



# IT'S NOT TOO MUCH TO ASK

## CAMPAIGN REPORT

APRIL 2007



WE ARE NOW



**newlife**  
THE CHARITY FOR DISABLED CHILDREN

Registered Charity Number: 1170125 in England & Wales.

HELP US CHANGE  
A CHILD'S LIFE

**fe**

and disabled  
families.

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## Foreword

"I hope everyone who cares about the needs of children born with disabilities will read this report, then act upon it.

When I visited BDF Newlife, an inspiring organisation that I am privileged to have based in my Cannock Chase constituency, I was told about the many families with disabled children who were turning to them and other charities for help because, where they lived, there was no assistance available to get even the basic items of equipment necessary for living.



This prompted the BDF Newlife Trustees, their CEO Sheila Brown and her team at BDF Newlife to set about finding out exactly what was going on around the country. They asked families, and surveyed Primary Care Trusts and Local Authorities. I encouraged them to turn their findings into a report that we could use to campaign for better provision everywhere.

This is that report. It makes disturbing and challenging reading. It's called It's Not Too Much to Ask because it is surely not too much to ask that children with disabilities can get the basic equipment they need without having to turn to charities to provide it.

The report will have served its purpose if it leads to all disabled children getting the essential equipment they and their families need and deserve."

**Dr. Tony Wright MP**

A handwritten signature in blue ink that reads "Tony Wright".



## Introduction

Most people would assume that disabled and terminally ill children are protected and provided for under established laws, using the taxes we pay into our welfare state system. But we believe this is far from reality for the majority of children in the UK.

In this report we will reveal the real issues behind a scandalously poor system of provision that has left many of these children without the special equipment they need to protect them from injury, prevent their condition worsening, enable them to reach their full potential and allow them to be cared for safely.

We have found that on average, statutory services spend little more than £30 per child on special disability equipment.

As many as a quarter of a million children are being failed by the state, despite protection by the law.

In investigating this situation we have achieved many firsts. We started to look at the issue when our Nurse Helpline received increased calls from families about lack of essential equipment. When we understood that the current system was failing, we set up a fast turnaround grants scheme to provide this equipment ourselves.

What we didn't know at that time was the speed at which the statutory system of provision was crumbling. We moved from funding £37,000 of equipment in the first year, to £500,000 the following year and three £750,000 in the last financial year.

In investigating the issues and in writing this report (and two interim reports) we have been moved and appalled, angered and driven to make sure that this situation cannot continue.

Why should this issue matter to you? It matters because inborn conditions remain the biggest threat to child health. These and other conditions such as infections, cause long term sickness, disability and terminal illness. Many of these conditions know no boundary of race, creed, wealth or locality. The child of any family could be affected. If we fail these, our most vulnerable and precious children, then what does this say about our society as a whole?

The UK has one of the most developed welfare systems in the world. The right to receive such equipment under this system is laid out in law.

But what happens when the law is clear and protects, but the state fails to deliver?

We have spoken to thousands of people about the situation and the vast majority simply cannot believe that this scandal is going on. But the real life experiences of real families up and down the country have proved how severe the impact is on children and families.

The personal outrage and passion of the families affected inspired us to launch a petition which has gathered thousands of signatories to call for change.

One of the 'firsts' we have achieved in this report is to bring together nationwide data which has never existed before using the Freedom of Information Act. We have provided on request this data to the Department of Health. In the UK there are believed to be in excess of 770,000 children with disabilities. We believe that one in three of these children may be having difficulties in getting essential, basic equipment. This equates to over a quarter of a million children.

The majority of inborn conditions which affect children do so from birth or their baby years, when dependency on the care of others is total. We know that children's conditions in particular can worsen rapidly as they grow. Timely provision is essential. They simply cannot face lengthy waits. Children grow quickly and equipment that they fit into today, will change every two or three years. Being on a 12 month plus waiting list for equipment is simply not practical.

As an independent charity receiving no state/government funding we can reflect the voices of the children and their families who are affected by these failings.

In this report are personal stories which show the problems they face. More than 250 families wrote their personal stories on our website showing for the first time the types and complexities of failure of provision all over the UK.

“...we have been moved and appalled, angered and driven to make sure this situation can't continue.”

“Children grow quickly and equipment that they fit into now will change every two or three years.”

We have seen pictures of children terribly injured, of children needing emergency admissions to hospitals, who needed surgery and therapy - all resulting from a lack of appropriate equipment or due to extended delays in providing equipment.

We have heard of parents who suffer illness and injury as a result of caring for growing children and we know of families who get into major debt trying to help their child when statutory services fail. We have met children who cannot go to school - no wheelchair, who have had to sleep on a mattress on the floor - no bed to keep them safe, and children who are clearly in pain and distress as ill-fitting equipment fails them.

From the teenage boy who loses his dignity as his mother washes him in the garage - as she is no longer able to carry him upstairs and there is no equipment to help her - to the child who died in pain before the essential equipment he needed was delivered.

We also heard for the first time, in confidence, of the frustrations and experiences of frontline caring health and social care professionals as they struggle seeing children's conditions worsen, seeing their pain, seeing the effects on families as the essential equipment needed is denied them by the statutory services.

So what equipment is being refused? It's not luxury items, but essential equipment for which proper assessment by qualified medical and therapeutic professionals has been made and includes mobility equipment, beds, seating, communication equipment, hoists and car seats.

We have for the first time established legal opinion that confirms that the statutory services should be providing this equipment based on the needs of the child.

Simply explained, Government provides funds for health provision through the Primary Care Trusts (PCTs) throughout the country. In Wales, Scotland and Northern Ireland PCTs are also known as Health Boards and Trusts.

Government fund Local Authorities also known as Councils to provide welfare services through grants and social service provision.

“Our son died before his equipment was delivered”

“He cries in pain - crammed into a chair that no longer fits”



In some areas of the UK, BDF Newlife has spent more money on equipment in that area than the PCT or the Local Authority.

### Angus, aged 10, Hampshire

*"Angus has severe Cerebral Palsy affecting all his body, he has limitations of independent movement and cannot sit or stand without specialist supportive equipment.*

*He needed new seating for a manual and powered chair as he has grown. We applied to Wheelchair Services who assessed him and agreed he needed new supportive seating, but their policy is one piece of equipment per child because of funding.*

*This decision meant that we worried how we would cope with one seat as transferring Angus would be hard as he is vulnerable in all positions. I try my best but I am not superwoman. It gets you down. I'm not asking for the world, just some help."*

How these statutory services then use these funds and discharge the duties placed upon them by Government and the law is up to decisions made locally.

This report details PCT and Local Authority spending. Many of these bodies failed to reply to us, despite the request being made under the FOI Act.

When you see the spending levels, we are sure you will find children in many areas of the country are poorly served or failed and in some cases there has been no spending at all on these children.

In processing over 1,000 grants, we have for the first time collected data on the reasons given as to why statutory services have denied or failed to provide equipment, despite the child being professionally assessed for it.

We have also achieved another first in looking at 'unmet need', to understand what happens when statutory services deny equipment to children. Looking at unmet need has meant that we can also establish the impact on charities, who are often called upon to 'plug the gap' when the state fails to provide for children with disabilities.

We hope the report is hard hitting because the effect on children and families of not delivering services is hard and grim. We have many examples where we have named and hopefully shamed some local areas into making changes for the future.

We believe our campaign has been influential in getting Ministers to write to the Chief Executives of Primary Care Trusts and Local Authorities setting the provision of equipment as a key challenge for 07/08. We also believe that the Department of Health review Transforming Community Equipment Services Project announced in June 2006 has been a valuable outcome following the launch of our campaign earlier that year.

But there is much to do. Will the Department of Health review and new system of equipment provision, planned to be in operation by autumn 2007, be fit for purpose?

There are pockets of good practice, areas where children get the help they need, places where they know it's not too much to ask. If these areas can do it, so can the whole country. Achieving a reasonable level of provision is not impossible.

In the meantime we will continue to help as many children as our resources allow by making grants, because for us and for other charities it is not an option to sit back and see suffering without action.

When you read this report ask yourself, what if it was my child? No-one ever thinks their family will be affected. As the mother of a disabled child I know the difficulties. I didn't think it would happen to me. It did and every day in the UK around 124 babies will be born with inborn conditions.

If we ignore the contents of this report, we continue to play a part in allowing this institutionalised failing to continue.

Don't just put this report aside. Pledge to help us challenge, change and provide so that with your help, voice and actions we can ensure every special child in our country is provided for. It's not too much to ask.



**Mrs. Sheila Brown OBE  
FRSM**

CEO

[BDF Newlife](#)

**Leah, aged 3,  
Staffordshire**

*"Leah has Cerebral Palsy. Her family were forced to turn to BDF Newlife when her PCT told them there was no funding available for the new walker Leah desperately needed.*

*Leah's mum said "Straight away it's clear that this will give Leah a lot more freedom. The walking frame she had before was really rickety, so she couldn't use it outside and we had to keep hold of her all the time. It means we will now be able to go to the park properly and she can walk around on her own. It's fantastic to get a new chair and walker, we're very grateful to everyone who has helped. It'll make such a difference to her and what a fantastic time to get it, just before Christmas."*

*Photo courtesy of  
The Sentinel, Stoke on Trent.*

**Dear BDF Newlife...**

*"The prolonged lack of appropriate seating for my daughter Autumn has been the cause of so much anxiety and strain, both physical and mental. Parents should not have to resort to asking for charity support, something must be done to improve therapy and equipment provision for disabled young people. Most parents are too exhausted to challenge and challenge again the short sighted approaches of local authorities who seem determined to deny our children the support they need."*

# Why We Started the Campaign

Who should be providing equipment to disabled children?

In the Spring of 2004, we started to receive calls to our Nurse Helpline from families who could not get the equipment they needed - such as specialist beds, buggies, wheelchairs, standing frames and car seats.

To help these children we started our Child and Family Grant Scheme. In March 2006 we noted a substantial increase in applications from families unable to get this essential equipment. So much so that the amount of money spent by BDF Newlife in providing equipment to children with disabilities had increased from approximately £37,000 to £500,000.

We used our network of contacts to appeal to families and professionals to tell us about their struggle to get the right equipment for their disabled and terminally ill children.

We were staggered by the response. They revealed long delays in assessments, applications being denied, children being injured, conditions worsening and parents being forced to pay for equipment by credit card or through finance, rather than see their child suffer.

## **So we questioned, who is responsible for providing this equipment?**

In recent years the Government has increased the amount of power it devolves to its statutory agencies. Budgets, responsibilities and pivotal decisions are passed over to agencies such as Primary Care Trusts, Local Authorities and their Local Education Authorities. The principle behind this is to give flexibility and choice in each area. However, this devolution of power has led to a 'shambolic' postcode lottery of provision.

**We see the provision of such equipment can be through the following bodies or their equivalents. It may vary in different areas off the UK, but essentially, they are the following:**

## **Primary Care Trusts**

Primary Care Trusts (PCTs) were set up to provide people with the care that they initially require locally when they have a health problem (for example doctors and dentist surgeries, opticians and pharmacies). PCTs combine services that were previously organised and managed separately, such as general practitioners, community health services, social care and support services. PCTs work with local authorities and agencies that provide health and social care to meet the needs of the community.

The current Government has devolved the majority of the NHS funding to Primary Care Trusts or General Practitioners who purchase healthcare from the hospitals. These new purchasers have little specialist expertise in making decisions about specialist equipment and yet they will have 80% of the annual NHS budget. We have even spoken to several PCTs, who were unaware of any department or service that deal with children and disabilities in their area. In simple terms, PCTs are responsible for providing wheelchairs, specialist buggies and equipment for health purposes like specialist beds.

In addition to PCTs, most major hospitals will have a multidisciplinary Child Development Centre where Paediatricians, Physiotherapists, Speech Therapists and Occupational Therapists work together to help disabled children.

Over the years they have acquired a great deal of expertise in managing the special needs of disabled children. In the past the selection of appropriate aids would have been made through these centres, but they have been put under increasing financial pressure as hospital budgets are being cut.



“long delays in assessments, applications being denied, children being injured, conditions worsening and parents being forced to pay for equipment by credit card or through finance”

### Local Authorities

Central and Local Government share responsibility for children's services. It is within Local Authorities' remit that Social Services Department and Children with Disabilities Teams work to provide equipment to aid a disabled child's welfare. Local Authorities are also responsible for giving LEAs a budget so that provision of equipment to aid disabled children at school can be made. The money comes from what the Government sets out to be a reasonable and affordable level of spending on education.

Each local authority must set its own education budget, taking account of local priorities. Once budgets are delegated, schools' governing bodies take decisions on precisely how to deploy the resources available.

Many of the problems that we see are based on confusion about who funds what. Families are confused and in many cases so are the professionals. So having finally established who is responsible, we focused on how much PCTs and Local Authorities had spent on such equipment in the last financial year 2005-06.

We asked Government sources to no avail. No one knew. We asked PCTs and Local Authorities but many did not respond and in the end we used the Freedom of Information Act 2000 and we were finally able to see the extent of the under funding.

We analysed data from England first and were appalled at the level of spending and decided it would be in the public interest to release the information for England first. We then went on to analyse the rest of the UK. Northern Ireland was unable to provide comprehensive and accurate statistics, therefore we are only able to add figures for Scotland and Wales.

### Members of Parliament

BDF Newlife wrote to 335 of the 646 Members of Parliament telling them about the plight of individual children in their own constituencies.

We have received nearly 60 responses from MPs offering to intervene on behalf of their constituents. Almost 40 have offered to back our campaign led by Labour MP for Cannock Chase, Dr Tony Wright. We received no replies from 191 MPs. We explained that we would contact them each time we awarded a Child and Family Grant in their constituency and we enclosed the child's Grant Authorisation Form to explain why they needed the equipment and why we had to fund it.

Many MPs said they were willing to take up individual cases where support had not been made available and wrote to their local PCT demanding answers. Some received letters back from the Department of Health explaining that the situation should improve when a spending review is completed.

The intervention by other MPs has in some cases lead to a reversal in the PCTs decision, however many MPs questions went unanswered. If MPs cannot even get a reply to their questions, what hope is there for individual families?

### **Kiera, aged 15, South West England**

*“Kiera has Cerebral Palsy and is blind. Kiera needs a special wheelchair to help her to stand to prevent her legs getting too rigid. She gets tired easily and needs to alternate from sitting to lying down.*

*To get this equipment our physiotherapist applied to the disablement centre with Wheelchair Services.*

*However, we had to wait around two years before we were even actually assessed. After the assessment they said they could not find anything suitable and have no way of getting the equipment. This decision meant that we were unable to go out as a family.*

*We would like decision makers to know that this type of wheelchair does exist and by saying they 'don't know of anything suitable' is sheer ignorance. How are charities able to do assessments and fund equipment and they can't?”*

**Aaron,  
Worcestershire**

*"Aaron has Duchene Muscular Dystrophy, a terminal muscle wasting condition. We needed an electric wheelchair and to be honest at the moment if feels like you name it, he needs it. BDF provided the grant for the wheelchair. Without it he wouldn't be able to go out of the house as he can't walk."*

# 'A Landscape of Failure'

BDF Newlife used information gathered with the Freedom of Information (FOI) Act 2000 to reveal the scale of failure in the state funding system for obtaining specialist equipment for disabled and terminally ill children across England, Scotland and Wales.

Such equipment is funded by Government through Primary Care Trusts and Local Authorities. The investigation showed some areas have spent nothing, others have spent very little on equipment, which includes wheelchairs, specially adapted beds and hoists. Many of these bodies reported not knowing what they spent and some told the charity it could only have the information if it was prepared to pay for it, which we have declined to do.

In using the FOI Act we also found an astonishingly high level of statutory services failing to reply, despite the legal requirement to do so within the Act.

The investigation has found on average that PCTs and Local Authorities in England, Scotland and Wales were spending on average as little as £30.42 on equipment for each disabled and terminally ill child, £19.73 coming from the PCT and £10.69 from the Local Authority.

BDF revealed that because children continue to grow, the potential spend for complex needs will average £20,000 per child, as wheelchairs can cost anywhere between £3,000 and £16,000, specialist beds come in at around £2,500 and adapted car seats are around £1,500. It is believed there are 770,000 disabled children in the UK\*

## Primary Care Trusts

Eighty-nine percent of PCTs responded to our Freedom of Information request.

Of those PCTs only 65% could provide a statistic. Thirty-five percent were unable to provide the information or provided us with incomplete data.

**On average PCTs spent only £45,613.57 on equipment for all disabled and terminally ill children in their area.**

Four English PCTs reported in writing spending nothing at all on this type of equipment. These were North Devon, North East Lincolnshire, South Tyneside and Wyre Forest.

Based on the information that we received, the following is a list of the highest and lowest spending Primary Care Trusts in the UK. A full breakdown of all of the responses from statutory services can be found at the back of this report.

## 10 lowest spending Primary Care Trusts

• Harlow PCT	£ 504.00
• Mendip PCT	£ 547.00
• South Western Staffordshire PCT	£1,000.00
• PCT refused permission to release data	
• West Hull PCT	£1,603.00
• Blackwater Valley and Hart PCT North Hampshire PCT	£3,000.00
• Hyndburn and Ribble Valley PCT	£4,336.99
• Central Cheshire PCT	£4,341.40
• Eastern Hull PCT	£ 4,475.00
• Uttlesford PCT	£4,545.12

## 10 highest spending Primary Care Trusts

• Somerset Coast PCT	£191,110.00
• Nottingham City PCT Broxtowe and Hucknall PCT Gedling PCT, Rushcliffe PCT	£226,075.00
• Lambeth PCT	£227,196.00
• Newham PCT	£246,275.00
• North Liverpool PCT Central Liverpool PCT	£260,906.47
• Central Suffolk PCT, Suffolk Coastal PCT Suffolk West PCT	£264,919.40
• West Gloucestershire PCT	£293,000.00
• Stockport PCT	£302,592.00
• Huddersfield Central PCT South Huddersfield PCT	£303,367.00
• Southampton City PCT	£441,820.28

*We recognise that the size and populations of the PCTs and local authorities will differ widely across the UK. We will leave it up to the public and the affected families in these areas to judge if spending is sufficient or not.*

“because children continue to grow,  
the potential spend for complex needs  
will average £20,000 per child”

### Local Authorities

We received replies from 93.5% of Local Authorities to our Freedom of Information request. Of those LAs who responded, only 30% could provide a statistic. 56% percent claimed not to be responsible. 6.5% failed to respond to the Freedom of Information request within 60 days (three times the recommended limit under the Freedom of Information Act) and 7.5% could not respond or failed to provide complete statistics.

The average Local Authority spent only **£58,777.16** on equipment for all disabled and terminally ill children in their area.

The total amount paid out in equipment grants by BDF Newlife in 2005/6 was just over £500,000. This is substantially more than the total spent by any of the PCTs and local authorities who replied. As we will see later in this report charities are filling the statutory services gap.

### 10 lowest spending Local Authorities

• Gwynedd County Council	<b>£850.30</b>
• Carlisle City Council	<b>£1,200.00</b>
• Conwy County Borough Council	<b>£1,676.00</b>
• Swansea City and Borough Council	<b>£3,500.00</b>
• City of London	<b>£3,659.00</b>
• Hounslow London Borough Council	<b>£4,074.00</b>
• Blackpool Borough Council	<b>£5,680.00</b>
• Denbighshire County Council	<b>£6,601.00</b>
• Ceredigion County Council	<b>£6,823.07</b>
• East Dunbartonshire Council	<b>£6,834.09</b>

### 10 highest spending Local Authorities

• Western Isles Council	<b>£159,972.10</b>
• Newham London Borough Council	<b>£167,972.03</b>
• Lancashire County Council	<b>£179,818.00</b>
• Lincolnshire County Council	<b>£225,434.00</b>
• Sunderland City Council	<b>£226,392.52</b>
• Glasgow City Council	<b>£229,628.00</b>
• Surrey County Council	<b>£230,000.00</b>
• Hertfordshire County Council	<b>£244,816.00</b>
• Cornwall County Council	<b>£250,000.00</b>
• Kirklees Metropolitan Borough Council	<b>£301,766.26</b>

This information is based on the written responses that we received and understand as being complete and relevant to the period 2005/2006. Statutory authorities who failed to respond or who provided incomplete or unusable data may have spent more or less than the statutory authorities listed here but we have no data to define this position.

### *Cael, a little boy in the UK*

*“Cael is blind and has Cerebral Palsy. We needed a car seat. BDF provided a grant for the equipment. If they hadn’t Cael would have been travelling unsafely to his appointments. The grant allowed Cael to travel in safety as well as more comfortably.*

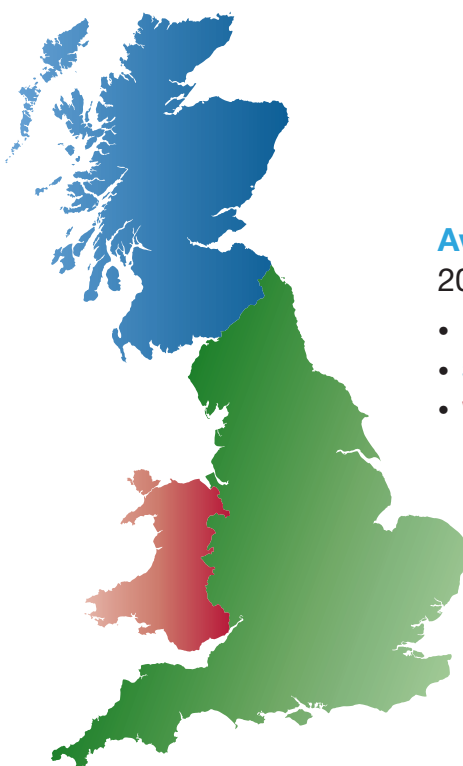
*We would like to say thank you so much for your help. The first time we saw the car seat we couldn’t believe the difference. Cael was much more secure in the seat and this was needed so much, as disabled children certainly need the extra restraint and support for them to feel safe.”*

**Tanisha aged 7 and  
Jackson aged 9,  
South East England**

*"Both of the children have infantile Battens Disease. They are terminally ill, have epilepsy, are blind, gastrostomy fed and are completely reliant on us as parents for all of their needs.*

*We needed a sleep system for the children. This was funded by BDF Newlife. This was really great news for us as you were the first charity we applied to, we are so grateful. This will improve our children's short lives. Without this equipment, we all suffer mentally and physically. Why should the disabled have to fight all the time for equipment? My children are dying, let there be quality in their lives as there is little quantity."*

# 'A Landscape of Failure'



## Average PCT Spend 2005/2006

• England	£45,500.16
• Scotland	£47,971.00
• Wales	£29,987.66

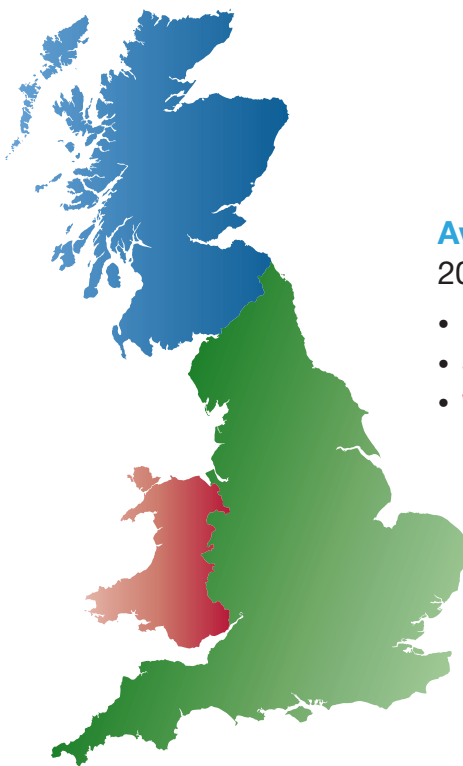
### What this data shows:

#### PCTs

Scotland is the top average spending PCT.  
England closely follows.  
Wales is the lowest average spending area.

#### Local Authorities

England is spending the most on average.  
Scotland follows but with a large gap.  
Wales is the lowest spending area on average.

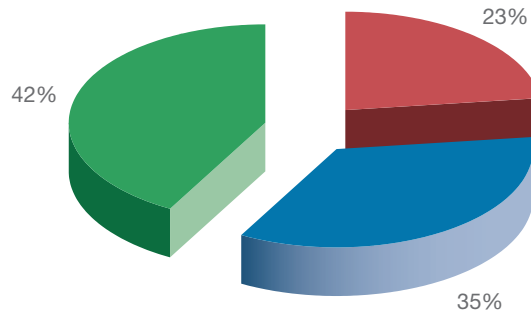


## Average Local Authority Spend 2005/2006

• England	£64,691.65
• Scotland	£46,783.61
• Wales	£32,253.03

### Combined Funding

- England **£110,191.81**
- Scotland **£94,754.61**
- Wales **£62,240.69**



## North / South Divide

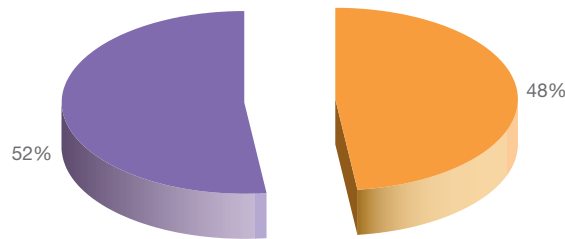
#### What this data means:

#### Combined PCT and Local Authority

North - **£114,468.83**

South - **£106,110.03**

This is an unusual finding as it indicates children in the North have more spent on them than those in the south.



#### FUNDING

- South England
- North England

#### Average PCT Spend 2005/2006

- North England **£44,110.39**
- South England **£46,875.30**

#### Average Local Authority Spend 2005/2006

- North England **£70,358.44**
- South England **£59,234.73**



# Unmet Need: Reasons Children Rely on Charities

Every time a Child and Family Grant application is made, we receive a letter from a professional involved in the child's care detailing the reasons why the family has had to approach a charity.

“We cannot negate real need by not making a budget provision to meet it.”

“A child's need must outway blanket policies”

## Alex, aged 20 months, Southern England

“Alex has Cerebral Palsy. He needed a pushchair with postural support and so we applied to Wheelchair Services. Eight months on we are still waiting for an assessment. I was advised that I could be moved up the priority list if I say my son is getting sores. This is so frustrating - how can I expect to move up the list if others are also being encouraged to lie?”

In the year that this campaign has been running, we have received and analysed almost 600 letters from professionals involved in the care of disabled children; children who are being refused basic, essential equipment.

These include Social Workers, Occupational Therapists, Physiotherapists, Key Workers and Hospital Consultants. Each one of these professionals has detailed to BDF Newlife the reasons why these children have been refused equipment.

### The following are a few examples of what we received:

- From a professional in Staffordshire about a 16-year-old boy with Cerebral Palsy needing a specialist seat, his last seat had lasted him for eight years: *“Unfortunately Social Services have never provided seating for comfort / change of position...budgets are limited.”*

**BDF NEWLIFE SAYS:** We find this statement remarkable, surely most people use seating for comfort or to change position. Why would a disabled child be any different?

- From another professional in Staffordshire about a four-year-old boy with Autism needing a specialist buggy: *“Parents have been informed that there is no local NHS funding for the next two years as the budget has been spent.”*

**BDF NEWLIFE SAYS:** This is simply not good enough. A lack of fiscal planning at the start of each year, when it is known there are needs, is inexcusable. We cannot negate real need by not making a budget provision to meet it.

- From a professional in Plymouth about a five-year-old girl with Achondroplasia needing a powered wheelchair:

*“A powered chair will not be provided to anyone who can walk a few steps indoors”*

**BDF NEWLIFE SAYS:** These few steps are laboured, unsteady and continued attempts to walk can cause pain and even worsening of a condition. The individually assessed needs of a child are what is important and must outweigh such blanket policies and is a child's legal right.

- From an SEN Co-ordinator in the South East about a nine-year-old girl with a genetic condition needing specialist seating:

*“Unfortunately in order to fund the buying of this, we would have to look at reducing her hours of (educational) support.”*

**BDF NEWLIFE SAYS:** This is scandalous. How are professionals meant to decide between the conflict of providing desperately needed educational support to a child or essential seating for postural management? The whole child's needs should be fully met, not bargained for in such a way.

- From a Paediatric Physiotherapist in Surrey about a four-year-old boy with severe Cerebral Palsy: *“The Wheelchair Service will not consider the child for an electric wheelchair at present (and certainly not this type) as they feel he is too young.”*

**BDF NEWLIFE SAYS:** Presuming that most children are walking at around two years of age, how can four-years-old be too young for a child with Cerebral Palsy to become mobile? This attitude smacks of discrimination due to disability. The National Service Framework for Children, Young people and Maternity Services 2004 Report sets the standard that “children and young people who are disabled or who have complex health needs receive co-ordinated, high-quality child and family-

“there are no funds available”

“beds are always a contentious issue regarding where the responsibility for funding and provision lies”

centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives.”

This child wasn't given the opportunity to demonstrate if he could use such a chair, so we see unlawful blanket policy.

From a professional in Northampton about a three-year-old girl with Cerebral Palsy needing a specialist buggy: *“Unfortunately the criteria in this health authority for funding of wheelchairs is very tight and I understand that our Occupational Therapists are now only providing chairs for indoor use at home.”*

**BDF NEWLIFE SAYS:** Can it be right that a child is housebound through lack of equipment, of course not. Any child needs stimulation from the outside world. To deny it, on the basis of cost, and under a blanket policy is a double whammy of failure.

- From a professional in Northern Ireland about a nine-year-old girl with Rett Syndrome needing a standing frame. This little girl was given six months to improve her standing otherwise she would need painful surgery: *“At present due to continuing cut backs and lack of funding within the South-Eastern Education and Library Board of Northern Ireland, funds are no longer available for large pieces of therapy equipment.”*

**BDF NEWLIFE SAYS:** This child would face painful and expensive surgery, expensive recovery, rehabilitation and after care and / or because of a principal failure of finances / policy. Surgery should not be an answer to such provision failure. Early intervention works and must be the active policy to protect all children.

- From an OT in Hampshire about a six-year-old girl with Rett Syndrome needing a specialist bed and seating. The bed this little girl was in had caused her injury and

was proving increasingly dangerous for her to sleep in: *“As the social services budget has been frozen until April, I am unable to get these pieces of equipment to the child quickly which I feel could be detrimental to her physical health and her family.”*

**BDF NEWLIFE SAYS:** When a qualified professional uses their skills and make an assessment of actual need (not “it would be useful”) there is a clear legal obligation to make the provision so such failures are unlawful as they leave a child at significant risk. There is little point in having valuable, qualified staff to do this job if statutory services ignore their assessments. How long until a child dies?

- From an OT in Devon about a six-year-old girl with Sanfilippo Syndrome needing a special sleep system: *“There would be great difficulty in securing funding for the sleep system needed. This is because we are seriously overspent on our equipment budget and beds are always a contentious issue regarding where the responsibility for funding and provision lies.”*

**BDF NEWLIFE SAYS:** There is no need for such provision to be contentious. The child's assessed needs and welfare are paramount. Too many times we hear about inter-department squabbling - is a special bed a health need or a welfare need? These squabbles should be resolved by creating local good practice agreements.

- From a Family Support Worker in South Wales about a 16-year-old boy with Duchenne Muscular Dystrophy needing a portable hoist: *“There are no funds available”*

**BDF NEWLIFE SAYS:** The condition won't go away or stop worsening whether the problem with this was “no budget set” or “all budget spent”. This child's needs continue and therefore his care needs to continue. Too many parents/carers suffer injury through lifting and carrying because hoists are denied.

“Surgery should not be an answer to such provision failure”

“Can it be right that a child is housebound because of lack of equipment?”

### Kieran, aged 8

*“Kieran has Cerebral Palsy and needed a walking frame, he outgrew his old one months ago. The NHS refused it because of a lack of funding. He stoops now as he walks which will worsen his condition. We try so hard with Physios to improve his condition and help him meet his potential.*

*I have complained to the commissioner of the PCT by e-mail and letter, I haven't even had a acknowledgement from him.”*



### Natalie, aged 8, South East Eastland

*"Natalie is unable to stand or walk and uses a powered wheelchair. We required a wheelchair accessible exercise machine. We never gave up badgering the NHS, social services, charities etc for items that allow our daughter to participate in all that her able-bodied twin sister does."*

*"We appreciate that equipment is expensive given the small volumes involved, but our total outlay on powered wheelchairs, lightweight manual wheelchairs, adapted trikes and an adapted car is tens of thousands of pounds. Charities are our lifeline in terms of promoting our daughter's confidence and independence."*

# The Right Equip Wheelchairs and Buggies

Having the correct wheelchair can give a child independence, safety and confidence.

Through our Child and Family Grant Scheme we have provided wheelchairs to children that range from £300 to almost £17,000. With over 29% of families with a disabled child in or near poverty, many children are unable to get the equipment that they so desperately need. Buggies for children with disabilities are often ten times the price of a standard buggy; costing between £180 and £3,000, for families who need this equipment but are unable to get it, the family home can become their prison. As a charity we hear of many families who are unable to get a suitable buggy through statutory services.

#### We understand that the main problems families face are:

- It is well accepted that has Wheelchair Services are under-funded. We believe that because of this under-funding Wheelchair Services have had to put in place strict criteria to limit the amount of children they provide wheelchairs to. We hear of children who are denied wheelchairs because they can take two or three steps and children who are refused powered wheelchairs because their conditions are not degenerative, despite these children being unable to propel the manual wheelchairs themselves.
- Assessments for wheelchair provision is based purely on 'clinical' needs. Because of this, Wheelchair Services are only required to provide the basic equipment, unbelievably they often do not cater for 'lifestyle' needs such as education or independence.
- Each Wheelchair Service Department across the county interprets the guidelines differently; therefore we believe provision is often a 'postcode lottery'.
- Children are often placed on lengthy waiting lists that can lead to a deterioration in their health / welfare.
- Equipment is rationed to a one piece of equipment per child policy. This can mean that a child needing a wheelchair for their

mobility and a standing frame for their posture will be forced to go without.

- Most children who are provided with a wheelchair or buggy are offered the very basic; this type of equipment is rarely suitable or will fully meet their needs.
- The child's disability is not considered physical (for example autism and ADHD) so a buggy / wheelchair will not be provided. However, if a child cannot walk, for whatever reason, then statutory services should meet their needs.
- Children not fitting increasingly rigorous age criteria; we have been told about Wheelchair Services that do not see children under the age of five.
- Wheelchair Services refusing to provide specialist buggies for children with disabilities, arguing that families with children without disabilities would also have to buy a buggy. This policy doesn't take into account the fact that the cost of a specialist buggy can be ten times the cost of a standard buggy.

#### The current failing system

Following a review commissioned by the Department of Health and Social Security in 1989, the Disabled Services Authority (DSA) was set up to manage the NHS Wheelchair Service. On 31st March 1991 the DSA was terminated and the management of Wheelchair Services in England was passed to Local Health Authorities and Trusts. This devolution of power has led to inconsistency and variations in standards, management structures, funding and service.

Below is the lengthy and difficult process a family will go through to get a wheelchair or specialist buggy for their child. At each stage there is an opportunity for delay:

- A referral form from a GP is passed on to the local Wheelchair Service
- The Occupational Therapist then arranges a meeting with the child at a children's wheelchair clinic to assess clinical needs, i.e. size, weight, height etc.



ment ▶▶

“to get an assessment we waited a total of 12 months”

“we don't ask for equipment on a whim, it's because we NEED it and it is either a medical necessity or improves our children's quality of life”

- A report is drawn up by the OT
- Report from the OT is forwarded on to a budget meeting where applications are scrutinised. Applications for the budget meeting are prioritised according to need. It is at this stage that applications for outdoor wheelchairs may be refused.
- If the application does pass the budget meeting, there are three options available to the family - see below.

#### Wheelchair Scheme options / NHS

##### Vouchers:

There are three options for children requiring wheelchairs:

1. Accept the wheelchair offered by the NHS (this is usually a basic style manual wheelchair such as a 'Blade'). Under this scheme the NHS owns the wheelchair and is responsible for its maintenance and repair. The family/child can also opt for one of the following schemes (2 and 3 below) using the Voucher Scheme. The Voucher Scheme (introduced in 1996) was designed to enable disabled people to use their own money to buy a specification of wheelchair, which is not normally provided by the NHS. The NHS then provides a voucher to the disabled person, for the value of an NHS specification wheelchair. (This scheme is only available in England).
2. Families can choose to contribute to the cost of a more expensive wheelchair. However, under this option/scheme the child/family will own the chair and the NHS are not responsible for its maintenance and repair. This is called the 'Independent Option'.
3. Families can choose to contribute to the cost of a more expensive wheelchair chosen from a selection approved by the local Wheelchair Service. Under this scheme the NHS owns the chair and is therefore responsible for its maintenance and repair. This is called the 'Partnership Option'.

##### Re-assessment:

If a child's needs change, or they grow out of the wheelchair provided, it is suggested by the Wheelchair Service to contact their GP or return to the Wheelchair Service that provided them with the wheelchair initially. Wheelchair Services often do not provide a formal re-assessment plan; therefore the responsibility for checking that the wheelchair is still suitable for the child lies with families. In some areas a child may be re-assessed if they attend a special needs school where a Physiotherapist or Occupational Therapist from a Disability Services team visits. In these circumstances, the therapist can contact both the family of the child and the Wheelchair Service to suggest re-assessment. In reality, we found that this rarely happens. Often therapists only suggest a re-assessment of a wheelchair when the child's clinical needs are no longer being met, for example an increase in height/size, and the family are often then on a lengthy waiting list for an appointment.

We have heard of families waiting 27 to 37 weeks just to be reassessed by an OT. We have even been told of a Wheelchair Service that hasn't assessed a child in three years, they have no money.

This process applies to children needing both manual and powered wheelchairs. However, the process for getting a powered wheelchair often incurs much longer delays and is more likely to be refused than a manual wheelchair.

We often hear of children left housebound because they are refused an electric wheelchair and teenagers who are forced to be pushed around school in a manual wheelchair by carers because they cannot propel their wheelchairs themselves.

We believe that if a child needs a powered wheelchair, statutory services should provide it.

“We have enough to do already without the hassle we get from people who are supposed to help us”

#### Mother in the South West

*“It's time families stopped having to jump through hoops in order to get equipment. If equipment is needed there should be a seamless system for its provision and a totally independent supervisory panel which can be contacted immediately if the 'powers that be' start messing you around. We all have enough to do already without the addition of the hassle we get from people who are supposed to help us!”*

### Hope, aged 13, South Coast England

*"Hope has gastric abnormalities, is blind, epileptic and has Cerebral Palsy. She likes to do everything her friends do but she can't. She cries a lot about this, it breaks my heart. Disabled children are treated like second class citizens. These children didn't ask to be born this way, they haven't taken drugs or abused their bodies, I think that if they need something, they should have it."*

"David can roll beside me to nursery, go from activity to activity, he plays chasing with his friends, and his self-esteem and confidence blossomed."

### A Family's Story

#### This is David's story.

David is four years old and has a terminal condition. His story is told by his parents.

"David has a diagnosis of Spinal Muscular Atrophy II - severe muscle weakness, has never stood / crawled, will become weaker as his body becomes heavier. At risk from chest infections, the condition is terminal."

"David needed a powered wheelchair. We applied to the Wheelchair Clinic for this. To get an assessment we waited a total of 12 months."

"We were refused because the NHS does not fund powered wheelchairs; they will provide a standard chair, which does not provide the child with accessibility for outdoor use. The NHS does not believe a powered wheelchair is needed for a young child as they can still fit in a pram."

"This decision left us in despair, we had a bright lively child who wanted to be independent and access all the activities his peers could at nursery etc. He did not want to be pushed around in a pram, especially when we met up with his friends."

"We couldn't afford the chair without assistance and it broke our heart to see what he could have had."

"If BDF Newlife had not been able to approve a grant we would have bought it with a loan or credit card or through family which would have put us in more debt. The chair is only part of the cost - there's the maintenance, insurance, ramps for the car and it's on top of all the other equipment we need for David. The grant provided the balance we needed to buy the powered wheelchair and within six weeks we had his chair. David can roll beside me to nursery, go from activity to activity, he plays chasing with his friends, and his self-esteem and confidence blossomed. I can open the door and off he goes! It's terrific for him and us as a family."

"We would like to tell decision-makers that we don't ask for equipment on a whim, it's because we NEED it and it is either a medical necessity or improves our children's quality of life, which as a parent to a disabled child is VERY important."

In the three year period that BDF Newlife has been providing Child and Family Grants, 135 wheelchairs and specialist buggies have been given to children with disabilities. With each of these grants, we have been given the reason by a professional that the family has had to apply for charitable funding.

Below is a breakdown of these reasons.

#### FUNDING

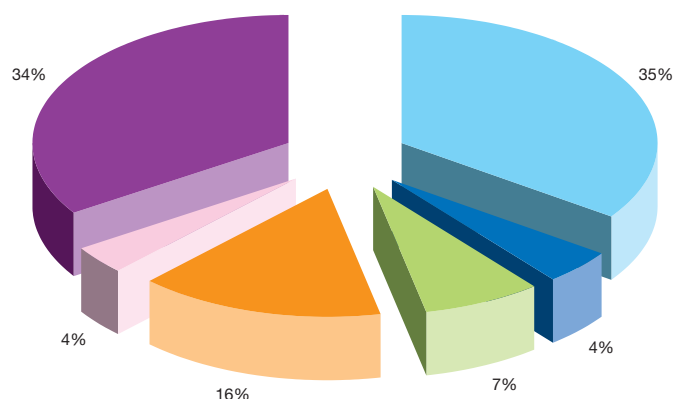
- No funding available
- No Budget

Total: 39%

#### POLICY

- Equipment rationing
- Does not meet the criteria
- Do not provide the type of equipment
- Do not provide specification of the equipment

Total: 61%



#### What this data means:

People may assume that a lack of funds is the main reason for refusing to provide wheelchairs to disabled children. However, in many cases statutory services are setting policies to 'ration out' funds and calling it 'policy decisions' which disguises underfunding. Wheelchairs are costly items so if low budgets are set they are very quickly eaten up. Statutory services need to assess each child based on their needs and properly plan financially for replacements and upgrades.

“Our kids should be treated as individuals”

**Aaron, aged 5,  
South East**

*“Aaron has severe Autism and needs 24/7 care. We needed a special buggy. We applied to our social services. After waiting nine months for an assessment we were refused the buggy because they said that as Aaron's disability was not physical he was not eligible. Our kids should be treated as the individuals that they are, just because they don't have a physical disability doesn't mean they are not physically disabled.”*

“This decision left us in despair, we had a bright lively child who wanted to be independent and access all the activities his peers could at nursery”



**Rebecca aged 16,  
Worcestershire**

Using equipment supplied by  
BDF Newlife

**Sura, aged 9, London**

*"Sura has Noonan Syndrome and is fed through a tube. We moved house last year and needed a bed. Social services refused to assess her for the bed, they just said "sorry, we don't supply furniture". Sura had to spend several weeks sleeping on the floor which posed potential risks. She could have kicked the heavy feeding machine and it could have fallen on her and caused injury or the tube could have twisted around her neck while she was sleeping."*

# The Right Equip

## Specialist Beds and Sleep Systems

Beds are a vital piece of equipment for many children with disabilities and the families that care for them. The right bed can benefit a child and their parents in many ways. A specialist bed will provide postural support and prevent deformities and contractures. Some children require tube feeding overnight and a bed that tilts is essential.

For the most severely affected children, their bed will be the place that they spend most of their time, this is the reason that statutory services must get it right.

For the carers it is vital that the bed is height adjustable so that they are able to provide care quickly and effectively. Some children need beds that have high or padded sides, this is particularly true of children with behavioural disorders.

Sleep systems are a key part of any 24-hour postural management programme for children who cannot independently alter their position during the night. Failure to provide an adequate sleeping system leaves children at risk of developing an asymmetric posture and contractures, complications that will often need expensive and painful surgery to correct. There is also a significant risk of children developing sores, if left untreated they can become infected and have serious consequences.

**We understand that the main problems families are facing are:**

- Disputes between social services and health professionals as to who is responsible for providing the bed / sleep system.
- Children falling outside of increasingly strict criteria.
- No budgets made available for specialist beds and sleep systems as a policy.
- Waiting lists are so long that by the time a child is given the correct bed, the damage has already been done to their health.
- Statutory services only providing a basic hospital bed. This bed will not fit the requirements of most children with complex disabilities.

- Beds being considered an essential household requirement by some statutory bodies and therefore they believe it is the families and not statutory services that should fund this.
- Some Social Services departments saying that a bed is not an essential piece of equipment.
- Some children being tightly strapped into their beds at night to control contractures and the straps then causing the child injury. This may sound like medieval torture, but it is happening now across the UK. A specialist sleep system would stop this immediately.
- Some children whose lives are put at risk because of an inadequate bed. We have heard of one example where a child fell through the bottom of an unsuitable bed and fractured his skull and broke his teeth, this was while he was on a waiting list to be provided with a suitable bed.

**The current failing system**

To get equipment, the professional involved in the child's care decides whether the equipment is a health or social requirement. This is assessed as either 'access' or 'pressure relieving' need.

- Access: The child has some general mobility and the bed is therefore more of a social need.
- Pressure: Tissue Viability Team decide that the child has very little or no mobility and is in need of continual support. Therefore it is a health requirement.

If budgets are tight in that area the professionals can apply to the Director of Finance at the local PCT for funding.



“it seems ridiculous that we spend all day putting Robert in a special seating and standard frame, just to undo all the hard work during the night...he needs a proper bed”

“Professionals don't bother to apply to their departments - they go straight to charities”

If the application is accepted the PCT releases funds to the equipment store (integrated / county) and the bed is provided. This bed only needs to fit the child's most basic needs and will usually be a standard hospital bed.

If the family's application for funding is refused, or the family requires something more than the basic, the professional will look for funding outside of statutory services, mainly charities.

Occasionally beds are funded jointly between social services and health, however, this is rare.

We spoke to many professionals within the Children's Disability Teams around the country (both Social Workers and OTs). When we asked how a family would go about getting funding for a specialist bed, most said that “it is very difficult if not impossible to get a bed”.

One OT even said that she would not bother attempting it through statutory services and would go straight to charities.

**A Family's Story**

**This is Robert's Story.**

“Robert is three years old and has Cerebral Palsy and Scoliosis\*. Robert needs 24-hour postural management so needed a sleeping system to keep his spine straight during the night. His Physio assessed his needs and applied to Social Services. We were told Social Services would not fund a sleeping system as it was considered a luxury item. It seems ridiculous that we spend all day putting Robert in a special seating and standard frame, just to undo all the hard work during the night.”

**Below is a breakdown of the reasons given for denying equipment.**

**FUNDING**

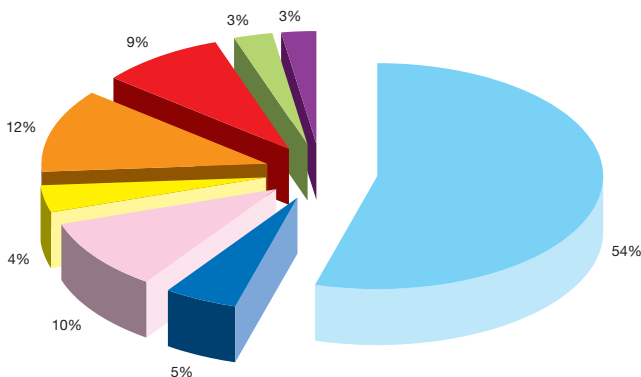
- No funding available
- No Budget

**Total: 59%**

**POLICY**

- Equipment rationing
- Does not meet the criteria
- Do not provide the type of equipment
- Do not provide specification of the equipment
- Inter agency squabbles
- Not considered a priority

**Total: 41%**



**What this data means:**

Beds / sleep systems are often the subject of squabbles between departments (Health and Social Services). However we still see policy to disguise spending rationing playing a major part in failure.

**Melvin, aged 4, Scotland**

“Melvin has Spinal Muscular Atrophy. We needed a powered wheelchair as Melvin can't self propel. We applied to wheelchair services via the occupational therapist. We had to wait nearly two years for the assessment from diagnosis.

We were refused this item because the NHS funds only allow for a basic powered wheelchair which was not entirely suitable for a child of Melvin's intelligence. No vouchers were offered and we were told we would have to meet the cost of non-standard equipment ourselves.”



# The Right Equip Specialist Car Seats

Most families with children will require car seats in the first couple of years of their lives. For disabled children this requirement can last much longer. Car seats for disabled children are usually larger and sturdier than normal car seats. These seats have increased safety measures such as stronger harnesses, and head and leg supports. These seats will provide exceptional support to children who are either unable to support themselves or do not have an understanding of danger.

Some specialist car seats are mounted on swivel bases to help transfer the child in and out of the car. This also reduces the risks associated with lifting and handling older children. BDF Newlife has provided many specialist car seats to many families. When asked, every family told us that they had to apply to charities because they couldn't get funding through statutory services. The problems that families face with car seats have become increasingly severe since the legislation was passed six months ago extending car seat laws. We've found that despite the law changing, provision by statutory services hasn't changed.

Families with a disabled child face increased amounts of pressure in their day to day life. For many, being able to leave the house and see other people is a lifeline. For all, safely taking their child to hospital appointments, physiotherapy and school is essential. While a car seat is legally essential for all children, parents of children without disabilities are not forced to pay up to £2,000 for car seat. Nor do they have to replace this car seat every few years until the child is 10, 11 or 12 years old plus.

#### **We believe the main problems families face are:**

- Budget restrictions within both health and local authorities which mean that families are unable to get a special needs car seat for their disabled child.

- Some statutory services do not view a car seat as an essential item.
- Some families are told that a car seat is an essential piece of equipment that they would have to provide for their child with or without a disability and therefore is not something statutory services should have to fund.

#### **The current failing system**

Ten years ago, car seats for disabled children were provided by Social Services. Since Primary Care Trusts have gained more autonomy, this provision has disappeared. Because of the increasing gap between demand and supply, charities are often turned to for financial assistance.

Legally, it is the duty of the local authority to provide practical assistance and additional facilities designed to secure greater safety, comfort or convenience to those people assessed as needing them. However, the interpretation of this seems to be very flexible with many local authorities unaware of it. In some areas there is a loan scheme for car seats, this will be based in the Children's Information Service in local regional council offices. As with wheelchairs, car seats appear to be another postcode lottery. Provision was originally from Social Services, however, it happens so rarely now that no one seems to be aware of this.

“The law changed but no one considered the impact on disabled children”

### **Chelsea, age 10 months, Kent**

*“Chelsea has SMA Type 1. This is a terminal illness. We needed a shed to store all of her specialist equipment, such as a travel seat, buggy, bath seat, Moses basket etc. We were told our local OT service do not provide storage for equipment. We could barely move for equipment in our house. We were at a loss as to who to ask for help.”*

“we don't understand why car seats aren't provided. We have been told that they just don't provide them”

**A Family's Story**

**Janus, aged two, Humberside.**

"Janus is registered blind with very unstable epilepsy, he has many medical and global problems with his muscle tone.

We needed a special car seat. Janus stopped breathing in his normal seat while we were stuck in rush hour traffic, this new special seat will help to keep him breathing.

To get this equipment we applied to Social Services, local charities, and Occupational Therapists. We had an assessment straight away, however we didn't receive any funding. We were told we couldn't get this equipment due to budgets. The local charity said that it was not their field, it is up to social services to provide it.

Social Services then said we can't give more than one car seat as everyone will want another. This decision meant that we lived in fear of Janus having a fit in the car, and due to this I was very depressed. This upset my other two children.

BDF provided a grant for the car seat. If they hadn't Janus could have stopped breathing again during a fit which could have resulted in Janus passing away.

The grants scheme gave us freedom to travel with ease. It has made such a big difference to our lives. Why can't disabled children have equipment that gives them a little bit of a normal existence?"

**A Professional's Comment:**

*"We don't understand why car seats aren't provided. We have been told that we just don't provide them. I thought that this is particularly strange because the O.T. called the seat dangerous and the doctor has urged them to consider funding..."*

In the three year period that BDF Newlife have been providing Child and Family Grants, 94 car seats have been given. With each of these grants we have been given the reason by a professional that the family has had to apply for charitable funding.

**Below is a breakdown of the reasons given for denying equipment.**



**Tom aged 4, The Midlands**

Using equipment supplied by BDF Newlife

**FUNDING**

■ No funding available

**Total: 72%**

**POLICY**

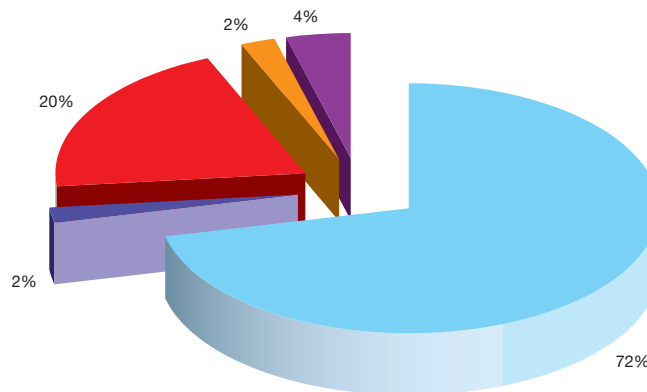
■ Does not meet the criteria

■ Do not provide specification of the equipment

■ Inter agency squabbles

■ No reason

**Total: 28%**



**What this data means:**

When the law changed in September 2006, no-one had planned to provide for disabled children. Perhaps this is why we see a clearer picture here. It is clear that finances are the real reasons and the rationing policies developed for the other equipment have yet to be developed.

**Josh, aged 6, Suffolk**

*"Josh has Cerebral Palsy and needed an electric standing frame. We spoke to Josh's Physio who contacted BDF Newlife, Josh would not have had the equipment provided anywhere else. Without this stand the muscles in his legs and posture would deteriorate. If we didn't get this equipment Josh wouldn't be able to stand and his posture would deteriorate."*

“I would like to tell decision-makers that disabled people are treated like second class citizens”

“How can a chair not be a necessity for a paralysed child?”

### Declan, age 3, Leeds

*“Declan has Spina Bifida and Hydrocephalus and needs a lot of equipment. The only item we have got for my son from the NHS was the manual chair and even then we had to wait 3 months for the suitable harness to be put on. He has an electric chair which was funded through BDF Newlife. He also has a trike which I had to fund. He still needs a car seat and a seating system, I'll have to find the money for these from somewhere.”*

# The Right Equip Specialist Seating

Many children with disabilities require specialist seating for different reasons. These seats may have headrests, harnesses or cushioning. Some children need it for postural management, to relieve pain/pressure for feeding and to ensure that their health does not deteriorate. Others need it to use at school or interact with their families.

#### We understand that the main problems families face are:

- Extensive waiting lists.
- Budget restrictions.
- Children being entitled to only one piece of equipment. If a child requires a seat at school as well as at home, the family must often choose which one they are going to fund.
- Statutory services only providing one type of seat, if this does not fit the child's needs then the family is required to fund an alternative.
- Debates between departments as to who should fund the seat, i.e. is it a piece of school equipment or is it a therapeutic aid?
- Seating equipment not being seen as a necessity.
- Families being told that pre-school children with disabilities do not require specialist seating. The alternative is lying the child down on floors and beds, however this can cause problems such as sores.

#### The current failing system

Provision of specialist seating appears to be split across many statutory services remits. In some areas a specialist seating clinic within Wheelchair Services is responsible for meeting children's seating requirements. If a child with disabilities is statemented for Special Educational Needs then it may be that the school is required to purchase the seating equipment. Alternatively the seating may come from Social Services. A typical example of the need for seating was of a nine year-old boy who had never sat at the table and eaten a meal with his family – Statutory Services refused the seating system he needed.

#### A Family's Story

##### This is Hope's story.

Hope is 13 years-old and has multiple disabilities.

This story is told by her mum. "Hope has gastric abnormalities, is registered blind, epileptic and has quadriplegic Cerebral Palsy. Hope likes to do everything her friends do but she can't. She cries a lot about this, it breaks my heart.

Over the years we have needed quite a lot of equipment for Hope. My husband is in the armed forces so I have done most of it by myself. A few years ago we needed to extend our house so that we could get all of Hope's equipment in. We applied for a Disabled Facilities Grant, we put some money to it but when we asked how long it would take they said, "how long is a piece of string?". They said that if we lived in a council house this would be easier, but we don't. We are now having to mortgage ourselves above our heads to do this.

We have also had problems getting respite care for Hope. We adopted her when she was a baby and I wouldn't change that for the world, but it's a struggle. We have lots of friends and family but we still need some help. All we are told is "funding, funding, funding", I feel like carers mean nothing in our society.

Last year we applied to BDF Newlife for a chair for Hope. Social Services bought one for her years ago but she has outgrown it. When we went to Social Services for another they said they don't provide these any more as they are not a necessity. I think it is. They said that funding is tight and they have to make cuts, it's just wrong.



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“statutory services only provide one type of seat, if this does not fit the child's needs then the family is forced to fund an alternative.”

Without a comfy chair for the lounge Hope spends all day strapped into a wheelchair and all night lying in her bed. It got so bad that her legs are permanently bent from sitting in one position all day.

I would like to tell decision-makers that disabled people are treated like second class citizens. These children didn't ask to be born this way, they haven't taken drugs or abused their bodies, I think that if they need something, they should have it."

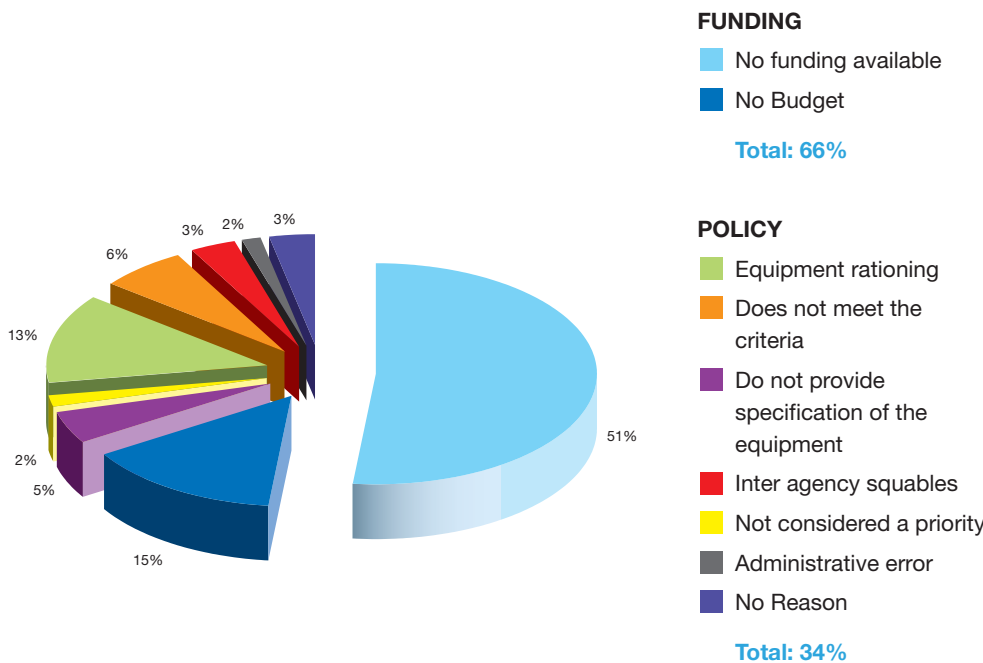
In the three year period that BDF Newlife has been providing Child and Family Grants, 62 specialist seating systems have been given. With each of these grants we have been given the reason by a professional that the family has had to apply for charitable funding.

**Below is a breakdown of the reasons given for denying equipment.**



**Daniel aged 11, Midlands**

Using equipment supplied by BDF Newlife



**What this data means:**

Again we see inter-department squabbles about funding. Proper seating is essential for comfort, pain relief and therapeutically. But while people see the role of a wheelchair, they don't always understand the important role of seating in a child's life and healthcare. We see here that lack of funding is the biggest reason, but it is likely that the rationing policies are less developed for this equipment and we have seen big increases in applications to the charity as statutory services introduce new rationing policies.

**A mother from Belfast**

“My son has Spina Bifida and Hydrocephalus. I think the general public are unaware of the financial pressures of bringing up a disabled child and more funding should be available so that their quality of life can be improved. Charities such as BDF Newlife are a wonderful thing and I'm sure they benefit so many lives, but it can't be left to charities alone, more governmental funding should be allocated.”



**Tyler, aged 4,  
Tamworth**

Using equipment supplied by  
BDF Newlife

**Anthony, aged 7,  
Yorkshire**

*"Anthony doesn't have a diagnosis for his condition. He is a wheelchair user and fed through a gastrostomy. Despite this he is a happy little boy. My son needed a special car seat. We were told that nobody will fund car seats and that it is totally up to parents to fund them. This decision meant that we had to make journeys as short as possible and often couldn't go out. I feel it is vital that children have this piece of equipment, after all it is law for everyone to be strapped into a car."*

# The Right Equip

## Walkers and Standing Frames

Providing a suitable walker for a child with mobility problems can change their lives. A walker can give a child independent mobility, good postural support, encourage tone, balance and co-ordination and prevent deformities and contractures.

### We understand that the main problems families face are:

- Families being told that they are only entitled to one piece of equipment for their child. This means that the child's actual needs are being ignored to fit with policy.
- Children being assessed for a walker but are then told by statutory services that they do not have the budget to purchase it.
- Children being assessed and then placed on lengthy waiting lists, by the time that the equipment arrives it is no longer suitable for them.
- Statutory services only providing one type of walker. If this walker does not fit the child's requirement, the family must find the money to buy a different one.
- Statutory services not providing any type of walker for children with disabilities.

### The current failing system

Walking equipment is usually considered mobility equipment and should therefore be provided by PCT funded Physiotherapists. However, other statutory agencies such as LEAs may contribute if the child is using the walker or standing frame at school. There are many types of walkers that are needed for children with different mobility problems. The prices of walkers can vary from £250 to more than £2,000.

### A Family's Story

#### This is Adolfo's story.

Adolfo is six years old and has Cerebral Palsy. This story is told by his mum.

"Adolfo has Cerebral Palsy and Epilepsy and wears glasses for Astigmatism as well as being long sighted. Adolfo's global development is delayed therefore he has learning difficulties and mobility is restricted.

Over the years we have required many items to help Adolfo around the home, in particular a walker. We spoke to Physiotherapists four years ago and we were provided with a K-walker, but it was of no use to Adolfo. This was the only walker that we were offered but it was taken back when it was noticed that it was not the right walker for him. We waited two years for a Social Services assessment. We were told that Social Services do not provide walkers.

This decision meant that we had to search for a walker for ourselves to no avail. Our Physiotherapist helped also and we met with representatives at schools to see if we could find a suitable walker. We thought however that we would never find a suitable one, but eventually we did.

ment

“we waited two years for a Social Services assessment”

“we would like to ask decision-makers why does it have to be a fight to get anything provided for our children?”

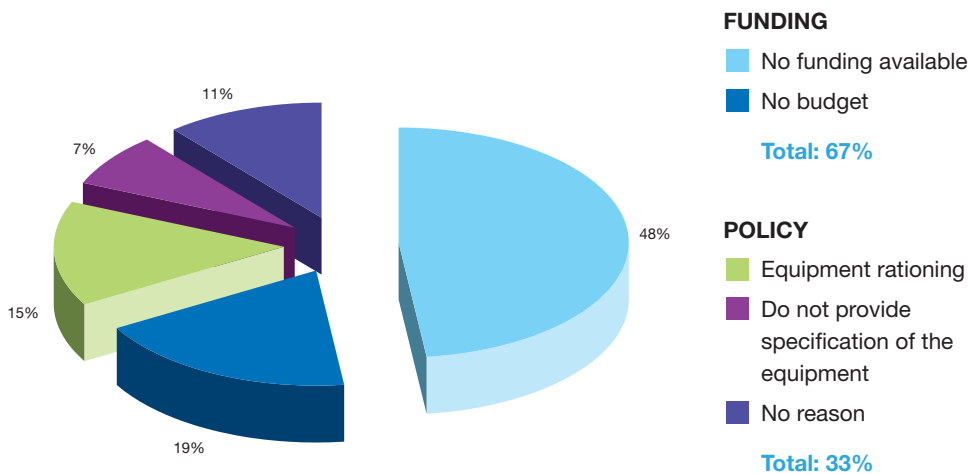
If BDF Newlife had been unable to approve the grant we would have had to save the money but it would have taken a long time. We already felt like we had wasted time getting help in finding the right walker. Time is crucial when you are looking for assistance for your child and we are all aware that the earlier our children are helped then the better the chance of them improving.

We would like to ask decision-makers why does it have to be a fight to get anything provided for our children? Surely the earlier that equipment is provided, the better the chance of our children’s lives improving. When you eventually stumble across someone who is willing to refer you, why does it take over two years? Why are you then assessed by the adult section of Social Services that don’t have a clue about children’s needs and the equipment they need?”

BDF Newlife’s very first grant was to a boy who was developing a spinal curvature through sitting all day. He was told it would be a nine month wait during which he would get worse and the pain would increase. We supplied the frame in a matter of days. A child’s health and welfare is important.

In the three year period that BDF Newlife has been providing Child and Family Grants, 27 walking or standing frames. With each of these grants we have been given the reason by a professional that the family has had to apply for charitable funding.

**Below is a breakdown of the reasons given for denying equipment.**



**What this data means:**

Here we see less rationing policies in place and this reveals the lack of financial planning.



**Paul aged 15, Cheshire**

Using equipment supplied by BDF Newlife

**Siobhan, aged 10, South East England**

“Siobhan had bilateral eye cancer, her left eye was removed and fitted with an artificial eye and the remaining eye has 10% vision. She needed a CCTV at home to read and do homework. We had to apply to BDF Newlife for this vital equipment. Without the CCTV Siobhan’s life would have continued to be dull. Before the CCTV Siobhan was heartbroken not to be able to do the things ordinary children enjoy such as reading a book or looking at magazines for girls.”

**Dalton, aged 4,  
Northumberland**

*“Dalton has Infantile Idiopathic Progressive Scoliosis and has been in a full body cast since he was one and a half. Without it Dalton would not make his 10th birthday. We needed a special mattress to help Dalton sleep better, but were told that the NHS had no money for it. This meant that it was usual for me to get to bed at approx 3am, check Dalton during the night to turn him so his circulation was not cut off for too long, then get up when he woke up and prepare to go to full-time work. I'd then get home from work and start Dalton's care again. You adapt to living on little sleep, one week I managed on eight hours sleep for the week while still working full-time.”*

# Reasons for Denying Provision

Below is a guide to the pie charts on the preceding pages. Please use this reference guide to understand fully the implications of the graphics.

## Funding

### No funding available:

For many children needing essential basic equipment, statutory services in their area have either provided too small a budget to provide this equipment or did not provide a budget at all.

### No budget:

Despite the clear need for a piece of equipment, for many children, statutory services in their area did not provide a budget for this equipment at the beginning of the financial year, therefore the child is forced to go without or the family attempt to self-fund.

## Policies

### Equipment rationing:

For some children with disabilities, they are entitled to only one piece of equipment. Most children who use for example a wheelchair or specialist buggy will also need a standing or walking frame. We know that most children with disabilities will need several pieces of equipment. This practice prevents many children with disabilities from reaching their full potential.

### Do not provide the specification of equipment:

While some statutory services will provide a certain piece of equipment to a child with disabilities, for many children the equipment that they are offered is very basic. Families are then forced to look for alternate funding from other sources. To provide improved specification.

### Inter-agency squabble:

This means that statutory services either do not understand their obligations and responsibilities or are so under funded that they have to constantly reduce their remit so they provide fewer services and types of equipment. This leads to families being passed between agencies while they squabble about who is responsible. Most families cannot wait the months that it often takes to establish responsibility, if responsibility is ever established. They often have a policy to dispute responsibility to fund certain equipment in an aim to get another statutory service to pay out.

### Doesn't meet criteria:

This means that the provision of many pieces of equipment is based on strict, often unreachable criteria, and not on a child's actual need. Such criteria is clearly due to ration out low budgets not to reflect the needs of the child.

### Not considered a priority:

Despite a child being clinically assessed by a trained professional employed by statutory services, statutory services are disregarding their assessment and saying it is not a priority to fund this. The professionals assessment must stand, not a funding based policy.

**Administrative error:**

There are children in the UK who do not have the equipment that they so desperately need because the administrative department with the statutory agency made an error. This is unfortunately quite common. Some families have been told that they are on a six month waiting list, only to find six months later that there is no record of their child's application. Others are told that someone forgot to order a part for the equipment and the family have to wait until the next financial year for the missing piece to arrive. These cases are not rare.

**No excuse:**

For some children statutory services did not feel compelled to provide a reason for refusing to fund their equipment. The answer was simply 'no.'

This gives families and professionals information to guide or inform them for the future. Surely a reason is not too much to ask, unless it is being used to cover up failings. We have heard of applications being automatically denied when funds run out and of departments that have had no budget for two years. Does 'No' hide these systematic failings?

**Do not provide the type of equipment:**

This means that for some children, statutory services will not even look at funding the equipment that they need. There is just a blanket refusal on the basis of type. This is a particular problem for younger children needing specialist mobility equipment. Statutory services often take the view that any child would need a buggy or a bed so parents of children with disabilities are told to cover this cost themselves. However, this policy fails to recognise that the higher cost of specialist equipment. It is often ten times higher than standard equipment.



**Morgan, aged 4,  
Cheshire**

*"Morgan has an Autistic Spectrum Disorder and mild Dyspraxia and conductive hearing loss. He has behavioural problems, no awareness of danger and tires when walking. He required a buggy with lap restraint.*

*The Occupational Therapy department is so busy that they may not even assess children with ASD. We were refused by statutory services because of budget problems and assessment restrictions.*

*Without BDF Newlife we would have been forced to fundraise alone or continue to campaign. We are now able to go out as a family and longer holidays and trips are now possible."*

“He has to constantly adjust his position to try to get comfortable”

### Tyler, aged 4, The Midlands

*“Tyler has conditions which affect his fine motor skills and movement. He needed a buggy but we were told there could be a wait of up to 12 months. We were not refused the item but told there could be a long wait. It made trips or days out more or less impossible as we never knew when Tyler would refuse to walk. At four stone he is far too heavy to carry any distance. The buggy helped us have a better social life as we can take Tyler out more easily.”*

## A Parent and Child's Point of View

Mother of two Donna Giles needed a seating system for her son Nathan, who has Cerebral Palsy and is unable to sit unaided. The system would allow him to sit with his family for a meal and make it easier for his mum to transport him from room to room.

Their local Occupational Therapy department had no available budget until after April 2007 and the family was told “there will remain significant delay with regard to funding for the foreseeable future.”

**Donna writes:** “From a parent's point of view, accessing any equipment for a disabled child always appears to take an enormous amount of time and effort.

While the professionals involved with your child can be very helpful, and know exactly what your child needs, the extremely 'ad hoc' way in which funding is allocated, more often than not leads to the frustration of a lengthy wait, especially if you are trying to order towards the end of the financial year. I have been told in December that Equipment Funding Panels in several departments will not be sitting until April, the start of the new financial year.

Previously, we have waited nine months for a chair for my son.

Lately, both my son and daughter have required new chairs. Our Physiotherapist approached her manager, who was not hopeful of funding, so she then approached Social Services Occupational Therapy, who said there would be a delay of at least three months.

Meanwhile, my son nearly fell out of one chair, and is so tightly squeezed into another; he can't get comfortable, which impacts on his concentration when trying to do his homework. When eating, he has to constantly adjust his position to try to get comfortable.

My daughter Cerys becomes frustrated when she can't feed herself, because her chair is so unsupportive. If she is tired, and even more floppy, I have had concerns about her choking. The Physiotherapist has suggested a chair on wheels, as I have to lift both children; this would mean that there would be less risk of me injuring myself, which would obviously impact on the statutory services I would have to receive.

There are very good clinical and life-enhancing reasons why professionals suggest certain pieces of equipment, and to deny children access to that equipment will hold back their potential and impact on their way of life, and the contribution they can make to society.

When a child is diagnosed as being disabled, would it not be sensible for an amount of money to be allocated, knowing they will need certain equipment, so that it is there when it is needed?

Looking after disabled children requires organisation, and more expense than having an able-bodied child anyway, without having to afford equipment that Funding Managers may not view as urgent or essential, but that the families waiting for them very definitely do.”

“my chair at home is too small - when I am trying to do my homework or eat at the table I am uncomfortable and don't feel safe so I can't concentrate”



**Her son Nathan Giles writes:**

“Not being able to have the equipment I need is a problem, because I can't work properly if I am not comfortable in my chair.

I have recently had a problem because my chair at home is too small - when I am trying to do my homework or eat at the table I am uncomfortable and don't feel safe so I can't concentrate.

I am going to be doing my Year 6 SATs soon, and I need to be able to practice for them, and concentrate on what I am doing. They are important to me and I want to do well.

Waiting for new equipment is like being starved of something, especially when you are not sure if you will ever have it.

I would like to know that all children can have the equipment they need, when they need it.”



**Mathew aged 14,  
Kent**

*Using equipment supplied by  
BDF Newlife*

**Louise, aged 5,  
South West England**

*“Louise has Sanfillippo Syndrome. She needed a special bed so we applied to the Occupational Therapist. We waited 18 months for an assessment. We were refused this equipment because of funding, funding, funding. The whole process is about money. We've got used to being refused help. Everybody thinks if you are disabled or your kids are disabled, you've won the lottery.”*

“Professionals involved in Ekram's care believe that if he had received the equipment five years ago, his behaviour would have been modified enough to stay in the family home.”

## Early Intervention

BDF Newlife believes that when it comes to providing equipment, early intervention is essential. We often hear from families that are denied equipment costing £1,000, where their child then goes on to develop physical problems that often costs the NHS £10,000 plus to manage / treat. This mis-management creates an unnecessary financial burden on the government and distress and pain to the child.

### CASE STUDY ONE

**Ekram: aged 18 years old**

**Condition:** Severe learning and behavioural difficulties.

**Equipment required:** SafeSpace

**Cost:** £2,944.

#### TIMELINE

Local Social Services “have been aware for some years about injuries suffered by the younger children” because of Ekram's uncontrollable behaviour.

**2001** - Family applied for SafeSpace - Ekram aged 13 years old.

**2003** - Mother suffers nervous breakdown. Both parents stop working. Family income now solely through benefit.

**2005** - Father goes to doctors about chest pain, doctor suspects Coronary Heart Disease. Angiogram shows no heart disease. Father diagnosed with stress due to home circumstances.

**2006** - BDF provides SafeSpace after senior management at Social Services are approached again for the equipment. However Children's Services budget overspent. Ekram now 17-years-old.

Two weeks after receiving the SafeSpace, Ekram has destroyed it. He is now moved into residential care. Professionals involved in Ekram's care believe that if he had received it 5 years ago, his behaviour would have been modified enough to stay in the family home.

#### Cost to statutory services:

- Injuries to siblings
- Mother's nervous breakdown
- Benefits to sustain a 6 member family
- Dad's suspected Heart Disease plus extensive tests and treatment.
- Ekram requiring 24/7 residential one on one care (approximated by professionals at £50,000+ a year)

### CASE STUDY TWO

**Janus: aged two-years-old**

**Condition:** Visual and hearing impairment, unstable epilepsy, global development delay, low muscle tone.

**Equipment required:** Special Needs Car Seat

**Cost:** £649.19

Family told by professionals involved in Janus' care that “this equipment is not statutory or locally provided and is therefore subject to independent / charitable funding.”

#### TIMELINE

**November 2006** - Janus has a seizure in his standard car seat and chokes. Mum has extreme difficulty in removing him from harness. Janus stops breathing and Mum is forced to resuscitate at the side of the road. An ambulance is called. Janus is admitted to hospital for the weekend due to the incident.

#### Cost to statutory services:

- 2 days / 3 nights of hospital stay for a severely disabled 2 year old child
- Ambulance service attending to Janus



“Michael has used up his ‘one peice of equipment per child’ quota”

“Michael is crying in pain”

### CASE STUDY THREE

**Michael: aged nine-years-old**

**Condition:** Cerebral Palsy affecting 4 limbs, partially sighted, epileptic, non-verbal.

**Equipment:** Specialist Chair.

**Cost:** £1441.00

Family told by their OT that as they had previously received seating equipment, although it was inappropriate, the family had used its equipment quota.

#### TIMELINE

**2004** - Michael has surgery on both hips. Family apply to Occupational Therapy for Chair. This is refused as Michael had used up his one piece of seating equipment per child quota. Support worker notes that Michael's suffering since surgery, one hip now seems considerably worse than the other and Michael is crying in pain.

**2005** - Parents apply to BDF Newlife for chair, this is funded. Michael has been forced to sit on a beanbag since his hip surgery and has developed curvature of the spine.

**2006** - Michael is now being assessed for corrective back surgery.

#### Cost to statutory services:

- Corrective back surgery for curvature of the spine
- Pain management costs
- Therapy required due to curvature of spine

### CASE STUDY FOUR

**Nathan: aged 13 years old**

**Condition:** Pelizaeus-Merzbacher Disease, a condition that is progressive and life-limiting.

**Equipment:** Specialist bed.

**Cost:** £2,016.30

Family told by their Social Worker “there is no statutory funding for this”. When BDF Newlife contacted the relevant departments in March to investigate, we were told that the PCT isn't refusing the application as there is a clear need, however there is no available cash to buy the bed. We were told “we're so financially stretched it's unbelievable, in fact we've been under a financial crunch since December”. When asked if it would improve in the new financial year we were told “probably not, it is an election year”.

#### TIMELINE

**February 2006** - Application made to Social Services for a specialist bed.

**July 2006** - Nathan falls out of his inappropriate bed, ripping his feeding peg from his abdomen. Nathan is hospitalised for two weeks including surgery to replace the peg. Nathan's Social Worker and Consultant write to the PCT asking for the bed as a priority. The PCT did not reply.

**February 2007** - Application received by BDF Newlife for a specialist bed. The bed was funded. To date there is still no response from the PCT.

#### Cost to statutory services:

- 15 day / 14 night hospital stay.
- Surgery to replace feeding peg.

“The PCT isn't refusing the application as it is clear there is a real need, however there is no cash to buy the bed”

“Nathan's Social Worker and Consultant write to the PCT asking for the bed as a priority. The PCT did not reply.”

## What the Families Say

When we began our campaign in April 2006 we asked families to tell us their stories. The response was overwhelming with more than 250 people telling us of their anger, disappointment and frustration with the system. Families wanted to tell us that statutory services are “not listening” and wanted to put over to policy makers the difficulties that they face.

Their full stories are available on our website. We invited all of these families to complete the following sentence; “I would like to tell the decision makers”, these are some of the responses that we received.

### Leighton

Aged four, *Northamptonshire*

“I would like to tell the decision makers that we think that the way they treat families with disabled children is disgusting. They made us wait months on end just for an assessment and then even longer for anything to happen from it. While we wait our child has to suffer with no support in his buggy, feeding chair, car seat etc.

We feel very upset with them as they tried to make us have second best just because it covers some of Leighton's basic needs, the decision shouldn't be made regarding basic needs it should be made to cover 100% of his needs.

Why should we feel as though our child is being punished for having a disability? We have to fight for everything and yet it just seems like we are banging our heads against a brick wall. As parents our health suffers as well from the heavy lifting and due to bending down a lot which comes from looking after and caring for our children (we would do anything for them). Things need to change for the better.”

### Louie

Aged ten, *Northamptonshire*

“I would like to tell decision makers that if you are lucky enough to get the needs of your child recognised in a reasonable amount of time, which in itself is rare, you are more than often told “yes your child needs that item or service but sorry there's no money.” You wait for months to be told something you know but the solution is not forthcoming and

you are quite literally shrugged off. Again we are left to search the internet and rely on the good of others in order to obtain the necessities for your child.”

### Jackson

Aged 13, *London*

“We would like to tell decision makers that life is hard for children with disabilities and their families. We have to fight to get the most basic things; an appropriate education, Physiotherapy, O.T. It seems that everything is under funded and disabled people are easily forgotten. Parents of disabled children feel isolated from a society which assumes that proper provision is made for them and their children. It is hard for mothers of disabled children to work, however, when they do, they are penalised and expected to pay for all but the most basic equipment.”

### Lauren

Aged five, *South Yorkshire*

“I would like to say to decision makers, swap lives with our family for six months to experience the difficulties and heartache every day, to see the most special part of your life taken over with the pressure of fighting for basic equipment.

I would also like to tell them that our child deserves the best start in life just like anyone else; Lauren did not ask to be disabled so why should she be penalised? These people need to realise that this can happen to



“Why should we feel our child is being punished for having a disability?”

“You wait for months to be told something you know but the solution is not forthcoming and you are quite literally shrugged off.”

“we have to fight to get  
the most basic things”

“it seems that everything is under-funded  
and disabled people are easily forgotten”

anyone, ordinary people like us, like them. We are not expecting miracles but just to stop putting obstacles in our way of trying to live a life as a family like I am sure they do.”

#### **Ashleigh**

Aged eight, *East Lothian*

“Ashleigh has developmental delay, allergic enteropathy, seizure disorder, visual impairment, macrocephaly, adrenache and dietary restrictions.

Ashleigh is dependent on me to meet all care needs. Ashleigh's disabilities mean that she requires support and supervision throughout her waking hours.

Ashleigh has partial seizures / night terrors. During these episodes Ashleigh jumps about in her bed. Ashleigh has no sense of danger and would jump out or fall out throughout the night. The whole family will benefit from a Safespace voyager. It would mean we could plan holidays, be able to have respite and mean Ashleigh can go to hospital overnight.

To get this equipment we asked our OT as the social work department couldn't provide a bed for Ashleigh to sleep in all the time. We also spoke to the hospital about overnight stays, what happens when Ashleigh needs to be admitted? We were told that she would sleep on a mattress on the floor which is not safe at all for Ashleigh.

We were refused this item basically because Ashleigh's needs are not the same as some other children and equipment that Ashleigh needs is not usually used for other children. People often don't understand the dangers.

The decision by statutory services to not fund this equipment meant we had to dismantle Ashleigh's cot bed and take it on holiday, but Ashleigh's far too big for this now because of her rapid growth.

BDF Newlife provided a grant for the equipment. If they hadn't I would have tried

fundraising, but I'm sure it would have taken a long time and we just can't afford to buy it. Because of childminding problems I can only work part-time. Without this equipment it would mean no respite through my parents. Also with no overnight stays at hospital, I would have to care for Ashleigh at home.

I would like to tell decision makers that they should think more about the impact that equipment can have on a child's life, instead of how much it costs. I think that they don't think about how difficult it can be without having to ask or beg for things that are really needed.”



#### **Alice**

Aged six, *Derbyshire*

“I would like to tell decision makers that just because a child is disabled shouldn't mean that they have to go without the things that other people take for granted. All equipment should be subsidised to bring costs in line with items for a non-disabled child. The difference in costs are too great, we should not have to beg for everything. E.g. Car seat for Alice £793.41, normal car seat £50.00. Bed for Alice £4010.00, normal bed £200.00. Buggy for Alice £1600.00, normal buggy, £200.00. The list is endless.”

“I would like to tell decision makers that they should think more about the impact that equipment can have on a child's life, instead of how much it costs.”

“We should not have to beg for everything.”



**Jade, aged 12,  
Staffordshire**

*Using equipment supplied by  
BDF Newlife*

# Who Meets the Need When the State Fails?

Using our figures and data collected from other grant giving charities, we have built up a picture of 'unmet need'.

In the same period that PCTs and Local Authorities spent £16 million on equipment for children with disabilities, UK charities spent over £4 million. This means that charities provided a 25% equivalent of the statutory spending.

For the first time we have surveyed the main equipment grant making charities to find out how they are helping to plug the gap in Statutory Services spending.

In speaking confidentially to professionals we have been told that in many areas it is now stated in the department's policy to apply to charities for equipment before using the departments budget.

BDF Newlife receives most of its applications for equipment grants from professionals, rather than families, as they desperately try to help the child when their departments fail.

When statutory services fail to provide a child basic essential equipment, the family must make a decision. They have three difficult choices, they can either:

## 1. Approach a charity for funding

As a grant-giving charity we have become increasingly aware of the amount of families being forced to approach charities for funding for essential equipment. BDF Newlife's Child and Family Grant Scheme has now been running for three years. In the first year we spent £37,000. In the second year we spent £500,000. Last year we spent over £750,000. These grants are not awarded for a 'Rolls Royce' specification. These grants are mainly made for essential basic equipment such as wheelchairs, car seats, beds and standing frames.

When we surveyed the charities we found that many have to have a waiting list as applications are now outstripping their funding resources.

## 2. Self-fund

There are many families in the UK who, when they are refused essential equipment by statutory services, try to self fund the item. We are already aware that families with a disabled child are under a financial burden and can only buy equipment on high interest credit cards.

As equipment can often cost in excess of the £2,000, this means that by the time the family finish paying for the equipment, the item is usually too small and is unusable for the child.

We hear constantly from families who are now suffering high levels of debt because of self funding equipment - who take on financial responsibilities that they can not meet because they can not face the prospect of their child suffering. We have heard of wheelchairs being bought on credit cards which at minimum payments will take a family ten years to pay off.

These families often call us in crisis, when their homes are about to be repossessed. By this stage, families have no faith left in statutory service providers.

## 3. Go without

The final option for a family is for their child to go without. Unfortunately there is no record of how many children in the UK have gone without essential equipment. These children and there families suffer in silence for years.

We believe that BDF Newlife is the first charity to assess unmet need. We are constantly told by PCTs and Local Authorities that while they spend very little on equipment for children with disabilities, there are no children in their area that have been assessed as requiring equipment and have gone without. We know that this is not true. We have spent almost £1 million this year on this equipment so we can prove they are wrong.

“in many areas it is now stated in the department’s policy to apply to charities for equipment before using the department’s budget”



**Elizabeth aged 17,  
Oxon**

*Using equipment supplied by  
BDF Newlife*

#### What this means

By assessing unmet need we hope to achieve the following;

- Highlighting to the Government that there are children in the UK who are not being funded by statutory services, despite there being an assessment showing a clinical need., ie an unmet need.
- Highlighting to the Government exactly how much they are under funding the services.
- Highlighting the role of charities in trying to plug the statutory services funding gap.

See the chart below.

Charity Name	Spend for 2005-06
Caudwell Charitable Trust	567,000.00
Association for Spina Bifida & Hydrocephalus	3,000.00
Roald Dahl Foundation	7,200.00
Children Today Charitable Trust	73,000.00
Lifeline 4 kids	174,425.00
National Blind Children's Society	28,563.00
Anonymous Charity	1,100,000.00
ACT Foundation	146,000.00
The Jennifer Trust for Spinal Muscular Atrophy	8,200.00
Action for Kids	464,700.00
Get Kids Going	743,750.00
React	357,152.00
Joseph Patrick Trust (Muscular Dystrophy)	94,125.22
BDF Newlife	507,001.47
<b>Total</b>	<b>£4,274,116.69</b>

Based on the information provided by these charities surveyed in March 2007.

“Families are buying wheelchairs on credit cards - desperate to help their child”

“In speaking to statutory bodies there appears to be a real lack of understanding about the responsibilities they have under the law.”

## What does the law say?

So far in this report we have examined and read about:

- The rapid **crumbling of the statutory system** for providing equipment. Can this go on?
- The **shambolic system of provision** and the **postcode lottery** existing throughout most of the UK. Is this reasonable?
- The **frustrations of professionals** told to apply to charities on behalf of a child/family rather than depend on their department's funds and we have been told of the inter-departmental squabbling that surrounds who funds what. Is this acceptable?
- The **impact that this failure** to assess and provide has on the safety, health, welfare and pain of children and their families.
- The **scandal of low spending** by the majority of PCTs and Local Authorities. With some even spending nothing in a whole year, while others were acting and investing in our children. Why such disparity?
- The stated and detailed **reasons why these statutory services have declined provision** to children and the myriad of ways they present those reasons, sometimes stating there is no money or developing policies to ration out provision, often regardless of assessments of real need.
- The **unmet need** and how families are paying on credit cards for essential equipment they have been refused and how some children are forced to go without with terrible consequences. We have also seen how the Third Sector (charities) is now substantially filling the gap left by these failing statutory services.

But what does the law say? Most people reading this report will be asking themselves how can this be happening? Surely children's rights and welfare are protected in law.

The UK has perhaps the most developed welfare and legal system anywhere in the world so in looking at who can act in the best interests of children for this type of need, we have looked to the law to try to establish if these failings are acceptable. Of course Scotland, Wales and indeed Northern Ireland may have differing legal frameworks but many of the guiding principles and some of the European laws may apply.

In speaking to statutory bodies there appears to be a real lack of understanding about the responsibilities they have under the law. Families are confused, professionals wonder what the position is in respect of provision. But no one seems to be clear if protection under the law exists.

For these reasons we approached leading Solicitors Leigh Day and Co. of London to advise us on how to establish legal guidance to clear up the wide spread and confused

state of affairs. Their established experience in the field of human rights, clinical negligence and personal injury initially gave us hope that protection did exist in law. However to be clear what the detail and weight of this protection was, through Leigh Day and Co. we appointed leading barrister Eleanor Gray to research the issues we raised and provide a written opinion of the matter.

We will be publishing her final opinion, 'hot off the press' alongside this report in April 07.

The questions we have asked her are driven by the experiences of real families and children. We essentially asked questions around 'is it lawful or defensible that assessments and provision is lengthy and often delayed and equipment often refused on the basis of resource availability?' We recognised that every case is different, but because many of the situations we see are common ones, we felt it was important to establish practical advice. In particular we asked her about:

- Timely **assessments, how long is reasonable** and what happens to children if their need is urgent but the waiting list for an assessment is many weeks or months long. It is not uncommon to hear of 26 to 37 weeks (two years in one case) waiting lists just to get an OT or Physiotherapist to attend a rapidly growing or seriously deteriorating child to make an assessment which may or may not result in equipment than being provided. Where disabled adults are concerned the authorities are expected to draw up eligibility criteria's so that the assessment can establish needs such as critical, substantial, moderate or low. However it is rare to find the same process applied to children's provision, despite their special circumstances. Re-assessments for equipment can be even longer – a real problem in fast growing children. Is this acceptable?
  - The **statutory responsibilities** of Local Authorities and Primary Care Trusts – what are their legal responsibilities?
  - The responsibilities of the statutory bodies to follow **national guidance in local areas** – we see locally set policies affecting many of the reasons for equipment being denied, often based on resource shortages, skills or funds. But are these shortages the 'exceptional circumstances' which would cause one of these services to work outside National Guidance?
  - The **weight of the assessments** in driving provision - so if a doctor or other professional makes an assessment of need can the statutory authorities disregard this when it comes to providing equipment?
  - Is it acceptable to state, despite the needs of the individual's circumstances or condition, that statutory authorities make **'blanket' policies** that exclude certain specifications or types of equipment being provided e.g. "We only supply the basic wheelchair – no adaptations" or "we don't supply special beds" Can such blanket policies be defended?
  - Should statutory services take regard of the needs of a child to assess equipment to give them a near **normal experience of life?** When we hear of children who cannot go to school because of a lack of a wheelchair or who cannot sleep without pain or who cannot sit at the table with their family like other children or who are housebound because of a policy to only provide indoor use wheelchairs, we ask surely this cannot be right?
  - What does the **Children's Act and the Human Rights Act** say about protecting children and in particular protecting them from coming to harm/injury or prevent a worsening of their conditions?
  - Can statutory services require **parents to pay towards essential equipment** when they do not have the means to pay. Or only provide the first hundred pounds towards and five thousand pounds wheelchair?
  - What are **the national guidelines** provided by Government and its Ministers?
  - What **existing examples are there where the courts** have already acted to protect children in respect of equipment provision?
  - Often children and families are refused equipment and given little or no information about why. So do statutory authorities have to be **transparent in their setting of policies and in the decisions** they make?
- We hope that in defining the guidance on these and other points we will be able to provide this information to:
- Statutory authorities to assist them in future decisions.
  - Families and children in helping them understand their rights.
  - MPs and charities to help them provide guidance to those calling upon them for assistance.

“Is it lawful or defensible that assessments and provision is lengthy and often delayed and equipment often refused on the basis of resource availability?”

# Local Authorities Landscape Statistics

This information was provided under the Freedom of Information Act. We asked every Local Authority and PCT in the UK for the following information for the last year that figures are available "the amount of money spent on the provision of equipment to disabled children in your area." These are the responses:

## Local Authorities that provided statistical information:

Local Authority Name	Money spent	Local Authority Name	Money spent
Gwynedd CC	£850.30	Portsmouth City Council	£20,200.00
Carlisle City Council	£1,200.00	Newcastle upon Tyne City Council	£21,352.16
Conwy County BC	£1,676.00	Hartlepool BC	£22,000.00
Swansea City & BC	£3,500.00	West Berkshire Council	£22,440.00
City of London	£3,659.00	Clackmannanshire Council	£22,896.85
Hounslow London BC	£4,074.00	Perth & Kinross Council	£23,588.32
Blackpool BC	£5,680.00	Bexley London BC	£24,000.00
Denbighshire CC	£6,601.00	North East Lincolnshire Council	£24,222.00
Ceredigion CC	£6,823.07	Stoke on Trent City Council	£24,535.00
East Dunbartonshire Council	£6,834.09	Tower Hamlets London BC	£25,437.00
East Renfrewshire Council	£7,500.00	Cheshire CC	£25,914.00
Pembrokeshire CC	£8,115.00	Walsall Metropolitan BC	£25,987.00
Bracknell Forest BC	£9,000.00	Monmouthshire CC	£26,333.79
West Dunbartonshire Council	£9,500.00	Kensington & Chelsea Royal BC	£27,046.28
Telford & Wrekin BC	£10,000.00	Dumfries & Galloway Council	£27,362.00
St Helens Metropolitan BC	£10,685.66	Havering London BC	£29,150.00
Darlington BC	£11,616.00	Sutton London BC	£30,000.00
Carmarthenshire CC	£11,625.74	Wrexham County BC	£30,000.00
Bournemouth BC	£12,300.00	Highland Council	£31,315.00
Bath & NE Somerset Council	£13,336.99	Shetland Islands Council	£31,409.28
Haringey London BC	£13,360.00	East Ayrshire Council	£32,464.04
Stockton-on-Tees BC	£13,631.00	Dudley Metropolitan BC	£34,440.00
Argyll & Bute Council	£13,987.00	Torbay Council	£35,879.00
Blaenau Gwent CC BC	£14,423.28	North Yorkshire CC	£36,115.55
North Tyneside Metropolitan BC	£15,000.00	Lambeth London BC	£36,247.12
Oxfordshire CC	£15,000.00	Oldham Metropolitan BC	£36,358.00
Stockport Metropolitan BC	£15,000.00	Plymouth City Council	£36,888.17
Windsor & Maidenhead Royal BC	£15,565.00	Thurrock Council	£38,079.15
Falkirk Council	£15,838.00	Leicestershire CC	£40,000.00
Medway Council	£16,000.00	Northamptonshire CC	£40,000.00
Merton London BC	£17,000.00	City of Wakefield Metropolitan DC	£42,815.00
Southampton City Council	£17,000.00	Derby City Council	£43,281.00
Reading BC	£17,700.00	Vale of Glamorgan Council	£44,635.90
Newry & Mourne DC	£18,119.00	Westminster City Council	£45,146.00
Rotherham Metropolitan BC	£19,000.00	Redbridge London BC	£45,235.00
Merthyr Tydfil County BC	£20,000.00	Crawley BC	£47,406.00
Wandsworth BC	£20,000.00	Swindon BC	£47,984.76

“We are already aware that families with a disabled child are under a financial burden”

“Families have no faith left in statutory service providers”



Local Authority Name	Money spent	Local Authority Name	Money spent
Worcestershire Council	£48,030.00	Harrow London BC	£92,697.00
North Lincolnshire Council	£48,615.70	Wiltshire CC	£95,913.00
Middlesbrough Council	£49,694.23	Derbyshire CC	£97,282.00
East Sussex CC	£50,000.00	Rochdale Metropolitan BC	£99,000.00
Northumberland CC	£50,000.00	Cumbria CC	£99,940.00
Bolton Metropolitan BC	£52,000.00	Sefton Council	£101,252.00
Hampshire CC	£53,211.00	Calderdale Metropolitan BC	£108,187.45
Bury Metropolitan BC	£53,964.00	Angus Council	£113,304.00
Wolverhampton City Council	£54,148.34	North Lanarkshire Council	£120,000.00
Waltham Forest London Borough	£56,039.00	Norfolk CC	£121,722.00
Peterborough City Council	£57,000.00	Nottinghamshire CC	£125,600.00
Torfaen County BC	£57,295.55	Manchester City Council	£132,662.32
York City Council	£57,296.00	City of Bradford Metropolitan DC	£137,096.00
South Gloucestershire Council	£57,939.00	Suffolk CC	£142,474.00
Nottingham City Council	£59,577.00	Herefordshire CC	£143,375.00
Slough BC	£60,569.00	Kent CC	£145,718.00
Bedfordshire CC	£61,719.00	Western Isles Council	£159,972.10
South Cambridgeshire DC	£62,000.00	Newham London BC	£167,972.03
Kingston upon Hull City Council	£64,331.00	Lancashire CC	£179,818.00
Essex CC	£65,000.00	Lincolnshire CC	£225,434.00
Caerphilly County BC	£67,606.00	Sunderland City Council	£226,392.52
Milton Keynes Council	£68,000.00	Glasgow City Council	£229,628.00
Dorset CC	£71,608.00	Surrey CC	£230,000.00
Stirling Council	£72,572.00	Hertfordshire CC	£244,816.00
Luton BC	£72,638.00	Cornwall CC	£250,000.00
Leicester City Council	£72,741.00	Kirklees Metropolitan BC	£301,766.26
South Tyneside Metropolitan BC	£72,794.00		
Hackney London BC	£78,215.59		
Leeds City Council	£80,000.00		
Durham CC	£80,401.00		
Ealing London BC	£83,392.55		
Barnsley Metropolitan BC	£84,734.00		
Sandwell Metropolitan BC	£85,761.90		
Buckingham CC	£87,153.00		
North Somerset DC	£90,000.00		
South Lanarkshire Council	£90,015.92		
Shropshire CC	£92,000.00		

\* This includes statutory services who we believe, based on their written response, to have provided a full information/figure.

Continue...

“25% of children’s needs were satisfied by the third sector”

“Our child deserves the best start in life just like anyone else”

...continued

# Local Authorities Landscape Statistics

## Local Authorities unable to provide statistical information or provided information that couldn't be used\*.

Barking & Dagenham London BC	Isle of Scilly Council
Birmingham City Council	Isle of Wight Council
Blackburn with Darwen BC	Knowsley Metropolitan BC
Bridgend County BC	Midlothian Council
Cambridgeshire CC	Oswestry BC
Camden London BC	Powys CC
Castle Point BC	Renfrewshire Council
Chester City Council	Richmond upon Thames London BC
Coventry City Council	Salford City Council
Devon CC	Solihull Metropolitan BC
Doncaster Metropolitan BC	Somerset CC
Dundee City Council	South Holland DC
Edinburgh City Council	Staffordshire CC
Fife Council	Wansbeck DC
Flintshire CC	Warwickshire CC
Gloucestershire CC	Wigan Metropolitan BC
Inverclyde Council	

## Local Authorities that failed to respond within the deadline†.

Barnet London BC	Londonderry City Council
Colchester BC	Newcastle under Lyme BC
Corby BC	Newport City Council
Croydon London BC	Orkney Islands Council
East Riding of Yorkshire Council	Redcar & Cleveland BC
Enfield London BC	Rhondda Cynon Taff County BC
Greenwich London BC	Rutland CC
Halton BC	Sheffield City Council
Hammersmith & Fulham London BC	Southend on Sea BC
Islington London BC	Southwark London BC
Royal Borough of Kingston upon Thames	Tonbridge & Malling BC
Lewisham London BC	Trafford Metropolitan Borough
Liverpool City Council	Warrington BC
Greater London Authority	West Sussex CC

\* This may include statutory authorities who :

- Provided the a figure for a period other than the financial year 2005/06.
- Provided a figure but could not distinguish between adult and paediatric budgets.
- Could not separate their funding from that of another statutory body
- Were unable to provide the information because of the way that they keep their records.

† This may include statutory authorities who failed to supply a figure or clarification of a figure within a time period despite being given a substantially longer than the 20 days stated under the Freedom of Information Act.

“Families often call us in crisis, when their homes are about to be repossessed. By this stage, families have no faith left in statutory service providers.”

## Primary Care Trusts that provided statistical information:

PCT Name	Money spent	PCT Name	Money spent
Wyre Forest PCT	Nil spending	Solihull PCT	£13,032.00
South Tyneside PCT	Nil spending	Isle Of Wight PCT	£13,340.00
North Devon PCT	Nil spending	North Surrey PCT	£13,609.00
North East Lincolnshire PCT	Nil spending	South Hams & West Devon PCT	£13,660.00
Harlow PCT	£504.00	South Worcestershire PCT	£14,000.00
Mendip PCT	£547.00	Redditch & Bromsgrove PCT	
South Western Staffordshire PCT	£1,000.00	Sedgefield PCT	£14,000.00
West Hull PCT	£1,603.00	Surrey Heath & Woking PCT	£14,000.00
Blackwater Valley & Hart PCT	£3,000.00	Telford & Wrekin PCT	£14,994.00
North Hampshire PCT		Darlington PCT	£15,000.00
Hyndburn & Ribble Valley PCT	£4,336.99	Mid Devon PCT	£15,000.00
Central Cheshire PCT	£4,341.40	Richmond & Twickenham PCT	£15,218.00
Eastern Hull PCT	£4,475.00	Slough PCT	£15,644.00
Uttlesford PCT	£4,545.12	Hambleton & Richmondshire PCT	£15,725.00
Newcastle-under-Lyme PCT	£4,580.00	Poole PCT	£16,000.00
East Elmbridge & Mid Surrey PCT	£4,756.25	Sussex Downs & Weald PCT	£16,020.04
Epping Forest PCT	£4,759.22	Derwentside PCT	£19,000.00
Swale PCT	£5,405.00	Preston PCT	£20,895.00
Royston, Buntingford &		Fylde PCT	£21,893.00
Bishop's Stortford PCT	£6,086.00	Medway PCT	£22,000.00
South East Hertfordshire PCT		North Hertfordshire & Stevenage PCT	£22,471.00
Bexhill & Rother PCT	£6,193.95	Maldon & South Chelmsford PCT	£22,900.00
Hartlepool PCT	£6,277.00	Eastbourne Downs PCT	£23,177.42
Amber Valley PCT	£7,778.00	Dacorum PCT	£23,798.00
South West Kent PCT	£8,657.80	Watford & Three Rivers PCT	
East Hampshire PCT	£8,744.00	East Cambridgeshire & Fenland PCT	£24,679.60
Fareham & Gosport PCT		Easington PCT	£25,000.00
Portsmouth PCT		Trafford North PCT	£25,000.00
Hastings & St Leonards PCT	£8,876.59	Trafford South PCT	
Broadland PCT	£9,000.00	Kensington & Chelsea PCT	£25,250.00
Norwich PCT		South Stoke PCT	£25,852.00
East Devon PCT	£9,639.06	Witham, Braintree &	
Bassetlaw PCT	£10,000.00	Halstead Care Trust	£26,160.00
Wolverhampton City PCT	£11,486.00	Bury PCT	£26,178.47
East Surrey PCT	£12,000.00	Guildford & Waverley PCT	£27,160.00
Eastern Cheshire PCT	£12,000.00	Halton PCT	£27,300.00
Erewash PCT	£12,186.00	Swindon PCT	£27,898.00
Derbyshire Dales & South Derbyshire		Kennet & North Wiltshire PCT	£29,027.66
North Stoke PCT	£12,467.52	West Wiltshire PCT	
Durham Dales PCT	£13,000.00		

Continue...

“We are constantly told by PCTs and Local Authorities that while they spend very little on equipment for children with disabilities, there are no children in their area that have been assessed as requiring equipment and have gone without. We know that this is not true.”

...continued

# Primary Care Trusts Landscape Statistics

## Primary Care Trusts that provided statistical information\*:

PCT Name	Money spent	PCT Name	Money spent
Durham & Chester-le-Street PCT	£30,000.00	Doncaster Central PCT	£52,310.00
Milton Keynes PCT	£30,389.00	Doncaster East PCT	
Wyre PCT	£32,120.00	Doncaster West PCT	
Castle Point & Rochford PCT	£32,208.61	Croydon PCT	£52,500.00
Langbaugh PCT	£32,819.34	Cambridge City PCT	£52,724.60
Crawley PCT	£33,000.00	Selby & York PCT	£54,085.00
Exeter PCT	£33,264.00	Haringey Teaching PCT	£56,000.00
South Cambridgeshire PCT	£34,775.80	Eastleigh & Test Valley South PCT	£60,433.00
Gateshead PCT	£35,000.00	New Forest PCT	-
Lewisham PCT	£35,200.00	Barking & Dagenham PCT	£61,224.73
Torbay Care Trust	£35,765.00	Tower Hamlets PCT	£61,337.00
Cheltenham & Tewkesbury PCT	£36,478.16	Hillingdon PCT	£63,164.00
Billericay, Brentwood & Wickford PCT	£38,000.00	Maidstone Weald PCT	£65,000.00
Rochdale PCT	£38,353.00	Ashford PCT	£66,000.00
Wandsworth PCT	£38,603.00	Shepway PCT	
Kingston PCT		Canterbury & Coastal PCT	
Plymouth Teaching PCT	£38,647.89	East Kent Coastal PCT	
Islington PCT	£38,970.00	Southport & Formby PCT	£76,050.35
Blackpool PCT	£39,116.00	Heart of Birmingham PCT	£79,767.00
Dudley Beacon & Castle PCT	£41,131.00	East Yorkshire PCT	£80,908.19
Dudley South PCT		Yorkshire Wolds & Coast	
Cotswold & Vale PCT	£41,286.68	Tameside & Glossop PCT	£81,037.47
Chelmsford PCT	£41,400.00	Luton PCT	£85,835.00
East Leeds PCT	£42,000.00	Eastern Wakefield PCT	£92,402.00
Leeds North East PCT		Bromley PCT	£94,320.00
Leeds North West PCT		North Eastern Derbyshire PCT	£98,876.00
Leeds West PCT		Chesterfield PCT	
South Leeds PCT		High Peak & dales PCT	
Havering PCT	£42,440.00	Bolton PCT,	£117,128.00
Calderdale PCT	£42,670.00	Charnwood &	
Westminster PCT	£48,000.00	NW Leicestershire PCT	£120,000.00
Western Sussex PCT	£48,234.71	Eastern Leicester	
Huntingdonshire PCT	£48,398.00	Leicester City West PCT	
Windsor, Ascot & Maidenhead PCT	£49,641.00	South Leicestershire	
Lincolnshire SW Teaching PCT	£50,874.08	Melton, Rutland & Harborough PCT	
Adur, Arun & Worthing PCT	£51,984.75	Bracknell Forest PCT	£127,000.00
Carlisle & District PCT	£52,000.00	North Manchester PCT	£132,282.00
		Ashfield PCT,	£136,447.00
		Mansfield & District PCT	
		Newark & Sherwood PCT	

“Provision of many pieces of equipment is based on strict, often unreachable criteria, and not on a child’s actual need”

“Charities met a 25% equivalent of statutory spending”

<b>PCT Name</b>	<b>Money spent</b>		
Burnley, Pendle & Rossendale PCT	£136,879.00	Somerset Coast PCT	£191,110.00
North Peterborough PCT	£147,840.00	Nottingham City PCT	£226,075.00
Brighton & Hove City PCT	£148,584.00	Broxtowe & Hucknall PCT	
Chorley & South Ribble PCT	£148,956.50	Gedling PCT	
Central Cornwall PCT	£149,483.00	Rushcliffe PCT	
North Tyneside PCT	£150,000.00	Lambeth PCT	£227,196.00
Wakefield West PCT	£163,379.93	Newham PCT	£246,275.00
Airedale PCT	£164,000.00	North Liverpool PCT	£260,906.47
Bradford City Teaching PCT		Central Liverpool PCT	
Bradford South & West PCT		Central Suffolk PCT	£264,919.40
North Bradford PCT		Suffolk Coastal PCT	
Birkenhead & Wallasey PCT	£178,000.00	Suffolk West PCT	
Beavington & West Wirral PCT		West Gloucestershire PCT	£293,000.00
City & Hackney Teaching PCT	£178,723.00	Stockport PCT	£302,592.00
Wednesbury &		Huddersfield Central PCT	£303,367.00
West Bromwich PCT	£187,169.00	South Huddersfield PCT	
Rowley Regis & Tipton PCT		Southampton City PCT	£441,820.28
Oldbury & Smethwick PCT			

\* This includes statutory services who we believe, based on their written response, to have provided a full information/figure.

“Most children with disabilities will need several pieces of equipment”

“Some families have been told that they are on a six month waiting list, only to find six months later that there is no record of their child’s application”

Continue...

“On average, statutory services spend little more than £30 per child on special disability equipment”

“In the UK there are believed to be in excess of 770,000 children with disabilities”

...continued

# Primary Care Trusts Landscape Statistics

**Primary Care Trusts unable to provide statistical information or provided information that couldn't be used\*.**

Ashton, Leigh & Wigan PCT	Mid-Sussex PCT
Barnet PCT	Newbury & Community PCT
Barnsley PCT	Eastern Birmingham PCT
Bath & North East Somerset PCT	South Birmingham PCT
Bedford PCT	North Birmingham PCT
Bedfordshire Heartlands PCT	North Dorset PCT
Bexley Care Trust,	North Kirklees PCT
Blackburn With Darwen PCT	North Lincolnshire PCT
Bournemouth Teaching PCT	North Somerset PCT
Brent Teaching PCT	North Warwickshire PCT
Bristol South & West PCT	Northampton PCT
Burntwood, Lichfield & Tamworth PCT	Northamptonshire Heartlands PCT
Camden PCT	Northumberland Care Trust,
Cannock Chase PCT	North Tees PCT
Central Derby PCT	Oldham PCT
Greater Derby PCT	Reading PCT
Central Manchester PCT	Rotherham PCT
Cherwell Vale PCT	Salford PCT
North East Oxfordshire PCT	Scarborough, Whitby & Ryedale PCT
Oxford City PCT	Shropshire County PCT
South East Oxfordshire PCT	South & East Dorset PCT
Cheshire West PCT	South East Sheffield PCT
Chiltern & South Bucks PCT	North Sheffield PCT
Colchester PCT	Sheffield South West PCT
Coventry Teaching PCT	Sheffield West PCT
Craven, Harrogate & Rural District PCT	South Gloucestershire PCT
East Staffordshire PCT	South Manchester PCT
Ellesmere Port & Neston PCT	South Sefton PCT
Great Yarmouth PCT	South Somerset PCT
Greenwich Teaching PCT	South Warwickshire PCT
Hammersmith & Fulham PCT	South West Dorset PCT
Harrow PCT	South Wiltshire PCT
Herefordshire PCT	Southend On Sea PCT
Hertsmere PCT	Southwark PCT
St Albans & Harpenden PCT	Sutton & Merton PCT
Heywood & Middleton PCT	Taunton Deane PCT
Horsham & Chanctonbury PCT	Tendring PCT
Ipswich PCT	Thurrock PCT
Middlesbrough PCT	Vale Of Aylesbury PCT
Mid-Hampshire PCT	Walsall Teaching PCT

Waveney PCT	North Glamorgan NHS Trust
Welwyn Hatfield PCT	Swansea NHS Trust
West Lancashire PCT	Velindre NHS Trust
West Lincolnshire PCT	Eastern Health & Social Services Board
West Of Cornwall PCT	Down Lisburn Trust
Wokingham PCT	The Royal Hospitals
NHS Ayrshire & Arran	Mater Hospitals
NHS Dunfries & Galloway	Causeway Health & Social Services trusts
NHS Highland	NHS Grampian
NHS Shetland	Bro Morganning NHS Trust
NHS Tayside HQ	North East Wales NHS Trust
Conwy & Denbighshire NHS Trust	Warrington PCT,

### Primary Care Trusts that failed to respond within the deadline<sup>†</sup>.

Basildon PCT	Teignbridge PCT
Dartford, Gravesham & Swanley PCT	Waltham Forest PCT
Ealing PCT	Waveney PCT
East Lincolnshire PCT	West Norfolk PCT
Enfield PCT	NHS Greater Glasgow & Clyde
Hounslow PCT	Lothian NHS Board
Knowsley PCT	NHS Orkney
Morecambe Bay PCT	NHS Western Isles
North & East Cornwall PCT	Carmarthenshire NHS Trust
Redbridge PCT	Ceredigion & Mid Wales NHS Trust
Rugby PCT	Gwent Healthcare NHS Trust
South Peterborough PCT	North West Wales NHS Trust
St Helens PCT	Pembrokeshire & Derwen NHS Trust
Staffordshire Moorlands PCT	Welsh Ambulance Services NHS Trust
Sunderland Teaching PCT	Southern Health & Social Services Board

### PCTs that refused to allow BDF Newlife to re-use the information they provided.

North Norfolk PCT	Southern Norfolk PCT
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\* This may include statutory authorities who :

- Provided the a figure for a period other than the financial year 2005/06.
- Provided a figure but could not distinguish between adult and paediatric budgets.
- Could not separate their funding from that of another statutory body
- Were unable to provide the information because of the way that they keep their records.

<sup>†</sup> This may include statutory authorities who failed to supply a figure or clarification of a figure within a time period despite being given a substantially longer than the 20 days stated under the Freedom of Information Act.

“Buggies for children with disabilities are often ten times the price of a standard buggy; costing between £180 and £3,000”

“One in three of these children may be having difficulties in getting essential, basic equipment”

“We don't think these children should have to face a lengthy wait, or be told they can't have the specialist equipment that would have a huge impact on their quality of life.”

# The Future of the Campaign

The scale of failing and the impact on children means our campaign will go on. We will focus on:

## Advocacy

Navigating the multitude of assessments, criteria and application forms can be complex and overwhelming and the families that we have helped have so far been very grateful for the extra assistance.

Our advocacy work ties in with the contact that we have with MPs. Working with MPs has been particularly successful where a piece of equipment has cost over £6,000. Here we have asked MPs to go back to statutory providers and query decisions.

In the time that we have been involved in this area we have had a decision not to provide a young man with a powered wheelchair reversed. We are also in the process of obtaining a £2,500 voucher towards a Child and Family Grant for a powered wheelchair after the family had been told no money was available by the Wheelchair Service. Most recently we have had a decision to not provide a child with a sleep system reversed, this child will be receiving her equipment soon.

## Annual Index

We pledge to annually audit:

- The spending of these statutory services
- The spending of charities in filling the unmet need
- The reasons for failure to supply equipment and families and professionals experiences.

We will publish this information annually to monitor and hopefully drive improvement.

## Child and Family Grants

We created this scheme because we heard too many times about too many children who weren't getting the help they need, when they needed it.

We heard of too many cases where a child was waiting too long for equipment they desperately needed, or where their family was told nothing was available.

Why should a child have to be strapped into bed because they don't have the proper support bed to fit them? Why should a child have to miss school because he can't get a wheelchair to get there?

We don't think these children should have to face a lengthy wait, or be told they can't have the specialist equipment that would have a huge impact on their quality of life. We don't think they should be caused pain or injury through lack of equipment. When a child is suffering, we want to help, and we do.

So far we have helped over a thousand children and families and we want to help many more. Moreover, we want the system to change so that these children don't have to face these problems.

Despite the fact that we are often replacing statutory services, we will continue for as long as our funds allow, to provide Child and Family Grants to families facing hardship because of a lack of equipment.

## Best Practice

We will endeavour to establish areas and examples of best practice in provision by areas and departments and we will disseminate this information to assist improvements and innovations in delivery of equipment. We will also annually ask families to nominate local areas and statutory services that are:

- Succeeding
- Improving
- Failing

We will then publish this information in the future to encourage and drive forward improvements.



“there is no statutory  
funding for this”

## Conclusion

Failing to provide properly for disabled children is a national disgrace and our report has found that in England, Scotland and Wales an average of just £30.42 is spent on essential equipment for each child. Families in Northern Ireland are telling us of major problems in getting essential equipment for their disabled children and we will be focusing on this area shortly.

**This cannot be allowed to continue.**

**We call upon the Government and its agencies to take action to:**

- Ensure the different government agencies work together and have clear lines of responsibility
- Set a standardised assessment criteria and end the 'postcode lottery' of provision
- Guarantee the spending on children with disabilities is ring-fenced from other pressures and is adequate
- Ensure the needs of disabled children and are addressed promptly and assign a key worker to each family with a child with complex disabilities
- Provide timely assessments carried out by trained professionals
- Provide equipment in a speedy and efficient manner

**We call upon the all MPs to support the following  
Early Day Motion**

BDF Newlife is asking our supporting MPs to take an Early Day Motion to be tabled in the House of Commons relating to our campaign. EDMs are parliamentary motions calling for a debate on a particular subject.

In modern Parliament they rarely lead to full debates, but are an effective means of canvassing support, discovering MPs views and keeping real issues in the political eye. People can support it by urging their MP to sign the EDM.

**Our EDM says** - “That this House supports the improved provision of essential equipment to disabled and terminally ill children.”

“That the House notes with concern that the current system is failing thousands of disabled and terminally ill children and their families.”

We call upon Government to ensure that these children are provided for based on their individually assessed need in a timely and holistic manner and that criteria for equipment is standardised to put an end to postcode lottery provision.

### **Leilani, aged 2, East Midlands**

*“Leilani has a rare chromosome disorder. This has meant she has low muscle tone and development delay and needed supportive seating. We were told that we couldn't apply to anyone because the equipment was too expensive to be funded by the playgroup that she attends.*

*Because Leilani didn't have the seating system that she needed, she was unable to join in with activities at playgroup. She couldn't do activities such as crafts and snack time and was unable to have eye contact with her support worker, who had to sit behind her to help and support her. It is particularly important that Leilani has eye contact so that she can develop her Makaton signing. Children grow up so quickly and any delay can affect their learning and family life a great deal.”*

“We will continue to stand up for the rights of disabled and terminally ill children and their caring families.”

## About BDF Newlife

BDF Newlife, was founded as the Birth Defects Foundation, in 1991 and is currently celebrating its 16th anniversary year. A group of parents, doctors and business people with a shared passion gave the charity a very clear aim - to fight birth defects which cause disability and terminal conditions.

Inborn conditions, or birth defects, are the syndromes, diseases and malformations that have a common link - they occur in the womb. These conditions can be minor, but others are life threatening. They can cause distress and heartache, affect ability, physical and mental development, senses, organs, limbs and lifespan.

### **Our aim is to tackle the problems these conditions bring by:**

- Funding pioneering research
- Providing services to support families
- Raising awareness among the general public and decision-makers

### **16 Years of Passion**

Over the last 16 years we have achieved many things. The term "birth defects" is now a phrase in common usage. It wasn't so when we began, but our campaigning has pushed awareness of birth defects into the public arena.

BDF Newlife is established as the leading child health, research and care services charity. We have developed a portfolio of services that actively benefit affected babies and children and make a real difference to them and their families.

We have funded well over a hundred research projects investigating the causes, treatment and prevention of these conditions. We have

raised awareness amongst the general public, and amongst targeted groups, about general and specific issues - such as using simple steps to reduce the risk of birth defects.

Recognising the need for practical help, we developed our Child and Family Grants service to provide a lifeline to families with very real and urgent needs. Our unique Special Source website information service gives useful and practical information to families and health professionals. These are just some of the ways we have helped.

### **Caring Today, Caring Tomorrow**

There is still much to do. While we've been fortunate to be able to help hundreds, thousands of families through our work, every day in this country, another 124 babies are born affected.

We will continue to care. We will continue to serve these very special disabled and terminally ill children. We will continue to develop and target our services to meet the specific needs of the babies, children and families who need us.

### **We Listen**

BDF provides information and support on over 3,000 conditions and covers thousands more where no diagnosis or condition name exists. This Key generic role across the UK allows us to see and respond to the very wide experiences of children and their families in

## “Newlife - giving new hope”

“every day in this country, another 124 babies are born affected”

the UK. We will continue to listen to these voices to understand the success's and the failures they encounter daily. We will continue to stand up for the rights of disabled and terminally ill children and their caring families.

### A Broad Vision

We have always taken a pioneering view on researching inborn conditions and have contributed many gene discoveries to the Human Genome Map that will shape the future direction of medicine in the next millennium. Our broad remit means that, unlike other condition specific research charities, we have supported research across a wide range of disabilities and benefited a great number of families.

Our start up projects are an innovative form of research funding in that they allow researchers to explore a research idea and if successful can apply to our own or other research charities for major funding. Some of the start up projects have been successful on their own such as finding a gene for a major heart defect while others have gone on to receive program grant support from Wellcome or MRC.

### Research Projects

BDF Newlife has supported over 70 projects in universities across the United Kingdom. Our relationship with the biomedical research community is excellent and this is reflected in

the very high standard of research that is funded. We have ensured that the results of the research is published and have funded researchers to present the work at national and international meetings where the results can be translated into improved clinical care for children and their families.

We have also funded national chromosome databases that allow all the diagnostic labs to share information about the rarer chromosome abnormalities.

We can undertake funding in partnership with other organisations. We can help fund family-led research (where a family is raising funds for specific research, possibly in memory of a child) and "leverage/part funding", where we can provide initial funding for a project, to help attract funding from other organisations.

We have a longstanding commitment to research into Noonan Syndrome, and fund the Noonan Syndrome Unit at St George's Hospital in London. This group found the gene for the disorder and now have transferred this to the NHS where a national testing service is available.

Our research has had many successes including the identification of new genes and new diagnostic tests for the disorders that cause disability in childhood. In some cases this has also lead to new approaches to treatment and with further research the opportunities for the future are very exciting.

“BDF Newlife research has had many successes giving hope to improve childrens health today and tomorrow”

## The final word

Many children and families have inspired this campaign. But asked which children put the passion into this campaign I would cite Jordan and Ben.

We here at BDF Newlife still cry in frustration when we think of them and the situations they faced. Their suffering gave us the passion to make a difference for children today and tomorrow. Read this page and join us in knowing that, for our precious children, it's not too much to ask that they get the equipment they need.

### Jordan from Wales

Jordan is nine years old and since birth he has suffered from severe seizures, a worsening condition that won't respond to treatment, Jordan's condition is considered life-limiting. To protect him from regular falls he has to wear a type of crash helmet and his family has spent his short life trying desperately to make their home safe. In a fall last year, he smacked his head so hard that it split the helmet and he cut his head badly. The family pleaded with the authorities to provide them with crash mats for use around the house. They all refused to help. When we saw these images, we knew that, unlike statutory services, we couldn't ignore Jordan, we had to act.



### Ben from the Midlands

Ben was diagnosed with Hunter's Syndrome. He died when he was 13 years-old. In the last three years of his life Ben lost the ability to see, walk, talk and eat solids. When Ben died he was incontinent and almost completely deaf.

Looking after Ben was a 24 hour a day job for his family. His family started asking for help getting him up and down stairs when he was six. They received a hoist to use in the house, but never received the help in respect of the stairs. Up until the day Ben died his mum and dad were still carrying him up and down the stairs. Ben was 13 years old and seven stone. This was not only difficult for them but because of his condition it caused Ben a huge amount of pain every time they carried him. When Ben passed away they were still waiting for the bedroom extension and the lift to be agreed. He never did get his car seat. Ben's mum told us "We were stranded by statutory services. Nobody seemed to understand that while they were arguing about who should pay for the equipment, Ben was suffering. I am still very angry about this."

### ACTION!

**For Jordan:** BDF Newlife provided Jordan's crash mats within three days of hearing from his loving Mum. Cost = £1,190

**For Ben:** To our enduring and heartfelt regret we heard of Ben and his wonderful family, too late to help him before his death. Cost = immeasurable.

Please don't delay, support this campaign in any way you can, to help more children like Jordan and Ben.

**Mrs. Sheila Brown OBE FRSM**

CEO

BDF Newlife

“Newlife - giving new hope.”

# References and Thanks

We have accomplished a lot through this campaign.

But there is much more that we want to achieve. The Trustees of BDF Newlife wish to thank all the parents, families, professionals and MPs. Also all the businesses and caring people who have helped us raise funds, who have worked with us and who want to make a difference, on behalf of the disabled and terminally ill babies, children and families in the UK.

In particular we would also like to thank:

**Dr. Tony Wright MP** without whom a campaign of this nature would not have been possible.

**Clare Griffiths**, BDF Newlife's Campaign Manager, for her tenacity, passion and skills in helping children and families.

**Chris Strange**, BDF Newlife's PR Manager, whose caring journalistic skills have brought the plight of hundreds of children and families to the attention of the media locally and nationally.

**BDF Newlife Nurses** and staff in our Grants and Care Services Department for their skills in listening and caring for frustrated, tired, desperate families and for processing grant applications to bring relief and joy to over a thousand children.

**All PCTs and Local Authorities** (Professional and Administrative staff) who responded to our enquiries.

**To the MPs** who offered support, especially those who have offered or intervened on behalf of families.

**To grant making charities** who provided data and information who make a difference to the health and welfare of so many children.

**To all those who signed the petition** or collected signatures. Every name counts, so Thank you for caring.

**A special thank you to all the families** who opened their hearts and shared their tears and told their real life stories of caring for very special children.

**To the children** who have told us, in their own words, of their plight and who speak for those children who have no voice to call out for help.

## REFERENCES

1) Government Every Child Matters Website  
<http://www.everychildmatters.gov.uk/socialcare/disabledchildren/facts/>

2) NHS England website  
<http://www.nhs.uk/England/AuthoritiesTrusts/Pct/Default.aspx>

3) Total spend of PCTs who replied to the request for information, divided by the number of PCTs that responded, multiplied by the amount of PCTs, divided by the approximate number of disabled children in the UK.

“I think that the authorities don't think about how difficult it can be without having to ask or beg for things that are really needed.”

# Glossary of Medical Terms

**Autism:** A developmental disorder with onset usually before the age of three. The main characteristics include problems with social interaction, difficulty with communication and difficulty with imagination.

**Achondroplasia:** Characteristics include a large head and mainly short arms and legs.

**Allergic enteropathy:** An allergy affecting the intestines or gut.

**Adrenache:** In puberty, it is the increase of the hormone androgen, which leads to growth of pubic hair etc.

**Battens Disease:** Characteristics include sight loss, seizures, unsteadiness and intellectual deterioration.

**Cerebral Palsy:** This is a term for a group of disorders in which there is impaired control of movement, caused by faulty development or damage to areas of the brain. The condition may be present from birth or acquired as a result of complications of pregnancy, extreme prematurity or neonatal illness.

**Duchenne Muscular Dystrophy:** A rare, inherited condition caused by loss of skeletal muscle tissues, which are replaced by fat and fibrous tissue. The main characteristics are reported to include delayed walking, clumsiness, falling, unusual gait (waddling), enlarged calf muscles with progressive weakness and wasting.

**Global developmental delay:** General developmental delay, including intellectual ability and mobility.

**Hemiplegia:** Damage to the brain which affects one side of the body.

**Macrocephaly:** Characterised by an abnormally large head.

**Neurofibromatosis Type 2:** This is an uncommon disorder characterised by benign tumours of the nerves that transmit sound impulses from the inner ears to the brain. The main characteristics include disturbance of balance, dizziness, headache, weakness, numbness or pain in the face, ringing in the ears and progressive hearing loss.

**Pelizaeus-Merzbacher disease:** There are several forms of this condition, which is a rare, progressive, degenerative disorder of the central nervous system.

**Reflux:** Reflux occurs when whatever happens to be in the stomach travels in the wrong direction - back into the oesophagus. The most frequent symptom is heartburn.

**Rett syndrome:** This is a rare disorder found almost exclusively in females and the main characteristics include loss of muscle tone, loss of previously acquired skills, slowing of head growth, uncontrolled hand movements such as handclapping and wringing, inability to control voluntary movements, walking difficulty, autistic behaviour and severe learning difficulty

**Sanfilippo syndrome:** Individuals experience progressive dementia and mental deterioration in childhood.

**Scoliosis:** Curvature of the spine.

**Spinal Muscular Atrophy:** There is an inability to sit unsupported, inability to lift the head or achieve normal milestones. Feeding and swallowing difficulties may occur. There is also an associated weakness of the muscles between the ribs.

## OTHER TERMS

**Freedom of Information Act (2000):** The Act requires all public authorities to be open with information. The Act gives a general right of access to all types of recorded information held by public authorities. It sets out exemptions from that right and places various obligations upon the authority. It means that any person who makes a request to a public authority for information must be informed whether they hold that information and, subject to exemptions, supply them with that information.

**Local Authority:** The term local authority covers a complex system of regional government agencies. This will include councils such as District, Borough, County and Metropolitan. The term also covers unitary authorities and education authorities.

**PCT:** A Primary Care Trust (PCT) is the organisation that manages the people that you normally see when you first have a health problem. It might be a visit to a doctor or dentist, an optician for an eye test, or just a trip to a pharmacist to buy cough mixture. NHS Walk-in Centres, and the phone line service NHS Direct, are also part of primary care. A PCT will work with local authorities and other agencies that provide health and social care locally to make sure a local community's needs are being met. PCTs are now at the centre of the NHS and control 80 per cent of the NHS budget.

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IN THE MATTER OF LEGAL ENTITLEMENTS TO EQUIPMENT FOR  
DISABLED CHILDREN

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1. **Introduction** I am asked to advise a charity, BDF Newlife (“BDF”), upon various issues concerning the legal entitlements to equipment possessed by disabled children and young persons. The request arises out of a report written by the charity, “It’s Not Too Much to Ask”, which revealed widespread failures to supply disabled children with essential equipment, and contained many worrying or distressing examples of children and their families suffering as a result.
  
2. I have been asked to frame my advice around eleven questions:-
  - a. The nature of the statutory responsibilities of social services authorities and NHS primary care trusts;
  - b. The right to a timely assessment of needs;
  - c. The weight of that assessment in any funding decision;
  - d. The content of any national guidance;
  - e. The importance of national guidance, in guiding local decisions;
  - f. The legality of ‘blanket’ policies;
  - g. The importance of giving disabled children as near as normal a life as possible;
  - h. Setting minimum standards: the importance of protecting a child from harm, and of protecting against a deterioration in that child’s condition;
  - i. Contributions to costs, from parents;
  - j. The obligation to give reasons;
  - k. Examples in which the courts have acted to protect disabled children.
  
3. It is difficult to cover these very wide-ranging topics without writing a text book. Inevitably, each child’s case will be different, and the legal problems – and solutions – will vary. During the course of the advice, I have used examples given to me by BDF. The details of each case were very short, and may have omitted material issues. Any parent, carer or young person who is affected by the general content of this advice would need to take specific advice about their particular situation. I have also been selective in the areas I have covered, seeking to address general themes rather than the specifics of particular statutory regimes. The focus is upon social services authorities and NHS primary care trusts; the interface with schools, local education authorities and special educational needs is not covered. Finally, this advice does not consider privately funded services, or the practices of private bodies, voluntary organisations or charities.

**Issue A: The Statutory Duties Owed by Social Services Authorities to Disabled Children.**

4. **Children’s Services.** The Children Act 1989 is the usual starting point for assessing the duties of social services to children in their area. Section 17 of

the Children Act 1989 imposes a general<sup>1</sup> duty on local authorities to provide appropriate services to children within their area who are “in need” – the definition covers disabled children, as well as (for example) children at risk of abuse or harm. The child’s needs should be assessed, and a decision then taken on what services should be provided.<sup>2</sup> Schedule 2 of the Children Act lays down more specific duties in relation to securing equality of opportunity for disabled children. An authority should provide services designed to “minimise the effect on disabled children within their area of their disabilities” and “to give such children the opportunity to lead lives which are as normal as possible.”<sup>3</sup> There is a certain degree of confusion as to the extent to which duties under Schedule 2 of the Children Act are enforceable by an individual – they are probably not,<sup>4</sup> in the courts, although this would not prevent the Local Authority Ombudsman from assessing service provision under these headings.

5. However, a Children Act assessment may also ‘include’ an assessment of needs under other enactments – including, for example, the Chronically Sick and Disabled Persons Act 1970. Section 2 of this Act provides a specific and enforceable duty to provide a range of services<sup>5</sup> whenever the authority is satisfied that it is “necessary” to make provision to meet certain needs. If the authority accepts that it is “necessary” to meet a need (and this is an important pre-condition), and that need is one that may be met under the Chronically Sick and Disabled Persons Act 1970, then there is an enforceable legal duty to meet that need).<sup>6</sup>
6. The Children Act 2004 is designed to support the government’s programme (see “Every Child Matters”, below) to integrate children’s services. It has established a duty on local authorities to make arrangements to promote co-operation between agencies and other bodies (eg voluntary bodies) in order to promote children’s wellbeing. There is a requirement for a Children and Young People’s Plan to be drawn up by each Local Authority.
7. It can be seen that these are broad, discretionary duties. In practice, the breadth of the discretion available to local authorities is circumscribed by central government guidance, as well as legal principle. These are discussed further below, at paragraphs 34-38.

### **The Statutory Duties Owed by Primary Care Trusts (“PCTs”) to Disabled Children.**

8. The legal background to the National Health Service is to be found, first, in the National Health Service Act 2006, the National Health Service (Wales) Act 2006, and the National Health Service (Consequential Provisions) Act

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<sup>1</sup> This is a “target” duty which is not enforceable by an individual.

<sup>2</sup> There is no equivalent of the obligation to assess which is found in s47(1) of the NHS and Community Care Act 1990 – for adults. However, in *R(G) v Barnet LBC and Others* [2003] 3 WLR 1194, Lord Hope found that there was nevertheless an implied duty to assess, to fulfil the s17(1) duty.

<sup>3</sup> Schedule 2, Part I paragraph 6, see also paragraph 8.

<sup>4</sup> See Clements, “Community Care and the Law” para 18.21 – 18.23.

<sup>5</sup> See the Act for full details – assistance may include ‘practical assistance in the home’, help in travelling outside the home to (eg) school, and adaptations of the home.

<sup>6</sup> *R v Bexley LBC v B* (2000) 3 CCLR 15; the local authority cannot avoid the duty by purporting to act under the Children Act 1979.



2006 (repealing and replacing the National Health Service Act 1977). This sets out the duties of the Secretary of State for Health and the Welsh Ministers respectively, to continue the promotion in their area of a comprehensive health service designed to secure improvement in people's physical and mental health, and in the prevention, diagnosis and treatment of illness<sup>7</sup>. The Secretary of State for Health and the Welsh Ministers has a general power to provide, "such services as [he / they]<sup>8</sup> consider[s] appropriate for the purpose of discharging any duty imposed on [him / them]<sup>9</sup>" by this legislation, and to, "do anything else which is calculated to facilitate, or is conducive or incidental to, the discharge of such a duty"<sup>10</sup>. He / they must provide, to such extent as he / they consider necessary to meet all reasonable requirements, particular services including, "medical, dental, ophthalmic, nursing and ambulance services"<sup>11</sup>; "such other services or facilities for the prevention of illness, the care of persons suffering from illness and the after-care of persons who have suffered from illness as [he/they] consider[s] are appropriate as part of the health service"<sup>12</sup>; and "such other services or facilities as are required for the diagnosis and treatment of illness"<sup>13</sup>. Schedule 1 of both Acts makes further provision about the Secretary of State / the Welsh Ministers and services under these Acts, including the provision of vehicles for disabled persons<sup>14</sup>.

9. Local health bodies, such as the Strategic Health Authorities, Primary Care Trusts and NHS Trusts (in England) and Local Health Boards and NHS Trusts (in Wales), which commission health services for their local population, work under powers delegated by the Secretary of State / Ministers for Wales under this legislation. There are a series of statutory instruments which achieve this transfer of powers.
  
10. It will be apparent to those reading this that health services for children, and for disabled children, are not the subject of specific Acts of Parliament. Rather, the NHS body is working within a broad statutory framework which requires it to consider, and promote the healthcare needs of, each section of the population. Inevitably, there will be difficult decisions to be made on the allocation of limited resources. There are no absolute entitlements to be provided with particular treatments or services by the NHS, and NHS bodies

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<sup>7</sup> See section 1 of the National Health Service Act 2006, and section 1 of the National Health Service (Wales) Act 2006. Section 3 of both Acts provides that the services so provided must be free of charge except in so far as the making and recovery of charges is expressly provided for by or under any enactment, whenever passed.

<sup>8</sup> As applicable.

<sup>9</sup> Section 2(1)(a) of the National Health Service Act 2006 / the National Health Service (Wales) Act 2006.

<sup>10</sup> Section 2(1)(b) of the National Health Service Act 2006 / the National Health Service (Wales) Act 2006.

<sup>11</sup> Section 3(1)(c) of the National Health Service Act 2006 / the National Health Service (Wales) Act 2006.

<sup>12</sup> Section 3(1)(d) of the National Health Service Act 2006 / the National Health Service (Wales) Act 2006.

<sup>13</sup> Section 3(1)(f) of the National Health Service Act 2006 / the National Health Service (Wales) Act 2006.

<sup>14</sup> Schedule 1, paras 9-11 of the National Health Service Act 2006 / the National Health Service (Wales) Act 2006.

may take their resources into account when deciding what treatments, etc should be made available.<sup>15</sup>

11. Again, as in the case of social services, these broad discretions are circumscribed by central government guidance, as well as legal principle.
12. **The divide between health and ‘social’ care.** The divide between health and social services has long caused problems. I am told that there are cases where the provision of (say) a specialist bed is delayed whilst health and social services argue about whether or not this is a ‘health’ or ‘social’ need, and who should fund it. But Ministers have made it plain that they expect “services and equipment for children with physical or mental disabilities and those with complex health needs” to be “jointly planned between the local authority and PCT, with plans based on a joint needs analysis, jointly commissioned and resourced from pooled budgets were appropriate.”<sup>16</sup> If such arrangements have not yet been set in place, the appropriate solution is for one organisation to take the lead by funding the equipment, and then to resolve the dispute between themselves – not to delay the decision until the dispute has been sorted.<sup>17</sup>

#### **Issue B: Prompt Assessments of Need.**

13. An expert assessment of needs is the starting place for any provision of equipment or specialist services. BDF’s experience is that there are significant problems in securing access to such assessments, typically because of very long delays and waiting lists before the assessment will take place. During the wait, children’s development, and their opportunities to live as normal a life as possible will be seriously curtailed. Even more seriously, there will be time when their health and safety is prejudiced by the lack of suitable of equipment, or by the continued need to use unsuitable equipment.
14. There are further problems in securing reassessments as and when needs change, once an initial assessment has taken place.
15. **Assessments of Needs by Social Services Authorities.** The “Framework for the Assessment of Children in Need and Their Families” (2000) remains the main tool for social services assessments under the Children Act 1989.<sup>18</sup> It was intended that the Framework would lead to a move from single agency service-led assessments to “assessments of the whole child by a co-ordinated

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<sup>15</sup> See for example *R v Cambridgeshire Health Authority ex p. B* [1995] 1 WLR 898 *R(Watts) v Bedford PCT* [2003] EWHC 2228, at paragraphs 44 – 55; *R v North and East Devon HA, ex parte Coughlan* [2000] 2 WLR 622, paragraphs 23 – 25.

<sup>16</sup> Letter to Chief Executives, PCTs and Chief Executives, Local Authorities: Gateway reference 7371. See, equally, the Children Act 2004 and the Childcare Act 2006, which impose duties on local authorities (in particular) to lead the work of securing partnership with other authorities and planning services jointly. See also NSF Standard Eight paragraph 3.20.

<sup>17</sup> Although it has to be noted that complex issues on funding would arise, given that non-NHS services can be charged for, but NHS services cannot. Thus, if integrated Community Equipment Services are developed which operate across the health and social care divide, councils will still retain the power to charge for equipment – so some items would be chargeable, others would not.

<sup>18</sup> There are now moves to develop and ‘roll out’ a Common Assessment Framework that would be used by all professionals, but as I understand it, its implementation continues.

group of professionals.”<sup>19</sup> An assessment should address the need for specialist disability equipment and assistive technology.<sup>20</sup>

16. Local Authorities should comply with the guidance unless local circumstances indicate exceptional reasons which justify a variation.<sup>21</sup> A general shortage of resources or staffing difficulties (problems common to many if not all local authorities) would not constitute such “exceptional” reasons. Further commentary on the need for local bodies to follow and implement national policies is set out below, at paragraphs 34 - 38.
17. The standard for a “core assessment” under the Framework (ie, a in-depth assessment) is a *maximum of 35 working days*<sup>22</sup> (approximately seven weeks). The guidance recognises that where specialist assessments have been commissioned by social services from other agencies or independent professionals, “they will not necessarily be completed within the 35 working day period.” However, “appropriate services should be provided whilst awaiting the completion of the specialist assessment.”
18. In the field of adult services, the Local Government Ombudsman has been ready to criticise substantial delays, to find them unlawful and to award compensation. For example, in reports in 1996, the Ombudsman found 6 month delays in adult assessments unlawful; if waiting lists are unavoidable, cases should be prioritised so as to ensure that the most urgent receive the quickest attention<sup>23</sup>. Notably, she reiterated her view that if there was a shortage of occupational therapists, then they should not be used for assessment purposes: “If such expertise is not available, councils need to find an alternative way of meeting their statutory responsibilities.”<sup>24</sup> The same conclusions should follow in the case of children, and the time scales may well be shorter, depending on the evidence of the harm which results from delay in children who may be developing rapidly.
19. The Ombudsman has also criticised a failure to inform people of the timescales involved in waiting for their cases to be assessed.
20. The Local Authority Complaints Process. Parents, carers or young persons should consider complaining to local authorities using the complaints process, if there are delays. They should ask for the complaint to go straight to “Stage 2” (the formal stage, when a reply should be expected within 28 days). The Ombudsman is a further resource, if the complaints procedure fails.
21. Assessments of Needs by Health Bodies. There is a lack of explicit national standards for NHS assessments. There is nothing comparable to the 35

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<sup>19</sup> Assessing Children in Need and Their Families: Practice Guidance, Chapter 3, paragraph 3.4.

<sup>20</sup> Assessing Children in Need and Their Families: Practice Guidance, Chapter 3, paragraph 3.23.

<sup>21</sup> Framework, Preface; *R v London Borough of Islington ex parte Rixon* (1998) 1 CCLR 119.

<sup>22</sup> Framework, paragraph 3.11.

<sup>23</sup> In a series of cases against Liverpool CC she held that ‘urgent’ assessments should take place in 2 months, ‘serious’ cases be assessed in four months and non-urgent ones in 6 months (Social Services Encyclopedia Vol 3, D1/120/0/1).

<sup>24</sup> Cited in Clements, “Community Care and the Law” p101 para 4.129.

working days standard for social services. The National Service Framework, Standard Eight<sup>25</sup> defines the following as a ‘marker of good practice’: “Early identification and intervention are provided through clinical diagnosis and the Framework for the Assessment of Children in Need and their Families. Interventions support optimal physical, cognitive and social development, and are provided as early as possible with minimum waiting times.” The Standard identifies access to rehabilitation and therapy services as a problem area, and requires local authorities and primary care trusts to review local therapy services to:

- a. “Promote self-referral, simplifying the care pathway, and *reduce excessive waits that may affect a child’s development*;
- b. ..
- c. Ensure that the supply of timely therapy services is sufficient to meet the needs of children and young people who require it, based on assessed needs. This *may involve increased capacity* to ensure all children and young people attending early education settings and mainstream or special schools have equal access to therapy.”<sup>26</sup> (*emphasis added*).

22. “Together From the Start”<sup>27</sup> requires that assessments, investigations and tests should be organised “as expeditiously as possible with services at district (secondary/local) and tertiary services *setting waiting time goals*.”

23. So local services should be:

- a. Reviewing provision;
- b. Setting waiting time goals;
- c. Ensuring those goals, or any waits, do not damage a child’s development; furthermore, in my view
- d. It would also be good practice to provide alternative services in the interim, to the extent possible.<sup>28</sup>

24. Again, the NHS does have a complaints process (although it too is plagued by lengthy delays). Ultimately, the Health Service Ombudsman can and does investigate complaints about delays in referral and access to treatment, and can award compensation for maladministration.

25. Assessments: Conclusion. In summary, in my view there is a legal obligation on both health and social services to minimise and manage delays. If capacity cannot be increased, then the Ombudsman recommends prioritising the most urgent cases.

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<sup>25</sup> “National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and those with Complex Health Needs” paragraph 3.15.

<sup>26</sup> Paragraph 3.15, box.

<sup>27</sup> “Together from the Start – Practical Guidance for professionals working with disabled children (birth to third birthday) and their families” (DfES, DoH 2003), paragraph 2.5.

<sup>28</sup> See the parallel with guidance for social services, both in relation to children (quoted) and in the Fair Access to Care Services guidance for adults.

26. **Reassessments.** These should be scheduled in advance, and timely. In the case of adult care services, the requirement is to hold a review at least annually; major items of equipment should be reviewed as to their suitability and safety on an annual basis.<sup>29</sup> Again, the standards seem to be less well defined in the case of children's services, but I can see no good reason why they should be any poorer; they should be tailored to meet a child's developmental needs. The situation cited by BDF, of wheelchair services failing to predict children's needs, so that by the time a reassessment has taken place and the child has then been placed on a 6 months waiting list, the old wheelchair is completely unsuitable and may be doing great harm, seems to me to be one of maladministration which could properly be taken up via complaints procedures, Ombudsmen<sup>30</sup> or (as a last resort) the courts.

**Issue C: The Weight of Expert Assessments.**

27. Assessments of need carried out by social services authorities should be child-centred<sup>31</sup> (focussing on the child) and rooted in child development (so that the appropriate developmental milestones are recognised and "the planned action is timely and appropriate in terms of the child's developmental needs").<sup>32</sup>
28. Any assessment should be 'holistic', taking into account the entire family context.<sup>33</sup> For example, providing 2 specialist buggies to enable a single mother to take 2 disabled twins out offends against this principle; a double buggy is needed to enable her to take the children out.<sup>34</sup>
29. It is very well established in relation to adult community care assessments that the assessment must be tailored to needs, and not the services which are available to meet them – service provision is a later decision. "It is easy to slip out of thinking 'what does this person need' into 'what have we got that he/she could have?'"<sup>35</sup> Although the same principle is not made explicit in the Framework for the Assessment of Need, it is, in my opinion, a principle which should rationally be observed in any assessment of a child – whether by health or social services. If an assessment demonstrates that the needs have become subservient to the services available, and that needs have not been recognised or distorted as a result, it should be open to legal challenge.
30. I have been asked what the weight of an expert assessment is, when a funding body considers whether or not to provide the equipment or support recommended by it. Any such funding body must recognise and respect the expertise of the clinicians or other professionals involved. Thus, it should be

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<sup>29</sup> "Fair Access to Care Services: Guidance on Eligibility Criteria for Adult Social Care" DoH, 1 January 2003, paragraphs 60 and 63.

<sup>30</sup> See for example case Northamptonshire County Council (05/B/611) on <http://www.lgo.org.uk/socserv.htm#Services%20for%20children>.

<sup>31</sup> See the Framework for the Assessment of Children in Need, para 1.33. – 1.45

<sup>32</sup> *op cit*, para 1.38.

<sup>33</sup> The need to assess the family context is apparent throughout the Framework, as well as NSF Standard Eight.

<sup>34</sup> In legal terms, the argument could be framed both as a failure to follow guidance and as a failure to take into account relevant considerations.

<sup>35</sup> 1991 Practice Guidance on the NHS and Community Care Act 1990; see further *R v Islington LBC ex parte Rixon* (1998) 1 CCLR 119 at 129B.

unusual for a clinical recommendation to be overruled on the ‘simple’ basis that it was wrong (for example, on the basis that the needs had been wrongly assessed), provided that the clinical opinion appears sound and is properly explained or justified.<sup>36</sup> A funding body would not generally possess the expertise to ‘second-guess’ a clinician. If there *is* a disagreement, the reasons for that disagreement must be clearly set out (and would be very carefully scrutinised by the courts if the matter was before them). However, clinicians or other professionals do not have the last word on funding. If their opinion is properly respected, but the authority says that it is not their policy to fund this particular need even when clinically established (eg, because it is not severe enough to fall within their eligibility criteria), then the legality or rationality of that policy will have to be attacked separately.

#### **Issue D: National Guidance.**

31. National guidance shapes local action. In relation to social services, I have already referred to the “Framework for the Assessment of Children in Need and Their Families” (2000), which remains the central document for the assessment of needs of children under the Children Act 1989. A Common Assessment Framework that will be used by all professionals working with children is also being developed and ‘rolled out’ (by 2008, it is planned). However, my understanding is that this Common Assessment Framework will primarily be a new tool for conducting shared assessments, rather than guidance on what services should be provided.
32. Both local authorities and healthcare bodies<sup>37</sup> are expected to follow ‘Every Child Matters’<sup>38</sup>, and the ‘National Service Framework for Children, Young People and Maternity Services’, especially ‘Standard Eight: Disabled Children and Young People and those with Complex Health Needs’<sup>39</sup>, when commissioning and providing services for disabled children and their families. The guidance in (in particular) Standard Eight and the associated “exemplar” on Complex Disability can be used as standards against which service decisions can be measured. For example, Local Authorities and Primary Care Trusts are enjoined to ensure that “Disabled children are able to use/access the equipment and assistive technology they need in all places they typically spend time (eg, school, home, short-term care settings).”<sup>40</sup> It has to be recognised, however, that many of the statements in these documents are couched in ‘aspirational’ rather than absolute terms, or represent standards which the public bodies should be ‘working towards’ meeting. So, although public bodies may be asked to explain what they are doing to meet the standards, if reasonable accounts are given of progress planned or made, the courts may not require anything more.

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<sup>36</sup> If the clinical opinion does not appear to make sense, for whatever reason, or can be seen to be based on an inadequate assessment of, or knowledge of, the child, then it might be proper to disregard it, or at least to seek clarification and/or reassessment.

<sup>37</sup> In particular, commissioning authorities such as Primary Care Trusts (PCTs) but also NHS Trusts, General Practitioners and other clinical specialists. I have tended to refer to all as ‘healthcare bodies’ but there would need to be a more detailed assessment of individual functions in individual cases.

<sup>38</sup> DfES, 2004.

<sup>39</sup> DoH, October 2004, Gateway Reference 3779.

<sup>40</sup> Paragraph 3.20.

33. Further and more specialised guidance may be relevant, depending on the exact issue. There is no substitute for checking to see whether additional or new material is available which is relevant to a particular problem.

**Issue D: The Importance of National Guidance.**

34. I have already stated that Local Authorities should comply with national guidance unless local circumstances indicate exceptional reasons which justify a variation. Thus, in relation to local authorities' duties to follow central government guidance, Mr Justice Sedley described the position as follows:

"... in my view Parliament ... has required local authorities to follow the path charted by the Secretary of State's guidance, with liberty to deviate from it where the local authority judges on admissible grounds that there is good reason to do so, but without freedom to take a substantially different course."<sup>41</sup>

35. A general shortage of resources or staffing difficulties (problems common to many if not all local authorities) would not constitute such "exceptional" reasons.
36. The position in relation to NHS bodies and guidance from the Secretary of State for Health is essentially the same.<sup>42</sup>
37. Central government guidance would need to be distinguished from handbooks or other publications from (eg) voluntary bodies. Such documents might evidence good practice but they would not have the same status.
38. In practical terms, a serious difficulty can be that guidance is frequently not prescriptive or clear. For example, we have seen that there is no fixed standard for waiting times for assessments, in relation to assessments carried out by healthcare bodies.

**Balancing Resources and Needs.**

39. Before addressing some of the more detailed questions asked by my clients (Issues E - H), I think it is important to set out how decisions on providing services may be made, and how central guidance is relevant.
40. When dealing with adult care services, local authorities are expected to draw up "eligibility criteria" which 'band' needs according to whether or not they are "critical", "substantial", "moderate" or "low".<sup>43</sup> Under "critical", for example, would be included situations in which life is threatened or significant health problems have or may develop, or "vital" involvement in work, education or learning cannot or may not be sustained. The authority must assess the likely cost of meeting each band of need, and decide which it can afford to meet. It would be expected to meet the "critical" level of needs;

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<sup>41</sup> *R v. Islington LBC, ex parte Rixon* [1997] 1 CCLR 119, 123J-K; see also the Preface to the Framework for the Assessment of Need.

<sup>42</sup> *R v North Derbyshire Health Authority, ex p. Fisher* (1998) 38 BMLR 76 at 81, 89 - 90

<sup>43</sup> See "Fair Access to Care Services: Guidance on Eligibility Criteria for Adult Social Care" DoH, 1 January 2003.

thereafter its ability to meet the needs of those in the lesser bands would depend on its resources. So it might decide only to meet the “critical” needs; or it might decide that it could also fund “substantial” needs, but not “moderate” or “low” ones.<sup>44</sup>

41. The resulting eligibility criteria will then be applied to the assessment of needs, and a decision made on whether or not the needs will be met. Once the authority has decided that the needs are ‘eligible needs’, it has a duty to meet them and should make sure that services are in place to meet those needs.

42. It follows that, if a service user was assessed as being eligible for community care services, it would not be acceptable then to:

- a. State that ‘there is no budget’, or that the “budget has run out”, or that (eg) equipment cannot be provided until the next financial year;<sup>45</sup>
- b. Place a person on a lengthy waiting list that had the effect of further restricting access to equipment or rationing provision – this is a disguised form of (a).<sup>46</sup> The service must be provided within a reasonable time; or
- c. Offer unsuitable equipment or vouchers which will not cover the cost of the equipment which is needed;
- d. Limit the numbers of pieces of equipment which will be provided to a fixed number, eg one or two.<sup>47</sup>

43. As far as I am aware, there is no central guidance on eligibility criteria for children’s services which mirrors “Fair Access to [Adult] Care Services”.<sup>48</sup> However, the standards set by that guidance are relevant<sup>49</sup>, and there is no rational reason why eligibility criteria for children’s services could or should be more restrictive than those for adults (there are arguments that they should be less restrictive). Therefore, I consider that the observations on lawful eligibility criteria made above at paragraphs 41 and 42 apply. For example, there should be consistency of provision within the local area: Managers should “monitor decisions following initial and core assessments ... and ensure that decisions are being made fairly and consistently for all children.

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<sup>44</sup> The extent to which the authority’s resources may be taken into account is however a complex one, as the answer varies according to the statutory scheme being considered. For example, in contrast to the position summarised above, when making decisions on Disabled Facilities Grants, a council may not have regard to its own resources: *R v Birmingham CC, ex parte Taj Mohammed* [1999] 1 WLR 33

<sup>45</sup> This is tantamount to making resources the single determinant in a decision, which is unlawful. See *R v Gloucestershire CC ex p Mahfood* (1997) 1 CCLR 7 at first instance. It also offends because it is arbitrary and discriminatory; those who apply later in the financial year receive worse treatment than those at the beginning, for no good reason. All those within the eligible ‘bands’ should have their needs met.

<sup>46</sup> See *R v South Lanarkshire Council ex p McGregor* (2000) 4 CCLR 188.

<sup>47</sup> If, once those one or two pieces of equipment had been provided, the user’s needs dropped below the eligibility criteria, the position might change. For example, it might be that, with a hoist and a wheelchair, a disabled person was reasonably independent. A specialist chair would also be desirable, but it might be reasonable to regard the need for this piece of equipment as lower.

<sup>48</sup> NSF Standard Eight enjoins local authorities to develop threshold criteria in partnership with health and education and voluntary sector providers (paragraph 3.16).

<sup>49</sup> Especially as they were developed in the wake of the *Gloucestershire* case, whose reasoning applies equally adults and children.



Service users with similar needs receive packages of care that are capable of achieving broadly similar outcomes.”<sup>50</sup>

44. Furthermore, local authorities are meant to develop threshold criteria in partnership with health and education and voluntary sector providers. All eligibility criteria should be transparent – ie published and readily available.<sup>51</sup> This should make it easier to challenge unreasonable criteria.<sup>52</sup>
45. Parents do face the hurdle of establishing that it is “necessary” to provide services to meet a need. Thus, for example, the local authority may not accept that it is “necessary” to supply specialist car seats. In relation to this example, it seems to me that it would be necessary for the authority to ask itself whether this was a need which flowed from the disability (yes), and whether it was “necessary” to meet that need. It would not be unlawful to ask whether the parents could reasonably be expected to meet that need<sup>53</sup> – but a policy which rigidly stated that car seats would never be funded because parents should provide car seats (despite the additional cost of an adapted one) or that the council would meet the additional cost only, is likely to be unlawful.<sup>54</sup>
46. Furthermore, when harsh decisions are made, in practice the Courts will scrutinise the procedure used to reach decisions by exacting standards.<sup>55</sup>

#### **Issue D: Blanket Policies**

47. I have been given the example of a local authority whose policy is to offer no more than £750 towards the cost of a standing frame; ie to meet the costs of a very ‘basic’ standing frame even when a very specialised one costing £13,000 is clinically indicated. The discussion below assumes that the family have not been assessed as being financially able to contribute over £12,000 towards the cost of the frame (see the subject of charges, below at paragraph 67).
48. It would be important to establish, first, that this was not a case where a ‘basic’ frame would meet the person’s needs and be adequate, but a more specialist one would be more ‘desirable’. If this hurdle is overcome, then it should be clear that the child’s ‘needs’ are not being met. This in itself may be unlawful, provided the needs are severe enough. In the case of adults, if the social care needs were ‘critical’ or ‘substantial’ they would probably be eligible for funding under the local authority’s “fair access to care” eligibility criteria. I have already stated (paragraph 43) that there is no discernable reason why children’s eligibility criteria should be any less well developed, or

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<sup>50</sup> NSF Standard Eight, paragraph 3.16.

<sup>51</sup> See NSF Standard Eight, paragraph 3.16, which also requires transparency and publication of eligibility criteria. This also follows from Article 8 ECHR’s requirement that decisions must be foreseeable to be lawful. Copies could also be obtained using the Freedom of Information Act.

<sup>52</sup> For example, the rationale for agreeing to supply only a buggy that would be used indoors and refusing to supply one if it would go outside is not immediately apparent.

<sup>53</sup> *R(S) v Wandsworth Borough Council* (2005) 1 WLR 258.

<sup>54</sup> *R v North Yorks CC ex p Hargreaves* [1997] COD 390. The decision relates to funding holidays for disabled people but the principles are more generally applicable and relate to the unlawfulness of ‘blanket’ policies or fettering of discretion. See also *R(Rogers) v Swindon PCT* [2006]; it should be possible to formulate exceptional cases in which the general rule will give way.

<sup>55</sup> See *R v Ealing LBC ex parte C* (2000) 3 CCLR 109 as an example.

more unfavourable. Authorities are now expected to publish the threshold criteria they use.<sup>56</sup> So that would be the first area to explore.

49. It is also generally unlawful to have ‘blanket’ policies which take no account of the situation of individuals and their families. That is, an authority is entitled to set eligibility criteria or other policies that are designed to ensure consistent decision-making. Indeed, it should do, because of the need not to make arbitrary decisions, and to ensure that like cases are treated alike. However, the authority has to be aware of its residual discretion, and that it still possesses the power to waive any guidelines. So it must be prepared to listen to a parent or carer, etc, who says that this child should be treated as an exception to the rules, and why. It should provide reasons for failing to make an exception to the rules. I have discussed the example of a refusal to fund specialist car seats at paragraph 45 above: a rigid refusal to even consider funding such seats is likely to be unlawful.
50. It also follows that any refusal to assess need for an aid, etc, on the basis that ‘we don’t provide this’ may well be unlawful, as it ignores the possibility of the case for an exception. This would need careful consideration in an individual case.

**Issue E: The importance of giving disabled children as near as normal a life as possible.**

51. I have already set out the terms of Schedule 2, Part I paragraph 6 of the Children Act 1989, in which local authorities are enjoined to provide services designed to “minimise the effect on disabled children within their area of their disabilities” and “to give such children the opportunity to lead lives which are as normal as possible.”<sup>57</sup>
52. The Act does not apply to Primary Care Trusts. However, the language echoes the language of (in particular) the UN Convention on the Rights of Persons with Disabilities, to which the UK is a signatory. Specifically, Article 7 of that Convention states:

“Children with Disabilities.

1. State Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities the best interests of the child shall be a primary consideration.
3. State parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them....”

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<sup>56</sup> NSF Standard Eight, see discussion above.

<sup>57</sup> Schedule 2, Part I paragraph 6, see also paragraph 8.

53. Public authorities are subject to Article 8 of the European Convention on Human Rights (see further below) and, in interpreting that Article, regard should be had to relevant international provisions such as the one just set out.<sup>58</sup> So, in practice, these are principles to which all public authorities should have regard.
54. In addition, both health and social care bodies are subject to duties under the Disability Discrimination Acts 1995 and 2005. These include having “due regard” to the need to promote equality of opportunity between disabled persons and other persons, and the need to encourage participation by disabled persons in public life.
55. It is clear, therefore, that all public authorities should have regard to, and bear in mind at all times, the principle of attempting to give disabled children as near as normal a life as possible.
56. The difficulty is that this is not a ‘trump’ card which overrides all other considerations – especially resources. There is no absolute legal entitlement to ensure equality of outcome.

**Issue F: Minimum Entitlements: the importance of protecting a child from harm, and of protecting against a deterioration in that child’s condition.**

57. As a result of these difficulties and the wide discretion possessed by public bodies in deciding what services to provide, I have been asked whether there are basic but ‘absolute’ standards of health and social care provision, which a local health or social services authority is required to meet.
58. In English law, there were traces of such arguments prior to 2000<sup>59</sup>, but no favourable decisions based directly upon them. However, the European Convention on Human Rights (“the ECHR”) is now directly enforceable, through the mechanism of the Human Rights Act 2000. Two provisions are particularly relevant:-

**“Article 3 – Prohibition of Torture”**

No one shall be subjected to torture or to inhuman or degrading treatment or punishment.”

**"Article 8 - Right to Respect for Private and Family Life"**

1. Everyone has the right to respect for his private and family life, his home and his correspondence.

2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the

<sup>58</sup> *R(A and B) v East Sussex CC* [2003] EWHC 167 (Admin).

<sup>59</sup> See McCowan LJ in *R v Gloucestershire CC ex parte Mahfood* (1997) CCLR 7 at 16L.

prevention of disorder or crime, for the protection of health and morals, or for the protection of the rights and freedoms of others.”<sup>60</sup>

59. Article 3 protects against “inhuman and degrading” treatment. It sets a high threshold, particularly when pain and suffering is not being deliberately inflicted: the treatment complained of must, to a seriously detrimental effect, deny the most basic human needs of a person.<sup>61</sup> Naturally occurring illness or disability is not by itself, inhuman or degrading “treatment”; it falls within the scope of the Article only “where it is, or risks being, exacerbated by treatment, whether flowing from conditions of detention, expulsion or other measures, for which the authorities can be held responsible.”<sup>62</sup> The state’s responsibility for degrading conditions is most easily to be seen in cases involving the custody of a prisoner.<sup>63</sup> At present, cases involving the provision of medical care or aids are probably better analysed under Article 8. However, if suffering has reached levels that would normally be regarded as engaging Article 3, that would be a highly relevant consideration when considering obligations under Article 8.

60. Article 8 protects a person’s ‘private and family life’. These are broad terms; they include the “right to personal development and [the] right to make and maintain relations with other human beings and the outside world.”<sup>64</sup> The State’s obligation to “respect” this right may require it to take steps to facilitate this personal development, *if* the failure to assist has sufficiently severe consequences: “.. there may be positive obligations inherent in effective respect for private life. A State has obligations of this type where there is a direct and immediate link between the measures sought by the applicant and the latter's private life.”<sup>65</sup>

61. The English courts have now recognised that a failure to make basic social welfare provision may (depending on its severity) amount to a breach of either of these two articles.<sup>66</sup> In general, the predicament of an individual will need to be severe enough to engage Article 3, but “Article 8 may more readily be engaged where a family unit is involved. Where the welfare of children is at stake, Article 8 may require the provision of welfare support in a manner which enables family life to continue”. Even if the family is not facing separation because of the failure to provide help, if “hideous conditions” mean

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<sup>60</sup> Also relevant is Article 14, which states: ““The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.” Discrimination on the grounds of disability would be covered by this Article.

<sup>61</sup> *R(Limbuela) v Secretary of State for the Home Department* [2005] 3 WLR 1014; Lord Bingham at paragraph 7.

<sup>62</sup> *Pretty v United Kingdom* 55 EHRR I, 33, paragraph 52.

<sup>63</sup> Eg, *Price v United Kingdom* (2002) 34 E.H.R.R. 53

<sup>64</sup> *Zehmalova and Zehnal v Czech Republic* (14 May 2002); Article 8 is “primarily intended to ensure the development, without outside interference, of the personality of each individual in his relations with other human beings.”

<sup>65</sup> *Marzari v Italy* (1999) 28 EHRR CD175

<sup>66</sup> See *Anufrijeva v London Borough of Southwark* [2004] QB 1124 and *R(Limbuela) v Secretary of State for the Home Department* [2005] 3 WLR 1014.

that family life is “seriously inhibited”, then Article 8 may be held to be infringed.<sup>67</sup>

62. It is worth quoting the key passage from a judgment when the failure of a local authority to meet the assessed needs of a family whose mother was disabled and confined to a wheelchair was held to be in breach of Article 8:-

“33. Following the assessments in September 2000 the defendant was under an obligation not merely to refrain from unwarranted interference in the claimants' family life, but also to take positive steps, including the provision of suitably adapted accommodation, to enable the claimants and their children to lead as normal a family life as possible, bearing in mind the second claimant's severe disabilities. Suitably adapted accommodation would not merely have facilitated the normal incidents of family life, for example the second claimant would have been able to move around her home to some extent and would have been able to play some part, together with the first claimant, in looking after their children. It would also have secured her "physical and psychological integrity". She would no longer have been housebound, confined to a shower chair for most of the day, lacking privacy in the most undignified of circumstances, but would have been able to operate again as part of her family and as a person in her own right, rather than being a burden, wholly dependent upon the rest of her family. *In short, it would have restored her dignity as a human being.*” (emphasis added).

63. That was a case of a duty owed to accommodate an adult under s21 of the National Assistance Act 1948, and one in which the duty to meet the need was accepted. However, in principle a similar result should follow under the legislation governing children's needs discussed above, provided that the need was accepted by the authority, or the facts are strong enough to sustain the conclusion that it could not rationally be denied.
64. There is no doubt that a high level of suffering will need to be present before Articles 8 or 3 would be infringed, and that litigation in this area would be moving onto ground which, if not wholly new, is not well travelled.

#### **Issue G: Contributions to costs, from parents**

65. It is generally lawful to charge for local authority social services, provided that the recipients can afford to pay. Thus, under the Children Act 1989, the council must “have regard to the means of the child concerned and each of his parents;” there are protections for those in receipt of income-related benefits.<sup>68</sup> No one can be expected to pay more than they “can reasonably be expected to

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<sup>67</sup> *Anufrijeva v London Borough of Southwark* [2004] QB 1124 at paragraph 43, *Bernard v London Borough of Enfield* [2002] EWHC 2282 Admin. See also *R(A and B) v East Sussex CC* [2003] EWHC 167 (Admin).

<sup>68</sup> See Children Act 1989 s17(7) – (9) and s29 for the details. Charges cannot be levied without having regard to the ‘means of the child concerned and each of his parents’, and there are protections for those in receipt of benefits.

pay,” but it is generally lawful to ask for repayment of the whole or part of the cost of providing local authority care services, if there are sufficient means. The position under s2 of the Chronically Sick and Disabled Persons Act 1970 is substantially the same. Note that in *R(S) v Wandsworth Borough Council* (2005) 1 WLR 2884, the Court also held that it was not unlawful to look at the resources of third parties (such as parents) to decide whether or not it was ‘necessary’ to provide a service under s2 of the Chronically Sick and Disabled Persons Act 1970<sup>69</sup>.

66. By contrast, NHS services are provided free of charge. This is one of the factors which may lead to arguments about whether or not needs are ‘health’ or ‘social’ ones, ie, whether or not a PCT or a social services authority should provide funding.

**Issue H: The obligation to give reasons, and transparency.**

67. Reasons. In general terms, public bodies should give reasons for their decisions. Assessments under the Children Act, for example, are meant to be clearly reasoned statements which are discussed and agreed with parents or carers. Similarly, if parents and children are to be involved in health planning and care decisions (as is clearly envisaged), it follows that there must be an entitlement to have the reasons for those decisions. This also follows from the principle of giving informed consent to what are, by definition, forms of treatment.
68. If reasons and care plans are not provided in writing, then they should be requested. Except in very complex and rare cases where providing certain pieces of information could be harmful to the health of the disabled child himself (or herself), there really is no excuse for a failure to provide them.
69. Transparency. I have mentioned the requirement to publish policies or criteria at various points. It is much harder to continue poor provision for disabled children, or to allow these services to be ‘Cinderella’ services, if policies have to be justified and the facts about provision – or the lack of it - are accessible.
70. It is therefore relevant to note that public bodies are now required to consider and assess their practices in relation to disabled persons, including children. In particular, public bodies were required to publish a “Disability Equality Scheme” by December 2006,<sup>70</sup> setting out how each fulfils its duties towards disabled persons, and how they assess the impact of their policies and practice on disabled people. Those duties include having regard to the need to promote equality of opportunity between disabled persons and other persons, and the need to encourage participation by disabled persons in public life.
71. So if, for example, waiting lists before an assessment by occupational therapy services are an issue, or delays in the provision of equipment after assessment are an issue, these things should be discussed by the Scheme. The Scheme should, in my view, make it plain what progress is being made to the review of

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<sup>69</sup> The position is the same under the Chronically Sick and Disabled Persons Act 1970.

<sup>70</sup> The Disability Discrimination (Public Authorities) (Statutory Duties) Regulations 2005, SI 2005/2966 and the Disability Discrimination Acts 1995 and 2005.

local therapy services required by the National Service Framework,<sup>71</sup> to take one example.

72. In addition, local authorities are required to publish a Children's Services Plan, setting out the details of the services provided by them to (amongst others) disabled children.

**Issue H: Examples in which the courts have acted to protect disabled children.**

73. There are relatively few court cases that I am aware of, focussing directly on the needs of disabled children to services and equipment.<sup>72</sup> There are more cases involving access to adult social services, and I have drawn on those in the advice above. Of course, the family courts act to protect the 'best interests' of children, when their welfare needs are disputed, on a daily basis. However, strictly that court has power only to declare what the best interests are, and cannot command that resources follow its declarations.<sup>73</sup> The Special Educational Needs and Disability Tribunal acts to secure (in particular) a child's right to a suitable education, but that area lies outside the scope of this Advice.
74. Many cases concerning adults do, of course, involve children as part of the family. See the *Bernard* case I have cited above at paragraph 62. Furthermore, it is more than possible that the strongest cases will not get to the stage of a reasoned and published judgment; they will be settled by the public authority before that stage. So the influence of the courts is often invisible or indirect.
75. **Conclusion.** The aspirations of treaties such as UN Convention on the Rights of Persons with Disabilities is that disabled children should be able to participate in the life of families and communities on as equal a basis as possible. The United Kingdom is a signatory to that Treaty. In the UK, there are widespread duties placed on public bodies to have regard to, and to promote such aims. However, legal obligations tend to fall short of an obligation to achieve this outcome. Public authorities have a wide discretion to prioritise needs and to allocate resources amongst different groups. Furthermore, although national guidance does limit those discretions, the existing guidance has many gaps when it comes to children. Much is still left to local bodies (for example, it seems there are no national examples of suitable threshold or eligibility criteria).
76. Nevertheless, the central guidance for children that has been developed recently is helpful in showing how authorities are expected to put children's needs at the centre of their decision-making, and to organise integrated services around those needs. The recent trend towards requiring eligibility

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<sup>71</sup> National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and those with Complex Health Needs" paragraph 3.15.

<sup>72</sup> Of course there are some: see for example *CD v Isle of Anglesey* [2005] 1 FLR 59, in which a local authority's care plan for a 15 year old disabled girl was struck down as it failed to take account of her expressed wishes, and placed unreasonable burdens on carers.

<sup>73</sup> *A v A Health Authority* [2002] 3 WLR 24.

criteria or standards to be published is equally positive; transparent and reasoned decision-making is more likely to be fair and consistent. Both the courts and Ombudsmen will uphold standards of good administration, and failures to meet them may be challenged.

77. Finally, the Human Rights Act 2000 offers a real possibility of developing minimum standards. If a child's life, health and social development are critically compromised, the argument that the State has a 'positive obligation' to intervene and prevent such impairment is one likely to be further considered and, it may be hoped, developed by the courts over the next few years. The evidence which BDF has is that there are families with disabled children whose basic needs are not being met. A campaigning charity such as BDF is well placed to play a critical part in supporting such families, and helping to secure legal rights to a basic 'safety net' of provision.

ELEANOR GREY  
39 ESSEX STREET  
22.4.07



## BDF Newlife Press Statement Following Legal Report

Today the legal opinion we have sought leads us to believe that many of the disabled children who have been forced to go without essential equipment may be able to take legal action against the statutory services who failed them.

These are children who have not received timely assessments, who have been victims of inter-department funding squabbles, who have been refused because of 'blanket' policies to deny certain types of equipment, or those who have suffered injuries or worsening conditions because of statutory services refusal.

If a case goes to court, statutory services will have to justify their policies, be transparent in their decision making, show that they acted properly and that there were truly exceptional reasons for not following current guidance in the provision of equipment to children with disabilities.

**BDF Newlife**

BDF Centre Hemlock Way,  
Cannock Staffordshire WS11 7GF

**Telephone:** 01543 468888

**Facsimile:** 01543 468999

**Email:** [info@bdfnewlife.co.uk](mailto:info@bdfnewlife.co.uk)

[www.bdfnewlife.co.uk](http://www.bdfnewlife.co.uk)



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