CHILDREN'S COMMISSIONER

Children waiting to leave hospital

March 2026

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Foreword from Dame Rachel de Souza

Recently I visited a children's hospital where I came across a little girl. She was tiny but said hello confidently. I asked who she was – and was told that she lived at the hospital. She was not too sick to leave, but her parents were unable – or unwilling – to take her home, and social care was not taking on responsibility for her care.

She did not attend nursery. She didn't leave the ward. Instead of cuddles and a bedtime story with her parents at night, she saw only medical staff.

She inspired this report. I have used my statutory powers as Children's Commissioner to collect the first data on how many more children like this are in our system.

Her story is one of a total systemic failure and a breach of her rights. And she is not alone.

My data shows that within this generation of children, more than 1,000 children spent over a year in hospital. Those with long hospital stays are disproportionately from deprived backgrounds or from ethnic minorities.

Moreover, many of the children spending long periods of time in hospital are doing so not because they need to, but because safe or appropriate options have not been found for them outside of the ward. Reasons for long stays include delays in setting up care packages, a lack of children's social care placements, and housing issues. This is a harrowing thought, particularly when we know that many of the children spending these long periods in hospital have life limiting conditions.

Some of these delays in discharging children from hospital go on for months, even years – and while this is largely acknowledged by those working in the sector, the scale of the problem is unknown. This is because the data mostly isn't being collected. As a result, neither the government nor the health service knows definitively how many children are waiting in hospital to be discharged, how long they stay for and how many bed days could be saved.

A lack of investment in community services and bottlenecks in the wider system, so crucial for determining children's outcomes, are leaving children and their families in impossible situations.

For all the attention in the public sphere given to adult hospital waiting times, adult social care, and adult wards, children are rarely mentioned. Until I carried out this research, there was no public record of how many children are admitted to hospital in a year, or how long they are spending in hospital.

As Children's Commissioner, I visit children's hospitals and hospices routinely, meeting with patients and the fantastic, inspiring staff caring for them. There is no question that as a country we want the best for our most vulnerable children, but the systems around them are simply not set up to support the realities of their lives. This fails children who want to be able to go to school, spend time with their siblings and friends, who want opportunities to play and be joyful, and fails families who are unable to maintain a livelihood, family time or community connections because they have no support around them.

As a clinician told my team about a family they worked with: *"This mum's two children have virtually had to live in hospital because we're not able to provide enough support for her to be always at home, or in a safe place that allows them to be out of here. And all mum has wanted to do for her second child is have a better quality of life with her and not constantly be stuck in hospital."*

In short, children are losing out on the innocence of childhood - and parents, instead of getting to just be Mum or Dad enjoying the ordinary, daily moments of family life, are taking on difficult long-term 'carer' roles.

And for children without families to advocate for them the situation can be even bleaker – like the little girl I met on that ward, left to navigate her earliest years alone.

Even for those children with loving families, they may live far from the hospital or have other caring responsibilities. Professionals and families both told my team about the importance of play and activities for children living in hospital, but both raised concerns that among the examples of brilliant practice like external trips or in-hospital cinemas, there were many long and empty hours for children on wards.

As one mother told us, *"A child is still going to, no matter how sick they are, they're still going to want to play, they want to learn something"*

At its heart, this is a report that shines a light on the often-hidden stories of children whose complex needs and circumstances mean their childhoods are far from ordinary. It is a spotlight on the dedicated professionals fighting every day to give them safety, dignity and the chance to simply be children, and on the families providing care around the clock, intensive care to their children with insufficient support.

It is a report that looks at the choices we face as a country – a country in which advances in science and hospital care have changed the outcomes of many thousands of children who have life-changing illnesses and life-limiting conditions, yet one where a lack of investment in children's community and social care has left both families and facilities on their knees.

It is the same story we see across children's services. Children's social care leaders talk of a severe lack of options to accommodate vulnerable children in their care, forcing them to pay extortionate costs for poor-quality – often illegal – placements. School leaders have told me they are deeply concerned about the gaps in support from wider community services, and deeply concerned that schools are being left to plug those gaps alone.

The question for policy makers to grapple with now is whether we continue to expect families and hospitals to shoulder impossible burdens of care, or whether we build the coordinated, compassionate system children deserve – with investment to match.

Content warning

This report is not intended to be read by children. This report discusses serious and upsetting themes relating to children who are ill and in pain, children who died and children who have hurt themselves.

If you are affected by the themes covered in this report, the following organisations can provide you with expert information, advice and support:

shout
85258
here for you 24/7

Shout provides 24/7 urgent mental health support: giveusashout.org, text SHOUT to 85258

NHS

You can also contact your local **NHS urgent mental health helpline** at nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline or call 111 for 24/7 advice.

Help at Hand

Help at Hand is the Children's Commissioner's advice and assistance service for children in care, children living away from home, children with a social worker, and care leavers.

The team can be contacted by phone, email, or via the Children's Commissioner's office website, either directly by children, or by their advocates, professionals, or family members on their behalf on **0800 528 073.**

The team offers support and representation to children and care leavers whose rights have been breached. This may involve contacting their social workers and responsible children's services managers, NHS professionals, staff in secure settings and, where necessary, government officials in departments with responsibility for children. In the most serious cases where a resolution has not been found, the Children's Commissioner writes personally to the local authority's Director of Children's Services, or the responsible directors in other agencies.

Acknowledgments

The Children's Commissioner's Office would like to extend sincere thanks to the parents and professionals that spoke to us for this project in our visits and interviews – by keeping the anonymity needed to conduct our interviews we cannot list them by name but are indebted to their time and huge consideration that they gave to this project.

We want to particularly thank the parents who spoke to us, generously telling us about their child's experiences and what needs to change. This includes parents whose children have tragically died, and took the time and extraordinary effort to tell us about their child's lives. This also includes parents whose children were still in hospital when we spoke to them, who despite the distressing circumstances they were in, took time to tell us about what their child had been through and the barriers they faced to going home.

The office engaged with a number of individuals and organisations as part of this project, who were generous in answering our questions, pointing us in the right direction and making connections for us. This includes people at: The five hospitals the office visited, NHS England, the Children's Hospital Alliance, the Royal College of Nursing, the Royal College of Paediatrics and Child Health, London Innovation and Improvement Alliance, London Borough of Camden, London Borough of Newham,

Together for Short Lives and their Advisory Council, Roald Dahl Marvelous Children's Charity, WellChild, Starlight, Children with Medical Complexity Nursing Network, King's College London, Department of Health and Social Care, Department for Education, Department for Business and Trade.

Executive Summary

Every year millions of children in England spend time in hospital. Most children are in hospital only for a short period, often just after they are born or during brief periods of illness. However, for a number of children, hospital becomes a place they spend months and sometimes years of their lives.

For the first time, this report shows how long children spend in hospital over their childhoods through new analysis of NHS data. This report sets out why children are waiting to be discharged and what their experience of delayed discharge is like.

For some children, time they spend in hospital waiting to be discharged is avoidable. That is particularly true for two groups of children.

First, children with serious and complex medical needs. While advances in modern medicine are making a monumental difference in giving them a stronger chance in life, the systems that surround these children – community and primary care, children's social care, palliative care, housing and education – have not kept pace. The Children's Commissioner's office has focused on what this means for children who are waiting in hospital, ready to be discharged.

Second, for some children admitted to hospital with social, emotional, behavioural and/or mental health needs. For children admitted with these needs but who do not meet the criteria for inpatient mental health services, their experience waiting in hospital for the right care and support in the community is similarly rooted in challenges facing health, social care and education which has resulted in them being let down, and being admitted to hospital in crisis - waiting for the right therapeutic support in the community.

This report brings together data on how long children spend in hospital across their childhoods, alongside the voices and experiences of families, health and care professionals working in hospitals, hospices, community nursing teams and care providers. It sets out the issues facing children whose hospitals stays are being prolonged or more frequent because the support they need to be in the community is not in place.

Key findings

1. **There are thousands of children spending long periods of time in hospital**. In one cohort of children[i], the office found that 260,141 children spend three weeks or more in hospital over their childhoods, 34,846 spend over three months, and 1,342 spend over a year. More than double the proportion of children from the most deprived backgrounds are spending more than three weeks in hospital compared to the least deprived children. Asian and Black children are more likely than white children to spend more than three weeks in hospital.

2. **Children are facing delays being discharged from hospital**. Across the country, children are waiting months and years for the right support in the community, suitable housing or a social care placement. Currently, the NHS does not consistently gather or publish data on the number of children in hospital who are ready to be discharged so the government and health service do not know the extent of this issue. One hospital that does collect this data reported to us that **5% of their children were medically ready to leave in June 2025.** Across the system, this means that huge numbers of children are stuck in hospital. The office estimates that **50,000 to 100,000 bed days are lost per year. That is hundreds of children in hospital each day who do not need to be there.**[1]

3. **Hospital stays mean that children can miss out on family life, play and education. Long inpatient stays for children puts families under extreme stress and financial hardship.**

4. **Children who are medically fit to be discharged are forced to wait in hospital for a range of reasons. Including:**
    - **Disjointed and complicated processes** in children accessing a 'package of care' resulting in children waiting for long periods to be assessed, receive funding and have care put in place so that they can go home. Children are being caught in funding battles between health and

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[i] This includes anyone who was aged under 18 as at 30th November 2024. The data includes children who were born in hospital and children who died in hospital including children who died (who, had they survived, would have been aged 0 to 17 on 30th November 2024)

social care, are subject to a postcode lottery of how much support they receive and are at the mercy of an underfunded and fragmented social care market.

- **A lack of care placements** for children with the most complex needs.
- **Inconsistent and under resourced healthcare in the community.** Children's community nursing capacity varies widely, and some children have to travel for hours to appointments and to get the treatment they need.
- **Inconsistent access to palliative and end of life care due to underfunding and variable commissioning practices.** In many parts of the country, children do not have access to the specialist care, and 24/7 care they may need to be at home.
- **Health, social care and education systems being fragmented and opaque**, making them hard for families to navigate.
- **A lack of therapeutic care** for children with social, emotional and mental health needs.
- **A lack of suitable housing**, and **long waits for home adaptations and equipment.**

Key recommendations

The problems facing these groups of children are by their nature complex but that should not preclude children and their families from good, joined up support. Many face challenges where the thresholds for support are not clear cut, they often rely on multiple services to provide support, and those services are required to work with the child and their wider family. However, while some children are benefiting from service working well together, the current approach doesn't give all children the best chance of getting the help they need. Our key recommendations are:

1. **The Department of Health and Social Care and Department for Education must develop a joint commissioning framework for health services, local authorities and schools to provide care for children with the most complex needs in the community.** This should enable strategic planning of support for these children, facilitate joint working, and ensure some of the most

vulnerable children are smoothly discharged from hospital into the community and are well supported no matter where they live.

2. **The Department of Health and Social Care and Department for Education should develop a national strategy for how to improve children's homecare services** and not let this crucial part of children's services fall through the gaps of current policy making.
3. **The NHS Neighbourhood Health Plans must ensure that all children are able to access 'virtual wards'**. It is essential that the move towards more local, integrated provision considers the particular experiences of children with complex medical needs.
4. **The Department for Education must introduce a Single Unique Identifier for children that allows all children's records to be matched across all health, social care and education data systems**. This should sit alongside a digital platform that allows families and, where necessary, professionals to access a child's information.
5. **Children and families must be allocated a key point of contact who can coordinate the delivery of children's treatment and care in hospitals and the community** – including social care and education. This will look different for children depending on the type and level of needs that they have.
6. **The Department for Health and Social Care should therefore mandate that children aged 16 to 17 are eligible for paediatric care as they are transitioned to adult care** to ensure they do not fall through the gaps in services, especially in palliative and end of life care.
7. **The Department for Health and Social care must sustainably fund palliative and end of life care and ensure Integrated Care Boards (ICBs) are meeting their legal duties to arrange palliative care services.**
8. **The Department for Heath and Social Care and the Department for Education must work together to ensure sufficient care placements for children who cannot be safely cared for at home.** These must be genuinely therapeutic and able to care for children with high levels of needs.

9. **The Department and Health and Social Care must collect and publish data on children's discharge delays and Children's Continuing Care.**

10. **The government must provide schemes which families can access to support them with the additional costs they face due to their child being in hospital long-term,** including travel to hospital, food and access to WiFi.

11. **The Department for Business and Trade should consult on introducing a form of paid leave for parents during times children are in hospital for an extended period, and when children are approaching their end of their lives.**

12. **The NHS guidelines for commissioning and designing health play services must be implemented to embed play into children's healthcare**

13. **Opt-out advocacy should be extended to all children with a statutory entitlement** to ensure children who are waiting to be discharged from hospital – children who might be non-verbal or need support to communicate – are appropriately advocated for. This should be delivered through a new national advocacy service.

14. **All children in, and preparing to leave hospital, should be able to access education**. The proposed new 'Specialist Support Packages' must work for children undergoing intensive treatment and those with fluctuating or developing needs.

15. **The government should increase the Disabled Facilities Grant in line with inflation** to ensure inaccessible housing is not a barrier to children returning home.

Introduction

This report is about children who are in hospital, especially when they do not need to be, and the problems in the system that are stopping them from being discharged as soon as they are medically ready to leave. It is also a report which aims to shine a light on the experience of children in England with some of the most complex needs, who need more attention from politicians, policy makers and those managing public services.

Background

Who are the children facing discharge delays?

Through scoping conversations with health professionals, academics and charities, the office identified two groups of children at the sharp end of discharge delays in hospital. Throughout this report we refer to children with 'complex medical needs', 'complex needs' and 'social, emotional and mental health needs'. These are broad terms we are using to describe the experiences of children with unique, variable needs and circumstances who we want to include in this report.

The cohort of children this report's qualitative findings broadly focus on are:

1. **Children who have complex medical needs, including conditions that are life limiting and life-threatening, who spend long periods and / or have frequent spells in hospital.**

A definition for childhood medical complexity is being developed, as there is no standard definition used by NHS England.[2] Guidance published by the Royal College of Paediatrics and Child Health (RCPCH) includes a description of the health issues children can be facing, along with a case study to illustrate what this can mean for children coming into hospital Emergency Departments.[3]

'*Children and young people can have complex medical needs as a result of their underlying condition. Children who are born too early may have the long-term consequences of extreme prematurity; others have inherited conditions, chronic illness or sustain life changing injury. The spectrum of conditions includes cerebral palsy with significant disability, intractable epilepsy, autism, chromosomal and genetic* *conditions, chronic lung disease, complex metabolic disease, complicated cardiac disease, oncology or post-transplant.*

There are children who are oxygen dependent, have tracheostomies and need regular suction. Some require enteral feeding, either nasogastric or by a gastrostomy or jejunostomy. Poly-pharmacy with unfamiliar medication is not unusual. New technologies such as vagal nerve stimulators, deep brain stimulators or intrathecal baclofen pumps are increasingly frequent. Palliative and end of life care plans may be in place.'[4]

Case study provided by the Royal College of Paediatrics and Child Health

'David' is eight years old. As a result of a complication at birth he has myoclonic epileptic encephalopathy, severe learning difficulties, and intractable epilepsy. He is hypotonic, unable to sit independently and uses a wheelchair. He is able to follow lights and responds to his parents' voices. David has had a Nissen fundoplication and bilateral femoral osteotomies. He has a breathing tube (a tracheostomy) and a feeding tube (a gastrostomy).

David has had frequent chest infections requiring intravenous antibiotics and has been admitted to hospital on many occasions, sometimes to a high-dependency area. David requires frequent suctioning of his breathing equipment and his family monitor his oxygen saturation.

David has seizures two or three times a day and has a seizure management plan in place for giving him medicine when these are longer than usual. David's regular medications include three anticonvulsants, antispasmodics and prophylactic antibiotics. He is on a ketogenic diet.

David has been to the Emergency Department on 30 occasions in the last three years, often with prolonged seizures, chest infections or floppy episodes. His parents are usually present but sometimes he comes by ambulance with a carer from his school.

David's family are very caring and very anxious about him but are also reluctant to see him admitted to hospital. Intravenous cannulation can be difficult and sometimes his parents ask if this can be avoided.

2. **The second group of children are children with social, emotional, behavioural and mental health issues who are admitted to hospital but do not meet the criteria for children's inpatient mental health services and are waiting for the right form of care and support in the community.**

The children the office focused on for this report are broadly part of a cohort the Nuffield Family Justice Observatory describes as 'children with complex needs in complex circumstances'. This means children who have behavioural and emotional needs that may be associated with past and ongoing childhood adversity, including abuse and neglect, poverty, racism, as well as complex trauma. Children may have a learning disability or be autistic, and have difficulties with their mental health and emotional regulation. Many children are at risk of exploitation. Their behaviour can put them and others at serious risk of harm.[5]

Professionals told us children with these complex needs often fall through gaps in services, and may have been failed by health, children's social care and education services. Their families may not have sought help from services or not be known to them before coming to hospital in crisis.

The following pen portrait is fictitious but serves to illustrate commonalities among the experiences of children who the Children's Commissioner's advocacy services, Help at Hand, have worked with who have had extended stays in hospital while awaiting the right support in the community.

Case study combining experiences of children worked with by the Help at Hand service

'Serena' has a learning disability and autism. She lived with her family until age 11 and then went to a residential special school and became a looked after child under Section 20. After two years, she started to become increasingly distressed and displayed behaviour that was challenging for the staff and other students, often requiring her to be restrained. The school served notice, but the local authority was unable to find an alternative specialist setting to meet Serena's needs. After a particularly difficult episode, Serena spent an extended time in hospital, although she did not meet the criteria to be held under the Mental Health Act. Following pressure to discharge her, the local authority arranged a placement in an Airbnb, with 4:1 care and a deprivation of liberty order. Stayed there for nine months, attempting to abscond several times and experiencing frequent episodes of restraint. Ultimately, the local authority worked with a care agency to purchase a property and create a bespoke solo placement for her, with an application for Ofsted registration, and with the deprivation of liberty order remaining in place.

Discharge delays in NHS paediatric care

No child should have to spend prolonged periods of time waiting to be discharged from hospital. Most importantly because they should be enabled to spend time in their communities, with their families, and those they love. But also because it affects the children who are waiting to access healthcare in hospital. For some children who need a place of safety, hospitals will always be there for them – but this should always be in the interests of the child and never prevent them from building a life in the community.

There are 153 hospitals providing inpatient care and some elements of High Dependence Care (HDC) to children in England. Of those, 23 provide intensive care to children. Around 2% of children who are admitted to hospital are admitted to a paediatric intensive care unit (PICU), and 8%-10% are admitted to HDC.[67]

The office's conversations with hospital leaders and professionals painted a picture of Hospital Trusts' paediatrics under pressure, with daily bed meetings, rigorous winter planning and escalation routes. It is essential that only children who need to be in hospital are there, yet the issue of 'delayed discharges' of children is poorly understood at the national level.

- Despite the work being done at local and regional levels, there is insufficient national data on children's discharge delays. **NHS England collects limited data on this and does not publish data on children's discharge delays.**[8] The sector knows that there are children who are facing discharge delays that go on for months and sometimes years, yet the extent of this issue cannot be seen in the data.[ii] **This means that quantitatively, the government and health system does not know how many children are waiting in hospital to be discharged, how long they stay for, or the cause of delays.**

- **According to published NHS statistics, demand for children's intensive care is increasing year on year** by 5%, and around 8% of elective care admissions are cancelled due to a lack of intensive care beds.[9][10] A lack of beds can also affect flow through hospitals, affecting children needing elective and emergency care.[11] Capacity issues at peak times also means that children have to travel across the country for a bed.[12] Additionally, current metrics do not reflect the full picture of demand and capacity in paediatric intensive care due to issues with data collection and reporting.[13] Available data shows that a bed in intensive care costs an average of £1,800 per day.[14]

The office heard of variable resources in hospital trusts for the work it takes to discharge children. Some hospitals had teams coordinating children's journey home, in others this work was dispersed across clinicians. Some professional spoke about the virtual ward systems being developed or in place that, for example, enabled children to be treated and monitored at home when they had an infection. Discharge teams and development of virtual wards (which requires investment in care in the community) are

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[ii] The office saw data from Hospital Episodes Statistics shows that thousands of child bed days are being lost to delayed discharge annually out of 13 children's hospitals looked at, but approximately 89.5% of admission spells had no value recorded in the discharge ready date field (with completeness varying by provider).

health system issues that can make a difference – however, what the office repeatedly heard was that change is needed outside hospital walls to make the changes needed for children with some of the most complex needs.

Scope

The Children's Commissioner's office has sought to quantify children's lengths of stay in hospital, identify the reasons behind children's delayed discharge from hospital, and understand the experiences of children with stays in hospital who face barriers to being discharged home, or to a preferred setting. The following areas and themes are therefore not part of this report:

- Preventing children being admitted to hospital, where possible, is essential, but this report is focused on children who have been admitted and how they can go home once medically ready.
- Parents spoken to for this report were overwhelmingly positive about the care children receive when they are in hospital – speaking about the dedication and expertise of staff across the board. This is certainly not the case for all children and families, so it is important to note for this report that this is the context in which our interviews with parents were conducted.
- In the absence of sufficient data on children's delays leaving hospital after being medically fit to be discharged, the office requested data from NHS England's Hospital Episode Statistics dataset to quantify children's lengths of stay, and the characteristics of children with long stays in hospital. This means that the report does not look at children's lengths of stay in mental health inpatient settings. Something the office will be looking at in more detail in the coming months.
- This report does not seek to assess children's medical care and treatment.

1. Numbers of children who spend a long time in hospital

Using the Children's Commissioner's powers under the Children Act 2004, the office acquired data from NHS Hospital Episode Statistics (HES) dataset. The office asked the HES team for details of hospital stays for children who, on 30th November 2024, were children (aged 0 to 17), including children born in hospital and children who spent time in hospital who had very sadly died.

Through new analysis of this data, the office found that on average, children spend 3.5 days in hospital over their childhoods. Some children spend much longer.

The office focused on children with long lengths of stay in hospital. As there is no official definition of a long stay, the measure the office chose to use was 21 days and over because of its use in some NHS statistics on all age lengths of stay.[15]

1.1 Children's lengths of stay over their childhood

Most children are born in hospital, so it is common for most children to spend some time, even if very brief, as an inpatient (see Annex B).[16] There are some children who spend substantially longer in hospital over their lifetime. 260,141 children (1.9%) spend 21 days or more in hospital over their childhoods (see Table 1).

Table 1. Number of children aged 0 to 17 (or would have been had they not died) who were admitted to hospital at any point up to 30/11/2024, by cumulative lengths of stay in hospital.

Time spent in hospital over lifetime	Number of patients	Percentage (%) of patients admitted to hospital
0 to 7 days	10,908,635	93%
8 to 20 days	599,892	5.1%
21 to 60 days	190,456	1.6%
61 to 90 days	34,839	0.3%
91 to ~1 year	33,504	0.3%
~ 1 to 2 years	1,197	0.01%
~ 2 to 3 years	97	0.001%
~ Over 3 years	48	0.0004%
Total	11,768,668	100%

There are some children spending years in hospital: 1,342 children had spent over a year in hospital over their lifetime.

The office was told by professionals about children who had spent years in hospital, including one child who had spent their whole life (over four years) in hospital. The data shows how the proportion of children experiencing years in hospital is small but nevertheless an experience had by far too many. To note, children who were still in hospital at the time of the office's data request are not included, as clinical coding for each episode takes place on discharge.[17]

The office found that over the past ~18 years, 5,212 children over the age of one had spent more than 10% of their lives in hospital (see Table 2).

Table 2. Number of children aged 1 to 17 (or would have been had they not died) who were admitted to hospital at any point up to 30/11/2024, by cumulative length of stay as a percentage of the patient's life.

Percentage of life (%)	Number of patients over the age of 1	Percentage of patients (%)
0% to 2%	11,089,368	99%
2% to 5%	54,092	0.5%
5% to 10%	13,536	0.1%
10% to 20%	4,232	0.04%
20% to 50%	915	0.01%
50% to 100%	65	0.0006%

Total	11,162,208	100%

For babies under one, long stays after birth make up a greater proportion of their lives. The office found that thousands of babies spend over one fifth of their lives in hospital (see Table 3).

This means that over the past ~18 years, **14,251 children have spent more than 10 per cent of their young lives in hospital, while 408 spent half their lives there**.

Table 3. Number of children under age 1 (or would have been had they not died) who were admitted to hospital at any point up to 30/11/2024, by cumulative length of stay as a percentage of the patient's life.

Percentage of life (%)	Number of patients under age 1	Percentage of patients (%)
0% to 2%	567,169	94%
2% to 5%	22,002	3.6%
5% to 10%	8,250	1.4%
10% to 20%	5,431	0.9%
20% to 50%	3,265	0.5%
50% to 100%	343	0.06%

Total	606,460	100%

1.2 Who are the children who have long hospital stays?

1.2.1 How long children spend in hospital by ethnic background

Asian and Black children, and children of “other” heritage[iii] are more likely to spend over three weeks in hospital over their childhoods (see Figure 1).

Figure 1: Percentage of patients spending a cumulative total of over 20 days in hospital (at any points up to 30/11/2024) compared to general population benchmarks, by ethnic group

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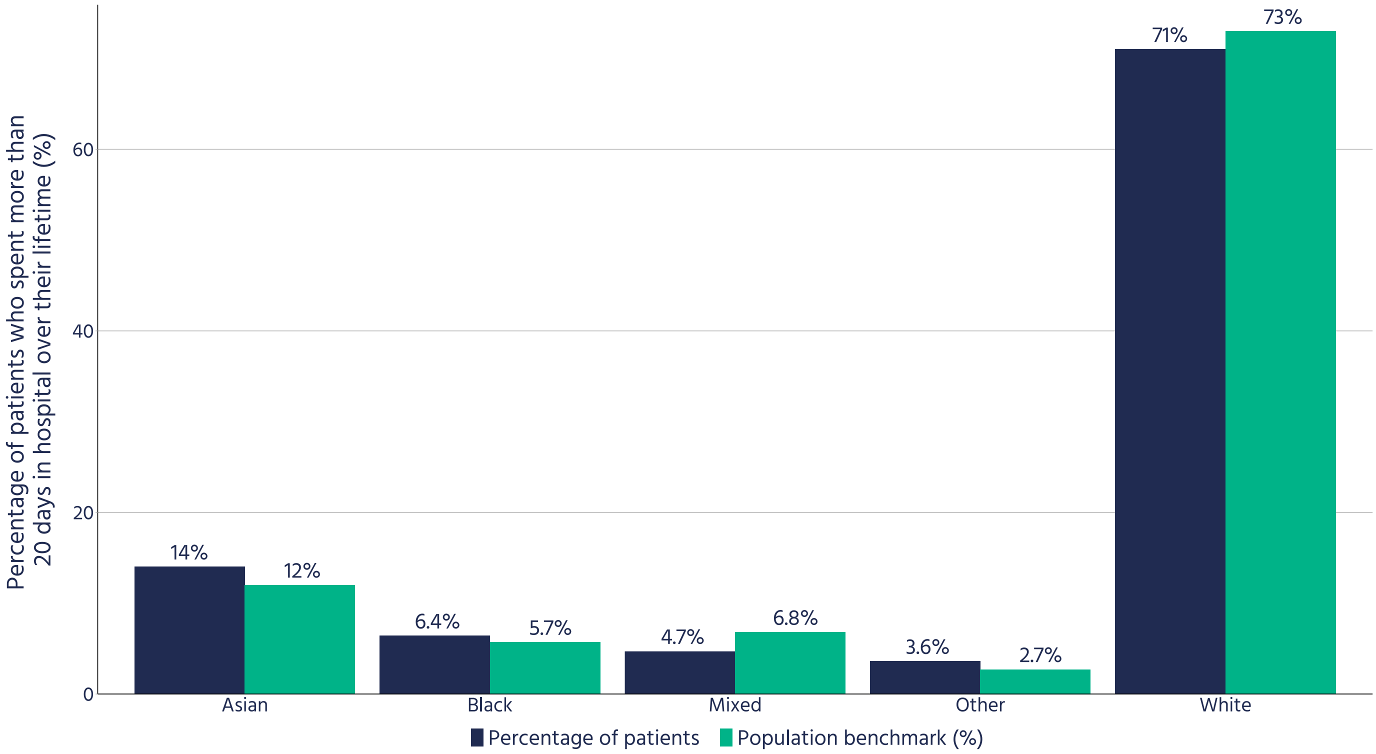
[iii] In the NHS system, the "other ethnic group" category is a catch-all term used for individuals that do not fit the basic ethnic categories given (see Figure 1) including those who identify as Arab, Hispanic/Latin American, Jewish and Sikh amongst others.



Of children who spend three weeks or more in hospital, Black and Asian children spend, on average, 6 to 7 days in longer in hospital than white children (see Table 4).

Table 4: The mean number of days children (with long stays over three weeks) spent in hospital over their lifetime, by ethnic group.

Ethnic group	Number of patients	Percentage of patients (%)	Mean time spent in hospital (days)
Black	14,756	6.4%	61.2
Asian	32,198	14%	60.0
Other	8,285	3.6%	58.2

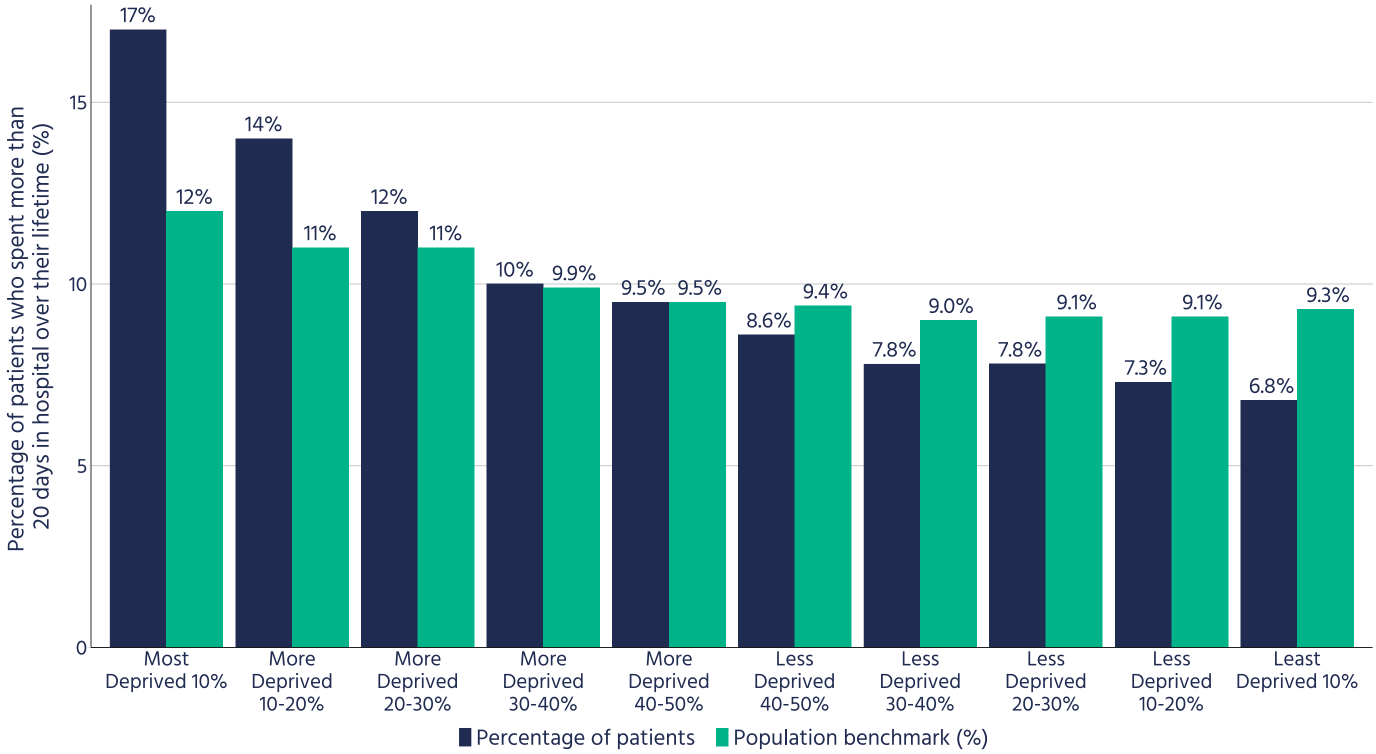
Mixed	10,912	4.7%	57.3
White	163,922	71%	54.1
Total	230,073	100%	55.4

Note: This table looks at all hospital stays over children over their lifetime. This data only includes those admitted to hospital at any point up to 30/11/2024 who had stays over three weeks.

1.2.2 How long children spend in hospital by deprivation level

Children living in more deprived areas are more likely to have long hospital stays over their childhoods. More than double the proportion of children from the most deprived backgrounds are spending more than three weeks in hospital compared to the least deprived children (see Figure 2). As shown in section 3.4, housing and homelessness are some of the leading causes in children's discharge delays.

Figure 2: Percentage of patients spending a cumulative total of over three weeks in hospital (at any points up to 30/11/2024) by deprivation index, compared to general population percentages by deprivation decile.



Note: Deprivation level based on the Indices of Multiple Deprivation Index.[18]

1.2.3 The diagnoses of children spending long periods of time in hospital

Of the 225,793 hospital episodes where children spent more than three weeks in hospital over their childhoods, 161,420 (71%) were for birth related issues, 57,015 (25%) for chronic conditions and 2,506 (1.1%) for mental health conditions.*

Professionals told the office that among children in the cohorts this report is focused on, they may not have a diagnosis to explain their complex medical needs. The data the office received from the NHS only included the primary diagnosis field completed for a child's spell in hospital. This means that the data presented in this report does not show a full picture of the diagnoses and complexity of diagnoses children may be admitted to hospital with.

The office found the most common diagnoses for children spending over three weeks in hospital with physical health problems for children include various forms of leukaemia (myeloid and lymphoid), cystic fibrosis and sickle-cell disorders (see annex Table A2). For birth related stays in hospital over three weeks, the most common diagnoses include necrotizing enterocolitis of foetuses and newborns and chronic respiratory disease originating in the perinatal period (see annex Table A3).

Among children who stayed in hospital over three weeks those with a mental health condition(s) have longer mean stays than children in hospital with a physical health condition(s).[iv] Of children in hospital with a mental health condition(s), the most common diagnoses include eating disorders, pervasive developmental disorders, depressive episodes and unspecified nonorganic psychosis (see annex Table A4).

**Birth related and mental health conditions are defined using the ICD-10 classification of diseases*[19] *which have chapters dedicated to both. Chronic conditions are defined using the Hardelid classification*[20]*, the industry standard for identifying complex and long-term conditions. Children who were born in hospital are included in these counts.*

1.3 Hospital level data on children's delayed discharges

There is insufficient data on children's discharge delays. NHS England collects limited data on this and does not publish data on children's discharge delays.[21] The sector knows that there are children who are facing discharge delays that go on for months and sometimes years, yet the extent of this issue cannot be seen in the data. To better understand the extent and nature of delays, the office looked for local data and received information from five children's hospitals about children in hospital who were waiting to be discharged, and the reasons behind the delays. There were children in every hospital waiting to be discharged.

It is deeply concerning that there is no consistent data collected on children in hospital who are ready to be discharged. The lack of data means that for this report it has only been possible to make a rough estimate of the number of bed days a year lost. The office extrapolated from the 5% figure for children in hospital being medically fit for discharge supplied by one children's hospital in the case studies below

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[iv] The dataset does not include childing staying in inpatient mental health wards.

and applied it to all occupied paediatric beds, to **give an estimate of 50,000 to 100,000 bed days lost per year. That is hundreds of children in hospital each day who do not need to be there.**[22]

The following section brings together a series of case studies to illustrate the nature and scale of these delays. Each case highlights the real world implications for children and families, while the accompanying data provides insight into systemic pressures. While the office does not know the medical conditions of the children reported on below, children that are awaiting a care package, for example, are likely to have serious and complex needs.

Children's Hospital A

One hospital shared with the Children's Commissioner's office that of 140 children staying in the hospital in June 2025, 7 (5%) were continually ready for discharge. The hospital had in months previous implemented an escalation process for housing delays, and had not seen delays due to housing since. Children's delayed discharge related to safeguarding concerns being assessed by children's social care, a wait for a suitable long term residential placement, and most frequently – waiting for assessment and arrangement children's care packages.

One of the children who needed a care package arranged had **four care providers**[v] **during their over two year admission, due to changes in local agencies and agency instability**. This included issues recruiting, training and retraining staff.

Reason for delay	**Number of children**	**Length of delay**
Care package arrangements	5	Over 4 weeks

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[v] This is covered in section 3.1. The majority of home (also known as domiciliary) care for children is provided by private companies who employ nurses and care workers to deliver personal care to children at home, at school and in the community ('care providers').

Awaiting a long term residential social care placement	1	Over 4 weeks
Safeguarding concerns	1	Over 4 weeks

Children's Hospital B

This hospital had seven children who were waiting to be discharged in June 2025. Additionally, three children were awaiting rehabilitation. The office was told of regional disparities in access to neurorehabilitation meaning children had to travel huge distances for rehabilitation (for example, the West Midlands to the South East), incurring costs some families cannot afford.

The most common reason for discharge delay was homelessness. Across the offices' visits, housing and homeless were major barriers to discharge particularly for children living in cities (this is covered in section 3.1.4). One of the children who was homeless was part of a family who were seeking asylum with no recourse to public funds. The Home Office had provided accommodation which was unsuitable for them to be discharged to because of the child's medical needs.

For the children experiencing homelessness, the hospital could not refer the children for a care package to be arranged without an address – meaning that further delays were likely.

For one of the children waiting for a care package to be arranged, their family were in the process of moving and the hospital could not arrange a care package in the interim, as no ICB were willing to take a referral for continuing care.

Reason for delay	**Number of children**
Child protection proceedings and awaiting foster family placement	1

Awaiting children's social care review	1
Experiencing homelessness*	3
Awaiting care package arrangement	2
Awaiting rehabilitation	3

Children's Hospital C

In June 2025, this hospital had four children waiting to be discharged for a number of reasons similar to issues shared by other hospitals. One child had been waiting for a foster placement for over a month. There is a national shortage of foster carers, and a particular shortage of specialist foster carers who can care for children with complex medical needs.

For one child, they had been waiting for a suitable home for over a month. The office was told by professionals in health that liaising with local authority housing teams could be challenging – children who are reliant on technology (e.g. oxygen), or who are immunosuppressed need to be in homes which can accommodate them.

Reason for delay	**Length of delay**
Awaiting children's social care review	0 – 2 weeks
Awaiting foster family placement	Over 4 weeks
Unsuitable housing - Family not engaging	2 – 4 weeks

Unsuitable housing - Disagreement between health and housing	Over 4 weeks

Children's Hospital C: Children on long term ventilation via tracheostomy

The office heard about particular challenges facing children on long term ventilation who were being discharged from hospital.

Unpublished research shared with the Children's Commissioner's office by staff at one children's hospital focused on children on long-term ventilation via tracheostomy. It compared two five-year periods between 1 August 2014 and 31 July and 2019, and 1 August 2019 and 31 July 2024.

The researchers explain how long-term ventilation has had a positive impact on the survival and quality of life of children with complex medical conditions. They observed increased complexity in children's medical needs which they hypothesised was having an impact on children's increased length of stay.

A third of the children included in the research became unfit for discharge after being medically fit for discharge. This can be because children on long-term ventilation can be susceptible to severe infections, for which they will need hospital treatment for.

The reasons behind the delays included waiting for suitable housing, issues relating to the setup of care packages and family psychosocial issues (this can include family anxiety about discharge and managing care at home, or safeguarding concerns around children being discharged).

Children faced the following delays to discharge:

	Period 1 (1 August 2014 and 31 July and 2019)	**Period 2 (1 August 2019 and 31 July 2024)**
Total number of children discharged home	30	15

Number of patients without a suitable home	10	6
Number of patients where care package delays issues caused delays to discharge	7	8
Number of patients where psychosocial concerns caused delays to discharge	8	8

Their findings showed that hospital stays for these reasons were longer in the more recent time period:

	Period 1 (1 August 2014 and 31 July and 2019)	**Period 2 (1 August 2019 and 31 July 2024)**
Median length of stay from initiation of portable ventilation to discharge home	194 days	248 days
Median length of stay for patients without a suitable home from initiation to suitable home being allocated	238 days	276 days
Median total length of admission delays	245 days	434 days

Children’s Hospital D: Bed days

In one children's hospital, they shared the number of excess bed days for each cause of delay. Children's social care, waits for inpatient mental health services and waits for equipment and adaptations caused some of the longest delays.

Reason for delay	**2023**	**2024**	**2025**	**Total**
Bed delay – inpatient CYPMHS	34	214	201	449
CYPMHS assessment/review		11	1	12
Equipment and adaptations		185	229	414
Parent/family support	2	6	170	178
Parental refusal	29	31	23	83
Parental training	62	32	172	266
Post discharge therapy not in place	36	130	2	168
Social care	64	1263	109	1436

2. Life in hospital

This report is focused on those children spending longer than necessary in hospital. This chapter seeks to show what the impact of these stays can be for children and their families. Even though many families spoke about the dedication of the professionals caring for their children, this chapter makes clear why more must be done to reduce any unnecessary stays in hospital.

Children's lives do not stop while they are receiving treatment or waiting to be discharged. Their worlds, although often so dominated by poor health, are also about play, learning and building relationships with parents, carers, family members and friends. Their families too, while dedicated to their child in hospital, still need to keep earning money, care for their other children, spend time together – as well as wash, sleep, eat and prepare for going home.

This chapter looks at life in hospital both for children with complex medical needs, and those with social, emotional and mental health needs – and while there will be some shared experiences between both groups of children, they also face distinct challenges.

2.1. Hospital stays for children with complex medical needs

2.1.1 Children's admissions to hospital

Families told us about their child's life-threatening and life-altering events which were often sudden, terrifying and painful. Other families spoke about long periods of time trying to understand distressing and painful symptoms. They told us about hearing the news that their child had a serious or life limiting condition and their experience in the years, months and days that followed.

"I googled what would this condition look like. I'd never heard of it. And about what I need to do to help my child with this condition. You are absolutely helpless in knowing what to do. Went back to [hospital], gave her a cuddle." - Bereaved mother

Children of the families we spoke to experienced distressing and painful symptoms, made more terrifying when their cause was unknown and children did not know what was happening.

"This time around was very, very scary because this infection kind of went, but we were just non-stop having seizures. We couldn't break the cycle. That was very scary." - Father of 14 year old

Their medical needs also mean that there is huge uncertainty day to day.

"We struggled at home, we struggled in hospital with him because he was so unpredictable and the dystonia[vi] *was very painful for him."* - Bereaved mother

This uncertainty can be terrifying and bring back previous trauma from life-threatening medical events that children have experienced.

Although essential, care and treatment can also be uncomfortable and painful for children. As one mother described:

"She [daughter] always remembers the NG [nasogastric] tubes and stuff and she hated them." – Mother of a 5-year-old

Parents told us about the long journey of finding the right drugs and treatments for their child while in hospital:

"Like the drugs that she's on, like the side effects that she's suffering from the drugs. She was feeding quite well before she started this recent drug and then her feeding's gone downhill." - Mother of baby

2.1.2 How children and families were treated and supported in hospital

Overwhelmingly, families we spoke to told us about the dedication and quality of care that their child had experienced while in hospital – although this is sadly not the case for every child spending time in hospital with complex medical needs.

Parents spoke about the dedication of the staff caring for their child,

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[vi] Dystonia is the name for uncontrolled and sometimes painful muscle movements (spasms). It's usually a lifelong problem, but treatment can help relieve the symptoms.

"we're just stunned with what they do, what the culture is, what everyone does." - Mother of baby

Many families were clear about the trust they felt in the staff looking after their children:

"I absolutely love staff here … [child's] teams are amazing." - Mother of 5 year old

Families spoke to us about the impact of individual staff members, from a range of disciplines including occupational therapists, nurses, doctors, nurse-social workers, dieticians, play workers and physiotherapists. After telling the office about how his son needed more support, one father told us about his child getting the support of a 'Roald Dahl Nurse':

"'We got to meet [Roald Dahl Nurse[vii]*] I'm not going to lie to you. She's such an amazing person, very helpful, very supportive."* – Father of 14-year-old

For some families who spend long periods of time in hospital, the working relationships between children, family and staff became very strong. These relationships were vital for children with life limiting conditions who may die in hospital rather than at home, out of choice, or because being cared for at home is not possible. As one mum told us:

" *We didn't want her bedroom to be where we remember her last breath … So we just said, and we saw, we were almost an extended family, the way [ward] nurses and the team were."* – Bereaved mother

For children who do not have families visiting them, or do not have families in their lives at all, relying on hospital staff to play a parental role can be difficult given the changeover of staff and demands on their time. The dedication of staff was clear though. Examples were shared with the Children's Commissioner's office of hospital staff becoming foster carers for children who had been awaiting a specialist foster care placement, allowing them to leave hospital.

[vii] Roald Dahl Nurses are nurses who support children with complex, lifelong conditions. See more in Section 2.1.8.

2.1.3 Life in hospital

Despite these strong working relationships, families and professionals were clear that hospital has an impact on children who are away from family, friends, community and the rhythms of ordinary life.

"[Children's hospital] became our second home over the years … you used to be on the wards and it's almost like you became a permanent fixture … in some ways it was positive because you know, obviously they thought the world of him as a patient but also from a negative point of view, I think it did cause him to be a little bit institutionalised. I'm not even sure if I'm using the right word, but … it was, I suppose it was his normal." - Bereaved mother

Hospital is an unusual environment. Hospital staff change every shift and are spread across multiple children. The surroundings are often loud and busy. Days are unpredictable. Children are surrounded by other children and families, also suffering through pain and experiencing traumatic moments. There is the additional risk of children becoming more unwell from infections that spread across hospitals. For children who are immunosuppressed, they may need to be isolated to protect them from illness.

"We're on the ground floor with barely [any] natural light, because it's just buildings all around, they haven't got access to a playroom because they've all got flu." - Specialist Long-Term Ventilation Nurse

Families and professionals spoke to us about the importance of play and activities where possible for children with long hospital stays. Examples such as accessible in-hospital cinemas, children's dogs being able to visit them on the ward, and efforts to support children to leave hospital on trips were shared with us. However, it was clear that children's experience often involved empty hours spent on a ward.

"So come there Wednesday afternoon onwards for the rest of the week, the weekend, absolutely nothing happens." - Complex Care Lead Nurse

Children's development, especially when they are babies, can be affected by long stays in hospital where medical needs take priority. One hospital we visited were putting a programme in place to support babies' development: *Long-term children would be laid in a cot on the ward. Mum and dad would come briefly because they've got other children and other commitments, the nurses go in and do their bits, but the majority of the day will just be laid. So that's all stopping now. There's a lot more structure to the day"* - Specialist Nurse.

Some children do not have families visiting and caring for them in hospital regularly or at all. This could be because of the demands on parents who have to work, have other children or who are single parents.

For children who live far away from the children's hospitals providing them with specialist care, this can mean they are less able to see their family. Some rare and / or complex conditions require treatment in specialist children's hospitals, so living a long way from hospital is common.

"A lot of the time not only are they stuck in hospital, they're also stuck on the other side of the country and away from everything. And yeah, the impact that has on the whole family is huge." - Clinical Lead, Children's Community Nursing Team

2.1.4 Children who do not have family, or do not have a family who visit them in hospital

Some children are looked after or become looked after by their local authority while in hospital.

One professional told us about a girl who had been in hospital for over two years, "*'She's not experienced being able to go to school or nursery or anything like that. She's stuck here … she's not like, getting out and seeing anything else other than medical professionals."* - Complex Care Lead Nurse.

Professionals spoke about the level of care required of parents of children with complex medical needs leading to children coming into the care of their local authority, often with parental consent when parents are unable to provide care at home. For some children, safeguarding concerns are raised when it is clear they are not receiving the right care and support to meet their needs at home.

Professionals in hospital spoke about children who had been in hospital their whole lives. For one child about the office was told about, the parents agreed to their child being taken into care under Section 20 of the Children Act after it was clear that they could not support their child at home following months of training. The parental pressures of caring for a child with complex medical needs led to children becoming looked after by their local authority, the office was told.

For children without family support, all of the challenges of hospital life become more acute.

2.1.5 Children's mental health and wellbeing

Long hospital stays, alongside the medical conditions and adverse events that have led children to be in hospital, shape children's mental health and can require the support of hospital mental health teams.

The transition between hospital and home, and requiring ongoing mental health support, was described as a concern by professionals. Some children with additional needs struggle but are not eligible for help from mental health services, the office was told.

"Children who fall between the gap of they're struggling with their emotional mental health because of what has happened, but they don't fit a CAMHS[viii] *criteria because it's not a mental health difficulty. This is a really difficult thing to be doing. Yeah, this is your life, isn't it? And they're struggling with that, going back into school."* - Child psychologist

Missing the friends and family who children cannot see in hospital adds to the challenge of being ill and in a strange environment. This can be made harder by the level of attention children may need from parents and unreliable hospital Wi-Fi preventing families from making keeping in touch with the outside world. Professionals told us missing key parts of their education had a huge impact on children's learning and development.

"If you miss like critical periods in your education, you go back, don't you? All your peer group, you've missed all that foundation stuff on top of it just compounds everything that's happened." - Child psychologist

Children's mental health and well-being is closely linked with that of their family members, who are experiencing the life-altering and terrifying events that lead to long hospital stays alongside them.

[viii] CAMHS refers to Children and Young People's Mental Health Services, also known as Child and Adolescent Mental Health Services.

"For three or so years, we did, we very much struggled. We struggled at home, we struggled in hospital with him because he was so unpredictable and the dystonia was very painful for him." – Bereaved mother

"'I think it's hard to separate just the child from the family. Definitely that's our work relationally … But there also has to be great thought given to parents and how they are, how they're supported … it can be so traumatic to be away from your home, away from your community, away from your family, away from your support structures, away from your friends, both for the child and parents. And often there can be a huge impact of separation on attachment and bonding." - Child psychologist

2.1.6 Play

Play is part of children's healthcare, as well as being a part of children's day-to-day life. For children undergoing treatment in hospital, play can be used to support children to understand what is happening and make treatments easier. One mother told the office how helpful the hospital's play provision had been:

"One of the biggest roles, I think, for [daughter], in the complexity that she had over the years, was the role of a health play specialist. I cannot describe it." – Bereaved mother

This parent spoke about the impact of a play specialist working with her daughter to understand a procedure with a doll. This meant that the procedure no longer required nurses to hold her daughter still and prevented her from experiencing more trauma. It also helped the mother herself, who needed to do the procedure at home.

Professionals spoke to us about programmes where they were employing play specialists to support children undergoing potentially stressful procedures, saving distress, time and money. We also heard that play specialists, play workers and play-based programmes struggle to get funded.

Families also told us about the play workers who made a huge different to their children's quality of life in hospital. One nine-month-old, had been in hospital since she was born. Her play worker had been vital in helping her and her sibling play together and get to know each other.

However, the office heard that parents and professionals perceived inconsistent or sometimes no access to play workers and specialists in hospitals for children, and that activities could vary from ward to ward. For children who might have developmental delay or limited mobility, active engagement is even more important.

"My son obviously isn't like a normal child, he doesn't run, he doesn't play. He needs you to interact with him, so there's nothing at a weekend, there's nothing during school holidays." – Mother of 7-year-old

Play helps families to bond and is a normal part of life that can be missed in hospital.

"Something once or twice a week would be amazing … like a little stay and play group for parents who've got babies that can be taken off the ward or toddlers that can be taken off the ward so that parents can get together and the kids can play together." – Father of baby

2.1.7 Education

The Children's Commissioner's School and College Survey found that around 17,000 pupils in England were unable to attend school, or attend full-time, due to treatment for serious or complex illnesses.[23] As a core part of every child's life, education played a particularly important role for children in hospital for the families we spoke to – as a way to support children's development, stay connected with friends and peers, and support their reintegration back into school. For children with certain conditions, such as acquired brain injury, education is key to recovery.

Children in hospital have access to hospital education when decided by a doctor.[24] This can look different depending on children's age, needs and issues such as children's mobility or whether they are immunosuppressed. The office met one parent who told us about a robot that connected her child to school via video, and these can be offered by a charity or local authority.

Families spoke to the office about the importance of continuing education for children while in hospital.

"He's come on leaps and bounds since he started going to the [hospital] school. He's started stretching out and reaching for things more. The teachers are really engaging with him … he's smiled and he's engaged. He's actually made eye contact with them. So he does really enjoy it." – Mother of 7-year-old

Technology, like robots that allow children to take part in school via video and acting as their presence in the classroom, help children stay part of school life and continue learning. Without being adopted fully by children's schools, however, it can be potentially superficial offer, as one mum described.

"'It's like this robot. I mean, they're doing it, but then, if they're only offering story time and assemblies, what's she gaining from that really?" – Mother of 5-year-old

2.1.8 A need for coordination

While in hospital, sometimes after a life-altering event or diagnosis, the complexity of children's needs can mean they come under the care of multiple consultants, nurses and Allied Health Professionals, all focused on different aspects of one child's health. Families spoke to us about the challenge of understanding, communicating and sometimes negotiating with so many professionals, often around critical decisions about their children's care.

"Rather than having to contact individuals across multiple teams, it'd be so much easier if we had one person who could crack the whip or round up the herds […] a more holistic approach where they talk to each other, it just feels very disjointed […] This week, for example, It's been particularly tricky because they've got a different consultant every single day this week […] it has, been a bit of a roller coaster at times and you don't really feel like you've got the control over the situation because, as you say, she doesn't have that single point of contact." – Parent of baby

The period just following diagnosis, or a life-altering event, was described as particularly difficult.

One mum told us that just after diagnosis*: "We were asked to, a room full of 30 people, and it was in a circle. It was awful … It was absolutely awful, so the reality, the reality of a circle of care, that was the reality … How did they all fit in together to support me and my husband? Some actually we never saw again."* – Bereaved mother

Another mum told us: *"There was [after admission] a lot of miscommunication. A lot of 'well, he said, she said, well, let's do this'. And I went 'I just don't want that'. I need one voice, you know, one single, one song sheet. That one person can go, 'Actually. No. We're going to do this.'"* – Mother of 7-year-old

Professionals echoed how difficult it could be to navigate complex care:

"The gastric people want to deal with the gastric problem, and the respiratory people want to deal with the ventilation problem, and the endocrine people want to deal with the blood sugar problem. But no one's really that keen to deal with the whole person." - Advanced Clinical Practitioner, Dietician

Roald Dahl Nurses

- Roald Dahl Nurses work with children and their families navigating multiple hospital departments, therapies, and community services. Their coordination of care aims to reduce duplication and to help children receive seamless care across hospitals, home, schools, GPs, and community teams (Impact Report)
- They are senior clinical specialists and help families manage complicated treatment pathways and improve understanding of diagnoses, prognosis, and care options. Nurses are band 7 paediatric nurses who are specialists in lifelong non-curative conditions, including epilepsy, sickle cell, and medical complexity.
- Hospital trusts in England apply for funding from the Roald Dahl Marvelous Children's Charity for the first two years of a nurse's salary, with a guarantee that the Trust will keep funding the post for years 3, 4 and 5.

2.2 Hospital stays for children with social, emotional and mental health needs

The office also heard about the experience of children admitted for different reasons – related to their social, emotional, behaviour and mental health needs.

Children's hospital admissions for mental health concerns (to acute wards specifically, not mental health inpatient wards) have increased over the last decade.[25] Some of these children will be waiting treatment in a mental health inpatient ward, or being treated for a medical need before being admitted to a mental health inpatient ward.

The group of children the office is focused on in this report are children who do not meet, for various reasons, the criteria for a mental health inpatient bed – they need specialist therapeutic support in the community. Without specialist support or placements available, many children are admitted to hospital in crisis, sometimes with medical needs as a result of injury, or not, and find themselves waiting to be discharged, or discharged to an inappropriate setting.

Many children admitted to hospital in these circumstances face multiple, overlapping difficulties. Some children are experiencing past or ongoing childhood adversity and complex trauma that can lead to behavioural and emotional needs.[26] Some children have a learning disability and might be autistic, and be in crisis.[27]

Although professionals told us there were multiple ways they sought to help the children who came into their care, they were clear that hospitals are not the right place for them.

2.2.1 Traumatic admission to hospital

The office's conversations with professionals brought to light the often highly distressing and traumatic circumstances in which children were admitted to hospital. Children may have self-harmed, be experiencing a break down in their living arrangements, rejection from their family or their care placement, or be brought in by the police.

The office heard that force was used against one boy with a severe learning disability admitted to hospital: *"[He] was brought in handcuffed by four police officers with a spit guard on … No mental health need, no physical health need. We gave him a mental health need because we traumatised him so much by admitting him to the hospital."* - Hospital leader.

Some children face waits in Emergency Departments, as hospitals try to assess what children's needs are, and how they can be met.

"Rooms now become residential care homes for young people stuck in the system […]So the first one that described to you right in the centre of a busy emergency department, right by the nurse's station … it causes increase in stress, so the state that they came in, they become even more dysregulated because of the environment they find themselves in." - Paediatric Emergency Medicine Consultant

2.2.2 Life in hospital for children with social, emotional, behavioural and mental health needs

Though children are often in hospital as a way to keep them safe, the environment is not homely or therapeutic. Children can be exposed to highly distressing events around them on hospital wards. Just as children with complex medical needs can spend empty hours in hospital, children with social, emotional and mental health needs are living away from their families and community and are often unable to take part in normal day-to-day activities.

Describing one boy's experience, a professional told us: *"He'd be in a side room the vast majority of the time. They were carers were taking him out for a for something to eat or for a walk but he is literally in a room with a window no television or anything in there … he was literally just sitting here waiting for a care placement to be found."* - Lead Nurse for Safeguarding Children

Children may need significant support to take part in activities or go outside because of behavioural and emotional needs that put them and others at risk. Ensuring children have this support can take significant planning and professional input.

"Because he could see outside, desperately wanted to get outside, but the challenges of getting him outside were massive … we managed it. It was difficult." - Hospital leader

Trying to make a hospital room or ward safe can mean the environment is very distressing for the children and the people caring for them.

"[Child] was such high risk of ligature or self-harm, we had to keep him on a mattress on the floor in a room, he had carers in with him all the time, which was so distressing to think we were, you know, you went home at night and you were leaving him like that." - Nurse for Safeguarding Children

Some children need constant monitoring; some may be sectioned under the Mental Health Act or in some instances there may be a deprivation of liberty[ix] order in place in the hospital. In previous research by the Children's Commissioner's office, children said that although they understand deprivation of liberty orders were intended to keep them safe, the restrictions place upon them had a significant impact on their mental wellbeing, education and relationships. They had experienced segregation during their hospital stays because staff on the ward found their behaviour challenging and a risk to others. These children had also been physically and chemically restrained while in hospital, for distress that their clinicians noted was made more acute by their prolonged stay in a hospital environment, which was not suitable for them. The children did not wish to speak in detail about these experiences, but information shared by their professionals and family indicates that this was a traumatic experience for them.[28]

Being able to support children with what they needed was important to professionals, but something they knew they could not always offer with the resources and training they had, which was distressing.[x]

"So we got proper [room protection]. So that's made a significant difference in being able to care for these young people with proper dignity, really, and care. Unfortunately, we only had money for one." - Lead Nurse for Safeguarding

Professionals told us that they knew children were not getting the care and treatment they required.

"Nurses with no real knowledge of mental health patients, feeling like they really, really, really want to help, but not confident in what they're doing … [they] have anxiety over looking after these patients, not only because they don't feel like they're competent in what they're doing … they feel like they want to do a really good job." - Ward Manager

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[ix] A deprivation of liberty occurs when restrictions are placed on a child beyond what would normally be expected for a child of the same age, and these restrictions happen without valid consent. This might mean constant supervision, being restrained, or living somewhere they are not free to leave.8 It can also include conditions such as being denied access to a phone or the internet, and controls over communication with others. See the office's report on: Children with complex needs who are deprived of liberty: Interviews with children to understand their experiences of being deprived of their liberty

Professionals described to us how there are occasions when hospital professionals are physically hurt by the children they are caring for.

The office heard repeatedly that young people in these circumstances can be easily misunderstood:

"It's really difficult for me to hear about children in crisis who then get othered because they're in the wrong place, hospital is the wrong place, particularly when you're in crisis and the world's feeling really scary" - Deputy Chief Nurse, Community and Mental Health

The office was also told that despite not being the right environment for children with these needs, they had worked with children who had tried to come back to hospital because they had positive experiences of being treated well by staff and valuing the routine of hospital.

But above all, professionals stressed how the young people coming into their care with these highly complex needs should be given the right support in the community, and that health and social care need to work well together, and be appropriately funded to ensure this.

"Our [hospital] front door, we're always that face of safety … but actually we're not giving the right therapy, we're not giving the right support, we're not giving the right love, you know, these children need love and play and affection and actually what we do is lock them in a room where they can't hurt themselves. and hope for the best and then hope that social care will come in. We don't have education for them, there's no teachers on the ward, the playroom, they can't go in the playroom because they're dysregulated. We've got a sensory room, there's too many ligature risks in there. So all of these patients come in and actually we don't meet the basic needs of any of these children" - Nurse (Mental Health Champion)

2.3 Long hospital stays – the impact on families

Throughout this project, the office heard how long hospital stays affect children's parents, siblings and extended family members.

On top of grappling with their child in hospital being ill, in pain, and facing a life limiting or life-threatening condition, these family members were faced with a number of challenges that affected their ability to meet their own basic needs – this in turn affects the wellbeing of the child being treated or waiting to be discharged in hospital.

2.3.1 Money and work

Months and sometimes years of hospital stays mean families lose income and incur costs from travel, food and other essentials they don't have access to away from home.[29]

Although the following section details the impact resulting from children's hospital stays, it's important to note that for many parents caring responsibilities for children often remain the same or increase once a child is discharged, meaning returning to work may be impossible.[30] The care undertaken by parents can be highly technical, carrying out tasks that some doctors and nurses said they would not know how to carry out themselves.

Due to her child's long stay in hospital (and wait to be discharged), and in anticipation of caring for her at home, one parent explained:

"'I've had to quit my job, well, I haven't just yet, I'm still technically I'm sick, but next month when my sick note runs out I will be quitting my job, so I'm losing a lot of money , so it's ,yeah, it's really hard. It's really hard" – Mother of 5 year old

For two families whose babies were in hospital, the newly introduced Neo-Natal Leave had significantly helped, but only benefits families who have babies who are premature or sick in the first 28 days after birth.[31] Unpaid parental leave is four weeks per child and requires 21 days of notice.[32]

"Neonatal care leave policy came in April, so we were both able to take advantage of that and both our workplaces paid us in full for the 12 weeks. … So we recognise that we have been very lucky. But obviously if she wasn't a baby, if she was an older patient that had to be here, then suddenly that's not there anymore. I don't really see why it's any different" - Mother of baby

For families with a parent who is trying to remain in their job, this impacts their health as well as their ability to see their child in hospital. The NHS Healthcare Travel Costs Scheme does not cover costs for visiting someone, including a child, in hospital.[33] The government recently announced upcoming changes to cover costs for children receiving cancer treatment in hospital – a change that could make a huge difference for some families – but still excludes a huge number of children receiving treatment for complex medical needs, or conditions like cystic fibrosis and sickle cell anaemia.[34]

The office heard about the stress families were experiencing travelling long distances and paying for travel, while trying to hold down a job.

"'Finances are a massive stress for families particularly when they're out of area… Some travel like 40 miles each way and it can be an hour and a half. And then petrol. So we've got a family at the minute whose dad's going to work. [They] live in [town], so he drives back for midnight to come back and then goes back to work the next day … I'm really worried about him driving [while tired] and making sure that he's eating and drinking, and that impact it's having on that family" - Child Psychologist

If parents lose work, getting a new job with an employer willing to give a parent time off when their child's health declines is difficult. One parent explained that:

"[partner] struggled then to get into some at full time because we were in and out in and out hospital. So that impacted on our employment. Yeah. Yeah, a lot" – Bereaved mother

The cost of being in hospital includes food, toiletries, phone bills (when wifi access is poor), washing clothes (children tend to get through more clothes when ill), parking and petrol (travelling long distances between home and hospital).

"It's those little things that do add up and you've still got to pay your bills at home to keep your house." – Mother of 7-year-old

Schemes to support families were in place in all the hospitals we visited, but access to these schemes varied across hospitals, and even wards and professionals reported challenges in ensuring they are sustainably funded.[35]

"When they're on intensive care ICU … They get more funds, so they get support with food, parking, they can use the underground car park … that all drops off when they get to the wards and there's so many of them that we do what we can to support them and they're here a long time and if they all had

a car parking space then nobody coming to appointments. It's just little things that they've had and then we take away when they probably need it the most I think" - Roald Dahl Nurse

The charity Sophie's Legacy was set up in memory of Sophie Fairfall, who spent time in hospital before dying at the age of 10 in 2021. She wanted improvements in hospitals, including food for parents staying with their child. Pilots funded by the charity have led to changes in the provision of food for parents– in the absence of employer flexibility and government support.

Without enough money, families spoke to us about finding it difficult to go out when they were able to.

"we do want to get [child] out more, but we're kind of grounded financially just because DLA [Disability Living Allowance] is just not getting out of the red" – Mother of 5 year old

Professionals spoke to us about how accessing welfare and other forms of financial support was difficult for families to arrange when they did not have the time, were preoccupied with their child's health, or might speak English as an additional language.

"because they're dealing with a sick child and the stress levels are through the roof. So the last thing on their mind is, am I entitled to a carer's premium because I'm looking after my child and I've given up work?" - Citizen's Advice Advisor

2.3.2 Wellbeing and mental health

Families can experience high levels of distress and trauma while caring for their child with complex medical needs in hospital. Many families have experienced their child being in life-threatening situations. Despite this, families are resilient and some were able to describe finding strength in difficult moments.

"It was very, very difficult ... I stayed strong, like my family, my mum, his mum, all of us, my brothers and sisters, everybody stayed strong" – Father of 14 year old

The level of care that many parents spoke to us about meant that they were under extreme pressure, and had little time to spend with their other children or take care of themselves.

"We do not feel like we can leave her without somebody in the room with her that knows her well ... so there is no rest. It is 24-7 making sure our baby is looked after. Weekends are the hardest because we

now have two daughters who need our full attention […] So it's very difficult for us to ever have time as a family together […] We're under a bit of fatigue. We haven't got a lot of the external help to help manage us as a family, as a core unit. So there's a lot of pressure and stress on us." – Mother of baby

The level of care provided by parents has an impact on their health.[36] The long periods of time spent in hospital caring for their child can also mean families notice a shift in their relationships with friends and wider family.

"'I think when people first come in, in a critical phase [of their child's treatment], both parents are usually around aren't they? They have a lot of support, family come and visit and then over time family start to talk about friends just dropping off the radar, relationships change" - Child Psychologist

3. Barriers to leaving hospital

3.1 Barriers to going home for children with complex medical needs

The office spoke to professionals and families about some of the key barriers children face when it comes to being discharged home or to a preferred setting for children with complex medical needs. These are some of the key reasons children face delays going home.

As one professional told us, while there is so much to celebrate in how many children are able to live longer and enjoy more of life thanks to the care and dedication or countless people, and medical and technical advances – children are being let down by support in the community not receiving proper investment.

"There are many, many, many good elements to what goes on. And the fact that, you know, a lot of the things that we send home are not the most complex anymore and are quite run-of-the-mill. is brilliant, isn't it? My patients now have wetsuits that they can wear that they can go to swim and they can do things that they never would have been able to do before because they would always previously have thought that they were going to get an infection and they're able to go on holiday and we're able to do all of those things that 20 years ago we wouldn't have been able to do"

"[However] this mum's children have virtually had to live in hospital because we're not able to provide enough support for her to be always at home or in a safe place that allows them to be out of here. And all mum has wanted to do for her second child is have a better quality with her and not constantly be stuck in hospital

"If you look at Department for Health, like we celebrate the medical progress, the fact you can do all these calculations and figure out exactly how to keep a child alive, we should celebrate it. But then what? We're not being human about it at any point, are we?" - Advanced Clinical Practitioner, Dietician

3.1.1 Children's care in the community – Children's Continuing Care and children's social care

Children with complex medical needs often need the support of nurses or care workers at home, who help children and their families who provide round the clock care and support.

Families and professionals told us repeatedly that these packages of care were one of the biggest barriers to children being discharged, and staying out of hospital.

"the packages of care are always an obstacle" - Clinical Manager, Children's Community Nursing Team

What is a care package?

The specifics of how this care is provided vary across the country – dependent on local arrangements of universal and specialist services that can include children's community nursing, district nursing, in-house or private providers of care and hospice and charitably funded community care provision (for example, hospice-run community care). But broadly, where children have an ongoing health need, their care is provided through a package called Children's Continuing Care, eligibility of which is decided by a child's ICB.[37]

The package of care is NHS-funded but can also involve children's social care and education funding and delivering a child's care. As well as nursing and social care provided in the community, a Continuing Care package can provide specialist equipment, like oxygen tanks and defibrillators.

It is estimated that around 4,400 children are in receipt of children's Continuing Care, although no data is publicly available about assessment or delivery of it.[38]

Issues with Children's Continuing Care assessments

Professionals told us that assessing children for Continuing Care is black and white, and there are few children who qualify for this health-funded support.

"it's very specific in terms of the needs that need to be ticked and very high end as well" - Community ACP

This means that some children with highly complex needs are not eligible, for example a child who is fed intravenously through a central line who is now able to live at home thanks to medical advancements. As one nurse explained:

"they're fed intravenously, so they have a central line, which is something that is really only done in hospital. There's a lot more children now having this at home, but they don't fit the criteria for any continuing health care support, so that's solely on the parents … The criteria to get continuing health care is high" - Roald Dahl Nurse

Fiscal constraints were described as part of what was driving decisions, as well as a lack of expertise and joined up working.

"I think something else that would help within that process as well is probably having a more joined up working on the assessments between the specialist centre where they're living and somebody that's probably never looked after a trachi-vent who comes in with a clipboard and ticks some boxes and then says this is how many hours I think you need. We've actually offered to try and take some of that over before so that we can give a more comprehensive view or work more collaboratively locally but it doesn't happen because they don't want, you know, it's their [ICB's] money" - Specialist Long Term Ventilation Nurse

Funding disputes

Where children have an ongoing social care need, they are provided with local authority funded social care support.[39] If children do not meet the threshold for Continuing Care, or if the NHS refuses to fund a child's care and/or equipment as part of the Continuing Care package, it is classified as a social care need that local authorities must meet.

Due to the pressure this places on children’s social care budgets, funding arguments arise. Evidence suggests frequent disputes between health (ICBs) and social care (local authorities), about how children’s care should be funded.[40][41] This was strongly reflected in what we were told by families professionals.

“[in] every case there's an argument between health and social care, every single one” - Specialist Long-Term Ventilation Nurse

The high threshold for receiving Continuing Care reported to the Office was indicated by professionals to be a factor in disputes between local authorities and ICBs. Care package costs can be very high, leading to disputes and push back from education and children’s social care.

“from social services and a money pressure that's pushing back at other disciplines like health and education to share the load, even though there's not a specific change in health need or that a need from the family, I think there's something else political going on at the moment.” - Community Advanced Clinical Practitioner Nurse

This can lead to consequences for children, they can be stuck in hospital, or they can be left unable to go to school. One mother explained that arranging a care package to enable her son’s school attendance took a year.

“It was then you've got obviously the care package as to how much I mean, he couldn't actually go [...] it was a year later because obviously if they had to have the funding in order to provide a nursing staff, caring staff to go with him to school”, Bereaved mother.

“we've got a child that's going to school, trying to access school, and they can't because no one can decide who's responsible to pay for it” - Specialist Long Term Ventilation Nurse

The Law Commission has recommended that new statutory guidance for disabled children should contain a section addressing the intersection between health and social care, with an expectation that disputes between health and social care do not affect meeting the needs of a child in the interim. The Commission also state that what qualifies as a health or social care need is a political decision.[42]

In the middle of these disputes are children, often children who have life limiting or life-threatening conditions waiting for the care they need to go home.

Lack of sufficient support

Regardless of the health and social care make-up of the care package, we heard the level of care families receive is often not enough – not enough to allow children to have a good quality of life, or families to be able to work, care for their other children and engage in their communities.

"Who is looking at this from a human being perspective and saying, someone needs to cut these parents a bit of slack? Yeah. We're expecting them to do things that most people in healthcare can't do themselves." - Advanced Clinical Practitioner, Dietician

Families told us about the pressure of caring for their child and keeping them occupied without enough support – this is despite becoming highly skilled in their own child's care. They also spoke about not being able to undertake daily tasks or leave the house, either because they had no care package or because the package of care always required them to be there in addition to a care worker for two to one support.

Inequities in access to care packages

Professionals and families also told the office that gaps in the provision of care in the community widened further as a result of how much families are able to advocate for their child.

"So there can be, there's disparity depending on where you live and also how hard you push. So I've got families who have children who I don't think are dependent on the ventilators, who I cannot imagine how they got a care package and they've got a full care package. And then I've got other children who don't have much help at all, sometimes because they haven't asked for it" - Long Term Ventilation Consultant

Variation between ICBs and local authority areas

One of the points families and professionals raised repeatedly was the huge variation in the amount of care children received between ICB and local authority areas, and huge variation in how it is delivered.

Part of this is because the legal framework for children’s Continuing Care is less robust, being non-statutory guidance, in contrast to the legal duty underpinning the adult equivalent.[43]

“Often it's not a 24/7 commissioned package. And that depends as well. So that's frustrating. So like this one particular child has only been given five nights. But my other child has got seven nights because it's a different ICB. So there can be disparity depending on where you live and also how hard you (parents) push” - Long Term Ventilation Consultant

Another part of this is that NHS Continuing Care nursing teams and / or private care providers will provide different hours across a week – for example, some local authority areas Nurses will work in shifts across 7 days and nights a week, in other local authorities, nurses will work in shifts from Monday to Friday.

As well as variation in the amount of care families receive, there is variation in how children’s care in the community is delivered. In some areas, children’s care teams are able to work with them at home, in school and then stay with them if they need to come into hospital. This helps with continuity of care, as well as ensuring that the hospital can meet the needs of children who require constant care, to help, for example a child on ventilation.

“not only does it help the child because obviously if they're coming in and they've got their regular carers that they know and they're comfortable with […]it also helps the hospital to be able to staff these wards properly and safely” - Clinical Manager, Children’s Community Nursing Team

However, in other areas, a lack of funding is not at the forefront of problems in care delivery but rather children’s care teams encounter red tape around insurance, funding and boundaries between different areas.

“So you've got an agency that's been paid to sit there [while the child is in hospital] and do nothing, while some poor bank nurse who's never met this incredibly complex child and has too many other patients and they're so understaffed has to do all of her care and it just blows all my mind” - Lead Children’s Community Nurse

here are examples across of the country of where children's care is being flexibly commissioned that show it is possible[xi].

Homeward Bound Hub Pilot in Berkshire, Oxfordshire and Buckinghamshire ICS.

- This example of flexible commissioning highlights what is possible without any changes in national policy or funding. **It is also one part of what should change in the commissioning of children's care and support. Children should have this flexible arrangement for readmission to hospital as well.**
- This four month pilot was a collaboration between the ICS, Oxfordshire University Hospitals Trust, Helen and Douglas House Hospice and Innovate Care in July-October 2024. Care workers cared for children in hospital who were technology dependent and living in hospital, medically fit for discharge but had been awaiting a package of care for 9 months. The children were usually cared for in intensive care on intensive 1:1 nurse-led care. Once care workers were 1:1 with the child, focused on wellbeing, development and rehabilitation, PICU and nurse capacity was released, and surgery cancellations were reduced. Children had company, play and continuity of care in hospital.
- The pilot was funded by the ICB and cost £120,000. It created 155 Paediatric Intensive Care Unit bed days, worth £383,625. It is reported to have prevented three major surgical cancellations cases directly attributed to Homeward Bound.

[xi] The following is based on unpublished research shared with the Children's Commissioner's Office, see more at: https://commissioning.togetherforshortlives.org.uk/case-studies/buckinghamshire-oxfordshire-and-west-berkshire-bob-icb/

3.1.2 Arranging packages of care in the community

After a package of care is agreed for children to be able to live at home, children and families then can face a huge number of challenges in their care at home being set up – delaying discharge.

How this care is delivered varies. In some areas, children are cared for by nurses employed by the NHS, or by care workers employed by their local authority.

For many children, home (also known as domiciliary) care for children is provided by private companies who employ nurses and care workers to deliver care to children at home, at school and in the community ('care providers'). The way each company operates and how each package of care is set up will vary, but children will often be cared for by one or a few nurses and care workers, overseen by a care manager or clinical lead, over a set number of hours each week. Care providers are usually commissioned by local authorities and / or ICBs who need to provide care according to a child's assessed needs within their respective budgets.[44]

Delays when setting up a care package

Setting up a care package, once it is agreed, can be a huge driver of children's long waits to go home.

As the case studies in this report show (Chapter 3.4), finding a provider that can set up the care package can cause significant delays. Part of this is recruitment of care workers, as one mother told us,

"they just couldn't recruit staff, so after a year I did say, look, can we try a different company?" - Mother of 7 year old

Professionals told us that often, once a provider has agreed to take up a child's care package, the provider needs to recruit, do background checks and train staff – a process which can take months. In comparison, the office was told that care workers in adult social care providers are more likely to be employed and trained when a care package is being set up, even though recruitment and retention is also a huge challenge in the adult social care sector.

"I think the adult world do it better in terms of recruitment. They have a lot more carers in the adult world, so whether it's just a case of advertising it more, more focused on children, medical complexity when these agencies are bidding" - Complex Care Lead Nurse

Challenges delivering complex care at home

Care workers caring for children with complex needs provide them with physical care, engage them in play, care for them at school and support their emotional wellbeing, as well as navigating a child's family life. The physical care provided can include risky, difficult tasks such as changing a child's tracheostomy tube,

"I've been through the training for trachies and I'll be honest, they scare me. They do. You know, I come from a from an acute clinical A&E background [...] They're coming from shop jobs, or they've done a bit of, you know, adult care … and they'd manage it. And oh my God, they're amazing how they do it" - Clinical Manager, Children's Community Nursing Team

Care might mean staying up all night with a child who is ventilated, ensuring they are safe. It means supporting a child who finds it difficult to regulate their emotions and behaviour. It also means delivering children's medication at home. For children with complex medical needs who rely on a large number of different medications, care workers are key in spotting changes or errors in prescriptions,

"we normally find that our carers will raise it [concerns] to us, the carers are very good at looking and going, oh, that's a different strength" - Clinical Lead, Care Provider

Care workers are also often operating alone in a family's home, and they face the risk of family members treating them badly, or even being abusive,

"they've been quite, quite abusive to the staff and that's a very small minority, I have to say. But these are the reasons why some packages will fall down sometimes" - Clinical Manager, Children's Community Nursing Team

Travelling to and between children's homes can be a key part of a care worker's role, but travel time is often not paid for, making it a huge drawback of the job – this is exacerbated in parts of the country which have expensive, unreliable public transport.

"They need a care package in order to come home. That is massive. We really, really struggle in our area because of, I think the nature of where we live [rural area] to have successful care packages. Recruitment seems to be an issue. Children can be awarded the package and they meet the criteria for it and there's

permission in there to pay for it, but then actually finding the staff and making it consistent -I've never really seen it work well and I've been working here six years" - Clinical Lead of a Children's Community Nursing Team

Despite these challenges, the impact a care worker can have on a child's life is invaluable. One parent explained that her son's carers had become part of the family,

"When we lost [son], we lost the carers as well who were like a branch of our family. And within 48 hours they were all gone, you know, and that was hard to deal with. Because these are people that we saw them sometimes more than we saw our family" - Bereaved mother

Families spoke to us about how much of a difference – after long waits for care package to be set up – having a care worker made,

"[Son's] the first child she's worked with and she's absolutely brilliant. She's fantastic." - Mother of 7 year old

Pay and working conditions in the sector

The care workforce is twice as likely as the average worker to be in poverty due to low pay and zero-hours contracts.[45] Planned reforms to improve pay and working conditions for the care workforce introduced in the Employee Rights Bill only cover the adult social care workforce in England, unlike Scotland and Wales where children's care workers are set to see benefits from ongoing reforms.[46][47]

"if we had, if that was a better job and was more fruitful financially and people could live on that money, then more people would do it and they wouldn't leave" - Long Term Ventilation Consultant

3.1.3 Quality of care packages

Although we heard of example of excellent care and support for children with complex medical needs, families also spoke to us about the unreliability and poor quality of care their children received from their packages of care. With recruitment and retention problems, and the necessity of nurses and care workers being trained in the specific needs of some children, care providers find it hard to offer flexibility or cover when staff are sick.

One parent spoke to us about the lack of training and briefing for her daughter’s team – meaning her and her partner could never take their eye off the ball.

“‘Agency nurses, I think the biggest problem were late cancellations, no prior briefings. I don't know who regulates agency nurses […] The quality of nurses that come through the door. There are some on a couple of occasions I just asked to leave … I cannot raise a flag to that more … No briefing ever. Never, ever happened. Also, last minute cancellations and no replacements caused a lot of stress and strain.” – Bereaved mother

Another parent told us that he felt his son’s care team were neglecting his needs, and his suspicions had led to him setting up a camera to make sure his son’s needs were being met. After finding out that his son was not receiving the right care, he spoke to nurses at his son’s hospital who offered to train the care team. The care provider refused the offer.

“They [care company] come out to us, they say, yeah, you know, we could take care, you know. It's like we have amazing staff with there and everything. It's just … To be honest with you, I don't know why people lie” - Father of 14 year old

While there are many excellent care providers, professionals told us that they suspected cost of care was the main factor in commissioning decisions. Lower costs of care can impact on the quality of care given.

“they [authorities] chose to go over provided slightly cheaper. Yes, sometimes it can be down to framework. It could be you know that they don't use us as a provider potentially so you know sometimes that could be a factor 9 times out of 10 it comes down to cost’” - Care Team Lead, Care Provider

Professionals were clear that breakdowns in care packages led to children being readmitted to hospital.

3.1.4 Healthcare close to home

To be at home, children with complex medical conditions need regular medical care and treatment (in addition to the nursing and care children are provided through Continuing Care or social care). For some children, that is not available close to home. This can mean children stay in hospital, or are at greater risk of being readmitted.

One element is a lack of capacity or resourcing in children's community nursing teams. The care that these teams provide – both in and out of hospital, makes a huge difference for children. This can include supporting children to go home, using a 'virtual ward' system.

"somebody in this community can monitor them follow. You know, we start them on a particular medication, they can review them at home if they're not needed … then we can support that back. And, you know, back in the community, we can sometimes, yeah, we can decrease that inpatient stay"" - Children's Community ACP

This enables children to have specialist care that helps them stay at home.

"these families wouldn't tend to go to the GP because that GP wouldn't be able to. Probably wouldn't feel confident enough to advise these families with a lot of the things [...] truck full of medications which are, you know, quite, you know, specialist medications. They just, they just, that's not where their strength or experience lies. And so it's difficult. So that's our job really for them", Community Advanced Clinical Practitioner

The presence of Advanced Clinical Practitioners in community nursing teams means children may be able to avoid a visit to the GP or hospital.

"they don't have to go to their GP or use them Open Access if it's safe. So that's, I guess, an immediate improvement on that front." - Clinical Lead, Children's Community Nursing Team

However, a lack of investment in children's community nursing teams means that some children are not able to access certain treatment.

"So we used to, community nurses used to go and give high antibiotics at home. Some still do [...] But, there are a lot now that if they're receiving drugs that …. take an hour, they won't do that because they're stuck in their house for an hour and they don't have a lot of capacity" - Bone Marrow Transplant Nurse

Children’s community nursing teams also have variable hours, capacity and skill mixes between different areas. Because of the way they are commissioned, boundaries between areas can mean significant differences in the type of care children receive, as well as affecting overall capacity.

“[In a neighbouring area, the community nursing team] don't look after the acute side of things, so … if they see the oncology children, they'll see them for the dressing changes, but they won't be able to do the bloods … It really can make a difference if you need that, you have to go into hospital as a child for your bloods” - Clinical Manager, Children’s Community Nursing Team

This means children living near each other in one area or city will have very different experiences of care. It can also mean longer stays in hospital, so that they can receive the treatment they need.

“there’s a real gap in inequities across [city] around children's community nursing. There are some services that run just Monday to Friday and there are others that are able to do certain settings … Because actually if they don't have someone Saturday or Sunday to deliver their IV antibiotics or their cellular syringe driver, they're staying in hospital” - Children’s Palliative Care Consultant

Due to the complexity of some children’s medical needs, they may not be able to use their GP or local hospital – for some children this means travelling long distances to tertiary centres for their care. This can be all the more difficult for children in pain, children who are technology dependent, for families without a car, and those living in areas where public transport is unreliable or inaccessible.

“So wheelchair dependent children often have artificial airways or suction requirements, need oxygen, find sitting in the car really, really hard. Some of them don't have access to cars. They need a wheelchair adapted vehicle to be able to travel. They need morphine to travel comfortably because of their postural deformities that they get, secondary to their condition … They've got a long way to go to get the input from the people that they need” - Clinical Lead, Children’s Community Nursing Team

This leads to families having telephone appointments, which can work well but is not always what children require.

“they might opt to not go and have a telephone call, which is great that they've got the option to do it, but it's also sad when sometimes we as a service, really want a specialist doctor to actually have eyes on that child” - Clinical Lead, Children’s Community Nursing Team

3.1.5 Care placements for looked after children

The office was told about a lack of suitable placements for children with complex medical needs, and how hospital stays can be prolonged as a result. In England, there is a lack of specialist foster carers and a limited number of children's care homes provide care for children with complex health needs.[48]

Specialist foster carers were described as critical in providing children with a good quality of life. In one hospital, staff gave us examples of members of staff who had left to become foster carers of children with complex medical needs that were living in the hospital.

Based on conversations with professionals, looked after children with complex medical needs were most at risk to have extremely long stays lasting months and years.

The office also heard from professionals in one hospice that explained that they provided a place of safety for some children with complex medical needs awaiting placement. Due to the lack of placements for children, however, children's stays could become long – something that puts hospice end of life services at risk.

3.1.6 Housing and adaptations

A major barrier to children being discharged is when their homes are unsuitable, or when they are experiencing homelessness. As the case studies of children waiting to be discharged show, in addition to the delay waiting for a suitable home, children were often put in bureaucratic limbo as care packages could not be arranged by ICBs and local authorities while children had no address.

One parent told us about how her family were looking for somewhere to live, but in the meantime, her daughter was waiting in hospital.

"That's the only thing that's stopping [discharge from hospital] is not having the house" – Mother of 5 year old

For some children, their homes may not be suitable for clinical reasons. Children who have respiratory conditions, for example children who are immunosuppressed, who have a Hickman or a central line –

accommodation that is overcrowded and damp is not clinically safe. Poor housing conditions are an issue professionals told us they saw again and again,

"It was not suitable for human habitation. It wasn't even. I mean, we have lowered our standards as to what we would accept, because we just had no choice in this, because all the houses in [city] have the degree of mould and all they just do" - Bone Marrow Transplant Nurse

Housing may also not be suitable if there is not enough space for children who are technology dependent, or who need care workers overnight.

For children who are ventilated *"they have to have their own bedroom and they have to be able to get their wheelchair in and out of the doors. They have to have plug sockets and sink and toilet facilities because they have their own care team watching them 24 hours a day. They have someone watching them all night so they need their own separate room and enough storage space for all their equipment that comes with them"* - Specialist long-term ventilation nurse

Some children may need their homes to be adapted. Getting those adaptations was described to us a battle. Part of this is the cap on the Disabled Facilities Grant, which has not risen since 2008.[49] This can lead to local authorities, who can give discretionary grants, taking more time to offer grants due to funding pressures. One parent told us how her family waited for three years for adaptations for her son. The funding for the adaptations was only granted after the family used legal aid for solicitors to fight their case.

"it took us three years to fight to get the adaptations … I mean at this stage we were still having to unplug oxygen downstairs. [Partner] picked him up. We had to walk upstairs with him and I would then be able to run upstairs because we had [to have]obviously oxygen … to get him up to bed" - Bereaved mother

One parent told us about his son needing to stay in hospital while a relatively small adaptation was made to their family home.

"He had to come back to the hospital because we didn't have a ramp for him or his bedroom … He came back here for a good few months, then the council got involved, got a ramp made" – Father of 14 year old

Arranging appropriate housing for children can take up significant amount of professionals' and families' time. Poor communication between services was spoken about repeatedly,

"We just came up against multiple, multiple barriers from housing, we just need to get them to answer the phone and emails are all ignored and you'll just continually escalating, escalating, escalating. Social workers were in the same position that we were … you write multiple tens of bands of letters of support for these home LAs [local authorities]. and they just go into some big black hole" - Bone Marrow Transplant Nurse

3.1.7 Equipment

The office also heard of children facing longer stays in hospital because of delays to unavailable equipment and equipment services.[50] Professionals told us about delays resulting in shortages in getting certain equipment,

"machines, nebulizers, saturation monitors all come from [local authority] Community Equipment Service. And usually it's great. You'll order it within 10 days. It's there, but over the past six months, maybe a little bit longer there has been a huge delay in patients being able to go home because there's been no saturation monitors available […] there was a delay in the children getting the equipment serviced as well" - Clinical Manager, Children's Community Nursing Team

3.1.8 Families' psychosocial needs

Professionals told us about the preparation staff and families put into being ready to leave hospital. For some parents, who cannot take time off from work, for whom English is not a first language or who might be disabled, this level of care and coordination can be especially challenging.

"So lots of training with the parents about how life is going to look like at home, lots of discharge talks with them, we do lots of practicing medications, because these children get over 30 plus meds, so parents really want help and support with that, particularly if they don't speak English or if they can't read or write" - Bone Marrow Transplant Nurse

Professionals also spoke to us about the strain on families, relationships and the parents who did not want to, or could not take care of their child at home. One professional reflected on the knock-on impact of parental relationship breakdown on planning for discharge

"[some parents] just walk out halfway through this process because it's just too hard. So then we have, we've set it up for both parents and then we realise we now only have mum" - Long Term Ventilation Consultant

Although it does not stop children from being discharged, the office heard of the mental barriers that children need to overcome once they are discharged home – because of the gaps in support and challenges around getting back to 'ordinary' life.

"you [child] are in a safety net that has huge amounts of holes in it, [imagine] how terrifying that feels. … How you [as a parent] navigate that and support your child to feel okay and to feel safe enough, and [you ensure] schools feel like they have the knowledge and understanding to take the child back and reintegrate them?" - Child Psychologist

The Kentown Support Programme

The Kentown Children's Palliative Care Programme is for children aged up to 19 years who are living with a life limiting or life-threatening condition. It was launched in 2022 as a three-year pilot in Lancashire and South Cumbria and now has a second programme in Manchester.

A recent evaluation found that the programme filled a critical gap in statutory provision through its offer of holistic, relational support and early access to palliative care for children and families. As well as nurses who provide advanced clinical care, care planning and emergency support, the programme operates as a form of whole family support. (Evaluation)

Kentown Nurses: The Kentown Nurses are Children's Palliative Care Community Nurse Specialists employed at Band 6 and 7 and are hosted by acute NHS Trusts. They are a consistent point of contact for families and provide advanced clinical care.

Family Support Workers: Support workers are managed by Rainbow Trust Children's Charity and provide practical and emotional support, including driving families to appointments, offering respite and sibling support, facilitating days out and guiding families through bereavement

Service Coordinators: Assess what services are available across the local area and ensure that families are aware of and connected to appropriate support – from welfare benefits to peer support groups.

3.2 Discharge barriers for children with palliative and end of life care needs

Many children with complex medical needs have life limiting or life-threatening conditions which means they will need specialist care that improves children's and families' quality of life, including the prevention and relief of suffering through early identification, correct assessment and treatment of pain and other issues – whether physical, psychosocial or spiritual.[51]

Some children with life limiting and life-threatening conditions will need to spend time, and sometimes long periods of time, in hospital. For these children, the office heard how palliative and end of life care is essential for enabling children to be discharged and stay in the community for the months and often many years that they may be living with a life limiting or life-threatening condition. However, children have inconsistent and inadequate access to palliative care. For children approaching the end of their lives, where being at home or a hospice is their preferred setting, end of life care provision varies across the country.

The office spoke to bereaved parents and professionals who have lost children they cared for. Each child with a life limiting or life-threatening condition is remarkable and the loss felt by children's parents, siblings, friends, grandparents and the people who cared for them is devastating.

3.2.1 Inequities in access

In England, there were over 80,000 children with life-limiting and life-threatening conditions in 2017-18 - a figure projected to rise.[52] It is a legal requirement for ICBs to arrange palliative care services. There are inequities in access to palliative and end of life care, which ICBs are under a duty to address, to ensure equitable access.[53] Palliative and end of life care is not consistently available for children across the country. Some children's hospitals do not have palliative services. Hospices (which specialise in palliative and end-of-life care) may not have places and support services are not always available for children at home.[54][55][56]

Families and professionals were clear with us that there is not fair and equal access for care for children approaching the end of their lives.

There are hospitals that cannot provide palliative care, and community nursing teams that require palliative care training.[57] One professional described the impact of this.

"They [Paediatric Palliative Care Nurses] can't possibly provide Advanced Care Plans for all the children that would benefit from them and that's because there is no Consultant services available in other areas" - Paediatric Resident Doctor

Without palliative care expertise, children may not receive the holistic care that they need.

Along with variation in palliative care services across the country, there is also a is a postcode lottery for end of life care at home. Together for Short Lives' research shows that less than a fifth of ICBs (19%) currently commission services that meet the National Institute for Health and Care Excellence (NICE) 24/7 standard.[58]

Most children with life limiting and life-threatening conditions who sadly die, spend the end of their lives in hospital.[59] Children from deprived areas, and children from ethnic minorities are less likely than children from less deprived areas and white children to die in a hospice, or at home.[60]

"Beyond [ICB area], it's a really, really different picture. So there isn't 24-7 service in the community anywhere else in the [region]" - Palliative Care Lead Nurse

Arranging end of life care in the community is challenging when there are disputes between areas about who is funding the care. That was the case for one boy who very sadly died a professional told us about,

"I just don't understand. I just want this dying boy to be able to receive end of life care. I don't want to worry about what they're going to fund … whereas getting tickets for a [football team] match and getting to go spend the day … get a signed t-shirt and meet every member of the team… That's straightforward. And that's the thing that should be hard" - Lead Children's Community Nurse

There are gaps in community end of life care for 16 to 18 year olds who fall between children's and adults' services.[61] Professionals told us about the challenges arranging care for children in their late teens, and the reliance on goodwill and luck to ensure they have the care they need at the end of their lives. If children are not known to services because their illness develops rapidly, this issue becomes more acute.

"'If I'm brutally honest, in my particular speciality, one of our biggest challenges is the 16 to 18 year olds. There's a little bit of a black hole there in services" - Lead Oncology Nurse

We were told about gaps for children with highly complex needs who may be technology dependent, due to issues such as potential lack of appropriate transport home and nervousness in local teams about managing a child's needs, which can prevent them from going home or to a hospice.

"So for children on intensive care who are intubated and ventilated, who are stable enough and not on lots of support, we would love to be able to offer compassionate extubation outside of the hospital so that we don't […] If we think they're going to die very quickly after stopping ventilation, at the moment, our only choices are the intensive care unit or [one hospice in region]" - Palliative Care Lead

Where services are available – in hospital, hospices and the community – they may not be adequately or sustainably funded, or may face challenges resulting from workforce shortages.[62][63]

This can have huge consequences on children who are faced with limited options for where they want to be as they approach the end of their lives.

"Deciding where my child holds her last breath, hospice or hospital, it was a very difficult decision… Had the hospice been better and more equipped, I would say, I would have chosen hospice as an alternative" – Bereaved mother

Where services are working well, it may often be a combination of charity-funded services and goodwill.

"So it's basically the goodwill of the hospice that we get 24/7 cover overnight. They aren't under any obligation to provide it and it's a really vulnerable situation" - Children's Palliative Care Consultant

Professionals told us that charities and hospices work to ensure children have the palliative and end of life care they need, forming a patchwork of services which are largely not funded by the government.

"we are masking the gaps in the system" - Hospice CEO

Within NHS services alike, teams go above and beyond to meet the needs of children.

"I have to recognise that sometimes there is a lot of goodwill that is offered on behalf of our team" - Lead Oncology Nurse

For children and families who want to be at home as much as possible while their child is living with a life limiting condition, and who want to be at home as children approach the end of their lives, the barriers set out in this report – including issues setting up care packages, problems coordinating across services, and access to equipment and medicines – mean that children spend longer in hospital when they could be at home. It means less time spent with family, in their home, with their friends and community.

3.3 Barriers to going home for children with social, emotional, behavioural and mental health needs

The office also heard about the experience of children with social, emotional, behavioural and mental health needs waiting to be discharged from hospital.

Many of these children should not need to be admitted to hospital at all, if the right care and support for them is in place. This support – from health, social care, education and beyond – was described as the key goal in ensuring that children with these type of complex needs never face the suffering that may lead to them being first admitted.

However, there are children who are and will continue to be admitted to hospital before preventative support in the community is available and has an impact. These children will continue to need care in hospital and bespoke support from across the system that will allow them to live well in the community. This is the focus of this report.

3.3.1 Closed doors

Some children are being admitted to hospital as a result of children's residential homes sending them to hospital, effectively closing their doors to the children in their care, the office was told. For the young people admitted with the most complex needs, professionals explained that this can lead to hospital being the only place that young people can be – as hospitals are open to patients at the point of need.

"for us in an acute trust, we can't close our doors, so they're in with us until we can find somewhere else" - Lead Nurse for Safeguarding

Describing the experience of one young person, one professional described the impact of this – felt in addition to not having anywhere to live.

"She'd been all over the country and yet another care home was saying, 'No, not having you back'. And just the level of rejection and trauma that she must have been through her entire life." - Lead Nurse for Safeguarding

3.3.2 Lack of the right care and support

One of the key messages we heard from professionals is a gap across systems in how children with these complex needs can be cared for, treated and supported.

"It's the young people who come in with some level of mental health but not in acute crisis. They don't need sectioning, they don't need a mental health bed, but they can't go home, they can't go back to placement. With the trauma, with the behavioural issues, it's those kids that it's incredibly challenging to find placements for" - Lead Nurse for Safeguarding Children

Professionals in social care told us about work at a regional level to increase local authority capacity to provide care and support to children, to avoid children's admission and stays in hospital, to avoid them being placed in a home far away from their local authority, and to avoid placing a child in an unregistered setting.

The office has conducted research which found that each year hundreds of children are being placed in unregistered – illegal – settings, which are homes that include caravans, holiday rentals, or AirBnB, usually under the ownership of private companies with no formal inspection or scrutiny of Ofsted.[64] This is not a safe alternative to hospital.

Even when support was put in place for young people for them to be discharged from hospital, some young people ended up being admitted to hospital again, again under highly distressing circumstances, having put their lives in danger.

3.3.3 Challenges working across systems

Professionals also spoke to us about the challenges they faced working across systems, including deciding how children's needs will be met.

"we get this kind of battle for a few days between social services and mental health. Who's going to take responsibility? Where are we at? So we're often holding them until we have numerous meetings, meetings, meetings, until we come down on one side" - Lead Nurse for Safeguarding Children

Barriers to working across systems the office were told about included: Building relationships and understanding the 'front door' of local authorities that hospital staff might not typically work with, but need to when a young person has travelled far from home; engaging the ICB with the issues children coming into hospital are facing; rushed discharges to meet hospital priorities which can lead to children going to unsuitable placements.

However, in some parts of the country, the system is working together to ensure children with these complex needs are better supported – including a project in North London.

North East London Provider Collaborative

- Speaking with local authority children's social care teams and London Association of Directors of Children Services,]theh office was told about a provider collaborative with funding from the ICB and social care set out to improve how children with social, emotional and mental health needs are discharged from hospital (inpatient and paediatric wards) to home.
- Challenges have included : Working together across system bureaucracy and electronic systems, lack of funding, and risk being held across systems and not on individuals.
- The work has focused on children staying within their kinship system once discharged, and the importance of avoiding a rushed discharge to an inappropriate setting in care.
- The work has started in Newham and intend to expand to other boroughs.

4. Life after hospital

Families and professionals were clear that the discharge barriers faced by children were linked to challenges they also faced in the community. These challenges make life at home much harder, can contribute to children's readmission to hospital and exacerbate inequalities.

4.1 Care

Families spoke to us about their experience seeking the care and support their children needed to live well at home. For some children, their parents provide their round the clock care, for other children, they have nurses and care workers to care for them at home – who can become part of the family. The constant theme of the office's discussion with professionals is the lack of support available to families.

When parents and children do not have sufficient support, and this is frequently the case, their quality of life can deteriorate and they can become cut off from their community, the office was told.

Families are often providing highly skilled and intensive care to their child at home throughout the day and overnight. This includes administering complex medicine regimes, changing tracheostomies and parenteral nutrition.[xii]

Professionals told us that families, most often parents, become experts in their child's care, often after training from nurses while their child is in hospital.

"before those parents go home, they're basically nurses" - Clinical Manager, Children's Community Nursing Team

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[xii] A tracheostomy (also called a tracheotomy) is a procedure where a hole is made at the front of the neck. A tube is inserted through the opening and into the windpipe (trachea) to help you breathe. Parenteral Nutrition (PN) is the intravenous administration of nutrients for patients who have intestinal failure.

Some families have support during the day, including when children go to school but can largely be providing intensive care for the rest of the time.

"Nighttimes and weekends were very hard" – Bereaved mother

For children who have a care package, their nurses and care workers are often employed by small care providers and need to be trained in a child's care. This means finding cover when member of staff is sick is often not possible and parents find it difficult to rely on the care hours that are in place. This can lead to readmission.

"[we see] patients coming back in because the care package has fallen apart. We've got a patient in [city], they cannot employ anybody. So he has no carers, they can't get anyone." – Long Term Ventilation Consultant

As this report has shown, the care packages children have can vary, and some children have very little care and support. The office heard that this can mean families rarely leave the house, parents are not able to work and children, siblings and parents can be cut off from their community.

4.2 Education

The office was told that, for children with complex needs, going to school or getting back to school following discharge could be delayed or made more complicated. The National Association of Hospital Education has highlighted that there is huge variation in what children are offered when in hospital or unwell in the community from their local authority. Some children will have teaching at home, some children will have access to online tutoring – with hours per week varying from 5 to 25 hours.[65]

Not all schools are equipped to meet the needs of children with complex medical needs and social, emotional and mental health needs. This is particularly the case where children require a significant degree of support, for example in medical interventions, help with self-care or managing behaviours that challenge.

The office heard from families and professionals that not all staff have the right training to support children's needs effectively or confidently. This results in children's needs escalating and leading to reduced attendance or to them leaving school.[66]

Children can be out of school while waiting for the right package of care to be in place. Children out of education waiting for a school place to meet their needs is a common theme for the office's advocacy service, Help at Hand – including children being left out of education because of funding disputes.[67]

One parent told us how her child waited for a year for the funding in place so that her child could attend school with support,

"he couldn't actually go…it was a year later because obviously if they had to have the funding in order to provide a nursing staff, caring staff to go with him to school" – Bereaved mother

Families and professionals also spoke to us about mainstream schools not making the adequate changes to ensure children with complex medical conditions could go back to school following a stay in hospital.

'we're trying to get back part time …. They're [the school] like just putting issues there that don't need to be there … she had an education meeting the other week which it was that bad. Everyone from every department that was in that meeting came to check on me the next day because it was like, it was just, they didn't want a good meeting" – Mother of 5 year old

This was despite the benefits of going back to the same school being clear for her child.

"she went to school [yesterday, on a visit out of hospital], she saw all her friends, she got to have a little playtime with her bestie after school, which was amazing" – Mother of 5 year old

The office was told by one parent how her child's special school stepped up and made a huge difference in her quality of life.

"the role of school was massive … It's the vital link to home care, to school care, to hospital" – Bereaved mother

4.3 Money and work

Parental caring responsibilities means parents often cannot work or work much reduced hours affecting their income. Research has shown how the poverty rate among working age carers increases with the number of hours they care for.[68]

The office also heard from professionals the many ways low incomes can put further pressure on parents' management of their child's complex medical needs. For example, for children on specialist diets, food can cost more, and take longer to prepare.[69]

One hospital the office visited had a team in place that supported families whose children were in hospital by providing advice and signposting them to other forms of support in the community. They explained that parents are under serious pressure:

"they'll be referred because they've expressed concerns about finances, but when you speak to them, it turns out that they've got debt as well. And they're also worried about their employers harassing them to get back to work and they're worried about what other sick pay tightens because they're off work, because they're in the hospital looking after the sick child." – Social prescribing team lead

4.4 Coordination

Another key finding from conversations with families and professionals was the immense challenge families face coordinating between professionals, organisations and different parts of the system to arrange their child's care – this is true both in hospital and in the community.

When it comes to organising children's care, support and life at home, families must liaise between hospitals, community care, social care, care providers, education, housing, pharmacies to name just some of the services. One parent told us about the systems she and her partner set up, and demands on their time, to manage their daughters care and support.

"I devised my own systems, tools and relationships to ensure that she had the dignity and the quality until her last breath. And it meant identifying and scheduling a core care team so I would train my core carers identifying with third party, with agency, nursing agencies" – Bereaved mother

One parent described to us how this started from the moment her child was diagnosed with a life limiting condition in hospital,

"at that point it was overwhelming … And who in the circle will practically help? It was a jigsaw for us. It was completely overwhelming. How can I take my child home now? That was my first thought. And a clear understanding of the circle support, I guess, came, there were no leads in this room of 30 people.

Everybody spoke, everybody, you couldn't absorb what their roles were. You couldn't understand how, where it all fitted. And there was actually no lead. Yet it felt like there were so many people" – Bereaved mother

One aspect of this is the demand on families to manage communication between healthcare professionals,

"So as a gastric person, we would go in [...] they'll go, oh, yeah, respiratory have been today. And we'll say, oh, what did respiratory say ... it's so much pressure ..., if something goes wrong, then they're on a different side of the table. But we're asking them to be the coordinator of all that is complex" - Advanced Clinical Practitioner, Dietician

Care being disjointed can start in hospital and can lead to some professionals not understanding children's conditions. One mum spoke about an experience where her son's conditions were overlooked and she was accused of harming her son, *"I thought, well, you've not seen it, but you've obviously not read his notes. He's got Cerebral Palsy, Dystonia, prone to breakages. Yeah. So that that was probably one of the worst experiences we had."* - Bereaved mother

Personal budgets can give children and their families freedom to arrange children's care. However, without sufficient support from services, they can add further work to parents' roles as coordinators of their child's care.

"And the budget, so we're getting funds from social care budgets. Luckily my husband would manage it after the money would come the wrong time. We have to pay the nurses. He created a whole Excel sheet to do the job. And he worked a way in which all the nurses were always paid on time." – Bereaved mother

Families found information about sources of support and community were not easy to find – even when seemingly on their doorstep,

"it also seems it very much depends on the person you're talking to as to what services you would maybe get offered for support or the information that's available from them. There doesn't seem to be a sort of this is you can get ABCD and get that information from everybody" – Mother of 7 year old

The office heard that this level of coordination was even harder for some families to undertake – because of a lack of confidence in liaising with professionals, because of language-barriers, because of balancing work and care of siblings.

4.5 Medicines

The office was also told about the challenges surrounding pharmacy and drug management.

This includes primary care systems not being equipped to support children's prescriptions which can result in medications being managed by hospitals. This can mean families are put in precarious positions as they rely on hospitals, including hospitals far from where they live, for their child's medicine – risking issues such as delays and missed doses.

Families are also being expected to manage highly complex pharmacological regimens at home, as the care providers and the care workers supporting children in the community. This can lead to errors that can put children's lives at risk. The complexity of medicine management and liaising between different parts of the system was described to us by staff at a care provider,

"sometimes I find that the discharge summaries, the medications aren't actually the medications that the child is going home on … we have multiple professionals to get them to change it. I had a situation where I first started here when we discharged a child where his medications weren't matching the discharge summary. So then obviously we couldn't then transcribe them because obviously they weren't matching then I was going back and forward to multiple consultants and no one seemed to really know"
- Clinical Lead, Care provider

To help parents and carers manage giving medications to their child, an app and website 'Medicines for Children' has been produced by WellChild, the Royal College of Paediatrics and Child Health (RCPCH) and Neonatal and Paediatric Pharmacists Group.[xiii]

[xiii] See: https://www.medicinesforchildren.org.uk/news/our-new-medicines-management-app/

4.6 Lack of short breaks care

The office was told about the impact of the lack of short breaks (or respite) care for parents of children with complex medical needs – as parental and carer exhaustion can lead to children being readmitted to hospital.

Where short breaks are available to families, what is offered can be too short or create additional stress which takes away from the purpose of children and their families having a break from routine.

"[Parents are] *trying to fight the system, which often I think they feel like they're doing to be offered like a two night respite stay, which they're very grateful to be offered, but actually [there are] practicalities of going there and packing up, making sure the child's got all of their equipment, sorting all the medication."* – Advanced Clinical Practitioner, Children's Community Nursing Team

The level of work, liaising with staff and ensuring they have everything they need did not make a two night break from caring worth the stress for one parent the office spoke to,

"It was a mammoth task to get to hospice, all the information. So you're back to take the care plan … you know, there was no centralized [information] … So again, to go to the hospice, you have to start again with everything. So is it worth, was it worth the effort that weekend that we didn't even wish to go?" – Bereaved mother

5. What needs to change?

Most children in hospital are cared and advocated for with extraordinary dedication – by parents who provide round-the-clock support, and by professionals who go above and beyond. But they are being let down by fragmented systems not designed around their needs. Children who are medically fit for discharge can wait weeks, months or even years for a suitable care package, a home, essential equipment, adaptations or a care placement. Children with social, emotional or mental health needs are waiting in hospital in crisis and are then waiting for support, or a placement that will provide them with the therapeutic care that they need.

This report sets out the changes needed to ensure that no child remains in hospital simply because the support required to care for them in the community is absent. It calls for a series of reforms that would establish clear, joined up pathways to make sure children can have the fulfilling lives in the community they so deserve, and to support them better during the time they do need to be in hospital.

One parent explained to the office what the vision for services for children with the most complex needs should be:

"if I could go back I would say an integrated circle of care and support plans and planning must be, must be centralised around the child, not the services individually, with a core lead coordinator team, clinical and community specialty health and education. I mean, if education hadn't stepped up, [child] would be at home and it would be miserable, absolutely miserable. So bringing together joined up working, home, hospice, community care, education service. So a lot of it, I felt, is not about budgets. A lot of it is simply about putting the pieces together. It's about thinking what one document do we need that we need to update … A dashboard view where parents, clinicians and other services have log in access. A joined up integrated IT system … there's still an opportunity to bring a dashboard together, the most complex of industry sectors do that. Why can't it be done here? It would save a lot of money and time and resources. Integrate across the delivery of services, so updated information, centralised biology reports, care plans, medication assessment, approval, funding, and live communication." - Bereaved mother

5.1 A dramatically improved model of joined up care for children being cared for at home

5.1.1 Introduce joint commissioning for children with the most complex needs

Families and professionals spoke about the long waits for care and support in the community, inconsistencies between areas and lack of flexibility in how that care is delivered. There is a joint commissioning duty on local authorities and their partner commissioning bodies (ICBs) in the Children and Families Act 2014 to provide support for children with special educational needs. However NICE set out that ‘this is only happening in parts of the system. There is no universally established framework at an organisational level to enable joint working across all 3 sectors [health, social care, education]’.[70]

Recommendation: The Department of Health and Social Care (DHSC) and Department for Education (DfE) must develop a joint commissioning framework for ICBs, local authorities and schools to ensure flexible commissioning and the effective delivery of services.

In time the funding for these commissioned services should come from a joint fund established for children with complex needs by DHSC and DfE (see recommendation 5.3.1).

Joint commissioning should allow for children’s care and support to follow them across settings – from home, to school, to hospital. This would enable children’s care to stay consistent. Care workers, nurses and Allied Health Professionals that provide care for children at home, should also be able to care for children in school and in hospital when needed. This has been achieved for some children, but commissioning practices vary across local areas. Allowing care workers and nurses based with children in the community into hospitals also frees bed capacity on paediatric intensive care units and nurse time, and crucially provides children with continuity of care.

In order to increase accountability for commissioning, the CQC should implement their powers to assess Integrated Care Systems (ICSs) under the Health and Care Act 2022.[71]

5.1.3 Higher quality care packages

One of the most common barriers to going home that was spoken about by families and professionals were the packages of care delivered by care workers and nurses employed by care providers in the community.

Recommendation: The Department of Health and Social Care and Department for Education should develop a national strategy for how to improve children's homecare services

This should include workforce reforms and market oversight of the children's homecare market in England. Currently, homecare workforce reforms – which will address pay and conditions in the sector - will only apply to adult social care in England in contrast to similar policy changes in Wales and Scotland which will apply in both children's and adult social care.[72]

5.1.4 Make Neighbourhood Health work for children

In its 25/26 Neighbourhood Health plan, the government was explicit that there should be focus on children with multiple and complex health needs.[73] While this is promising, there needs to be more consideration of how the system currently works for children, and what is needed to ensure healthcare is moved from hospital to the community. The commitment to roll out virtual wards for children in all areas, in 2023, is also welcome – it is now essential to ensure that all children across the country have access to virtual wards when needed, and that the workforce is resourced and equipped to carry this out safely and effectively.

Recommendation: The Department of Health and Social Care should must sufficiently invest in children's community nursing to ensure the effective roll out of virtual wards that enable children to stay at home, or be discharged sooner.

5.1.5 Unique ID and a digital platform to support children and families with the management of children's care

In order for parents, professionals and children to be able to navigate across systems in the design and delivery of children's care, support and education, a comprehensive version of the proposed Single Unique Identifier for children to be needs to be introduced so that children's records can be better matched across all data systems.

Recommendation: The Department for Education should ensure that the new 'Single Unique Identifier' covers all children and be used across all relevant data systems, to ensure that children's GP, hospital, social care, and education records can be better matched across all data systems.

With the plan being digitised and, as appropriate, made visible to parents to help them engage with the state and improve people's experience of receiving support, parents and carers should be able to understand their child's medical needs, social care interactions and educational experiences, and state services should be able to use a child's plan to understand the wider context of their lives.

Recommendation: The government should develop a new platform for establishing children's needs and setting out the support they are entitled to. Any plan for ongoing support offered to a child should be set out through the platform.

5.1.6 Introduce a key point of contact for children with the most complex needs

The office heard about the web of professionals, number of assessments, opaque systems and conflicting information families experience from the services intended to treat and support children.

Families and professionals told us that because some children's needs are particularly complex they require support from different specialities and multiple parts of the health, social care, education systems and beyond. They told us that there needs to be a professional, or coordinated team, for families where a child has highly complex needs who can support the coordination of a child's care, get to know the child and family, and offer guidance on navigating the system.

Recommendation: All children with the most complex needs should have a key point of contact – for some children this may be a specialist nurse appointed by a hospital who ensures children's treatment and care in health is coordinated, for some children, this could mean a 'Family Coach' in a local authority or community health team who supports children and their family to navigate services in the community.

5.2 Fully funded equitable, timely access to palliative and end of life care across all settings

The office was told about children's inconsistent access to palliative and end of life care.

Professionals told us about how a lack of funding, sometimes as a result of confusion over whether ICBs or specialist commissioners should be providing funding, meant that services were not delivering their duties to meeting NICE quality standards in providing palliative care to children.[74]

Children need access to palliative and end of life care across all settings. This means funding of the necessary training for professionals in palliative care – including for resident doctors training to become consultants in palliative care, specialist training for nurses and care workers.[75] It also means funding the hospices and charities that play such a vital role in caring for children with life limiting and life-threatening conditions.

The government has announced its development of a Modern Service Framework (MSF) on palliative and end of life care.[76] Any MSF must be implemented alongside adequate funding to ensure children and their families are provided with the excellent care and support they need.

Recommendation: The Department for Health and Social care must sustainably fund palliative and end of life care and ensure ICBs are meeting their legal duties (individually or working together) to arrange palliative care services and addressing health inequalities to ensure equitable access.[77]

One theme that emerged from the research was how older children – 16 and 17 year olds – fell through the gaps between adult and paediatric palliative care, which in some areas and for some services ends at 16. It can be a particular challenge for children diagnosed with a life limiting condition at 16, who are therefore not already known to paediatric or adult services. Additionally, children and young people, especially those with learning disabilities and neurodisability, must be given developmentally appropriate care after the age of 16.

Recommendation: The Department for Health and Social Care should therefore mandate that children over 16 are eligible for paediatric care as they are transitioned to adult care to ensure they do not fall through the gaps in services.

5.3 Increased provision of appropriate care placements for children who cannot stay at home

There is a lack of specialist, therapeutic support for children with social, emotional and mental health needs, including those at risk of being deprived of their liberty. Likewise, there is a lack of residential and foster care for children with complex medical needs that could provide children with short breaks, long term care placements and step-down care from hospital.

5.3.1 Joint statutory fund for children with the most complex needs

Recommendation: The Department for Health and Social Care and the Department for Education should establish a joint statutory fund for placements for children who need them, and this should be delivered at a regional level, through Regional Care Cooperatives (RCCs).

As RCCs are rolled out across the country they should align with the footprints of the newly reorganised ICBs which in turn should be part of the RCCs. There must be specific provision for therapeutic settings which can cater to children with complex needs, including those at risk of being deprived of their liberty. This fund should drive up the provision of in house local authority provision for children in care, as part of plans to tackle profiteering within the children's home market.

The fund and levels of contribution should be put on a statutory footing and regularly reviewed. Commissioning decisions should be made centrally with input from partner agencies across health, social care, and education.

As RCCs become embedded they should also take on responsibility for commissioning services to support children at home, alongside care placements for children – enabling the smooth delivery of joint commissioning of services for children with the most complex needs.

5.3.2 Fast-tracked registration for in house children's home provision

Recommendation: To introduce these vital settings at pace, Ofsted and the Department for Education should consult on registration and inspection requirements for children's homes run by Local Authorities. There should be a 'fast-track' registration system for Local Authorities opening their own homes, where ultimate responsibly lies with the Director of Children's Services, given that Local Authorities are also inspected under the ILACS regime.

5.4 Mandatory data collection on children's discharge from hospital and children's continuing care

NHS England does not collect data on children's lengths of stay in hospital after being medically fit to be discharged. This means that quantitatively, the government and health system does not know how many children are waiting in hospital to be discharged, how long they stay for, or the cause of delays**.**

There is also no publicly available data on the assessment process for, or how many children are in receipt of Children's Continuing Care, despite data collection on adult's Continuing Healthcare being mandatory.[78] This can mean, for instance, that we do not know how access to Children's Continuing Care varies from area to area.

Recommendation: The Department and Health and Social Care must collect and publish data on children's discharge delays and Children's Continuing Care.

5.5 Improved experiences when children are in hospital

This report focuses on children who spend longer in hospital than they need to but also seeks to highlight what children and their families' experiences of long stays are like – for most children these extended stays are essential and will be inevitable over the course of their lives. To ensure that they are their families do not suffer needless impact on their wellbeing, more needs to be done to provide them with support during some of the most challenging moments of their lives.

5.5.1 Ensure families' access to essentials

Recommendation: The government needs to provide schemes which families can access to support them with the additional costs they face due to their child being in hospital long-term.

This needs to include:

- A form of **financial support for travelling to hospital**, this is especially important for families who do not have a car, or who must travel long distances. The NHS Healthcare Travel Costs Scheme does not cover costs for visiting someone, including a child, in hospital. [79] The government recently announced upcoming changes to cover costs for children receiving cancer treatment in hospital – a change that could make a huge difference for some families – but still excludes a huge number of children receiving treatment for complex medical needs, or conditions like cystic fibrosis and sickle cell anaemia.[80]
- **Access to essentials including food and toiletries.**
- **Reliable internet connection**, given that it is a key part of children and families' lives, as a way to access education, play, contact and support from friends and family, as a way to contact services crucial for children's care and education.

5.5.2 Introduce paid parental leave

The newly introduced Neo-Natal Leave had significantly helped some of the families the office spoke to, but only benefits families who have babies who are premature or sick in the first 28 days after birth.[81] Current forms of carer's leave and parental leave beyond maternity and paternity are unpaid and/or have conditions which are impractical for parents of children who are seriously ill. [82][83]

Families whose children become seriously ill, including children with complex medical needs and mental illnesses, must not be punished financially when their children need to be their focus.

The government has committed to a consultation that will include consideration of 'Hugh's Law', named in memory of Hugh Menai-Davis after a campaign by the charity set up by his parents called It's Never You. Hugh's Law seeks to guarantee paid leave for parents of seriously ill children from day one of their illness.

Recommendation: In considering an introduction of a specific leave for parents of seriously ill children, the Department for Business and Trade must ensure that parents of all children with serious physical and mental illness are eligible for this leave.

- It is encouraging that the government are intending to consult on paid leave for parents of seriously ill children**.** As this report shows, some children have complex needs that mean they are admitted to hospital multiple times during their childhoods. This leave should be reasonably available to parents over the course of their children's lives, and not available as a one-time form of leave.
- Parents and primary caregivers, including foster carers, kinship carers and families members providing the majority of a child's care should be eligible for this leave.
- A day one eligibility for parents is crucial to ensure financial stability for families in the first months of their child's serious illness. The diagnosis of a child should not be a barrier to eligibility – for example when a child has a Syndrome Without A Name, a rare condition or complex medical needs that are challenging to diagnose.
- Some children have lifelong conditions and disabilities that may mean they require significant support from their family, this should not preclude their parents from eligibility of parents' leave if their health deteriorates for a prolonged period of time, requiring hospital stays or more intensive care at home.
- For parents of children who are approaching the end of their lives, a separate form of paid leave which they can take at short notice and is flexible to uncertain circumstances must be available.
- Some parents may need to take unpaid parental or carer's leave for their child who may have long-term or lifelong care requirements, and should be reasonably able to do so in addition to taking this new form of leave.

5.5.3 Play embedded in children's healthcare

"'A child is still going to, no matter how sick they are, they're still going to want to play, they want to learn something."- Bereaved mother

Play has enormous benefits beyond entertaining children while in hospital, as well as when children with complex medical needs are at home.[84] The office was told examples of how play and activities make a huge difference to a child's experience in hospital, and how Play Specialists can reduce the level of trauma children experience during procedures. There is also reason to believe that play delivered through the charity Starlight's services may be able to save the NHS money by reducing treatment time and need for sedation.[85]

We heard from hospital leaders that play is not seen as a priority because it is not a medical need, but it is an aspect of care that they view as key to children's health and wellbeing.

Recommendation: The NHS guidelines for commissioning and designing health play services must be implemented to embed play into children's healthcare via ICBs

5.5.3 Improve non-instructed advocacy for children

Children must be at the centre of the services designed to provide treatment, care and support to them. The office met with families and professionals dedicated to ensuring that children's wishes and desires were at the centre of the care, but were also told that more needs to be done to ensure children are being listened to.

This is especially important for babies and young children, and children who are non-verbal and need support to communicate. It could also be key to ensuring that children who are stuck in hospital (sometimes for their whole lives) are being appropriately advocated for.

The role of an advocate is to support children and young people to express their wishes and feelings to decision-makers, and ensure their rights are upheld. Looked after children, care leavers, disabled children, children with Special Educational Needs and Disabilities (SEND), children in mental health hospitals, and children in custody all rightly have a statutory right to independent advocacy. Children who cannot communicate clearly, or who lack capacity to understand certain issues and make decisions will need non-instructed advocacy.[86]

Recommendation: The Department for Education should:

5. Extend an opt out model of advocacy provision to all children who have a statutory entitlement to advocacy.
6. Establish a new independent, national advocacy service to ensure genuinely independent and high-quality advocacy for children and young people.
7. Establish a minimum qualification standard for non- instructed advocates. As well as teaching advocates about the legal framework for children's rights, non-instructed advocates should be trained in how to support children with complex needs and disabilities. Moreover, non-instructed advocates should be required to have prior experience in working with children with complex needs and disabilities.[87]

To ensure close involvement of children's social care, local authority social care teams should be required to visit a child in hospital after three weeks, rather than the current three months, in order to establish relationships with families and check that children have been allocated an advocate.

5.6 Better support for children to transition home from hospital

5.6.1 All children with complex medical needs should be able to access education

The office heard from families that described their child moving schools following life-changing medical events and diagnoses, and how for some children, their schools were not supportive of their return to education. For others, schools played a pivotal role in their child's quality of life.

As part of the implementation of the School's White Paper:

- DHSC and DfE should work together to consult on the conditions and medical treatment that result in barriers to learning as part of their wider research into what works for Specialist Provision Packages. This must specifically include detail on those with potentially temporary or fluctuating, but nonetheless very high level needs – for example children undergoing chemotherapy or children with acquired brain injuries. Statutory support must not cease or pause because of a child being admitted to hospital.

- The government should update its statutory guidance on supporting pupils with medical conditions in school, and include new guidance on how schools support children who are ready to be discharged from hospital.

5.6.2 Housing reform

This report sets out the long-term change that needs to happen across the country to ensure children waiting in hospital for a suitable home, or waiting for their home to be adapted to their needs no longer face the months and years of delays we heard about throughout this project.

There is work across the country to overcome some of these entrenched issues around finding children a suitable home, the office was told. This includes a successful escalation policy developed in Alder Hey Children's Hospital. Long term, the government needs to tackle the lack of suitable housing for children with complex needs through its planned housing reforms.

Recommendation: The government should increase the Disabled Facilities Grant

The Disabled Facilities Grant (DFG) should be increased in line with inflation. It is promising that the government is looking to update the way it allocates the DFG to local authorities and is reviewing an uplift of the £30,000 entitlement.[88]

Methodology

This report is based on analysis of data acquired from NHS England on children admitted to hospital, interviews conducted between June and December with 12 parents of children with 76 professionals working in health and children's social care. The report also draws upon previously unpublished data from 4 hospitals.

Quantitative data

Using the Children's Commissioner's powers under the Children Act 2004, the Children's Commissioner's office requested data from NHS England on children admitted to hospitals. This data was requested on 12 December 2025 and sourced from the NHS Hospital Episodes (HES) data team.

The dataset covers how long children spent in hospital over the course of their lives, their demographics and diagnoses. The data includes anyone who was aged under 18 as at 30th November 2024. The data includes children who were born in hospital and children who died in hospital including children who died (who, had they survived, would have been aged 0 to 17 on 30th November 2024)

The data provided by the NHS includes the length of time child spent in hospital over the course of their lives broken down by gender, ethnicity, age, deprivation region and primary diagnosis.

The Children's Hospital Alliance shared unpublished analysis with the office that it had conducted using Hospital Episode Statistics on children's delayed discharges from hospital. Using NHS England data for 2025, the office calculated that on average, 68% of paediatric and neonatal general, acute and intensive beds were occupied. Applying the 5% rate for children clinically ready for discharge to the number of occupied beds, and multiplying by 365, results in an estimate for bed days per year.[89]

The office also received data and unpublished research on discharge delays from 4 hospitals visited as part of this research.

Notes on and limitations of the data

1. Children: Data cover spells and episodes where the patient was not known to have died and was aged less than 18 years old on 30/11/2024, or, was known to have died and, had they still been alive at 30/11/2024, would have been aged less than 18 years old.

2. Duration: Episode duration is calculated as the difference in days between the episode start date and the episode end date. For children with multiple episodes, durations were combined for each patient and then provided as a single figure per patient. For example, a child who between their date of birth and 30/11/2024 had 3 episodes with durations of 5, 10, and 15 days, would be included in the data with a single episode duration of 30 days. Some may spend all their lives in hospital but do not appear in this data because they have not been discharged yet.

3. Age: The data provides the age of the child on 30th November 2024, providing they are not known to have died prior to that date. Patients who died before 30/11/2024 are included in the data as the age at which they died.

4. Unit of analysis: the data aims to describe the experiences of children, rather than admittances to hospital of children, as in published data. But it is possible that the same child may be recorded more than once. For example, where a child has a valid gender recorded on one record but left blank on another (although this is uncommon). Similarly, this may occur where a child has an incorrect ethnicity recorded in one episode due to human error or data quality issues.

5. 'Long' lengths of stay: There is no official definition of a 'long' hospital stay. This report's definition of a long stay was used after discussion with some health professionals and on the basis that the NHS for some of its metrics uses 21 days and over as a long stay.

6. Change over time: The office has not made comparisons between children's and adults length of stay, or change over time.

7. Deprivation: To determine levels of deprivation, HES data uses the Index of Multiple Deprivation (IMD)90. The index measures deprivation at Lower Super Output Area level based on the home address of the child. Areas are ranked from least deprived to most deprived on seven different dimensions of deprivation and an overall composite measure of multiple deprivation. The data uses IMD version 2004 on hospital activity up to and including 2006-07; IMD version 2007 on

activity between 2007-08 and 2009-10; IMD version 2010 on activity from 2010-11 and M10 2022-23; IMD version 2019 from M11 2022-23.

8. In some cases, IMD data may be NULL, either because the patient was recorded as living outside England or else did not have a valid postcode that could be matched to an LSOA. For the data shared with the office, the NHS counted each patient as having whatever IMD Decile was recorded against them in the last episode they had up to 30th November 2024, so each child is counted only once when analysing by IMD. However, this could mean that the IMD decile assigned to a patient is not the area they lived most of the time. For example, if a patient had episodes totalling 50 days while resident in a very deprived decile then moved address to an area in a less deprived decile, after which they had another episode lasting 2 days, they would be presented as having had episodes lasting 52 days, coded against the less deprived decile.

9. Diagnosis: There are twenty diagnosis fields that can be populated per episode. These fields contain information about a patient's illness or condition. The field DIAG_01 contains the primary diagnosis, which represents the main condition treated or investigated during the episode. The other diagnosis fields contain secondary/subsidiary diagnoses. The codes are defined in the International Statistical Classification of Diseases, Injuries and Causes of Death (ICD)91. For this analysis, the NHS have only looked at the primary diagnosis that was recorded against the last episode associated with each spell. This may not always be the same as the primary diagnosis for which the patient was originally admitted. For this analysis it is possible that some patients may be recorded more than once. This is because the same person could have multiple episodes with different primary diagnoses, so the patient will be recorded once against each.

10. In order to protect patient confidentiality, the NHS used asterisks ('*') to suppress counts of children between 1 and 7 in the data. In such cases, instead of discarding the data, the office has assumed this number to be 1 - the lowest possible number - to avoid overestimation.

11. Chronic conditions in this report are defined using the Hardelid classification92, which is regarded as the industry standard for identifying and classifying chronic conditions in children and young people using International Classification of Diseases (ICD-10) codes in administrative health data. The classification defines chronic health conditions as any health problem likely to require follow-

up for more than 1 year, where follow-up could be repeated hospital admission, specialist follow-up through outpatient department visits, medication or use of support services.

Qualitative data

A range of qualitative data was gathered and analysed in 2025 and 2026 for this report:

- To scope and plan the project, the office held meetings with over 40 stakeholders across representative organisations, charities, government and NHS England.
- The office assembled case studies to illustrate children's experiences and particular services. The Help at Hand pen portrait is fictitious but serves to illustrate commonalities among the experiences of children who the Children's Commissioner's advocacy service, Help at Hand, have worked with who have had extended stays in hospital while awaiting the right support in the community. The four case studies were based on information provided to the office from four hospitals.
- The office undertook visits to hospitals, including four tertiary hospitals and one district hospital and one hospice between August and November 2025. During these visits and in additional online interviews the office interviewed 76 professionals, working across England in hospitals, children's community nursing teams, a children's care provider, children's social care, research, charities and information and advice organisations.
- To understand the experiences of children with complex medical needs, the office spoke to 9 families and 79 professionals across England. The children we met were babies, children who were non-verbal, children who had learning disabilities, and children who had acquired brain damage – they were advocated for by their parents who we spoke to. They were aged between 4 months and 14 years old. We also spoke to two bereaved parents whose children have tragically died. The families were recruited via the hospitals the office visited, and the Together for Short Lives Advisory Council. The office asked questions relating to: children's experiences in hospital, families' experiences of their child's hospital stays, issues relating to children's discharge from hospital, and what interviewees wanted to see change. Some quotes have been edited for clarity.

- The office is grateful for the time of five members of the charity Starlight’s Young Panel aged 14 to 17 who gave the office advice on its findings and recommendations on 16 December 2025; and attendees at a roundtable held by the office in November 2025, whose feedback informed the project’s data request and recommendations.

Annex A – Additional tables

Table A1. Children's mean number of days spent in hospital over their lifetime, by deprivation decile.

IMD decile	Number of patients	Percentage of patients (%)	Population benchmark (%)	Mean time spent in hospital (days)
Most Deprived 10%	40,592	17%	12%	57.5
More Deprived 10-20%	33,236	14%	11%	56.8
More Deprived 20-30%	28,446	12%	11%	56.9
More Deprived 30-40%	25,192	10%	9.9%	56.6
More Deprived 40-50%	23,055	9.5%	9.5%	55.6
Less Deprived 40-50%	20,869	8.6%	9.4%	56.1
Less Deprived 30-40%	19,127	7.8%	9.0%	55.8
Less Deprived 20-30%	18,954	7.8%	9.1%	55.7
Less Deprived 10-20%	17,802	7.3%	9.1%	54.8
Least Deprived 10%	16,503	6.8%	9.3%	53.9

Table A2. Most common primary non-birth related physical health diagnoses for children in hospital, arranged by mean time spent in hospital

Primary diagnosis	Number of patients	Mean time spent in hospital (days)
Myeloid leukaemia	823	92.7
Unknown and unspecified causes of morbidity	2,116	80.6
Cystic fibrosis	1,566	67
Postprocedural disorders of digestive system, not elsewhere classified	619	64.1
Lymphoid leukaemia	2,552	56.6
Malignant neoplasm of brain	1,205	52.9
Unspecified acute lower respiratory infection	3,105	49.2
Sickle-cell disorders	644	46.5
Complications of cardiac and vascular prosthetic devices, implants and grafts	729	44

Epilepsy	1,436	43.3
Gastro-oesophageal reflux disease	971	43.2

Table A3. Most common birth-related diagnoses, by mean length of stay in hospital

Primary diagnosis	Number of patients	Mean time spent in hospital (days)
Necrotizing enterocolitis of fetus and newborn	1,851	58.1
Congenital malformations of oesophagus	813	57.8
Chronic respiratory disease originating in the perinatal period	4,405	57.7
Other perinatal digestive system disorders	946	52.4
Congenital malformations of aortic and mitral valves	809	51
Congenital malformations of great arteries	1,318	47
Congenital malformations of the musculoskeletal system, not elsewhere classified	1,502	46.4

Other congenital malformations of intestine	1,330	44.7
Disorders related to short gestation and low birth weight, not elsewhere classified	101,108	44.3
Other disturbances of cerebral status of newborn	1,270	42.2

Table A4. Most common primary non-birth-related mental health diagnoses for children in hospital, by mean time spent in hospital

Primary diagnosis	Number of patients	Mean time spent in hospital (days)
Pervasive developmental disorders	172	113.9
Obsessive-compulsive disorder	39	107.7
Emotional disorders with onset specific to childhood	24	104.2
Reaction to severe stress, and adjustment disorders	61	99.7
Other behavioural and emotional disorders with onset usually occurring in childhood and adolescence	50	97.0
Other anxiety disorders	54	93.6

Hyperkinetic disorders	70	93.2
Unspecified nonorganic psychosis	74	87.2
Persistent mood [affective] disorders	20	81
Conduct disorders	22	78.2
Dissociative [conversion] disorders	39	77.3
Eating disorders	1,532	70.9
Depressive episode	116	66.5
Acute and transient psychotic disorders	38	56.9

Annex B – How many children are admitted to hospital?

NHS statistics include an age breakdown of admittances to hospital, of which there were 2.2m of children in 2024-25, but do not publish the number of children admitted to hospital each year.[93] For this report the Children's Commissioner's office requested this data from NHS England: in 2023-24, there were 913,621 children admitted to hospital.

This figure does not include children who were born or died in hospital. The National Child Mortality Database reports that there were 2,654 deaths of children in hospital in 2023-24, and the Office for National Statistics reports there were 549,736 maternities (births of one or more babies) in England in NHS establishments in 2024.[94][95]

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