Richmond Joint Health and Social Care Strategy for people with autism 2016-2019

(updated April 2016)





Richmond Clinical Commissioning Group

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Executive Summary The Richmond Joint Autism Strategy covers children, young people and adults on the whole of the autistic spectrum. It has been prepared as a response to, but goes beyond,

the requirements set out in the Autism Act 2009 and the national autism strategy 'Fulfilling and Rewarding Lives' (March 2010) as well as subsequent updates, which only apply to adults. The Richmond Joint Autism Strategy is a partnership strategy between Children and Adult Social Care and Health Services in the London Borough of Richmond upon Thames.

The inequalities in access to all services and opportunities faced by people with Autism Spectrum Conditions (ASCs) and the resulting poor social and health outcomes require a holistic strategy that covers all aspects of life. This strategy also aims to ensure people with ASC are supported to realise their full potential at all stages of their lives.

This strategy is an update from the original Joint Health and Social Care Strategy for people with autism, implementation of which started in Q1 2013. It takes account of the national legislative and policy changes and updates as well as the substantial developments made locally and nationally to date.

There will be three areas of priority through which we will aim to achieve the developments required by national statutory guidance, which are:

- Training and Awareness-Raising
- Integration of Service into "Business as Usual"
- Innovation and Service Development

This updated strategy was developed in partnership with the Autism Programme Board, including Experts by Experience. It is also based on feedback received throughout the period of the original Joint Health and Social Care Strategy for people with autism (2013 – 2016) as well as an open meeting held following the publication of the updated National Autism Strategy and relating statutory guidance.

Introduction

The Richmond Joint Autism Strategy sets out the vision, aims, objectives and plans of health and social care as well as wider council and other services for people of all ages who have Autism Spectrum Conditions (ASC). This update has been produced as a response to the National Autism Strategy Update *Think Autism, Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update*¹ and the subsequent updated statutory guidance which was published in March 2015².

It brings together key partners to ensure that there is commitment across agencies to tackle the inequalities that exist in relation to ASC locally and beyond.

Throughout this strategy the term Autism Spectrum Condition (ASC) is used as an umbrella term for all conditions on the autistic spectrum, including Autism, Asperger Syndrome, High Functioning and Atypical Autism.

ASC is a lifelong developmental condition. It is estimated that more than half a million people in England are on the autistic spectrum, which is equivalent to more than 1% of the population³.

¹ <u>https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-</u><u>strategy</u>

² https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance

³ Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey <u>https://catalogue.ic.nhs.uk/publications/mental-health/surveys/esti-prev-auti-ext-07-psyc-morb-surv/esti-prev-auti-ext-07-psyc-morb-surv-rep.pdf</u>

Autism affects the way a person experiences the world around them, how he or she communicates and relates to other people. The term spectrum is used because of the wide range of difficulties that people experience. The core features include: difficulties in social interaction and communication as well as potential stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests. Individuals with ASCs may also experience sensory hyper- or hyposensitivities to, for example, noise, light or touch and have difficulties processing information. It is therefore essential to consider the needs of the individual person.

ASCs are neither a learning disability nor a mental health problem, although both can cooccur with ASCs. In particular anxiety and depression are common among people with ASC. Around 70% of people with autism also meet diagnostic criteria for at least one other (often unrecognised) psychiatric disorder that further impairs psychosocial functioning⁴. Estimates on the prevalence of learning disabilities in individuals with autism vary; however, a systematic review of studies in this area published in 2010 suggests that ASC and learning disability co-occur in just over 50% of individuals⁵.

Asperger syndrome is on the autism spectrum and is sometimes referred to as high functioning autism due to the fact that people with Asperger syndrome often have good verbal / language skills and are often of average or above average intelligence.

It is important to note at this point that while there can be a tendency to focus on the negative aspects and difficulties people on the autistic spectrum can experience, there are also a number of positive traits that people on the autistic spectrum can display. Examples of this include honesty and loyalty, a great eye for detail and an enjoyment of routine and repetition as well as very good memory, original points of view that can aid problem solving, dedication to agreed tasks and a strong commitment produce the best work possible.

Please see **Appendix A** for more information on ASC and further sources of information.

Whilst there have been significant improvements since the implementation of the Autism Act 2009 and the initial National Autism Strategy *Fulfilling and Rewarding Lives* which followed, there remain individuals with ASC across the whole autistic spectrum who experience social and economic exclusion. Their condition can be overlooked by healthcare, education and social care professionals; this creates barriers to accessing the support and services they need to live fulfilling, independent lives. Individuals with ASC can experience difficulties when trying to access general healthcare, education etc. and may not be able to access appropriate preventative and treatment services.

Changes in the London Borough of Richmond

There have been significant developments and changes in the availability of services to people with ASC in Richmond since the publication of the first Richmond Joint Autism Strategy in February 2013. The list below is not exhaustive, but is meant to give an overview of the main achievements to date to showcase the level of commitment that the borough as a whole has demonstrated.

Training and Awareness-raising

⁴ NICE 2011 Autism: recognition, referral and diagnosis of children and young people on the autism spectrum. NICE guideline 128

⁵ http://www.improvinghealthandlives.org.uk/uploads/doc/vid_8731_IHAL2010-05Autism.pdf [accessed 21.08.2015]

- Re-development of the e-learning in partnership with parents / carers and integration of the course in the Equality and Diversity training package completed by all new staff, as well as directorate-level encouragement of existing staff to complete the new e-learning, with good take-up across departments.
- Development of a number of classroom-based courses at varying levels and increasing the number of courses available. Targeting of specific departments, for example leisure services.
- Following the allocation of a grant from Skills for Care, production of three Autism Awareness films featuring local service users and carers, which will be advertised nationally by Skills for Care and are already available on the Richmond webpages.
- Completion of the first borough-wide Autism Awareness Week, including an artexhibition, drop-in sessions at local libraries and participation events for service users, carers / parents and the general population.
- Development of <u>www.richmond.gov.uk/autism</u>, a portal for information, signposting and involvement for individuals with ASC, carers, parents, friends, professionals and the general population.

Health services

- Development of an ASC diagnostic assessment pathway for adults who do not have a learning disability, as well as improving access to additional therapeutic input as required.
- Improved partnership working between services working with adults with ASC.
- Review of ASC diagnostic assessment- and therapeutic input- pathway for children and young people.

Services for people with ASC

- Commissioning of two social skills development groups for adults with ASC who are not able to access LD or MH services.
- Established social groups for children and young people with ASC who do not have a co-occurring learning disability.
- Development of a pathway for adults with ASC to access an assessment of their social care needs, when this is not completed through LD or MH services.
- Provision of specialist ASC advice and signposting to all teams and professionals working with individuals with ASC.
- Secured a grant from the Department of Health Autism Innovation Fund to develop and project manage a 3D online learning environment to support individuals with ASC to increase skills relating to employment. Work on this project is ongoing and progressing well.
- Secured grants from the Department of Health as well as local organisations to realise a specialist sensory garden environment in a newly developed supported living environment for young adults with ASC and behaviour that can challenge.
- Make available specialist ASC signposting and information on services and support available.
- Provide input into the consultation on and implementation of the Children and Families Act 2014, the Care Act 2014 as well as number of strategies locally and nationally.

Carers

- Work in partnership with Richmond NAS to offer two carer support groups, each meeting monthly.
- Established termly EarlyBird, EarlyBird Plus and Cygnets training courses for parents of children with a diagnosis of ASC, or those on the pathway to one.
- Make available specialist ASC signposting and information on services and support available.

Vision and Aims

Vision

Our vision is in line with the national strategy⁶.

We believe that children, young people and adults with ASC living in Richmond upon Thames 'should be able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents'.

Aims

Based on the achievements and changes made since the introduction of the first Richmond Joint Autism Strategy, the aims over the next three years are to:

- Continue focussing on and further develop the ASC awareness raising and training of health and social care staff, including those commissioned to provide services, as well as wider local authority, public and health services to ensure that staff are appropriately trained to identify and work with individuals with ASC.
- Continue to raise awareness and develop opportunities in the general population of the London Borough of Richmond upon Thames to increase understanding and reduce barriers.
- Integrate current diagnostic pathways into long term 'business as usual', ensuring that it is used effectively and, if required, leads to an assessment of social care needs and carers assessment.
- Ensure that access to assessment and support services for social care needs is equal to that of individuals in other service user groups.
- Continue to closely monitor and support as appropriate young people with ASC moving from children to adult services to enable young people with ASC to fulfil their potential.
- Consider additional transitions in life and ensure that appropriate support systems are available and accessible when required.
- Continue to ensure that the needs of individuals with ASC are considered in the implementation of strategies and changes throughout the local authority.

⁶ DH (2014) 'Think Autism, Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update'

- Continue offering preventative services and services which develop and increase independence to enable individuals with ASC to live as independent and fulfilling a life as possible.
- Continue working in partnership with individuals with ASC and their families, carers and friends to ensure that all of the above is relevant to and based on local need.

Over the longer term, the strategy will contribute to those with ASC⁷:

- Being an equal part of the local community and recognised as an individual, with the opportunity to connect to others
- Having their race, gender and sexual orientation taken into account and being safe from risks of discrimination and abuse
- Getting the right support at the right time during their lifetime, including diagnosis, support for the various transitions in life and support for their carers
- Being listened to and having their views and aspirations taken into account locally, including how ASC affects the individual and how this changes throughout life
- Being able to access everyday services which have been reasonably adjusted to meet their needs, as well as adapted specialist services for additional needs such as learning disability or mental ill health
- Having the same opportunities to develop skills and independence as everyone else, and being able to access support to find employment
- Having their needs recognised and considered when dealing with the criminal justice system

National Context

The national autism strategy *Fulfilling and Rewarding lives* (2010), and linked statutory guidance⁸ arising from the Autism Act 2009⁹ set out requirements for local authorities and NHS bodies to work with partners to improve services and support for people with ASC. Following the requirements set out in the Autism Act, as well as widespread and significant changes across public services (for example the SEND reforms and the Care Act 2014), the national autism strategy was reviewed in 2013/14 and the update *Think Autism*¹⁰ was published in April 2014. The review was also an opportunity to take stock of the changes that had been achieved already and move forward from there.

Think Autism builds on, rather than replaces, the requirements and themes set out in the 2010 Adult Autism Strategy. The updated strategy is based on a comprehensive consultation exercise, which involved over 2000 people (people with ASC and their carers, as well as commissioners and service providers) taking part in events and conferences and over 1100 individuals with ASC responding to an online survey. Also taken into consideration was the data gathered from the annual self-assessment exercise for local authorities in 2012 and 2013.

⁷ Based on the Priority Challenges for Action in DH (2014) *'Think Autism, Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update'*

⁸ DH (2010) A Vision for Adult Social Care: Capable Communities and Active Citizens

⁹HMG The Autism Act 2009

¹⁰ DH (2014) Think Autism, Fulfilling and Rewarding Lives, the strategy for adults with autism in England: an update

Following this consultation, the Department of Health identified 15 priority challenges for action under the following headings:

- An equal part of my local community
- The right support at the right time during my lifetime
- Developing my skills and independence and working to the best of my ability

On the 27 March 2015 the Department of Health then published updated statutory guidance for local authorities and NHS organisations¹¹ to support the implementation of the national autism strategy. This guidance covers 9 areas:

- 1. Training of staff who provide services to adults with autism
- 2. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services
- 3. Planning in relation to the provision of services for people with autism as they move from being children to adults
- 4. Local planning and leadership in relation to the provision of services for adults with autism
- 5. Preventative support and safeguarding in line with the Care Act 2014 from April 2015
- 6. Reasonable Adjustments and Equality
- 7. Supporting people with complex needs, whose behaviour may challenge or who may lack capacity
- 8. Employment for adults with autism
- 9. Working with the criminal justice system

The progress of local authorities in complying with this statutory guidance will continue to be monitored through Autism Self-Assessment Framework (Autism SAF). The results of the most Autism SAF, which was completed in the spring of 2014, are now available online, in an interactive mapping tool which allows users to compare all local authority areas in England as well as contact and rate their local area. You can find this online tool here:

https://autism-connect.org.uk/users/myarea

Local Authorities and NHS bodies in England must follow the guidance, or provide good reasons if they are not doing so (an example might be that a better service is already being provided). Legally, there is some flexibility to "deviate from it where the authority judges on admissible grounds that there is good reason to do so, but without freedom to take a substantially different course"¹².

¹¹ DH (2015) Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy

¹² HMG (1970) Local Authority Social Services Act 1970

The new statutory guidance takes into considerations the significant changes in many parts of the health and social care system, including changes to the statutory framework, which have come into effect since the Autism Act 2009. These include the Children and Families Act 2014 and the Care Act 2014, which are described in more detail below.

The statutory guidance should be read alongside, and makes reference to, a number of guidance documents on what constitutes effective practice to improve health and social care outcomes for people with ASC. These have been set out by the Social Care Institute for Excellence (SCIE) and the National Institute for Health and Clinical Excellence (NICE).

SCIE guidance *Improving access to social care for autism* (2011)¹³ recommendations include:

- Staff supporting people with ASC need to make adjustments in how they work with people with ASC so that services can be more accessible to people with ASC.
- Managers and commissioners of services also need to be flexible, creative and collaborative in how they meet the needs of people with ASC. People with ASC whose behaviour challenges services and those with Asperger syndrome, or high functioning autism in particular, need better access to services.
- Support with social interaction and practical everyday living tasks can address some of the needs people with ASC commonly have at relatively low cost.
- Multidisciplinary specialist ASC services can provide good outcomes for people with ASC. Professionals should offer carers support in their own right and work in partnership with them to provide the best possible assessment and service provision.

The above recommendations are due to be updated, but it is not yet certain when an update will be published.

In January 2014, NICE published Quality Standard 51, covering "autism in children, young people and adults, including both health and social care services"¹⁴. The aim of the standard is to inform the commissioning of services for individuals across all age groups, focusing on the key areas for improving existing services. Commissioners are expected to work with providers to ensure these standards are being met.

The document provides 8 quality statements, which include quality measures and outcomes designed to drive measurable quality improvements. Where required, there is separate guidance on children & young people and on adults. The statements are based on and make reference to 4 guidance documents:

- NICE clinical guideline 128 Autism: recognition, referral and diagnosis of children and young people on the autism spectrum
- NICE clinical guideline 142 *Autism: recognition, referral, diagnosis and management of adults on the autism spectrum*
- NICE clinical guideline 170 Autism: the management and support of children and young people on the autism spectrum
- SCIE guide 43 Improving access to social care for adults with autism

¹³ SCIE (2010) Improving access to social care for autism. SCIE

¹⁴ NICE (2014) NICE quality standard 51: guidance.nice.org.uk/qs51

The 8 quality statements are:

- 1. People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.
- 2. People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.
- 3. People with autism have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team.
- 4. People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.
- 5. People with autism have a documented discussion with a member of the autism team about opportunities to take part in age-appropriate psychosocial interventions to help address the core features of autism.
- 6. People with autism are not prescribed medication to address the core features of autism.
- 7. People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.
- 8. People with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

The quality standard, in combination with the guidelines listed above, sets out in detail what a local pathway for recognition, referral, diagnosis, follow-up treatment and further outcomes / referrals should include. It recommends the provision of an age-appropriate multidisciplinary, autism specific team to provide diagnostic services, assessment for coexisting physical health and mental health conditions and develop plans for appropriate support, including potential psychosocial interventions.

The recommended make-up of the team is dependent on the age-group. For children and young people it should include appropriate psychiatry, speech and language therapy and educational and / or clinical psychology, as well as access to neurology, occupational therapy, and other professionals such as health visitors, nurses, social workers and specialist teachers. For adults, the list is similar: clinical psychology, nurses, occupational therapy, psychiatry, social work, and speech and language therapy. However, in addition to this also included should be primary health services and support staff to support, for example, with access to housing, education and employment opportunities.

In addition to the above, there is guidance on the use of medication, in particular but not exclusively in relation to behaviour that challenges as well as coexisting mental illness and / or learning disability. In line with guidance from the national strategy, it is also recommended that a strategy group is in place to oversee awareness raising and training (including, but not limited to, local pathways and services), transitions and local data collection and audit.

Children and Families Act 2014 and Care Act 2014

As mentioned previously, there are two major recent legislative changes in education, health and social care for children and young people as well as adults, which have important implications for improving provision of services.

The implementation of the Children and Families Act 2014¹⁵ has reformed the approach to meeting the needs of children with special educational needs and disability. Specifically, children who would previously have a statement of special educational needs (SEN) and young people over 16 who would have a learning disability assessment, are now assessed in a holistic way and receive a single Education, Health and Care Plan. This plan can is to be reviewed annually up until the young person is 25. Those with existing statements are in the process of being transferred. In addition to this the SEND Code of Practice makes it clear that, under statutory guidance accompanying the autism strategy, SEND coordinators in schools should inform young people with autism of their right to a community care assessment.

The Care Act 2014¹⁶ is the most comprehensive change in legislation in relation to adult social care in over 60 years. There now is a focus on preventing and delaying need, and the 'wellbeing principle' has been created. This principle, underpinning the care and support system, means that the wellbeing of the person and their desired outcomes are at the heart of every decision. The needs of carers are now given the same significance as those of the people they care for, and a duty for local authorities to provide advocacy for certain individuals has been introduced. There is also a focus on providing timely information and advice, and the safeguarding of vulnerable adults was put on a statutory footing for the first time. Emphasis is also placed on the provision of timely information and advice and offering appropriate advocacy services to ensure that they are able to participate in any decisions to the best of their abilities.

A second phase of the implementation of the Care Act 2014 is due in 2020. This phase relates to capping the amounts that individuals have to contribute towards the cost of their care and support, and increased financial support for those with medium amounts of assets and/or savings. For more information on the implementation of the Care Act in Richmond, please visit:

http://www.richmond.gov.uk/home/services/adult_social_care/adult_social_care_policy/th e_care_act/care_act_changes.htm

To further improve awareness and knowledge across services, additional guidance and recommendations is being published in a number of areas. The revised Mental Health Act Code of Practice¹⁷ came into force in April 2015. Chapter 20 of the Code gives detailed considerations to be had when working with individuals with learning disabilities and autism and raises a number of training and expertise needs for practitioners / professionals.

Also, in October 2015 the Department of Health published the "CPD curriculum guide for social workers who are working with people on the autism spectrum"¹⁸, augmenting the Skills for Care / Skills for Health Autism Skills and Knowledge List published in 2011. **ASC in Richmond**

Prevalence of ASC

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/467394/Pt2_Autism_Guide_A ccessible.pdf

¹⁵ HMG (2014) *The Children and Families Act 2014*

¹⁶ HMG (2014) *The Care Act 2014*

¹⁷ DH (2015) Mental Health Act 1983 Code of Practice: https://www.gov.uk/government/publications/code-ofpractice-mental-health-act-1983

The most recent estimates on the prevalence of ASC in adults in England indicate that around 1.1% of people have ASC. The rate is currently estimated to be higher in men (2.0%) compared to women $(0.3\%)^{19}$. The overall prevalence rate translates to roughly 1 person in every 90, and is similar to the number of people that have dementia.

These estimates are based on a recent study that extended the Adult Psychiatric Morbidity Survey (2007) to take account of the higher prevalence of ASC among those that have a learning disability.

Table 1 below shows the estimated number of individuals with ASC in the London Borough of Richmond based on the above prevalence figures and the most recent estimate on the population available (2013).

In predicting the number of children with ASC in Richmond, we have assumed that the prevalence rate for adults with ASC is also relevant to estimating the number of children and young people with ASC. However, a survey by Baron-Cohen et al (2009)²⁰ suggests that the prevalence could be as high as 1.57%, with the ratio of known to unknown cases being about 3:2, so the actual number of children with ASC could be higher than in the table below.

The Projecting Adult Needs and Service Information (PANSI) and Projecting Older People Population Information (POPPI) systems look at a wide range of needs and provide projections on the likely numbers over a number of years. The figures projected take into account population number estimates, and data gathered from these systems predicting the number of adults with ASC in Richmond for 2015, 2020 and 2030 show that there is an expected increase of 5.6% until 2020 and 17.8% until 2030 from current estimates.

However, this expected increase does not necessarily mean there will be an increase in prevalence, as the population as a whole in Richmond is projected to increase over this time period.

Table 1 Estimates of numbers of Richmond residents with ASC based on population estimate for 2013				
Richmond population		Prevalence of ASC	Estimated number with ASC	
All ages				
Male	94052	2.00	1881	
Female	99533	0.30	298	
All	193585	1.10-1.15	2179	
Under 18 yrs				
Male	21821	2.00	436	
Female	21035	0.30	63	
All	42856	1.10-1.15	499	
18 yrs and over	•			
Male	72231	2.00	1444	

¹⁹ Brugha T et al. (2012) *Estimating the Prevalence of Autism Spectrum Conditions in Adults: Extending the 2007 Adult Psychiatric Morbidity Survey* The Health and Social Care Information Centre, Social Care Statistics, 2012

²⁰ Baron-Cohen et al (2009) *Prevalence of autism-spectrum conditions: UK school-based population study* British Journal of Psychiatry, 2009, 194 (6) 500-509

Female	78498	0.30	235
All	150729	1.10-1.15	1679

Prevalence: Brugha et al 2012 Estimating prevalence of autism spectrum conditions in adults. Study (combined Adult psychiatric morbidity survey 2007 & learning disability study) NHS Information Centre. Population: ONS mid 2013 population estimates (2011 census based)

There are no reliable estimates on the prevalence of Asperger syndrome. However studies suggest that around 50% of all those with ASC also have a learning disability, and that the other 50% are likely to have high functioning ASC including Asperger syndrome. This would suggest that around 840 adults and 250 children and young people have high functioning ASC in Richmond. The nature of high functioning ASC can mask significant difficulties and therefore people with Asperger syndrome can be overlooked by services. Those with Asperger syndrome are potentially highly vulnerable and at risk of social exclusion.

There will be a need to ensure that services are able to adapt to increases in demand with the increase in population size over the coming years.

Number of people with ASC known to services in Richmond

There are 230 children on Education, Health and Care plans (EHC) and SEN statements (as at September 2015) with a main presenting need of ASC identified. In addition to this there are 155 EHC plans and SEN statements with a main presenting need of Speech Language and Communication Need and 163 without a main presenting need being recorded; it is considered likely that a high proportion of the children in these two categories also meet the diagnostic criteria for ASC. In total, all three categories combined account for over 50% of all EHC plans and SEN statements in Richmond.

Through planning in relation to transitioning to adulthood it is known that there are currently (September 2015) 76 young people between 14 and 17 (inclusive) years of age who have an SEN statement / EHC plan and have a diagnosis of ASC. Of these, it is anticipated that at least 38 of them are in need of support and planning to ensure successful transition into Adult Social Care over the next 4 years.

There are currently around 200 adults with ASC as a presenting need known to the local authority (August 2015). The majority of individuals receive a service from the Richmond Community Learning Disability Team.

The number of people with ASC known to specialist health services is largely dependent on whether or not the person has a mental health problem or a learning disability in addition to the ASC.

Of those known to the adult specialist community mental health teams, there are 16 individuals with a known diagnosis of ASC (Asperger Syndrome, Autism and Atypical Autism)

Hospital Episode Statistics (HES) data on mental health related adult admissions to acute hospitals indicates that there are very low numbers (<5) of people from Richmond being admitted to any acute hospital with either a primary or secondary diagnosis of ASC (ICD 10 codes F84.0; F84.1; F84.5).

Current Service Provision and Access to Support in Richmond

Children and young people

The care pathway for referral, diagnostic assessment and service provision for children and young people has been in place for a number of years. As part of the implementation of a new strategy for improving the emotional wellbeing and mental health of children and young people, this pathway for ASC has been reviewed and updated recently. For more information, please visit the Local Offer website of Achieving for Children (http://www.afclocaloffer.org.uk/).

Parents concerned about their child can discuss their concerns with anyone in Universal Services, which includes GPs, health visitors, nurses, children centres etc. and decisions about further assessment will be communicated directly with the person completing the referral. If concerns remain the parent and / or any professional can contact the Single Point of Access (SPA) for advice. In addition to this it might be possible to access services through the SPA whilst on the pathway to a diagnosis.

Young children between 0-5 years will, if an assessment is deemed appropriate, be referred to the Child Development Team for a developmental assessment. Further, multidisciplinary assessments of varying complexity can be accessed through the Social Communication Clinic if required.

Children and young people of school age who show signs of possible ASC can be referred by any professional working in primary care, education or social care to the Children and Adolescent Mental Health Services (CAMHS). Depending on the needs identified, the child / young person will be referred for an assessment through Tier 2 or Tier 3. Tier 2 involves an initial assessment with the Emotional Health Service to establish if the needs can be met through support at that point. If the assessment indicates that a diagnosis of ASC is possible, the information is passed on to the Neurodevelopmental Assessment Team for a full assessment.

The multi-disciplinary Neurodevelopmental Assessment Team undertakes a specialist diagnostic assessment of ASC. The outcome of the assessment is shared with the parents and the child/young person and with other key professionals (such an educational psychologist or teacher). The assessment information and identified support needs can then be incorporated within an Education, Health and Care Plan (EHC plan), if one is required for the child/young person due to it not being possible to meet their needs through the SEN support available at their school. Referral to other appropriate services may be made to address coexisting mental health conditions and/or a learning disability.

Those children / young people referred through Tier 3 are referred directly to the Neurodevelopmental Assessment Team.

A diagram of each diagnostic pathway is attached in appendix B (young children 0-5 years) and appendix C (children and young people of school age).

Recommended interventions may include home-based and/or nursery based support with speech and language or other specialist support. Over the past 12 months Achieving for Children has been offering training courses for parents / carers of children with a diagnosis of ASC or those on the pathway to one. There are 3 courses offered, depending on the age-group of the child: EarlyBird and EarlyBird Plus for children aged 0-4 and 4-8 respectively, and Cygnets for older children. These courses have been very well subscribed and it is planned that further courses in both EarlyBird and EarlyBird Plus will be offered every school term. In addition to this, courses on specialist subjects (for example: teenage years, sexuality and relationships) are being discussed at present.

The review of the ASC pathway for children and young people has identified a number of areas for improvement. These include:

- Increase awareness and understanding of professionals working in health, education and early years children services of the care pathway for children and young people on the autism spectrum. In particular, training should focus on responsibilities and skills to ensure the effectiveness of the process for initial assessment and referral of children and young people with social communication and behaviour problems (and possible autism) both with respect to preschool and school age groups. This should involve training of key professionals including Special Education Needs coordinators (SENCOs), education psychologists and GPs.
- Develop arrangements to ensure that after diagnostic assessment, an appropriate 'contact' professional is identified to ensure children and young people have access to the required follow up support and services and ongoing review of progress.
- Ensure information and support is available to parents and/or carers about the care
 pathway for children and young people on the autism spectrum and the services that
 are available.
- Review the level of therapy services (particularly occupational therapy) that is required to ensure effective input to both the preschool and school aged children care pathway for children with developmental needs and possible autism.

Transition

Transition has been highlighted as a priority area in the Health & Wellbeing Strategy as well as both the updated National Autism Strategy and Statutory Guidance on Autism. It is a cross-cutting issue that requires strong partnership working and joint planning between organisations. Without good transition protocols in place, vulnerable young people with ASC may not receive the most appropriate support.

Richmond has good transition arrangements for young people with disabilities in place. A transition framework has been established to ensure improved shared working arrangements, oversight and scrutiny, and to deliver a robust professional service to young people moving to adulthood. The governance structure consists of:

- Virtual transitions team a virtual group of professionals who operationally plan, oversee and deliver the transitions arrangements for individuals
- Transition Management Group a multi-agency panel which ensures that appropriate transition arrangements are in place for individuals
- Strategic Transition Board a senior, multi-agency board with a strategic oversight to ensure that a high quality transition service and clear pathways are in place

A transition tracking list is used to record young people within the wider SEN population who are likely to need health or social care support as adults. There are 38 young people between 13 and 17 (inclusive) years of age with ASC who are on the Transition Tracking List and who require detailed transition planning.

Current arrangements in Richmond work well on the ground and have been built upon good personal relations. A large amount of work has already been done to improve the transition between children's and adult services.

There are generally clearer eligibility criteria for support from adult social care and health services. Young people with mild/moderate needs who have been receiving support from children's services may not subsequently meet the criteria for support from adult services.

Key issues

- Young people with ASC and mild/moderate mental health problems may have been receiving support from CAMHS but may not subsequently meet the eligibility criteria for adult mental health services
- At the age of 18, the legal position around decision-making also changes where the young person is assumed to have capacity to make their own decisions, supported by health and social care professionals. This can be a difficult experience for the young person and their carers. Expectations of individuals and families may also not match the provision of services after age 18, potentially resulting in anxiety and difficult relationships with professionals.
- There is a group of young people transitioning into adult services that are unlikely to meet eligibility criteria for ongoing support through adult social care, but nevertheless would benefit from preventative and/or signposting support. A significant proportion of this group are young people with ASC. This is a recognised difficulty and discussions as to how this need can be met are ongoing.

Adults

As stated previously, there have been significant changes in the legislative framework relating to the provision of adult social care. In addition to this, there have been substantial changes in the availability and accessibility of both health and social care services for adults with ASC locally.

Social Care

All adults who feel that they would benefit from support to meet their social care needs should contact the Access Team in the first instance. If the person is already known to any of the teams supporting adults in the London Borough of Richmond upon Thames (the Community Mental Health Teams (CMHT), the Learning Disability Team, the Twickenham and Teddington Locality Team or the Richmond Locality Team), that team will usually retain responsibility.

Adults who are not known to the Adult Social Care Department can find out if they are likely to be eligible for support online (http://www.richmond.gov.uk/home/services/adult_social_care.htm). If appropriate, the Access Team will complete a contact assessment, and, if the person is likely to have eligible social care needs, refer on for a full assessment. If the person has additional mental health problems, the full assessment should be completed by the CMHT. If the person has an additional physical disability, the full assessment should be completed by the relevant locality team. All other cases (adults with ASC with or without an additional learning disability) should be referred to the Learning Disability Team for assessment.

It is important to note that the Council does not necessarily consider the diagnosis as the primary reason for a social care assessment of an individual, but considers their

presenting needs. For individuals who may have eligible social care needs but do not have a diagnosis of ASC a decision on the most appropriate team will be made on a case by case basis.

Health Services

The health needs of adults with a learning disability who also have ASC/ suspected ASC can be referred to the commissioned Specialist Health Care Team and/or the Psychology and Challenging Behaviour Team for a health assessment and treatment. This is currently provided through a contract with Your Healthcare. The overall aim of the service is the provision of specialist health care support to meet the specific needs of adults with learning disabilities.

The team links with other services to support access for patients to the full range of health, education, employment and social services. The team provides increased support for people with complex needs, and provides continuing care to those receiving NHS continuing care funding. The definition covers those with ASC who have a learning disability. The team provides specialist diagnostic assessment for people with a learning disability and ASC.

Adults who do not have a learning disability but are seeking a diagnostic assessment for ASC can be referred through their Richmond GP to the commissioned diagnostic assessment and therapeutic service. This service is also currently provided through a contract with Your Healthcare. The service also accepts referrals from the CMHT and the Richmond Wellbeing (IAPT) service, and will work in partnership with these services although case responsibility will remain with the referring service.

At present the service available for adults with ASC through Your Healthcare is limited to psychology services and behaviour analysis if required. Other therapeutic services, such as Speech and Language Therapy, Psychiatry, or Occupational Therapy would need to be commissioned on a case-by-case basis or be accessed through other (for example CMHT) services if appropriate. A visual representation of the adult diagnostic pathway is attached in appendix C.

Local voluntary and charitable services

The National Autistic Society (NAS) has a local presence in Richmond through the Richmond NAS Branch, helping to support those with ASC and their families. Their objectives are to provide support, information and awareness through a variety of means, including a website, comprehensive information pack and carer groups.

The Richmond NAS Branch continues to be proactively involved in the shaping and development of services in the Richmond area and beyond.

EnhanceAble is a Kingston-based charity which offers a range of services for disabled individuals and their carers. Since Achieving for Children provides children services for both Kingston and Richmond, EnhanceAble is now also starting to offer some of their services for residents in Richmond, in particular social skills groups for young people and teenagers with high functioning autism and Asperger syndrome.

Richmond MENCAP provides a number of services for adults with a range of disabilities, including adults with ASC.

Training on ASC

One of the key factors in ensuring the needs of those with ASC are met is training. The updated national strategy makes the need for ASC awareness-raising and training aimed at the various levels of specialism for different staff groups explicit. Involvement of "experts by experience", such as individuals with ASC, their informal carers and friends

will ensure that training focuses less on the theory of ASC and instead gives staff an insight as to the way in which ASC actually affects peoples' lives.

The training provided not only needs to ensure that all staff are able to understand the main difficulties faced by people with ASC, but also how to make reasonable adjustments in their behaviour, communication and services (following the Disability Discrimination Act 1995). Specialist training is recommended not only for those completing assessments with individuals with ASC, but also those in positions of decision making, for example managers making funding decisions. In addition to this, appropriate training and awareness of frontline staff will aid in the early identification and appropriate referral to diagnostic services if required.

Skills for Health/Skills for Care published the "Autism skills and knowledge list, for workers in generic social care and health services" in summer 2011. In addition to this, the "CPD curriculum guide for social workers who are working with people on the autism spectrum" was published by the Department of Health in October 2015, and all training should comply with the criteria set out in these two documents.

At present Richmond have an e-learning ASC awareness course available to LBRuT staff, commissioned services and those living in Richmond, which was developed in partnership with experts by experience. In addition to this 2 full day "Understanding ASC" and 2 half day "Basic Awareness" courses are planned for the next 12 months - places for which are available to staff of LBRuT as well as commissioned services and carers / parents. Specialist training for social workers and other professionals in assessment roles is currently being planned.

Achieving for Children, who deliver Children Services for the London Borough of Richmond, have a variety of ASC training available at different levels suitable for various levels of expertise required. This is under continuous review and will be amended as at when necessary.

Taking forward our strategy in Richmond

National guidance combined with the knowledge we have gathered about existing pathways and services, as well as the issues and concerns experienced by people with ASC and their carers / family members / friends, lead us to a number of actions required over the next three years.

These actions, and how we will measure progress, are listed in the priority areas on the following pages. Below is a table as to how the 9 sections of the statutory guidance are covered within our priorities.

Section of statutory guidance	Priority Area	Notes
1. Training of staff who provide services to adults with autism	Training and Awareness Raising	
 Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services 	Integration of services into "business as usual"	
3. Planning in relation to the provision of services for people with autism as they move from being children to adults	Integration of services into "business as usual"	Significant work in this area is taking place through Transitions – work streams, and this will continue with input re. ASC rather than creating a separate work stream for this here.
4. Local planning and leadership in relation to the provision of services for adults with autism	Integration of services into "business as usual"	
5. Preventative support and safeguarding in line with the Care Act 2014 from April 2015	Innovation and Service Development Integration of services into "business as usual"	
6. Reasonable Adjustments and Equality	Training and Awareness Raising Innovation and Service Development	
7. Supporting people with complex needs, whose behaviour may challenge or who may lack capacity	Innovation and Service Development Integration of services into "business as usual"	
8. Employment for adults with autism	Training and Awareness Raising Innovation and Service Development	
9. Working with the criminal justice system	Training and Awareness Raising	The applicable actions in S9 are only relating to training and awareness raising in the criminal justice system, as there is no prison within the London Borough of Richmond upon Thames.

Delivering the Strategy

PRIORITY 1: Training and awareness raising

Training and awareness-raising is an overarching priority affecting all aspects of this strategy. Existing services will not be appropriate and efficient without the right level of training. Decision making, service development and innovation is unlikely to happen or meet the needs of individuals with ASC and their carers if those in key positions are not aware of the needs and difficulties being faced. Whilst significant developments have taken place since the start of the implementation of the original autism strategy, this area should therefore be a continuous focus-point throughout the period of this strategy.

OVERALL ACCOUNTABILITY: TBC			
Objective / Change Required	Action toward achieving change	Timescale for completion	Measurable benefits
Ensure that e-learning is completed by new and existing staff throughout council departments and commissioned services	 Promote e-learning regularly internally throughout year Monitor uptake of course through various departments and target promotion accordingly Promote e-learning through Provider Forum 	ongoing	Improved experience of service user and carer experience when accessing council and provider services. To be measured through consultation / survey by end of Q3 2016/17, to be repeated by the end of Q3 2018/19.
All staff working directly with individuals with ASC and their managers to be trained to a level appropriate to their tasks	 Targeted training to be offered for different levels of knowledge required Classroom-based ½ and full day awareness courses to continue Specialist training for those with assessment and care and support planning – responsibilities and those in decision-making positions Refresher courses are offered at regular intervals 	Classroom based training ongoing Specialist training for adult services to be developed by end of Q1 2016/17, and ongoing thereafter. Specialist training in children services to continue	Appropriate assessments and care and support planning – feedback to be sought by end of Q3 2016/17 through consultation / survey to be repeated by the end of Q3 2018/19

Raising of awareness in police, probation and primary and secondary healthcare services	 Use of Richmond awareness films / DVD Partnership working with specialist healthcare provider Your Healthcare to use existing training partnerships with GP practices and local hospitals Partnership working with local police force and probation service to encourage awareness / offer on-site training 	Start tour of GP practices in Q2 2016/17 Link with local police force by Q1 2016/17 Link with probation services by Q1 2016/17	Increased confidence when working with individuals with ASC and their carers in GP practices and the local police and reasonable adjustments made as required. Feedback to be sought from GP practices and local police in Q4 2016/17 and repeated in Q4 2018/19
Raising of awareness in services relating to finding employment	 Continue partnership with Twickenham Jobcentre and offer future awareness sessions as required Ensure supported employment provider is trained to an appropriate level 	Partnership with Twickenham Jobcentre ongoing Link with supported employment provider by Q2 2016/17	Increased confidence when working with individuals with ASC and their carers in GP practices and the local police and reasonable adjustments made as required. Feedback from service users and carers sought by end of Q3 2016/17 through consultation / survey to be repeated by the end of Q3 2018/19
Raising of awareness in local businesses (both large and small) to aid search for employment and customer experience	 Seek partnerships with local business associations, business community meetings at council, etc. Provide information and awareness raising opportunities 	Establish links by Q2 2017/18	Increased awareness and employment opportunities for individuals with ASC in the local community
Raising of awareness in the general population of Richmond	Using events and other opportunities to raise awareness, such as national Autism Awareness Week, ASC art exhibitions, drop-ins, etc. to promote awareness and e- learning	Ongoing – ASC awareness week 2016: 27/03 - 02/04/2016	Increased awareness and understanding in the general population. Feedback from service users and carers sought by end of Q3 2016/17 through consultation / survey to be repeated by the end of Q3 2018/19

Visual way of identifying individuals and businesses who are ASC aware	 Development of Autism- aware logo / badge for individuals and businesses to display (see Dementia Awareness) when e- learning completed / Autism aware films watched Consider learning from recent Autism Alliance UK project which created an "Autism Charter" that retailers and businesses can sign up to 	Q4 2016/7	Increased awareness in local community and improved customer experience. Impact to be tested through "mystery shopper" exercise in Q2 2017/8
Provide an opportunity for individuals with ASC and their carers to identify as being diagnosed with ASC and highlight reasonable adjustments required	 Continue work on more generic hospital passport for vulnerable people and ensure this is suitable for individuals with ASC Ensure primary health services are aware of hospital passport Provide information re. ASC aware cards available through the NAS and include information re. this in awareness raising 	Q2 2016/7 Awareness raising of passport and ASC cards ongoing thereafter	Improved experience when accessing services and the local community. Feedback from service users and carers sought by end of Q3 2016/17 through consultation / survey to be repeated by the end of Q3 2018/19

PRIORITY 2: Integration of services into "business as usual"

Since starting the implementation of the Joint Autism Strategy 2013-2016 there have been significant changes improving availability of and access to services for individuals with ASC, their carers, friends and families. In order to ensure that the benefits of this continue it is important to develop and embed sustainable service delivery and integrating current services into "business as usual". This will have a significant impact on the longevity of the changes achieved to date and give an opportunity for further development and innovation in other areas.

OVERALL ACCOUNTABILITY: TBC			
Objective / Change Required	Action toward achieving change	Timescale for completion	Measurable benefits
Continuation of ASC adult diagnostic pathway and therapeutic services	 Integration of commissioning of ASC diagnostic and therapeutic service into the usual CCG commissioning portfolio, including: Tendering for long-term provider of ASC diagnostic and therapeutic service 	Tendering to be completed by Q1 2017/18, service to be continued under current commissioning until then	Long-term diagnostic and therapeutic service in place and pathway advertised to ensure awareness in appropriate services
ASC to be included in strategic planning throughout the local authority and CCG	 Completion of Equality Impacts Needs Assessment (EINA) Continuous review of ASC being considered where appropriate in new and existing strategies throughout the local authority and CCG including, but not limited to, the Joint Strategic Needs Assessment (JSNA) 	EINA to be completed in Q1 2016/7 Input into JSNA ongoing Input into other strategies and policy documents ongoing	ASC is as standard considered throughout strategy and policy documents in all relevant areas of the local authority.
The needs of individuals with ASC to be considered in all planning relating to transition from children to adult services	 The Transitions Development Officer to ensure that the needs of individuals across the autistic spectrum are considered in transition planning The virtual transitions team to seek support from the Autism Specialist Worker as and when required 	This work is already in progress and will be ongoing. No separate work-stream will be required as the needs of individuals across the whole of the autistic spectrum are already integrated into ongoing work	The needs of young people across the whole of the autistic spectrum are considered in transition planning and signposting and support is provided in a timely, appropriate manner.

Individuals with ASC are receiving support through mainstream employment services as well as specialist supported employment services as and when required	 Partnership working with the local Jobcentre Plus, in particular relating to the Autism Network and training being created by the DWP for Jobcentre Plus offices by 2016/17²¹ to ensure that mainstream services are equipped to support individuals with ASC to find work Continuation of making available specialist support to individuals with ASC to find and maintain employment when the Jobcentre is not able to do so 	Ongoing – the DWP is working on creating the Autism Network during 2015/6 and 2016/7.	The proportion of individuals with ASC finding and maintaining employment increases.
National sources of support are more widely accessed to augment local provision for individuals with ASC	 Potential sources of support, such as Disabled Students Allowance and funding provided directly through the Department of Business, Innovation and Skills (BIS) to further education (FE) providers, are recognised and used to their full potential through working in partnership with local FE providers Information on potential sources of support is easily accessible for individuals with ASC and their carers through an updated website 	Work with FE providers ongoing and to be increased throughout 2016/17 Website to be updated by Q3 2016/7	Better use of national resources and better opportunities for individuals with ASC to access FE provision and other services.

²¹ As reported in the Progress Report on Think Autism, published by the DH in January 2016: https://www.gov.uk/government/publications/progress-report-on-strategy-for-adults-with-autism

Continuation of preventative support developed to date	 Evaluation of impact of existing social skills / drop in support for adults with ASC without a co-occurring LD / MH, information to be considered alongside research by University College London – 1st phase of report due in March 2016²² Consider long-term funding options for established groups for both carers and individuals on the spectrum to ensure sustainability Monitor impact of and requirement for training courses for parents to ensure continuation as required 	Evaluation to be completed by end of Q1 2016/17, subject to UCL report being published Funding for continuation of groups to be sought temporarily in the meantime Monitoring, evaluation and continuation of courses for parents ongoing	Individuals with ASC and their carers are able to access preventative support and services to avoid crisis situations. Feedback from service users and carers sought by end of Q3 2016/17 through consultation / survey to be repeated by the end of Q3 2018/19. Impact of services to be monitored by providers, too.
Support for those with complex needs and behaviour that may challenge to be available as close to their local community as possible	 The needs of individuals with complex needs and behaviour that may challenge to be considered throughout the current tendering process for adult social care Local provision of supported living through projects such as Lock Rd (Badger House) and The Lodge (see also next section re. further development of similar schemes) 	Ongoing – Lock Rd to be ready for occupation in Feb 2016 and The Lodge by end of Q1 2016/7	Individuals with ASC and complex needs are integrated into the local community and supported close to their family and friends.
Joint strategic management of implementation of Joint Autism Strategy to include all key stakeholders	 Regular meetings of the Autism Programme Board (Terms of Reference in Appendix E) to continue 	ongoing	Key stakeholders, including Experts by Experience and local National Autistic Society branch, are fully involved in the planning and implementation of the strategy

²² As reported in the Progress Report on Think Autism, published by the DH in January 2016: https://www.gov.uk/government/publications/progress-report-on-strategy-for-adults-with-autism

PRIORITY 3: Innovation and Service Development

In Richmond we strive to continually improve how we work and deliver services. We aim to find new, innovative ways of working with individuals with ASC and their carers, family and friends. Through proactively seeking opportunities to share good practice, develop innovative ways of working and creating partnerships with key stakeholders we will aim to enable individuals to have the best possible outcomes whilst recognising and working within the current financial constraints.

OVERALL ACCOUNTABILITY: TBC			
Objective / Change Required	Action toward achieving change	Timescale for completion	Measurable benefits
Development of additional services, including but not limited to for those with complex needs and behaviour that may challenge, to meet the housing and support needs of individuals with ASC as close to their family home as possible	Continuation of partnership working between colleagues within LBRuT, external Housing Association and other partners to seek potential funding opportunities and develop services when possible	Ongoing	Development of future services aiming to meet the needs of all service users, including those with ASC, as close to home as possible.
Further development of the Richmond Online Environment and potentially expanding the project to other service user groups as well as including the Jobcentre Plus	 Work in partnership with individuals with ASC and volunteers to continue developing the current project Work with partners and stakeholders to seek further funding opportunities to expand project Work with partners to develop the Twickenham Jobcentre Plus into a pilot-site for innovative online delivery of Jobcentre services through avatars Share good practice and learning with other areas and projects 	Current project ongoing Funding opportunities to be explored as and when possible / available Jobcentre Plus pilot-site to be explored by Q2 2016/17	Information and signposting is available within the online environment. Individuals with ASC can access volunteer- led training to increase skills and confidence in relation to employment. Creation of online peer-support groups, reducing / preventing future needs. The online environment is available to other service users groups. Jobcentre services are available via avatar.

Creation of ASC- friendly and low- sensory stimuli meeting spaces for local authority services	 Adjusting one existing meeting space to make it appropriate for individuals with sensory hyper- and hyposensitivities Creating a replica of the main council building and meeting space above in the online environment to allow individuals with ASC to 'practice' using it 	Meeting space to be completed by Q3 2016/17 Online replica to be completed by Q1 2017/18	Appropriate meeting space in place and used by all departments as and when necessary.
Seek opportunities for innovation and development as and when they present through partnerships, potential grant funding being made available etc.	 Work with partners and stakeholders to identify opportunities for innovation and development Apply for grants when possible, and support partners and stakeholders to do so when required 	Ongoing	Further opportunities for innovation and development are realised within existing financial constraints as grant funding is sought from sources external to the local authority

Appendix A – Sources of further information about ASC

The Girl with the Curly Hair

Alis Rowe, a young woman with a diagnosis of autistic spectrum disorder who lives in the London Borough of Richmond, has published several books in living with autism and aiming to help people with autism and their neurotypical (not-autistic) friends and family to communicate. Details can be found on her website:

<u>http://thegirlwiththecurlyhair.co.uk/</u>, where you will also find links to her blog, Facebook page etc.

Further reading

The list of suggested reading below is taken from the "CPD curriculum guide for social workers who are working with people on the autism spectrum", published by the Department of Health in October 2015:

Historical context and the development of the concept of autism

The Autistic Brain:

http://www.slate.com/articles/health_and_science/medical_examiner/2013/05/temple_gr andin_s_the_autistic_brain_an_excerpt_on_the_history_of_the_autism.html

Science and ethics blog: http://autismcrisis.blogspot.co.uk/

So what exactly is autism? <u>http://www.aettraininghubs.org.uk/wp-</u> content/uploads/2012/08/1_So-what-exactly-is-autism.pdf

Frith, U. (2003) *Autism: Explaining the enigma (second edition).* Oxford: Blackwell Publishing

Baron-Cohen, S. (2008) *Autism and Asperger Syndrome: the facts*. Oxford: OxfordUniversity Press

Boucher, J. (2009) *The autistic spectrum: Characteristics, causes and practical issues.* London: Sage

Frith, U. (2008) Autism: A very short introduction. Oxford: Oxford University Press

Causation, prevalence and co-existing conditions

Myths, facts and statistics: <u>http://www.autism.org.uk/about-autism/myths-facts-and-statistics/statistics-how-many-people-have-autism-spectrum-disorders.aspx</u>

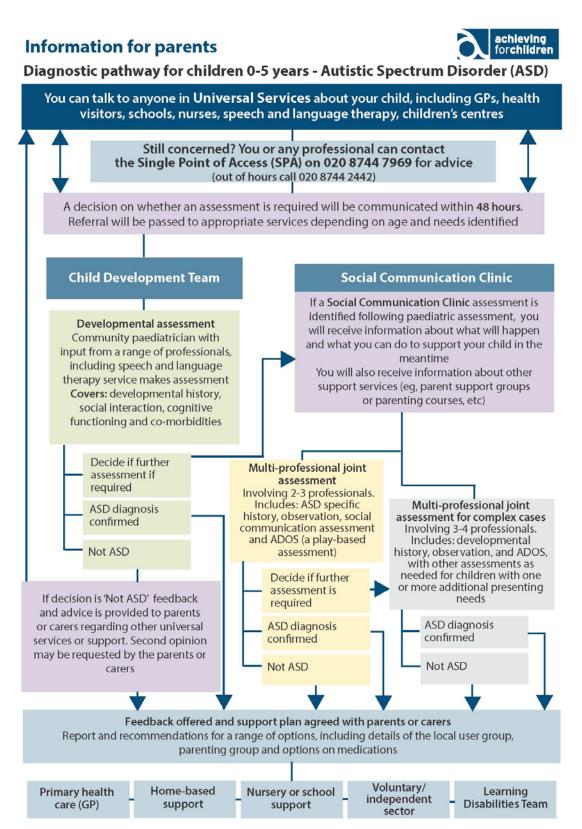
Review of Unstrange Minds: Remapping the World of Autism: http://www.unstrange.com/images/grinkernejm2007.pdf

Mental health and Asperger syndrome: <u>http://www.autism.org.uk/working-with/health/mental-health-and-asperger-syndrome.aspx</u>

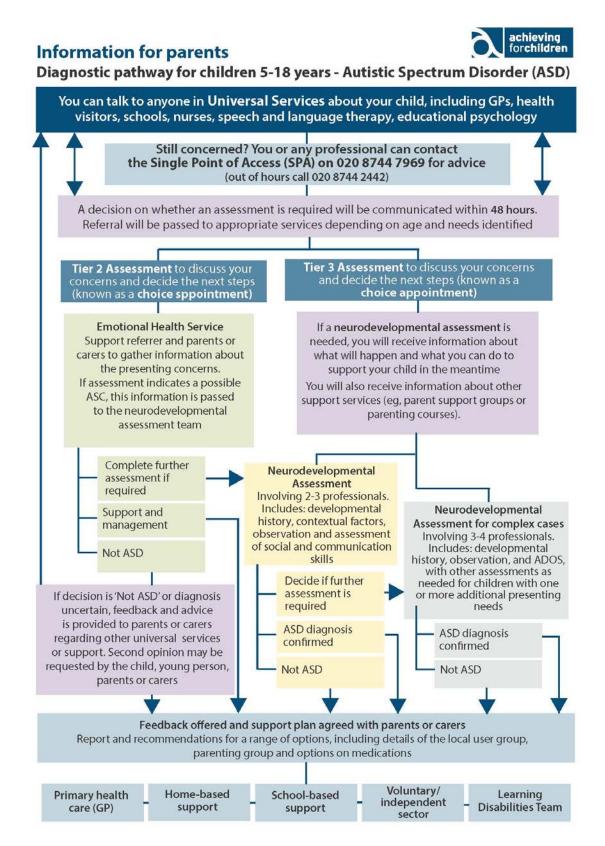
Medical comorbidities in Autism Spectrum disorders: <u>http://www.autismtreatment.org.uk/wp-content/uploads/2013/07/Medical-Comorbidities-in-Autism-Spectrum-Disorders-2013.pdf</u>

Kutscher, ML. (2007) *Kids in the syndrome mix of ADHD, LD, Asperger's, Tourette's, bipolar, and more!: The one stop guide for parents, teachers, and other professionals.* London: Jessica Kingsley Publishers

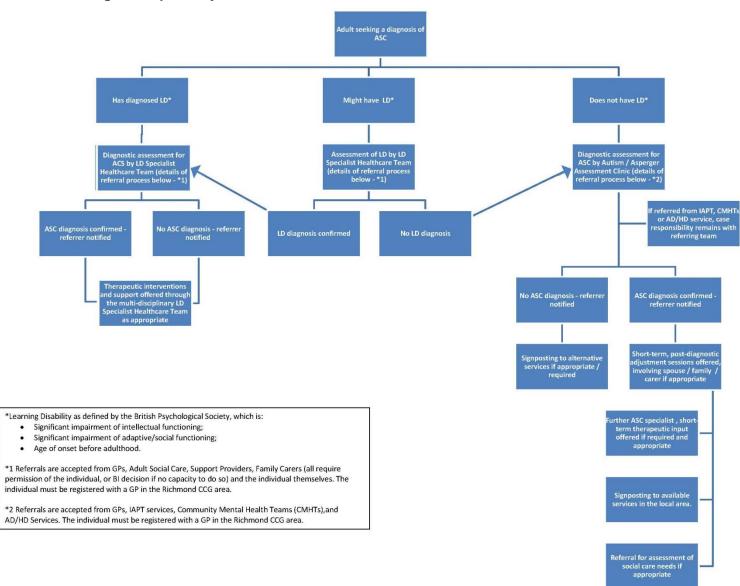
Appendix B - ASC diagnostic pathway for young children 0 – 5 years



Appendix C - ASC diagnostic pathway for children and young people 5 – 18 years



Appendix D – ASC diagnostic pathway for adults



Appendix E – Autism Programme Board Terms of Reference and Membership

Autistic Spectrum Conditions (ASC) Strategy

Programme Board Terms of Reference

CONTEXT

Following on from the Autism Act in 2009, the government published the national autism strategy for England Fulfilling and Rewarding Lives in 2010, which sets out the vision that:

'All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.' (DH, 2010).

The national strategy was updated in April 2014 and new statutory guidance was issued in March 2015. This updated statutory guidance covers the following key areas:

- 1. Training of staff who provide services to adults with autism
- 2. Identification and diagnosis of autism in adults, leading to assessment of needs for relevant services
- 3. Planning in relation to the provision of services for people with autism as they move from being children to adults
- 4. Local planning and leadership in relation to the provision of services for adults with autism
- 5. Preventative support and safeguarding in line with the Care Act 2014 from April 2015
- 6. Reasonable Adjustments and Equality
- 7. Supporting people with complex needs, whose behaviour may challenge or who may lack capacity
- 8. Employment for adults with autism
- 9. Working with the criminal justice system

PURPOSE OF THE AUTISM PROGRAMME BOARD

The Autism Programme Board will bring together local Experts by Experience (EbE – individuals on the autistic spectrum and their carers), representatives from departments within Children as well as Adult Social Services, representatives from other departments of the local authority and local Joint Commissioning Collaborative (JCC) commissioners to discuss, action and, where action is not directly possible, make recommendations on the development and provision of services for those affected by autistic spectrum conditions in the London Borough of Richmond upon Thames (LBRuT).

The Autism Programme Board will:

- 1. Translate the strategic Department of Health objectives into local priorities and actions.
- 2. Provide a forum for open discussions between all members on services provided and required in LBRuT.
- Take into consideration the views of EbEs who are not able to take part in the programme board by inviting and seeking feedback through the Autistic Spectrum Conditions (ASC) carer groups, Drop-in groups and through information / updates

provided online and via newsletters.

4. Involve members of the reference group in board meetings when appropriate, and involve in task specific "Task and Finish" groups as required.

FREQUENCY OF MEETINGS

The Autism Programme Board will meet quarterly. It is anticipated that meetings will last for a maximum of 1.5 hours.

The frequency and duration of the meetings may be changed with the consensus of its members.

GOVERNANCE

Minutes and agendas will be produced for each meeting of the Autism Programme Board; administrative support is provided by the Admin Hub 2.

An agenda and previous minutes will be produced at least 2 weeks in advance of each meeting.

The Autism Programme Board will advise, make recommendations to and report progress to:

- Health and Wellbeing Board
- Joint Divisional Management Team
- CCG Governing Board
- Achieving for Children (used to be Children's Trust Board)

The Autism Programme Board does not have strategic decision making powers. Its role is to action tasks within existing processes as well as advise on and represent the views of EbEs, commissioners and department representatives during the decision making process and to be consulted as part of the decision making process.

MEMBERSHIP

For every meeting:

Title / Team	Organisation	Name
Head of Learning Disability and Mental Health, Autism Lead	LBRuT	John Street
EbE / Co-chair		tbc
Autism Specialist Worker	LBRuT	Rebecca Swist
Specialist Educational Psychologist / Autism Lead	Achieving for Children	Tom Connor
EbE	NAS Richmond	Alison and Kevin Sears
Commissioning Manager	Joint Commissioning Collaborative	Robert Colquhoun
Workforce Development Team	Achieving for Children	Claire Grayson
Workforce Development Team	LBRuT	Anita Woods / Rhiannon Cardillo

Performance Management	LBRuT	Carl Fenty	

Reference Group as required:

	1	1
Title / Team	Organisation	Name
Work Services Manager,	DWP	Kuldip Bath
Twickenham Jobcentre		
Housing Development Manager	LBRuT	Paul Bradbury
Acting Sergeant / Inspector	MET Police	Tim Brown / Lucy Perrett
Employment and Involvement	Richmond AID	Jamie Cutler
Manager		
HIA Manager, Housing	LBRuT	Jasber Dodson
Operations		
Resettlement Team, Housing	LBRuT	Louise Brice
Operations		
Care Act Implementation Project	LBRuT	Nadine Hassler
Manager		
ASD Specialist, Planned Care	Hounslow and	Clare Miller
and Long Term Conditions	Richmond	
-	Community Health	
Richmond Works	Remploy	tbc
Join Manager / Consultant	Your Healthcare	Ewa Rula (Barbara
Clinical Psychologist (Head of		Ogden)
Service, Specialist LD Service)		

The Autism Programme Board will establish task specific "Task and Finish Groups (TFG)" which will have an assigned person / lead responsible for the completion of the task required. It is the purpose of these groups to work on the implementation of specific aspects of the Autism Strategy and as such it is envisaged that these will disband when a specific task has been completed and new groups to be formed as and when tasks are identified. It is the TFG leads responsibility to consider membership of their group, and this may extend beyond the above list.

The Autism Programme Board has 2 co-chairs who work in partnership. One of the cochairs will be from the statutory sector and the other will be an EbE.

Expenses will be paid to EbEs to cover travel and the cost of caring responsibilities whilst attending the Autism Programme Board meetings and agreed related activities.

ROLE & RESPONSIBILITIES OF BOARD MEMBERS

Members of the Autism Programme Board are expected to:

- Regularly attend meetings of the board
- Be honest, open and provide constructive and balanced feedback
- Work positively with other members

- Undertake actions they have agreed to at meetings
- Where possible seek the views of others and represent these views on the board
- Be responsible for the active engagement and involvement of their respective organisation and services
- Send a representative if they are unable to attend. If unable to do so, provide feedback on their actions to the chair ahead of the meeting.
- Use personal issues only to demonstrate a point of principle

In addition to the above, the Co-chairs are responsible for the effective operation of the Partnership Board by:

- Setting the agenda
- Checking progress with tasks and activities agreed
- Ensuring members are able to participate and are listened to
- Maintaining a code of conduct
- Clarifying agreements, actions and recommendations
- Representing the Autism Board at other meetings as required, or nominate a representative

October 2015