

# From the Front Line

Reporting on the UK's disabled children's  
equipment provision.

Summer 2012



WE ARE NOW

**newlife** **life**

THE CHARITY FOR DISABLED CHILDREN

Registered Charity Number: 1170125 in England & Wales.

HELP US CHANGE  
A CHILD'S LIFE

children

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“Reporting on responses from 4,367 professionals from across the UK.”

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For reasons of confidentiality, some names in this report have been changed.

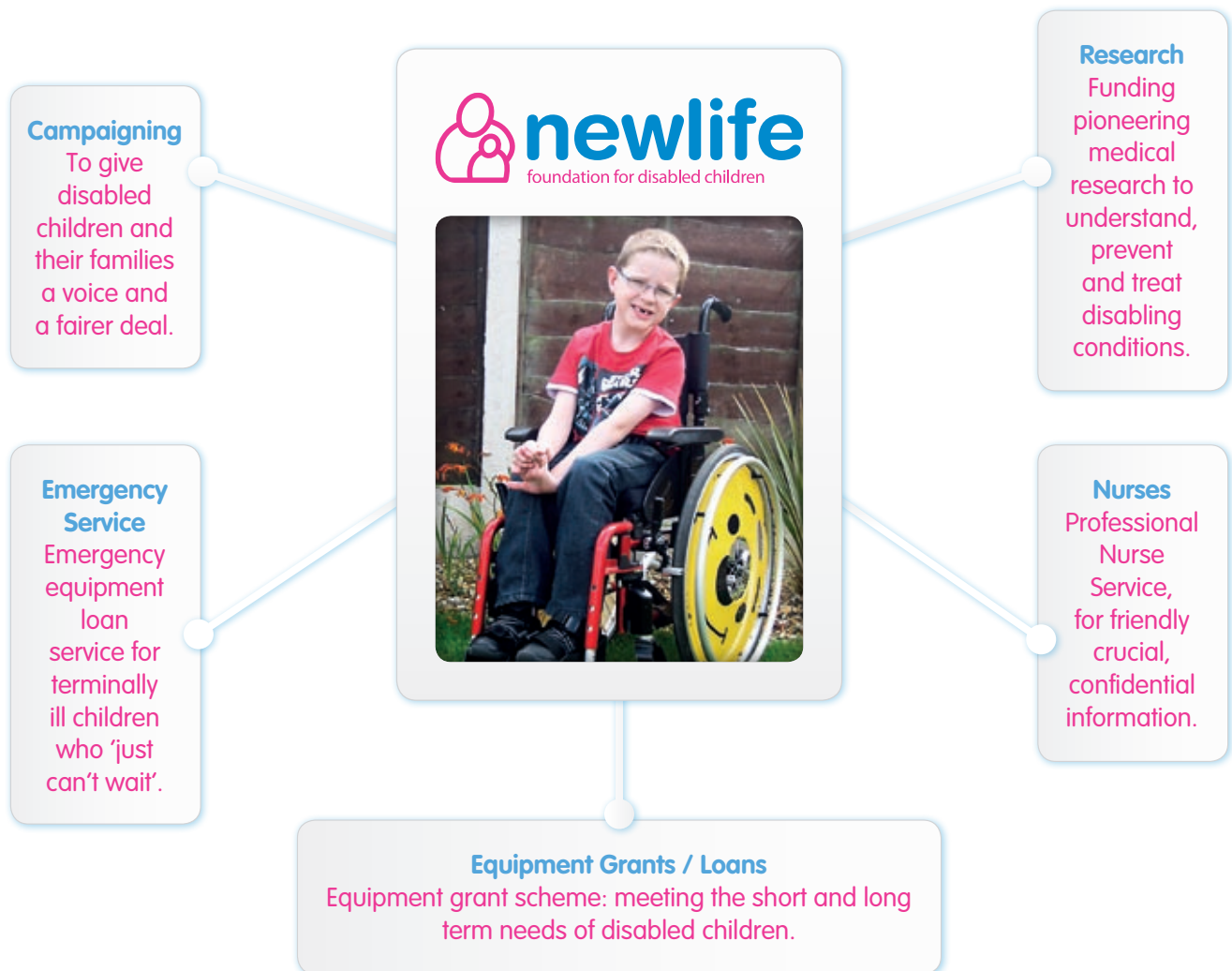
All statistical information referred to in this report has been obtained as a result of requests made to professionals working with statutory services across the UK.

Newlife Foundation is not responsible or liable for any inaccuracies in the information with which it has been provided.

About Newlife...

# Putting disabled children and their families first

Newlife Foundation puts disabled children and their families at the heart of all that it does. If it doesn't help disabled children then, simply put, Newlife doesn't do it. Newlife are the specialists for special children helping disabled children and their families in a number of important ways. The child, their needs, their health, their welfare and the support of their family is central to Newlife's work every day.



## Newlife Equipment Grant and Emergency Service.

Through our specialist services, we fill the void being left by statutory services across the UK. That is the focus of this report, using responses from 4,367 front line professionals across 91 UK counties.

# Overview

Most people would assume that in the UK, disabled and terminally ill children in real need would be provided with a wheelchair, pain-relieving bed, seat, communication aid or other vital equipment by the local statutory services. After all, this equipment would help them overcome or manage their condition, safeguard their health or stop a condition from worsening. This is what most people think. But they are often wrong. Disabled and terminally ill children's needs are, more often than not, failing to be met.

In this report we will reveal some of the real issues behind a widely failing system of provision of equipment for disabled and terminally ill children.

Newlife were prompted to analyse the reports on our files from 4,367 front line professionals, who are working for the state in roles such as Occupational Therapists, Physiotherapists and others. Why? Because they told Newlife Nurses that they were often being asked to compromise their professional and clinical assessments and that they are being placed in the firing line - trying to help children, but too often being repeatedly let down by the system of provision.

Over three quarters of these professionals knew there was no point in applying to their local statutory services for funding for such equipment. We believe our data shows that the vast majority have lost faith in the system of provision. In fact the evidence shows that, driven by dedication to the children they serve, they know that in many cases the best way to help a child is to support an application to a charity such as Newlife, who continue to fill the void left by the state.

## Hard to believe

When we tell people that here in the UK, disabled children have had to sleep on a mattress on the floor because no one will give them a safe-sided bed, that children cannot go to school because they have no wheelchair, or that children who are dying don't get their equipment until it's too late, they find it hard to believe. But these are the facts. The Newlife Nurses hear these stories all the time. Our Equipment Grants fulfil a vital role, but the need is so much greater than our funds can cover, so we have tried to understand, from the front line professionals why these failings occur. Who better to ask than the people who really know?

So, why is this happening? We believe at the heart of this issue is the failure to monitor 'unmet need.' This means many

disabled children's needs are unknown, invisible to those who are meant to provide. Every time a local statutory service (i.e. local authority, Primary Care Trust etc.) fails to supply a piece of equipment, they fail to record the need. So the next year when they plan their budget, they fail to recognise this unmet need. This means that the budget doesn't get increased in line with the real level of need. It continues to be set unrealistically low, year after year after year.

## How do we know?

Every time a family applies to Newlife for an equipment grant for a disabled child, we ask for the application to be supported by a professional involved in their care - usually a Physiotherapist, Occupational Therapist, or other paediatric front line worker. We ask every professional two simple questions;

- 1) Has an application to the local statutory services been made (before applying to Newlife) and if so, why was it refused?
- 2) If you haven't made such an application, why not?

By analysing the responses, we can reveal the real picture of why children are denied the help they need and they deserve.

## Budgets are set unrealistically low

The responses to question one paint a picture of barriers, restrictive lists of the type of equipment available, criteria for eligibility set far too high and of rationing policies. Why? Because budgets are set unrealistically low, so these restrictions are put in place to eke out insufficient funds.

## Professionals know the score

The responses to the second question show that the front line professionals know the score. Their perception that an application will be refused, is supported by the reality of our

“ Three out of four professionals, who help families apply to Newlife for equipment, said there was no point in applying to local statutory services. ”

findings. Every professional has an enormous caseload - so they understandably don't want the child to wait months or even years to be told no. So they help them by using the most direct route available to them, which is by supporting an application to a charity.

### Can we continue to tolerate such failure?

Every day children become disabled, through prematurity, accidents and cancers, as well as those who are born disabled. If we cannot supply the basic equipment they need, what does that say about our society? Can we continue to tolerate such failure affecting our most vulnerable children and their families?

In trying to get the equipment their child needs, families are constantly telling us, "We have to fight for everything." Their children are properly assessed (eventually, and even this can take a year) but too often they are told that despite this assessment, they can't have the equipment they need or they must make do with inferior and often inadequate items. The result is that these children's health and welfare is in jeopardy and their lives can be damaged further.

Last year Newlife had to launch a nationwide emergency service to supply urgently-needed equipment to terminally ill children. Things were so bad that not even dying children were receiving the equipment they needed. We feel the general public will be appalled to be shown this reality.

We know that everyone's budget belt has been tightened, but these children were being failed before the recession. Further reduction, we believe, blights lives and fails a generation, who will be unprepared to play their part in society in the future. Let's not forget, many disabled children suffer pain and distress as a result of their condition which the right equipment can relieve, or reduce.

### We commend front line professionals

We wish to recognise and commend the thousands of front line professionals who are delivering high quality services, despite difficult bureaucratic systems. We also need to recognise and commend those local areas where real attempts have been made to find improvements. But these areas are the minority.

### We need to act now

Becoming the parent of a disabled child can happen to anyone. It's no longer enough to save lives: we must also care for those we save and meet the needs of short or long term disability. The right equipment provided at the right time is key to this.

Things must change - for the sake of our children. We call on Government to ensure local statutory services act now.



**Mrs Sheila Brown O.B.E, FRSM**

CEO Newlife Foundation for Disabled Children



“ ...not even dying children get their equipment in time. ”

“ ...disabled children's health and welfare is in jeopardy... ”





# Headlines

## No point

Over three quarters (77%) of UK professionals supporting applications to Newlife for equipment reported that they didn't apply to their local statutory services. Newlife believes this is because they knew there was no point and our findings show they were right.

## Funding problems

In over 90% of all equipment grant applications made to Newlife, the professionals supporting grant applications reported that locally set restrictions on equipment provision or lack of local funds meant the assessed equipment couldn't be provided locally.

## Professionals know the score

The majority of professionals who supported equipment applications to Newlife stated that they didn't apply to statutory services because they already knew that restrictions put in place would prevent provision of the equipment or that there was no budget available. There is a clear correlation between the answers given by professionals who applied to local statutory services and were refused and the answers from those who came straight to Newlife.

Newlife believes that Professionals understand the reality and know the score. Instead of applying to local statutory services, they supported a Newlife application instead.

## Fill the void

Despite having limited budgets, charities are forced to bail out statutory services, providing essential equipment to disabled children who are in urgent need.

## Statutory services effectively hide insufficient budgets

Newlife Nurses who operate our equipment grant service have heard alarming stories from some of the frontline professionals supporting children's applications in communities across the UK. They told of instances where:

- they had been told to "downgrade" their clinical assessments, so that cheaper or more readily available in-house equipment would do.
- they had been told to delay assessments of children until new budgets were available, despite the clinical needs and suffering of a child.
- locally, terminally ill children were refused equipment as they wouldn't get long term use out of it.
- they were forced to choose between two urgently needed items because of "one item, one child, in one year" policies.
- they know that despite their efforts, the wheels of bureaucracy were so slow that children sometimes died before the equipment arrived.
- when the service managers found that demand and spend was high on a particular type of equipment, a ban was put in place preventing the supply of this equipment, regardless of desperate need.
- locally, a policy of rationing existed, regardless of urgent need for equipment.
- they had been told not to bother applying to local statutory services, but to go to charities directly.
- statutory services would only provide vouchers towards the cost of equipment, representing only part of the cost.
- if an item was provided, they were then told to tell families they couldn't apply for equipment for five years, regardless of whether the child deteriorated or grew out of the item.

“Dedicated professionals do what's best for the child in their care.”



# What is the current situation?

Imagine the national provision of equipment to disabled children is like the making of a suit. How can the suit be made if the tailor does not know the size of the person or whether a previous suit fitted? Who will pay for it? What material is needed for the climate?

This is like the current predicament regarding equipment provision. There is no understanding of the total level of need in the UK meaning that local statutory bodies have to play a guessing game when setting annual budgets; in effect making the suit without proper measurements.

On top of this, the instinct all too often is to make the suit as small as possible, to save cloth and money, but in reality this means the suit just won't fit. The wearer then has to choose whether to try and make the suit fit or decide not to wear it at all. Many professionals and families face the same dilemma. Insufficient budgets mean that often local statutory services cannot afford the right piece of equipment for the long term. This means that disabled children can be put in the wrong piece of equipment which only partially meets the child's needs. It can also bring long term health complications for the child, for instance on a child's posture. As a result of this, professionals are forced to leave the 'shop' run by local statutory services and shop elsewhere for the right piece of equipment.

This starts to explain why so many professionals do not apply to local statutory services, but come directly to charities for essential pieces of equipment. If you think about it, as a shopper you would go where you know you can get what you are looking for and this is what many dedicated professionals are forced to do.

This leads directly to perhaps the most significant problem that local statutory services face - unmet need. (They don't know how many children they are failing.) As a result of many professionals turning elsewhere and getting funding from charities, local statutory services are not aware of who is filling in the gap, providing funding for those children who cannot get funding from local statutory services. Some families go into substantial debt to provide the equipment that their disabled child needs because they grow tired of having to 'battle' to get the equipment so desperately needed. Since 2007, Newlife has urged government to look into this issue because until the true level of need is assessed, statutory budgets will continue to fall well short and disabled children's equipment needs will remain unmet by the local statutory services.

This view is backed up by the Care Quality Commission (CQC) who are the independent regulator of all health and social care services in England. In their recently published report 'Health Care for Disabled Children and Young People' they state:

*"Without a basic awareness of what the needs of the local population are, it is hard to understand how a PCT can assure itself it is commissioning services to meet them. We therefore urge commissioners to improve the quality of information they hold about these services."*

“...they don't know how many children they are failing.”





Within the same report, the CQC asked Primary Care Trusts (PCTs) how many disabled children and young people were in their area. Most PCTs had to 'estimate' this number, reflecting the concerns that Newlife has.

Astonishingly five PCTs told the CQC that they had no disabled children or young people in their area.

The census of 2011 may give an indication of the number of disabled children in the UK because Newlife was successful in its petition for inclusion of an appropriate question in the census regarding childhood disability. It may also give us some indication of the numbers of disabled and terminally ill children who need more help from statutory services. We wait and we hope.

#### We know that:

- many disabled children's equipment needs across the UK are not being met.
- the number of disabled children and young people in the UK is unknown.
- professionals are doing their best against what is, a slow bureaucratic process that says 'no' too often.
- there are no solid plans to turn this tide of failure which is affecting a generation.
- that charities such as Newlife are needed to fill the enormous gap left behind. This is becoming increasingly more challenging during a difficult economic climate.
- many families are forced into debt to try and fund the essential pieces of equipment that their children require because they cannot get urgent equipment from statutory services.

“...no plans to turn the tide of failure which is affecting a generation.”

# Results from the Front Line

We analysed the data from 4,367 professionals, specifically looking at:

- The reasons why those professionals who did apply for local statutory funding were refused
- The reasons why so many professionals did not apply for local statutory service funding

## Issues that professionals face with statutory service provision:

When looking for local funding for equipment for disabled children, professionals come across issues that prevent them from providing this equipment. This can result in applications being turned down or, because professionals know the score, understand local policies and recognise that equipment applications are likely to be refused, they support families when they turn to charities for essential funding.

Issues that many professional face when trying to get equipment for disabled children include:

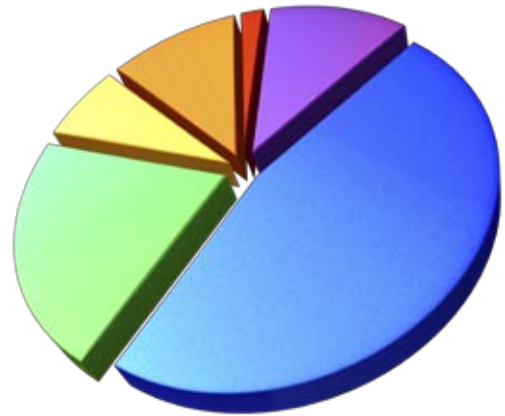
- **Restrictive equipment list**  
Many local statutory services impose limits on the type and range of equipment provided e.g. "We don't provide powered wheelchairs".
- **Insufficient/No budget**  
Simply put, many local statutory services do not assign an adequate budget and often run out part way through a year. Therefore despite a clinical need, established by professionals, applications can and are routinely refused due to budgetary constraints.
- **Locally set criteria**  
Some local statutory services set restrictions that exclude many disabled children. For example, children who can walk a few (painful) steps cannot receive funding for a wheelchair or buggy.
- **Rationing**  
Newlife has learnt from professionals that, in some cases, rationing prevents applications from being successful irrespective of a child's needs. Examples of rationing include 'one piece of equipment per child per year' despite the child's assessed need and despite the fact that many disabled children have complex needs that require a suite of equipment to ensure that their health and welfare needs are met.
- **Delays**  
Delays may occur in getting an assessment, in waiting for available funds, or simply through the red tape of bureaucracy. In its recent report 'Health Care for Disabled Children and Young People', the CQC revealed that some disabled children have to wait up to a year to get essential equipment. Long delays can have a detrimental effect on the child's wellbeing, which means that dedicated professionals support applications to charities such as Newlife who provide equipment to disabled children when it is needed.

“...4,367 professionals' responses analysed and reported.”

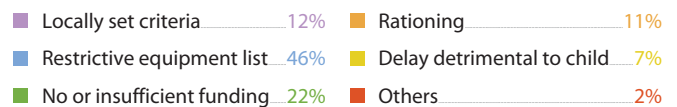
## Applications refused

The graph to the right shows that:

- 46%, almost half of the cases referred to us, were originally declined by statutory services because of **restrictive equipment lists** that were put in place.
- 22% almost a quarter of cases referred to us, told us that their original application to statutory services had been refused because their was **no budget** available to meet the need.
- **Locally set criteria** (12%), **restrictive equipment lists** (46%) and **rationing** (11%) are all locally determined restrictions that are put in place by statutory services often without consultation, rationale or proper transparency.
- This means that along with **insufficient funds** (22%) nearly **90%** of all refusals by statutory services to applications made by professionals are as a result of **an inadequate budget based on a poor understanding of total local need**.



Professionals who applied to statutory services for equipment but were refused



## Applications not made

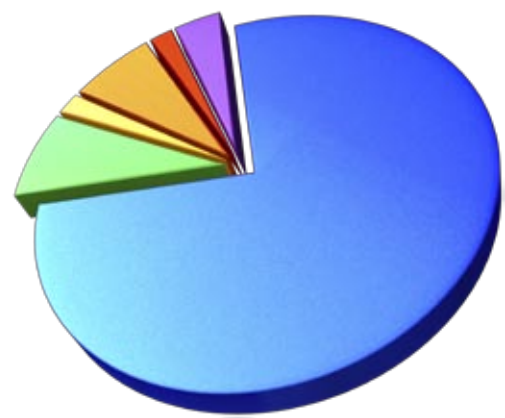
When looking at the reasons why professionals did not apply to statutory services more closely, it is interesting to note that there are many similarities between the reasons given by professionals as to why they didn't apply to statutory services compared to the actual reasons as to why those who did apply, were refused. In effect...

...reality mirrors the perception

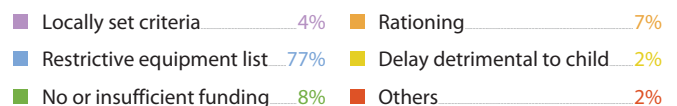
Locally set criteria, restrictive equipment lists, lack of funds, delays and rationing were all reasons provided by professionals for why they had not applied. This we believe, indicates that many experienced professionals understand how the system works and act accordingly, choosing not to waste valuable time making often fruitless applications.

The graph to the right shows that:

- A staggering 76.6%, over three quarters of professionals told us effectively that there was no point in applying as **restrictive equipment lists** would prevent any application from being successful
- There are a number of similarities with the first graph, looking at applications for equipment that have been declined by statutory services. In both cases **restrictive equipment lists** proved to be the most significant reason provided, followed by **insufficient funds**. This suggests that professionals understand how the systems work and choose not to waste valuable time applying to statutory services for vital equipment but instead choose to go directly to charities for funding.



Reasons why professionals did not apply to statutory services for equipment



- Professionals are aware of **restrictive equipment lists** (77%) of **locally set criteria** (4%) and of **rationing** (7%) in local statutory service areas and therefore do not apply to them for equipment.
- This means that along with **insufficient funds** (8%) **96%** of these professionals who did not apply to local statutory services, did so **because they were aware that there was no chance of getting funding**.



**newlife**

foundation for disabled children

“ Is it reasonable... that a child who cannot speak, gets to use a communication aid at school, but cannot take it home. He can speak to his teacher but not his family? ”



# This has to stop.









- Disabled & terminally ill children are suffering pain and distress.
- Professionals are doing their best against the odds.
- But they cannot get the equipment that children need.
- We don't believe any local statutory services set out to deny these children.
- It's the system and the culture that needs to change.
- It's all do-able. Things can and must change.

# Next steps

Newlife is a very practical charity. So rather than just report on and complain about the situation, we have created the following 'Next Steps' to offer a very practical detailed approach to the possible ways forward. We are not just calling on Government or local services to make changes, we are willing to suggest ways forward, models of working and partnerships, as we believe it is meeting the child's needs that is important and that innovation from the charity sector can be useful in making this happen.

Current roadblocks faced in statutory service provision.	The way ahead for central Government and local statutory services to improve provision of equipment for disabled children.
 <p>...misunderstanding the reality of how many disabled children there are in the UK. If the numbers of disabled children remain unknown, how can local statutory services even start to meet their needs?</p>	 <p>We call on central Government to release figures from the 2011 census, to help local statutory services plan to meet local need. Also to widen public health monitoring of disability and health conditions including birth defects.</p>
 <p>...local statutory service budgets being based on the previous year's spend ignoring all those that failed to get equipment.</p>	 <p>We call on local statutory services to ensure that realistic and adequate funding for equipment is made a priority. Funding must be based on total need requiring an assessment from local statutory services of 'unmet need'.</p>
 <p>...assessments that are made by qualified professionals being diluted by financial and other constraints.</p>	 <p>We call on Government and local statutory services to make the assessment prescription 'king' in the process, to meet the properly assessed need.</p>
 <p>...local statutory services from putting in place restrictive policies to hide inappropriate budgets.</p>	 <p>We call for greater transparency in relation to how locally-set policies and restrictions are made, by ensuring stakeholder consultation and effective scrutiny.</p>
 <p>...the waste which fails to refurbish and recycle and the parochial behaviour which won't allow cross boundary partnerships or exchanges of equipment.</p>	 <p>We call on Government and local statutory services to commit to seeking opportunities to share and recycle much-needed equipment and get "best value" from each item, to work across localities and swap, trade or share equipment more openly. Equipment under-used in one area is often needed elsewhere.</p>



Current roadblocks faced in statutory service provision.	The way ahead for central Government and local statutory services to improve provision of equipment for disabled children.
 <p>...heavily bureaucratic systems impeding the timely provision of equipment. While impossible to calculate, the costs of saying 'no' to disabled children are significant, wasting funds and leaving children in need.</p>	 <p>We call on local statutory services to strip out the bureaucracies which pile on costs, re-directing these funds towards the actual provision of equipment.</p>
 <p>...ignoring the need and expecting charities to bail out the system. Local statutory service providers have a legal duty to meet the properly assessed needs of a child, but often fail to meet this need.</p>	 <p>We call on local statutory services to ensure that if a child's need is met by other means (eg charity or self-funded), this is registered and plans are made to meet any future need. We also call on central Government and local statutory services to work in partnership with charities, co-funding equipment and liaising closely with those who provide equipment within the Third Sector.</p>
 <p>...denying the assessments of professionals. Many report being worn out by a constant battle to get the funds to do their job. Many are demoralised by this fight and the lack of opportunity to respond to need. One said... <i>"You would not expect a surgeon to operate without a scalpel, yet we can see the need and have no equipment to provide."</i></p>	 <p>We call on the Government and local statutory services to support and enable the frontline staff to provide a high quality equipment service and supply to children with disabilities.</p>
 <p>...being so slow. Children get trapped in hospitals, are unable to go to school, are left in pain or are at risk of injury; yet in many areas statutory services do not run a 'fast track' scheme.</p>	 <p>We call on Government to ensure that local statutory services identify those in acute need and respond in days - not months, or when it's too late. Newlife can do this in 24 - 72 hours so surely a PCT or council with much bigger resources can do the same.</p>

# How Newlife helps children

Newlife started offering grants to disabled children and their families in 2004 for a whole range of equipment that children needed - from seating which may cost a couple of hundred pounds to high-tech powered wheelchairs which can cost up to £20,000. In particular, Newlife has spent substantial funds on:

- Wheelchairs that prevent conditions from deteriorating and also give much needed independence.
- Car seats that allow families to go on days out, visit family and friends and attend hospital appointments safely.
- Specialist beds which prevent pain and give all family members the opportunity for a good night's sleep.
- Pushchairs that allow families to simply go to the shops but provide the necessary support and can transport complex equipment.
- Sensory or 'play' equipment which is not only fun but, crucially, also develops cognitive or sensory ability.

**Since 2004 we have funded over 5,000 grants for equipment for children with disabilities, totalling over £7 million. We are not limited by the number of children in need, only by the funds we have available and can raise.**

## 'Just Can't Wait'

The situation has become so desperate that even equipment to support end of life care for disabled and terminally ill children is too often unavailable or slow to arrive. Newlife has been told by distraught families of equipment that has arrived at the doorstep after the child has died.

As a direct result Newlife was moved into action. In 2011 Newlife set up the innovative and unique 'Just Can't Wait' service for children who are terminally ill and simply can't wait. This service provides vital equipment on a loan basis within 72 hours of the need being established and an application being received. Equipment is delivered, sensitively and speedily picked up when no longer needed, maintained and stored before re-issue when needed.

Newlife is able to provide loan equipment efficiently as a direct result of a recycling operation that is in place that works in the following way:

- As well as holding equipment, purchased from leading suppliers and held ready for despatch, Newlife also receives offers of equipment from households across the UK that is often in good condition, but is no longer required.

- Newlife works with a number of equipment providers who can pick up this equipment, examine it, refurbish it to ensure it is in a good condition, fix any parts that are required and clean the product.
- Once this process is complete, the equipment is then added as available on a spreadsheet with the relevant specifications provided which can be accessed by professionals.
- When professionals need equipment urgently to help a child, they apply for the piece of equipment from the suite as a loan. This loan application process is simple and short.
- Newlife then contacts the supplier who dispatches the piece of equipment so that it gets to the child within 72 hours of the initial application.
- When the piece of equipment is no longer required, the supplier will sensitively and speedily pick up this piece of equipment, take it back for any necessary refurbishment and clean ready for re-listing.

Information about the Newlife application process is available on our website [www.newlifecharity.co.uk](http://www.newlifecharity.co.uk) - or via our Nurse Helpline Tel: 0800 9020095 (freephone)





It is often the case that children with short-term needs do not require highly sophisticated equipment with longer term benefits. At this critical point in their lives, their needs can often be met by standard pieces of equipment which can be provided cost effectively and speedily.

If a charity like Newlife can operate such an efficient and effective system of timely provision with removal, refurbishment and recycling, why can't local statutory services? This is a way of providing more equipment to more children at a significantly reduced cost, through recycling to a high clinical standard and still meeting the prescribed standards of provision – not 'making do' with inferior items. Some areas we know do run stores but too often these only supply basic not bespoke items so not all needs are met and areas are often parochial in their working. So if a child in the adjoining area needs an item they have in their store, it cannot be transferred due to ownership or bureaucratic issues.

For terminally ill children and their families, the 'Just Can't Wait' service (JCW) makes a huge difference. JCW can prevent children from having to go into hospices, allowing those children who are in in-patient care to return home, allowing families to care for their children and most importantly, enjoy quality time together. 'Just Can't Wait' also helps tight budgets to stretch further.

Newlife feels that this scheme represents a real opportunity for government and statutory service providers to help more of the most vulnerable children in society today, by understanding this unique Newlife provision model, helping children in 72 hours – not weeks or months.

## Summary

Newlife believes 'Just Can't Wait' represents an opportunity for Government to adopt a cost effective model that can make a real difference to the lives of disabled and terminally ill children.



# The history of failure

## Prior to 2004

Newlife started to receive an increasing number of calls from families to its Nurse Helpline, many families could not get the equipment they needed for their disabled children. As a direct response, Newlife set up an Equipment Grant Service.

## By early 2006

We had seen a substantial increase in applications for essential equipment - our grant-making rose from £37,000 to £500,000 that year - so Newlife started asking families and professionals to talk about their experiences in trying to get the right equipment for their disabled and terminally ill children. We were staggered by the response.

### We were told of:

- long delays in assessments
- applications being denied
- families forced to go into debt to pay for basic equipment
- children being injured and left in pain
- children's conditions deteriorating for want of equipment
- the provision of inappropriate 'stop-gap' equipment

Newlife could not sit idly by. We established, through specialist legal opinion, that statutory services should be providing equipment to meet the assessed needs of a disabled child. We also asked Primary Care Trusts and local authorities, via the Freedom of Information Act, to report on the total spend on equipment for disabled children.

We brought the information together in our 2007 report, "It's Not Too Much to Ask". This collection of data was a first and it resulted in representatives from the National Health Service and Department of Health requesting the information collected and a Government review being initiated. It demonstrated clearly that many statutory bodies had failed in their legal obligations to our most vulnerable children.

'It's Not Too Much to Ask' revealed:

- a scandalously poor and worsening system of equipment provision by local statutory services (Primary Care Trusts and local authorities) with huge variations across the UK.
- Primary Care Trusts and local authorities together were spending on average just £30.42 per child.
- A much greater level of need than was actually met at that time by statutory provision (ie unmet need).
- That charities\* were filling the void created by inadequate statutory provision. Just 14 charities had funded a quarter of the total amount spent by all statutory services during 2005/06.

Government was compelled to respond to such comprehensive failure and did so in the following ways...

\* Caudwell Charitable Trust, Association for Spina Bifida & Hydrocephalus, Roald Dahl Foundation, Children Today Charitable Trust, Lifeline 4 kids, National Blind Children's Society, Anonymous Charity, ACT Foundation, The Jennifer Trust for Spinal Muscular Atrophy, Action for Kids, Get Kids Going, React, Joseph Patrick Trust (Muscular Dystrophy), Newlife Foundation.



“Based on what professionals on the front line are telling us, we continue to have serious concerns about the current broken system of provision.”

## Government initiatives...

2007

- **Aiming High for Disabled Children** - This made commitments to transform and modernise support services for disabled children and their families
- **Transforming Community Equipment & Wheelchair services (TCE&WS)** - This was established at the Department of Health looking at new and innovative ways of providing equipment, particularly through a retail model, a scheme to make simple equipment available through prescription.

2010

- **CSED (Care Services Efficiency Delivery)** published its report on behalf of the Department of Health “Models and options for Children’s Equipment & Related Services”. This report included a list of what was considered to be “essential” equipment. However this did not have mandatory force.
- **Strategic Health Authorities** were offered £50,000 by the Department of Health to bring forward proposals to improve children’s equipment and wheelchair services across the UK.

2011

- The Department of Health published **NHS at home: Children’s Community Nursing Services**. This included a “wish list” of outcomes and achievements such as:  
*“The needs of children, young people and their families will be met when... families have reliable, simple and easy access to the resources required to provide optimal care for their child”.*
- NHS London published **Commission Principles for Children’s Community Equipment**. This also included a list of equipment considered to be essential from 0-19 years inclusive.





“...let’s make all the words in all the reports, that repeatedly say how we are failing to get equipment to disabled children, translate into front line action. Words are not enough.”

### Any Qualified Provider (AQP)

In 2010, the Coalition Government signalled its intention to radically reform the NHS. As part of this programme, a range of community services - including Paediatric Wheelchair Services - would be opened up to the private and third sector as well as public sector providers. However there are a number of concerns about the AQP model.

#### We are concerned about:

- Fragmentation
- Limited range
- After-care services
- Inappropriate provision
- Regulation and monitoring

While we welcome innovation through new models of delivery such as AQPs, we do not believe they will be the “silver bullet” which resolves the problems that disabled children and their families face when trying to get the equipment they need.

### Care Quality Commission’s 2012 report

This report, “Health Care for Disabled Children and Young People” looked at what health and care organisations are doing to support the health care needs of disabled children and their families, the aim of the report being to remove/reduce barriers to access appropriate care.

The report revealed that around a third of PCTs set local eligibility criteria based on a child’s age. It also reported that a third of all PCTs revealed that children waited between 11 and 50 weeks for wheelchairs.

### Community Equipment Code of Practice Scheme (CECOPS)

Newlife Foundation welcomes the Care Quality Commission’s support for the Community Equipment Code of Practice Scheme (CECOPS).

The CECOPS framework represents the first code of practice for the commissioning and provision of equipment to all disabled people, including children, despite the fact that the public sector alone supplies 12 million pieces of equipment to over 4 million people every year.

2012

# The word from professionals

Don't just take our word for it. Dedicated professionals write to us, frustrated at not being able to provide the essential equipment which would make such a difference to the lives of disabled and terminally ill children.

(All names have been changed for Data Protection purposes).

“William is in urgent need of such equipment to ensure he can be seated safely and correctly at home. Unfortunately there are no other funds available at this time for a specialist chair.”

“I am a paediatric physiotherapist... I am writing as the provision of postural equipment in our district has become extremely fragmented and services are being withdrawn. Therapists and families are becoming increasingly anxious as a need is identified for a child, but there is nowhere to send the referral!”

“Seating systems are not provided by the NHS in our area anymore.”

“...there are no other funds available for home equipment for children living in (location given). My service continues to work hard to change this unfortunate situation.”

“Specialist beds and cots have been cut in (location given).”

“There is a tiny budget of just £3,000 to cover all walking frames and standing frames, for all the children within (location given). We are only therefore now able to fund equipment costing less than £500 in total.”

## Three quick 'stupid' stories...

*A three-year-old Fife boy, who has short-limbed dwarfism, has been classed as having 'no assessed needs' by local statutory services. Newlife is funding his £2,425 specialist bed. His mum said: "How can anyone say he has no assessed needs when he is almost four years old and cannot sit up? We turned to Newlife because without an assessment, we won't get any equipment. Most of the equipment we have got was being thrown out of the local Child Development Centre until I said: 'Please don't - we'll have it'."*

*A one-year-old Midlands boy, who was born extremely prematurely, and is having his development assessed, has been told he can't have a seating system because local statutory services can't afford one. His physiotherapist is pushing for him to have one to prevent bad sitting posture. His mum said: "It's obvious his therapist wants him to have one now, before any issues develop, but it seems that statutory services would rather wait until he's bigger, older and has more problems. It makes no sense."*

*Ten-year-old Oliver from Surrey, was struggling to participate in school lessons because he desperately needed a special hearing system that the local statutory services refused to fund. Despite his consultant supporting his application, the local authority refused to help because he did not meet "the criteria for funding" yet he couldn't hear and so couldn't learn at school and his parents were repeatedly told no... Newlife stepped in to help Oliver.*

“... let budgets be set sensibly, compassionately and in ways that enable disabled children.”

## The final word

In spite of all the good intentions and the search for better ways of providing essential equipment to disabled children, they are still missing out. They are still suffering. Their families are despairing and their professionals are frustrated.

In 2007 Newlife reported on the scandalously poor system of equipment provision as revealed by responses from Primary Care Trusts and local authorities. Today it is the dedicated professionals who reveal the true story; that provision of vital equipment for disabled children is still too often and too widely inadequate. Newlife and the disabled children and their families we support, live in hope. Sadly, too many disabled children suffer in the meantime.

As revealed in this report, this is even the case for terminally ill children. Newlife felt it had to set up the emergency loan scheme 'Just Can't Wait', because terminally ill children were not getting the urgent equipment they needed.

We know that it's the sort of care and service the public believe is important. This is what Newlife does every day.

We know that professionals really care and are committed.

We know that budgets have to be set - but let them be set sensibly, compassionately and in a way to enable disabled children.

We know that children continue to suffer pain, are put in danger, have their lives limited by a lack of equipment.

We know many families are pushed to breaking point and many children end up needing extra care in hospitals, hospices and at respite centres. Some even go into long term care - because equipment has been denied!

We know it's do-able to help these children - we are doing it daily. We know change can be achieved - but often the appeals of children and mums and dads go unheard.

Please listen.

Please act on this report.

Please support our call for change.



Newlife Foundation for Disabled Children.

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