



Cheshire East

All-Age Autism Strategy

2020-2023

Cheshire East
SEND Partnership



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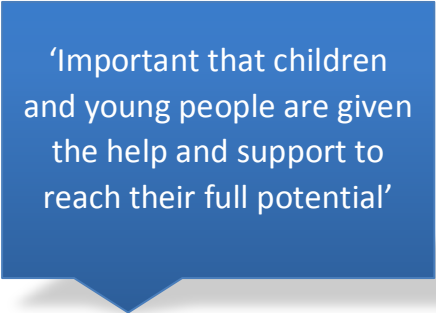
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The strategy contains quotes and thoughts from some Cheshire East residents; parents, carers; children and young who experience autism in their daily lives, captured during recent consultation in the development of the strategy

Foreword

This strategy has been developed through co-production and engagement with all our partners; stakeholders, and importantly Autistic people, their families, and carers in line with the TOGETHER co-production principles. “Think Autism”, the National Strategy, places an expectation on local councils and health services to develop plans to ensure that Autistic people who live in their area get the help that they need. This strategy responds to that expectation, developed in line with the Autism Act (2009); the National Autism Strategy and the local Written Statement of Action following the local area SEND inspection.¹

Autism is a lifelong condition that can significantly affect the lives of people living with it, and it is part of the daily life of around 600,000 people in the UK.² In Cheshire East, there are an estimated 1,594 children and young people assessed onto the autism spectrum, and 728 adults³. **Autistic people** are valued members of our communities and this Strategy reflects a shared commitment to improve the health, wellbeing, and opportunities for both children and adults with autism.



‘Important that children and young people are given the help and support to reach their full potential’

Preparing for adulthood is a recognised challenge. While most young people with autism will not need specialist services as an adult, they will need support as they move towards adulthood in developing independence – for example; learning additional life skills, travelling independently and seeking opportunities for further education, employment, and independent living.

The Strategy seeks to ensure that **Autistic people**, their families and carers are able to achieve their full potential by bringing together health and social care, educational settings, local employers, service providers, voluntary organisations and the people of Cheshire East.

To do this, the Strategy contains clear aims and objectives, which have been defined and shaped by the key priorities. The Strategy is supported by a Delivery Plan - which will be updated throughout the lifespan of the Strategy, reflecting changes in national and local policy to ensure we capture every opportunity to further enhance our vision for improved health, wellbeing, and quality of life for **Autistic people**, their families, and carers.

We would like to thank all of you who have contributed to its development. The Strategy provides an opportunity to make a significant difference to the lives of **Autistic people** and its success lies in the extent to which it achieves this. Our challenge now is to work together and make those aspirations real.

¹ [Cheshire East Written Statement of Action for Special Educational Needs and/or Disabilities \[SEND\] Aug 2018](#)

² [The NHS Long Term Plan S.2.31. January 2019](#)

³ [Cheshire East JSNA](#).

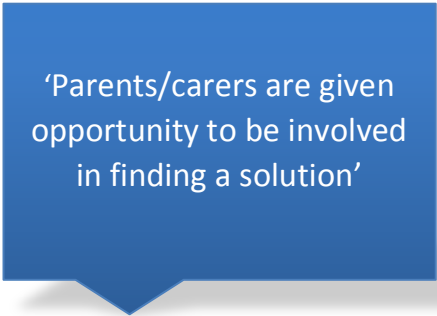
Executive Summary

The Cheshire East All Age Autism Strategy makes a commitment to improving services and support for children and adults with autism, and their families and carers. This Strategy acts as a roadmap for commissioning intentions and service re-design and improvement initiatives throughout its lifespan.

Autism touches the lives of many people in Cheshire East, and it is therefore essential that we have an all-age Strategy which enables us to work in partnership to support **Autistic people** and their families in the most effective way. This includes raising awareness and understanding of autism in our wider communities, whilst also ensuring young people in the transition into adulthood reach their educational potential, gain employment, have a choice of housing, and have access to local services which are autism friendly.

To steer and inform the strategy, a working group was established of **Autistic people**, their families, and carers, representatives from Social Care, Education, Housing, Local Area Coordinators, Health, Employment Support, Criminal Justice, Police, Advocacy, autism specific agencies, as well as community and third sector organisations.

As the Strategy highlights, we have also collected the thoughts, experiences, and suggestions of people with autism, their families, friends, and carers in what needs to be improved. Combining this with recent national and local data and evidence, we have identified key themes and priorities, which are explored throughout the Strategy.



'Parents/carers are given opportunity to be involved in finding a solution'

Autism is everyone's business, and we know if we get things right for children and young people, they are more likely to enter adulthood with the appropriate level of advice, information, self-management strategies, and support and therefore have greater opportunity to achieve their aspirations and live happy and safe lives.

Our Vision

In Cheshire East we are committed to improving the lives of individuals who experience autism. We will do this by working with **Autistic people**, families, carers, local groups, and partner organisations to address the existing issues in accessing a number of services. It is critical that a significant amount of focus is placed in improving access to a multi-disciplinary assessment pathway to support diagnosis. Our vision includes a consistent and integrated autism assessment pathway, which is compliant with NICE guidance and Quality Standards, and includes access to evidence-based pre and post diagnostic support.

We want to empower individuals and families to participate in decisions about assessments and diagnosis, to receive support, information and advice as early as possible as soon as needs have been identified. We want to provide support to help families to understand the diagnosis pathway.

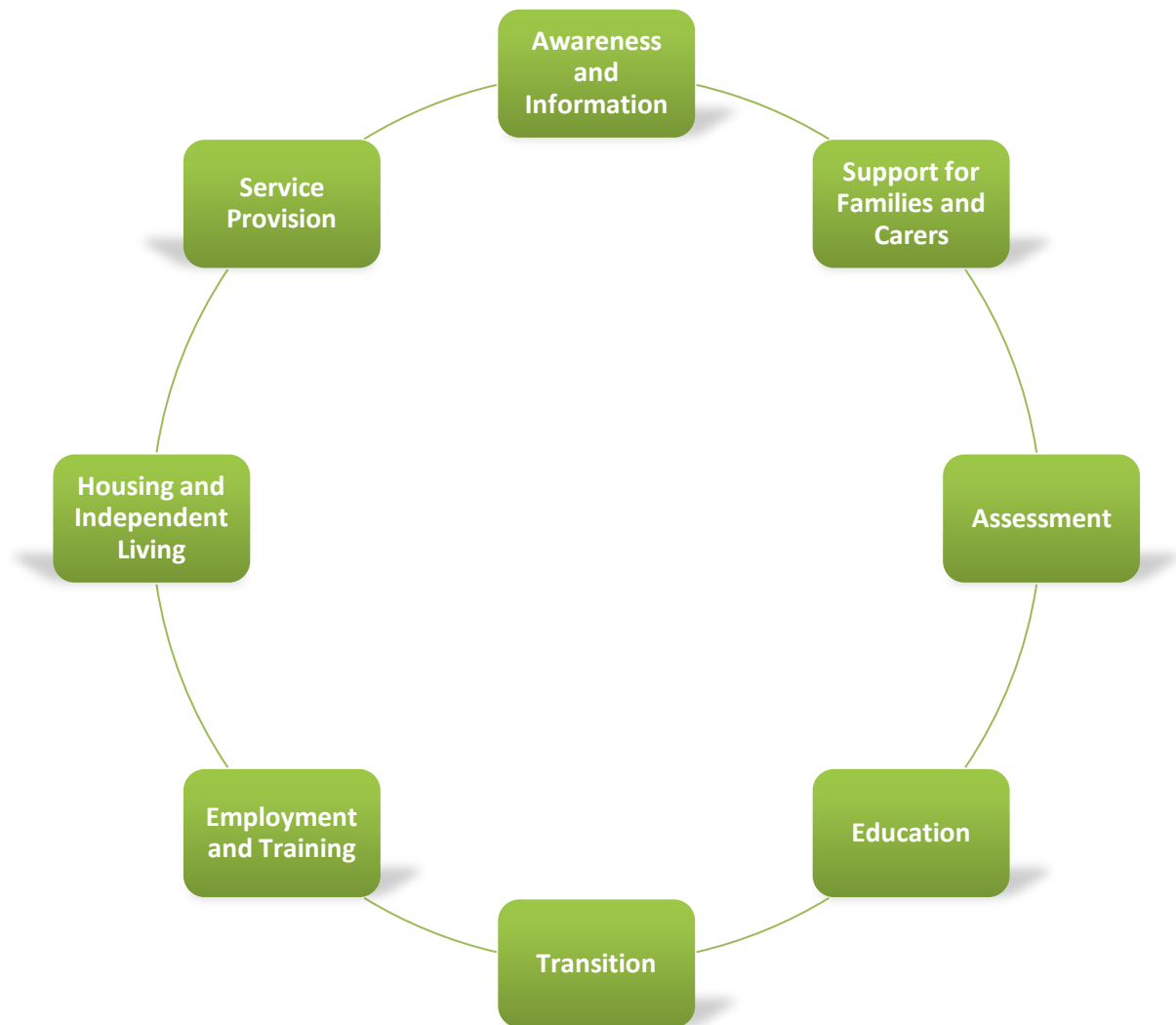
The strategy is intended to provide more consistent and effective early intervention support to children, young people, adults, and families. There is an ambition that having appropriate and timely advice, information, self-management strategies and support for our residents who experience autism. As far as possible, we wish to ensure that all professionals and organisations working with children, young people, and adults are able to demonstrate a good understanding of both autism and reasonable adjustments and arrangements needed to enable **Autistic people** to access services, education, employment, and housing.

Our approach will emphasise the importance of effective, well led transition planning throughout an individual's life by promoting independence and enhancing lives. We want people to feel that Cheshire East is a place where you can participate socially, feel safe and lead an independent life, including reaching their educational potential, gaining and maintaining employment, living close to family and social networks, and taking part in leisure and social activities.

The purpose of this strategy is to help guide us towards achieving our vision over the next 3 years, by setting the tone and direction to improve outcomes for **Autistic people** and their families. Our ambitions and the success of the priorities are dependent on partner organisations working in an integrated way to achieve the same goals.

Our priorities

In order to meet the ambitions set out within this Strategy, we have agreed a number of key priorities, which have been co-produced through extensive engagement and working with Autistic people, their families and carers and professionals within the sector.

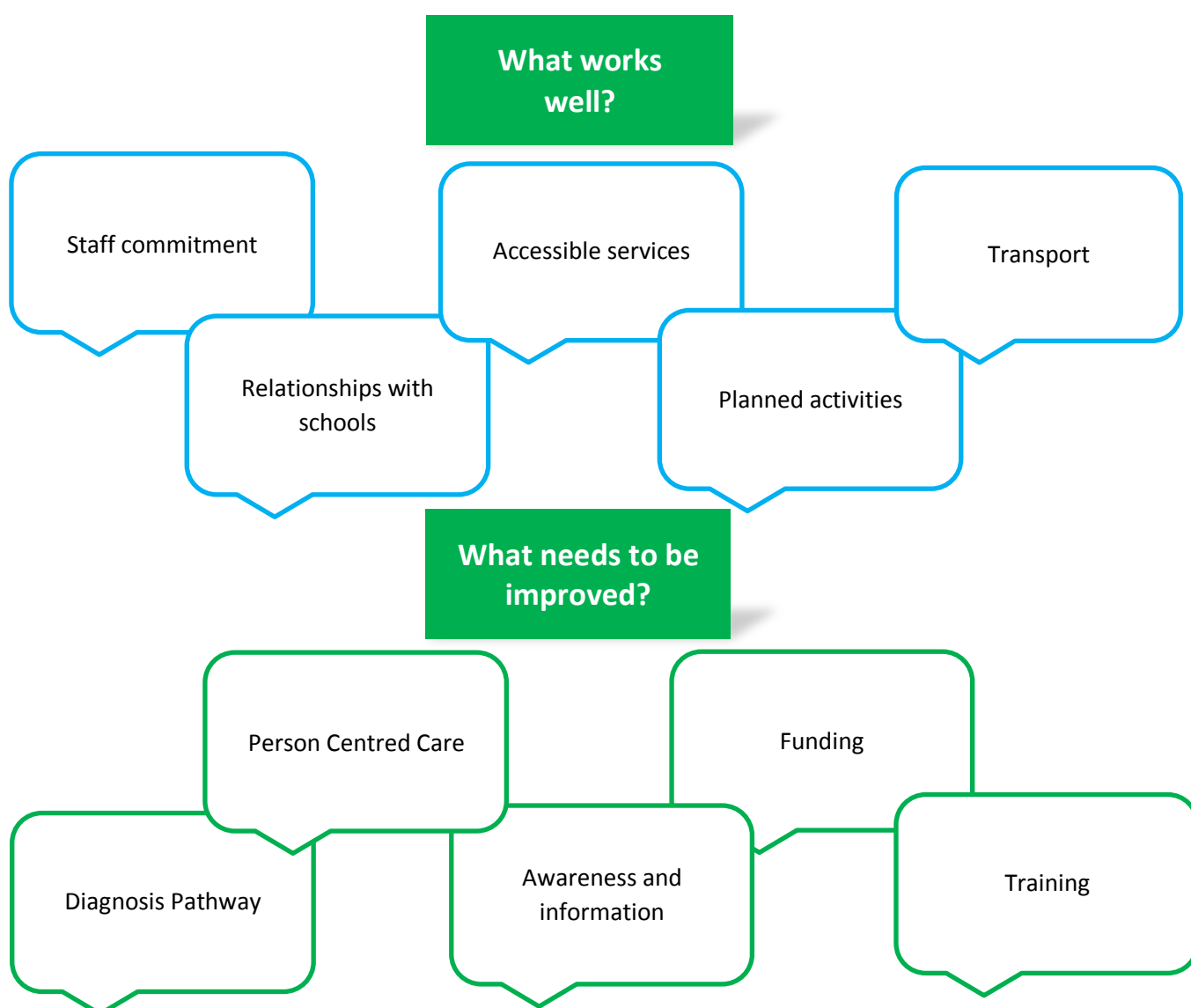


How this strategy was developed

Co-production and consultation

The development of our All Age Autism Strategy has been linked to the updating of our Cheshire East Joint Strategic Needs Assessment (JSNA)⁴, through a multi-agency Autism Strategy and JSNA Working Group. Further, we have been working extensively to develop this strategy through consultation events over recent years within the SEND Partnership, service users, and parent carers.

A formal consultation was conducted during February and March 2019 in which 82 respondents were received (See Appendix 3). We consulted with individuals and groups of people who experience autism on a daily basis, seeking views on the strategy through face to face conversations; telephone calls; emails; meetings; workshops and questionnaires⁵ - in which the following was clearly emphasised and which have informed and shaped the key priorities of this Strategy:



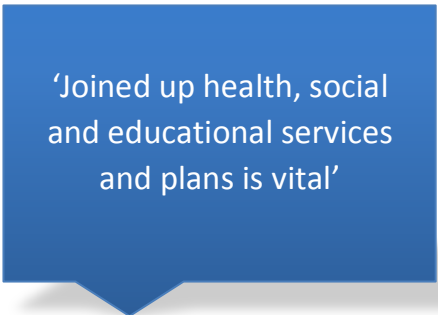
⁴ [Cheshire East JSNA](#)

⁵ To further support the development of the Strategy, a service user online questionnaire, hosted by The independent [Cheshire East Parent Care Forum](#). The Autism Questionnaire was sent out to a number of service user and parent carer groups throughout Cheshire East between December 2018 and January 2019. 28 returns were received, together with personal comments

How the strategy will be used

This Strategy represents the collective view of Autistic people and their families as well as professionals and organisational representatives, on priorities for Autistic people in Cheshire East for the next three years.

We have deliberately chosen to maintain a focus on the themes that have arisen through consultation and joint working and improvements that families, people with lived experiences and organisational representatives view as needed in the future. Strategies usually start with where we are now, set out work undertaken as part of the previous strategy, and then describe future needs and priorities. We've chosen to focus on the future and not dilute the message by detailing work that has already been done. We are not underestimating the effort that has gone into developing services and support for Autistic people over the last three years, but are choosing to focus on the future.



'Joined up health, social and educational services and plans is vital'

There are many different views on what the priorities should be. Given the wider national context in public service funding, there is no new money. What needs to be achieved must be done within existing, and possibly reducing resources. Everyone involved in producing the strategy therefore agreed that focus and clarity is key. Our aims were:

- To get as clear about the priorities as we could
- To accept that tough choices have to be made about the use of limited resources
- To support commissioners in making choices by identifying criteria against which decisions could be measured

Terminology

For consistency with the National Strategy and associated guidance, recent research into terminology, and in line with an aim to de-medicalise autism, the terms 'autism community', 'autism' and 'autistic' will be used in the context of our All Age Autism Strategy. These terms are taken to cover various descriptions of autism, diagnosed or otherwise, and include Autistic Spectrum Disorder (ASD), Asperger's Syndrome, Autistic Spectrum Condition (ASC), and neuro-divergence.

Defining autism

Autistic individuals experience the world differently and often view autism as a fundamental aspect of their identity. Autism is not an illness or disease. In order to de-medicalize autism, thereby removing the overuse of inappropriate terminology, support is growing for the reframing of autism as a socially constructed human difference rather than pathology. Autistic individuals, their families and carers, have a great many gifts and strengths.

With the right sort of support, everyone can learn, develop, and live more fulfilling lives of their own choosing. However, it needs to be acknowledged that living with autism is often stressful and stress is linked to episodes of mental and emotional ill health. Periods of increased vulnerability can occur at many life stages. For example during transition of late adolescence to early adulthood.

An individual's quality of life, as well as that of their families or carers, can be substantially affected. Where no crisis pathway is in place, autistic individuals often fall through service gaps. The long-term nature of autism, and any variation in the severity of impact, means that the needs of individuals, families, and carers are not directly comparable with people requiring care and support for other reasons.

Autism is a lifelong condition that affects how a person communicates with and relates to other people and the world around them. Autism touches individuals in many different ways, although Autistic people will experience difficulties in the following areas:⁶

- Social Communication: Using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice
- Social interaction: Recognising and understanding other people's feelings and managing their own
- Restrictive Behaviours: The world can seem a very unpredictable and confusing place to autistic people, who often prefer to have a daily routine so that they know what is going to happen every day
- Highly Focused Interests: Many autistic people have intense and highly-focused interests, often from a fairly young age. These can change over time or be lifelong, and can be anything from art or music, to trains or computers.

Some Autistic people may also have a learning disability and many of these qualify for support from learning disability services.⁷ Others may be of average or above average intellectual ability, have good communication skills and show knowledge or skill in specific areas. They may still experience significant difficulties in key areas but, since they do not require support for a learning disability, find a lack of alternative support to meet their needs. This leaves people in this situation more dependent on families, universal services, and community based support delivered by local authorities and through the voluntary and community sector.

'Housing is potentially one of the greatest challenges...commissioners should plan not just for today'

Research indicated that even though mental illness can be more common for people on the autism spectrum than in the general population, the mental health of Autistic people is often overlooked.⁸

An inability to communicate effectively, meet self-expectation or those of others, or problems engaging in everyday life can lead to anxiety or depression. Insufficient understanding of autism can also lead to risk of misdiagnosis, such as psychosis or obsessive-compulsive disorder, with inappropriate prescribing of drugs. Difficulties with communication, interaction, and social imagination can also leave people vulnerable to misunderstanding others' intentions and sometimes poor judgement which can lead to exploitation, exposing individuals to risk of victimisation or criminalisation.

Autistic people can also experience a number of additional neurodevelopmental conditions such as Attention Deficit Hyperactivity Disorder (ADHD) and attachment Disorders. ADHD is common in Autistic people. If someone has ADHD, they have significant difficulties with things like poor attention, over-activity and impulsiveness. This can lead people to experience difficulties accessing support and services.

⁶ [National Autistic Society: What is autism](#)

⁷ Around 40% of Autistic people have a learning disability, compared with just 1% of people without autism. [Autistica \(autism research charity\)](#). March 2019.

⁸ Dr Anastasios Galanopoulos, Dr Dene Robertson, Ms Debbie Spain, and Dr Clodagh Murphy. This information is drawn from an article that first appeared in the Mental Health supplement of [Your Autism Magazine, Vol 8\(4\), Winter 2014](#).

National context

The Autism Act (2009) Section 29 states that we need to make services better. It says that Autistic people may not always get the help that they need; it is the only condition-specific legislation of its type in England. The statutory guidance places a duty on all local authorities and NHS bodies to produce an autism strategy. We must legally take notice of the guidance and follow the relevant sections, failure to do so without a good reason why specific actions have not been met can lead to us being liable for judicial review or action by the Secretary of State.¹⁰

The need for an All Age Autism Strategy for Cheshire East has been informed by several drivers;

- Think Autism 2014
- Equality Act 2010)
- The Care Act 2014
- Care and Support Assessment regulations (2014) & Transforming Care Recommendations
- Accessible Information Standards NHS England 2016
- United Nations Convention for the Rights of the Child
- Supporting Pupils at School with Medical Conditions 2014
- Safeguarding requirements
- NICE Guidance CG142, QS51 & Professional Standards and guidance
- Children and Families Act 2014
- Lenehan Report (January 2017)
- Building the Right Support 2015
- Keeping Children Safe in Education Act 2014
- Working Together to Safeguard Children 2018
- The NHS Long Term Plan 2019

Transforming Care

Transforming care is all about improving health and care services so that more people can live in the community, with the right support, and close to home. The function of Transforming Care Partnerships is to work with people with a learning disability, autism or both and their families and carers to agree and deliver local plans for the programme.

There has been a greater focus on children and young people more recently concerning services and pathways to avoid children and young people being required to go into hospitals or residential placements and supporting them to remain in mainstream education.

Care Education and Treatment Reviews

Care Education and Treatment Review (CETR) standards have been set out to offer a process for those at risk of admission or who have been admitted. This Strategy should be read in conjunction with the Care and Treatment Review Standards. Either a CETR or a CTR always needs to be commissioned for any autistic person who might be at risk of admission or has been admitted to any mental health or learning disability inpatient unit regardless of the reason for admission in line with national guidance. CETR are for people whose behaviour is seen as challenging and /or for people with a mental health condition. They are used by commissioners for people living in the community and in learning disability and mental health hospitals.

⁹ [Autism Act 2009 S. 2](#)

¹⁰ [Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy](#)

Building the Right Support

Building the Right Support was published in 2015, and sets out a clear framework to develop more community services for people with learning disabilities and/ or autism who display behaviour that challenges, including those with a mental health condition, and closes some inpatient facilities.

Think Autism Strategy (2014) – Review

The government's decision to update the National Autism Strategy in England to include children and young people has been welcomed by the sector, who had been calling for a national strategy to meet the needs of children on the autism spectrum. Through the review the Government will collect evidence from autistic children, families and their carers on how to improve current levels of support. This is explored throughout this Strategy, in which to capture:

- Continued improvements to the needs autistic children's and young people holistically
- Increase poor understanding of autism
- Develop diagnostic services to seek diagnose autism earlier, in line with clinical guidance
- Enhance the transition pathway between children and adult services

The Lenehan Reports

The Lenehan report provides strategic overview and recommendations about the practical action that can be taken to co-ordinate care, support and treatment for children and young people with complex needs (and behaviour that challenges) involving mental health problems and learning disabilities and/or autism. The 'Think Autism' national strategy (published in 2014) and the subsequent 'Statutory Guidance for Local Authorities and NHS organisations' (published in March 2015, and then updated in 2018, to support implementation of the 'Adults Autism Strategy') have provided detail on what improvements need to take place to make meaningful changes for Autistic people.

The NHS Long Term Plan

The NHS Long Term Plan¹¹ released in January 2019 goes some way to address physical health issues as it sets out the intention for the delivery of health services in England over the next 10 years. Amongst a wide range of sections and priorities that will apply to autistic people there are certain specific items on the physical health of autistic people. The NHS Long Term Plan includes Autism for people of all ages, and in particular seeks to address the needs of children and young people and the health inequalities that those on the autistic spectrum may face. It states: 'Across the NHS, we will do more to ensure that all people with a learning disability, autism, or both can live happier, healthier, and longer lives.'

With the focus on prevention, the NHS Long Term Plan promises to offer timely support to children, young people, and their families. It also commits to ensure reasonable adjustments are made to enable access to mainstream health services and improve the health and wellbeing of children and adults on the autistic spectrum. This includes access to eyesight, hearing, and dental services for children as part of the general screening reviews. By 2023/24 a 'digital flag' on patient records will identify if a patient has a known learning disability or autism. It further seeks improvements by the introduction of diagnosis Waiting List Standard for children and young people.

¹¹ [NHS England. NHS Long Term Plan January 2019](#)

The local context

Economic Impact

A respected study commissioned by *The National Autism Project*¹² estimated spend on autism across the lifespan to range from £0.80million to £1.23 million depending on the co-occurrence of an additional intellectual disability diagnosis. This research shows that for adults with autism the highest spend are those generated by health and social care provisions (59%), followed by lost employment (36%) and family expenses (5%).

We should approach the spending challenge with an attitude of invest to save. With this economic perspective in mind, it is essential to have a firm appreciation of the current level of autism funding in order to strategically invest in interventions that lead to better outcomes. High care spending is often associated with crisis situations, which have arisen as a consequence of unmet need.

Housing and independent living

Within the autism community, almost half of adults over 25 continue to live in the family home and over half are dependent on their parents for financial support.¹³ Moving out of the family home is one of the biggest milestones in a person's life. However, for autistic individuals this can be a long and challenging process. We have chosen to take an all-age approach to its strategy in order to ensure commitment and collaborative working across services. By working in partnership with individuals, families, and carers, gaps in provision can be identified and predicted, therefore ensuring that resources are used wisely which, in turn, should enable smoother transitioning from children to adult services, and into older age.

Locally, of the 234 residents with a recorded health condition of autism who had contact with adult social care during 2017/18:¹⁴

- 50 (24.9%) are living in a care or nursing home setting
- 49 (24.4%) are living in accommodation with structured support e.g. sheltered housing, Shared Lives
- 75 (37.3%) are living with friends or family
- 27 (13.4%) are living independently (owner occupier / shared ownership scheme; tenant – social housing; tenant – private landlord; other temporary accommodation)

All resident over 65 are living in accommodation where there is support from others, either in a care or nursing home, sheltered accommodation or living with family/friends. Commissioners will look to encourage care and support providers to develop bespoke accommodation within Cheshire East which is autism-friendly and sensory buildings that underpin the support required.

While continuing to contribute to the Vulnerable and Older People Housing Strategy,¹⁵ we will ensure that provision is designed for a range of people including those who struggle with sensory issues and/or sharing space, those who struggle with change and also those that present behaviours that cause harm to themselves or others. We aim to focus on commissioning support to reduce the behaviours that are of concern and promote skill building to support greater independence.

¹² [The Autism Dividend: Reaping the rewards of better investment](#). Martin Knapp Et al. January 2017

¹³ [Housing with support options](#). National Autistic Society November 2015

¹⁴ [Cheshire East JSNA July 2019. Housing](#)

¹⁵ [Cheshire East Council Vulnerable and Older People Housing Strategy](#)

Access to employment

Through a study by The National Autistic Society¹⁶ It is estimated that only 15% of autistic individuals are in full-time employment and 9% are in part-time employment. 79% in receipt of out-of-work benefits say they would like to work but require the right support. Moreover, 26% of autistic graduates are unemployed; around twice the proportion of any other disability group.

Experiences in Cheshire East of the 234 residents with a recorded health condition of autism who had contact with adult social care during 2017/18, 52 (22%) have an unknown employment status. 99% of the 182 adults where employment status was recorded are of working age (aged 18-64). Analysis of these people shows that:

- 94% (171) are not in paid employment, of which only 4% are actively seeking work
- While only 6% are in paid employment, less than 1% work 16 hours or more

One third (34%) of residents (79) with a recorded health condition of autism are aged 18-24 years. 25% of these residents having an unknown employment status. Of those where employment status was recorded, 97% are not in paid employment and 88% are not seeking work. It is not known whether 7% who are not in paid employment are seeking work.

Criminal justice system

Over the past decade, there has been significant increase in the understanding of Autistic people within the criminal justice system.¹⁷ However, there is a clear lack of data, both nationally and locally of its prevalence. Autistic young people and adults frequently experience increased episodes of trauma due to their additional needs going unrecognised.

We are committed to identifying and addressing the barriers to support and participation experienced by specific groups such as older people, people from BAME communities, women, and those who are LGBTQ+. We will set up an engagement plan with community organisations working with BAME communities, LGBTQ+ communities, older adults, and women for autistic adults and family members in order to try to understand what those barriers are and to encourage people from those communities to access support and services. After a period of scoping we will develop a plan for each of those groups to increase engagement.

Ethnicity

Ethnicity remains a key determinant of health inequalities in England.¹⁸ Individuals, families, and carers from Black and Minority Ethnic (BAME) communities face disparity in relation to healthcare access, positive outcomes, culturally sensitive support, and innovative forms of engagement. Autism within BAME communities is less likely to be diagnosed, and those affected by autism are unlikely to be in receipt of appropriate service provision.

Gender

It is becoming clear that women of all ages and ethnicities may be underrepresented in terms of diagnosis. Published studies reveal high rates of suicide among autistic individuals, with women at greatest risk of taking their own lives.¹⁹ A non-gender biased model that encompasses the varied ways in which autistic traits present would go a long way toward reducing the invisibility of autistic girls and autistic women.

¹⁶ [The Autism Employment Gap](#). The National Autistic Society. August 2016

¹⁷ [Autism, Culpability and The Criminal Law](#). Daniele Age UWL. Vol 5 Issue 1 April 2019

¹⁸ [Diverse Perspectives: The challenges for families affected by autism from BAME](#). Guy Slade National Autism Society 2014

¹⁹ [Girls and Autism: Flying under the radar](#). NASEN March 2016

Prevalence in Cheshire East

Nationally, the prevalence of autism is rising. Based upon the combined Adult Psychiatric Morbidity Surveys (APMS), there are approximately 700,000 people on the autism spectrum in the UK – that is more than one in 100. If you include their families, autism is a part of daily life for 2.8 million people.²⁰ This suggests that nearly 15,000 people are affected daily within Cheshire East.

The local picture for children and young people (0-24)²¹

1,594

Estimated number of children and young people assessed as being on the Autistic Spectrum in Cheshire East

The National Autistic Society has published estimates of the prevalence of autism in the UK, which note that although the figures for the prevalence of autism cannot be precisely fixed, it appears that a rate of around 1 in 100 is a best estimate of the prevalence in children. The children and young people may not necessarily have been diagnosed as having autism. There will also be children who are receiving support from schools / colleges who are not recorded on council systems and there may be children and young people with ASC who do not need additional support from services.

The current Cheshire East Autism Spectrum Condition JSNA includes more details on how local numbers of children and young people with ASC compare with the estimated numbers. However, the age distribution shows lower than expected numbers of school age children identified as requiring support from associated services than would be expected using latest national prevalence estimates. Very few children are recorded in local authority systems in their first 4 years of life. Levels of identified need peak at age 13-14 years, the age children move to secondary school, when the number of children in contact with services exceeds those that might be expected.²²

It is acknowledged that current there remains differences in assessments for male and female. Currently there is no evidence to suggest that neurodiversity disproportionately affects boys more than girls, but studies suggests that girls are less likely to receive a diagnosis due to differences in presentation and the preconceptions of a male model focused observer. This has resulted in no agreed prevalence rate for ASC in females but might be as high as one female for every two males. An increase in the number of females diagnosed will increase the national prevalence above 1.5%.²³ Studies have shown a steady increase in prevalence over the years. A recent large US study reported an overall prevalence of 1.68% in 8 year olds but rates ranged from 1.31-2.93% across the study sites.²⁴ If the maximum age-specific rate of 2.8% is the true prevalence within Cheshire East, there are

‘In our experience transition seems to throw up the greatest challenge to all stakeholders’

²⁰ [The NHS Information Centre, Community and Mental Health Team, Brugha, T. et al \(2012\)](#). Estimating the prevalence of Autism spectrum conditions in adults: extending the 2007, updated in 2014. Adult Psychiatric Morbidity Survey. LNHS Information Centre for Health and Social Care

²¹ [Cheshire East JSNA](#)

²² [Cheshire East JSNA](#). Children and young people aged 0-24 diagnosed and those receiving support

²³ [Cheshire East JSNA](#). Prevalence of autism and gender differences

²⁴ [Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities](#) Baio J, Wiggins L, Christensen DL, et al. (2014) Monitoring Network, 11 Sites, United States, 2014. MMWR Surveill Summ 2018;67(No. SS-6):1–23. DOI: Link to article

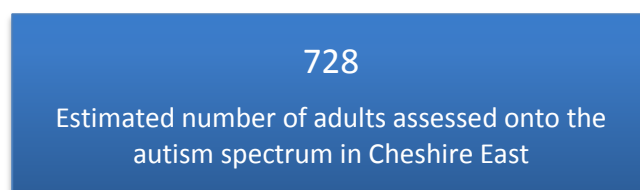
potentially over 1300 more children and young people (0-24 years) currently awaiting diagnosis or not yet recognised as having autism in Cheshire East. The majority of these are currently pre- and primary school age. Autistic people can also experience a number of additional neurodevelopmental conditions such as Attention Deficit Hyperactivity Disorder (ADHD) and attachment Disorders. ADHD is common in people with autism. If someone has ADHD, they have significant difficulties with things like poor attention, over-activity, and impulsiveness. This can lead people to experience difficulties accessing support and services.

Assessment and support

The Thrive model is being used to organise services (pathways) to respond to the needs of CYP with autism. Taken from mental health service re-design it promotes a flexible response to CYP, families and carers recognising different levels of need at different times in children's lives:



The local picture for adults



Across Cheshire East, there are 728 adults over 25-year olds assessed with autism, which is a shortfall of over 3,600 across both NHS Clinical Commissioning Groups (CCG) compared to the estimated 4,374. These low diagnosis rates and the low numbers of adults accessing support indicates that the needs of adults with autism may not be known or being met effectively.

Data from GP systems giving the numbers of people diagnosed by age of diagnosis shows an increase in the number of people age 25 and over coming forward for a diagnosis in the last 10 years.²⁵ Older adults with autism have received little attention to date, at least in part because historically there has been a lack of awareness, understanding and acceptance of the condition, highlighting the need to improve the identification of autism in older adults to ensure needs are being met effectively.

²⁵ [Cheshire East JSNA](#). Estimated prevalence compared to numbers diagnosed across Cheshire East for adults aged 25 and over

Service Provision

Children and young people

Assessment

The care pathway for referral, diagnostic assessment, and service provision for children and young people is currently being reviewed. Preschool children who show possible signs of autism, communication, or behavioural issues can be referred for a general developmental assessment; an autism specific diagnostic multi-disciplinary assessment may be undertaken within the preschool social communication clinic. Children and young people of school age who show signs of possible autism can be referred by any professional working in primary care, education, or social care to The Cheshire East Autism Team (CEAT).²⁶ Importantly, a diagnosis of autism is not needed for CEAT to become involved in supporting a child or young person.

The pathway for referral, diagnostic assessment, and service provision for children and young people is set out in Appendix 4. Preschool children who show possible signs of autism, communication, or behavioural issues can be referred for a general developmental assessment; an autism specific diagnostic multi-disciplinary assessment may be undertaken within the preschool social communication clinic. Children and young people of school age who show signs of possible autism can be referred by any professional working in primary care, education, or social care to a multi-disciplinary assessment for on-going support.

Support in educational settings

The Cheshire East Toolkit for SEND provides educational settings with detailed guidance on how they can identify children and young people with different types and levels of special educational need, and information on appropriate steps and strategies to support them. It provides clear information about when a request for an Education, Health, and Care needs assessment, or specialist services, may be required.

Transition

From home to early years setting – If a child has significant identified needs which are highly likely to impact upon transition into an early year setting there is a Settling In Process, which is linked to a Settling In Grant. The named Health professional can liaise with the setting to coordinate a transition planning meeting and invite a representative from the Early Start Team. This takes place for all children with significant special educational needs of all types, and so is not ASC specific.

From Early Years (EY) setting to school – During the summer term prior to the child starting school, the setting, supported by the Early Start team, organise a transition planning meeting linking in with the receiving primary or special school.

If a child has Autism or social communication difficulties, Cheshire East Autism Team (CEAT) will be invited to attend, so that school receive CEAT support from September when the child transitions into school. As above, this process is not an ASC specific offer. Cheshire East continues to develop and administer an effective transition arrangement for young people with disabilities preparing for adulthood. A new transition framework will be established to ensure improved shared working arrangements, oversight and scrutiny, and to deliver a robust professional service to young people moving to adulthood.

²⁶ [Live Well Autism CEAT](#)

Where an individual is on the autistic spectrum but without an associated learning disability, the learning disability service will consider such referrals for assessment. Depending on the presentation of the individual, such assessments will be conducted jointly with another service, such as mental health. Upon transition from children to adult's service, this joint assessment would determine which service is best able to support the service user if they are eligible for care and support under the Care Act 2014.

Adults

Assessment

The pathway for adults with autism for a Care Act assessment is via the First Point of Contact and will depend on whether or not the person has an accompanying learning disability or not. People with autism and a learning disability will be referred to the learning disability team and those without an accompanying learning disability will be referred to the mental health social workers. From January 2019, the Council introduced a new model of social work support within the CMHTs so that acceptance by them of a referral is no longer determined by the eligibility criteria of the Care Programme Approach (CPA). Under the CPA, the primary criterion for eligibility is the presence of a severe and enduring mental illness, thus precluding many Autistic people. From January 2020, mental health social workers will be working to the eligibility criteria of the Care Act.

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

Operating models

The Care Act 2014 provides the statutory framework for the assessment of adult social care needs, including young people who may be eligible for care and support when they reach the age of 18. The fundamental starting point of the Care Act is the wellbeing principle which includes:

- Personal dignity
- Physical and mental health and well-being
- Protection from abuse and neglect
- Control by the individual over day to day life
- Participation in work, education, training or recreation

Both the learning disability team and the community mental health teams will now be working to new team operating models, which have an explicit acceptance of autism within their acceptance criteria. It is important to note that the Council is in the process of re-establishing a specialist learning disability team and some people with a learning disability and or autism will continue to be managed by generic community teams, until the learning disability team has been fully established. It will, however, take full responsibility for all young people with a learning disability and or autism coming through from transition from January 2019.

The social workers within the community mental health team will continue to work in a multi-disciplinary environment with Cheshire and Wirral Partnership (CWP), but from January 2019 will work with Care Act eligible adults with autism who may or may not have a severe and enduring mental health problem. Currently, acceptance into the community mental health team is predicated on the presence of a severe and enduring mental illness, which can exclude some Autistic people who still have significant needs.

Commissioning

Services which are by Cheshire East Council through a Dynamic Purchasing System (DPS) for individuals (16+) with complex care needs, including those with ASC. These services will be outcome focused and enable individuals to be confident and reassured that they receive the right support, at the right place and right price. Services commissioned through DPS include supported living; floating support; day opportunities and befriending services.

Cheshire East Council have also commissioned a more flexible offer of respite support which is available to adults and those in transition to adulthood who have eligible support needs, including those with autism, this includes accommodation-based overnight respite and community-based respite. Through this new model we will be able to deliver a more effective range of respite services to be available to both carers and the cared for person, offering a range of personalised options, appropriate to meet the needs of many and offering best value.

Delivering our priorities

The monitoring of the Strategy through progress reports will be undertaken by reporting to the Health and Wellbeing Board, through the multi-agency SEND Partnership Board; Health Governance; the Autism Group and the Learning Disability Partnership Board. Quarterly reports will be submitted to the Health and Wellbeing Board and Directorate Senior Management Team and published annually to support the Strategy aims and objectives.

During the lifetime of our strategy, we will;

Awareness and information	
Our ambition....	Increasing awareness and understanding of autism is central to this strategy and is fundamental to achieving our ambition of making Cheshire East an autism-friendly borough, in which the general population are aware of autism and have a better understanding of the condition
We plan to....	<ul style="list-style-type: none"> Assess the level of training needed for each member of staff within the Council, based on their role Ensure that an e-learning programme is available for raising autism awareness Develop an autism champion network of knowledgeable individuals, their families and carers to promote consistency and clarity Maintain the Live Well pages ensuring that there is clear transparent information for parent carers and children Ensure support and information is available for autistic people and their families to access as soon as it is needed
Outcome....	<ul style="list-style-type: none"> Autistic people, their family and carers and professionals report increased awareness of the resources available Autistic people, their family and carers and professionals report satisfaction with the information and resources available Everyone is aware who their autism champion is – including a database of champions throughout the support networks of individuals with autism, their families and carers and professional

Support for families and carers	
Our ambition	Our Strategy aims to ensure that carers are identified, supported, and empowered to manage their caring role, and are able to have a life outside of caring. When professionals understand autism, the positive effects on the individual, their families, and carers can be immense
We plan to....	<ul style="list-style-type: none"> ▪ Embed Think Carer throughout services and Continue to strengthen Person Centred Planning ▪ Provide appropriate support throughout transition stages from Children and Young People's Services / CAMHS into Adult Services ▪ Promote Respite provision, developing databased of Respite requests
Outcome.....	<ul style="list-style-type: none"> ▪ Access to information and advice so that the right support can be identified and provided effectively ▪ Set standards of self-advocacy ▪ Improved and flexible services available for Autistic people and their carers including respite

Assessment	
Our ambition....	As a partnership, working together to jointly commission a consistent and integrated autism assessment pathway, which is compliant with NICE guidance and Quality Standards , and includes access to evidence-based pre and post diagnostic support. We will reduce waits for autism assessment.
We plan to....	<ul style="list-style-type: none"> ▪ Create a single point of access for autism assessment ▪ A co-ordinated, multi-disciplinary assessment and decision-making to support assessment ▪ Address the gaps in diagnosis for BAME Autistic people ▪ Focus on needs of adults ▪ Manage access to a clear local offer ▪ Provide greater choice and breadth of provision
Outcome....	<ul style="list-style-type: none"> ▪ The first concern and assessment pathway and post support for children and adults crisis and risk support to be clear, transparent and communicated effectively ▪ Simplified access and a standardised referral process ▪ Reduction in waiting time ▪ Providing the most appropriate interventions, support and strategies to ensure all professionals are working together in partnership with the family to deliver a single, agreed plan of support

Education	
Our ambition....	Making sure that everyone has access to appropriate educational provision so they can fulfil their potential as learners
We plan to....	<ul style="list-style-type: none"> ▪ Ensure all pre-school child facing staff receive good quality autism awareness training from trainers such as Autism Education Trust (AET) ▪ Toolkit for SEND or relationship with EHCP quality improvement ▪ Continue to collect and analyse data through the JSNA on the number of children and young people on the autism spectrum in the area ▪ Record where young people go after they leave school and post 16 education to help assure themselves that they are equipping pupils on the autism spectrum as effectively as possible for adult life
Outcome....	<ul style="list-style-type: none"> ▪ Ensuring that children, young people and their families are supported at the earliest stages ▪ Improved intelligence to inform commissioning decision making ▪ Raised awareness of autism amongst all education professionals ▪ Continually support through the child and young person's transition
Transition	
Our ambition....	We will ensure that additional and relevant advice, information, and support are provided at all transition points to facilitate a smooth transition. This will ensure a seamless transition for children throughout their lives and entering adulthood, including during childhood, specifically into school / primary to secondary or mainstream to special school.
We plan to....	<ul style="list-style-type: none"> ▪ Improve the quality of transition assessments ▪ Provide appropriate information sharing agreements in place ▪ Improve access to support within the further education / training setting ▪ Provide more life skills training for young Autistic people
Outcome....	<ul style="list-style-type: none"> ▪ A clear understanding of young people's needs so the right support will be put in place to achieve their full potential ▪ Young people will not have to retell their story and information will be shared between services appropriately ▪ An increased number of young will achieve qualifications, which will lead to employment ▪ Increased opportunities for children, young people and adults to access meaningful employment and vocational training

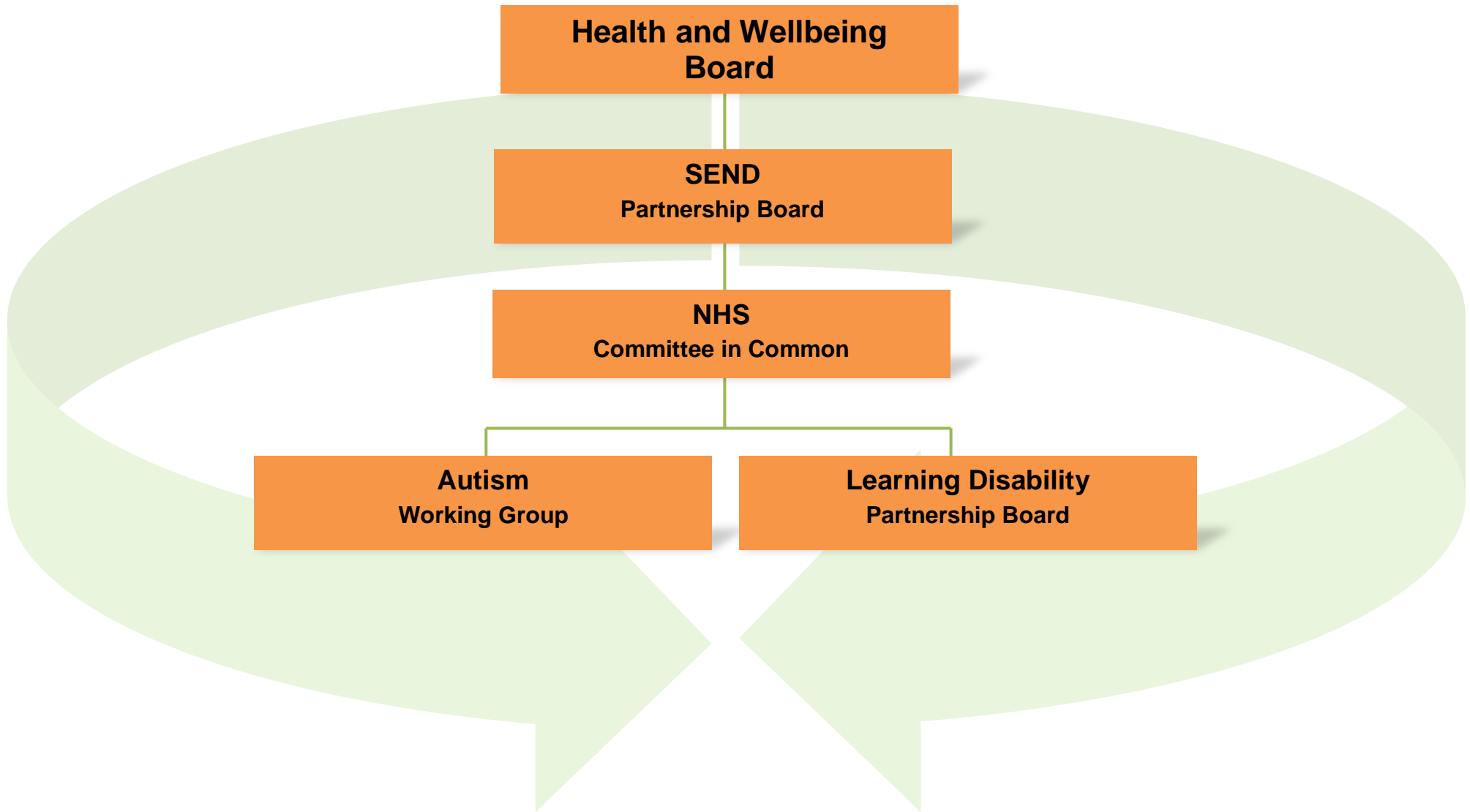
Employment and training	
Our ambition....	We will develop pathways to suitable employment and training is not just important economically; it also offers the opportunity for individuals to feel valued, respected and included in society and can help prevent isolation. We will increase the number of Autistic people into work
We plan to....	<ul style="list-style-type: none"> ▪ Promote the uptake of autism awareness training among local employers ▪ Promote the Government's Disability Confident scheme among local businesses / organisations ▪ Increase the number of Supported Internship Places in Cheshire East ▪ Increase the take up of Individual Placement and Support ▪ Increase the number of people with more complex conditions (including complex autism) into paid or voluntary work ▪ Increase the take up of disabled people into Council posts
Outcome....	<ul style="list-style-type: none"> ▪ Increase awareness of autism and improved employment and training opportunities ▪ Increase opportunities for young disabled people in transition with an EHCP, including young Autistic people ▪ Greater awareness and confidence within the local business sector

Housing and independent living	
Our ambition....	We will ensure that everybody has the opportunity to live in their own home, within a community setting, with their own front door and access to local amenities. We will improve the housing offer and seek to provide choice, opportunities, support and ensure people feel safe. We will reduce the number of people living in Nursing Homes
We plan to....	<ul style="list-style-type: none"> ▪ Work with developers and providers in the provision of appropriate housing and to ensure that housing needs are identified ▪ Reduce the number of people with assessed needs living in inappropriate housing ▪ Continually support the option for independent living ▪ Continue to work with Spatial Planning and Strategic Housing to further develop needs, by improved intelligence
Outcome....	<ul style="list-style-type: none"> ▪ Better housing offer for Autistic people within Cheshire East ▪ Greater involvement of the autistic community in the planning and execution of decisions that directly affect them to live independently ▪ Further enhancing our data for need and contribution to specialised supplementary planning documents

Service provision	
Our ambition....	More specialist health and social care services will be provided and will be easily accessed by those who need them. Individuals and families encounter a range of high-quality services that are joined-up, easy to navigate and appropriate for their needs
We plan to....	<ul style="list-style-type: none"> ▪ Engage with and stimulate with the provider market to increase and enhance the range of available provision to support young people and adults with autism who have eligible support needs ▪ Develop first concerns and crisis / risk pathways ▪ Further develop the local Dynamic Support Database - a Risk Register to ensure there appropriate support is available and put in place ▪ Continue to improve workforce capability and capacity ▪ Further develop our knowledge base of need and cohort intelligence
Outcome....	<ul style="list-style-type: none"> ▪ A more joined up, person centred approach to commissioning provision across Children's and Adults will ensure a smooth transition and improved outcomes for individuals with autism who require care and support services ▪ Improved co-ordination, communication and information sharing between core services such as health and education ▪ Improved intelligence in relation to people with autism

Appendix 1:

Governance Arrangements



Appendix 2:

Glossary of Terms

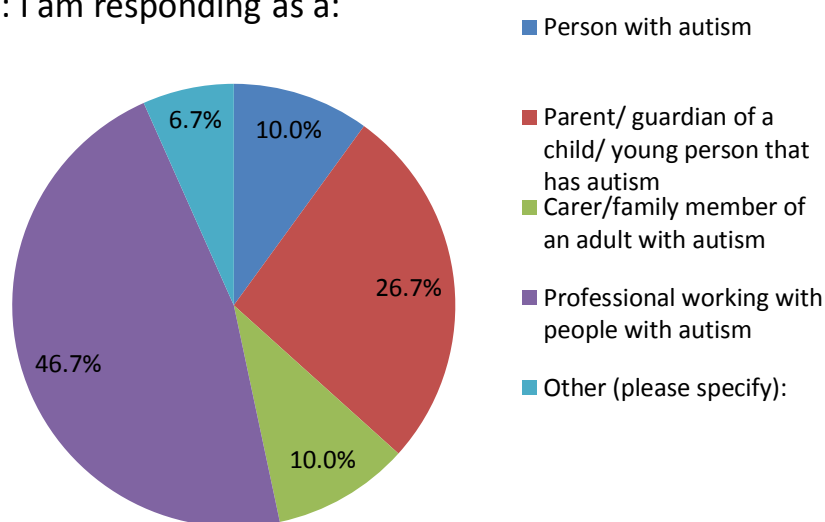
AS	Asperger Syndrome
ASC	Autistic Spectrum Condition
ASD	Autistic Spectrum Disorder
CeTR	Care Education and Treatment Review
CEAT	Community Early Autism Team
CCG	Clinical Commissioning Group
CQC	Care Quality Commission
Diagnosis	When someone is told what his or her medical condition is
DEA	Disability Employment Advisors
EHCP	Education, Health and Care Plans
HFA	High Functioning Autism
NICE	National Institute for Clinical Excellence
NHS	National Health Service
OT	OT Occupational Therapy
Outcome	Outcome The difference something makes
Pathway	Pathway A map that sets out the routes to access services
SEND	Special educational needs and / disabilities
Strategy	Strategy A plan that sets out what should be done to make things better
Transition	Transition A process or period of change

Appendix 3:

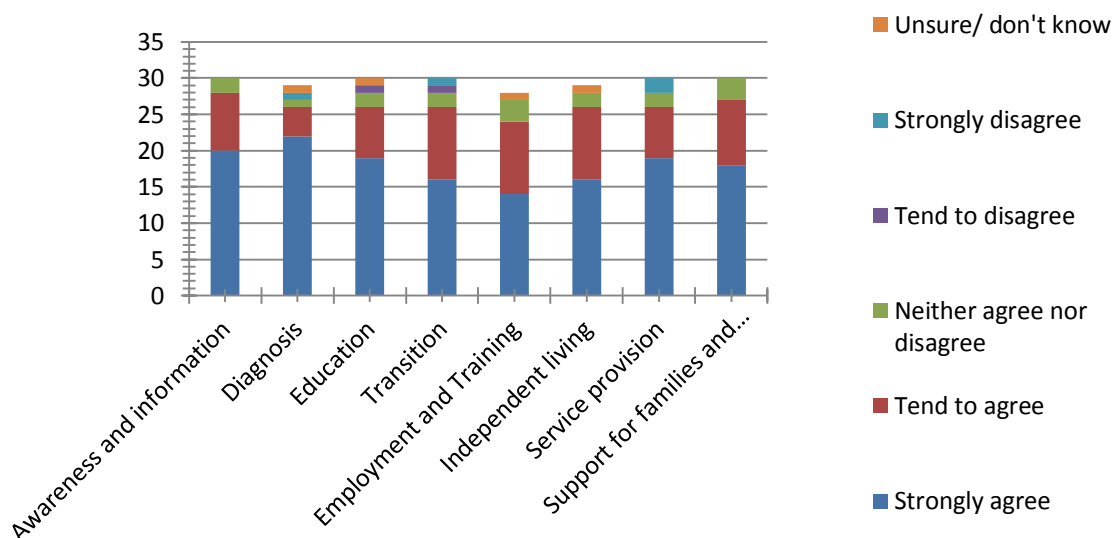
Consultation Summary

The Strategy experienced formal public consultation between 04 February 2019 and 11 March 2019, in which 90 responses were received and detailed in the Cheshire East All Age Autism Strategy Consultation. A summary of

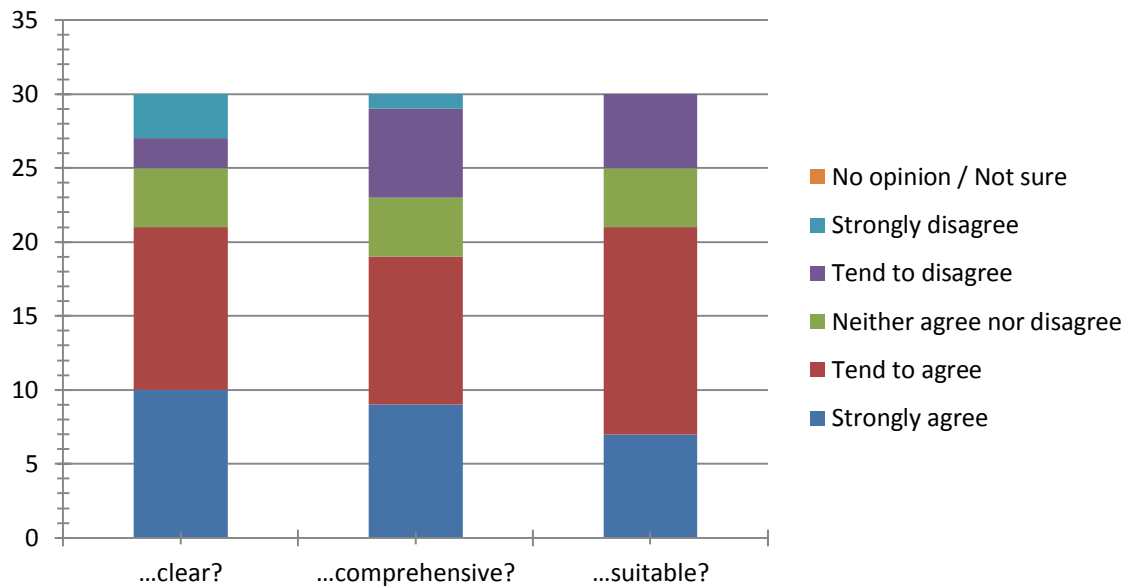
Q1: I am responding as a:



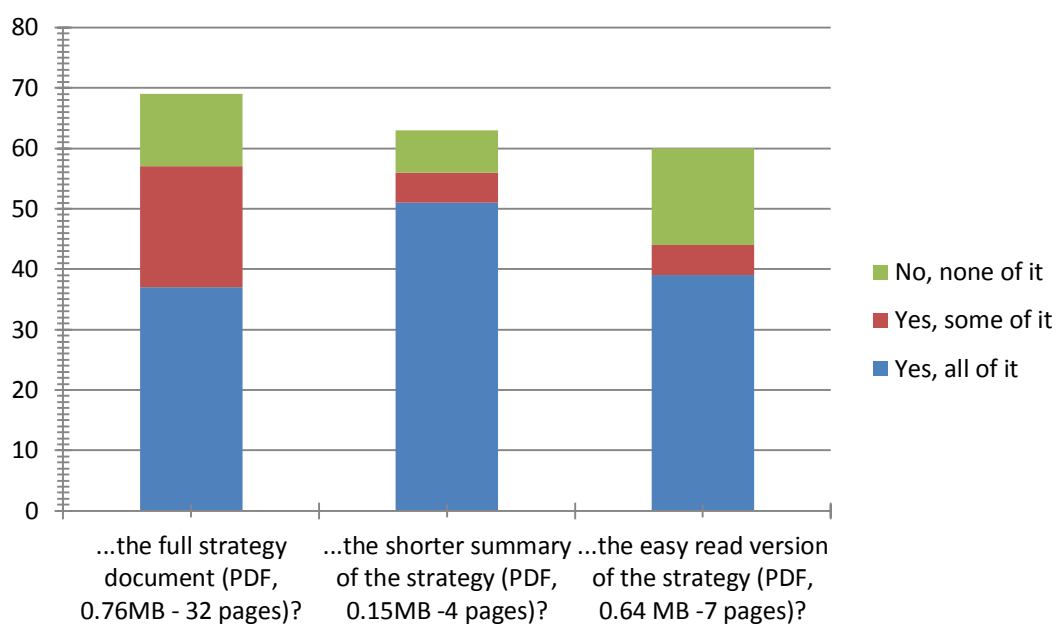
Q2: How strongly do you agree or disagree with each of the 8 key themes as identified within the draft Autism Strategy?



Q3: How strongly do you agree or disagree that the Autism Strategy is...



Q4: Have you read...



Autism Assessment Pathway (0-19 years)

