

Healthwatch York Report: “Listening to Neurodivergent Families in York” January 2025.

Summary

1. This report is for the attention and action of Board members, sharing a report from Healthwatch York, in partnership with the Land, York Carers Centre, York Disability Rights Forum and Parent Carer Forum York which shares local experiences of families of neurodivergent children and young people.

Background

2. Healthwatch York provides information and advice about health and care services, signposts people to support, and listens to their experiences when accessing health and care services. Through our information and signposting service we have recently become more aware of specific challenges being experienced by families of neurodivergent children and young people.
3. When we visited the Land to hear more about their plans, we listened to their stories of navigating health and care. Alongside partners York Carers Centre, York Disability Rights Forum and Parent Carer Forum York, we agreed to bring these experiences together. We believe these will be helpful for the work the Public Health team is currently doing completing a Neurodiversity Health Needs Assessment.

Main/Key Issues to be considered

4. Our report’s key findings are:
 - Societal awareness and understanding of ND is still low, and parents experience stigma from friends, family and services.

- Parent blame is still often the first thing parents seeking help experience.
- Parent experiences are also worsened by poor administration and poor communication from services.
- Support is still focused in silos, with thresholds for support, making finding the right help for a range of lower-level issues challenging. Capacity in the system is overstretched, leaving many services looking for how to say “no” to providing a service.
- Some schools are still not considering the needs of neurodivergent children at times of transition. Others support transition well but do not maintain support beyond transition and fail to see the signs when a child begins to struggle.
- School behaviour charters often ask for behaviour that is impossible for neurodivergent children. This reinforces negative views many neurodivergent people already hold about themselves – that there is something wrong with them and they are not good enough. There is a significant challenge in setting behaviour codes that maintain a good environment for all pupils without punishing ND pupils. However, meeting this challenge is vital. Low self-esteem increases the problems many neurodivergent children grapple with, but there are many strengths associated with neurodivergence which need to be recognised, valued and celebrated.
- There is significant overlap between children who are neurodivergent and children who are gender questioning. Our systems are not geared up to support these young people. Many are asked to choose which they want support with and may also be advised to ‘hide’ part of themselves to receive support with the other element of their identity.

Consultation

5. In producing this report, we recorded the experiences and concerns of those who contacted our information and advice service, we asked partners to share case studies, and York Disability Rights Forum held a focus group gathering experiences along thematic lines.

Options

6. There are recommendations within this report set out on pages 77-79.

Implications

7. There are no specialist implications from this report.

- **Financial**

There are no financial implications in this report.

- **Human Resources (HR)**

There are no HR implications in this report.

- **Equalities**

There are no equalities implications in this report.

- **Legal**

There are no legal implications in this report.

- **Crime and Disorder**

There are no crime and disorder implications in this report.

- **Information Technology (IT)**

There are no IT implications in this report.

- **Property**

There are no property implications in this report.

- **Other**

There are no other implications in this report.

Risk Management

8. There are no risks associated with this report.

Recommendations

9. The Health and Wellbeing Board are asked to:

- i. Receive Healthwatch York's report,
- ii. Provide a response to the recommendations to be collated for the July Health and Wellbeing Board,

Reason: To keep up to date with the work of Healthwatch York and be aware of what members of the public are telling us.

Contact Details

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Chief Officer Responsible for the report:

Report Approved

Date 09.01.2025

Wards Affected: All

All

For further information please contact the author of the report

Background Papers:

Annex A - <https://www.healthwatchyork.co.uk/wp-content/uploads/2025/01/Listening-to-Neurodivergent-Families-in-York-January-2025.pdf>