

**EQUIPMENT**

**CRISIS**

**#FIXTHEFOUR**

**FOR DISABLED CHILDREN**

 **newlife**  
THE CHARITY FOR DISABLED CHILDREN

# ABOUT

**IF IT WAS A CHILD YOU LOVED,  
YOU WOULD WANT THE BEST FOR  
THEM – THIS IS WHY NEWLIFE EXISTS.**

Newlife is the UK's largest children's charity provider of specialist disability equipment, spending £2.5m a year providing equipment such as; wheelchairs, specialist beds, specialist car seats, walking and standing frames and communication aids.

Without Newlife thousands of disabled children, many of whom have reached crisis point would be living in pain, unsafe, unable to do the things that we all take for granted and denied the opportunity to reach their potential.

For 27 years Newlife has been trusted by disabled children and their families. Newlife does not receive any government funding and is reliant on income from its unique recycling and retail operation and funds raised by volunteers and supporters from all around the UK.

Newlife funds pioneering Medical Research to tackle the biggest threat to child health today; birth defects, and campaigns on behalf of disabled children and their families on the issues that really matter to them.

Newlife charity supports families nationally, through a range of free services including:

- **Nurse Helpline** – When families need vital information, support or care, the dedicated Newlife Nurses are there to help via a helpline or online nurse chat service.
- **Equipment Grants** - Providing the right equipment at the right time that changes lives.
- **Emergency Equipment Loans** - Meeting the emergency need when children and families are at crisis point. Newlife loans essential equipment to anywhere in the UK within just 72 hours.
- **Play Therapy Pods** – The importance of play should never be underestimated. Designed by play therapists, these specialist toys aid child development and encourage families to play together, often for the first time.

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# FOREWORD

*Why does this matter? Because no family is immune from having a disabled child.*

If like me, it's your family - **a child you love** - you want them to have the best chance to live life to the full. You would want to have their pain reduced, keep them safe, benefit from treatment and therapy and be the best they can possibly be. That's what every family would want.

In 2007 we exposed the widespread failings in provision of equipment for disabled children in our report, 'It's not too much to ask'. The government launched a major review of provision but recently a children's occupational therapist with 28 years service, blinked back tears as she told me "things have never been worse". She told me that professionals are seeing disabled children suffering, but they are unable to give them the equipment they really need.

Last year the number of disabled children rose by 15% to 1.1 million, the highest ever, but equipment provision has simply failed to keep pace. The number of children and families left in crisis situations is growing. Without Newlife's equipment services, many would be left to suffer, despite the dedication of frontline professionals.

We have our finger on the pulse every day, because we support children regardless of the type of disability, we cover the whole of the UK and we provide an enormous range of specialist equipment.

As well as being able to meet the emergency needs of children, Newlife also provides equipment for long term use, when the local statutory services say no. What else can we do? We don't want to just turn away, knowing someone's child is at serious risk of injury or death. Yes, it really is that bad.

The law protects these children. It recognises their vulnerability and needs, but we know children's rights are not being observed locally, to give them the equipment they really need. To help change this, we commissioned a series of barristers' reports, so that everyone involved can be clear about what the law says.

We have 27 years experience and while there are lots of complex reasons why children are being failed, we believe that if the four big issues highlighted in this report are fixed, hundreds of thousands of our children will benefit. We have successfully campaigned for change before - we even secured an amendment to the law. Today our aim is to ensure that all disabled children get the equipment they need.

So this matters to every family - cancers, accidents, birth defects, infections and other risks are with us every day. No one thinks it will ever happen to them I didn't, but that's the reality. Please read this report and help us to change young lives giving them the care and support they genuinely deserve.



Mrs. Sheila Brown, OBE, FRSM - Newlife CEO



# EXECUTIVE

## SUMMARY

All children have the right to be safe and live without fear or pain. A right to learn, to develop skills, talents and abilities and a right to live a full life, without disadvantage.

Yet every day, right here in the UK, disabled and terminally ill children are failed and routinely let down because of a hidden equipment crisis. Thousands of the most vulnerable disabled children are denied equipment that could change lives. Children refused essential equipment are left to suffer in pain, their safety compromised, isolated from the world. They are repeatedly denied the chance to go to school, unable to develop vital skills for their future, while their families face insurmountable barriers in giving their child the opportunity to be the best they possibly can be.

In the last year the number of disabled children leapt by a staggering 15% to 1.1 million – the highest it's ever been<sup>1</sup>. Improvements in medical advances mean children born with conditions or who acquire disabilities as a result of illness or accidents are surviving, often with very complex needs. This translates directly to them needing a greater level of support and, in many cases, multiple pieces of specialist equipment. Demand for equipment is reaching critical levels. Yet recent figures show that a quarter of local statutory services actually cut spending on essential equipment during 2016/17, despite a substantial increase in need<sup>2</sup>.

In this report we identify the key barriers preventing disabled and terminally ill children from having the right kind of specialist equipment at the right time, and outline a comprehensive four-point-plan that will improve equipment services for disabled children and their families.

Newlife commissioned leading barristers' advice explaining what the law says about equipment services for disabled children throughout the UK. This advice features throughout this report and is available in full by country on our website.

## EVERY CHILD HAS THE RIGHT TO:

### BE SAFE AND FREE FROM PAIN

Every child has the right to be safe, protected both physically and emotionally. Yet disabled children are habitually left in danger, their already fragile lives put at risk because they don't have access to specialist equipment. For those children whose conditions cause them to behave in an erratic way that can put them at risk of injury, specialist protective buggies, car seats and beds help eliminate the dangers the world around them presents. As well as alleviating immediate risk, equipment also protects disabled children from long term damage and deterioration. Poor posture, for example, causes premature death. Depriving a disabled child of the right seating, standing or sleeping system WILL shorten their life; this is the reality many families face.

### A CHANCE TO LEARN

Every child has the right to an education. This does not and must not exclude disabled children. Yet children become prisoners in their own homes, unable to go to nursery or school simply because they don't have the equipment that provides the security and safety they need. Children are isolated, the world around them inaccessible, because they don't have the right wheelchair or seating system that would allow them to interact with their peers. For those unable to walk or talk independently, having access to a specialist frame or communication device has a far-reaching impact on their ability to do what most others take for granted.

### REACH THEIR POTENTIAL

Every child has the right to reach their potential regardless of diagnosis or disability. Yet children are deprived equipment that will enhance their lives, giving them a chance to be the best they can be, because it's not considered 'essential'. Denying children the opportunity to participate fully in as many aspects of life as possible is inherently wrong. Similarly, for those with severe medical conditions who are unable to walk, eat or communicate for themselves, equipment provides a crucial lifeline. Disabled children should not be defined by what they can't do – but rather given the opportunity, with the right equipment, to show the world what they can.

## KEY FACTS

**8%**

of children in the UK  
are disabled  
(total = 1.1 million)

**3x**

It costs three times more  
to raise a disabled child  
than it does to raise a  
non-disabled child <sup>3</sup>

**15%**

increase in the number of  
disabled children on the  
previous year.

**40%**

40% of disabled  
children live in poverty <sup>4</sup>

## WHY EQUIPMENT MATTERS

- Reduces pain and suffering.
- Stops conditions from getting worse.
- Removes risk of injury or death.
- Improves treatment success.
- Better quality of life.
- Keeps families together.

The law protects the rights of all disabled children – Removing barriers that prevent frontline professionals from assessing and supplying essential equipment will, without doubt, change thousands of childrens' lives. In this report we outline a clear and comprehensive four-point-plan that will make a real difference; improving equipment provision for disabled children in the UK:

**1**

### CEASE THE USE OF BLANKET BANS FOR RATIONING EQUIPMENT

Blanket bans are commonly used as a means to manage budget constraints. This means essential equipment is denied to children under any circumstances, and is consequently arbitrary and fails to respond to their assessed needs.

**2**

### ESTABLISH AN EMERGENCY EQUIPMENT RESPONSE SERVICE

Children in crisis, cannot get equipment quickly enough. The majority of local statutory services don't have an effective emergency equipment response service for those in most need. This needs fixing to prevent injury, to allow hospital discharge and to relieve pain.

**3**

### INTRODUCE A MAXIMUM WAITING TIME FOR EQUIPMENT ASSESSMENTS ACROSS HEALTH AND SOCIAL CARE

Waiting times for assessments for essential equipment are not capped, and there are widespread lengthy delays - families can wait months, sometimes years before their child is prescribed the equipment they need. This leaves disabled children living in pain or at risk of injury, and their families in constant anxiety. They can't wait.

**4**

### ENSURE EVERY DISABLED CHILD IS COUNTED

Disability registers are failing. Without an accurate measure, health and social care services cannot budget to meet the need. Local authorities must put in place an accurate way to measure the number of disabled children to ensure that no child is invisible.

**#FIXTHEFOUR**

see and hear more at  
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# BLANKET BANS

When a local statutory service refuses to provide a particular piece of equipment 'under any circumstance' - this is a blanket ban which is likely to be unlawful. Blanket bans are often used as a way to ration budgets. Set at authority level, the impact of a blanket ban means frontline health and social care professionals are forced to deny disabled children equipment, despite having assessed and identified a need.

Each authority has its own criteria for applying blanket bans for example; no wheelchair assessments for under threes, no walking frames for those who cannot walk independently, or no specialist beds for children with an intellectual disability. The use of a blanket ban is likely to be unlawful & therefore can and should be challenged.

The most prevalent use of a blanket ban today is the widespread refusal of councils to fund specialist car seats for disabled children, despite there being clear medical or safety needs identified by

a qualified professional (such as an occupational therapist or physiotherapist). All children in the UK are legally required to have a suitable car seat until they are 12 years old or 135cm (whichever comes first). While a standard high-street purchased car seat costs in the region of £100, a specialist car seat for a child with disabilities can cost up to £3,500. Families can apply for a special exemption that precludes the need, in law, for their child to use a car seat. It is not acceptable for a disabled child to be denied the same rights as any other child. This does not resolve the problem, it does not keep all children safe.

**Car seats are not luxury items, they can tilt to stop children with compromised airways from choking to death; they can have side and head supports so that when a child has a seizure, they are safe; car seats can have a swivel base to prevent parents from damaging their backs when lifting and moving their child in and out of the car – often to attend multiple medical appointments.**

**WHAT THE LAW SAYS:** The barristers advise that local bodies that apply a rigid one size fits all policy that refuses to allow for exceptionality are likely to be acting unlawfully. (Newlife barristers advice 2018)

## COMMON BLANKET BANS:

- Refusing to provide specialist protective car seats to ensure safe travel.
- Denying children under three wheelchairs and buggies regardless of their complex needs.
- Declining requests for high sided cots and beds to keep children safe at night.
- Rejecting applications for walking frames because the child will never walk unaided.
- Turning down referrals for sleep systems which would allow children to sleep comfortably and reduce the need for painful surgery as they grow.

**THE FIX:** An end to blanket bans and 'we don't do' mindset. Every local authority and health service must have an identified, transparent process for reviewing equipment requests. Where children do not meet the formal criteria, there must be a way for their request to be reviewed by clinical professionals and exceptionality determined at a special panel meeting.



**83%**

**of local authorities in England have a blanket ban that prevents provision of specialist car seats to disabled children.<sup>5</sup>**

# MALACHI'S STORY

A blanket ban by local statutory services on providing specialist protective car seats for disabled children resulted in three-year-old Malachi Bartolomeu nearly choking to death several times, once on the way to Great Ormond Street Hospital for treatment.

Malachi has extensive brain damage. He is unable to sit up or control his own head and has to be hooked up to a machine three times a day which pumps milk directly into his stomach through a tube.

Malachi, who has a healthy twin sister Amelia, struggles to clear his own airways and must be supported at all times, otherwise secretions build up in his throat that can cause him to choke and projectile vomit, disrupting his medication dosage.

Malachi is unable to use a standard shop bought car seat because it doesn't provide the support he needs to keep his airways clear. Banned from going on public transport because of Malachi's frequent vomiting, his Mum Sylvia had no choice but to use taxis to take her three other children aged eight, seven and three, to school.

Every single journey is a nightmare; Malachi in distress from constant choking, his brother and sisters having to watch their Mum desperately trying to suction him while perched on her lap, and frequently turning up at school covered in vomit.

Despite the desperate guilt of inflicting multiple taxi journeys on Malachi every day, the harsh reality was she had no choice but to get the other children to school or face being fined by the local authority. Some days he had to endure up to eight journeys because of his many frequent medical appointments.

During one journey Malachi stopped breathing. After being sick, thick secretions completely clogged his airway. For a few heart-stopping moments Sylvia frantically tried

to get him breathing again - in front of his horrified siblings. Thankfully she succeeded, but the impact of almost losing Malachi forced her to stop going out, leaving the whole family housebound and isolated.

Despite Malachi's obvious medical needs and the clear risk to his life, the local statutory service wouldn't fund a specialist car seat because of the use of a blanket ban.

*Sylvia said: "If a child can't walk, they are entitled to a wheelchair. If a child can't feed properly the NHS provide a feeding system. But if a child can't use a standard car seat because their health and life is put at risk when they do – they don't get anything. This just isn't right."*

Since receiving the specialist car seat from Newlife, Malachi's health has dramatically improved. He's no longer sick on journeys, and maintaining the right dosage of his daily medication. He's even started smiling when he's in the car! Sylvia is also now learning to drive so the family don't have to rely on expensive taxi journeys and give her the freedom and peace of mind to take her children wherever they need to go, knowing that Malachi is safe in his special car seat.



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# NO EMERGENCY EQUIPMENT RESPONSE

There are some situations that require specialist equipment in an emergency, the ability to respond urgently to help a child or family in crisis. The safety of children and their families is regularly compromised because health and social care services don't have immediately accessible equipment that can be delivered quickly to meet their emergency needs. Equally, children with only a few months to live and discharged from hospital to spend the time they have left with their families just don't have the many months it takes to wait for assessments, funding decisions, and ultimately, equipment.

In most areas, local health and social care services jointly commission integrated equipment stores. These warehouses hold vast amounts of standard equipment suitable for adults including chairs, walking frames and hospital beds. The equipment can be delivered rapidly to adults in need – either because of a recent terminal diagnosis, a deterioration in their condition or a planned hospital discharge. But when it comes

to children, no such publicly run, effective service exists. Community equipment stores are too often unable to respond urgently to children with more complex, bespoke needs and are therefore failing some of the most vulnerable in our society. In such cases the specialist equipment needed to ease the pain and suffering of a child with a disability is only available through a protracted, bureaucratic route that can, in some cases, take many months or years to materialise.

**FIRST AND ONLY:** For the past five years Newlife has been running the UK's first and only Emergency Equipment Loan service delivering specialist equipment to disabled children in crisis within 72 hours of request. We've proven it works and that demand for such a service is increasing year on year; in the last 12 months Newlife helped 338 children in crisis, supplying them and their families with the equipment they desperately needed fast.

## OLIVER WOULD HAVE DIED ON A WAITING LIST

Oliver was born with a fatal genetic condition. At four months his health began deteriorating rapidly. To ensure he could spend time at home with his family he needed a specialist pushchair so he could lie completely flat and that could accommodate the medical equipment his life relied on - an oxygen tank and suction machine. The statutory route for such a piece of equipment via wheelchair services meant he would have had to wait up to six months for an assessment, and then many months more for the equipment. Following a referral from a healthcare professional, a specialist buggy was delivered to Oliver within 72 hours through Newlife's Emergency Equipment Loan service. Oliver died seven weeks later. If our Emergency Service didn't exist - Oliver would have died on the wheelchair service waiting list.



**3 Fold**  
increase in Newlife  
emergency loan applications  
in the last five years.

**THE FIX:** Every integrated equipment store in the UK must include equipment suitable for children in crisis. We must ensure that no child is in danger because they don't have the right bed that can keep them safe, that no family face caring for their child at the end of their life on a mattress on the floor.



# MAX AND FREDDIE'S STORY

Every room in the Giles' house is stripped bare; blinds and curtains ripped from windows that have been reinforced with shatterproof glass. In the middle of the room is a corner sofa that faces the TV, mounted high up on the wall, way out of reach.

Just getting to the end of each day is an achievement for Nikki and Simon Giles, who care for their three children, eight year old Isobel and seven-year-old twins Max and Freddie.

Max and Freddie both have 'core' autism and severe learning disabilities, while Isobel has ADHD and autism, although to a much lesser extent than the twins. Dad Simon works full-time while Mum Nikki was forced to give up work to provide round the clock care, with the support of a personal assistant.

Over the last year Max's behaviour has become increasingly more agitated and aggressive; breaking windows and injuring himself as well as physically hurting those around him, in particular his brother and sister, parents and personal assistant. On more than one occasion Freddie has been left in agonising pain and at risk of serious infection because Max has pulled out the tube inserted into his stomach to feed him. When this happens, his parents have just 20 minutes to get Freddie to hospital for treatment, otherwise he has to be admitted for days which sends the family's care routine – as it is – into complete disarray.

Max's aggression is worse at night. His erratic behaviour builds and builds – constantly banging on the windows, trying to break the glass and escape, in spite of the locks on the doors and bars on the windows. If he does escape he has no concept of danger and puts his own life on the line without realising; once climbing onto the roof of their terraced house ready to jump.

The noise, the banging and sheer aggressive behaviour from Max has a knock-on effect, triggering both Freddie and Isobel's anxieties. No-one in the house has slept properly for years. The family are at breaking point. They are in urgent need of help, and equipment.

Nikki explains: "Every day is a battle to keep Max safe from himself and trying to keep the other children safe from Max. My biggest fear is that he'll escape and drown in the lake opposite the house. We do everything we can to keep him safe but I fear it's not enough."

Newlife provided a safe and secure place for Max to retreat to at night – and during the day – this has had a huge impact on everyone's life – his parents, the personal assistant and his siblings. Specialist beds of this type are not readily available to help children like Max and never in an emergency.



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# DELAYED EQUIPMENT ASSESSMENTS

Any kind of delay in assessing a child with a disability has a detrimental impact on their health and wellbeing, particularly as children grow every day. With the exception of wheelchair services, there is currently no standard time frame for the maximum length of time a child should have to wait to be seen for an assessment.

**We have received calls to our Nurse Helpline from families who have waited several months and even years before their child is assessed for equipment – never mind for the equipment to be provided. Unnecessary delays can result in a child’s condition deteriorating and in them having to endure increased pain. Delays can result in children being isolated from the world around them, unable to go to school, visit family or go to vital hospital appointments.**

Under the NHS Constitution in England, all patients have the right to access certain services within maximum waiting times – this is called ‘Referral To Treatment’ (RTT). NHS England has adopted a RTT for its wheelchair services for children due to

severe criticism of the lengthy delays experienced by families, stating children should not wait longer than 18 weeks for an assessment and wheelchair/buggy to be provided. During 2017/18, 82% of eligible children received their wheelchair within 18 weeks, demonstrating the effectiveness of the introduction of benchmarks<sup>6</sup>. This is needed across all equipment categories.

## VINNIE HAS ALREADY WAITED OVER A YEAR FOR AN ASSESSMENT

Nine-year-old Vinnie has severe autism and profound learning disabilities, and requires one-to-one supervision at all times. He’s unable to speak, displays obsessional and ritualistic behaviours, rarely sleeps and has no understanding of danger. At night, Vinnie wanders around the house, climbing on furniture and playing with taps in the bathroom – he has even fallen from a chest of drawers in the middle of the night and injured himself. Despite being near the top of the list of children at the highest level of risk, Vinnie has already been waiting over a year for an assessment. It is likely he’ll have to wait at least another year before he is seen by a children’s occupational therapist and assessed. The impact of this delay means Vinnie continues to be at risk of hurting himself every night, while his Dad is forced to continue to sleep on the floor next to him to ensure his safety.

**WHAT THE LAW SAYS:** There is no defined time period for how long it should take for a local authority to assess for equipment. However the barristers advise that assessments should be carried out in a ‘timely’ manner. Critically, where needs are identified at any stage of the assessment process, the child should not have to wait until completion of the assessment before appropriate services are provided to support the family.

**THE FIX:** Introduce a maximum assessment waiting time to all children’s disability equipment services. We must ensure that no child has to endure excessive delays to be assessed.



# 1/2

**children in need of equipment are suffering due to delays in assessments<sup>7</sup>.**

# MAKING EVERY CHILD COUNT

**By not counting how many disabled children need equipment services how can services budget to meet their needs?**

50% of frontline health & social care professionals assessing for specialist equipment tell Newlife there is not enough funding to meet the needs of all of the disabled and terminally ill children in their respective areas (Newlife applications, 2018). However, there is not currently a universal, transparent and effective way for services to identify the true number of children in need of equipment and subsequently plan budgets and resources to meet this need. One way public authorities have of obtaining this key data is through children’s disability registers – giving families the option to add their child to a local register. However, Newlife has evidence to show this is completely ineffective.

**WHAT THE LAW SAYS:** The Children’s Act 1989 requires all local authorities in England to ‘establish and maintain’ a register of children with a disability within their area<sup>8</sup>. Although all disabled children are entitled to be on this register, as it is voluntary a significant number of families don’t sign up, meaning the bodies responsible for delivering services, including equipment provision, simply don’t know how many disabled children there are in their area. 11 local authorities are currently breaking the law as they do not have an active children’s disability register.

In England, through a Freedom of Information Act request we found 89% of the 942,000<sup>9</sup> disabled children living in England were not officially registered as ‘known’ to services.



**89%**  
of children are missing from  
disability registers in England.

## FALLING BETWEEN THE BUDGETS

Alex is ten months old and has epilepsy so severe he has 40 seizures a day. He needs a special seat to position him safely. Without this, he cannot eat solid foods or use his hands to play with toys. His occupational therapist assessed him and recommended equipment costing £1900. But the budget wasn’t designed for the number of children needing support. The healthcare professional supporting Alex said: *“Due to the change in processes, we have moved from one overall health budget to three separate budgets. The budget for special equipment remains in a grey area and no one can decide who should pay for what item and who is responsible. We currently have a backlog of over £10k worth of equipment with no-one agreeing the funding. It is extremely frustrating.”*

**Knowing the true number of disabled and terminally ill children in need of services allows for effective financial and resource planning. If only 11% of the actual number of the children with disabilities are identified in an area, it is impossible to budget to meet the true level of need and therefore plan budgets and resources effectively.**

**THE FIX:** A re-evaluation of disability registers to establish how useful they are. Consider solutions to improve effectiveness such as incentivising families to sign up to the register through local attraction passes, store discounts and access to events. Some authorities are already trying this. Where registers are failing, the local authority must have an alternative method for identifying and counting disabled children. We must ensure that no child is invisible to decision makers.

# EVERY CHILD DESERVES A VOICE

## LAILA'S STORY

For nearly 16 years Laila Nahir has been locked in a silent, solitary world; unable to speak to her family, to make her own wants and needs known and make her own choices.

Laila has a rare condition called Patau syndrome that affects one in 7,000 children and causes significant development delay, learning difficulties and is typified by a cleft lip and palate, making speech impossible. Despite coming from a strong and loving family, not being able to communicate causes Laila to become unbelievably frustrated – which manifests in outbursts of aggression towards those who care for her so deeply.

Mohamed, Laila's brother explains: *"Everything happens around her. The only way she can tell us what she wants or needs, is to grab it and to hold onto whatever it is and just not let go. But she gets so upset and angry when we don't understand what she's trying to tell us."*

Now for the first time, Laila has been given a voice. Her school has loaned her a specialist device that enables her to communicate and interact with the staff and other children at school.

According to her teachers, the device has transformed every aspect of Laila's personality. She's so much more confident, has developed brand new friendships with children she's been at school with for years, and even enables her to choose what she wants to eat for her lunch in the canteen.

However, Laila isn't able to take the communication device, which costs around £3,000, home with her. So every day, after school, she's forced back into a world of silence making her even more frustrated and angry, knowing she can communicate but just doesn't have the tools to do so at home.

Mohamed continues: *"I don't know what's worse – never having the chance to speak and be understood, or being given the chance then having it snatched away. When Laila was born, the doctors said she'd never amount to anything and wouldn't be able to participate in society. In seeing the difference this specialist piece of equipment has had on her confidence and personality just proves them all wrong. It allows her to say, I'm here, I can speak, I can do anything."*



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# NEWLIFE'S FOUR-POINT-PLAN

# #FIXTHEFOUR

The hard truth is some of the most vulnerable children in the UK, like Max and Freddie, Malachi and Laila are being failed because they cannot get the essential equipment they need, when they need it. This is happening every day to children and their families across the UK and is having a devastating effect on their health, their safety, their ability to learn and it puts their future in doubt.

This report exposes a hidden equipment crisis through the stories of the families facing this reality day in day out.

## Newlife's four-point-plan will:

- Keep children safe and free from unnecessary pain
- Help children to learn
- Enable children to be the best they can be, to reach their potential.

All disabled children throughout the UK are protected by the law. Every child has a right to a full and thorough assessment of their individual needs. Once a qualified professional has identified what a child needs, there is a responsibility to meet that need.

We are calling on national government and individual local statutory services to work with us to put in place our four-point-plan which will change thousands of children's lives, the lives of some of the most vulnerable disabled and terminally ill children in the UK.

## 1

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### ESTABLISH AN EMERGENCY EQUIPMENT RESPONSE SERVICE

Children in crisis, cannot get equipment quickly enough. The majority of local statutory services don't have an effective emergency equipment response service for those in most need. This needs fixing to prevent injury, to allow hospital discharge and to relieve pain.

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### INTRODUCE A MAXIMUM WAITING TIME FOR EQUIPMENT ASSESSMENTS ACROSS HEALTH AND SOCIAL CARE

Waiting times for assessments for essential equipment are not capped, and there are widespread lengthy delays - families can wait months, sometimes years before their child is prescribed the equipment they need. This leaves disabled children living in pain or at risk of injury, and their families in constant anxiety. They can't wait.

## 4

### ENSURE EVERY DISABLED CHILD IS COUNTED

Disability registers are failing. Without an accurate measure, health and social care services cannot budget to meet the need. Local authorities must put in place an accurate way to measure the number of disabled children to ensure that no child is invisible.

## #FIXTHEFOUR

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*Having a disabled child is challenging enough but seeing my child's condition deteriorate because of a*

## **LACK OF EQUIPMENT**

*is beyond heart breaking for the whole family.*

*It's very unfair how parents of a disabled child are treated. I didn't ask for my child to be disabled and I always feel like I'm having to beg for help.*

## **IT SHOULDN'T BE LIKE THIS.**

*As a parent of a child with special needs I spend my whole time completing application forms and then*

## **APPEALING AND ARGUING MY CASE**

*to get access to the services my child needs.*

*The impact felt by the whole family when help and support isn't there, or isn't there quickly enough is huge. It takes time you often haven't got, repeating the same information over and over again - and you can feel*

## **VERY ISOLATED AND ALONE**

*sometimes not knowing where to go for help.*

*Please improve waiting times for assessments. You can wait six months or more to be seen and during this time*

## **YOU FEEL SO ALONE.**

*I have been a paediatric occupational therapist for 28 years and I can honestly say it's never been*

**AS BAD AS IT IS NOW.**

*Almost every day I am told by my manager to*

**DOWNGRADE MY ASSESSMENT**

*regarding the equipment a child needs, I can't even go and assess some children.*

*I have been told I can't now support a family to apply to a charity –*

**WHAT HOPE DOES ANY CHILD HAVE**

*of getting the equipment they need?*

## REFERENCES

### PAGE 2 - EXECUTIVE SUMMARY

<sup>1</sup> Family Resource Survey, 2016/17. DWP

<sup>2</sup> Newlife the Charity for Disabled Children - Freedom of Information request on Disability equipment spend by Local Authorities and Clinical Commissioning Groups during 2016-17.

<sup>3</sup> Contact a Family - Counting The Costs 2012 [https://contact.org.uk/media/381221/counting\\_the\\_costs\\_2012\\_full\\_report.pdf](https://contact.org.uk/media/381221/counting_the_costs_2012_full_report.pdf)

<sup>4</sup> Disability Rights, June 2013, Risk of major disability poverty rise

### PAGE 4 - BLANKET BANS

<sup>5</sup> Newlife the Charity for Disabled Children - Freedom of Information request on Disability equipment spend by Local Authorities and Clinical Commissioning Groups during 2016-17.

### PAGE 8 - DELAYED EQUIPMENT ASSESSMENT

<sup>6</sup> Wheelchair services: Operational Data Collection 2017/2018 [www.england.nhs.uk/publication/wheelchair-services-operational-data-collection-quarter-4-dataset-2017-18-january-march-2018/](http://www.england.nhs.uk/publication/wheelchair-services-operational-data-collection-quarter-4-dataset-2017-18-january-march-2018/)

<sup>7</sup> Newlife the Charity for Disabled Children – Family Feedback Survey.

### PAGE 9 - MAKING EVERY CHILD COUNT

<sup>8</sup> Schedule 2 of the 1989 Children's Act

<sup>9</sup> Family Resource Survey, 2016/17. DWP and Newlife the Charity for Disabled Children - Freedom of Information Request on Disability Registers.

# #FIXTHEFOUR

for disabled childrens specialist equipment  
see and hear more at [newlifecharity.co.uk/fixthefour](https://newlifecharity.co.uk/fixthefour)

END BLANKET BANS

TACKLE ASSESSMENT DELAYS

IMPROVE EMERGENCY RESPONSE

COUNT EVERY CHILD

