

Humber Autism Strategic Framework

2021 – 2026

Inclusive Care



<i>Document Configuration</i>		<i>Document Ref:</i>
<i>Date</i> 11.02.2021	<i>Version</i>	1
<i>Author Name / Job Title</i>	<i>Clarissa Thompson/ Autism Access Lead</i>	
<i>Directorate Name</i>	<i>Nursing and Medical</i>	
<i>Clinical / Executive Sponsor</i>	<i>Hilary Gledhill</i>	
<i>Reporting Committee</i>		
<i>Trust Board Ratification</i>		
<i>Review Date</i>	<i>March 2026</i>	
<i>Distribution Channels</i>	<i>https://www.humber.nhs.uk</i>	
<i>Regulator Link</i>		
<i>Key Internal Documents</i>	<i>Patient and Carer Experience Strategy (2018-2023)</i> <i>Communications Strategy (2017-2022)</i> <i>Equality, Diversity and Inclusion Policy</i>	
<i>Key External Documents</i>	<i>Autism Act (2009)</i> <i>Fulfilling and Rewarding Lives</i> <i>Think Autism</i> <i>NICE Guidance Autism spectrum disorder in adults: diagnosis and management (2012)</i> <i>NICE Guidance Autism spectrum disorder in under 19s: recognition, referral and diagnosis (2011)</i> <i>NICE Guidance Autism spectrum disorder in under 19s: support and management (2013)</i> <i>Core Capabilities Framework for Supporting Autistic People (2019)</i> <i>NHS Long Term Plan</i>	

Contents

Section 1: Introduction by the Director of Nursing, Allied Health and Social Care Professionals	4
Section 2: Autism - What is it?.....	5
<i>2.1 Autism Defined</i>	5
Section 3: Context	7
<i>3.1 Prevalence of Autism</i>	7
<i>3.2 National Reports</i>	7
<i>3.3 Local Context</i>	9
<i>3.4 Current Service Provision</i>	9
<i>Section 4: Alignment with the Trust Strategy</i>	12
Section 5: Priority Areas of Work	13
<i>5.1 Development Process</i>	13
<i>5.2 The Vision</i>	20
<i>5.3 Priority 1 - Understands Autism</i>	21
<i>5.4 Priority 2 - Accepts Autism</i>	23
<i>5.5 Priority 3 - Supports Autism</i>	25
<i>Section 6: Next Steps</i>	27
References	28

Section 1: Introduction by the Director of Nursing, Allied Health and Social Care Professionals

It gives me great pleasure to introduce the Trusts first strategic framework for Autism which has been produced in consultation with staff, patients, carers and experts by experience. The Humber Autism Strategic Framework (HASF) which aims to deliver excellence in care for autism has been developed alongside a service improvement project reviewing health services for autistic people across Hull and East Riding. Information has been gathered from patients, service users, carers and staff through face to face conversations and surveys to ensure the needs of autistic people have not only been considered but have informed the priorities. The framework applies to all services delivered by Humber Teaching Trust with an expectation that all divisions will develop plans to take forward the aspects that are relevant to their services which will be included in their specific quality improvement plans.

For the purposes of this document the term autism is used as an umbrella term to encompass the many descriptors of autism including autistic spectrum disorder, autistic **spectrum condition, Kanner's syndrome, Asperger's** syndrome, high functioning autism, Rett syndrome, childhood disintegrative disorder, Pervasive Development Disorder Not Otherwise Specified (PDD-NOS) and neurodiversity. This is in line with the terminology used in the International Classification of Diseases 11th Edition (ICD-11) and The Diagnostic Statistical Manual 5th Edition (DSM 5), the most up to date sets of criteria for diagnosing autism. This strategic framework also adopts identity first language when describing autistic people in acknowledgement that **autism is part of an individual's identity**.

This strategic framework sits as part of a suite of strategies and work programmes which together will enable our aspirations to be a provider of outstanding care. The Trusts PROUD leadership programme launched in 2019 supports the development of the leadership culture and capability that is required to achieve the priorities in this strategy. In addition our Patient and Carer Experience strategy supports a culture of co-production to ensure services are developed and delivered in line with the needs of the communities we serve.

We recognise that knowledge and understanding about autism is an evolving field, therefore, to ensure our strategic framework remains current it will be reviewed on an annual basis to ensure the most recent legislation and evidence bases are utilised in meeting the objectives.



Hilary Gledhill
Executive Director of Nursing, Allied Health and Social Care Professionals

Section 2: Autism - What is it?

2.1 Autism Defined

Autism can be described 'as a lifelong disability which affects how people communicate and interact with the world,' (National Autistic Society, 2020). Autism is not a learning disability but people with autism can also have a learning disability. Autism is recognised as a spectrum condition, which simply means that whilst autistic people share certain characteristics they do not all act in the same way. This can make autism very challenging for health professionals to understand.

Autism is an example of neurodiversity, which refers to individual differences in brain functioning (Graby, 2015). The neurodiversity movement supports the view that these **differences are as intrinsic to the autistic person's character as any** other neurological variation. The concept of neurodiversity challenges traditional medical models that suggest autism is a disorder and something that can be treated (Kapp et al., 2013). Neurodiversity recognises that some of the characteristics of autism may create challenges when interacting with the world but moving forward the emphasis should be placed on the world changing rather than the autistic person (Dyck and Russell, 2020).

Autism is currently diagnosed in the UK using criteria from the ICD-11 and DSM 5. The main criteria for diagnosis are that the individual displays persistent difficulties with social communication and interaction. They also need to demonstrate restricted and repetitive patterns of behaviours, activities or interests. In order to meet the diagnostic criteria these difficulties need to be present since childhood or when demands exceed capacity and impact **on an individual's ability to function** across contexts.

It is important to highlight that not all autistic individuals will appear to be what is commonly considered as autistic. Depending on a multitude of factors such as the environment, time of day, mental health and personal circumstance autistic characteristics may not all be present at the same time or to the same intensity. This means that health professionals working with autistic people need to adopt a non-judgemental and flexible approach.

2.2 Autism – The Impact

The neurodiverse community are keen to stress there can be positives to being autistic. These can include the ability to think differently, attention to detail, a methodological approach, and good observational skills, particularly in areas related to interests. However, strengths can also be weaknesses. Attention to detail can over-ride ability to think holistically or problem solve novel situations, methodological approaches can prevent taking **into account unquantifiable factors such as others' opinions and acute observational skills** can prevent effective filtering of information. Autistic individuals can also experience **difficulties in communication and 'cognitive and behavioural flexibility, altered sensory sensitivity, sensory processing difficulties and emotional regulation difficulties'** (National Institute of Clinical Excellence (NICE), 2012, p.5). These difficulties can impact their lives in a number of ways, some of which are explored below.

Autistic people are at a higher risk of developing mental health conditions such as depression, anxiety, self-harm and suicidality (Lever and Geurts, 2017). Cassidy et al. (2014) found in their study of 374 autistic people that 66% had expressed suicide ideation and 35%

had made an attempt on their lives. Risk factors linked to an increased risk of suicidality include autistic traits such as difficulties with social interaction, poor support and camouflaging - the practice of hiding autistic characteristics to fit in with society (Cassidy et al., 2018). Autistic people are also at a higher risk of social and economic exclusion which has been linked to the development of mental health problems (Smith and White, 2020; Hedley et al., 2018).

Autistic people find it more difficult to access relevant health services due to a lack of understanding about autism from professionals and limited access to appropriate therapies (Camm-Crosbie et al., 2019). It has also been found, particularly in individuals who have been diagnosed later in life, that autistic people are more likely to have been misdiagnosed with mental health conditions (Au-Yeung et al., 2019) and personality disorders.

Alongside mental health difficulties autistic people can experience poor physical health outcomes. The premature mortality rate of autistic individuals is estimated to be significantly more than the general population (Smith DaWait et al., 2019). It has been found that autistic individuals are more likely to be predisposed to a number of physical health conditions, particularly heart, lung and diabetic problems (Weir et al., 2020). Unfortunately due to a lack of understanding from health professionals about autism and physical health, symptoms of illness have been wrongly attributed to the core features of autism and diagnosis and treatment has been subsequently delayed.

Most recently the COVID pandemic has created new challenges for the autistic community. As mentioned previously autistic people are more likely than the average population to have co-morbid health conditions (Rydzewska et al., 2020) which places them in a high risk patient category. This fact coupled with social distancing measures that may disrupt already fragile support networks (den Houting, 2020) can lead to declines in mental health and wellbeing. A recent report from the National Autistic Society found that since the pandemic autistic people are 7 times more likely to be chronically lonely than the general population. It is therefore paramount that professionals strive to develop their understanding of autism and provide support in a timely and appropriate manner.

Section 3: Context

3.1 Prevalence of Autism

Autistic people get diagnosed both in childhood and as adults. Prevalence figures for autism vary depending on the study, with the most recent evidence suggesting 1.1 in 100 people will be autistic (Brugha et al. 2016), which means that there are just over approximately 700 000 autistic adults and children living in the UK.

Autism affects men and women. It was initially suggested that males were four times more likely than females to be autistic (Kanner, 1943; Ehlers and Gillberg, 1993) however more recent studies suggest this ratio is more likely to be 3:1 (Loomes, Hull and Mandy, 2017). Females may be diagnosed less than males due to the fact that they present differently and diagnostic tools are skewed towards male autistic traits (Bargiela et al. 2016).

As autism is not routinely recorded in patient records it is extremely difficult to get a definitive count of how many autistic people there are nationally. This can negatively impact the organisation and planning of future services.

3.2 National Reports

A number of national reports have been published related to the provision of care and services for autistic people. Please note that there are numerous reports, publications and articles that can be applied to autistic people and the wider population but only the documents that specifically apply to autism have been discussed below.

The Autism Act (2009)

Following a campaign led by the National Autistic Society to improve access to services the Autism Act was made law. The act stipulated that there had to be a government strategy to support autistic people accessing both health and social care services. Changes following the act include improved access to diagnostic pathways and care assessments. However the National Autistic Society reported in 2019 that 10 years on there is still a lot of work needed with 2 out of 3 autistic adults not getting the help they need, ending up isolated, developing mental health problems and falling into crisis.

Fulfilling and Rewarding Lives (2010) and Think Autism (2014)

Following the Autism Act these national strategies were created to set out the framework for meeting the needs of autistic individuals in England by improving the provision of relevant services by local authorities and the NHS. The strategy documents outline three main ambitions including that local authorities should know how many people with autism live in the area, ensuring a clear diagnostic pathway is available locally and that health and social care staff should know when to make reasonable adjustments.

NICE Guidance

There are three NICE Guidance documents that relate to autism, these are:

- NICE Guidance Autism spectrum disorder in adults: diagnosis and management (2012)
- NICE Guidance Autism spectrum disorder in under 19s: recognition, referral and diagnosis (2011)
- NICE Guidance Autism spectrum disorder in under 19s: support and management (2013)

These guidance documents support the above strategies and provide recommendations about how to improve access to health services for adults and children. NICE have also produced a set of quality standards to inform the commissioning of autism services for children, young people and adults. The quality statements cover areas such as assessment, diagnosis, treatment and managing behaviours of concern.

Core Capabilities Framework for Supporting Autistic People

(Dept. Health and Social Care, 2019)

This document outlines the core skills that health professionals working with autistic people should have. It comprises of 19 capabilities which are grouped into 5 domains. These include understanding autism, personalised support, physical and mental health, risk, legislation and safeguarding and leadership.

In line with NICE guidance the framework suggests a three tier approach to training which recognises that the type of professional role will dictate the level of skills and knowledge required. The framework also recognises that no one person should be expected to possess the skills for every capability but competence should be spread across a team, creating a flexible and diverse workforce.

NHS Long Term Plan

The latest plan from the NHS includes ambitions of improving mental health teams for autistic children and adults, reducing diagnosis waiting times and adopting an annual health check for autistic people.

CQC: Closed Cultures

In addition to the above the CQC has undertaken a focused piece of work on closed cultures which they define as *'a poor culture in a health or care service that increases the risk of harm. This includes abuse and human rights breaches. The development of closed cultures can be deliberate or unintentional – either way it can cause unacceptable harm to a person and their loved ones'*.

They go on to say that closed cultures are more likely to develop in services where:

- people are removed from their communities
- people stay for months or years at a time
- there is weak leadership
- staff lack the right skills, training or experience to support people
- there is a lack of positive and open engagement between staff and with people using services and their families

In these services, people are often not able to speak up for themselves. This could be through lack of communication skills, lack of support or abuse of their rights to speak up.

CQC recognises that a closed culture can develop anywhere, but there are certain services and groups of people that will be at greater risk. This includes services that provide care for people with a learning disability and/or autistic people, and older people who may not have regular contact with families.

In the delivery of this strategic framework the work of the CQC regarding closed cultures will be taken forward within a context of ensuring patients, families and carers are involved in all decisions about care. By working with those who use the Trust services and their families to develop new ways of working and acting on concerns when things do not go as

expected, services will remain open and transparent. The Trust will continue to develop the leaders and staff to ensure a culture is in place that respects human rights, prevents abuse and puts the needs of patients and service users at the heart of all we do.

3.3 Local Context

East Riding Autism Strategy (2019-2024) & Hull Autism Strategy (2015-2020) & North Yorkshire Autism Strategy (2015-2020)

In line with the Autism Act Hull, East Riding and North Yorkshire have developed autism strategy documents. Whilst the structure and layout of each strategy is different, all three reports have the same aim, to improve the lives of autistic people living in the local areas.

HASF will further support these documents by aiming to enhance the experience of accessing health services for autistic people across Hull, East Riding, Scarborough, Ryedale and Whitby.

From the strategies prevalence rates of autism in the East Riding and Hull are 5100 and 3900 respectively. There is an estimated 6000 autistic people living in North Yorkshire, with approximately 1100 individuals in the Scarborough district. These numbers are merely estimates due to the lack of hard information about how many people there are with autism in the local area and it again highlights the need for accurate information. Estimates in the context of lack of accurate, evidence based data are, of course, not able to account for regional differences in the distribution of autistic populations. Given the effect of life chances on autistic people outlined above, it is likely that autistic people will cluster in areas where there is greater economic deprivation, therefore estimates calculated from national prevalence rates alone are almost certainly too low.

Key objectives from the local strategies relevant to HASF include timely diagnosis and support, clear pathways for autistic people without a learning disability, system wide understanding of autism and an integrated and transparent approach to the care of autistic people.

The Autism Partnership Boards

Hull and East Riding both have separate Autism Partnership Boards which meet on a regular basis and are designed to offer an opportunity to autistic people, carers and professions to come together to discuss the main issues affecting autistic people in their local communities and to discuss ways of making positive changes happen. The HASF will be reviewed within each of the Partnership Boards to ensure the local communities agree with the priority areas.

The Autism Services Project

Funded by the Transforming Care Partnership the post of Autism Access Lead was created in May 2020. This post was given the brief of producing a report that highlights the gaps in services that influence the mental health of autistic people within the Hull and East Riding. Within this post data was gathered from autistic people, carers and staff members working in The Trust via surveys, patient records and face to face. This data has been used to inform some of the objectives of the HASF.

3.4 Current Service Provision

A brief summary of specialist services that work with autistic adults and children, with and without a learning disability in Humber Teaching NHS Foundation Trust.

East Riding Children's Autism Assessment Team

In 2019 the Trust **took over management of the East Riding children's autism team from the local authority**. The team provides assessment of autism for children and young people under the age of 18. It is currently an assessment only service. Referrals can come from speech & language therapy (SALT), educational psychology (EP), paediatricians, portage and CAMHS.

Assessments are completed in line with NICE guidance and due to the geography of the area tend to take place in a clinic setting.

Hull Children's Autism Assessment Team

Similarly to East Riding the Hull assessment team provide assessment of autism for children and young people under the age of 18 and is also an assessment only service. Referrals can be made via Special Educational Needs Co-ordinator's (SENCO), SALT's, Paediatricians, EP's and Portage Workers. Assessments are completed in line with NICE guidance and generally take place in the school environment.

As well as assessment the Hull team has **worked collaboratively with Matthew's Hub to provide training to Hull school SENCO's about autism and attachment**. The team also provided consultation about the environmental recommendations for the new Inspire Mental Health Unit to ensure it met the needs of autistic children and young people.

In the future there are plans for an intervention pathway to be established and currently there is a small project underway to offer support to autistic children and families known to CAMHS for anxiety and depression.

The Children's Speech and Language Service

The Children's Speech and Language service provides assessments, interventions, strategies and support for children with social communication needs and autism across Hull and East Riding. Part of the social communication assessment may include making a referral to the Autism Assessment Team for a formal diagnosis assessment.

Children with social communication needs and autism are supported at home, nurseries and schools ranging from primary to specialist provisions. The Speech and Language Therapy service has a clinical pathway which supports children from early identification to post diagnostic intervention and support. The service works in partnership with the **Children's Autism Assessment Services**.

Humber Adult Autism Diagnostic Service (HAADS)

HAADS provides assessment of autism for people over the age of 18 living in Hull and the East Riding of Yorkshire. It is currently an assessment only service which means that it does not undertake any treatment but will refer individuals onto other services. The team within HAADS offer consultation and supervision to other services when needed.

HAADS is hopeful to expand in the future to provide a full neurodiversity service for autistic adults and other neurodiverse conditions such as ADHD. The aim of the team will be to deliver training to the Trust, offer supervision sessions as needed and provide treatment for complex patients who have been unable to access mainstream services due to their autism.

Learning Disabilities Services

There are a number of teams that support adults and children with autism and a learning disability across Hull and East Riding. These include community teams, an intensive support team (IST) and inpatient services.

The adult and children's community teams utilise a multidisciplinary team approach to support the health needs of their patients across Hull and East Riding.

The IST works with adults who require more intensive support at a given time to manage risk, prevent placement breakdown or an inpatient admission. If an admission is unavoidable the inpatient service at Townend Court provides assessment and treatment for individuals from across the Transforming Care Partnership (Hull, East Riding, North Lincolnshire, and North East Lincolnshire).

Forensic Outreach Liaison Service (FOLS)

FOLS works with patients over 18 who have a Learning Disability and/or Autism. It is funded through the Transforming Care Partnership. The team covers Hull, East Riding and North East Lincolnshire. FOLS work with transforming patients who are in secure hospitals across the region and receive referrals from community learning disability teams, IST, prison, probation and police. The team will accept individuals with a diagnosis of autism with and without a learning disability but they do not co-ordinate care so the client will need to be seen within another team as well.

Matthew's Hub

Matthew's Hub is a third sector support service for autistic people without a learning disability aged 13 or over, living in Hull or the East Riding who have or are waiting for a diagnosis. The Hub provides advice and support in relation to employment, education, housing, benefits, health, and diagnosis. **Matthew's Hub has been commissioned to work in partnership with HAADS to provide pre and post diagnostic support to individuals.**

Autism Services for Scarborough, Whitby and Ryedale.

The Retreat in York provides autism assessment for adults and children in Scarborough, Ryedale and Whitby. The Retreat also provides support for adults living in Scarborough, Ryedale and Whitby including post diagnostic group work, one to one sessions, sensory assessments or modified therapies.

Section 4: Alignment with the Trust Strategy

The strategy has been designed to support delivery of the Trust's Mission, Vision and Values.



To implement this strategy, the priorities have been aligned to the Trust's six strategic goals:



Section 5: Priority Areas of Work

5.1 Development Process

This section highlights 6 key themes that have been identified through consultation with autistic people, carers and staff working within the Trust. These themes are also supported by the reports and documents discussed in section 3. These themes have been used to develop the vision of the HASF and the main priority areas.

Understanding

Provisional findings from the Autism Services Project suggest that autistic people and carers want health services to have a greater understanding of autism. This finding has been mirrored across the U.K, for example a main outcome from a recent study commissioned by the Welsh Health Councils (2019) is to develop a better understanding of autism amongst NHS staff.

As part of the Autism Services Project staff from across The Trust services completed a survey about their experience working with individuals with autism. It was clear from the findings that staff cared about their patients and that they wanted to understand autism and be empowered to make the reasonable adjustments needed for this client group. There were some excellent examples of reasonable adjustments including longer appointment slots, adopting a flexible approach to therapy and using visuals within the sessions. Some health professionals however felt they could not work effectively with autistic people because they did not know enough about the condition.

A greater understanding of autism will reduce delays in getting a diagnosis, prevent wasted time on misdiagnosis and ensure access to appropriate treatment. This will in turn reduce the long term support needs of autistic people.

"I might have gotten more help as a kid, my school were very dismissive of me and they would say naughty child"

Autistic Female

"The most important thing I have learned from working with this service user group is that one size does not fit all"

Humber Staff Member

What we need to do:

- Develop an autism aware workforce through training and education
- Provide staff with access to specialist supervision and support when needed
- Empower staff to make the necessary reasonable adjustments for autistic patients
- Share examples of good practice throughout the Trust

Communication

Communicating with an unfamiliar person can cause a lot of anxiety for autistic people. It has been widely documented that autistic people can find it hard to verbally communicate with unfamiliar health professionals and need time to get to know the person (Cummings, Pellicano and Crane, 2020). Sometimes autistic individuals were not able to find the right words to describe how they were feeling. This may mean that some approaches used in health e.g. check-up calls are not always appropriate.

The Trust currently provides an excellent communication awareness training module through the Adult Community Learning Disability Team. This training provides a basic understanding of the communication needs of individuals with a learning disability and autism. Also available through The Trust is training in intensive interaction, a specialist communication strategy that can be utilised with the most complex nonverbal autistic patients. There is currently no access to training about the communication needs of autistic people without a learning disability.

From the Autism Services Project, autistic people that were surveyed preferred face to face and virtual contact over using the telephone. In response to the COVID pandemic The Trust has started using virtual mediums to engage with clients and this has been positively received within the autistic community.

Some of the feedback from the Autism Services Project included that when attending assessments autistic people felt it would be useful to have an outline of what was going to be discussed during appointments and a summary provided afterwards. A focus on using visuals also helped individuals to process what was being said. When arranging appointments it was felt that a choice of times and appointment reminders would be useful.

"Being able to have an online assessment made a difficult and stressful (although long-hoped for) appointment much, much easier"

Autistic Male

"He is anxious about a lot of things but presently it's communicating with anyone outside of his immediate family"

Parent

What we need to do:

- Cultivate an awareness of the communication needs of autistic people throughout the Trust
- Ensure that the communication preferences of the patient are considered during every interaction
- Adopt a flexible approach to communication within all services

Diagnosis

A priority that is highlighted in both the East Riding (2019) and Hull (2020) Autism Strategies is a clear pathway to timely diagnosis for children and adults.

NICE guidance recommends that assessments should be accessible and completed within a specialist multi-disciplinary autism team and this has been reflected in the practice of the **Trust's** children and adult assessment teams. In line with the NICE (2014) Quality Standards for autism services, assessments should be offered within 3 months of the initial referral. **This is a goal that both the children's and adult** assessment teams continue to work towards.

Following diagnosis NICE guidance for adults also recommends that autistic individuals have access to support and information about autism and a record of specific needs and any reasonable adjustments that are required is accessible by health professionals.

The diagnostic process is extremely important and can help to answer a lot of questions and uncertainties an individual or their family has. It is the ideal time to identify physical and mental health needs and make recommendations.

Feedback from the Autism Services Project indicated that whilst many autistic adults and carers found that diagnosis offered the answers they had been looking for, others felt **overwhelmed by a new 'label' and this led to** deterioration in the **individual's** mental health. Matthews Hub currently works in partnership with the Trust to support autistic adults post diagnosis to help individuals understand their autism.

"I thought the diagnosis would help him understand himself and his struggles, to make some sense of his life and pave the way for happier times for him. The opposite happened and it has been a huge downhill spiral since diagnosis, he has gradually withdrawn and regressed"

Parent

"[Diagnosis] gave me a lot of understanding, a lot of pennies falling into place"

Autistic Female

What we need to do?

- Continue to develop clear pathways to diagnosis in both the children and adults teams.
- Review what support autistic individuals and their families need post diagnosis and make sure this is available.

The Right Support

In the Trust there are no commissioned autism specific support services. The Learning Disability Teams will work with anyone who has a learning disability including autistic individuals and offer a wide range of support for a variety of health needs utilising multidisciplinary teams of psychiatrists, specialist nurses, psychologists and allied health professionals. Whilst there is no similar provision for individuals without a learning disability, Matthews Hub do work in partnership with the Trust to provide pre and post diagnostic support as well as offering a range of social opportunities for its members.

Individuals without a learning disability can access mainstream services such as CAMHS, MIND, the Emotional Wellbeing Service and adult mental health services. Findings from the Autism Services Project suggest that the mainstream support offered was not always appropriate **for the individuals' needs** and that a diagnosis of autism sometimes excluded them from services. From the Project there were some good examples of healthcare **professionals listening to the autistic person's** view and providing treatment plans based on this.

The autistic community is extremely heterogeneous and can be a challenging group to provide equitable care with the current resourcing in mainstream services. This has been recognised by the Trust and is one of the reasons that both the **children's and adult** assessment teams are developing intervention pathways including clear supervision support for the wider teams.

As mentioned previously health outcomes for individuals with autism tend to be poorer than compared to the general population (Weir et al., 2020). To help improve the general health of the autistic population the Trust is currently working with other healthcare partners to establish annual health checks for both autistic individuals with and without a learning disability.

Sometimes autistic people present with behaviours of concern, which can cause difficulties living in the community and occasionally inpatient admissions. NICE guidance (2012) recommends that there needs to be more autism specific support when working with individuals who present with these behaviours and ensure the approaches remain person centred.

"My GP listened, rang back and is now putting a care plan into action for [my son] around all of these issues"

Parent

What we need to do:

- o Explore the experience of using health services in Hull and East Riding to identify examples of good practice and any gaps in service provision.
- o Enhance knowledge and understanding about the health needs of autistic people across the Trust
- o Support services to develop a consistent approach to the care of autistic people.
- o Continue to build strong partnerships with third sector providers who support autistic people

A Meaningful Life

Autistic people told the Autism Services Project that being able to live independently, structure time effectively, access employment and a supportive friend group would all be beneficial to their lives.

It was also found that parents and carers had concerns that their children were isolated and dependent on them for their needs. Many carers reported that supporting an autistic child or adult had a direct impact on their lives including relationship breakdown, giving up work and mental health illness.

Sensory differences can also impact an individual's ability to participate in day to day life. It is very common for autistic people to experience hypersensitivity and hyposensitivity to sensory input and this has been included as a criterion for diagnosis within the DSM 5. Sensory differences often create a range of barriers to engaging in activities, including housekeeping, education, leisure and employment.

In 2020 The Trust commissioned The Sensory Processing Service which will support children and young people with sensory needs including individuals with autism. The adult learning disability team also provides sensory support for autistic individuals with a learning disability. There is currently no equivalent sensory service for autistic adults without a learning disability.

The Trust has recognised the importance of the contribution sensory friendly environments to good care and in recent builds such as the Inspire mental health unit has incorporated recommendations to provide autism friendly spaces.

Autistic people are extremely vulnerable to loneliness and isolation, especially since the occurrence of COVID and lockdown. Matthews Hub has been an excellent community resource for individuals without a learning disability, providing social groups and access to **peer support**. **However even with Matthew's Hub individuals still** continue to require additional support with their mental and physical health.

"I have basically had to give up my life to support her and cope with it all. It is very isolating"

Parent

"Behavioural activation (maintaining an active lifestyle) is proven to help with the physiological symptoms of depression and can impact positively on an individual's mood."

Private autism specialist therapist

What we need to do:

- o Work collaboratively with partners in the local authority, education and the third sector to identify the types of support needed by autistic people and their families.

Transition

NICE guidelines (2013) recommend transition planning for young people with autism and mental health needs to begin from 14 years old ensuring a smooth transition to adult services. This includes a comprehensive assessment from both health and social care. From the Autism Services Project there were no examples of transition planning from 14+ and not all autistic young people had an Educational Health Care Plan that health professionals could contribute to. Parents and carers also reported that they found it difficult to know what adult services were available.

The National Autistic Society recommends that the professionals within children's services, for example CAMHS should be responsible for supporting Autistic young people through the transition process including introducing them to anyone from adult services that will be involved in their future care. Young people should also know what health services are available for them to access.

Transition is a time of change and can be very difficult for autistic people to cope with, resulting in a decline in health (First et al. 2016). Some parents who provided feedback for the Autism Services Project advised that they had not been prepared for this and would have liked more advice on how to support their child into adulthood.

"You have to know what you want when sometimes you don't know what is available or what is needed"

Parent

What we need to do:

- Develop a clear multiagency transition pathway for autistic young people
- Ensure transition is planned from an early age with contributions from both **children's** and adults teams.
- Ensure that health needs are clearly considered within Educational Health Care Plans
- Provide clear guidance about the types of adult services that are available

5.2 The Vision

Humber Teaching NHS Foundation Trust celebrates neurodiversity and is committed to providing services that understand, accept and support autistic people.

Humber Autism Strategic Framework



Promoting inclusive health services for autistic people across Hull and East Riding

5.3 Priority 1 - Understands Autism

To create an autism aware workforce that understands and embraces autism and autistic people.

To create awareness throughout The Trust of how autism affects the presentation of physical and mental health conditions.

To empower staff working with autistic patients to feel confident, capable and supported to carry out their role.

		Strategic Alignment					
No.	Key Objectives	Innovating Quality	Enhancing Prevention	Fostering Integration	Developing Workforce	Maximising Organisation	Promoting People
1	Ensure autism awareness training is included within general equality and diversity training programmes for all staff						
2	Implement a tiered system of training to ensure frontline staff and those responsible for making decisions on behalf of autistic people have the appropriate knowledge and skills which adhere to the Core Capabilities Framework.						
3	To develop a network of 'autism champions' across the trust to promote person centred care delivery for autistic adults, children and their carers/families.						
4	To develop a consultation network for all teams to be able to access specialist support from the children and adults' autism teams when needed.						

Short Term Deliverables and Long Term Sustainable Change

Year 1	<ul style="list-style-type: none">• Enhance current equality and diversity training module with autism content• Develop outline of the 'autism champion' role and identify candidates across the trust• Develop model of supervision for adult and children teams
Year 2+3	<ul style="list-style-type: none">• Develop and deliver clinical training package for frontline staff• Establish autism champions across the trust including quarterly CPD meeting.• Initiate access to specialist supervision for clinical staff in primary and secondary mental health teams.
Year 4+5	<ul style="list-style-type: none">• Research and evaluation to demonstrate impact of specialist training in relation to positive service user outcomes.• Review supervision model and if successful roll out to the rest of the trust.

5.4 Priority 2 - Accepts Autism

Establish a neurodiversity assessment and treatment pathway that will be mirrored across both adult and **children's** services.

Improve transition through consistency of service provision by creating a life span service.

Ensure service specifications within teams do not exclude individuals based on their diagnosis of autism.

		Strategic Alignment					
No.	Key Objectives	Innovating Quality	Enhancing Prevention	Fostering Integration	Developing Workforce	Maximising Organisation	Promoting People
1	Establish a marker of autism on patient records to support therapeutic and strategic future planning.						
2	Establish a clear autism diagnostic pathway including post assessment advice and support from external autism service providers.						
3	Ensure the diagnostic pathway for adults and children adheres to relevant NICE guidance relating to autism assessment.						
4	Work with commissioners to develop specialist autism intervention services that are not currently commissioned within the local area e.g. specialist autism therapist, adult sensory service.						

5	To review and develop a transition pathway for autistic children and young adults with local authority and educational providers.						
6	To ensure all services across the trust are able to identify and make reasonable adjustments e.g. adapting environments, a choice of appointment times, provision of visuals to support sessions...etc.						

Short Term Deliverables and Long Term Sustainable Change

Year 1	<ul style="list-style-type: none"> • Collaborate with Business Intelligence to devise best method of coding autism across all services • Audit diagnostic teams (number of referrals vs assessment capacity) • Review possible recruitment options to meet demand. • Identify which services are missing for autistic needs. • Develop Transition project to review processes. • Develop online reasonable adjustment workshop for services. • Complete audit of how autism friendly clinical environments are.
Year 2+3	<ul style="list-style-type: none"> • Roll out method of coding autism to gate keeper services (Children’s and Adults’ autism teams, GP’s and Mental Health Response Service). • Develop a MDT health intervention pathway as part of the autism diagnostic services (adults and children) • Utilise findings from the transition project to inform a pathway of best practice • Develop online reasonable adjustments toolkits
Year 4+5	<ul style="list-style-type: none"> • Review prevalence of autistic individuals accessing the trust services. • Audit diagnostic teams to explore effect of change • Embed autism transition pathway into practice • Evaluate service’s ability to make reasonable adjustments.

5.5 Priority 3 - Supports Autism

To promote neurodiversity throughout the Trust and in local communities.

Ensure autistic people have a voice in what happens within the Trust.

To promote professional and voluntary roles within the Trust for autistic people. .

No.	Key Objectives	Strategic Alignment					
		Innovating Quality	Enhancing Prevention	Fostering Integration	Developing Workforce	Maximising Organisation	Promoting People
1	Creation of an Autism portal on the intranet that provides resources to support services to be more autism friendly e.g. environmental checklists, COVID support, communication guidance and available services.						
2	Develop strong partnerships with autism specific third sector providers to provide post diagnostic and social support.						
3	Ensure Trust representation at meetings that guide autism and neurodiversity policy in the local area to ensure the views and experiences of our patients and service users inform policy development e.g. Autism Partnership Boards						
4	Encourage patient and carer participation and involvement in service redesign and developments to ensure services are developed aligned to the needs of patients and their families/carers.						

5	To promote employment opportunities for autistic people						
---	---	--	--	--	--	---	---

Short Term Deliverables and Long Term Sustainable Change

Year 1	<ul style="list-style-type: none"> • Develop basic content of autism portal • Create clear profiles of all third sector providers and what they can provide our patients. • Establish good Trust representation at the Autism Partnership Boards • Develop a strategy with The Trust's Patient Experience department to ensure autistic participation • Develop employment reasonable adjustments toolkit
Year 2+3	<ul style="list-style-type: none"> • Enhance portal with reasonable adjustments toolkits • Officially launch autism portal to staff teams • Trust to review opportunities to co-produce patient experience resources. • Work with voluntary services to identify opportunities for autistic people
Year 4+5	<ul style="list-style-type: none"> • Evaluate effectiveness of portal and the resources it contains • Continue to update Portal with relevant information

Section 6: Next Steps

The HASF is an ambitious plan to create an environment of inclusive healthcare based on the best available evidence for autistic people across the Trust. The new strategy will be launched in 2021 with a series of short virtual workshops to share the vision of the future of autism services within Humber Trust.

The HASF has been designed to complement our partner strategic documents in Hull, East Riding and North Yorkshire. The HASF will be used to shape the future of autism services within the trust. Delivery and evaluation of the strategy will be co-ordinated through the autism and learning disability services, as well as the newly appointed autism champions. Individual work streams will have an identified task and finish group aligned to them to ensure a focus on delivery and impact is maintained. The autism portal on the Intranet will allow regular updates on progress to be shared and also provide a resource for new evidence, guidance, good practice, innovation and celebration of successes.

We will know we have realised the aspirations that have driven our strategy when we have achieved the following:

- An autism aware confident workforce
- Positive feedback from autistic people, their families and carers about the services
- Diagnostic times will be within 3 months from referral
- An established autism portal on the intranet
- An established autism pathway following diagnosis

References

- Au-Yeung, S.K., Bradley, L., Robertson, A.E., Shaw, R., Baron-Cohen, S. and Cassidy, S., 2019. Experience of mental health diagnosis and perceived misdiagnosis in autistic, possibly autistic and non-autistic adults. *Autism*, 23(6), pp.1508-1518.
- Bargiela, S., Steward, R. and Mandy, W., 2016. The experiences of late-diagnosed women with autism spectrum conditions: An investigation of the female autism phenotype. *Journal of autism and developmental disorders*, 46(10), pp.3281-3294.
- Brugha, T.S., Spiers, N., Bankart, J., Cooper, S.A., McManus, S., Scott, F.J., Smith, J. and Tyrer, F., 2016. Epidemiology of autism in adults across age groups and ability levels. *The British Journal of Psychiatry*, 209(6), pp.498-503.
- Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S. and Cassidy, S., 2019. **'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality.** *Autism*, 23(6), pp.1431-1441.
- Cassidy, S., Bradley, P., Robinson, J., Allison, C., McHugh, M. and Baron-Cohen, S., 2014. Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. *The Lancet Psychiatry*, 1(2), pp.142-147.
- Cassidy, S., Bradley, L., Shaw, R. and Baron-Cohen, S., 2018. Risk markers for suicidality in autistic adults. *Molecular Autism*, 9(1), p.42.
- Community Health Council. 2019. How well does the NHS in Wales meet the needs of people with autism? Available at <http://www.wales.nhs.uk/sitesplus/documents/899/National%20CHC%20report%20Autism%20%28English%29%20FINAL.pdf>. (Accessed 18.10.2020)
- Cummins, C., Pellicano, E. and Crane, L., 2020. **Autistic adults' views of their communication skills and needs.** *International Journal of Language & Communication Disorders*, 55(5), pp.678-689.
- den Houting, J., 2020. Stepping out of isolation: Autistic people and COVID-19. *Autism in Adulthood*, 2(2) pp 103-105
- Dyck, E. and Russell, G., 2020. Challenging Psychiatric Classification: Healthy Autistic Diversity the Neurodiversity Movement. In *Healthy Minds in the Twentieth Century* (pp. 167-187). Palgrave Macmillan, Cham.
- Ehlers, S. and Gillberg, C., 1993. The epidemiology of Asperger syndrome: A total population study. *Journal of child psychology and psychiatry*, 34(8), pp.1327-1350.
- First, J., Cheak-Zamora, N.C. and Teti, M., 2016. A qualitative study of stress and coping when transitioning to adulthood with autism spectrum disorder. *Journal of Family Social Work*, 19(3), pp.220-236.
- Graby, S., 2015. Neurodiversity: **Bridging the gap between the disabled people's movement and the mental health system survivors' movement.** *Madness, distress and the politics of disablement*, pp.231-244.
- Weir, E., Allison, C., Warrier, V. and Baron-Cohen, S., 2020. Increased prevalence of non-communicable physical health conditions among autistic adults. *Autism*, pp.1-14
- Hedley, D., Uljarević, M., Foley, K.R., Richdale, A. and Trollor, J., 2018. Risk and protective factors underlying depression and suicidal ideation in autism spectrum disorder. *Depression and anxiety*, 35(7), pp.648-657.
- Joshi, G., Wozniak, J., Petty, C., Martelon, M.K., Fried, R., Bolfek, A., Kotte, A., Stevens, J., Furtak, S.L., Bourgeois, M. and Caruso, J., 2013. Psychiatric comorbidity and functioning in a clinically referred population of adults with autism spectrum disorders: a comparative study. *Journal of autism and developmental disorders*, 43(6), pp.1314-1325.
- Kanner, L., 1943. Autistic disturbances of affective contact. *Nervous child*, 2(3), pp.217-250.

Kapp, S.K., Gillespie-Lynch, K., Sherman, L.E. and Hutman, T., 2013. Deficit, difference, or both? Autism and neurodiversity. *Developmental psychology*, 49(1), pp.59.

Lever, A.G. and Geurts, H.M., 2016. Psychiatric co-occurring symptoms and disorders in young, middle-aged, and older adults with autism spectrum disorder. *Journal of autism and developmental disorders*, 46(6), pp.1916-1930.

Loomes, R., Hull, L. and Mandy, W.P.L., 2017. What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, 56(6), pp.466-474.

National Autistic Society 2020, *What is Autism*, National Autistic Society, viewed 20 October 2020, <www.autism.org.uk/advice-and-guidance/what-is-autism>

National Institute for Health and Care Excellence (2011). *Autism spectrum disorder in under 19s: recognition, referral and diagnosis*. Available at <http://pathways.nice.org.uk/pathways/autism-spectrum-disorder> [Accessed 11th June 2020]

National Institute for Health and Care Excellence (2012) *Autism spectrum disorder in adults: diagnosis and management*. Available at: www.nice.org.uk/guidance/cg142 [Accessed 26th May.2020]

National Institute for Health and Care Excellence (2013). *Autism spectrum disorder in under 19s: support and management*. Available at <http://pathways.nice.org.uk/pathways/autism-spectrum-disorder> [Accessed 11th June 2020]

National Institute for Health and Care Excellence (2014). *Autism*. Available at <http://nice.org.uk/guidance/qs51> [Accessed 12th June 2020]

Rydzewska, E., 2012. Destination unknown? Transition to adulthood for people with autism spectrum disorders. *British Journal of Special Education*, 39(2), pp.87-93.

Sala, R., Amet, L., Blagojevic-Stokic, N., Shattock, P. and Whiteley, P., 2020. Bridging the Gap Between Physical Health and Autism Spectrum Disorder. *Neuropsychiatric Disease and Treatment*, 16, p.1605.

Smith DaWalt, L., Hong, J., Greenberg, J.S. and Mailick, M.R., 2019. Mortality in individuals with autism spectrum disorder: Predictors over a 20-year period. *Autism*, 23(7), pp.1732-1739.

Smith, I.C. and White, S.W., 2020. Socio-emotional determinants of depressive symptoms in adolescents and adults with autism spectrum disorder: A systematic review. *Autism*, pp.136-140.