

Camden's plan for people with autism

2016-2021



AUTISM

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1. Introduction

1.1 Our aim for Camden is that it is **a community where everyone has a chance to succeed and where nobody gets left behind**¹. Camden's plan for people with autism highlights how we are working to be inclusive by meeting the needs of children, young people and adults with autism. It responds to central government guidance and legislation and to priorities that have been agreed locally.

1.2 The 2010 national strategy Fulfilling and Rewarding Lives, updated in 2014 under the banner of Think Autism, "represents a shared approach towards a common goal; a society that not only accepts and understands autism, but also provides real opportunities for people with autism to live fulfilling and rewarding lives". For the purpose of this document we will be referring to people who have a diagnosis of autism as 'people with autism' though we are aware that some people prefer to use other terms to describe themselves.

1.3 For children's and young people, Camden's plan for people with autism is a part of our approach to special educational needs and disabilities (SEND) in Camden and needs to be seen alongside our overarching **Strategy for Children and Young People aged 0 to 25 with Special Educational Needs and**

Disabilities 2016-20 and our Accessibility Strategy for Education Settings 2016–2020 that is currently being finalised. All three documents are interrelated and lay out Camden's approach and priorities for children, young people and adults with complex and additional needs

1.4 This plan focuses on increasing awareness and understanding of autism spectrum conditions in Camden, improving education, health and social care outcomes and removing barriers that prevent people with autism from being included in their community. It identifies how Camden can: provide access to a range of local education settings to meet children's needs during their school life; ensure that transitions from primary to secondary education, and to post-16 settings are successful; and that there are appropriate and consistent pathways for adults to diagnosis through to advice and assessment for care and support services. The plan will facilitate access to accommodation, enable people to exercise choice and control over the services they use, and ensure no-one is managed inappropriately in the local criminal justice system. It also prioritises: improving access to high quality local services that are responsive to the needs of people with autism; improving local data collection; promoting reasonable adjustments and autism awareness training, and ensuring people with autism are at the centre of planning and commissioning decisions for local services.

¹ The Camden Plan 2012-2017



About Autism

Throughout this report, unless otherwise specified, the term 'autism' is used to refer to all diagnoses on the autism spectrum, including Asperger Syndrome, high-functioning autism, Kanner² syndrome or classic autism.

Autism occurs early in a person's development. Someone with autism can show marked difficulties with social communication, social interaction and social imagination. They may be preoccupied with a particular subject or interest. Autism is developmental in nature and is not a mental illness or a learning disability. However, people with autism may have additional or related problems, which frequently include anxiety. These may be related to social factors associated with frustration or communication problems or to patterns of thought and behaviour that are focused or literal in nature.

A person with autism may also have sensory and motor difficulties, including sensitivity to light, sound, touch and balance. These difficulties may result in a range of regulatory behaviours, including rocking, self-injury, and avoidance such as running away. Often these are coping mechanisms. There can also be a repetitive or compulsive element to much of the behaviour of people with autism. The person may appear to be choosing to act in a particular way, but their behaviour may be distressing even to themselves. However, these behaviours can also be an important self-calming mechanism and should not be stopped or discouraged or seen as a deficit.

Autism is known as a spectrum condition, both because of the range of difficulties that affect children and adults with autism, and the way that these present in different people. For example, Asperger syndrome is a form of autism. People with Asperger Syndrome typically have fewer problems with speaking than others on the autism spectrum, but they do still have significant difficulties with communication that can be masked by their ability to speak fluently. They are also often of average or above average intelligence.

² Kanner, L., (1943), "Autistic disturbances of affective contact" in *Nervous Child* 2:217-250. Available at: <http://simonsfoundation.s3.amazonaws.com/share/071207-leo-kanner-autistic-affective-contact.pdf>

2. Vision

2.5 This plan aims to make Camden a place where people with autism can:

- be an equal part of their local communities
- access the right support at the right time throughout their lifetimes
- develop their skills and independence and work to their best of their ability

2.6 Achieving this vision needs a cultural shift, where the challenges of autism are understood throughout the community in Camden.

2.7 When we achieve this vision, people in Camden with autism will:

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

2.8 This is a joint plan across Camden's education, health and social care economy because we recognise the need to work together to develop a seamless response. People with autism need health, social care and "universal" services which work in an integrated way to enable them to live a good quality of life.

3. Strategic priorities

The national context for this plan

3.1 The principle legislation underpinning this plan is the Autism Act 2009. This was the first ever disability-specific law in the UK and it led to the publication of Fulfilling and Rewarding Lives: the strategy for adults with autism in England.³ This strategy was refreshed in 2014 under the banner of Think Autism⁴ and a stocktake of progress was taken in early 2016⁵.

3.2 In summary, the 2015 statutory guidance⁶

specified that both councils and all NHS bodies:

- should provide autism awareness training for all staff
- must provide specialist training for key staff, such as GPs and community care assessors
- develop a clear pathway to diagnosis and assessment for adults with autism in line with National Institute for Health and Care Excellence (NICE) guidelines and standards
- cannot refuse care and support needs assessments for adults with autism based solely on IQ, and should make post-diagnostic support available even if the person does not meet criteria for social care support
- must appoint an autism lead in their area
- need to commission services based on adequate population data.

3.3 Statutory guidance to support the implementation of the national adult Autism Strategy expects that there is a meaningful local autism partnership arrangement that brings together different organisations, services and stakeholders locally, including Camden Clinical Commissioning Group (CCG), and people with autism, and sets a clear direction for improved services.

3.4 This plan is also informed by the NICE autism quality standard (QS51), and clinical guidelines: Guidance on Autism in under 19s (CG128 and CG170) and Autism in Adults (CG142). Nationally, the Transforming Care programme⁷ aims to improve services and support for children, young people and adults with autism and/or learning disabilities who display behaviours that challenge. The focus of Transforming Care is to reduce the use and length of stay in hospitals for this group. This will be achieved by:

- improving services available within the community, offering more innovative care options from multi-disciplinary teams;
- empowering people and their families to have more say in their care, strengthening individuals' rights;
- providing personal budgets to help people select the right, personalised care and support to meet their needs;
- discharging individuals from hospitals to more appropriate community-based settings;
- providing intensive support earlier for those who need it, to prevent new unnecessary hospital admissions and help people stay in the community close to home;

³ Department of Health (2010), "Fulfilling and Rewarding Lives: the strategy for adults with autism in England". (Published under the coalition government). Available at: <https://www.gov.uk/government/news/fulfilling-and-rewarding-lives-the-strategy-for-adults-with-autism-in-england>

⁴ Department of Health (2014), "Think Autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update." (Published under the coalition government). Available at: <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>

⁵ Department of Health (2016), "Progress Report on Think Autism: the updated strategy for adults with autism in England". Available at: <https://www.gov.uk/government/publications/progress-report-on-strategy-for-adults-with-autism>

⁶ Department of Health (2015) "Adult Autism Strategy: statutory guidance." Available at <https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance>

⁷ Details of the Transforming Care programme are available at: <https://www.england.nhs.uk/learningdisabilities/care/>

- ensuring that appropriate hospital care is available closer to home for those who need it but only for as long as they need it.

3.5 The Government and NHS England have now outlined in Building the Right Support⁸ a national plan to reduce hospital beds by 50% for people with autism and/ or learning disabilities. 48 Transforming Care Partnerships have been set up across the country to reshape services to meet local needs in line with the principles set out in a new service model. Camden has joined up with Islington, Barnet, Enfield and Haringey to establish the North Central London Transforming Care Partnership. Key priorities are outlined in our transforming care plan.⁹ Progress is subject to rigorous reporting to and scrutiny by NHS England. The vision of Transforming Care is for people with autism and/ or learning disabilities to have the same opportunities as anyone else to have a home in the community, relationships and a safe, fulfilling life.

Local strategic priorities

3.6 The Camden Plan sets out a clear long-term ambition to make Camden a better borough, a place where everyone has a chance to succeed and where nobody gets left behind. Its five strategic objectives are:

- providing democratic and strategic leadership fit for changing times
- developing new solutions with partners to reduce inequality
- creating conditions for and harnessing the benefits of economic growth
- investing in our communities to ensure sustainable neighbourhoods
- delivering value for money services by getting it right first time

3.7 Camden CCG has a vision of “working with the people of Camden to achieve the best health for all”. Its mission is “to lead the development of the local healthcare system with our partners and the people of Camden to ensure access to and the delivery of safe, effective and responsive services that reduce inequalities, meet identified needs and ensure maximum positive health impact within the resources available”.

3.8 This plan for people with autism is informed by these local priorities, including the CCG’s Commissioning Plan and Intentions¹⁰, the All Together Better integrated child health project, the Child and Adolescent Mental Health Services Transformation Plan¹¹, Camden’s Local Care Strategy, Camden’s Adult Social Care Vision, and the North Central London transforming care plan¹², as well as the Resilient Families framework and its emphasis on outcomes. Agreed objectives include improving the quality and safety of commissioned services and enabling local services to deliver the right care in the right setting at the right time.

3.9 The national Think Autism¹³ strategy has three main priority areas, with outcomes under each priority. These have been prioritised locally, through engagement with staff and the Autistic Spectrum Disorders parents group, in the order shown:

Priority 1: An equal part of my community

- Make sure my community understands about autism and accepts and includes me.
- I want everyday services to understand autism and help me do things other people do.
- I want to be safe in my community.
- See me as a person, not just a person with Autism.
- I want to link to other people and groups.
- My local area thinks about what is important to me. I know if they are doing as well as other places.

Priority 2: The right support at the right time during my lifetime

- Staff in education, health and social care services understand how autism can affect me.
- Services understand how to support me when there are big changes in my life.
- I want the right support at the right time in my life.
- I need the police, courts and other law services to understand about autism.
- I want my family to get the help and support they need.
- I want my local area to think about autism and understand the services I need.
- I want people to understand my autism and know how to support my other needs.

⁸ NHS England, ADASS and Local Government Association (2015), “Building the Right Support”. Available at: <https://www.england.nhs.uk/wp-content/uploads/2015/10/13-nat-imp-plan-oct15.pdf>

⁹ Camden’s transforming care plan is available at <http://www.camdenccg.nhs.uk/what-we-do/transforming-care-programme.htm>

¹⁰ Camden CCG’s commissioning intentions are available at: <http://www.camdenccg.nhs.uk/Downloads/ccg-public/What%20we%20do/NHS-Camden-CCG-Commissioning-Plan-and-Intentions-2016-17.pdf>

¹¹ Camden CCG (2015), “Transforming child and adolescent mental health services in Camden 2015-2020”. Available at: <http://www.camdenccg.nhs.uk/publications/htm>

¹² The North Central London transforming care plan is available at: <http://www.camdenccg.nhs.uk/what-we-do/transforming-care-programme.htm>

¹³ Department of Health (2014), “Think Autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update.” (Published under the coalition government) Available at: <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>

Priority 3: Developing my skills and independence and working to the best of my ability

- I want to be independent and make the most of my skills and abilities.
- I want support to get and keep a job.

How this plan was developed

3.10 The development of an all age autism plan during 2015/16 was informed by the 2014 autism self-assessment framework results¹⁴ and 2016 self-assessment process. We also engaged almost 50 stakeholders in a dedicated workshop, including service users, parents and carers, adults and officers. This workshop was supplemented on request by a special parent's forum. An operational development group was re-launched in April 2015 to meet regularly and inform the development of the Plan, including representation from education, health and social care, independent supporters and parents.

3.11 Consultation included liaison with a Planning Together Forum for learning disabilities, including parent carers and local service providers, with GPs with special interests in autism, and with adults with autism through the Asperger London Area Group.

3.12 This engagement has helped to co-produce the Plan and the high level actions identified in the action plan in Appendix A.

4. Financial context

4.1 In the current economic climate, public services are under increased financial pressure to achieve ever improving outcomes for local residents against a backdrop of ever diminishing resources. These financial constraints will require us to reduce bureaucracy and increase effectiveness to ensure that provision targets children, young people and adults with autism to best effect.

4.2 Since 2010, core government funding to local authorities (from which social care and other support is funded for children and adults with autism) has been reduced by 42%, and by 2019/20 is expected to have been reduced by 57% over that period. In terms of health elements of autism support and services, Camden CCG's funding is currently expected to remain close to static over the next few years in light of the recent NHS England redistribution of CCG funding

against the fair share formula. Across North Central London the health and care economy is expecting a £876m shortfall by 2020/21 as a result of rising demand far outstripping funding. A Sustainability and Transformation Plan is being developed to deliver the efficiencies and new approaches that will be required to address a financial gap of this size

4.3 From 1st April 2013 (for children and young people) the government changed the way in which all schools, including academies, were to fund special educational needs (SEN) provision of which autism is an aspect. As a result mainstream schools now receive funding for pupils with special and additional educational needs from two sources: the majority of funding is delegated to schools from the "Schools Block" funding, whilst 'top up' funding for individual pupils with high level, low incidence SEN is provided via the "High Needs Block". We are expecting Camden's funding from the government to reduce over the next few years in the light of its proposal to introduce "fairer funding" for schools. We are reviewing our "High Needs Block" funding and how it is used to ensure that we can manage any reductions that could apply in April 2018

4.4 It is anticipated that these changes along with the increased diagnosis of autism will put pressure on schools and envisage that our review will help us to manage some of these pressures.

4.5 In general terms the plan focuses on the better use of existing resources, awareness raising, training, clearer pathways to services, early support and intervention and more joined up support. This will help achieve better value for money while meeting people's outcomes more effectively. The plan also focuses on providing services locally, close to where people live in a more effective way. This will ensure that children, young people and adults are not placed in often expensive out of borough residential provision that does not always meet their individual needs. The autism legislation and statutory guidance from the Government came with no extra financial resources attached to it, as it was of the view that implementation of the guidance will achieve a better and more effective use of existing resources.

4.6 We continue to invest in a range of services for children, young people and adults including diagnostic/assessment services. See sections 7 and 8 below.

4.7 There are proposals within the plan to look at developing further secondary school provision for pupils with autism and behaviour that challenges.

¹⁴ Public Health England (2016), "Autism self-assessment framework 2014 – results." Available via <http://www.improvinghealthandlives.org.uk/projects/autisaf2014results>

The local authority has identified £5m capital funding for this development. This will ensure that there are more local options for young people with autism. See sections 8.5 and 8.6.

4.8 The plan also commits to reviewing the adult autism diagnostic pathway and provision of post-diagnostic support, with a view to better meeting people's needs. Improved services and outcomes will be secured within existing resources as far as possible, through seeking efficiencies, improving communications, and pursuing regional collaboration to secure economies of scale.

5. National trends

5.1 There is a general trend for an increase in diagnoses of autism. A recent publication by the Royal College of Psychiatrists¹⁵ concludes:

'Increased diagnosis may partially reflect increase in rates of behaviour associated with autism and/or greater parent/teacher recognition of associated behaviours.'

5.2 The National estimate of the prevalence of autism in adults is 1.1 per cent. Based on Camden's estimated adult population¹⁶ of 192,504 this suggests there are around 2118 adults in the borough living with autism. Despite a 25-fold increase in the diagnosis of autism in the last 30 years¹⁷, the diagnosed prevalence remains lower than population-level estimates would predict. Only around two-thirds of the expected numbers of children and one in 10 adults with autism have a diagnosis.

5.3 Around four times more men than women have diagnosed autism, although this may be partly a result of under-recognition and misdiagnosis of autism in women as they may be better able to mask their social difficulties. The specific needs of people with autism from black, Asian and ethnic minority communities may also be under-identified due to statutory organisations finding these communities 'harder to reach'. Autism is also under-diagnosed in older adults, which may be due to autism not having been widely recognised or diagnosable when those who are currently over 65 were children.

5.4 Some people with autism also have other learning disabilities and mental health problems. A study of autism and learning disability found that around 50%

of people with autism have a learning disability, and the prevalence of autism increased with greater severity of learning disability/ lower verbal IQ.¹⁸

5.5 Around 70% of individuals with autism also meet diagnostic criteria for at least one other (often unrecognised) mental or behavioural disorder¹⁹, and 40% meet diagnostic criteria for at least two disorders, mainly anxiety, attention deficit hyperactivity disorder and oppositional defiant disorder.

5.6 A study led by the London School of Economics and Political Science²⁰ estimates that autism is the most costly medical condition in the UK, costing the country at least £32 billion per year in treatment, lost earnings, care and support for children and adults with autism.

5.7 The provision of services for people with autism is varied across England and Wales, particularly with regard to services for adults²¹. There is evidence that poor awareness of autism means that the condition is often not recognised – particularly amongst older adults and women – and that people with autism and their families can find it difficult to get help and support from health, social care, education and employment services, difficulties that can be compounded by other factors such as language and cultural barriers.

6. Local picture

6.1 During summer 2015, Camden and Islington Public Health was commissioned to provide analyses of trends and patterns for children assessed for autism (under 5s, 5-18s), children with autism enrolled at Camden schools (5-18s), and adults diagnosed with autism and learning disability. The analyses looked at trends and patterns including age, gender, ethnicity and deprivation. They relied heavily on existing service datasets from MOSAIC (Making Our Services All Integrated in Camden - the integrated service for disabled children, young people and their families from birth to 18 years of age, providing assessment, therapy and family support, including Short Breaks), the Camden School Census, and Camden Learning Disabilities Service.

Key findings of these analyses are highlighted below.

6.2 Early years

¹⁵ Russell, G., Collishaw, S., Golding, J., Kelly, S.E. and Ford, T. (2015), "Changes in diagnosis rates and behavioural traits of autism spectrum disorder over time". In *British Journal of Psychiatry Open* Oct 2015, 1 (2) 110-115. DOI: 10.1192/bjpo.bp.115.000976/ Available at: <http://bjpo.rcpsych.org/content/1/2/110>, accessed 6 January 2016.

¹⁶ Greater London Authority 2015 round population projections, available at: <http://data.london.gov.uk/dataset/2015-round-population-projections>, accessed 2nd September 2016.

¹⁷ NICE (2012), "Autism in adults: diagnosis and management." NICE Clinical Guidelines 142. Available at: <https://www.nice.org.uk/guidance/cg142>

¹⁸ Brugha T., Cooper S.A., McManus S., Purdon S., Smith J., Scott F.J., Spiers N., Tyrer F. (2012), "Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey". (NHS Information Centre). Available at: <http://www.hscic.gov.uk/pubs/autism11>

¹⁹ NICE (2011), "Autism in under 19s: recognition, referral and diagnosis." NICE Clinical Guidelines 128. Available at: <http://www.nice.org.uk/guidance/CG128/informationforpublic>

²⁰ Buescher A. V., Cidav Z., Knapp M., Mandell D. S. (2014), "Costs of autism spectrum disorders in the United Kingdom and United States of America". In *Journal of the American Medical Association Pediatrics* (JAMA) 168(8) pp721-728. Available at: <http://archpedi.jamanetwork.com/article.aspx?articleid=1879723>.

²¹ NICE (2014), "Autism." NICE Quality Standard 51, p3. Available at: <http://www.nice.org.uk/guidance/qs51/chapter/List-of-quality-statements>

- Over the two years 2013/14 and 2014/15 69 children (under 5 years old) were assessed for autism.
- Of these, 65% (45) were diagnosed with autism, with a further 15% (10) receiving other diagnoses (e.g. atypical autism and learning disability).
- Black and minority ethnic (BME) children accounted for the majority of young children assessed for autism. The number of assessments of White children increased from 5 to 9 and assessments of BME children increased from 22 to 24 over the two year period.
- Children living in more deprived areas accounted for a larger number of assessments.
- It is projected that by 2020 there will be a 22% increase in assessments of young boys for autism (from 32 to 39).

6.3 School age

- For the population of statutory education age (5 to 18 years) the number of referrals for assessment has increased from 67 to 73 between 2012/13 and 2014/15, and is expected to almost double (to 138) by 2019/20.
- The number of assessments has remained the same during this period (46 children), reflecting capacity limitations of the services.
- There was an increase in the number of BME children assessed in recent years (2013/14 and 2014/15) while the number of White children being assessed has fallen.
- There were more boys being assessed than girls over the period, reflecting the overall gender profile in autistic spectrum conditions.
- In the 10 years between 2009/10 and 2019/20 there is a projected increase of 105 more referrals for assessment of children and young people aged 5-18 years old. This is from 33 referrals for assessment to 138.
- The number of school age boys recorded with a diagnosis for autism is projected to increase from 180 in 2015 to 224 in 2020 (+24%), and from 39 to 55 (+41%) among girls, assuming that there is no change in the number of assessments carried out each year.
- 258 children and young people with an autism diagnosis are in receipt of an Education, Health and Care plan or statement of special educational needs.
- The Preparing for Adulthood Team records 102 young people with autism between the ages of 12 and 19.

6.4 Adult population

- Population projections suggest that the numbers of adults with autism in Camden will increase year on year, to almost 2500 by 2040.²²
- 407 (336 male, 71 female) patients registered with a Camden GP are assigned an autism code.
- In 2015, 144 adults were recorded with a diagnosis of autism and learning disability in Camden, most of whom have been known to services for several years. 45% (65) were aged between 18 and 29 years old.
- About two thirds (66%, 95) of adults diagnosed with autism and learning disability are not in employment.
- Referrals of adults without learning disabilities to Camden and Islington NHS Foundation Trust for an autism assessment were running at about 130 per year by 2016 from both Camden and Islington. The service was originally funded for an estimated 80 referrals a year, which indicates the potential numbers of adults living with autism in Camden who are unknown to the local authority and partner organisations.
- There are a small but important group of adults with autism spectrum disorders who do not meet threshold for learning disabilities service but who do have significant care needs.
- There are several individuals with autism who do not have learning disabilities admitted to inpatient settings at any time.

6.5 In addition to the needs assessment undertaken by Public Health, analysis of other operational databases and the School Census for the Special Educational Needs and Disability Virtual Register 2015 identified 339 children and young people with autism, of which 263 were identified as part of the high needs cohort of 1,202 equating to almost 22% of this cohort presenting with a primary need of autism.

6.6 This local needs assessment highlights that not all people with autism in Camden are known to the local authority or partner organisations. Therefore only estimates of the total numbers of people in Camden with autism are actually known. Many people with autism are likely to be managing with some combination of their own coping mechanisms and help from friends and relatives and thus will not be known to local services. Further work will be undertaken as part of the implementation of the plan to obtain a more comprehensive picture of the autism population in Camden.

22 Calculated by applying the national prevalence rate to the Greater London Authority 2015 round population projections. Available at: <http://data.london.gov.uk/dataset/2015-round-population-projections>, accessed 2nd September 2016.

7. Service review

7.1 In Appendix B we highlight the services that are currently available to children, young people and adults. This plan's primary focus is to re-shape and re-design current services to better meet the needs of people with autism in Camden. This will be achieved by working with local providers to develop clear and credible plans which continue to deliver quality, innovation, productivity and prevention within financial resources, in line with national requirements (including excellent outcomes), and local joint health and wellbeing strategies. These plans will seek to enhance local community based provision and increase access and availability to local universal services to ensure that the Council and the CCG channel the right resources, at the right time, in the right place, to the right people.

7.2 The impact of legislation and an increased awareness of autism has progressed the development of services. For children and young people this has been primarily focused on improved diagnosis and support services through the Child Development Team and the Social Communication Assessment Service managed through MOSAIC. These services are complemented and supported through Camden's Integrated Early Years Service and integrated, jointly commissioned outreach education and health services, e.g. Camden Language Communication Service and Camden Speech and Language Therapy Service for Young People, as well as the Royal Free London Paediatric Occupational Therapy Service. However, only the Social Communication Assessment Service is specifically funded for autism, with the result that expenditure on the condition can only be attributed after diagnosis. MOSAIC currently estimates expenditure on children and young people with autism to be £200,000 per annum. These provide access to a range of services that help parents to better understand the diagnosis and support them in supporting the child and or young person with autism.

7.3 Some people with autism grow up without their condition being recognised. Often adults with undiagnosed autism have known for a long time that they have specific difficulties, but have not been able to explain them. The persistent and cumulative effect of the difficulties they have in managing their everyday lives and the barriers society creates for them may, in some cases, result in mental illness – particularly anxiety and depression – whereas in the general population a major life event may trigger a reactive mental illness. A timely and sensitive autism diagnosis can therefore be a relief, because it means adults can learn about their condition and understand for the first

time why they have difficulties. Not having a diagnosis and appropriate support can adversely impact on education and employment prospects, health and wellbeing.

7.4 Demand for diagnosis and assessment services remains high. For children and young people there was a 16 week wait, as of August 2016, for the first assessment appointment with the Social Communication Assessment Service This has improved from April 2016 when the waiting time was 18 weeks. Some additional one off funding has helped to manage this. These waiting times are regularly monitored by Social Communication Assessment Service and are reported to the Partnership Group that oversees Camden's Integrated Children's Service (CICS) alliance agreement. Camden is also working with its North Central London partners to see what improvements can be made to pathways and what we can learn from each other.

7.5 The adult autism diagnostic pathway is comprised of two diagnostic services.

7.6 For adults with learning disabilities a diagnostic service is provided through Camden Learning Disabilities Service, for which the waiting time for an autism diagnostic assessment is currently 6 weeks (September 2016). This waiting time is monitored by the Camden Learning Disabilities Service and commissioners

7.7 For adults without learning disabilities, an Adult Autism Diagnostic and Consultation Service is jointly commissioned with the London Borough of Islington as part of the neuro-developmental disorders diagnostic service at Camden and Islington NHS Foundation Trust. The current waiting time for an autism diagnostic assessment from this service is 40 weeks (as of September 2016; this is a combined Camden and Islington figure). When the service started in November 2013 the waiting time for assessment was 72 weeks (18 months) for both boroughs. At the end of 2015/16 the average waiting time was 28 weeks due to the provision of additional one-off funding in year, however, due the high referral rate, the waiting time has risen again. Waiting times remain above the NICE guidelines (12 weeks), due to both funding constraints and the challenges experienced in identifying potential demand for the service when it was first developed. The waiting time is monitored by the Adult Autism Diagnostic and Consultation Service, which in turn is monitored as part of Camden's contract with Camden and Islington NHS Foundation Trust. Camden is now working jointly with Islington to review the pathway, understand the

cause of high referral rates (which may be linked to increased awareness of autism and the service) and explore options for reducing waiting times with partners across North Central London.

7.8 GPs and other primary care services have a key role in the identifying the possibility of autism in adults, making referrals to the autism diagnostic pathway, and providing and coordinating support. Many people who live with autism in Camden are not recorded on GP registers of people with autism. This means that some people may not be receiving appropriate levels of support and follow-up in primary care, and that some adults remain undiagnosed.

8. Gap analysis and the design of future provision

8.1 There remains a significant pressure on local resources arising from a 30% year on year increase in the diagnosis of children with autism, and the demand for adult autism assessment growing at a far higher rate than was expected or commissioned for. The information from the needs assessment, service review and consultation highlights implications for the following areas.

8.2 Primary school aged children - from a recent audit approximately 23% of children known to the special educational needs team in mainstream primary schools/resource bases in Year 3 with a diagnosis of autism do not have it listed as their primary area of need.

8.3 Secondary school provision - particular pressure has been identified in the secondary education phase where students with autism are supported in local maintained schools or resource based provision, but there remain a number of students placed in costly independent / non-maintained sector placements. Whilst there has been significant progress in reducing the overall numbers of out-of-borough pupils we have not made the anticipated progress in reducing the numbers of the secondary age cohort placed out of borough. There is a group of young people with autism but no other significant needs who do not necessarily receive additional support outside of universal health and education services. Following the end of formal schooling, this group can become socially isolated and develop challenging behaviours due to the lack of structure in their lives. Plans are being considered to increase capacity within existing secondary school provision with the development of additional ASD resource bases – see 7.5 below.

8.4 Training - in Camden we recognise that there are a range of practitioners with differing training needs with regard to the amount and type of information that is helpful. The Autism Development Group has therefore designed a tiered system of training to focus on four different levels, from basic information to specialist. Each level of training builds on the previous one, and the more specialist practitioners require the highest level of training. Since September 2010 courses have been run by Camden's Training and Development Service in line with annual identified needs. It is important that autism awareness training is made available across universal services, and highlights the particular issues faced by women with autism, people with autism from black, Asian and ethnic minorities, and older people with autism.

8.5 Camden's Child and Adolescent Mental Health Services Transformation plan 2015-20²³ also reiterates that we expect to see:

- an increase in provision of secondary age autism resource bases
- strategy and services co-designed with children, young and families.

8.6 A project team is in the process of further developing the budget, design brief and delivery programme for the secondary resource base, to include the options of the expansion of an existing school, whether as a single school or more than one school. This will involve liaison with the schools, feasibility work and costed options.

8.7 All Together Better (Camden's integrated child health project) is also key in meeting the needs of people with autism. It recommends improving access and improving outcomes through integration, with particular emphasis on:

- developing and delivering a rolling education programme for GPs and Practice Nurses.
- developing and delivering a package of training for health visiting and school nursing staff.
- continuing the development of the needs-based tool for Camden's GP website.
- continuing to improve the integrated model for Child and Adolescent Mental Health Services as set out in the transformation plan.
- developing a shared digital record, for every Camden child (or family where appropriate) that has information relating to all services involved with the

23 Camden CCG (2015), "Transforming child and adolescent mental health services in Camden 2015-2020". Available at: <http://www.camdenccg.nhs.uk/publications/html>

child and accessible by any service involved in the care of that child including urgent care providers.

- reviewing and improving current pathways between adults and children's services for young people with long term conditions.
- having a named GP for children with special educational needs and/or disabilities, mental health concerns, long-term conditions, troubled families.

8.8 Preparing for adulthood – in Camden, we are developing positive Preparing for Adulthood and Transitioning Services with a view to ensuring that young people with disabilities including those with autism in the borough routinely transition safely and smoothly into adulthood, and that the support they receive enables them to achieve their aspirations.

8.9 In practice this means that holistic transition planning will start at age 14 and be better co-ordinated so that:

- parents/young people are empowered to make informed choices and enabled to have their views heard
- support plans are co-produced and tailored to suit individual needs
- services are cohesive, emphasise continuity of care and are aligned towards achieving articulated outcomes
- opportunities exist beyond education, which enable young people to be as independent or inter-dependent as they can be and remain in Camden.

8.10 In order to achieve this, we commissioned a review of the services available across children and adults teams and have developed a holistic pathway into adulthood for young people with disabilities aged 14 to 25. As part of this, we have aligned and improved social work practice and intend to further align SEN support and local health care provision so that the local offer is more clearly defined and more aligned to the resilient families' way of working which promotes a bespoke and flexible approach to help build resilience and improve outcomes.

8.11 Some of the options available for young people currently include internships with Great Ormond Street Hospital supported by Swiss Cottage School. There is a 3 year part-time course at Westminster Kingsway College with a focus on employability; training/ support is provided at the Alexandra Centre, including residential short breaks to enhance independent living skills and the local offer signposts opportunities. Travel training is provided for those using local authority

transport or can be privately funded. Students have Individual Learning Plans focusing on health, employment and independence. There are also local work support schemes and employability pilots (see section 8.19 and 8.20 below.)

8.12 Young people/adults - consultation with carers and adults with autism during the development of this plan particularly highlighted the restricted options for diagnosis, support and access to education and employment opportunities for young people with autism. Age-related restrictions in the offer for further education to under 25 year olds serve to limit the wider social opportunities provided through the structure of formal education.

8.13 Adults - there is currently a significant wait for autism diagnosis, above waiting times specified in NICE guidelines, as the demand for assessments is running far higher than the service was originally commissioned for. In addition there are significant gaps in post-diagnostic support, particularly for the small but important group of adults with autism who do not meet thresholds for learning disabilities services but do potentially have eligible care and support needs that are not currently well addressed. Camden is committed to reviewing the pathway to ensure that there is a clear pathway to diagnosis for adults of all ages that meets NICE guidelines and standards, and that adults with autism with eligible needs can access assessments and care and support they are entitled to under the Care Act.

8.14 As part of this review, options are being considered for providing a specialist support function for adults with autism and care and support needs (including those with high functioning autism/ Asperger's syndrome). For example, London Borough of Islington have recently appointed a senior social worker and a social care worker to link closely with Adult Autism Diagnostic and Consultation Service and provide specialist input for adults and young people with autism who do not have learning disabilities or mental health conditions.

8.15 Adults with autism who do not have eligible care and support needs, a global learning disability or mental health needs - during consultation people told us that opportunities for peer support and low-level psychological support would make a substantial difference in their lives. Camden's most recent self-assessment framework process revealed gaps around low-intensity/ prevention offers. In addition, during consultation, adults with autism told us that it is vitally important to their wellbeing to have the opportunity to develop good relationships with friends and family

and to pursue meaningful things to do (such as employment, recreation and hobbies). This requires appropriate support and development opportunities to be available, such as peer groups for sharing coping strategies and learning and practising social skills to overcome the challenges of conversation and relationship building. Mainstream support services for adults, particularly older adults, must also work for people with autism.

8.16 Universal services - people who do not need formal care and support, including people with autism depend on local universal services and community/voluntary sector provision in order to live well. People need clear information at the right time and in the right format so that they can choose what is right to meet their health and wellbeing needs; however this information can be difficult to find and is not currently brought together in one place. Communications and information for individual adults with autism must also be in line with the Accessible Information Standard.

8.17 Adults with Asperger's highlighted during the consultation on this plan the importance of developing universal services that accept neuro-diversity and understand the needs and aspirations of people with autism and how to support them. Universal services (e.g. GPs, dentists, libraries, leisure centres, theatres etc.) should be accessible for everyone to use, however, Camden's most recent self-assessment framework process revealed gaps around reasonable adjustments in universal services. Consideration should therefore be given to promoting reasonable adjustments and advising public services/ employers in order to create autism friendly environments, in line with Equality Act 2010 duties²⁴.

8.18 Transforming care - in line with recommendations, everyone with a learning disability and/ or autism should have access to integrated, community-based, specialist multidisciplinary health and social care support in their community. The service should be readily accessible, when needed, by children, young people and adults with a learning disability and/ or autism, including those who may have come into contact with or are at risk of coming into contact with the criminal justice system. Key functions of this specialist support should include: support to enable people to access mainstream health and social care services, work with mainstream services to develop their ability to deliver individualised reasonable adjustments, support to commissioners in service development and quality monitoring, and the delivery of direct assessment and therapeutic support

8.19 Employment and housing - during the consultation to develop this plan, adults with autism highlighted the importance of support to find and maintain employment, to secure appropriate housing and to maintain financial stability that helps to prevent the development of comorbid mental health problems such as depression and anxiety, poor physical health, or crisis that prevent them living fulfilling and rewarding lives.

8.20 Specifically, people told us about the lack of opportunities for employment-related support that would make a substantial difference in their lives, whilst Camden's most recent self-assessment framework process revealed gaps around support for people with autism to find or stay in work. The Council is already working with Job Centre Plus to jointly commission support to build on and improve existing pathways to work for residents facing health/disability barriers, to trial different approaches and inform future commissioning decisions. These interventions include developing Individual Placement Support, an approach aimed at increasing paid employment and health and wellbeing outcomes for people with mental health conditions. Individual Placement Support relies on co-location and joint working between employment and clinical specialists. A pilot programme has also been commissioned to improve job opportunities for people with disabilities and long-term health conditions including autism, through developing employer focused interventions and improving access to in-work support.

8.21 Housing - adult social care services will work collaboratively with housing colleagues to develop pathways and effectively signpost to support services. Camden will implement a commitment to give new placement options within Camden, and to repatriate people who live out of Borough who would like to return to Camden, including the development of suitable accommodation options, particularly for those with more complex needs. An accommodation panel, including commissioners and providers, has been established in Camden Learning Disabilities Service to maintain an overview of the allocation of property to those who are need of alternative accommodation and identify appropriate options including effective use of all private sector, sheltered/extra care sheltered and supported housing options in the Borough

8.22 Community inclusion - consultation with adults with autism, parent carers and providers has highlighted the importance and potential to enhance a community and neighbourhood focus to deliver the key outcome of community inclusion. Members of the Asperger London Area Group indicated the need to

²⁴ An example of such support has been developed and launched by Kirklees Council and the South West Yorkshire Partnership NHS Foundation Trust to improve the environment for people with autism. See <http://kirklees.firmstep.com/default.aspx/RenderForm/?FName=cy9nTeEY8LpandHideToolbar=1>

develop an autism-aware society, utilising tools such as the Autism Charter, in order to remove barriers to inclusion and wellbeing for people with autism, such as confusing public services and transport, people's attitudes and assumptions, and a lack of quiet space from over-stimulating light and noise. The Greenwood Place development will see Camden open its first Centre for Independent Living from 2018, which will include services and activities that promote the wellbeing and independence of adults with autism. It could build upon, for example, the recent opening of the Westminster Society drop-in and outreach service operating from a community base near Kentish Town. Such developments will support the Council's Resilient Families Programme objectives to develop resilience in the local community.

8.23 Criminal justice services are members of the Camden Safeguarding Adults Partnership Board and are involved where appropriate in individual cases. We will revisit the membership of this group to ensure they are involved in the most appropriate way.

8.24 The Transforming Care service model recommends liaison and diversion schemes should seek to support people through the youth or criminal justice system pathway enabling people to exercise their rights and/or where appropriate, diverting people to appropriate support from health and social care services. Clear pathways for diversion to appropriate health and social care services should be established through local multi-agency protocols. Further scoping should consider the opportunities to deliver targeted autism training for custody and court staff.

8.25 Co-production - it was highlighted that a new relationship is needed between people with autism and services, whereby a co-production approach is taken to the review, development and delivery of services that listen, act in people's best interests and are held to account. Camden's most recent self-assessment framework process also revealed gaps in co-production of services with people with autism and their carers. Under the national autism strategy Camden is required to establish an Autism Partnership Board, which could facilitate the development of this new relationship.

9. Commissioning and procurement implications

9.1 The commissioning priorities will include:

- maintaining the existing diagnostic services and keeping them under review to see how they are meeting demand
- improving access to high quality local services responsive to the needs of people with autism (including developing a clear, consistent pathway for the diagnosis)
- improving local data collection (including local information on the numbers of adults with autism by gender, ethnicity and age, particularly older adults, and their needs) to support service planning, and
- ensuring that people with autism are at the centre of planning and commissioning decisions for local services.

9.2 It is also important to develop a market of specialist and reasonably adjusted universal services that meet the needs of people with autism, including personal assistants, in order to grow autism-friendly communities.

9.3 As existing contractual arrangements are reviewed, commissioners will ensure that:

- each service which provides information and advice across Camden provides a range of information detailing local services and support, including links to support networks across the borough.
- service specifications endorse NICE clinical guidelines and quality standards for autism including the recognition, referral, diagnosis and management of children and adults with autism.
- all service specifications and contracts for commissioned services include requirements to make reasonable adjustments for the diverse needs of people with autism and that services recruit staff with the appropriate level of autism knowledge and skills to help meet these needs.

10. Monitoring arrangements

10.1 Once the plan has been endorsed, the functions of an Autism Partnership Board will be developed as recommended in national guidance, including people with autism and their families. This Board's primary role and purpose will be to set a clear direction for improving services and the local offer.

The Board will seek to implement, monitor and track progress of the plan, ensuring that progress is reviewed and that it obtains regular updates. Options will be considered for the structure and governance of the Board, and the fit with the existing Autism Development Group.

10.2 The Autism Development Group, facilitated through the Educational Psychology Service that meets half-termly. This includes multi-agency representation from health, education, social care and parent representatives.

10.3 It is envisaged that there will be a number of small sub-groups formed underneath the Board, whose role will focus on working to complete key actions for each of the strategic objectives outlined in this plan. These sub-groups will be required to provide regular feedback to the Autism Partnership Board on their progress. Membership of these sub-groups will include people with autism and family and parent carers as well as professionals from a range of different service areas and organisations.

10.4 It is anticipated that the Autism Partnership Board will want to further develop the high level action plan proposed at Appendix A, including:

- specific actions that will be taken to achieve the strategic outcomes and goals
- timescales for each action
- which partner organisation will lead on each action
- how we will know when each action has been achieved.

10.5 It will also want to use the findings and evidence from the Special Educational Needs (SEN) CCG diagnostic checklist that is currently being completed to see where we are compliant with the duties on the CCG (through the Children and Families Act 2014) and where further work is required.

10.6 On an annual basis, the Autism Partnership Board will report progress on the implementation of this plan to an appropriate governance structure, which may include Camden's Health and Wellbeing Board.

11. Appendices

Appendix A – High level action plan

Appendix B – Service review

Appendix C – Assessment pathways

Appendix D – Needs assessment

Appendix E – Glossary

Appendix A – High level action plan

A high level action plan is presented here. There are more detailed proposals that will be further developed and agreed by

Camden plan for people with autism

Our Vision

Camden is a place where people with autism can be an equal part of their local community, and develop their skills and independence and work to the best of their ability

Our strategic context

National context

- Autism Act 2009.
- “Fulfilling and Rewarding Lives: the strategy for adults with autism in England 2010” & “Think Autism 2014”
- NICE autism quality standard (QS51)
- Guidance on Autism in under 19s (CG128 and CG170)
- Autism in Adults (CG142).
- Transforming Care programme
- “Building the Right Support 2015”

Local context

- Camden Plan 2012-17
- Resilient Families Programme
- Strategy for children & young people aged 0-25 with special educational needs and/or disabilities – 2017 – 2020
- Accessibility strategy for educational Settings 2016 – 20
- Transforming child & adolescent mental health in Camden 2015-2020
- All Together Better
- Minding the Gap
- Adult Social Care Vision
- Local care strategy

Our needs

Children & young people

- Increasing number of assessments for the under 5s and over 5s
- By 2020 there will be a 22% increase in assessments of young boys under 5s for autism
- Number of school aged boys diagnosed with autism is projected to increase by 24%
- 258 children & young people currently have education, health and care plans or statements

Adults

- There will be a year on year increase in adults with autism by 2040 – to almost 2500 people
- About two thirds of adults diagnosed with autism and learning disability are not in employment
- There are a small number of adults with autism who do not meet the threshold for LD services but have significant care needs

by the Autism Partnership Board (APB) once it has been established.

access the right support at the right time throughout their lifetimes

Our top priorities	The outcomes this will achieve
<ul style="list-style-type: none"> ■ Establish an Autism Partnership Board to take forward the autism plan and develop a detailed action plan ■ Develop capacity within existing local secondary school provision with the possibility of developing more autism spectrum disorder resource bases so that families have more local options. ■ Ensure that All Together Better programme meets the needs of children and young people with autism ■ Continue the implementation of an integrated Preparing for Adulthood Team ■ Review the adults with autism pathway to ensure that adults can get the right help at the right time. ■ Address the waiting times for diagnostic services ■ Consider the option of providing specialist support function for adults. ■ Assist universal services to be more accessible to people with autism. ■ Review and promote an autism training programme across the partnership ■ Implement Transforming Care in Camden in line with national guidance ■ Ensure liaison and diversion schemes divert people to appropriate health and social care services ■ Implement plans in relation to housing and employment ■ Continue to review, develop and deliver services for people with autism with co-production at its heart. ■ Improve local data collection, reporting and use to support needs identification, service planning and commissioning, and tracking of outcomes. ■ Include an in depth chapter on autism in the local Joint Strategic Needs Assessment 	<div data-bbox="1050 707 1497 853" style="background-color: #1a3d54; color: white; padding: 5px;">By 2021, people with autism and their carers will:</div> <ul style="list-style-type: none"> ■ achieve better health outcomes ■ be included and economically active ■ live in accommodation that meets their needs ■ benefit from the personalisation agenda in education, health and social care, and access personal budgets ■ no longer be managed inappropriately in the criminal justice system ■ be satisfied with local services, as will their families ■ be actively involved in planning the services that affect their lives

Appendix B - Service review Children and young people

- The Social Communication Assessment Service as part of MOASIC is specifically funded to undertake assessments for autism.
- Where there is a need for direct intervention around their language and communication, children with a diagnosis of autism who attend a primary school in Camden receive direct support from Camden Language Communication Service and Camden Speech and Language Therapy Service for Young People. This is in the form of speech and language therapy or specialist language and communication teacher time.
- Children with a diagnosis of autism and identified occupational therapy needs, who attend both primary and secondary schools in Camden, access occupational therapy services provided by the Royal Free Paediatric Occupational Therapy team.
- Since 2009 pre-school and primary provision has been developed which provides a local pathway for children with autism. Provision includes enhanced places at maintained nurseries, outreach support to mainstream schools, resource bases for complex cases and/or high functioning autism, and special school placements.
- There are resource bases at Woodlands (Netley), Kentish Town Primary School and at Acland Burghley secondary school for young people with mild to moderate autism, whilst Swiss Cottage School Development and Research Centre provides for young people with autism and more significant learning disabilities.
- The national charity KIDS facilitates an autistic spectrum disorders parents' forum, members of which contribute to the Autism Development Group. Netley Campus hosts book lending meetings and support groups for parents of children diagnosed with autism.



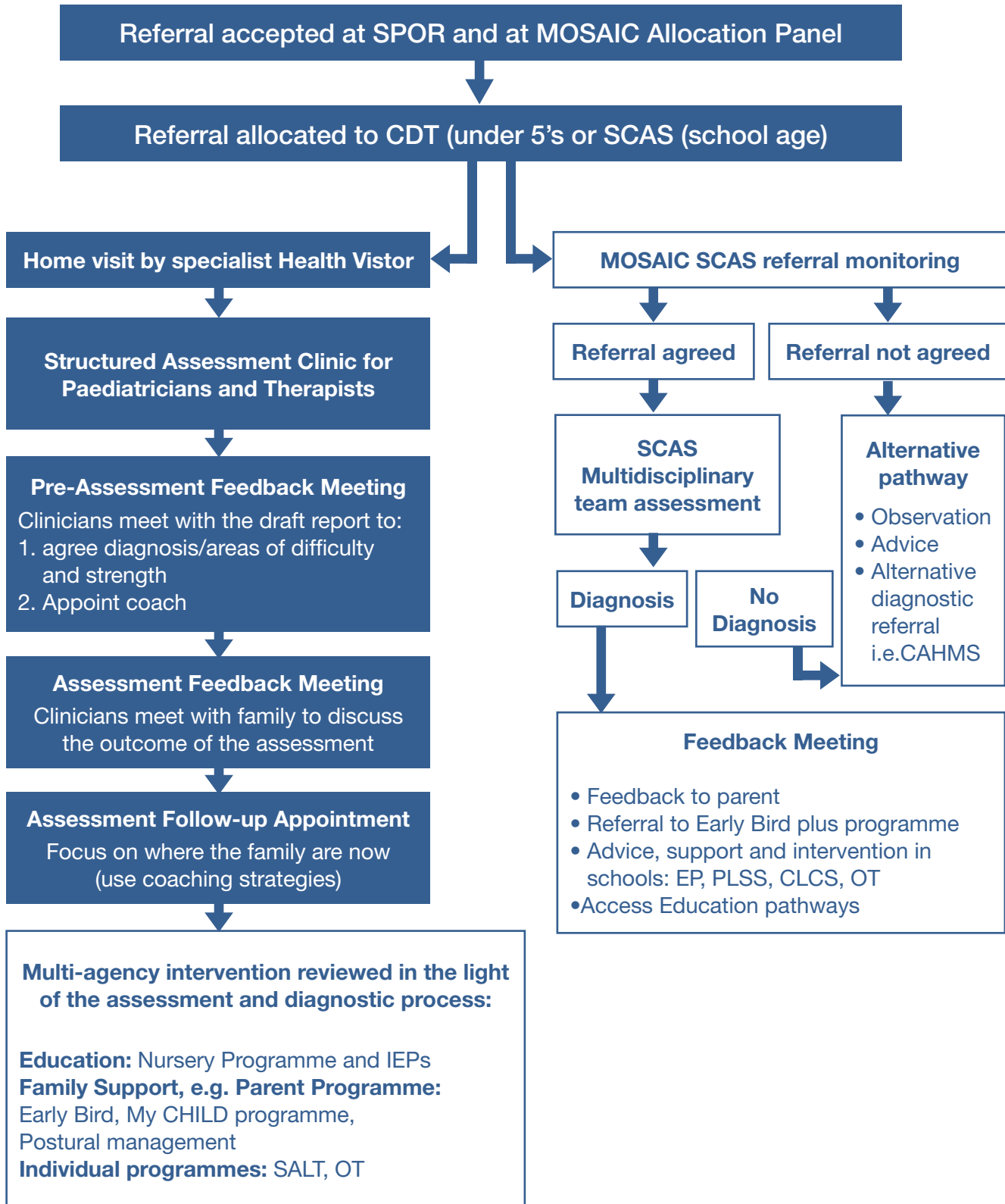


Adults

- The adult autism diagnostic pathway is comprised of two diagnostic services (see Appendix C). For adults without learning disabilities, an Adult Autism Diagnostic and Consultation Service is jointly commissioned with the London Borough of Islington as part of the neuro-developmental disorders diagnostic service at Camden and Islington NHS Foundation Trust. For adults with learning disabilities a diagnostic service is provided through Camden Learning Disabilities Service.
- Following diagnosis the current care and support pathway consists of feedback, advice and information; referral back to the GP for management within primary care; and signposting on to voluntary sector organisations, including Autism London and the National Autistic Society. The Adult Autism Diagnostic and Consultation Service offers some psycho-education as well as consultation for adults diagnosed with autism.
- There is a small service for adults with autism, including for adults diagnosed with Asperger's high functioning autism without learning disabilities, provided by the speech and language therapists at Camden and Islington NHS Foundation Trust, but it is insufficient to meet need. Run as communication skills groups, the focus is on social learning tasks for everyday communication within work and social situations, which improves social interaction
- Adults with autism and a comorbid mental health condition, such as obsessive compulsive disorder, attention deficit hyperactivity disorder, psychosis, anxiety or depression, are referred on to appropriate Camden and Islington NHS Foundation Trust teams for diagnosis and treatment. A small number of people are referred to other services, such as Team Around the Practice, that are not specialist services for people with autism.
- For specialist psychotherapeutic intervention, patients can be referred to the Tavistock Lifespan Service.
- Adults with autism who also have a global learning disability have access to the full range of integrated health, care and support services available from Camden Learning Disabilities Service. Under the Care Act, any adult with the appearance of care and support needs (including people with autism without comorbid conditions) is entitled to a social care needs assessment, regardless of their IQ or financial situation. However the pathway is not always clear and is currently under review.
- Any carer of an adult eligible for social care support can be referred, or self-refer, for a carer assessment and, if eligible, a support package. Camden currently benefits from the NHS England Liaison and Diversion programme, operating across London for vulnerable young people and adults engaged with the criminal justice system.

Appendix C: Assessment pathways

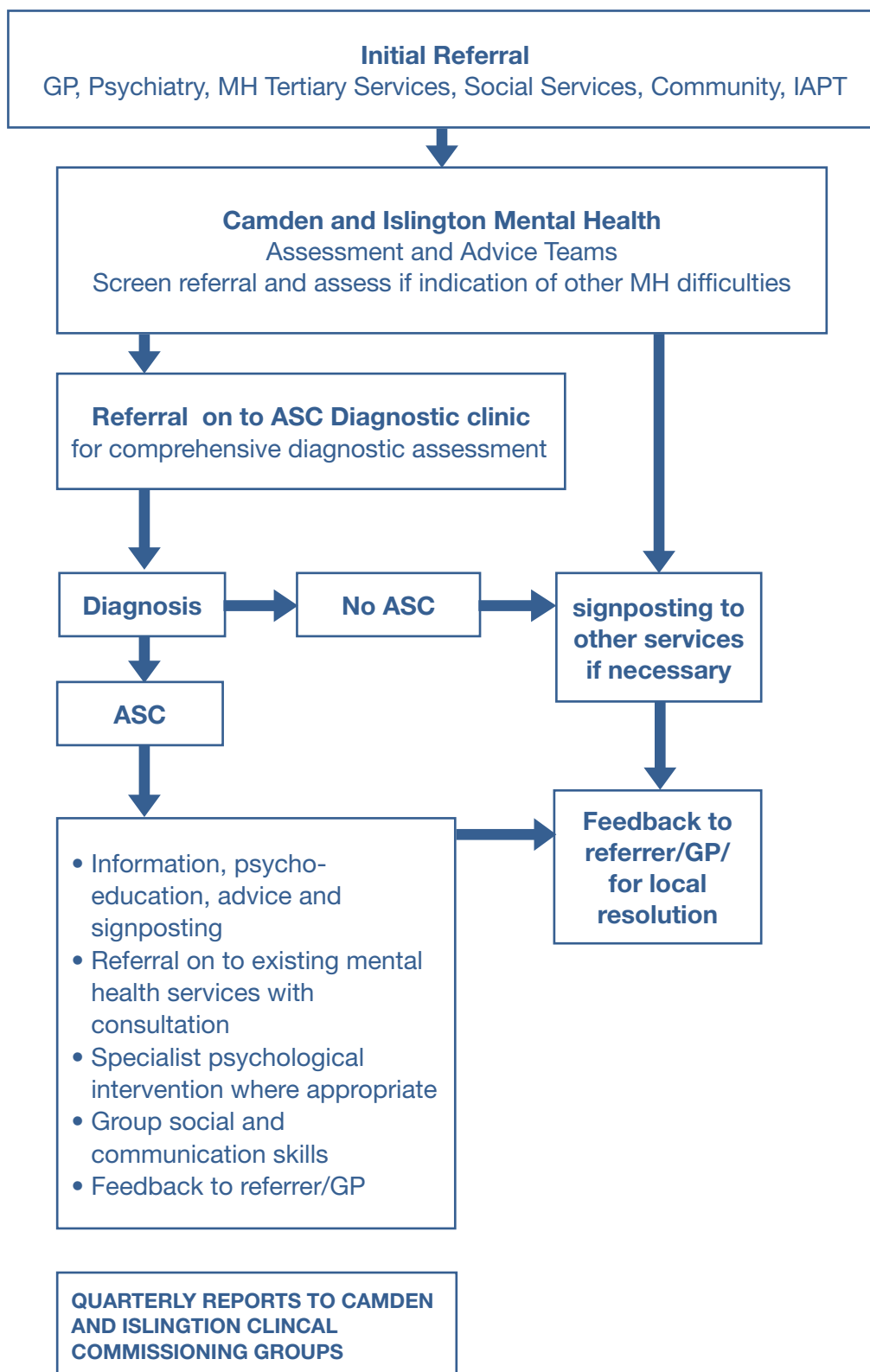
Autism Assessment Pathways C&YP



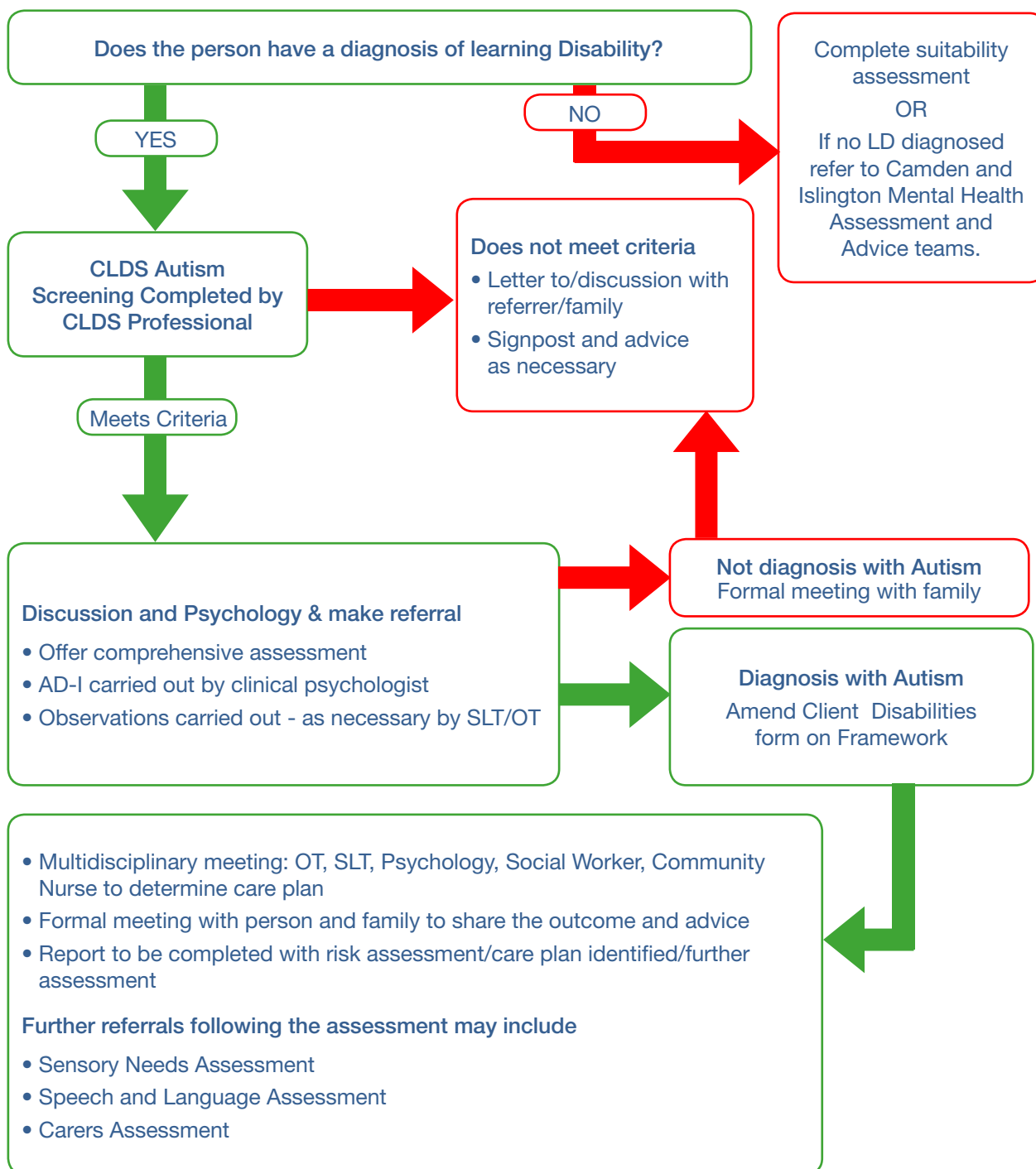
Adult Autism Assessment Pathways

Adults with Autism without Global Learning Disability

Care Pathway and Service Description



Autism Assessment Pathways for people who have learning disabilities



Appendix D: Needs assessment

During summer 2015, Camden and Islington Public Health was commissioned to provide analyses of trends and patterns for children assessed for autism (under 5s, 5-18s) and children with autism enrolled at Camden schools (5-18s),²⁵ and adults diagnosed with autism and learning disability resident in Camden.²⁶ Thematic audits of Children and Young People and Adults services have been undertaken through the development of the plan, including parent representation through the Autism Development Group, to identify:

- Where we are
- Where we need to be
- What we need to do

Responses were received parents of children and young people with autism, Camden Language Communication Service, Camden Speech and Language Therapy Service for Young People, Royal Free Paediatric Occupational Therapy team, MOSAIC, Integrated Early Years Service, Swiss Cottage Special School, Independent Supporters, and Netley Primary School's Woodlands Autism Spectrum Conditions resource base.

For adult services, qualitative and quantitative returns included in the 2014 Self-Assessment Framework²⁷ were relied upon, along with engagement meetings with the neuro-developmental disorders diagnostic clinics at Camden and Islington NHS Foundation Trust, with the Asperger London Area Group and with Camden's Learning Disability Partnership Board "Planning Together".

²⁵ Camden and Islington Public Health (2015), "Autism Assessments in Children and Young People: Camden". Available at: <https://opendata.camden.gov.uk/Health/New-analysis-on-autism-in-Camden-children-and-young-people>

²⁶ Camden and Islington Public Health (2015), "Autism and Learning Disability Assessments Adults: Camden". Available at: <https://opendata.camden.gov.uk/Health/New-analysis-on-autism-and-learning-disability-in-12dm-iclf>

²⁷ Public Health England (2014), Camden Autism Self-Assessment Framework. Available at: <http://www.improvinghealthandlives.org.uk/projects/autisaf2014results>

Appendix E: Glossary

Word	What this word means
Assessment	The way of working out what a person's needs are.
Attention Deficit Hyperactivity Disorder	A common behaviour disorder that affects around 10% of children and around 2% of adults. People with ADHD struggle to sit still, pay attention and focus on details.
Autism Development Group	A group of professionals from education, health and social care in Camden, working with parents to develop services and training to meet the needs of people with autism.
Autism Friendly Environment	Changes which can be made to a particular room or environment. This could include bookshelves, walls, furniture, soft furnishings and different flooring can all be used to create a calm, structured environment for a person with autism.
Carer	A person who provides unpaid support to a partner, family member, friend or neighbour who is ill or disabled who could not manage without this help.
Clinical Commissioning Group	A Clinical Commissioning Group (CCG) is a group of GP practices that are responsible for commissioning most health and care services for patients.
Co-produce	When you as an individual are involved as an equal partner in designing the support and services you receive. Co-production recognises that people who use social care services (and their families) have knowledge and experience that can be used to help make services better, not only for themselves but for other people who need social care.
Commissioning	How services are planned and paid for and checked that they are of good quality.
Community Inclusion	Involving everyone in society, making sure all have opportunities to work or take part in social activities even though they may have a disability.
Consultation	To seek information/views from people about a topic or theme.
Criminal Justice System	The criminal justice system encompasses the way that offenders are dealt with when they commit harm. The system includes the Police, Courts, Prosecution and Defence teams, witness service, prisons and the actual sentences available for courts to use in the disposal of convictions. Criminal Justice is distinct from civil justice and different courts and enforcement procedures are used. If appropriate, defendants are diverted away from the Criminal Justice System into services where it is deemed appropriate by the Police or Court or where the defendant lacks mental capacity.
Diagnosis	The process of finding out the nature and cause of a medical condition through looking at a patient's history and through carrying out medical assessments.

Appendix E: Glossary

Direct Payments	Payments made directly to someone in need of care and support by their local authority to allow the person greater choice and flexibility about how their care is delivered.
Education, Health and Care Plan	An Education, Health and Care plan is for children and young people aged 0 to 25. It focuses on identifying individual outcomes and puts children, young people and their families at the centre of the assessment, planning and review process.
Eligible	When your needs meet your council's criteria for council-funded care and support. Your local council decides who should get support, based on your level of need and the resources available in your area. The eligibility threshold is the level at which your needs reach the point that your council will provide funding. If the council assesses your needs and decides they are below this threshold, you will not qualify for council-funded care.
GP	General Practitioner: A doctor whose practice is not limited to a specific medical speciality but instead covers a variety of medical conditions in patients of all ages.
Hypersensitivities	This is when a person's sensory awareness is very acute. Some people with autism can be extremely sensitive to certain sounds or light, or to things they touch, smell and taste.
Joint Strategic Needs Assessment	A Joint Strategic Needs Assessment is an on-going process by which local authorities, CCGs and other public sector partners jointly identify and describe the current and future health and wellbeing needs of its local population and agree priorities for action.
Learning disability	Is defined as including the presence of: a significantly reduced ability to understand new or complex information, and to learn new skills (impaired intelligence); with a reduced ability to cope independently (impaired social or adaptive functioning; and childhood onset of such difficulties which are lifelong.
Local authority	An administrative unit of local government.
Neuro-diversity	The natural fact that people's brains and minds differ from one another, which should be recognised, respected and valued in the same way as other types of human variation.
NHS Foundation Trusts	NHS foundation trusts differ from other existing NHS trusts. They are independent legal entities and have unique governance arrangements. They are accountable to local people, who can become members and governors. Foundation trusts are overseen by Monitor.
Outcomes	In social care, an 'outcome' refers to an aim or objective you would like to achieve or happen – for example, continuing to live in your own home, or being able to go out and about. You should be able to say which outcomes are the most important to you, and receive support to achieve them.

Appendix E: Glossary

Personal Budgets	This is a statement that sets out the cost to the local authority of meeting an adult's care needs. It includes the amount that the adult must pay towards that cost themselves (on the basis of their financial assessment), as well as any amount that the local authority must pay. This may combine resources from different funding streams to which the individual is entitled but is most often related to meeting social care needs.
Practitioner	A health and care professional who is currently practising in their profession.
Provider	An individual, institution, or agency that provides health, care and/or support services to people. E.g. 'education provider' could be an early years provider, nursery, school, FE or specialist post-16 provider.
Refer	To ask someone else to provide care, treatment or other services which are beyond your scope of practice or, where relevant, because the service user has asked for a second opinion.
Safeguarding	Making sure that children or adults who may be at risk of harm are not being abused or neglected.
Sensory	Problems with working out sensory information such as sounds, sights and smells.
Signpost	Pointing people in the direction of information that they could find useful.
Special educational needs and disability	Special educational needs and disability that affect a child's ability to learn can include their: <ul style="list-style-type: none"> ■ behaviour or ability to socialise, e.g. not being able to make friends ■ reading and writing, e.g. they have dyslexia ■ ability to understand things ■ concentration levels, e.g. they have Attention Deficit Hyperactivity Disorder ■ physical needs or impairments
Strategic Objective	A goal or action which are set to achieve a plan (Strategy)
Strategy	A plan
Transition	The process of change a person goes through, for example growing from childhood into adulthood. For people with disabilities this process of reaching adulthood can mean changing the services from which they receive support and this can take place over a long period.
Voluntary (Organisations)	Organisations independent of the Government and local councils.
Wellbeing	Being in a position where you have good physical and mental health, control over your day-to-day life, good relationships, enough money, and the opportunity to take part in the activities that interest you.

