

**Children and Young People's
and Adults Wellbeing and
Health Overview and
Scrutiny Committee**

19 December 2023

**Valuing Neurodiversity in
County Durham**



**Report of John Pearce, Corporate Director of Children and Young
People's Services**

Purpose of the Report

- 1 The purpose of the report is to provide members of Children and Young People's and Adults Wellbeing and Health Joint Special Overview and Scrutiny Committee with information regarding work undertaken through the Starting Well Partnership (SWP) to support families of our neurodivergent children and young people.
- 2 Whilst the main driver for the work is to support those awaiting assessment, there is no exclusion criteria and any changes and improvements made will also support children, young people and families where some neurodivergence may be present, but they are not on the assessment waiting list.
- 3 Likewise, families who have been through the assessment process will also benefit, regardless of the outcome of their assessment.

Executive Summary

- 4 There are currently 4000 children and young people waiting for a neurodiversity assessment in County Durham. The waiting times for children and young people under 18 is approximately 48 months, while the waiting times for adults 18 years and over is approximately just over three years. Tees, Esk and Wear Valley NHSFT (TEWVFT) provide an assessment service for both adults and children.

- 5 An updated all age Autism Strategy was presented at Cabinet on 13 December 2023, and a briefing report is being prepared for Children and Young People's Overview and Scrutiny Committee in early 2024.
- 6 The vision for the Valuing Neurodiversity project is to meet the needs of children, young people and families at the point of identification without having to wait for a formal diagnosis. This work is expected to take three to five years to complete and annual reports will be taken to appropriate groups. A project board has been set up with subgroups led by the most appropriate people across the system.
- 7 There are currently four key subgroups delivering work on:
 - Training
 - Communication and Engagement
 - Support Offer Mapping
 - Support in Schools Pilot

Recommendations

- 8 That Children and Young People's and Adults Wellbeing and Health Joint Overview and Scrutiny Committee receive the presentation.
- 9 Co-production is a key part of this work to ensure the help, advice and support available is what families need. Whilst we are closely engaged with Making Changes Together, our Parent/Carer Forum, the Joint Overview and Scrutiny Committee is asked to advise on ways to expand the reach of this aspect of the project.

Background

- 10 The Children and Young People's Overview and Scrutiny Committee requested information on the Valuing Neurodiversity work when developing it's 2023/24 work programme.

Valuing Neurodiversity in County Durham

Language and Terminology

- 11 The terms *Neurodiversity*, *neurodivergent* and *neurotypical* refer to differing ways the brain functions. The result of being neurodivergent can be difficulty functioning in modern society which can manifest in a number of ways. Some of these, such as Attention Deficit and Hyperactivity Disorder (ADHD) can be helped using medication. Some, such as Autism, cannot. Some conditions, such as Foetal Alcohol Syndrome Disorder (FASD), can present very much like autism or

ADHD but the root cause, and therefore any medications, are quite different.

- 12 Further information from The Brain Charity can be found [here](#).

Context

- 13 There are currently over 4,000 children and young people waiting for a neurodiversity assessment in County Durham. Tees Esk and Wear Valley NHSFT (TEWVFT) provide the assessment service for both adults and children. The children and young people's assessment looks at all neurodivergent conditions together, then the formulation process identifies (or not) the most appropriate condition relevant to the presenting behaviours of the individual child.
- 14 The waiting time for children and young people (under 18) is around 48 months. The waiting time for adults (18 and over) is just over 3 years.
- 15 TEWVFT operate a continuous improvement culture and, as such, are constantly looking to improve their services. However, they are hampered by a national increase in demand for neurodiversity assessment as well as recruitment and retention challenges for staff.
- 16 The updated all-age Autism strategy is being presented to Cabinet on 13 December and a briefing will be prepared for Scrutiny Committee in early 2024.

Vision

- 17 The vision for the Valuing Neurodiversity project is to meet the needs of our children, young people and families at the point of identification without a need to wait for a formal diagnosis. This requires all parts of the system (health, education, social care, families) to move away from a diagnosis-led model to a needs-led model.

Governance and timescales

- 18 It is expected to take 3 – 5 years from March 2023 to complete this work. Annual reports will be taken to appropriate groups. The work, and therefore sub-group structure, is expected to change on an annual basis.
- 19 A Project Board has been set up with sub-groups. The sub-groups are led by the most appropriate people from across the system. The project sits under the System Transformation sub-group of the SWP but also reports into the Mental Health, Learning Disability and Autism Partnership and the Think Autism Strategy Group. Presentations have also been given to the SEND Strategic Partnership and Making Changes Together Parent Carer Forum conference.

Current work

- 20 There are currently 4 key sub-groups delivering work
- a. Training
To identify the current offer, gaps and overlap then identify what, if any, additional training is needed. Training is for professionals and families.
 - b. Communications and Engagement
To ensure a co-produced project
 - c. Support offer mapping
To map and gap the support currently available
 - d. Support in schools pilot
Supporting the conversations families have with education staff when neurodivergence is first suspected. Funded from the Mental Health, Learning Disability and Autism Partnership until March 2024.

Conclusion

- 21 The Valuing Neurodiversity project aims to improve the help, advice and support available and accessible to families, children and young people, regardless of diagnostic status.
- 22 The whole-system project is long term, over 3 – 5 years, to deliver the culture change required to move from a diagnosis-led system to a needs-led system.
- 23 Initial work to identify available training, map current support available and support education setting staff is already underway.

Background papers

- None

Authors

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Appendix 1: Implications

Legal Implications

None

Finance

None

Consultation

None

Equality and Diversity / Public Sector Equality Duty

None

Human Rights

None

Climate Change

None

Crime and Disorder

None

Staffing

None

Accommodation

None

Risk

None

Procurement

None