

# The Changing Landscape of Autism in North Yorkshire 2015-2020

Update: September 2019

The current all-age autism strategy for North Yorkshire was launched in October 2015. We wanted to see North Yorkshire become an autism friendly place and ensure that the right services are in place to meet the needs of autistic people and their families, friends and carers.

The implementation of the strategy has been overseen by the Autism Strategy Steering Group. The group includes representatives from Children and Young People's Services, Health and Adult Services, North Yorkshire Police, the Clinical Commissioning Groups and the District Councils.

The strategy is structured according to the seven key themes listed below. For each theme we have recapped what we said we would do, summarised what has been achieved and outlined what we still need to do.

## Theme 1: Support for people with autism and their families

### What did we say we would do?

We know that it can be challenging for people on the autism spectrum and their carers to know where to go for support. We said we would ensure that the support available is of a high standard, support active engagement of people with autism in local communities, ensure that all mental health staff can identify the mental health needs of people with autism effectively, particularly during a crisis, and we would help people with autism to feel included and safe within their communities.

### What have we done?

- Developed a strength-based approach to assessments

The Care and Support team in Health and Adult Services have developed and implemented a strength-based, person-centred approach as part of the Care and Support Pathway. Staff now look at how the person is currently supporting themselves, what they can do for themselves, and what assets exist within family support or within the community to help the person remain as independent as possible. This also means making better use of services available in a person's community, including voluntary services. Anyone who is assessed by social care in North Yorkshire will be assessed in this way.

- Reviewed the Best Practice Guide and Tool for adult social care staff carrying out an assessment

Additional resources are also available to staff who are assessing someone on the autism spectrum. In 2017 the Best Practice Guide and Best Practice Tool for working with individuals on the autism spectrum were revised and circulated to all Health and Adult Services staff working with and supporting people on the autism spectrum.

The Best Practice Guide provides up to date information about autism. It provides vital information prior to assessing someone to reduce any stress or anxiety for the person and to help provide a

suitable environment. The guide gives clear prompts of what to do, what to avoid and what to adjust to get an accurate assessment of the person's needs.

The Best Practice Tool ensures the individual's unique autism is captured and provides an opportunity to document how it may affect the person. The Tool is broken down into sections to ensure the whole person's needs can be embedded within the document and includes a section to note any actions.

- Developed an improved prevention offer in Health and Adult Services including the Living Well service

The Council has developed an improved prevention offer to help people remain well and independent in their communities. This includes the Living Well service which supports people on the cusp of needing long term care and support. Living Well supports people for up to 12 weeks. Support is free and tailored to the person's needs. Some examples of the support provided include giving someone information and advice, helping people get online either in their home or community, helping someone to become a volunteer, get involved in the community and develop their practical skills such as travelling independently. The staff also have access to a communications toolkit which was developed in 2019 to help them communicate better with the people they support, including people on the autism spectrum.

- Developed the Safe Places Scheme

The current strategy committed to continuing to develop Safe Places in North Yorkshire. The premise of the scheme is that businesses and organisations register to be a Safe Place and display the nationally recognised symbol in their window. People can register to become a member and will be able to go to a Safe Place if they need help and support. In June 2019 there were 186 businesses and organisations signed up as a safe place and 92 people signed up as members. Membership has grown month on month during the lifetime of the strategy, with a total increase of 66 businesses and organisations and 67 members since 2015. Plans are in development to further promote the scheme and involve community groups to help raise awareness.

- Reviewed the Autism Champions' role across the Council and developed the role of Practice Advisor in Health and Adult Services

In the current strategy there are a number of commitments around the Autism Champion model. When we looked at this further in Health and Adult Services we recognised that there were inconsistencies in how the Champions' role had developed in different teams. There was also variability with commitment and understanding of the role. To address this a new model is being developed to introduce Practice Advisors which will enhance the current Champions model. There will be Practice Advisors within the assessment teams, the Living Well service and the Council's in-house services. As well as having Practice Advisors for autism, there will also be Advisors for a number of other areas including dementia, learning disabilities, carers, assistive technology and end of life care.

The successful implementation of these new roles will embed knowledge and good practice, and identify gaps in knowledge to support existing staff and new starters. The use of Practice Advisors will allow the reach of the Senior/Practice Lead to increase further and have greater impact, helping with the embedding of the evidence informed best practice. The Practice Advisor role will also provide another area for practitioners to develop new skills, knowledge and help with identified role or professional development.

The Autism Champion role has continued to evolve in Children and Young People's Services as well. The training offer for the Champions is currently being reviewed to increase opportunities available. This will include attending termly continued professional development sessions with the Communication and Interaction Network in addition to their own training. Bespoke training for Champions across the Healthy Child Programme including Compass Reach and CAMHS (Child and Adolescent Mental Health Service) is currently in development, and is expected to include Cygnet Practitioner.

- Increased the number of Cygnet training courses offered to parents

Cygnet training is offered to all parents in North Yorkshire at the point of their child's autism diagnosis. It runs regularly across the County in a range of venues. Cygnet is a parenting support programme for parents and carers of children and young people aged up to 18 years who have received a diagnosis of autism. It forms a key part of the post-diagnostic pathway and allows parents to develop vital support networks not only with professionals but also with families having similar experiences.

The core Cygnet programme is delivered over six two and a half hour sessions which work towards relevant and appropriate behaviour management for children and young people. The sessions cover autism and diagnosis, communication, sensory issues, understanding behaviour and managing behaviour, with parents and carers having the opportunity to decide how best to use the last session. Additional sessions on siblings, puberty and sexuality are also available.

- Developed a range of activity-based groups for children with disabilities, including those with autism

There is now a broad range of activities running across North Yorkshire for children with disabilities to access, including children with autism. The groups are run by a range of organisations including the district and borough councils, the county council and local voluntary and community groups. Activities include art, swimming, yoga, football and garden-based activities. Further information on the different groups is available online at <https://www.northyorks.gov.uk/send-local-offer>.

#### What do we still need to do?

- Ensure mental health staff are able to identify the needs of people on the autism spectrum, including children and young people.

Discussions with people on the autism spectrum, their families and carers during the implementation of the strategy have highlighted that work still needs to be done to ensure that mental health staff have appropriate knowledge and training in order to effectively identify the needs of people on the spectrum and reasonably adjust support for their mental health needs, particularly during a crisis. We are linking with Tees, Esk and Wear Valleys NHS Foundation Trust and Bradford District Care Trust as part of our action planning for the remaining time on the current strategy, and the Adults Autism Operational Group have agreed to make this the group's priority for the last year of the current strategy.

## Theme 2: Assessment and diagnosis

### What did we say we would do?

We know families and people with autism wanted to receive a diagnosis closer to home and without waiting for long periods of time. We said we would provide accessible diagnostic services, review the existing pathways to make sure it meets people's needs, ensure people have the opportunity to provide feedback and review the available at post-diagnostic support.

### What have we done?

- Commissioned a local diagnostic service for adults

The Tuke Centre in York has been commissioned since January 2016 to deliver the North Yorkshire and York Autism and ADHD Diagnostic Service. Referrals can be made either by someone's GP or by Social Workers within the local Community Mental Health Team. The service offers screening and assessment for both autism and ADHD and a limited number of sessions for post-diagnostic support. This support comprises either two one to one sessions or five group sessions. People are given the opportunity to provide feedback on the service and this is shared with the Clinical Commissioning Groups.

The Tuke Centre covers all North Yorkshire except Craven district, which is covered by the Bradford and Airedale Neurodevelopmental Service (BANDS). As with The Tuke Centre referrals can be made either by someone's GP or by Social Workers within the local Community Mental Health Team. At present, however, the service is closed to new referrals due to staffing issues. The service is for assessment only and does not include provision of post-diagnostic support.

- Continued to deliver local diagnostic services for children and young people.

Diagnostic services for children and young people are delivered by several organisations across North Yorkshire including Harrogate and District NHS Foundation Trust, The Retreat based in York in partnership with Healios and Tees, Esk and Wear Valleys NHS Foundation Trust. Referrals can be made by health and social care professionals. Post-diagnostic support can vary between services, but generally includes a follow-up appointment to discuss the diagnosis and provision of information and advice.

For children and young people living in Scarborough and Ryedale CCG area, as well as having face to face appointments for assessment either in Scarborough or York, virtual consultations are also available through Healios where appropriate and providing the family are happy with this approach.

### What do we still need to do?

- Work with the Clinical Commissioning Groups to develop a sustainable service model for diagnostic services in North Yorkshire.

We recognise there are ongoing issues around waiting times to access diagnostic services in North Yorkshire. As of December 2018 the average wait between referral and assessment at The Tuke Centre was 57 weeks. The Clinical Commissioning Groups that commissioned the service have agreed to extend the current contract until 31<sup>st</sup> March 2020 and undertake work with partners throughout 2019 to develop a sustainable service model integrated across health and social care.

Similar work to review the service model is being done for BANDS. The service has been working to resolve the staffing issues and is looking at an alternative staffing model. In the meantime capacity from other diagnostic services has been purchased in order to start assessing people on the waiting list.

Discussions are ongoing around how to address the issues accessing diagnostic services for children and young people. The service model has been reviewed in order to make best use of available resources and maximise service capacity, and alongside this partners including the council and clinical commissioning groups are looking at how to address the waiting list.

- Review the information which is available to people both pre and post-diagnosis

As part of reviewing the diagnostic services we would also like to look at what information is available to people pre and post-diagnosis. This includes looking at where the information is, what formats it is available in and how people might find out about it, as well as what the information tells people.

## Theme 3: Raising awareness and training

### What did we say we would do?

We know autistic people and their families would like to access mainstream services and find suitable reasonable adjustments have been made to ensure provision is autism friendly. We said we would raise awareness of autism generally within local communities, map current training on autism throughout public sector agencies in North Yorkshire, support the development of universal, targeted and specialist training opportunities available to all public sector agencies and encourage frontline services to become autism friendly.

### What have we done?

- North Yorkshire County Council adult services are accredited by The National Autistic Society

The Autism Accreditation is an internationally recognised quality standard provided by The National Autistic Society. It is the UK's only autism-specific quality assurance programme of support and development for all those providing services to autistic people.

North Yorkshire County Council was the first local authority to have all of its adult services accredited in the UK in 2016. In total 17 services were accredited, all of which are being re-inspected in 2019. This includes the countywide Supported Employment service. In addition to the re-inspection of the adult services, the Living Well Service is also undertaking the accreditation process and is due to be inspected in 2020.

- Reviewed online autism awareness training for North Yorkshire County Council

North Yorkshire County Council's online autism awareness training has been refreshed and the new training was launched in May 2019. As with the previous training it is available to all staff at the Council and mandatory for all staff working in Health and Adult Services. As of July 2019, 64% of staff in Health and Adult Services and 10% of all staff at the Council have completed the online training.

More specialist training is available for staff groups who work more closely with autistic people. All Short Break Staff, Day Service Staff, Supported Employment and Living Well Staff have completed

the Autism Competency Based Training Booklet within a classroom setting. This training is also available to all staff working in Elderly People's Homes and the Extra Care schemes. It is now mandatory for any new starters and the Reablement Teams across North Yorkshire will also receive this training from October 2019.

- Tees, Esk and Wear Valleys NHS Foundation Trust (TEWV) has developed an autism framework which includes a three levels of training dependent on someone's role.

TEWV's mission is to improve people's lives by minimising the impact of mental ill health or a learning disability. The autism framework was been developed in consultation with people they support, their carers, staff and partner organisations to design the framework. It was launched in March 2018 and looks at how to apply TEWV's values and mission to working with autistic people. The framework includes TEWV's autism ambition that autistic people should have equal access to mental health and learning disability services and be treated by autism-aware staff who are able to make reasonable adjustments when required. As part of their approach to realise this ambition, TEWV has developed a three level approach to autism training. Level one is basic autism awareness training which all staff are required to complete. Level two is for clinical staff who are likely to encounter patients with autism. Level three is more in-depth training for people who are responsible for making decisions with or about the service for autistic people.

- Developed continued professional development opportunities for health and social care professionals working with autistic children and young people

Cygnnet Practitioner training was delivered across Children and Young People's Services, to staff at Compass Reach and to Health Visitors within the first year of implementing the strategy. Cygnnet Practitioner is an accredited course which is moderated externally by Barnardos. It is now offered to any professionals working with autistic children and young people across North Yorkshire. Cygnnet Practitioner is a 2 day course for professionals working with children and young people with autism. It echoes the content of the parent Cygnnet course and covers understanding autism and understanding and changing behaviour.

The Inclusive Education Service has also mapped all areas of the Children and Young People's Services directorate to determine what training levels are needed for which roles. The recommendations are awaiting confirmation and approval from senior managers, following which additional training will be sourced and rolled out. Within the last year, all staff working in the Inclusive Education Service have received training on autism, pathological demand avoidance, sensory needs and associated behaviours including challenging behaviour to raise awareness.

- Established the Autism Education Trust hub for post-16 delivery

Within the first year of implementing the strategy, the Council secured a bid to become the Autism Education Trust training hub for Yorkshire and Humber for post-16 delivery, as well as the existing early years' hub. Although we no longer hold this licence following the change in the licencing terms last year, we still use the Autism Education Trust framework with schools.

- Held activities as part of Autism Awareness Week

To raise awareness amongst North Yorkshire County Council staff and the general public, the Council has put on a number of activities during World Autism Awareness Week. This has included numerous teams putting up information stands and display boards in different settings across North

Yorkshire, hosting or linking with local coffee and cake mornings and continuing to make links with local employers.

#### What do we still need to do?

- Develop a better understanding of the training available across the public sector

While the training available to Council staff has been reviewed and we now have a better understanding of what training is provided to staff working in the NHS, we feel we could better understand what that training entails, what training is available in the wider public sector and whether there are any gaps we can help to meet.

- Continue to raise awareness of autism amongst the wider public

While we have undertaken various activities as part of Autism Awareness Week and will continue to do so, we would like to look at what else we can do throughout the year to help the wider public understand autism, how it can impact on people's lives and what they could do to help.

## Theme 4: Information and signposting

#### What did we say we would do?

We know navigating services can be difficult for people with autism and their families and it can be difficult to understand different access criteria. We said we would improve the way we communicate with people on the spectrum and their families, provide easily accessible information about autism, improve information and signposting available and make it easier for people to know how to access appropriate services and support.

#### What have we done?

- Made information on support and activities in communities available online

Information covering a range of areas linked to supporting children, young people and adults on the autism spectrum is available through the Council's website.

The Council has information on activities and groups for children and young people with SEND and their families on its website, including a specific section around autism. This includes information about local, regional and national groups and networks. As well as being listed on the Council's main site, the local SEND offer is also available through North Yorkshire Connect.

North Yorkshire Connect is North Yorkshire's online community directory available at <https://northyorkshireconnect.org.uk/>. People can search for information on activities, groups and support available in their local community from a range of different organisations. Categories of groups and support available include information and advice, local attractions and places to visit, business and jobs, charities, educations and learning, food and drink, health and housing.

- Made autism resources available within NYCC public libraries and made the libraries more autism friendly.

The library service have added 27 books about autism to their collection. The titles in the Fresh Perspective collection include novels and memoirs focusing on characters on the autism spectrum and aim to raise awareness of autism. The books are available in 12 libraries including Skipton,

Harrogate, Malton, Richmond, Sherburn, Northallerton and Scarborough, and can be reserved through any North Yorkshire library.

Library staff have received training to help them support people on the spectrum including the online awareness training and sessions with local organisations and the Adult Learning and Skills Service. By 2020 the Council's libraries service aims to make all 42 libraries in North Yorkshire autism friendly. Skipton became the first library to achieve autism friendly status in April 2018. One way they did this was to produce a site plan and a social story to explain what happens when someone visits the library. This helps to reduce the uncertainty someone on the autism spectrum may feel about visiting. Site plans have now been produced for the majority of the libraries and a social story has also been written for Ripon library.

- Reduced the number of referral points for families of children and young people with autism

There is now a single point of referral for the Inclusive Education Services to receive support around education, the Prevention Service to receive family support and the Healthy Child Service. The SPA (Single Point of Access) Panel takes place weekly during term time and has specialist representatives from all of the Inclusive Education Service areas. Cases are allocated based on the child or young person's need rather than any diagnosis. This ensures that the right service is allocated as quickly as possible with a contact made within two weeks of referral.

#### What do we still need to do?

- Involve people more closely in developing communications

We recognise we need to do more to tell people on the spectrum, their families, friends and carers what we are doing and involve them in this process. This includes involving them in developing communications so that everyone who is interested in what is happening has the opportunity to stay informed and get involved.

## Theme 5: Employment and education

#### What did we say we would do?

Many young people find school difficult and understanding of autism varies significantly across educational settings. We also know not enough people with autism are able to find or maintain work. We recognised we needed to improve education and employment opportunities locally. We said we would improve the knowledge, understanding and inclusive practice in educational settings (0-25), develop appropriate peer support for children and young people with autism, work with schools to become autism friendly and improve and expand employment opportunities for people with autism.

#### What have we done?

- Supported people on the spectrum to gain and maintain employment

Support to gain and maintain employment is available to people on the spectrum from North Yorkshire County Council either through the Support Employment service or from Living Well. The Supported Employment Coordinators work with people who has been assessed as being eligible for support from social care. The Coordinators will work with the person and their Social Care Assessor to develop an outcomes-focused, progressive plan. If someone does not meet eligibility criteria to

receive social care support but would benefit from support around employment, they can still access support through the Living Well team. The team work with people to develop their skills and confidence to both seek and maintain employment. Support from Living Well is free and is available for up to 12 weeks.

- Developed continued professional development opportunities for staff across all educational settings

Autism Awareness training is now offered to all education settings for children and young people aged 0-25 including nurseries, playgroups, schools and colleges. This is free at the point of delivery.

The Council worked with NYPACT (North Yorkshire Parents and Carers Together) to deliver the Inclusion conference in summer 2018. The conference focused on communication and interaction and was attended by parents and professionals. Schools and settings are offered twilight sessions which are tailored to the children and young people's needs; training days by Inclusive Education Service; signposting to other events and support from the SENCO network (Special Education Needs Co-ordinator). The network meets once per term and brings all of the SENCOs from the locality together to receive information, training and support.

- Developed peer support opportunities for children and young people on the autism spectrum.

A number of groups have been developed to provide peer support for children and young people on the autism spectrum including the Talkabout, Lego and Sibling groups on the coast and peer awareness in Harrogate schools. The groups are set up by specialist teachers and schools then continue to run them once they are established. We are continuing to work with teams in local areas to identify further opportunities for peer support groups across North Yorkshire.

#### What do we still need to do?

- Continue to work with partners to improve employment opportunities for people on the autism spectrum

We will continue to work with autistic people around employment through the Supported Employment service and Living Well. We would also like to better understand what employment support is available from other organisations including the local Job Centres and how we can work more closely with partners to further improve employment opportunities for people on the spectrum.

- Continue to work with schools to become autism friendly

We will continue to work with schools, parents, children and young people to understand what we can do to build on the work we have already done to make schools more accessible and autism friendly.

## Theme 6: Supporting people with autism through key life changes

### What did we say we would do?

We know key life changes such as moving from school to university or employment can be particularly challenging for people with autism and their families. We said we would remove the perceived 'cliff edge' for young people and their families through implementing a seamless model of support and provide high quality support locally to meet the needs of autistic people.

### What have we done?

- Developed a new approach to supporting young people moving from Children and Young People's Services to Health and Adult Services.

We have reviewed our approach to supporting children and young people who are moving to adult social care. Social workers in Children and Young People's Services and Health and Adult Services will work more closely together in future, and social workers from adult social care will take a more prominent role in future planning of support. For example this includes social workers from Health and Adult Services becoming involved in the young person's support planning sooner and jointly developing care and support plans. This approach is currently being implemented and governance structures to enable better working together are being developed to support this.

- Improved the transition from primary to secondary school for children with autism

We send out the Autism Education Trust transition guide to all schools where a child or young person is transitioning to a new school or education setting in the autumn. The guide gives advice and information on how to support the child or young person with the change in setting.

We also signpost people to the national organisation SENDIASS (Specialist Education Needs and Disabilities Impartial Advice and Support Service), Family Outreach Workers and other professionals within the Inclusive Education Service. During the summer term staff within the Inclusive Education Service liaise with primary and secondary schools to ensure that when a child moves from Year 6 into Year 7 and into a new school, they are also moved to the member of the Inclusive Education Service who provides support in their new school.

We will also design bespoke packages of intervention for transition support for vulnerable children. This may involve an intense period of one to one sessions in the weeks leading up to moving schools, assisting with individual visits and creating a package of provision tailored to their needs if they cannot cope with full time mainstream school.

### What do we still need to do?

- Finish implementing the new approach to transitions from Children and Young People's Services to Health and Adult Services.

We are currently implementing the new model described above. We will finalise the new governance structures, ensure the new approach is embedded across North Yorkshire and monitor the impact of the new model.

## Theme 7: Working together

### What did we say we would do?

We know it is important to get all agencies that work with or support people with autism to play a part in implementing the aims of this strategy. We said we would improve communication with the voluntary sector, continue to ensure people with autism and their families are centrally involved in developing autism support in North Yorkshire, share progress and celebrate success.

### What have we done?

- Developed a governance structure for implementing the strategy with a range of partners and stakeholders

We created the Autism Steering Group to oversee the implementation of the strategy. The group includes someone on the autism spectrum and representatives from Children and Young People's Services, Health and Adult Services, Clinical Commissioning Groups, North Yorkshire Police, TEWW mental health trust and the district councils.

Within Health and Adult Services we established an Adults Autism Operational Group. As the Steering Group oversaw the overall progress of the strategy and joint actions affecting children, young people and adults, this group focuses on completing the actions relating more to adults' services. Its counterpart, a Children and Young People's Operational Group, has also been established to bring together wider partners to implement actions relating to children and young people.

We also set up a Co-production and Engagement Group and mailing list for adults on the spectrum, family members and carers for autistic people. This was based on the membership of the Virtual Reference Group which was set up when we were writing the strategy. The group was for people who were able to attend meetings, and working with them and the health and social care professionals who attended we were able to do a lot of work to map the assessment, diagnostic and support pathway in North Yorkshire. We also maintained a mailing list for the people who were unable to attend meetings due to other commitments or who did not wish to attend meetings.

- Worked with parents to develop parent support in Craven district

We worked with parents to co-produce parent support in Craven. Children and Young People's Services were commissioned by Carers' Resource to co-produce a behaviour management parent programme. The programme took a few weeks to develop and was designed over several meetings with parents. The programme consists of 3 sessions which are approximately 3 hours each. Following completion it was delivered by staff from CYPS and Carers' Resource and can now be repeated on a rolling programme. We have received very positive feedback about the programme and we hope to run it again this year.

### What do we still need to do?

- Develop a range of ways for people on the spectrum, their families, friends and carers to find out about opportunities to help develop services and get involved.

We learnt a lot from working with the Co-production and Engagement Group and were very grateful that people came to speak to us about their experiences and help us progress work on the strategy. We know however that North Yorkshire is a big place and having meetings in one town is not always easy for people to get to, and attending meetings is not how everyone would like to get involved. We would like to better understand how people prefer to be contacted about and involved in different opportunities, and work to give people a real choice about how they can do this.

- Ensure that we are including voluntary and community sector organisations in developing services

As well as ensuring we maximise opportunities for people on the spectrum, their families, friends and carers to get involved, we also want to make sure we are working closely with voluntary and community sector organisations when developing services and support. We want to involve people in the development of the future all-age autism strategy for North Yorkshire and understand how we can best link the voluntary sector into ongoing work to improve services and support.

## What are we doing next?

- Writing an action plan for the last year of the current strategy

We still have one year left before *The Changing Landscape of Autism in North Yorkshire* ends. We want to make the best use of this time to look at some of the things we still need to do. For example, one of the priorities for this year will be to look at reasonable adjustments for autistic people accessing mental health services. We know we might not be able to finish everything we still need to do, so if after this year there are still some outstanding actions from this strategy we will include these in the next strategy and its action plan.

- Talking to people to understand what we need to do for the next strategy

From 1<sup>st</sup> October – 30<sup>th</sup> November 2019 we are talking to people about how we have done on this strategy and what they would like us to look at as part of the next one. We want to hear from people on the autism spectrum, parents, carers, friends and family members of people on the autism spectrum, health and social care professionals, voluntary and community sector organisations and anyone else who would like to speak to us about this. There are a number of different ways people can get involved including attending an event and completing a survey. Further information about how you can get involved is available at [www.northyorks.gov.uk/autismmatters](http://www.northyorks.gov.uk/autismmatters).

If you have any questions about the information in this document or what is happening next, please contact us at [autismmatters@northyorks.gov.uk](mailto:autismmatters@northyorks.gov.uk) or by phoning 01609 535995.