



Disabled  
Children's  
Partnership

# **SUPPORT ISN'T OPTIONAL**

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**Why Every Child with  
SEND Needs a Legal  
Guarantee**



# **Support isn't Optional: Why Every Child with SEND Needs a Legal Guarantee**

Survey – Parent Carers of  
Disabled Children and Young  
People, 0-25 years.

Research by the Learning Hub at the Disabled  
Children's Partnership

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# 1. Summary

Government's upcoming schools white paper will lay out its plans to reform the Special Educational Needs and Disabilities (SEND) system. Reviews of the current SEND system, introduced in 2014 as part of the Children and Families Act 2014<sup>1</sup>, have concluded that it is too often a negative experience for children, resulting in poor outcomes for them and their families<sup>2</sup>.

Children and young people with special educational needs or who are disabled want the same ordinary things that other children can take for granted, such as a nursery, school or college place where they are happy, feel like they belong and can achieve. Parents also want the same ordinary things as other parents, such as getting the support their children need without an unnecessary fight. However, this is not the reality that families currently face.

In January 2025, the Public Account Committee<sup>3</sup> reported the current system is unviable and at risk of creating a lost generation of children without reform. Good outcomes for children and parental confidence is cited by the committee as a key indicator of a good system that supports SEND children effectively. Therefore, during December 2025 and January 2026 the Disabled Children's Partnership conducted an online survey of Parent Carers of disabled children and young people, aged between 0-25 years in England.

The aim of the survey was to understand parents' experiences of the support available to their children in their education or training setting, and explore positive approaches that should be included in a reformed SEND system. Just under 1500 parents or carers responded to the survey. We are grateful to all those who took the time to tell us about their experiences.

## 1.1 Key Findings

Our survey confirms that parents do not have confidence in the current system. Despite 62% of parents having children who have Educational Health and Care Plans (EHCPs), legal documents that detail their support across education, health and care, they do not feel their child receives the support to reach their potential or access to the specialist support they require.

- almost half (47%) do not get sufficient support to safely care for their child from education, health or social care.
- 2 in 5 do not think their child receives the right amount of support to reach their potential.

Parents accounts illustrate the distance that exists between the support their children need and what and how it is provided. There is some way yet to go, to ensure the SEND system is underpinned by a culture that values disabled children and young people and gives them a sense of belonging and access to support that allows them to reach their long-term goals.

- 47% do not feel their child attends a setting with access to specialist staff they need to meet their needs.

- 1 in 4 (27%) do not feel their child is safe at school or their setting due to the level of support they receive.

*My child has lost faith in the system, she does not believe that anyone believes in her or cares about her other than myself. She has lost over two years of education when she was on track for high GCSE passes. I now doubt she'll even be in a position to take any. She feels hopeless about her future and I feel broken and exhausted*

Parents do not have confidence in the system. Their experiences with staff and decision makers across organisations have eroded their trust in commissioners and providers responsible for their child's support.

- 3 in 5 (57%) feel they have been lied to by authorities who are meant to support their child.

*Local authority staff have lied, and deliberately and routinely break the law. They refuse to progress complaints or mediate. They ignore emails and abuse the tribunal process. They abuse families who try to hold them to account.*

This lack of support leads to half of parents reporting poor mental health and 39% reporting poor physical health, with 37% giving up their employment or career.

*I have had to reduce my working hours. It puts an immense strain on us as a family mentally, emotionally and financially. Over 8 months with no provision. I am broken. We are broken.*

Parents also told us about approaches and the type of support that would work for their children and should be included in upcoming reforms. There was a strong call for legal duties to be extended to all children with SEND, with a strong SEND system to include approaches underpinned by a whole school approach to inclusivity not just for learning but across activities that instil a sense of belonging.

- 98% of parents think there should be a legal guarantee that every child with SEND gets the support outlined in their written record.
- 94% parents think that all children with special educational needs and / or disability should have a written record of support

## 1.2 Recommendations

The findings from our survey emphasise that reform of the SEND system is paramount to ensure the generation of disabled children and young people can achieve what they want in life. The Government has set out five principles for SEND reform. That support should be early, local, fair, effective and shared. It states children should receive support they need as soon as possible and it should be local, close to their home. All schools should be resourced to meet needs and be able to adapt as they change, with support grounded in evidence to promote good outcomes for children, with effective partnership across education, health and care.

In response to our findings, we are calling on Government to ensure that the upcoming reforms:

- provide a legal guarantee of support for every child who needs it, so that accountability is baked into the system and fosters trust.
- strengthen SEN Support in mainstream schools by giving it statutory force.
- ensure nurseries, schools and colleges are set up for children with SEND, with the right training for staff, access to specialists and support from properly functioning multi-agency partnerships between the Local Authority and NHS in order to rebuild trust between families and authorities meant to support them.
- ensure reform delivers earlier help, not fewer rights;

Reform of the SEND system must mean stronger support, earlier intervention and enforceable rights. Anything less risks deepening the crisis and failing a generation of children.

## 2. Detailed Findings

### 2.1 Introduction

The DisabledChildren’s Partnership conducted an online survey, between 16th December 2025 and 19th January 2026, of parents and carers of disabled children and young people in England. The aim of the survey was to understand parents’ view of support available when their child is at their education or training setting, such as nursery, school, college, apprenticeship or university.

The Disabled Children’s Partnership, a coalition of more than 130 organisations that campaign for improved support for disabled children, young people and their families<sup>4</sup>. For the purpose of this report, disability is defined, as per the Equality Act 2010, as a physical or mental impairment that has substantial and long-term negative effect on your ability to do normal daily activities.

### 2.2 Who took part in our survey?

A total of 1480 parents or carer took part in the online survey. A quarter of parents have more than one disabled child. Children had an average of five disabilities 3 in 5 (60%) respondents had a disabled child at school ages (5-10 and 11-15 years). The majority (69%) of parents had two or more children in their family.

Just over half of those responding to our survey had children in a mainstream (30%) or special school (26%), with 13% of young people attending a post-16 college or training setting. However, 9% did not have an identified place or could not attend their setting due to a lack of support. In addition, a further 6% are home educated or educated other than at school (EOTAS). A further 3% attended independent school with 2% attending each of the following settings: learning hub or resource base, alternative provision or pupil referral unit, early years provision, residential school or college and 1% at University. Additional demographic information is available in Appendix One. The findings from the survey explore parents’ confidence in the SEND system, and their views of the support they receive at their educational or training placement. It also outlines the impact that the lack of support has on parents and their views on approaches that a reformed SEND system should include.

### 2.3 SEND System

The vision for children with SEND, as laid out in the SEND code of practice<sup>5</sup> is the same as the expectation for all children, that they achieve throughout their educational journey and lead happy and fulfilled lives.

*Figure 1: Who are the 1.7 million children with SEND?*

- Autistic children
- Children with learning disabilities, such as Down’s Syndrome
- Children who are physical disabled
- Children with lifelong speech and language challenges
- Children with life-long chronic conditions or life limiting illnesses
- Children with hearing or visual impairments
- Children with mental health conditions

It aimed to create a system with less confrontation, with children and young people and their parents or carers central to the decisions about their support. The current SEND system consists of a two-tier system, with children receiving SEN support or an Education Health and Care Plan (EHCP).

An EHCP is a legal document that outlines a disabled child's needs and details provision to be co-ordinated across educational, health and/or social care. As part of the process, children's needs are identified and assessed with the plan drawn up, reviewed annually as children's needs change or their outcomes are met. The majority of parents responding to our survey had children who had an EHCP (62%) and 24% received SEN support. However, 1 in 7 parents responding told us that their child had an EHCP, but the provision outlined in it was not provided.

In contrast to a SEND system that co-ordinates support across education, health and/or social care, almost half (47%) of Parent Carers taking part in our survey told us that they do not get sufficient support to safely care for their child (from education, health or social care). In fact, almost 3 in 5 (57%) parents feel they have been lied to by authorities who are meant to support their child. This ranged from providing parents with poor information, gatekeeping access to services, through to failing to adhere to legal responsibilities. Parents provided examples from their interactions with local authorities, school staff, social care-teams or health services.

*Local authority staff have lied, and deliberately and routinely break the law. They refuse to progress complaints or mediate. They ignore emails and abuse the tribunal process. They abuse families who try to hold them to account.*

*The entirety of their internal processes are not transparent. They refused to conduct an emergency EHCP review at the point of placement breakdown and continue to ignore me.*

*His primary school told me not to pursue an EHCP as I wouldn't get it because my son is too clever. I was discouraged and due to that his care was delayed and he missed nearly a full year of school*

*When my daughter was very young, I asked support from Social Services but I was told that my daughter is too young and hence my responsibility.*

## 2.4 Education or training setting

To have confidence in the SEND system, parents also need to feel confident in the setting their child attends in providing the support that they need, whether that be a nursery, school, college or training placement. Parents report delays and constant battles with the current system to obtain a suitable place where their child can thrive. A third (32%) of parents do not think their child attends the right setting to meet their overall needs (learning, support for their disability/ condition, socialisation).

Delays identifying children's needs in the classroom mean they remain unsupported and at risk of their needs escalating. Without the correct consistent support in place throughout the day, children are not in a position to learn or join in educational

opportunities that their peer group have access to. 2 in 5 (42%) parents report that their child does not receive the right amount of support at their setting to ensure they reach their potential.

*No flexibility in curriculum, so she sat in classes she didn't need to be in because they had no support elsewhere in school but she wasn't put in for subjects at GCSE. She was also left unsupervised in the gym area with a physical disability that limited mobility.*

*He is currently 17 years old and taking GCSE'S this year. Before his burnout his was predicted 9 GCSE'S at grade 6 and above. Now he will barely get 5 GCSE'S at grade 4 due to the trauma of the education system. This trauma also means he never returned to school and has missed out on vital social development.*

*He has missed significant learning and loves to learn. Sense of lostness and confusion at how life has changed. Confirmation of autism at end of year 8.*

Disabled children or young people may sometimes need more help than their peer group when attending an education or training setting. For example, they may need equipment to move around or to communicate with their friends or staff. A teaching assistant might provide support in the classroom or helping when moving around the school. In addition, disabled children may require access to support with personal care, support to take medication. They might need access to specialist interventions such as physiotherapy, occupational therapy or speech and language therapy.

However, our survey revealed that 1 in 4 (27%) do not feel their child is safe at school or their setting due to the level of support they receive. Examples were provided across the age range of children and the type of setting they attended:

*My child is not attending nursery due to lack of trained staff to effectively suction him. This means we have to stay nearby and be on call. This means we don't really have a break from our caring role.*

*[At primary school] There was not sufficient support for him, so he was not able to go. The difference with 1-1 support at high school means he has been in every day, all day. He was also so stressed and couldn't eat, so we were nearly at tube feeding. High school support has been life changing for him and the rest of the family.*

*My eldest was treated as Children Missing Education for approximately nine months, including a period when an EHCP was in place, yet no education, support, safeguarding oversight, or reintegration planning was provided, despite his known vulnerabilities. As a result, his mental health deteriorated significantly, culminating in suicidal ideation and an acute crisis, requiring constant parental supervision to maintain his safety. He has been unable to return to school, and mainstream education is no longer viable due to trauma and loss of trust.*

If disabled children are not attending the correct setting, it is not inclusive or fails to provide reasonable adjustments, life throughout the day becomes difficult. Children feel isolated from their peers and do not feel part of the wider school community.

Wider research shows the importance the school environment plays in facilitating friendships for disabled children<sup>6</sup>. In particular, when accessible activities may be sparse in their local community or they spend long periods travelling to schools or colleges outside of their local community, there is less opportunity to spend time socially with their peer groups and make friends. Sadly, 1 in 4 (26%) parents told us that their child has not made friends at their setting.

*The mainstream school my son was accepted at in the April decided they would not meet his needs, 2 weeks before a formal diagnosis and 3 weeks (end of June) until the summer holidays, meaning he missed his first year of formal school education.*

*He struggles with other kids and feels overstimulated and stressed in school. He had to stop doing sports because he is exhausted, and that's affected his sleep, which is now a cycle that's hard to break.*

Parents also reported examples of their child experiencing punitive measures as a consequence of the correct support or inclusive practices not being in place. 2 in 5 (42%) parents report that their child has received an unfair sanction or punishment at school because they have a special educational need or disability.

*It's meant the college tries to impose threats of sanctions even though they're not putting agreed support in place to prevent son getting overwhelmed*

*My child has chronic illnesses that mean simply 'getting them back in' is not an option. They need long term flexibility as they are often too ill to study and that is unlikely to change anytime soon. This has meant they were left with no education for 3 years and I had a lengthy battle to get them educational*

If disabled children do not experience reasonable adjustments and instead encounter a rigid curriculum, inflexible assessments, punitive measures and do not feel part of the wider school community, they are less able to attend education or training. It was common for parents to report reduced attendance due to the lack of support available. Our survey found that just a third of parents felt that their disabled child's attendance was ok. In addition, 1 in 4 (26%) parents reported that their child is persistently absent (more than 4 weeks absence per year), with 1 in 8 missing more than 24 weeks or 2/3 of the school year.

*My child has been out of school for 2 years. He had a complete breakdown due to school ignoring his needs even though I had been meeting with them for 2 years about his difficulties. It has taken him 12 months to adjust and start working with a tutor at home. He struggles to leave the house. I had to give up my job to care for him*

*Initially our child put their attendance first and pushed through physical disability for a long time before realising that the school did not care for their education, just their attendance.*

*He had letters from doctors and physios asking for a reduced timetable when his condition first flared up in March but school refused so he ended up with no education until October. My son is in mainstream and very bright child. His disability is physical and medical. School have refused to do an EHCP referral as they say he*

*is too bright, but then also say they have no-one to meet his medical needs for him to be in school.*

There are clear examples of reduced attendance instigated by settings, which also adds to the challenge of making friends or feeling part of the school community and subsequently has a direct impact on family life.

*School will only have my son there from 9.20-11.15 every day as they cannot meet his needs. It has been this way from him starting in reception and he's now in year 2. I cannot work any more than 10 hours a week due to this.*

*Child is reluctant to attend school, feels isolated from peers from not being able to attend full time. Misses out on parts of school from not being able to cope and has to leave early.*

*He's so emotionally burnt out after school that we've had to stop after schools clubs and finish work early.*

In addition to the approach taken by education or training providers, parents also need confidence in the staff working with their children. This included understanding of their child's needs, that they were well trained and when needed that their child had access to appropriate specialist support. Sadly, a third (31%) of parents responding to our survey do not feel that their child attends a setting with staff trained to meet their child's needs.

This reflects findings from wider research around the lack of SEN teacher training. Research commissioned by TES reported that 68% of primary school teachers and 61% of secondary teachers feel prepared to teach children with special needs<sup>7</sup>. In addition, further research found that Initial Teacher Training providers are concerned about teachers' readiness to support pupils with SEND<sup>7</sup>, with condition specific research also confirming the mis-match between what children and young people need and what staff may provide<sup>9, 10, 11,12,13</sup>.

For those who need access to specialist staff such as speech therapists or occupational therapists, the findings show a clear gap in provision. Almost half (47%) of parents do not feel their child attends a setting with the specialist staff they need to meet their needs.

*Although school meets my child's needs there is a lack of support for my child's mental health. This is an ongoing issue and has meant that I have to pay privately as CAHMS is not fit for purpose (refused many referrals). This has had an impact on my child's attainment due to missed school.*

*My daughter has not sat any assessment or exams since she began high-school, only SALT and EP assessments. I have to take her to her Alternative Provision as she's not independent enough to go to it alone so this has meant more time out of my business, taking and picking her up. [more than 120 days]*

## 2.5 Impact of lack of support on Parents

The culmination in inadequate support means that half of parents have poor mental health, 2 in 5 (39%) have poor physical health, with 1 in 4 (25%) unable to work due to carer burnout.

*Because of the lack of support our son has ended up in psychiatric ward for 6 months. It was the most traumatic time for him and us as his parents.*

*My partner has been severely unwell for the majority of 2025 and is still recovering, whilst also looking after a newborn baby (now 6 months). The additional unexpected childcare has made it difficult for her to attend to the newborn's needs as well as the older child's complex additional needs, whilst also being unwell. I have had to work remotely for the majority of the time....this has put my job at risk at times and has seriously affected my own mental health.*

*If I have any more sick time before September 2026 I can be dismissed. My Employer no longer offers carers leave either. I don't have any annual leave left and my husband is in the same boat.*

As parents plug the gap in support, and with their mental and physical health suffering it is not surprising that parents face barriers to employment.

- 37% have given up their employment or career
- 34% have to reduce the hours they work
- 31% have to rely on benefits
- 22% have changed jobs for more flexibility  
*I had to leave employment to fully support my child, her mental health was at rock bottom, she cannot do even the things she used to enjoy*

*It is impacting my employer's trust that I am a reliable and trustworthy member of staff. I have had to cancel key commitments and ask for additional support. I fear I will lose my job in the future. My child struggles to transition back to school and it impacts his sleep and regulation also.*

*Maintaining support is a constant worry as funding cuts and reduction of staff puts SEND support in jeopardy*

The additional pressure that reduced or lack of employment brings to a family means that 1 in 5 (18%) parents report that their relationship has broken down due to a lack of support for their child.

*My marriage has ended due to the stress. My child has had no education for the majority of the last year. They now attend 4hrs of health-related provision, but this is for a maximum of 12 weeks and nothing is being put in place for after this ends. It has put a massive strain on our marriage. It has impacted my ability to sustain my own friendships and I'm now in an incredibly isolated place with very few people understanding what's going on.*

## 3. Solutions

Our survey also canvassed views from parents with disabled children about approaches that would mean that their children are able to experience the same ordinary things that other children take for granted. For example, a nursery, school or college place where they are happy, belong and can achieve with the opportunity to make friends and take part in activities and clubs during and after school.

### 3.1 Legally Guaranteed Support

The Children and Families Act placed duties on the local authorities to secure special educational provision, health and care in accordance with the needs identified in children's EHCPs. EHCPs are legal documents completed following an assessment of need, with provision and intervention included in the plans to enable children to achieve positive outcomes. In the current SEND system, SEN support is not on the same statutory footing as EHCP.

However, 98% of parents taking part in our survey told us that they think there should be a legal guarantee that every child with SEND gets the support outlined in their written record. This would extend existing rights and protections to all children with SEND. 94% of parents think that all children with special educational needs and/or disability should have a written record of support. This record would record the support they should receive, how it should be monitored and reviewed.

At present parents are faced with a postcode lottery when accessing support for their disabled children. 67% of parents think that written records of support for children with SEND should follow a national format. A national format would stop the customary postcode lottery. Parents highlighted that support included in individual records should be specific and measurable.

*A standard EHCP should expressly stating services - none of this "access to" wording but clear statements, e.g. "5 hours of Speech and language therapy per term.*

*It is important that as with non-disabled children, standards of care and support are set at a national level so that all local authorities and schools understand what a good baseline and good support looks like for a SEND child and so that it is embedded culturally. This is what a SEND child deserves and can expect and no less.*

### 3.2 Approach to Inclusive Provision

On a practical level, parents were asked for views on how their child could be better supported in education or training. There are implications for the workforce and investment in the SEND system from the findings below. The type of support parents reported as beneficial to their child's learning or to enable them to reach their potential includes smaller group sizes and increased 1:1 support, specialised support or trusted adult (pastoral support such as a mentor).

The type of support parents report as beneficial to their child's learning or enabling them to reach their potential is as follows:

- 72% smaller groups
- 68% 1:1 support
- 58% Access to quiet areas
- 55% Flexibility with sensory toys
- 50% Specialist support within their week
- 48% Pastoral support
- 48% Visual Support Aids
- 43% Adjustments to school timetable
- 39% Access to assistive tech/devices
- 35% Adjustment to uniforms

Similarly, approaches that parents reported beneficial to help their child make friends and improve attendance on the whole rely on a whole school approach to SEND, with better training and understanding of children's needs across the workforce.

Parents reported that they felt the following approaches would help their child make friends.

- 73% Staff supporting pupils to make friendships
- 70% Activities to encourage children to make friendships
- 55% Provision of accessible activities
- 45% Buddy system
- 35% Same opportunities to play and socialise at breaks and lunchtimes as their non-disabled peers

Parents felt the following approaches would improve their child's attendance:

- 90% Better understanding of their child's needs
- 77% Improved SEN training for staff
- 72% Specialist support within their week
- 57% Access to quiet areas, small groups and corridor passes
- 44% Flexibility of sensory items
- 43% Adjustment to school timetable
- 36% Access to assistive tech, up to date equipment and devices
- 35% Better approach when returning to school
- 33% Adjustment to uniform

Of those parents who reported that their child did not attend a setting with staff trained to meet their needs or access to specialist staff they needed, the following approaches would improve their child's level of support and experience:

- 3 in 4 (76%) Access to specialised staff
- 3 in 4 (75%) Teams that work together to share knowledge about my child's needs

- 7 in 10 (73%) Whole school staff training
- 7 in 10 (72%) Staff that listen and act on their child's views
- 7 in 10 (70%) Staff that welcome input from parents
- 7 in 10 (68%) Staff that set realistic and aspirational targets for my child
- Almost 7 in 10 (66%) Staff trained in evidence-based approaches
- 3 in 5 (60%) Adequate ratio of special educational needs co-ordinators (SENCOs) to number of disabled children at the provision

## 4. Conclusion

Our survey findings demonstrate a SEND system failing to meet children's needs. It is clear that Parents' do not have confidence in the current system. Almost half report that they do not get sufficient support to safely care for their child from education, health and social care. 2 in 5 do not receive the right amount of support at their setting to ensure they reach their potential and lack of support impacts their children's sense of belonging, their friendships and attendance. The lack of support available for children leaves parents plugging the gaps, with a detrimental impact on their mental and physical health. It also restricts their employment opportunities, with 37% giving up their employment or career.

It is evident that a whole school approach to the SEND workforce is needed to ensure children are supported by staff who understand their needs and trained in evidence-based interventions to support them. It is also imperative that when a specialist need is identified, children have access to support from specialised staff in a timely manner.

The overwhelming agreement that parents want legal guarantees extended to all children with SEND, exemplifies the urgency with which a reformed SEND system is needed. We are calling on the government to:

- ensure nurseries, schools and colleges are set up for children with SEND, with the right training for staff and support from properly functioning multi-agency partnerships between the Local Authority and NHS
- provide a legal guarantee of support for every child who needs it;
- strengthen SEN Support in mainstream schools by giving it statutory force;
- ensure reform delivers earlier help, not fewer rights;

Reform must mean stronger support, earlier intervention and enforceable rights. Anything less risks deepening the crisis and failing a generation of children.

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## Appendix One - Demographics

### Number of disabled children

- 1 disabled child 76%
- 2 disabled children 20%
- 3 or more disabled children 4%

### Age of disabled children

- 5 years and under 5%
- 6-10 years 26%
- 11-15 years 34%
- 16-19 years 22%
- 20-25 years 12%
- 26 years and over 0%

### Size of family

- 1 child 44%
- 2 children 31%
- 3 or more children 25%

### Parent Type

- Mother 86%
- Father 8%
- Grandparents 4%
- Non-parent guardian 1%

### Type of disability or condition \*more than one applies

- Autism 80%
- Social, emotional and mental health needs 57%
- Speech, language and communication needs 51%
- Learning Disability 42%
- ADHD 41%
- Physical Disability 20%
- Multi-Sensory Impairment 21%
- Genetic Conditions 17%
- Life-Limiting Conditions 7%
- Undiagnosed or newly acquired disability 7%
- Acquired Brain Injury 6%
- Hearing Impairment 6%

### Type of Support \*more than one may apply

- EHCP 62%
- SEN Support 24%
- EHCP but provision is not provided 14%
- No support in place but should have 9%
- Applied for an EHCP (awaiting assessment) 0%

- or outcome of assessment) 8%
- Currently appealing to SEND Tribunal 6%
- Waiting to see Educational Psychologist 5%

### **Ethnicity**

- White Asian Black Mixed 85%
- ethnic minority groups 5%
- \*4% did not declare 3%
- 3%

### **Region**

- South East 21%
- London 21%
- South West 13%
- North West 12%
- East of England 10%
- Yorkshire & Humber 8%
- East Midlands 7%
- West Midlands 7%
- North East 4%