



From crisis to care – making social care work for disabled children

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Foreword

Getting the right support to thrive as a child shouldn't rely on luck. But right now, that's the case for 1.8 million disabled children and their parents across the country who are being let down by the government.

Access to high quality support can be life changing. It is the difference between a child feeling lonely and disconnected from their community, with limited opportunities to try new things, and a child having the support they need at home to grow, learn and thrive. It is families getting a well-deserved break, helping them to carry on caring.

However, disabled children are consistently shut out. They are not considered a priority in a fragmented and confusing system. As a result, families are forced to battle through multiple assessments, face significant wait times, and even when funding is offered, the services that they need are rarely available. This delays essential care, adds unbearable stress, and leaves too many children without the support they are entitled to.

Parents are exhausted, often providing round-the-clock care with no real break. They feel isolated, overwhelmed, and fearful that their children are missing out on vital opportunities to grow, learn, and thrive. The fight for social care brings immeasurable pressure, and in the worst cases, some parents stop asking for help altogether.

Our new research pulls together findings from interviews with Sense families, wider literature, polling, and insights from our Parent Reference Group. It sets out what needs to change to move from a model of crisis care, to one of early intervention and high-quality support provision.

Fundamentally, new laws are needed. We're urging the government to establish a clear and consistent pathway to support for every disabled child. A national threshold must be set to assess all disabled children for support as soon as needs are identified. This must be underpinned by the funding and infrastructure to invest in more local services across the country. No family should have to fight to get the care that they deserve.



We would like to thank the families who generously shared their stories with us. We hope politicians will listen and make the changes needed to give every disabled child the best chance to thrive, not just survive.

James Watson-O'Neill

Chief Executive

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1. Bardet-Biedl Syndrome UK
2. British Association of Social Workers
3. Cause Communications
4. Contact
5. Disabled Children's Partnership
6. Dingley's Promise
7. Family Fund
8. Kids
9. The Law Commission
10. Mencap
11. National Children's Bureau
12. National Deaf Children's Society
13. Rainbow Trust
14. Roald Dahl Charity
15. Social Care Institute for Excellence
16. Seashell Trust
17. Special Needs and Parents (SNAP)
18. Speech and Language UK
19. The Children's Society
20. The Children's Trust
21. WhizzKidz



Executive Summary

Social care can be a lifeline for disabled children and their families. However, all too often disabled children are unable to access the support they need.

This research seeks to better understand the experiences of families' when accessing social care support for their disabled child. It is informed by a literature review, 8 interviews, two sets of polling of parent carers of disabled children, and discussions with our Parent Reference Group.

Findings can be summarised in three key themes:

- 1. The social care system is not set up to support disabled children and their families.** Current laws prioritise child protection, with a lack of focus on providing disabled children with the care and support they need. There is no national threshold for local authorities to follow, meaning stark variation across the country.
 - a.** Over half of parents struggle to access support and services that meet the needs of their disabled child.
 - b.** Half of parents have had to top up or fund additional support for their disabled child themselves.
 - c.** 40% of families who access social care support had to fight for it at tribunal so their child could get the support they need.
- 2. There is a lack of understanding and prioritisation of the services disabled children need by policy makers.** The funding available for specialist services and commissioning across the country is inadequate and inconsistent, leaving some areas with no services at all.
 - a.** 61% of parents felt decisions made by their local authority were motivated by cutting costs.
 - b.** Almost half of parents do not trust their local authority to provide the care and support their disabled child is entitled to.



- 3. Parents face stigma when accessing social care for their disabled child,** particularly those from minoritised communities. Parents are often shamed and blamed, rather than supported. Many are in fear of asking for help at all, for fear of having their child taken away.
- a.** Over half of parents felt stigma around accessing support from social services for their disabled child.
 - b.** 70% of parents and carers are losing sleep because they are worried about a lack of support for their disabled child.

Summary of recommendations

We are calling on the government to:

- **Change the law to create a simple and streamlined process for all disabled children to easily access the right support.** A new legal duty to assess all disabled children should be set, and a national eligibility threshold should be established to ensure more consistent access to social care across the country.
- **End the postcode lottery of care and patchy provision.** Provide long-term, ring-fenced funding for the services disabled children need and support commissioners with evidence and guidance of what works. Early intervention is key, and social care should be available as soon as a child's support needs are established.
- **Improve collaboration and training for professionals so parents don't feel like the only experts in their child's care.** All local authorities should ensure a Designated Social Care Officer is available. They should provide specialist training and effective multi-agency working for professionals across care, health and education.
- **Make disabled children visible by counting them.** More investment is needed in data infrastructure, to better understand where and when disabled children need support. This will mean local authorities can be smarter with the way services are planned, commissioned and funded.



More detailed recommendations can be found at the end of this report.

Key terms

- **Children’s social care** refers to the different kinds of support that children, young people and their families receive from their local authorities when they need extra help. It has a broad remit, including child protection, adoption services, support for disabled children and their families, and looked after children¹.
- **Disabled children’s social care** describes all forms of personal care and other forms of support for children and young people with additional support needs require².
- **Disabled children.** This report refers to “disabled children” as any child with a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on their daily activities, as set out in the Equality Act 2010³.
- **Disabled children with complex needs.** This refers children who have a combination of conditions that impact their daily lives, including learning disability, physical disability, sensory loss/deafblindness, neurodivergence, and mental illness⁴.
- **Children in need.** Generally, children’s social care supports ‘children in need’, which disabled children are automatically considered as under the Children Act 1989⁵.
- **Section 17.** This refers to Section 17 of the Children Act 1989⁶, which gives local authorities the power to provide support to families with a ‘child in need’, which includes disabled children.
- **Section 17 Assessment.** A ‘child in need’ assessment under Section 17 should identify the needs of the child and ensure that the family are given the appropriate support in enabling them to safeguard and promote the child’s welfare.

¹ An illustrated guide to the children’s social care national framework, Department for Education (2023) https://assets.publishing.service.gov.uk/media/657ad8e9254aaa000d050d10/An_Illustrated_Guide_to_the_Children_s_Social_Care_National_Framework.pdf

² What is Social Care, Contact, <https://contact.org.uk/help-for-families/information-advice-services/social-care/what-is-social-care/>

³ Section 6, Equality Act 2010 <https://www.legislation.gov.uk/ukpga/2010/15/section/6>

⁴ Children and young people with complex medical needs, Royal College of Paediatrics and Child Health https://www.rcpch.ac.uk/sites/default/files/Children_and_young_people_with_complex_medical_needs.pdf

⁵ Section 17, Children Act 1989 <https://www.legislation.gov.uk/ukpga/1989/41/section/17>

⁶ Section 17, Children Act 1989 <https://www.legislation.gov.uk/ukpga/1989/41/section/17>



Introduction

Demand for social care is growing

All disabled children are legally entitled to an assessment for care to support them to thrive, under Section 17 of the Children Act 1989⁷. The amount of support a child receives is determined through a needs assessment, but it is widely understood that there is huge variability across the country in the way this support is being decided, commissioned, funded, and accessed.

The number of disabled people with complex needs, including children, is growing⁸. This is in part due to developments in healthcare, meaning people are surviving and living longer than they have before. As a result, the number of children being cared for at home by their family is growing, with many parents and carers carrying out complex health and care procedures themselves⁹. While care at home is the preferred option for most, the parent carer workforce is far too often relied upon to deliver every aspect, with few breaks or opportunities for support¹⁰.

Uncounted, unheard and invisible

It is estimated that thousands of disabled children are missing out on life-changing care. The full scale of unmet need is not well understood, but national data suggests a stark picture. **There are around 1.8 million disabled children in the UK¹¹ – yet only 32,150 Children in Need were registered with disability as their primary need in 2024¹².**

⁷ Section 17, Children Act 1989 <https://www.legislation.gov.uk/ukpga/1989/41/section/17>

⁸ Quantifying Complex Disabilities, Sense and NatCen (2022) <https://natcen.ac.uk/publications/quantifying-complex-disabilities>

⁹ The challenges of caring for children who require complex medical care at home: 'The go between for everyone is the parent and as the parent that's an awful lot of responsibility', Page et al (2020) <https://pmc.ncbi.nlm.nih.gov/articles/PMC7696130/>

¹⁰ Give Carers a Break, Sense (2023) <https://www.sense.org.uk/get-involved/campaign/give-carers-a-break/>

¹¹ Family Resources Survey: Financial year 2022 to 2023, Department for Work and Pensions (2024) <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2022-to-2023/family-resources-survey-financial-year-2022-to-2023#disability-1>

¹² Children in need, Department for Education (2024) <https://explore-education-statistics.service.gov.uk/find-statistics/children-in-need>



As a result of this poor data and understanding, disabled children remain largely uncounted, unheard, and invisible in policy conversations about social care. The legal framework is also letting children down, lacking clarity and consistency, as well as any national thresholds to ensure uniformity in the way support is determined¹³.

When it comes to disabled children with complex needs, like those supported by Sense, high-quality social care support is essential to be independent, grow, and thrive. Our polling found that 59% of parents who did receive social care said it made a positive difference to their family¹⁴ – but without it, children are held back from experiencing the everyday things their non-disabled peers take for granted, and left unable to reach their full potential.

Evidence-based solutions are available

Over the last few years, politicians across parties have acknowledged the need to address and tackle the poor provision of care disabled children are facing. The previous government commissioned an independent review into social care, which published its findings in March 2022¹⁵. Alongside this, they published an improvement plan for SEND and alternative education provision, which included plans for social care support.¹⁶

As a result, new schemes were launched and new guidance produced, creating a prime opportunity for the current government to evaluate and embed evidence-based interventions. For example, local authorities were strongly encouraged to appoint social work leads who strategically lead on disability – Designated Social Care Officers (DSCO). As of 2024, there were 68 DSCOs in post in 89 local authorities, with five more actively

¹³ Disabled Children's Social Care – Summary of the Consultation Paper, Law Commission (2024) https://cloud-platform-e218f50a4812967ba1215eaecede923f.s3.amazonaws.com/uploads/sites/30/2024/10/24.117_LC_Disabled_childrens_social_care_Summary_WEB.pdf

¹⁴ Polling of Parents who had some form of children's social care, Censuswide, Poll of 1001, parents/guardians of a disabled child under 18, Undertaken between 4th to 9th September, 2024

¹⁵ The Independent Review of Children's Social Care, 2022, Available at <https://webarchive.nationalarchives.gov.uk/ukgwa/20230308122449/https://childrensocialcare.independent-review.uk/final-report/>

¹⁶ Special Educational Needs and Disabilities (SEND) and Alternative Provision (AP) Improvement Plan, HM Government (2023) https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1139561/SEND_and_alternative_provision_improvement_plan.pdf



recruiting for the role¹⁷. Evidence has shown the positive impact of the introduction of this role^{18 19}.

Also, as a result of the Independent Review into social care, in early 2025 the Law Commission launched a consultation to review the laws around disabled children's social care²⁰. The findings of this review will provide invaluable help to government to set out robust legal reform, informed by the experiences of disabled children and their carers. After years of reviews and trial schemes, there is now a significant opportunity for action.

What do we know already?

From the wider literature we found:

- **Demand for social care for disabled children is rising.** The charity NewLife found 60% of local services had seen their waiting lists grow in 2024, and almost 1 in 4 local authorities have children waiting over one year to be assessed, some exceeding three years²¹.
- **The law is outdated and ineffective.** The law on disabled children's social care in England is currently governed by a patchwork of legislation, some of which dates back more than five decades. This has contributed to variation in the amount and quality of support provided by local authorities, and unnecessarily complicated routes to accessing support for the parents and carers of disabled children²².

¹⁷ Mapping survey, Council for Disabled Children (2024) contact details available on request

¹⁸ Roles and Responsibilities within Local SEND and Alternative Provision Partnerships: Leadership in the "Middle", What works in SEND (2024) <https://whatworks-send.org.uk/resources/roles-and-responsibilities-within-local-send-and-alternative-provision-partnerships-leadership-in-the-middle/>

¹⁹ Implementing the Designated Social Care Officer role in Shropshire, What works in SEND (2024) <https://whatworks-send.org.uk/resources/implementing-the-designated-social-care-officer-role-in-shropshire/#downloads>

²⁰ Disabled Children's Social Care – Summary of the Consultation Paper, Law Commission (2024) https://cloud-platform-e218f50a4812967ba1215eaecede923f.s3.amazonaws.com/uploads/sites/30/2024/10/24.117_LC_Disabled_childrens_social_care_Summary_WEB.pdf

²¹ Fight For Our Future: Act Now for Disabled Children, NewLife (2024) https://newlifecharity.co.uk/wp-content/uploads/2024/04/Fight_For_Our_Future_Final-5.pdf

²² Disabled Children's Social Care – Summary of the Consultation Paper, Law Commission (2024) https://cloud-platform-e218f50a4812967ba1215eaecede923f.s3.amazonaws.com/uploads/sites/30/2024/10/24.117_LC_Disabled_childrens_social_care_Summary_WEB.pdf



- **Families of disabled children face a postcode lottery of support.** There are significant disparities in support offered across local areas. This can be seen through local authorities placing ‘thresholds’ on families trying to access support; the Disabled Children’s Partnership found 1 in 4 parents had been told their child did not meet a threshold for a social care assessment to take place²³. Many families Sense supports have found there are little to no suitable services available in local areas that can support their child, and many families travel for hours to access Sense’s services.
- **Historic lack of investment in social care for disabled children.** Economic analysis from the Disabled Children’s Partnership found a funding gap of £573 million in 2019/20, and this is likely to have grown since this research was completed²⁴. There is a considerable amount of unmet need and others self-funding additional support. As a result, it is likely the funding gap is even bigger than estimated. Recent research has shown the funding challenges facing local authorities – in 2023/24 85% of local authorities reported an overall cumulative high needs deficit²⁵– meaning many are unable to invest sufficient funds into services supporting disabled children.
- **Lack of available social care workforce.** Research has shown the biggest barrier to sufficient social care provision is the recruitment and retention of the workforce²⁶, including when it comes to trying to hire personal assistants with direct payment money. This is often stated as a key challenge with direct payments, with funding being there but often not able to be used because the services are not²⁷.
- **Disabled children are more likely to live in poverty and be impacted by the increased cost of living than their non-disabled peers.** Research has shown 58% of children with SEND stated their family struggled to heat their homes, and 69% of charities reported an increase in children with SEND not having access to sufficient

²³ Failed and Forgotten, Disabled Children’s Partnership (2023) <https://disabledchildrenspartnership.org.uk/our-campaigns/failedandforgotten-read-our-new-report/>

²⁴ The gap widens, Disabled Children’s Partnership (2020) <https://disabledchildrenspartnership.org.uk/the-gap-widens/>

²⁵ Towards an Effective and Financially Sustainable Approach to SEND in England, Local Government Association (2024) <https://static1.squarespace.com/static/5ce55a5ad4c5c500016855ee/t/669fcedacd1a1f608546f52b/1721749338168/SEND+report.pdf>

²⁶ Coram Family and Childcare Survey 2024 <https://www.familyandchildcaretrust.org/childcare-survey-2024>

²⁷ Failed and Forgotten, Disabled Children’s Partnership (2023) <https://disabledchildrenspartnership.org.uk/our-campaigns/failedandforgotten-read-our-new-report/>



and high-quality food²⁸. A recent survey found that 62% of parent carers had given up work or reduced their hours, including leaving their careers. As a result, they lost £21,174 on average from their family income²⁹. Research has also shown childcare costs have increased, and that childcare is more expensive for disabled children³⁰.

- **There is a lack of understanding of the role of social care in supporting disabled children.** Wider understanding of social care for disabled children can be distorted by the role social care has in protecting children from abuse, and perceptions of social care often focus on child protection, safeguarding, and the care system. Assessment processes often take a one size fits all approach and families often feel scrutinised rather than supported³¹.
- **Minoritised groups face particular challenges when accessing social care support.** The Disabled Children's Partnership found that assumptions about race mean social workers tend to approach minoritised families through a child protection lens, rather than offering support. As a result, these children often face higher levels of anxiety and isolation³².
- **Parent carers rarely get a break, impacting their wellbeing and ability to carry on caring.** Previous research by Sense found that 34% of family carers of disabled people do not receive any support to take a break, and over 65% of carers say they are burnt out and exhausted³³. Studies have also shown poorer mental health among parent carers; a recent study found that 41% of parent carers had thought about ending their lives³⁴.

²⁸ The impact of the cost-of-living crisis on children and young people with special educational needs and disabilities, The Childhood Trust (2023) <https://www.childhoodtrust.org.uk/wp-content/uploads/2023/06/The-Childhood-Trust-SEND-REPORT-June-2023.pdf>

²⁹ Counting the Costs, Contact (2024) <https://contact.org.uk/help-for-families/campaigns-and-research/counting-the-costs/>

³⁰ Family and Childcare Survey, Coram (2024) <https://www.familyandchildcaretrust.org/childcare-survey-2024>

³¹ Support Not Suspicion, Disabled Children's Partnership (2024) <https://disabledchildrenspartnership.org.uk/our-campaigns/support-not-suspicion/>

³² Support Not Suspicion, Disabled Children's Partnership (2024) <https://disabledchildrenspartnership.org.uk/our-campaigns/support-not-suspicion/>

³³ Give Carers a Break, Sense (2023) <https://www.sense.org.uk/get-involved/campaign/give-carers-a-break/>

³⁴ Suicidal Thoughts and Behaviours in Parents Caring for Children with Disabilities and Long-Term Illnesses, O'Dwyer et al (2024) <https://www.tandfonline.com/doi/full/10.1080/13811118.2024.2363230>



- **Disabled children are more likely to be looked after by the care system**, remain in care for longer, and have a higher risk of being placed inappropriately in comparison to non-disabled children^{35 36}.
- **Families have often reached crisis when asking for help.** Families often spend the early years of their children's lives navigating complex diagnoses alone, juggling appointments, and not knowing where to turn for help³⁷.

Our findings

1. The system is not set up to support disabled children and their families

"The system is set up to make you not do it. I don't ever actually know what's going on."

"You need a parent who has the time to understand the system and then is unbelievably persistent to get through it and actually get help. If one of those isn't there, the children are basically doomed."

"It took four years to get our first carer hired. It has been a lot of fighting. Anything we have got, we had to fight tooth and nail to get. We've been through two tribunals in two and a half years."

Families are not being told about their children's rights

Often, families of disabled children are unaware of the support their child is entitled to. This means many families miss out on accessing vital support, which has a knock-on effect on family wellbeing, finances, and their child's development. Our polling showed over a

³⁵ Looked after children data bulletin, Council for Disabled Children (2008)

<https://councilfordisabledchildren.org.uk/sites/default/files/uploads/attachments/LAC%20data%20bulletin.pdf>

³⁶ Permanence and stability for disabled looked after children, The Institute for Research and Innovation in Social Services (2011)

<https://www.iriss.org.uk/resources/insights/permanence-stability-disabled-looked-after-children>

³⁷ The challenges of caring for children who require complex medical care at home: 'The go between for everyone is the parent and as the parent that's an awful lot of responsibility', Page et al (2020) <https://pmc.ncbi.nlm.nih.gov/articles/PMC7696130/>



quarter (26%) of parents were unaware their disabled child is legally entitled to have their needs assessed and to receive any support they are entitled to by children's social care.

Additionally, over a fifth (21%) of parents were unaware that children's social care includes support for disabled children and their families, and over half (52%) of parents struggle to access support and services that meet the needs of their disabled child. As a result of spending time seeking support, many families are also left feeling helpless and like a burden. One parent we interviewed said **'it makes you feel like you are begging for something completely unreasonable'**.

When a child has an Education Health and Care (EHC) plan assessment³⁸, the assessor has an opportunity to ask the family if they would like support from social care. One parent we interviewed told us **'I ticked the box on the EHC plan form saying I wanted to access these social care services. But I didn't hear back about it, and I don't know how to access it.'** Even when families follow all the right steps in this complicated system, they are still often ignored and de-prioritised.

Families are having to jump through hoops

Families told us they had negative experiences with trying to access social care support in the first place. Our polling showed that, for families who were getting some support from children's social care, over half (57%) had multiple assessments before they were able to access the support they needed, and 44% were unable to access the respite support they were entitled to.

We also found that some families (17%) had to wait more than a year to be seen by social services, and nearly a third (32%) of parents say they have been unable to access the support they need from children's services. Many families were also spending their own money on support. Our survey found that on average, parents have spent more than

³⁸ Children with special educational needs and disabilities (SEND), Department for Education <https://www.gov.uk/children-with-special-educational-needs/extra-SEN-help>



£1,500 of their own money on support for their disabled child over the past six months, and over 1 in 20 parents (5%) have spent over £5,000.

Families we interviewed were told their child did not meet their local authority's 'threshold' for its disabled children's service, even though there are no national threshold rules in place. One was told their child was '**not quite multi-sensory impaired (MSI) enough at the moment to qualify for MSI support**'. One family stated, '**the local authority identified loads of actual needs, but said he didn't meet their threshold**'. Families faced either significant delays after requesting support or had been continuously turned down. Several said they had been assessed several times, without hearing an outcome.

Families battle bureaucracy at every step

Parents we interviewed also told us they had to escalate issues to get the support they needed. Half of those we interviewed had to put in a formal complaint to their local authority. One parent shared their experience, telling us that only their social worker was allowed to attend the panel. The parent said, '**we don't have access to anything ... what we can do is put in formal complaints, which we did, but then nothing happened**'. Our polling showed that 40% of families had to go to tribunal for their disabled child to access social care support.

One parent from our Reference Group told us that she had completed a master's degree so she could navigate the system and advocate for her child. "**I worked out that in order not to be abused by professional services that I need to state the appropriate laws, use the court of protection to support my case, select care companies that are outstanding, and lay down clearly that I will only accept staff that are perfect.**"

In the interviews, parents spoke of their stress trying to get through to social services. Worryingly, parents told us the fight for support can be so hard that they stop asking for help.



Support families are assessed for is often delayed or unavailable

Even when a package of support is offered, families often face significant delays in this being implemented. There is also a chance their package of support may be reduced. One family said, **'I've gone all summer without it when I really needed it... it's set up to make you not do it'**. One parent had their package reduced after significant delays. They said, **'we had to go through the funding panel three times before they agreed to fund it, and they reduced the package as well'**.

Another parent shared how they found the process of applying for financial support through their local authority so stressful, that they would rather try and do it themselves. Many other parents shared how they needed to pay out of their own pocket to get the support their child needed. Our polling showed half of parents (50%) have had to top up or fund additional support for their disabled child. Parents told us they have had to leave their jobs and spend money from savings to get her child the support they needed. Others recounted how delayed payments from the local authority meant some weeks were **'very expensive'**.

On top of these extra costs, many parent carers had been forced out of work. Our polling found that 48% of parents found it difficult to work, as the care for their disabled child was inconsistent, and 43% could not work at all as they did not have adequate support in place. Two in five parents (40%) had to quit their jobs entirely to fight for their disabled children's rights, whilst more than half have had to reduce their hours. One parent we spoke to was pleased with the support offered through direct payment to hire a Personal Assistant, but was worried about losing this support in the future due to delays in local authority payments.



Ben's story

"We first got involved in social care through our adoption support worker, who said we should get some support. But it took four years to get our first carer hired. It has been a lot of fighting. For anything we have got had to fight tooth and nail to get. We've been through two tribunals in two and a half years.

Ben had a mental health crisis at the beginning of the year. And we asked for help. We called everybody we could think of, CAMHS, every social worker we could think of. And nobody offered us any help. After two months the social worker came and was unhappy, so referred us to child protection.

This is still ongoing. We still have not received any more support. We've not received any more help. There's been a huge lack of understanding about disability. Every social worker we've come across hasn't really had a good understanding about disability. It's been eye opening."



2. There is a lack of understanding and prioritisation of the services disabled children need by policy makers

“With every contact, it kind of makes you feel like you’re asking the impossible. Like I’m begging for something that’s completely unreasonable.”

“I purposely don’t think about the future, it’s too worrying. I’m too scared about what happens when I’m not here.”

The system is set up to respond to safeguarding, rather than support

Several families we spoke to recounted negative attitudes from professionals they had interacted with. One parent told us that the reason for their application being rejected was **‘the family is coping’**. They said their social worker was helpful, but the system was **‘very frustrating’**. Another recounted they had been dubbed a **‘confident parent’** so were perceived to need less support. One parent spoke of a **‘constant mistrust’** in social services, and that it made them feel like they were ‘asking for the impossible’.

Our polling showed that 46% of parents do not trust their local authority to provide the care and support their disabled child is entitled to. This puts a lot of stress on families, who are already doing everything they can to support their child. One parent reflected on this, stating **‘I am a single parent. I can’t go under...I simply can’t fail at this’**.

Cost-cutting and inadequate funding is impacting care

Many parents feel that local authorities have taken essential funding away from disabled children’s social care. In our polling, 61% of parents felt decisions made by their local authority were motivated by cutting costs, and 57% said there had been cuts to locally funded services for disabled children. As a result of this, half of parents (50%) have had to top up or fund additional support for their disabled child. When families did have access to support, 46% did not get enough funded hours to meet the needs of their disabled child.



There is a lack of specialist support available

Some parents we spoke to had been offered support from professionals with a lack of relevant training, or simply not offered any support. One parent felt **'nervous'** about agency staff, and one parent was worried about the level of training provided to support staff on complex needs.

One parent told us **'every social worker you've ever come across, hasn't had a good understanding of disability'**, and one parent had to **'correct the work'** of their social worker, calling their experience **'terrible'**. Our polling found that over half of parents (52%) struggle to access support and services that meet the needs of their disabled child, and 58% would like more support for their family as a whole.

We do know that when a child receives good support from a social worker, it makes all the difference. One family we spoke to have had a positive experience with their social worker, due to having one single point of contact and the social worker having a good understanding of disability. The parent told us **'she (the Social Worker) has always been very good at characterising it... my daughter has an inherent vulnerability because of her disability, and that's why they're supporting the family, not because they have any concerns'**. This example shows the value of having a single point of contact in the local authority – yet in our polling, less than half (49%) of parents who were getting social care support had this.



Aidan's story

“My son Aidan had a great social worker - but only when we moved areas - so it clearly is a postcode lottery. Also, the bar set for access to the Disabled Children's Team in each area is different, there isn't a national framework. It's all down to luck, depending often on the budget & financial situation of each council. Some don't advertise the eligibility criteria so they can tell families they don't meet the criteria when in fact they do, and others will just plain refuse to do an assessment.

What this does is create a two or three tier system where if you have the “right” needs and live in the right area, like my son, we got access to well qualified social workers who can often provide great support. Whereas if you don't qualify or live in an area where funds are stretched you end up with social workers who have vast caseloads and very little time or expertise.”



3. Parents face stigma when accessing social care for their disabled child

"I didn't want social care swooping in with people assuming what was going on and thinking things were dysfunctional."

"So much of social care, your perception of it is around child protection and not around support."

Parents fear judgement and their child being removed from their care

Many parents are nervous around accessing social care for their disabled child, due to negative stereotypes that often exist around social care and social services as an organisation. Our polling showed that over half (54%) of parents felt there was a lot of stigma around accessing support for their disabled child, and a similar number (53%) were anxious about contacting social services for support. This means many families are missing out on accessing vital support for their child.

One parent told us of her experience as part of a minority group. She told us '**I got scared off by the child protection angle**', and '**thought processes around how different ethnic groups behave is often misdirected and misunderstood... I feel that people need to be a bit more aware of the intersection between race and disability**'. This emphasises the challenges highlighted in previous research, and the intersectional nature of the barriers families of disabled children face when accessing care.

Parents are looked at as child protection cases

Another challenge parents face is the child protection and safeguarding lens that is used to assess children for support. Several parents we spoke to told us that in their local authority, they are required to fill out a 'child in need' form that contained a number of child protection references. Many local authorities do not have a separate process or form for families accessing social care support for their disabled child.



Families told us this increased fear and trepidation amongst parents who are already nervous about asking for help; one parent told us **'so much of social care... your perception of it is around child protection, not support'**, and another parent called the process **'very off putting'**. This has also had an effect on how some social care professionals view the assessment for disabled children; one family told us **'we've never had any direct contact from anybody from social care other than when there's an issue domestically'**.

Another parent told us they almost changed their mind about asking for social care support once they realised they would need to fill out a child in need form. They told us **'the first time we did this, we didn't like it at all, and wanted to change our minds'**. It is immensely stigmatising that parents of disabled children are often forced to go through the same processes as if they had a child who was in danger, and parents are at risk of feeling to blame for challenges they may face in supporting their child. Our polling found that 70% of parents feel overwhelmed by the complex processes involved in accessing support for their disabled child, and 70% are losing sleep because they are worried about the lack of support. Given the huge challenges parent carers face - their high-risk of burn-out, stress, and mental illness³⁹, it is unacceptable that the system further perpetuates these feelings.

³⁹ Suicidal Thoughts and Behaviors in Parents Caring for Children with Disabilities and Long-Term Illnesses, O'Dwyer et al (2024)
<https://www.tandfonline.com/doi/full/10.1080/13811118.2024.2363230>



Sasha's story

“Social care support came up as part of Sasha's EHC plan, so that was our first introduction to it. However, it was a terrible experience. I had to correct the social worker's work.

In my area, you have to go through a child protection form to get access to social care. To a number of people – I can only speak my own ethnic group – black people do not want to be involved in social care in any way, because thought processes around how different ethnic groups behave is often misdirected and misunderstood.

To give access to social care via a child protection form is the absolute worst way you could do it. I got scared off by the child protection angle.

I still haven't got access to any support. I've gone all summer without it when I really needed it. We're now approaching October, so we're coming up on a year. Before I've actually got any access to anything.”



Conclusion

The social care system for disabled children is inaccessible, unfair, and alienating. Even when families try their hardest to access support, they are often shunned and demonised. The demand for social care support is rising, yet children face a postcode lottery of support. The law around social care for disabled children is outdated and is not being followed by local authorities, and there is a lack of investment in interventions to support disabled children.

Through a combination of interviews, polling, and discussions with the Parent Reference Group, we were able to generate a clearer picture of the challenges facing parents and carers of children with complex needs when trying to access social care support. Our findings support those found in previous literature: that the system is simply not set up to support disabled children and their families. There is a lack of understanding and prioritisation of the services disabled children need by policy makers, and parents face stigma when accessing social care for their disabled child, particularly those from minoritised communities.

However, there are significant opportunities to change this. The recent review of disabled children's social care by the Law Commission will provide answers to some of these tricky challenges, and it is time for government to act. Changing the law will be key to delivering the government's opportunity mission and ensuring more disabled children can reach their full potential. Alongside this, a national framework for disabled children's social care should be set out, underpinned with a sustainable funding plan and investment in data and services to end the postcode lottery in support families are facing.



Recommendations

- 1.** Change children's social care law so every disabled child gets the support they need.
 - a.** The government should introduce a single statutory duty to assess disabled children for their social care needs, leading to a specific pathway for disabled children to access care and support.
 - b.** A national eligibility threshold for support should be outlined, set at a level to ensure all children with complex needs are assessed, alongside a national minimum standard for support and care.
 - c.** Care plans should be portable, and care should be transferred seamlessly if a child moves to a different local authority.
- 2.** Disabled children's social care should be embedded in cross-government strategy on disability, in line with the government's mission to ensure every child gets the best opportunities in life.
 - a.** The Cabinet Office should lead on embedding cross-departmental working to ensure more joined-up planning across governmental departments, especially for those with identified health needs eligible for continuing health care funding.
- 3.** The Department for Education should set out national targets to improve services and support for disabled children, with tailored advice and guidance for local authorities to take forward best practice.
 - a.** To improve accountability, the Department for Education should produce a tailored version of the national children's social care framework that specifically focuses on the needs of disabled children and their families.
 - b.** The Department for Education should conduct national audits on the quality of advice and guidance provided, including on local authorities' local offers and timelines for assessment and support.



curriculum, and each trainee should be encouraged to undertake a placement with disabled children's social care.

- b.** Local authorities and NHS Trusts should provide training to ensure all professionals working on children's social care understand how to support disabled children, including specialist training when needed.

About Sense

Sense is here to support disabled people from the first weeks of life through all the major milestones of adulthood. We offer personalised, creative and flexible support in people's homes, and in our centres, colleges and residential services.

With Sense, children can develop new ways to communicate and play; young people and adults can develop skills and confidence for work and life; and families can feel seen, supported and valued.

Together, we can achieve long-term change. Through our campaign work we step up in the face of adversity and unite alongside disabled people with complex needs across the UK.

Contact us

For more information, please contact us at policyresearch@sense.org.uk



Appendix

Methodology

This report draws on new research carried out by Sense. The research was carried out in three parts – first polling, followed by interviews, then a questionnaire to our Parent Reference Group.

Polling

Polling was undertaken in two parts, in September 2024 and March 2025. Both sets of polling were of parents with a disabled child under the age of 18. The questions focused on social care and other topics including Special Educational Needs and Disabilities.

The first polling was of 1,001 parents and took place between 4th to 9th September 2024. The second polling was of 1,000 parents and took place between 25th February and 4th March 2025. All polling was undertaken by Censuswide.

Interviews

We carried out eight interviews with parents of children with complex needs between January and September 2024. Most participants were recruited through our services, but some were recruited through word of mouth and staff members' external networks.

The interviews held a semi-structured format, following an interview guide. They usually lasted around 45 minutes and were all conducted via Microsoft Teams. Prior to the interviews, the interviewers outlined the format of the research and how the data would be used. Consent was gained from all participants before proceeding with the interview.

Parent Reference Group questionnaire

In January 2025, we sent a questionnaire to our Parent Reference Group, comprised of eight parents with disabled children who access Sense's services. The questions focused



on what social care means to their family, and what they would change about it if they could.