

Disabled Children at the Table

Lizzie Arnold

Council for Disabled Children

August 2024



About

This report is a collaboration between the Council for Disabled Children (CDC) and the Disabled Children's Partnership. It has been inspired by the Children at the Table campaign, led by the Children's Charities Coalition, and its influential roadmap report published in November 2023 which set out a series of recommendations for putting children at the heart of the new government. Utilising these recommendations as a framework, this report calls for disabled children and their families to be put at the heart of government policy making and demonstrates why well resourced and properly coordinated services must be a priority.

The Council for Disabled Children

The Council for Disabled Children is part of the National Children's Bureau family. We are the umbrella body for the disabled children's sector with a membership of over 300 voluntary and community organisations and an active network of practitioners that spans education, health and social care. We interrogate policy, uncover evidence and develop more effective ways of supporting disabled children and their families.

The Disabled Children's Partnership

The Disabled Children's Partnership is a major coalition of more than 120 charities, parent groups and other organisations – supported by a network of thousands of parent carers and allies – who campaign for improved support across education, health and social care for disabled children, young people and their families.

1. Why we must act

The proportion of children and young people in the UK classified as disabled or having special educational needs in England has increased but their experiences and needs are all too often not prioritised by public services and key government departments¹.

The responsibility for ensuring that disabled children and their families have their needs recognised and met through well resourced and properly coordinated services must be a priority for the government.

The government's overarching vision is a future where children are healthy and happy². Yet disabled children and young people and those with SEN continually face barriers to accessing basic support and services that enable them to thrive and fulfil their aspirations³. The Good Childhood Report found that children who are 'limited a lot' by their disability or long-term illness are almost four times as likely to be unhappy with life on the whole as children who do not have a disability or illness⁴. This is likely to reflect the constant difficulties they face when seeking accessible activities, high quality care and inclusive education.

Only 1 in 5 parent carers feel that their disabled child receives the correct level of support to meet their needs from health services⁵, and gaps have been continually identified in mental health support for young people with autism and mental health needs⁶.

The wellbeing and mental health of disabled children and young people was disproportionately affected during the pandemic, with vital services such as therapies and medical appointments delayed or withdrawn. The initial Pandemic guidance from NHS England did not safeguard services to disabled children. During the pandemic, 71% of disabled children's progress in managing their conditions regressed⁷. The effect of the pandemic and lockdown on disabled children has been raised time and time again by children, parents and professionals, yet the previous government failed to provide a targeted programme of recovery policies or funding.

Disabled children and young people have been overlooked by policy makers for too long and the impact is clear. We are calling for the government to put disabled children and young people at the heart of government policy making, backed by a step-change in investment to transform childhoods across the UK.

Child poverty

A child's health, wellbeing and life chances are shaped by the circumstances of their birth and their early life experiences, and for too many disabled children this means a double disadvantage of poverty and disability that denies them a fair start in life.

This double disadvantage has been exacerbated by the cost of living crisis that has created an even more challenging set of circumstances for families with disabled children⁸. Disabled children are more likely to live in a single-parent household than non-disabled children⁹ and single-parent families are at higher risk of poverty¹⁰. Families with a disabled child or health needs can face additional barriers to work because of difficulties in organising childcare for disabled children¹¹. 46% of parent carers stated that they were not able to work and were experiencing poverty as a result¹².

The government has committed to developing an ambitious child poverty strategy¹³.

This is vital as it is clear that our systems aren't sufficiently protecting disabled children and their families from the impact of poverty, and this must be addressed through coherent government action to tackle barriers to the labour market, support with employment and increased social security provision to ensure families are able to provide for their children while meeting the additional costs associated with disability in childhood.

Physical health, mental health and wellbeing

The earliest years of a child's life lay the foundations for their future health and wellbeing, yet disabled children's wellbeing is often overlooked in the design of policies to support children and young people's mental health and emotional wellbeing.

Children with learning disabilities are 4.5 times more likely to have a mental health problem than other children¹⁴ and 36% of children with SEND said they 'often, always or some of the time' felt lonely¹⁵. Schools and colleges are playing an increasing role in identifying children and young people at risk of or experiencing mental health conditions, and yet recent research shows mental health support teams are often not meeting the needs of students with SEN¹⁶. Unmet needs around mental health and SEND are key factors associated with children missing school¹⁷, which indicates the importance of the government's commitment to reforming children and young people's mental health services and making sure it is inclusive in its design. The 2017 review into residential special schools and colleges highlighted that many disabled children in these settings struggle to access mental health support, partly due to thresholds denying them access¹⁸.

Children's social care

The children's social care system is not working for disabled children and their families. Disabled children and their families often experience the children's social care system as bureaucratic and complex, with parent carers frequently struggling to navigate routes to through to support. Current funding gaps in children's services are significant – recent evidence from the Association of Directors of Children's Services revealed that £778m is needed to close the current budget gap¹⁹. This pressure on resources is particularly acute for disabled children, with research from The Disabled Children's Partnership (DCP) finding that 3 in 4 local authorities have dedicated 10% or less of the children's social care workforce to disabled children²⁰, yet disabled children are more likely to be re-referred to children's social care than other children²¹.

Families of disabled children have said that thresholds for support are very high, with 1 in 4 parents reporting they have been told that their disabled child does not meet the threshold for a social care assessment to take place²². When assessments do take place, they can be intrusive and feel like a one size fits all assessment that does not take the needs of disabled children and their families into account²³.

It is vital that the Law Commission review looks at how the legal framework can be simplified and modernised and how a more needs lead approach can be introduced²⁴. The review's recommendations must be implemented and prioritised alongside a programme of wider reform to Family Help and assessments that is suitably tailored and leads to disabled children and families being able access the support and services available to them more easily.



2. Making the UK the best place to be a child

An ambitious cross-Government strategy and outcomes framework

To transform disabled children's lives, we must transform the policy and decision-making process that impacts them, and this report sets out a roadmap to achieving that. The government needs to commit to an ambitious, multi-year strategy and outcomes framework involving all departments. We want all parties to commit to producing a cross party disabled children's strategy, in line with the DCP manifesto²⁵. Linked to this, the government has committed to introducing a consistent child identifier to enable better data matching between health, education and social care²⁶, and for disabled children, this will be vital to prevent them from falling through the cracks. For example, recent data linkage in Bradford via their new live data dashboard has enabled them to have a continuous focus on children and young people with multiple vulnerabilities such as those with an EHCP who are missing education²⁷. The government has committed to making improvements to the children's social care sector²⁸, and it is important any changes to the disabled children's social care system always align and are coordinated with other programmes and reforms taking place across the SEND system, with children and families always at the centre of any policies or plans.

Recommendations:

Commit to an ambitious cross-Government strategy and outcomes framework to drive improvements for disabled babies, children and young people growing up in the UK.

- The Prime Minister to drive forward coordinated and aligned work to deliver the strategy through a Cabinet Committee attended by ministers across government to ensure disabled children today and tomorrow are safer, happier, healthier and have more equal access to opportunities.
- Introduction of a consistent child identifier to enable improvement in information sharing across agencies to keep disabled children safe.

Involving children and young people every step of the way

Disabled children and young people are the experts in their own lives and they must be involved every step of the way. It is also important to involve parent carers and families as their experiences and knowledge of the system are crucial to ensuring we have a system that is fit for purpose. This should include prioritising disabled children's views and experiences of transitions, to ensure they are involved and understand the changes taking place. The recent report from the Children's Commissioner's Office '*We all have a voice*' showed that the voices and experiences of disabled children and young people are all too often not at the centre of decision-making about their lives²⁹, and they must have a clear place in local and national reform strategies going forward. This requires a real move towards engaging disabled children and young people meaningfully as expert partners from the start and throughout. The government needs to ensure that the cross-Government strategy has a 'check and challenge' committee of children and young people, representing diverse communities and needs, including disabled children and those with SEN, that shadows the development and implementation of the cross-Government strategy and framework.

Recommendations:

A new approach to decision-making that places disabled children's interests, wishes and outcomes at its heart, involving disabled children and young people and their families every step of the way.

- Cultural shift towards genuine co-production with disabled children and young people and their families, engaging with them meaningfully as expert partners from the start and throughout.
- A 'check and challenge' committee of children, young people and parent carers representing diverse communities and needs, that shadows the development and implementation of the cross-Government strategy and outcomes framework.

Focused investment in early intervention and prevention

There is a rich evidence base showing the cost benefits of investing in health, education, children's social care and welfare. Public services are caught in a cycle of increasing demand and late intervention, which means fewer resources for preventative work and fewer early intervention services³⁰. So far, the government has only committed to funding early-language interventions in primary schools³¹. Prevention and early intervention are crucial to ensuring disabled children and young people's health and development. A recent study found that less than 30% of families in the UK who have a child with a learning disability had access to targeted early intervention support in the preceding 12 months³². Disabled children often have to wait too long to get the help they need, and sometimes it is not until they have reached crisis. As the Lenehan 2017 Review said, "*there is something fundamentally wrong with a financial system that appears to reward crisis but disincentives early intervention*"³³. There is a clear case for the economic benefit of early intervention, improving the safety and outcomes for disabled children, and enabling them to be supported in their local area with their family. Joint planning and commissioning across health, education and social care plays an important role in early intervention services, helping create a more integrated approach that is more responsive to local needs.

Alongside this, the education system is not currently consistently meeting the needs of disabled children. This needs to be addressed by the government, through a test and learn approach to co-developing system-wide solutions for creating a more inclusive education system, in addition to implementing the Special Educational Consortium's manifesto asks³⁴.

Recommendations:

Invest more of our national wealth in improving the lives of children and young people that fully benefits those who are disabled; and spending strategically on early intervention and prevention.

- A commitment to increase the proportion of our national wealth that we invest in disabled children and young people.
- A commitment to eradicate child poverty once and for all.
- Wholesale reform of disabled children's social care backed by significant investment in early intervention services.
- A commitment to creating a more inclusive education system that properly supports disabled children and young people.

Conclusion

Disabled Children at the Table means:

- Committing to an ambitious cross-Government strategy and outcomes framework to drive improvements for babies, children and young people.
- A new approach to decision-making that places disabled children's needs, wishes and outcomes at its heart, involving disabled children and young people every step of the way.
- Investing more of our national wealth in improving the lives of disabled children and young people and spending strategically on early intervention and prevention.



References

- ¹ [Family Resources Survey: financial year 2022 to 2023 – GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2022-to-2023) Family Resources Survey: financial year 2022 to 2023 (Department for Work and Pensions, 2024)
- ² <https://labour.org.uk/updates/stories/labours-child-health-action-plan-will-create-the-healthiest-generation-of-children-ever/> Labour's Child Health Action Plan will create the healthiest generation of children ever (Labour Party, 2024)
- ³ https://assets.childrenscommissioner.gov.uk/wpuploads/2023/10/We-all-have-a-voice-Disabled-childrens-vision-for-change_final.pdf 'We all have a voice' Disabled children's vision for change (Children's Commissioner, 2023)
- ⁴ [The Good Childhood Report 2023.pdf \(childrenssociety.org.uk\)](https://www.childrenssociety.org.uk/what-issues-and-challenges/our-research/the-good-childhood-report-2023) The Good Childhood Report 2023 (The Children's Society, 2023)
- ⁵ [Failed-and-Forgotten-DCP-report-2023.pdf \(disabledchildrenspartnership.org.uk\)](https://www.disabledchildrenspartnership.org.uk/research/failed-and-forgotten-dcp-report-2023) Failed and Forgotten – Research by the Learning Hub at the Disabled Children's Partnership (Disabled Children's Partnership, 2022)
- ⁶ [The Longest Lockdown – Disabled Children's Partnership \(disabledchildrenspartnership.org.uk\)](https://www.disabledchildrenspartnership.org.uk/research/the-longest-lockdown) The Longest Lockdown (Disabled Children's Partnership, 2021)
- ⁷ [#LeftInLockdown – Pandemic Campaign and Research Overview – Disabled Children's Partnership \(disabledchildrenspartnership.org.uk\)](https://www.disabledchildrenspartnership.org.uk/research/left-in-lockdown) Left in Lockdown – Pandemic Campaign and Research Overview (Disabled Children's Partnership, 2021)
- ⁸ [The cost of caring – Family Fund](https://www.familyfund.org.uk/research/the-cost-of-caring) The Cost of Caring: A report exploring the challenges facing families raising disabled children (Family Fund, 2022)
- ⁹ [caring_more_than_most_full_report.pdf \(contact.org.uk\)](https://www.contact.org.uk/research/caring-more-than-most) Caring More Than Most: A profile of UK families caring for disabled children (Contact, 2017)
- ¹⁰ [All worked out - Final report - Jul23.pdf \(actionforchildren.org.uk\)](https://www.actionforchildren.org.uk/research/all-worked-out) All worked out? The limits of work as a route out of poverty and hardship (Action for Children, 2023)
- ¹¹ [Causes of poverty | CPAG](https://www.cpag.org.uk/our-research/cause-of-poverty) Cause of poverty (Child Poverty Action Group, 2024)
- ¹² [Failed-and-Forgotten-DCP-report-2023.pdf \(disabledchildrenspartnership.org.uk\)](https://www.disabledchildrenspartnership.org.uk/research/failed-and-forgotten-dcp-report-2023) Failed and Forgotten – Research by the Learning Hub at the Disabled Children's Partnership (Disabled Children's Partnership, 2022)
- ¹³ <https://labour.org.uk/wp-content/uploads/2024/06/Labour-Party-manifesto-2024.pdf> Change: Labour Party Manifesto 2024 (Labour Party, 2024)
- ¹⁴ Emerson, E. & Hatton, C. (2007) [Mental health of children and adolescents with intellectual disabilities in Britain](https://www.bps.ac.uk/journals/bjp/2007/43/43-3-mental-health-of-children-and-adolescents-with-intellectual-disabilities-in-britain), The British Journal of Psychiatry.
- ¹⁵ https://assets.childrenscommissioner.gov.uk/wpuploads/2023/10/We-all-have-a-voice-Disabled-childrens-vision-for-change_final.pdf 'We all have a voice' Disabled children's vision for change (Children's Commissioner, 2023)
- ¹⁶ [Early evaluation of the Children and Young People's Mental Health Trailblazer programme: Interim report \(birmingham.ac.uk\)](https://www.birmingham.ac.uk/research/early-intervention-of-the-children-and-young-peoples-mental-health-trailblazer-programme) Early intervention of the Children and Young People's Mental Health Trailblazer programme – Interim Report (University of Birmingham, 2023)
- ¹⁷ <https://assets.childrenscommissioner.gov.uk/wpuploads/2023/02/cc-response-to-persistent-absence-inquiry.pdf> Attendance is everyone's business – Children's Commissioner's submission to the persistent absence inquiry (Children's Commissioner, 2023)

- ¹⁸ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/657418/Good_intentions_good_enough_-_a_review_of_residential_special_schools_and_colleges.pdf Good intentions, good enough? A review of the experiences and outcomes of children and young people in residential special schools and colleges (Department for Education, 2017)
- ¹⁹ [ADCS Safeguarding Pressures Phase 8 Full Report FINAL.pdf](#) Safeguarding Pressures Phase 8 (The Association of Directors of Children's Services, 2022)
- ²⁰ [Failed-and-Forgotten-DCP-report-2023.pdf \(disabledchildrenpartnership.org.uk\)](#) Failed and Forgotten – Research by the Learning Hub at the Disabled Children's Partnership (Disabled Children's Partnership, 2022)
- ²¹ https://assets.publishing.service.gov.uk/media/5a820cdce5274a2e8ab573ca/Analysis_of_repeated_referrals_to_childrens_services_in_England.pdf Analysing repeated referrals to children's services in England – Research report (Department for Education, 2017)
- ²² [Failed-and-Forgotten-DCP-report-2023.pdf \(disabledchildrenpartnership.org.uk\)](#) Failed and Forgotten – Research by the Learning Hub at the Disabled Children's Partnership (Disabled Children's Partnership, 2022)
- ²³ [Independent review of children's social care – final report \(publishing.service.gov.uk\)](#) The independent review of children's social care – Final report (The Independent review of Children's Social Care, 2022)
- ²⁴ [Disabled Children's Social Care – Law Commission](#) Disabled Children's Social Care (Law Commission, 2024)
- ²⁵ [DCP-MANIFESTO-2024.pdf \(disabledchildrenpartnership.org.uk\)](#) A Manifesto for Disabled Children and their Families (Disabled Children's Partnership, 2024)
- ²⁶ [Change Labour Party Manifesto 2024](#) Change: Labour Party Manifesto 2024 (Labour Party, 2024)
- ²⁷ Pinney, A., Martin-Denham, S., Horridge, K. and Scott, N. (2024) [Putting together the data jigsaw: Linking administrative data sets on children with SEND](#), University of Sunderland.
- ²⁸ [Change Labour Party Manifesto 2024](#) Change: Labour Party Manifesto 2024 (Labour Party, 2024)
- ²⁹ https://assets.childrenscommissioner.gov.uk/wpuploads/2023/10/We-all-have-a-voice-Disabled-childrens-vision-for-change_final.pdf 'We all have a voice' Disabled children's vision for change (Children's Commissioner, 2023)
- ³⁰ <https://www.instituteforgovernment.org.uk/sites/default/files/2024-07/Fixing-public-services.pdf> Fixing public services – Priorities for the new Labour government (Institute for Government, 2023)
- ³¹ <https://labour.org.uk/wp-content/uploads/2024/06/Labour-Party-manifesto-2024.pdf> Change: Labour Party Manifesto 2024 (Labour Party, 2024)
- ³² Sapiets, S. J., Hastings, R. P., Stanford, C., & Totsika, V. (2022) [Families' Access to Early Intervention and Supports for Children With Developmental Disabilities](#), Journal of Early Intervention.
- ³³ [These are our children: a review by Dame Christine Lenehan \(publishing.service.gov.uk\)](#) These are our children – A review by Dame Christine Lenehan (Department for Education, 2017)
- ³⁴ [SEC Manifesto Asks .pdf \(councilfordisabledchildren.org.uk\)](#) Special Educational Consortium Manifesto Asks (Council for Disabled Children, 2024)

About CDC

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to other UK nations. We are the only national body that brings together the diverse range of organisations that work with and for disabled children to support the development and implementation of policy and practice. Our work impacts on over 800,000 disabled children and their families. CDC hosts Making Ourselves Heard, the IASS Network, the Special Educational Consortium and the Transition Information Network.

Find out more



councilfordisabledchildren.org.uk



facebook.com/councilfordisabledchildren



[@CDC_tweets](https://twitter.com/CDC_tweets)



linkedin.com/company/council-for-disabled-children/



INFORMATION,
ADVICE & SUPPORT
SERVICES NETWORK



TRANSITION
INFORMATION
NETWORK



MAKING
OURSELVES
HEARD



SPECIAL
EDUCATIONAL
CONSORTIUM

COUNCIL
FOR DISABLED
CHILDREN
Part of the family



United for disabled children

The Council for Disabled Children brings people and organisations together to drive change in society and deliver a better childhood for disabled children the UK. We interrogate policy, uncover evidence and develop more effective ways of supporting disabled children and their families. Together with National Children's Bureau we are united for a better childhood.

Let's work together: 020 7843 6000 | cdc@ncb.org.uk

London: 23 Mentmore Terrace, London, E8 3PN

Part of the family
NATIONAL CHILDREN'S BUREAU

National Children's Bureau is registered charity number 258825 and a company limited by guarantee number 00952717. Registered office: 23 Mentmore Terrace, London E8 3PN.