sense

From crisis to care:

Building a better social care system for disabled children and families.

Social care can be a lifeline for disabled children and their families. However, all too often they are unable to access the support they need. This research from Sense seeks to better understand the experiences of families when trying to access social care support for their disabled child, to detail the challenges of the fragmented system and lay out recommendations for change.

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 of Sense

Research findings

The findings of this research were informed by a literature review, eight interviews, polling of parent carers of disabled children, and discussions with our Parent Reference Group, carried out across 2024 and 2025.

> “Life is just a battle which is so complicated, so draining and just wastes so much time. It’s soul destroying.”
>
> Leanne, parent

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. 40% of families who access social care support had to fight for it at tribunal so their child could get the support they need.

c. 17% of families have been waiting more than a year to be seen by social services.

> “I’m terrified of hitting that crisis...I am a single parent. I can’t go under. It’s as simple as that. I simply can’t fail at this.” Amir, parent

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.

c. Half of parents have had to top up or fund additional support for their disabled child themselves.

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 worrying about a lack of support for their disabled child.

What needs to change

> “We know social care is there, but accessing it seems to be way more trouble than it’s worth. Some families seem to have everything, but others absolutely nothing. We know we need a bit of help but just keep putting it off because I don’t have the energy to fight at the moment.”
>
> Kathy, parent

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.

> **“Times have never been harder for many of the families we support at Sense. Many travel for miles to come and get the specialist support that works for their child. If we weren’t here, then their child would probably go without.”**
>
> Caroline, business support manager, children and young people’s services.

For more information, contact:

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If you, or someone you know, requires this information in a different format, such as large print or braille, please contact our supporter services team using the details below.

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