





AUTISM JSNA 2019

Author: Stephan Brusch

1.Introduction: Why it matters.

What is Autism?

Autism Spectrum Disorder (ASD) is a lifelong developmental disability that affects how people perceive the world and interact with others. It is a spectrum condition, meaning that while all autistic people share certain difficulties, they are affected by them in different ways¹.

Autism Spectrum Disorder is characterized by two main features: persistent difficulties in social interaction and communication, and the presence of stereotypic (rigid and repetitive) behaviours, resistance to change or restricted interests².

Co-occurrence

ASD does not often present itself as a single presenting condition.

At the higher functioning end of the spectrum, many people with ASD have average or high intelligence. Almost half (44 percent) of people with ASD have a co-occurring learning disability³, defined⁴ as a significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development and being a lifelong condition. An additional group of people with ASD perform in the borderline learning disabilities adaptive functioning range⁵ – while a quarter of people with ASD are non-verbal.

ASD also commonly co-occurs with other neurodevelopmental, psychiatric, neurologic, chromosomal and genetic diagnoses in up to 83 percent of cases⁶.

¹ Autism.org.uk. (2018). Autism - NAS. [online] Available at: https://www.autism.org.uk/about/what-is/asd.aspx# [Accessed 6 Aug. 2018].

² National Institute for Health and Care Excellence (2016) *Autism spectrum disorder in adults: diagnosis and management* (NICE Clinical Guideline 142). Available at: https://www.nice.org.uk/guidance/cg142/chapter/Introduction [Accessed 08 August 2018].

³ Baxter AJ, Brugha TS, Erskine HE, Scheurer RW, Vos T, Scott JG. The epidemiology and global burden of autism spectrum disorders. *Psychological Medicine*, 2015; 45(3): 601–13.

⁴ Department of Health (2001) Valuing People A New Strategy for Learning Disability for the 21St Century.

⁵ Salvador-Carulla L, Garcia-Gutierrez JC, Ruiz Gutierrez-Colosia M, Artigas-Pallares J, Garcia Ibanez J, Gonzalez Perez J *et al.* Borderline intellectual functioning: Consensus and good practice guidelines. *Revista de Psiquiatría y Salud Mental*, 2013; 6(3): 109–20.

⁶ Levy SE, Giarelli E, Lee LC, Schieve LA, Kirby RS, Cunniff C et al. Autism spectrum disorder and co-occurring developmental, psychiatric, and medical conditions among children in multiple populations of the United States. Journal of Developmental & Behavioral Pediatrics, 2010; 31(4): 267–75.

Risk Factors

Available scientific evidence suggests that there are probably many factors that make a person more likely to have an ASD, including environmental and genetic factors. Some of the factors associated with an increased prevalence of autism include⁷:

- A sibling with autism
- Birth defects associated with central nervous system malformation and/or dysfunction
- Gestational age <35 weeks
- Parental schizophrenia-like psychosis or affective disorder
- Maternal use of sodium valproate in pregnancy
- A learning disability
- Attention deficit hyperactivity disorder
- Neonatal encephalopathy or epileptic encephalopathy, including infantile spasms
- Chromosomal disorders such as Downs syndrome
- Genetic disorders, such as Fragile X
- Muscular dystrophy
- Neurofibromatosis
- Tuberous sclerosis.

Available epidemiological data are conclusive that there is no evidence of a causal association between measles, mumps and rubella vaccine, and ASD. Previous studies suggesting a causal link were found to be filled with methodological flaws^{8, 9}.

There is also no evidence to suggest that any other childhood vaccine may increase the risk of ASD. Evidence reviews of the potential association between thiomersal preservative and aluminium adjuvants contained in inactivated vaccines and the risk of ASD strongly concluded that vaccines do not increase the risk of ASDs.

Societal Cost, Impact and Quality of Life

Lack of recognition of ASD in children and adults lead to people with ASD being overlooked in terms of their health and social needs. They may develop mental and physical health problems as a consequence of this; and be unable to access the appropriate treatment. They are also less likely to be able to live independently, find paid employment, and experience a fulfilling life. Those who have higher functioning autism or Asperger Syndrome feel they have a 'hidden' condition which is not easily recognised or understood by professionals or the public.

The economic impact associated with ASD is substantial and includes direct medical, direct non-medical and indirect productivity costs¹⁰. Studies estimate the lifetime cost of caring for an individual with ASD and learning disabilities to be £1.5million in the United Kingdom (UK); though the figures drop £0.92 million in the UK for ASD without learning disabilities¹¹. Also, if unrecognized or untreated, ASD can contribute to poor educational attainment and difficulty with employment, leading to negative economic implications.

Dyer C. BMJ 2010;340:c696. 2 February 2010. (accessed 16 December 2018).

⁷ National Institute for Health and Care Excellence (2016) *Autism spectrum disorder in adults: diagnosis and management* (NICE Clinical Guideline 142). Available at: https://www.nice.org.uk/guidance/cg142/chapter/Introduction [Accessed 08 August 2018].

⁸ Wakefield's affair: 12 years of uncertainty whereas no link between autism and MMR vaccine has been proved Maisonneuve H, Floret D. Presse Med. 2012 Sep; French. (accessed 16 December 2018).

⁹ (2) Lancet retracts Wakefield's MMR paper

¹⁰ Amendah D, Grosse SD, Peacock G, Mandell DS. The economic costs of autism: A review. In Amaral D, Geschwind D, Dawson G (eds.). Autism spectrum disorders. Oxford: Oxford University Press, 2011: 1347–60.

¹¹ Buescher AV, Cidav Z, Knapp M, Mandell DS. Costs of autism spectrum disorders in the United Kingdom and the United States. JAMA Pediatrics, 2014; 168(8): 721–8.

Autism can affect the quality of life of those living with it as well as their families. Some people with ASD can lead independent lives but for many the impact can be extreme. ASD interferes with the quality of their lives and their parents lives (including productivity). Many experience increased anxiety and depression. Family members often have to decrease hours worked due to their child's diagnosis¹².

The families of many children with autism worry about their education and time spent at school. Only 52% of parents feel that their child is making good educational progress, and 63% of children with autism are not in the kind of school their parents think would best support them¹³. Children with autism often find school to be a difficult environment: a quarter of children with autism are not happy at school, and one in five do not feel safe¹⁴.

Adults with ASD do not have access to the support and services required to live independently or enter employment. Over 44% of adults with autism live at home with their parents, and only 32% of adults with autism are in some form of paid work¹⁵.

Key Drivers

International

In 2008, the United Nation General Assembly (GA) adopted resolution A/RES/62/139 designating 2 April each year as World Autism Awareness Day increasing international awareness about ASDs. In 2012 the (GA) adopted resolution 67/82: "Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities". The U.N. outlined that the full employment by people with ASD will contribute towards advances in social and economic development of societies and communities. The GA voices its concern "that persons with autism spectrum disorders [...] continue to face barriers in their participation as equal members of society" and calls this "discrimination" and "a violation of the inherent dignity and worth of the human person". It recommended that:

- Member states enhance access to appropriate support services
- Equal opportunities for inclusion and participation is enhanced
- Training and awareness raising is provided
- Innovative and integrated approaches for effective and sustainable intervention programmes are developed
- Inclusive education programmes for infants, children and adults with ASD are developed
- Data, information and statistical information is improved.

National

The report "Supporting People with Autism throughout Adulthood" by the National Audit Office increased the awareness and understanding of people with ASD and highlighted the need to improve their quality of life. The subsequent Autism Act 2009 - the only syndrome specific legislation in UK law - instructed the Secretary of State to set out a strategy for meeting the needs of adults in England with ASD. This resulted in the publication of the National Strategy for Autism in 2010. Reviewed and refreshed in 2014, "Think Autism" places an obligation on the NHS and local authorities to meet the

¹² Azeem MW, Dogar IA, Shah S, Cheema MA, Asmat A, Akbar M et al. Anxiety and depression among parents of children with intellectual disability in Pakistan. Journal of the Canadian Academy of Child and Adolescent Psychiatry, 2013; 22(4): 290–5.

¹³ Reid, B. (2011). Great Expectations. London: The National Autistic Society

¹⁴ Reid, B. (2011). Great Expectations. London: The National Autistic Society

¹⁵ The National Autistic Society (2016). The autism employment gap: Too Much Information in the workplace.

needs of people with autism. It is underpinned by Statutory Guidance that includes 65 recommendations, including 'must dos' for local authorities and NHS bodies on:

- Diagnosing Autism
- Identification of people with autism
- Assessment of their needs
- Transition planning
- · Planning for relevant services
- · Reasonable adjustments
- Workforce Development
- Local Leadership.

The annual Autism Self-Assessment Framework, implemented by Public Health England tests the implementation of the national strategy and statutory guidance.

The **NHS Long Term Plan (NHS England 2018)** sets out the ambition for the NHS and it identifies ASD as a priority and commits actions to:

- 1. Tackle the causes of morbidity and preventable deaths in autistic people, by:
- Piloting the introduction of a specific health check for people with autism, and if successful, extend it more widely.
- Ensuring that 75% of people with learning disabilities aged over 14 will receive an annual health check every year.
- Reduce the usage of psychotropic drugs
- 2. Improve the whole NHS understanding of the needs of people with autism, and work together to improve their health and wellbeing, by:
- NHS staff receiving information and training on supporting people with autism.
- Sustainability and Transformation Partnerships (STPs) and integrated care systems ICSs being expected to make sure all local healthcare providers are making reasonable adjustments to support people with autism.
- National improvement standards being implemented and applied to all services funded by the NHS. These standards will promote greater consistency, addressing themes such as rights, the workforce, specialist care and working more effectively with people and their families.
- 2023/24, a 'digital flag' in the patient record will ensure staff know a patient has autism.
- Working with the Department for Education and local authorities' awareness of, and support for, children and young people with autism or both will be enhanced.
- NHS England working with partners to bring hearing, sight and dental checks to children and young people with autism or both in special residential schools.
- 3. Children and young people with suspected autism wait too long before being provided with a diagnostic assessment. Reduce waiting times for specialist services, by:
- Testing and implementing the most effective ways to reduce waiting times for specialist services
- Children and young people with autism with the most complex needs will have a designated keyworker. Key worker support will first be provided to children and young people who are inpatients or at risk of being admitted to hospital.
- 4. By March 2023/24, inpatient provision will have reduced to less than half of 2015 level, through:
- Local providers being able to take control of budgets to reduce avoidable admissions, enable shorter lengths of stay and end out of area placements.

- Where possible, people with a learning disability, autism or both will be enabled to have a
 personal health budget (PHBs).
- Increase investment in intensive, crisis and forensic community support so that people receive more personalised care in the community and closer to home.
- 5. Focus on improving the quality of inpatient care across the NHS and independent sector. By 2023/24, all care commissioned by the NHS will need to meet the Learning Disability Improvement Standard, by:
- Working with the CQC to implement recommendations on restricting the use of seclusion, long-term segregation and restraint for all patients in inpatient settings, particularly for children and young people
- All areas of the country implementing and being monitored against a '12-point discharge plan' to ensure discharges are timely and effective.
- Reviewing and looking to strengthen the existing Care, Education and Treatment Review
 (CETR) and Care and Treatment Review (CTR) policies, in partnership with people with a
 learning disability, autism or both, families and clinicians to assess their effectiveness in
 preventing and supporting discharge planning.

Building the Right Support (NHS England, ADASS and Local Government Association 2015) sets out a whole-system approach to ensure that community services are developed to reduce reliance on mental health inpatient units. It provides service standards for local health and social care commissioners to ensure inclusion of people with learning disabilities and or autism.

NICE clinical guidelines elaborating on the identification, diagnosis, and management of ASD in children and adults were published in 2012. It includes eight quality standards:

- 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.
- People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.
- 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.
- People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.
- 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.
- People with autism are not prescribed medication to address the core features of autism.
- People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.
- 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 Autism and Education in England Report (2017) by the All-Party Parliamentary Group has made 22 recommendations for Government, Local Authorities and the Education System. It includes the call for a national children and young people autism in education strategy. It focusses on:

- Workforce development around SEND and autism for teachers
- · Ensuring that there is a special curriculum for people with autism who need it
- Setting out reasonable adjustments for schools
- Reduce bullying and harassment through greater awareness raising

- Setting out clearer guidances around diagnosistics, including potential pathways between diagnosis and education health and care plans
- Better alignment between schools and mental health services
- National review of SEND funding
- Development of local hub models to share information.

In response to the report, the Government has agreed to publish a new autism strategy in November 2019 that will include children and young people.

Health Education England and Skills for Health are developing the the first national Autism Core Capabilities Framework for health and care staff, and staff in organisations with public facing responsibilities. The framework will be required to span all ages and will inform the new revised autism strategy. Health Education England has quality assured a range of available <u>autism training</u> resources.

NHS Improvement (2018) has published <u>Learning Disability and Autism improvement standards for NHS Trusts</u> that focus on:

- · respecting and protecting rights
- inclusion and engagement
- workforce
- specialist learning disability services.

Local Picture

Kingston SEND Transformation Plan 2019/20 to 2020/21

The plan addresses the financial challenges to services working with children with special educational needs and disabilities (SEND) as well as responding to the most recent OFSTED and CQC inspections. With pupils with autism being the main presenting need in local education, health and care plans, this plan will be a key driver for children and young people with autism in Kingston. It is framed around six workstreams:

- Governance and Strategy
- · Commercial thinking
- Developing local provision
- · Early intervention and transition
- Assessment and planning
- Home to school travel

It commits to the development of a dedicated autism school in Kingston.

The Tolworth Area Plan (2018) identifies the action to support Express in their asset of community value plan for a hub to support young people with autism.

The Liberal Party Manifesto (2018) identifies the following autism specific actions:

- Support Express CIC to open an autism centre in Tolworth
- Work with partners in health to speed up the diagnosis of children who may be autistic
- Set up further provision in mainstream schools for autistic pupils.

Alignment with other strategies

"Thrive," the Kingston Mental Health and Wellbeing Strategy for 2017 to 2021 recognizes the need to ensure appropriate mental health care is offered for people with ASD inside the borough. It also shows that there is a need to provide places where people with ASD feel safe and secure, and to improve their employment opportunities.

The local all age learning disability strategy (2018-2023) focusses on increasing employment, people living in their own home and reducing health inequalities, this includes those with learning disabilities and autism.

The strategy is aligned to the Marmot Review which set out the key drivers of inequalities in health outcomes. The review set out key policy recommendations on the social determinants of health throughout the life-course.

The focus of the strategy is to further integrate commissioning and provision of dedicated learning disability services, whilst ensuring that community assets and universal services are accessible to people with learning disabilities.

The strategy identifies key interventions to early years, transition and adulthood and which are framed around the themes of maximising independence; strengthening the pathway from education to employment; being part of Kingston and good health that includes positive mental health.

2. Data and Outcomes

There is no data collected on the total number of people with ASD on a national or regional scale. The estimation of approximately 700,000 people with ASD in the UK is based on two epidemiological studies on the prevalence of ASD in the UK, applied to figures from the 2011 Census¹⁶. Using the same logic, this prevalence rate of 1.1% can be applied to the total population of Kingston (179,581)¹⁶ to provide an estimate of a total of 1,975 people with ASD living in Kingston.

Children

Information on the number of children with autism known to schools is collected by PHE. In England as a whole, there were 108,403 children with autism known to schools in 2017. This equates to 12.5 school-aged children per 1,000¹⁷.

In Kingston, there were 387 children with autism known to schools in 2017, equating to 13.3 schoolaged children per 1,000. This data has only been kept since 2015, and has been fairly static since then - with 390 children with autism known to schools in Kingston in 2016, and 363 in 2015¹⁸. There are 3,577 children and young people with SEND aged 0 to 25 in Kingston upon Thames; 1,130 of these children and young people (32%) have an education, health and care plan (EHCP) to describe and put in place the educational provision and support that they need. The main presenting need in local EHCPs is autistic spectrum conditions (35%).

When compared to the national level, Kingston has a similar number of children with autism known to schools. Local authorities with similar levels of children with autism known to schools include Barking and Dagenham, Barnet, Brent, Bromley, Enfield, and Hounslow. Local authorities with lower levels of children with autism known to schools include Camden, the City of London, Hackney, Harrow, Havering, and Kensington and Chelsea. Local authorities with higher levels of autism in children known to schools include Bexley, Croydon, Greenwich, Hammersmith and Fulham, Hillingdon, Islington, and Lambeth¹⁹.

This data does not capture children with autism who are not in school, or who live in Kingston, but are in school out of borough.

¹⁶ Autism.org.uk. (2018). Autism - NAS. [online] Available at: https://www.autism.org.uk/about/what-is/asd.aspx# [Accessed 6 Aug. 2018].

¹⁷ Public Health England (2017). Public Health Profiles.https://fingertips.phe.org.uk/. [Accessed 09 Aug 2018].

¹⁸ Public Health England (2017). Public Health Profiles.https://fingertips.phe.org.uk/. [Accessed 09 Aug 2018].

¹⁹ Public Health England (2017). Public Health Profiles.https://fingertips.phe.org.uk/. [Accessed 09 Aug 2018].

Adults

Population projections for Adults aged 18 to 64 with ASD in Kingston using the estimated prevalence rates

ASD - all people	2017	2020	2025	2030	2035	% increase 2017- 2035
People aged 18-24 predicted to have ASD	177	179	185	211	219	23.7%
People aged 25-34 predicted to have ASD	288	289	288	280	292	1.4%
People aged 35-44 predicted to have ASD	288	298	312	317	314	9.0%
People aged 45-54 predicted to have ASD	238	252	268	284	294	23.5%
People aged 55-64 predicted to have ASD	172	186	208	224	238	38.4%
Total population aged 18-64 predicted to have ASD	1163	1204	1261	1317	1358	16.8%

Source: PANSI.org.uk. (2017). Autism Spectrum Disorders: People aged 18-64 predicted to have Autism Spectrum Disorders, by age and gender, projected to 2035.

http://www.pansi.org.uk/index.php?&PHPSESSID=ar0fobbe0tvbd0hf53q1o7f2h3&sc=1&pageNo=392&loc=8353

Population projections for Adults over the Age of 65 with ASD in Kingston using the estimated prevalence rates

ASD - all people	2017	2020	2025	2030	2035
People aged 65-74 predicted to have ASD	127	131	139	157	175
People aged 75+ predicted to have ASD	95	105	130	150	170
Total population aged 65+ predicted to have ASD	222	236	269	307	345

Source: POPPI.org.uk (2017). People aged 65 and over predicted to have autistic spectrum disorders. http://www.poppi.org.uk/index.php?&PHPSESSID=ar0fobbe0tvbd0hf53q1o7f2h3&sc=1&pageNo=428&loc=8353.

Overall, there are predicted to be 1,385 adults with ASD in Kingston in 2017, increasing to 1,530 people by 2025, and 1,703 people by 2035. The most affected age groups are people aged 25-64. There is a lower number of older people identified with ASD, possibly because of more recent awareness and improvements in diagnosis²⁰. Many adults find it difficult to obtain a diagnosis of ASD if the features of autism were not recognized in school.

There are currently 65 adults recorded on the Integrated Autism System with autism who meet social care eligibility criteria. Of those 35 are also assessed as having a learning disability and 30 individuals are also in receipt of mental health services. 19 individuals with autism are in receipt of a personal budget.

²⁰ Autism.org.uk (NAS). A History of Autism Studies. https://www.autism.org.uk/about/what-is/myths-facts-stats.aspx. [Accessed 10 Aug 2018].

Number of Autistic Children/Young People in Years 10-13 and Numbers who have completed the Transition Process (2017/18 academic year).

Total Number of autistic children/young people in	n Years 10 -13.	114
Number of autistic children/young people who ha	ave completed the transition process.	51

Source: Data provided by AfC (2018)

Community Engagement

While the call for greater community involvement is strong across public sectors, people with autism are often less involved²¹(2014) often because of their ASD related behaviour. Whilst people with learning disabilities and mental health issues have a strong history of peer advocacy, this is less the case for autistic children and adults. Engagement is centred around strategy development and sporadic, rather than an ongoing process to support the development of a community voice.

Recent workshops and online surveys reached 54 participants (a mix of adults with ASD, their parents and service providers). The main issues raised were:

- The lack of local specialist provision and mainstream services that lacked understanding around autism
- Workforce development and the need the raise awareness in the general public
- Ensuring that reasonable adjustments are shared across organisation to disseminate learning
- · Communication and signposting including a strong demand for a community hub
- Pathway development, including the entry points of diagnosis to the health and social care services.
- Employment and Education to ensure that people are supported to live independent lives.

3. Current Services

Diagnostic Services

There are currently three autism diagnostic services in Kingston.

Age Range	Commissioner	Provider	Service	Source of referral
0-5 years	Kingston CCG	AfC	Community Paediatricians	Self-referral or through Single Point of Access
5-18 years	Kingston CCG	Southwest London and St George	CAMHS	Phone for referral. Young person needs to be registered with GP in Kingston
18+	Kingston CCG	Your Healthcare	Neurodevelopmental Services	Open referral system

²¹ Pellicano, Elizabeth, et al. "Views on Researcher-Community Engagement in Autism Research in the United Kingdom: A Mixed-Methods Study." *PLoS ONE*, vol. 9, no. 10, 2014.

Children up to 5 years are seen by Community Paediatrics based at the Moor Lane Centre. For children above that age, they are first been seen by a GP, or school, or social worker or paediatrics and referred to Kingston CAMHS SPA, who then screens the referral and collects additional necessary information, and may offer an initial face-to-face appointment. They then refer on to the Neurodevelopmental Team (NDT) which is part of South West London-St George's Mental Health Trust or, if appropriate, offer services in Kingston CAMHS itself, or signpost the family elsewhere e.g. a voluntary and community organisation. If accepted by the NDT, there is an 8-12 week wait for a multidisciplinary assessment, following which the NDT write a report for the family, GP, etc. This includes recommendations for support e.g. Tier 2 worker for anxiety management. Post-diagnostic support includes local CAMHS teams if there are severe problems and treatment such as medication or Cognitive Behavioural Therapy is needed. There is a recognition by service providers that there is a need to better integrate commissioning, funding, and delivery of health and social care for children and young people with autism in Kingston and South West London generally.

Other support services include:

- Balance CIC helps adults with higher functioning autism develop independence and confidence in clients to allow them to achieve their long and short term goals
- Practical help (benefits, emotional health, welfare and employment) and Social Groups
- The organisation providing support to children, young people and adults with autism can be found on the local offer website published by Achieving for Children
- Workshops at Grand Avenue Primary School for siblings and parents of children and young people with autism.
- AfC also run ASD social skills group for children and young people.
- AfC also provide Early Bird and Early Bird Plus which are National Autistic Society (NAS)
 licensed programmes for parents. Programme aims to support parents in the period between
 diagnosis and school placement, empowering and helping them facilitate their child's social
 communication and appropriate behaviour in their natural environment.
- NAS Kingston raises awareness of autism locally by arranging talks/workshops by professional speakers on topics such as behaviour, sleep, toileting etc.
- AfC's family coaching provide intensive support to parents and carers of children with complex challenging behaviour that may include autism/autistic spectrum disorder (ASD).
- Express CIC have therapists who run a group that aims to meet the specific and unique social
 and emotional needs of autistic children using creative tools such as drama, puppetry, art,
 music and storytelling. 6 places on weekly session during term time. They also provide a
 social space for young siblings of children with autism.
- Express run telephone/email support and pre & post diagnosis support on a one to one basis. Express offer DLA/EHCP support and guidance. Express run six different Therapy Groups each week for young people on the spectrum and siblings groups supporting over 30+ children a week. Express offer a Counselling Service for parents/carers with SEN children. In addition there is a careers guidance service for young autistic people from CV to gaining work experience and employment. Express are working with the local authority to create an Autism Centre of Excellence and to ensure the autistic community has a voice. Express run regular workshops, talks and events including their Annual Autism Conference at the Rose Theatre.

- Fastminds is a user-led group run entirely by volunteers, providing support, friendship and understanding to adults in our community living with ADHD, ASD and comorbid disorders regardless of diagnoses.
- The Connect Clinic at the Wolverton Sexual Health Centre, Kingston Hospital runs a sexual health clinic for people of all ages who are autistic or have learning disabilities.
- A new free school for children and young people with special educational needs and disabilities (SEND) is being established at Moor Lane, Chessington in September 2022, and will provide 90 places for children and young people aged five to 19 who have Autistic Spectrum Disorders (ASD). The new school will help to reduce the number of children with ASD having to travel to schools outside of the borough.

4. Recommendations

- CAMHs, St George's Mental Health Trust, AfC, Adult Social Care, NHS and voluntary and community sector organisations should collect and triangulate reliable information across services on the number of children, young people and adults with ASD in the borough so as to inform commissioning decisions
- 2. AfC and Adult social care should review and update the existing autism strategies for adults and children and young people into a single document covering all ages (in line with national direction of travel) and ensure that the strategy is aligned to national and local drivers and best practice
- 3. Adult Social Care, AfC, Public Health Your Healthcare, CAMHS and St George's Mental Health Trust Fully develop the autism board, including strengthening the voice of children, young people and adults and including their families on the board.
- 4. The chairs of the learning disabilities, mental health and SEND Partnership Boards need to ensure that autism is included in the board agendas.
- 5. CAMHs, St George's Mental Health Trust, AfC, Adult Social Care, NHS and voluntary and community sector organisations should ensure that the pathway for diagnosis and management of children, young people and adults with ASD and whole family assessments are clear, for healthcare professionals, service users, carers, and families
- 6. The autism board should clarify the proposal for developing a community hub and ensure that organisation are linked in to provide relevant information and signposting
- 7. The autism board should have oversight of the development of a multi-organisational training and provide autism awareness training for local government, healthcare, and support staff. Accelerate the uptake drastically.
- 8. The autism board should have oversight of the development and dissemination of reasonable adjustments and what they look like in different setting to spread learning.
- 9. The autism board should have oversight of raising awareness of identification and assessment of autism amongst the general public, teachers, and healthcare workers, so that diagnosis takes place at an earlier stage.