# ADULTS SCRUTINY COMMITTEE 7 JANUARY 2025

#### **AUTISM STRATEGY AND ACTION PLAN UPDATE**

#### **SUMMARY REPORT**

## **Purpose of the Report**

- 1. To update Adult Scrutiny Committee on the progress in relation to the National Autism Strategy and the subsequent actions within Darlington.
- 2. This is a joint position statement from Integrated Care Board, Tees and ESK Wear Valley Foundation trust and Darlington Borough Council, Peoples Group.

## **Summary**

#### **National Context**

- 3. Autism is a lifelong developmental disability that affects how people perceive, communicate and interact with others, although it is important to recognise that there are differing opinions on this and not all autistic people see themselves as disabled. With an estimated 700,000 autistic adults and children in the UK most people probably know someone who is autistic. In addition, there are an estimated 3 million family members and carers of autistic people in the UK (National Autistic Society).
- 4. Autistic people see, hear and feel the world differently to other people. Autism varies widely and is often referred to as a spectrum condition, because of the range of ways it can impact on people and the different level of support they may need across their lives. While autism is not a learning disability, around 4 in 10 autistic people have a learning disability (Autistic).
- 5. Some autistic people will need very little or no support in their everyday lives while others may need high levels of care, such as 24-hour support in residential care. People may need help with a range of things, from forming friendships, coping at school, managing at work, or being able to get out and about in the community. In this strategy, we also talk about neurodiversity, which refers to the different ways the brain can work and interpret information. It is estimated that around 1 in 10 people across the UK are neurodivergent, meaning that the brain functions, learns and processes information differently (<a href="Embracing Complexity Coalition">Embracing Complexity Coalition</a>, 2019).
- 6. Legal Obligations / Statutory Framework: Autism Act 2009; Two strategies published in 2010 and 2014. <a href="https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy">https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy</a>; 2019 inclusion of Autism as a priority within

- the NHS Long Term Plan; 2021-26 Autism Strategy; 2022 Health and Care Act.
- 7. The prevalence of Autism in adults is about 1.1%, with relative consistency across studies.
- 8. The proportion of males to females diagnosed with ASD varies across studies but always shows a greater proportion of males to females, mostly ranging from 3:1 to 5:1.
- 9. Almost 8 out of 10 autistic people experience mental health difficulties (Cassidy and Rogers, 2017).
- 10. % of autistic people with mental health problems is 4 x higher (51%) than people without (11%) (Taylor 2021).
- 11. More than 25% of autistic people receive two or more diagnoses of mental health problem (Taylor 2021).
- 12. Around 15% of autistic people (compares to 2.8% of non-autistic people) are hospitalised due to a mental health problem (Taylor 2021).
- 13. The prevalence of autism within an adult psychiatric outpatient service was 19% with another 5 10% having just sub threshold symptoms (Nyrenius et al 2022).
- 14. More than 6 out of 10 autistic people have considered suicide (Cassidy and Rogers) (2017).
- 15. More than 3 out of 10 autistic adults have attempted suicide. (Cassidy et al) (2022).
- 16. Autism and autistic traits are risk factors for suicidal behaviour study showed that evidence of autism was significantly higher in those who died by suicide (11.8%) than the 1.1% prevalence of autism in the UK. When autistic traits were taken into account this rose to 41%.
- 17. The management and support of an autistic people and their families, partners, and/or carers incurs substantial costs to the health and social care services and the wider public sector (National Collaborating Centre for Mental Health, 2012).
- 18. Autism costs the country an estimated £32 billion per year, making it the single most expensive health condition, exceeding cancer, heart disease, and stroke (Buckley, 2017).
- 19. The total cost, including accommodation, treatment, loss of earnings, and health care, for an autistic person over their life span has been estimated to range between £1.5 million to £0.92 million for a person with or without intellectual disability, respectively (Howes, 2018).

## **Darlington Context:**

20. The partners have developed a position statement and future actions to ensure the objectives of the National Strategy are delivered within Darlington.

#### Recommendation

- 21. It is recommended that: -
  - (a) Scrutiny Members note the content of the report.
  - (b) The report is shared with Children's scrutiny.
  - (c) Deliver an annual update to Scrutiny.

# Joss Harbron Assistant Director of Adult Social Care

# **Background Papers**

No Background papers were used in the preparation of this report.

Joss Harbron, Chris Bell, Tony Murphy, Dominic Gardner, Martin Short Extension: 5278 (Joss Harbron)

| Council Plan                    | This report and activities are consistent with the aims of the council plan. |
|---------------------------------|--|
| Addressing inequalities         | This report and actions aim to address inequalities.                         |
| Tackling Climate Change         | No impact within this report but will continue to be considered.             |
| Efficient and effective use of  | The report and activities will consider the effective                        |
| resources                       | and efficient use of resources.  |
| Health and Wellbeing            | The objectives of the Darlington response to the                             |
|                                 | National Autism Strategy relates to the Health and                           |
|                                 | Wellbeing Priorities.  |
| S17 Crime and Disorder          | N/A  |
| Wards Affected                  | All  |
| Groups Affected                 | People with Autism, Family Carers.   |
| Budget and Policy Framework     | No impact on budget currently.   |
| Key Decision                    | N/A  |
| Urgent Decision                 | N/A  |
| Impact on Looked After Children | This report has no impact on Looked After Children                           |
| and Care Leavers                | or Care Leavers, however there may be leavers or                             |
|                                 | looked after children who have autism.                                       |

#### **MAIN REPORT**

## **Information and Analysis**

22. Not applicable.

# **Outcome of Consultation**

23. Not applicable at present. The report is an update on the previous position from 2023. Subsequent reports will demonstrate feedback and consultation from stakeholders.

#### **National Context**

- 24. Autism is a lifelong developmental condition that affects how people perceive, communicate and interact with others, although it is important to recognise that there are differing opinions on this and not all autistic people see themselves as disabled. With an estimated 700,000 autistic adults and children in the UK most people probably know someone who is autistic. In addition, there are an estimated 3 million family members and carers of autistic people in the UK (National Autistic Society).
- 25. Autistic people see, hear and feel the world differently to other people. Autism varies widely and is often referred to as a spectrum condition, because of the range of ways it can impact on people and the different level of support they may need across their lives. While autism is not a learning disability, around 4 in 10 autistic people have a learning disability (Autistica).
- 26. Some autistic people will need very little or no support in their everyday lives while others may need high levels of care, such as 24-hour support in residential care. People may need help with a range of things, from forming friendships, coping at school, managing at work, or being able to get out and about in the community. In this strategy, we also talk about neurodiversity, which refers to the different ways the brain can work and interpret information. It is estimated that around 1 in 10 people across the UK are neurodivergent, meaning that the brain functions, learns and processes information differently (Embracing Complexity Coalition, 2019).
- 27. Legal Obligations/Statutory Framework: Autism Act 2009; Two strategies published in 2010 and 2014.
  - a) <a href="https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy">https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy</a>.
  - b) 2019 inclusion of Autism as a priority within the NHS Long Term Plan; 2021-26 Autism Strategy; 2022 Health and Care Act.
- 28. The prevalence of Autism in adults is about 1.1%, with relative consistency across studies.
- 29. The proportion of males to females diagnosed with ASD varies across studies but always shows a greater proportion of males to females, mostly ranging from 3:1 to 5:1.
- 30. Almost 8 out of 10 autistic people experience mental health difficulties (Cassidy and Rogers, 2017).
- 31. The percentage of autistic people with mental health problems is 4 x higher (51%) than people without (11%) (Taylor 2021).
- 32. More than 25% of autistic people receive two or more diagnoses of mental health problem (Taylor 2021).
- 33. Around 15% of autistic people (compares to 2.8% of non-autistic people) are hospitalised due to a mental health problem (Taylor 2021).

- 34. The prevalence of autism within an adult psychiatric outpatient service was 19% with another 5 10% having just sub threshold symptoms (Nyrenius et al 2022)
- 35. Cassidy and Rogers (2017)
  - a) More than 6 out of 10 autistic people have considered suicide.
  - b) More than 3 out of 10 autistic adults have attempted suicide.
- 36. Cassidy et al (2022)
  - a) Autism and autistic traits are risk factors for suicidal behaviour study showed that evidence of autism was significantly higher in those who died by suicide (11.8%) than the 1.1% prevalence of autism in the UK. When autistic traits were considered, this rose to 41%.
- 37. The management and support of an autistic people and their families, partners, and/or carers incurs substantial costs to the health and social care services and the wider public sector (National Collaborating Centre for Mental Health, 2012).
- 38. Autism costs the country an estimated £32 billion per year, making it the single most expensive health condition, exceeding cancer, heart disease, and stroke (Buckley, 2017).
- 39. The total cost, including accommodation, treatment, loss of earnings, and health care, for an autistic person over their life span has been estimated to range between £1.5 million to £0.92 million for a person with or without intellectual disability, respectively (Howes, 2018).

## Priority Areas of Focus for the 2021-26 National Autism Strategy

- 40. Improving understanding and acceptance of autism within society.
- 41. Improving services for autistic children and young people, access to education and supporting positive transitions into adulthood.
- 42. Investment in Preventing Mental Health Crisis for People with Autism
- 43. Supporting more autistic people into employment.
- 44. Tackling health and care inequalities for autistic people.
- 45. Building the right support in the community and supporting people in inpatient care.
- 46. Improving support within the criminal and youth justice system.

## Improving Understanding and Acceptance of Autism Within Society

## 47. What the strategy sets out:

- a) We will significantly improve the public's understanding and acceptance of autism and show that autistic people feel more included and accepted in their communities.
- b) We also want the public to understand how autism can affect people differently, including the difference in how autistic women and girls present, and to help change people's behaviour towards autistic people and their families.
- c) We want many more businesses, public sector services and different parts of the transport system to become more autism-inclusive, so that autistic people can access these spaces and services, just like everyone else.

# 48. What we are doing:

- a) Within Darlington Borough Council (DBC) Children and Young People Services we have a multi-agency steering group who have driven the changes to date and will continue to meet. This group can support the development of a multi-agency strategy.
- b) DBC People's Group have promoted Autism Awareness, Dementia Awareness and Mental Health Awareness training to ensure staff development across the directorate and wider council/wider partnership. Using Strength Based Methodologies, including MINDSPACE - WFD Team Intranet and Relational Practice -WFD Team Intranet we try to provide training, tools and resources to support the workforce.
- c) DBC People's group are currently working with staff in both Children and Adults Services, HR, the Parent Carer Forum, NEAS, and colleagues from North Yorks (in an advisory capacity) regarding the development of our own bespoke Autism Training Programmes:
  - Autism Awareness programme for Darlington which will include an Ac10 module, Autism Podcasts (that include the voice of staff, Autism specialists, and the real voice of Adults, Families and Children we work with) and tools/resources.
  - ii. Autism Training for Practitioners bespoke / advanced training for practitioners working with Adults/Children/Families.
  - iii. Content Creation Podcasts, short films, vlogs all capturing and promoting the voice of Darlington people.
  - iv. Experts in Practice (EXiP) EXiP is a unique programme designed by DBC and Newcastle University research unit. It is a funded internship for staff to develop as research and training experts in chosen fields, of which Autism is a key area chosen by Darlington. We also have existing training, resources and

- platforms that staff/partners have accessed/can access. Please see page 16.
- v. DBC has a Welcome to the Workforce Development 'Autism' Intranet Page. Here you will find information, training, links, tools, and resources that will help DBC staff members, to help others. The page gives a direct link to the national Oliver McGowan Autism Training, which is also mandatory training in the ICB, as well as access to locally developed content.

Improving services for autistic children and young people, access to education and supporting positive transitions into adulthood

## 49. What the strategy sets out:

- a) We want the Special Educational Needs and Disability (SEND) system to enable autistic children and young people to access the right support, within and outside of school.
- b) We want schools to provide better support to autistic children and young people, so they can reach their potential, and to show that fewer autistic children are permanently excluded or suspended from school due to their behavior.
- c) We will make improvements to the support autistic people get in their transitions into adulthood, so that more autistic people can live well in their own communities, find work or higher education or other opportunities. This is important in preventing more young people from avoidably reaching crisis point or being admitted into inpatient mental health services.

#### 50. What we are doing:

- a) We are working with young people and adults to develop life skills and be able to access apprenticeships and employment through support from Project Choice, Learning and Skills and large firms offering apprenticeships e.g. Amazon.
- b) A new free school will be built in Darlington to ensure children with special educational needs and disabilities can get the help that they need earlier. The local authority's bid for the new facility was approved by the Government and will support pupils with autism spectrum disorder (ASD). Up to 48 full-time places will be provided for pupils aged 11-19 with autism and will see them benefit from a specific environment tailored to their needs with dedicated staff.
- c) Training of education and other front-line professionals Working with the local authorities to determine how training can be accessed and rolled out to LA staff and education professionals Autism in Schools is a national programme Positively, Darlington has the highest number of schools involved in this initiative across the region and has been involved since the earliest phases of this project. A review of the commissioned SEND Outreach Services has been undertaken through 2023/24, this has included the social, communication and outreach service and is focused upon how the service respond to individual child level needs and have an integral role in the upskilling of a range of professionals. There is a growing prevalence of

Emotional Based School Avoidance for children and young people with neurodivergent needs. The needs of this group of young people will be considered as part of the broader outreach service review work.

- d) Commencing a programme of review of the current SEND education resources bases Through the review programme the base at Heathfield from September 2024 will have a primary remit of supporting reception, Year 1 and Year 2 children with communication and interaction needs in response to the changed needs of children with SEND in Darlington. The base will be filled on an incremental basis each year by 8 places up to a maximum capacity of 24 places. Further joint review work in respect of the remaining basis will be undertaken throughout 2024/25, with a particular focus on the secondary school provision and opportunities for expansion in line with the presenting needs of Darlington children and young people.
- e) Increase in public awareness through a national campaign the steering group in place for Children & Young People (CYP) will work collaboratively to support this national campaign. Links are already in place for promotion of services available.
- f) **Expansion of the Disabled Facility Grant Regulatory Reform Fund Policy** to widen the support that can be provided for children and adults with autism/behaviours that challenge, including the provision of safe spaces.
- g) **Multi-Agency Sleep Service** across Tees Valley and via hosting of a Sleep Service website.
- h) CYP Neurodevelopmental pathway Professional Consultation Line and Increase in Specialist Assessments - Following review of the Waiting List Initiatives commissioned by the ICB and delivered by TEWV which included Reducing the backlog of Screenings by introducing a Pre-Referral Consultation approach to manage the increasing demand for referrals which evidenced the positive impacts on referrals and positive responses from the wider children's system (professionals have access to bespoke advice, support and guidance in making referrals and recommending needs-led support).

## **Preventing Mental Health Crisis for People with Autism**

- 51. What the strategy sets out:
  - a) Improving Access to Mental Health Services. The strategy emphasises the importance of timely and tailored access to mental health services for individuals with autism. It sets out plans to ensure that mainstream mental health services, including crisis care, are better equipped to support people with Autism.
  - b) It includes a commitment to reduce waiting times for mental health support, particularly through **increasing early intervention** options to prevent crises from occurring or worsening.

- c) Training and Awareness for Mental Health Professionals. A key part of the strategy is to enhance autism training for mental health professionals, particularly those involved in crisis response, such as emergency care staff and crisis intervention teams. This training aims to improve professionals' understanding of autism-specific needs and communication styles, reducing the likelihood of misunderstandings, and ensuring that autistic people in crisis receive compassionate and appropriate care.
- d) Personalised Crisis Care Plans. The strategy advocates for personalised crisis care plans for autistic people. These plans are meant to be developed in collaboration with individuals and their families or caregivers, considering sensory sensitivities, communication preferences, and specific stressors or triggers that may contribute to crisis situations. The goal of these personalised plans is to have a predefined response in place, helping healthcare providers better support individuals with autism in a crisis.
- e) Autism-Friendly Crisis Intervention Services. The strategy encourages the development of autism-friendly crisis intervention options, which may include quiet spaces, alternative modes of communication, or the option for family or a trusted person to be present during a crisis intervention.
- f) Some localities have begun implementing *safe spaces* or specific crisis services tailored for people with autism, and the strategy calls for these types of supportive interventions to be more widely available.
- g) Community-Based Crisis Alternatives. The strategy highlights the need for more community-based crisis alternatives, such as crisis houses, helplines, or peer support networks, where people with Autism can receive support outside of a traditional clinical setting. By expanding the types of crisis response services available, the strategy aims to reduce the need for inpatient care and to provide support in less restrictive and more comfortable environments for individuals with autism.
- h) Support for Comorbid Mental Health Conditions. Recognising that people with Autism often experience higher rates of comorbid mental health conditions (like anxiety and depression), the strategy calls for better screening and early intervention for these conditions within autism services.
- Early identification and treatment of mental health needs can reduce the likelihood of a mental health crisis, providing preventive support that addresses underlying issues before they escalate.
- j) Data Collection and Monitoring. The strategy includes goals to improve data collection and monitoring of mental health outcomes for people with autism, especially those who experience crises. Better data allows policymakers and service providers to understand the prevalence and causes of mental health crises within the autistic community and to make targeted improvements.
- k) This data collection extends to monitoring the outcomes of crisis interventions to ensure they are effective and appropriate for people with Autism.

- Collaboration with Families and Carers. Family members and caregivers play a crucial role in supporting autistic people, especially during crises. The strategy highlights the importance of involving families and carers in mental health crisis planning and intervention. It also calls for greater support for families and carers themselves, recognising that they may need guidance or respite when managing the complex needs of a loved one in crisis.
- m) Reducing Hospital Admissions and Avoiding Inappropriate Detentions. The strategy aims to reduce unnecessary hospital admissions and inappropriate detentions under the Mental Health Act for people with autism. By focusing on community-based care and specialised crisis intervention, the goal is to avoid situations where individuals are inappropriately held in inpatient settings, which can often exacerbate stress and anxiety.

## 52. What are we doing:

- a) We have recognised the high percentage of children and young people (CYP) who come onto the Neurodevelopmental pathway with needs associated with anxiety. Within DBC, CYP services have aligned the 0-19/MHST offer to the triage element of the pathway for earlier support.
- b) Darlington has a sensory offer (Sunflower programme) which is available to parents of CYP from 4-12 increased sensory difficulties can cause anxiety. A programme is being developed for a sensory offer to the under 5's and over 12's.
- c) The Dynamic Support Register for CYP with Autism and/or a Learning Disability is now in place across the TV. Monthly multi agency meetings happen to review all CYP. All CYP on the DSR have a Key Worker.
- d) Adults Dynamic Support Register is in place across Darlington with a Care and Treatment Review process (CTR).
- e) Key Worker project commenced August 2021 to work with families of children who have a Learning Disability and or Autism from 4-12 or who have needs associated with either diagnosis. These are more complex families whose needs are greater than those who can access support through the Family Support Service.
- f) Complex Commissioning workstream multi agency approach to supporting the needs of our most complex CYP. Significant ACE's, trauma and behaviour underpin the needs of this cohort. The adverse experiences pilot, operated through the neurodevelopmental pathway panel has been very successful and family feedback is strong. This has now been extended for another year. Last year, 10% of children who were diverted to the adverse experience pathway returned to the neurodevelopmental pathway at the point they initially applied and underwent an assessment for ASD/ADHD. This pilot is a **Joint Commissioning** between health, social care, and education.

- g) The ICB is investing £2 million across North East and North Cumbria to work with all local authorities on a draft proposal for a MDT Team of professionals supporting children and young people at risk of out of area placement/first time entrants into care/first time entrant in youth justice (from an early point) where there is significant attachment and trauma.
- h) There is a **Professional Consultation Line** that is now well established. This means that schools can discuss cases at the request of families and ensure that referrals are appropriate and timely. This is now being funded on a recurrent basis.
- TEWV have developed a Trustwide Autism Service. The team have a range of functions including; training (mandatory and specific/bespoke); supervision and consultation for clinicians across all specialities; support for pathway development/reasonable adjustments; input into patient safety and risk management processes; sensory / environmental work; policy development
- j) The TEWV Autism Service have also been engaged in specific projects with inpatient services, crisis and liaison psychiatry services.

## **Supporting More Autistic People into Employment**

## 53. What the strategy sets out:

- a) We will make progress on closing the employment gap for autistic people, ensuring that more people who are able and want to work can do so and that those who have found a job are less likely to fall out of work.
- b) We want more employers to be confident in hiring and supporting autistic people, and to improve autistic people's experiences of being at work.
- c) We will drive improved employer awareness of autism, so they better understand the benefits of employing autistic people and are able to make the adjustments needed to recruit and properly support them.
- d) Continue to promote better access to employment support programmes for autistic people and move forward with our plans to improve the benefits system for disabled people to ensure these better supports autistic people who are unable to work.
- e) We will continue to engage with employers through the Disability Confident Scheme. This provides advice and support to employers, and to promote the skills, talents, and abilities of autistic people, as well as other disabled people.
- f) We also want to ensure that autistic people who are unable to work can access the benefits and support they might need.

# 54. What we are doing:

a) Encouraging employers through the disability confidence scheme.

- b) Utilising and raising awareness of the Access to Work scheme through the Department of Work and Pensions.
- c) Intensive Personalised Employment Support Programme (IPES).

# Tackling Health and Care Inequalities for Autistic People

# **Darlington Context**

55. Adults: Number and Time Waited for Diagnostic Assessment.

| 0-1   | 1-2    | 2-3    | 3-6    | 6-9    | 9-12   | 1-2   | 2-3   | Over3 | Total |
|-------|--------|--------|--------|--------|--------|-------|-------|-------|-------|
| Month | Months | Months | Months | Months | Months | Years | Years | years |       |
| 20    | 11     | 7      | 22     | 27     | 33     | 106   | 54    | 4     | 284   |

56. Children and Young People: Number and Time Waited for Diagnostic Assessment.

| 0-1   | 1-2    | 2-3    | 3-6    | 6-9    | 9-12   | 1-2   | 2-3   | Over 3 |
|-------|--------|--------|--------|--------|--------|-------|-------|--------|
| Month | Months | Months | Months | Months | Months | Years | Years | years  |
| 4     | 5      | 3      | 18     | 26     | 90     | 258   | 63    | 16     |

57. Darlington Borough Council Adult Social Care (People with Autism Diagnosis on caseload).

| Primary Support Reason                                | Clients |
|---|---------|
| Learning Disability Support                           | 82      |
| Mental Health Support                                 | 15      |
| No PSR  | 3       |
| Physical Support – Personal Care Support              | 4       |
| Sensory Support – Support for Visual Impairment       | 1       |
| Social Support – Support for Social Isolation / Other | 1       |
| Support with Memory & Cognition                       | 2       |
| Total   | 108     |

- 58. Of the 108 people with Autism known to Adult Social Care, 63 also have an additional health condition.
- 59. The strategy says:
  - a) We will work towards our vision by tackling long diagnosis waiting times for children and young people, as well as adults.
  - b) We will work to improve the quality of post diagnostic support.

- c) We will take actions in the first year to improve health and care staff understanding of autism. Subject to evaluation, we will move forward with our commitment to develop Oliver McGowan Mandatory Training for all health and care staff.
- d) We will improve professionals' ability to identify autistic people across the health service so they can make necessary adjustments and develop programmes intended to improve autistic people's physical health, such as trialling autism health checks.
- e) Better understand the health inequalities faced by people with autism to enable this LeDeR will include deaths of all autistic adults where they are notified to the programme which will enable the death to be reviewed.
- f) We want to reduce the health and care inequalities that autistic people face throughout their lives, and to show that autistic people are living healthier and longer lives.
- g) In addition, we want to have made significant progress on improving early identification, reducing diagnosis waiting times and improving diagnostic pathways for children and adults, so autistic people can access a timely diagnosis and the support they may need across their lives.

## 60. What we are doing:

- a) Investment in finding new ways to reduce waiting times ICB investment in TEWV to double the MAAT's, national interest in our needs led pathway and use of triage, discussions on an ICB footprint around best practice. The neuro-development pathway has been exceptionally impactful supporting children to receive time support through a range of different multi-agency interventions tailored to the child and their needs.
- b) A procurement process has been underway to procure a service for 16+ pre and post diagnostic (needs led) service. In place from the first of April 25.
- c) Support the commitment to develop and roll out Oliver McGowan Mandatory Training for all health and care staff.
- d) Investment from the ICB service development fund to develop a framework for accredited providers to carry out assessment to reduce the long waiters and overall waiting list.
- e) We will improve professionals' ability to identify autistic people across the health service so they can make necessary adjustments and develop programmes intended to improve autistic people's physical health, such as trialling autism health checks.
- f) Better understand the health inequalities faced by people with autism to enable this LeDeR will include deaths of all autistic adults where they are notified to the programme which will enable the death to be reviewed.

- g) We will continue to focus on preventing avoidable admissions, increasing the use of our Dynamic Support Register for adults.
- h) We will ensure intelligence and themes from CTRs, and Oversight Visits is used to improve people's experience of inpatient care and address gaps.
- Working with our Provider Market we will support the social care workforce and service design to ensure services are able to meet the needs of autistic people, embedding co-production into planning and commissioning.
- j) As part of our forward planning, we will continue to work across the wider system to maximise development and investment opportunities for both crisis and long-term community support.

# Building the Right Support in the Community & Supporting People in Inpatient Care

## 61. The strategy says:

- a) We will achieve the targets set out in the NHS Long Term Plan to reduce the number of autistic people and people with a learning disability being admitted into inpatient mental health services.
- b) We will do so by improving the treatment of autistic people in mental health legislation to prevent people from being avoidably admitted to inpatient care and improving the provision of community mental health and crisis support.
- c) We will also improve the suitability and availability of housing support and social care.
- d) In addition, for people who do need to be in inpatient mental health settings, the quality of care will be better and more tailored to their individual needs and people
- e) will be discharged back into their communities as soon as they are well enough to leave.
- f) Investment through the LTP to prevent avoidable admissions and improve community care including multidisciplinary teams, Keyworkers (CYP), Community Discharge grants to LA's, improving respite support for CYP.
- g) We will move forward with a number of actions to improve the quality of inpatient care, including reducing the use of restraint, seclusion, and segregation.
- h) We will invest £4 million in 2021 to 2022 to roll out the Transforming Care for Children and Young People accelerator programme. The latter involves NHS local systems, local authorities, parent carer forums and the voluntary sector working together to put in place appropriate support to reduce the number of children being permanently excluded from school.

- i) We will work with the National Body for Home Improvement Agencies to offer support to LA Disabled Facilities Grant teams and will reach out to autism charities to raise autistic people's awareness of how DFG can support autistic people.
- j) We are committed to sustainable improvement of the adult social care system and will bring forward proposals in 2021. The objectives for reform are to enable an affordable, high quality adult social care system that meets people's needs, while supporting health and care to join up services around them.
- k) We need a better understanding of the types of community support that meet autistic people's needs before and during crisis.
- I) We are also taking actions specifically aimed at improving the quality of inpatient care for autistic people who often find these settings distressing.

# 62. What we are doing:

- a) We will aim to reduce the number of people with autism or a learning disability in an inpatient setting. There is ICB project group whose focus is on reducing hospital admissions for people with autism or a learning disability.
- b) Investment through the LTP to prevent avoidable admissions and improve community care including multidisciplinary teams, Community Discharge grants to LA's.
- c) We have reviewed the national guidance on Disabled Facilities Grant and widen the offer to provide adaptations as identified for children and adults with Autism to support their independence at home.
- d) To improve the culture of care across Tees Valley is commissioning training around Gloriously ordinary lives; this will include inpatient care alongside community care. The Training and subsequent training would look to improve the quality of lives for people across the region with a learning disability and autistic people. The offer will look at offering 140 places of training followed by a train the trainer's course to implement change across the region as 'Gloriously ordinary lives change maker'. The aim is to support a range of organisations who offer support to people across Tees Valley the chance to embody the essence of Gloriously Ordinary Lives and with the train the trainer, build organisations own ability and capacity to do this, rather than needing to buy more training and support every year.

### Improving Support into the Criminal and Youth Justice Systems

#### 63. The strategy says:

a) We are clear that autistic people who come into contact with the criminal justice system should have equal access to healthcare and social care. Health and justice partners will continue to work together to improve access to assessments and referrals for support for autistic people in contact with the criminal and youth justice systems.

- b) We will improve the police and wider criminal and youth justice system staff's understanding of autism so that autistic people are more able to receive the right support, adjusted to their needs, as well as ensuring that different parts of the justice system from prisons to courts become more autism-inclusive.
- c) Training will be rolled out across all front-line staff.
- d) Encourage more prisons and probation areas to undertake the National Autistic Society's Autism Accreditation scheme.
- e) Explore how we can find alternatives to prosecution and custody for autistic adults and those with other vulnerabilities.

# 64. What we are doing:

- a) Durham Constabulary's Autism Association has funded wellbeing boxes to help support victims and witnesses who are neurodiverse when they find themselves in the unfamiliar surroundings of a police station.
- b) Liaison and Diversion (L&D) services exist in all police custody suites to identify people who have mental health, learning disability (including autism), substance misuse or other vulnerabilities when they first come into contact with the criminal justice system as suspects, defendants, or offenders. The service can then support people through the early stages of criminal system pathway, refer them for appropriate health or social care or enable them to be diverted away from the criminal justice system into a more appropriate setting, if required.
- c) Neurodiversity Managers have been employed in all NE public sector prisons.
- d) A Reconnect Service exists in all Northeast Prisons to provide care after custody for people leaving prison who have ongoing health vulnerabilities, including autism. We are also piloting a Reconnect Hub outside HMP Durham.

## Improving Understanding and Acceptance of Autism within Society

### 65. The strategy says:

- a) We will develop and test an autism public understanding and acceptance initiative, working with autistic people, their families, and the voluntary sector. We want this initiative to help the public adapt their behaviour towards autistic people and recognise the diversity of the autistic community; that every autistic person is different.
- b) To raise the profile of neurodiversity including autism, across the Civil Service we will encourage the establishment of a neurodiversity priority for Disability and Inclusion Champions within government departments.

- c) We resumed our <u>'it's everyone's journey'</u> campaign on 25 May 2021, which is aimed at helping the public to be more mindful of passengers, including those who are autistic, and the challenges they may face when using transport.
- d) We want to encourage businesses and organisations across the country to take steps to become more autism friendly.

# 66. What are we doing:

- a) We will have reviewed the national strategy against progress within Darlington and propose that we will have a reset of the Autism Strategy within Darlington: within partners including Local Authority, TEWV, Providers, Voluntary Community Sector, Community Safety, Economic Regeneration, Schools, Parent Carers Forum, Carers Services and Young Carers etc.
- b) In 2024/5 we plan to commission Inclusion North to re-establish the Autism Local Working Group and support it to meet regularly with agreed priorities and focus. The intention is to ensure a diverse, committed, and stable group that is led by both partners e.g. TEWV, ICB and DBC and Darlington residents with lived experience of autism.
- c) Inclusion North exists to make inclusion a reality for all people with a learning disability, autistic people, and their families. Inclusion means everyone living good lives as valued members of society.
- d) We work to change society so that everybody can have a good life. We raise awareness of the barriers to inclusion for people with a learning disability or autism and their families, and work to remove them.
- e) We include people with a learning disability, autistic people, families, carers, the organisations that support them and communities in our work.

#### This work

67. The aim of this work is to re-establish the Autism Local Working Group and support it to meet regularly with agreed priorities and focus. The intention is to ensure a diverse, committed, and stable group that is led by both council officers and Darlington residents with lived experience of autism.

#### The focus of this work will be to:

- 68. Engage with existing members of the working group to bring them back together across the year.
- 69. Help to establish the Autism Local Working Group in regular meetings and communications, with members working closely together on shared priorities.
- 70. Co-create a three-year autism strategy for Integrated Care Board, Tees and Esk Wear Valley Foundation Trust and Darlington Borough Council. This strategy will be co-produced

by the Local Working Group and will lay out a plan for improving life of autistic people in Darlington.

### This work will include:

- 71. Arranging and chairing bi-monthly in-person meetings for the Local Working Group.
- 72. Establishing a co-chair with lived experience of autism to ensure meetings are focused on the right things and that the voice of autistic people is amplified.
- 73. Working alongside the co-chair to establish agendas, prep for meetings and carry out follow-up.
- 74. Identifying and connecting with new potential members to join the Local Working Group.
- 75. Facilitating an initial session with previous members of the Local Working Group and new members to establish a plan for the year.
- 76. This will help Darlington to fulfil its responsibilities around the national autism strategy. It will ensure that the local autism strategy is rooted in the needs and hopes of autistic residents. It will also build a sense of collective endeavour and embed the plan in all council departments.

#### The Work

- Engage with existing Local Working Group members to arrange initial session.
- Create a calendar for bi-monthly meetings, lasting 2 hours, and establish a venue for these dates.
- Identify and collectively agree a co-chair from the Local Working Group. Create a plan for working together with the co-chair for effective collaboration.
- Co-chair Local Working Group meetings, create agendas and follow up each meeting.
- Support the Local Working Group in the creation of a 3-year autism strategy.
- Identify ways to hold the council accountable on the strategy and set review dates.
- Capture data and evaluation information to understand the impact of the Local Working Group and to understand how to improve its functioning.
- Drafting autism strategy and any other documents required for the Local Working Group and Partners.
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- Drafting autism strategy and any other documents required for the Local Working Group and Partners.

#### Time Involved

Across the year this would need:

- 9 days project worker time
- 5 days of regional manager time (this would drop to 3 days for year 2 & 3)
- 3 days of administrator time

## This would cover:

- 6 meetings a year (including prep, travel time, follow up, and co-chairing the meeting itself). Each meeting lasting 2- hours long.
- Initial engagement to re-establish group
- Engaging with potential new members
- Drafting strategy and other documents in-between meetings
- Working alongside the co-chair with lived experience.

#### Conclusion

77. In conclusion, the *National Autism Strategy* represents a significant step toward creating a more inclusive and supportive society for people with Autism. By setting out clear aims and objectives, the strategy seeks to address the specific needs of autistic people across multiple areas, including health, education, employment, and community inclusion. At its

- core, the strategy aims to reduce inequalities, improve access to services, and promote a society where autistic people can lead fulfilling and independent lives.
- 78. Implementing this strategy at a local level is crucial for achieving these goals. Within Darlington the local authority, health and social care providers, education providers, and employers play a central role in translating national objectives into practical, community-based support.
- 79. Our responsibilities involve developing autism-friendly policies, ensuring adequate training for professionals, and collaborating closely with people with Autism and their families to create tailored support plans.
- 80. We must be must also commit to ongoing evaluation and adjustment of out approaches, recognising that meeting the diverse needs of autistic people requires flexibility, innovation, and an inclusive approach.
- 81. The success of the *National Autism Strategy* hinges on its consistent, compassionate application at a local level with joint accountability and ensuring as a community we drive meaningful change, ensuring that people with Autism have the support they need to thrive.

#### 82. Climate Considerations

There should be no impact or increase in carbon emissions in relation to the actions of this reports.

All partners will consider how to reduce emissions as part of the development of the strategy and action plan.

The proposal will have no impacts on biodiversity.

The strategy will explore how to encourage and promote active travel, healthy lifestyles and wellbeing of people with Autism.

A key aim of the strategy is to support the employment opportunities for people with Autism. There will be active exploration to develop the opportunities locally.