Policy Briefing

How Continuing Care for Children fails those with the most complex health needs (England)

Introduction

Too many disabled children with complex health needs and their families miss out on vital NHS-funded support due to a postcode lottery of care. This support, known as continuing care, provides tailored care packages for children with complex - often life-limiting - health needs that cannot be supported through normal health services. Families whose children receive this support live with a constant fear that this support will be withdrawn or reduced.

Children who need continuing care funding may have rare genetic conditions, severe epilepsy and/or complex physical disabilities or learning disabilities. They are dependent on others for all their care and require round-the-clock help with breathing, seizures, moving, suctioning, eating and pain management. Yet these children have weaker legal protection than adults who need health-funded support.

New data obtained by Contact suggests just 4,402 children in England get continuing care – a fraction of those that need support. More than half of children referred for a continuing care assessment are rejected. As a result, families are left to provide nursing and complex care for their child including managing ventilators, monitoring seizures, tube feeding and tracheostomy care.

What is continuing care for children and young people?

Continuing care is an ongoing NHS funded, tailored, package of care for children and young people under 18 with complex health needs due to disability, accident, or illness. It is like - but different from - continuing healthcare for adults.

A continuing care package can make a world of difference to children and their families. It can provide a child with nursing care at home, support with needs during the night, or specialist equipment like oxygen tanks and hoists.

How do children qualify for continuing care?

To qualify, a child must be assessed as having complex health needs that cannot be met by local or specialist health services alone. Even if a child has high needs, they still might not meet the high threshold for support. Integrated Care Boards (ICBs) are responsible for assessing a child's continuing care needs, but they can commission NHS trusts to conduct assessments and agree care packages on their behalf.

Continuing care packages for children can involve different agencies jointly providing (and funding) ongoing care including health, education, and social care. Health, social care, or education professionals can make referrals. Services are provided directly to children and families, or families can receive a direct payment of a Personal Health Budget to arrange services themselves.

A postcode lottery of care

More than half the children referred to continuing care rejected

New data[1] obtained by Contact from Integrated Care Boards (ICBs) shows over half of the most sick and disabled children in England referred for children's continuing care support were rejected. Of the 99,000[2] children in England living with a life-limiting or life-threatening condition, just 4% (4,402 children and young people) are in receipt of continuing care funding.

Despite the number of children living with a life-limiting condition rising by 205%[3] overall ICB spending on children's continuing care fell. We found wide variations in the number and amount spent on children's continuing care packages between ICBs with similar size populations, indicating a postcode lottery of care for families.

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[1] Data obtained by Contact's Freedom of Information request to 42 ICBs, February to May 2025

[2] Estimating current and future prevalence of life-limiting conditions in children in England, LK Fraser, 2021

[3] Ibid

Some ICBs fund more care packages per child population. NHS Birmingham and Solihull funded 434 care packages for child population of 335,179, while Hertfordshire and West Essex ICB with a similar child population, funded only 10, meaning a child with complex health needs in Birmingham is 42 times more likely to get continuing care support than a child in Stevenage.

Urgent reform needed to support vulnerable children

Contact believes every child with complex health needs deserves fair, consistent, and legally guaranteed support. We are calling for urgent reform, so no child is denied the care they need because of where they live. The NHS 10 year Plan implementation framework needs to explicitly address how it will transform care for this highly vulnerable group of disabled children.

Case study

Two of Leanne’s children were diagnosed with the rare genetic condition PCH Type 6.
Cory who sadly died last year, only received continuing care in the last two months of his life. His sister Mia,16, has the same progressive condition and relies on oxygen overnight for her respiratory problems.

Mia has multiple seizures a day and cannot move without being hoisted. She can only eat blended food via a tube. Her mother provides 24-hour medical and personal care.

Yet Mia has been repeatedly screened out for continuing care at the initial assessment stage. Social care provides 36 hours social care support a week, but this does not cover her medical support needs. Since the local respite centre closed, the family now get only get very sporadic overnight respite from a local hospice.

Detailed findings from our Freedom of Information requests to ICBs

Contact sent Freedom of Information Requests (FOIs) to 42 English ICBs in February 2025. Currently ICBs are not required to publish this data. Our requests asked for data on applications, assessments, care packages, joint funding, and total spending from 31 March 2021 to 31 March 2024. Our findings include:

- An estimated 4,402 children and young people are in receipt of continuing care funding – a fraction (4.2%) of the 99,000* children in England living with a life-limiting or life-threatening condition.

- In 2023-4, 53% of the children and young people referred for continuing care assessment in 2023-24 were denied support.
- Some ICBs spent significantly more on care packages than others: The average package across all ICBs is £79,000. In Gloucestershire the average expenditure on care packages was £159,434 in 2024, while in Birmingham it was £15,156.
- NHS Mid and South Essex spent 22 times more on continuing care for children than NHS Hertfordshire and West Essex despite having fewer children and young people living in their area. Children in Mid and South Essex are over 16 times more likely to receive a continuing care package than those in Hertfordshire and West Essex (see Table 1)
- A significant minority of ICBs are unwilling or unable to provide key data on children's continuing care packages. Only 15 out of 42 ICBs (35%) provided complete data in their response to our FOI request.

Data tables

Table 1. Comparing three neighbouring Essex ICBs, 2023/24

ICB	Child population	Total CCC Spend 23/24	Child population per capita CCC spend	Average per care package spend	No. of care packages	Care packages per 100,000
NHS Mid and South Essex	261,516	£5,977,584.	£22.85	£46,700	128	49
NHS Herts and West Essex	337,682	£ 271,107.	£ 0.80	£27,111	10	3
NHS Suffolk and North East Essex	194.936	£2,041,147	£10.47	£40,823	50	21

Table 2. Comparing ICBs in South West region

ICB	Child population	Total CCC spend 23/4	Child population per capita CCC spend	Average per care package spend	No. of care packages	Care packages per 100,000
NHS Bath and North East Somerset, Swindon and Wiltshire	193,178	£3,380,000	£17.50	£75,111	45	23

NHS Bristol, North Somerset and South Glos.	195,376	£4,504,094	£23.10	£128,688	35	18
NHS Cornwall and The Isles of Scilly	105,734	£2,401,393	£22.70	£114,352	21	20
NHS Devon	223,304	£5,337,507	£23.90	£56,781	94	43
NHS Dorset	140,020	£8,593,271	£61.37	£119,351	72	51
NHS Gloucestershire	140,964	£8,131,178	£57.68	£159,435	51	36
NHS Somerset	110,680	£1,458,171	£13.18	£58,327	25	23

Table 3. Comparing 3 West Midlands ICBs

ICB	Child population	Total CCC spend 23/4	Child population per capita CCC spend	Average per care package spend	No. of care packages	Care packages per 100,000
NHS Leicester, Leicestershire and Rutland	239,016	£3,707,271	£15.50	£31,686	117	49
NHS Notts and Nottinghamshire	232,935	£11,496,198	£49.30	£118,518	97	42
NHS Derby and Derbyshire	212,223	£4,099,000	£19.30	£45,044	91	43
NHS Northamptonshire	173,345	£5,353,427	£30.88	£97,335	55	32

Weaknesses in the children's continuing care legal framework

The legal framework for continuing care for children is weaker and less robust than for adult's continuing healthcare.

Adult continuing health care (CHC) is underpinned by a clear legal duty[4]. By contrast, children's continuing care is guided by the 2016 National Framework for Children and Young People's Continuing Care, non-statutory guidance that does not impose a legal duty in the same way[5]. This means children with the most complex needs are forced to rely on a weaker combination of policy guidance and statutory duties to get their needs met.

The Decision Support Tool (DST) and checklist tool used to assess adults are legally recognized and widely used to determine eligibility, with a strong emphasis on consistency and accountability.

The children's DST it is less prescriptive and more reliant on subjective professional judgment and multi-agency collaboration, which can lead to wide variations in the way it is applied by ICBs and the hospital or NHS trusts that conduct assessments on their behalf.

Table 4. comparing legal rights for children and adults.

	Adult Continuing Healthcare (CHC)	**Children's Continuing Care (CCC)**
Legal Status	Statutory duty	Non-statutory guidance
Assessment Tools	Legally recognised Decision Support Tool	Advisory Decision Support Tool
Appeals Process	Statutory right to request independent review process from NHS	Informal/local processes and the right to complain to the parliamentary and healthcare ombudsman
Funding	Fully NHS-funded	Joint NHS/LA funding
Transition Support	Ongoing provision	Risk of service drop-off

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[4] Health and Social Care Act 2012. National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012, which requires the NHS to provide CHC to adults who have a primary health need.

[5] The children and young people's continuing care framework (2016) draw on duties spread across the **NHS Act 2006, Children Act 1989:** Duty to safeguard **Children and Families Act 2014** and **Care Act 2014** (for transition

The need for transparency

Neither the Department of Health and Social Care (DHSC) nor ICBs publish data on continuing care for children. This means there is no single official source of data on how many children in England receive or are turned down for continuing care or how much is spent supporting this highly vulnerable group of disabled children.

Since April 2025, ICBs have been required to submit children's continuing data to the DHSC. Contact would welcome the DHSC publishing this data to provide greater transparency and oversight on how well continuing care meets the needs of our most vulnerable children.

Worryingly, our FOI survey found some ICBs were unable or unwilling to provide key data on continuing care packages. Nine out 42 ICBs responded to our request with insufficient data to allow any meaningful analysis; 18 provided partial data enabling some analysis while only 15 out (35%) provided complete data in their response.

Other common issues with continuing care funding for children and young people

Families report a range of additional problems with the continuing care process and provision. These include:

- Disputes between ICBs and local authorities over funding and responsibilities, leaving families without timely support.
- Problems with the assessment toolkit, particularly when assessing epilepsy.
- Insufficient funding for personal health budgets, leaving families unable to attract care staff to work with their child or ensure continuity of care. Some families get £13 per hour to pay health staff to help their child live – just 79p above the National Living Wage.
- Families live in constant fear that their child's continuing care package will be removed or reduced, even when their needs are unchanged.
- Ongoing shortages in health-trained care workers to provide support at home.
- Fear of support falling away at the child's point of transition to adult services
- A lack of advocacy and support for families navigating or challenging the continuing care process for their child.
- Lack of robust routes of redress to challenge packages or refusals to conduct a full assessment.
- Parents being unable to refer their child for continuing care assessments. Referrals are usually only accepted from a professional involved in their child's care.

Disputes between health and social care services

A joint funding approach between health and social care is vital for disabled children with the most complex health needs. These children and their families usually need social care support and significant help to access school.

Duties in section 26 of the Children and Families Act 2014, and the SEND Code of Practice set out clear expectations for joint commissioning and cooperation between health and social care. Local authorities and ICBs *must* work together to make Education Health and Care (EHC) plans work and that these arrangements *should* include an agreement on how continuing care fits with the EHC process *"to create a 'coherent package of care across health, education and social care for children and young people eligible for continuing care".*

However, ICBs and local authorities do not consistently follow these duties, or they treat them as optional. Contact supports families with children who have complex health needs denied continuing care and then are refused adequate support by local authorities as their needs are deemed too complex for social care.

Case study

Becci, mum to six-year-old Keir who has the rare genetic condition GABRB3, said:

"We have been trying to get continuing care for Keir for three years. He is under palliative, gastroenterology and neurology consultants at Birmingham Children's Hospital and requires 24-hour care, but we were told he does not meet the criteria.

Keir can have 3-4 seizures a night and is on morphine. I sleep downstairs with Keir, so he does not disturb his siblings and dad. I have to use a pump, nebuliser, suction, peg feeding and administer medication.

I was a head of department at school but had to give that up and now work at a performing arts group as much as I can.

I just want some help as it is not sustainable." Read Becci's story and watch her feature on Channel 4 News.

Contact’s FOI survey of ICBs found wide variations in joint commissioning to support children with complex health and social care in some areas.

- On average, 54% of children’s continuing care packages were joint-funded in 2023-4, down from 61% in 2022-3.
- The percentage of IBCs’ joint-funded care packages ranged from as little as 0% in NHS Black Country ICB and 8% in NHS Bath and North East Somerset, Swindon and Wiltshire to 100% joint-funded in others like NHS Dorset.
- Under 30% of care packages were jointly funded in 7 ICBs
- 15 ICBs were unable to tell us what percentage of their care packages were jointly funded.

The Law Commission’s 2024 consultation paper on disabled children’s social care found families frequently faced long delays for support due to funding disputes between ICBs and local authorities. Confusion over lines of responsibility leaves families providing round the clock care to their children with very complex needs in a support-free no-man’s land between health and social care.

Contact supports the Law Commission’s proposal for a legal duty to be placed on ICBs and local authorities to work together and its call for a clearer definition of the law* to show which agency is responsible for different types of support to prevent children falling through the cracks.

Problems with epilepsy assessments

Many children who need continuing care packages have drug-resistant epilepsy. Families have raised safety concerns over how ICBs use the Decision Support Toolkit (DST) to assess epilepsy risk.

The toolkit covers 10 domains of the child’s health and wellbeing, including mobility, cognition, behaviour, communication, and breathing and scores each with Low, Moderate, High, Severe, or Priority. A child may be eligible for support if they score ‘Priority’ in any domain or ‘Severe’ in multiple domains.

One assessment scored a child who had up to three tonic seizures every night, alongside occasional seizures including absences in the last three months that required carers to minimize the risk of harm, as having ‘moderate needs’. A child whose needs are assessed as ‘moderate’ is unlikely to qualify for continuing care unless they score severe in at least one other health domain.

The parent described the Decision Support Toolkit’s risk assessment as “dangerous”:

“There are serious risks for a child having three tonic-clonic seizures every night including sudden and unexpected death in epilepsy, not to mention the extreme and chronic sleep deprivation and trauma parents and carers experiences managing these seizures. “

Staffing and recruitment

Children with complex health needs often require bespoke care packages delivered by highly trained staff. There is a growing shortage of health-trained care staff including community children’s nurses and care agency workers. There is currently no dedicated national plan to grow and support the workforce delivering home-based care for children with complex health needs.

Families need support from specialist providers with the skills and confidence to deliver safe, consistent care to their child at home and community settings. Agencies often lack staff trained in paediatric medical technologies such as tracheostomy and gastrostomy care**.** This means families face lengthy delays or breakdowns in care packages due to staffing gaps.

Families who have personal health budgets say they are insufficient for recruiting care staff with the right skills.

Case study

“We have had massive issues in care hours not being delivered. When we complained about this the care agency withdrew from our care package with immediate effect citing 'a breakdown in the relationship' because we complained.

The carers who had worked on our package resigned on the spot then approached us asking if we would employ them directly via a personal health budget. We initially agreed to a reasonable level of direct payment which enabled us to recruit, but after year-on-year refusal to increase the level, it soon reduced to minimum wage levels, and we simply couldn't recruit.

We went through a very bruising complaint process where there were a lot of 'extreme arguments'. We were told: "it didn't matter if care packages weren't delivered as long as we were not left with literally nothing".

Father of twins who require 24/7, 3:2 care.

What needs to happen?

1. **Strengthen the law to end the postcode lottery of care and improve joint commissioning of care**

- Put the 2016 National Framework on a statutory footing (like the SEND Code of Practice) to ensure it is applied consistently across all ICBs and local authorities.
- Amend the NHS Act 2006 and Children Act 1989 to include explicit duties on ICBs and local authorities to work together to ensure joint commissioning and care planning for children with complex needs.
- Clearly define in law which agency is responsible for different types of support to prevent children falling through the cracks.

2. **Increase transparency**

- Introduce a legal duty for ICBs to report anonymized data on assessments, decisions, appeals, and outcomes to support transparency and service improvement.
- Commit to publishing children's continuing care data from April 2026 in the new All-Age Data Set (NHSE/DHSE).

3. **Provide advocacy to families**

- Establish a legal right to independent advocacy and a formal appeals process with time limits and external review to make sure already overburdened families can navigate the system and challenge decisions.

4. **Improve transition planning**

- Introduce a statutory requirement for transition planning starting at age 14, with joint accountability between children's and adult services, to end the poor management of transition to NHS Continuing Healthcare.
- Amend the Children and Families Act 2014 requiring inclusion of continuing care packages in EHC plans where applicable to ensure continuing care is more aligned with their plan.

5. **Improve assessments**

- Review epilepsy risk scoring in the children's Decision Support Tool used to assess children for continuing care needs to make them safer for children with treatment-resistant epilepsy.

6. **Address the shortage of trained care staff who can work with children with the most complex needs**

- Conduct a national review of workforce capacity and training needs in paediatric continuing care.
- Develop specialist training pathways for care workers, nurses, and allied health professionals.
- Invest in recruitment and retention incentives, especially in under-served areas.
- Ensure the children's continuing care workforce needs are including the NHS Long Term Workforce Plan and Integrated Care Board (ICB) strategies.
- Ensure personal budgets and direct payments funded adequately so families can recruit and retain trained staff.

7. **Ensure NHS Plan implementation explicitly addresses how its new neighbourhood models of care will improve support for children with continuing care needs**

- Ensure each new children's neighborhood team includes professionals trained in children's continuing care, such as children's community nurses, learning disability nurses, and social workers.
- Include a designated continuing care coordinator in each team to oversee complex cases and liaise across health, education, and social care.
- Set clear standards for response times when children's needs escalate and require teams to report on continuity of care, hospital avoidance, and family satisfaction for children with complex needs.

What can MPs do?

- Write to health ministers Ashley Dalton MP (child health) and Dr Zubir Ahmed (SEND and disabilities).
- Raise constituents' cases with ICBs and local authorities.
- Support legislative reforms that strengthen rights to continuing care and simplify access to services.
- Push for accountability by asking Parliamentary Questions or requesting debates on delays and inequalities in continuing care provision.

About Contact

Contact is the national charity for the UK’s two million disabled children and their family carers. Families face a constant battle to secure the help they need – a battle that costs time, income, relationships, and wellbeing.

We provide life-changing advice on benefits, social care, education, health and wellbeing and information on continuing care for children.

On average, parent carers lose £21,174 in household income each year, with 62% reducing or giving up work entirely due to caring responsibilities.

Help us to campaign for urgent reform of children’s continuing care by signing our petition.

Contact.org.uk

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