



**inclusion
north**

Desire for a diagnosis

**Understanding family
carers need to access an
autism or learning
disability diagnosis for
their child in Newcastle**

July 2024

Executive Summary



InclusionNorth

Overview

[Collaborative Newcastle](#) is moving towards a needs-led approach to providing services and support for autistic children, children with a learning disability or other neurodiversity. This means that people can access support without the need of a formal diagnosis. [Inclusion North](#) was commissioned by Newcastle City Council to explore the reasons why parents and family carers commonly feel they need a diagnosis for their child despite this.

Inclusion North engaged with parents, family carers and professionals in the field to better understand the reality of seeking support for children both with and without a diagnosis. Inclusion North created a survey to capture peoples view and experiences on various points including:

- Why having a diagnosis for their child felt important,
- What barriers children & families face to accessing support,
- What support people experienced during and post diagnosis, and
- What support they would like to see.

Several key themes emerged. For parents and family carers, the importance of a diagnosis cannot be overstated. It provides essential validation, understanding, and a gateway to crucial services that support the child's development and family well-being. The diagnosis often leads to better school experiences, access to specialised services and a sense of empowerment for parents, family carers and their children.

Professionals also highlighted the importance of a diagnosis in providing clear explanations for a child's behaviour, which aids in reducing societal judgment and stress for families. However, they also acknowledged the inconsistencies in support depending on the child's diagnosis status and the variation in service delivery due to capacity constraints and funding issues.



The full report lays out some of the experiences of parents and family carers in accessing existing services and support, both with and without a diagnosis. It highlights the significant challenges faced by parent carers in Newcastle when seeking a diagnosis for autistic children and children with a learning disability. Based on the experiences shared by parents and family carers trying to access support for their children and the responses from professionals, below are recommendations and suggested actions that could help to improve outcomes for these families. These are aimed at Collaborative Newcastle.

Recommendations

- 1. Raise awareness and reduce stigma** of learning disabilities, autism and other neurodiversity.
- 2. Make information more accessible** for parents and family carers around support and services available.
- 3. Improve communication throughout the support and diagnostic process** to help parents, family carers and their children feel supported.
- 4. Improve training opportunities for parents and families** to develop greater confidence and to improve mental wellbeing.
- 5. Enhance training for professionals** to enable earlier identification of learning differences and support needs.
- 6. Increase extracurricular support for children** to ensure equal access to opportunities.
- 7. Promote a culture of collaboration** between services and VCSE organisations.
- 8. Co-produce a plan to tackle these issues with children, parents and family carers** to make sure that services and support meet their needs properly. "For us, By us."

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. We include people with a learning disability, autistic people, families, carers, the organisations that support them and communities in all our work.

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