

Neurodivergence Task and Finish Group Workshop

Parent Carer Feedback – January 2025

Introduction

The Department for Education (DfE) asked the Council for Disabled Children (CDC), in their role as Strategic Reform Partner for SEND, to develop and pilot a series of opportunities for parent carers who do not usually get the chance to speak with Government.

The aim of these sessions is for DfE to share information on a range of topics related to Special Educational Needs and Disabilities and Alternative Provision (SEND and AP) and to have the opportunity to hear about parent carers experiences of different aspects of the system and how these experiences can help inform DfE's ideas for making the system better.

The meeting held on 28 January 2025 was focused on the newly formed DfE Neurodivergence Task and Finish Group. The Department for Education (DfE) want to improve the support given to neurodivergent children and young people, particularly in mainstream schools and colleges. The feedback from the session is being shared anonymously with the Neurodivergence Task and Finish Group, which is made up of a range of experts, so they can hear what Parent Carers have to say on this important subject.

Methodology

The session was planned in collaboration with DfE and the Neurodivergence Task and Finish Group, structured as a 90-minute webinar with breakout rooms. The key areas of the discussion were focused on the following areas:

- Experience – what are the barriers you have experienced and what's working well?
- Support – what support have you received, or not received, for your neurodivergent child or young person in school?
- The interaction between school, health and social care – has this worked well or not?
- How could support be improved within mainstream settings for neurodivergent children or young people?

The breakout sessions were focused specifically on these 2 sets of questions:

- Breakout Room 1
 - **Questions:** What are your experiences of education for your neurodivergent child/young person? What has worked and what has not?
- Breakout Room 2
 - **Questions:** What are your ideas for change, to make education inclusive for neurodivergent children/young people? What changes are the most important?

32 parent carers attended the session. Additionally, a short survey of the questions was shared with a broader group of parent carers who couldn't attend the meeting, and **4**

responses were received. Annex 1 sets out the responses from the parent carers to the short survey that was shared.

Key findings

Key Themes on the Experiences of Education

There were 5 main thematic areas raised by parent carers in response to the breakout room questions, which have been outlined below – accompanied by 3 short case studies of parent carers who attended the session.

1. Communication and Support:

- One parent carer mentioned that it took a long time to get a social worker, and many parents don't trust social workers.
- There is a lack of transparency and information about the availability and criteria for short breaks.
- Several parents mentioned that they face a 'wait and see' culture in the early years, making it difficult to access timely early interventions and prevention approaches.

Case Study 1: Parent Carer to a Child with Autism, apraxia and ADHD

This parent shared that they faced difficulties in early years due to the "wait and see" culture. They emphasised the importance of early identification and regular training for schools. Their positive experience included having half-termly meetings with the school to discuss challenges and problem-solve together.

2. Challenges in Education:

- Teachers have varying levels of SEND knowledge, often relying on parents to educate them on how best to meet neurodivergent children's needs. There are clear gaps in teacher training on SEND and there is a lot of variation in understanding neurodivergence.
- Many parents commented that EHCPs are often inadequate, lack ambition, or are difficult to secure.
- The move from primary to secondary school is a very stressful transition for a lot of neurodivergent children and young people. It often results in a loss of support, and creates a move from a smaller school environment to a much larger, more overwhelming school environment. Many mainstream secondary schools are difficult for neurodivergent children to navigate, due to overwhelming sensory environments, strict timetables and 'itchy' uniforms. This can create school-related trauma, which makes engaging with school going forward very difficult for some neurodivergent children.

- There needs to be more tailored support available in mainstream secondary schools, including more reasonable adjustments and flexibility. There is still far too much focus on attendance in mainstream secondary schools.
- Many parents argued that mainstream schools are always not going to be suitable for all neurodivergent children, and there needs to be more specialist school places available.

Case Study 2: Parent Carer

One parent shared a positive experience with a school that provided full-time 1:1 support before receiving funding from the local authority. The headteacher's background in special education contributed to the inclusive practice. This case study highlights the importance of having a supportive school leadership and the willingness to provide necessary support.

3. **Impact on Families and Parental Blame:**

- Parents often have to fight for recognition of their child's needs and are sometimes accused of fabricating illnesses. In addition to parental blame, the lack of adequate support and respite impacts the health and well-being of parents. The combination of these factors creates burnout amongst parents, which can sometimes lead to families presenting in crisis.
- Parents often feel humiliated and demeaned by the process of applying for support such as short breaks. One parent described the process as demeaning, soul-destroying, and humiliating.
- There are always going to be differences in parental capacity to challenge and understand the system, and there needs to be greater recognition of this within the SEND system.

4. **Reliance on Charities and Community Support:**

- Due to inadequate local authority provision, many families rely on local charities for support.
- A few parents mentioned that community support is crucial to them as a family, and they receive a lot of support from other families and parent carer networks. They pool resources and learnings, and this has been invaluable to helping them cope with the SEND system.

5. **Post-16 and Further Education Challenges:**

- Many children lose funding, assistance and/or support when transitioning to college or sixth form.

- The existing system does not adequately support young people beyond secondary school. There is a clear cliff-edge for neurodivergent young people at 16, and again at 18.

Key Themes on Ideas for Change

There were 5 main thematic areas raised by parent carers in response to the breakout room questions, which have been outlined below – accompanied by 2 short case studies of parent carers who attended the session.

1. **Child-centred approaches and Flexibility:**

- There needs to be a clear move away from a one-size-fits-all approach in mainstream education - this approach is failing neurodivergent students. There needs to be greater emphasis on adopting individualised, child-centred strategies that acknowledge different learning needs.
- It is important that mainstream primary and secondary schools teach children that everybody is different, and that is built into the school culture and teaching approach.
- Alternative learning models, such as Montessori and vocational learning, should be explored and integrated into the mainstream education system where possible.
- It is important that mainstream schools are flexible and utilise progressive education models.
- Schools should embrace neurodiversity rather than medicalise it—moving away from “deficit-based” language and stigma.

Case Study 3: Parent Carer

One parent emphasised the need for flexible education options, such as online schools and self-directed learning settings. They shared how their child thrived in a more flexible and individualised learning environment, which allowed them to pursue their interests and learn at their own pace.

2. **Teacher Training and Accountability:**

- There are significant gaps in teacher training regarding neurodivergent conditions (e.g., autism, ADHD, dyslexia). This needs to be addressed via mandatory training on neurodiversity, including PDA (Pathological Demand Avoidance), for all staff.
- Mandatory training needs to be followed up with monitoring and accountability, to ensure inclusive teaching practices are being implemented effectively.

- One parent shared that schools that acknowledge their lack of expertise and meaningfully engage with parent carers tend to be more effective in supporting children.

Case Study 4: Parent Carer

The Specialist Autism Support Service in Bath and North East Somerset was mentioned as a successful initiative. This service supports autistic children and young people up to the age of 25 by providing school training, parent groups, and direct support to children. This case study highlights the importance of specialized services that offer comprehensive support to both children and their families.

3. Systemic Issues:

- There needs to be clearer guidelines and standardised terminology across the SEND system in relation to education. This would help prevent misunderstandings between parents and schools. This is particularly important in relation to EHCPs.
- Schools need to be transparent with parents, and ensure that they are meaningfully co-producing with parents where possible to improve the experience of neurodivergent children at mainstream schools.
- The bureaucratic and adversarial nature of the system forces parents to fight for support. This needs to be addressed, to ensure that parents aren't continually feeling blamed for their child's difficulties.

4. Transition Support & Flexibility in Learning Pathways

- Key transition points (e.g., primary to secondary school) are often poorly managed, leading to student disengagement and increased anxiety.
- Post-16 education should offer a greater variety of pathways, including more vocational and project-based options.
- Schools need to provide more flexibility in subject choices, learning styles, and attendance policies to accommodate neurodiverse students.
- Homework policies should be reconsidered—tasks that take a neurotypical student 30 minutes may take a neurodivergent student three hours.

5. Individualised and Strength-Based Approach:

- Transition planning should focus on the strengths and aspirations of young people, rather than just their limitations. Parents emphasised the need for a strength-based approach and to focus on what young people can do, rather than forcing students into subjects they struggle with.

- A personalised approach is crucial, recognising that each family's needs are different. Parents highlighted the importance of personalising support to meet the unique needs of each family. The current curriculum is too rigid and content heavy.
- Schools should provide multiple forms of assessment beyond traditional exams (e.g., project-based learning, practical skills). Self-directed and interest-led learning approaches should be also explored as viable educational models.
- Schools should deprioritise attendance statistics and instead focus on student engagement and wellbeing.
- Uniform policies should be flexible, accommodating sensory sensitivities.
- Schools should invest in creating sensory-friendly environments with trained staff to support students.

6. Alternative Provision and Structural Changes

- Mainstream schools should have integrated specialist hubs to prevent children from reaching crisis points before alternative provision is considered.
- Floating specialist teaching assistants should be employed within mainstream schools to support neurodivergent students.
- Multi-agency working (health, education, social care) must improve, as current communication breakdowns place unnecessary stress on families.
- The multi-academy trust (MAT) system may not be beneficial for neurodivergent students—more oversight and flexibility are needed.
- Local Authorities should be held accountable for delays in support, including Educational Psychology assessments.
- Funding should be ring-fenced to ensure money allocated for SEND students is actually spent on their support.

Case Study 4: Parent Carer

A parent discussed the benefits of alternative provision, such as outdoor education and vocational curriculums, as early intervention to reduce disengagement. They mentioned the importance of having flexible schooling options, such as flexi-schooling in secondary schools, to cater to the diverse needs of neurodivergent children.

Evaluation

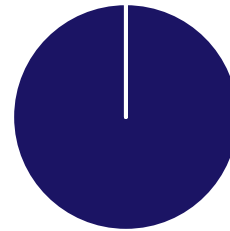
17 parent carers filled out the evaluation form that was shared after the meeting. The full PDF of responses is attached in Annex 2.

Which region are you from?



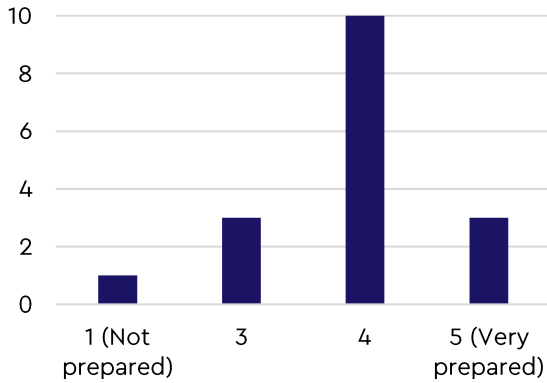
- East of England
- East Midlands
- West Midlands
- North West
- South West
- South East
- Yorkshire and Humber

What ethnic group best describes you?

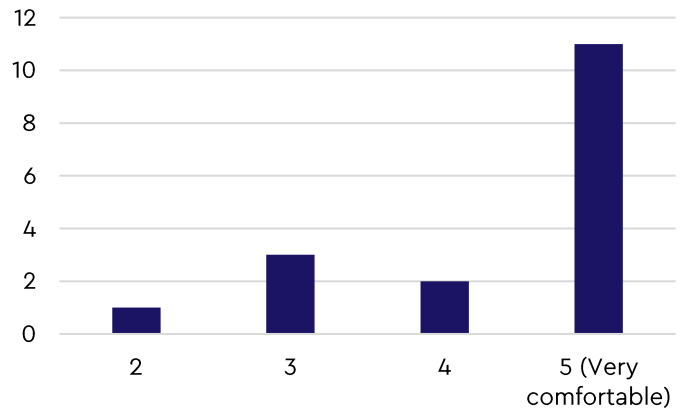


- White British

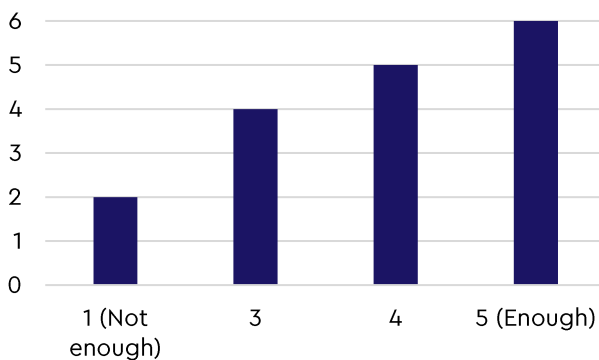
How prepared did you feel before the meeting based on the information you were provided?



How comfortable did you feel sharing your views?



Did you feel the presentations gave enough information?



Would you be happy to attend future meetings?

