



**THE MENTAL HEALTH
CRISIS FACING PARENT
CARERS OF CHILDREN AND
YOUNG PEOPLE WITH SEND**

INTRODUCTION

Across the UK, mothers, fathers, and other carers of children and young people with Special Educational Needs and Disabilities (SEND) face an escalating mental-health and wellbeing crisis. These individuals carry an intense emotional, physical and financial burden – far beyond what most people imagine. They are often isolated, exhausted, and under constant pressure, while also navigating a complex, bureaucratic system that demands advocacy and resilience.

Recent research underscores the severity of this problem. A dedicated study of parent carers by the University of Birmingham found alarming levels of suicidal thoughts and behaviours among carers: 41% had thought about killing themselves, 8% had made a plan, and 2.5% had attempted suicide.

Equally concerning, a new report by Cerebra reveals widespread “systems-generated trauma” (SGT): family carers overwhelmingly described public services (health, social care, education) as hostile, traumatising, and deeply distressing, with many reporting that navigating support systems caused more harm than their child’s disability itself.


This report documents the lived realities faced by parent carers, raises urgent concerns about their safety and wellbeing, and offers concrete recommendations for professionals and systems to better support them – acknowledging parents as people first, and experts in their own right.

WHAT THE RESEARCH SHOWS

Findings from University of Birmingham

- Compared to parents without caregiving responsibilities, parent carers for children or adults with intellectual disabilities reported 5 times greater likelihood of severe anxiety, and 4–10 times greater likelihood of major depression.
- In its 2024 follow-up study, 41% of parent carers in England who care for a long-term ill or disabled child had considered suicide; many had made plans or even attempted it.

Findings from Cerebra: “Systems-Generated Trauma”

- Based on responses from over 1,200 parent carers, the report documents a persistent pattern of trauma caused not by disability itself, but by the very systems designed to support disabled children and families.
 - Parents described public services as “hostile, relentlessly bureaucratic, and combative,” reporting severe impacts on mental health, family relationships, financial stability and overall wellbeing.
 - Some parents reported suicidal thoughts directly linked to their experiences navigating health, education, and social services.
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Combined, these studies paint a stark picture: being a parent carer of a child with SEND is associated with very high risk of depression, anxiety, suicidal thoughts, and chronic stress.

THE LIVED REALITY: BURDEN ON PARENT CARERS

Parent carers often manage:

- Diverse and complex SEND needs – from sensory/communication issues, medical needs, behavioural challenges, to neurodevelopmental conditions.
- Medical interventions and equipment, frequent appointments, therapies, environmental adaptations, and constant vigilance for safety and wellbeing.
- Child-on-parent violence, challenging behaviour, sensory overload and public stigma when accessing community spaces.
- Social isolation as public outings become difficult or exhausting, compounded by public judgment or misunderstanding.
- Financial hardship – due to increased costs of care, inability to work (reduced hours or giving up work altogether), and benefit insecurity.


This environment erodes mental health, identity, and resilience. Carers describe feeling invisible, misunderstood, judged – and ultimately alone.

As one parent quoted in the Cerebra report says:

“Having a disabled child is not the traumatic part. The trauma is seeking (or trying to seek) support from education, health and social care services.”

SYSTEMIC CAUSES OF HARM: NOT DISABILITY, BUT THE SYSTEM

The issue is not the child’s condition – it is the system’s repeated failures:

- Bureaucratic inertia and relentless, repeated assessments.
 - Lack of coordination between health, social care, education and welfare.
 - Professionals who do not treat parent carers as people – instead treating them as cases, forms, or burdens.
 - Frequent demands to retell traumatic histories – each retelling a re-traumatisation.
 - Inadequate access to respite, therapy, specialist services or crisis support.
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- False expectation that families should use their limited benefits (such as DLA) to fund “extras” like respite, equipment, or activities.

Cerebra refers to the result as “Systems Generated Trauma” – harm caused by dysfunctional public systems.

RECOMMENDATIONS: WHAT MUST CHANGE

To stop the harm, services and professionals must act. Parent carers must be treated as people, not cases. They must be recognised as experts in their own right. The following are required:

1. Respect and identity

- Use parents’ names. Acknowledge them as individuals with their own lives, identities and needs – not just “parent of”.
- Treat their lived experience and insight into their young person as expert knowledge.

2. Reduce bureaucratic burden and avoid retrauma

- Streamline processes – avoid repeated assessments and unnecessary retelling of traumatic history.
- Enhance inter-agency coordination so information is shared without burdening the parent.

3. Enable positive parent–child relationships and respite

- Allow short-break/direct payment funds to be used for positive, fun, or restorative activities (not just basic care).
- Encourage local businesses and community providers to offer SEN-specific or low-sensory sessions to support inclusion.

4. Accessible mental health support for carers

- Offer tailored mental health services for parent carers, recognising their unique stressors, trauma, and risk factors (including suicidal thoughts).
- Include carers in national suicide-prevention strategies.

5. Empathy, trauma-informed practice and training

- Provide training for all professionals interacting with SEND families – social workers, health staff, educators, therapists.
- Encourage compassion, avoid judgement, and understand the impact of cumulative trauma.

6. Financial and systemic support

- Recognise that DLA and other benefits are often already stretched to cover essential needs – do not expect them to fund “extras”.
- Ensure adequate funding of short-breaks, respite, therapies, adaptations, and transport support.
- Provide flexible, responsive crisis support systems.

7. Community connection and peer support

- Facilitate parent-carer peer support groups, safe community spaces, and regular social events – reducing isolation and building resilience.
- Provide accessible information and guidance on financial help, energy grants, and support services.

CONCLUSION

Parent carers of children and young people with SEND are facing a mental health and wellbeing crisis – not because of their children’s needs themselves, but because of repeated systemic failures, chronic stress, isolation, and lack of meaningful support.

If public services and professionals do not urgently change how they engage with these families, more will suffer: more mental illness; more suicide attempts; more families broken by bureaucratic trauma; and tragically, more children and parents lost to despair.

Parent carers are people, experts, and lifelines. They deserve respect, support, and systems that work with them, not against them.

It is time for a fundamental shift – from treating them as “cases” to supporting them as individuals with lives, identities, hopes and deserving dignity.

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