Tees All Age Autism Strategy

2019 - 2021



This strategy relates to children, young people and adults living in the Tees area who have Autism. This area includes the local authorities of Hartlepool, Stockton-On-Tees, Middlesbrough and Redcar and Cleveland. The Tees Autism Partnership includes representation from:

MAIN
Daisy Chain
ESPA
Family Parent Carers
People with Autism
Local service Providers
Middlesbrough Council,
Hartlepool Borough Council,
Redcar and Cleveland Borough Council
Tees Esk and Wear Valleys NHS Foundation Trust.
South Tees Clinical Commissioning Group,
Hartlepool and Stockton-On-Tees Clinical Commissioning Group (HAST)

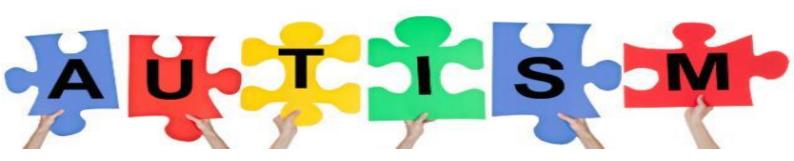
Acknowledgements

Our sincere thanks to the following groups who have actively contributed to the formation of this strategy:

- The children, young people and adults with Autism along with their parents and carers from across the four Local Authority areas.
- The many children, young people and adults with Autism, parents and carers, educators, professionals and service providers that have participated in surveys and engagement processes.
- The educators, professionals and service providers from each of the Local Authority regions.
- The South Tees Clinical Commissioning Group, Hartlepool and Stockton-On-Tees Clinical Commissioning Group (HAST) and Tees, Esk and Wear Valleys NHS Foundation Trust.
- Each of the 3 Local Authorities, Middlesbrough, Hartlepool and Redcar and Cleveland Borough Councils.
- Members of the Tees All Age Autism Partnership.



| Contents: | Page |
|-----------------------------------|------|
| Acknowledgements | 2 |
| The Vision | 4 |
| The Top Ten Objectives | 4 |
| What is Autism? | 5 |
| The National Picture | 6 |
| The Local Picture | 8 |
| Challenges for the Future | 11 |
| What Next & Future Priorities | 15 |
| Tees All Age Autism Action Plan | 16 |
| Appendices - Engagement | 19 |
| National Legislation and Guidance | 34 |
| Services in Tees | 37 |



The Vision

Our vision for people with Autism, is to create a society where everyone can participate fully, and be included. We look to deliver improvements to ensure people with Autism have the same opportunities as the general population along with tackling health inequalities. We want to reduce the health gap and support people with Autism to live full, healthy and independent lives. We want to ensure all children, young people and adults with Autism, along with their families, are able to receive early assessments and early access to appropriate services.

We want to ensure all children and young people with Autism have a smooth transition into adulthood.

We will support people with Autism to fulfil their aspirations through education, training, employment and volunteering so they become independent, active and engaged members of their local community and are able to achieve rewarding and fulfilling lives. We are committed to improving access into employment for people with Autism so they are able to get into and stay in work, training or volunteering.

The Tees All Age Partnership want to ensure children, young people and adults with Autism increasingly become active participants in the development of their own services - this will be an on-going process. We continue to strengthen our engagement methods with people and their families, through constructive dialogue and collaboration.

We know this will help us get the right approach to commissioning making sure we have excellent local services which enrich and enhance people's lives.

The Top Ten Objectives of this Autism Strategy are to:

- 1. Find local solutions in the adoption of evidence-based national guidance and best practice.
- 2. Ensure our services are centered around the child, young person, adult and their families.
- 3. Increase the awareness, understanding and skills of front line professionals who work with children, young people and adults with Autism.
- 4. Develop practices for early identification and prompt assessment and diagnosis.
- 5. Support children, young people and adults with Autism to be actively involved in their local community.
- 6. Establish clear, consistent pathways for young people transitioning to adult services.
- 7. Provide services that are effective, led by existing and future need which focus on measurable outcomes.
- 8. Develop services that offer choice, in order to better meet the individual needs of children, young people, adults and their families.
- 9. Work with local communities to improve access to services and support for all children, young people and adults with Autism.
- 10. Support children, young people and adults with Autism to achieve their life goals and aspirations.

"Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them."

(National Autistic Society)

Autism Spectrum Disorders or Autism Spectrum Conditions are the names given to a number of conditions including Autism and Asperger's Syndrome. For the purposes of this document we will referr to them all as Autism Spectrum Disorders (ASD). People with ASD will have:

- difficulties with social communication and social interaction
- restricted and repetitive patterns of behaviors, activities or interests (this includes behaviors)

All of which having been present since early childhood, to the extent they have a significant impact on everyday functioning.

Autism:

People with Autism normally have below average intelligence and often have a learning disability. They may have more significant problems with speech.

Asperger's Syndrome:

People with Asperger Syndrome have average or above average intelligence. They do not usually have a learning disability but may have specific learning difficulties. They have fewer problems with speech but may still have difficulties with understanding and processing language.

Other conditions which often fall under ASD include:

- Atypical Autism
- Pervasive Developmental Disorder (PDD)
- Pathological Demand Avoidance (PDA)
- Semantic Pragmatic Disorder

ASD is a hidden disability which affects 1% of the population. It is estimated 700,000 people in England have the condition. 70% of this number meet the criteria for other disorders such as epilepsy, Downs's syndrome, anxiety disorders, depression and other mental health disorders and Attention Deficit Hyperactivity Disorders (ADHD). Adults with Autism are socially and economically excluded with only 15% of adults in full-time employment.

The signs of Autism are normally noticeable in childhood although a confirmed diagnosis may not be available until much later. There are normally more males diagnosed than females. Research suggests ASD is under diagnosed in females as it is felt females are better able at disguising their difficulties in order to be "accepted", learning to copy the behaviors of others by masking the condition.

ASD presents differently in every individual, with every individual's needs differing at every stage of their lives. Some people with ASD will need relatively little support whilst others will need a lifetime of intensive specialist support.

There is no cure for Autism, but there are lots of interventions to support people to lead fulfilling and rewarding lives.

The National Picture

The Autism Act¹ was introduced in 2009 and was the first piece of disability specific legislation. It placed a duty on the Secretary of State for Health to introduce a Strategy and Statutory Guidance for improving the lives and outcomes of Adults with Autism.

The Government's vision:

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

"Fulfilling and Rewarding Lives"— the Strategy for Adults with Autism was published in 2010 along with the First Year Delivery Plan³. The Strategy focused on improving support and provision of local services for Adults with Autism whilst the Delivery Plan set out the Governance structure, timescales and responsibilities for implementing the Plan.

A review of the Strategy took place in 2013/2014 via the Autism Self- Assessment Framework which all Local Authorities were asked to complete. The information provided the Government with progress as well as highlighting key areas for future development.

"Think Autism4" – Fulfilling and Rewarding Lives, the Strategy for Adults with Autism: an update was published in 2014. It set out fifteen new priority challenges which people with Autism and other stakeholders identified as needing further change. The update focused on the following four areas:

- 1. Advice and information
- 2. Gaining and growing skills for independence
- 3. Early intervention and crisis prevention
- 4. Employment, particularly involving the use of apprenticeships

The Government provided Capital and Revenue funding to support the delivery of key themes identified in the update to ensure:

- Communities are more aware of and accessible to the needs of people with Autism by introducing "champions for change".
- Innovative local ideas, services or projects which can help people in their communities.
- How advice and information on services can be joined up better.

The introduction of the **Care Act**⁵ (2014) put a stronger focus on personalised care, choice and control. The Care Act put the onus on Local Authorities to provide a range of services which prevent or delay people developing care needs in the future.

The Government published new **Statutory Guidance** – **Think Autism**⁶ in March 2015 to make Local Authorities and Health Services aware of their statutory duty. This includes specifics for

2

 $\frac{http://webarchive.nationalarchives.gov.uk/20130104203954/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH 113369}{\frac{http://www.dh.gov.uk/en/Publicationsandstatistics/PublicationsPolicyAndGuidance/DH 113369}{\frac{http://www.dh.gov.uk/en/Publicationsandstatistics/PublicationsPolicyAndGuidance/DH 113369}{\frac{http://www.dh.gov.uk/en/Publicationsandstatistics/Publi$

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/216129/dh_122908.pdf

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_Strate_gv.ndf

¹ https://www.legislation.gov.uk/ukpga/2009/15/contents

⁵ http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

⁶ https://www.gov.uk/government/publications/adult-autism-strategy-statutory-guidance

training, community care assessments, pathways to diagnosis and assessment and commissioning based on population data. The Guidance contained five new chapters covering:

- Prevention and Safeguarding
- Reasonable adjustments
- Supporting people with complex needs
- Employment
- Criminal justice

It also posed fifteen priority challenges to all Local Authorities in the form of "I" statements.

The Governments **Progress Report – Think Autism (2016)**⁷ made it clear, failure to provide adequate services or to make reasonable adjustments would result in "**costly consequences**". The Report identifies how some people with Autism Spectrum Disorders, especially those with identified low level need, often "slip through the net", fall into crisis with a result of requiring costlier support services. It highlights if people with Autism don't receive the right support they will be unable to:

- lead fulfilled lives
- connect with their local communities
- pursue things the general population take for granted (such as employment ambitions)

The Progress Report continued the momentum from Think Autism – Fulfilling and Rewarding Lives, promoting co-productive engagement as a way to sustain improvements for people with Autism Spectrum Disorders. The Progress Report posed thirty one actions which include:

- Changes to Special Educational Needs and Disability (SEND) to improve support for children and young people along with an emphasis on preparing for adulthood.
- Support to help employment opportunities (for both the employee and employer)
- Improved Autism awareness in the Criminal Justice System
- Improved reporting and use of information which will help Commissioners plan better services for people with Autism and their families

The **National Institute for Health and Care Excellence** (NICE) have issued a number of national guidance documents⁸ which relate to children, young people and adults with Autism. The guidance represents evidence-based best practice advice on things such as:

- diagnosis and assessment
- personalised planning
- · co-ordination of care and support
- services for people with Autism and their families

The Prevent Strategy forms part of the Governments wider counter terrorism strategy. Autism has been identified as one of the 3 high risk conditions within **Prevent**⁹ referrals. The Home Office are currently working on the production of guidance on Autism and concerns about people with Autism – to inform assessment and support offered.

⁷ https://www.gov.uk/government/publications/progress-report-on-strategy-for-adults-with-autism

⁸ https://www.nice.org.uk/guidance/conditions-and-diseases/mental-health-and-behavioural-conditions/autism#panel-pathways

⁹ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/694002/individuals-referred-supported-prevent-programme-apr2016-mar2017.pdf

The Local Picture

The Tees Adult Autism Partnership (previously known as the Tees Adult Autism Strategy Delivery Group) was formed in September 2005. The group produced a Tees Autism Adults Strategy (2013) in response to the Autism Act (2009) and the Government's Autism Strategy (2010) – Fulfilling and Rewarding Lives: The strategy for adults with Autism in England.

The Tees Children and Young People's Strategy Group was formed in 2014 to actively engage with children and young people with ASD. Their main aim was to continually improve services and the support children and young people receive.

The two groups merged in 2017 to form a Tees All Age Autism Partnership with a commitment to improving lifelong services for people with Autism.

Both "Think Autism" and the "Progress Report" have proved challenging to Tees Local Authorities especially in the current Austerity climate. However it remains essential for all ASD services across Tees to continually improve. By working together we can ensure children, young people and adults with Autism are able to:

- access assessment and diagnosis pathways as early as possible
- have information, advice (pre and post diagnosis)
- have access to additional support

Each Local Authority takes part in completing a Public Health England bi-annual Autism Self-Assessment Framework¹⁰ exercise which details specifics on:

- Local Demographics
- Planning
- Training
- Diagnosis
- Care and Support
- Employment
- Criminal Justice System

Local Authorities are able to compare how their area is performing against other local and national areas. The process provides information on priority work using the Red, Amber Green rating system (RAG). The numbers of children, young people and adults are captured during the process using the SAF data collection tool.

Across Tees, Commissioners work with a number of Charities and have established effective twoway communication systems with people with ASD and their families. This consultation and intelligence gathering process mirrors that described in the Government's Autism Strategy. This approach continues to keep the momentum going, ensuring Autism remains a high priority throughout the Tees area.

The above intelligence, along with information contained in the Joint Strategic Needs Analysis (JSNA), provides the basis for Commissioning. It aids the commissioning of innovative and effective services which are able to change and meet the continual evolving needs of people with ASD in our local area.

Tees Commissioners work to ensure services are:

10

https://khub.net/web/guest/welcome?p p state=normal&p p mode=view&refererPlid=47826390&saveLastPath=false& c om_liferay_login_web_portlet_LoginPortlet_mvcRenderCommandName=%2Flogin%2Flogin&p_p_id=com_liferay_login_web_portlet_LoginPortlet&p p lifecycle=0& com_liferay_login_web_portlet_LoginPortlet redirect=%2Fweb%2Fphe-learning-disabilities-observatory-ihal-

- centred around the person
- based on achieving positive outcomes
- cost-effective and 'needs' led
- effectively co-ordinated

A **Tees Autism Framework** has been established to ensure local people with ASD have a range of Specialist Providers who deliver tailored support packages unique to the person. Strong partnership working across Tees helps to prevent people having to move away from their local area in order to receive specialist care. Tees Commissioners continue to stimulate the local market, ensuring people with ASD have the choice of cost effective services reducing the need for costly crisis intervention including admission to Hospital treatment and assessment beds along with including education and day opportunities.

We fully support NICE Guidance and intend to develop local solutions based on the advice provided within the guidance. Some of our key aims include improving:

- Access to services
- The organisation and delivery of services
- Knowledge and training for health and social care professionals
- Social and physical environments
- Information and involvement in decision-making
- Support for families and carers
- Anticipating and preventing behaviors that challenge
- Assessment and initial/early intervention for behaviors that challenge
- Transition to adult services

Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV), have developed person-centred pathways of care for children, young people and adults with ASD. The diagnosis of people with ASD is made by teams who have training and expertise in Autism. However waiting times for assessment and diagnosis continue to be challenging.

Workforce awareness has been developed across Tees in order to increase knowledge and skills around Autism. This includes behaviors that challenge services and people with high risk profiles.

Members of the frontline workforce, (those with direct links with people with ASD) are able to access Autism specific training including intermediate, advanced levels and there is a three year MSc Autism Practice course delivered by the local University.

The **Tees Advocacy Hub** is overseen by Middlesbrough CAB and began operating in June 2014. It offers a single point of referral to a framework of Advocacy Providers who offer:

- **General Advocacy**, support for issues relating to housing, health and social care systems (available to people aged 18 and over) of which there are 3 general types:
 - Short-term issue based or crisis advocacy
 - Non-instructive advocacy
 - Health advocacy (support to attend and understand procedures)
- Independent Mental Capacity Advocacy¹¹ (IMCA available to people aged 16 and over) a statutory advocacy service introduced by the Mental Capacity Act (2005) allowing people who lack capacity the right to receive support in the form of an IMCA.
- **Independent Mental Health Advocacy**¹² (IMHA available to people aged 16 and over) introduced under the Mental Health Act (2007) with the legal duty to provide Independent

¹¹ https://www.scie.org.uk/mca/imca/do

¹² https://www.scie.org.uk/independent-mental-health-advocacy/

Mental Health Advocates (IMHAs) for all eligible people. An IMHA is an independent advocate who is specially trained to work within the framework of the Mental Health Act (1983) to support people to understand their rights under the Act and participate in decisions about their care and treatment.

People with Autism Spectrum Disorder are supported to find and sustain **employment opportunities**. Step Forward Tees Valley¹³ help and support local people to overcome the complex reasons preventing them from finding work. Local Voluntary Development Agencies support people into volunteering with the intention of gaining valuable experience that will assist them to find employment.

There continues to be a significant reliance on **out of area** Education and Residential placements for people with ASD living across the Tees, due to the lack of local provision. The availability of Speech and Language Therapy is recognised as a key factor as to why young people with Autism attend out of area education placements. Communication support for deaf people with Autism continues to be problematic especially people having access to appropriately trained interpreters. There is a lack of Residential facilities including learning disability / Autism specific inpatient beds, for children and young people with ASD resulting in large numbers of costly out of area placements.

A number of Autism awareness and specific training courses along with advice on classroom strategies take place in some schools across Tees. These are provided by Education Psychologist and Speech & Language Services.

In 2014 the Government provide funding to support the implementation of Think Autism. The money was used for a variety of innovative improvements across Tees which included:

- Purchase of iPads loaned out via a User Led Organisation
- Development of 2 Autism Friendly areas in a local college
- Environment changes to a GP Surgery
- Purchase of therapeutic equipment

¹³ https://www.sfteesvalley.co.uk/

Challenges for the Future

Early intervention / Prevention / Crisis

Despite some progress in Mental Health and Learning Disability Services over the last decade, people with Autism largely remain socially and economically excluded. Many rely on the care and support provided by their families. Without such support, the risk of severe physical and mental health problems, homelessness, addiction and descent into crime is greatly increased as young people reach maturity¹⁴.

Preventative services should be explored in greater depth and include:

- Employment support
- Apprenticeships
- Increasing people's social skills

The Care Act (2014) clearly states low level services and early intervention can delay the need for crisis or costly care services. The Care Act (2014) calls for Local Authorities to move away from examining if people are "eligible" for Social Care support and instead explore how low level services are able to provide preventative measures that could avoid crisis situations.

The good practice guidance on commissioning services for people with Learning Disabilities and Autism Spectrum Conditions¹⁵ moves towards services that understand and support people, reducing their reliance on care agencies by transforming the way support is delivered.

There should be greater focus on Older People with Autism who may have received a late diagnosis. Older people within the general population need additional support and this will be reflected in the Autism Community.

Consideration should be given to additional health issues as well as age related conditions such as:

- Arthritis
- Dementia
- Frailty
- Eyesight / Hearing loss

Across Tees there is very little Pre and Post Diagnostic Support Services available. This is especially true for people who have or appear to have low level support needs. Post Diagnostic Support Services could contribute towards preventing or delaying people with ASD from developing or having extra care and support needs. In turn this could prevent or delay Carers and families from developing care and support needs or requiring crisis intervention services. Such services should not only promote wellbeing but be able to integrate people in their local community.

Post Diagnostic Support in particular, would ensure people with ASD are treated with dignity and respect whilst developing and maintaining relationships making them able to lead active lives in their local community. Post Diagnostic Support Services require a highly skilled workforce who are able to work with people who display behaviors that challenge. This would bring about a change in culture by ensuring people with ASD are in control of the type of services they access enabling them to live safe and healthier lives.

¹⁴ 'Fulfilling and rewarding lives': The strategy for adults with Autism in England (2010), Department of Health, 2010.

¹⁵ https://ipc.brookes.ac.uk/publications/Commissioning for People with Learning Disability.pdf

Care and Treatment Reviews

The introduction of Care and Treatment Reviews¹⁶ (CTR's) in relation to inpatient and community settings initially focused on the needs of people with learning disabilities and Autism (full IQ spectrum). The CTR process is aimed at preventing unnecessary admissions and keeping people who have more complex needs in a safe care environment.

Work is advancing to support people with ASD who have specific needs including those who have been in assessment and treatment beds. Engagement takes place with clinical experts along with people with lived experience of Autism (including families) to enhance services resulting with less hospital admissions and more community treatment taking place.

Criminal Justice System

People with Autism are more likely to be victims and witnesses of crime than perpetrators of crime. When people with ASD commit an offence, it may be due to:

- Social naivety and wanting to have friends which may lead to them being befriended by criminals.
- Difficulty with change or change to routine which causes anxiety and distress leading to aggressive behavior.
- Misunderstanding social cues such as eye contact and in some cases could be interpreted as unwanted sexual advances.
- Rigid adherence to rules, if other people break the rules this could cause anxiety and distress leading to aggressive behavior
- Not understanding the implications of their behavior and not being able to learn from past experiences becoming repeat offenders.
- Obsessional behavior which could lead to contact with the Police.

Autism has been identified as one of 3 high risk conditions within Prevent referrals. The Home Office are currently working on the production of guidance on Autism and concerns about people with autism —to inform assessment and support offered. There are indications some people in local Tees Prisons could have ASD which has yet to be diagnosed. Criminal Justice System Organisations require improved Autism training and understanding (including front line Police Officers). Improving training and understanding could reduce the numbers of people with ASD coming into contact with Courts, Probation and Crown Prosecution Services.

Awareness Raising

Autism Awareness raising must be co-produced by people with ASD. This will help them to not only develop a greater understanding of their own diagnosis and condition but will raise awareness with members of the general public.

Hosting co-produced awareness raising could address some issues which have been highlighted by people with ASD:

- Accept me as I am
- Know how best to support me
- Take into account my views and aspirations
- Make sure I can be included in my local community

Having access to appropriate literature that has an explanation on Autism along with details of individual diagnosis should be made available not only to people with ASD and their families but to the wider general population.

Work must begin on developing Autism Champions in different working environments such as:

_

¹⁶ https://www.england.nhs.uk/learning-disabilities/care/ctr/

- Banks
- GP Surgeries
- Hospitals
- Retailers

Autism Champions could actively promote Autism awareness to staff and customers as well as influence changes in working environments.

World Autism Day should be used as a vehicle to raise general awareness but should also celebrate achievements in the Tees area.

Employment

It is estimated only 15% of adults with Autism are in full time paid employment. Work should be undertaken to gather intelligence on the employment needs of people with ASD living in Tees (including young people). This will provide evidence on how best to support people which could enable young people and adults with ASD to find and maintain meaningful employment. Work across Tees should include examining the barriers to employment for young people and adults with ASD along with how best to link in with potential Employers / Employment Agencies to identify solutions.

Training and support should be provided to adults and young people with ASD so they are "job ready". This could include:

- Preparing a CV
- Interview tips and mock interviews
- Developing protocols and ideas on how to best to deal with working environments Vocational opportunities and Apprenticeships can help people find the right employment role. Autism training and support should be offered to Employers along with advice on how to make reasonable adjustments for members or future members of their workforce.

Diagnosis

Over the past few years, public awareness in relation to Autism has increased. There has been an increase specifically in the identification and diagnosis of Autism in children and young people. Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV), are working towards being recognised as a "Centre of Excellence" along with being seen as an "Autism Friendly Organisation". This is being achieved by ensuring staff undertake Autism training appropriate to job roles. Work is ongoing to:

- Develop a clear pathway to diagnostic assessment which meet Nice Guidance
- For all staff to undertake Autism Awareness training
- For relevant clinical staff to undertake training to a higher level of Autism expertise
- For the service to have an improved understanding of mental health in people with ASD

The numbers of people from BAME backgrounds diagnosed with Autism is much lower in Tees than the national average. This suggests work should be undertaken with schools and education settings, to raise awareness of Autism including how to access diagnostic and care pathways.

There is ongoing CCG and Multi Agency development of a neurological pathway for children up to the age of 18 years, to deliver improved and sustainable services, in order to meet the present and emerging needs of the local population.

This work has taken place in the North of Tees, but plans are in place to review and embed this pathway more widely to ensure there is a consistent approach across the whole of the Tees footprint.

Education

In the UK, Autism is recognised as the second most common primary special educational need by Pupil Level Annual School Census (PLASC). There continues to be an increase in the numbers of children and young people who have complex learning needs where Autism coexists with other difficulties. In Tees there has been a significant reliance on 'out of area' educational and residential placements for people with Autism. We continue to work with providers to develop appropriate local placements, particularly for people with complex Autism, which will prevent the reliance on out of area placements.

Personal Budgets

Personal Budgets enable more person-centered support as well as greater control and flexibility by people who require support. Further work is required to increase the uptake of Personal Budgets in families with children and young people with ASD. This work must include information on:

- How to access a Personal Budget
- Where / how Personal Budgets can be spent.

Carers

There are over 6 million Carers providing unpaid care in the UK many of whom do not identify as being a Carer. The Care Act (2014) introduced major reform to the legal framework for adult Carers in England whilst The Children & Families Act (2014) strengthened the rights of Young Carers. The Government understand Carers are an integral part of the Health and Social Care system and are "experts by experience". Services across Health and Social Care focus on Prevention and Early Intervention. This approach must also be taken with Carers which will not only improve support for Carers but could alleviate pressures on Health and Social Care in the future.

Although Carer support services have improved, specifically since the introduction of the Care Act (2014), it is recognised a high proportion of Disadvantaged / Seldom Heard Carer Groups are not receiving information and or advice on how to access Carer support – this includes Carers of people with ASD.

Carers are entitled to a Carers Assessment even if the person they care for is not in receipt of support services. The numbers of Carers who support children, young people and adults with ASD are low when compared to numbers of people diagnosed with Autism known to services. Improved awareness of Carer Assessments is crucial in improving support for Carers of people with ASD. Professionals working with children, young people and adults with Autism should promote Carers Assessment with families and partners at every available opportunity.

What's Next?

All change needs to be driven through good planning and strong local leadership. In order to ensure the ambitions of this strategy are fulfilled we will:

- Develop an action plan aligned to this strategy
- Establish multi-agency task and finish groups to develop and implement the work
- Appoint a lead officer for Tees, responsible for monitoring and reviewing the action plan and its progress.
- Monitor and regularly report on the implementation of the strategy to our partners in Tees.
- Continue to engage with children, young people, adults and their families, to ensure they remain at the center of this strategy.
- Improve the way we collect and assess data in order to provide the evidence we need to make appropriate, informed decisions.
- Establish protocols for improved working

Priorities attached to this Strategy:

Priority 1

Map out and examine Autism Diagnosis Pathways for children, young people and adults.

Priority 2

Map the needs of the current workforce and identify training needs for now and in the future

Priority 3

Develop a business model for pre and post diagnostic support

Priority 4

Develop and improve relationships with Criminal Justice System Organisations so there is an improved understanding of Autism along with how reasonable adjustments can be implemented

Priority 5

Develop local support services which prevent people with complex Autism having to access out of area provision

Action Plan

| | Specific to | LA area | Lead | RAG | | | | | | | | | | | | | |
|---|----------------------------|---------|-----------|--------|-----|-----|-----|-------|-------|-----|------|------|-----|------|-----|-----|-----|
| PLANNING | group (C, YP, A, AA) | LA dica | Lead | rating | Dec | Jan | Feb | March | April | Мау | June | July | Aug | Sept | Oct | Nov | Dec |
| Completion of Joint Autism SAF 2018 | All Age | All | LA / NECS | | | | | | | | | | | | | | |
| To ensure the Joint Strategic Needs Assessment considers the needs of children and young people with Autism. | All Age | All | LA/CCG | | | | | | | | | | | | | | |
| Improve data collection in relation to people referred to and/or accessing social care and/or health care where Autism is recorded as either the primary or secondary identified need | All Age | All | LA/CCG | | | | | | | | | | | | | | |
| Improve recording and data collection on the total number of people currently known to social care with a diagnosis of Autism who meet eligibility criteria for social care including- - People assessed as having Autism who meet social care eligibility criteria. - People assessed as having Autism and a learning disability who meet social care eligibility criteria. - People assessed as having Autism, who are also in receipt of treatment for mental health problems, who meet social care eligibility criteria. | All Age | All | LA | | | | | | | | | | | | | | |
| Ensure people with Autism and their families / carers are engaged with. | All Age | All | LA/CCG | | | | | | | | | | | | | | |
| Undertake audits to improve reasonable adjustments in general Local Authority services to improve access and support for people with Autism. | All Age | All | LA | | | | | | | | | | | | | | |
| Undertake audits to improve reasonable adjustments in all NHS services including primary care or GP services, mental health and acute services to improve access and support for people with Autism. | All Age | All | CCG | | | | | | | | | | | | | | |
| Ensure people with Autism and their Carers/ families have access to health and social care information, support and advice. | All Age | All | LA/CCG | | | | | | | | | | | | | | |
| Undertake audits to improve reasonable adjustments in universal services (i.e. colleges and universities, libraries, etc.) for people with Autism. | All Age | | PARTNERS | | | | | | | | | | | | | | |
| Make sure transition processes from children's services to adult services take into account the particular needs of young people with Autism. | Children & Young People | All | LA/CCG | | | | | | | | | | | | | | |
| Improve recording and data collection to identify how many children with Autism, were in Year 10, 11, 12, 13 in the school year and how many people complete transition from school. | Children & Young People | All | LA/CCG | | | | | | | | | | | | | | |
| Explore how the needs of people aged 65 or over who have received a diagnosis of Autism, are met. | Adults | All | LA/CCG | | | | | | | | | | | | | | |
| Explore how the needs of women who have received a diagnosis of Autism, are met. | All Age | All | LA/CCG | | | | | | | | | | | | | | |
| Develop arrangements for meeting the needs of people from BAME communities who have received a diagnosis of Autism. | All Age | All | LA/CCG | | | | | | | | | | | | | | |

| TRAINING | Specific to group (C, YP, A, AA) | LA area | Lead | RAG rating | Dec | Jan | Feb | March | April | May | June | July | Aug | Sept | Oct | Nov | Dec |
|--|--|---------|---------------------|---------------|-----|-----|-----|-------|-------|-----|------|------|-----|------|-----|-----|-----|
| Develop a multi -agency Autism training plan. | All Age | All | LA/CCG/ PARTNERS | | | | | | | | | | | | | | |
| Ensure Autism awareness training is provided to staff working in health and social care and the number of staff having undertaken training/ type of training is recorded and can be evidenced. | All Age | All | LA/CCG | | | | | | | | | | | | | | |
| Ensure specific training is available to staff undertaking statutory assessments which includes how to make adjustments in their approach and communication. | All Age | All | LA/CCG | | | | | | | | | | | | | | |
| Clinical Commissioning Groups to ensure all primary and secondary healthcare providers include Autism training (at levels outlined in the statutory guidance) as part of their on-going workforce development. | All Age | All | CCG | | | | | | | | | | | | | | |
| Encourage staff in Criminal Justice System services (Police, Probation, C.P.S.) to undertake Autism awareness training. | All Age | All | All CJS PARTNERS | | | | | | | | | | | | | | |
| DIAGNOSIS | Specific to group (C, YP, A, AA) | LA area | Lead | RAG rating | Dec | Jan | Feb | March | April | May | June | July | Aug | Sept | Oct | Nov | Dec |
| Ensure local Autism diagnostic pathways (children and adults) meet NICE Guidelines. | All Age | All | CCG | | | | | | | | | | | | | | |
| Improve the recording, reporting systems and processes on a Trust-wide basis in relation to the following: * number of referrals for assessment * number of completed assessments * time elapsed between initial referral and diagnosis * referral for social care assessment * further assessment and onward referral * support provided for those people who do not meet care act eligibility. * Case management arrangements for wherever the person is being maintained within the Trust. | All Age | All | CCG | | | | | | | | | | | | | | |
| Undertake audits to improve reasonable adjustments in: - Psychology Assessment - Speech and Language Assessment - Occupational Therapy Assessment - Clinical Psychology | All Age | All | CCG | | | | | | | | | | | | | | |
| Review Crisis support provision to ensure an appropriate response is provided for people with and without a Learning Disability with Autism. | All Age | All | CCG | | | | | | | | | | | | | | |

| CARE AND SUPPORT | Specific to group (C, YP, A, AA) | LA area | Lead | RAG rating | Dec | Jan | Feb | March | April | May | June | July | Aug | Sept | Oct | Nov | Dec |
|---|--|----------|-----------------------------|---------------|-----|-----|-----|-------|-------|-----|------|------|-----|------|-----|-----|-----|
| Develop a single identifiable contact point where people with Autism (whether or not in receipt of statutory services) can access information signposting Autismfriendly entry points for a wide range of local services. | All Age | All LA's | LA | | | | | | | | | | | | | | |
| Ensure there is a pathway for people with Autism but without a learning disability to access a care assessment and other support. | All Age | All | LA | | | | | | | | | | | | | | |
| Ensure commissioned advocacy includes a requirement for advocates to undertaken specific Autism training to better supporting people with Autism. | Adults | All | LA | | | | | | | | | | | | | | |
| Ensure support offers are available for people with Autism who do not meet Care Act Criteria and this information is recorded. | Adults | All | LA | | | | | | | | | | | | | | |
| ACCOMMODATION | Specific to group (C, YP, A, AA) | LA area | Lead | RAG rating | Dec | Jan | Feb | March | April | May | June | July | Aug | Sept | Oct | Nov | Dec |
| Ensure the Housing Strategy and Market Position Statements in Local Authorities include a focus on people with Autism. | All Age | All | LA | | | | | | | | | | | | | | |
| EMPLOYMENT | Specific to group (C, YP, A, AA) | LA area | Lead | RAG rating | Dec | Jan | Feb | March | April | May | June | July | Aug | Sept | Oct | Nov | Dec |
| Establish employment options for people with Autism. | All Age | All | LA | | | | | | | | | | | | | | |
| Ensure transition processes to adult services have an employment focus. | Children & Young People | All | LA/CCG | | | | | | | | | | | | | | |
| CRIMINAL JUSTICE SYSTEM | Specific to group (C, YP, A, AA) | LA area | Lead | RAG rating | Dec | Jan | Feb | March | April | May | June | July | Aug | Sept | Oct | Nov | Dec |
| Ensure Criminal Justice Services (police, probation and, if relevant, court services) are engaged with the All Age Partnership. | All Age | All | LA/CCG / CJS PARTNERS | | | | | | | | | | | | | | |
| Ensure access to an appropriate adult service is available for people with Autism in custody suites and nominated 'places of safety'. | All Age | All | LA / POLICE | | | | | | | | | | | | | | |

Appendices (1 - 8)

Engagement

This strategy is being supported by considerable on-going engagement with our stakeholders. We have worked and continue to work with a range of stakeholders, including:

- Children and young people and adults with Autism
- Parents and carers
- Professionals who work with people with Autism, including educators
- A wide range of service providers

Engagement has greatly improved our understanding of Autism in Tees, both for those that have it and for those where it plays an important part in their lives. They have told us about their experiences with Autism and given us their views on what works and doesn't work. Below are a list of engagement events:

- 1. Working Together for Change event to support development of the Tees Strategy for Adults with Autism September 2010
- 2. Working Together for Change event to support development of the Strategy for Children and Young People with Autism October 2014
- 3. Stakeholder Surveys January 2015
- 4. Engagement event at Beverley School February 2015
- 5. Adult Consultation Event October 2015
- 6. Care Act Survey October 2015
- 7. James Cook University Hospital Autism Awareness April 2016
- 8. Summary of All Age Strategy Engagement Event October 2016
- 9. Young People's Engagement February 2018

Information gathered from the consultations, workshops and surveys has been used by members of the Tees Autism Partnership Group to develop the Tees All Age Autism Action Plan.

Appendix 1 - Working Together for Change

Working together for change is a simple process that draws on 'person-centred' information to inform strategic change and service development.

Since its initial launch in 2007 it has developed into an eight step process that is being used nationally to develop and inform service provision. The revised process puts greater emphasis on action planning, on measuring progress and on learning and review. It is designed to work cyclically and to be embedded within the core of the commissioning and business planning cycles that takes place¹⁷.

The diagram below describes the eight steps of the current Working Together for Change 18 process:



¹⁷ Working Together for Change: Citizen-led change in public services, Groundswell Partnership, 2012

¹⁸ The Eight Steps, Working Together for Change, Groundswell Publications, 2012

Appendix 2 - Working Together for Change (Children and Young People)

In October 2014 stakeholders, including families, completed a two day Working Together for Change (WTfC) workshop to support the development of strategy for children and young people with Autism across Tees¹⁹. Drawing on information collected from around 60 families the group identified the following seven key thematic areas of activity:



¹⁹ Working Together for Change in Tees: Developing a strategy for children with Autism across Tees, North of England Commissioning Service (NECS), October, 2014

Appendix 3 - Stakeholder Surveys

In January, 2015 three stakeholder surveys were conducted and covered across the 2 x CCG areas. Three main stakeholder groups were targeted separately in the three surveys:

- Parents and Carers of children and young people with Autism
- Schools (Early Years, Schools and Academies)
- Service Providers (Specialists and other professionals who really work with children with Autism)

Parents and Carers

Highlights from the engagement include:

- 218 parents and Carers responded from each of the four Tees local authorities, with the largest number coming from Stockton, 108 (49.5%).
- 91.4% of parents/ Carers said that their child had received a diagnosis, 2.3% said their child hadn't, while 6.2% replied it was 'on-going'.
- 70% (119) of parents and Carers responded as receiving adequate support from Education services and ASC Support within School services 66.3%. In contrast, Emotional Wellbeing Support Services (13.4%), Support for Assessed Sensory Problems services (15.6%) and Social Care (19.8%) were apparently less positively viewed.
- When parent were asked if they had received parent-specific ASC training just under half (45%) replied yes, 50% while the remainder responded that that didn't know.
- 137 (or 76.5%) of parents/ Carers indicated 'no' when asked if they receive support for their own needs.

What you told us:

- "As a parent and a teacher within the authority even with the new local offer webpage it is difficult to know what services are available".
- "Once they get to 18, services stop even though supposed to be 0-25! Very difficult to get a social worker once they get to adulthood".
- "There needs to be a centralised approach across the region, it is very piecemeal at present."
- "(The) Choice and control of having a personal budget (has been) taken away and replaced by a care plan."
- "Like many parents, I've given up. I need help, I can't get it. Work needs to be done to get back the lost parents, instead of concentrating on those who shout the loudest".
- "Need more activities in school holidays".
- "Diagnosis should be earlier as my daughter missed out on years' worth of support".
- "Staff need more training and experienced teachers not newly qualified teachers used for ASC children."
- "More courses should be made available for parents and professionals to help children and adults with Autism. Schools should have more help with children with special needs who are going through the diagnosis process. My son didn't get any additional help without the diagnosis when he was four and the school was not given any additional money to support him even though he desperately needed it to reduce his negative behavior."
- "Training for parents with those children and young people with challenging behavior. Practical help to know how to safely handle things."
- "Additional help should be available to single parents. I am a single parent with an ASC (child), no support from friends or family. It is frankly overwhelming!"
- "There is little support for older children with ASC regarding welfare rights etc."

Primary and secondary schools

51 educators responded to this survey. The largest number of respondents came from Stockton (49%). The number of the children and young people with Autism at each educational institution ranged from 0 to 140 or 494 in total, with an average of just under 13 per school.

Educators reported relatively high numbers of their children were on various measures (84.6% had SEN Support Plans, 56.4% had Statement of Special Educational Needs for instance.)

| SEN Support Plan | 33 | 84.62% |
|--|----|--------|
| Statement of Special Educational Needs | 22 | 56.41% |
| Education Health Care Plan (EHCP) | 8 | 20.51% |
| Learning Difficulty Assessment | 4 | 10.26% |

- When asked about how they engage with the parents of children with Autism answers included parent contact meetings, drop-ins, telephone conversations, annual reviews were all common responses.
- 31% responded that their staff receive regular mandatory training, with a further 58.6% receiving some training. Three or 10.3% indicated that their staff received no training.

| None | 3 | 10.34% |
|---------|----|--------|
| Some | 17 | 58.62% |
| Regular | 9 | 31.03% |
| Total | 29 | |

When asked about on-going training needs linked to Autism responses varied widely, from the 'upskilling' of particular staff to whole school and whole family training and support. .

What you told us:

- "Too many services are not available until a child has a formal diagnosis, this means valuable time is wasted and children's anxieties are heightened. Basic support services should be available for children going through this process and parents should be kept better informed."
- "Revisiting creating an ASD friendly classroom and strategies to deal with individuals,"
- "Currently the funding for the ASD pupils in school is non-existent as the child has attended our two-year-old group and now nursery. We are committed to the inclusion of ASD pupils, but the funding needs to (reflect the) level of need and be available much earlier."
- "To feel safe and secure in the school environment and have people around them who can help
 them to make sense of the world in which they live in. To provide provision to support children to
 achieve academically and socially and to provide children with appropriate resources. To have
 specialists at hand to advise/train staff in school, good links with The Autism Outreach Team and
 other ASD specialists."
- "Main area of need is how best to support children with ASD and what resources are available to do this."
- "All staff who work with ASD children are fully qualified with the latest information. Working closely with parent's advice, attending courses with parents."
- "Autism Outreach Team and Daisy Chain are fantastic services with excellent resources who give
 excellent support and guidance for pupils, parents and staff."
- "We are increasingly finding it very challenging to support both children and their families who are going through the diagnosis route and the difficulty we have in securing support/advice throughout this process. During this time, families are often really struggling to cope with the emotional journey of their child's difficulties. Their child is often finding the school environment difficult to navigate and staff-work to try to support them but without specialist diagnosis and specific advice we are left to do the best job we can. This can make it very difficult for parents and professionals."

Service Providers

59 service providers responded to this survey. The largest number of respondents came from Hartlepool (40.7%).

When asked 'What kind of service provision are you?' providers gave the following responses:

| CAMHS | 8 | 17.02% |
|-------------------------------|----|--------|
| Speech and Language Therapy | 2 | 4.26% |
| Physiotherapy | 1 | 2.13% |
| O.T. | 1 | 2.13% |
| School nursing and HV | 2 | 4.26% |
| Pediatrician Services | 4 | 8.51% |
| Educational Psychologist | 6 | 12.77% |
| Youth Offending | 1 | 2.13% |
| LDD Social Workers | 4 | 8.51% |
| Voluntary sector organisation | 18 | 38.30% |
| Total | 47 | |

- Many services responded that they were unsure of the total number of children and young people diagnosed with Autism that they worked with.
- When asked 'What support do you think children with ASD require?' respondents cited a wide range of support services, including early years and transition services and a more multi-disciplinary approach.
- When asked 'How does your service provision engage with parents whose children are affected by ASD?' responses included regular contact through family meetings, tailored contact through support planning, regular support groups for parents/ Carers and home visits. Some indicated that their only contact was through formal clinical treatments.

What you told us:

- "Support will vary according to the child's age and identified needs but I feel it would be helpful to
 have additional support in school, to be able to access suitable social provision, to be able to
 access therapy (this may include CAMHS, SLAT, OT etc.) as required and to be able to access
 age appropriate psycho education with regards to understanding their diagnosis."
- "Understand how the Children's strategy links to Adults."
- "Young children need: support from specialist Early Support Team and Portage specialist outreach support to early years settings - support for family and siblings (offered via charity -Daisy Chain) - additional funding to early years settings to provide support - additional training for practitioners in settings - additional support from Autism Outreach Team when start in school."
- "Clinicians all have a degree of knowledge and understanding around ASD but this is variable.
 Regular update training would be beneficial."
- "It is always important to hear the latest updates from research as there is so much money and
 effort being pumped into it at the moment and we need to stay up to date with how it applies to
 practice."
- "We find obtaining sensory profiles difficult. This information would help the staff team understand the child's sensory needs and allow for appropriate care planning. Access to hydrotherapy which some of our children enjoy is very difficult".
- "We find it unhelpful that services are siloed and specialised as this means that families with children with complex needs are ranging from service to service rather than having a one stop neuro-clinic where they can access diagnosis, assessments, support, therapy, and family support for a single or multiply complex condition that includes Autism but is not just Autism. It needs to be a holistic, all age service".
- "Funding issues around training for parents. Difficulties with access to CAMHS and then
 inconsistent quality. I am aware that these issues have regularly been raised."

Appendix 4 - Engagement Event at Beverley School

What things in life are important?

"Air. Water. Social life. Friends. Having fun."

In February, 2015 an engagement event was held at Beverley School, a specialist school for children and young people with Autism. Importantly, it was the children and young people themselves that conducted the engagement and recorded the results.

What they told us:

```
"Family. Music. Playing video games."
"Health. Family. Sport. Education."
"Music, movies and Minecraft. And my family."
"My friends and family."
What things in life do you want to improve?
"Reduce negative comments and unkindness."
"Learn how to take a bus."
"Life. Amount of fun."
"To draw the Sonic team."
"School toilet paper (it hurts my butt.) Horror movies (they need a happy ending). Swear words
(crap is not a swear word.)"
"Making friends"
"Art"
"Don't get stressed. I like to improve."
What do you want to do in the future?
"Live by myself and have a decent life".
"College"
"To become an award-winning film director."
"I haven't thought about that yet. But I have a few ideas."
"Joinery"
"Paleontologist"
"Living independently. Studying sport at college. Learning a trade (like bricklaying)"
```

Of course, answers were as diverse as you would expect from any group of children and young people. What is clear is that just like any child, respondents have hopes and dreams. They value:

Family

"Be an artist."

- Friends
- Independence

"Do cooking at college."

- Video games and social media
- Community involvement
- Education and employment

Appendix 5 - Adult Engagement Event

A Consultation event was held in October 2015 focusing on four main themes:

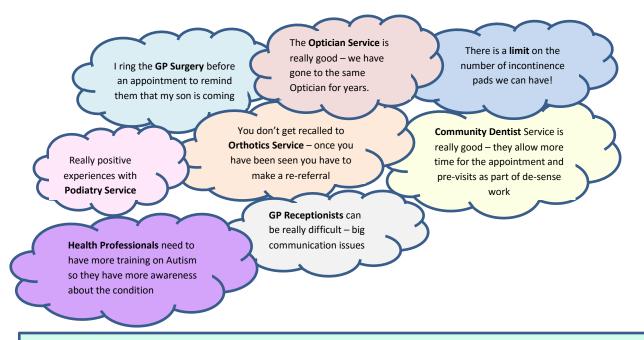
- Keeping Safe
- Good Health
- Good Support
- Good Life

These are some of the comments we received from people with Autism Spectrum Conditions and their families:



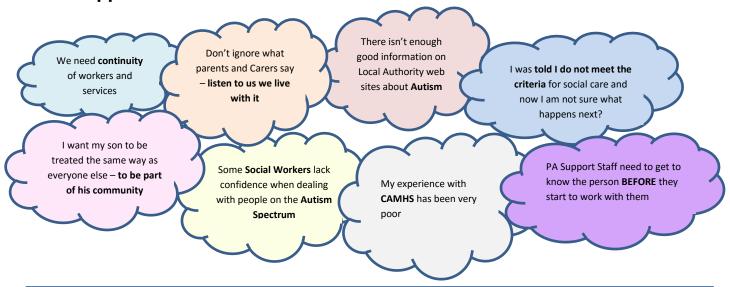
I know a person with Autism who was being texted by a single female who had a baby – she said she was his girlfriend and needed money. Another person I knew with Autism was being targeted by a prostitute and drug dealers.

Health



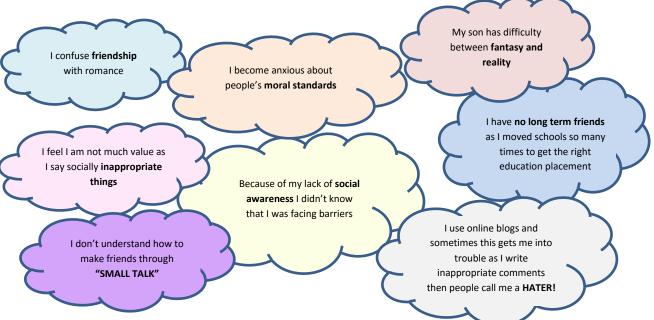
We still have some issues with GP Surgeries – it's better than it was but there could still be more improvements. Parents should join GP Patient Groups and make changes to Surgeries for people with Autism Spectrum Conditions

Good Support



We have lost good PA's because they don't feel supported or have someone to off load to. My daughter's PA has helped her to stay in a shop for more than 20 minutes – this is a massive achievement and took over a year to achieve!

Good Life



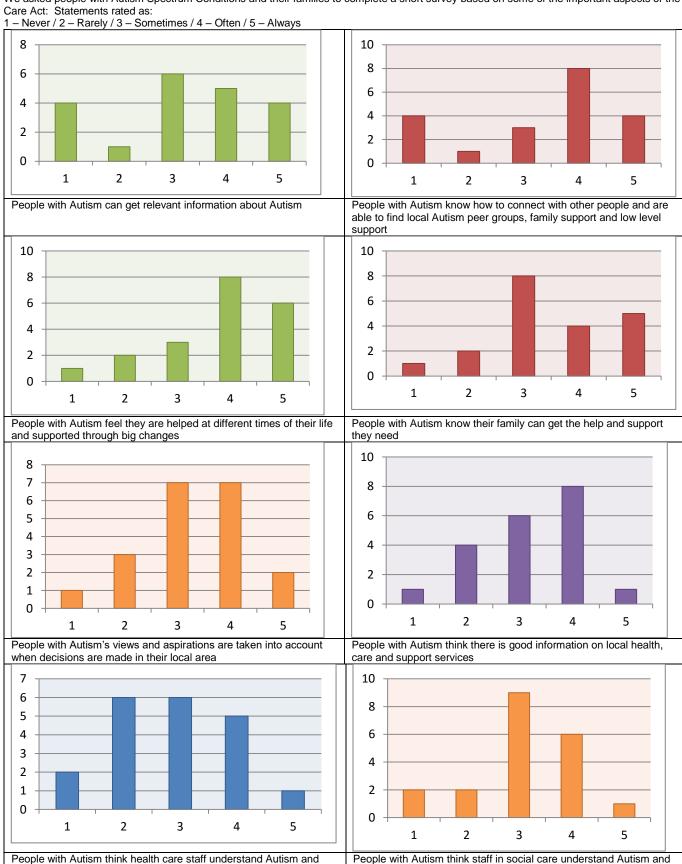
All my friends are made through my hobby. I don't see how you can make friends unless you have a common interest. I have no interest in meeting them outside of my hobby time – I can't do social unless it's linked to my interest.

Appendix 6

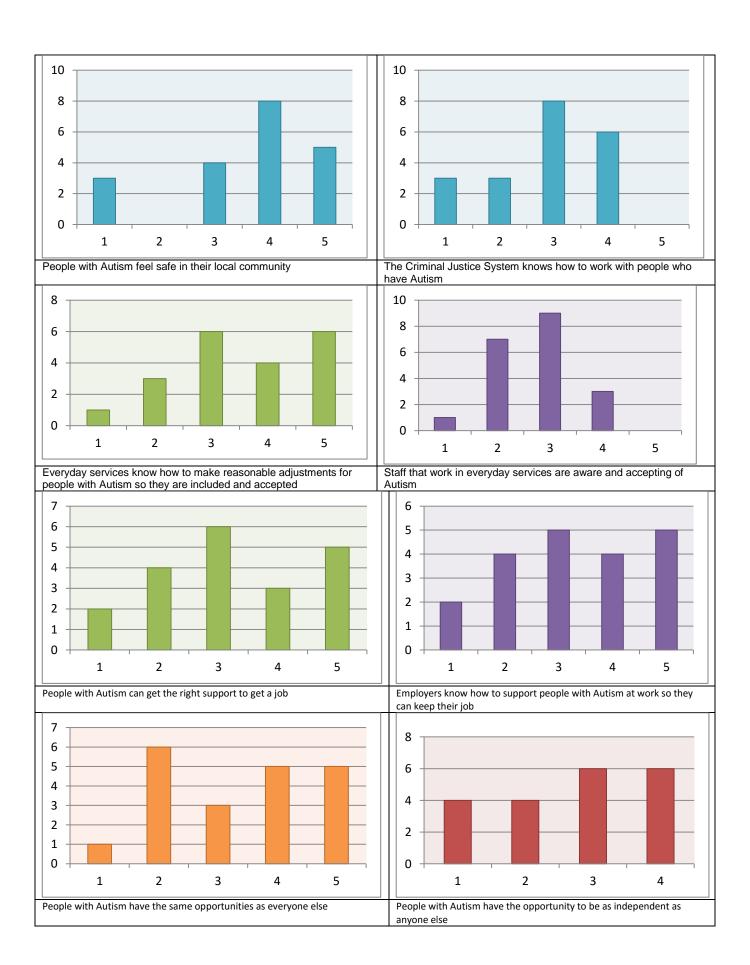
Care Act Survey

how Autism affects people

We asked people with Autism Spectrum Conditions and their families to complete a short survey based on some of the important aspects of the



how Autism affects people



An Autism Awareness session which took place in the Atrium at James Cook University Hospital identified a gap in providing information to extended family members - namely Grandparents. Grandparents stated:

- Once their grandchildren have been diagnosed they are not included in conversations and feel left on their own. They don't know who to go to for help or where they can get information about available services.
- Grandparents are at "logger heads" with their own children how to treat their grandchildren differently, what to say / what not to say, how to say things in a different way.
- Some Grandparents are fearful of not being able to see grandchildren if they suggest a different
 way of dealing with a diagnosis.
- Grandparents have difficulty understanding what Autism actually is along with how they need to adjust to a different parenting style.

Appendix 8

All Age Strategy Engagement Event November 2016 Summary

| Diagnosis | Lvent November 2010 Summe | Post Diagnosis | |
|---|---|--|--|
| What's Working | What's Not | What's Working | What's Not |
| Led to self-awareness | Lack of information, advice and support for people and their families | Welfare Rights support | Lack of signposting options can lead to crisis situations |
| Early Bird (but big demand) | No clear referral pathway | Local Authority Online Directories – knowing where to go and who can provide support | Mental Health support / interventions to prevent need for long term mental health support |
| Outreach Team | Lack of resources - CAMHS is at breaking point | Specialist schools | Single Point of Access don't recognise Autism as a disability / not looked at under the Care Act |
| Diagnosis Meetings | Involvement and engagement with parents / families | Early Bird | Education for people and families to understand a diagnosis |
| Medication not needed following diagnosis | Specialist support services (OT / SALT / Sensory, etc.) | | Explanation about coping strategies |
| Support for sensory issues | No follow up or signposting to appropriate support | | Lack of resources to support people with a diagnosis |
| CPN / Mental Health Nurses | Process is too long | | No Post Diagnostic Support Service in Tees |
| | Screening for females needs to improve | | Support needs to change through life cycle |
| | Consistent team to work with the person through the process | | Applied Behaviour Analysis |
| | Lack of education and knowledge among professionals (social workers, GP's, Nurses, Education environments, etc) | | Need 1 Tees Online Directory which has all the information people would need |
| | No pre-diagnosis support available | | |
| | Not person centred | | |
| Employment & Education | | Carer Support | |
| What's Working | What's Not | What's Working | What's Not |
| Supported employment | Lack of Autism awareness and reasonable adjustments in working environments | Early Bird | Therapeutic support / mental health and crisis support |
| Reasonable Adjustments | Lack of education and awareness with Job Centre Plus staff, employers, employees | Free training | Lack of provision |
| Pre-employment support | Opportunities specific to Autistic people | Carers Breaks | Lack of resources and training |
| Welfare Rights Benefit advice | Support to maintain employment – buddy / mentor systems | Welfare Rights Advice | Holisitc assessments with a whole family a[[roach |
| Using a person's skills and abilities | Specialist equipment | Parent Carer Forums | Parent carer involvement |
| | Lack of information about people such as one page profiles or employment passports to support people through their employment | Direct Payments / Personal Budgets | Support to complete forms |
| | Providing training on interview techniques, CV writing etc | Commissioned Carer Service which has information, advice, guidance for Carers | LAC support |
| | Welfare Rights benefit advice | Local Authority Online Directories – knowing where to go and who can provide support | Effects of caring not recognised |
| | Careers support in schools specific to ASD | Consistent professional support | Lack of understanding on what's available |
| | | | 1 1 |
| | Lack of knowledge / awareness training in education environments | Being listened to and involved | No one stop shop |

| Hobbies, Interest & Friends | | Autism Friendly Communities | |
|---|---|---|---|
| What's Working | What's Not | What's Working | What's Not |
| Charity Organisations and the different types of support they provide | Online forums and vulnerability of people with ASD | ASDA and other large supermarkets having Autism shopping time | Venues which contribute to sensory overload |
| Autism friendly venues | Sex education and relationship information specific for people with ASD | Autism Friendly Cinema / Theatre showings | Unrealistic times for Autism activities |
| Inclusive facilities | Lack of activities for ASD community | Headphones and Irlen lenses look cool and help deal with sensitivity issues | GP Surgeries – appointment times, waiting rooms - lack of reasonable adjustments, |
| Obsessive interests | No specialist support for LGBGT Autistic people | Changing Places / RADAR Toilets | Autism awareness in local communities |
| | Transport to get around | Staff who understand customer needs | Transport |
| | | Travel training | |
| | | Having more choice | |

Appendix 9

Young People's Engagement February 2018

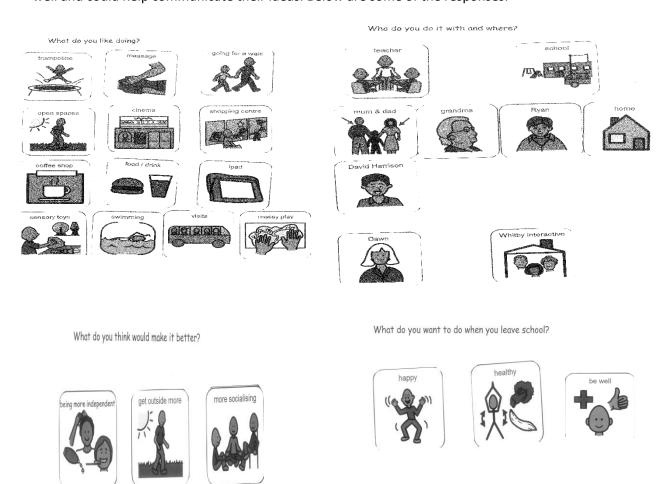
The consultation was led by the South Tees Autism Operational Group with the aim of informing on future service development. Sessions took place over the course of a week in February 2018. Approximately 100 young people (aged 14+ years) with Autism from across South Tees which included:-

- Beverley School
- Priory Woods School
- Kilton Thorpe School
- Kirkleatham School
- Middlesbrough College
- CCAD
- Pursglove College
- Redcar College

All sessions were facilitated in partnership and graphically recorded based on 4 questions:-

- 1. What do you like doing?
- 2. Where do you go and who do you do it with?
- 3. What do you think would make it better?
- 4. When you leave school / college what will you do?

Young people with complex needs were supported in smaller groups or individually with staff who knew them well and could help communicate their ideas. Below are some of the responses:



National Legislation and Guidance

Major national legislation and guidance released over the last few years which have actively shaped this Strategy includes:

The Autism Act 2009

The National Institute for Health and Care Excellence (NICE), Guidance.

The Care Act 2014.

The Children and Families Act, 2014

Fulfilling and Rewarding Lives: The strategy for adults with Autism in England, 2010.

This strategy placed legal duties on local authorities to identify and address the needs of adults with Autism.

Local voices, local choices, The National Autistic Society, 2014

Think Autism, Fulfilling and Rewarding Lives, the strategy for adults with Autism in England: an update. 2014.

Working Together for Change: Citizen-led change in public services, Groundswell Partnership, 2012

References

The Adult Social Care Outcomes Framework 2015/16, Department of Health, November, 2014 https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/375431/ASCOF_15-16.pdf

Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the Autism spectrum, NICE clinical guideline 128, National Institute for Health and Care Excellence (NICE), September 2011

 $\frac{http://www.nice.org.uk/guidance/cg128/resources/guidance-Autism-diagnosis-in-children-and-young-people-pdf}{}$

Autism: The management and support of children and young people on the Autism spectrum, NICE clinical guideline 170, National Institute for Health and Care Excellence (NICE), August 2013

http://www.nice.org.uk/guidance/cg170/resources/guidance-Autism-pdf

Autism Pathway, National Institute for Health and Care Excellence NICE 2014. http://pathways.nice.org.uk/pathways/Autism

Care Act factsheets, February, HM Government, 2015.

https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets/care-act-factsheets--2

Children and Families Act 2014, Chapter 6, HM Government, September, 2014. http://www.legislation.gov.uk/ukpga/2014/6/pdfs/ukpga-20140006_en.pdf

Children and Young People (0-25) in Tees with Autism, Primary Care Data, March, 2015, North of England Commissioning Support Unit

The Eight Steps, Working Together for Change, Groundswell Publications, 2012 http://www.groundswellpartnership.co.uk/eight-steps

'Fulfilling and rewarding lives': The strategy for adults with Autism in England (2010), Department of Health, 2010.

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_113405.pdf

If you've met one child with Autism, you've met ONE child with Autism Deceivingly Normal, February 1, 2013.

https://deceivinglynormal.wordpress.com/2013/02/01/if-youve-met-one-child-with-Autism-youve-met-one-child-with-Autism/

Local voices, local choices: A guide to consulting young people with Autism on your local offer, The National Autistic Society, 2014

http://www.Autism.org.uk/products/core-nas-publications/local-voices-local-choices.aspx

National Autism Plan for Children (NAPC): Plan for the identification, assessment, diagnosis and access to early interventions for pre-school and primary school aged children with Autism spectrum disorders (ASD), National Initiative for Autism: Screening and Assessment, March 2003

http://www.Autism.org.uk/About-Autism/Our-publications/Reports/Other-reports/The-National-Autism-Plan-for-Children.aspx

Person Centred Pathway of Care for ASD in Children and Young People, Esk and Wear Valleys NHS Foundation Trust, 2013

South Tees: ASD Strategy Meeting Report, Tees, Esk and Wear Valleys NHS Foundation Trust, 25 February, 2015

Tees Autism Strategy, 2013-2018, Tees Valley Autism Strategy Delivery Group, 2013

Tees Children's Autism Strategy - Education Providers Survey, North of England Commissioning Service (NECS), February, 2015

Tees Children's Autism Strategy – Parents and Carers, North of England Commissioning Service (NECS), February, 2015

Tees Children's Autism Strategy – Service Providers, North of England Commissioning Service (NECS), February, 2015

Tees Joint Strategic Needs Assessment, 2012 http://www.teesjsna.org.uk/

Think Autism Fulfilling and Rewarding Lives, the strategy for adults with Autism in England: an update. Social Care, Local Government and Care Partnership Directorate, Department of Health, April 2014.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299866/Autism_S trategy.pdf

What is Autism? The National Autistic Society

http://www.Autism.org.uk/about-Autism/Autism-and-asperger-syndrome-an-introduction/what-is-Autism.aspx

Working Together for Change: Citizen-led change in public services, Groundswell Partnership, 2012

<u>file:///C:/Users/Chris/Downloads/109704784-Groundswell-Partnership-WTfC-2012-Report-Web.pdf</u>

Working together for change: Using person-centred information for commissioning, Putting People First Programme/ Personalisation, Department of Health, 2009
http://www.thinklocalactpersonal.org.uk/ | library/Resources/Personalisation/Personalisation_advice/WTFC_Final.pdf

Working Together for Change in Tees: Developing a strategy for children with Autism across Tees, North of England Commissioning Service (NECS), October, 2014

Local Support Services for Children & Young People

Stakeholders told us that they would like to see a central hub where all local offers are shared. Links to the local service offers for children with special educational needs and disabilities for each local authority area are included below:

Hartlepool:

http://hartlepool.fsd.org.uk/kb5/hartlepool/fsd/local_offer.page

Redcar and Cleveland:

http://www.peoplesinfonet.org.uk/kb5/redcar/directory/localoffer.page

Middlesbrough:

http://search3.openobjects.com/kb5/middlesbrough/fsd/home.page