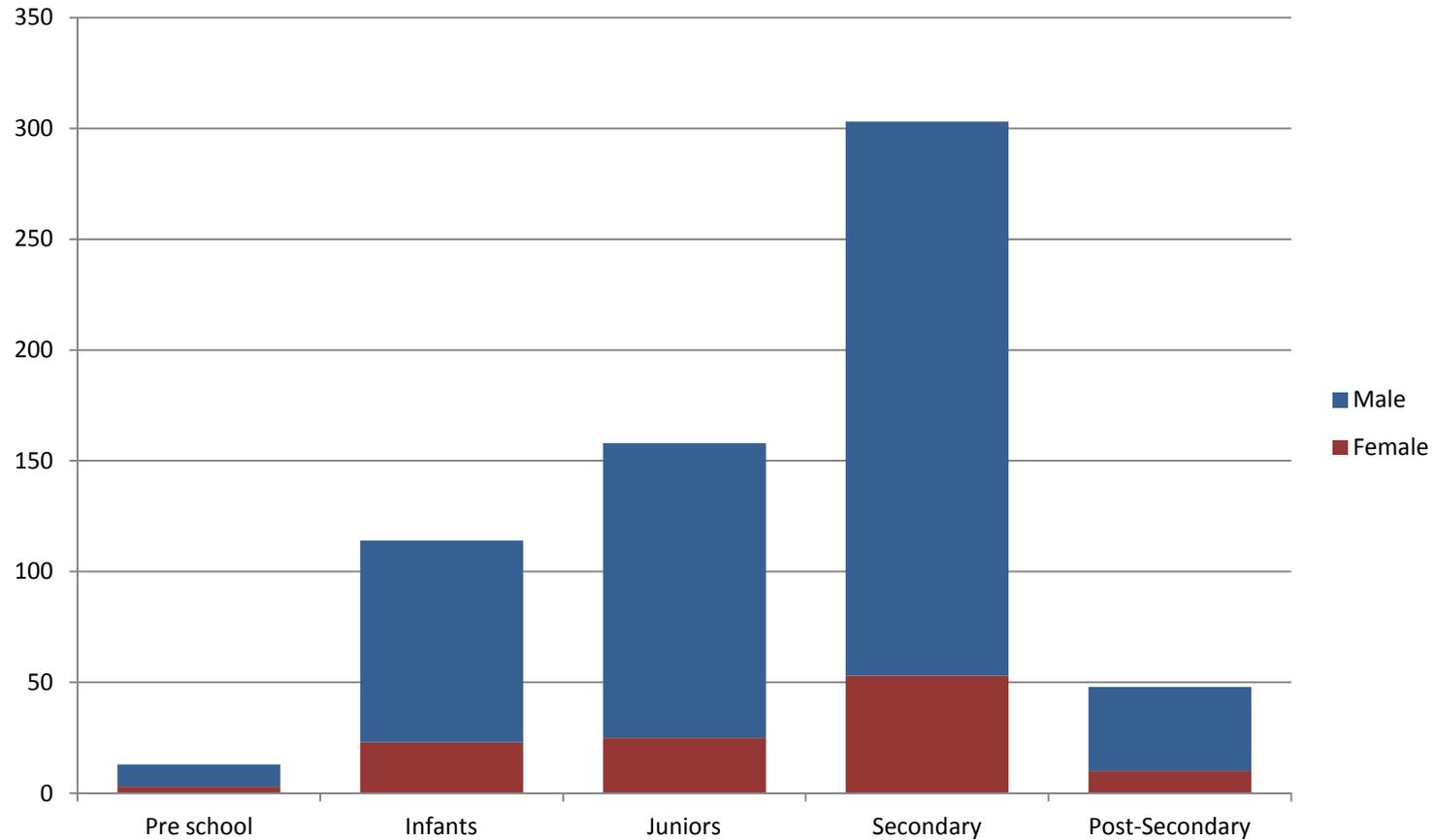


Numbers of children on Haringey's SEND database with autism

Primary Need	Secondary Need	Number of children
ASC	None	563
ASC	Speech, Language and communication Needs	24
ASC	Severe Learning Difficulty	20
ASC	Behaviourial, Emotional & Social Difficulty	11
ASC	Moderate Learning Difficulty	5
ASC	Specific Learning Difficulty	5
ASC	Social, Emotional & Mental Health	3
ASC	Hearing Impairment	2
ASC	Visual Impairment	2
ASC	Physical Disability	1
Hearing Impairment	ASC	1
Physical Disability	ASC	1
Severe Learning Difficulty	ASC	1
	Total	639

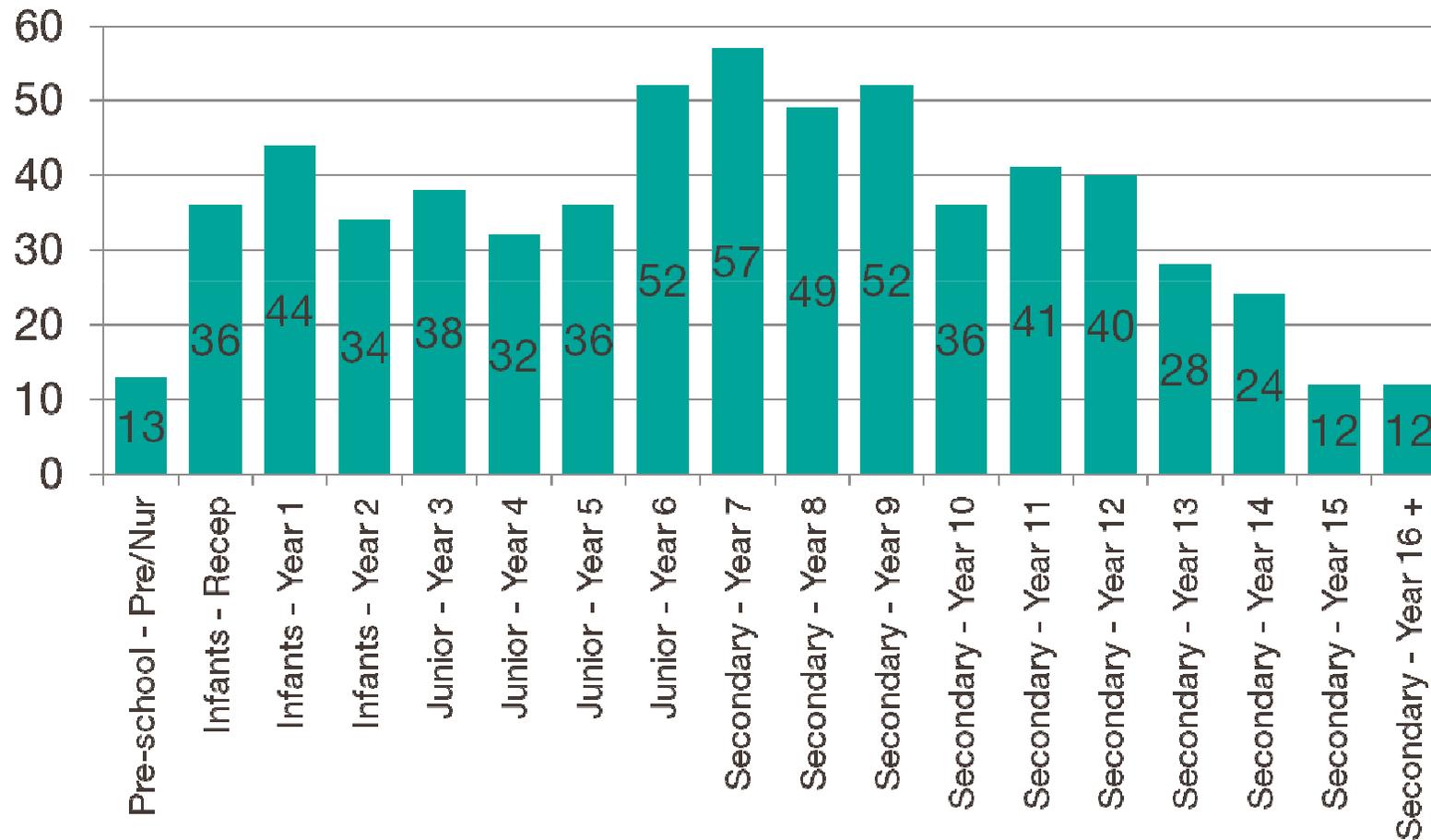
Appendix 1 – Full data

Distribution of autism by school stage and sex



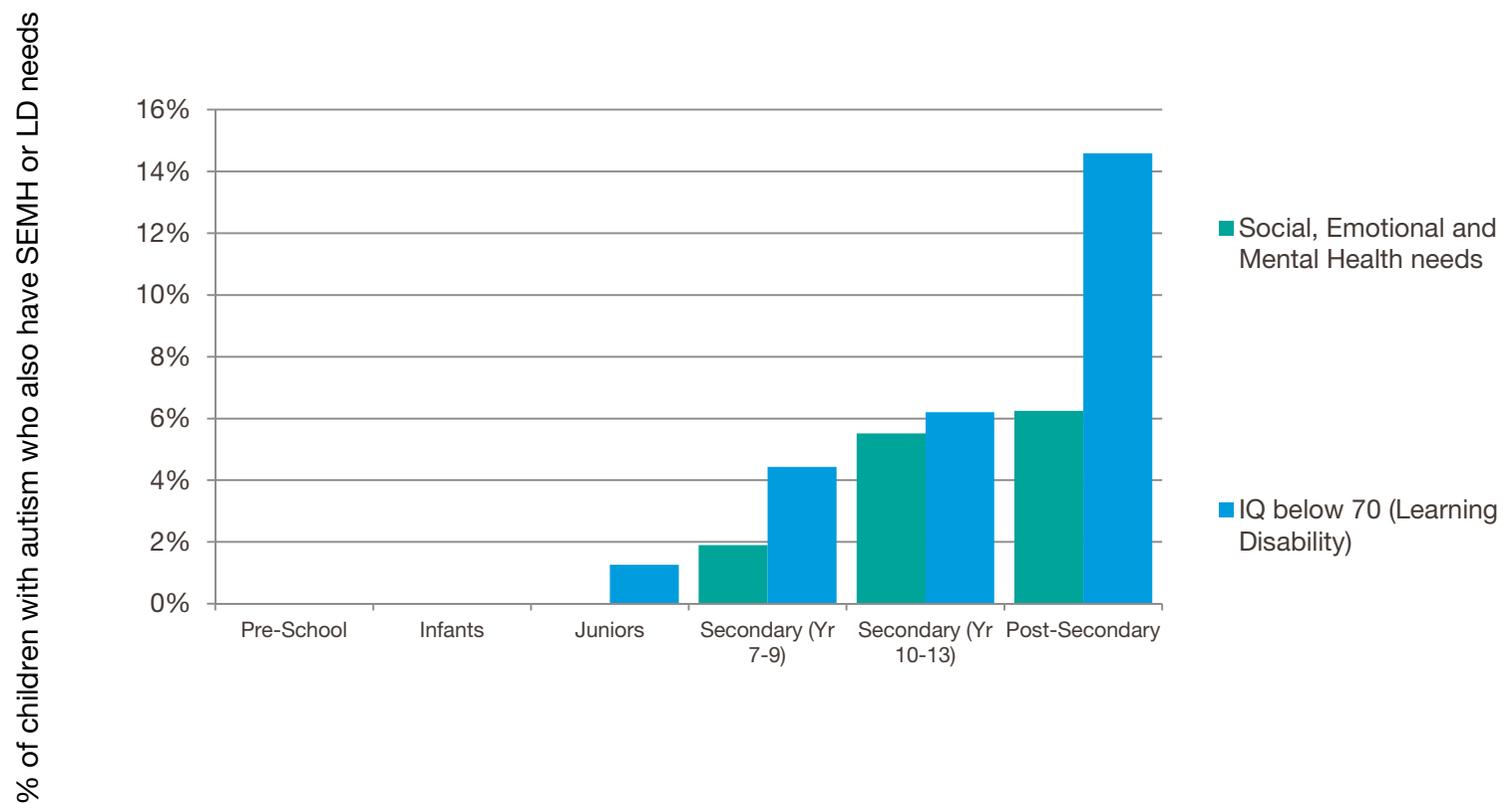
Appendix 1 – Full data

Distribution of autism by school year – numbers of children with autism as a primary need



Appendix 1 – full data

Rates of additional needs among children in Haringey with autism, by school stage



Appendix 1 – full data

Summary of age and gender of people with autism accessing Adult Social Care in Haringey 2015-16



Appendix 1 – full data

Service type	Number of people receiving this service type 2015/16
SDS Direct Payments	56
SDS Day Care	43
LD Residential Care	39
Adults Day Care	23
LD Day Care	22
Direct payments	20
SDS Assessed Contribution	16
SDS Support Worker	11
SDS Home Care	9
Support Worker	9
Learning Disability Supported Housing	7
SDS Supported Housing	7
Adults Supported Housing	5
Training College	5
Transport	5
Direct Payments Respite	4
LD Home Care	4
Adult placement scheme	3
Adults Residential Care	3
Adults Residential Respite	3
Visual impairment equipment	3
Property Care	2
SDS Transport	2
Sensory impairment service	2
Physical Disabilities Supported Housing	1
Specialist Orders	1
Therapeutic services	1
Toileting Equipment	1

NB this adds up to more than 104 as any one person may be in receipt of more than one service within one year

Costs of Adult Social Care services for adults with autism

	Planned cost in 2015/16
Average (mean) spend per person	£44,796
Average (median) spend per person	£31,408
Minimum spend per person	£0
Maximum spend per person	£206,572
Total spend across 104 adults with autism	£4,748,358

NB this only relates to people whose autism is known and recorded in the Adult Social Care database – there may be others with autism being supported but their autism diagnosis is not recorded

Appendix 1 – full data

Estimated economic cost of supporting an adult with autism per year

Average annual cost per adult with ASD

	Adults with high-functioning ASD			Adults with low-functioning ASD			
	Private household	Supporting People	Residential care	Private household	Supporting People	Residential care	Hospital
Accommodation	£1,669	£66,191	£69,232	-	£66,190	£69,232	-
Hospital services	£871	£871	£871	£98	£168	£38	£84,647
Other health and social services	£545	£545	£545	£793	£525	£649	-
Respite care	-	-	-	£1,723	-	-	-
Day services	£2,496	£2,496	£2,496	£4,208	£4,063	£930	-
Adult education	£3,237	£3,237	£3,237	£1,609	£954	£3,719	-
Employment support	-	-	-	565	£1,226	-	-
Treatments	£166	£166	£166	£70	£70	£70	-
Family expenses	£2,121	-	-	£2,441	-	-	-
Lost employment (parents)	£4,131	-	-	£4,131	-	-	-
Subtotal	£15,236	£73,506	£76,547	£15,638	£73,196	£74,637	£84,647
Lost employment (person with ASD)	£22,188	£22,188	£22,188	£25,102	£25,102	£25,102	£25,102
Total (excluding benefits)	£37,424	£95,694	£98,735	£40,739	£98,298	£99,739	£109,749
Benefits	-	-	-	£7,517	£4,845	£4,845	£1,037
Total (including benefits)	£37,424	£95,694	£98,735	£48,256	£103,142	£104,584	£110,786

Appendix 1 – full data

Estimated economic cost of supporting a child with autism and LD per year

Average annual cost per child with low-functioning ASD

	Living in residential or foster care placement			Living in private households with family		
	Ages 0-3	Ages 4-11	Ages 12-17	Ages 0-3	Ages 4-11	Ages 12-17
Residential/foster care placement	£17,495	£25,192	£35,806	-	-	-
Hospital services	-	967	£1,780	-	£967	£1,780
Other health and social services	£656	£7,747	£449	£656	£7,747	£449
Respite care	-	-	-	-	£3,169	£4,131
Special education	-	£10,252	£30,962	-	£10,252	£30,962
Education support	-	£1,328	£1,118	-	£1,328	£1,118
Treatments	-	£20	£17	-	£20	£17
Help from voluntary organisations	-	-	-	-	£945	£108
Benefits	-	-	-	£4,213	£4,486	£4,486
Lost employment (parents)	-	-	-	-	£2,339	£2,339
Total annual cost (excluding benefits)	£18,151	£45,506	£70,131	£656	£26,768	£40,904
Total annual cost (including benefits)	£18,151	£45,506	£70,131	£4,869	£31,254	£45,390

Note: Expenditure on social security/welfare benefits could partly double-count the costs of lost employment for parents, which is why two totals are provided above.

Appendix 1 – full data

Estimated economic cost of supporting a child with autism without LD per year

Average annual cost per child with high functioning ASD

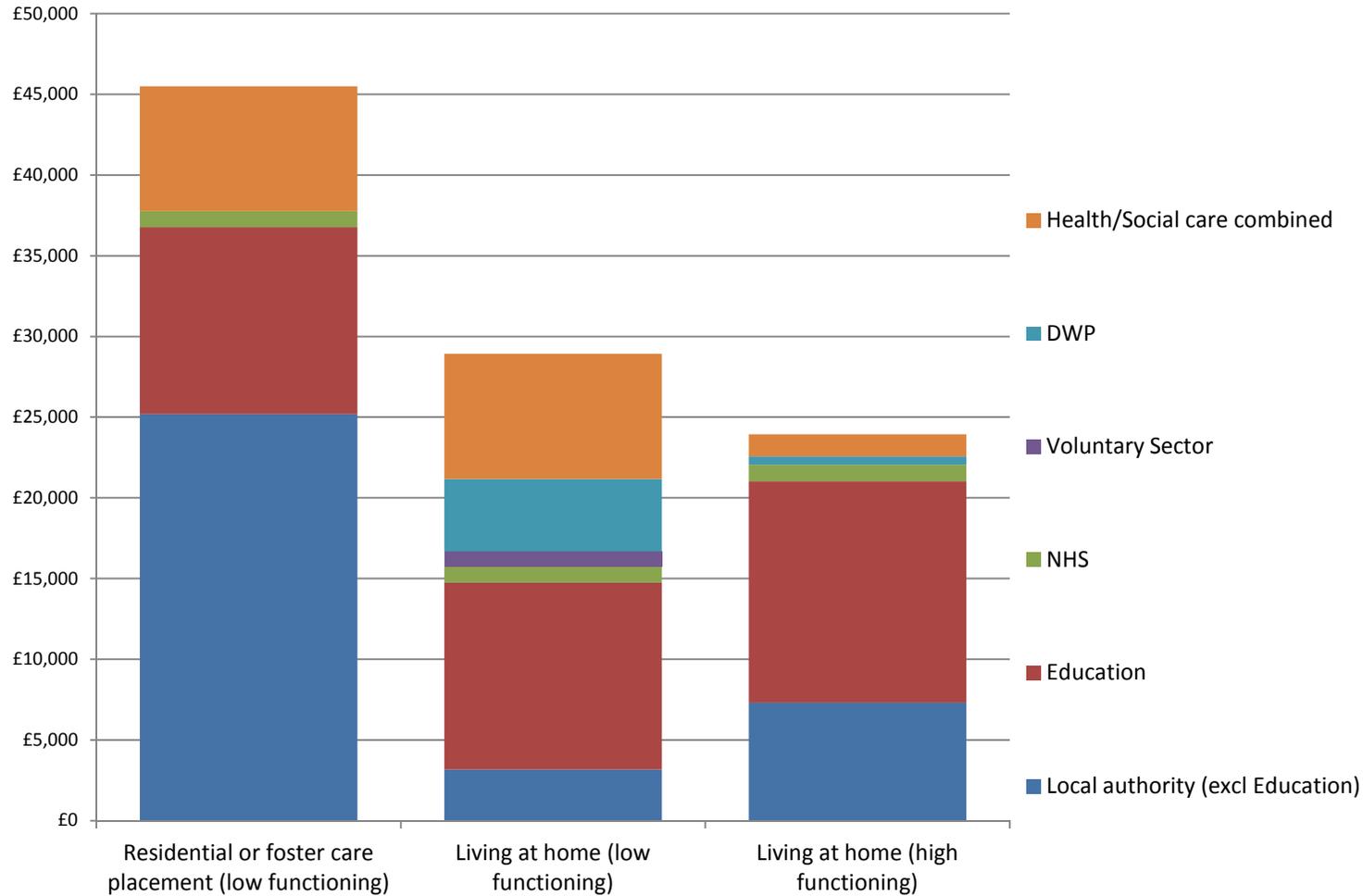
	Living in private household with family		
	Ages 0-3	Ages 4-11	Ages 12-17
Hospital services	-	£871	£871
Other health and social services	£1,361	£1,361	£1,361
Respite care	-	£7,301	£7,301
Special education	-	£13,099	£13,099
Education support	-	£611	£611
Treatments	-	£166	£166
Help from voluntary organisations	-	-	-
Benefits	£526	£526	£526
Lost employment (parents)	-	£242	£242
Total annual cost (excluding benefits)	£1,361	£23,651	£23,651
Total annual cost (including benefits)	£1,887	£24,177	£24,177

Note: Expenditure on social security/welfare benefits could partly double-count the costs of lost employment for parents, which is why two totals are provided above.

Appendix 1 – full data



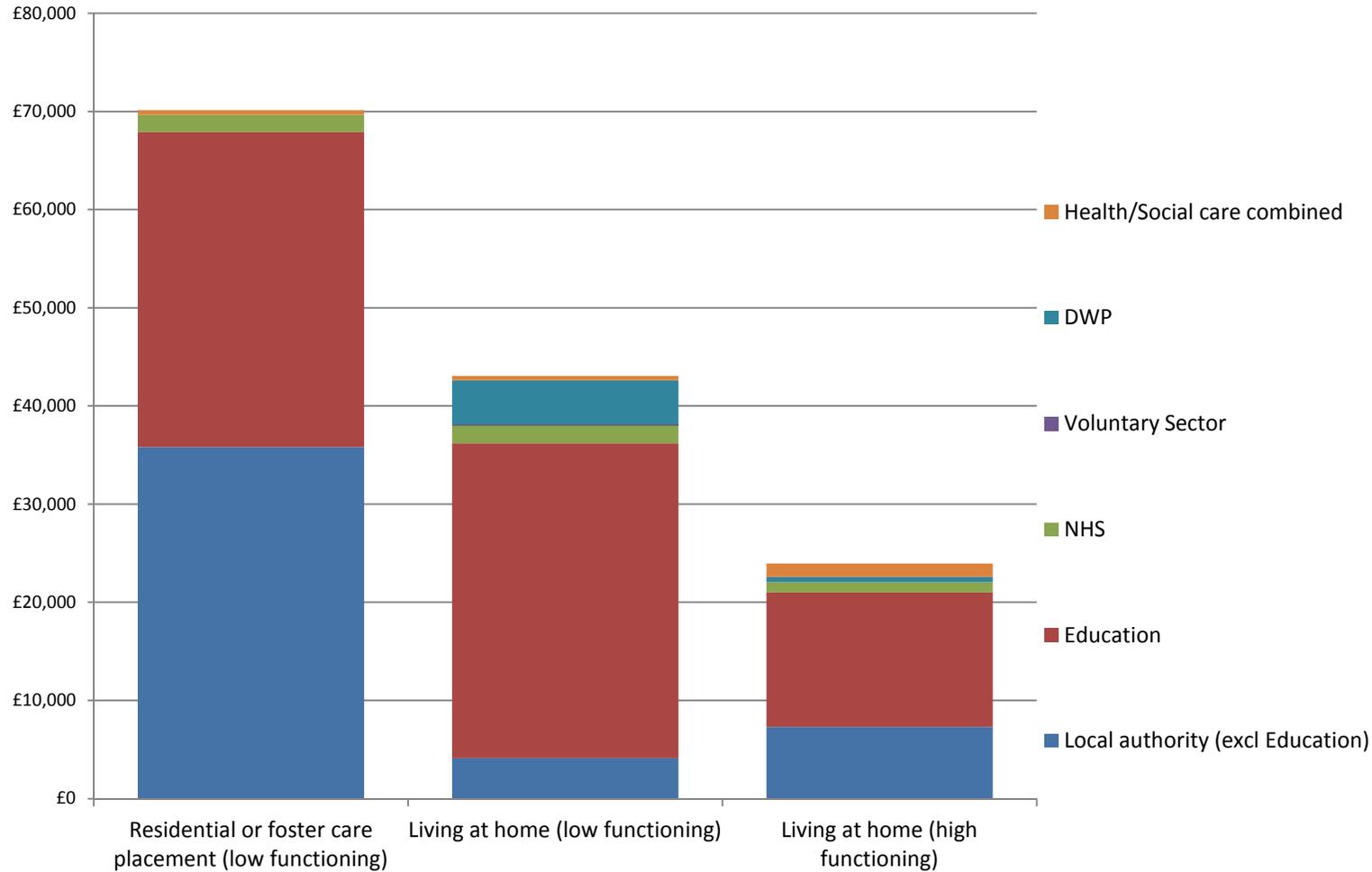
Estimates of costs associated with caring for a child aged 4-11 with autism (Curtis 2011)



Appendix 1 – full data

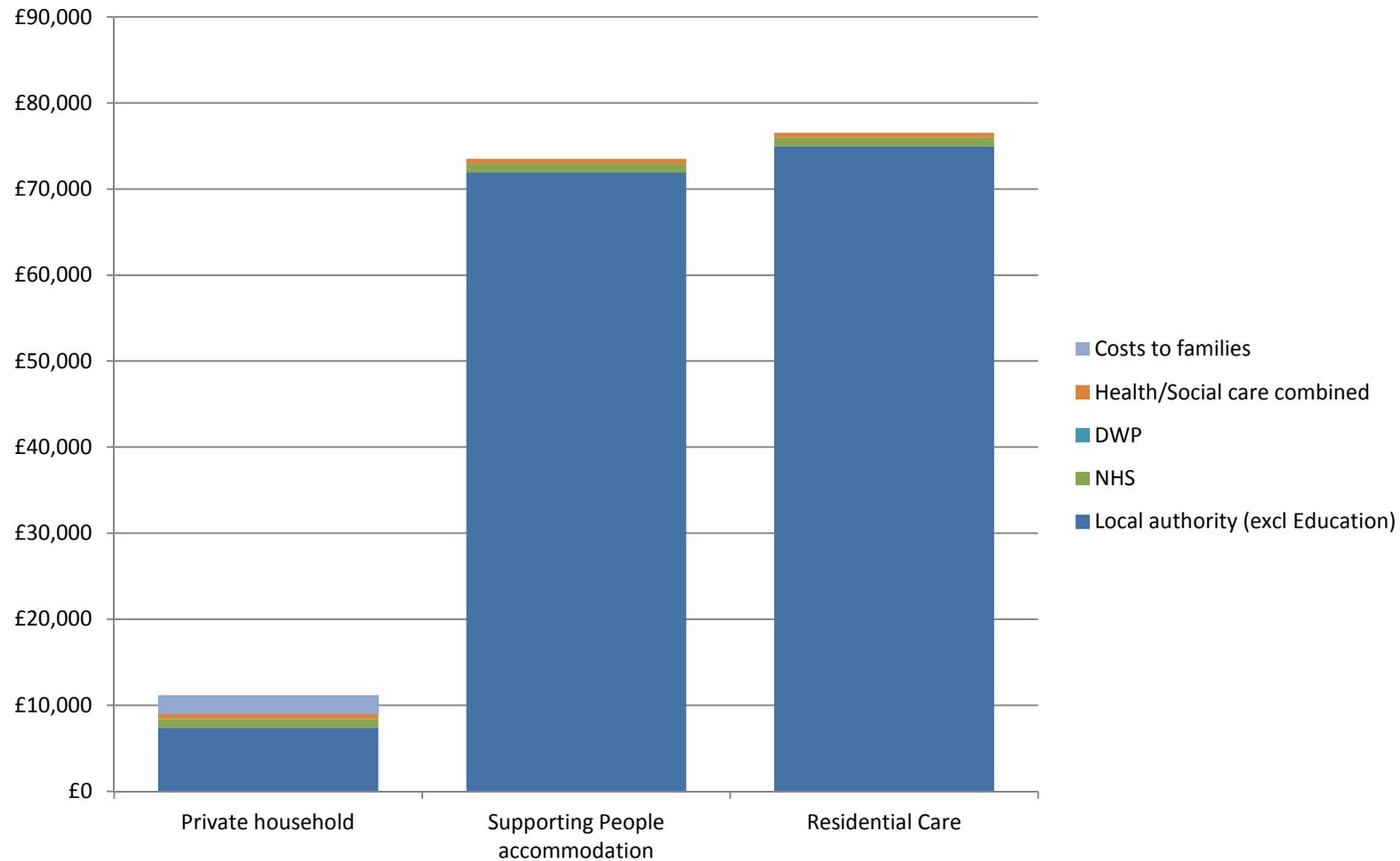


Estimates of costs associated with caring for a child aged 12-17 with autism (Curtis 2011)



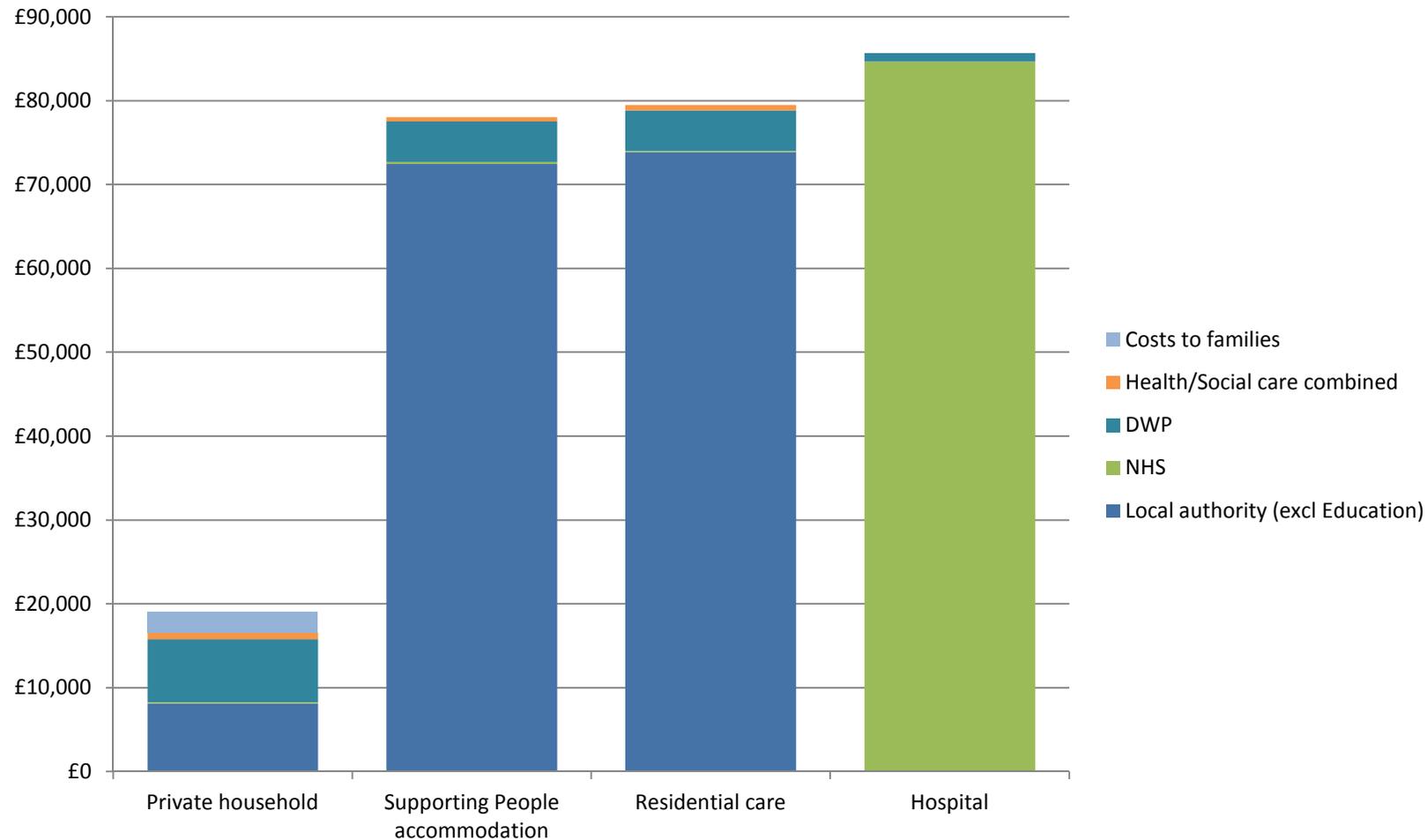
Appendix 1 – full data

Estimates of costs associated with care for high functioning adults with autism (Curtis 2011)



Appendix 1 – full data

Estimates of costs associated with care for low functioning adults with autism (Curtis 2011)



Appendix 2 - National evidence on service costs



- In this study the lifetime societal cost of individual with autism but without LD was estimated at £3.1m (“discounted cost £0.8m using a rate of 3.5%”)
- For individuals with autism and LD it was estimated at £4.6m (discounted cost £1.23m)
- This study estimated 44% of those with autism have no LD, 56% have LD (adults)

Place of residence	No LD - numbers	No LD - Percentage	LD - numbers	LD - Percentage
Private household	153,842	79%	83,304	35%
Supporting people accommodation	9,737	5%	16,661	7%
Residential care	31,158	16%	123,767	52%
Hospital services	0	0%	14,281	6%
Total	194,737		238,013	

Appendix 2 - National evidence on service costs



	Children					
	Living in residential or foster care placement (Low functioning)		Living in private households with family (Low functioning)		Living in private household with family (High functioning)	
	Age 4-11	Age 12-17	Age 4-11	Age 12-17	Age 4-11	Age 12-17
Local authority (excl Education)	£25,192	£35,806	£3,169	£4,131	£7,301	£7,301
Education	£11,580	£32,080	£11,580	£32,080	£13,710	£13,710
NHS	£987	£1,797	£987	£1,797	£1,037	£1,037
Voluntary Sector			£945	£108		
DWP			£4,486	£4,486	£526	£526
Health/Social care combined	£7,747	£449	£7,747	£449	£1,361	£1,361
Costs to families						

	Adults						
	Living in Private Household		Supporting People accommodation		Residential Care		Hospital
	High functioning	Low functioning	High functioning	Low functioning	High functioning	Low functioning	Low functioning
Local authority (excl Education)	£7,402	£8,105	£71,924	£72,433	£74,965	£73,881	
Education							
NHS	£1,037	£168	£1,037	£238	£1,037	£108	£84,647
Voluntary Sector							
DWP		£7,517		£4,845	£0	£4,845	£1,037
Health/Social care combined	£545	£793	£545	£525	£545	£649	£0
Costs to families	£2,121	£2,441					

Appendix 2 - National evidence on service costs



NICE commissioning guidance [1]:

- Implementing the national guidelines may deliver the following benefits and savings:
 - “Fewer repeat attendances to GPs because of earlier recognition of adults with possible autism... giving a financial benefit to primary care organisations and an improved patient experience for adults with autism
 - Taking a more multi-agency approach to assessment could lead to savings through avoiding duplication of work
 - Setting up multidisciplinary teams could lead to better access for adults with autism to relevant support networks and benefits
 - Earlier recognition and diagnosis of autism could lead to appropriate care tailored specifically to each person’s needs being given at an earlier stage in the patient pathway
 - An increase in the number of adults with autism in employment could provide financial benefits to the economy, while also improving their self-esteem and overall mental health and having a positive effect on the lives of carers”

NAO study [2]

- Identifying and supporting six per cent of adults with high-functioning autism and Asperger’s system would save £38m per year. An eight per cent identification rate would save £67million per year

[1] <https://www.nice.org.uk/guidance/qs51/resources/support-for-commissioning-for-autism-253717885>

[2] National Audit Office (2009) Supporting people with autism through adulthood - <https://www.nao.org.uk/wp-content/uploads/2009/06/0809556.pdf>

Appendix 3 – Acknowledgements



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Appendix 4 – Glossary



- ABA** – Applied Behavioural Analysis (an umbrella term for a number of different therapeutic approaches which combine intensive work with a child to identify and modify specific behaviours in order to improve function)
- Asperger’s Syndrome** – a sub-type of autism often used interchangeably with “high functioning autism” to refer to those without a learning disability [1]
- IAPT** – Increasing Access to Psychological Therapies (NHS programme providing CBT and other psychological therapies for the treatment of common mental health conditions)
- LB** – London Borough of
- LD** – Learning Disability/ies (usually equivalent to IQ below 70, also known as Global Learning Disability)
- LDP** – Learning Disabilities Partnership (a joint team of local authority and NHS staff working to support people with Learning Disabilities)
- MH** – Mental Health
- MOSAIC** – database used by Adult Social Care services in Haringey
- NAS** – National Autistic Society
- NICE** – National Institute for Health and Care Excellence, responsible for producing evidence-based guidance and advice for health, public health and social care practitioners
- OP** – Older People
- OT** – Occupational Therapy
- PD** – Physical Disabilities
- SEND** – Special Educational Needs and Disabilities
- SLT** – Speech and Language Therapy

[1] <http://www.autism.org.uk/about/diagnosis/criteria-changes.aspx>