



The Charity for Disabled Children

# Fight For Our Future:

Act now for disabled children

# Contents

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Page 1	Foreword
Page 3	Executive Summary
Page 4	Leadership Lapse
Page 5	Rhys' Story
Page 6	Specialist Shortage
Page 7	Clemency's Story
Page 8	Assessment Anxiety
Page 9	Roman's Story
Page 10	Money Matters
Page 11	Endnotes

**"A society is strong when it cares for the weak, rich when it cares for the poor, and invulnerable when it cares for the vulnerable."** – Jonathan Sacks



# Foreword - Kathryn Griffith

Kathryn worked for 10 years in parliamentary and governmental affairs before taking a career break to focus on her young family. She first entered the world of additional needs when her second child was diagnosed with ASD. Kathryn was delighted to join the Newlife board of trustees in January 2020 where she lends her personal and professional skills to support the charity's mission.



As a parent, your number one priority is to ensure your child's needs are met, allowing them to grow and flourish, meeting the potential you know they have. It sounds simple, achievable, and rewarding – the very basics of parenting.

But then imagine you are trying to do this within a system that is doing all it can to undermine you. A system that prevents you from meeting your child's most basic needs, tells you that your child isn't a priority, leaving you to stand by and see their potential wasted, no-one available to help and support you. **This is the lived experience of too many disabled children, their parents and families, and it is simply not acceptable.**

Newlife has been working tirelessly to understand better the scale of the problems facing disabled children and their families. A bleak picture has emerged – a system characterised by under-funding and a failure to protect those most in need, a lack of investment in critical professional services, and missed opportunities to join-up and strengthen provision.

It is scandalous that only two-fifths of families feel their child has all the specialist equipment they need to live a full life; that three-quarters of professionals express concern that children under their care are living without equipment they deem "essential"; and that in the last 12 months alone, 60 per cent of local services have seen their assessment waiting lists grow whilst almost half have cut their equipment spend. **As our report shows, the cost to the most vulnerable of children is immense.**

The inaction of the system contrasts so painfully with the fight and resolve of the parents we talk to. Their ability to continue the fight for their children despite the continued disappointments and let-downs of the system is truly inspiring, but it is also exhausting and unfair. **Enough is enough – it is time to make a change and ensure every child is treated with the care and respect they are owed.**

With this report we at Newlife, along with the children and families we represent, the professional workforce and our charity partners are joining together with one voice to call on the Government to make disabled children a priority. Dedicated leadership is needed to drive the changes we are seeking. It is critical that our children and their families are respected at the highest level and represented by a Minister for Disabled Children – someone to advocate for change, fight for fair funding and tackle the inadequacies that currently plague the system.

**With the changes we propose, we believe that every disabled child will be able to fulfil their potential and every parent will have the opportunity to deliver the future for their child they so desperately want. Join the fight today.**





**“We are an invisible army caring for our children night and day, not complaining because we do what we do out of love. However, the constant fight for equipment makes our lives so much harder. Now, with the cost-of-living crisis, we have the added struggle of making ends meet.”** – Parent surveyed



# Executive Summary

**All children deserve the right to live a life free from pain and to reach their full potential. However, too many disabled children are being let down as they lack essential support and equipment such as wheelchairs, buggies and beds.**

The number of disabled children in the UK has nearly doubled in the last decade to over 1.6 million<sup>1</sup>. As such, it has never been more important for local services to be responsive to the increasing need, and take a holistic and proactive approach to equipment provision.

Over the past year, Newlife The Charity for Disabled Children has worked with hundreds of families and professionals to understand their experiences with

local services. This was supported by extensive research on waiting times and budgets across the UK to establish how local authorities are responding to the increasing demands.

These findings reveal a harsh reality for disabled children and their families, who lack the crucial support they need. Four key themes have emerged: a lack of government leadership, a shortage of suitable professionals, growing assessment waits and insufficient equipment budgets.

This report explores these themes further and proposes cost-effective recommendations to break these barriers and build a better future for disabled children.

## Key Findings

- **Only 2 in 5 families** feel their child has all the specialist equipment they need<sup>2</sup>.
- **75% of professionals** are concerned by unmet equipment needs in their area<sup>3</sup>.
- **Over 60% of local authorities** across the UK have seen assessment waiting lists rise in the last year<sup>4</sup>.
- **Almost 1 in 4 local authorities** have children waiting over one year to be assessed - some exceeding three<sup>5</sup>.
- **73% of professionals** concerned by long assessment waits attribute this to staff shortages<sup>6</sup>.
- **7 in 10 professionals** concerned about unmet equipment needs blame a lack of funding<sup>7</sup>.
- **Nearly half of local services** cut their equipment spend in the last year<sup>8</sup>.

## Recommendations to policymakers



**Establish a dedicated Minister for Disabled Children with cross-departmental authority.**



**Issue clear guidance defining the responsibilities of local services regarding equipment provision.**



**Expand paediatric apprenticeship programmes and improve staff retention.**



**Work with external organisations such as charities and manufacturers to improve equipment training.**



**Implement maximum wait times for children's Occupational Therapy assessments.**



**Create a ringfenced budget for specialist children's equipment that is sufficient to meet all needs.**

# Leadership Lapse: Establishing responsibility for disabled children

**“Disabled children have never been more vulnerable than they are now. If they truly were a government priority, then I wouldn’t witness simple failures so often.”** – Clemency, Occupational Therapist



## Lack of government leadership

Disabled children and their families lack a strong voice in government. Until December 2023, they were represented by the Minister for Disabled People, a small government role within the Department for Work and Pensions. This role primarily focused on adult issues such as benefits and access to work.

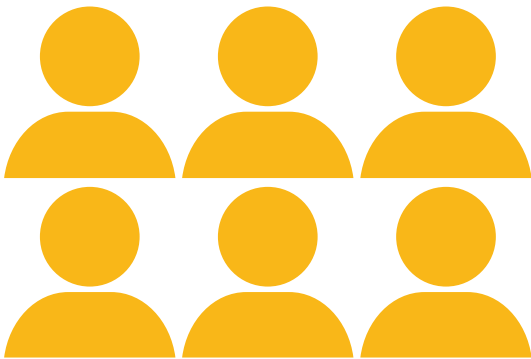
Rather than bolstering the representation of disabled children, the Government recently demoted this role to the most junior Ministerial position. Disabled children should instead be at the heart of decision-making, impacting policies across a range of departments such as health, education and transport.

## The impact

Local services are hindered by the lack of government direction, particularly the absence of national guidance outlining what types of equipment can be provided and which service is responsible. As a result, different areas operate different policies, creating a postcode lottery. These policies are often restrictive and leave many children without the necessary equipment.

The absence of leadership has also created friction between different local services. Families are often caught in the middle of disputes over who is responsible for their child’s care, leaving them in a never-ending fight for crucial support. They deserve a system which works for them, not against them.

## Did you know?



There have been **6 different** disability Ministers in the last **7 years**.

**“We struggle to fight all the fights to get my child what they need. I need an admin assistant. I’m exhausted. I’m having to work full time to be able buy some of their equipment because we aren’t getting the support we need.”** –

Parent surveyed



## Recommendation to policymakers:

**We call for a dedicated Minister for Disabled Children who will issue national guidance to clarify the roles and responsibilities of local equipment services.**

The Government can show that disabled children are a priority through giving a dedicated Minister cross-departmental authority to shape a range of policies. All major parties are also committed to supporting integration of local services. One way this can be achieved at negligible cost is through issuing guidance to clarify the responsibilities of local equipment services.



# Rhys' Story: A two-year wait for equipment that did not meet his needs

**Rhys Porter, 15 years old from London, has cerebral palsy, which affects both his arms and legs. He was left to cope for two years without a hoist he urgently needed. This meant he could only use the toilet with a bucket and commode seat. Unbelievably, his parents had to drag him once a week to the bathroom for bathing, risking injury to all.**

Mum Kelly explains: "We needed a portable hoist to move Rhys safely because our house isn't big enough to accommodate a larger fixed hoist. Rhys needed major surgery to break and reset both his hips and femurs, so a hoist was crucial post-surgery, as we wouldn't be able to do any manual handling of him.

"We began speaking with the local authority in early 2020, more than two years before the surgery was scheduled." However, the local authority only

conducted an assessment at their house two years later and decided to install a fixed hoist. Mum Kelly added: "We were getting close to the surgery date when a static hoist was finally delivered, two years after telling them this wouldn't fit. It was completely unusable."

Rhys faced having his surgery cancelled as there was no way to move him at home safely. In desperation, Kelly contacted Newlife, who provided Rhys with a portable hoist in a matter of days. The surgery went ahead.

**"I was left feeling exhausted. We do all the right things but feel constantly failed. Everything is a massive battle. No one should have to fight just for their basic human rights."**



# Specialist Shortage: Tackling the paediatric workforce crisis

**“About once a month I dream of working at Tesco. I always used to say that if I won the lottery, I would still want to be an Occupational Therapist. Now I would think about it.”** – Occupational Therapist



## Recruitment and retention crisis

There is a national shortage of paediatric professionals. According to the Royal College of Occupational Therapists<sup>9</sup>, 6 in 10 children’s Occupational Therapists say their teams are understaffed. Similarly, 62% report ongoing difficulties with recruitment – an increase from 39% in 2022. This is especially damaging given the rising demand for their services.

With only one-third of professionals primarily trained in paediatrics<sup>10</sup>, not enough Occupational Therapists are entering children’s services. Research from Newlife<sup>11</sup> has identified a particular skills gap within this workforce, with only half feeling confident instructing families how to use equipment. Two-thirds are interested in further training.

Consequently, 63% of Occupational Therapists cannot provide the level of input children need – up from 43% in 2022<sup>12</sup>. Many report how the pain of having to deny support is driving them and their colleagues out of the workplace. This is causing a retention crisis today and is hindering efforts to attract the next generation of professionals to these roles.



**“It’s always been a huge battle getting Occupational Therapists. We get a year or two maximum with the same professional, and then it’s a different one and you’re back to square one.”** – Parent surveyed

## Reset relationships

The workforce crisis limits the number of professionals with the skills and experience to meet the needs of disabled children. High staff turnover also creates a vacuum of knowledge. The constant cycle of starting over is an inefficient use of local resources and is detrimental to both child and family.

Understaffed paediatric teams also result in worsening wait times for assessments. This will be explored further in the following chapter.



England’s **‘NHS Long Term Workforce Plan’**<sup>13</sup> launched last year, pledges to increase the number of clinical staff trained through apprenticeship routes **from 7% today to 22% by 2031/32**. It also sets out a series of measures to improve workplace culture to **ensure 130,000 fewer staff leave over the next 15 years**.

While both Conservatives and Labour are committed to implementing this plan, further details are required on how the specific challenges facing paediatric services will be addressed.





## Recommendation to policymakers:

**We call for the expansion of paediatric apprenticeship programmes and improved equipment training.**

The Government should deliver a strong paediatric workforce through expanding apprenticeship programs and working with manufacturers and charities to strengthen equipment training. This would come at limited expense and would help to reduce waiting lists – a top priority for all major parties.

# Case Study: Clemency Hibell

**Clemency Hibell is a children's Occupational Therapist with over 15 years of experience in the NHS, social care and schools. She now runs a private practice across the UK. In an interview with Newlife, she voiced her concerns about the challenges facing disabled children in need of specialist equipment.**

Clemency said, **"Disabled children have never been more vulnerable than they are now."** She feels a lack of government leadership is at the heart of these issues, saying, "If disabled children were truly a government priority then I wouldn't be witnessing these simple failures so often."

She noted the effect this has on local services: "What's the role of the local authority? What's the role of the NHS therapy department? It's so disjointed – I'm often unaware of what is happening in different departments, and it's unclear who does what and when."

Clemency witnesses the critical shortage of paediatric professionals across the country. She explains: **"I've been asked to help in departments where there is perhaps one or two Occupational Therapists covering a whole city or county."**

As a result, waiting times for assessment have grown substantially. Clemency describes: "This is the biggest issue facing disabled children and their families. On average it's around two years, but in some places it is longer. We are missing windows of opportunity to get in there quickly and treat children."

The implications of this are devastating: "Children aren't getting the right equipment quickly enough. This increases the likelihood of surgery and creates

a greater need for equipment in the future." She continues: "The pressures are immense. The criteria of what you can assess for is so small, and because of service restrictions you can't always meet those needs. In some departments, you can't even order new equipment."

**"I've spoken to therapists who know they are not giving the child the right piece of equipment, but it's that or nothing. This is extremely demoralising for professionals. Many are leaving the profession because they don't want this on their conscience."**



# Assessment Anxiety: Ending unacceptable waiting times

**“My son now has scoliosis because we spent nine months waiting for a new wheelchair to support his posture. By the time they did it, his spine had gone. Now he’s in a back brace 20 hours a day and he’s possibly going to have spinal surgery when he is 12 because he did not get the postural care we needed in time.” – Parent surveyed**



## Worsening wait times

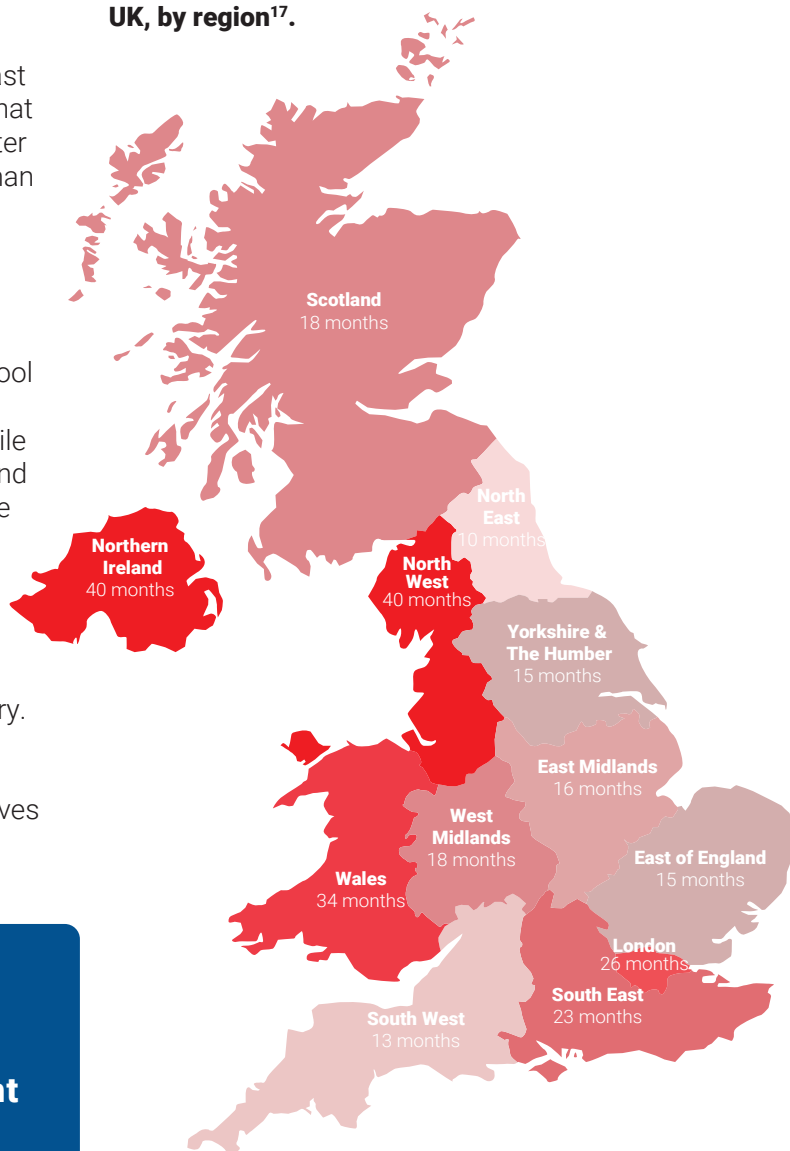
Growing numbers of disabled children in need of equipment face a crisis of extensive waiting times to be assessed by an Occupational Therapist. Research from Newlife reveals that assessment waiting lists have increased by over 30% in the last two years<sup>14</sup>, with some professionals reporting that year-long waits are the new norm. Nearly a quarter of local authorities have children waiting more than one year, with some waiting more than three<sup>15</sup>.

## The impact

Disabled children often live in pain and miss school or hospital appointments due to assessment delays. Many see their conditions deteriorate while waiting, which is devastating for both the child and family and causes preventable long-term reliance on local services. Timely provision of the right equipment would negate this human and financial cost.

Waiting times for Occupational Therapy assessments vary significantly across the country. For instance, children in one area face 21-month waits, while those across the border are waiting just 2<sup>16</sup>. This postcode lottery is unjust and deprives too many children of timely access to essential services.

**Maximum waiting time for assessments across the UK, by region<sup>17</sup>.**



**“It is incredibly disheartening to have to advise families that it is 12-14 month wait for assessment when they are struggling now.” – Professional surveyed**



NHS Wheelchair Services are judged on a statutory timescale of treating all children 18 weeks following initial referral. **This target is met over 80% of the time<sup>18</sup>.**

In contrast, Occupational Therapy assessments are not subject to any statutory timescales. **In 2023, children across the UK waited an average of 4 months just to be assessed, let alone prescribed the equipment they need<sup>19</sup>.**



### **Recommendation to policymakers:**

**We call for maximum waiting times to be implemented for children's Occupational Therapy assessments.**

All major parties have committed to reduce NHS waiting lists. Capping waiting times for paediatric Occupational Therapy assessments is a simple way for the Government to work towards this. Statutory timeframes would enforce standards and drive performance.

## **Roman's Story:** A year long wait for the buggy he needed

**Roman Pearse, aged two from Plymouth, has cerebral palsy affecting all four limbs. He can't sit up, crawl, or roll over unaided, which makes having the correct postural support crucial.**

Local services agreed Roman needed a specialist buggy to keep him supported and prevent long-term damage. However, they estimated it would be 12 months until this could be provided.

"I was gutted when I heard how long the wait time was," said Roman's mum, Lauren. "Statutory services told us to apply to Newlife for an Emergency Equipment Loan, which is usually provided for around six months."

Thankfully, Newlife promptly provided the loan of a buggy to meet Roman's needs and granted an extension until his buggy arrived from statutory services.

Lauren said: "It was a godsend and made our lives so much easier – but what if Newlife hadn't been able to help us?"

**"Children are suffering. It's hard for any family to get the equipment they need at the right time. We are seeing children deteriorate and not being able to achieve their full potential due to the lack of equipment and wait times.**

**"I'd like to see the government make services more accessible and make equipment easier to access. For families like mine, it would mean less time spent worrying."**





# Money Matters: Spending equipment budgets wisely

**“There is a major lack of funding for children with additional needs. We rely on charities for equipment when this should be provided by the local council.” – Family surveyed**



## Restrictive equipment budgets

Across the UK, equipment budgets are failing to keep pace with escalating demand. In the last year, nearly half of local services reduced spending and provided fewer pieces of equipment than the year before<sup>20</sup>. 7 in 10 professionals concerned by unmet needs in their area attribute this to insufficient funding and rising demand<sup>21</sup>.

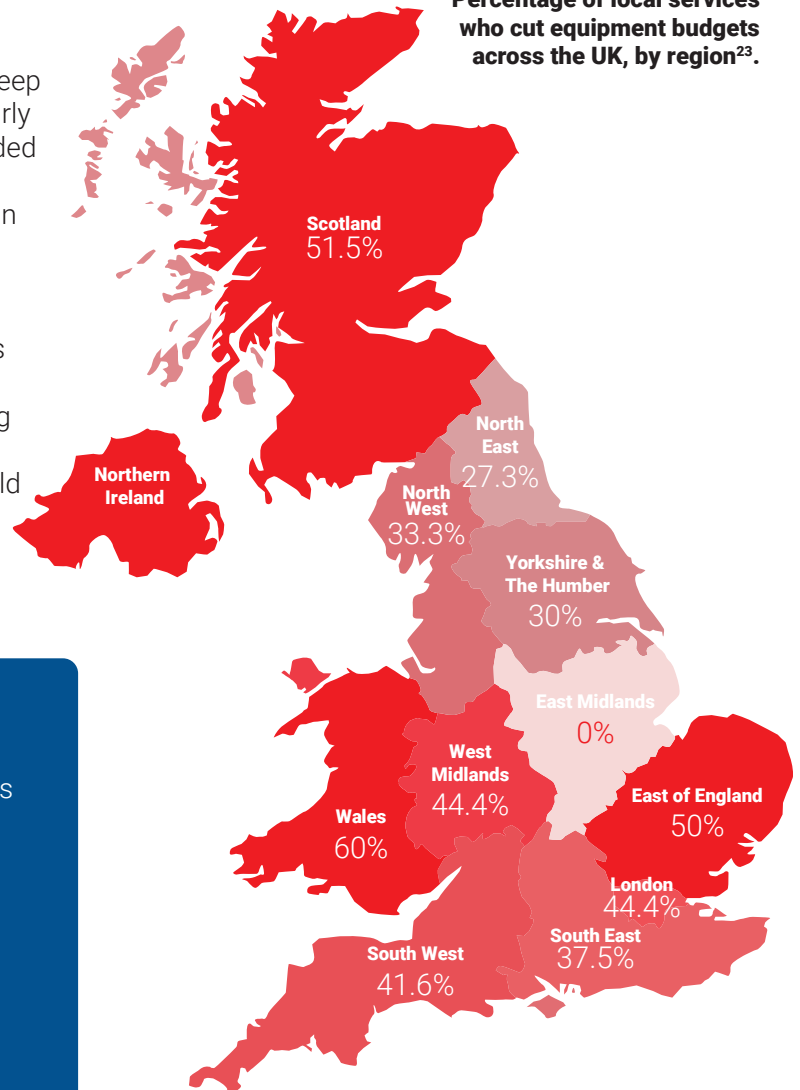
Professionals also emphasised that local services could save money on long-term care costs by prioritising early intervention and better integrating services. Pooling budgets between health, social care and education in a joint equipment fund would stop children being provided unsuitable provision. Similarly, assessing needs and providing timely support would stop conditions from deteriorating while waiting.

### Did you know?

A 2014 study from the British Healthcare Trades Association modelled the impact that meeting all specialist equipment needs would have on long-term medical care expenses.

**Modest projections predicted local services would recoup the expenditure over time, while more optimistic estimations predict savings of more than £600million<sup>22</sup>.**

Percentage of local services who cut equipment budgets across the UK, by region<sup>23</sup>.



## Plugging the gap

Without adequate support from local services, more families are turning to charities. Last year, the number of applications for equipment grants from Newlife doubled, resulting in £2.5 million being spent<sup>24</sup>. Others resort to self-fundraising, however this is often unviable given the cost-of-living pressures facing families across the country.

Charities and families are doing their best to plug the gap. However, these avenues are no replacement for adequately funded local services. This seems set to worsen, with 69% of local authorities requiring cuts to children’s social care to balance their 2024/25 budgets<sup>25</sup>. Without immediate government action, many disabled children will continue to fall through the cracks.



## Recommendation to policymakers:

**We call for children's equipment budgets to be pooled, ringfenced and sufficiently resourced to meet all needs.**

All major parties have stressed the importance of taking a preventative approach to health and social care. One way this can be achieved is through meeting the right equipment needs at the right time. By ringfencing a pooled budget that is sufficient to meet all needs, the Government could 'invest to save', helping disabled children now to reduce the need for future medical interventions.

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# Endnotes

- 1 'Family Resource Survey 2021-2022', UK Government.
- 2 'Newlife Stakeholder Research', nfp Research, 2023 (811 respondents).
- 3 'Newlife Stakeholder Research', nfp Research, 2023 (256 respondents).
- 4 Freedom of Information research, Newlife The Charity for Disabled Children, 2023 (118 respondents).
- 5 Freedom of Information research, Newlife The Charity for Disabled Children, 2023 (157 respondents).
- 6 'Newlife Stakeholder Research', nfp Research, 2023 (205 respondents).
- 7 'Newlife Stakeholder Research', nfp Research, 2023 (189 respondents).
- 8 Freedom of Information research, Newlife The Charity for Disabled Children, 2023 (167 respondents).
- 9 'Children and young people's occupational therapy survey 2023', Royal College of Occupational Therapists, 2023.
- 10 'Newlife Stakeholder Research', nfp Research, 2023 (238 respondents).
- 11 'Newlife Stakeholder Research', nfp Research, 2023 (238 respondents).
- 12 'Children and young people's occupational therapy survey 2023', Royal College of Occupational Therapists, 2023.
- 13 'NHS Long Term Workforce Plan', NHS England, 2023.
- 14 Freedom of Information research, Newlife The Charity for Disabled Children, 2023 (118 respondents).
- 15 Freedom of Information research, Newlife The Charity for Disabled Children, 2023 (157 respondents).
- 16 Freedom of Information research, Newlife The Charity for Disabled Children, 2023.
- 17 Freedom of Information research, Newlife The Charity for Disabled Children, 2023 (157 respondents).
- 18 'National Wheelchair Data Collection, Quarter 3, 2023-24', NHS England, 2023.
- 19 Freedom of Information research, Newlife The Charity for Disabled Children, 2023 (134 respondents).
- 20 Freedom of Information research, Newlife The Charity for Disabled Children, 2023 (167 respondents).
- 21 'Newlife Stakeholder Research', nfp Research, 2023 (189 respondents).
- 22 'The economic benefits of better provision of equipment for disabled and terminally ill children', British Healthcare Trades Association, 2014.
- 23 Freedom of Information research, Newlife The Charity for Disabled Children, 2023 (155 respondents).
- 24 Equipment Grant Service data 2022 – 2023, Newlife The Charity for Disabled Children.
- 25 'Local government budget setting surveys 2024/25', Local Government Association, 2024.

