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A Health Needs Assessment for Children and Adults with Neurodevelopmental Conditions in Liverpool

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EXECUTIVE SUMMARY

This report has been commissioned by Liverpool Clinical Commissioning Group (CCG) to identify the current health needs and service provision for adults and children with neurodevelopmental conditions in Liverpool; focusing on Attention Deficit Hyperactivity Disorder and Autistic Spectrum Disorders. The findings from this report will be used to inform decisions relating to the commissioning and delivery of local services for individuals with neurodevelopmental conditions

METHODOLOGY

This rapid needs assessment involved three stages:

- a literature review of the published and grey evidence on outcomes and interventions for children and adults with neurodevelopmental conditions;
- a service audit involving interviews with stakeholders from providers of neurodevelopmental services in Liverpool,
- a desktop study of national and local data sources to map current need and provision to identify gaps

PREVALENCE IN LIVERPOOL

The estimated prevalence of neurodevelopmental conditions among children in England is between 3-4%. Attention Deficit Hyperactivity Disorder (ADHD) is the most common neurodevelopmental condition in the UK affecting 1-2% of children and young people (although some estimates suggest this is higher). ADHD is more commonly diagnosed among boys than girls and it is suggested that this skewed prevalence is due to symptoms being more commonly among boys. Prevalence of ADHD in Liverpool is estimated at 1.74% and 2,506 children are predicted to have ADHD in the city including 600 5-10 year olds and 465 11-16 year olds.

Despite ADHD being perceived as a largely childhood disorder, research suggests that approximately 65% of children diagnosed with ADHD continue to experience symptoms in adulthood; with 0.6-1.2% of all adults retaining a full diagnosis at age 25 years. In 2013 PHE estimated that there were 10,891 young people aged 16-24 years living with ADHD in Liverpool.

Autism spectrum disorder (ASD) is thought to affect 1% of children and young people in the UK and prevalence is higher among men (1.8%) than women (0.2%). A survey by the National Autistic Society suggests that is more difficult for females to get a diagnosis and they are more likely to be misdiagnosed. In Liverpool there are 1,152 children with ASD stated as their primary special educational need and this includes an estimated 450 children aged 5-9 years and 130 children aged 9-10 years. There are 3,130 adults (aged 18-64) predicted to have ASD in Liverpool. In 2015, there were 201 Liverpool residents with Asperger's on the caseload of Mersey Care and Cheshire and Wirral Partnership NHS Trusts.

COMORBIDITY

Research suggests that between 20-25% of adults have uncomplicated ADHD (i.e. not comorbid with another condition). The most commonly seen co-morbid conditions are oppositional defiant disorder, conduct disorder and anxiety. Autism has also been associated with a number of comorbid conditions with 78.7% of children and adolescents reporting a comorbid condition (including intellectual disability). Studies suggest that children and adults with ADHD have much higher rates of physical and mental health conditions. Dual diagnosis of ADHD and ASD has long been a problematic issue and the evidence on comorbidity is limited. However, there is growing evidence to suggest that the conditions do frequently co-occur and the revised DSM-V criteria published in 2013 allowed dual diagnosis of the two conditions for the first time.

HEALTH AND SOCIAL OUTCOMES

There has been an increase in the number of studies reporting long term outcomes of ADHD in the past three decades which suggests both increased global interest and a growing recognition of the associated impairments and consequences. In addition, there has been an increase in ADHD studies among adolescents and adults highlighting increasing acknowledgment that ADHD is a lifelong disorder. ADHD has been shown to lead to a number of continuing problems in adolescence and adulthood including: increased mental health problems, increase contact with the criminal justice system, poorer academic achievement and employment and higher levels of risk behaviour including smoking, alcohol consumption, illegal substance use and self-harm. The evidence suggests many of these outcomes continue into adulthood but there is a lack of longitudinal studies which follow participants beyond their mid-twenties.

SERVICE AUDIT

An audit of services for children and adults with neurodevelopmental conditions was undertaken to review a range of factors including provision, demand and staffing levels. A detailed profile of each service is available in chapter 5. Key findings from the service audit include:

DEMAND: all interviewees acknowledged that demand for their service had increased in recent years. In most cases demand had exceeded capacity and this had resulted in staff shortages and longer waiting times. More than half of participants felt this increased demand was due to greater awareness of neurodevelopmental disorders among healthcare professionals and the wider public. This increased awareness was attributed to increased and improved: training, education, experience, confidence and communication. Several service providers also believed there was an increased complexity of need and higher levels of comorbidity. A number of participants also observed an increase in diagnoses among young people which was associated with a reluctance to diagnose teenagers in children's services and difficulties with self-management during the transition to high school.

WAITING TIMES: increased demand impacts upon the waiting time for services and the majority of services have seen increases in waiting times, with one service having a waiting list of two years. In general, service providers prioritise according to need. Service delivery impacted upon waiting times and participants described how they often needed to have multiple contacts with clients over weeks/months to enable them to move forward and this could be both time consuming and logistically challenging when meeting the needs of complex families. This in turn limits the number of individuals the services can support at one time. Insufficient staffing levels and a shortfall in funding also impacted on waiting times with the demand for services exceeding current capacity in many services.

DISCHARGE FROM SERVICES: some services do not officially discharge clients reflecting the lifelong nature of neurodevelopmental conditions but rather allow them to dip into provision when required. The term "discharge" is not generally used by some services as clients become concerned that they cannot re-enter the service. Discharge is variable across services and tends to be led by client need.

SERVICE PROVISION

CWP ADULT ADHD SERVICE: 236 Liverpool residents accessed CWP ADHD clinic in 2015/16 and there were 283 referrals made to the service. The majority of referrals were made by a GP (72.1%). At the end of 2015/16 there were 446 individuals on the service waiting list and the average waiting time was 54 weeks. In total, 1,192 appointments were made in 2015/16 of which 39% were either cancelled or DNAs by the patient. A total of 117 individuals were discharged of which 50% were made by a doctor and 47% were due to not attending any appointments.

ADHD FOUNDATION: 261 clients accessed the ADHD foundation in 2015/16 of which four fifths were aged 0-14 years. Just over a quarter (28%) had one or more comorbid disability of which the

most common were other neurodevelopmental conditions. Over a third of clients (37%) had two or more complexities recorded of which ASD/Asperger's were the most common. Just over one in ten clients (14%) reported on or more Adverse Childhood Experience (ACE) of which the most common was parental separation. A third of all clients had severe ADHD and 16% moderate ADHD. Just under half of clients had at least one additional presenting need of which the most common were behavioural difficulties (including conduct disorder and ODD), generalised anxiety, social anxiety and obsessive compulsive disorder. In total 223 clients were referred to the service during 2015/16 and the mean number of days between referral and assessment was 56. The mean number of appointments per client was three and three in ten clients did not attend at least on appointment. Consultations with parents and group work with either children/young people or parents/carers were the most common interventions delivered and between 88-100% of clients recorded positive outcomes depending on the type of intervention received. The mean number of days between referral and discharge was 193.

LIVERPOOL ADULT ADHD - LADDERS OF LIFE (LOL): there were 549 individuals accessing LoL at the time of reporting of which the largest proportion were aged between 18-30 years (39%). On average, between 90-100 people are supported by the service each week through individual sessions (30-35 clients per week), group sessions during the day (35-40 clients per week) and evening (15-20 clients per week) and group sessions with family members/partners (15-20 clients per week). On average between 7-10 referrals are received per week from a range of services including government, health, housing, social care, community organisations and educational institutions. Service users report a range of positive outcomes across health and the wider determinants, including but not limited to: improved engagement with health services, reduction in aggression and aggressive behaviour, reduced social isolation, improved family coherence and happiness and improved relationships and understanding between partners and family members.

ALDER HEY: in 2015 190 children and young people were referred to the ADHD pathway and 897 were referred to the ASD pathway. The mean *did not attend* (DNA) rate for the service is approximately 10%. Often families and young people will request that they are not discharged from the service due to limited provision for young adults; currently approximately 325 young people eligible for transition to adult services are still under review by a paediatrician and a further 100 young people will reach transitional age in the next 12-24 months.

Data is also included in the full report to give an indication of prescribing, primary care access, hospital admissions and school provision for adults and children with neurodevelopmental conditions.

INTERVENTIONS

Studies which have compared treatment for ADHD versus no treatment suggest that treatment can indeed make a difference to number of areas in an individual's life including service use, academic attainment, antisocial behaviour, self-esteem and social functioning. The available evidence on interventions for ADHD suggests that combination treatment is an effective approach in the treatment of ADHD. Combination treatment involves applying different treatments together for each client; for example stimulant medication and Cognitive Behavioural Therapy (CBT). The evidence suggests that these approaches yield the largest improvements in symptoms and outcomes in both the short term. However, further research is needed to examine the longer term outcomes of this approach as well as its role in tackling specific outcomes.

There is currently no medical treatment for the core functions of ASD (although some medications alleviate certain aspects of mood and behaviour) and so interventions are the primary source of treatment and these are frequently delivered through families or the education system. The two most common types of interventions are focused interventions designed to produce a certain behavioural outcome and comprehensive treatment models designed to achieve broader impacts on the core

symptoms of ASD. No single intervention has been identified which is effective for every individual and the most effective treatment may involve a combination of several approaches. The quality of evidence for interventions beyond pharmacological treatment and CBT is limited. Some interventions such as Treatment and Education of Autistic and Communication Handicapped Children (TEACHH), Early Intensive Behavioural Intervention, Milieu Training, Picture Exchange and Social Skills Groups show promising evidence of effectiveness.

The lifetime cost of ADHD is estimated at £102,135.89 including education, healthcare and employment costs. The lifetime cost of ASD is estimate at £0.8 million including health and wider social care costs.

RECOMMENDATIONS

1. Ensure that children, young people and adults with neurodevelopmental conditions and their parents/partners are regularly consulted during the development of neurodevelopmental services and that their feedback is incorporated into any changes in provision.

DIAGNOSIS

2. Some adults with ADHD will remain undiagnosed through childhood and into adult life. The 2014 Adult Psychiatric Morbidity Survey suggests that up to 9.7% of the adult population screen positive for at least four of six ADHD characteristics. It is therefore vital that services such as primary care are able to recognise the symptoms of ADHD in adults. In addition, screening in certain settings where ADHD populations are higher such as psychiatric outpatient clinics and the criminal justice system may be beneficial in identifying undiagnosed ADHD.
3. ASD and ADHD in Liverpool remain more common among males than females, and there is some evidence to suggest that this may be due to more recognisable symptoms among males and perceptions that these are male conditions, leading to misdiagnosis in females. It is therefore important that all aspects of the neurodevelopmental pathway reflect all genders. For example, education and awareness raising materials that feature both genders and reflect the different ways in which symptoms can be visible among males and females, and equal provision of screening and support for females.
4. ASD and ADHD appears to be associated with deprivation and the socio-economic environment. Consider staggering awareness raising of the conditions and shared care in primary care by first targeting staff working in areas of higher deprivation.

COMORBIDITY

5. Children and adults with ADHD and ASD experience higher comorbidity with a wide range of physical and mental health conditions including conduct disorder and learning disability. This highlights the importance of shared care and partnership working not only across the neurodevelopmental pathway but with wider primary and specialist healthcare providers. In addition, it is important that GPs are participating in shared care for clients with ADHD and ASD and are competent in recognising symptoms amongst those presenting to primary care with other conditions.

TRANSITIONS

6. The neurodevelopmental pathway must take a life course approach and recognise the importance of key transitions for children and adults with ADHD and ASD. Key transitions are:

6a) Transition to adult services: ASD is a lifelong condition. Evidence suggests that around 65% of children with ADHD will have symptoms which persist into adulthood and a least 37% will need continued specialist mental health support after leaving paediatric services. Transition to adult services is therefore a key time in the lives of young people and it is vital that they have a smooth and prompt referral to adult care. This transition needs to allow for the continuation of their current care and link to support for wider issues in adult life such as employment, housing, and substance misuse.

6b) Transition to secondary education: the transition from primary to secondary education was described by stakeholders as a key time for young people with ADHD and ASD particularly those with mild/high functioning symptoms who do not attend regular outpatient reviews. These young people may experience difficulties in self-regulating and managing their condition during the transition to secondary education. It is important that schools have strong links with specialist services to enable young people to access the support they need.

6c) Transition to higher education: a high proportion of young people with ASD and ADHD leave school without any qualifications. However, some individuals including those with high functioning ASD have clear post-secondary education goals which are often hindered by a range of factors including social support needs, confidence and accommodation concerns. Ensure that young people who are transitioning to adult care have appropriate post-secondary education support by building strong links with University and FE college disability support and outreach services.

OUTCOMES

7. There is a lack of evidence on the wider health and social outcomes experienced by adults with ADHD and ASD. It is therefore important that neurodevelopmental services routinely monitor outcomes including but not limited to: substance misuse, smoking, educational attainment, housing and employment, to allow for more efficient allocation of resources, services and interventions which accurately reflect the population's need.
8. Evidence suggests higher levels of risk behaviours among adolescents and young adults with ADHD including substance and alcohol misuse, risky sexual behaviour, self-harm and smoking. Substance misuse and sexual health services are therefore key services in which to raise awareness of ADHD among staff and implement screening.
9. There is evidence to suggest that adults with ADHD are at increased risk of harm due to impaired driving experience. Awareness raising among driving instruction companies may therefore be beneficial. In addition, A&E presentations for repeat road traffic collisions (RTCs) and driving related incidents may be another key opportunity to screen for ADHD.
10. Improve employer awareness to support people with ADHD and autism in the workplace. Use simple adjustments like making job interviews more accessible and providing assistance to understand the 'unwritten rules' of the workplace.
11. Provide training for those who work in the criminal justice system including police, court and custody suite staff on recognising, approaching, communicating and interviewing/questioning those with ADHD and autism and strengthen collaboration between health and social care providers and partners.

12. Implement school awareness raising for students, staff and parents about living with ADHD and ASD to reduce the stigmatisation and bullying associated with both conditions. This could include a peer-led element.

SERVICE PROVISION

13. Consider the development of a single neurodevelopmental pathway for adults with ADHD and ASD. The pathway should either be combined with the current children's pathway or have well established transition procedures for young people moving between the two pathways. The pathway should combine medical treatment and psychological support with wider social support services to provide a model which supports individuals with neurodevelopmental conditions across all the wider determinants of health. This can be achieved by establishing shared care arrangements between NHS specialist services, primary care and third sector support services.
14. The neurodevelopmental pathway must reflect the complex and non-linear nature of progression through neurodevelopmental services and allow for multiple contacts in varying time periods. Whilst some individuals may be ready to reduce the level of NHS outpatient care received, the pathway must allow individuals to move back and forth between stages at times of need for example: the key transition periods discussed above.
15. Stakeholder feedback and service data suggest that current staffing levels in many services are insufficient resulting in longer waiting times. The development of the neurodevelopmental pathway should include a full review of the staffing and capacity of all services involved to identify areas of workforce need and both existing arrangements and future opportunities for sharing of resources and partnership working.
16. Reconsider the use of the term "discharge" as this is creating anxiety for clients who think they will not be able to re-access services should they need them. By developing two linked pathways for adults and children across the lifespan which combine outpatient, primary and third sector care, clients will be able to access a level of support which is appropriate for their current needs but still feel secure that they can access additional or different support should they require it. One example of this is the "step-down" phone clinic provided by one service once clients stop accessing face-to-face support.
17. Consider strategies to improve DNA rates across all services to ensure maximisation of resources for services working to capacity. A review of the reasons why clients DNA appointments could be used to develop a strategy for improving attendance e.g. text message/ email reminders. Strategies must reflect the needs of clients with ADHD/ASD.

INTERVENTIONS

18. Evidence suggests that a combination approach which brings together stimulant treatment (where needed) and psychosocial interventions (such as CBT) are effective in improving both health and wider outcomes for individuals with ADHD. Liverpool CCG should consider developing a pathway which incorporates interventions across the pharmacological and psychosocial approaches.
19. The evidence on interventions to improve outcomes for individuals with ASD is mixed and the quality of evidence for interventions beyond pharmacological treatment and CBT is limited. Some interventions such as TEACHH, Early Intensive Behavioural Intervention, Milieu Training, Picture Exchange and Social Skills Groups show promising evidence of effectiveness. Where these interventions are already implemented, thorough evaluation should be implemented to allow decisions to be made about the effectiveness of these interventions locally over time. Similarly,

where new interventions are being piloted, thorough evaluation of both the process and outcomes should be implemented from the outset to inform future service development.

20. Continue to review the evidence on effective psycho-social interventions for ASD and ADHD as this evidence base develops, particularly for adolescents and adults.

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1. INTRODUCTION AND METHODOLOGY

1.1 REPORT AIM

This report has been commissioned by Liverpool CCG to identify the current health needs and service provision for adults and children with neurodevelopmental conditions (including Attention Deficit Hyperactivity Disorder and Autistic Spectrum Disorders) in Liverpool. The findings from this report will be used to inform decisions relating to the commissioning and delivery of local services for individuals with neurodevelopmental conditions.

1.2 DEFINITIONS

Children and young people with neurodevelopmental impairments and conditions are the largest group of disabled children and young people in the UK and the estimated prevalence is between 3-4% of all children in England. Attention Deficit Hyperactivity Disorder (ADHD) is the most common neurodevelopmental condition in the UK affecting 1-2% of children and young people (measured against the narrower ICD-10 criteria; although some estimates suggest this is higher, see section 3 below) and autism spectrum disorder is thought to affect 1% of children and young people in the UK [8].

Neurodevelopmental disorders: The World Health Organisation define neurodevelopmental disorders as disabilities in the functioning of the brain that affect a child's behaviour, memory or ability to learn e.g. dyslexia, attention deficit hyperactivity disorder (ADHD), learning deficits, intellectual disability and autism. Children with neurodevelopmental disorders can experience difficulties with learning, memory, behaviour, speech and language, motor skills and other neurological functions. The symptoms and behaviours of neurodevelopmental disabilities often evolve and change as a child grows older but some disabilities are permanent.

Attention Deficit Hyperactivity Disorder (ADHD): is a neurobiological disorder caused by an imbalance of some of the norepinephrine and dopamine neurotransmitters found in the brain. People with ADHD have significant difficulties in areas such as attention, over activity and impulsiveness. There are three main types of ADHD namely: predominantly inattentive, predominantly hyperactive-impulsive and combined (both inattentive and hyperactive-impulsive). ADHD is common in people with autism. ADHD is also sometimes referred to as attention deficit disorder or hyperkinetic disorder [3, 4].

Autism: is a lifelong developmental disability which affects how individuals communicate and relate to others and how they experience the world around them. Autism is a spectrum disorder, so whilst all people with autism will share certain difficulties, the ways in which their condition affects them will be different; some people with autism are able to live relatively independent lives whilst others will require specialist support [4].

Asperger Syndrome: is a form of autism. People with Asperger Syndrome have difficulties in three main areas (referred to as the triad of impairments): social communication, social interaction and social imagination. People with Asperger Syndrome have fewer problems with speech than those with autism and are often of average or above average intelligence. People with Asperger Syndrome do not generally have learning disabilities which are associated with autism but may have specific learning difficulties such as dyslexia, dyspraxia or conditions such as ADHD [4].

AUTISM SPECTRUM DISORDER

THE AUTISM ACT [9]

“An Act to make provision about meeting the needs of adults with autistic spectrum conditions; and for connected purposes”

The Autism Act was the first to specifically consider the needs of adults with autism. The Act stated that the Secretary of State must prepare and publish an “autism strategy” for meeting the needs and improving NHS and Local Authority provision for adults with autism and that the strategy must be kept under review and revised as necessary. In addition, the Secretary of State was also required to issue guidance to Local Authorities, NHS Bodies and NHS Trusts about the exercise of their functions concerned with the provision of relevant services and both Local Authorities and NHS Bodies and Trusts were obliged to act upon this guidance according to the Local Authority Social Services Act (1970).

THINK AUTISM, THE AUTISM STRATEGY [10]

“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.” (p.4)

The latest Autism Strategy, published in 2014, builds upon the previous **Fulfilling and Rewarding Lives strategy (2010)**[11]. The new strategy has been updated to reflect and take stock on the work that has been done towards the previous strategy. It thus meets the requirements of the **Autism Act (2009)**[9] to review the previous strategy and also reflects the widespread transformation of public services which has happened since the publication of the 2010 strategy. The strategy identifies 15 priority challenges for action identified by people with autism, their carers and professionals who work with them.

An equal part in my local community

1. I want to be accepted as who I am within my local community. I want people and organisations in my community to have opportunities to raise their awareness and acceptance of autism.
2. I want my views and aspirations to be taken into account when decisions are made in my local area. I want to know whether my local area is doing as well as others.
3. I want to know how to connect with other people. I want to be able to find local autism peer groups, family groups and low level support.
4. I want the everyday services that I come into contact with to know how to make reasonable adjustments to include me and accept me as I am. I want the staff who work in them to be aware and accepting of autism.
5. I want to be safe in my community and free from the risk of discrimination, hate crime and abuse.
6. I want to be seen as me and for my gender, sexual orientation and race to be taken into account.

The right support at the right time during my lifetime

7. I want a timely diagnosis from a trained professional. I want relevant information and support throughout the diagnostic process.
8. I want autism to be included in local strategic needs assessments so that person centred local health, care and support services, based on good information about local needs, is available for people with autism.

9. I want staff in health and social care services to understand that I have autism and how this affects me.
10. I want to know that my family can get help and support when they need it.
11. I want services and commissioners to understand how my autism affects me differently through my life. I want to be supported through big life changes such as transition from school, getting older or when a person close to me dies.
12. I want people to recognise my autism and adapt the support they give me if I have additional needs such as a mental health problem, a learning disability or if I sometimes communicate through behaviours which others may find challenging.
13. If I break the law, I want the criminal justice system to think about autism and to know how to work well with other services.

Developing my skills and independence and working to the best of my ability

14. I want the same opportunities as everyone else to enhance my skills, to be empowered by services and to be as independent as possible.
15. I want support to get a job and support from my employer to help me keep it.

STATUTORY GUIDANCE FOR LOCAL AUTHORITIES AND NHS ORGANISATIONS TO SUPPORT THE IMPLEMENTATION OF THE ADULT AUTISM STRATEGY [12]

The Department of Health published this statutory guidance in 2015 to secure the implementation of the updated *Think Autism* strategy by giving guidance to local authorities, NHS foundation trusts and NHS bodies. The guidance focuses on nine key areas, namely: Training staff that provide services to adults with autism; identification, diagnosis and assessment of autism in adults; planning of service provision as people with autism transition from child to adult services; local planning and leadership in relation to the provision of services for adults with autism; preventative support and safeguarding; reasonable adjustments and equality; supporting people with complex needs; employment for adults with autism; and working with the criminal justice system. Progress against these outcomes is measured through the autism self-assessment framework with the third self-assessment exercise taking place in 2014/15.

There are a range of recommendations which should be undertaken by Local Authorities, NHS Bodies and NHS Foundation trusts in collaboration. The guidance also identifies a number of guidelines specifically for Clinical Commissioning Groups (CCG) including workforce planning and training, establishing, maintaining and promoting local autism diagnostic pathways, working with local authorities to ensure the health provision set out in Education, Health and Care (EHC) plans and ensuring equal access and awareness among wider providers including GPs, psychological therapy services, occupational health and prison services.

NICE GUIDANCE: AUTISM IN UNDER 19S: RECOGNITION, REFERRAL AND DIAGNOSIS: CG128 (NICE, 2011)

The NICE 2011 guideline [13] outlined a number of key priorities for implementation:

Local autism pathway

Firstly, a local autism multi-agency strategy should appoint a lead professional who is responsible for a local autism pathway for the recognition, referral and diagnosis of children and young people. The group should be responsible for raising multi-agency awareness of the symptoms of autism, developing the local pathway and diagnostic services and improving early recognition. The group should also support the smooth transition from the pathway to adult services and robust data collection and audit of the pathway. Each area should also have an autism team with a single point of referral which should include a paediatrician and/or child and adolescent psychiatrist, a speech and language therapist, a clinical/educational psychologist and an occupational therapist as well as any other professionals who contribute to autism diagnostic assessment.

Autism diagnostic assessment for children and young people

Secondly, each child having a diagnostic assessment should have a case coordinator and each assessment should include: questions about the parent/carers and child/young person's concerns; details of their home life, education and social care; a developmental history; assessment of social and communication skills/behaviours (through interaction and observation); medical history; physical examination; consideration of differential diagnosis; and assessment for co-existing conditions and development of a profile of their strengths, skills and impairments to inform a needs-based management plan. The assessment findings should be communicated to parent/carer and also to the child/young person where appropriate. With consent from parent/carers and child/young person the profile can also be made available to professionals in education and social care.

NICE QUALITY STANDARD FOR AUTISM (NICE, 2014)

In 2014, NICE published a quality standard for autism in children, young people and adult's health for consideration by health and social care services [14]. The aim of NICE quality standards is to set out a list of prioritised statements against which quality improvements can be measured; in this case eight quality statements were identified:

Statement 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.

Statement 2: People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.

Statement 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.

Statement 4: People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.

Statement 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.

Statement 6: People with autism are not prescribed medication to address the core features of autism.

Statement 7: People with autism who develop behaviour that challenges are assessed for possible triggers, including physical health conditions, mental health problems and environmental factors.

Statement 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.

ADHD

ATTENTION DEFICIT HYPERACTIVITY DISORDER: DIAGNOSIS AND MANAGEMENT: CG72 (NICE, 2008)

The NICE guidance on ADHD sets out recommendations concerning both the diagnosis and the treatment of ADHD in children, young people and adults [15].

Principles of diagnosis

Diagnosis should be based on a clinical and psychosocial assessment, which includes a full developmental and psychiatric history and observer reports, and is carried out by a specialist paediatrician, psychiatrist or other appropriately qualified healthcare professional. This assessment should include assessment of the patient's needs, coexisting conditions, social, familial and educational or occupation circumstances and physical health.

Treatment recommendations

Post diagnostic advice for patients should include general tips, for example dietary advice and behavioural techniques. Drug treatment should always be part of a comprehensive treatment plan which also includes psychological, behavioural and educational advice and interventions. All patients should have a full pre-treatment assessment and the choice of drug should take into account the patient's age, comorbidities, response to previous drug therapy, availability and the risk of stimulant misuse or diversion. A range of comprehensive treatment recommendations for children, young people and adults are briefly detailed below:

- **School-age children and young people with ADHD and moderate impairment:** drug treatment is not recommended as first line treatment unless the individual is unwilling to undergo non-drug interventions or symptoms persist after parent training programmes.
- **School aged children and young people with severe ADHD (hyperkinetic disorder) and severe impairment:** drug treatment should be recommended as first line treatment and parents should also be offered group based training.
- **Transition to adult services:** adolescents receiving ADHD treatment should be reassessed at school-leaving age. Following transition to adult services, young people should be assessed for personal, social, occupations and educational functioning and co-existing conditions such as drug misuse of emotional, personality or learning problems.
- **Adults with ADHD:** drug treatment should be the first-line therapy unless a psychological approach is preferred. Drug treatment should be part of a comprehensive programme to address psychological, behavioural and occupational needs.

NICE QUALITY STANDARD FOR ADHD: QS39[16]

The Quality Statement covers the diagnosis and management of ADHD in children (aged 3 years and over), young people and adults. The NICE quality standards provide a list of prioritised statements against which quality improvements can be measured; in this case seven quality statements have been identified:

Statement 1: Children and young people with symptoms of attention deficit hyperactivity disorder (ADHD) are referred to an ADHD specialist for assessment.

Statement 2: Adults who present with symptoms of attention deficit hyperactivity disorder (ADHD), who do not have a childhood diagnosis of ADHD, are referred to an ADHD specialist for assessment.

Statement 3: Adults who were diagnosed with and treated for attention deficit hyperactivity disorder (ADHD) as children or young people and present with symptoms of continuing ADHD are referred to general adult psychiatric services.

Statement 4: Parents or carers of children with symptoms of attention deficit hyperactivity disorder (ADHD) who meet the NICE eligibility criteria are offered a referral to a parent training programme.

Statement 5: Children and young people with moderate attention deficit hyperactivity disorder (ADHD) are offered a referral to a psychological group treatment programme.

Statement 6: People with attention deficit hyperactivity disorder (ADHD) who are starting drug treatment have their initial drug dose adjusted and response assessed by an ADHD specialist.

Statement 7: People with attention deficit hyperactivity disorder (ADHD) who are taking drug treatment have a specialist review at least annually to assess their need for continued treatment.

1.3 METHODOLOGY

The rapid needs assessment involved three stages: a literature review of published and grey evidence on the outcomes and existing interventions for adults and children with neurodevelopmental conditions; a desktop study of national and local data sources and a service audit with stakeholders involved in the provision of neurodevelopmental services. The rationale and details of the data collection methods are outlined in greater detail below:

LITERATURE REVIEW

The first stage of this needs assessment involved undertaking a review of all relevant literature, including academic peer reviewed journals and grey literature. The review considered literature on adults and children with ADHD and ASD, and focused specifically on: health and wider social needs and outcomes; interventions to improve these health and social outcomes and the cost effectiveness of these interventions. The search focused mainly on evidence from the UK, Western Europe, North America and Oceania. In general, only literature published after 2000 was included. The review covered all age groups and considered interventions which had short and long term impacts on behaviour.

DESKTOP STUDY

Anonymised, aggregated data on adults and children with neurodevelopmental conditions was provided by Liverpool CCG and a range of local services. Four local services (ADHD Foundation, Alder Hey NHS Hospital Trust, Cheshire and Wirral Partnership NHS Trust and Liverpool Adult ADHD – Ladders of Life) provided data on service provision. Additional data were provided by Liverpool CCG on primary care provision, hospital admissions, school provisions and sensory integration therapy. Prescription data was accessed from the Health and Social Care Information Centre. This was collated along with nationally available data to identify the size and characteristics of the population and establish their health and wider social needs as well as quantifying current service provision. Data shared were aggregated and non-patient identifiable and stored securely in accordance with Public Health Institute (PHI) policy.

SERVICE AUDIT

A service audit of key providers involved in the provision of services for adults and children with neurodevelopmental disorders was undertaken. The aim of the audit was to find out more about each service and professional stakeholders views on their provision for this population in Liverpool.

Health care professionals and other service providers from both NHS and third sector organisations involved in current provision were identified by the lead commissioner of neurodevelopmental services at Liverpool CCG. They included: NHS Cheshire and Wirral Partnership ADHD team, Mersey Care NHS Trust Asperger's and Learning Disability Team, Liverpool Community Health Speech and Language Therapy and ASD Teams, Alder Hey NHS Trust ASD team and third sector organisations: ADDvanced Solutions, ADHD Foundation and Liverpool Adult ADHD - Ladders of Life. In total 17 individuals were invited to participate in a service audit interview of which nine accepted.

Participant contact details were provided by the lead commissioner. The commissioner was initially provided with a participant information sheet and asked to complete a gatekeeper consent form before providing contact details for all potential participants via introductory emails. An email invitation to partake in a short, semi-structured telephone interview was then sent by the PHI research team to each potential participant outlining the purpose of the study and providing them with a participant information sheet and a consent form. Interested participants were contacted to arrange a time and date for interview.

Nine telephone interviews were carried out by the PHI Telephone team and authors between June and October 2016. Consent was verbally confirmed. The semi-structured interviews discussed the main aspects of each service and stakeholder's perspectives on key issues relating to provision including: demand, capacity, waiting times, discharge from services and shared care arrangements. All interviews were recorded and transcribed verbatim.

Analysis

Manual thematic analysis was undertaken. Transcripts were coded into units, similar units were identified and categorised into broader themes. A profile was constructed for each service. The main themes that emerged revolved around demand for the service, wait times and discharge from the service. Illustrative verbatim quotations are used to support the analysis.

2. RISK FACTORS FOR NEURODEVELOPMENTAL CONDITIONS

2.1 RISK FACTORS FOR ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)

The aetiology of ADHD involves multiple genetic and environmental factors and while ADHD is viewed as a heterogeneous condition, there are different subtypes which result from the interplay of different combinations of these risk factors. It is important to acknowledge that genes and the environment do not work independent of one another; rather inherited genetic risks are also likely to increase the likelihood of exposure and sensitivity to environmental risks. Similarly, environmental factors can also impact on development through epigenetics (by influencing how genes are expressed) and these epigenetic effects can be transmitted and reversed across generations [17].

GENETIC INFLUENCES

There is evidence to suggest that ADHD does run in families with first degree relatives (i.e. parents, children, siblings) of those with ADHD showing higher rates of the disorder (4 to 5 times increased odds) [18]. No single gene has been identified as having a large effect on ADHD; instead there are several DNA variants with a small effect which each increase the susceptibility of ADHD by a small amount [19]. Twin studies estimate that the mean heritability of ADHD is between 0.6 and 0.91 meaning that approximately 60-91% of the variation of ADHD symptoms in the population is due to genetic factors [20, 21],[18, 22]. This is similar to other neuropsychiatric disorders such as bipolar disorder and schizophrenia [21]. Compared to other psychiatric disorders, there is a fairly substantial body of early candidate gene studies (including dopamine D4, dopamine receptor DRD5, SNAP-25)[18] which have either been replicated or show association in meta and pooled analysis studies suggesting that genetic factors are important in the aetiology of ADHD. However, the size of risk identified in these studies is small and so they do not identify a predictive value or any novel biological mechanisms [17]. Similarly, there have been no genome-wide association studies of sufficient size to identify common genetic variants of ADHD [17]. The absence of this evidence has led to some critics to question whether ADHD should be a categorically defined medical disorder or whether it should be considered a part of normal variation. Given the small predictive value of the associated genes, genetic susceptibility testing for ADHD is not done in clinical practice[19].



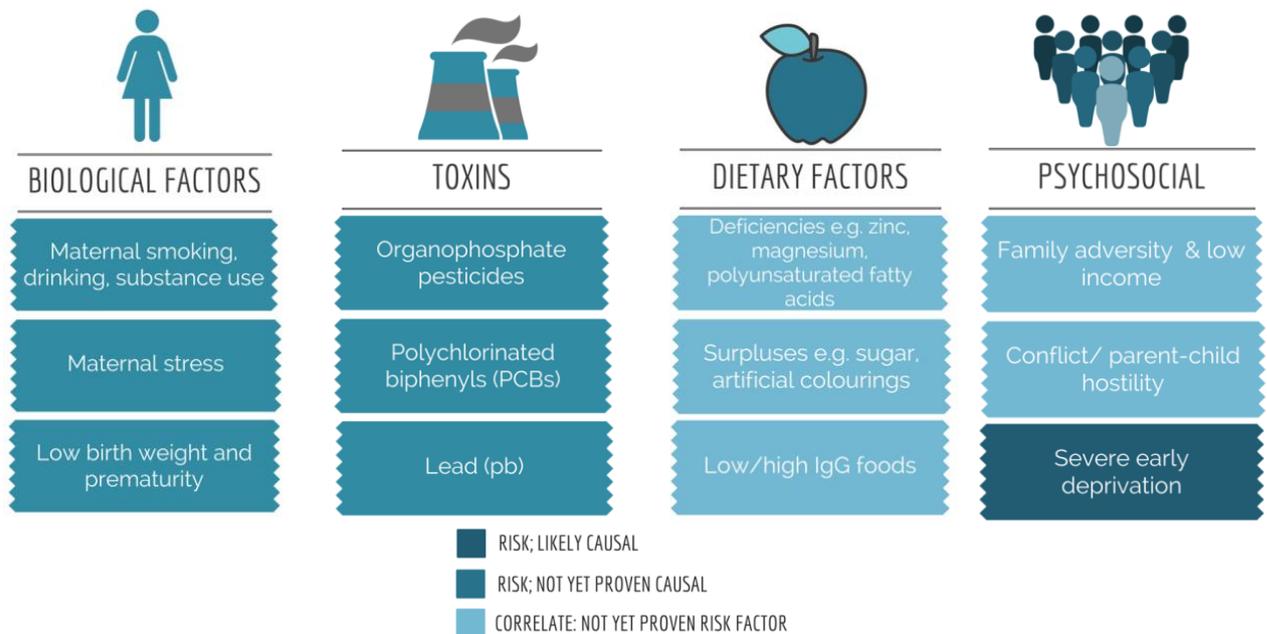
0.6-0.91

mean heritability of ADHD

ENVIRONMENTAL FACTORS

A range of biological, dietary and psychological factors have been associated with ADHD [19] but it is difficult to identify which factors are causal and for ADHD this evidence is largely lacking. Table 1 provides a summary of the risk factors most commonly studied in relation to ADHD and the level of evidence available.

Table 1: Environmental factors most commonly studied in relation to ADHD



Source: adapted from Thapar et al, 2013 [17].

BIOLOGICAL RISKS

One of the most commonly studied pre and perinatal risk factors for ADHD is maternal smoking during pregnancy with systematic reviews suggesting an odds ratio of 2.36 [23] and studies suggest a dose-response relationship with ADHD risk increasing with the amount smoked [22, 24]. Exposure to other substances have also been found to be associated with ADHD in some (but not all) studies including foetal alcohol syndrome, moderate alcohol use during pregnancy and exposure to illicit substances [17]. A small number of studies have also been published exploring the role of prenatal caffeine exposure and prenatal exposure to antihypertensive (labetalol) antidepressants (bupropion). While some studies have identified significant associations the results are mixed and the methodological limitations of these studies mean it remains an area for further investigation [22].

ADHD has also been associated with maternal stress and while there are plausible biological mechanisms through which these risks could lead to ADHD there is no clear evidence to say that this relationship is causal. Genetically sensitive studies (for example where a mother has smoked during one of two pregnancies or where the child has been conceived with assistance and remains unrelated to the mother [25, 26]) suggest that the associations between maternal stress, smoking and ADHD are at least partially due to confounding genetic or household factors.

Low birth weight and prematurity has also been significantly associated with ADHD and inattentive subtype ADHD in particular with an odds ratio of 2.6 for low birth weight [27]. However, once again there is a lack of evidence to suggest that these relationships are causal and only a very small proportion of individuals with ADHD were born prematurely or at a low birth weight.

TOXINS

Exposure during prenatal and postnatal life to certain pollutants has also been considered as a risk factor for ADHD. The most widely studied is organophosphate pesticides with one cross sectional study finding that children and adolescents with above median metabolite concentrations had double the odds of ADHD compared with those with untraceable levels [28]. Secondly, polychlorinated biphenyls (PCBs) have also been studied in relation to ADHD. PCBs were once mass-produced for a

variety of industrial and commercial uses including cooling and cutting fluids. Production has now been banned but they still remain as an environmental contaminant for example through waste water discharges. Studies in humans and animals have found that PCB leads to impairments comparable to those seen in ADHD including impairments in memory, cognitive flexibility and response inhibition [29-31]. Lastly, exposure to lead even at low levels can also lead to cognitive effects which are relevant to ADHD including alertness, vigilance and cognitive flexibility as well as wider effects on neurodevelopment and cognitive function [17].

DIETARY FACTORS

The influence of dietary factors in ADHD has attracted a great deal of attention in the media and public domain and diets which eliminate sugar, additives, food colourings and E numbers are a widely used intervention, often implemented without medical advice. There is some research which demonstrates a link between additives and preservatives in the diet and levels of hyperactivity in a small proportion of children [32] but there is insufficient evidence of a causal relationship. An English study by McCann et al [33] of 297 children found that food colour additives and preservatives were significantly associated with more ADHD symptoms in children with specific genetic polymorphisms.

The US Food and Drug Administration review [34] concluded that exposure to colourings and preservatives may be associated with adverse behaviours in certain susceptible children but this was not considered sufficient to place warnings on foods containing these ingredients [22]. Similarly, supplementary diets have also been used as an intervention for ADHD and there has been some research into nutritional deficiencies and ADHD including magnesium [35], zinc [36] and polyunsaturated fats [37].

PSYCHOSOCIAL FACTORS

Psychosocial factors, including family adversity and low income, have been found to be associated with a number of childhood mental health problems; including ADHD. Children who suffer maltreatment also show a high incidence of ADHD. However, it is difficult to identify in which direction there is a relationship between ADHD and these psychosocial factors; for example families with ADHD are more likely to be in conflict but it is not clear whether this is a cause of ADHD or occurs as a consequence of it. Some studies of mother and son hostility suggest that ADHD symptoms impact on this hostility and studies which have examined the impact of stimulant medication suggest this improves not only ADHD symptoms but also mother and child relationships [17, 38]. The available evidence does seem to suggest that ADHD symptoms contribute to family conflict but there is some evidence to suggest that, while these psychosocial factors are not causal in ADHD onset, they may still modify ADHD presentation and result in adverse secondary consequences such as antisocial behaviour [39].

The impact of severe deprivation in early life is considered to be a likely causal risk factor for ADHD; a quasi-experimental study of English and Romanian adoptees examined the impact of exposure to extreme early deprivation among adopted away children and found that this early deprivation can result in ADHD-type symptoms as well as quasi-autistic symptoms [40, 41]. However, exposure to this kind of adversity is likely to be rare among the ADHD population as a whole and there is no evidence which examines the role of milder forms of early adversity [17].

2.1 RISK FACTORS FOR AUTISTIC SPECTRUM DISORDER

ASD is recognised as a heterogeneous disorder. The aetiology of ASD is known to be highly genetic, although genetics cannot explain all forms of ASD, and the environment has also been found to play a part [42].

GENETIC INFLUENCES

There is a strong heritability of ASD; having a sibling with autism is the strongest predictor of autism, associated with a 22-fold increased risk [43]. The same Swedish study found relative risk of ASD was about twice as high if the mother had been diagnosed with a psychiatric disorder.

Although research has recognised many genes that are linked with ASD but no single variant gene has been identified causing researchers to conclude autism is not a single clinical entity but a behavioural manifestation of tens or maybe hundreds of genetic and genomic disorders [44]

ENVIRONMENTAL INFLUENCES

Research has suggested that although genetics are part of the aetiology of ASD, it is thought that this is influenced by multiple factors including the environment. Although research has identified a number of environmental risk factors such as drugs and both physical and psychological factors, it has been suggested that key factors may still remain unidentified [45].

Higher maternal and paternal age appear to be associated with increased risk of a child being diagnosed with ASD [46], however the quality of the evidence is low and further research is needed [47].

A systematic review and meta-analysis in 2016 [48] found an increased risk of ASD with increasing exposure to air pollution in early life, although not consistently across all chemical components. The strongest evidence was between prenatal exposure to particulate matter and ASD, however further research is needed. Many studies have found no link between maternal smoking or alcohol use and ASD, though more rigorous studies are needed [49].

A cohort study conducted by Larsson et al (2009) [50] suggested that maternal smoking, condensation on windows; a proxy for low ventilation rate in the home, PVC flooring especially in the parents' bedroom to all be significantly associated with ASD diagnosis. In addition airways symptoms of wheezing and physician-diagnosed asthma in the baseline investigation were associated with ASD 5 years later. ASD was also associated with economic problems in the family. These variables warrant more extensive further investigation.

Researchers have also tried to understand why ASD is more common in males and some have argued that this is due to foetal testosterone and typical sex differences between brain structures, however, this may be more likely due to increased recognition in males [51]. Further research is also needed on this topic.

Despite the media coverage in the late 1990s of the Wakefield et al study linking the MMR vaccine and autism [52], numerous studies have found no link between MMR imitation and ASD [53].

3. PREVALENCE OF NEURODEVELOPMENTAL CONDITIONS

3.1 ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD) PREVALENCE

Attention Deficit Hyperactivity Disorder is most frequently diagnosed among children aged 3-7 years but in some cases it may not be recognised until much later in life and sometimes not until adulthood [14]. ADHD is more common among boys and the diagnosed prevalence ratio of boys to girls ranges from 9:1 to 2.5:1 depending on the population studied [14]. It is suggested that this skewed prevalence could be due to more commonly recognised symptoms in boys such as hyperactivity and impulsivity whilst girls with ADHD more commonly have inattentive symptoms which are less disruptive and so can remain undiagnosed. ADHD in girls is associated with more severe cognitive and language problems and greater social problems [3].

ADHD is a strongly genetic condition with a 30-40% chance that the sibling of a child with ADHD will also have the disorder. Despite ADHD being perceived as a largely childhood disorder, research suggests that approximately 65% of children diagnosed with ADHD continue to experience symptoms in adulthood. A national survey of paediatricians and child psychologists highlighted the impact of undiagnosed ADHD with 98% believing ADHD had a significant impact on children's academic progress, 97% stating that children with ADHD were more likely to drop out of school early when compared with their peers, 90% believing it had a serious impact on children's relationships leading to low self-esteem and exclusion and 85% believed that untreated childhood ADHD could lead to adult mental health problems such as depression and suicide [3].

Defining ADHD: International Classification of Diseases v 10 (ICD-10) versus Diagnostic and Statistical Manual V (DSM V) definition

There is no single, internationally agreed definition for ADHD; both clinicians and research studies tend to use either the ICD-10 criteria for hyperkinetic disorder or the DSM IV criteria for ADHD. However, the ICD-10 and DSM IV criteria for identifying ADHD have long been at odds with some commentators regarding the narrowly defined hyperkinetic disorder (HKD) identified by ICD-10 as more valid diagnostic criteria than the broader attention-deficit hyperactivity disorder (ADHD) used in DSM-V [5]. More recent editions of ICD-10 and DSM-V reflect an effort to harmonise the two terms with the type and number of symptoms required for a diagnosis specified on ICD for the first time; bringing it in line with DSM-V.

However, ICD-10 and DSM-V continue to differ in three ways: firstly ICD-10 requires that the full syndrome be evident in two independent situations (e.g. home and school) while DSM-V states that it must impede "social, academic or occupational functioning" in two or more situations. Secondly, ICD-10 defines it as a single disorder defined by symptoms of inattention, impulsiveness *and* hyperactivity whilst DSM-V allows for the diagnosis of "ADHD predominantly inattentive" and "ADHD predominantly hyperactive-impulsive" if only one of these symptoms is present. Thirdly, ICD-10 discourages multiple diagnoses and, with the exception of hyperkinetic conduct disorder, encourages the diagnosis of other disorders when present. In contrast, DSM-V allows, with a few exceptions, for multiple co-morbid diagnoses with ADHD.

As a consequence, the criteria result in different prevalence rates; with ADHD (DSM-V) twenty times more prevalent than HKD (ICD-10) and studies suggest that, whilst there is some crossover, the HKD diagnosed group have greater neurodevelopmental, academic and cognitive impairment and show greater response to stimulant medication than the ADHD group [5-7].

ADHD IN CHILDREN & YOUNG PEOPLE

Prevalence estimates of ADHD vary considerably depending on the measure used; based on the narrower ICD-10 criteria it is estimated that ADHD affects between 1-2% of children and young people in the UK, however when the broader DSM-V criteria is applied this rises to 3-9% of school aged children and young people in the UK. The NICE guidance on ADHD [19] uses pooled estimates from a number of studies to suggest that prevalence in the UK is around 2.4%.

Expected numbers of children with ADHD have been estimated by applying the prevalence rate of 2.4% reported by the NICE [19] to local populations. Figure 1 shows the numbers of children aged 0-19 years estimated to have ADHD in Liverpool, projected to 2025. In 2015, there were 2,506 children predicted to have ADHD. Numbers are set to rise slightly annually and by 2025, projections indicate that there will be 2,623 children with ADHD across Liverpool.

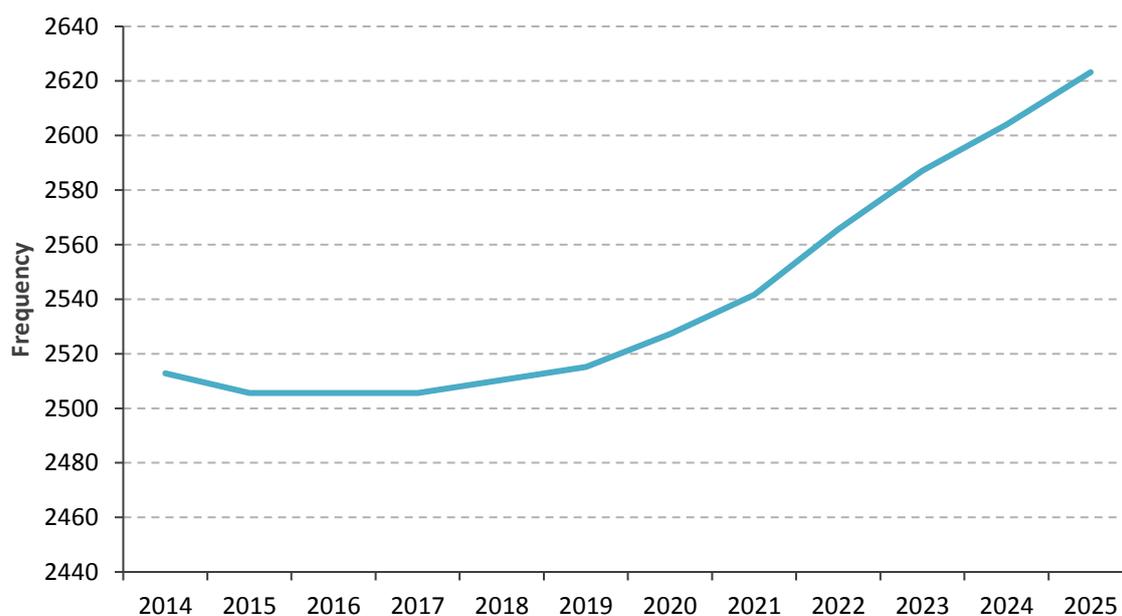


1.74%

hyperkinetic disorder in children

Prevalence of hyperkinetic disorder in children, Liverpool 2015

Figure 1: Projected estimates of numbers of children with ADHD, Liverpool 2014-2025.



Source: Based on 2.4% prevalence estimate applied to population projections (NICE)

Public Health England estimate that prevalence of hyperkinetic disorders among children aged 5-16 years in Liverpool in 2014 was 1.74%; higher than the England average (1.54%). Comorbidity of ADHD and conduct disorders is high; the estimated prevalence of conduct disorders among children aged 5-16 years in Liverpool in 2014 was 6.45% which was also higher than the national average (5.61%) [54].

It has been estimated that ADHD affects between two and four per cent of teenagers in the UK, with rates consistently higher in boys than girls [55]. Key symptoms of ADHD are inattention, impulsiveness and hyperactivity and these can have significant effects on young people's educational attainment, peer relationships, self-esteem and can contribute to youth offending. Table 2 demonstrates the higher rates of ADHD in young men [56], but in the absence of new representative surveys it is not possible to ascertain if there has been an increase in prevalence in recent years [55].

Table 2: Rates of hyperkinetic disorders in 11-16 year olds in Great Britain, by gender, 1999-2004

Young people aged 11-16 years	1999%	2004
Males	2.3%	2.6%
Females	0.5%	0.3%

Source: Green et al (2005), *Mental health of children and young people in Great Britain, 2004* [56]

Table 3 uses the prevalence estimates from Green et al [56] to give an indication of the number of children with ADHD at each age group. As previously discussed Table 3 highlights the higher numbers of boys with ADHD when compared to girls.

Table 3: Estimated number of children with hyperkinetic disorders by age group and sex, 2014¹

	Children (5-10 yrs)	Children (11-16 yrs)	Boys (5-10 yrs)	Boys (11-16 yrs)	Girls (5-10 yrs)	Girls (11-16 yrs)
NHS Liverpool	600	465	525	410	80	60

Source: CHIMAT CAHMS Needs Assessment (2015) based on Green, H. et al (2004). CCG population estimates aggregated from GP registered populations (Oct 2014).[56, 57]

ADHD IN ADULTS

Despite ADHD being perceived as a largely childhood disorder, research suggests that approximately 65% of children diagnosed with ADHD continue to experience symptoms in adulthood with 15% retaining the full ADHD diagnosis [32]. If these proportions are applied to the prevalence rates most commonly seen in children; it could be expected that between 0.6-1.2% of adults retain a full diagnosis by the age of 25 years with 2-4% of adults in partial remission [32]. These estimates are consistent with adult population surveys which place prevalence at between 3 and 4% [58, 59]. In addition, some adults with ADHD will remain undiagnosed during their childhood; one UK based study of five psychiatric outpatient clinics found just under 24% of undiagnosed adults screening positive for ADHD on the Adult ADHD self-report scale [60].

The 2014 Adult Psychiatric Morbidity Survey (APMS) used the Adult Self-Report Scale (ASRS) to screen for six ADHD characteristics among adults in the last six month. The survey found that 9.7% of the adult population in England reported 4 or more ADHD characteristics with 3% of adults reporting five characteristics of ADHD and 0.7% reporting all six characteristics. The survey found that prevalence of ADHD decreased with age with the highest proportion among 16-24 year olds, where 14.6% scored four or more on the APMS compared with 4.2% among those aged 75 years and over [61].

Public Health England has used the slightly lower prevalence rates from the 2007 APMS report [62] prevalence rate to produce adjusted estimates of the number of young people aged 16-24 with ADHD. In 2013, PHE estimated there were 10,891 young people aged 16-24 with ADHD in Liverpool [54].

3.2 AUTISTIC SPECTRUM DISORDER (ASD) PREVALENCE

In 2013 the American Psychological Association published the fifth edition of its Diagnostic and Statistical Manual for Mental Disorders (DSM-V) in which it drew together the various diagnoses of autism, autistic spectrum disorder and Asperger's under one umbrella diagnosis of "autistic spectrum disorder (ASD)". The defining characteristics of ASD are impairments of communication, social interaction and imagination and often a reliance on repetitive and habitual behaviours and activities.

¹ The figures in this table have been rounded to the nearest five so cannot be totalled.

The diagnosis has three levels of severity and there is an additional related diagnosis of social communication disorder [55, 63].

The UK, unlike the USA, does not have a single administrative resource or survey which can provide data on the number of adults and children living with ASD [8]. The National Autistic Society note several reasons for the lack of firm estimates of the number of people living with ASD. For example, some very able people with ASD may never come to the attention of services as having special needs, because they have learned strategies to overcome any difficulties with communication and social interaction and found fulfilling employment that suits their particular talents. Other people with ASD may be intellectually able, but have need of support from services, because the degree of impairment they have relating to social interaction hampers their chances of employment and achieving independence [64]. The European Commission in 2005 highlighted the problems associated with establishing prevalence rates for ASD[65]. These include inconsistencies of definition over time and between locations. Unlike learning disabilities, there is no register of ASD held by general practice. However, using data from prevalence studies, it is possible to estimate numbers and so a range of prevalence estimates and data sources have been included below to give an indication of the size of the population living with ASD in Liverpool.

DIAGNOSIS

Nationally, ASD prevalence is higher among men (1.8%) than women (0.2%; [62]) and the National Autistic Society notes the need for further exploration of how autism affects males and females differently. In a survey of around 3,000 people with autism and 5,500 carers, they found that it was more difficult for females to get a diagnosis and that females were more likely to be misdiagnosed; with only one fifth of females with Asperger Syndrome or high functioning autism diagnosed by age eleven compared with half of males. It is suggested that this discrepancy could be because autism is often viewed as a male condition [66].

The survey also found that overall, 55% of people with autism felt it took too long to get a diagnosis and found a lack of awareness amongst those making diagnostic referrals (GPs and health visitors). The survey also highlighted some key social issues for people with autism; 27% had been excluded from school (compared with 4% of children without autism) and 38% of adults still lived at home with their parents with just under half of this group (48%) saying they would like to live in their own home either with or without support.

NICE Guidance: Autism in Children (2014) [2]

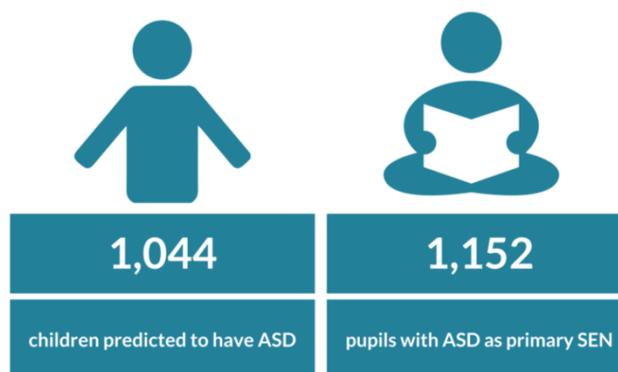
NICE guidance states that clinicians should suspect ASD in children if any of the following signs or symptoms are consistently present across different settings:

- Language delay, regression (pre-school children) or unusual characteristics (pre-school and primary school)
- Unusual or reduced communication behaviours (secondary school)
- A reduced, absent or negative response to others (pre-school and primary school)
- Reduced, absent or unusual social interaction with others
- Reduced non-verbal communication e.g. eye contact, pointing and other gestures (pre-school and primary school)
- Unusual or restricted interests and /or rigid and repetitive behaviours
- Reduced or absent ideas and imagination (primary school)

NICE: Autism in Children, 2014

ASD IN CHILDREN

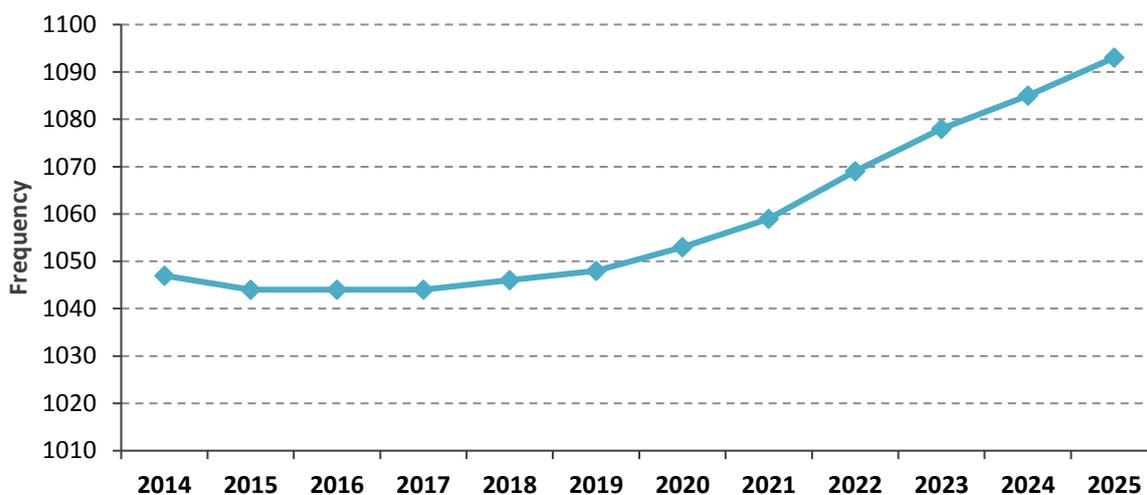
Whilst there is no single source of administrative data on the number of children with Autistic Spectrum Disorders nationally there are several sources of data which can give an indication of the size of this population. The only national survey with data related to ASD prevalence is a 2004 ONS Survey by Green et al which suggested that prevalence of ASD was approximately 1% [56]. Based on these figures, the National Autistic Society estimates there are approximately 133,500 young people (under 18 years) with ASD in the UK [55, 64].



Children with ASD, Liverpool 2015

Expected numbers of children with ASD have been estimated by applying the prevalence rate of 1% reported by the National Autistic Society [64] to local populations. Figure 2 shows the numbers of children aged 0-19 years estimated to have autism in Liverpool, projected to 2025. In 2015, there were 1,044 children predicted to have autism. Numbers are set to rise slightly annually and by 2025, projections indicate that there will be 1,093 children with ASD across Liverpool.

Figure 2: Projected estimates of numbers of children with ASD, Liverpool 2014-2025.



Source: Based on 1% prevalence (Green et al, 2005) [56] estimate applied to ONS 2012 population projections [67]

Data on the number of school pupils with statements or school action plus for ASD is recorded in the school census which is published in the special educational needs dataset by the Department of Education. Data from 2015 shows that there are 1,152 children with ASD as their primary special educational need in Liverpool representing just under one in ten of those with an SEN (Table 4). The rate of ASD among school age children is 1.65%, significantly higher than the rate for England (1.08%) [54]. In special schools, pupils with ASD as their primary SEN represent a higher proportion at one quarter (25%) of those with an SEN.

Table 4: Pupils with ASD as primary special educational need (SEN), 2015

	Number	% of all children with a statement of need	% of all school aged children
Special schools	322	25.3%	
State funded secondary schools	404	8.6%	1.65%
State funded primary schools	426	7.5%	
Total	1,152	9.9%	

Source: DofE, School Census Data, 2016 [68]

AGE

Public Health England have used data from age-specific cohort studies to estimate the numbers of children with ASD in certain age groups. A cohort study of 56,946 children in South East London estimated that the prevalence of ASD in children aged 9-10 years was 116.1 per 10,000 population (with the prevalence of autism estimated at 38.9 per 10,000 [69]. A survey by Baron Cohen et al (2009)[70] which combined the SEN register with a survey of school children aged 5-9 years found a combined prevalence for ASD of 157 per 10,000 with the ratio of known to unknown cases at 3:2. PHE have used these prevalence rates to estimate the number of children in Liverpool aged 5-9 years and 9-10 years with ASD; they estimate that there are 450 children with ASD aged 5-9 years and 130 children with ASD aged 9-10 years (table 5).

Table 5: Estimated number of children with autistic spectrum disorders by age group, Liverpool 2014

	ASD in children aged 5-9 years	Autism in children aged 9-10 years	Other ASDs in children aged 9-10 years	ASD (total) in children aged 9-10 years
NHS Liverpool CCG	450	45	85	130

Source: CHIMAT (2015) [57] based on Baird et al (2006) [69] and Baron-Cohen et al (2009) [70]. CCG population estimates aggregated from GP registered populations (Oct 2014).

ASD IN ADULTS

A review of the local authority autism self-assessment framework process in 2011 [71] identified major gaps in local information such as the number of people with autism, and what services they use. In the absence of known numbers, estimates can be calculated using the national morbidity survey on autism in adults. The survey found an ASD prevalence of 1.0% in the adult population [62] with a higher rate among men (1.8%) than among women (0.2%) in line with the profile found in childhood population studies.

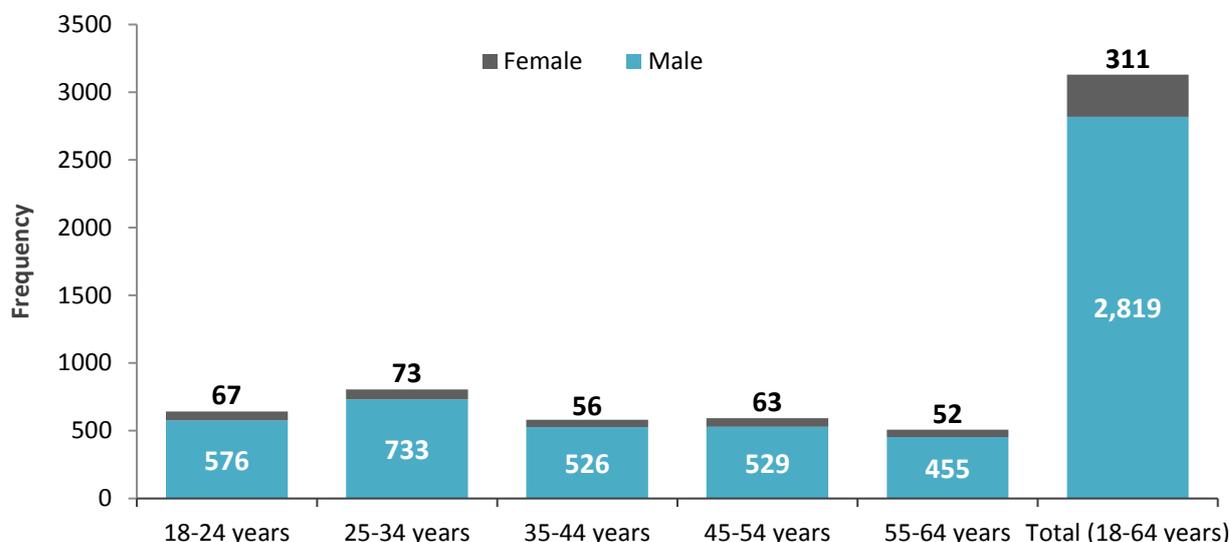
The Projecting Adult Needs and Service Information (PANSI)[72] database applies these prevalence rates to ONS male and female population estimates (18-64 years) to give the numbers expected to have autistic spectrum disorder. Figure 3 shows the expected prevalence of ASD amongst adults aged 18-64 across Liverpool, with 2,819 males and 311 females (3,130 in total). There are around 12 times more males than females expected to have autism.



Adults with Autistic Spectrum Disorder, Liverpool 2015

Figure 3: Males and females predicted to have an autism spectrum disorder (ASD) aged 18-64 years, 2015

Source: PANSI, 2016 [72]



AUTISM AND LEARNING DISABILITY

Autistic spectrum disorders are co-occurring in between 20%-33% of adults and between 40 - 67% of children with learning disabilities known to local authorities [73, 74]. The Joint Adult and Social Care Self-Assessment Framework (SAF) shows the numbers of individuals having both learning disability and autism. Amongst adults with learning disabilities in Liverpool, 5% (n=101) also had a diagnosis of autism [75].

ASPERGER'S SYNDROME

There is little information available specifically for Asperger's and there is a real need to know more about the numbers and needs of people with High Functioning Autism and Asperger syndrome, in order to support them better, particularly as they are unlikely to meet stringent eligibility criteria for social care services [71].

In 2015, there were a total of 302 people on the Liverpool and Sefton Asperger's Team caseload of which 188 (62%) were resident in Liverpool CCG. Cheshire and Wirral Partnership also provided data on the number of individuals with a primary or secondary diagnosis of Asperger's. There were 288 people with Asperger's who had contact with CWP 2015 of which 13 (4.5%) were resident in Liverpool. Between the two services there were 201 Liverpool residents seen in 2015 and there were 123 referrals to the two specialist Asperger's Teams. Data from 5 Borough Partnership was not available at the time of publication and so the numbers accessing care may be slightly higher.

Table 6: Liverpool residents with Asperger Syndrome accessing services by provider, 2015

	Merseycare	CWP	Total
NHS Liverpool CCG	188	13	201

Source: Data provided by Mersey Care and Cheshire and Wirral Partnership, 2015

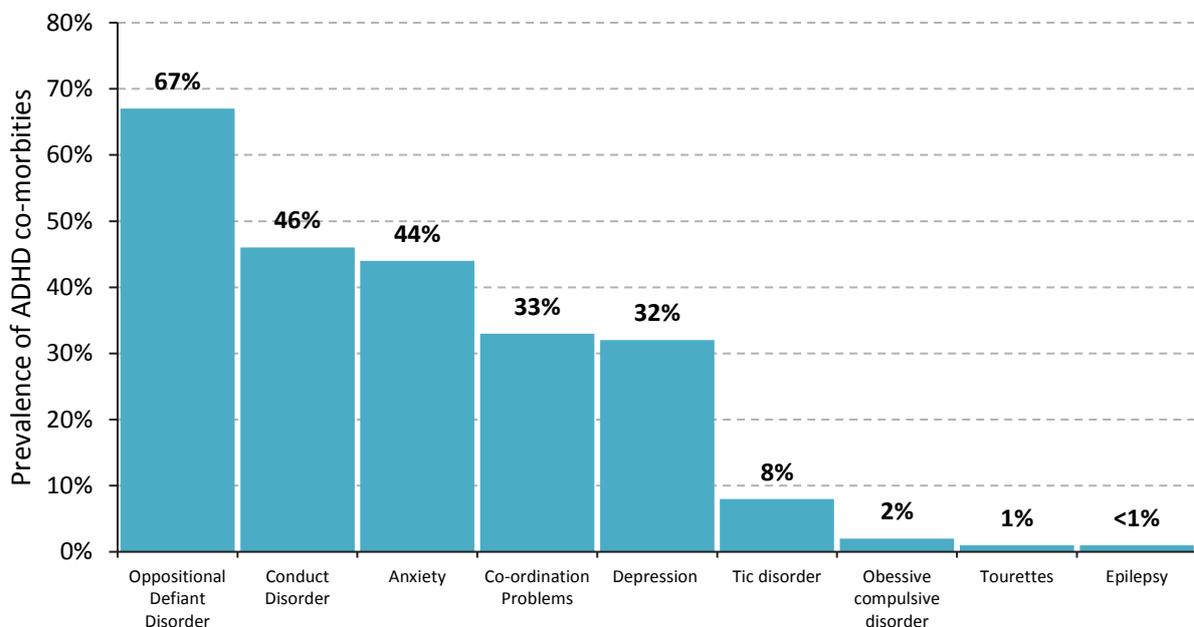
3.3 NEURODEVELOPMENTAL CONDITION COMORBIDITY

ADHD COMORBIDITY

Paediatric ADHD commonly co-occurs with multiple psychiatric disorders including mood, anxiety and disruptive behavioural disorders. Adult ADHD is also associated with comorbid mood, anxiety and substance-use disorders. However ADHD in adults is not always comorbid with other psychiatric conditions and research suggests that between 20-25% of adults will have uncomplicated ADHD [76]. However ADHD in adults is not always comorbid with other psychiatric conditions and research suggests that between 20-25% of adults will have uncomplicated ADHD [76]. It has been suggested there may be other more common comorbidities, such as antisocial personality disorder and substance use [77]. The comorbidities that adults suffer from may differ from those experienced by children, with adults being more likely to suffer from an anxiety disorder and children more likely to suffer from oppositional disorder. One study found that adults who were clinic referred, rather than being diagnosed with ADHD during childhood, have higher rates of psychiatric comorbidity [78]. Similar results were found in a study examining psychiatric comorbidity in adults at the time of diagnosis of ADHD [79].

The European Attention-deficit/hyperactivity Disorder Observational Research in Europe (ADORE) study examined co-existing symptoms of psychiatric and other conditions among a cohort of 1,478 children with ADHD which is presented in Figure 4 below. The authors of the study acknowledge that co-existing conditions were based on overall clinical ratings rather than a detailed assessment of associated mental disorders which may account for the particularly high prevalence recorded. The most common co-existing disorder was oppositional defiant disorder present to some degree in 67% of participants followed by conduct disorder (46%) and anxiety (44%) [80].

Figure 4: Prevalence of co-existing conditions among a European cohort of children with ADHD (ADORE Study)



Source: ADORE study [80]

ASD COMORBIDITY

Autism has been associated with a number of comorbid conditions and disorders; around 46.1% of children and adolescents had a comorbid disorder and when intellectual disability is included this rises to 78.7% [81]. Young people with ASD report a significantly higher number of comorbid conditions than young people without ASD. Joshi et al (2010) [82], in a study of school aged youth, found that 95% of those with ASD had three or more comorbid conditions and 74% had five or more.

With the exception of Asperger's syndrome, intellectual disability is the most frequently co-occurring condition and the symptoms of ASD, in particular language delay, stereotypies and self-injury, increase with the severity of intellectual disability[83]. An association has also been found between a number of genetic syndromes with the most common being tuberous sclerosis (mean rate 1.1% from 11 studies) and Down Syndrome (mean 0.7% from 12 studies) [84].

Studies suggest that individuals with ASD have much higher rates of various medical conditions including ear and respiratory infections, food allergies, allergic rhinitis, atopic dermatitis, type I diabetes, asthma, hypertension, autoimmune conditions, gastrointestinal problems, sleep disorders, schizophrenia, migraines, seizures and muscular dystrophy [85, 86]. There is an increased, though variable, risk of epilepsy among individuals with autism and prevalence varies by age, cognitive level and language disorder. Prevalence estimates of autism and epilepsy range from 5% to 38.3% with the age distribution of seizures reaching two peaks at age 5 and 10 years. The highest prevalence has been found in studies of adolescents and young adults and individuals with moderate to severe mental retardation, motor deficits or severe receptive language deficits [87],[81]. In addition, the prevalence of gastrointestinal problems with children range from 9-91% [81], between 77-81% of children with autism suffer from sleep problems [81] and a US study of 154 children with ASD suggests that motor impairment is prevalent with 51% showing symptoms of hypotonic and 34% with symptoms of apraxia[88].

Studies also suggest that between 11% and 84% of children and young people with ASD experience some degree of anxiety with two studies specifically examining the prevalence of anxiety disorders reporting prevalence of 45-55% among children and 56% among adults [89], [81], [90]. Some of the most frequently reported anxiety disorders and symptoms included simple phobias, generalized anxiety disorder, separation anxiety disorder obsessive-compulsive disorder (8-37%;[91, 92] and social phobia [89]. There are a small number of studies which suggest that depression is also relatively common with studies suggesting that prevalence is around 2% in children with autism and as high as 30% in children with Asperger's syndrome[83] with one study reporting that 24% of children with ASD were borderline for depression [93].

According to NICE (2014)[94], adults with autism often suffer from at least one other psychiatric disorder, with the most common including depressive disorders, anxiety disorder and agoraphobia. Studies have also found that adults with ASD are also likely to have one or more psychiatric disorders. One study found that 80% of study participants had a psychiatric disorder, with depression and other mood disorders being the most common [95], however it should be noted that the sample size for this study was reasonably small, with 28 participants included. Other studies analysing the differences between adults with ASD and those without found that those with ASD were more likely to have psychiatric disorders such as depressive and anxiety disorders [96]. Studies with larger sample sizes, over longer periods of time have also found that adults with ASD may suffer from at least one other psychiatric disorder. A study with a sample size of 129 individuals who had been diagnosed with ASD in the 1980's found that 56.6% currently met the criteria for at least one psychiatric disorder, while 69% presented with symptoms of a psychiatric disorder across their lifetime [97].

COMORBID ASD AND ADHD

Whilst ADHD and ASD have their own distinct diagnostic criteria, as neurodevelopmental disorders they do share some similarities. Dual diagnosis of ADHD and ASD has been a problematic issue; the DSM-IV included ASD as an exclusion criterion for diagnosing ADHD and so until recently research on their clinical co-occurrence has been limited. However, there is growing evidence to suggest that the two disorders frequently co-occur and the revised DSM V, published in 2013, allows a comorbid diagnosis of ADHD and ASD for the first time [98]. Children with ADHD frequently show symptoms of autism spectrum disorder and vice versa. Autism spectrum disorders are characterised by impaired communication and social interaction and repetitive and restrictive behaviours and behaviour symptoms can include hyperactivity, aggressiveness, short attention span, impulsivity and temper tantrums. The similarities between ASD and ADHD can mean that early childhood diagnoses suggest that both conditions are present and then as the child grows older the differences become more distinct and one disorder will emerge as the true condition. Children with ASD and additional ADHD symptoms often show more exaggerated impairment in adaptive behaviour and executive control. One community based study found that up to 80% of all people meeting the criteria for Asperger's also met the ADHD criteria and data from the USA National Survey of Child Health (which included over 60,000 children aged 6-17 years including 5,000 children with ADHD) found that ASD prevalence among children with ADHD was 6% compared with 0.6% in the general population [99].

4. HEALTH AND SOCIAL OUTCOMES

4.1 HEALTH AND SOCIAL OUTCOMES FOR INDIVIDUALS WITH ADHD

There has been an increase globally in the number of studies reporting long term outcomes of ADHD in the past three decades which suggests both an increased global interest in ADHD and growing recognition of the associated impairments and consequences. In addition, there has been an increase in ADHD studies among adolescents and adults in recent years highlighting increasing recognition that ADHD is a lifetime chronic disorder [100]. Nigg [101] and Eme [102] argue that ADHD is often recognised prior to the development of many other complicating risk conditions. Thus, it may be one of the earliest reliable predictors of long term poor health outcomes for children and is therefore a powerful target for secondary prevention in early life.

The evidence on ADHD outcomes shows that both the symptoms and problems of ADHD persist beyond childhood into adolescence and adulthood [103]. ADHD, along with co-occurring disorders such as conduct disorder, has been shown to lead to a number of continuing problems in adolescence including: increased mental health problems such as bi-polar, mood or anxiety disorders, increased contact with the criminal justice system, poorer academic achievement and higher levels of health risk behaviours in adolescence including smoking, alcohol consumption and illegal substance use. The evidence suggests that many of these outcomes continue into adulthood to some extent although there are a lack of longitudinal studies which follow-up study populations beyond their mid-twenties [103]. In particular, adults with ADHD are at higher risk of substance use, antisocial and criminal behaviour, personality disorder, emotional problems and issues with interpersonal relationships as well as lower academic achievement and occupational status [104, 105].

This section will review the evidence on both health and wider social outcomes for children, adolescents and adults with ADHD (for data on comorbidity with other mental health conditions, see section 3.3). Where available, reference will be made to evidence which outlines the role of treatment in altering these outcomes and a full review of both pharmacological and non-pharmacological interventions for ADHD is included in section 6.

QUALITY OF LIFE

A systematic review of quality of life (QoL) studies in children with ADHD found that parents reported negative impacts on the quality of life across psychosocial and achievement domains. In contrast, children self-reported their quality of life less negatively than their parents and did not always view themselves as functioning worse when compared to their peers. The effect of ADHD on quality of life appears comparable to other disorders and there is some evidence to suggest that QoL improves with effective medical treatment [106].

HEALTH OUTCOMES

SUBSTANCE USE

There is a sizable body of research which suggests that ADHD is significantly associated with higher levels of both substance use and substance use disorders. A meta-analytic review of longitudinal studies found that children with ADHD were significantly more likely to have ever used nicotine and other substances (but not alcohol) and were more likely to develop disorders of abuse or dependence for nicotine, alcohol, marijuana, cocaine and other substances (unspecified in the studies)[107]. Those diagnosed with ADHD during childhood were no more likely to have ever used alcohol than the general population, however they were 1.7 times more likely to meet the criteria for alcohol abuse or dependence. Similarly, they were nearly three times as likely to report marijuana use and twice as likely to report marijuana dependence; twice as likely to develop cocaine abuse or dependence and 2.6 times as likely to develop general substance abuse or dependence [107].

The Multi Treatment for ADHD (MTA) study found that children with ADHD reported significantly higher levels of illicit substance use compared to children without ADHD (17.4% vs 7.8%) and that this substance use was predicted by moderate to serious delinquent behaviour. Children with ADHD who were receiving intensive behavioural treatments exhibited lower rates of substance use at 24 month follow up; however, treatments had no impact on substance use at 36 month follow up [108].

Research also indicates that individuals both with and without ADHD misuse stimulant medications intended for the treatment of ADHD. A systematic review found that those with ADHD stimulants were at highest risk of misusing and diverting stimulants and that between 16-29% of college age students prescribed stimulants had been asked to give, trade or sell their medications in their lifetime. This highlights the importance of monitoring high risk individuals for the misuse of stimulants and educating adults with ADHD about the problems of misusing and diverting medications [109].

SMOKING

Research suggests that adolescents and young adults with ADHD are at increased risk for smoking [110]. A systematic review found that those diagnosed with ADHD during childhood were twice as likely to have ever used nicotine in their lifetime and nearly three times as likely to report nicotine dependence in adolescence or adulthood [107]. This emphasises the importance of smoking prevention for children and adolescents with ADHD [111]. There is also evidence to suggest that smokers with ADHD have greater difficulty quitting and that females in particular experience more severe withdrawal symptoms during early smoking abstinence [112].

There have been several theories suggested for this higher smoking prevalence among young people with ADHD including: self-medication to alleviate symptoms; cognitive factors such as problems with self-regulation and coping strategies; individual factors including poor school adjustment and novelty seeking and, the heightened importance of social influences including peers, family and norms. However, the evidence on these theories is sparse and none have been sufficiently investigated in populations of adults and young people with ADHD [110].

OBESITY

Recent studies suggest a possible co-morbidity between ADHD and obesity suggesting that hyperactivity is not protective against excess weight [113]. A number of studies report higher mean Body Mass Index (BMI) among children with ADHD. For example, a German study by Holtkamp et al [114] of 97 boys aged between 5 and 14 years found that children with ADHD had a significantly higher BMI and were more likely to be overweight or obese when compared to boys without ADHD of the same age. A systematic review found that ADHD prevalence ranged between 13-58% among clinical population studies of obese adults, adolescents and children [113]. A meta-analysis of 42 studies suggests that the prevalence of obesity is 70% higher among adults with ADHD compared with the general population and 40% higher in children [113, 115, 116]. The studies suggest that this association may be due to: abnormal eating behaviours or impulsivity associated with binge eating in individuals with ADHD; a form of self-medication, or alternatively, that both obesity and ADHD are the expression of a common underlying neurobiological dysfunction in a subset of individuals.

SELF-HARM AND UNINTENTIONAL INJURY

There is evidence to suggest that ADHD is associated with increased risk of injury among children, adolescents and young adults. A study of 47,000 older adolescents admitted to hospital in New South Wales over a five year period found that 16-19 year olds admitted for self-harm or drug overdose were respectively twelve and three times more likely to have ADHD. Older adolescents were also more likely to stay in hospital for longer suggesting that they sustain more severe injuries [117]. A number of studies suggest that there is an association between ADHD and self-harm and that ADHD may in fact be a risk factor [118]. A systematic review of psychiatric disorders among patients presenting to hospital following self-harm found that ADHD was one of the most frequent disorders among younger

patients (along with conduct disorder). ADHD was reported for a quarter of patients from three studies (although there was wide variation between studies [CI 1.2-61.7%]) [119].

Reviews have also identified a link between ADHD and suicide; ADHD symptoms have been found to occur more frequently in suicidal populations and may be the reason for completed suicide. In addition studies have suggested a link between completed suicide in young adult males and suicidal ideation in female adolescents [118].

ADHD may also interfere with driving competence thus putting those with ADHD at greater risk of injury due to impaired driving performance. A review of longitudinal and clinic based studies by Barkley and Cox (2007)[120] reported a number of adverse outcomes for drivers with ADHD including higher numbers of collisions, speeding incidents, reckless driving incidents, both licence suspensions or revocations and incidents of driving without a licence. Drivers with ADHD were also more likely to have repeat occurrences of these incidents. Studies also suggest that drivers with ADHD report lower driving knowledge and higher levels of driving anger [121, 122]. These reviews also identified a small number of studies which suggested that stimulant medications improved driving outcomes for drivers with ADHD [120] with four randomized double blind studies indicating positive medication effects on driving risks [121, 122].

SEXUAL HEALTH

ADHD symptoms have been linked with increased risky sexual behaviour [123, 124] including earlier initiation of sexual activity, higher numbers of sexual partners, increased casual sex, higher rates of treatment for STIs, and increased teenage pregnancy and partner pregnancy among males [125, 126]. A small scale Canadian study which recruited a community sample of 58 young people aged 13-18 years found that those with ADHD reported having more than double the number of lifetime sexual partners when compared with their peers. Females with ADHD reported shorter romantic relationships than their peers and males reported their first sexual intercourse to be almost two years earlier than their peers [127]. A combination of increased risky sexual behaviour and ADHD symptoms experienced during childhood also places adolescent females at greater risk of sexual victimisation [128].

CARDIOVASCULAR EVENTS

There has been some concern that prescription stimulants may be associated with adverse cardiovascular events such as stroke, myocardial infarction and sudden death. A recent systematic review of studies in adult and child populations found that the majority of studies in children and young people reported no association (six out of seven studies) but that among adults two out of three studies reported a significant association between prescription stimulant use and adverse cardiovascular outcomes with an increased risk of transient ischemic attack and sudden death. However, the existing evidence is mixed and further study is needed to confirm these results [129].

HEALTHCARE COSTS

There are no published estimates on the healthcare costs for individuals with ADHD in the UK; however, US studies suggest that healthcare costs are greater compared with age matched controls (US\$4,306 vs US\$1,944) and this is likely to reflect increase injury following accidents, higher use of substance misuse and other outpatient facilities and poor medication compliance. Among children with ADHD the highest costs incurred are related to healthcare and education whilst the largest costs to adults are related to productivity and loss of income [130]. A systematic review of cost effectiveness studies found higher health costs for both children with ADHD versus matched controls (difference ranged from US\$503 to US\$1,343) and adults (US\$4,929 – 5,651 vs US\$1,473-2,771). In addition some studies have also indicated higher costs: to families, related to criminality, related to accidents, related to psychiatric and medical co-morbidities and indirect costs related to work loss [131]. One US study of a single large company reported excess costs of \$3.7 million due to work loss for adults with ADHD

and their adult family members [132]. Increased service use is also seen in the relatives of those with ADHD with one study reporting indirect medical costs twice as high when compared with control families. This difference was largely due to increased mental health service use reflecting higher levels of stress, parental depression and alcohol related disorders [133].

TRANSITION TO ADULT SERVICES

The NICE guidelines on ADHD highlight the need to provide transition services for young people with ADHD who will continue to require services as they reach adulthood. A review of 139 young people (aged 14 years and over) at a UK ADHD clinic found that 102 were on ADHD treatment and 50% had well controlled ADHD. Just under three quarters (71%) had a comorbid condition, a third (33%) had an intervention from Child and Adolescent Mental Health Services (CAMHS) and 17% had offended. Among this group of young people, 37% were likely to need to transition to adult mental health services as soon as they left the paediatric service whilst 36% would benefit from a specialist nurse working with either their GP or adult mental health [134].

SOCIAL OUTCOMES

EDUCATION

ADHD can have significant impacts on the school life and educational attainment of children. Primary school aged children with ADHD can often experience academic failure, rejection by their peers and low self-esteem [133]. Mrug et al [135] measured the effects of peer rejection on 300 children receiving treatment for ADHD and found that peer rejection predicted cigarette smoking, delinquency, anxiety and global impairment at 6 years after baseline (mean age 14 years) and global impairment at 8 years after baseline (mean age 16 years). Children with ADHD also score significantly lower on reading and arithmetic achievement tests are more likely to: be temporarily or permanently excluded from school, absent from school, repeat a year or grade and access special educational services including tutoring, remedial classes and after school programmes [136]. For example, a US longitudinal study of 370 children with ADHD found significantly lower median reading scores at age 12 when compared with children without ADHD (45 vs 73), and significantly higher levels of absenteeism. Children with ADHD were 3 times as likely to repeat a grade and 2.7 times more likely to drop out before graduation (23% vs 10%)[137].

Young people with ADHD are at higher risk of academic failure and dropping out of school or college [133]. A US study of 364 young adults with ADHD and 240 young adults without ADHD found that those with ADHD were less likely to pursue education post high school and had lower levels of post-high school attainment (e.g. undergraduate, graduate level qualifications) [138].

Pharmacological treatment for ADHD and behaviour management have been found to reduce the symptoms of ADHD and increase academic productivity including quality of note taking, amount of written language output, scores on class based activities and homework completion. However these treatments are not associated with improved standardised test scores or improved educational attainment, although it is important to note that most studies are short term and compared against controls without ADHD rather than a non-treatment group [136]. A review on the influence of teacher related factors on academic and behavioural outcomes for children with ADHD found that certain teacher behaviours can have a profound impact on student outcomes. For example: the use of gestures by teachers can have a profound impact on performance in certain academic puzzles; and, teacher opinions about certain medications can influence student behaviour and the types of interventions which are implemented in the classroom. The review found that teachers who demonstrate patience, knowledge of intervention techniques, an ability to collaborate with interdisciplinary partners and a positive attitude towards children with SEN can have a positive impact on student success [139].

Whilst the evidence on school based interventions for children with ADHD remains limited, a number of specific school level interventions have been identified which warrant further investigation: namely small class sizes, reducing distractions, specific academic intervention strategies (such as peer tutoring, choice making and computer aided instruction), increasing physical activity, alternative methods of discipline and systems change (including improved education for teaching and administrative staff, collaboration between school staff, families and health care professionals and improved tracking of educational outcomes [136].

EMPLOYMENT

Adults with ADHD report poorer work-related outcomes. A US study of 364 young adults with ADHD and 240 young adults without ADHD found that young adults with ADHD were 11 times more likely to be unemployed or not in education compared with the control group. In addition, those with ADHD were four times more likely to be in unskilled versus clerical positions and six times more likely to be in unskilled versus professional positions [138]. Data from the US Health Longitudinal study also reported that individuals with childhood ADHD earned nearly 30% less than those without ADHD [140].

Adults with ADHD are more likely to be dismissed from employment and will frequently try a number of jobs before they find one in which they can succeed [133]. Furthermore, adults with ADHD are likely to face impairment across all areas of the labour market including job searching and interaction with the Job Centre, job interviews and the work environment [78].

In the workplace, adults with ADHD can experience interpersonal problems with employers and colleagues and are more likely to have problems with lateness, absenteeism, reduced job performance, higher numbers of work related accidents, excessive errors and inability to accomplish expected workloads [78, 133]. Kuriyan et al's study [138] found that young adults with ADHD were more likely to have ever been fired from a job compared with the control group (61% vs 43%), more likely to have been made redundant (33% vs 13%) and more likely to have quit a job due to dislike (53% vs 36%). Similarly, a US study which compared employer relevant outcomes from a large multi-employer database found that individuals with ADHD and caregivers to children with ADHD had significantly higher absence days, turnover and higher health benefit costs than employees in general [141]. Data from the WHO Mental Health Survey Initiative found that on average workers with ADHD have 8.4 days out of role per year, 21.7 days of decreased work quantity and 13.6 days of decreased work quality [142]. A small scale study by Biederman et al (2005)[143] compared 18 non-medicated adults with ADHD and 18 adults without ADHD in a simulated workplace setting found that the participants with ADHD had significant deficits in the workplace environment particularly in relation to reading comprehension, maths fluency and self-reported attention difficulties.

SELF-ESTEEM

ADHD is also associated with impaired self-esteem and social functioning. A recent systematic review found that individuals with untreated ADHD had a higher percentage of poor self-esteem and social functioning outcomes when compared with non-ADHD controls with children reporting the highest proportion of poor outcomes. Treatment of ADHD was found to result in significant improvements in self-esteem and social function outcomes when compared with pre-treatment baseline and individuals with untreated ADHD [144].

There is evidence to suggest that stigmatization of individuals with ADHD is common and this can have a potentially important role in outcomes such as treatment seeking and social functioning for individuals of all ages and developmental stages. Data from the US National Stigma Study – Children (NSS-C) found that 42% of adults surveyed were able to correctly identify ADHD based on a vignette describing a child's symptoms but that a fifth of these respondents did not consider ADHD to be a mental illness and the number of respondents who considered ADHD symptoms a serious problem for the individual with ADHD (38%) was less than half the proportion who gave the same response for

depressive symptoms (84%). A fifth of respondents felt they would definitely or probably be unwilling to interact with a child with ADHD symptoms. Studies also suggest that teachers and parents are vulnerable to biases when evaluating the academic abilities of children with ADHD and that parents of children with ADHD also bear a considerable burden of stigmatisation [145].

DEPRIVATION

A systematic review of parental socioeconomic disadvantage and childhood ADHD found a significant univariate association between ADHD and socioeconomic disadvantage with meta-analysis suggesting that children in families with low socio-economic status are between 1.85-2.21 times more likely to have ADHD than children from families with high socio-economic status. Children whose mothers have low educational qualifications were, on average, 1.91 times more likely to have symptoms of ADHD and children with single parents were 1.85 times more likely. UK data from the Avon Longitudinal Study of Parents and Children found associations between ADHD and a number of indicators of socio-economic disadvantage including financial difficulties, social housing tenure, younger maternal age and single parent status. Financial difficulty, characterised as difficulties in affording heating, clothing, rent/mortgage, food or other items for the child, was associated with the greatest increased odds for ADHD [146].

A study of 1,069 Liverpool children diagnosed with ADHD found that prevalence up to the age of 16 years was 9.9 per 1,000 population with a male to female ratio of 6:1. The study found that small area (known as LSOA) ADHD prevalence was negatively associated with deprivation suggesting that ADHD is associated with the level of deprivation in an individual's residential area. This suggests that improving the socio-economic environment may significantly improve overall outcomes for children with ADHD [147].

CRIME AND ANTISOCIAL BEHAVIOUR

Children with ADHD have been shown to be at increased risk of antisocial behaviour although it is not entirely clear whether this increased risk is due to ADHD itself or the co-morbidity of ADHD with other problems such as conduct disorder [108]. The multimodal treatment study (MTA) on ADHD found that 27.1% of children had engaged in moderate delinquency (e.g. shoplifting, stealing from someone's desk or locker, causing injury to someone else through hitting, carrying or using a weapon) compared to 7.4% of children without ADHD. Only about one third of these children also met the diagnostic criteria for conduct disorder although conduct disorder was found to significantly increase the likelihood of delinquency [108].

Data on 288 males with childhood ADHD from the Pittsburgh Longitudinal ADHD Study (PALS) was compared with 209 demographically similar males without ADHD to examine the association between ADHD and juvenile delinquency. The study found that males with ADHD had worse delinquency outcomes with those with ADHD and Conduct Disorder reporting significantly worse outcomes than all other males in the study across almost all of the indices of offending. Males with ADHD reported earlier ages of delinquency initiation, a greater variety of offending and higher prevalence of severe delinquency when compared with the control group [148].

Research suggests there are a disproportionately high number of individuals with ADHD in contact with the criminal justice system. European and North American studies suggest that up to half of adult prisoners and two thirds of young offenders screen positive for childhood ADHD with 14% of adult male offenders, 10% of adult female offenders and 45% of young offenders remaining symptomatic. UK studies suggest similar levels, with one study finding ADHD prevalence of 33% in Forensic Mental Health Services. One study found 24% of male adults screening positive for childhood ADHD with 14% having persisting symptoms and another study reporting a rate of 43% among 14 year old young offenders. Those with persisting ADHD symptoms were found to account for 8 times more aggressive incidents than other prisoners, higher rates of recidivism and had a significantly younger onset of

offending (16 years vs 19.5 years). In addition, individuals with ADHD can find it hard to control their behaviour in institutional settings making them less likely to be eligible for early release [149]. For individuals with ADHD, the criminal justice system often represents the conflux of any number of behaviour, mental health and substance use issues [150].

A Swedish study of 25,656 patients with ADHD suggests that pharmacological treatment can improve criminal outcomes; with medicated periods resulting in a 32% reduction in the criminality rate for men and 41% reduction for women compared with non-medicated periods[151].

HOUSING

Data from the 1970 British Cohort Study (BCS70) found that at age 30 years, men and women with childhood ADHD were more likely than those without ADHD: to be living in temporary or social housing and living in a workless household. Men with childhood ADHD were also significantly more likely to have experienced homelessness by age 30 [152]. A small Spanish study of 193 homeless people at a hostel reported that current ADHD prevalence of 8% with 14% in total likely to have had symptoms in childhood which warranted an ADHD diagnosis [153].

4.2 HEALTH AND SOCIAL OUTCOMES FOR INDIVIDUALS WITH ASD

Children with ASD often have significantly poorer outcomes than their peers including higher levels of co-morbid conditions, poorer health and reduced social outcomes including educational achievement and difficulties with forming friendships, social isolation and bullying. As with ADHD, there is a considerable focus in the literature on health and social outcomes for children with ASD but substantially less evidence on the outcomes for individuals with ASD as they move through adolescence and into adulthood [154]. Adults with autism spectrum disorder, including high functioning individuals, are significantly disadvantaged in a range of outcomes including: quality of life, physical and mental health, employment and social relationships [155].

HEALTH OUTCOMES

SMOKING

Smoking prevalence among those in contact with mental health services tend to be higher than the general population however there is some evidence to suggest that smoking prevalence is lower among those with ASD. A Swedish study of 95 adults with ASD found that 12.6% were smokers compared with 19% of the general population and 47% in a control group of 161 adults diagnosed with schizophrenia [156].

OBESITY

There is some discussion to suggest that children with autism are more likely to be obese; data from the US National Survey of Children's Health found that children with autism are at least as likely to be obese as children without autism. The prevalence of obesity among children with autism in their study was 30% compared with 24% in children without autism [157].

MORTALITY

Adults with ASD are at greater risk of excess mortality; a Danish cohort study (n=341) study found that the mortality risk among adults with ASD was almost twice that of the general population and this was particularly high among females [158].

SELF-HARM AND VIOLENCE

A Swedish prospective follow-up study examined violence and self-injury among 120 individuals diagnosed with childhood ASD to age 17-40 years; 50% had engaged in moderate or severe degrees of self-harming behaviours at some time, 19% were reported to show extremes of violent behaviours and 23% were violent often or severely enough to cause considerable concern [159].

HEALTH CARE COSTS

Autism Spectrum Disorders can potentially have a range of economic impacts across both health and social services and for both individuals and their families. Knapp et al (2009) estimate that the cost of supporting children with ASD in the UK were £2.7 billion per year and for adults the costs were £25 billion per year [160]. For children with ASD, 95% of the costs are associated with publically funded services with the remaining 5% costs to the family. Among adults, 59% of the costs are attributable to publically funded services, 36% due to individual loss of employment and 5% due to family expenses. The lifetime cost for those with ASD and intellectual disability is approximately £1.23 million and the cost for those with autism without intellectual disability is £0.08 million.

ASD can also have significant impacts on the parents and family of those with ASD; in particular mothers are more likely to experience higher caregiving stress and as a consequence lower physical and mental health[161].

SOCIAL OUTCOMES

Studies examining social outcomes for children, young people and adults with ASD tend to focus on education level, independent living, employment and social relationships. A historical review of studies suggests that the proportion of individuals reporting poor outcomes has declined from 65% in the 1960-70s to 46%. Individuals with higher functioning Autism and Asperger's syndrome tend to have better social outcomes in terms of employment, education and independent living [162].

BULLYING

In a recent survey of people with autism, 63% of young people reported having been bullied at school, rising to 75% in secondary school and as many as 82% of those with high functioning autism or Asperger's syndrome [66]. Higher rates of bullying victimization among children with ASD appears to be related to child age, internalizing and externalizing mental health problems, communication difficulties, number of friends and parental mental health problems [163].

EDUCATION

The Department of Education's Better Communication Research Programme (BCRP) was commissioned to examine the needs of pupils with autistic spectrum disorders and language impairments in mainstream classrooms, the ways in which their needs are met and the extent to which the level of support provided is related to the severity of their language difficulties and/or social behaviour. The study found that pupils with ASD displayed considerably lower language scores, verbal and nonverbal measures of memory and reading comprehension difficulties which worsened over time for those with language, social and communication difficulties so that they were falling further behind their peers. Teacher reports highlighted that pupils with ASD had heightened behavioural, emotional and social difficulties and impoverished peer interactions. ASD pupils reported lower quality of life in particular scoring much lower on social acceptance and bullying. Teachers reported that pupils with ASD were receiving higher levels of support from learning support assistants (LSAs) and speech and language therapists (SLTs) although SLT involvement was significantly reduced for secondary school pupils [164].

Approximately 50-60% of students without autism leave school without any formal academic or vocational qualifications [162]. A US study of 66 adults with ASD found that 14% were pursuing post-secondary education at college or university [165]. An interview with 21 high functioning adolescents with ASD reported that while the participants had clear postsecondary education goals, both the individuals and their parents had particular concerns about the readiness of postsecondary institutions to meet their needs including a lack of recognition of their needs in institutional disability policy and social support needs including the individuals attitude and confidence, housing and roommate concerns and the need for peer mentoring and support [166].

SOCIAL ISOLATION

In the 2012 UK survey of people with autism, 22% of young people said they had no friends at all and half said they would like more friends [66]. Amongst adults, 1 in 4 (24%) said they had no friends, with 66% saying that their main friend was a family member or their carer and 65% saying they would like more friends. For those adults with autism who also had a learning disability, the proportion who said they had no friends was higher, at one-third. According to one US longitudinal survey, young adults with ASD are significantly more likely to never see or be called by friends, never be invited to activities and be socially isolated when compared to their peers [167]. The UK survey found that the support that people with autism most want is to help them to socialise and become less isolated [66].

There has been a small amount of research into specific behaviours which are linked to social isolation; namely barriers to the development of romantic relationships among young people and adults with ASD and engagement in screen based activities such as television and video games. Studies suggest that 5-10% of participants with ASD are married or have long-term sexual relationships [162]. A study of 25 ASD adolescents and adults (age 13-36 years) found that the ASD group relied less upon peers and friends for social and romantic learning when compared with controls and were more likely to focus their attention on celebrities, strangers, colleagues and ex-partners and pursue their interest longer than controls. The authors therefore suggest that individuals with ASD have certain preponderance towards intrusive and stalking behaviours and diagnosis is pertinent when prosecuting under stalking legislation [168].

Data from the US National Longitudinal Transition Study- 2 (NLTS2) found that young people with ASD spend more time using non-social media and less time using social media when compared with their peers. The majority of young people with ASD (64%) spent their free time using non-social media (e.g. television, video games) whilst only 13% spend time on social media [169]. A study of boys aged 8-18 years (n=141) found that boys with ASD spend more time playing video games than boys with typical development and are at greater risk of problematic video game use [170].

CRIMINAL JUSTICE SYSTEM

The most recent guidance produced by NHS England [171] acknowledges that a disproportionately high number of prisoners have ASD however there is currently no national data to give the exact figures. In a recent systematic review King and Murphy [172] acknowledge that it is not uncommon for people with ASD to show challenging behaviours which can become chronic thus requiring specialist interventions and putting the individual at risk of entering the criminal justice system. Four factors are suggested which may make people with ASD more likely to carry out criminal acts, namely: an increased social naivety which puts them at risk of manipulation by others; disruption of routine or over rigid adherence to rules may lead to aggression; poor negotiating skills and lack of understanding in social situations may lead to aggression and, obsessional interest and failure to recognise the implications of their behaviour may lead to committing an offence through pursuit of that interest.

Studies suggest that the prevalence of ASD in Criminal Justice System (CJS) is higher than the prevalence of ASD in the general population however this conclusion is modified by the poor methodologies and biased samples used in the studies which formed part of King and Murphy's review [172]. Similarly the prevalence of offending in ASD populations is also difficult to interpret but suggests that adults with ASD commit the same or fewer offences than those in non-ASD populations. This suggests that people with ASD are less likely to commit a criminal offence than other people of the same age and gender or that if they do show offending type behaviour this is dealt with outside the CJS. It is also difficult to draw conclusions from the available evidence about the types of offences committed by those with ASD. One study interestingly found that those with ASD are less likely to commit probation violations whilst another study found that people with ASD are more likely to

commit crimes involving school disturbances perhaps reflecting the difficulties experience by some adults living with ASD when coping in the school environment [172]. A US study suggests that young people with ASD are more likely to commit crimes against the person (e.g. assault) than their peers but less likely to commit property crimes (e.g. arson, trespassing) and the authors speculate that this is perhaps because individuals with ASD are more likely to lash out violently during altercations but that impairments in executive functioning mean they are less likely to be involved in premeditated crime [173].

Guidelines: ASD and the Criminal Justice System

Austim: a guide for Criminal Justice Professionals (2011[1]): the National Autistic Society provides guidance for those working in the criminal justice system. The key focus of the document is to provide guidance for professionals on: recognising and approaching people with autism in the CJS and communicating with people with autism. This includes specific guidance on questioning and interviewing people with autism in the CJS.

Autism Accreditation Programme: The National Autistic Society has developed a set of standards for prisons which allow the prison to claim internationally recognised “autism accreditation”. The accreditation involves a self-audit process followed by a formal review against set criteria which evidence that the organisation has:

- Specialised knowledge and understanding of autism
- Knowledge and understanding of autism that consistently informs the organisation, resources and management of the organisation
- Knowledge and understanding of autism that consistently informs the assessment and support plan for people who use the service
- Knowledge and understanding of autism that consistently informs all aspects of practice

EMPLOYMENT

The National Autistic Society (NAS) survey found that only 15% of adults with autism were in full-time paid employment. Of those aged 16-24, one third were not in education, employment or training (NEET). Of those aged over 55, 41% had spent ten years or more with no paid job and 43% had left or lost a job because of their condition. Only 10% received employment support, whereas 53% would like such support [66].

Individuals with ASD may have difficulties negotiating the labour market including difficulties in finding a vocational niche, securing work aligned to their ability levels (mal-employment), maintaining employment and negotiating social relationships [174]. There is also evidence to suggest that young adults with ASD have lower mean wages than those without ASD [175]. The NAS survey authors recommend simple adjustments like making job interviews more accessible and assistance to understand the ‘unwritten rules’ of the workplace [66]. Under the Disability Discrimination Act (and now, the Disability and Equality Act, 2010)[176], employers are obliged to make adjustments in the workplace for staff if they are disadvantaged, including recruitment procedures and employment policies [177]. A survey carried out by Broad [177] for ‘Community Care’ found that 77% of firms used normal recruitment methods when handling applications by people with learning disabilities, as

opposed to the specialist services that exist. If more employers had specialist recruitment schemes that made it easier for people with ASD to apply for jobs then a lot more would be in work.

A systematic review identified a number of factors which lower the chances of good work outcomes for individuals with ASD, namely: the severity of their diagnosis, comorbidities, lower IQ, language and speech difficulties, maladaptive behaviour, social impairments, level of education, lack of drive, family involvement and institutionalisation. Often it is a combination of these factors which lead to limited employment outcomes [178].

According to the 2013 Autism Self-Assessment Framework (SAF), 24% of LAs nationally rated their promotion of employment for people with autism at the highest level. A further 65% gave themselves an amber rating indicating that local employment services include autism, that there is some contact with local job centres in most areas and that autism awareness training is delivered to employers on an individual basis. In addition, 49% of local authorities report detailed reference to employment in their transition to adult services processes [179].

HOUSING AND INDEPENDENT LIVING

Many adults with ASD continue to remain highly dependent on their families or other support services well into adulthood with studies suggesting that between 50-60% of individuals still live with their parents or in sheltered residential accommodation [162].

According to the 2013 Autism Self-Assessment Framework (SAF), 18% (n=28) of local authorities specifically referenced people with autism in their local housing strategies and had a broad range of housing options to meet their needs [179].

Interventions which shift stimulus control for individuals with ASD away from continuous adult management to an alternative stimulus have been successful in increasing independent skills including self-monitoring interventions, video modelling and individual work systems [180].

5. SERVICE AUDIT

A service audit of key providers involved in the provision of services for adults and children with neurodevelopmental disorders was undertaken. The aim of the audit was to find out more about each service and professional stakeholders views on their provision for this population in Liverpool. A full methodology for the audit is provided in section 1.3. This section begins with an outline of each service including provision, demand, clients, the time individuals spend in the service, waiting times, staffing levels and partnerships and collaborations. Three key themes: demand for neurodevelopmental services, waiting times and discharge from services emerged from a thematic analysis of the audit interviews.

ADHD FOUNDATION

The ADHD Foundation is a third sector organisation which works in partnership with individuals, families, doctors, teachers and other agencies to provide a range of services that will improve health and learning outcomes for children and young people (aged 3-25 years) with a diagnosis of ADHD / ASD and their parents and carers based in Merseyside and Cheshire. A range of services are available including, skills training for parents, children and young people, family therapy, cognitive behavioural therapy, stress management and support with sleep and related difficulties. The Foundation accepts self-referrals from teenagers aged 14 with a diagnosis of ADHD / ASD for counselling and participation activities and parents who have previously accessed service. Referrals are made by Alder Hey Children's Hospital, clinicians/paediatricians, GPs, schools and other agencies. Parents are firstly contacted to invite them to an initial Choice Appointment / Information Advice and Guidance session. At this appointment the young person or their parents can explain what support they believe they need and agree which services they would like to access. A drop in service is provided on Friday mornings in the Liverpool city centre and other contact is by telephone.

Service Name:	ADHD Foundation
Provision of services	<ul style="list-style-type: none"> • Information, advice and guidance • Screening: pre diagnostic screening using the QbTest, a digital health screening tool; a battery of assessment questionnaires and i-convergent screening tools • Psycho-educative interventions for parents, children under 11 and adolescents • Psychological therapies: Cognitive Behavioural Therapy, Solution Focused Therapy, Systemic Family Therapy, and Eye Movement Destination and Reprocessing (EMDR) therapy; counselling / coaching • Drop- in service twice a week, one for young people, one for parents • Training for professionals • Volunteering opportunities for service users and non-service users • Participation activities: a service user board of advisors, a young people's board of advisors, and Duke of Edinburgh Award Scheme targeted at young people who self-harm • Multi agency collaborative support for a variety of different meetings in different settings
Demand on Service	<ul style="list-style-type: none"> • Demand for therapies is very high and increasing year on year, exceed output contracted to provide for Liverpool CCG by at least 100%
Client	<ul style="list-style-type: none"> • Children and young people and parents.
Time in Service	<ul style="list-style-type: none"> • Life span service • Variable, but no definite time, between six week and six months • Allow parents to decide level of needs

	<ul style="list-style-type: none"> • Dip in and out of service as needed • Parents are seen initially and then work with the child
Waiting Times and Prioritisation	<ul style="list-style-type: none"> • Waiting lists for therapies – prioritise based on assessment of need • Can provide Psycho-educative Information, Advice and Guidance within a couple of weeks
Follow up and Discharge	<ul style="list-style-type: none"> • No official discharge from service • Open service, clients are able to get touch when services are required.
Staff	<ul style="list-style-type: none"> • Social Workers • Counselling Psychologists • Registered Mental Nurses (RMNS) • Systemic family therapists • CBT Counsellors • 3 members of staff involved in training professionals, former Head-teachers, deputy Head teacher, former special educational needs coordinator (SENCO), all with senior management experience in secondary education
Staff Levels	<ul style="list-style-type: none"> • Not enough to meet demand • Greater need for therapists with specialist skills to work with young people who have neurodevelopmental disorders like autism / ADHD
Shared Care Collaborations Partnerships	<ul style="list-style-type: none"> • As a CAMHS provider work collaboratively with the other CAMHS providers, and Alder Hey, where referrals come from • Few GP referrals –they tend to use another provider, pre-diagnosis
Particular Concerns and Issues	<ul style="list-style-type: none"> • Key transitions (school / health care) problematic for young people with ADHD • Transition from Children to Adult Services biggest weakness in the care pathway - up to a 2 year waiting list for Adult Clinic in Liverpool • Trying to plug that gap with non-statutory resources

LIVERPOOL ASPERGER'S TEAM (MERSEY-CARE)

Mersey Care has two specialist Asperger's Services in Liverpool and Sefton that provides assessment, diagnosis and post diagnostic interventions and support to working age adults living with Asperger Syndrome and other neurodevelopmental conditions within Liverpool. The team consists of nurses and social work colleagues, with support from medical colleagues within the Liverpool community learning disability team. The service is accessible to anyone aged 18 years and over who can self-refer or be referred by another person for example a family member; GP or other mental health professional.

Service Name	Liverpool Asperger Team
Provision of services	<ul style="list-style-type: none"> • Provide assessment, diagnoses and post diagnostic interventions for people with Asperger's syndrome and their support networks • Referrals received from Self-referrals, GP, Mental health, Probation, Family members • Already have a diagnoses - develop a care plan and risk assessment and then the post interventions <ul style="list-style-type: none"> • For diagnostic assessment - involve interviews with the service user, using Diagnostic Interview for Social and Communication Disorders (DISCO) and the Autism Diagnostic Observation Schedule (ADOS) 2 NICE recommended assessments, report and recommendations • Everyone attends a group session

	<ul style="list-style-type: none"> • Offer a number of post diagnostic intervention group sessions: <ul style="list-style-type: none"> ▪ understanding your diagnoses - four to six weeks ▪ anxiety management group - six weeks ▪ social skill - four and six weeks • Social Inclusion Hub runs twice a week providing clinical interventions and opportunity for networking • One-to-one interventions with psychology or with nursing or anxiety management or family therapy for more complex service users • Provide a more social programme
Demand on Service	<ul style="list-style-type: none"> • Has increased • Greater awareness of Asperger's syndrome so people identify or question whether they have Asperger's • People are identified younger and more self-referrals.
Clients	<ul style="list-style-type: none"> • Young people and adults with Asperger's syndrome
Time in Service and Prioritisation	<ul style="list-style-type: none"> • Variable depending on service users' needs • For a diagnosis -time of entering service to dialogistic assessment - between 6 and 8 months • For diagnosis and intervention - last from year to year • For already diagnosed –straight for intervention - between eight and 12 months • For support service e.g. evidence of Asperger's syndrome for benefit claim or a pick review – may take two or three letters or an email or a phone call
Waiting Times	<ul style="list-style-type: none"> • Current waiting list in Liverpool 6 months to enter service • From the initial first assessment appointment to completion of the assessment time -between 4 and 6 months
Discharge	<ul style="list-style-type: none"> • No absolute criteria • Considered at weekly multi-disciplinary team discussion • Use a step down programme so people are able to contact service on a pre-arranged monthly phone clinic for 6 months for advice
Staff	<ul style="list-style-type: none"> • One clinical psychologist • Two community nurses from mental health • One clinical specialist in Asperger's • Assistant health practitioner • Social Inclusion officer • Administrative staff
Staff Levels	<ul style="list-style-type: none"> • Insufficient for current provision resulting in longer waiting lists for assessment and diagnoses • More pressure on the team in term of post diagnostic interventions
Concerns / Issues	<ul style="list-style-type: none"> • Running a lot of clinical groups at moment might be similar groups that clients could be signposted on to as opposed to running these groups ourselves – less duplication of work

ADVANCED SOLUTIONS

A third sector non-clinical not for profit social enterprise commissioned by Liverpool CCG to deliver a range of services, interventions and support to parents, professionals, families, children young people who are affected by neurodevelopmental conditions: Autistic Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD) and Sensory Processing Difficulties (SPD). ADDvanced solutions service aims to equip and empower parents, carers, children and young people with the skills, tools, knowledge and confidence to better recognise, understand and meet the needs of their family.

Service Name:	ADDvanced Solutions
Service Provision	<ul style="list-style-type: none"> • Use learning, teaching and mentoring style interventions to empower people - equip them with skills and encourage them to move forward • Background in teaching and education important for development and design of effective courses • Solution focus drop in groups over 6 weeks in various locations co-facilitated by different specialists (continence team, speech and language therapist, dietician)
Demand on Service	<ul style="list-style-type: none"> • Increased demand due to more recognition and greater awareness
Clients	<ul style="list-style-type: none"> • Parents, professionals, families, children and young people who are affected by neurodevelopmental conditions
Time in Service	<ul style="list-style-type: none"> • Variable and dependent on needs, some will come for one or two sessions, dip in and out, or access services for three years • May attend a six week course, with an exit plan for accessing community networks, with available drop-in with the professionals and access to youth activities what needed • Maintain contact service via Facebook page • Can become a Community Network Champion and deliver training programmes
Waiting Times and Prioritisation	<ul style="list-style-type: none"> • No waiting times – open access support service giving clients the support and help they need from initial contact
Staff	<ul style="list-style-type: none"> • 3 full time staff (Director of Community Development who works with the families, Director of Learning, Coaching and Mentoring who works with the young people and the professionals and Director of Standard procedures who puts all the policies in place) • Part-time employee (0.75FTE) involved in coaching learning and mentoring - mainly with professionals and the young people supporting the Director • Part-time employee to support Community Network Development • Youth worker • Government specialist worker • Associates: specialist in their field (e.g. speech and language occupational therapists, educational psychologists, development workers, youth justice youth workers) brought in for specific work • Volunteers - Network Community Champions – trained to co facilitate the service so that in the future they can redeliver the service • Part-time administrator
Staff Levels	<ul style="list-style-type: none"> • Insufficient given recent commission by St Helen's CCG– require more staff, in particular a full time administrator and a part time deliverer

Shared Care Collaborations Partnerships	<ul style="list-style-type: none"> • Neurodevelopmental Practitioners who are based in Alder Hey • Speech and language therapists, occupational therapists, disability welfare rights and a sleep team specialist all co- deliver sessions • Design and develop evidence- based courses in partnership with specialists (e.g. Occupational Therapists, Continence Team, Dieticians and Speech and Language Therapists)
Concerns / Issues	<ul style="list-style-type: none"> • Advantages of partnership working not always recognised by some providers - they need to recognise that meeting lots of parents in a group is efficient and cost effective and has a positive impact

CHESHIRE AND WIRRAL PARTNERSHIP ADULT ADHD SERVICE

The adult ADHD service at Cheshire and Wirral Partnership provides assessment, diagnosis and treatment to adults with ADHD in Wirral and Liverpool. The service is staffed by a psychiatrist and a nurse. Patients are referred to the service by their GP, paediatric ADHD service or a mental health practitioner. The service is currently funded by Liverpool CCG to provide 4 hours of psychiatrist and 8 hours of nurse practitioner/prescriber each week.

Service Name: Cheshire and Wirral Partnership NHS Foundation Trust	
Provision of services	<ul style="list-style-type: none"> • Since 2009 Liverpool CCG have funded 90 assessments a year • Only provide medication – often there is no call for other specialist services as medication is very effective • Very recently started to provide QbTest to measure for ADHD - integrated into assessment and used in follow up to test efficacy of medication
Demand on Service	<ul style="list-style-type: none"> • Increasing • Funded for 90 referrals p.a. but actually referred ~300 p.a. • Increasing due to higher recognition of the disorder and more referrals now being made from community mental health teams and the Access Team • High demand from Liverpool may be because GPs are reluctant to treat ADHD in primary care (see below)
Clients	<ul style="list-style-type: none"> • Adults with ADHD • Often comorbidity with depression and anxiety
Time in Service	<ul style="list-style-type: none"> • Assessment and then an average of six follow up appointments where they titrate the dose
Waiting Times and Prioritisation	<ul style="list-style-type: none"> • Up to two years on waiting list, only going to grow as more and more patients are referred • Seen in order of referral, no prioritisation strategy • Any patients coming from paediatric service into adult – paediatrician refers to adult service and patient joins the waiting list • Previously been funded by CCG to clear waiting list and it was reduced to six months. Now back to a 2 year wait • Waiting list would be shorter if GPs initiated more ADHD medication (see below)
Follow up and Discharge	<ul style="list-style-type: none"> • Number of follow-up appointments depends on response to dose • Can be discharged once dose is settled, provided the GP is happy to manage the condition • At point of discharge most patients don't need any other support and can be well supported in primary care

Staff	<ul style="list-style-type: none"> • Psychiatrist (4 hours per week) • Nurse practitioner and prescriber (8 hours per week) • New band 3 support worker delivering QbTest • Psychiatrist sees the more complex cases and nurse practitioner sees the simpler cases
Staff Levels	<ul style="list-style-type: none"> • 2:1 nursing to clinical support • Insufficient funding for enough staff hours to provide service that is demanded
Shared Care Collaborations Partnerships	<ul style="list-style-type: none"> • Close links with ADHD Foundation and Liverpool Adult ADHD - Ladders of Life • Signpost to mental health services for any patients with comorbidity • Challenge working with some GPs in Liverpool (see below) • Insufficient support available for those with co-morbid ADHD and ASD
Particular Concerns and Issues	<ul style="list-style-type: none"> • Long delay and waiting list • Insufficient number of staff/resources to see all patients referred • Would like to look at how to save money by increasing nursing care and reducing number of clinician appointments • Currently Wirral provide 3 times more funding to the service than Liverpool • Challenge discharging from service as some GPs reluctant to conduct annual medication reviews. GPs need more training around this • For any patients transitioning from child service to adult there can be a 2 year waiting list – this is a challenge when the GP refuses to prescribe medication. Paediatricians have been keeping patients on (past aged 18) until they reach the top of the Adult ADHD waiting list, however this is unfunded so it cannot continue • Service has more face-to-face contact with GPs in Wirral so better relationship and they have more confidence so will ring the psychiatrist for advice – longer history in the area • GPs in Wirral historically prescribe more ADHD medication and are confident to support patients in primary care, in Liverpool this is less common • The GPs in Liverpool are getting to know him better and some are starting to call for advice but they lack the confidence to manage the condition in primary care. Need to increase training to GPs to build up their confidence • About to pilot a system in Wirral where an ADHD nurse will be available in primary care who can be contacted to support GPs with annual reviews

LIVERPOOL ADULT ADHD - LADDERS OF LIFE

An award-winning social enterprise, helping to support adults with ADHD and related conditions such as Autism or Asperger's in Liverpool. The service provides information, advice and practical support and signposting to enable individuals to achieve within and better manage, employment, education and community life. The service aims to enable adults with ADHD to reach their full potential through a combination of specialist services and peer support. Evolving in response to a lack of support services for those with ADHD, they hold general membership get-togethers weekly on a Thursday from 11am-3pm and fortnightly on a Wednesday evening 6-9pm in Kirkdale, close to Liverpool city centre. These sessions have guest speakers and offer general support that complements and supplements the full range of daily specific individual and group work that focuses upon understanding and managing ADHD, employment and education, and reducing social isolation. It is run on a membership basis and uses the support of professionals in field and talks from other related services.

Service Name	Liverpool Adult ADHD - Ladders of life
Provision of Service	<ul style="list-style-type: none"> • Provision of information, advice, signposting and practical support to Adults with ADHD and related conditions • Individual or group sessions to explore and understand ADHD symptoms and issues (depression, anxiety) managing and coping strategies. Structured sessions with a central focus on health and well-being e.g. healthy eating, relaxation techniques • Intensive support to individuals to manage their condition, their relationships with others e.g. family members, employers, colleagues • Signpost to relevant agencies e.g. counselling support • Intensive support to help people manage their interaction with public agencies or housing, debt, welfare, health, education • Training awareness to public sector agencies e.g. Disability Employment Advisors in Job Centre Plus, and private companies • Provide educational and employment programmes – a bespoke employment-focused service combining ADHD understanding and job ready skills to gain and sustain employment • Provide empathy as members have or experience impacts of ADHD – reducing social isolation
Demand on Service	<ul style="list-style-type: none"> • Increasing • People come with multiple and complex needs and will dip in and out of the service over a life time
Clients	<ul style="list-style-type: none"> • Adults impacted directly or indirectly by ADHD and related conditions
Time in Service	<ul style="list-style-type: none"> • Lifespan service
Waiting Times	<ul style="list-style-type: none"> • No formal waiting time or list, initial appointment and then access services
Staff	<ul style="list-style-type: none"> • 2 full-time Directors/ADHD Specialists • Specialist sessional/project support as and when required • Board of Directors – all volunteers • Finance Manager- volunteer • Education and Training Director • 3 main volunteers who are mentors – ex-offender, teacher, counsellor
Staff Levels	<ul style="list-style-type: none"> • Staffing is quite comprehensive but would like further investment in staff team relative to demand for services and future development
Shared Care Collaborations Partnerships	<ul style="list-style-type: none"> • Informal in/out signposting arrangement with Consultant Psychiatrist • Receives referrals and provides joint support to clients from a wide range of services not limited to government agencies (DWP, National Probation Service, Jobcentre Plus), Health, Social and Housing Services (Liverpool CCG, Liverpool City Council Adult Social Services, Liverpool Asperger Team, Inclusion Matters, Registered Social Landlords), national and local community organisations (Merseyside Disability Federation, ADDaction, ADHD Foundation, ADDvanced Solutions, Whitechapel Centre, Everton Development Trust (EDT), STEC, GTDT, AVCT, Inspire Learning Consortium, WECC, ADDISS, Prince’s Trust and Nugent Care) and Educational Institutions and Colleges across Merseyside • Specialist education, employment and enterprise support services and programmes developed and delivered in partnership with Everton Development Trust (EDT) and Department for Work and Pensions (DWP)
Concerns / Issues	<ul style="list-style-type: none"> • To increase the team and organisation with formal funding support - currently in talks with CCGs

SENSORY INTEGRATION PILOT SERVICE FOR CHILDREN WITH SENSORY PROCESSING DIFFICULTIES

This is a short term pilot service for children whose difficulty in processing sensory information is having a significant impact on their daily functioning. The aim is to reduce the impact that sensory difficulties have on children's functional ability in activities of daily living, both at home and at school. This project set up in November 2014 was part funded by the NHS and developed in collaboration with the Neurodevelopmental Pathway. Referrals were accepted from across the continuum of need based on mild, moderate, and high impact. Currently the service is no longer accepting any new referrals.

Service Name	Sensory Integration Pilot Service for children with sensory processing difficulties
Provision of Service	<ul style="list-style-type: none"> Information, advice and guidance for parents of referred children Observational consultation per child provided by a sensory integration trained Occupational Therapist (1 hour hands on) Sensory processing awareness training to parents once a month (4 hours) Awareness training to professionals once a month (3 hours) An initial Drop in service working alongside ADDvanced Solutions to talk to another trained Occupational Therapist (OT)
Demand on Service	<ul style="list-style-type: none"> Difficult to ascertain - originally set up to see the first 100 referrals but stopped at 350-400 referrals as demand exceeded capacity Increased demand due to more recognition and greater awareness from other professionals No service provision offering this type of expertise in Liverpool
Clients	<ul style="list-style-type: none"> Parents and their children Associated professionals
Time in Service	<ul style="list-style-type: none"> An average of 10 weeks but probably 10/15 weeks 10 sessions of sensory integration of 1 hour hands on therapy per child per week
Waiting Times and Prioritisation	<ul style="list-style-type: none"> Variable Parents expected to attend awareness training before attending clinic but this held OT's back on how many children could be seen in clinic. Now seeing more through clinic than actually come through awareness training
Staff	<ul style="list-style-type: none"> 2 full-time OTs trained in sensory integration
Staff Levels	<ul style="list-style-type: none"> Insufficient staff Full-time OT and an Occupational Therapy assistant required to provide service going forward
Shared care Collaboration and Partnerships	<ul style="list-style-type: none"> ADDvanced Solutions who deliver the awareness training do all the organising for the day and liaison directly with parents to co-ordinate ADDvanced Solutions buy-in from Sensory Integration Network, one individual to deliver presentations The sensory integration trained Occupational Therapist attend to answer any questions

PAEDIATRIC (CHILDREN'S) CONTINENCE PROMOTION SERVICE

The Paediatric (Children's) Continence Promotion Service is a community based service offering advice, assessment, treatment and management of bladder and bowel dysfunction (bedwetting, daytime wetting, constipation and soiling) to all children and young people from 0 – 16 years across the Liverpool and Sefton area. The service sees children who have failed first line interventions by Health Visitors/school health or require further support.

Service Name	Paediatric (Children's) Continence Promotion Service
Provision of Services	<ul style="list-style-type: none"> • Assessment for bowel, usual constipation incorporating impacting bowel or withholding behaviours • Assessment for wetting, either day-time wetting or night-time wetting • Currently piloting sensory training as a first step, to parents of ASD children with ADDvanced Solutions. Then as next step toilet training is done as a group with nurses (nurse-led service improvement)
Demand on Service	<ul style="list-style-type: none"> • Increased tremendously due to differences in measurements • Previously children under five were sent back to Health Visitors but now see under-5's • Unsure if problems have always existed or are increasing, but all are waiting
Clients	<ul style="list-style-type: none"> • Mainly children with ASD, fewer with ADD or ADHD Children with continence issues who have ADHD, ASD, Asperger's, or neurodevelopment conditions • Focus tends to be with children with ASD around bowels
Time in Service	<ul style="list-style-type: none"> • Variable • Majority of children from 6 years up to about 12 years: anything up to 6 years in the service • By young adolescence most have sorted out issues unless child has a severely developmental delays
Waiting Times and Prioritisation	<ul style="list-style-type: none"> • Increase in waiting times • 1600 children on caseload - difficult to manage • Referrals come in from CAMHS predominantly main patients • Triage on a daily basis, a child who is impacted would be prioritised and seen within 48 hours • Children referred with long standing complications and medication prescribed by the GP have a longer wait otherwise child are fast track
Discharge	<ul style="list-style-type: none"> • Will discharge if constipation has resolved but can re-enter service • Discharge letter sent to GP, parent and referrer, school nurse
Staff Levels	<ul style="list-style-type: none"> • Insufficient due to demand and capacity to meet needs • Paediatric Nurse is not a learning disabilities nurse or ASD specialist nurse. Lack of expertise of speciality to conditions of children
Shared Care Partnerships Collaborations	<ul style="list-style-type: none"> • Voluntary Partnership arrangement with ADDvanced Solutions (social enterprise) offering training and drop in sessions for parents to get the right information and support

OVERALL AUDIT FINDINGS

Three overarching themes emerged from all the interviews, these are presented in a general discussion below with illustrative quotes.

THEME 1: DEMAND FOR NEURODEVELOPMENTAL SERVICES

All interviewees acknowledged that demand for their service was increasing and that in most cases demand had exceeded capacity. This has resulted in staff shortages and longer wait times. A range of reasons were put forward for the increase in demand:

Greater awareness of the problem

More than half of the service providers maintained that demand for services is rising because of a greater awareness of neurodevelopmental disorders. Knowledge about and recognition of ADHD, ASD and Asperger's by health professionals and the general public has grown and led to an increase in referral and self-referral. Better awareness has been attributed to training and education, more experience in working with neurodevelopment disorders, increased confidence in and better communication within health services.

...in terms of more referrals it's probably that there is a greater awareness of Asperger's syndrome, I think there is also greater awareness of where other conditions of difficulties have presented ... where clinicians have difficulties working with people now think actually these difficulties could be related to autism as oppose to this is OCD or this is anxiety you know. (P3)

Yeah it's increased yeah because of recognition...I think it's because you know awareness raise and training, education.... So I think that people are more aware now and I think it comes to the front so it's more awareness raising and I think that it's the way that the education system is set up as well I think that it has a huge implication (P5)

I suppose because we have self-referral people, you know people see stuff on the TV, so here that you know I think our understanding of vast ASD, Asperger's in say for instance female populations has changed over the years so now that you know people are more knowledgeable about say how it might present differently ASD in female as in male patients. So people perhaps are either identifying that or that question has been asked as more (P3)

People are beginning to recognise ADHD more....they Access Team are picking up ADHD a lot more, the community mental health team are referring more. The recognition of the disorder is increasing across the board. (P7)

Several service providers were of the opinion that demand is increasing because there is a greater complexity of need, both in terms of the clients themselves who are presenting with co-morbidities and the assessments which are more complex:

Demand is getting higher because we are seeing a greater level of complexity, more co - morbidities in terms of increasing number of children with a dual diagnosis of ADHD/ Asperger's, which is quite often the case; and also an increasing number of children with ADHD who have co-morbid anxiety, depression and emotional distress, you know, across a range of kind of indices. (P6)

I mean I suppose the factor is the volume -the ones who have got ADHD, with either co-morbidity of Autism of Asperger's Syndrome, those numbers are increasing. We see lots of people a week. (P2)

Identification and referral of young people

Some service providers were of the opinion that there was a significant increase in demand in the adolescent population. Various reasons were proposed for the steady rise in neurodevelopmental disorders in young people. It was suggested that long waiting lists for adult services and a reluctance to diagnose teenagers in child services might account for the rising trend. Transitions within the school system was also considered a significant factor in particular for young people on the milder end of the spectrum who are undiagnosed or who are not necessarily medicated and do not go for regular outpatient reviews, but who find it much more difficult to self-regulate and self-manage their ADHD once they transition into secondary school.

That's been a steady rise over the past four years, but included in that are young people of 16,17,18,19,20, because a lot more young people now are having to stay in education or training till 18, so we think that's a factor; because obviously cognitive capacities or deficit really come into play obviously in an educational and employment training setting. And with the increasing number of young people being sort of coming through, particularly on self-referral, with their co-morbidities such as dyslexia, dyspraxia, Asperger's, were never ever picked up, and those things are being diagnosed much later because they are being picked up by an FE College or their University or even their employment or training provider. (P6)

Yes, and key transitions, particularly transition to secondary school is often disastrous for kids with ADHD. Transition from Children's Services to Adult Services is dire, absolutely dire. Because the waiting list for the Adult Clinic in Liverpool is anything up to two years. So what happens to a person at eighteen who's been discharged from Community Paediatrics? Transition is dreadful. (P6)

Unmet needs

For one service provider involved in a pilot project, demand was fuelled by the fact that her unique service was addressing a previously unmet need.

I think it's just because there's never been this service before, and there is a huge need for advice and support for parents of these children with sensory processing difficulties. It's not a service you would usually get provided by the local council. Obviously we're jointly funded via the NHS so I don't think it's usual for this sort of service but it's definitely a need UK wide (P4)

THEME 2 – WAITING TIMES

One of the implications of increased demand on services is the resultant increase on waiting times. Although a couple of services do not have wait times and are able to support clients from initial contact, this is not the case for most of the services. Wait times are variable and often depend on what service/treatment is required. For example, specialist provision such as therapies tend to have a longer wait times. In general, service providers prioritise based on need. A range of factors that impact on wait times were cited by the participants.

Service delivery model

Factors impacting on wait times include the service model and how provision is delivered. Providers may need to see clients more than once to move them forward, e.g. a school visit, work with parent to develop a plan, and then support the parents. Multiple contacts over a period of weeks/months can be time consuming and logistics can be challenging given the complex needs of many families. For certain services, provision is limited by the number of children providers can work with at any one time – they must see the child through before they can take the next one on – with only two trained staff, delays are inevitable.

Yeah there will be an increase in waiting times yeah cos you know you don't see them once and it's sorted, you know you have to go into schools, you have to do a plan for the parents, you have to work together... But you know you are hoping to move those children forward to gain confidence but as I say even though you just give a plan they do need support as well and you know families vary some can take things on. (P1)

...because it's the systemic family therapy - again the logistics of that sometimes, you know, for families; and of course then there are a lot of families you know with two sets of parents because Mum and Dad have split up. There are issues where you are working with two different families because of one child. (P6)

Insufficient Staffing

Wait times are exacerbated by insufficient staffing levels and a lack of investment in the service. All providers stated that demand exceeded current staffing levels and potentially limited provision. Of significant concern to one provider in particular was the fact that key staff are not being replaced as they leave due to the Trust cost improvement programmes and austerity measures. Another service was particularly concerned about the 2 year waiting list for their service, they were funded to treat 90 Liverpool patients a year but were being referred approximately 300 patients a year.

The other thing that impacts on waiting times is if we actually provide sensory integration ... they get 10 weeks of sensory integration or up to and that is 1 hour per week of actual hands-on therapy, and obviously we have to see that child through before we can take the next 1 on. And with there only being 2 of us there's only so many children we can have on at the same time as well as doing the clinic consultations. (P4)

"[the number of referrals and lack of resources] causes a massive bottle neck and they just wait and wait and wait. A new patient I saw yesterday had been referred in 2014 and waited over two years." (P7)

Reluctance of GPs to treat in primary care

One service felt the demand on their service was, in part, due to the reluctance of GPs in Liverpool to initiate ADHD medication or manage the treatment in primary care. They felt this differed to GPs in Wirral who were more confident and willing to manage ADHD patients within primary care. They were particularly concerned about the impact on patients' lives when they had to wait up to two years for appointment.

"In Liverpool a lot of the GPs are reluctant to initiate it [ADHD medication] so I end up writing a lot of prescriptions which could be done in primary care. That sort of makes the Liverpool service more inefficient as obviously I have to find the time to do the prescribing. That is a big lesson Liverpool could learn...and I think they are. (P7)

THEME 3 – DISCHARGE FROM SERVICES

Because neurodevelopmental disorders are lifelong conditions that require a *'longer sweep of action and intervention'*, some providers offer a lifespan service and do not officially discharge clients but rather allow them to dip in and out of provision; to maintain support as and when required. The term 'discharge' is not used by some of the services as clients find it distressing and become concerned that they cannot come back to the service. Discharge is variable across the services and tends to be led by the needs of the clients.

It's very simple ADHD and related conditions are lifetime conditions... some people come to the service, they get their lives back on track, we help them with all manner of things, they go with their sort of mental tool kit, they know that we are always at the end of the phone or they can pop into the group and see us and some people go from nothing to going into employment and we mightn't see them for six months and then there is an issue and then they come back or they need some support or need some help and then we have people who are very severe Asperger's syndrome or very severe ADHD and that is longer, I mean you know we have had member who have been members for years which is fine because they dip in and out but it's all about maintaining that support. (P2)

So they're not sent away in that sense. We used the word 'discharged' years ago, and it just frightened parents. So we say come back to us if you need any additional support. And sometimes that might be a phone call, sometimes it might be an email, it really does vary. And there are some families that dip in and out. (P6)

It's depending on their need... loads of people do six week courses and then they have got nowhere to go after that. We can deliver a six week course and then they we have a get out plan with our community networks and then we have...then they can go to all the drop-ins with the professionals, and then they can access all the youth stuff, children's work and you know the professionals can access and then so people can dip in and out and then if they want to they can become a Community Network Champion which is going on the training programmes to help we deliver the service if that's what they want it's totally up to them, some people come for one or two sessions get what they need and off they go on their lives again so (P5)

One provider commented on the difficulty they had discharging clients from their service – because clients felt safe within the service and were reluctant to move on. As such, a ‘step down’ programme was developed- a phased discharge whereby clients have access to a phone clinic for six months post discharge should they need it.

But having said that when you come to discharge its quite difficult because people will often they have heard the word “discharge” they start to worry and they can never come back to the service even though we assure them that they can if ever they need to. And in the past quite often people would be quite reluctant to be discharged or would become quite distressed and end up coming back into the service, even before they are discharged. So now we developed what we call step down programme so when people are discharged they are still able to contact the service on a pre-arranged well a monthly phone clinic for the next six months so they are able to access if they have got anything that they want to discuss. And if they do access that service by phoning us on specific days specific times once a month then either we can offer them advice or guidance and they don’t need to come back into the service or obviously if it is more serious they can come back into the service or we would signpost them to other services, or people just don’t use that service then they having that as a cushion they know that that’s there then they don’t tend to find the discharge process as distressing (P3)

Another service felt GPs in Liverpool were not confident enough to manage ADHD patients in primary care and were reluctant to conduct annual medication reviews.

NICE guidance for ADHD says people who are on ADHD medication need to have an annual review by a specialist. And that’s the bit they [the GP] are unhappy about...I think part of the problem is that ADHD in adults is still quite a new idea. People think there is something special about the annual review, but the annual review is basically “are you still benefitting from your medication?” Most people who take ADHD medication will forget the odd dose so they will know very well whether they still need it. It doesn’t get much more complicated than that.” (P7)

This service also felt there were problems with patients being discharged from paediatric service and being referred into the adult service; patients transitioning had to join the two year waiting list before they could be seen in the adult ADHD service. If the patients could be seen in primary care this was not too big a problem as their GP could manage the medication whilst waiting for the appointment in adult services. However, if the patient’s medication could not be managed in primary care this could have serious consequences for their health and wellbeing.

[Long wait between paediatric and adult service] becomes a problem when the GPs refuse to prescribe [ADHD medication] in which case the person would be without medication until they get to see me and lives can fall apart in that period” (P7)

6. SERVICE DATA

6.1 ADHD SERVICE USE

CHESHIRE AND WIRRAL PARTNERSHIP (CWP) ADULT AND CHILD CLINIC ATTENDANCE

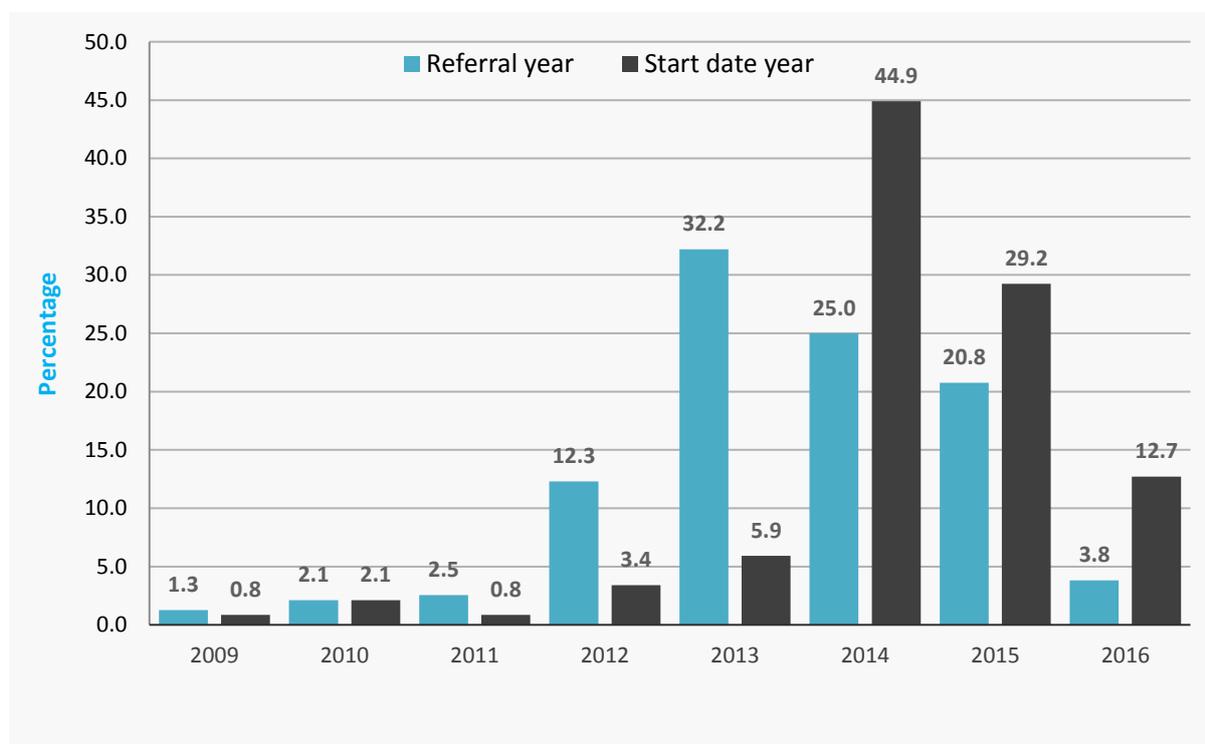
Adult ADHD services for Liverpool residents are commissioned by Liverpool CCG and provided by Cheshire and Wirral Partnership NHS Trust.

CURRENT CASELOAD

There were 236 Liverpool CCG residents on the CWP ADHD caseload in 2015/16. Figure 5 below shows the current case load by year of referral and start date. Approximately one third (32.2%) of patients currently on the caseload were referred to the service in 2013. A further quarter were referred in 2014 (25%) and just over one fifth (20.8%) were referred in 2015. As illustrated in the graph below, there is a time lag in the distribution of start date compared with referral date for the current caseload. This reflects the waiting time for the service which is considered in greater detail below. The largest proportion (44.9%) of those currently on the caseload started accessing the service in 2014 with a further 29.4% starting in 2015.

Of the current caseload, 49 individuals (21%) were referred during 2015/16 and 80 (34%) started accessing services (data not shown). The mean number of days between referral and start date for the current caseload was 281 days (range= 0 to 825).

Figure 5: Current ADHD caseload referral and start date by calendar year, March 2016



Source: CWP data provided by Liverpool CCG

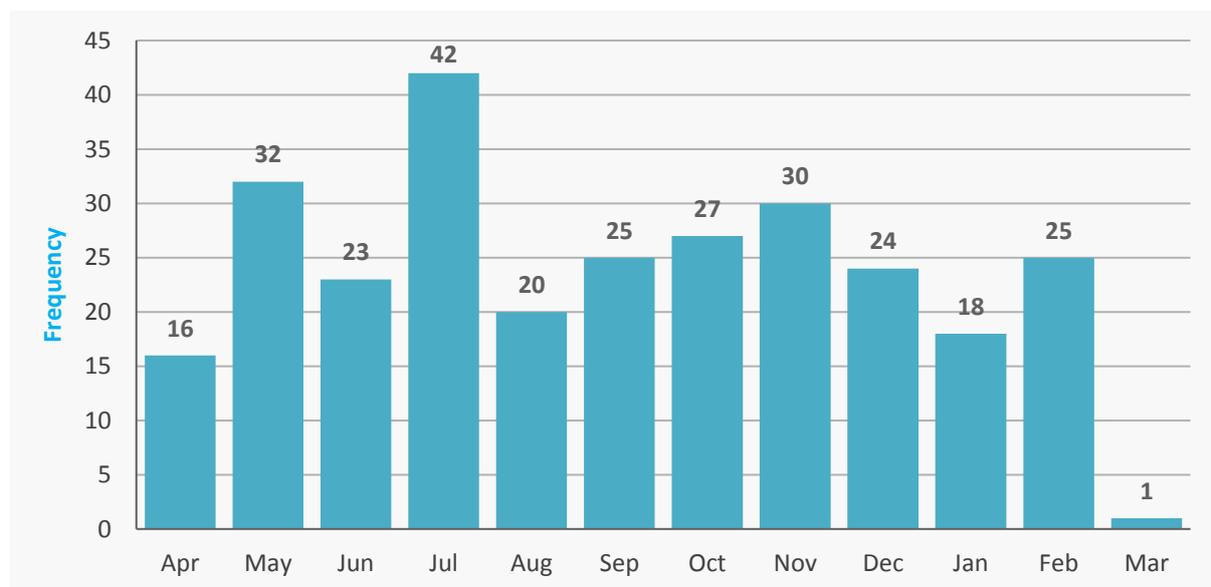
Data from a 2013/14 audit completed for Liverpool CCG also provided information on patients' GP practice. The 188 individuals attending the clinic in 2013/14 were registered at 77 different practices² in Liverpool. The largest proportion of practices (17%, n=32) had just one registered patient attending the ADHD clinic. Brownlow Group practice had the largest number of patients attending the ADHD clinic during the period (n=10) followed by Belle Vale Health Centre (n=8), Edge Hill Health Centre (n=6) and Aintree Park (n=6). Brownlow also had the largest number of patients attending for their first appointment at the ADHD clinic during the period (n=5) followed by Aintree Park (n=3) and Edge Hill Health Centre (n=3).

REFERRALS

In 2015/16 there were 283 referrals to the service. Figure 6 below shows the monthly distribution of referrals. The highest number of referrals were in July (n=42) followed by May (n=32). Just over one in five (20.8%) of those referred in 2015/16 had been taken onto the caseload (start date) and 2% of referrals were rejected.

The majority of referrals were made by a General Practitioner (GP; 72.1%) with a further 20.5% referred by a specialist clinical department. The remaining 7.4% were referred by community paediatrics, self-referred or were referred by a hospital or other source (figure 7).

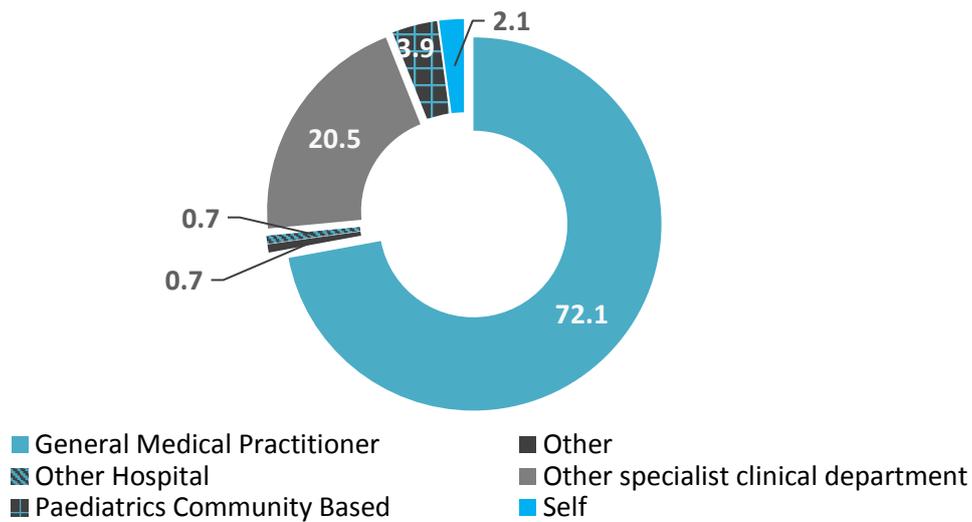
Figure 6: Number of referrals to the ADHD service by month, 2015/16



Source: CWP data provided by Liverpool CCG

² GP practice was missing for one patient and 3 patients had been registered at more than one GP practice during the period so their GP practice at the last clinic attended during the year was used in the analysis.

Figure 7: ADHD service referrals by source, 2015/16



Source: CWP data provided by Liverpool CCG

WAITING TIMES

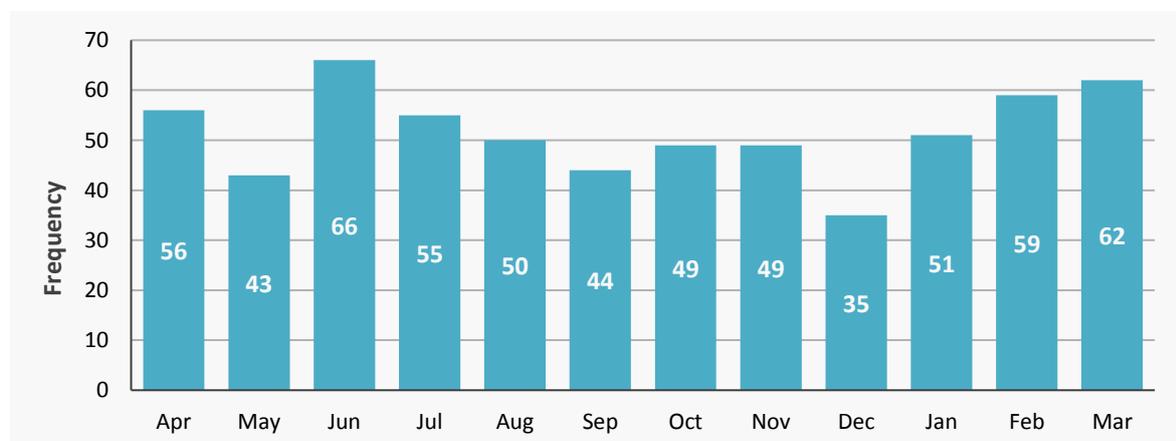
At the end of 2015/16 there were 446 individuals on the ADHD service waiting list. The waiting list is made up of those who have an accepted date but do not yet have a start date. The average amount of time on the waiting list in 2015/16 was 54 weeks (375 days) with the waiting time ranging from 2 to 1,007 days. Just over 5% (n=24) of patients on the waiting list had been offered at least one appointment by the service of which 21 were “to be attended” (either confirmed or unconfirmed by the patient) and 3 were either DNAs or cancelled by the patient.



OUTPATIENT APPOINTMENTS

In total there were 619 outpatient appointments in 2015/16 of which 86% were follow-up appointments and 14% were first appointments. Figure 8 shows the monthly distribution of appointments; the proportion of appointments per month was fairly evenly distributed with the highest proportion of appointments in June (11%) and the lowest proportion in December (6%).

Figure 8: Number of ADHD outpatient appointments per month, 2015/16



Source: CWP data provided by Liverpool CCG

Data provided for 2015/16 does not allow for calculation of the number of appointments per person. However, data from an audit completed for Liverpool CCG in 2013/14 can be used to give an indication of the average number of attendances per person. Table 7 below shows the number of clinic attendances made by individuals to the clinic between April 2013 and February 2014. The largest proportion attended the clinic twice over the period (38.3%, n=72) followed by those who attended three times (25.5%, n=48). Just under a quarter of individuals attended the clinic once in the period (23%, n=44) whilst 13% attended four times or more. The mean number of attendances was 2.3 per individual.

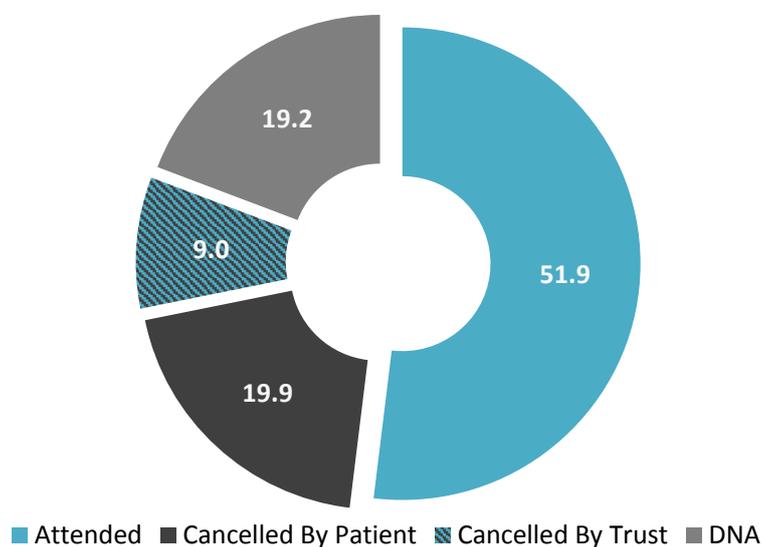
Table 7: Number of ADHD clinic attendances per individual, Liverpool residents April 2013- Feb 2014

Number of attendances	Number of individuals	%
1	44	23.4
2	72	38.3
3	48	25.5
4	19	10.1
5	<5	2.1
8	<5	0.5
Total	188	100.0

Source: CWP data provided by Liverpool CCG

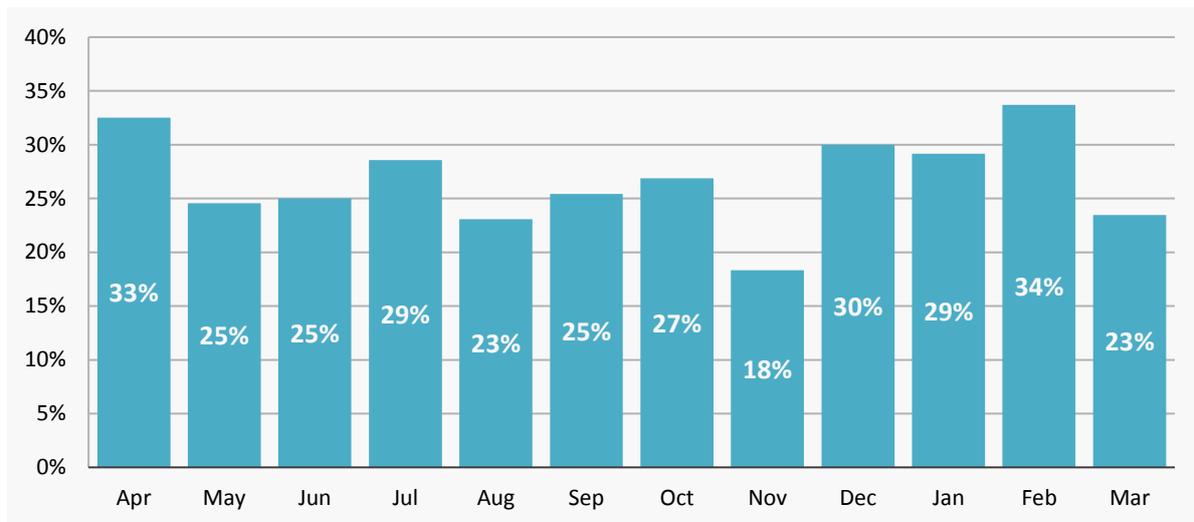
In total, 1,192 appointments were made in 2015/16, of which 52% were attended. Of the missed appointments 20% were cancelled by the patient, 19% were DNAs and 9% were cancelled by the trust (figure 9). Figure 10 shows the monthly rate of DNAs for the 2015/16 period; 11 out of 12 months had a red RAG rating with a DNA rate of more than 22%. The DNA rate ranged from 18% in November to 34% in February.

Figure 9: ADHD outpatient appointments by attendance type, 2015/16



Source: CWP data provided by Liverpool CCG

Figure 10: DNA rate for ADHD outpatient appointments, 2015/16

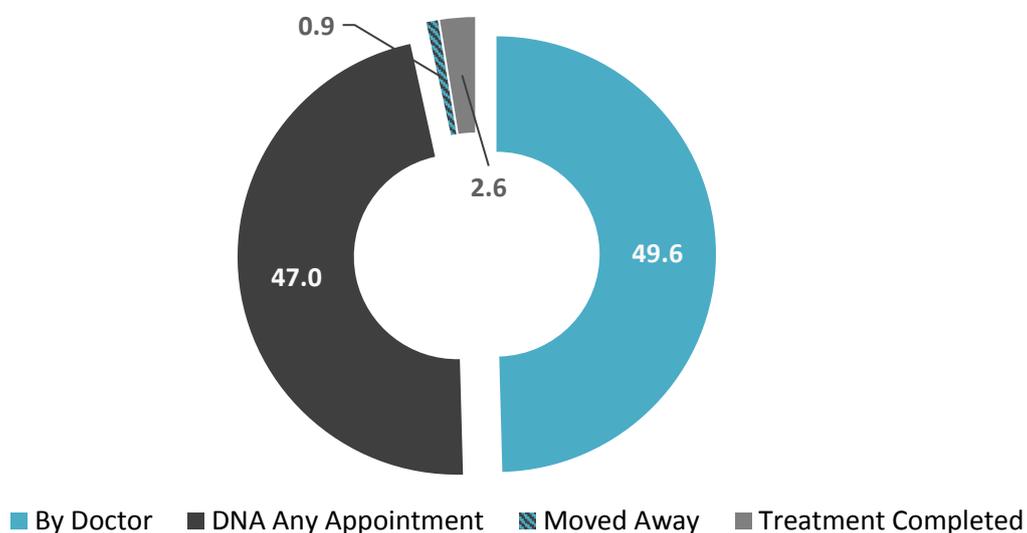


Source: CWP data provided by Liverpool CCG

DISCHARGED

In total, 117 individuals were discharged in 2015/16. The majority (50%) were discharged by a doctor and 47% were discharged because they did not attend any appointments. The remaining 4% were discharged either because their treatment was complete or they had moved away (figure 11). The mean time between start date and discharge date for individuals discharged in 2015/16 was 319 days (range = 0 to 1,443 days).

Figure 11: ADHD outpatients discharged by reason, 2015/16



Source: CWP data provided by Liverpool CCG

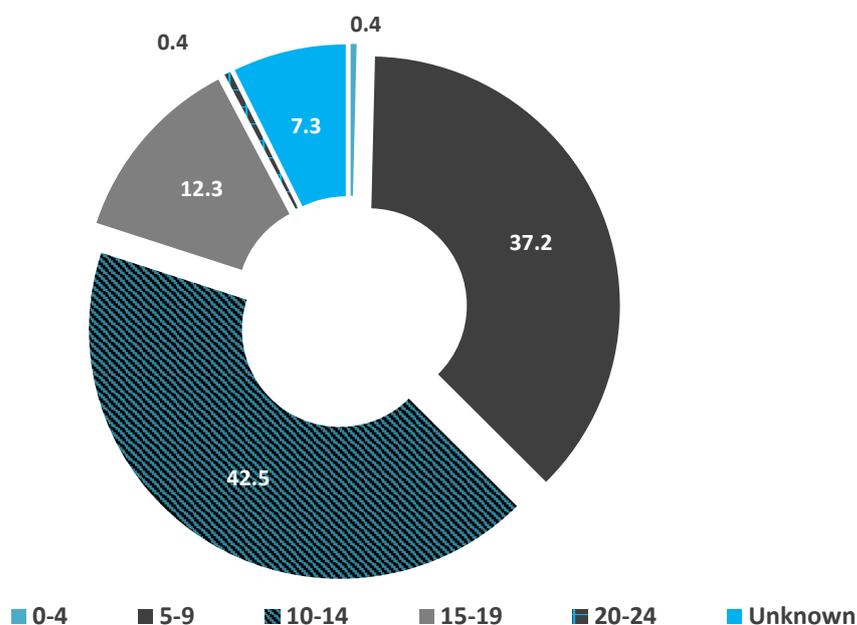
ADHD FOUNDATION

CLIENT PROFILE

Between Quarter 1 and Quarter 4 2015/16, 261 individuals accessed the ADHD Foundation. The majority (68%) were male and over two fifths (43%) were aged between 10-14 years. Four fifths (80%) of clients were aged 0-14 years with a further 12% aged 15-19 years and under 1% aged 20-24 years (figure 12).

Sexuality was recorded for just over one in ten clients (11%) of which 97% were recorded as heterosexual and 3% as questioning. Geographically, the clients were fairly representative of the city as a whole; clients resided in 29 of Liverpool's 30 wards (with the exception of St Michaels). A further 4% of clients were accessing services from outside the Liverpool area and ward of residence was unknown for 9% of clients. There is no significant correlation between the number of clients and the level of neighbourhood deprivation in each ward. For clients whose ethnicity was known, 90% were recorded as white British. For those whose Education, Training and Employment status was recorded, 47% were in secondary school and 41% in primary school.

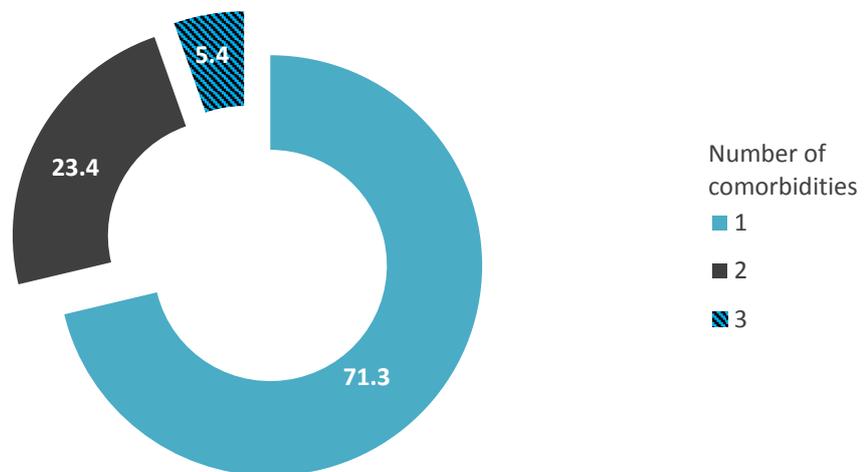
Figure 12: ADHD Foundation clients by age group, 2015/16



COMORBIDITIES AND COMPLEXITIES

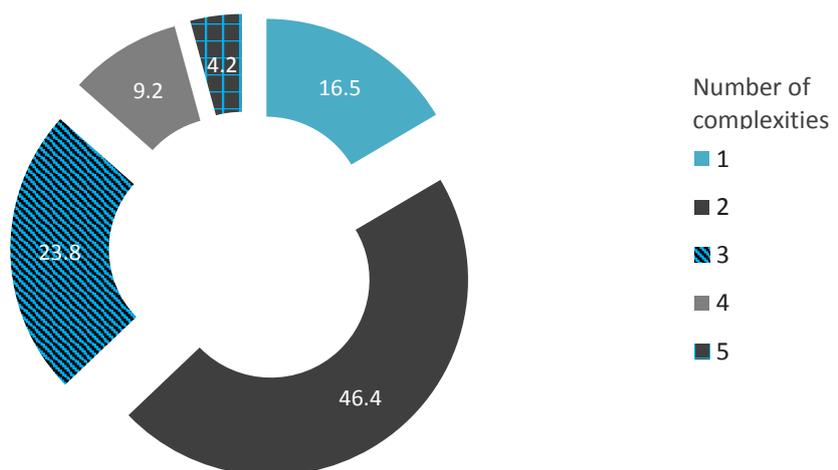
Data was provided on any comorbid disabilities/conditions experienced by clients alongside their ADHD. The majority of clients (71%) had no comorbid disabilities/ conditions while just under a quarter (23%) had one comorbid disability and 5% had two. The most common comorbid conditions were other neurodevelopmental conditions (22%) while 6% reported a learning disability/ developmental condition and 3% a learning difficulty. A further 2.3% had "other" condition recorded and 1% had a hearing impairment.

Figure 13: Clients by number of comorbidities



Data were also provided on complexities experienced by clients. The majority (81%) had neurological issues recorded as their main complexity. The largest proportion of clients (46%) had one complexity recorded while 24% had 2 recorded. Around 15% of clients had either no complexities or three or more complexities recorded (17% and 13% respectively). After neurological issues, the main complexities recorded were pervasive developmental disorders (autism/Asperger’s; 21%), parental health issues (8%) and being a Looked After Child (5%). The remaining complexities included: being deemed a child in need of social services input (4%), a serious physical health issue (2%), contact with the youth justice system (0.8%), a current protection plan (0.4%) and “other” complexities (5%).

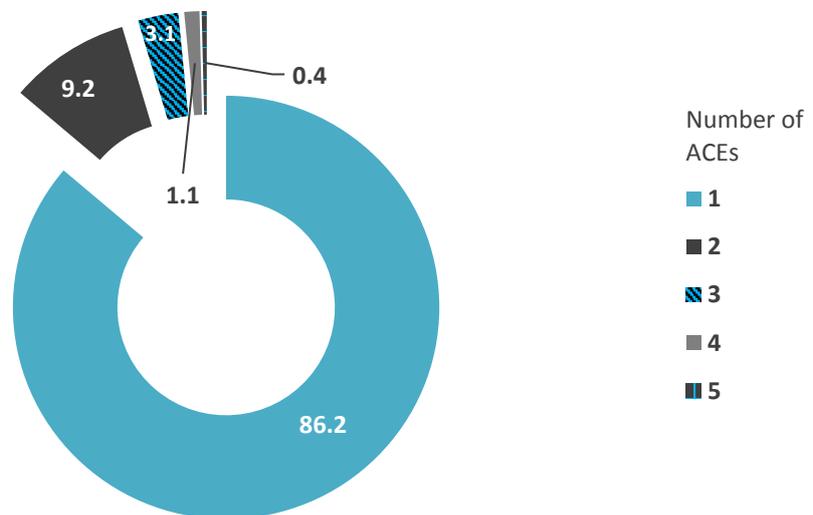
Figure 14: Clients by number of complexities



Data were also included on Adverse Childhood Experiences (ACEs); previous studies have demonstrated an association between ACEs and adult health risks behaviours and outcomes including

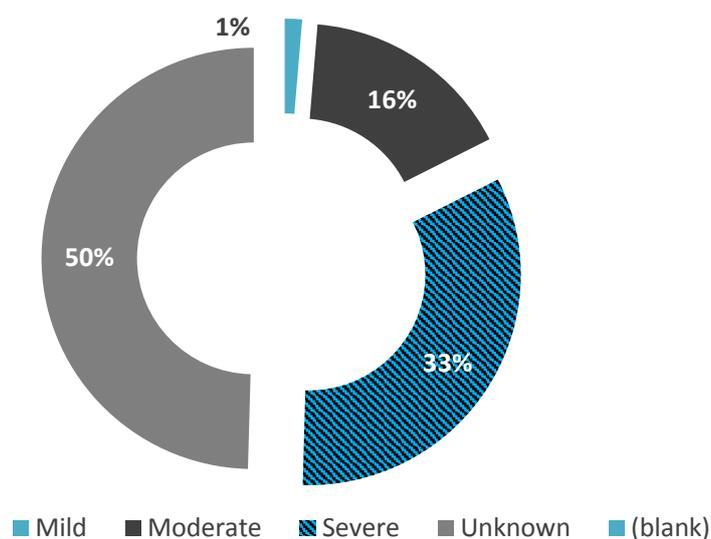
chronic diseases [181]. Just under one in ten clients (9.2%) reported one ACEs, 3% reported two ACEs and 1.5% 3 or more. The most commonly experienced ACE was parental separation (5% clients).

Figure 15: Clients by number of Adverse Childhood Experiences (ACEs)



Finally, data was also provided on main presenting needs. The primary presenting need for all clients was recorded as ADHD (*“difficulties sitting still of concentrating ADHD/Hyperactivity”*) but data were also provided on additional presenting needs. The severity of ADHD was recorded for 115 clients (50.4%). A third of all clients (32.8%) had severe ADHD, 16.2% had moderate ADHD and 1.3% mild ADHD (figure 16).

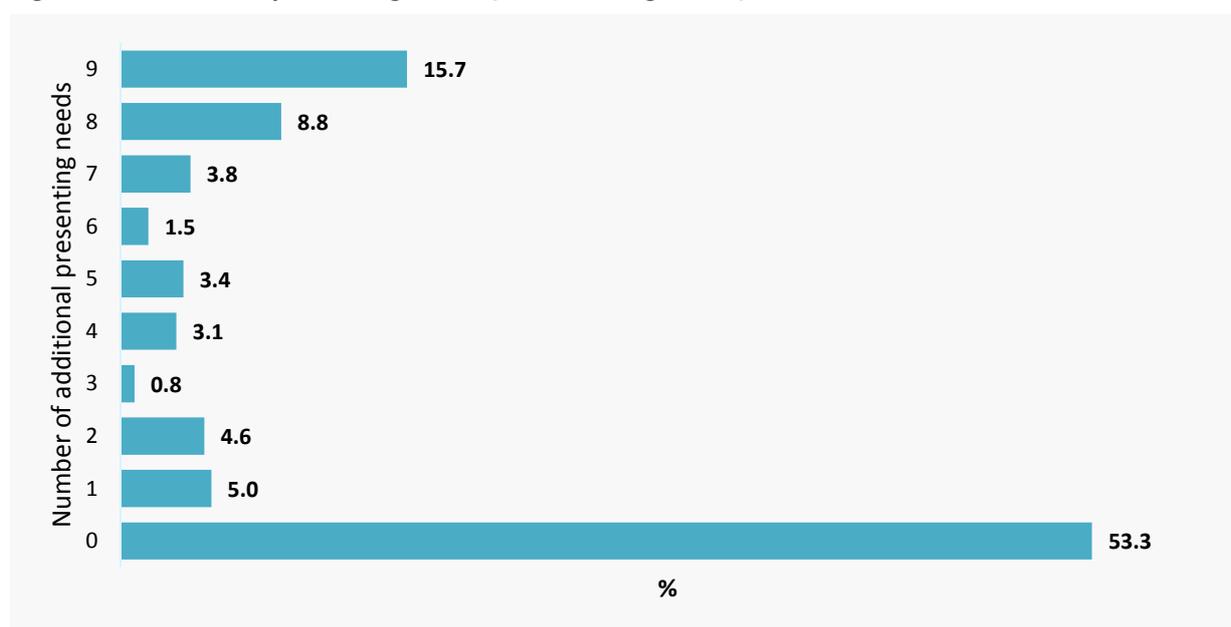
Figure 16: Severity of ADHD among clients, 2015/16



Just under half of clients (46.7%) had at least one additional presenting need; the greatest proportion of clients with additional presenting needs (15.7%) had 9 additional presenting needs recorded (figure 17). The most common presenting needs were *“behavioural difficulties (conduct disorder or oppositional defiant disorder)”* (27.6%) being *“generally anxious (generalised anxiety)”* (24.9%), being

“anxious in social situations (social anxiety/phobias)” (23.4%) and being “compelled to do or say things (obsessive compulsive disorder)” (20.7%).

Figure 17: Additional presenting needs (not including ADHD), 2015/16



REFERRALS AND WAITING TIMES

Data was provided on referrals for 223 clients during the period. Two thirds of referrals (66.4%) were routine referrals and just over a quarter (26.5%) were re-referrals. The remaining referrals were self-referrals (7.2%).

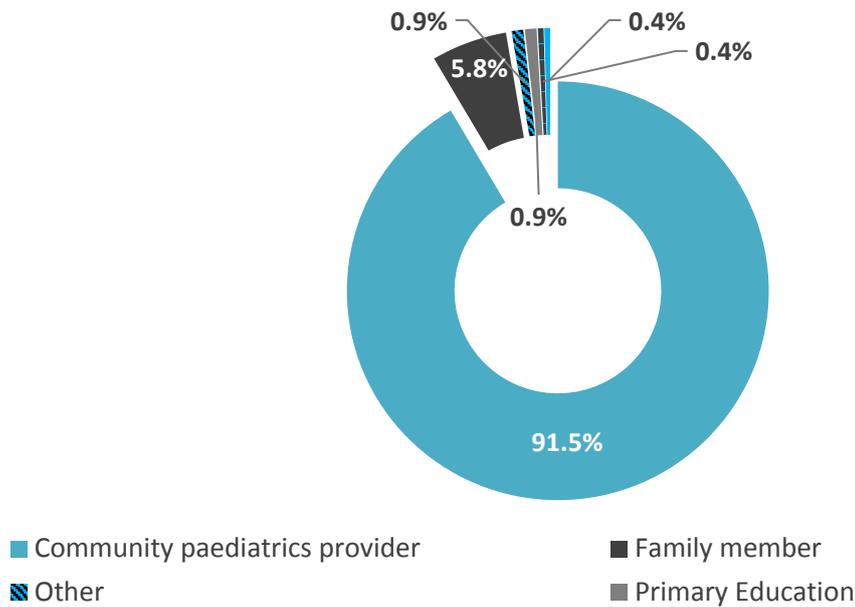
The mean number of days between referral date and assessment date was 56 days (range = 1 to 153 days). Table 8 below provides a breakdown of the waiting time between referral and assessment. The majority of clients (60%) waited 8 weeks or less for a referral.

Table 8: Number of weeks between referral and assessment, ADHD clients 2015/16

Weeks between referral and assessment	n	%
<4 weeks	21	15
4-8 weeks	63	45
9-12 weeks	29	21
13-16 weeks	21	15
17-20 weeks	6	4
21-24 weeks	2	1

Where data on referral outcome was available, 48.8% were allocated with 40.2% either on a waiting list or pending action. A breakdown of primary referrer is included in figure 18 below; the majority of referrals (92%) were made by a CAMHS provider. Four referrals were made through the Early Help Assessment Tool (EHAT) and two EHATs were raised.

Figure 18: ADHD foundation clients by primary referrer, 2015/16

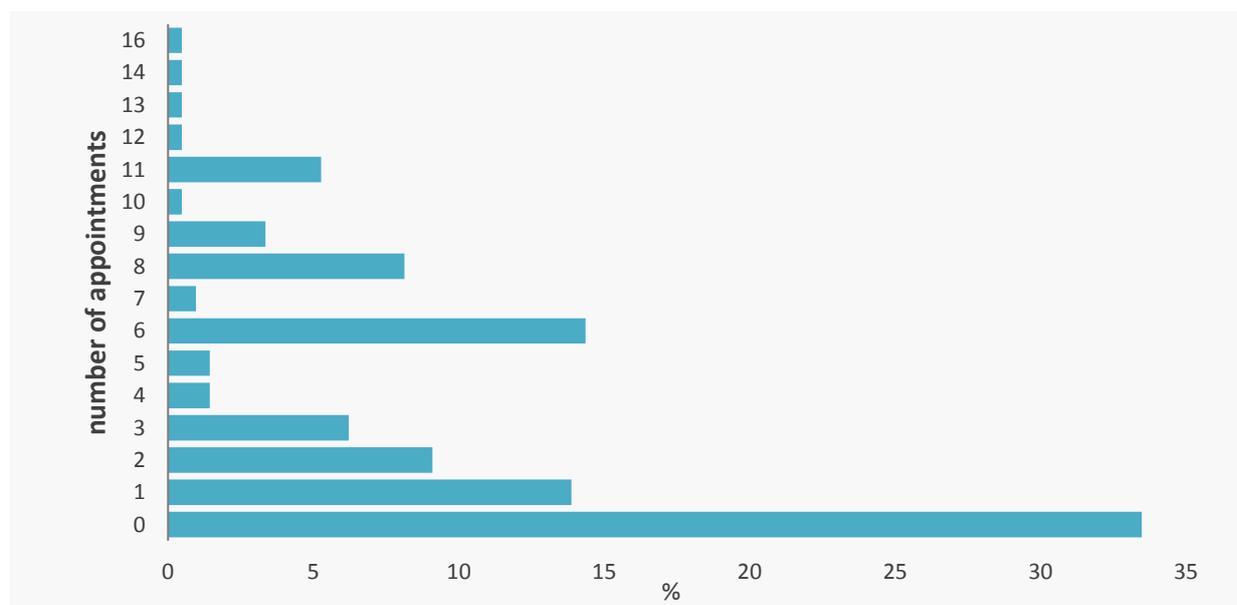


CLINIC ATTENDANCE

Figure 19 below shows the number of appointments per client in the reporting period. The mean number of appointments per client was 3.4 (range = 0 to 16 appointments). The majority of appointments took place in the voluntary sector (78%) with a small proportion in either an educational establishment or multiple locations (22%).

Around three in ten (31.6%) clients who attended across the data collection period did not attend at least one appointment (range 1 to 7 DNAs) with 11.6% of clients not attending one appointment.

Figure 19: ADHD Foundation clients by number of appointments, 2015/16



INTERVENTIONS AND OUTCOMES

The mean number of days between assessment and intervention was 74 days (range = 4 to 223 days). The majority of interventions involved working with parents/carers (99%). A breakdown of the type and length on interventions delivered is included in table 9 below. Please note that intervention length was not available in all cases so row total may be higher than the breakdown in the previous columns. Consultations with family members and group work with either children or young people or parents/carers were the most common interventions delivered.

Table 9: ADHD Foundation interventions by type and length, 2015/16

Intervention type	4 weeks or less	5-8 weeks	9-12 weeks	13-17 weeks	Total
Consultation with family members	62	0	0	0	64
Parent/Carer Group work – time limited	0	22	51	0	73
C&YP Group Work – time limited	13	5	33	0	51
Pre-therapy	3	0	0	0	3
Cognitive behavioural Therapy	0	0	1	0	1
Counselling including integrative, person-centres	1	1	1	1	4
Other	1	0	0	0	1

Table 10 below summarises the outcomes for each type of intervention. The percentages below are calculated as a proportion of interventions for which outcome data was available. The numbers are the proportion of interventions rather than clients with successful outcomes; clients may have received multiple intervention types over the data collection period.

Table 10: ADHD Foundation intervention outcomes, 2015/16

Intervention type	Improved	No Change
Consultation with family members	92.3%	7.7%
Parent/Carer Group work – time limited	97.1%	2.9%
C&YP Group Work – time limited	88.7%	11.3%
Pre-therapy	100%	-
Cognitive behavioural Therapy	100%	-
Counselling including integrative, person-centres	100%	-
Other	-	100%

DISCHARGE

The mean number of days between referral and discharge was 193 days (range = 3 to 545 days) and the mean number of days between assessment and discharge was 185 days (range 1 day to 457 days). The most common reason for discharge was patients non-attendance (67.9%) followed by mutual agreement (19%).

LIVERPOOL ADULT ADHD - LADDERS OF LIFE (LoL)³

Liverpool Adult ADHD - Ladders of Life (LoL) is a social enterprise which provides a suite of services to adults with ADHD and related conditions such as Asperger's and ASD. LoL's ethos centres on being a non-threatening, user-friendly and confidential service provider that is based in the heart of Kirkdale (one of the Liverpool communities with the highest level of deprivation); whose services are philosophically and practically-based upon the twin overarching themes of:

- **Personalisation:** involving the close engagement with the individual with the aim of ascertaining their needs and developing a strategy and means of meeting targets that are attainable and will lead to an improvement in their quality of life and management of and understanding of their condition.
- **Co-Production:** involving service users in the design and provision of the services they access and need, so that services are able to effectively respond to the complex and unique service users' needs. At LoL this is a key aspect of the delivery model aiming to reduce social isolation and increase confidence.

Services provided by Ladders of Life

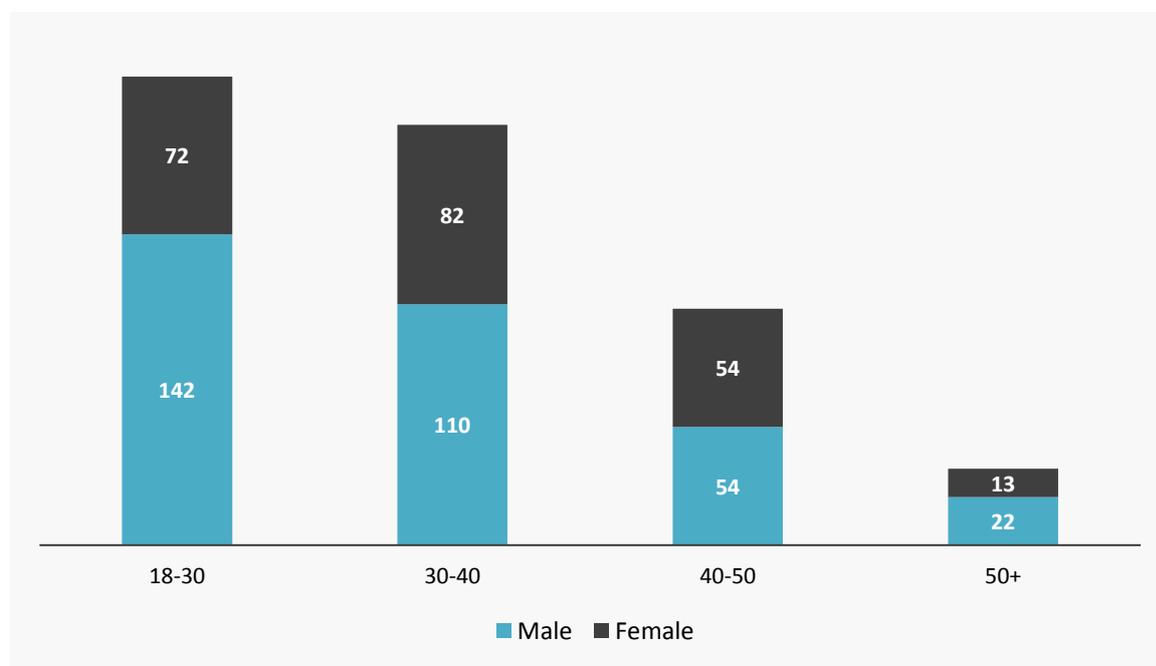
- Daily/Thrice weekly Individual and/or Group Sessions to explore and understand ADHD symptoms and issues – including managing and coping strategies related to core symptoms and the depression and anxiety they can cause, with special focus upon health and well-being. These sessions are structured with a clearly defined learning / experiential outcome; and in terms of the group sessions are periodically complemented with guest speakers, fun activities and health-related themes such as healthy eating, relaxation techniques *etc.*
- Daily intensive support to help individuals manage their condition and their relationships with others (such as family members or employers and/or work colleagues) including signposting to other relevant services, such as assistance pre and post-diagnosis; and counselling support from organisations like Inclusion Matters.
- Daily intensive support to help individuals manage their interaction with public services or government agencies related to issues of housing, debt, welfare, health and education *etc.* This includes some general advocacy and access to information support in tandem with the Advocacy Hub. Furthermore, LoL also provides information sessions and training for both public bodies, such as DWP/JCP Disability Employment Advisers *etc.* and private companies.
- Daily innovative, accessible and inclusive educational and employment programmes and opportunities for learning that are delivered in an empathetic, proactive and sensitive manner – particularly so when accommodating individual learning styles and modes of working. For example, ADHD Works! © is a bespoke employment-focused programme developed by LoL that combines understanding and coping with ADHD with acquiring job-ready skills and gaining and sustaining employment – this is an award-winning course that is hugely successful and is delivered in partnership with Jobcentre Plus and the DWP.

³ Information provided by the service. Text is Copyright of Liverpool Adult ADHD - Ladders Of Life©

CLIENTS

There are currently 549 service users accessing LoL services. Figure 20 below gives a breakdown of service users by age and gender. There are slightly more males (n=328, 60%) than females (n=221, 40%) accessing the service. The largest proportion of service users were aged between 18-30 years (39%) followed by those aged 30-40 years (35%).

Figure 20: Liverpool ADHD - Ladders of Life Service Users by age and gender, 2016.



SERVICE USE

On average, between 90-100 people are supported per week across a range of group and individual sessions (more detail about the services provided is outlined in the box above).

Table 11: Average LoL weekly service use by session type, 2016

Session type	Average number of clients supported per week
Individual sessions	30-35
Group sessions: ADHD	35-40
Group sessions: ADHD (evening/ after work)	15-20
Group sessions: family members/partners	15-20
Total	95-115

REFERRALS

LoL works and receives referrals and provides joint support to clients from a wide range of services not limited to government agencies (DWP, National Probation Service, Jobcentre Plus), Health, Social and Housing Services (Liverpool CCG, Liverpool City Council Adult Social Services, NHS Consultant Psychiatrists, Liverpool Asperger's Team, Inclusion Matters, Registered Social Landlords), national and local community organisations (Merseyside Disability Federation, ADD Action, ADHD Foundation, Whitechapel Centre, Everton Development Trust, Speke Training & Education Centre, Granby Toxteth Development Trust, Alt Valley Communiversity, Inspire Learning Consortium, West Everton Community Council, ADDISS, Prince's Trust and Nugent Care) and Educational Institutions and Colleges. On average, between 7-10 new service users seek support from LoL each week.

Feedback provided by LoL suggests that services users cite a number of reasons for seeking support from the service, namely: a lack of available adult ADHD services, frustration at a lack of understanding of the difficulties they experience in their daily lives in particular regarding education, employment and accessing effective treatment and support and difficulties managing relationships and social interaction without support.

OUTCOMES

LoL provided data on a number of outcomes for service users across a range of areas including the relieving of health problems and wider health inequalities. The outcomes are summarised in table 12 below. The numbers refer to the number of cumulative positive interventions over the last year. Individuals with ADHD have multiple and complex needs which translates into multiple, consistent and cumulative interventions across the lifespan.

Table 12: LoL clients by outcomes, 2016

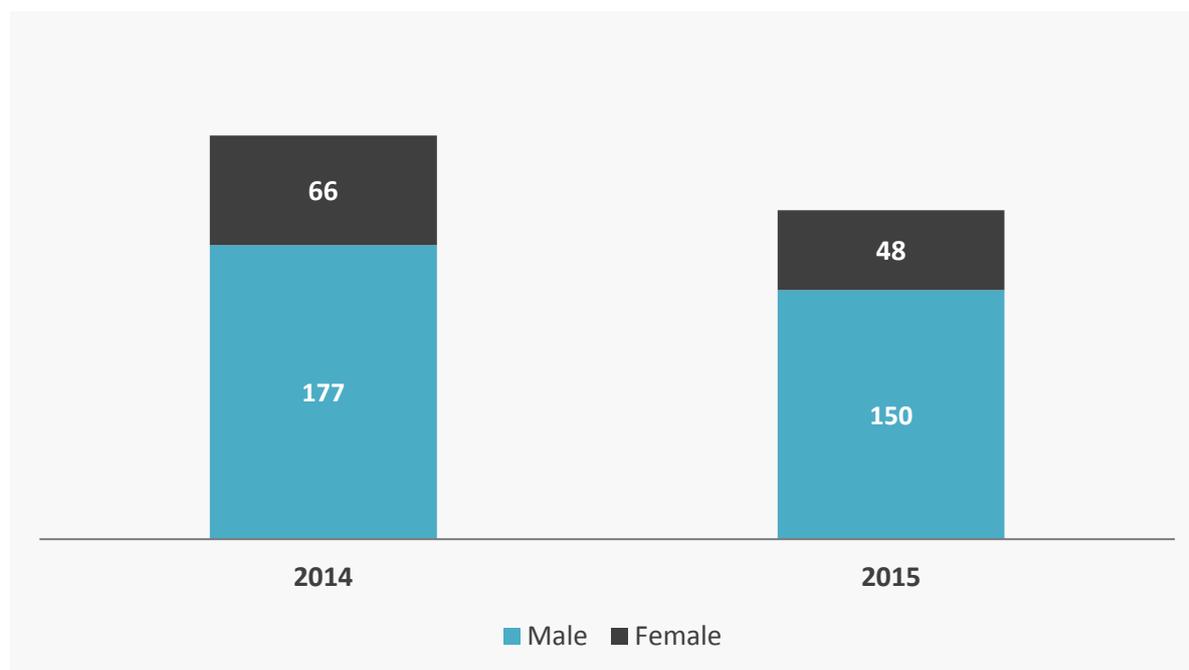
Outcome	Number of clients ⁴
Improved engagement with health services relating to their condition, including keeping appointments and committing to / being supported with treatment.	428
Cessation of addictions to alcohol and substance abuse	49
Cessation of re-offending and recidivism	28
Marked reduction in aggression and aggressive behaviour	198
Marked reduction in depression and anxiety relation to their condition and circumstances	349
Reduced social isolation and a feeling of being valued and supported to achieve attainable goals	528
Improved relationships and understanding with and between partners and family members	312
Improved family coherency and happiness – both for nuclear and single parent families	367
Achieving qualifications and progressing to further education	93
Achieving employment, especially after being long-term unemployed	22
Becoming a volunteer and learning new social skills	53
Sustaining employment as a result of support and encouragement	35
Improved relationships with work colleagues, and improvements in support and understanding from both employer and union delegates	43
Improved relationship and understanding with their landlord around housing needs and support.	88
Improved understanding and support for issues around quantifying and managing debt.	102
Improved support and understanding from educational institutions and training providers.	93

⁴ Column cannot be totalled as clients have had more than one outcome

ALDER HEY: ADHD CLINIC

Figure 21 below shows the number of individuals who attended referral to Alder Hey ADHD clinic in 2014 and 2015. It is important to note that the number of clients below may under report the numbers of children and young people accessing services for ADHD at Alder Hey as children with multiple conditions/complexities may be accessing support for ADHD alongside other conditions. In addition, children under 5 years of age frequently access consultant clinics rather than nurse led services and so may not be reflected in the numbers below. The mean DNA rate for the service is approximately 10%.

Figure 21: Attendances at Alder Hey ADHD clinic, 2014-15



DISCHARGE

Once a diagnosis and appropriate support has been given, and if drug therapy is not required children can be discharged from the department of developmental paediatrics with the option for future re-referral should there be any change in condition requiring further medical input. However, there is evidence to suggest that historically young people with ND conditions have not been discharged from the Alder Hey community paediatric service due to limited onward provision for young adults. Often it is families and young people who request that clinicians do not discharge them from the service once medical input is complete as they do not wish to lose this support. Data provided by Alder Hey reports that there are approximately 325 young people who are eligible for transition to adult services but are still under review by a paediatrician. Alder Hey estimate that over the next 12-24 months a further 100 young people will reach transitional age.

PRIMARY CARE DATA FOR ADHD

At the end of 2015/16, there were 1,941 individuals with diagnosed ADHD registered at a GP practice in Liverpool; a rate of 3.83 per 1000 GP registered population. As illustrated in figure 22 below the crude rate of diagnosed ADHD varied considerably by practice (median=17 patients per GP practice). Brownlow Group Practice had the largest number of patients with diagnosed ADHD (n=84) representing 4% of the city total. The practice with the highest crude rate of diagnosed ADHD was Robson Street (10.29 per 100,000). However, caution must be taken when interpreting these crude rates as demographics (including age, sex and gender) of the patients registered at each practice varies considerably.

Figure 23 below provides a breakdown of GP registered patients with ADHD by age group. Just over half of patients (51%) were aged between 11 and 20 years with 18% aged 21-25 years and 12% aged 6-10 years. In total, 15% of those with ADHD were aged over 25 years and just under 1% were aged between 0-5 years.

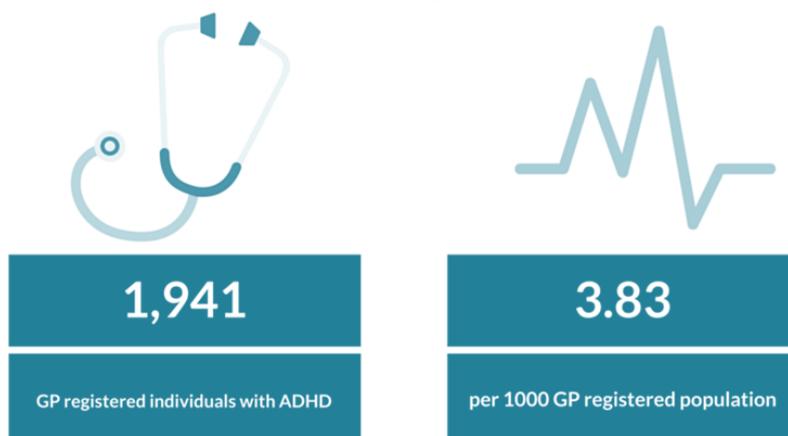


Figure 22: Proportion of patients with diagnosed ADHD by GP Practice, Liverpool CCG 2015/16

Source: Liverpool CCG

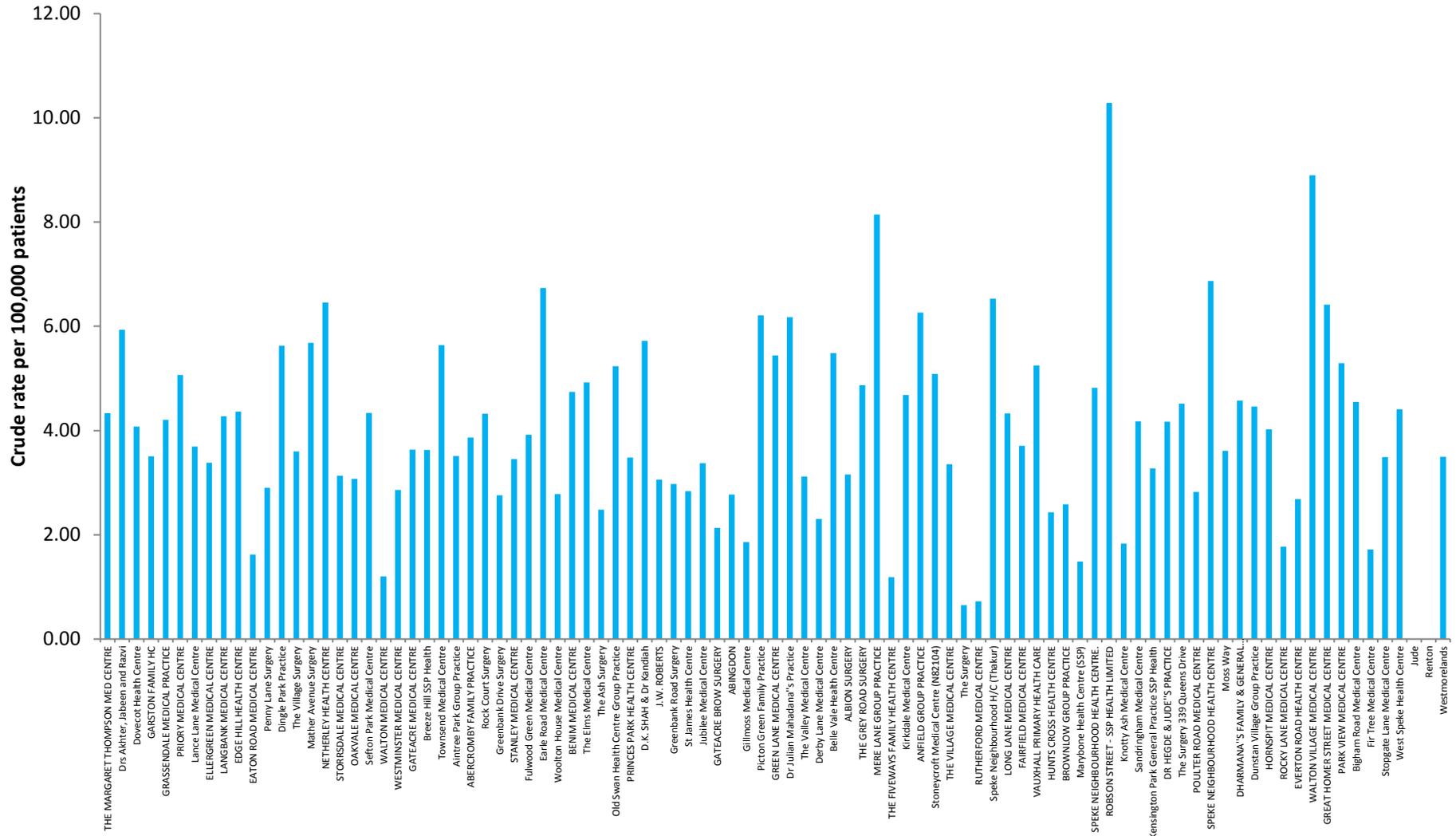
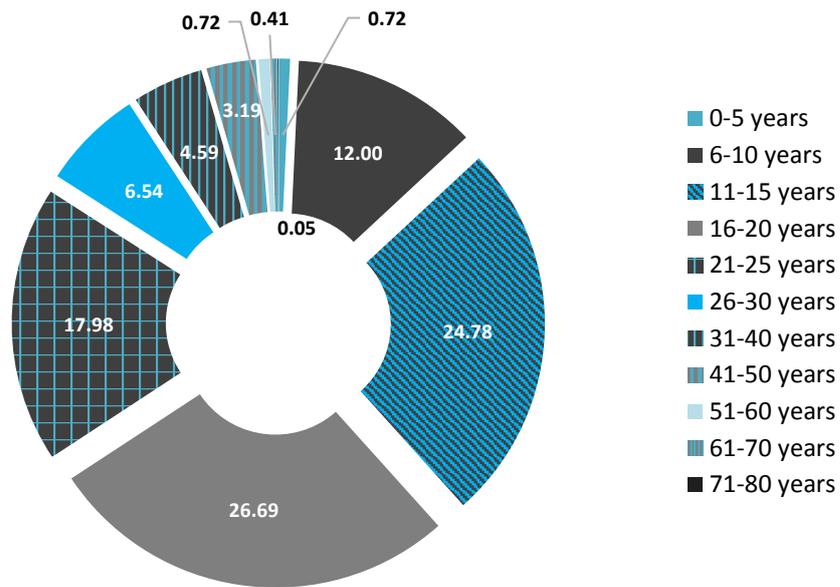


Figure 23: GP registered patients with ADHD by age group, Liverpool CCG 2015/16

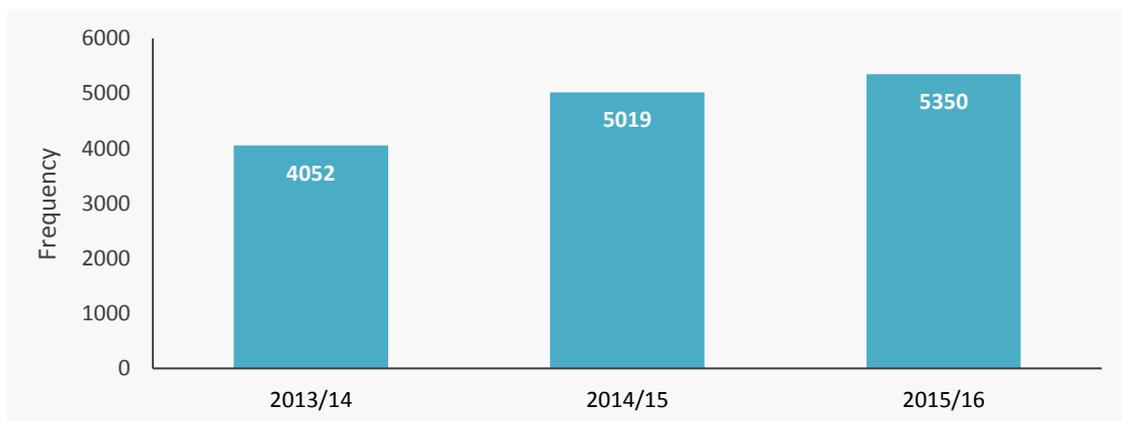


There were 200 GP registered patients who were not diagnosed with ADHD but were being prescribed ADHD medications. The majority (60%) of these individuals were aged 25 years and under with a quarter aged between 21 and 25 years. Whilst some of these individuals may have undiagnosed ADHD it is also important to note that some ADHD medications are prescribed for other conditions (e.g. Modafinil, Dexafatamine and Methylphenidate can also be used in the treatment of narcolepsy).

PRESCRIBING FOR ADHD

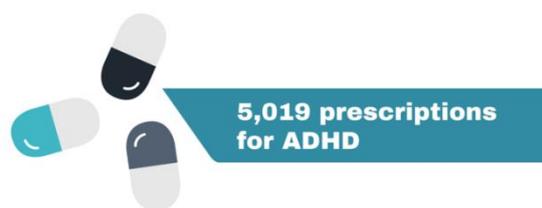
The annual number of prescriptions for central nervous system (CNS) Stimulants and drugs used for ADHD prescribed in Liverpool CCG has increased annually over the past three years with 4,052 items prescribed in 2013/14 rising to 5,350 items in 2015/16.

Figure 24: Prescriptions for CNS Stimulants and drugs used for ADHD, Liverpool CCG 2013/14-2015/16



Source: HSCIC (2016): GP Prescribing by practice iView tool

In 2014/15 there were 5,019 prescriptions for “CNS Stimulants and drugs used for ADHD” made in Liverpool CCG. Table 13 below shows the number of prescriptions per quarter; the number of prescriptions increased slightly from quarter one to quarter three before decreasing slightly in quarter four. The cost of CNS Stimulants and drugs used for ADHD in 2014/15 was £228,393.84.



Prescriptions for ADHD, Liverpool 2014/5

Table 13: Prescriptions for CNS Stimulants and drugs used for ADHD, Liverpool CCG.

	Q1	Q2	Q3	Q4	Total
Items	1003	1238	1413	1365	5019
Actual Cost	£48,376.07	£56,491.84	£62,228.66	£61,297.27	£228,393.84
NIC	£52,309.12	£61,024.17	£67,291.31	£66,218.45	£246,843.05

Source: HSCIC (2015) GP Prescribing by practice via iView tool

Table 14 below provides a more detailed breakdown of CNS Stimulant and ADHD drug prescriptions in Liverpool by drug type. Methylphenidate Hydrochloride was the most commonly prescribed drug in 2014/15 (3,682 items) followed by Atomoxetine (699 items). Dexafetamine and Lisdexafetmines are used as an alternative in children who do not respond to the previous drugs. Modafinil is a CNS stimulant which is generally used for the treatment of narcolepsy. Similarly, Dexafetamine and Methylphenidate can also be used in the treatment of narcolepsy.

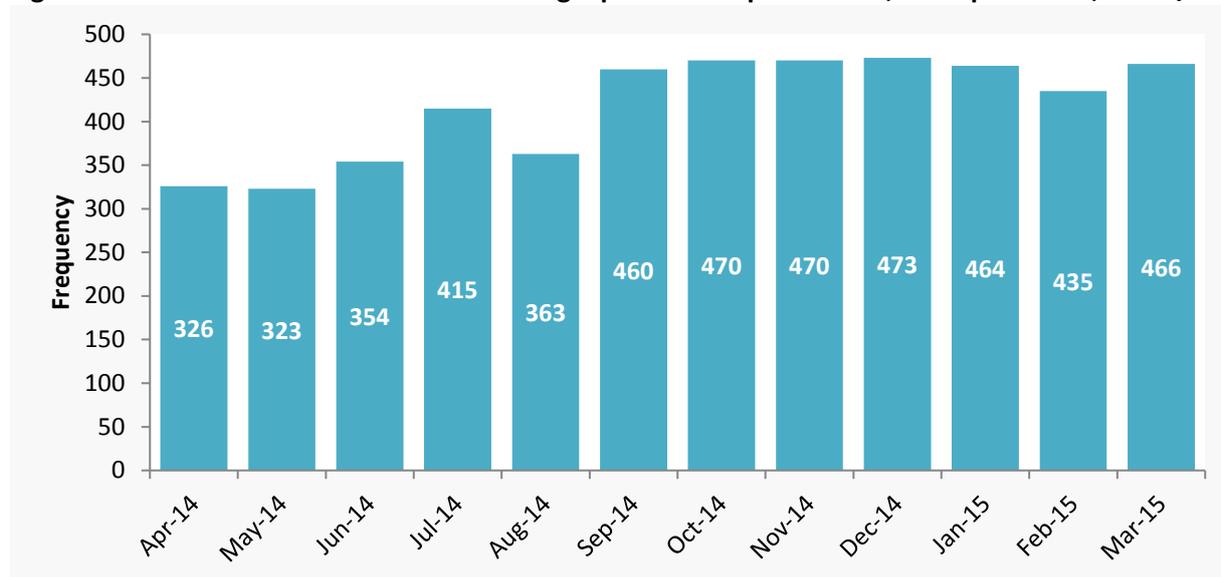
Table 14: Prescriptions for CNS Stimulants and drugs used for ADHD by drug type, Liverpool CCG, 2014/15

Drug name	Number of items
Atomoxetine	699
<i>Atomoxetine HCl</i>	695
<i>Strattera</i>	4
Dexamfetamine Sulfate	149
<i>Dexmethylphenidate Sulfate</i>	149
Lisdexamfetamine Mesilate	24
<i>Lisdexamfetamine</i>	24
Methylphenidate Hydrochloride	3682
<i>Methylphenidate HCl</i>	1402
<i>Ritalin</i>	23
<i>Concerta</i>	1561
<i>Equasym</i>	390
<i>Medikinet</i>	305
<i>Tranquilyn</i>	1
Modafinil	465
<i>Modafinil</i>	459
<i>Provigil</i>	6
Total	5019

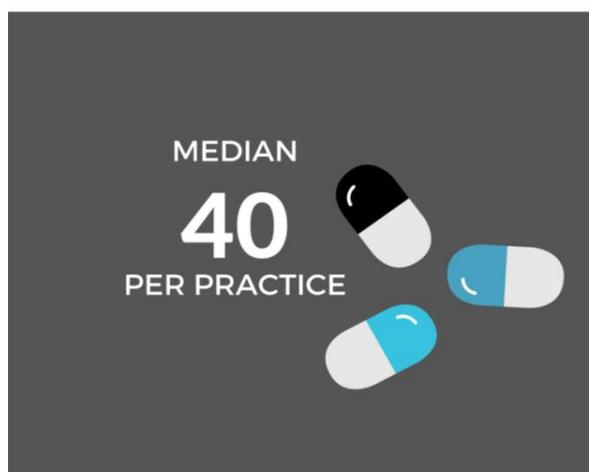
Source: HSCIC (2015) GP Prescribing by practice monthly files, April 2014-March 2015

Figure 25 shows the number of CNS Stimulant and ADHD drug items prescribed per month in Liverpool CCG during 2014/15. Despite some fluctuations (e.g. August), the number of prescribed items increased during the year from 326 in April 2014 to 466 in March 2015 with the highest number of prescriptions made in December 2014 (473 items).

Figure 25: CNS Stimulant and ADHD drugs prescribed per month, Liverpool CCG, 2014/15



Source: HSCIC (2015) GP Prescribing by practice monthly files, April 2014-March 2015



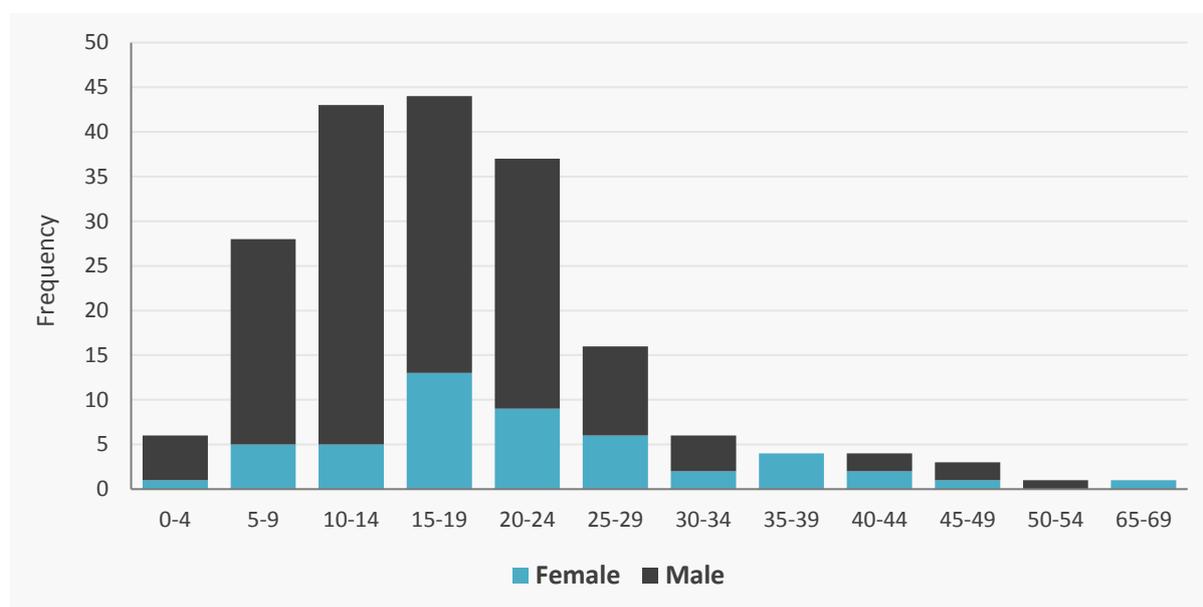
The number of CNS Stimulant and ADHD items prescribed varied considerably by GP practice. The number of items prescribed ranged from 1 to 219 items across the 12 month period and the median number of items prescribed per practice was 40. The five practices with the highest and lowest levels of prescribing are illustrated above; Brownlow Group Practice prescribed the highest number of items in 2014/15.

HOSPITAL ADMISSIONS FOR ADHD

Hospital admissions data for 2015/16 was provided by Liverpool CCG for any Liverpool resident who had ADHD (ICD-10 Code F900 “Disturbance of activity and attention”) recorded in one of up to 12 diagnoses codes recorded for the patient. It is acknowledged that this may underestimate the number of admissions among individuals with ADHD as it is dependent on this code being included in the patient record which may not always occur depending on the nature of the admission. The total adjusted Market Forces Factor (MFF) cost of these admissions was recorded as £237,832.57.

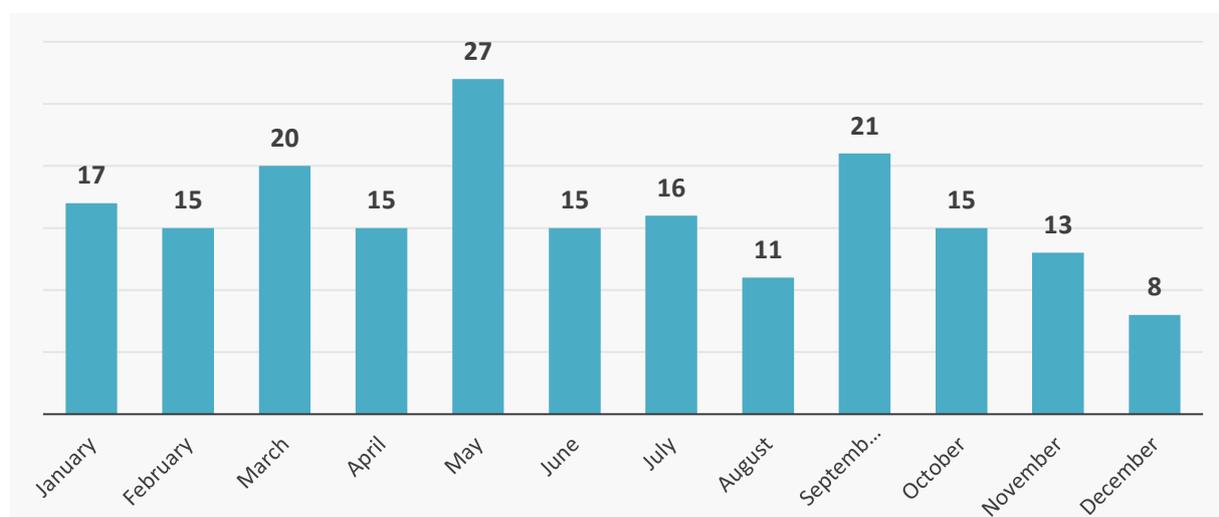
Between April 2015 and March 2016, there were 193 hospital admissions recorded among individuals with ADHD. The majority of these individuals were male (n=144, 74.6%) and over two fifths (n=87, 45%) were aged between 10 and 14 years. Just over three quarters were of white British ethnicity (n=145, 75.1%).

Figure 26: Hospital admissions among individuals with ADHD by age and gender



Admissions for individuals with ADHD peaked in May 2015 (n=27) with the lowest number of admissions in December 2015 (n=8).

Figure 27: Admissions among individuals with ADHD by month 2015



The majority of admissions for individuals with ADHD was at Alder Hey Children’s Trust (n=87; 45%) which corresponds with the age breakdown of admissions discussed above (48% aged 0-19 years). A further 28% were admitted to either Royal Liverpool & Broadgreen Universities Hospital Trust or Aintree University Hospitals Trust (n=55). A full breakdown is included in figure 28 below. The majority of admissions (n=71, 58.2%) were elective admissions with the largest proportion recorded as “Elective admission- waiting list” (n=38, 31.1%) A further 35% (n=43) were recorded as emergency admissions with one in five of the total recorded as emergency admissions at A&E (n=25, 20.5%). The remaining 7% were recorded as maternity admissions and transfers (figure 28).

Figure 28: Admissions among individuals with ADHD by hospital trust, 2015/16

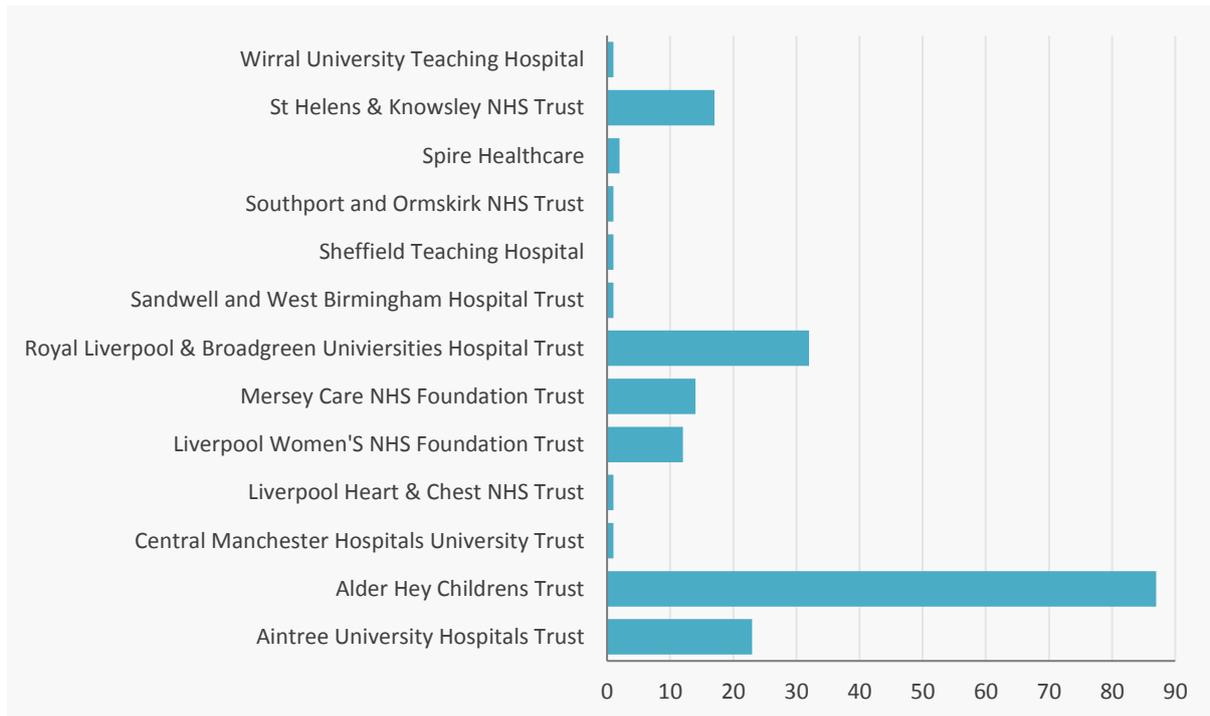
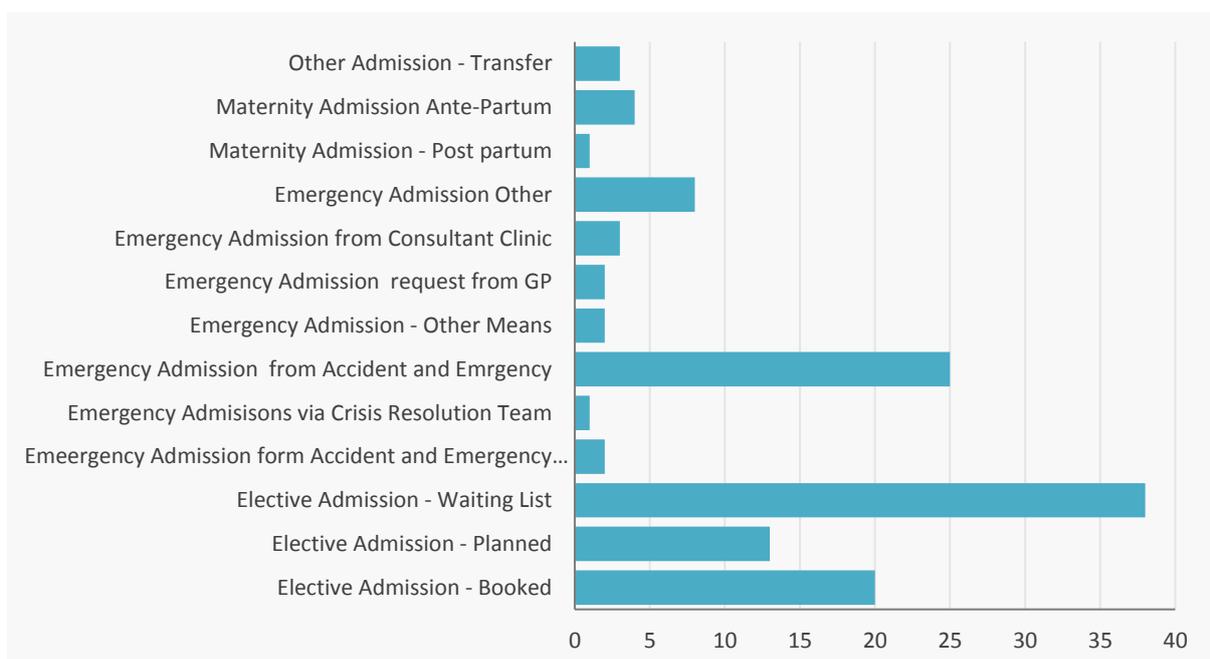


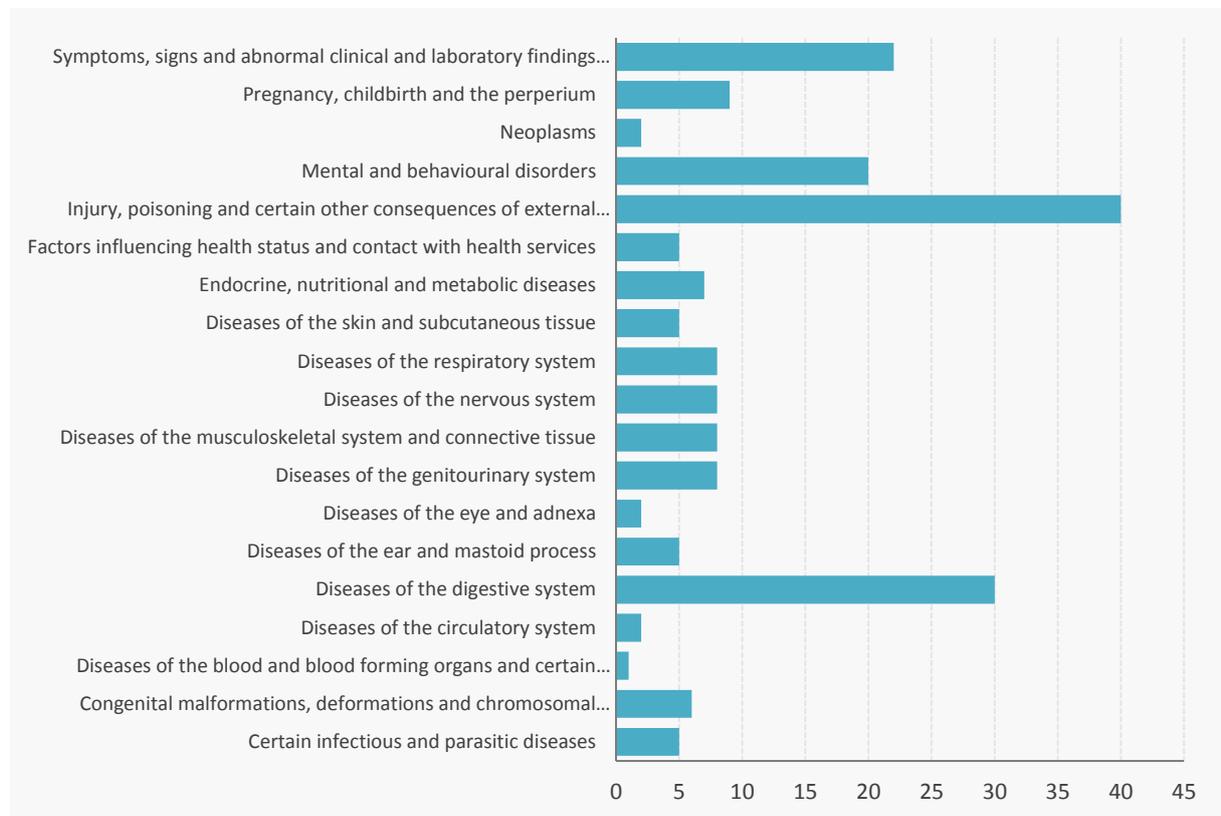
Figure 29: Admissions among individuals with ADHD by admission method 2015/16



The average length of stay for admissions among individuals with ADHD in 2015/16 was 1 night per admission. The number of nights ranged from 0 (n=122) to 20 (n=1).

The primary diagnosis code was used to give an indication of the reason for admission among individuals with ADHD. The broad ICD-10 chapter headings [182] have been used in figure 30 below to group admissions. Just over one in five (n=40, 20.7%) were recorded as “Injury, poisoning and certain other consequences of external causes” of which the largest proportion (n=12) were recorded as injuries to the head. A further 12 admissions were related to drug use either due to poisoning (n=6) or mental and behavioural disorders due to psychoactive substance (n=6). These trends concur with the existing literature which suggests higher prevalence and severity of both childhood injuries and substance misuse among individuals with ADHD. A high proportion were also admitted due to diseases of the digestive system (n=30, 15.5%) and mental and behavioural disorders (n=20, 11.4%) suggesting levels of comorbidity with these conditions.

Figure 30: Admissions among individuals with ADHD by primary diagnosis (broad ICD-10 groupings), 2015/16



6.2 ASD SERVICE USE

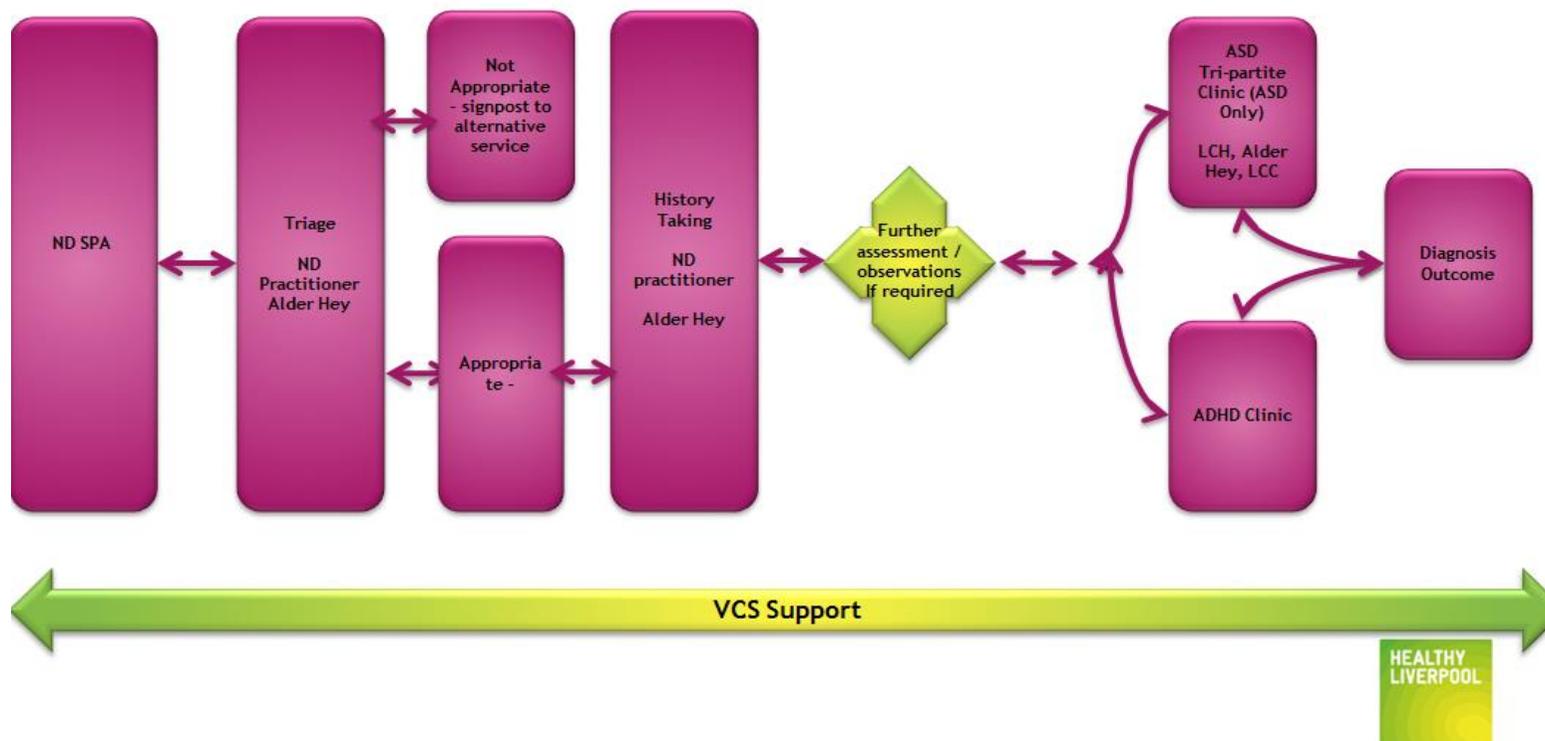
INTEGRATED CHILDREN'S PATHWAY

Liverpool CCG have a single integrated pathway for ND which provides a single source of assessment and referral for all ND conditions including ADHD and ASD. The pathway has been developed around five principles: improving services for children, young people and their families; participation and engagement; workforce development; community based support and, living well and digital technology. The pathway is designed to support children and young people with ND and their families across six stages of neurodevelopmental conditions. This begins at pre-diagnosis with accessible information, self-care and early help through to referral to the ND pathway, followed by assessment and diagnosis, family based support and finally by supporting transition to appropriate adult services. Key elements of the pathway are summarised below:

- **ACCESSIBLE INFORMATION AND SELF-CARE:** an information leaflet has been developed in consultation with all stakeholders in the ND pathway including children, young people and their families. The leaflet includes information on ND conditions, the support available and expectations. In addition, a website hosted by ADDvanced Solutions includes a range of information including the services available, the local offer and resources.
- **EARLY HELP:** a range of early help options are available including community based drop-ins, family learning programmes, consultations, awareness raising, assessment through the Early Help Assessment Tool (EHAT) and Early Help Pre-assessment tool (Pre-EHAT) and training and awareness of the workforce
- **REFERRAL TO ND PATHWAY:** EHAT and Pre-EHAT assessment tools are available as part of early help and, through ND outcome based referral forms, referrals are made to a single point of access through an ND SPA based at Alder Hey Children's Hospital.
- **ASSESSMENT AND DIAGNOSIS:** assessment and diagnosis is completed by ND Practitioners based at Alder Hey Children's hospital. Triage, history taking, further assessments and observations are completed as appropriate at the ND clinic.
- **FAMILY BASED SUPPORT:** Family are supported to access appropriate provision and an ND support plan is put in place to meet the family's needs. This includes input from VCS services, ND practitioners and specialist practitioners. A range of family support is available including sibling groups, family learning programmes, coaching, mentoring and training, sensory integration therapy, care co-ordination, medication, skill building groups, children and young people's groups, key workers and discharge and transition planning. In addition, open access community based drop-ins are available which include general information, speech and language therapy, continence, feeding, CAMHS, sensory processing difficulties and sleeping.
- **TRANSITION:** Transition workers and ND practitioners co-ordinate care for young people transitioning to adult services. This is supported by community networks and champions.

Figure 31: ND Children and Young People’s pathway assessment and diagnosis⁵

Assessment and Diagnosis

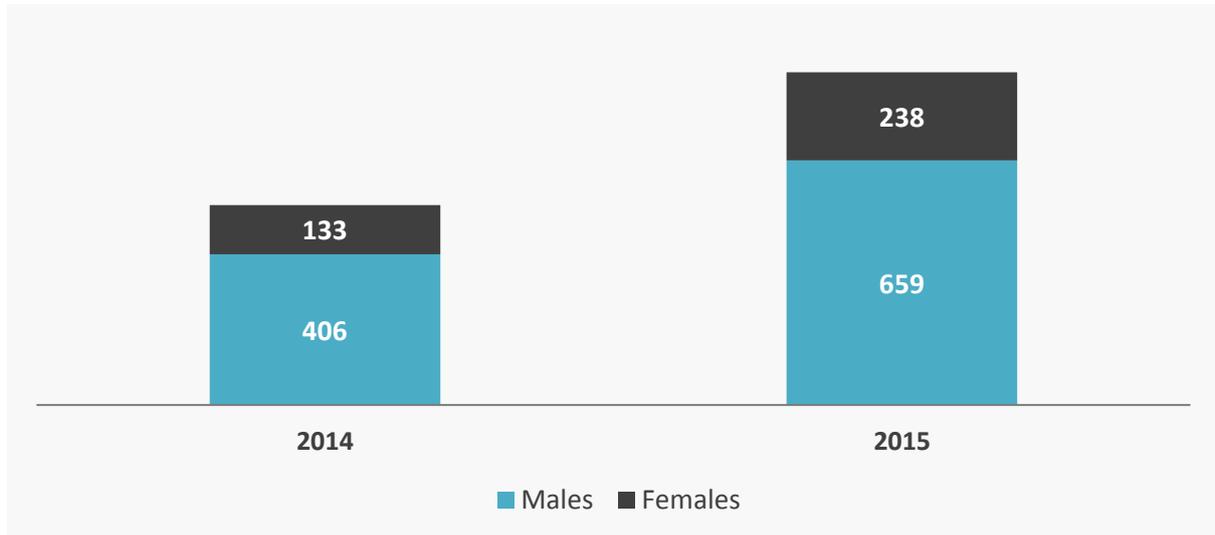


Source: Liverpool CCG

⁵ The pathway is currently being updated.

Figure 32 below shows the number of individuals who were referred directly to the Alder Hey ASD pathway (prior to any triage of information) in 2014 and 2015. Please note that data from 2014 may under represent numbers as referral information is not available for all clients.

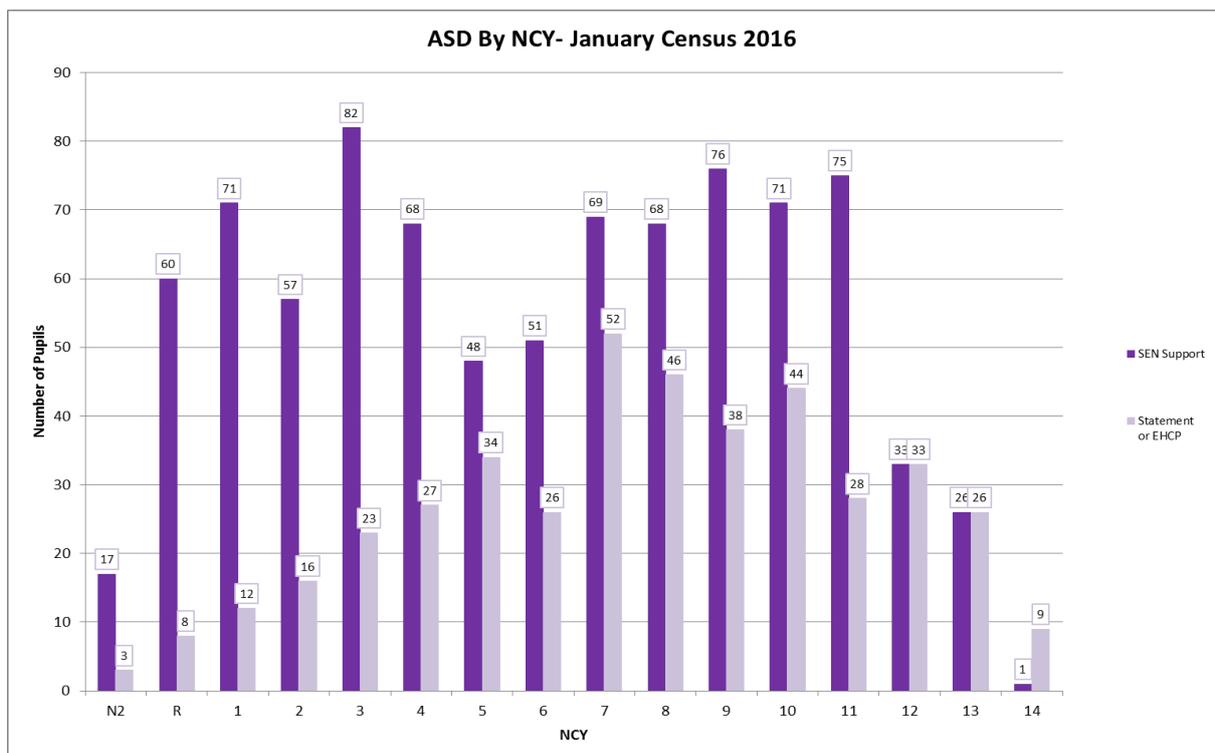
Figure 32: Referrals to the Alder Hey ASD pathway, 2014 -2015



SCHOOL SUPPORT FOR PUPILS WITH ASD

According to the 2016 School Census, there are 873 pupils with ASD as a primary SEN support need and 425 with a statement of EHCP. In line with national trends, there has been an increase in the prevalence of ASD among pupils with statements for SEN or EHC (from 20.5% in 2011 to 26.8% in 2015). Figure 33 below, provides a breakdown of pupils receiving support for ASD by National Curriculum Year.

Figure 33: Liverpool school pupils receiving support for ASD by national curriculum year, 2016



Among pupils with a primary ASD ECHP or Statement, 75% are receiving education at a Special School, 24% in mainstream school and 1% in a free school. Conversely, among pupils with SEN support for ASD, 96% are attending a mainstream school, 2.9% a free school, 0.9% a special school and 0.2% a pupil referral unit (PRU).

Current provision for ASD in mainstream schools includes element 2 SEN funding which is provided to all schools to meet the needs of children with SEN and disabilities. Schools may also apply for Local Authority top-up funding (element 3) if they have exhausted all avenues of additional support. Outreach support is provided to mainstream schools from the specialist sector and resourced provision is provided at 2 primary (St Michael in the Hamlet Primary, 8 places and Phoenix Primary School) and 2 secondary schools (Broadgreen International School, 8 places and Enterprise South Liverpool Academy, 16 places).

Specialist provision is available at six schools, namely: Abbot's Lea Special School (all ages, 213 places), Bank View Special School (secondary, 150 places), Millstead Special School, Princes Special School, Palmerston Special School and Redbridge Special School.

Case Study: Liverpool Sensory Integration Pilot

Between November 2014 and March 2016, Liverpool CCG commissioned Liverpool City Council to run a sensory integration pilot to provide an occupation therapy service for children with Sensory Processing Difficulties up to the age of 18 years. The pilot used Sensory Integration Therapy (SIT) to address underlying sensory difficulties which impact on children and young people's behaviour and motor skills. The pilot objectives were to provide advice, assessment and interventions to parent and professionals and support referrers working with children with who experience sensory difficulties. In addition the pilot aimed to find identify the level of need for SIT in Liverpool, find evidence of SIT's effectiveness and build capacity among Occupational Therapy staff to support children and young people's sensory needs.

Pilot Structure

Two Occupational Therapists were trained to level 3 in SIT and the pilot was delivered in partnership with ADDvanced Solutions. The pilot had a five tiered structured approach:

Level One	Awareness raising sessions for parents and professionals to support self-help and better management of children's health, education and care environments.
Level Two	Solution based drop in for parents. Giving reassurance, support and signposting to parent and professionals face-to-face and via email and telephone.
Level Three	Referral triage: assessed against acceptance criteria and identifying levels of need via request for assessment form from professionals. Referrals received by CareLine and triaged by SI Therapists. Child's need categorised using Care Aims Admission/Treatment Indicators tool.
Level Four	Assessment by SI Therapist if required and activity programmes offered to parents and school. Guidance is given for parents who have sources private SIT but require assistances applying the recommendations; further assessment, advice and strategies at home and in school can be offered.
Level Five	Direct therapy intervention offered to some children depending on assessed need.

Referrals and outcomes

In total 308 referrals were made between November 2014 and November 2015. Referral rate was higher in the first half of the pilot (225 referrals) before dropping in the second half (86 referrals). In total, 108 referrals were accepted onto the pilot of which 92 became active referrals.

A total of 9 professional awareness sessions were delivered to 120 professionals with an additional 80 professional consultations and 16 support sessions. In addition, 8 parental awareness sessions were delivered to 137 parents plus 6 parent solution drop-ins and 146 parent consultations.

There were 60 initial assessments undertaken and 28 further assessments. Seventeen children received a 10 session therapy programme. Each child participating in the therapy sessions had a Goal Attainment Scale (GAS) outcome measure and all children who completed the therapy sessions achieved their goals which include measures such as increased independence in activities of daily living, improved sleep and improved behaviour regulation.

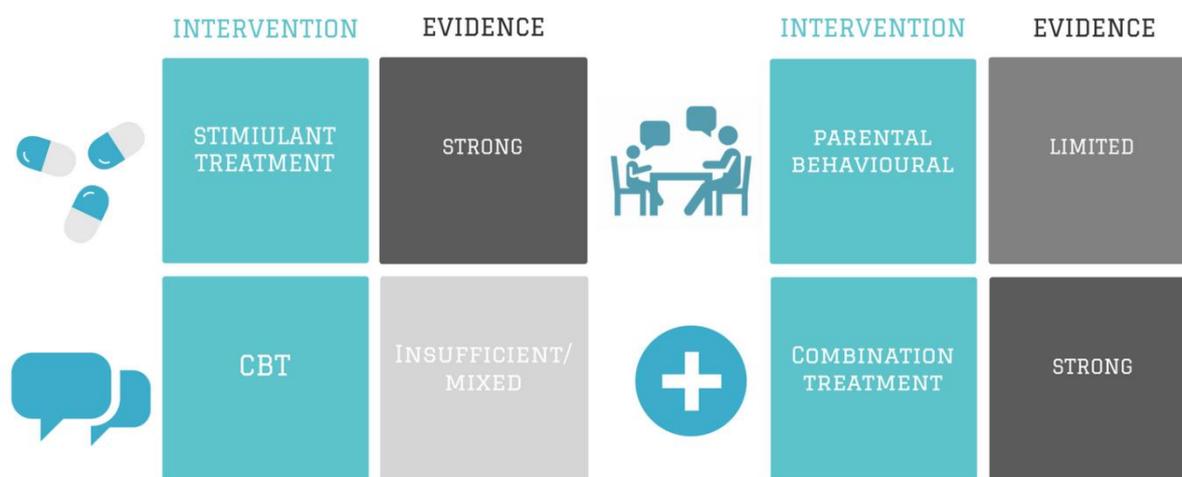
Parent evaluations were returned by 35% of parents. Of those completing an evaluation, 75% rated the pilot good or outstanding including in areas of advice and strategy provision, improving knowledge and awareness of sensory processing and access to the OT service.

7. INTERVENTIONS

A review of the literature was undertaken to identify the range of interventions designed to improve outcomes across the psycho-social-biological model for individuals with neurodevelopmental conditions. The review focuses on systematic reviews and meta-analyses and attempt to consolidate the evidence on the nature, effectiveness and limitations of these interventions.

7.1 INTERVENTIONS FOR ADHD

Figure 34: Summary of the evidence on interventions for children and adults with ADHD



STIMULANT TREATMENT

Stimulant treatment is the most prominent and widely reviewed treatment for ADHD and there is evidence that it can be effective for both adults and children. For example, Surman, Hammerness, Pion and Faraone (2013)[183] found support for this in their study of adults based on self reported measures. Stimulant treatment is often given when someone is first diagnosed with ADHD due to its short-term effectiveness [184]. Other studies have assessed the longer term effectiveness of specific stimulants such as methylphenidate and amphetamine for adults. In a recent systematic review, Fredriksen, Halmøy, Faraone and Haavik (2013) found that stimulant treatment was more effective than a placebo, including at a 24 week follow up[184].

A variety of specific stimulant treatments have been found to have positive effects on those with ADHD. A meta-analysis of the efficacy of methylphenidate and amphetamine found that the effect sizes for amphetamine are significantly greater than those for methylphenidate [185]. Prasad et al. (2013) found that methylphenidate, dexamfetamine and mixed amphetamine all benefitted children's on-task behaviour and the completion of their academic work [186]. However, while stimulant treatment is regarded as one of the most effective psychiatric treatments due to the effect size, some have found that this treatment does have limitations[187]. A number of studies have also questioned the quality of some research into its long-term effects [188, 189].

While research suggests that stimulants may be one of the most effective and commonly used treatments for ADHD, it has been suggested that the number of children being prescribed them is reducing due to parental concern of their side effects [190]. Other interventions are therefore being utilised and examined.

PARENTAL BEHAVIOURAL INTERVENTIONS

Parental intervention is an alternative treatment for ADHD, where training is provided to parents of children with ADHD, to assist them in managing some of the challenging behaviour often associated with ADHD. There is evidence to indicate that this approach can be more effective than some other treatments. A meta-analysis including eight trials comparing parental interventions against control conditions found that the former performed better and resulted in significant improvements for preschool children with ADHD [190]. However, the longevity of the impact of parental interventions has been questioned as over a long period of time the effect sizes may decrease. In 16 studies that examined parent-rated outcomes in follow ups ranging between three and 12 months, Rimestad, Lambek, Christiansen, & Hougaard (2016) [191] examined both the short- and long-term outcomes of parent training on preschool children and found that there were moderate effect sizes for parent-rated outcomes.

Some research has been undertaken into the environments in which interventions take place. One study highlighted that although they appear to be effective in the home, there was a scarcity of research in a school setting [192]. A later review of ADHD behavioural intervention studies did, however, find that parental interventions can be most successful when they are implemented both at home and in a school setting [193]. This may be a topic needing further exploration.

As parental interventions may only have a moderate effect size in the longer term, it has been acknowledged that combining behavioural treatments with stimulant medication may be more beneficial than parental interventions alone because stimulant treatment appears to address most of the problems that are associated with ADHD [193].

COGNITIVE BEHAVIOURAL THERAPY

Cognitive behavioural therapy (CBT) is also being used to treat ADHD, usually in adults. There is, however only a limited amount of research into its effectiveness in comparison to that for stimulant treatment. Although CBT is most often used, Toplak, Connors, Shuster, Knezevic and Parks (2008) [194] suggest that there are a number of other cognitive-behavioural intervention approaches towards ADHD, but that they are not considered to be evidence-based practice. After calculating effect sizes for a number of studies examining cognitive-behavioural, cognitive and neural-based interventions, they concluded that although there was some evidence that some interventions may help to treat ADHD, more research is needed [194].

Studies examining specific types of CBT include Rapport, Orban, Kofler and Friedman (2013) who evaluated the idea that the use of computer-based cognitive training can help to repair executive functions which may be underdeveloped in children because of ADHD [195]. A meta-analysis of 25 cognitive training studies found that significant improvements have not yet been found as a result of cognitive training, but, due to methodological limitations, evidence may be found in future studies. Current research therefore suggests that while there is some, limited, evidence that CBT can be successful in treating ADHD, more studies are needed to confirm that this is the case.

COMBINATION TREATMENT

Combination treatment involves applying different treatments together to try to maximise their benefits by addressing a wider range of symptoms. For example, a number of adults may combine both stimulant medication and CBT. This approach would seem to offer additional benefits when compared to individual treatments. A review of the long-term benefits of combining medication treatment and behavioural treatments found both that this produced the greatest improvements for both symptoms and functional outcomes and that it may also lead to lower medication doses which would in turn lessen side effects of the medication [108]. Other reviews of the literature that looked at long term outcomes of more than two years have found that outcomes from a combination of

pharmacological and non-pharmacological treatment yielded the highest amount of improved outcomes (83%) [196]. While the review found that both pharmacological and non-pharmacological treatments were individually effective, combination treatments were the most consistently effective mode of treatment. This may be due to the two types of treatments addressing different ADHD symptoms.

However, it is evident that further research is needed into the longer term effectiveness of both individual and combination treatments and interventions. A study that reviewed treatments that lasted for longer than one year concluded that there was evidence to suggest that a combination of pharmacological and behavioural interventions, or solely pharmacological interventions can be an effective treatment for the core ADHD symptoms and have an effect of academic performance [188]. The study found that these effects were observed up to 14 months, but that they may decrease over a longer period of time. It has also been suggested that more research is needed to identify if the current combinations of treatment are successful in allowing specific outcome to be reached with regard to longer-term outcome [196].

The benefits of a combination of non-pharmacological and pharmacological treatments may extend beyond longevity to a large effect size. Emilsson et al (2011)[197] used a randomised controlled trial to evaluate a CBT group programme administered alongside medication treated adults. It was found that there were significant effect sizes for the improvement of ADHD symptoms at both the end of treatment and at follow up, with follow up also showing effectiveness for treating comorbid problems [197]. The notion that a combination of treatments can be more effective than separate individual treatments is further supported by a meta-analysis by Van der Oord, Prins, Oosterlaan, & Emmelkamp (2008), who examined the effect sizes of combining psychosocial interventions and methylphenidate [198]. The study found that there were large effect sizes for the combination of the two treatments, while both treatments on their own had a moderate effect size. While treatments can be beneficial on their own, a combination can be more effective in treating ADHD problems.

TREATMENT/INTERVENTION VS. NO TREATMENT/INTERVENTION

Research has also focused on the effectiveness of treatment in general. Some studies have compared the outcome of individuals who have received a treatment or intervention for their ADHD to those who have not. A systematic review of 351 individuals examined the long term effects of treatment and interventions on ADHD with regard to 9 main outcomes: academic, antisocial behaviour, driving, non-medicinal drug use/addictive behaviour, obesity, occupation, services use, self-esteem, and social function outcomes [199]. The treatment of ADHD was found to have led to improvements in all categories, when compared to those who were not treated [199]. This suggests that treatment can indeed make a difference to a number of areas of an individual's life.

OTHER INTERVENTIONS

Some studies have compared a range of different treatments to each other. For example, McGoey, Eckert, and DuPaul (2002)[192] examined 26 articles to evaluate the efficacy of pharmacological, parent training, and behavioural interventions and found that pharmacological treatments were the most effective although there were associated with side effects.

Medical or psychological treatment on its own may not produce the best outcomes. Murphy (2005)[200] suggested that in addition to examining the impact of treatment, it was also important to ensure that those with ADHD had a good understanding of the condition, as this is believed to have a positive impact on them and help to individualise treatment. Moreover, as adolescents with ADHD lacked self-confidence and felt uncertain, feelings of hope may encourage them to engage fully with their treatment.

While research into ADHD treatment is extensive, there are still gaps in its scope and limits to its validity. A review into the effectiveness of non-medical interventions found that there is a lack of studies that have examined the effectiveness of non-medical interventions on academic performance, as most studies focused on medical interventions. Reviewing the literature, the study suggested that research investigating non-medical treatment of ADHD did not include a sample that was representative of the characteristics and population of those with ADHD. The study also suggested that studies examined a restricted range of academic subjects [201]. It has also been suggested that current research into ADHD could be strengthened by using larger sample sizes [192].

7.2 INTERVENTIONS FOR ASD

There is currently no medical or biological treatment for the core features of ASD, although there are medications which alleviated certain aspects of mood or behaviour. The primary source of treatment is interventions which are frequently delivered through families or the education system [202]. There are a range of interventions for ASD which encompass a variety of techniques and target an array of behaviours or symptoms; some of the most common therapies accessed by parents of children with ASD include speech/language therapy, applied behaviour analysis (ABA), occupational therapy and sensory integration therapy (SIT) as well as medication treatments and special diets [203]. An online survey of 552 US parents of children with ASD found that on average parents reported using seven different treatments; with speech therapy the most commonly reported (70% of parents) followed by visual schedules, sensory integration, applied behaviour analysis and social stories. In addition, 52% of parents were currently using at least one medication to treat their child, 43% were using vitamin supplements and 27% were using special diets. The number of treatments used decreased with child age and increased with severity of ASD [204]. However, the popularity of interventions and the frequency with which they are accessed does not always correlate with the level of empirical support for each intervention [203].

There are two types of interventions which are commonly considered in the literature; focused interventions which are designed to produce a specific behavioural or developmental outcome (e.g. prompting, social stories or peer mediated interventions). These focused interventions occur over a relatively short period of time with the intent of demonstrating a change in a targeted behaviour. The second classification of interventions is comprehensive treatment models (CTMs) which consist of practices designed to achieve a broader learning or developmental impact on the core symptoms of ASD (e.g. Early Start Denver Model, UCLA Lovaas Early Intensive Behavioural Invention Model, TEACHH model). CTMs have multiple components, occur over an extended period of time (e.g. a year or more) and are intensely applied (e.g. 25 hours per week) [205].

The primary goals of ASD treatments are to minimize both the core symptoms of ASD and associated deficits, to maximise both quality of life and functional independence and to alleviate stress for families. These goals can be accomplished by facilitating development and learning, promoting socialisation, reducing maladaptive behaviours and educating and supporting families. Interventions should help to reduce the burden of the core features of ASD including communication deficits, impaired social reciprocation and repetitive or restrictive behaviours [206].

There are a number of evidence based interventions that service providers, teachers and parents can use to inform their practice. However, it is important to note that no single intervention has been identified which is effective with every child and the appropriateness of interventions can be affected by a range of characteristics including age and levels of functioning. Clinical practitioners will use their clinical expertise when designing a treatment plan and it is essential that interventions are implemented according to the child's need, ongoing assessment and outcomes. As demonstrated by the evidence base, the most effective treatment may involve the combination of several approaches [207].

Increasing numbers of children diagnosed with autism are now entering adulthood and, as previously discussed, there is limited evidence on the outcomes for this cohort post childhood. A systematic review of 25 studies suggests that the outcomes reported in adulthood are highly variable. Most studies report that adaptive functioning and the severity of autism related behaviours improve over time. However, while some studies report that social functioning, language skills and cognitive ability remain relatively stable, others suggest deterioration over time [208].

Figure 35 below, provides a summary of the evidence on interventions collated by the UK charity Research Autism. This is followed by a review of some of the available evidence on interventions for ASD in adults and children.

Figure 35: Summary of the evidence on interventions for children and adults with ASD

	INTERVENTION	EVIDENCE		INTERVENTION	EVIDENCE
	ARIPIRAZOLE	VERY STRONG		DISCRETE TRIAL TRAINING	LIMITED
	DIETARY SUPPLEMENTS	UNABLE TO RATE		EIBI	STRONG
	INCIDENTAL TEACHING	INSUFFICIENT/MIXED		MELATONIN	STRONG
	MUSIC THERAPY	LIMITED		PIVOTAL RESPONSE	LIMITED
	RISPERIDONE	VERY STRONG		SOCIAL STORIES	INSUFFICIENT/MIXED
	STIMULANT MEDICATION	UNABLE TO RATE		THEORY OF MIND	LIMITED
	VITAMIN SUPPLEMENTS	INSUFFICIENT/MIXED		ANIMAL THERAPIES	INSUFFICIENT/MIXED
	TEACHH	STRONG		VISUAL SCHEDULES	INSUFFICIENT/MIXED

	INTERVENTION	EVIDENCE		INTERVENTION	EVIDENCE
	CBT	VERY STRONG		LEAP	LIMITED
	METHYLPHENIDATE	STRONG		PORTAGE	INSUFFICIENT/MIXED
	SUPPORTED EMPLOYMENT	LIMITED		VIDEO MODELLING	INSUFFICIENT/MIXED
	AUDITORY INTEGRATION	INSUFFICIENT/MIXED		COLOURED FILTERS	INSUFFICIENT/MIXED
	DAILY LIFE THERAPY	INSUFFICIENT/MIXED		DIR METHOD	LIMITED
	MILIEU TRAINING	STRONG		OLANZAPINE	LIMITED
	PICTURE EXCHANGE	STRONG		RELATIONSHIP DEVELOPMENT	INSUFFICIENT/MIXED
	SENSORY INTEGRATION	INSUFFICIENT/MIXED		SOCIAL SKILLS GROUPS	STRONG

Adapted from: Research Autism (2016)[209]

CHILDREN

PSYCHO-EDUCATIONAL INTERVENTIONS

A wide range of psycho-educational interventions for children with autism have been proposed and many have claimed beneficial effects. Educational intervention research has largely focused on younger children as there is evidence to suggest that early identification and intensive intervention may result in substantially better outcomes. It is important to note that there is limited evidence for interventions with children aged under two years of age which is perhaps unsurprising as the average age of ASD diagnosis is four years [203]. A variety of methodologies are used in educational programmes of which the most common include applied behaviour analysis (ABA), structured teaching (or TEACCH method), developmental models, speech and language therapy, social skills instruction and sensory integration therapy [206]. The evidence on these commonly used models is variable; the evidence on ABA is well established whilst for others such as the TEACCH and Colorado Health Science model there is little evidence to suggest that they are well established or efficacious [210].

EARLY INTENSIVE BEHAVIOURAL INTERVENTION (EIBI): EIBI has been considered by a number of reviews to be well-established and effective in treating ASD [211]. EIBI recognises that children with ASD often have significant difficulties in learning; specifically related to learning through imitation and listening as their peers do [212]. EIBI focuses on remediating deficient language, imitation skills, pre-academic skills, self-help and social-interaction. These are broken down into discrete components (known as discrete trial training) which are taught at home or at school on a one to one basis using a range of techniques including: reinforcement, backward chaining, shaping, and extinction, prompting and prompt fading. Parental participation is also considered essential to achieve generalisation and maintenance of outcomes. EIBI is effective when it is both intensive (approx. 40 hours per week) and extensive (minimum 2 years) [213].

A number of systematic reviews have reported that children with ASD receiving EIBI outperformed control groups in intellectual functioning (including IQ and non-verbal IQ), adaptive behaviour, language (including receptive and expressive language) communication and social abilities (including daily living skills and socialization [210, 213, 214]. The largest effect sizes were seen for IQ, non-verbal IQ and receptive and expressive language [210].

The number of behavioural objectives achieved by EIBI has been shown to be directly linked to a higher number of treatment hours and lower child age with children between two and seven years of age showing increased treatment benefits with hours spent in treatment [211]. Warren et al (2011) compared different model variants of EIBI interventions and found that University of California Los Angeles/ Lovaas based interventions reported clinically significant gains in language and cognitive skills in some children as did one RCT using the Early Start Denver Model [215]. Specific parent-training approaches produced short time gains in language functioning and challenging behaviours.

However, there are some limitations to the EIBI approach which are worth highlighting. Firstly, the 30-40 hours of training in the home required by EIBI can be burdensome to both families and service providers. Secondly, as previously mentioned, there has been less focus on interventions for children under 2 years of age who are at risk for or diagnosed with ASD. A systematic review by Bradshaw et al (2015)[203] reported on nine early interventions for infants at risk of ASD. These studies provided preliminary support for effects on infant behaviour including increased liveliness and improved social communication but highlight the need for further investigation and intervention development.

TREATMENT AND EDUCATION OF AUTISTIC AND COMMUNICATION-HANDICAPPED CHILDREN (TEACCH): sometimes also referred to as structured teaching, TEACCH is a psychoeducational intervention developed by Eric Schopler in the 1960s [216] which can be delivered in both home and school settings. TEACCH's approach is based on understanding the culture of autism.

Its main principles are developing and individualized person and family centred plan for each individual, structuring the physical environment and using visual supports to make daily activities easy to understand and support individual tasks. Structured teaching was first introduced in the UK in 1990 and quickly became established in classroom practice. A number of systematic reviews suggest that TEACHH has positive effects on problem behaviours and increases independent task organisation and engagement. However, there remains limited evidence on the effects of TEACHH on wider social outcomes (e.g. wellbeing and quality of life) as well as limited evidence to evaluate the experiences of those who implement and receive TEACHH interventions [217].

SENSORY INTEGRATION THERAPY (SIT): Although not part of the diagnostic criteria for ASD, studies suggest that sensory impairments such as avoiding ordinary visual, tactile, oral and auditory stimuli is common although prevalence varies considerably across studies. Sensory Integration Therapy (SIT) is built upon the hypothesis that these abnormal behaviours are caused by a deficit in the nervous system leading to sensory stimuli being processed abnormally. It proposes that, given the nervous systems ability to change (neuroplasticity), providing certain forms of sensory stimulation in the appropriate dosage may improve the nervous systems ability to process sensory stimuli. However, it must be noted that the exact nature of the impairment to the nervous system and the influence of SIT on sensory processing remains the subject of much ongoing research and debate [218].

SIT is among the most common interventions delivered to children with ASD and typically involves a set of activities based on a child's sensory profile involving tactile, vestibular or proprioceptive sensory stimulation. This aims to support: self-regulation and sensory awareness of movement, alertness and motor control. Examples of activities include wearing a weighted vest, being brushed or rubbed with various objects and swinging [218]. Three systematic reviews of SIT [218-220] and an additional review which specifically considered Auditory Integration Training (AIT)[221] report that existing studies are of mixed methodological quality and there is current insufficient evidence to support the use of SIT as a therapy for children with ASD. Yunus et al (2015) suggest that tactile-based therapies (e.g. massage) are the most promising in reducing behavioural problems [219].

SOCIAL SKILLS DEVELOPMENT

Social communication interventions exist for children and young people across the 0-18 year's age range, although as previously stated there are less interventions for children under 2 years of age. In addition to interventions for all age groups, there are a number of age specific common interventions. Parent-implemented, naturalistic and pivotal response training interventions are common for infants and toddlers. Interventions such as peer mediated interventions, social narratives, visual supports and cues, video modelling and self-management interventions become more common with increasing age. Similarly, the outcomes targeted by these interventions vary beginning with joint attentional skills and functional play skills for infants and toddler with focus moving towards socio-emotional reciprocity and social relationship skills with older children [207].

The evidence on both the quality and effectiveness of these interventions varies considerably. Computer based interventions (CBI) show established evidence based practice [222] and video modelling has been identified as a potentially promising intervention [223, 224] although the evidence on this is mixed [223]. There are a number of promising interventions to increase social motivation, initiation and participation including social skills groups, the Picture Exchange communication system, joint attending interventions and parent-mediated strategies [225, 226].

PEER MEDIATED INTERVENTIONS: Individuals with ASD often require interventions to address deficits in social interaction, communication and academic achievement. Peer-mediated intervention (PMI) involved peers (e.g. classmates) being trained to act as the intervention agents. Peers in schools can take on a number of roles including instructional programmes, behavioural interventions and facilitating social interactions. Most commonly, these interventions include initiating simple play or

attempting to engage participants in conversation and can include elements such as training peers to: maintain interactions, prompt certain behaviours (e.g. play, communication, and motor skills) and academic instruction (e.g. clarifying teacher instructions, rephrasing written instructions or reading passages). The majority of PMIs report positive outcomes including: communication, initiating play, maintaining social interactions, turn taking, academic and reading skills and decreasing challenging behaviour [227]. A meta-analysis of peer-related social competence interventions reviewed 37 studies and found that, on average, the interventions produced a moderate to strong effect. It is worth noting that the estimates of effect size did vary considerably with adult mediated, combined child specific, peer mediated and multi-component studies producing strong effect sizes and social narratives and collateral skill interventions falling in the moderate range [228].

Making use of the numerous peers in schools appears a practical approach to efficiently provide services to the increasing numbers of children and young people being identified with ASD by increasing their access to intervention whilst reducing the burden of demand on teachers and professionals. In addition, the direct interaction between students facilitated by the intervention may also increase inclusion for those with ASD in school settings and opportunities to practice skills with multiple people. However, there are several concerns regarding PMI, in particular that peers may inadvertently highlight the deficits of the individual with ASD leading to stigmatization and increase social exclusion; that peers delivering instruction as part of these interventions may be missing out on instruction themselves; that these interventions may be delivered with less constancy than those delivered by professional leading to failure, and that these interventions may need the typical classroom routine to be reconsidered [227].

Typically developing siblings of children with ASD have also been suggested as a logical extension of peer mediated interventions; allowing children with ASD to frequently practice social skills that can be potentially generalised across peers in school and in the community. A systematic review of 17 studies with sibling involvement found that these studies produced similar results to peer mediated interventions and lead to positive outcomes for children with ASD including skill acquisition and decreases in problematic behaviour [229].

PARENT MEDIATED INTERVENTIONS: Involving parents in the implementation of interventions allows continual opportunities for children's learning in range of situations; parents as "co-therapists" allows consistent handling and ensures that interventions are appropriate in enhancing children's earliest social relationships. In addition, as well as benefits for children, parental interventions have the potential to produce benefits for parents through reduced stress and renewed confidence [230], particularly as intervention studies for children do not routinely measure parental and family outcomes [231]. A systematic review of 12 studies involving parent mediated interventions found that there is sufficient evidence that parent training can work in improving observed social communication skills in children; this is confirmed by multiple baseline studies which found positive language and behaviour change. Multiple baseline studies also indicated positive effects on parents including increased parental knowledge, performance and skills with one study also reporting reduced stress. The review also suggested that parent training does produce a positive effect on children's social communication behaviour, parental performance and parent child interactions [230].

COMPUTER BASED INSTRUCTION: School-aged children with ASD often appear unresponsive to traditional literacy teaching techniques and, regardless of the educational setting, children with ASD frequently have difficulties with: learning symbols, communicating academic concepts, difficulties forming relationships with teachers and peers and, challenging behaviour which may also impede their academic progress. Computer based instruction (CBI) is a potentially viable approach to teaching literacy skills to students with ASD for a number of reasons: firstly, research shows that children with ASD respond well to information presented visually, secondly CBI could minimise the social deficits experienced by children with ASD by reducing the quantity and complexity of teacher-student

interactions, thirdly, research suggests students with ASD are highly responsive to using computers and finally CBI can be used to individualize instruction by selecting difficulty settings appropriate to each student's ability level. A review by McCoy et al (2016)[222] found that CBI had established evidence based practice; however, a systematic review of 12 studies which used CBI to improve literacy among children with ASD reports that the current evidence is limited with inconsistent findings on the effectiveness of CBI on literary skills [232].

SOCIAL STORIES: have been suggested to positively affect the social understanding and behaviours of children with ASD [233]. Social Stories describe a situation, skill, or concept in terms of relevant social cues, perspectives and common responses to share social information with patients in a reassuring manner. It is a short story written for an individual that describes a specific activity and the behaviour expectations associated with that activity and can be either read, through audio or video equipment or through computer based programmes. A review of six RCT trials using Social Stories found that it may be beneficial in modifying target behaviours among children with high functioning ASD however there is no evidence on the long term maintenance of these effects, the effectiveness of the intervention in other, less controlled settings or the optimal dose/frequency and this requires further research [234]. Similarly, a review of 22 social stories interventions found mixed findings of effectiveness suggesting they might be more effective for some participants than for others [235].

OTHER

CHOICE: Research suggests that embedding the opportunity for children with ASD to make choices (e.g. which task to complete, the order tasks are completed or the materials used) into interventions has the potential to improve motivation, engagement and academic performance while also reducing challenging behaviours. A systematic review of single-case design studies examined the role of choice in interventions to improve academic outcomes. The review found that providing a choice component results in improvements in student work completion, behaviour (including a reduction in challenging behaviour) and affect and interest. Studies with a choice component outperformed studies with no choice component [236].

DIETARY INTERVENTIONS: Gluten Free and Casein Free (GFCF) diet interventions linked to "the Opioid-excess theory" (which proposes that ASD is linked to insufficient enzymatic activity, increased gastrointestinal permeability, and the absorption of toxic by-products of incompletely digested proteins from dairy and cereals) and suggests that it may be possible to alleviate autistic symptoms by not allowing individuals with ASD to eat gluten or casein. A systematic review of 14 studies of GFCF interventions among children and young people with ASD aged between 2 -17 years found that the current body of research does not support the use of GFCF in the treatment of ASD. In addition, the GFCF diet has been linked to a number of health risks including an increased risk of nutritional deficiencies and suboptimal bone development with reduced bone cortical [237].

FEEDING INTERVENTIONS: Feeding difficulties are fairly common among children with ASD but there is limited evidence on effective treatment. The majority of studies are small scale, experimental design and use an operant conditioning style intervention where the child is prompted to perform an action and receives a contingent response. Favourable intervention outcomes were observed in terms of increasing the volume but not necessarily the variety of foods consumed; further research in the form of randomised controlled trials are needed in this area [238].

MUSIC THERAPY: Children and young people with ASD and significant limitations in verbal and non-verbal communication are found to respond positively to music therapy. Music is considered an effective medium because it contains many levels of structure and yet provides a flexible and variable medium to counteract some of the more rigid characteristics of ASD pathology. Music therapy interventions involve both active, improvisational and receptive music therapy approaches and it is suggested that outcomes include facilitating motivation, communication skills and social interaction

as well as sustaining and developing attention. A systematic review of music therapy interventions for ASD found two RCTs which examined the short term effects; significant effects were found even with small sample sizes highlighting the potential for music to improve outcomes. Case series studies of improvisational music therapy found that communicative behaviour, language development, emotional responsiveness, attention span and behavioural control improved over the course of the intervention [239].

MEDICATIONS

Siegel and Beulieu [240] undertook a systematic review of 33 RCTs of common psychotropic medications for children with ASD including antipsychotic, mood stabilizer, selective norepinephrine reuptake inhibitor, serotonin reuptake inhibitor and stimulant medications. Three antipsychotic drugs were found to have established evidence of effect namely: risperidone and aripiprazole for treatment of irritability and hyperactivity, aripiprazole for treatment of stereotypy and a haloperidol for the treatment of negative behavioural symptoms. These findings agree with a second systematic review by McPheters et al [241] but this review also highlighted strong evidence of significant adverse effects associated with both risperidone and aripiprazole including weight gain, sedation and risk of extrapyramidal symptoms. A number of other treatments also showed promising or preliminary levels of evidence including methylphenidate for treatment of hyperactivity (promising), naltrexone and atomoxetine for hyperactivity (preliminary), risperidone for repetitive behaviour and stereotypy and pentoxifylline in combination with risperidone for irritability and social withdrawal [240].

Secretin, a gastrointestinal polypeptide, was a subject of increased interest after the publication of an uncontrolled non-blinded case series of 3 children with ASD who reported social, cognitive and communicative gains after synthetic intravenous secretin. However, there is little evidence to support secretin as a treatment for ASD with a systematic review of 13 randomized studies revealing no evidence for the effectiveness of single or multiple doses secretin in children or adults with ASD; despite exhaustive RCT studies there is no clear evidence that it has treatment benefits for children with ASDs [242].

Some studies suggest that the prevalence of sleep abnormalities in children with ASD when compared with their peers; ranging from 40-86%. Melatonin is a hormone and neurotransmitter produced by the pineal gland and is commonly used for insomnia in children as an inexpensive, readily available in often efficacious drug with a favourable side effect profile. A systematic review of 35 studies of Melatonin use in children with ASD found evidence of improved daytime behaviour, sleep duration, sleep onset and night-time awakenings. A meta-analysis of the results from five randomized double-blinded placebo-control trials found significant improvements for melatonin use with large effect sizes in sleep duration compared with both baseline and control [243].

ADULTS

PHYSICAL EXERCISE (ADULTS AND CHILDREN)

Individuals with autism are more likely to experience difficulties with balance, gait, joint flexibility, postural stability and speed of movement and these difficulties in movement may be exacerbated by reduced opportunity to engage in physical activity. A systematic review of 16 studies across individuals with ASD aged 3-41 years which aimed to increase participation in physical exercise through a range of means including running, jogging, swimming, water aerobics and a range of other activities found that such interventions result in increased stereotypy or self-stimulatory behaviour and, to a lesser extent, improvements in physical fitness and academic functioning [244].

A second systematic review of 13 studies which used exercise interventions specifically for children (aged 16 years and under) with ASD. Interventions including jogging, horse riding, martial arts, swimming and yoga/dance resulted in improvements in numerous behavioural outcomes including

socio-emotional functioning, stereotypic behaviours, cognition and attention. Horse-riding and marital arts produced the greatest results with moderate to large effect sizes respectively. Results indicate that exercise may be an effective intervention for multiple behavioural outcomes in this population. More specifically, exercise may result in a decrease in stereotypic behaviours and improvements in social-emotional functioning, cognition and attention [245]. One systematic review also reported preliminary evidence that daily yoga and brief exercise may improve classroom performance and behaviour and that group physical activities may improve school readiness [246].

ANIMAL-ASSISTED INTERVENTIONS (YOUNG ADULTS AND CHILDREN)

Animal assisted interventions (AAI) have been used in a range of clinical populations to improve psychosocial wellbeing; with documented outcomes including reduced stress, loneliness and isolation, lower heart rate and blood pressure and increase social interaction, connection and socio-emotional functioning. AAI has been suggested as a potential intervention for individuals with autistic spectrum disorder. A systematic review of 14 studies of AAI including horses, dogs, guinea pigs, rabbits and llamas found preliminary support for the concept of AAI for individuals with ASD with increased social interaction and communication outcomes and reduced problem behaviours, autistic severity and stress. However, the studies reviewed are preliminary in nature with few high quality studies and many methodological weaknesses and more rigorous research will be necessary to progress from preliminary studies to clinical trials [247]. This concurs with the findings of a systematic review of 20 AAI studies for children with ASD, which found that whilst AAI studies report either positive or mixed results there are multiple methodological flaws and further investigation is needed [248]. Similarly, the evidence on pet dog ownership for families with a child with ASD is also limited and as Crossman and Kazdin [249] state; while there is no need to discourage pet ownership and the associated benefits, the evidence on the effect of pet ownership remains methodologically weak and unestablished.

ADAPTIVE SKILLS

Independent functioning is an important issue for people with high functioning ASD and adaptive behavioural measures along with IQ and level of support have been found to be closely linked to overall social functioning and independent living. As previously mentioned, several reviews have analysed adaptive skill building in children with EIBI appearing the most promising approach; however, few studies have looked at adaptive skill building in young adults (aged 16 years and over). A systematic review of 20 studies in high functioning young adults with autism found that improvements in adaptive skills in 19 studies, with low or high tech assisted procedures (e.g. video modelling, visual cues, self-recording, self-reinforcement, self-prompting), reinforcement contingencies and corrective feedback prompts the most promising [250].

VOCATIONAL INTERVENTIONS

Interventions to assist individuals with vocational skills as they reach adolescence and young adulthood are not well understood. A systematic review of five studies which all involved supported employment found that the methodological quality of these existing studies was poor. There is some evidence to suggest that supported employment may increase rates of employment for young people with ASD and limited evidence to suggest improved quality of life and cognitive functioning; however, due to the quality of the existing studies this evidence is limited [251]. A systematic review suggests that the use of tablet and mobile technologies for vocational skills may increase occupational performance as do cognitive orientation to occupational performance, sensory integration and contextual interventions [246].

MEDICATION

Medication treatments for ASD are primarily directed towards improving associated symptoms for individuals with ASD, as opposed to behavioural interventions where the focus tends to be on improving core symptoms. Many treatments for children with ASD have been studied but there has been less focus on treatment interventions among young adults despite: medication use being

common in this group [252] and, symptoms, support requirements and response to pharmacotherapy will differ considerably from childhood to adulthood [253]. Systematic reviews suggest that the quality of existing research is poor [252, 253]. A systematic review of 8 studies among young adults with ASD (aged 13-30 years) found that only half of the studies were of reasonable quality and there was insufficient evidence for all medication associated outcomes. However, there is some moderate evidence to suggest that the atypical antipsychotic risperidone is successful in treating problem behaviour such as aggression, repetitive behaviour and sensory motor behaviours although there is also evidence for adverse associated events including weight gain and sedation [252].

COGNITIVE BEHAVIOURAL THERAPY (CBT)

It is estimated, that as much as 50% of young people with ASD experience clinically significant anxiety. CBT has been modified to treat anxiety symptoms in young adults with high functioning ASD but the findings have been mixed. A systematic review of 14 studies with 511 youth found that CBT demonstrates robust efficacy in reducing anxiety symptoms among young adults with high functioning ASD. Similarly, a review of 12 studies among young people with ASD indicated that CBT produced reductions in anxiety, obsessive compulsive disorder and depression (Walters et al, 2016)[254]. Meta-analysis of psychosocial interventions to reduce anxiety in young people with ASD found that these interventions were superior to wait-list and treatment as usual controls however the difference in self-reported outcome measures between the intervention groups and controls failed to reach statistical significance [255].

TECHNOLOGY AIDED INTERVENTIONS

Literature review of technology aided interventions examined the use of technology in educational settings, in the home and in the community for adolescents with ASD and their families. There has been little focus on young adults in the intervention literature, however given the evidence of poor post-school outcomes for young adults, technology assisted interventions are very important for young adults as they reach the end of their school careers were they might access support for technology use. A literature review of technology aided interventions published between 1990 and 2013 identified 30 studies which documented the efficacy of different forms of technology and their impacts on academic attainment, adaptive behaviour, challenging behaviour, communication, independence, social competence and vocational skills [256].

GROUP SOCIAL SKILLS INTERVENTIONS

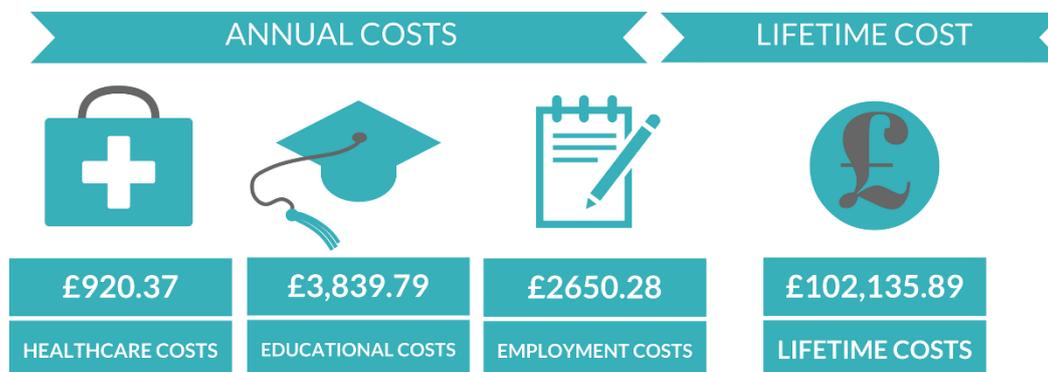
Social skills interventions have been shown effective in improving socio-communication skills in children with ASD but little is known about the effectiveness of these interventions for adults with high functioning ASD. A systematic review of five studies found that group social skills interventions show tentative effectiveness in enhancing social knowledge and understanding , improving social functioning, reducing loneliness and potentially alleviating co-morbid psychiatric symptoms; however, there is a degree of variation in the structure, duration and content of these interventions and well as several methodological limitations [257].

LIFETIME COSTS OF ADHD AND ASD

THE COST OF ADHD

Khong (2014) pooled estimates from a number of studies to estimate the annual and lifetime costs of ADHD across four domains: healthcare, education, employment and crime [258].

Figure 36: Lifetime costs of ADHD



(Source Khong, 2014 [258])

Cost of healthcare

The pooled annual healthcare costs of ADHD from five studies were found to be £920.37 (range: £311.09 - £1,410). The healthcare costs measured in each study varied considerably with no cost being consistently recorded across all five studies. Costs included across the studies were medication costs and NHS costs including psychiatrist, paediatric, primary care and mental health visits and hospital admissions. There was also inconsistency in the criteria used for ADHD diagnosis. However, all five studies indicate a significant cost from healthcare utilisation for ADHD patients.

Educational Costs and Outcomes

The pooled average annual educational costs from three studies were found to be £3,839.79 (range: £3153.84-£4,472.15). All three studies considered the indirect effects of ADHD and education and how this could affect both future likelihood of criminality and future employment outcomes. All three studies suggest a significantly higher outcome cost for individuals with ADHD compared with controls.

Direct effects on employment

Evidence from two US studies suggests the average annual income loss due to ADHD is £2650.28 [range: £1,913.88-£3,386.69]. The studies found that individuals with ADHD generally have poorer employment outcomes than individuals without ADHD and this is likely due to the indirect effect of education and poor academic outcomes on future employment and earnings. European and US studies disagree on the magnitude of the earnings gap between individuals with and without ADHD (50% in European Studies compared with 11-15% in US studies) and it has been suggested that this is due to differences in ADHD diagnosis thresholds and social welfare policies. This highlights the need for UK based cost evidence.

Effect on crime

Perhaps surprisingly, the general consensus is that ADHD has no clear consequences on criminal activity or recidivism. Instead, recent papers report that other disorders and conduct disorder in particular confound these outcomes and that there is little difference between individuals with and without ADHD when these other disorders are controlled for.

Lifetime costs of ADHD

Education, healthcare and employment values have been used to calculate the lifetime cost of illness. The lifetime cost of illness is estimated at £102,135.89 [£69,656.56 - £131,085.32] based on an individual born in 2013 over the course of 50 years with an annual discount rate of 2.5%.

THE COST OF ASD

Autism Spectrum Disorders can potentially have a range of economic impacts across both health and social services and for both individuals and their families. Knapp et al (2009) estimated that the cost of supporting children with ASD in the UK was £2.7 billion per year and for adults the costs were £25 billion per year [160]. For children with ASD, 95% of the costs are associated with publically funded services with the remaining 5% costs to the family. Among adults, 59% of the costs are attributable to publically funded services, 36% due to individual loss of employment and 5% due to family expenses. The lifetime cost for those with ASD and intellectual disability is approximately £1.23 million and the cost for those with autism without intellectual disability is £0.08 million. The estimated average annual cost per adult living with autism ranges from £37,000 (for those with high functioning autism and living in a private household) to £110,000 (for those with low functioning autism and living in a hospital setting [259, 260].



£80,000

LIFETIME COSTS

The cost of Conduct Disorder and behavioural problems

Both ADHD and ASD have high level of comorbidity with conduct disorder and severe behavioural problems. The cost of these problems therefore has important bearing on the costs associated with neurodevelopmental conditions. Various attempts have been made to estimate the long-term costs of severe behavioural problems across the life course; however, it is acknowledged that these are likely to underestimate the costs due to the broad range of associated outcomes and the difficulty expressing these in monetary terms [261]. Scott et al [262] report that by the time children with conduct disorder reach their last twenties, they will have public sector costs ten times the costs of those without behavioural problems. Most studies focus on public sector costs and suggest broad annual estimates of £5,000 per child taking into account health, social care, education and criminal justice. Romeo et al [263] suggest that annual costs per child are as high as £15,000 when taking into account the wider costs to families. One study which attempted to measure the societal rather than public sector costs suggests the lifetime costs amount to around £260,000 per case with the lifetime costs of moderate problems at around £85,000 per case. Similarly a study of early onset conduct disorder found that this poses an economic burden of around £225,000 per child over their life time [264, 265]. Costs of crime relate to two-thirds of this total and it is believed that this estimate may omit some other associated costs for example bullying which is a common behaviour among individuals with severe behavioural problems [261].

THE COST OF ADHD AND ASD INTERVENTIONS

ADHD INTERVENTIONS

PSYCHOLOGICAL THERAPIES: there is some evidence that psychological interventions may have an impact on core ADHD symptoms such as disruptive behaviour. NICE recommend cognitive behavioural therapy and social skills training for school aged children with ADHD. NICE suggest that these interventions have moderate beneficial effects on parent-rated ADHD symptoms and conduct problems at 3-6 month follow up compared with control. However, teacher rated symptoms showed no improvement suggesting the outcomes do not transfer from home to school and positive findings on CBT are not consistent across evaluations [261].

Evidence from school based Social and Emotional Learning (SEL) programmes for conduct disorder has been used to model the ten cost savings of SEL programmes for a ten year old with conduct disorder. Without SEL it is estimated that 46% of children have conduct problems throughout their life course 24% have conduct problems in childhood that do not persist, 20% develop conduct problems in adolescence and 11% have life-course persistent conduct problems [160]. The model estimates that school-based SEL programmes achieve a 9% reduction in transition between conduct health states (e.g. conduct problems, moderate conduct problems and severe conduct problems). The model estimates that SEL produces cumulative cost pay offs of £6,369 after 5 years and £10,032 after ten years. The greatest savings are crime related costs including criminal justice, victim costs and other crime costs (Knapp et al, 2009)[160].

GROUP PARENTING: NICE recommends parent training programmes for children with ADHD. Parenting programmes teach behaviour management techniques to the parents of children for ADHD and examples include the Incredible Years Programme. The focus is on conduct problems and, by strengthening parenting skills and involvement, aims to prevent, reduce and treat behavioural and emotional problems in children aged 2-12 years. The sessions last 2 hours and run for 14-18 weeks. Parenting programmes have moderate effects on ADHD symptoms and disruptive behaviour in children displaying conduct problems but further research is needed to evaluate how psychological and psycho-educational interventions impact upon other impairing features of ADHD. Group parenting interventions cost £1,211 per participant and the benefits are estimated at £1,654 [261]. Benefit cost ratio is 1.4:1. Knapp et al [160] place this slightly lower at £1,177 per family. Findings from conduct disorder studies suggest that without intervention conduct disorder could persist in around 50% of children [160].

A study specifically focusing on conduct disorder considers the costs and savings up to age 30 for a 5 year old child whose parents attend a parenting programme. The model assumes that the intervention decreases the chance of early onset and thus avoids high costs to society. Over the 25 years the gross savings from parenting programmes amount to £9,288 per child; exceeding the cost of intervention by 8 to 1. These savings are across social services, education, criminal justice (including costs to perpetrators and victims) and voluntary sector and include £3,368 savings to the public sector of which £1,278 is to the NHS. Interventions provide a positive return to the public sector in year 8 and to the NHS in year 14.

PHARMACOLOGICAL INTERVENTION: NICE discuss the use of pharmacological interventions in severe cases of ADHD where psychosocial treatments are not working. They must be implemented by a qualified health professional with expertise in ADHD and a full physical, social and historical assessment of the individual and family should be taken beforehand. Evidence shows that pharmacological treatment when taken in the correct dosage can be effective in reducing ADHD symptoms particularly relating to behaviour. However, it is important to monitor side effects and drugs should always be administered as part of a comprehensive treatment programme [261].

MULTIMODAL THERAPY: multi-modal therapy (MMT) is an example of a treatment combining medication management and behavioural interventions. Evaluation of MMT in children with ADHD suggests a small to moderate effect on disruptive behaviour but not on ADHD symptoms. Group treatment costs £1,495 per year per participant and the benefit cost ratio is 2:1. However, individual MMT is not cost effective because of its very high cost (£13,568 per individual). The benefits derived from group based MMT result mainly from increased earnings and cost savings in the education system. There is some evidence that programmes for younger children and cognitive behavioural therapies and social skills training may be cost and clinically effective in improving outcomes and reducing burdens related to ADHD. However, there is limited evidence on the effectiveness and value for money of teacher-led interventions and pharmacological interventions [261].

ASD INTERVENTIONS

The substantial societal costs of autism in adults and children highlights the importance of effective interventions to improve the quality of life for people with autism and reduce the costs borne by people with autism and their families, health and social care services and wider society [260]

Studies estimating the costs and cost savings of ADS interventions are limited especially in a UK setting. NICE provide some suggested costs associated with the implementation of the NICE recommended guidance on ASD in adults which are summarised in the table below. However, the guidance focuses solely on healthcare costs and does not provide any indication of how frequently these contacts occur on average across the adult life course nor does it give any indication of the wider societal costs and savings associated with implementing the guidance [260].

Table 15: Costs and savings of autism intervention in adults (NICE, 2012)

	Potential Costs	Potential Savings
Identification and initial assessment of possible autism	Commissioner cost of each extra referral to autism team = £136-£290	Each additional outpatient referral avoided =£290 Each GP appointment avoided =£53
Comprehensive assessment of suspected autism	Training in use of Autism Diagnostic Observation Schedule – Generic (ASOS-G) test per clinician =£2,000	More appropriate diagnoses and improved tailoring of care (no economic cost calculated)
Psychosocial interventions for the core symptoms of autism	Cost per hour of specialist nurse time = £19.77	Fewer mental health problems (e.g. depression; no economic cost calculated)
Psychosocial interventions focused on life skills	Average annual costs of employment support services = £1,798 - £7,124	Reduction in mental and other health and social care service use will offset costs.
Residential care	High cost, wide range (no economic cost calculated)	Increased independent living and stress management skills. Increased access to preventative health services potentially reducing the use of emergency, secondary and specialist tertiary services.

8. RECOMMENDATIONS

1. Ensure that children, young people and adults with neurodevelopmental conditions and their parents/partners are regularly consulted during the development of neurodevelopmental services and that their feedback is incorporated into any changes in provision.

DIAGNOSIS

2. Some adults with ADHD will remain undiagnosed through childhood and into adult life. The 2014 Adult Psychiatric Morbidity Survey suggests that up to 9.7% of the adult population screen positive for at least four of six ADHD characteristics. It is therefore vital that services such as primary care are able to recognise the symptoms of ADHD in adults. In addition, screening in certain settings where ADHD populations are higher such as psychiatric outpatient clinics and the criminal justice system may be beneficial in identifying undiagnosed ADHD.
3. ASD and ADHD in Liverpool remain more common among males than females, and there is some evidence to suggest that this may be due to more recognisable symptoms among males and perceptions that these are male conditions, leading to misdiagnosis in females. It is therefore important that all aspects of the neurodevelopmental pathway reflect all genders. For example, education and awareness raising materials that feature both genders and reflect the different ways in which symptoms can be visible among males and females, and equal provision of screening and support for females.
4. ASD and ADHD appears to be associated with deprivation and the socio-economic environment. Consider staggering awareness raising of the conditions and shared care in primary care by first targeting staff working in areas of higher deprivation.

COMORBIDITY

5. Children and adults with ADHD and ASD experience higher comorbidity with a wide range of physical and mental health conditions including conduct disorder and learning disability. This highlights the importance of shared care and partnership working not only across the neurodevelopmental pathway but with wider primary and specialist healthcare providers. In addition, it is important that GPs are participating in shared care for clients with ADHD and ASD and are competent in recognising symptoms amongst those presenting to primary care with other conditions.

TRANSITIONS

6. The neurodevelopmental pathway must take a life course approach and recognise the importance of key transitions for children and adults with ADHD and ASD. Key transitions are:

6a) Transition to adult services: ASD is a lifelong condition. Evidence suggests that around 65% of children with ADHD will have symptoms which persist into adulthood and a least 37% will need continued specialist mental health support after leaving paediatric services. Transition to adult services is therefore a key time in the lives of young people and it is vital that they have a smooth and prompt referral to adult care. This transition needs to allow for the continuation of their current care and link to support for wider issues in adult life such as employment, housing, and substance misuse.

6b) Transition to secondary education: the transition from primary to secondary education was described by stakeholders as a key time for young people with ADHD and ASD particularly those with mild/high functioning symptoms who do not attend regular outpatient reviews. These young

people may experience difficulties in self-regulating and managing their condition during the transition to secondary education. It is important that schools have strong links with specialist services to enable young people to access the support they need.

6c) Transition to higher education: a high proportion of young people with ASD and ADHD leave school without any qualifications. However, some individuals including those with high functioning ASD have clear post-secondary education goals which are often hindered by a range of factors including social support needs, confidence and accommodation concerns. Ensure that young people who are transitioning to adult care have appropriate post-secondary education support by building strong links with University and FE college disability support and outreach services.

OUTCOMES

7. There is a lack of evidence on the wider health and social outcomes experienced by adults with ADHD and ASD. It is therefore important that neurodevelopmental services routinely monitor outcomes including but not limited to: substance misuse, smoking, educational attainment, housing and employment, to allow for more efficient allocation of resources, services and interventions which accurately reflect the population's need.
8. Evidence suggests higher levels of risk behaviours among adolescents and young adults with ADHD including substance and alcohol misuse, risky sexual behaviour, self-harm and smoking. Substance misuse and sexual health services are therefore key services in which to raise awareness of ADHD among staff and implement screening.
9. There is evidence to suggest that adults with ADHD are at increased risk of harm due to impaired driving experience. Awareness raising among driving instruction companies may therefore be beneficial. In addition, A&E presentations for repeat road traffic collisions (RTCs) and driving related incidents may be another key opportunity to screen for ADHD.
10. Improve employer awareness to support people with ADHD and autism in the workplace. Use simple adjustments like making job interviews more accessible and providing assistance to understand the 'unwritten rules' of the workplace.
11. Provide training for those who work in the criminal justice system including police, court and custody suite staff on recognising, approaching, communicating and interviewing/questioning those with ADHD and autism and strengthen collaboration between health and social care providers and partners.
12. Implement school awareness raising for students, staff and parents about living with ADHD and ASD to reduce the stigmatisation and bullying associated with both conditions. This could include a peer-led element.

SERVICE PROVISION

13. Consider the development of a single neurodevelopmental pathway for adults with ADHD and ASD. The pathway should either be combined with the current children's pathway or have well established transition procedures for young people moving between the two pathways. The pathway should combine medical treatment and psychological support with wider social support services to provide a model which supports individuals with neurodevelopmental conditions across all the wider determinants of health. This can be achieved by establishing shared care arrangements between NHS specialist services, primary care and third sector support services.

14. The neurodevelopmental pathway must reflect the complex and non-linear nature of progression through neurodevelopmental services and allow for multiple contacts in varying time periods. Whilst some individuals may be ready to reduce the level of NHS outpatient care received, the pathway must allow individuals to move back and forth between stages at times of need for example: the key transition periods discussed above.
15. Stakeholder feedback and service data suggest that current staffing levels in many services are insufficient resulting in longer waiting times. The development of the neurodevelopmental pathway should include a full review of the staffing and capacity of all services involved to identify areas of workforce need and both existing arrangements and future opportunities for sharing of resources and partnership working.
16. Reconsider the use of the term “discharge” as this is creating anxiety for clients who think they will not be able to re-access services should they need them. By developing two linked pathways for adults and children across the lifespan which combine outpatient, primary and third sector care, clients will be able to access a level of support which is appropriate for their current needs but still feel secure that they can access additional or different support should they require it. One example of this is the “step-down” phone clinic provided by one service once clients stop accessing face-to-face support.
17. Consider strategies to improve DNA rates across all services to ensure maximisation of resources for services working to capacity. A review of the reasons why clients DNA appointments could be used to develop a strategy for improving attendance e.g. text message/ email reminders. Strategies must reflect the needs of clients with ADHD/ASD.

INTERVENTIONS

18. Evidence suggests that a combination approach which brings together stimulant treatment (where needed) and psychosocial interventions (such as CBT) are effective in improving both health and wider outcomes for individuals with ADHD. Liverpool CCG should consider developing a pathway which incorporates interventions across the pharmacological and psychosocial approaches.
19. The evidence on interventions to improve outcomes for individuals with ASD is mixed and the quality of evidence for interventions beyond pharmacological treatment and CBT is limited. Some interventions such as TEACHH, Early Intensive Behavioural Intervention, Milieu Training, Picture Exchange and Social Skills Groups show promising evidence of effectiveness. Where these interventions are already implemented, thorough evaluation should be implemented to allow decisions to be made about the effectiveness of these interventions locally over time. Similarly, where new interventions are being piloted, thorough evaluation of both the process and outcomes should be implemented from the outset to inform future service development.
20. Continue to review the evidence on effective psycho-social interventions for ASD and ADHD as this evidence base develops, particularly for adolescents and adults.

LIST OF ABBREVIATIONS

ADHD	Attention deficit hyperactivity disorder
ADOS	Autism Diagnostic Observation Schedule
APMS	Adult Psychiatric Morbidity Survey
ASD	Autistic spectrum disorder
BMI	Body mass index
CAMHS	Child and adolescent mental health service
CCG	Clinical commissioning group
CJS	Criminal justice system
CNS	Central nervous system
CWP	Cheshire and Wirral Partnership
DISCO	Diagnostic Interview for Social and Communication Disorders
DNA	Did not attend
DWP	Department of Work and Pensions
EDT	Everton Development Trust
EMDR	Eye Movement Desensitization and Reprocessing
LA	Local authority
LJMU	Liverpool John Moores University
LSOA	Lower super output area
ND	Neurodevelopmental
OCD	Obsessive compulsive disorder
OT	Occupational therapist/therapy
PCB	Polychlorinated biphenyls
PHI	Public Health Institute
RTC	Road traffic collision
SENCO	Special educational needs coordinator

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