

**Children and Adults Autism Update
'Think Autism in County Durham'**

Report of Denise Elliott, Head of Commissioning, Durham County Council, and Janet Crawford, Principal Educational Psychologist, Durham County Council

Purpose of the Report

- 1 The purpose of this report is to present an update on the development of an all-age approach to autism in County Durham, which encompasses:
 - a) The delivery of a revised 14+ Autism Strategy Implementation Action Plan
 - b) The strategic review for children and young people with complex social communication needs including autism and proposed Integrated Autism and Social Communication Strategy for County Durham.

Executive Summary

- 2 This report provides an update on the joint strategic approach to autism in County Durham across the age range involving Health, Social Care, Education and other partners.
- 3 The report and action plan has been presented for approval at the various Durham County Council Adults, Children, Young People and Health management teams, as well as to relevant Clinical Commissioning Groups and Tees, Esk and Wear Valley (TEWV) NHS Foundation Trust senior managers.
- 4 The report reflects the work undertaken by multi-agency planning groups, including engagement with stakeholders such as people with autism, parents, families, carers and providers.
- 5 The Autism Act 2009 required the Government to produce a strategy to make sure adults with autism get the help they need. Originally entitled *Fulfilling and Rewarding Lives*, the strategy was published in March 2010 along with statutory guidance for local councils and health

bodies. An updated strategy called *Think Autism* was published in April 2014. A formal review of the strategy is expected in 2019.

- 6 An Action Plan to implement this autism strategy in County Durham was first developed in 2014. A multi-agency Autism Strategy Implementation Group (ASIG), led by the Council's Commissioning service, oversees the development of the action plan, monitors its progress and coordinates the completion of the self-assessments.
- 7 The revised action plan, *Think Autism in County Durham*, is a working document, which is monitored and updated as required through the work of the ASIG. The action plan includes a section on Transitions and efforts have been made to include the needs of people with autism of all ages and align the Think Autism 14+ Strategy Action Plan with a proposed strategy action plan for children and young people with autism and social communication needs.
- 8 Following the Health and Wellbeing Board meeting in September 2018 it was agreed that there should be a combined 'Think Autism in County Durham' all-age strategy and action plan for 2018-20. This has been developed with both the ASIG and Children and Young People's Autism Steering groups (See Appendix 2).

Recommendation(s)

- 9 Members of the Health and Wellbeing Board are recommended to:
 - a) Note the contents of this report and next steps.
 - b) Note that the detailed all age action plan has been developed and is available on request.
 - c) Receive further information regarding the World Autism Day programme of events and consider the participation of Health and Wellbeing Board member organisations in these events.

Background

- 10 Autism is a spectrum condition that affects the way a person communicates and relates to others and makes sense of the world around them. People with autism may experience hypersensitivity or lack of sensitivity to sound, touch, taste, smell, lights or colours.
- 11 Approximately 1% of the population have autism and it affects individuals differently. Data from Public Health suggests that within the population of County Durham there is an approximate 1.1% prevalence rate of people on the autism spectrum.
- 12 Life with autism can be confusing, frightening and isolating. Autism is not a learning disability or a mental health problem and many people

with an autism spectrum disorder can be high functioning. However, mental health issues can be more common among people with autism and one in three adults with a learning disability are also thought to have autism.

- 13 This report provides an update on the joint strategic approach to autism in County Durham across the age range involving Health, Social Care, Education and other partners.
- 14 The report and action plan has been approved at the various Durham County Council Adults, Children, Young People and Health management teams, as well as to relevant Clinical Commissioning Groups and TEWV NHS Foundation Trust senior managers.
- 15 The report reflects the work undertaken by multi-agency planning groups including engagement with stakeholders such as people with autism, parents, families, carers and providers.

Previous Reports

- 16 On 20 March 2018, the Health and Wellbeing Board received a progress report on the statutory self-assessment feedback and the Autism Strategy Implementation action plan for County Durham, which relates to people age 14 years and over.
- 17 In May 2018, the Health and Wellbeing Board received a report on the process for transitions from Children and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) within Tees, Esk and Wear Valley (TEWV) NHS Foundation Trust. The report made reference to some children and young people with autism needing access to specialist mental health interventions.
- 18 For children and young people there is a Special Educational Needs and/or Disabilities (SEND) Strategy for County Durham (2015-2018). There is not a requirement for a separate Autism Strategy for children and young people, however, the need to complete a strategic review of children and young people with complex social communication needs (including autism) featured as part of the SEND Action Plan for County Durham. The strategic review and resultant action plan was presented to the Integrated Steering Group for Children in September 2018. Some revisions were suggested and amendments to the children and young people's elements of the plan were made.

Update on Progress

The National Adults Autism Strategy and the 14+ Autism Strategy Implementation Action Plan for County Durham

- 19 The Autism Act 2009 required the Government to produce a strategy to make sure adults with autism get the help they need. Originally

entitled *Fulfilling and Rewarding Lives*, the strategy was published in March 2010 along with statutory guidance for local councils and health bodies. An updated strategy called *Think Autism* was published in April 2014. A formal review of the strategy is expected in 2019.

- 20 Statutory guidance was updated in March 2015 and a new governance structure was published in March 2018 to oversee the two overarching national autism strategy objectives:
- a) Reducing the gap in life expectancy for people with autism.
 - b) People with autism are able to play a full role in society.
- 21 Progress on the national strategy will be measured within five domains incorporating nineteen overarching strategic objectives. The domains are:
- a) Measuring, understanding and reporting the needs of autistic people
 - b) Workforce development
 - c) Health, care and wellbeing
 - d) Specific support
 - e) Participation in local community
- 22 Local authorities and NHS bodies are required to carry out a statutory self-assessment against priorities set out in the national autism strategy. There have been four self-assessments to date since 2011. The results are analysed and published by the Public Health England's Learning Disabilities intelligence Team.
- 23 An Action Plan to implement this autism strategy in County Durham was first developed in 2014. A multi-agency Autism Strategy Implementation Group (ASIG), led by the Council's Commissioning service, oversees the development of the action plan, monitors its progress and coordinates the completion of the self-assessments.
- 24 County Durham's 2016/17 self-assessment feedback was reported to the Health and Wellbeing Board in March 2018. It demonstrated areas of progress (e.g. reasonable adjustments within general Council services; carer support; advocacy; training; access to information and support; and interfaces with employment, housing and the criminal justice system) and areas requiring improvement (e.g. data collection; diagnostic pathways and waiting times; crisis support and post diagnosis support/reasonable adjustments for people who have autism without a learning disability).

- 25 The action plan has been revised as part of the strategy development, following the latest statutory guidance and feedback from stakeholders, in response to the last self-assessment in 2016/17 and in preparation for the 2018 self-assessment, which was completed and submitted on 17th December 2018. This takes into account the Care Act and Children and Families Act obligations.
- 26 The revised action plan, *Think Autism in County Durham*, is a working document, which is monitored and updated as required through the work of the ASIG. The action plan includes a section on Transitions and efforts have been made to include the needs of people with autism of all ages and align the Think Autism 14+ Strategy Action Plan with a proposed strategy action plan for children and young people with autism and social communication needs.

Strategic review for children and young people with complex social communication needs, including autism and proposed Integrated Autism and Social Communication Strategy for County Durham

- 27 Until recently, the needs of children with autism have been dealt with separately to the adult autism strategy and are included in the Special Educational Needs and/or Disabilities (SEND) Strategy for County Durham (2015-2018).
- 28 Meeting the needs of children and young people with complex social communication needs is a high priority for the local area and this group was specifically referenced in the Local Area SEND Inspection 2017.
- 29 On available information, it is estimated that approximately 1,200 children and young people under 19 in County Durham have social communication needs and who might meet diagnostic criteria for autism. This does not include additional children and young people who do not fully meet the criteria for diagnosis but who may present with some autism traits and additional needs requiring support.
- 30 In August 2017 Durham County Council and partners completed a strategic review for children and young people (0-25 years) with complex social communication needs, including those with autism.
- 31 In December 2017, the findings and recommendations of the strategic review were reported to the Children and Young People Services Management Team and then the Healthy Child Programme Board in January 2018, where the following proposals were agreed:
- a) Develop an 'Integrated Autism and Social Communication Strategy and action plan for County Durham' based on the recommendations of the strategic review.

- b) Explore joint commissioning options relating to the action plan that will facilitate detailed planning relating to the risks and recommendations.
- c) Establish a 2 year time limited post, jointly funding through Health and the Local authority to identify priorities with key stakeholders and promote and develop this agenda.
- d) Adopt and promote 'Autism Aware' status across the Local Area, embedding the recommendation of this review, and link with the Adults autism strategy implementation with a view to working towards a joint planning approach.

32 Since the Healthy Child Programme Board meeting the Children and Young People Service Autism Steering group developed an integrated strategy and commissioning options plan outlining risks and recommendations. This was presented to Education SLT in June 2018 and the Integrated Steering Group for Children in September 2018.

33 This has now been combined with the 14+ Strategy Action Plan.

Developing a Combined Approach

34 Following the Health and Wellbeing Board meeting in September 2018 it was agreed that there should be a combined 'Think Autism in County Durham' Action Plan and an overarching all-age strategy for 2018-20. This has been developed with both the ASIG and Children and Young People Autism Steering groups (See Appendix 2).

Next Steps

35 The key leads for the Think Autism 14+ Autism Strategy and the Children's Integrated Autism and Social Communication Strategy will continue to establish an all-age collaborative approach to autism for County Durham with Clinical Commissioning Groups, TEWV and other key partners.

36 The elements of the Integrated Autism and Social Communication action plan that relate to children and young people, and also 14+ to adults will be filtered to support planning and progress monitoring within the two stakeholder steering groups.

37 Both action plans will be updated as further engagement work is undertaken with stakeholder groups and the autism self-assessment has been completed for submission in December 2018.

38 'Think Autism in County Durham' is to be promoted with service and stakeholders in time for World Autism Day 2019; this will be linked with the Think Autism Strategy implementation action plan.

39 Members of the Health and Wellbeing Board are recommended to receive further information regarding the World Autism Day programme of events and consider the participation of members of the Health and Wellbeing Board in these events.

Contact: Tricia Reed	Tel: 03000 269095
Janet Crawford	Tel: 03000 263333
Paul McAdam	Tel: 03000 268407

Appendix 1: Implications

Legal Implications

N/A

Finance

There may be a financial implication in terms of resource on further exploration of the actions

Consultation

All work is in co-production with multi-agency partners, people with autism and their families.

Equality and Diversity / Public Sector Equality Duty

Actions contained within the action plan to ensure compliance in relation to people with autism and their families/carers.

Human Rights

None highlighted

Crime and Disorder

None highlighted at this stage; needs in relation to criminal justice will be incorporate into the action plan.

Staffing

There may be a staffing implication in exploration of commissioning intentions from proposed action plan and capacity issues to fully implement the autism strategy in addition to other competing priorities.

Accommodation

None highlighted at this stage; housing and accommodation needs will be incorporated into the action plan.

Risk

There are a number of risks highlighted within the proposed action plan outlined as associated with gaps in provision and actions.

Procurement

Potential procurement on exploration of action plan and future commissioning intentions.

